

***DECONSTRUCTING AND RECONSTRUCTING
'BEST INTERESTS':
DECIDING FOR LEGALLY INCOMPETENT PATIENTS***

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**A thesis presented for the degree of Doctor of Philosophy in
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I declare that I have composed this thesis, that this work is my own and that it has not been submitted for any other degree or professional qualification.

Andrea J. Fenwick

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ABSTRACT OF THESIS

'Best interests' is a panacea within medico-legal decisions for incapacitated patients. Its scope is extensive and its range of application situationally diverse, yet the meaning of best interests remains relatively obscure. To clarify its character this thesis deconstructs best interests by critically examining current law regarding treatment decisions for incompetent patients (Chapters 1 and 2). The conceptual implications of using 'interests' are then considered through exploration of philosophical approaches to sources of interests (Chapter 3). Certain important distinctions are raised and the notion of an 'interest network' is mooted. The possibilities for reconstruction of best interests are considered in Chapters 4 and 5. The importance of autonomy, including competence construction and patient perspective in alternative decision-making mechanisms, is considered. The meaning of welfare, together with quality of life and personhood are also explored in the context of incapacitated persons. Reconstruction then begins in earnest. 'Respect' is proffered as the most suitable ethic for governing 'best interests'. A new synthesis of respect is developed through Chapters 6,7 and 8. It is argued (Chapter 6) that we should admit a wider range of interests, recognise the importance of relationship, and differentiate between input and decision-making authority. A 'whole life, over time' approach is proffered in Chapter 7, including a reclassification of *incompetence*, and a process for ascertaining interests outlined. The final chapter embraces ethical issues, conflict resolution and criteria for justified decision-making. Discussion concludes by developing a normative framework to legally represent the improved respect synthesis within 'best interests'.

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This thesis is dedicated to all those incapacitated patients who have been the subjects of 'best interests' treatment decisions.

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INTRODUCTION

Medical treatment of legally incompetent patients is problematic. A paradox exists such that these patients may need treatment, but are unable to provide consent to it. Absent consent, proceeding to treat could constitute an assault, whereas refraining from treating fails to meet the patient's clinical needs and may undermine his/her health and quality of life. Moreover, patients who are unable to make their own decision about treatment need our support, care and compassion as fellow human beings. Well-being is part of what makes human life valuable, and it is understandable that we should seek to restore or enhance it in a patient that is incapacitated. Treatment decisions are therefore needed to protect and promote these patients' interests.

'Best interests' is the mechanism that has evolved to resolve the lacuna of consent regarding incompetent patients. With its roots in welfare it has grown and adapted to bridge the gap that occurs where incapacity robs patients of the ability to determine treatment decisions for themselves. In recent years its application has developed in response to the progression of medical science and legal provisions such as the Human Rights Act (1998). The case law on best interests in medico-legal decision-making is now extensive and its range of application diverse. The outcome of these decisions impacts the lives (and sometimes deaths) of individuals concerned, with concomitant emotive repercussions for individuals and families alike - sometimes in tragic circumstances. 'Best interests' is at the sharp end of resolving these treatment dilemmas. Yet, despite its extensive use in onerous medico-legal decisions, the character of best interests remains elusive. Its meaning and function are often obscured, now tangled in a mass of decisions concerning minors and adults regarding withdrawal/withholding of life-sustaining treatment, surgical sterilisation, obstetric intervention, refusal of treatment by incapacitated patients, diagnostic testing, bone marrow donation, transplant surgery, dialysis, and most recently the surgical separation of conjoined twins.

This thesis seeks to elucidate best interests, initially by deconstructing its historical and jurisdictional origins (in Chapter 1). Its progression to, and development in, the

medical law context is addressed in Chapter 2 through identification of consistent themes regarding: *gateways* (giving access to the best interests mechanism), *function* (in terms of decision *purpose*, and *role* of interests), and *content* (accorded to influential factors of best interests). This initial deconstruction starts to reveal the current character of best interests, and critical evaluation of existing decisions also enables deficits in its current construction to be established. While much of the value of best interests lies in its flexibility and beneficent motivation, it is presently found to be failing to fulfill its potential for protecting the interests of incapacitated patients. This deconstruction acts as a useful guide to the need for, and structure of, a more valuable reconstruction of best interests.

Conceptual aspects of 'interests' are explored in Chapter 3 as a means of better understanding the scope for attributing interests to incapacitated patients and to identifying the range of potential interests. Important distinctions are raised as a means of enhancing clarity, and the idea of an interest network for individual patients is developed.¹ The relevance of other interested parties is also considered, and a connected concept of interests established.

From this improved understanding of what best interests currently comprises, and what we might mean by 'interests', the possibilities for reconstructing 'best interests' can then be considered through appropriate appeals to value. These refer to the purposive aspects - what we seek to protect, achieve or promote - through best interests. Chapter 4 evaluates the relevance of autonomy, initially by examining competence construction to establish the location of decision-making authority. A role for autonomy regarding incapacitated patients is established - even in proxy decisions - through the notion of individuality. Alternative decision-making mechanisms are also considered as a means to identifying valuable autonomy-based aspects in decision-making. Chapter 5 then evaluates welfare through the traditional assessment standard of 'quality of life', finding the value of life to be more than biological,² and considers the relevance and impact of personhood in attributing moral status and interests to incapacitated patients.

¹ The concept of an interest network originates from the work of J. Feinberg, *Harm to Others, The moral limits of the criminal law*, Volume one (1984) Oxford University Press Inc., New York, 55-61.

² The notion of 'biographical' life is seen in the work of J. Rachels, *The End of Life, Euthanasia and Morality* (1986) Oxford U.P., Oxford.

The strengths of both autonomy and welfare are then employed as a synthesis as reconstruction of best interests becomes the focus in Chapters 6,7 and 8. 'Respect' is proffered as a better overarching aim of decision-making for incapacitated patients, because it embraces both existing values and allows for development of additional elements oriented specifically towards those with incapacity. These new elements include attribution of a wider range of interests than are currently permitted, and an exploration is made of the relevance of 'relationship' to incapacitated patients. This approach seeks to take account of - and respect - patients more fully as individuals, despite their incapacity. In Chapter 7 this approach is supported further by adopting a notion of 'whole life, over time' as a means to enabling a proxy decision-maker to become truly 'informed' about the individual upon whose behalf s/he acts. The focus remains firmly with incompetent patients in proffering a reclassification of *incompetence* that allows for incorporation of temporal aspects, identified earlier, in order to enable incapacitated patients to participate as fully as possible in their treatment decisions. The final chapter argues that decision proxies should act 'responsibly in the name of common humanity', which is considered initially in terms of ethical aspects of conflict resolution and justifiable decision-making. These conclusions are then translated into a legal framework to represent this synthesis of respect within a decision process that better respects and protects the interests of incapacitated patients under best interests.

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CHAPTER ONE

POSITIONING A PANACEA

1 Chapter 1 - Positioning a panacea

1.1 A panacea

Making medical treatment decisions for others is a risky venture; we fear getting it 'wrong'. But, incapacitated individuals sometimes need treatment, requiring that others decide for them. Medicine and law strive to shoulder this responsibility, in the face of seemingly irreconcilable choices about life and death and contentious quality of life judgments. Constant developments in medical technology increase complexity. The legal and ethical mechanism traditionally employed in the U.K. to resolve these onerous decisions is 'best interests'.

1.1.1 All things to all (incompetent) patients?

The best interests principle has become a panacea for incompetent patient (IcP) decision-making. It is increasingly used in expanding range of treatment situations, including, *inter alia*: withholding¹/withdrawal² of life-sustaining treatment from infants and from adults in persistent vegetative state (p.v.s.)³; physical treatment of a mentally ill adult⁴; sterilisation of intellectually disabled patients⁵; bone marrow testing of an intellectually and physically disabled adult⁶; treatment of mature minors⁷; and obstetric intervention regarding adult females⁸. The scope of best interests is extensive and its range of application diverse. Situations of application

¹ Eg: Re J (A minor) (Wardship: medical treatment) [1990] 3 All ER 930; Re J (A minor)(Wardship: medical treatment) [1992] 9 BMLR 10; Re T (A minor)(Wardship: medical treatment) [1997] 1 All ER 906.

² Eg: Re C (A minor)(Wardship: medical treatment) [1989] 2 All ER 782; Re C (A baby) [1996] 2 FLR 43; Re C (A minor)(Medical treatment) [1998] 1 FLR 384.

³ Eg: Airedale NHS Trust v Bland [1993] 1 All ER 821; Frenchay Healthcare NHS Trust v S [1994] 1 WLR 601.

⁴ Eg: Re C (Adult: Refusal of treatment) [1994] 1 WLR 290.

⁵ Eg: Re F, *sub nom* F v West Berkshire HA [1989] 2 All ER 545; Re W (Mental patient) (Sterilisation) [1993] 1 FLR 381; Re S (Medical treatment: adult sterilisation) [1998] 1 FLR 944; Re SL (Adult patient) (Medical treatment) [2000] 2 FCR 452.

⁶ Re Y (Mental incapacity: Bone marrow transplant) [1996] 2 FLR 787.

⁷ Eg: Re R (A minor)(Wardship: medical treatment) [1991] 4 All ER 177; Re W (A minor)(Medical treatment) [1992] 4 All ER 627.

⁸ Eg: Re S (Adult: refusal of medical treatment) [1992] 4 All ER 671; Re MB (Medical treatment) 1997 2 FLR 426; St George's Healthcare NHS Trust v S (No. 2), *sub nom* R v Collins & others ex p S (No. 2) [1998] 2 FLR 728.

have little in common other than the patients' legal incompetence; making its potential for further application in treatment decisions considerable.⁹

Treatment decisions for IcPs revolve around intense issues such as life, death, bodily integrity, reproduction, privacy, personal relationship and human dignity. Resolving these weighty issues affords best interests a potent role. However, its significance parallels its role in family law where it is widely used in decisions on adoption, custody and care of children.¹⁰ Indeed, diversity and flexibility may be its greatest strength. Flexibility is apparent in the broad spectrum of admissible factors, already including, *inter alia*: views of patients,¹¹ parents,¹² medical professionals¹³ and the court¹⁴; evaluation of welfare¹⁵ and quality of life¹⁶; ethical values of self determination and sanctity of life¹⁷; various interests¹⁸; benefits and burdens of treatment¹⁹; relevance of risk of harm²⁰; and need for post-operative familial support.²¹ This flexibility enables courts (and medical professionals²²) to adapt best interests as a decision mechanism. In effect, best interests is an instrumental tool

⁹ However, the Adults with Incapacity (Scotland) Act 2000 omits any reference to 'best interests', preferring the purpose of treatment to be safeguarding or promoting a patient's physical or mental health (s47). This is, however, similar to the interpreted meaning of 'best interests' in the English case *Re F*, above.

¹⁰ The origins of best interests in relation to family law are considered below, paragraph 1.3.

¹¹ E.g. *Re C (Adult: refusal of treatment)* [1994] above.

¹² E.g. *Re T* [1997] above.

¹³ E.g.: re doctors/professional bodies, see *Swindon & Marlborough NHS Trust v S* [1995] *Med. L. Rev.* 84; re nurses/carers, see *Re C (A minor)(Wardship: medical treatment)* [1989] 2 *All ER* 782.

¹⁴ E.g. *South Glamorgan County Council v W and B* [1993] 1 *FLR* 574.

¹⁵ E.g. *Re J (A minor)(Wardship: Medical Treatment)* [1990] 3 *All ER* 930.

¹⁶ E.g. *Re B (A minor)(Wardship: medical treatment)* [1981] 1 *WLR* 1421.

¹⁷ *Re T (Adult: Refusal of treatment)* [1992] 3 *WLR* 782; *St George's Hospital case*, above.

¹⁸ E.g.: in bodily integrity, see *Re LC (Medical treatment: sterilisation)* [1997] 2 *FLR* 258; in chance of a future life, see *Re S (A minor)(Medical treatment)* [1993] 1 *FLR* 376; in emotional, psychological and social benefits, see *Re Y (Mental incapacity: bone marrow transplant)* [1996] 2 *FLR* 787.

¹⁹ E.g. *Airedale NHS Trust v Bland*, above.

²⁰ *Re F* [1989] above; *Re W* [1992], above; *Re S (Medical treatment: adult sterilisation)* [1998] 1 *FLR* 944; *Re X (Adult sterilisation)* [1998] 2 *FLR* 1124.

²¹ *Re T* [1997] above.

²² In *Re F* [1989] above, Lord Brandon's equiparation of lawfulness with best interests (p551) and the House of Lords' application of the Bolam test (*Bolam v Friern Hospital Management Committee* [1957] 2 *All ER* 118) at pages 549, 559, 561, 567 and 571, places many treatment decisions for incompetent patients in the hands of medical professionals. However, the views of Dame Butler-Sloss (P) in *Re SL* [2000] above, now raise doubts about wholesale medical application of the Bolam standard. Furthermore, certain incompetent patient decisions must still be brought before the English courts, including: non-therapeutic sterilisation; bone marrow harvesting; decisions involving wards, and contested decisions involving minors. Relatedly, in Scotland, certain treatments may have special provisions attached (*Adults with Incapacity (Scotland) Act 2000*, s48).

capable of fashioning a variety of outcomes, dependent on individual needs and circumstances.

Acceptance of best interests, by courts and healthcare professionals (HCPs),²³ also stems from the principle's beneficent motivation; seeking the course of action most beneficial to the patient. We seek valuably to protect the patient from unnecessary harm and to improve his/her current situation. This underlying beneficence, combined with inherent flexibility, seems to enable best interests to be all things to all incompetent patients. However, this author submits that this capacity is not fulfilled under current formulations of best interests. I submit that the best interests formula can fulfil this potential, and it is the overarching aim of this thesis to demonstrate how this can be so.

1.2 Background perspective

1.2.1 The nature of the best interests problem

Fundamentally, the need for a mechanism for treatment decisions regarding IcPs is bound up in the law of trespass to the person. If medical treatment proceeds without appropriate consent it could constitute a battery, potential creating tortious and/or criminal liability. English and Commonwealth cases clearly limit tortious trespass to situations lacking *any* consent to medical intervention.²⁴ The power of consent is in

'mak[ing] the touching legally innocuous'.²⁵

This power depends on validity, which requires it to be freely given by a legally competent patient, and not contrary to public policy.²⁶ However, IcPs cannot meet

²³ Best interests is adopted in England and Wales, and previous Scottish decisions include: *Lawrence, pet'r* (1996) SCLR 538; and *Law Hospital NHS Trust v Lord Advocate* [1996] SLT 26, 848 & 869. Its use is now omitted from the recent legislation on incapacitated adults. Best interests has also been used by the Irish Supreme Court, see *In the Matter of a Ward of Court* [1995] 2 ILRM 401. However, best interests is not unequivocally accepted: in the USA 'substituted judgment' is adopted, see *Re Quinlan* 355 A2d 647. Substituted judgment seeks to determine what the patient would choose (if able) and is considered in Chapter 4, below.

²⁴ See, for example, *Chatterton v Gerson* [1981] QB 432, and *Reibl v Hughes* (1980) 114 DLR (3d) 1, respectively. *Any* consent in contrast to consent that merely is vitiated by insufficient information disclosure (which concerns negligence rather than trespass, see *ibid*).

²⁵ Per J.K. Mason, R.A. McCall Smith and G.T. Laurie, *Law and Medical Ethics* (2002) Butterworths/Reed Elsevier (UK) Ltd, London, paragraph 10.7, citing: Attorney-General's Reference (No. 6 of 1980) [1981] 2 All ER 1057; and, in Scotland, *Smart v HM Advocate* [1975] SLT 65.

²⁶ Certain behaviours are deemed contrary to public policy and amount to criminal trespass despite consent, see *R. v Brown (Anthony)* [1994] AC 212. In the medical context, active euthanasia would

these criteria due to fundamental lack of *competence*.²⁷ This places HCPs in an untenable position; the patient needs treatment but cannot provide requisite consent, yet treating without consent might constitute battery. Further, it leaves the IcP in a state of limbo: needing treatment, which cannot be given unless some means is found to treat without transgressing the law.

Historically, this paradox could have been overcome by judicial exercise of *parens patriae*. But its loss in England and Wales leaves a lacuna whereby no one is now able to consent to medical treatment on an incompetent adult's behalf.²⁸ Unsurprisingly, therefore, most IcP treatment decisions are post-1975,²⁹ and appear to be increasing in number.³⁰ A burgeoning ethical role for autonomy in healthcare has witnessed a correlative importance in the role of consent generally.³¹ Additionally, developments in medical technology raise further conceptual problems; ability to sustain life artificially (and consequent redefinition of death) creating new categories of incompetent patients.³² Ongoing refinement of medical techniques, diagnosis and knowledge also change potential duration and quality of life, in turn, altering expectations of patients and families and fuelling battles over treatment choice. Best interests represents one possible means of resolving ensuing battles, particularly as it seeks to locate the 'best' response to a patient's identified clinical needs, and is associated with the established legal justificatory concept 'necessity'.

constitute unlawful homicide despite a patient's informed consent, because it is regarded contrary to public interest.

²⁷ In some cases undue influence by a third party vitiates consent by undermining the patient's *exercise of choice*, see *Re T (Adult: Refusal of treatment)* [1992] 3 WLR 782.

²⁸ The jurisdiction was lost by legislative accident resulting from combined effects of the Mental Health Act (1959) and revocation by warrant under the Sign Manual (see *Mason et al*, above, paragraphs 10.31-10.32); G.T. Laurie, *Parens patriae jurisdiction in the medico-legal context: The vagaries of judicial activism* (1999) ELR 3, 95; and J Seymour, *Parens patriae and wardship powers: Their nature and origins* (1994) 14 OJLS 159). Use of the jurisdiction survived in: Scotland (see *Law Hospital* [1996] above); Ireland (see *In the matter of a Ward*, above); Canada (see *Re Eve* (1986) 31DLR (4th) 1); and Australia (see *Secretary, Department of Health & Community Services (NT) v JWB and SMB* (1992) 66 ALJR 300).

²⁹ One of the earliest being *Re D (A minor)(Wardship: sterilisation)* [1976] 1 All ER 326.

³⁰ Developments are discussed in Chapter 2, below. This is understandable, given strengthening human rights (Human Rights Act 1998), heightened public scrutiny of medicine, and increased willingness to litigate.

³¹ See the seminal statement of Cardozo J: in *Schloendorff v Society of New York Hospital* 105 NE 92 (NY 1914). Also, Lord Donaldson in *Re T* [1992] above, 786.

³² See the House of Lords' decision in *Bland*, above, particularly the views of Lords Goff, Lowry and Browne-Wilkinson (pp 865(g), 877(e-f) and 878(a), respectively). See also, *Butler-Sloss LJ* in the earlier CA decision, *ibid* 842(j).

1.2.2 Background issues

Best interests operates against two background issues, necessity and lawfulness. 'Necessity' may justify an otherwise-unlawful action, recognised in tort,³³ and in criminal law.³⁴ Thus, the law acknowledges beneficent behaviour that responds to perceived need.³⁵ In the medical context the role of necessity is regarded as justificatory,³⁶ and not limited purely to emergency treatment.³⁷ However, necessity will only justify action that is needed *and reasonable*,

'acting in the best interests of the assisted person'.³⁸

While inconsistency exists regarding the roles of necessity and best interests,³⁹ Lord Goff's view posits 'necessity' as a justificatory principle to which best interests may appeal, (rather than an element of best interests).⁴⁰ Hence, necessity is the *backdrop* against which best interests is played out.

The second background element '**lawfulness**' concerns the decision process. We tend to assume that the court's role is to make decisions about whether, and which, treatment should be given to an IcP. However, in some circumstances the court is limited merely to declaring whether a particular treatment action would be 'lawful'. In treatment decisions for minors courts retain considerable responsibility through the extensive judicial powers of wardship,⁴¹ substantiated further by statute.⁴² Clearly, the court's decision can be characterised, therefore, as an active 'treatment decision', reflected in: breadth of judicial consideration, willingness to weigh

³³ E.g.: *Esso Petroleum Ltd v Southport Corpn.* [1956] AC 218; *Home Brewery plc v William Davis & Co (Leicester) Ltd* [1987] QB 339.

³⁴ Inherently in private defence (of self, another or property): *Gladstone Williams* (1984) 78 Cr App Rep 276; *Beckford v R* [1987] 3 All ER 425; *Sears v Broome* [1986] Crim LR 461. See also *Re A (Conjoined twins: medical treatment)* [2001] 1 FLR 1.

³⁵ For discussion of the contrast between English and Scots law on self defence, see J. Casey, *Self defence*, *R v Martin* and Scots law, [2000] SLT 25, 195.

³⁶ Per Lord Goff in *Re F*, above, 564(f): '[i]t is this criterion of a need which points to the principle of necessity as providing justification'.

³⁷ See *ibid* 565(c-f).

³⁸ *Ibid* 566(a).

³⁹ Neill LJ (CA) in *Re F*, [1989] 2 FLR 378, 404(b), sees necessity as an element of best interests, asking '[w]hat action does the patient's health and welfare require?' In contrast, Lord Goff regards best interests as an aspect of necessity, above, 565(c-f).

⁴⁰ *Ibid*.

⁴¹ Exemplified by Lord Donaldson MR in *Re R* [1991] above 186(g-h).

⁴² The Children Act (1989) provides for specific issue, or prohibited steps orders, to be made without resort to full wardship.

relevant factors,⁴³ admittance of a range of views,⁴⁴ address of quality of life,⁴⁵ specific reference to court responsibility,⁴⁶ and consideration of non-clinical issues.⁴⁷ However, even regarding minors, *consent* is formally distinguished from the *treatment decision*.⁴⁸ So, while these decisions bear all the hallmarks of a treatment decision, formal characterisation as consent is simultaneously denied. In relation to incompetent adults, absence of *parens patriae* limits courts formally to purely declaratory jurisdiction of lawfulness, equating 'lawful' treatment with best interests.⁴⁹ That is, treatment:

'to save their lives or to ensure improvement or prevent deterioration in their physical or mental health'.⁵⁰

The significance is that type of jurisdiction *predisposes* best interests to particular types of formulation that confuse the *purpose* of best interests.⁵¹ Further, it may distort best interests assessment,⁵² creating linguistic ambiguity within single cases, attenuating perspective and inappropriately curtailing range of interests. However, some blurring of the distinction is occurring.⁵³ And some recent developments more closely mirror proactive decision-making dominant in minors' cases.⁵⁴ By blurring definitional boundaries the courts could be *progressing*, and although lack of

⁴³ E.g. Re J [1990] above; Re E (A minor)(Wardship: medical treatment) [1993] 1 FLR 386.

⁴⁴ Eg: Re E, *ibid*, (patient's view); Re T [1997] above, (parent's view); Re C (A minor)(Medical treatment) [1998] above (clinician's view); Re C (A minor)(Medical treatment) [1989] above (views of nursing staff).

⁴⁵ Re C [1998], *ibid* 782; Re B [1981] above; Re J [1990] above; Re C [1989] above.

⁴⁶ Re S (A minor)(Medical treatment) [1993] above; Re C (A baby) [1996] above.

⁴⁷ Re T [1997] above, however, where certain dicta seem to indicate that this is *not* a treatment decision. But these comments may really seek to avoid compelling doctors to treat contrary to clinical judgment, see also in Re W [1992] above, 637(g-h).

⁴⁸ See Lord Donaldson MR who characterises consent as a 'threshold requirement', while decision whether to treat is one of clinical judgment: Re R [1991] above, 187(h). Confirmed in A NHS Trust v D [2000] 2 FCR 577.

⁴⁹ See Lord Brandon in Re F, above, 551(h-j). There have been high-profile requests for reinstatement of appropriate jurisdiction, see Bland (above): Lords Lowry p875(j), and Goff, 864(g-h).

⁵⁰ Per Lord Brandon, Re F, *ibid*, 551(c-d).

⁵¹ Perhaps seeking what is *not in*, rather than *in*, a patient's best interests, see my earlier paper: A.J. Fenwick, Applying best interests to persistent vegetative state - a principled distortion? J. Med. Eth. [1998] 24, 86, 87, attached below as appendix 8.

⁵² *Ibid*.

⁵³ Indeed, in Re F [1989] above, 557(h-j), Lord Brandon suggested that 'whichever of the two forms of procedure...were to be used, the nature of the inquiry which would have to be made by the court, and of the reasoned decision...would be substantially the same'. Further, references in adult IcP cases to *weighing*, (Re F, *ibid*, 569(c-d); Re LC (Medical treatment: sterilisation), above, 261 (C, E and F-G)), and *dignity* interests (Bland, above, 870(f-g)) suggest that - informally - courts *are* considering more than pure lawfulness.

⁵⁴ See further, Chapter 2.

jurisdiction remains a formal problem it may become a superficial one in practice. This view is confirmed by subsequent cases - relatively few of which expressly refer to necessity, focusing instead on best interests as the active decision-making principle.⁵⁵ Nonetheless, this blurring could also add to *confusion* surrounding the content of best interests, how it should be determined, which factors are admissible and the roles of parties involved.

1.3 Origins - non-medical landmarks for 'best interests'

Judicial involvement in medical treatment decisions is a relatively recent phenomenon. Jurisdiction forges some links, but additional connections are ascertainable from landmark cases, representing significant points in the journey of best interests, from the traditions of custody to application in the medical context.⁵⁶

1.3.1 Early markers: 'welfare'

'Welfare', now an important feature in protective jurisdiction and best interests, was not always so. An Act in 1839,⁵⁷ makes no mention of welfare, being concerned purely with mothers' rights regarding custody and access. Even by 1873 there was still no mention of welfare.⁵⁸ However, this legislation did highlight 'benefit',⁵⁹ focusing on impact upon child subjects rather than parental rights. The 1886 Act expressly made child welfare the central issue and strengthened judicial discretionary powers.⁶⁰ By the time this Act was partially repealed, in 1925, the legislature was willing to embrace the importance of welfare:

⁵⁵ However, 'need for treatment' is still significant, but perhaps in a redefined (negative) form: *futility* may negate any need to continue treatment; also *absence of risk of pregnancy* in non-therapeutic sterilisation may make treatment unnecessary (see A.J. Fenwick, *Re S (Medical treatment: Adult sterilisation) Retrenching on Risk - revising the lawful boundaries of sterilisation* [1999] CFLQ 11(3) 313 attached hereto as appendix 10. See also the views of Dame Butler-Sloss (P) on necessity in *Re F (Adult: court's jurisdiction)* [2000] 55 BMLR 81.

⁵⁶ These cases are identified by working backwards from citations in modern treatment decisions, through decisions about minors in the twentieth century, to their source in custody.

⁵⁷ An Act to amend the Law relating to the Custody of Infants, 1839, 2 & 3 Vict. C54, also known as Sergeant Talfourd's Act.

⁵⁸ An Act to amend the Law as to Custody of Infants, 1873, 36 Vict. Ch 12.

⁵⁹ *Ibid*, s2: 'no Court shall enforce any such agreement if the Court shall be of opinion that it will not be for the benefit of the infant'.

⁶⁰ Guardianship of Infants Act 1886, 49 & 50 Vict. Ch 27, see particularly s 3(3), 5 and 6.

'Where...the custody or upbringing of an infant...is in question, the court, in deciding that question, shall regard the welfare of the infant as the first and paramount consideration'.⁶¹

These legislative developments emphasised the move away from property towards protection that had been initiated in wardship during the nineteenth century. A series of landmark cases in the twentieth century enhanced the role of welfare,⁶² giving increasing recognition to minors' interests and protective jurisdiction.⁶³

Of course, early source cases reflected an absence of any 'welfare principle', but its roots are visible. In *Wellesley v The Duke of Beaufort*, concerning custody and property of minors,⁶⁴ although argument before the Court referred to its authority regarding welfare,⁶⁵ it was unmentioned in Eldon LC's judgment. This is understandable, given the need to exercise *parens patriae* through application of property at that time.⁶⁶ The House of Lords (dismissing the father's appeal on jurisdiction)⁶⁷ emphasised the court's protective role founded in trust, morality and care, confirming the earlier views of the Lord Chancellor. The direct influence of this is visible in early medical treatment decisions. Both *Re D (A minor)(Wardship: sterilisation)*,⁶⁸ and *Re B (A minor)(Wardship: sterilisation)*,⁶⁹ cite Lord Eldon LC's views regarding

'the obvious necessity that the law should place somewhere the care of individuals who cannot take care of themselves'.⁷⁰

Heilbron J reiterated, in *Re D*,⁷¹ Eldon LC's observations on the protective nature of jurisdiction in harm prevention.

The House of Lords, in the *Wellesley* appeal, also referred to applying property for the minors' 'benefit'.⁷² They emphasised this further in *Guardianship of the Marquis*

⁶¹ *Guardianship of Infants Act 1925*, 15 & 16 Geo. 5 Ch 45, s 1

⁶² See, for example, *Re X (A minor)(Wardship: restriction on publication)* [1975] 1 All ER 697; *J v C* [1969] 1 All ER 788; *Official Solicitor v K* [1963] 3 All ER 191; *Re Thain. Thain v Taylor* [1926] All ER, Rep. 384.

⁶³ Recent legislative provisions continue to embody welfare: it remains the governing principle in the *Children Act (1989)*, see s1(1). See also *Guardianship of Minors Act (1971)*, s1.

⁶⁴ (1827) 2 Russ 1, in ER 38, 236.

⁶⁵ *Ibid*, 239.

⁶⁶ *Ibid*, 243, per Eldon LC: 'It is not...from any want of jurisdiction that it does not act, but from a want of any means to exercise its jurisdiction'.

⁶⁷ *Wellesley v Wellesley* (1828) 4 ER 1078, 2 Bli N.S. 124, reprinted [1824-34] All ER Rep 189.

⁶⁸ [1976] 1 All ER 326, 332(f-g).

⁶⁹ [1987] 2 All ER 206, 210 (h-j).

⁷⁰ (1827) above, 243.

of Bute,⁷³ an appeal from the Court of Session regarding custody, domicile and education of a ward. Discussing judicial protective duty, the Lord Chancellor regarded benefit as the test of its proper exercise.⁷⁴ This burgeoning recognition of impact on the minor evolved into 'welfare' in *Re Goldsworthy*,⁷⁵ mirroring the legislative drive in the late nineteenth century.⁷⁶ Lord Coleridge CJ focused on safety and welfare,⁷⁷ while Pollock B initiated tentative associations between welfare and interest(s).⁷⁸

1.3.2 'Best interests' - a new notion?

Shortly before developments of 'welfare', a novel concept began to emerge in custody cases. In *Warde v Warde*, Cottenham LC, considered it the Court's role:

'to adopt that course which seems *best* for the *interests* of the children',⁷⁹ (emphasis added).

At this stage, best interests appeared less conceptual than linguistic; expressing the judicial role of arbiter.⁸⁰ In 1861, together with focus on 'welfare' and 'benefit', 'best interests' received mention by the House of Lords.⁸¹ It was introduced as an express conceptual argument in Jones's case (1890),⁸² regarding a dispute between a child's mother and his carer (Dr Barnardo) about religious upbringing. The Court of Appeal preferred that the mother's wishes be followed unless there was some 'good reason'.⁸³ Dr Barnardo's argument that

⁷¹ Above, 333(b-c).

⁷² Above, 193(F).

⁷³ Macq. Appeal Cases 1861-65, vol. 4, 1.

⁷⁴ Ibid, 60. 'Benefit' has endured in the Adults with Incapacity (Scotland) Act 2000, and the Convention on Human Rights and Biomedicine, European Treaty Series/164, 4.IV, 1997, Article 6.1, see R. Beattie, Adults with Incapacity (Scotland) Act 2000 [2002] Scottish Partnership for Palliative Care, Edinburgh, 1.

⁷⁵ QBD (1876) vol. II, 75.

⁷⁶ Initiated by 'benefit' in the Custody of Infants Act 1873, and culminating in 'welfare' in the Guardianship of Infants Act 1886.

⁷⁷ Above, 83, relying on Wellesley (1828) above, and *Ex parte Fynn*, 2 De G. & Sm., 457.

⁷⁸ Ibid, 85.

⁷⁹ (1849) 2 Ph. 786, available in ER Vol. 41, 1147.

⁸⁰ Ibid, 1149.

⁸¹ In *Guardianship of the Marquis of Bute*, above, Lord Chelmsford criticised jurisdictional disputes between Scottish and English courts and suggested 'cordially co-operating to advance the best interests of the infant', *ibid* 72.

⁸² Also known as *The Queen v Barnardo* [1891] 1 QB 194.

⁸³ Per Lord Esher MR, *ibid*, 207-208.

'[t]he wishes of the mother...at most, are only an element to be considered in deciding what is for the child's best interest',⁸⁴

is strikingly similar to that of the local authority and *guardian ad litem* in *Re T (A minor)(Wardship: medical treatment)*.⁸⁵ There - unusually in the present day - the Court of Appeal again favoured the mother's view.

Best interests swiftly found its way into a Privy Council judgment in *Smart v Smart*,⁸⁶ a Canadian custody appeal that heavily emphasised the welfare of children and families.⁸⁷ Moreover, recognition of expanded judicial authority since *Wellesley*,⁸⁸ and support for the earlier view of Lord Cottenham in *Warde v Warde*,⁸⁹ effectively endorsed an association between *best interests* and *protective jurisdiction*.

Further impetus from mercantile law raised tentative connections between necessity, duty, best interests and reasonableness.⁹⁰ This approach proved directly influential in *Re F* [1989], employed by Lord Goff to derive the fundamentals of 'necessity'.⁹¹ He concluded that where these necessity criteria were fulfilled interference would not be unlawful.⁹² Thus, central themes of protection, welfare and duty, which emerged through incorporation of best interests in the nineteenth century, have endured to its modern day use. Indeed, traditional terminology still resonates. In *Re Thain*,⁹³ welfare constituted

'the first and paramount consideration'.⁹⁴

This has been reiterated in the twenty-first century,⁹⁵ and *Re Thain* displays other terms that have become paradigmatic in best interests, such as 'well-being' and the need to 'attach weight' to relevant issues.⁹⁶

Post-*Thain*, Lord Jamieson expressly adopted best interests in the Scottish custody case *M'Lean v M'Lean* in 1946, closely linking it with paramountcy of welfare.⁹⁷ His

⁸⁴ *Ibid*, 202.

⁸⁵ [1997] above, see 911(h).

⁸⁶ [1892] AC 425.

⁸⁷ See *ibid*, 432, 435, 436.

⁸⁸ *Ibid*, 433; *Wellesley v Duke of Beaufort*, above.

⁸⁹ Above.

⁹⁰ See *Australian Steam Navigation Co v Morse* (1872) LR 4 PC 222, per Sir Montague Smith, p230.

⁹¹ See *Re F* [1989] above, 565(j).

⁹² *Ibid* 566(c).

⁹³ Also known as *Thain v Taylor* [1926] All ER Rep. 384.

⁹⁴ *Ibid*, per Lord Hanworth MR, 387.

⁹⁵ For a recent example, see *Re MM (Medical treatment)* [2000] 1 FLR 224, 234(A).

colleague Lord Mackay raised the issue of 'weighing' within paramountcy,⁹⁸ an issue that has attained an equally significant role in the expansion of best interests between 1950 and 1975.

1.3.3 Expansive developments

The importance of 'weighing' factors to derive best interests, alluded to in *Re Thain and M'Lean v M'Lean*, was developed by the Privy Council in the Canadian custody appeal *McKee v McKee*.⁹⁹ Welfare was, by now, considered the paramount consideration to which 'all others yield'.¹⁰⁰ Hence, all circumstances potentially relevant to welfare were to be taken into account and weighed.¹⁰¹ In addition, this approach illustrates that the range of relevant factors was open to development, and resolution of conflict between those factors was reserved to the court.

In *Official Solicitor v K*,¹⁰² the House of Lords began to bridge the gap from custody to medicine, exercising wardship jurisdiction over disclosure of confidential psychiatric reports in relation to the care and custody of two minors. The Court looked to the infants' welfare as the decision purpose in resolving conflict between the interests of minors and those of parents.¹⁰³ In addition, Lord Jenkins acknowledged that wide judicial discretion was needed to determine best interests,¹⁰⁴ and Lord Evershed alluded to harm avoidance.¹⁰⁵ The decision represents a significant expansion: its context was new; terminology ('balancing' and 'harm') innovative; and their Lordships recharacterised 'welfare' as the beneficent goal that legal principle must serve.

Application of these principles was tested in the House of Lords in *J v C*.¹⁰⁶ This complex custody case represents a landmark consolidation of principle. The Spanish parents of an 11-year-old boy, born and fostered in England, contested the

⁹⁶ Above, 386(H) and 387(H), respectively.

⁹⁷ [1947] SLT, Reports, 36, 42.

⁹⁸ *Ibid*, 41.

⁹⁹ [1951] 1 All ER 942.

¹⁰⁰ *Ibid*, per Lord Simonds, 948 (G-H).

¹⁰¹ *Ibid*, 946(H).

¹⁰² [1963] 3 All ER 191.

¹⁰³ See *ibid*, 196(E), and 210(D).

¹⁰⁴ *Ibid*, 205(C-D).

¹⁰⁵ *Ibid*, 195(I).

¹⁰⁶ [1969] 1 All ER 788.

appropriateness of paramountcy of welfare as the dominant principle. Dismissing the appeal, the Law Lords comprehensively reviewed authorities over the past century, and resoundingly concluded welfare to be paramount. Lord MacDermott construed its scope widely (from the 1925 Act, s1) to:

'mean more than that the child's welfare is to be treated as the top item in a list...[rather it] connote[s] a process whereby, when all relevant facts, relationships, claims and wishes of parents, risks, choices and other circumstances are taken into account and weighed, the course to be followed will be that which is most in the interests of the child's welfare'.¹⁰⁷

This indirectly summarises the task for best interests, as the governing principle, to serve the end objective; welfare. It also characterises *determination* as a process. This idea is developed as this thesis progresses. *J v C* also set the tone for parental views, within best interests, as a factor but being not determinative.¹⁰⁸

1.3.4 Limiting developments?

S v S; *W v Official Solicitor*,¹⁰⁹ propelled best interests into the realms of medical procedure, concerning the blood testing of minors to establish paternity. *Prima facie*, the views of the Law Lords varied and were suggestive of limitations on the protective nature of best interests.¹¹⁰ However, these views can arguably be interpreted as holding that the court's duty is to protect best interests, but not necessarily to *promote* them, especially not in the light of other important interests. Further, the Court looked to the minor's long-term interests,¹¹¹ and refined best interests by distinguishing positive benefits from action not contrary to his/her interests.¹¹² The case clearly evinced best interests' controversial nature and openness to varying interpretation.

In Re X (A minor)(Wardship: restriction on publication) resolution of direct conflict between the interests of a 14-year-old girl and the public interest in press freedom

¹⁰⁷ Ibid, 820(I)-821(A).

¹⁰⁸ See *ibid*, 835(C-D). This is still reflected in judicial powers to overrule parents, and parental views yielding to consent by a Gillick-competent minor, considered below, Chapter 2. Around the same time the scope of competence of the Scottish courts in custody/access hearings was extended to include persons other than parents, see *S v S* (1967) SC, 46 and *Syme v Cunningham* [1973] SLT, Notes, 40.

¹⁰⁹ [1970] 3 All ER 107.

¹¹⁰ See *ibid* 112(f)-113(c); 115-118; 124(c-g); cf. 120-122.

¹¹¹ *Ibid* 120-122.

¹¹² *Ibid* 112-113.

resulted in a limitation on protective jurisdiction.¹¹³ The case concerned publication of a book about X's father, the content of which was potentially psychologically damaging to her. Despite acknowledging the unlimited nature of wardship jurisdiction and the court's general protective role the Lords Justice declined to exercise (and extend) jurisdiction,¹¹⁴ suggesting practical limitations lay in the impossibility of protecting a ward against all potential harms.¹¹⁵

By this stage, terminology had become established - 'welfare', 'harm', 'interests' and 'balancing'. However, *Re X* indicated that paramountcy of a vulnerable person's welfare was not absolute and protection may be restricted where interests conflict. Medical treatment decisions would, subsequently, severely test this approach to conflict resolution. These cases are discussed in more depth in Chapter 2. However, the point to note at this juncture is that the stage was set by the courts for considerable conceptual confusion in the way in which the best interests test would come to be used in that context. It is one of the objectives of this thesis to explore and to clarify this state of confusion, and in order to do so we must begin by considering the moral dilemmas that underpin this entire area.

1.4 Moral dilemmas

Although courts recognise the relevance of moral issues to incompetent patient decisions, they vary in their willingness to address them.¹¹⁶ However, moral issues *are involved* on several levels: the everyday; the definitive; and the philosophical.

1.4.1 Everyday conflict of reasons

In layman's terms, IcP decisions are dilemmas because they involve difficult moral issues that conflict with one another, each based on plausible reasoning. For example, in deciding about continuing life-sustaining treatment for a severely

¹¹³ [1975] 1 All ER 697.

¹¹⁴ Alternative jurisdiction, under Guardianship of Minors Act (1971) s1, was dismissed because this case did not involve custody (*ibid*, 707(c-e)).

¹¹⁵ *Ibid*, 706(h).

¹¹⁶ In *Bland*, above, Sir Thomas Bingham MR and Hoffman LJ (CA) embraced the decision's moral significance, incorporating sanctity of life, autonomy and dignity. Hoffman LJ (p852) also acknowledged that inherent conflict between ethical principles might require choice and compromise. However, the Law Lords were less inclined to address moral aspects, Lord Browne-Wilkinson limiting judicial responsibility for resolution (p878-879), and Lord Mustill confining himself to legal rather than ethical aspects (p885).

disabled infant, we are caught in a conflict of not depriving the child of life, yet not causing him/her pain or poor quality of life. Realistically, we cannot avoid both harms; we have a dilemma of choice. Further, these are moral dilemmas because of the nature of the issues involved: life, death, pain, bodily integrity, respect, social interaction and living. These issues embody the human experience, compelling us to make sense of that experience. In essence, we feel morally obliged, simultaneously, to follow two courses of action, yet are *unable* to do so because they are mutually exclusive, having irreconcilable outcomes.

1.4.2 Defining dilemma - Carson

In discussing risk-taking in healthcare generally, Carson distinguishes between 'risks' and 'dilemmas':

'[r]isk-taking is...choosing to act to achieve beneficial results in an awareness that harms might result. Risk-taking...*only*...include[s] those occasions when one option is to do nothing and that option will not cause any harm. However...a dilemma is...defined as those occasions of risk-taking when action must be taken because inaction, the status quo, is causing harm'.¹¹⁷

IcP decisions fulfil the 'dilemma' criterion because, in any IcP situation, action *must* be taken because the status quo causes harm: a severely ill neonate may already be in pain; an infant may die without a transplant; a mature minor may die without a transfusion; a mother in labour may lose her life or the baby's life without a caesarean section; an intellectually disabled woman might suffer a traumatic pregnancy without effective contraception; or a p.v.s. patient will continue to suffer bodily invasion and intermittent infection during continued treatment. Thus, harm ensuing from inaction compels us to make *some* sort of decision about how to proceed. *Aliter*, we are deciding but by default.

1.4.3 Philosophical moral quandaries - Benn

Further understanding of moral dilemmas can be gained outwith the medico-legal environment. Benn's work on freedom includes an illuminating consideration of conflict resolution,¹¹⁸ focusing on the nature of 'quandaries'.¹¹⁹ For present purposes

¹¹⁷ D. Carson, Risk-taking policies [1988] J. Soc. Welf. Law, 328, 329.

¹¹⁸ A Theory of Freedom (1988) Cambridge University Press, Cambridge.

its value lies in exposition of hard cases and conflicting reasons. This helps us to understand the difficulties facing decision-makers and to acknowledge the 'imperfection' of decisions made. Benn's views on ranking highlights the problems of prioritising values and weighing alternative options. Moreover, it is used here to explore these issues in relation to treatment choice, and to demonstrate the current bias which is inherent in the decision-making process.

Benn's approach to moral quandaries bears striking similarity to Carson's definition:

'if one cannot avoid action of *some* sort...then *whatever* one decides to do, one will simply have to disregard all the reasons against doing that and for doing something else instead and so one cannot avoid doing wrong'.¹²⁰

Applied to IcP decisions, this helps to deconstruct the complexities; good medical/non-medical reasons may exist both for and against available treatment options. For example, sterilising an intellectually disabled adult female may *benefit* her by: (1) avoiding traumatic pregnancy and relinquishing a child; and (2) allowing her more sexual/social freedom. Yet, there is also potential *harm* through: (3) denying her reproductive capacity; (4) risk of sexually transmitted disease; and (5) increased danger of any sexual assault upon her going unnoticed. It is not clear if any of these varied reasons override others, yet a decision *is* required because continued inaction could deny the benefits (1) and (2). Thus, the decision-maker cannot avoid some 'wrong-doing'; not sterilising loses benefits (1) and (2), whereas, sterilising the patient potentially incurs harms (3), (4) and (5).¹²¹ Any choice must incur one or the other.

Benn's outline of quandaries takes us further, allowing us to deconstruct the difficulties into component parts. IcP decisions involve multiple, conflicting 'good reasons' for competing treatment actions, some choice of action is required which involves 'ordering' reasons (but it is not obvious which reasons should dominate) and it is impossible ultimately to support all reasons. This is the essence of the task facing 'best interests'. But, if all actions will be 'wrong' in some sense, how can these quandaries be addressed? Benn offers *ranking*, where we

¹¹⁹ Benn prefers 'quandaries' to 'dilemmas', perceiving dilemmas to be 'logical' whereas quandaries may be less capable of being 'logical', *ibid* 4.

¹²⁰ *Ibid* 3.

¹²¹ Relatedly, other contraceptive methods also carry other long-term health risks.

'recognize the force of the opposing arguments as reasons for action...but can see no way of reconciling them...[w]e resort to words like "weighing" and "balancing" in our efforts to rank the arguments'.¹²²

'Best interests' may represent Benn's scales,¹²³ but lack of patient interests (as in p.v.s.) can render nothing to place in them. Additionally, variety of dis/advantages of treatment options may make direct comparison impossible, and plurality means that no clear value preference emerges to tip the scales one way or another. Thus, in IcP decisions it can be hard 'to cash the metaphors out'.¹²⁴ Unsurprisingly, wide variance and confusion can result.

1.4.4 Benn - conflicting commitments

Conflict is key in IcP decisions. We can apply Benn's general graphical approach to conflict resolution to specific IcP situations as a means of *exposing* underlying conflicts (rather than *resolving* them). This allows us to contrast starkly the underlying moral issues, thereby clarifying the nature of the dilemma. The reader is referred to Appendix One.

Benn characterises moral quandaries as a conflict of role commitments.¹²⁵ Each role is 'informed...by a characteristic value or principle' which guides its action, represented on the *x* and *y*-axis. He then positions action options by ranking each according to its fulfilment of each role commitment, based on clear beliefs about each role.¹²⁶ Ranking requires consideration of how well the option fulfils the relevant commitment, and how 'salient' that role to the overall situation.¹²⁷ Implicit in ranking is 'trade-off';¹²⁸ that is, acknowledging that we must 'surrender one commitment in favour of another in some consistent way'.¹²⁹ Benn employs Pareto's Theory of Indifference Curves to compare plotted options on a diagram. Essentially, the infinite number of points on each curve are equivalent (i.e. indifferent) in *overall* commitment to both roles, though differ in combinations of commitment to *x* and *y*

¹²² Ibid 7.

¹²³ Ibid.

¹²⁴ See *ibid*.

¹²⁵ See Benn's Chapter 3, particularly pp46-64.

¹²⁶ Ibid 53.

¹²⁷ Ibid 51.

¹²⁸ Ibid 48-49.

values. The gradient of curves is determined by trade-off rate between the two axes, which represents how much commitment to one value diminishes, in committing more strongly to the other.

If we apply this to a situation of sterilisation of an intellectually disabled adult female,¹³⁰ the two conflicting values might be termed 'patient autonomy' and 'patient welfare', represented on the x and y -axis, respectively. Autonomy-oriented factors concern the patient's reproductive interest, bodily integrity and sexual freedom. Welfare protects the incapax from harm of pregnancy or sexual assault, and enhances quality of life through sexual relationship. Conflict arises because the more we commit to protecting her from pregnancy (by sterilising) the less we can commit to protect her bodily integrity. Alternatively, preventing pregnancy promotes welfare (enhancing quality of life through relationship), but increases risk (i.e. reduces our commitment) to her reproductive interest. The mechanics of this application are explained in Appendix One.

In essence, Benn's approach illuminates IcP situations by explaining why some options are counter-intuitive and other options equally plausible but opposing one another. However, his approach has limits. Although Benn posits it as a resolution theory, its practical capacity for resolution is questionable: plotting is too imprecise mathematically, yet too value-laden as a philosophical tool.¹³¹ This is exacerbated by complexity of values to which a decision-maker feels committed, and complexity also makes ranking options difficult.¹³² Weaknesses would be exacerbated in resolving IcP decisions, where values such as autonomy and welfare are highly complex and lack consensus about significance and content.

¹²⁹ Ibid. However, trade-off is not possible in all IcP situations, where substitution of either value may seem morally impossible. Benn's 'irrationality of intersecting preference thresholds' aids understanding of these dilemmas, below.

¹³⁰ See Appendix One, based on Benn's Figure 2, Chapter 3.

¹³¹ Gradient ratio cannot be derived mathematically, because it is contingent upon a (potentially subjective) value judgment by the decision-maker about relationship and substitutability of the two roles.

¹³² E.g. where a role-commitment is multi-faceted an option may display commitment to some facets but not others.

1.4.5 Benn - irrationality of threshold choices

The difficulties intensify when a case involves a “threshold value”, 'below which no option would be acceptable'.¹³³ The failure of any action to fulfil requisite minimum threshold(s) renders rational choice impossible. Benn divides these situations into 'incomplete structures' and 'threshold values in two dimensions'. The 'incomplete structure' (where no available option can be countenanced by the decision-maker, because they fail to meet one threshold) is applied in Appendix Two regarding withdrawal of treatment from p.v.s. patients.

This situation contrasts with 'thresholds in two dimensions', where action *is* countenanced but meets only one threshold.¹³⁴ Any action will be 'wrong', in failing to fulfil the minimum threshold level of opposing role commitment, involving 'choosing the lesser of two evils'.¹³⁵ Both situations attempt to trade-off role commitments in intolerable areas. However, the 'incompleteness' in Appendix Two arises from the indifference of the p.v.s. state - no decision can realistically improve, or worsen, the situation. Neither option is 'right', nor clearly 'wrong'. Whereas, in Appendix Three –a case involving withdrawal of treatment from a sentient neonate - both options cause harm, but a decision is required because present *inaction* is also causing harm. Thus, the decision-maker is forced to 'make the best of a bad job' and seek the next-best solution.¹³⁶

1.4.6 Best interests - panacea for a moral precipice

The main purpose here in applying Benn's work to IcP situations is only *illustrative*. It highlights the conflict inherent in these decisions, requires us to identify possible underlying values and to recognise their inverse relationship. It signifies the importance of evaluating treatment options consistently, and explains why some treatment options seem intuitively untenable.¹³⁷ Benn's theory brings focus to the central problem in resolving IcP decisions: the decision-maker's commitment to juxtaposed values, and the difficulty of ranking options due to conflict.

¹³³ See Benn, above, 56. Benn terms this 'irrationality of intersecting preference thresholds', *ibid* 56-59.

¹³⁴ An adaptation of Benn's Figure 5 is shown in Appendix Three.

¹³⁵ Benn, above, 59.

¹³⁶ See *ibid* 59-64.

¹³⁷ I.e. because they lack any significant role commitment.

Derivation of 'best' (or 'next-best') in IcP decisions clearly involves the decision-maker in commitment to conflicting moral values. In trying to resolve this duality - to 'do the right thing' - s/he is forced to fall below his/her minimum threshold and go beyond personal (and societal) moral limits. This is why decisions for incompetent patients are hard cases. Best interests is much vaunted as a panacea for resolving these moral and legal battles but, in seeking to adapt to these acute dilemmas and 'make the best of a bad job', best interests has been forced to metamorphose. This has resulted in varying formulations of best interests. This is not to deny that there is much value in a best interests analysis. Indeed, it is the central purpose of this thesis to defend such an analysis based on a more realistic conceptualisation of what is at stake and what can be achieved. It is submitted that the search for an optimal outcome in all cases is misconceived. That is, that when we talk about 'best' interests our focus should not be on seeking to achieve an unachievable optimal outcome for the subject (patient), but rather we should be concerned with ensuring our full engagement with the decision-making process, taking account of all relevant factors, and making the 'best' of the very difficult situation which lies before us.

This chapter has outlined the legal origins of the best interests test wherein the seeds of confusion were already sown, and it has offered an example of how the underlying moral pressures on best interests could well lead to such an outcome. To understand the current formulation of the test we must next identify its medico-legal evolution where it will be seen that the moral and legal confusion has been compounded yet further.

CHAPTER TWO

DEVELOPMENTS AND BATTLES

Chapter 2 - Developments and battles

To enable us to understand best interests, we must deconstruct its use in treatment decisions in order to clarify its components and purpose. Three distinct phases of evolution have taken place: early markers; development markers; and recent redefinition.

2.1 Early markers

Although early medico-legal markers are sporadic, they represent significant indicators of things to come, highlighting issues that have proven persistently difficult for best interests.

2.1.1 Re D (a minor)(wardship: sterilisation)¹

Re D concerned proposed contraceptive sterilisation of an 11-year-old girl with Soto's syndrome. D's mental function was not severely impaired and she was expected to develop capacity to marry, but her inability to care for herself or children would persist. While D's mother and consultant paediatrician supported sterilisation, other professionals challenged that view.

This was the first contraceptive sterilisation decision heard by the High Court and Heilbron J drew from Wellesley (1827) regarding the *protective* role of wardship.² In exercising this protective function he emphasised welfare and best interests,³ and acknowledged sterilisation as

'deprivation of a basic human right'.⁴

The judgment's prophetic quality is seen in its exceptional conclusion (that sterilisation was not in D's best interests); such a refusal would not recur for some 17 years.⁵

¹ [1976] 1 All ER 326.

² Above, Chapter 1.

³ Above, 333(f). Use of the adjunctive 'and' suggests the two are not necessarily synonymous. Rather, 'welfare' is the weightiest *factor*, contributing to the (broader) notion of 'best interests'.

⁴ Ibid, 332(h). While courts have since shied away from rights terminology in sterilisation decisions (e.g. Re B (A minor)(Wardship: sterilisation) [1987] 2 All ER 206; Re P (A minor)(Wardship: sterilisation) [1989] 1 FLR 182; Re F [1989] above; Re W (Mental patient) (Sterilisation) [1993] 1 FLR 381; Re S [1998] above), the Human Rights Act 1998 brings terminology full circle; Heilbron J's judgment was ahead of its time in this sense.

⁵ In Re LC (Medical treatment: sterilisation) [1997] 2 FLR 258.

Although a seminal case, *Re D* embodied several important aspects of best interests in its new context, including: relevance of policy and human rights implications; the importance of patient capacity;⁶ scope for patient interests to vary over time; respective roles of 'necessity' and clinical opinion; and the close relationship between best interests and welfare.

2.1.2 **Re B (a minor)(wardship: medical treatment)**⁷

Within a few years, best interests was tested in a more dramatic life/death context. *Re B* concerned a baby born with Down's syndrome, complicated by a potentially fatal intestinal blockage that required surgery, whereupon life expectancy might be 20-30 years. B's parents withheld consent and the local authority sought authorisation of surgery under wardship. The first instance decision, respecting parental views, was overturned on appeal, where the test emphasised the minor's 'best interests'. The Court of Appeal's short judgment bears significant markers in the progression of best interests. By accepting the genuineness of parental views, yet adopting a different evaluation of the minor's best interests, the Court effectively acknowledged the complexity of this test. This complexity may give rise to distinct perspectives (parental, judicial, medical, or indeed the subject's own views) of the same individual's best interests. On this basis, best interests is more than merely medical or familial, set within the bigger picture of determining overall, *individual* best interests. Templeman LJ embodied responsibility in a new test, deciding:

'whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die, or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die'.⁸

Ultimately the operation was deemed to be in B's best interests. This new test imported quality of life as a central issue in withdrawal of treatment decisions. The absence of precedent indicates the novelty of the quality of life context at that time. And, while the tests may change, the issues endure.⁹

⁶ [1976] above, 335(c-d). Incompetence represents a gateway to engaging best interests.

⁷ [1981] 1 WLR 1421.

⁸ *Ibid*, 1424(B-C).

2.2 Development markers

During the last 20 years rapid diversification has occurred in the volume and range of medico-legal best interests decisions. Here, landmark cases have been selected for the insight each provides to development of best interests spanning an expansive phase through 1989-1996.¹⁰ In order to analyse these cases meaningfully and effectively we must deconstruct best interests to identify a series of generic elements. This leads to the identification of three groupings; judicial statements generally pertain to the 'function', 'content' or 'gateways' of best interests.

- **Function** comprises two aspects: (1) *roles of parties concerned*, namely the judicial position on respective roles of patient, family/parents, HCPs, and the court influences *who* makes a treatment decision. Roles are influenced by jurisdiction, professional ethics, public policy, and recognition of a patient's relationships; and (2) *decision purpose*, namely the focal point for deriving best interests. Purpose is strongly influenced by roles. For example, if ultimate responsibility is reserved to the court then the judicial process of deciding constitutes 'determination' of best interests. Whereas, if medical opinion is accorded greater significance the court's decision is more akin to 'definition', the purpose shifting to medical liability;
- **Content of best interests** reflects the 'interests' in best interests, comprising *factors* considered and including *welfare, dignity, quality of life, and human rights*; each importing particular concepts. These issues are placed in the scales, to be weighed by those responsible (under function (1)), deciding with function (2) in mind. Purpose (function (2)), creates variance in content of best interests within different contexts;
- **Gateways to best interests** represent access points through which a decision enters the realms of best interests. Regarding adults the principal gateway is *legal incompetence*; best interests is invoked as a decision-making mechanism when a patient cannot self-determine. This represents

⁹ Templeman LJ left open the possibility that in different circumstances a 'court might be driven to a different conclusion', *ibid* 1424(C).

an ethical gateway (beneficence and non-maleficence) based on the patient's *need* for treatment. Certain decisions may include other specific gateways (such as 'risk of harm'). A more controversial gateway is '*personhood*', concerning attribution of moral status.¹¹ These gateways connect moral dilemmas and legal protection. Further practical gateways may also be employed regarding bringing a patient's case for decision. Although gateways form a preliminary consideration in treatment decisions, they are considered here as the final group because significant developments relating to them have occurred later than those relating to function and content.

Developments are considered by evaluating how important cases contributed to these groups to establish how best interests has evolved.¹²

2.2.1 Development of Function

2.2.1.1 Re C (A minor)(Wardship: medical treatment)¹³

Baby C was born severely brain damaged and terminally ill. As a 16-week-old ward, the court was required to decide whether treatment should be withdrawn, given the hopeless prognosis and eventual 'inevitability' of infection or illness. At first instance, the High Court directed that C be treated so as to end her life peacefully. On appeal, at the instigation of the Official Solicitor, withdrawal of treatment was authorised.

Both **purpose** and **role** are closely associated in this case, drawing on Heilbron J's assessment in Re D.¹⁴ As to role, Lord Donaldson MR rejected a 'normalisation' approach, rather emphasising the need to treat according to circumstance,¹⁵ and effectively making the court an adjudicator in differences of professional opinion. However, the Court's approach to purpose is ambivalent. The Court sought to

¹⁰ Some redefinition has taken place since, however expansion is still occurring, see paragraph 2.3 below.

¹¹ See Chapter 5, below.

¹² Some cases are considered under more than one grouping.

¹³ [1989] 2 All ER 782.

¹⁴ Ibid, 784(h-j).

¹⁵ Ibid, 784(g-h).

minimise C's 'pain, suffering and distress', while ensuring her 'greatest dignity',¹⁶ but declined to specify which treatments (e.g. antibiotics/tube-assisted feeding) should be withheld if necessary, preferring to authorise treatment within the parameters of expert medical opinion. While this approach retains flexibility by allowing responsiveness to a patient's needs in prevailing circumstances it also represents a power shift towards the medical profession, potentially alienating parental opinion, and limiting judicial protective responsibilities under wardship.

2.2.1.2 Re F, sub nom F v West Berkshire HA & Another (Mental Health Commission intervening)¹⁷

A landmark of enduring significance regarding adult IcPs occurred around the same time. Re F concerned contraceptive sterilisation of a seriously mentally disabled 36-year-old female patient, involved in a sexual relationship with a male patient resident at the same mental hospital. The consequences of any resultant pregnancy were deemed 'disastrous' for F, and alternative contraceptive measures were medically unsuitable due to concomitant health risks.

Heard by both the Court of Appeal and House of Lords the case bore significant precedential value. Declaring sterilisation lawful, both courts reached certain mutual conclusions regarding irrelevance of the Mental Health Act 1983 in relation to physical treatments,¹⁸ implicit policy issues and common law context being 'necessity', and lawfulness being based in the patient's 'best interests'. However, beyond this, judicial opinion diverges regarding both function and content.¹⁹

¹⁶ Ibid, 787(d).

¹⁷ [1989] 2 All ER 545.

¹⁸ See Lord Brandon (HL) *ibid*, 550(j) and 553-554, and Neill LJ (CA) [1989] 2 FLR 376, 398. The issue of force-feeding has been contested since in *R v Ashworth HA ex p Brady* [2000] Lloyd's Rep. Med. 355, and *R (on application of Wilkinson) v the Responsible Medical Officer, Broadmoor Hospital and others*, 65 [2001] BMLR 15. In the latter case, the Court of Appeal rejected a *super-Wednesbury* approach (whereby the court reviews but does not substitute itself as authorised decision-maker, *ibid*, paragraphs 17-18 and 27) regarding patients contesting their competence, in favour of judicial responsibility for assessing patient capacity and whether forcible administration of treatment would infringe the HRA 1998.

¹⁹ Content is addressed below, paragraph 2.2.2.

The Court of Appeal unanimously viewed judicial **role** to be approbatory on grounds of public policy.²⁰ In contrast, the House of Lords rejected this approach,²¹ preferring declaration. However, despite formal limits, emphasis on 'desirability' of judicial involvement,²² relevance of court opinion to best interests,²³ 'pragmatic' conflation of declaration and approval,²⁴ and Lord Griffiths' formal dissent indicate tensions in their Lordships' position.²⁵ But, unanimous invocation of the Bolam standard in the House of Lords, dealt a severe blow to any approbatory approach in contrast to the Court of Appeal's earlier resounding rejection of it.²⁶

The position adopted on respective roles is closely associated with the characterisation of 'necessity' in meeting decision **purpose**. The Court of Appeal effectively considered necessity of *treatment* as a component factor of best interests (i.e. content), enabling them to demand treatment be necessary in the view of the 'general body' of specialist medical opinion. Whereas, the Law Lords effectively construed need for a *decision* in the sense of a background purpose, leaving little room for judicial opinion on appropriateness of *treatment*. This represents the first conflation of best interests and the *Bolam* standard.

2.2.1.3 Minors - the Re J cases

Re J (a minor)(wardship: medical treatment),²⁷ (hereinafter Re J #1), concerned a premature baby suffering severe, permanent brain damage, anticipated substantial disability and uncertain life expectancy; J was *not* terminally ill. The Court of Appeal concluded that ventilation could be withheld in J's best interests. Two years later a separate case, Re J (a minor)(wardship: medical treatment)²⁸ (herein Re J #2), also reached the Court of Appeal, concerning future ventilation (and/or life-saving measures) of a 16-month-old minor for whom accidental injury had caused severe

²⁰ Above (CA), 392(D), 404(E), and 413(G) per Butler-Sloss LJ analogising with provisions regarding property of incompetent adults under RSC Ord. 80 and requesting development of a new rule.

²¹ See above (HL), 556(g), 548(e), 571(e-f) and 569(c). This rejection was probably correct in view of jurisdictional limits, but contrast Re F (Adult: Court's jurisdiction) [2000] 55 BMLR 81.

²² Ibid 548(f) and 552(a).

²³ Ibid, 557(f) and 569(c).

²⁴ Ibid, 557(h-j).

²⁵ Ibid, 561-562.

²⁶ As 'insufficiently stringent' in treatment decisions for IcPs, per Neill LJ (CA) above, 403-404. See also 414(B-C).

²⁷ [1990] 3 All ER 930.

microcephaly, cerebral palsy, epilepsy and cortical blindness. Life expectancy was short. Both decisions developed the boundaries of function.

Re J #1 has significance regarding **role** and **purpose**. Lord Donaldson initially outlined the respective **roles** of doctors, parents and the court,²⁹ acknowledging treatment choice as

‘a joint decision of the doctors and the court or parents’.³⁰

Use of the adjunctive 'or' indicates that the parents' views would not prevail against the court's,³¹ and the latter's role was approbatory and ultimate.³² In terms of **purpose** the minor's best interests were (rightly) the focus, rejecting public interest or dominance of parental views. Further, it seemed that assessment of those best interests might be from the child's (assumed) perspective.³³ However, Lord Donaldson MR was keen to build flexibility into the decision to allow for future change in circumstance, and declined to restrict clinical judgment.³⁴ Thus, although formal approbatory power resided with the court, the weighty significance of clinical judgment perhaps facilitated a purpose too of protecting clinical judgment, which soon influenced role.

Although **Re J #2** is unremarkable in terms of the best interests' *content*, it laid down a significant functional (**role**) marker by centring on whether doctors could be compelled, under judicial determination of best interests, to treat a minor contrary to clinical judgment. The case involved a divergence of opinion between: (1) the HCPs and the father (unanimously supporting withholding future reventilation); and (2) J's mother, and (initially) the local authority (both of whom sought that all available treatment be provided). The Court of Appeal drew support from **Re J #1**,³⁵ to

²⁸ [1992] 9 BMLR 10.

²⁹ [1990] above, 934(e-g).

³⁰ Ibid, 934(h).

³¹ Indeed Taylor LJ expressed this, *ibid*, 943(b-c).

³² Ibid, 939(j) and 934(f).

³³ Ibid 945(d).

³⁴ Ibid, 939(e).

³⁵ Expressly relying, at p16, on Lord Donaldson MR's views [1990] above, 934(g-h) that '[n]o-one can dictate the treatment to be given to the child, neither Court, parents nor doctors' and, at 939(e), that restricting doctors' freedom to later favour more active intervention would be 'inimical' to a child's interests.

conclude that doctors could not be obliged to treat contrary to their clinical judgment.³⁶ Lord Donaldson MR concluded that

'[c]onsent by itself creates no obligation to treat...No doctor can be required to treat a child, whether by the court in exercise of its wardship jurisdiction, by the parents, by the child or anyone else. The decision whether to treat is dependent upon an exercise of his own professional judgment'.³⁷

Thus, while *Bolam* formed no part of the judgment, pragmatically medical opinion held sway in this case regarding minors as it had done regarding adults. Certainly, medical expertise is crucially important, but cases regarding adults have since highlighted its insufficiencies as the *wholly* determinative role (see below). Further, while clarification of respective roles is welcome, this functional aspect has been allowed to obscure purpose and in particular the importance of the subject's individual interests. Implicit judicial endorsement of an association between clinical judgment and quality of life also bore implications for content; affecting the *type* of interest imported and weighed in the balancing process. Rather, best interests decisions should take account of a wide range of interests beyond the purely medical whenever relevant (see further below).

2.2.1.4 Mature minors: *Re R (A minor)(Wardship: medical treatment)*³⁸ and *Re W (A minor)(Medical treatment)*³⁹

Re R and *Re W* represented new territory for best interests, concerning mature minors with definite views about their own treatment that were refusing medical intervention. Any decision had to be made in the light of the House of Lords exposition of consent in *Gillick*.⁴⁰ Additionally, the Children Act (1989) required consideration to be given to the child's wishes and feelings.⁴¹ Inevitably, any resolution would test the boundaries of respective roles. The two judgments are addressed together here because they developed the same issues regarding differing age groups. **R** was a 15-year-old ward suffering mental health problems, including hallucinations and some violent behaviour. During rational and lucid periods **R**

³⁶ All three Lords Justice declined to compromise clinical judgment: [1992] above, 19-21.

³⁷ *Ibid*, 18, citing from *Re R* [1991] above.

³⁸ [1991] 4 All ER 177.

³⁹ [1992] 3 WLR 758.

⁴⁰ *Gillick v West Norfolk & Wisbech AHA & DH&SS* [1986] 1 AC 112.

⁴¹ s1(3)(a).

objected to taking anti-psychotic medication. The local authority sought leave for the adolescent psychiatric unit treating R to administer medication (including anti-psychotic drugs) despite her refusal. At first instance the order was granted in view of R's lack of capacity. An appeal was dismissed on the different ground that a court could override a minor's refusal (Gillick-competent or not) if in the minor's welfare interests so to do.

Re W concerned treatment of a 16-year-old girl for anorexia nervosa. Due to deterioration in her condition the residential adolescent unit sought her transfer to a specialist hospital, but W declined. The local authority applied (under s100(3), Children Act (1989)) requesting that the court exercise its inherent jurisdiction to authorise treatment. The High Court granted leave to transfer W. W then appealed, during which her condition worsened and an emergency order was made enabling transfer. The appeal was eventually dismissed, holding that a minor's views could not veto court consent; the court could override them where the minor's best interests demanded. These cases pitched the minors' capacity to *refuse* against the *court's* power of consent. The cases focus on role as a means to achieving the purpose of best protecting the minor. Relevant roles can be considered as: judicial, 'keyholder', and clinical.

In **Re R**, the Court of Appeal unanimously construed **judicial role** in wardship widely,⁴² being 'wider than that of parents',⁴³ and regarding a minor's refusal as effecting no practical limit upon it.⁴⁴ Lord Donaldson's obiter comments on the Family Law Reform Act 1969 (FLRA 1969), also suggested parental consent could remain effective despite a 16/17 year old's refusal. Despite receiving heavy criticism,⁴⁵ this was reaffirmed in **Re W**, where the unlimited scope of inherent jurisdiction allowed narrow construction of the FLRA (1969) as 'enabling'.⁴⁶ Indeed, Nolan LJ posited 'inescapable responsibility' for decision-making with the court, in effect framing the decision purpose as being:

⁴² Above, 186(g-j), 189(c-g) and 192 (g).

⁴³ Per Lord Donaldson MR, *ibid*, 186(g-j).

⁴⁴ A lacuna existed because legal provision had been made for minors under 16 years (**Re R**), adult ICPs (**Re F**), and *consent* (but not refusal) by 16/17 year olds (Family Law Reform Act 1969, s8).

⁴⁵ E.g. A. Bainham, *The judge and the competent minor* (1992) 108 LQR 194; R. Thornton, *Multiple keyholders - wardship and consent to medical treatment* (1992) CLJ 34.

'to ensure so far as it can that children survive to attain [majority]'.⁴⁷

Together with Gillick, this reserved final decision to the court regarding minors less than 18 years, predisposing decisions towards treating wherever prognosis is sound.

Judicial interpretation of Lord Scarman's seminal statement in Gillick,⁴⁸ characterised consent in **Re R** as

'a key which unlocks a door'.⁴⁹

That is, it permits, but cannot compel, treatment. Further, Lord Donaldson differentiated between 'determination' and 'consent', construing the former as broader and equating it with *refusal*.⁵⁰ This distinction's purpose is wholly enabling: once a minor is Gillick-competent, the parents may not effectively *refuse* as the child's *consent* enables treatment; conversely, if a Gillick-competent minor *refuses*, parents or a court can still *consent* enabling treatment.

Subsequently, in *Re W*, Lord Donaldson regretted his **keyholder** analogy, having overlooked that

'keys can lock as well as unlock'.⁵¹

Instead, he preferred the notion of consent as a 'legal "flak jacket"', only needing to be supplied by *one* competent party to protect HCPs.⁵² This raises the question as to who the court is protecting; the minor's interests, or the medical professionals involved? However, the purpose seems to remain one of *enabling* treatment, Gillick (or statutory) competence engendering concurrent powers of consent, rather than a transfer of rights from parent to child. However, despite espousal on the importance of minors' views,⁵³ the Court ultimately reserved its judicial discretion to override them on the basis of welfare.

⁴⁶ I.e. the statute (which aimed to protect HCPs from trespass litigation) *enabled* 16/17 year olds to *consent* to treatment, but not to *refuse*, see [1992] above, 764-766, 772 and 774(C-D).

⁴⁷ *Ibid*, 781(H).

⁴⁸ [1986] above, 188-189.

⁴⁹ Per Lord Donaldson, above, 184(c-e).

⁵⁰ Other appellate judges in *Re R* confined themselves to commenting on court jurisdiction to overrule minors.

⁵¹ Above, 767(B)

⁵² *Ibid*, 767(B-C).

⁵³ *Ibid*, 767(D), 772(E), 776(E-F), and 781(D-E). See also *Re M* (child: refusal of medical treatment) [1999] 2 FCR 577, where the increased sensitivity of the approach has received supportive commentary: G. Douglas, *Fam. Law* (1999) 753; and J. Fortin, *Children's rights and the developing law* (1998) Butterworths, London, Update 4, Chapter 5.

In **Re R** and **Re W**, following the **Re J #1** and **#2** approach, **clinical role** remained; no one could compel a doctor to treat a child. However, in **Re W**, the Court of Appeal distanced itself a little from wholesale support for clinical judgment (displayed in **Re J#2**), by reference to judicial *discretion* when choosing between two course of action, each supported by responsible medical opinion.⁵⁴ However, Gillick competence leaves ample scope for clinical judgment to dominate minors' capacity for 'full understanding', because:

'[minors'] lack of competence to make an informed decision can be imposed upon them by the professionals involved'.⁵⁵

The functional purpose and respective roles in best interests were soon set to become even more acute in the context of treatment withdrawal from incompetent adults.

2.2.1.5 Airedale NHS Trust v Bland⁵⁶

The Bland decision significantly raised the profile of best interests, constituting a significant further step (regarding medical support of incapacitated adults). The case concerned the lawfulness of continuing/withdrawing life-sustaining treatment from a twenty-one year old patient who had been in a persistent vegetative state (p.v.s.) for three and a half years consequent on a severe chest injury sustained in the Hillsborough Stadium disaster (1989). His injuries had caused anoxia, irreparably damaging his brain cortex, with no prospect of recovery or improvement. Airedale NHS Trust sought, with the support of Anthony's family, a judicial declaration that withdrawing naso-gastric feeding and life-prolonging treatment would be lawful. The Official Solicitor appealed the decision to the House of Lords. Courts throughout declared lawfulness, but their reasoning varied considerably, particularly between the two appellate courts. At first instance it was acknowledged that:

'[t]his case clearly raises serious moral, medical and ethical issues'.⁵⁷

⁵⁴ Above, 770(G-H), see also 777(B-C), 780(E) and 781(H). This transpired to be necessary in the conjoined twins case [2001] above.

⁵⁵ C. McCafferty, *Won't consent? Can't consent! Refusal of medical treatment* (1999) Fam. Law 335.

⁵⁶ [1993] 1 All ER 821.

⁵⁷ Per Stephen Brown P, *ibid*, 826(a-b).

Indeed, it directly impacts the function and content of best interests, and casts a penumbral shadow over certain gateway elements. This impact is considered, therefore, under all three headings herein.

The two appellate courts concurred on some **purposive** aspects of the case. Butler-Sloss and Hoffman LJ finding common ground with Lords Goff and Browne-Wilkinson in distinguishing between (unlawfully) *causing* the patient's *death*, and (lawful) *non-prolongation* of *life*.⁵⁸ However, unlike earlier cases on withholding treatment from minors (e.g. Re C [1989]), in p.v.s. death was *not* imminent, rather becoming so only *as a result of* withdrawing/withholding treatment. In p.v.s. it is difficult to see how 'not prolonging' differs substantially from 'ending'.⁵⁹ Motivation for the distinction accrues from their Lordships' acceptance of the traditional legal context of acts and omissions,⁶⁰ categorising withdrawal of treatment as an 'omission', and averting problems of criminal liability. Although the distinction might have been a means to an end,⁶¹ it risks deluding us about the decision's true purpose (to end the patient's life) and has implications for content and how we view a patient's interests.

Both appellate courts acknowledged the relevance of underlying values such as self-determination and sanctity of life.⁶² However, their divergent responses foreshadowed fundamental functional differences regarding **role**. While the Court of Appeal willingly shouldered responsibility for moral and ethical questions raised,⁶³ the House of Lords considered it for the legislature's address.⁶⁴ Up to this point, courts were willing and able in minors' cases to take an active role in the decision, framing purpose as paramountcy of welfare,⁶⁵ whereas, regarding adult IcPs, the House of Lords had focused on *medical* purpose, deferring to HCPs as the prime

⁵⁸ Ibid, 848(j), 856-857; and 869(c), 894, and 883(b-c), respectively.

⁵⁹ The Law Lords' distinction has raised accusations of semantics. See my earlier article (1998), above, attached as Appendix 8. Also, G.M. Craig, On withholding nutrition in the terminally ill: has palliative medicine gone too far? *J. Med. Eth.* (1994) 20, 139, 141. J.K. Mason and G.T. Laurie, The management of the persistent vegetative state in the British Isles, *Juridical Review* (1996) 4, 263, 280 emphasise designation of 'cause of death' as a factor.

⁶⁰ [1993] above, 867-868, and 881-883.

⁶¹ Indeed, its suitability in the p.v.s context was doubted by Lord Mustill, *ibid*, 885(j).

⁶² *Ibid*: 835-836, 842-843, 845(d), and 851(b)-852(j) (CA); and 861(g-j) and 865-866 (HL).

⁶³ *Ibid*, 835(g), 852(f).

⁶⁴ *Ibid*, 878(b-c), and 889(a-c).

⁶⁵ Re B [1981], Re C [1989] and Re J [1990] above.

assessors.⁶⁶ In *Bland*, however, although the decision as to withdrawal of treatment had situational parity with individualistic, quality of life (per *Re J* #1), jurisdictionally, the case paralleled the more generalised formulation of *Re F*. This duality gave rise to fundamental differences in appellate opinion. The Court of Appeal's apparent acceptance of both lines of authority (that is, *Re J* and *Re F*) as relevant,⁶⁷ influenced content and led the court to recognise Anthony Bland's continuing possession of relevant interests despite permanent insentience. In contrast, their Lordships preferred *Re F*, and rejected endurance of interests. This discord resulted in the Court of Appeal perceiving its role as *balancing* relevant interests, while the House of Lords identified nothing to balance.

Where a need to balance is identified, it is a small step to admit a judicial role that is functionally *determinative* of best interests.⁶⁸ In this light, the Court of Appeal majority rejected any overriding role for *Bolam*.⁶⁹ Whereas, the majority of the Law Lords elevated the role of *Bolam*,⁷⁰ finding no duty to continue treatment,⁷¹ and made *medical reasonableness* determinative.⁷² Only Lord Mustill expressly cautioned (obiter) that

'the decision is ethical, not medical, and...there is no reason in logic why on such a decision the opinions of doctors should be decisive'.⁷³

This author has criticised use of *Bolam* in this context as excessively medicalising best interests assessment.⁷⁴ While reliance on medical evidence is obviously necessary, allowing it to play a comprehensive determinative role insupportably abrogates judicial responsibility, and risks courts merely 'rubber-stamping' medical decisions.⁷⁵

⁶⁶ In *Re F* [1989], above.

⁶⁷ Above, 844(f-g), 857(d-e), and 857(g).

⁶⁸ Reflected in Butler-Sloss LJ's view of judicial involvement as an important safeguard, *ibid*, 849(f).

⁶⁹ Hoffman LJ, *ibid* 858(b-f) limited *Bolam* to evidential input. See also Butler-Sloss LJ, 845(c).

⁷⁰ E.g. *ibid*, 871(f-g).

⁷¹ *Ibid*, 861(f).

⁷² *Ibid*, 883(g).

⁷³ *Ibid*, 895(h).

⁷⁴ See A.J. Fenwick [1998] above, 90.

⁷⁵ A danger that seemed to manifest in the haste of judicial decision in *Frenchay Healthcare NHS Trust v S* [1994] 1 WLR 601, where diagnosis was less certain and no opportunity was created for independent reports to be obtained.

2.2.1.6 Law Hospital NHS Trust v The Lord Advocate⁷⁶

The Law Hospital decision formally adopted Bland, but raised certain functional differences. The case concerned a forty-three year old female patient who had been in p.v.s. for three years with no prospect of improvement. The patient's family supported the application for declarator. The Court of Session (Inner House) unanimously adopted best interests as the relevant test,⁷⁷ considering that, as no benefit would be gained from continued treatment, it would *not* be in the patient's interests.⁷⁸

Given the Inner House's unanimous recognition of the availability of *parens patriae* in Scotland,⁷⁹ we might have expected a dynamic, determinative judgment. However, it is unclear whether the function of the court is to *determine* or *define* best interests. Lord President Hope emphasised the acceptability of best interests under both wardship and declaratory jurisdictions,⁸⁰ assuming both applications to comprise the 'same test'.⁸¹ However, in the derivation of best interests at that stage the two tests were *not* functionally synonymous. While the **purpose** in both situations might have been expressed as *deciding in the patient's best interests*, the relative roles and authority to achieve this differed under the two approaches. The lack of clarity about whether the court should perform a *balancing* function may not be crucial where 'futility' clearly justifies withdrawal, but becomes more important the closer we move to addressing quality of life decisions. Further, it does little to clarify the use of best interests in non-futility cases where balancing may be fundamental to decision-making.

This confusion as to approach is exacerbated by the Court's ambivalence towards Bolam. Grubb suggests that the Inner House really regarded the House of Lords as having determined Anthony Bland's best interests themselves, considering - but not deferring to - medical opinion.⁸² If correct, this raises two concerns. First, this approach compounds tensions inherent in Bland, because absence of elucidation as to

⁷⁶ [1996] SLT 26, 848 and 869.

⁷⁷ Ibid, 858, 861, 863, and 866.

⁷⁸ Ibid, 859(E), 861(F) and 866(G-H).

⁷⁹ Ibid, 857(B), 862(L), 863(L), 866(C) and 866(L).

⁸⁰ Ibid, 858(C-J).

⁸¹ Ibid, 858(F).

function and role fit under *parens patriae* means the Court of Session perpetuated the acceptability of formally *defining* one thing and informally *determining* something else. Second, while Grubb rightly suggests that the Inner House was willing to *determine* best interests,⁸³ functional disparity between the House of Lords' and the Inner House extends into role. That is,

- *medical role*, despite following Bland, surprisingly little mention is made of Bolam.⁸⁴ Perhaps this dearth of reference accrues from its irrelevance to an approbatory jurisdiction, but this sits uneasily with simultaneous wholesale adoption of Bland,⁸⁵
- *judicial role*, consistent with availability of *parens patriae* the Inner House accepted that withdrawing treatment from IcPs was a matter for the court,⁸⁶ and jurisdictionally the Court had power to demand its own *determination* of treatment withdrawal.⁸⁷ However, Lord Hope did not envisage court application being necessary in every case, leaving responsibility for deciding whether to apply with HCPs.⁸⁸ This results in a curious position; the Inner House's approach being unnecessarily narrow given its extensive jurisdiction, and the House of Lords informally requiring p.v.s. cases to be heard judicially - despite lacking formal jurisdiction to so demand;⁸⁹
- *patient 'role'*, as the patient is insensate, this comprises the question of admitting a subjective viewpoint. Lord Hope's leading judgment showed willingness to encompass a patient's *express* views,⁹⁰ but the majority

⁸² A. Grubb, Incompetent patient (p.v.s): withdrawal of feeding (Scotland), *Med. L. Rev.* 4 [1996] 300, 305.

⁸³ *Ibid.*

⁸⁴ Only Lord Hope refers to Bolam, above 859(F-I), in the context of futility.

⁸⁵ The Adults with Incapacity (Scotland) Act 2000 attempts to clarify medical role, but its practical success in achieving this remains to be established.

⁸⁶ Above, 852(J-K), 863(F-H), 863(L), 866(F) and 866(L).

⁸⁷ However, the Inner House recognised its civil limits of jurisdiction by avoiding encroaching on the Lord Advocate's entitlement to prosecute irrespective of declarator by the Court of Session.

⁸⁸ *Ibid.*, 860(D). This remains open to appeal by 'interested others' under the recent Act (s50), or for inclusion within designated treatments requiring safeguards (s48(2)).

⁸⁹ The requirement of court involvement in England and Wales continues by virtue of the Official Solicitor's Practice Note 1 May 2001, adopted as 'valuable guidance' by Dame Butler-Sloss (P) 14 December 2001, both reported at [2002] 1 All ER 794.

⁹⁰ Above, 860(J).

approach is implicitly objective (like Bland). Lord Clyde held a minority view giving precedence to subjectivity, framing the question as whether

'it is or is not just and proper to grant the authorisation in the circumstances as viewed from the position of the patient'.⁹¹

This approach more reflects the Court of Appeal's view in *Re J #1* and, *prima facie*, resembles substituted judgment. But it is more sophisticated: reference to the 'justness of granting authorisation' means that Lord Clyde's position may be an assessment of circumstances from both an objective and subjective perspective. His linguistic contrast is significant; drawing emphasis away from professional liability, to focus (rightly in terms of proxy decision-making) on the well-being of the IcP. Lord Clyde's approach reminds the decision-maker to tread carefully, for, s/he acts *on behalf of* another adult. However, the majority approach in *Law Hospital* seems to be a functional opportunity lost; with suitable jurisdiction available it had offered landmark potential to clarify the various roles involved.⁹²

2.2.1.7 *Re Y* (Mental Incapacity: bone marrow transplant)⁹³

An increasingly expansionist role is seen in the case of *Re Y*. *Re Y* concerned a 25-year-old female, severely mentally and physically handicapped from birth. Y's 36-year-old sister (the plaintiff) suffered from a pre-leukaemic bone marrow disorder. The plaintiff's deteriorating condition required a bone marrow transplant for her survival. Y was the only sibling likely to match as a donor, but Y's disabilities precluded her consenting to blood testing and/or donation. The plaintiff requested a declaration of lawfulness under the court's inherent jurisdiction.⁹⁴ This case, and others such as *Re S* (medical treatment: adult sterilisation),⁹⁵ highlighted growing application of best interests across varied treatment contexts, including those of a

⁹¹ *Ibid*, 863(I-J).

⁹² This has been left, ultimately, to be developed by the legislators in the Adults with Incapacity (Scotland) Act 2000.

⁹³ [1996] 2 FLR 787.

⁹⁴ Under RSC Ord. 15, r16.

⁹⁵ [1998] 1 FLR 944.

non-curative nature. Connell J was required to resolve any potential conflict of interests, between the plaintiff's need for a donor and the defendant's need for protection from invasive surgery, in a functionally consistent way. This involved both purpose and role.

Re Y was distinguishable from Re F on the basis of **purpose**; the procedure was *not* aimed at *improving/preventing deterioration of Y's physical/mental health*. Rather, the benefit was to the health of Y's sister, but Connell J seemed swayed by the *family's* plight as a whole.⁹⁶ Prior to this case, donation by adult ICPs had never been ruled out despite its anticipated 'special category' status. And, despite the attractions of substituted judgment (that might find *if* Y could understand her sister's needs, *then* she (Y) *would* want to be a donor),⁹⁷ Connell J was bound by precedent to reject it. Having established best interests as the relevant test, the donation situation had to be squared with the traditional purpose of benefiting the *IcP*. In addressing this he added a gloss to the test, such that benefit to another (i.e. a recipient donee) is irrelevant *unless*, as a result (of acting as donor), the procedure is in the *donor's* best interests. In other words, some (indirect) positive benefit **must** accrue to the incompetent adult.

This *reformulated* purpose also required redefinition of 'benefit'; for, how can a procedure that is not diagnostic, prophylactic, or curative possibly 'benefit' an *IcP*? Connell J, drawing on the American case, *Curran v Bosze*,⁹⁸ expanded the range of 'benefits' to include *psychological benefit based in relationship*.⁹⁹ While there was very limited evidence of a sufficiently close relationship between Y and her plaintiff sister,¹⁰⁰ Connell J based benefit to Y on the desirability of maintaining existing relationships within the whole family, the procedure thereby being

'to her [Y's] emotional, psychological and social benefit'.¹⁰¹

⁹⁶ Referring to the urgency of the plaintiff's need, her young daughter's status as an only grandchild, and the potential impact on the already-poor health of Y's mother, [1996] above, 789-791.

⁹⁷ See *ibid*, 791(F-G).

⁹⁸ (1990) 566Ne2d 1319. Cited in the instant case, 791(G)-792(F).

⁹⁹ See also *Strunk v Strunk* (1969) 445SW2d 145, where a close relationship had warranted donation of non-regenerative tissue by an adult *IcP* to his brother in.

¹⁰⁰ Above, 790(F-G).

¹⁰¹ *Ibid*, 794(A-B).

This extends **purpose** considerably; almost any procedure could aim to achieve at least one such benefit. Implications of this for *content* are discussed below. But, shifting purpose into emotional and social realms begins to alter **roles** - the remit being no longer purely medical.

Connell J's requirement that future cases involving bone marrow harvesting on adult incompetents should be 'ventilated' in court,¹⁰² seems a welcome extension of judicial role. Although this terminology ('ventilation') avoids directly confronting either the approbatory/declaratory roles, it effectively creates a bridge between formal jurisdictional limits, and informal acknowledgment of a judicial need actively to *determine* best interests. Medical evidence still has an important informative role to play. Yet, ironically, in some respects valuable medical opinion is not maximised; Feenan rightly criticises the absence of professional assessment of Y's psychological development and the anticipated psychological impact of reduced contact between Y and her mother.¹⁰³ Thus, considerable further role clarification was (and is) still warranted.

2.2.2 Development of Content

Throughout this expansive period, the content of best interests had also witnessed marked development.

2.2.2.1 Re C (A minor)(Wardship: medical treatment)¹⁰⁴

The Court of Appeal's decision raises a number of content developments. Lord Donaldson MR clearly made C's 'well-being, welfare and interests' paramount,¹⁰⁵ consolidating the close association between best interests and **welfare**. However, the selectivity of his reliance on precedent is also apparent. While emphasising paramountcy from Re B,¹⁰⁶ a factual distinction was drawn between Re B and this

¹⁰² Above, 794(E-F).

¹⁰³ D. Feenan, A good harvest? *Re Y (Mental incapacity: bone marrow transplant)* CFLQ (1997) 9(3) 305, 309.

¹⁰⁴ [1989] 2 All ER 782.

¹⁰⁵ *Ibid*, 787[g-h].

¹⁰⁶ [1981] above, cited *ibid*, 786(j).

case, permitting differing outcomes without inconsistency of principle. *Pace* Re B, C's best interests were the guiding principle, but C's situation was more severe:

'the quality of...[C's]...life will be demonstrably awful and intolerable'.¹⁰⁷

Hence, C's situation comprised the exceptional scenario, previously left open by Templeman J in Re B. Certainly, in assessing **quality of life** Re C confirms that physical pain is a significant element,¹⁰⁸ but not the *only* factor. The Court's clear objective was to minimise pain, suffering and distress while maximising dignity, protecting C's **interests** in physical welfare, and bodily integrity, respectively. But, this indicates that, whatever formal *content* is accorded to best interests, pragmatic *protection* of those interests often depends upon function.¹⁰⁹

2.2.2.2 Re J (a minor)(wardship: medical treatment)¹¹⁰

Re J #1 entered the gap between the moribund status of Re C [1989] and the potential longevity of Re B [1981]. Re J #1 was the first judicial decision to withhold treatment from a *non-terminal* minor.¹¹¹ The Court of Appeal adopted a basic test of paramountcy,¹¹² and framed the requisite balancing exercise as a '**critical equation**'.¹¹³ This 'non-mathematical' formulation started from a strong presumption favouring prolonging life, which was rebuttable by resulting factors such as pain, suffering and poor quality of life. This approach, in effect, combines the formulations of Re B *and* Re C. However, Lord Donaldson then diverted away from Re B's quality of life terminology,¹¹⁴ seemingly preferring the Canadian approach of substituted judgment as illustrated in *Superintendent of Family and Child Service v Dawson*.¹¹⁵ This approach has never taken hold in the United Kingdom but its normative appeal in IcP decisions is considered further in Chapter 4. In addition, the Court of Appeal took the unprecedented step of allowing withholding

¹⁰⁷ Ibid, 787(b-c).

¹⁰⁸ See also Mason, McCall Smith and Laurie, *Law and Medical Ethics* (2002) paragraphs 16.34 and 16.39.

¹⁰⁹ The initial order authorising 'treat[ing] the minor to die' was amended to read 'allowing her life to come to an end peacefully and with dignity', above, 787(f-g).

¹¹⁰ [1990] 3 All ER 930.

¹¹¹ Because in Re B [1981], above, the court had opted to *treat*.

¹¹² Above, per Balcombe LJ, 942(h), in accordance with both Re B (1981) and Re C (1989).

¹¹³ Ibid 938(e).

¹¹⁴ I.e. that quality of life would be 'demonstrably awful'.

¹¹⁵ (1983) 145 DR (3d) 610.

of treatment in an otherwise non-terminal situation, albeit on the dubious basis of the act/omission distinction. This terminology proved catalytic in later developmental cases such as Bland. However, *welfare* was becoming an intense focal point regarding mature minors.

2.2.2.3 Mature minors: Re R (A minor)(Wardship: medical treatment)¹¹⁶ and Re W (A minor)(Medical treatment)¹¹⁷

While **welfare** was merely hinted at in Re R,¹¹⁸ it featured prominently in Re W, where Lord Donaldson limited the extent of a minor's developing autonomy:

'good parenting involves giving minors as much rope as they can handle without an unacceptable risk that they will hang themselves'.¹¹⁹

In so doing, he closely associated best interests with welfare and prudence, the latter meaning:

'avoiding taking risks which, if they eventuate, may have irreparable consequences or which are disproportionate to the benefits which could accrue from taking them'.¹²⁰

Thus, the minor's wishes may be incorporated as an element of best interests until they operate against the decision's functional protective goal. Although Balcombe LJ included autonomy more explicitly:

'[i]t will normally be in the best interests of a child of sufficient age and understanding to make an informed decision that the court should respect',¹²¹

this was tempered by judicial power to override the minor's views. However, Balcombe LJ declined to define the point at which that should occur.¹²²

Nolan LJ made the most transparent exposition of welfare, citing s1(1) of the Children Act (1989) to evince paramountcy, then construing it in the light of s1(3), to include: *ascertainable wishes and feelings of the child; his/her needs; effects of changing circumstances; background characteristics, risk of harm, and capacity of*

¹¹⁶ [1991] 4 All ER 177.

¹¹⁷ [1992] 3 WLR 758.

¹¹⁸ Above, 192(g-h).

¹¹⁹ Above, 770(D).

¹²⁰ Ibid, 770(C-E).

¹²¹ Ibid, 776(D).

¹²² Ibid, 777(C).

others to meet his/her needs.¹²³ This certainly aids clarification of **relevant factors**. However, the point at which protective intervention (and therefore the overriding of a mature minor's views) becomes justified was couched only as avoiding 'serious and imminent risk' of 'grave and irreversible harm'.¹²⁴ We see here how both 'best interests' and 'welfare' can be used in broad, vaguely justificatory ways. Hence, while 'welfare' has valuable *scope* to include personal (non-medical) **interests**, it can also cover a multitude of interpretations of best interests in any one case. The *content* accorded depends on function and perspective. In relation to mature minors, it seems that purpose (preserving life until the age of (competent) majority)) dominates content. This is exemplified in the curious absence of reference to 'balancing'.¹²⁵ This raises doubts about *how*, or indeed *whether*, balancing is performed regarding mature minors. Clearly, by deciding to override, *some* balance point is judicially perceived to have been passed. But judicial reluctance to define the decision process renders weighing invisible. We can only conclude that resolution revolves around arcane judicial discretion, aimed at ensuring the minor's survival to adulthood.¹²⁶

2.2.2.4 Re F¹²⁷

A mandate for treatment was also occurring regarding adult IcPs, but with more specific, narrowly medical content. This variance in content reflects the varying functional approaches to minors and adults. The Court of Appeal found justification for sterilising F based on treatment of adult IcPs being in the public interest, provided that *treatment* is necessary (and suitably safeguarded).¹²⁸ While the House of Lords, accepted the significance of public interest to a degree,¹²⁹ their Lordships framed necessity as a need for others to *take decisions and/or care for the IcP*.¹³⁰ By raising the level of abstraction to need for a *decision* (rather than a need for *treatment*), the

¹²³ Ibid 780-781.

¹²⁴ Ibid 781(H).

¹²⁵ Only Nolan LJ cited Thorpe J's view at first instance, regarding the need to 'balance...the vehemently expressed wishes and feelings of the child and the harm which the child is at risk of suffering', *ibid* 778(G).

¹²⁶ Ibid, 781(H).

¹²⁷ [1989] 2 All ER 545.

¹²⁸ [1989] 2 FLR 378, 401-403, and 409-410.

¹²⁹ Above, 551 (d-e), and 561(d-e).

Law Lords' reframed necessity as *purposive*, rather than as a component element of best interests.

This opened up best interests to development of new content. Lord Brandon seized this opportunity, considering that treatment would be in best interests:

'if, but only if, it is carried out in order either to save their lives or to ensure improvement or prevent deterioration in their physical or mental health'.¹³¹

This broad formulation of content has become the seminal exposition of best interests in adult IcP decisions. The judgment was clearly not intended to be restricted to sterilisation decisions and the Lords had sidestepped the broad 'welfare' approach (favoured by the Court of Appeal). In contrast to welfare's ability to embrace both medical and non-medical interests, this new construction invited purely medical factors to dominate the best interests of adult IcPs, particularly in invoking Bolam as the relevant standard. As has already been stated the effect of the Lords' attributed content was such that, if a responsible body of skilled medical opinion considered that treatment aimed to save the patient's life, or improve or maintain his/her health, then treatment would be in the IcP's 'best interests'. Unlimited contextual relevance created a licence lawfully to treat.

2.2.2.5 Bland¹³²

The differing approaches of the Court of Appeal and House of Lords in Bland regarding function are also apposite in relation to content. The Court of Appeal attempted to reconcile two distinct lines of authority, recognising (from Re F) that: (1) lawfulness of treating adult IcPs turned upon best interests; and (2) Bolam generally governed the duty to treat thereby,¹³³ and simultaneously (importing from Re J#1): (3) the need to balance issues; and (4) the relevance of underlying values analogous to the life/death context of Bland.¹³⁴

¹³⁰ Ibid, 551(e), and 567(a-b). *Aliter*, Lord Bridge suggested IcPs could be deprived of beneficial treatment, *ibid*, 548(h).

¹³¹ Ibid, 551.

¹³² [1993] above.

¹³³ Ibid, 844(f-g), and 857(d-e).

¹³⁴ Ibid, 857(g). Indeed, Butler-Sloss LJ explicitly applied Re J#1, *ibid* 846(a-b).

However, reconciling these two approaches was never really viable because of the jurisdictional limitations outlined above. Perhaps mindful of these dangers, the Law Lords preferred a straight application of *Re F*; *Re J #1* was effectively distinguished due to Anthony Bland's insensate state.¹³⁵ However, the real motivation for this finding was content-oriented; the total absence of any prospective benefits meant that **no weighing** was needed in p.v.s. and continued treatment would be futile.¹³⁶ In other words, the best interests scales contained nothing, therefore no balancing function was required. This contrasted with a sensate (minor) patient, whose quality of life is influenced by factors such as pain, hazards, and invasiveness of treatment, which give content to the weighing process.

Interests and the need for balancing are closely associated; generally conflict within a patient's interests creates the need to reconcile or balance them. Interests and balancing represent content and function, respectively. *Possession* of interests becomes a gateway criterion to decide *in* an adult patient's best interests. The Bland decision reflects the *type* of interest that courts are willing to recognise, namely only experiential interests (see further Chapter 3). Again, on this issue the two appellate courts were discordant. The Court of Appeal recognised non-medical interests such as bodily integrity and how others remember the patient.¹³⁷ Relatedly, Hoffman LJ considered Bland had

'a recognisable interest in the manner of his life and death which help the court to apply the principles of self-determination and the value of the individual'.¹³⁸

Thus, Hoffman LJ recognised a type of interest beyond a patient's current, conscious experience. In contrast, the House of Lords acknowledged no significant interest, Lord Browne-Wilkinson rejecting Butler-Sloss LJ's incorporation of intangible factors as unduly reflecting a judge's (subjective) moral view.¹³⁹ Lord Keith considered Bland 'indifferent' to his own continued life or death,¹⁴⁰ and this

¹³⁵ Ibid, 861(a), sentience (to pain) being one traditional criterion for moral status. Sentience and personhood are considered below, Chapter 5.

¹³⁶ See particularly Lord Goff, *ibid*, 870(a) and (d-e).

¹³⁷ Ibid, 840(b-c).

¹³⁸ Ibid, 854(b-c). Recognising possession of some interests influenced all three judges to incorporate a balancing role, see *ibid* 840(a-c), 857(g), and 846(a-j).

¹³⁹ Ibid, 879(f-j).

¹⁴⁰ Ibid, 861(a-b).

attenuated approach to interests reaches its climax in Lord Mustill's conclusion that Anthony Bland

'has no best interests of any kind'.¹⁴¹

The irony of these differing approaches is that, in the p.v.s. context, 'best interests' takes no account of a patient's previously existing personality. It is impossible to reconcile this with the artificial viewpoint that may be imputed regarding a severely disabled baby who has never actually possessed competence, opinions, or beliefs (Re J#1). Arguably, however, the House of Lords was wrong. Having no current or future interest in living does not automatically equate to "no interests". Certain interests deriving from a p.v.s. patient's previous personality are surely still attributable, such as religious beliefs, previous views about this type of situation, concerns about family and friends, and perhaps even beneficence (e.g. a strong personal belief in organ donation). We can only form a truer picture of the whole individual by looking at this rounder view of 'interests',¹⁴² which would provide a firmer basis for determining 'best' interests. This argument is developed as this thesis progresses.¹⁴³

Fundamentally, the Bland judgment fails on content, formally promoting a narrow medicalised conception of 'interests', and leaving no room for personal (non-medical) interests.

In terms of content Bland is divisive; formally separating the meaning of tests applicable to minor and adult IcPs. However, the issue of patient interests was to persist, coming under further scrutiny in Re Y.

2.2.2.6 Re Y (Mental Incapacity: bone marrow transplant)¹⁴⁴

Although best interests had scope for a wide range of benefits, its diversity had fallen victim to the long shadow cast by Bolam and consequent emphasis on *medical*

¹⁴¹ Ibid, 894(f). However, Lord Mustill did acknowledge that 'glimmerings of awareness may give the patient an interest which cannot be regarded as null', making legal/ethical issues 'altogether more difficult', 896(d). But this caveat has gone unheeded with recent extension to non-p.v.s. cases, see further below.

¹⁴² In the Matter of a Ward of Court [1995] 2 ILRM 401, 463-465 applied 15 'factors' to best interests, including life history, previously expressed views; family/carer's view; privacy, dignity, autonomy; and the 'common good' in protecting life.

¹⁴³ See Chapter 3 and particularly Chapters 6-8.

¹⁴⁴ [1996] above.

interests. Re Y, redeveloped the approach to adult IcPs, referring to **psychological, emotional and social benefits**. Additionally, Connell J opted to weigh these benefits against any detriments to Y,¹⁴⁵ drawing authority from very limited reference to judicial 'balancing' in Re F.¹⁴⁶ In Re Y a broader set of **factors**, including familial relationship, psychological benefit, and avoidance of consequential harm were evaluated.

However, the obvious difficulties of finding a donation to be positively *in* a donor's best interests forced development of, what is effectively, a **negative construction** of best interests. In Bland *continued* intervention was *not in* his best interests (i.e. the overriding concern was to avoid harm). In Y, Connell J suggested that *not* intervening would be *against* Y's interests and this itself would be a harm. This, in conjunction with a perceived (albeit minimal) psychological benefit, led to the conclusion that intervention was *in* Y's interests. Hence, by adjusting *content* the decision's *purpose* is transposed into 'protecting' the IcP from (an albeit remote) **indirect harm**. The superficially compelling appeal to **harm prevention** becomes dominant where opposing detriments weigh lightly. But, this weighting can be skewed by poor risk assessment. Feenan highlights the incomplete assessment of risks inherent in bone marrow procedures in re Y.¹⁴⁷ Relatedly, Mumford suggests assessment should include the potential psychological impact upon the (incapax) donor of an *unsuccessful* transplant.¹⁴⁸ Thus, a court should be equally willing to consider harmful consequences flowing both from *proceeding* and *not* proceeding. Inclusion of additional factors must be addressed consistently, whether harms or benefits.

Re Y's incorporation of interests beyond the purely medical received a mixed reception from commentators. Some welcomed inclusion of emotional and social well-being,¹⁴⁹ while others warned that wider interpretation might risk manipulation of the best interests test to achieve dubious outcomes.¹⁵⁰ In essence these tensions

¹⁴⁵ Ibid, 792(G).

¹⁴⁶ [1989] above. Lord Goff attempted to reserve final judgment to the court, ibid 569(c).

¹⁴⁷ Above, 309.

¹⁴⁸ S.E. Mumford, Bone marrow donation - the law in context, CFLQ [1998] 10(2) 135, 141.

¹⁴⁹ See R. Bailey-Harris, Re Y (Mental incapacity: bone marrow transplant), Fam. Law 27 (1997) 91, 92.

¹⁵⁰ See Mumford, above, 139.

arise where the interests of others are admitted.¹⁵¹ While *Re Y* contains a somewhat artificial construction of psychological benefit, and expansion of benefit may have been a means to another's end, it is equally plausible that the decision simply acknowledges that others' interests *may* be relevant to an IcP's interests (see Chapter 3). This may better reflect the reality of relationship; IcPs do not exist in isolation from environment, or their social and emotional needs. As Feenan suggests, *Re Y* may positively 'honour relationship'.¹⁵²

Although this important step was taken on rather flimsy evidence in *Re Y*,¹⁵³ it has not opened the floodgates to profligate claims by others upon IcPs. *Connell J* limited its precedential relevance to the context of non-regenerative tissue,¹⁵⁴ and required benefit to the IcP.¹⁵⁵ Furthermore, Grubb highlights that implicit limits arise through need for close relationship, excluding IcPs whose

'mental disability or...age prevented them from forming such a relationship'.¹⁵⁶

The decision did expand best interests' boundaries to encompass types of interest previously rejected. In this sense, *Re Y* hints at the growing need for redefinition (which is considered presently). However, one remaining area had been developed through this period of best interests: gateways.

2.2.3 Development of Gateways

2.2.3.1 *Re T* (Adult: Refusal of treatment)¹⁵⁷

Re T concerned a twenty-year-old female patient in premature labour who consented to proposed Caesarean section but refused any blood transfusion, following a conversation with her mother (a practising Jehovah's Witness (JW)). She signed an unexplained, unread form to this effect. Following surgery, which delivered a

¹⁵¹ Such admission was rejected a short while earlier by the Court of Session in *Law Hospital*, above, 866(H), cf. Lord Clyde (obiter) 863(F-J).

¹⁵² Above 306.

¹⁵³ *Ibid*, 306-308. Also, Feenan suggests that 'only a 40 per cent chance of [the plaintiff's] survival for 18 months' meant that 'there was a less-than-even chance of a temporary benefit [to Y]', *ibid*, 311.

¹⁵⁴ Above, 794(B-C).

¹⁵⁵ *Ibid*, 791(B-C).

¹⁵⁶ A. Grubb, *Adult incompetent: Legality of non-therapeutic procedure, Re Y*, *Med. L. Rev.* 4 [1996] 204, 206.

stillborn baby, T's deteriorating condition required transfusion, and her father and boyfriend sought a court order declaring transfusion lawful. This declaration, granted at first instance and upheld on appeal, was made because T's mother unduly influenced her refusal.

The starting point for all three appeal judges was that a competent adult patient has a legal **right to refuse** treatment,¹⁵⁸ irrespective of his/her reasons:

'[a]n adult patient who...suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered...This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent'.¹⁵⁹

Prima facie, therefore, the gateway to best interests is firmly closed regarding competent patients. However, certain pragmatic limitations exist. The right of refusal is contingent on patient competence. Further:

'the presumption of capacity to decide, which stems from the fact that the patient is an adult, is rebuttable'.¹⁶⁰

Clearly, it is right that if a person is incompetent, they need our protection and we should decide on their behalf. However, this earmarked **competence** for future contention.¹⁶¹

Incapacity may rebut the presumption. His Lordship acknowledged that both long-term, and temporary factors such as unconsciousness, confusion, shock, severe fatigue, pain or drugs,¹⁶² might rebut the presumption. Further, capacity should be

'commensurate with the gravity of the decision...The more serious the decision, the greater the capacity required'.¹⁶³

This gradation broadens scope for finding patients 'incompetent'. The Court identified two further factors capable of vitiating patient choice: **undue influence** by

¹⁵⁷ [1992] 3 WLR 782.

¹⁵⁸ Ibid: 786(G-H), 799(B); 800(A-B); and 803-804.

¹⁵⁹ Per Lord Donaldson MR, *ibid*, 786, drawing cross-contextually from *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] AC 871.

¹⁶⁰ Above, 799(B-C), see also 800(A) and 803(H).

¹⁶¹ T's capacity was not central because her consent was otherwise vitiated. However, see *ibid* 795(C).

¹⁶² *Ibid* 796(F).

¹⁶³ *Ibid*, 796(H).

another,¹⁶⁴ and **insufficient scope** in a patient's refusal.¹⁶⁵ Both vitiating factors (undue influence and limited scope) may operate irrespective of capacity. Hence, they do not question a patient's *ability* to refuse, but rather his/her actual *exercise* of that right.

The net effect of finding a patient incompetent, through incapacity or vitiation, is resort to **best interests**.¹⁶⁶ In *Re T*, once **access** to best interests was established, the Court of Appeal followed the *Re F* approach, employing necessity to justify intervention.¹⁶⁷ While *Re T* contributed little to content or function of best interests,¹⁶⁸ it focused attention on circumstances that bring the best interests mechanism into play. Incompetence acts as a **gateway** to best interests. The resulting legal position is arguably asymmetrical in practice. The effect of presuming competence is that all patients are regarded competent, until *s/he refuses*. Only once a patient *refuses* are doubts raised about competence, and/or validity. Thus, *Re T* opened an expanse of potential application for best interests regarding patients who might be termed '*questionably competent*'.

It was clear that best interests really had no situational limits, its influence by now extended well beyond the early sterilisation and ventilation decisions. Lord Donaldson (*obiter*) left open a further gateway regarding a possible qualification on the pregnant women's right of refusal when carrying a viable foetus. This has proven situationally prophetic, and is considered under redefinition.¹⁶⁹ However, different rules were developing regarding capacity of mature minors.

¹⁶⁴ See *ibid* Staughton LJ, *ibid* 804(G) and 799(F-G).

¹⁶⁵ *Ibid* 799(G); 803(E); 804-805. Where the patient's (competent) refusal does not fit actual circumstances, refusal is invalid. This is potentially exclusive because of the difficulty of foreseeing medical circumstances, and the dependency of a patient's knowledge upon information disclosure by HCPs.

¹⁶⁶ See *ibid*, 796(H).

¹⁶⁷ *Ibid*, 800(G) and 804(B-D).

¹⁶⁸ One noteworthy functional point was made by Lord Donaldson, clearly distinguishing between cases involving medical treatment of teenagers and those involving adults, *ibid*, 786(G). This left open the way for continued separate development of those two categories.

¹⁶⁹ Below, paragraph 2.3.1. Recent legislative changes in Scotland place responsibility for capacity assessment with HCPs.

2.2.3.2 Mature minors: legislation, *Re R*¹⁷⁰ and *Re W*¹⁷¹

It has already been established that both under statute and at common law, mature minors in England and Wales do not have a *right* to refuse medical treatment. In Scotland, the Age of Legal Capacity (Scotland) Act (1991) enables 16 and 17-year-old minors (under no incapacity) to enter any transaction.¹⁷² Minors under 16 years may also consent to surgical, medical or dental procedures or treatment if they show requisite capability to understand.¹⁷³ In *Houston*, applicant, concerning a 15-year-old, Sheriff McGowan interpreted (obiter) s2(4),¹⁷⁴ effectively regarding consent and refusal by minors in Scotland as symmetrical;¹⁷⁵ that is, a patient capable of validly consenting to treatment is also capable of validly refusing it. However, as s2(4) is an *exception* to the general rule (against minors under 16 years entering transactions), it seems likely that the Scottish courts would retain overriding authority in the face of refusal by a competent minor under 16 years.

Lord Donaldson, in *Re R*, considered that consent need only be obtained from one competent **keyholder**, and that keyholders' powers existed concurrently. The position of parents and the court as keyholders is considered under function, above. The Court's limitations on minors as keyholders opened the gateway to best interests.¹⁷⁶ Mature minors' capacity is made one-dimensional, aimed only at consent. In *Re W*, Balcombe LJ recognised certain illogicality in this asymmetry of abilities.¹⁷⁷ However, Mason and McCall Smith do not perceive it inappropriate because the serious consequences of refusal warrant a need for

'greater understanding than does acceptance'.¹⁷⁸

¹⁷⁰ [1991] above.

¹⁷¹ [1993] above.

¹⁷² S1(1)(b). Those aged 16 years or over, who are deemed incompetent, would now be classed as incapacitated adults within s1(6) of the Adults with Incapacity Act 2000.

¹⁷³ S2(4).

¹⁷⁴ (1996) 32 BMLR 93.

¹⁷⁵ See *ibid*, 99.

¹⁷⁶ In *Re E* (a minor)(wardship: medical treatment) [1993] 1 FLR 386, Ward J had already determined the court's jurisdiction to overrule even a Gillick-competent minor's wishes, and imputed that nothing short of 'full understanding' would suffice.

¹⁷⁷ Above, 776(B-C).

¹⁷⁸ Mason *et al* (2002) above paragraph 10.47. R. Huxtable counters this view on the basis that in medical decisions most lay people function 'from a position of limited understanding', and asks whether this mean we must always defer to medical professionals regarding best interests: *Re M* (Medical treatment: consent) Time to remove the 'flak jacket'? CFLQ [2000] 12(1) 83, 85.

Admittedly, if a decision's implications are seriously detrimental, we should not be afraid to ensure that any refusal is well informed. However, Huxtable suggests the resulting position to be a

'distinction in the law based merely on status, [which]...does not usually inform medical law'.¹⁷⁹

Whatever the merits of asymmetry, this status-based approach currently dominates treatment decisions regarding mature minors through its effect on gateway; access to best interests does not depend on a mature minor's capacity. Where a mature minor *consents*, the gate to *judicial* determination of best interests remains closed (the minor has handed access to HCPs). Hence, only medical best interests are given effect unless someone objects to treatment. Whereas, *refusal* by a mature minor automatically throws opens the gate, allowing parental consent, or judicial determination of best interests. In summary, gateway in relation to mature minors is medicalised.

2.2.3.3 Bland¹⁸⁰

The House of Lords in Bland considered that the patient's (current and foreseeable) absence of cognitive capacity negated any preservation of his personal interests.¹⁸¹ In contrast, Hoffman LJ (CA) suggested:

'[i]t is demeaning to the human spirit to say that, being unconscious, he can have no interest in his personal privacy and dignity'.¹⁸²

Nonetheless, the ruling in the House of Lords suggests that logically we might expect 'nil interests' to close the gate on using best interests. Strictly speaking, the Lords' approach should mean that as a p.v.s. patient has *no* (weighable) interests and, by corollary, access to best interests ceases because - by definition - '*best* interests' is based on *interests*. Having declared 'no interests', 'best' then surely becomes superfluous.¹⁸³ However, closing the gate would give the decision-maker a problem;

¹⁷⁹ Ibid, 84.

¹⁸⁰ Above.

¹⁸¹ See *ibid*, 861(a-b) and 873(b-c).

¹⁸² *Ibid*, 854(b).

¹⁸³ This point is first raised in my paper [1998] above, Appendix 8 hereto. And is developed in my response letter: Best interests in persistent vegetative state, *J. Med. Eth.* [1999] 25, 59, attached as Appendix 9.

lack of decision-making mechanism. The resulting lacuna perhaps caused the Lords to adopt a mirrored, negative construction of best interests (that *prolonging* treatment would *not* be in the patient's best interests),¹⁸⁴ in order to re-establish access to best interests. This could countenance a gamut of dubious solutions in other contexts that are 'not in' a patient's interests,¹⁸⁵ and has created tenuous distinctions whereby patients in non-p.v.s. states (e.g. low cognitive awareness) are determined on the basis of *Re J#1* - despite being in a state closer to Bland's.¹⁸⁶ Arguably, back-door negative constructions are unnecessary. We could construe interests differently - accepting less tangible and non-experiential interests - enabling a decision still to be made *in* an insentient patient's best interests.¹⁸⁷

By this stage of development, distinct formulations of best interests were visible in two dimensions:

- contrasting (a) minors with (b) incompetent adults; and
- differentiating (c) sentient patients from (d) the insentient (irrespective of age).

In view of the effect of the Bland decision upon gateways, we can now substitute a third dimension, for (c) and (d):

- contrasting (e) patients with interests, from (f) patients who have lost all relevant interests, which influences **factors** considered in the decision, **functional roles** attributed and the **format** of best interests equation adopted.

By the end of this highly expansive phase of jurisprudential development best interests had evolved into a principle of *piecemeal* formulation; its content and function varying contextually. Most formulations were *heavily medicalised*, excluding a person's wider (non-medical) interests and minimising account of

¹⁸⁴ *Ibid*, 869.

¹⁸⁵ A more neutral mid-point also exists: an action may be *not against* a patient's overall interests, conferring neither benefit nor detriment. This distinction was raised by R. Gillon in his editorial, Persistent vegetative state, withdrawal of artificial nutrition and hydration, and the patient's best interests, *J. Med. Eth.* (1998) 24, 75, regarding the author's paper [1998] above. The author's response is noted [1999] above.

¹⁸⁶ See also, below, paragraph 2.3.4.2.

¹⁸⁷ This argument is developed in Chapters 3 and 6-8, below.

previously-competent p.v.s. patients' personalities, yet some form of patient perspective was being incorporated into best interests assessments of young minors and intellectually disabled donors (neither of whom had ever been legally competent). In sum, use of the best interests principle was becoming disparate, questionably sound and unpredictable. Redefinition was overdue by the late 1990s.

2.3 Recent redefinition

Recent decisions have begun to redefine some aspects of best interests. In certain areas, such as sterilisation, restriction has occurred. However, the tide generally remains expansive. Redefinition impacts all three elements already identified: function, content and gateway. However, in addition to capacity, distinctly new aspects of redefinition are identifiable: relationship; risk assessment; and human rights. Each is considered in turn.

2.3.1 Capacity and legal competence

Competence has already been shown to be the gateway giving access to best interests regarding adults. Where a patient's competence is unclear, through fluctuating mental state, intellectual disability or environmental stress (herein termed 'grey areas' of competence) assessment of capacity is axiomatic, but had sometimes been overlooked thus far. However, three cases heightened the profile of in/capacity as a prerequisite to best interests: *Re C*, *Re MB*, and *St George's*.

2.3.1.1 *Re C* (Adult: refusal of treatment)¹⁸⁸

C, a 68-year-old male patient suffering from chronic paranoid schizophrenia, was diagnosed with a gangrenous, ulcerated foot requiring below-knee amputation. C refused emphatically.¹⁸⁹ But, without amputation C's chances of survival were estimated at 15%. C agreed to more conservative surgery, which was successfully carried out. However, as the hospital authority declined to give an undertaking to C's lawyer respecting C's refusal in the event of future need for amputation, C sought a

¹⁸⁸ [1994] 1 WLR 290.

¹⁸⁹ See *ibid*, 291(F).

restraining injunction under the court's inherent jurisdiction. The High Court's declaration is a rare occasion of judicial support for refusal by a less-than-fully-competent patient. Importantly, Thorpe J redefined the test for competence, founding his support for C's refusal on *Re T*.¹⁹⁰ The central issue was whether C fell within Lord Donaldson's previous qualification on **right of refusal**, that

'an adult patient may be deprived of his capacity to decide by long-term mental incapacity'.¹⁹¹

If so, the gateway would open to use of best interests. By starting from a presumption of **capacity** - despite C's schizophrenia - Thorpe J did not automatically equate mental illness with inability to make a treatment decision. Although Thorpe J rejected a (low-level) 'minimal competence test',¹⁹² he defined the question as whether C could

'understand the nature, purpose and effects of the [treatment]'.¹⁹³

This understanding he perceived in three-stages:

'first, comprehending and retaining treatment information, second, believing it and, third, weighing it in the balance to arrive at choice'.¹⁹⁴

This test governs capacity of adults over 16 years,¹⁹⁵ but has had a mixed reception being criticised variously as: vague and difficult to assess;¹⁹⁶ capable of demanding high levels of comprehension and ability to choose;¹⁹⁷ and setting a higher requisite standard than for consent.¹⁹⁸ Additionally, while capacity to *consent* focuses on *ability*, Thorpe J's construction regarding refusal seems to concern *actual* understanding such that s/he

¹⁹⁰ [1992] above.

¹⁹¹ *Ibid*, cited by Thorpe J here at 294(F-G).

¹⁹² I.e. 'capacity to understand in broad terms the nature and effect of the proposed treatment', above, 295(D).

¹⁹³ *Ibid*, 295(C) and (E).

¹⁹⁴ *Ibid*, 295(C-D).

¹⁹⁵ E.g. *Re C* (Detention: medical treatment) [1997] 2 FLR 180. However, even if 'competent' on this test, a court may still override a minor's refusal (*Re W*, above).

¹⁹⁶ Mason *et al* (2002) above, paragraph 10.57.

¹⁹⁷ See I. Kennedy and A. Grubb (eds.), *Principles of Medical Law* (1998) Oxford U.P., Oxford, 140-147.

¹⁹⁸ See M. Gunn, The meaning of incapacity, *Med. L. Rev.* 2 [1994] 8, 10-11, who criticises the information processing aspects of the test.

'has understood and retained [information]...in his own way believes it, and...has arrived at a clear choice'.¹⁹⁹

This creates some uncertainty about when the gate to best interests is shut by patient competence.²⁰⁰ However, Thorpe J made three positive redefinitions:

- by associating capacity with the decision task, Thorpe J permitted a patient to be competent regarding certain aspects of life, while incompetent regarding others. Furthermore, mental illness does not *automatically* open the **gateway** to best interests by precluding competence. C's delusions did not negate his capacity;²⁰¹ C's ability to *exercise* his capacity remained sufficiently unimpaired;²⁰²
- **functionally** this case shows the importance of *choosing* wherever medical evidence conflicts. Thorpe J preferred the view of psychiatric witnesses (finding no direct link between C's refusal and his delusions), to that of C's regular doctor.²⁰³ This conflict shows the inherent weakness of Bolam as both views could accord with 'a responsible body of medical opinion'. Thorpe J actively evaluated C's capacity, considering C's oral evidence, and finding him

'ordinarily engaged and concerned',²⁰⁴ [and that C's] 'answers...seemed measured and generally sensible...[with]...no sign of inappropriate emotional expression'.²⁰⁵

While this evaluation can be criticised as importing rationality (referencing 'sensible' answers and 'emotion'), it adds a useful dimension, demedicalising assessment and ensuring airing of relevant evidence,²⁰⁶

¹⁹⁹ Above, 295(E). M.A. Jones and K. Keywood contrast ability and actual understanding, see *Assessing the patient's competence to consent to medical treatment*, *Med. Law Int.* (1996) 2, 107, 113-117, particularly 116.

²⁰⁰ Normative aspects of competence construction are considered below, Chapter 4.

²⁰¹ Above, 394(C)-395(F).

²⁰² In contrast to *Re T*, where T's exercise had been unduly influenced.

²⁰³ See above, 293(H)-294(B).

²⁰⁴ *Ibid.*, 294(C).

²⁰⁵ *Ibid.*

²⁰⁶ I.e. of independent medical assessments, opportunity for C to evince his beliefs and admittance of evidence about C's understanding of consequences, see 293(F).

- Thorpe J's implicitly acknowledged **underlying values** in accepting Dr Eastman's evidence regarding the relationship between preservation of life, autonomy and capacity.²⁰⁷

This case redefined capacity by substantiating the need for incompetence to be proven as a prerequisite gateway to best interests. It upheld a requirement for assessment and the right of ICPs to be heard. Sadly, subsequent cases display less openness: relatively few patients have since been declared competent under the three-stage test,²⁰⁸ and a spate of cases in 1996 found pregnant women 'incompetent' on questionable grounds.²⁰⁹ While these decisions overshadowed Re C's redefinitional quality, the Court of Appeal eventually employed it to redress the balance in Re MB.

2.3.1.2 Re MB (Medical treatment)²¹⁰

MB, aged 23, was 40 weeks pregnant carrying a baby in breech position, which created a 50% risk to the unborn child, but little physical danger to her. MB agreed to Caesarean section, but her fear of needles meant she refused venepuncture for blood samples or anaesthesia.²¹¹ Attempted anaesthesia by mask was unsuccessful, MB withdrawing her consent in the operating theatre. By now, labour had started and MB was declining to discuss intervention. The hospital obtained a declaration of lawfulness to proceed using necessary reasonable force. MB's appeal was dismissed

²⁰⁷ Ibid, 292(G).

²⁰⁸ Cases declaring patients competent include: Re JT (Adult: refusal of medical treatment) [1998] 1 FLR 48 where refusal of dialysis by a learning-disabled woman was accepted (but dialysis requires ongoing co-operation and JT's objections would have made imposition difficult in practice). Relatedly, impracticality warranted non-imposition of dialysis based on an incompetent patient's best interests in Re D (Medical treatment: mentally disabled patient) [1998] 2 FLR 22. Sometimes the MHA 1963 is used as an alternative means to treat: Riverside Mental Health NHS Trust v Fox [1994] 1 FLR 614; Re KB (Adult)(Mental patient: medical treatment) (1994) 19 BMLR 144; B v Croydon HA [1995] 1 All ER 683 -despite B's capacity under the Re C test, s63 of the MHA 1983 still enabled treatment. Most recently, for endorsement of Re C, see Re AK (Medical treatment: consent) [2001] 1 FLR 129.

²⁰⁹ See Tameside & Glossop Acute Services v CH [1996] 1 FLR 762. A patient's mental history was (inappropriately) raised as an issue in Norfolk & Norwich Healthcare NHS Trust v W [1996] 2 FLR 613. See also Rochdale Healthcare (NHS) Trust v C [1997] 1 FCR 274 and Re L (Patient: Non-consensual treatment) [1997] 2 FLR 837.

²¹⁰ [1997] 2 FLR 426.

²¹¹ Staff at the antenatal clinic knew of MB's phobia at 33 weeks of pregnancy.

the same night (reasons reserved), after which MB agreed to co-operate and a successful Caesarean delivery took place.

The dominance of MB's 'abnormal mental condition' of needle phobia,²¹² was considered to preclude her ability to choose.²¹³ *Prima facie*, this accords with earlier decisions, finding enforced Caesareans lawful and denying the competence of pregnant women. However *Re MB* struck an initial blow for patient autonomy in obstetrics by closing the gap left open by Lord Donaldson's obiter view in *Re T*, effectively overturning an earlier decision that overruled a competent woman's refusal of intervention on religious grounds.²¹⁴

Re MB stemmed an expanding tide of declarations based on increasingly perfunctory considerations of **patient competence**. By applying the *Re C* three-stage test,²¹⁵ the Court at least allowed *scope* for a pregnant woman to be found 'competent'. To some extent the test was refined, because the *belief* element is not expressly included in the *Re MB* formulation. Nonetheless, Butler-Sloss LJ's reference to phobia stifling belief,²¹⁶ effectively elides the second and third stages into a single stage of *use*.

Additional **procedural safeguards** were posited. Express inclusion of these provided an important judicial defence of patient autonomy. However, while guideline (1) indicates that patient capacity must be at issue, guideline (8) requires evidence regarding competence only

'if competence is in issue' (emphasis added).²¹⁷

The Court also endorsed the view of the Royal College of Obstetricians and Gynaecologists (RCOG), that:

'it is inappropriate, and unlikely to be helpful or necessary, to invoke judicial intervention to overrule an informed and competent woman's refusal...even though her refusal might place her life and that of her fetus at risk'.²¹⁸

²¹² Above, 430(F-G).

²¹³ Ibid, 431(B-C).

²¹⁴ The Court of Appeal in *Re MB* doubted (p440) the correctness of approach of *Re S* (Adult: refusal of medical treatment) [1993] Fam. 123. See also S. Michalowski, Court-authorized Caesarean sections - the end of a trend? MLR 62(1) (1999) 115, 117.

²¹⁵ Above, 433(F-G) and 437(D-F).

²¹⁶ See *ibid*.

²¹⁷ Ibid, 445(B) and (F). I. Kennedy suggests such inconsistency undermines confidence, see Consent: adult, refusal of consent, capacity, *Re MB* (Medical treatment), Med L Rev 5 [1997] 317, 325

²¹⁸ Above, 438(F-H), RCOG guidelines, A consideration of the law and ethics in relation to court-authorized obstetric intervention, paragraph 5.12, available on www.rcog.org.uk.

Despite this, weaknesses persist. While Butler-Sloss LJ limited rationality to an evidential role,²¹⁹ its 'symptomatic' significance inevitably leaves scope for backward-chaining reasoning to flow from it to evince incompetence. The validity of referencing rationality depends heavily on the framework and safeguards within which it is considered. This inconsistency is exacerbated by paragraph (6) of the judgment's conclusions on capacity:

'careful scrutiny of the evidence is necessary because fear of an operation may be a rational reason for refusal to undergo it. Fear may also, however, paralyse the will and thus destroy...capacity'.²²⁰

Fovargue and Miola identify the resultant position being that:

'patients are allowed to be fearful of operations, but not too fearful as this may eliminate their ability to consent to the operation'.²²¹

If correct, one wonders what interpretation a court might make of a patient refusing treatment but expressing no fear. Would total absence of fear be construed simply to infer lack of understanding and incapacity? Essentially, this is about rationality; fear is okay within rational limits. This position flies in the face of *Re T*.²²² The bizarre resulting position is that

'it is better for [the patient] to refuse to give a reason for her lack of consent, and then there will be no attempt to deem her incapable to provide such consent'.²²³

Re MB leaves uncertainty about the relevance of rationality, fear and panic within competence. We can say, with certainty, that in some circumstances these factors indicate incompetence (opening the way to best interests), while in others these factors remain within a competent patient's right of refusal. But, which situations give rise to which circumstance is unclear. The Court of Appeal's ready acceptance of psychiatric evidence that MB's fear 'dominated all' raises concerns. Michalowski considers it

²¹⁹ Above, 437(C), defining irrationality as a 'decision which is so outrageous in its defiance of logic or of accepted moral standards that no sensible person who had applied his mind to the question to be decided it could have arrived at it', *ibid* 437(B).

²²⁰ *Ibid*, 437(G-H).

²²¹ S. Fovargue and J. Miola, *Policing pregnancy: implications of the A.G.'s Reference (No. 3 of 1994)*, *Med. L. Rev.* 6 [1998] 265, 283.

²²² Certainly, the C-test left scope for rationality, but *Re MB* seems to shift it, testing a patient's relative weight attribution (of issues) against a rationality scale; if *actual* choices fail the scale (i.e. are irrational), then this indicates *inability* to decide.

²²³ S. Fovargue and J. Miola, *above*, 283.

'deplorable that the court expressed its conclusion that the patient was incompetent without any careful application of the legal standards so meticulously outlined'.²²⁴

Its failure to put theory into practice has led to accusations of lip-service autonomy.²²⁵ Further, the Court's broad definition includes scope for factors such as confusion, shock, fatigue and pain to 'completely erode capacity'. As Brazier suggests,

'[i]ncompetence is so defined that few women in labour could hand on heart declare themselves competent'.²²⁶

It may be that *Re MB* was simply the 'wrong' case in which to test these issues. MB's strongly phobic reaction may mean this particular case was rightly decided. But, this does not eradicate the niggling doubt that the Court did not practise what it preaches, and that the gateway to best interests remains ajar due to factors present in almost all medical treatment decisions.

In terms of **role**, dearth of reference to *Bolam*, and express procedural requirement for court involvement, created a *determinative* (rather than *definitive*) judicial role. Indeed, Butler-Sloss LJ suggested that, in terms of scope, best interests

'have to be treated on similar principles to the welfare of a child'.²²⁷

But, this is inconsistent with the Court's citation of *Re F*. The Court's conflation of the two is criticised by Michalowski:

'this woman based her life on autonomous values and decisions which should be respected when making a treatment decision on her behalf'.²²⁸

As Butler-Sloss LJ provided no further material to resolve the confusion we may only speculate about the significance of this equiparation. Perhaps, in haste to escape the clutches of *Bolam*, the Court stumbled over its linguistics and authorities. But, with hindsight, this seems to have been the start of the Court of Appeal's more proactive role in best interests decisions for adult IcPs.

²²⁴ Above, 119.

²²⁵ See: S. Michalowski, *ibid*, 120; Fovargue and Miola, 'the assertion of the autonomy of a pregnant woman has a hollow ring to it', above 283; and I. Kennedy, above, 323, '[p]aternalism...is the trumping principle'.

²²⁶ M. Brazier, *Hard cases make bad law?* *J. Med. Eth.* [1997] 23, 341, 343.

²²⁷ Above, 439(C-D).

²²⁸ Above, 120.

The Court's approach in *Re MB* was **purpose** oriented, distinguishing between her consent to Caesarean (regarding which MB was 'competent'), and her decision to refuse anaesthesia (where she was 'incompetent' due to phobia). Combined with a goal of MB's desire for her child to be born alive, it was easy to conclude that

'[i]t must be in the best interests of a woman carrying a full-term child whom she wants to be born alive and healthy that such a result should if possible be achieved'.²²⁹

By adding a dash of harm prevention (regarding potential psychiatric damage consequent on loss/handicap of the child),²³⁰ the Court's case for intervention became more compelling. Despite saying relatively little about best interests these comments exposed the decision to further criticism of insufficient weighing,²³¹ and – given the minimal physical danger to MB²³² – possible protection of foetal interests by the back door.²³³ However, judicial re-evaluation of MB's best interests regarding the Caesarean might have been a disservice to her autonomy; she had already made a choice about the surgery itself, only the anaesthetic was at issue.²³⁴ But, we cannot be too careful regarding use of reasonable force. The harsh realities of force raise doubts about enforced Caesarean ever being in a woman's 'best interests'. Plomer, discussing an unreported American case, outlines the real scope for invasion and abuse:

'[t]he woman who refused consent...was handcuffed. Her ankles were attached to her bed with leather straps to prevent her moving and she was taken into the operating theatre screaming for help and biting through her intravenous tubing in an attempt to get free. Her husband later committed suicide'.²³⁵

This kind of invasion should not be justifiable by reference to best interests, and this stark example reminds us why *IcP* decisions must be made with honest, compassionate and full consideration of issues, under the spotlight of public scrutiny. *Re MB* lay on the cusp of best interests' expansion and redefinition. It is a redevelopment, a phase combining both plausibility and inconsistency. It reflects the

²²⁹ Above, 439(B).

²³⁰ *Ibid*, 439(B-C).

²³¹ See Michalowski, above, 121-122.

²³² Above, 429(A).

²³³ See Fovargue and Miola, above, 290.

²³⁴ See Michalowski, above, 122.

underlying battle inherent in all IcP decisions; preservation of autonomy (such as it is), in the face of conflicting welfare choices. Although, it may have done little to dispel the views of Widdett and Thomson (pre-Re MB) that

'women are afforded less respect than men in terms of self-determination, bodily integrity and autonomy'.²³⁶

The Court also attempted a *refinement* of **content**, by declining (obiter) to accord **interests** to the unborn child in the context of caesarean section.²³⁷ The Court founded its view on lack of jurisdiction,²³⁸ and its own line in *Re F (In utero)(Wardship)*.²³⁹ This effectively overruled the earlier position of *Re S*,²⁴⁰ distinguished the criminal law decision of *A.G. Reference (No. 3)* of 1994,²⁴¹ and civil and criminal statutes.²⁴²

In addition to all of the above, Butler-Sloss LJ indicated that

'[b]est interests are not limited to best medical interests',²⁴³

and supported this procedurally, by requiring that information on a patient's circumstances and background be made available.²⁴⁴ Fovargue and Miola criticise this as

'provid[ing] the judiciary with a free hand to decide whether a woman with a history of drug and alcohol problems should be able to make decisions concerning her own body in the latter stages of pregnancy'.²⁴⁵

However, given previous criticism for excessive medical deference, any shift away from *Bolam* required development of relevant interests beyond the purely medical and is to be welcomed. Admittedly, however, the Court of Appeal's motivation for

²³⁵ A. Plomer, *Judicially enforced caesareans and the sanctity of life*, *Anglo-American Law Review* (1997) 26(2) 235, 262.

²³⁶ C. Widdett and M. Thomson, *Justifying treatment and other stories*, *Feminist Legal Studies* V(1) [1997] 77, 88.

²³⁷ Above, 444(F).

²³⁸ *Ibid*, 440(B).

²³⁹ [1988] 2 FLR 307, cited in *Re MB* at 440(G) and 444(G).

²⁴⁰ [1993] above.

²⁴¹ [1996] QB 581. Normative aspects of attributing interests *in utero* are considered below, Chapter 5.

²⁴² *Ibid*, 441(E)-442(A). Decisions by the European Commission of Human Rights were also considered, but found to be unhelpfully ambivalent, *ibid*, 442(B)-444(C). Judicial views of the mother-foetus relationship are considered below under paragraph 2.3.2.

²⁴³ Above, 439(A).

²⁴⁴ *Ibid*, 445(G).

²⁴⁵ Above, 283.

admitting non-medical interests may have been teleological (finding a psychological benefit to MB in a successful birth).²⁴⁶

2.3.1.3 St George's Healthcare Trust v S; *sub nom* R v Collins and others, *ex parte* S²⁴⁷

This case (hereinafter St George's) concerned a 28-year-old woman who was 36 weeks pregnant when she registered with a NHS doctors' practice. She had sought no antenatal care, and pre-eclampsia was immediately diagnosed. Despite advice regarding risk to her and the baby's health, S refused treatment (including induced delivery), saying she wanted a natural birth. A social worker applied successfully under s2, MHA 1983 for S's admittance to a psychiatric hospital for assessment. There, the GP's diagnosis of depression was confirmed and S was transferred, against her will, to St George's hospital for obstetric treatment. S continued to refuse treatment, and was indifferent to the potentially fatal consequences of non-treatment. She provided articulate written reasons for her views and psychiatric evidence recorded that S's capacity appeared intact, fully understanding reasons for treatment and consequences of refusal. Although S took legal advice, her lawyers were not consulted during the hospital's successful *ex parte* application for High Court declaration to proceed without S's consent. S continued to object and, in light of legal advice, offered no resistance to sedation, but expressly refused to sign a consent form prior to undergoing safe delivery by Caesarean. Once the s2 detention ended, S discharged herself contrary to medical advice and sought judicial review of her admission, transfer, detention and treatment and appealed the High Court's declaration. The Court of Appeal found S had been unlawfully transferred and detained, that the Caesarean amounted to trespass and the declaration would provide no defence to damages against St George's hospital.

Prima facie, this is not a case about best interests, but the decision follows and extends the provisions of Re MB, making important redefinitions in areas apposite to IcP decision-making, including: autonomy, competence, procedure, and foetal interests.

²⁴⁶ Above, 439(B-C). As Michalowski caveats any such benefits should require establishment regarding the individual concerned (rather than presumed), above 121.

The Court's starting point was **autonomy**, which founds a competent patient's right of refusal,²⁴⁸ and it warned against any incremental erosion of competent individuals' personal liberty.²⁴⁹ This 'salutary warning' set the tenor of the whole judgment,²⁵⁰ leading to narrow construction of mental health legislation,²⁵¹ and concluding that foetal interests may not prevail against those of a competent mother. Thus it reaches beyond *Re MB*, seeking to translate the theory of autonomy into practice.

While giving little express consideration to **competence** the Court chose between conflicting psychiatric notes on S's detention,²⁵² and was strongly influenced by S's 'highly articulate' written record of her views.²⁵³ The Court concluded that she

'knew perfectly well what she was doing: without resort to any presumptions, and however the question is tested, there is no sufficient evidence from which to conclude that her competence...was in question'.²⁵⁴

Further, the Court considered that irrationality would not amount to incompetence under the Act; inferring existence of a mental disorder merely from a patient's unusual attitude would constitute 'prohibited reasoning'.²⁵⁵ In other words, presuming mental illness merely because no-normal-mother-could-possibly-think-like-that is inappropriate. Additionally, the Court concluded that mere irrationality did not warrant detention under the Act,²⁵⁶ treatment for pregnancy, alone, was not treatment for mental disorder,²⁵⁷ hence detention could not restrict self-determination unless a patient is deprived of capacity,²⁵⁸ (in accordance with *Re JT*).²⁵⁹

²⁴⁷ [1998] 2 FLR 728.

²⁴⁸ *Ibid*, 739(D)-740(D).

²⁴⁹ *Ibid*, 740 (E-G).

²⁵⁰ *Ibid*, 740(G). R. Bailey-Harris describes the judgment as 'underpinned by an unflinching adherence to the principle of individual/patient autonomy', *Commentary*, *Fam. Law* 28 (1998), 526, 527.

²⁵¹ In *Re S* [1993], above, the President of the High Court had overruled a mother's competent refusal in the interests of the foetus, while in *Tameside v CH*, above, induction and Caesarean were deemed 'treatment for a mental disorder' within s63 MHA 1983, and in *Norfolk v W*, above, the patient's psychiatric history and the MHA were implicated in determining a labouring patient 'incompetent'.

²⁵² Above, 734(C), 734(G), 737(E), and 738(H).

²⁵³ *Ibid*, 734(G)-735(C).

²⁵⁴ *Ibid*, 738(E-F).

²⁵⁵ *Ibid*, 746(G-H).

²⁵⁶ *Ibid*, 766(G).

²⁵⁷ *Ibid*, 749(G-H). I.e. treatment for pregnancy is not within s2(2)(a) and s13, thereby negating application for admission under s2, see *ibid*, 749(D-E), 749(G-H), 751(D-E), and 752(D).

²⁵⁸ *Ibid*, 748(C) and 747(H).

²⁵⁹ [1998] above. The current position in Scotland is governed by the Adults with Incapacity (Scotland) Act 2000. Therein, 'incapable' is defined in terms of acting, making, communicating or understanding decisions, or retaining memory of them, due to mental disorder or physical disability

This redefines the *interaction* of legislation and common law competence in the obstetrics context. The Court's separation of: (1) treatment for pregnancy; and (2) treatment for mental disorder,²⁶⁰ is effectively analogous to a 'but for' causation test. We could ask: would an application for admission/detention be sought *but for* the patient's physical condition? A negative response would suggest failure to separate mental and physical issues (i.e. an application made for the wrong reasons).²⁶¹ Indeed, even in the present, deficiencies in competency assessment persist from the St George's case:

- the focus on mental health legislation, and S being competent, renders the Court's views on common law competence *obiter*. This is compounded by the failure to expressly overrule the Rochdale and Tameside decisions, leaving ambiguity.²⁶² Additional vagueness, about *how* the Court of Appeal progressed from evidence of capacity to conclusion of competence means that temporary factors, such as 'fatigue, shock, pain or drugs',²⁶³ may leave the door open to finding pregnant women whose refusal is less articulate to be 'incompetent'.
- the Court may also have adopted (by reference to Re C),²⁶⁴ Re T's associated 'risk-related standard' of competence. Maclean suggests that such a standard

'confuses the importance of getting a decision right with the competence required to do so'.²⁶⁵

(regarding communication) (s1(b)). Arguably, this definition is too wide as *any* of these elements will suffice, and an individual who is not mentally impaired could rightly feel unjustifiably undermined if his/her physical disability negates competence. Even the statute's qualification regarding communication by human/mechanical assistance does not safeguard a presumption of competence sufficiently, as too little onus is placed on efforts to *enable* patients. No explanation is made of the nature of 'understanding' or 'making decisions'. Furthermore, assessment and certification of incapacity rests with the responsible medical practitioner (s47(1)), and current provisions allow for certification to be future-oriented applying up to a year from date of certification. Despite rights of appeal, these provisions regarding definition and assessment of capacity seem insufficiently stringent and undermine the Act's requirement for incapacitated adults to participate in their own affairs (s1(5)).

²⁶⁰ Above, 750(A-C).

²⁶¹ Proposed reform of the MHA 1983 retains a treatment distinction, concerning only 'treatment for mental disorder' (paragraph 2(5)). On this basis other treatments for incapacitated adults sadly remain limited to Governmental policy statements, discussed below, paragraph 2.4.2.

²⁶² See L. Jewell, Treatment without consent, Fam. Law 28 (1998) 774, 775-6.

²⁶³ Espoused in, *inter alia*, Re JT, above.

²⁶⁴ [1994] above.

On this basis, the autonomy of less-obviously-competent pregnant patients might still be undermined, as lacking capacity commensurate with a decision's grave consequences. In *St George's* the Court of Appeal expanded on *Re MB*, extending its advice beyond the obstetric context, to apply to *any* case of surgical or invasive treatment involving capacity, and binding HCPs and health institutions generally.²⁶⁶ The guidelines advocate:²⁶⁷ early identification and assessment regarding competence (guidelines (iv) and (v)); legal representation of patients ((vi)(vii)); *inter partes* hearings (vii); and availability of all accurate information, including reasons for treatment, risks, alternatives, and reasons for patient refusal (if available), enabling the court to make informed conclusions about patient capacity and best interests' (viii).²⁶⁸ Yet, lacunae persist. Guidelines (iii)-(v) leave competence assessment with HCPs; judicial assessment arises only where 'serious doubt' exists about competence *and* there are 'serious or complex issues' (guideline (v)).²⁶⁹ Moreover, G.P.s may assess competence, independent psychiatric assessment being warranted only in

'serious or complex cases involving difficult issues about the future health and well-being or even of the life of the patient'.²⁷⁰

This risks patients being treated differently, not on the basis of differences in competence, but on anticipated decision consequences.

2.3.1.4 Conclusion on capacity

We can conclude this section by identifying a number of **persisting problems with capacity**. Ambiguities in competence construction regarding **adults** include:

- whether capacity concerns *ability* or *actual* understanding and processing;²⁷¹

²⁶⁵ A.R. Maclean, *Caesarean sections, competence and the illusion of autonomy*, Web JCLI [1999] 1, 5.

²⁶⁶ Application is outlined in guidelines (i)-(iii).

²⁶⁷ Above, 758-760.

²⁶⁸ The importance of early applications to court, legal representation and hospital protocols has also been emphasised regarding termination of pregnancy in an IcP. Contrary to the patient's request, the High Court refused to declare a termination lawful as continued pregnancy was deemed less detrimental to the patient's interests, *Re SS* (medical treatment: late termination) [2002] 1 FLR 445.

²⁶⁹ See also A.R. Maclean, above, 5.

- *prima facie*, competence seems task-specific,²⁷² concerning particular treatment decisions. However, allusion to past mental history suggests that general competence may be informally influential;²⁷³
- the requisite level of understanding is unclear. In the cases of *Re C* and *St George's*, the court accepted the earlier proposition (of *Re T*) that requisite degree of capacity must be commensurate with the gravity of harmful consequences. This risk-related consequentialist approach permits the threshold to shift situationally, creating uncertainty about just how much capacity is 'enough';
- while no formal asymmetry exists between capacity to consent and refuse treatment,²⁷⁴ in practice asymmetry creeps in because competence is often raised when a patient *refuses* treatment - making capacity to refuse more demanding than to consent;
- variation exists regarding who makes the competence assessment.²⁷⁵ Inevitably this creates variance in perceptions of capacity in different cases, particularly as no guidance is issued about how one reasons from single evidences of incapacity to a conclusion of incompetence;
- any formal role for rationality in competence is denied.²⁷⁶ However, it has creeping influence in practice. Objective irrationality about consequences may be deemed inability to process information. And, inability to decide sensibly may infer incapacity for comprehension.²⁷⁷ Thus, while

²⁷⁰ *Guideline (v)*, *ibid*.

²⁷¹ The *Re C* test intimates ability (to comprehend, retain, believe and weigh information), but Thorpe J then examined whether *C had so done* – suggesting actuality.

²⁷² See *Re MB*, above, where the patient could address the decision task on surgery, but not on anaesthesia.

²⁷³ E.g. in *Norfolk & Norwich Healthcare (NHS) Trust v W*, above, one of the grounds for finding a patient incompetent was that her decision was more difficult because of (past) mental history, even though she had no mental problems at the time.

²⁷⁴ I.e. *Re T* allows refusal for irrational, or no reasons; in theory, reasons for consent/refusal need not be objectively sound.

²⁷⁵ The court made the assessment in *Re C* and *St George's*, but in the latter advocated assessment by HCPs in clearer cases, or those where health issues are not serious/complex. This permits assessment to vary based on anticipated *consequences* rather than issues of *competence*.

²⁷⁶ By the *Re T* 'right of refusal' principle, and as 'prohibited reasoning' in *St George's* case. Indeed, in *Re JT* [1998] above, even the patient's (irrational) unfounded belief that she would receive an organ transplant did not dent her competence.

²⁷⁷ E.g. *Re X (Adult sterilisation)* [1998] 2 FLR 1124.

irrationality, alone, does not constitute incompetence, it may be regarded heavily symptomatic of it.²⁷⁸ In practice, the difference is difficult to discern;

- any role for temporary factors is obscure. Fatigue, pain, confusion and emotional stress are accepted potentially to undermine capacity.²⁷⁹ The impact of such factors must be strong enough to negate a patient's ability to decide,²⁸⁰ but these factors are often present in situations of ill-health anyway;
- where a patient's capacity is fluctuating, there is an inclination to regard him/her 'incompetent', despite possible periods of lucid competence,²⁸¹ or seemingly well-oriented awareness of the situation.²⁸² This suggests capacity must be durable and is lost easily even to *temporary* inhibiting factors.

Although application of tests for minors' competence is clearly delineated by age, **minors'** competence is trivialised:

- Gillick-competence appears, *prima facie*, task specific. However, the 'gloss' derived from subsequent interpretations of Gillick-competence (as a developmental concept) suggest requisite capacity to be more generalised;²⁸³
- the developmental nature of Gillick-competence precludes acceptance of temporally-fluctuating capacity;²⁸⁴
- the requisite capacity level is high, demanding ability to understand 'fully',²⁸⁵

²⁷⁸ See Re MB, above.

²⁷⁹ See Re T [1992], above, (obiter), Norfolk and Norwich NHS Trust v W, above, Re L (Patient: non-consensual treatment) [1997] 2 FLR 837, and Rochdale Healthcare (NHS) Trust v C, above.

²⁸⁰ Re MB, above.

²⁸¹ See Re D (Medical treatment: mentally disabled patient) [1998] 2 FLR 22.

²⁸² The Official Solicitor found the patient in the Tameside case to be so aware, yet evidence of incapacity was judicially deemed 'overwhelming'.

²⁸³ See Re R [1991], above.

²⁸⁴ See Re L (Medical treatment: Gillick competence) [1998] 2 FLR 810, applying the gloss added to Gillick competence in Re R, above.

²⁸⁵ See Re E (A minor)(Wardship: medical treatment) [1993] 1 FLR 386.

- asymmetry (between consent and refusal) is plainly accepted; the content of common law and statute, and the interaction of roles between minors, parents and courts is wholly enabling;
- asymmetry requires significantly more capacity to refuse treatment than to consent.²⁸⁶ In England and Wales the competence threshold for minors shifts with his/her decision outcome, refusal raising the level and consent lowering it;
- it appears acceptable to withhold information from minors,²⁸⁷ despite this necessarily inhibiting a patient's ability to show 'full' understanding.

Whatever the competence of minors, no matter how much capacity a minor exhibits s/he may never be 'competent enough' to refuse treatment because:

- no right of refusal (rational or irrational) is accorded to competent minors;²⁸⁸
- treatment decisions for minors are consequence-driven; the impetus is to enable the minor to reach the age of majority, when s/he is then able to decide for him/herself.²⁸⁹ So, pro-treatment outcome takes interim precedence over minors' competency;
- a minor's view is relevant to, but not determinative of, the treatment decision.²⁹⁰ In effect, capacity is not the issue, because a court may decide on the basis of best interests - irrespective of a minor's 'competence', which the court should take into account, but is often accorded only lip service consideration, as teleological reasons drive the decision. This illustrates the important association between best interests and promotion of particular values and perspectives.

²⁸⁶ In Scotland it seems that the capacity required of minors to consent and to refuse treatment is symmetrical, see Houston, above.

²⁸⁷ See Re L [1998] above, where information about the process of death was withheld from a 14-year-old patient despite her maturity.

²⁸⁸ In contrast with that accorded to adults by Re T [1992] above.

²⁸⁹ See Re W [1992] above, 781(G-H).

²⁹⁰ See Re C (Detention: medical treatment) [1997] 2 FLR 180, and the effect of Re E [1993] above, where the minor's wishes were deemed relevant, but ultimately departed from.

2.3.2 Relationship

Relationship is the **functional** representation of a dual interest: the patient's interest in other people and the interests of others in the patient. *Functional* because its non/recognition is part of a decision-maker's determinative role, and is often geared towards decision purpose. Relationships, which can take many forms: parent/child, siblings, maternal/foetal, and emotional affinity, are not the prerogative of the competent. Yet, relationship has not always been a focus in IcP decision-making, perhaps to escape the historical parental dominance regarding children, and to circumvent fears of undue influence. Judicial references to relationship have crept in indirectly,²⁹¹ or for specific purposive goals (such as evincing risk,²⁹² or allowing donation).²⁹³ Arguably, in *Re Y*, relationship was the central foundation - without it her best interests could have been determined to very different outcome.²⁹⁴ Feenan welcomes this 'honouring' of relationship,²⁹⁵ because

'[it] gets closer to the experience and interests of the individual'.²⁹⁶

Two recent cases fuel the importance of relationship, which is set to develop under human rights provisions (see below).

2.3.2.1 St George's Healthcare Trust v S; *sub nom* R v Collins and others, *ex parte S*²⁹⁷

Much of the substance of this decision has been discussed above. However, the Court effectively drew a distinction between competent and incompetent women in the relevance of maternal/foetal relationship to (a) respect for the autonomy of the former, and (b) the assessment of the best interests of the latter, and did nothing to displace the disproportionate importance of the role of that **relationship** in the context of incompetent women which had been laid down in a number of previous

²⁹¹ E.g. reference to familial distress, in Bland, above, 870(g).

²⁹² In *Re F* [1989], F's relationship was acknowledged to infer risk of pregnancy, but ignored in terms of the possibility of F's partner taking responsibility for contraception. On the latter issue see D. Carson, The sexuality of people with learning difficulties (1989) *J. Soc. Welf. Law* 355, 363-364.

²⁹³ *Re Y*, above.

²⁹⁴ See, for example, USA cases where benefit has been insufficient: *In re guardianship of Pescinski* (1975) 226NW2d 180; *Re Richardson* (1973) 284 So2d 185; and *Curran v Bosze* (1990) 566NE2d 1319, together with discussion by Mumford, above, 140.

²⁹⁵ Above, 306.

²⁹⁶ *Ibid*, 307.

²⁹⁷ [1998] above.

cases.²⁹⁸ The status of foetal interests has relevance for this thesis regarding personhood,²⁹⁹ impact of relationship on best interests determination, and analogy with conflict resolution in other IcP contexts.³⁰⁰ The Court accepted that, while a foetus could not be dismissed simply as 'nothing',³⁰¹ neither did it constitute a 'person'.³⁰² But, drawing upon aspects of the criminal case A-G Reference (No. 3 of 1994),³⁰³ the Court did not deem the foetus merely to be a part of the mother.³⁰⁴ This precluded the mother's refusal from concerning only herself.³⁰⁵ Rejecting other arguments based on sanctity of life, potentiality, and relative harms regarding mother and foetus,³⁰⁶ the Court justified the dominance of maternal rights through self-determination.³⁰⁷

Faced with a catch-22 situation, where denial of foetal interests could be criticised as unrealistic yet their recognition could inappropriately justify paternalism towards the mother, the Court opted for a middle road. They acknowledged moral relevance of foetal interests, but preferred to give legal protection to maternal autonomy. The Court supported its autonomy-oriented view with case law evincing absence of *locus standi* pre-natally,³⁰⁸ and making the *obiter* view in Re MB part of the *ratio* here:

[t]he foetus up to the moment of birth does not have any separate interests capable of being taken into account...in respect of a Caesarean section operation. The law does not have the jurisdiction to protect the interests of the unborn child even at the point of birth'.³⁰⁹

²⁹⁸ E.g. the Norfolk & Norwich case, above, the Tameside case, above, (both of which may be doubted but have not been overruled), Re L [1997] above; Re MB, above.

²⁹⁹ Chapter 5, below.

³⁰⁰ See Chapters 6-8.

³⁰¹ Above, 741(D-E).

³⁰² Ibid, 741(G-H).

³⁰³ Above.

³⁰⁴ Above, 741(H)-742(B).

³⁰⁵ Ibid, 742(B-C).

³⁰⁶ Ibid, 742(C-E), based on USA cases.

³⁰⁷ See *ibid*, 742(F), cf. the views of Fovargue and Miola, above, 288, who consider the Court's 'personalisation' of the foetus as 'something' could lead to attribution of foetal interests, ultimately undermining maternal autonomy.

³⁰⁸ Above, 742-746, citing: Re MB, above; *Paton v British Pregnancy Advisory Service Trustees & Another* [1979] QB 276; *C v S* [1988] QB 135; *Re F (In utero)* [1988] 2 FLR 307; the majority view in *Winnipeg Child and Family Services v G* [1997] Lexis 92; and aspects of A-G's Reference (No. 3 of 1994), above.

³⁰⁹ [1997] above, 436-437, cited 743(F). Foetal interests are considered further, below, Chapter 5.

However, the Court's approach does engender concern. While protecting maternal autonomy is a **policy** choice,³¹⁰ discussion of policy issues is very limited, leaving any change to the remit of Parliament. Stauch criticises *Re MB* for similar failure to express policy.³¹¹ Also, judicial denial of any **conflict of interests** inappropriately attenuates the nature of 'conflict' to

'deciding on one form of treatment which risked one of their lives in order to save the other'.³¹²

The net impact of *St George's* case in terms of relationship is that:

- where a **competent** woman refuses treatment, although the maternal/foetal relationship is acknowledged contextually, that relationship is subject to the woman's right of self-determination;
- in contrast, where a woman is found **incompetent** - and resort made to best interests - relationship seems to become centrally important enabling intervention.

While procedural and capacity guidelines may help to distinguish the 'competent' from the 'incompetent', the effect of that distinction supports an impression that judicial **use of relationship in IcP decisions is teleological**. Thus, the outcome is the main focus, and best interests - seen, at least in part, in terms of the in/significance of relationship - is the justificatory means of getting there. For example, **sterilisation** decisions relating to incapax persons emphasise actual relationships,³¹³ or vulnerability to sexual relationships,³¹⁴ as connoting requisite risk of pregnancy.³¹⁵ Allusion is often also made to relationships with family and parental concerns.³¹⁶ Stark contrast is identifiable in overt judicial reliance on an IcP's in/direct relationships justifying non-therapeutic intervention in *Re Y*.³¹⁷ Even

³¹⁰ Just as the earlier High Court decision in *Re S* [1992] above, made a policy choice to opposite effect.

³¹¹ M. Stauch, Court-authorized Caesarians and the principle of patient autonomy, Nottingham LJ 6 (1997) 74, 84.

³¹² Above, 742(C).

³¹³ E.g. *Re F* [1989] above.

³¹⁴ E.g. through community-based residency: *Re W (Mental patient)(Sterilisation)* [1993] 1 FLR 381; *Re HG (Specific issue order: sterilisation)* [1993] 1 FLR 587.

³¹⁵ However, see the redefinition of *Re S (Medical treatment: adult sterilisation)* [1998] 1 FLR 944, below, paragraph 2.3.3.1.

³¹⁶ E.g. *Re W* [1993] above, 383(C), *Re HG* above, 592(D).

³¹⁷ Above.

an IcP's relationship with HCPs can be influential where a patient's co-operation is important to treatment; lack of therapeutic relationship with staff may warrant no intervention.³¹⁸

In contrast, in **p.v.s.** where 'futility' is the justification for the withdrawal, relationship is effectively denied by absence of relevant patient interests, focusing attention away from familial impact other than *en passant* suffering of the patient's family and patient 'dignity'.³¹⁹ In *Re G*,³²⁰ the courts were forced to address the issue more directly as G's wife agreed with medical opinion (to withdraw), but G's mother disagreed. The High Court held that, while doctors must take account of the views of relatives, the latter's opposition cannot act as a veto. In other words, relationships may be a factor in determining best interests, but only to the extent they help to justify decision **purpose**.

Regarding **minors**, dominance of the parent/child relationship is denied wherever parental view contradicts medical opinion, variously by focusing firmly on the child's needs,³²¹ or characterising parental view as just one factor,³²² as a rebuttable presumption,³²³ having 'little foundation in reality',³²⁴ or in combination.³²⁵ In relation to **mature minors**, the parent/child relationship is construed as *enabling*, being recognised where the parent consents, but denied where the parent refuses to consent.³²⁶ In either event, the mature minor's relationship with the court is deemed most significant - enabling overruling.³²⁷

Prima facie, the one exception is *Re T* (a minor),³²⁸ as the only parent/child case where relationship was so significant it allowed the parental view to prevail against medical opinion.

³¹⁸ *Re D* [1998] above. However, in a similar context, contrast *Re JT*, above, where the patient was found *competent* and her refusal abided by.

³¹⁹ *In Bland*, above.

³²⁰ [1995] 3 Med. L.R. 80.

³²¹ E.g. *Re B* [1981] above; *Re R* [1992] above.

³²² The effect of Johnson J's weighing in *Re O* (A minor) [1993] 19 BMLR 148.

³²³ *Re C* (HIV test) [1999] 2 FLR 1004, 1020(E)-1021(F).

³²⁴ E.g. *Re S* (A minor)(Medical treatment) [1993] 1 FLR 376, 380(F); see also *Royal Wolverhampton Hospitals NHS Trust v B* [2000] 1 FLR 953.

³²⁵ E.g. *Re C* (a minor)(medical treatment) [1998] 1 FLR 384.

³²⁶ *Re R* [1991] and *Re W* [1993] above.

³²⁷ *Re W*, *ibid*.

³²⁸ [1997] 1 All ER 906.

2.3.2.2 Re T (a minor)³²⁹

This case concerned an eighteen-month infant, born with biliary atresia (a life-threatening liver defect). Having undergone unsuccessful corrective surgery, a liver transplant was C's (the minor's) only hope of extending his life beyond an anticipated two-and-a-half years. Although complex, chances of transplant success were good with prognosis for a 'normal' life. C's parents refused to consent, and appealed an order by Connell J authorising surgery. The case was complicated by the father's employment overseas (where transplant surgery was unavailable), as C and his mother joined him there periodically. Both of C's parents were trained HCPs, experienced in care of sick young children. Unexpectedly, given earlier precedents,³³⁰ the Court of Appeal supported parental refusal.

As surgery would make this far from a 'no-hope' situation, the Court's decision employed a redefinition of **purpose**:

'to prolong life...is not the sole objective of the court and to require it at the expense of other considerations may not be in the child's best interests'.³³¹

This enabled independent and complete view of evidence beyond the purely clinical.³³² Further, the Court accepted a responsible **role** for weighing these issues:

'the starting point - and the finishing point too - must always be the judge's own independent assessment of the balance of advantage or disadvantage of the particular medical step under consideration'.³³³

However, strong emphasis was placed on C's relationship with his mother. Butler-Sloss LJ considered mother and child to be

'one for the purpose of this unusual case...The welfare of this child depends upon his mother'.³³⁴

This is remarkable, given that generally courts are keen to differentiate between interests of minors and parents. In contrast, in *Re S (A minor)(medical treatment)*,³³⁵

³²⁹ [1997] above.

³³⁰ Particularly: *Re B* [1981]; *Re C* [1989]; *Re J* [1990]; and *Re W (mental patient)(sterilisation)* [1993] all above.

³³¹ Per Butler-Sloss LJ, above, 916(b-c). Also: Waite LJ considered welfare should be 'appraised in all its aspects', 917(f-g); and Roch LJ, '[n]or are such decisions to be taken solely with medical factors in mind', 919(c).

³³² A. Grubb describes the Court's approach as 'refreshing', *Med. L. Rev.* 4 [1997] 315, 318.

³³³ Above, 917(e). See also Roch LJ, *ibid*, 918(e-f).

³³⁴ *Ibid*, 914(j)-915(a).

³³⁵ [1993] 1 FLR 376.

the court consented (contrary to parental wishes) to blood transfusion for a young child suffering T-cell leukaemia, even though chance of success was 50:50 (i.e. *less* than that in *Re T*) and resulting familial stress was dismissed as unrealistic.³³⁶

The principal reason proffered for recognising relationship was that the level of parental commitment, post-operatively, would affect clinical efficacy of treatment.³³⁷

This reasoning has been criticised in view of the distinction made of *Re B*.³³⁸ Doubts are also raised about the validity of basing a child's best interests on the demands his/her care places upon others. Grubb queries whether

'a parent's lack of devotion and support can neutralise the child's interests in living'.³³⁹

If so, the effect of the Court of Appeal's redefinition through relationship subordinates a minor's best (medical) interests to parental best interests. This is exacerbated by the issues the Court considered, characterising C's dependency by reference to: the mother's ability to cope; the need for C to reside in England,³⁴⁰ and/or C's father to leave his post abroad;³⁴¹ financial implications;³⁴² and jurisdictional difficulties of enforcement.³⁴³ Davies suggests that this means

'undue reliance is once more being placed on parental consent...under the guise of declaring that the lack of confidence of the parent in the treatment proposed means that the medical prospects of its success are diminished'.³⁴⁴

However, a decision cannot be entirely divorced from practical care difficulties as quality of life is not a purely health-based issue, and young children *are* dependent on parents (and parental circumstances). Simply adopting a limited medical view brings us no closer to accurate assessment of an individual's best interests.

³³⁶ The parental view of a minor's welfare was also considered to be rebuttable with regard to testing of a baby for HIV in *Re C* (HIV test) above.

³³⁷ Above, 915-916.

³³⁸ [1981] above, where the Court committed B's parents to lengthy care responsibilities. See: M. Fox and J. McHale, In whose best interests? *MLR* 60 (1997) 700, 703; J. Loughrey, Medical treatment - the status of parental opinion, (1998) *Fam. Law* 28, 146, 148; S. Michalowski, Is it in the best interests of a child to have a life-saving liver transplantation? *Re T* (Wardship: medical treatment), *CFLQ* 9(2) [1997] 179, 184.

³³⁹ *Med. L. Rev.* 5 [1997] 315, 318.

³⁴⁰ Above, 915(a).

³⁴¹ *Ibid.*, 915(a) and 919(g-h).

³⁴² *Ibid.*, 919(g-h).

³⁴³ *Ibid.*

³⁴⁴ M. Davies, Selective non-treatment of the newborn - in whose best interests? In whose judgment? *NILQ* (1998) 49(1), 82, 88. However, the court did reject a reasonable parent test, above, 913(j).

The key to understanding redefinition in *Re T* lies in judicial motivation for playing the relationship card. Recognition of relationship is often employed to justify an end goal. In part, this goal may have concerned conflict:

'construing the mother and child as one permitted the Court of Appeal to minimise the potential conflict between the interests of the woman and child'.³⁴⁵

But, as the parents were medical professionals, Fox and McHale rightly suggest this may have 'blurred' any knowledge disparity between them and the doctors concerned.³⁴⁶

In truth, the Court's purpose may have been to choose between professional medical opinion (as in previous minors cases), and accepting the mother/child relationship was a means to admitting an essentially professional view.³⁴⁷ As Mason *et al* suggest, given reluctance to compel doctors to treat contrary to clinical judgment,

'[i]t may not...be a decision taken against the stream'.³⁴⁸

Although subsequent cases confirm the importance of considering parental views,³⁴⁹ preference for clinical judgment is also affirmed. Hence, despite parents requesting treatment, the courts will not compel doctors to treat against their clinical judgment regarding future-oriented withdrawal of ventilation.³⁵⁰ The Court of Appeal also declined to make a parentally requested anticipatory order regarding a seriously disabled 12 year-old in the absence of specific treatment circumstances.³⁵¹ Further, where communication breaks down between parents and HCPs, the court is willing to act as an adjudicator in the minor's best interests.³⁵² Indeed, this judicial role seems to be increasingly necessary. In *Re MM*,³⁵³ Black J expressly considered the risks and benefits of potential treatment options,³⁵⁴ including longer-term impact,³⁵⁵

³⁴⁵ M. Fox and J. McHale, above, 706.

³⁴⁶ See *ibid*, 707. See also A. Grubb, above, 319.

³⁴⁷ Waite LJ refers to the injurious implications of a coercive order against the mother's medical and maternal judgment, above, 917(h).

³⁴⁸ (2002) above, paragraph 16.55.

³⁴⁹ E.g. *Re MM* (Medical treatment) [2000] 1 FLR 224, 234.

³⁵⁰ Even though the parents' argument emphasises the infant's emotional relationship with them: *A NHS Service Trust v D* [2000] 2 FCR 577; and *Royal Wolverhampton Hospitals NHS Trust v B*, above.

³⁵¹ *R v Portsmouth Hospitals NHS Trust ex p Glass* [1999] 2 FLR 905, Lord Woolf MR suggesting that while legal principle is clear, anticipatory application of principle is very difficult, *ibid*, 911.

³⁵² See: *Royal Wolverhampton case*; *ex p Glass*; and *Re MM*, all above.

³⁵³ Above.

³⁵⁴ *Ibid* 230-234.

and parental anxieties.³⁵⁶ And, it reached its pitch in a clear need for judicial choice regarding treatment options in the conjoined twins case.³⁵⁷

However, relationship has also been considered judicially where the views of two parents were opposed. In *Re J* (Specific issue orders: child's religious upbringing and circumcision),³⁵⁸ the Court of Appeal determined that it was not in J's best interests to be circumcised (for religious reasons rather than necessity) contrary to the wishes of his 'primary carer'. Thorpe LJ emphasised Ward J's earlier focus on J's (secular) day-to-day upbringing and home environment,³⁵⁹ and endorsing the consent requirement (of both parents) for such procedures under s2(7) Children Act (1989).³⁶⁰

2.3.2.3 Conclusions on relationship

The purpose of this section has been to reveal a stark reality that persists in ICP decisions, namely, that the patient cannot be the sole focus of our attention. Indeed, all individuals' lives are filled with meaningful relationships that cannot be ignored in any decision-making process. Moreover, an ICP's life is also filled with parties who each have a potentially significant interest in the outcome of any decision. To date, this reality has only been recognised sporadically by the courts. We shall see in chapter 6 how it can be better integrated into the overall decision-making process as part of this thesis.

2.3.3 Risk assessment

Decisions about medical treatment for ICPs require us to risk our judgment on their behalf, and to assess risks associated with relevant factors and treatment options. *Re S* (Medical Treatment: Adult Sterilisation)³⁶¹ confronted risk head-on and retrenched

³⁵⁵ *Ibid*, 233(B-E).

³⁵⁶ *Ibid*, 230-233.

³⁵⁷ [2001] above. Considered below, paragraph 2.3.4.3.

³⁵⁸ [2001] 1 FLR 571.

³⁵⁹ *Ibid*, 574(C-D).

³⁶⁰ *Ibid*, 576(D). See also *Dame Butler-Sloss* (P), *ibid*, 577. The significance of relationship is also considered in the non-medical context of best interests application regarding minors in Scotland. In *Reid v Cardno* [2000] GWD 1026, a declarator supported contact between child and father (and extended family) based in the minor's best interests where the mother vehemently opposed it.

³⁶¹ [1998] 1 FLR 944.

from previous expansion.³⁶² In incapaces sterilisation, persistent boundary extension had incorporated downgrading important risk factors such as sexual activity,³⁶³ and supervision.³⁶⁴ Legal criteria had also shifted from necessity and welfare³⁶⁵ to vague evaluations of 'interests overall',³⁶⁶ and consideration of others' interests.³⁶⁷ Procedures were also relaxed regarding therapeutic sterilisations.³⁶⁸ The net effect was virtually non-existent risk assessment; vulnerability of patients (to non-consensual activity) being mistaken for a need to sterilise.³⁶⁹

Disparate risk assessment is evident in other IcP contexts. In *Re C*,³⁷⁰ weight of medical evidence favoured amputation. However, at the time of giving expert evidence, a consultant forensic psychiatrist (Dr Ghosh) was unaware that less extensive surgery had already been carried out, thereby averting the 85% risk of death,³⁷¹ and she was unaware that below-knee amputation also carried a (15%) mortality risk.³⁷² The Court preferred alternative medical opinion, but this illustrates the importance of informedness. Poor risk evaluation is also starkly illustrated in obstetric cases. Even in *Re MB* the Court of Appeal accepted psychiatric evidence that she was likely to suffer significant psychological damage from death of the child, but would not suffer lasting damage from enforced administration of anaesthetic.³⁷³ This view of risk is blinkered because:

- as MB was needle phobic, administering anaesthetic would compel her to confront her phobia which, by definition, involves an *abnormal psychological* fear response and excessive *physiological* response. Being compelled involuntarily to confront this phobia surely would result in

³⁶² The author's views on this case have been published earlier: A.J. Fenwick [1999] above, see Appendix 10, hereto.

³⁶³ *Re W* [1993] above.

³⁶⁴ *Re HG* [1993] above.

³⁶⁵ *Re F* [1989] above.

³⁶⁶ *Re HG*, above.

³⁶⁷ *Ibid.*

³⁶⁸ (*Re E (A minor) (Medical treatment)* [1991] 7 BMLR 117, and *Re GF (Medical treatment)* [1992] 1 FLR 293.

³⁶⁹ E.g. *Re HG*, above.

³⁷⁰ [1994] above.

³⁷¹ *Ibid.*, 294(A).

³⁷² *Ibid.*, 294(B) and 293(C-D).

³⁷³ Above, 439(C). Indeed, at first instance, the court did not even envisage 'any particular short-term trauma as a result of the forcible procedure' and that the 'non-consensual nature of the injection would not be a matter of lasting importance to Miss MB', *ibid.*, 431(F-G).

short-term trauma from these responses, and exacerbate the sense of loss of control inherent in phobic response;

- Stauch also identifies two further sources of harm in enforced Caesarean section: (1) enforcement may damage the woman's 'general sense of herself as an autonomous agent'; and (2) the 'attendant physical harm' of surgical intervention.³⁷⁴ Relatedly, Thomson suggests evidence of 'increased incidence of post-natal depression and ambivalence towards the child',³⁷⁵ accompanied by 'feelings of anger, isolation, humiliation and self-blame'.³⁷⁶ Physical risks flowing from Caesarean section, include: increased incidence of maternal death,³⁷⁷ infection,³⁷⁸ haemorrhage;³⁷⁹ increased pain and damage to other organs;³⁸⁰ and increased need for repeat Caesareans,³⁸¹ limiting the number of advisable pregnancies.³⁸²

These risks are significant and sound assessment of best interests requires all risks of long-term damage to be considered and weighed against opposing risks (such as long-term psychological damage of unsuccessful delivery). Revision of risk assessment as a gateway to best interests was long overdue when *Re S* stepped into the breach.

2.3.3.1 *Re S* (Medical treatment: adult sterilisation)³⁸³

Re S concerned a 22-year-old intellectually disabled woman, who was not sexually active. Sexual assault was the only source of risk. Johnson J considered S's daily routine, supervisor/client ratio, tactile behaviour, respite care supervision, and

³⁷⁴ Above, 83.

³⁷⁵ M. Thomson, *After Re S*, *Med L Rev* 2 [1994] 127, 135. Higher incidence of post-natal depression is also noted by A. Morris and S. Nott, *The law's engagement with pregnancy*, Chapter 3 in Bridgeman and Millns, *Law and Body Politics* (1995), 55, 60.

³⁷⁶ *Ibid*, 135, citing from: G Douglas, *Law, fertility and reproduction* (1991) Sweet & Maxwell, 56; and P Gilfix, *Electronic fetal monitoring: physician liability and informed consent*, (1984) 10 *American Journal of Law and Medicine*, 31, 34.

³⁷⁷ M. Thomson, *ibid*, 135. Also Stauch, above, 83 n39.

³⁷⁸ Thomson, *ibid*, 135 n57, (citing from D. Knox and C. Karagianis, *Caesarean births: high rates, impassioned debate*, *Boston Globe Magazine*, 21.10.84, 10, 58 n209): the rate of infection in Caesarean mothers is 5-10 times that following vaginal birth.

³⁷⁹ Thomson, *ibid*.

³⁸⁰ Stauch, above, p83 n39.

³⁸¹ Thomson, above, 135.

³⁸² Morris and Nott, above, 60.

³⁸³ [1998] above.

general need for supervision. Johnson J found parity with *Re LC*, based on responsible parental supervision minimising any risk of pregnancy.³⁸⁴ Johnson J required an

‘identifiable rather than speculative [risk]’.³⁸⁵

The final paragraph of the judgment reserves responsibility for the sterilisation decision to the court.

Essentially, risk was the only available judicial means to redefinition. For, once *any* risk of pregnancy was identified, lawfulness of sterilisation was based on the Bolam standard. In this author’s earlier article, the approach of Carson is highlighted regarding lack of distinction between consequence and likelihood,³⁸⁶ and emphasis on harm rather than benefit.³⁸⁷ On this view, previous (expansive) sterilisation cases display poor risk assessment, confusing **risk** (of pregnancy) with consequent **trauma**. This consequence-driven approach results in sterilisation seeming ‘necessary’ in the patient’s best interests. Johnson J’s retrenchment deconstructed risk, allowing consideration of an *intermediate harm* (risk of pregnancy), permitting a more accurate perspective and evaluation to take place. Further, the decision accepted the significance of *risk agent*. This broadened the **range** of relevant risk factors, drew attention to **likelihood** and resurrected risk as an important **gateway** criterion to best interests in sterilisation cases.³⁸⁸

However, some potentially relevant factors are still absent. A one-sided perspective persists, with statistical risks,³⁸⁹ painful side effects, and psychological impact of surgical sterilisation being trivialised. And, IcPs’ personal inviolability may still be overlooked regarding surgery and sexual assault. Carson also identifies the risk of sexually transmitted disease,³⁹⁰ which surely should be considered if we aim to

³⁸⁴ The High Court had earlier refused authorisation in *Re LC* (Medical treatment: sterilisation) [1997] 2 FLR 258 (decided in 1993) partly because levels of care and supervision ‘would effectively eliminate the risk of sexual abuse to L’, *ibid*, 260(F).

³⁸⁵ *Ibid*, 949(E).

³⁸⁶ D. Carson, Risk-taking policies (1988) *J. Soc. Welf. Law* 328, see particularly 328-329.

³⁸⁷ *Ibid*, 329.

³⁸⁸ However, see discussion of male sterilisation, below.

³⁸⁹ See A. Hill, Alert over female sterilisation, *Scotland on Sunday*, 14.2.99, p7, cols 1-7, with reference to a report by RCOG.

³⁹⁰ Carson, above, 360.

protect, yet has received minimal consideration thus far.³⁹¹ Lack of risk assessment regarding other non-medical interests such as sexuality, privacy, bodily integrity and social development also still permits medical concerns to dominate best interests evaluation.³⁹² A broader perspective on interests is warranted; ‘best interests’ surely suggests evaluation of an ICP’s procreative welfare in full sight of *all* factors and circumstances.

In **Re X (Adult sterilisation)**,³⁹³ the ‘risk’ criterion applied again, but to different effect; X’s interest in sexual activity creating a sufficiently ‘real risk’. Holman J addressed a series of questions about X’s capacity, risk of pregnancy, risk of consequent harm, and risks associated with alternative contraception. However, once a ‘real risk’ was identified, judicial focus turned to Re F’s lawful acceptability of a responsible body of medical opinion.³⁹⁴

However, more reframing took place in **Re A (Male sterilisation)**,³⁹⁵ regarding a 28-year-old male patient with Down’s syndrome, whose intellectual impairment was borderline significant/severe. A regularly attended a day centre, was sexually aware and had been involved in sexual incidents with women. He was fertile, but had no understanding of causal connection between intercourse and pregnancy, and was unable to use contraceptives. Although currently resident with - and closely supervised by - his mother, he would be entering Local Authority care. In view of this anticipatory change, A’s mother argued A would have greater opportunity for sexual relationship and sterilisation (by vasectomy) would improve his quality of life by enabling relationship. Psychiatric evidence was divided; one consultant regarded sterilisation as contributing to A’s freedom, while a second disagreed, considering actual risk of intercourse to be very small, and unlikely to occur while under his mother’s supervision. Sumner J decided sterilisation would not be in A’s best

³⁹¹ The only case believed to consider these issues is *Re A (Male sterilisation)* [2000] 1 FLR 549, discussed below.

³⁹² See also N. Cica’s distinction between ‘medical’ and ‘social’ interests, *Sterilising the intellectually disabled: the approach of the High court of Australia in Department of Health v JWB and SMB* 1 Med. L. Rev. [1993] 186, 195. Therapeutic sterilisation remains distinct; *Re ZM and OS (Sterilisation: patient’s best interests)* [2000] 1 FLR 523.

³⁹³ [1998] 2 FLR 1124.

³⁹⁴ [1989] above, 567(A) and 571(H). In contrast, in *Re S* [1998] above, no reliance on *Bolam* was apparent. See commentary by A. Grubb, *Incompetent adult (sterilisation): best interests and the risk of pregnancy* Med. L. Rev. 6 [1998] 354, 354-6.

³⁹⁵ [2000] above.

interests, not adding significantly to his quality of life. The Court of Appeal upheld this position on evaluation of interests and quality of life rather than risk,³⁹⁶ considering the first instance decision

'to concentrate too much on the evaluation of risks...some of which seem to me at best hypothetical. A risk is no more than a possibility of loss and should have no more emphasis in the exercise than the evaluation of the possibility of gain'.³⁹⁷

This effectively regards risk as embodied within the general assessment of best interests (rather than as a prerequisite gateway to determination).

Dame Butler-Sloss (P) also focused on interests, reiterating her view in *Re MB* that

'best interests encompasses medical, emotional and all other welfare issues',³⁹⁸

and reserving responsibility to the Court. Furthermore, she warned against sterilisation for convenience of carers, and denied any relevance to third party or public interest (the need to protect A's prospective partners being understandable, but irrelevant hereto).³⁹⁹ In effect, this denies any significant role for 'relationship'.

Although non-sterilisation of an IcP is welcome in the absence of realistic, imminent harm from inaction,⁴⁰⁰ concerns arise about consistency of application. Certainly, A's sexual awareness, history of sexual involvement, and degree of opportunity (at the day centre) make this case differ from *Re LC* and *Re S*. But, A's case is more closely analogous to *Re X* where, in contrast, risk was identified and sterilisation declared lawful.⁴⁰¹ Hence, judicial willingness to sterilise X, while refraining from

³⁹⁶ Surgery must be 'not negligent' and 'necessary' in the patient's best interests, see High Court's approval of the Official Solicitor's Practice Direction reported at [2002] 1 All ER 794, citing *Re A*, *ibid* 796.

³⁹⁷ Per Thorpe LJ, *ibid*, 561(A). However, the Court indicated that *when A* went into L.A. care then a re-application might be appropriate, aiming to protect A's freedom and quality of life. This leaves open the possibility of re-balancing if circumstance or environment change to increase risk.

³⁹⁸ *Ibid*, 555(F).

³⁹⁹ *Ibid*, 556(C-D).

⁴⁰⁰ Indeed, MENCAP suggested '[i]t would be quite wrong to impose medical treatment on him and unethical to take away his freedom', reported by S. Hall, *Woman loses fight to have son sterilised*, *Guardian* 21.12.99, p5, cols 6-8.

⁴⁰¹ X was sexually aware, had been involved in sexual incidents and was under general parental supervision, but had some opportunity for relationship in attending an adult training centre. Familial relationships in the two cases are employed to particular ends; the mother/son relationship in *Re A* is characterised as supervisory (a risk-inhibitor), while in *Re X* the *concerns* of her parents are emphasised, together with their support for sterilisation (a risk-enhancer).

sterilising A, raises doubts about consistent application of principle regarding male and female IcPs, exacerbated by Dame Butler-Sloss' (P) observation that

'[a]n application on behalf of a man for sterilisation is not the equivalent of an application in respect of a woman'.⁴⁰²

However, the President prefers balancing on a case-by-case basis,⁴⁰³ considering here that

'there is no direct consequence for a man of sexual intercourse other than the possibility of sexually transmitted diseases'.⁴⁰⁴

Certainly, any harm of pregnancy to a male IcP is indirect and vicarious, while pregnancy for a female IcP can cause direct, traumatic physical and mental harm. This consequentialist ethic means that regarding male sterilisation the only relevant harm is the *ultimate* harm (pregnancy), and this is effectively too remote to be relevant to his interests. On this basis, it seems that consequential trauma (or lack of it in the male context) may still be the real influence on decisions whether to sterilise.

Arguably, this approach perpetuates outdated social constructs that place responsibility for contraception on women:

'[i]t would...be likely that the woman concerned would be the object of protection rather than A'.⁴⁰⁵

Male sterilisation really concerns the extent to which interests of others should affect an IcP's best interests.⁴⁰⁶ However, the *risk* of A *causing* pregnancy does seem more than 'speculative'.

Certainly, while risk is an important gateway to best interests, it should not become a barometer for best interests; consideration of patient interests should still allow for sterilisation to be declined if other factors counter it. The Court of Appeal's refusal to sterilise A, on the basis no-risk-now-but-perhaps-try-later, may do him no favours by curtailing his quality of life in the interim.⁴⁰⁷ Furthermore, if this really was a decision about A's interests being unaffected by any pregnancy, then increased risk

⁴⁰² Re A, above, 557(D-E).

⁴⁰³ Ibid.

⁴⁰⁴ Ibid, 557(E). Dame Butler-Sloss (P) considered any psychological consequences were unlikely to impinge on an incapacitated man, and any detrimental restriction on freedom should be considered case-by-case, *ibid* 557(F-G).

⁴⁰⁵ Per Dame Butler-Sloss (P), *ibid*, 558(B).

⁴⁰⁶ The validity of third party interests is considered below, Chapter 3.

⁴⁰⁷ And, it may bring harm to female partners who would bear the consequences.

at a future date should make little difference. This suggests that some account might be taken of the interests of any future partner of A. This is telling, given that the court expressly denied this possibility in its own judgement. One is tempted to conclude – as the previous section has shown – that the Court itself could not wholly ignore the interests of others in its decision as it related to A.

2.3.3.2 Redefining beyond risk - Re SL (Adult patient: sterilisation)⁴⁰⁸

The courts' traditional approach basing best interests on medical evidence and opinion is criticised by Plomer, who suggests (citing the RCOG view on obstetric cases) that such reliance is inherently uncertain, as medical evidence is 'seldom infallible' and subject to limited accuracy and effectiveness regarding pregnancy.⁴⁰⁹ Re A had hinted at revision of best interests content, and a shift away from Bolam. This was developed by the Court of Appeal's decision in Re SL, offering more radical redefinition; reserving final determination of best interests to the court and relegating Bolam to an evidential role.

SL was a 29-year-old female with severe learning difficulties resident with her mother, but a move to a local authority home was anticipated. There, she might be unsupervised in mixed company and S's mother sought a declaration of lawful sterilisation, arguing: (1) avoidance of risk of pregnancy; (2) therapeutic treatment to eliminate menstruation which distressed S; and (3) that hysterectomy was favoured due to S's phobia of hospitals. At first instance, Wall J concluded treatment to be necessary for contraceptive and therapeutic purposes. However, he left determination of the method of treatment (surgical sterilisation or Mirena coil) to the doctors and S's mother. The Official Solicitor appealed that: (a) sterilisation was against the weight of evidence, and insufficient regard had been paid to the principle *primum non nocere* (first, do no harm); and (b) Wall J had wrongly relied on Bolam to find *either* treatment option lawful. Butler-Sloss LJ, for the Court of Appeal, upheld the first ground of appeal in view of the weight of medical evidence supporting the less invasive (IUD) method, and the need for a *proportional* response.

⁴⁰⁸ [2000] 2 FCR 452.

⁴⁰⁹ A. Plomer, above, 268.

Although, *prima facie*, this seems to contrast with earlier decisions (indicating that therapeutic sterilisation decisions were now unlikely to reach court),⁴¹⁰ this case can be brought into line with *Re GF* because it failed to meet all of the *Re GF* criteria.⁴¹¹ Unremarkably, the appellate decision in *Re SL* followed the weight of medical evidence,⁴¹² and played down the relationship aspect - denying significant weight to the mother's view, which fits my earlier observations about teleology. However, the Court's reasoning displays landmark redefinition of three aspects of best interests.

In expressly requiring a '**proportional**' response,⁴¹³ Dame Butler-Sloss (P) emphasised disabled patients' right not to have drastic surgery imposed on them, unless in his/her best interests.⁴¹⁴ This posits sterilisation decisions within personal inviolability (rather than the previously contentious right of reproduction),⁴¹⁵ and reflects the Australian approaches in *JWB* and *SMB*,⁴¹⁶ and *Re L* and *M*.⁴¹⁷ Indeed, parallels with the Australian approach go beyond the functional purpose of the decision, to dramatically change respective **roles**.

While citing *Re F* regarding applicability of best interests, the Court - to all intents and purposes - departed from the authorised roles of *Re F*. Dame Butler-Sloss (P) clearly reserves determination to the Court,⁴¹⁸ locates *welfare* as the paramount consideration,⁴¹⁹ and diminishes the relevance of **Bolam** to evidential status.⁴²⁰ Thus, the Court's approach more closely resembles the judicial role regarding minors,

⁴¹⁰ See *Re E* (a minor)(medical treatment) [1991] 7 BMLR 117, and *Re GF* (medical treatment) [1992] 1 FLR 293.

⁴¹¹ Certainly, in *Re SL*, the IUD treatment option constituted a 'practicable, less intrusive means', thereby failing the third *Re GF* criterion. Furthermore, in *Re SL*, Thorpe LJ had indicated that cases on the boundary should be referred for court declaration, above, 469(d).

⁴¹² However, *medical evidence* was unusually weighted towards the *less-invasive* option.

⁴¹³ Above, 462(b).

⁴¹⁴ *Ibid*, 462(b-c).

⁴¹⁵ In this regard, *Re SL* builds on the inviolability aspects regarding risk in *Re S* [1998] above. The Court supported the patient's right through the ethical principle *primum non nocere*.

⁴¹⁶ *Secretary, Dept. of Health and Community Services v JWB and SMB* (1992) 66 ALJR, 300 where the majority of the Australian High Court considered sterilisation a 'last resort', justified only when 'alternative and less invasive procedures have all failed or that it is certain that no other procedure or treatment will work', *ibid* 315(B-C). Brennan J also referenced proportionality (and purpose) as legal factors relevant to therapeutic sterilisation, *ibid* 321(C).

⁴¹⁷ *Re L and M: Director-General, Dept. of Family Services and Aboriginal & Islander Affairs*. (1993) 17 Fam. LR 357, where Warnick J developed guidelines within the *JWB* parameters, emphasising proportionality (determinable by reference to *medical fact*), and the 'last resort' character of sterilisation.

⁴¹⁸ Above, 461(e). Similar to the majority in *JWB*, above, 315(A).

⁴¹⁹ Above, 461(d-e).

⁴²⁰ *Ibid*, 465(c).

than the declaratory role regarding adult ICPs. Medical opinion is limited to informing the court whether, or which, treatment options lie within a range of acceptable, reasonable opinion (i.e. which options are *Bolam-competent*). Beyond this, *Bolam* is made irrelevant. Indeed, *Re SL* represents the point at which *Bolam* breaks down - the availability of more than one treatment option required a choice, such that:

‘judicial decision ought to provide the best answer not a range of alternative answers’.⁴²¹

The drift away from *Bolam* in England and Wales was initiated in the negligence case *Bolitho v City and Hackney HA*.⁴²² Although the immediate impact of the Law Lords’ decision therein was uncertain, cases,⁴²³ and opinion,⁴²⁴ since seem to have consolidated the judicial drift. Lord Woolf has recently opined in a non-judicial context on the causes of this change.⁴²⁵ *Inter alia*, he notes increasing awareness of patients’ rights,⁴²⁶ commonwealth approaches,⁴²⁷ and recent cases concerning medical ethics.⁴²⁸ Regarding the latter, he refers to several decisions concerning incompetent patients.⁴²⁹ He suggests these cases

‘provoke heartfelt and real disagreement among members of the medical and legal professions as well as members of the public’, causing the courts ‘to adopt a more proactive approach to resolving conflicts’.⁴³⁰

Hence, it seems that these tense best interests decisions may now be influencing the traditions of medical negligence, rather than the other way around. Lord Woolf considers that such case law developments now make courts the ‘final arbiters’, and

⁴²¹ Per Butler-Sloss (P), *ibid*, 464(f). Judicial involvement in sterilisation decisions (re. incompetent adults or children) remains essential, see O.S. Practice Direction reported and endorsed [2002] above.

⁴²² [1997] 4 All ER 771. However, impetus in other common law countries had occurred earlier, a useful overview is given by Mason, McCall Smith and Laurie, *Medical Law and Ethics* [2002] paragraphs 10.121-10.124.

⁴²³ See particularly *Pearce v United Bristol Healthcare NHS Trust* [1999] 48 BMLR 118.

⁴²⁴ See *Mason et al*, *ibid*. Also M. Brazier and J. Miola, *Bye-Bye Bolam: A medical litigation revolution?* 8 *Med. L. Rev.* [2000] 85.

⁴²⁵ Delivering the inaugural Provost’s lecture at UCL, London, 17.01.01: *Are the courts excessively deferential to the medical profession?* 9 *Med. L. Rev.* [2001] 1.

⁴²⁶ *Ibid*, 3.

⁴²⁷ *Ibid*, 4.

⁴²⁸ *Ibid*.

⁴²⁹ E.g. the conjoined twins case (*Re A*), the *St George’s* case, the *Glass* case, and *Re F* [1989] all above.

⁴³⁰ Above, 4.

have raised public interest intervention.⁴³¹ The importance of an impartial decision-maker and transparency are themes developed in the remainder of this thesis.⁴³²

Re SL also encompasses broader ethical, social and moral considerations - beyond the purely medical.⁴³³ The Court of Appeal's single-handed demedicalisation of best interests goes to the heart of best interests decisions, taking a broad view and actively weighing issues. But such dramatic remarcation creates inconsistency as, despite purported concurrence with the (precedentially more authoritative) Re F approach, fundamentally the decision departs from it, and is pitted against an authoritative volume of contrary (medicalised) precedent regarding adult IcPs. Subsequent cases are sure to test Re SL's authority and it is unclear from where the Court of Appeal has suddenly derived **jurisdiction** to determine best interests (given lack of *parens patriae*). Thorpe LJ's reading of Re F as establishing that

'the declaratory decree, was to be exercised upon the same basis, namely that relief would be granted if the welfare of the patient required it and equally refused if the welfare of the patient did not',⁴³⁴

is questionable, particularly as it is not substantiated or explained further. Given that *parens patriae* jurisdiction embodied protective welfare jurisdiction regarding adults, while declaratory jurisdiction concerned protection from liability, revival of the former under the guise of the latter seems doubtful.⁴³⁵ However, this author does endorse the sentiments of the Court of Appeal in broadening the range of interests and demedicalising roles. These changes may be supported further through the momentum currently being created by human rights provisions.

⁴³¹ Ibid 13.

⁴³² See Chapters 6-8.

⁴³³ Above, 461(d), following the Court's own view in Re A [2000] above. Also highlighted by the majority in JWB, above, 311(B) (social and psychological consequences of sterilisation). Relatedly, Re L and M, above, 10, identified medical, social, philosophical, moral and even economic issues as relevant.

⁴³⁴ Above, 467(b).

⁴³⁵ Policy proposals would rectify the lack of jurisdiction if developed and implemented through a Court of Protection. These proposals are considered below. However, implementation is not imminent. Alternative guidelines are formulated in this thesis and proffered in Chapter 8.

2.3.4 Human rights - mandatory redefinition

The Human Rights Act 1998 incorporates into domestic law the long-standing European Convention on Human Rights.⁴³⁶ These generalised rights must be interpreted by UK courts, and citizens will be able to assert their need for protection of rights before UK courts, rather than resorting to lengthy and expensive appeal processes in Europe. The implications in terms of IcPs were raised in two cases decided shortly before the Act came into force in England.

2.3.4.1 Re F (Adult: court's jurisdiction)⁴³⁷

This case concerned detention of an 18-year-old IcP in local authority care, contrary to her family's wishes. Although medical treatment was not the issue, the Court of Appeal's judgment contains relevant jurisdictional and human rights elements. The Court of Appeal unanimously supported Sedley LJ's comments foreseeing the relevance of human rights under Articles 5 and 8.

Article 5 protects individual right to liberty and security of person, subject to the State's lawful detention of, *inter alia*, persons of unsound mind. Sedley LJ considered the State's power, in turn, subject to two constraints that:

- detention must be in accordance with procedures prescribed by law; and
- that law must respect the provisions of Article 8.⁴³⁸

This essentially ensures individual rights of due process and representation, and pre-empted conflict between Articles 5 and 8. **Article 8** concerns the right to respect for private and family life, and limits justifiable State interference to specific grounds including, *inter alia*, protection of health, or protection of the rights and freedoms of others. Sedley LJ made some general observations about the nature of this right, considering it to be non-proprietary in relation to the parent or child, being a societal interest as much as an individual interest.⁴³⁹ Further, he construed the right's principal purpose regarding children being to ensure the child's safety and welfare,

⁴³⁶ The Convention for the protection of Human Rights and Fundamental Freedoms (the European Convention on Human Rights)(Rome, 4 November 1950; TS 71 (1953); Cmd 8969).

⁴³⁷ [2000] 55 BMLR 81.

⁴³⁸ *Ibid* 99-100.

⁴³⁹ *Ibid*.

limiting individuals to benefits of family life that are 'benign and positive'.⁴⁴⁰ This precludes the child/parent role from gaining further weight by way of the Act. He also noted that

'the tabulated right is not to family life as such but to respect for it'.⁴⁴¹

In other words, T's welfare remained 'the single issue',⁴⁴² and provided due consideration is given to familial views, it seems likely 'respect' will have been accorded. Interestingly, this interpretation strays little from the purpose and content accorded through best interests, framed in protective welfare, and admits relationship only to facilitate perceived individual welfare.

Although redefinition seems minimal it is possible to foresee potential issues for the **medical treatment context**. The **Article 5** exception for detention of those of 'unsound mind' seems set to reinforce the importance of competence where patients refuse treatment. The way is open to patients to

- dispute adherence to legal procedure under which s/he has been detained, including opportunity for representation;⁴⁴³ or
- dispute that legal procedure's compliance with Articles 5 or 8.⁴⁴⁴

Further substantiation may be available under Article 6 (right to a fair trial), which entitles individuals to a fair and public hearing in determining his/her civil rights. On this basis, the procedural guidelines of *Re MB* and *St George's* may begin to carry more force.

Article 8's express scope for State intervention on grounds of protecting health (rightly) leaves the way open for ICPs to be treated without contravention of their human rights. However, 'protection' is potentially broad, as is Sedley LJ's attribution

⁴⁴⁰ Ibid.

⁴⁴¹ Ibid.

⁴⁴² Ibid.

⁴⁴³ These legal procedures are set for reform in both Scotland (Mental Health (Scotland) Bill, SP Bill 64 (2002)) and England and Wales (Mental Health Bill (2002)). Both retain 'best interests' in some form (see s163(2)(c) and 170(b) of the Scottish bill and s115(3) (implicitly), and s115(4)(c) regarding specialist treatments in the English bill). Neither bill says much about best interests, but the Scottish provisions set out the need to consider patient views (s170(6) and s169(2)) and patient resistance to certain treatments for mental disorder (s162-164). The English provisions refer only to 'likelihood' of resistance (s115(3)), and scope for treatment is subsumed under approved care plans (s117).

of content based on 'welfare'.⁴⁴⁵ Furthermore, his differentiation between 'respect for' private/family life and (absolute) *entitlement* to family life, means that Article 8 would be satisfied providing *consideration* (i.e. respect) has been given to a decision's effect on family/private life; this right need not dominate the decision.⁴⁴⁶ Thus, Article 8 cannot be used by families to slam closed the gate to judicial determination of IcP treatment in his/her best interests. Parental role was considered in the following case, which moved human rights issue into the IcP context.

2.3.4.2 A National Health Service Trust v D⁴⁴⁷

This case concerned future ventilation of a 19-month-old boy, ID, born with serious disabilities including a severe, deteriorating lung condition, congestive heart failure, hepatic and renal dysfunction and severe developmental delay resulting from brain abnormalities. His life expectancy was short, and he was admitted repeatedly to intensive care for respiratory failure and fever. During his last admission to hospital, the HCPs and ID's parents disagreed about whether to transfer him to an intensive paediatric unit. As a result, the hospital trust and Official Solicitor sought a declaration that, in the event of future respiratory and/or cardiac failure, it was in ID's best interests (and therefore lawful) not to resuscitate him by mechanical ventilation, and to administer palliative care permitting his life to end peacefully. The court was required to clarify that this would not infringe ID's human rights. Medical opinion was unanimous on the appropriateness of treatment. But, ID's parents strongly opposed the application as premature in view of ID's developmental progress. Cazalet J granted the declaration, subject to the appropriateness of non-ventilation remaining given prevailing clinical conditions on any future hospital readmission.

In reconsidering familiar issues, Cazalet J relied heavily on existing authorities, particularly *Re J*,⁴⁴⁸ construing **purpose** of withholding ventilation to be non-

⁴⁴⁴ The need for prompt hearing by M.H. Review tribunal in accordance with Article 5(4) is confirmed by the CA in *R (on the app'cn of C) v M.H. Review Tribunal London and S.W. Region* [2001] EWCA Civ. 1110, where the (usual) lapse of 8 weeks was considered too long.

⁴⁴⁵ Welfare is considered under Chapter 5.

⁴⁴⁶ Respect is considered in Chapters 6-8.

⁴⁴⁷ [2000] 2 FCR 577.

⁴⁴⁸ [1990] above. Other authorities cited included, *inter alia*, *Re B* [1981] above, *Re C* [1989] above, and the Canadian case *Re Superintendent of Family and Child Service and Dawson* (1983) above.

prolongation (rather than active termination). The **role** of medical opinion dominated the decision; Cazalet J considered it 'well-established' that courts will not compel doctors to treat contrary to clinical judgment, and the declaration gave responsibility for the clinical decision to the HCP involved at that future decision time. Meanwhile, the significance of the parent/child relationship was played down, with parental views of ID's development deemed 'over-optimistic'. The paramount consideration remained ID's best interests. With regard to **content** of best interests, while sanctity of life was acknowledged, the *critical equation* was endorsed as the means to balance preservation of life against quality of life.⁴⁴⁹ ID's best interests were located in withholding ventilation due to invasiveness and pain of mechanical ventilation for ID, his poor quality of life (beginning from such a low baseline), short life span, and weight of medical evidence favouring palliative care.⁴⁵⁰ Thus, the function and content of best interests followed a relatively predictable route. The only remarkable feature (other than human rights) was its determination of *future* treatment. Although the parents' lawyer argued that the decision would be premature and inconsistent with the Glass decision,⁴⁵¹ Cazalet J emphasising decisional urgency in the event of respiratory failure distinguished Glass. Fundamentally, this distinction turns on role and relationship; the mother's request for treatment compulsion in Glass differing from the doctors' request to 'discontinue one special practice' in the instant case.

Despite minimal reference in the judgment to **human rights**,⁴⁵² this is where redefinition occurs. Implicitly, the very inclusion of human rights issues indicated the future context of IcP treatment decisions; the need for best interests determination to comply with human rights obligations. Furthermore, by the Trust and the Official Solicitor seeking reassurance on human rights aspects, it is clear that courts need to give *content* to human rights in the medical context.

⁴⁴⁹ Cazalet J preferred the Dawson approach above (viewing quality of life from the patient's standpoint) on this issue rather than the 'intolerable' yardstick of Re B [1981] above.

⁴⁵⁰ This situation was consistent with the 'no-chance' situation outlined in the Royal College of Paediatric and Child Health guidelines on Withholding Life Saving treatment in Children, A framework for practice (1997).

⁴⁵¹ Above, where it was deemed inappropriate to make a declaration in advance of a particular problem and circumstance.

⁴⁵² Articles 2 and 3 are discussed briefly in the judgement's penultimate section.

Additionally, citing the earlier case of *D v UK*,⁴⁵³ Cazalet J confirmed that Article 3 (prohibiting torture, inhuman or degrading treatment) includes a right to die with dignity. This enabled him to frame the declaration as protecting, rather than derogating from this right. This view seems curious given the earlier dismissal of any relevance for parental distress at undignified intensive treatment. Yet, where an ICP is too young for awareness of ‘dignity’, indignity can surely only be perceived through the eyes of others. However, this imputation also seems doubtfully extensive. Grubb questions Cazalet J’s reading of *D v UK* as embracing a right to die with dignity.⁴⁵⁴ Mason, McCall Smith and Laurie rightly observe in light of this case

‘a relatively steady – and significant - extension of the conditions which render non-treatment lawful’.⁴⁵⁵

Further, they suggest the recent *Re C* cases may signify a changing emphasis towards quality of life assessments based on

‘the glimmers of a legal recognition of the ‘personhood’ construct’.⁴⁵⁶

However, in terms of these infants’ relationships with their parents, those authors draw a pragmatic division between treatment that is futile and that which is *medically* futile.⁴⁵⁷ If warranted, arguably, **relationship** is currently being overlooked in assessing quality of life, and as an interest (held between parent and child) in best interests evaluation. It is these incremental shifts of non/treatment boundaries regarding ICPs – even in the face of human rights – and the camouflaged relevance of issues such as relationship that demand overhaul of best interests construction. Issues such as relationship and personhood require full and frank exploration. This thesis seeks to achieve this, arguing for a fuller understanding of interests *and* of underlying values and constructs.

⁴⁵³ (1997) 24 EHRR 423.

⁴⁵⁴ A. Grubb, *Incompetent patient (child): withholding treatment and human rights*, *A NHS Trust v D*, *Med. L. Rev.* 8 [2000] 339, 341, suggesting rather that in *D v UK* ‘inhuman treatment’ lay in unavailability of treatment, lack of accommodation and familial support for an AIDS sufferer if deported, *ibid* (see p446 of judgment).

⁴⁵⁵ (2002) above, paragraph 16.50.

⁴⁵⁶ *Ibid*. Referring to *Re C (a minor)(medical treatment)* [1998] 40 BMLR 31, and *Re C (a baby)* [1996] 2 FLR 43. Personhood is considered below, Chapter 5.

⁴⁵⁷ *Ibid*, paragraph 16.51.

Dignity is another such construct. Confusion lies currently in excluding interests of others, yet emphasising dignity (which is perceived by, or in the context of, others).⁴⁵⁸ Two recent IcP decisions have emphasised dignity. In *NHS Trust A v M*; *NHS Trust B v H*,⁴⁵⁹ withdrawal of a.n.h. from two patients in p.v.s. was considered regarding Articles 2 and 3.⁴⁶⁰ Dame Butler-Sloss (P) considered the act/omission distinction in *Bland* to accord with Article 2 because

‘[a]n omission to provide treatment...will...only be incompatible with article 2 where the circumstances...impose a positive obligation on the state to take steps to prolong a patient’s life’.⁴⁶¹

Further, a responsible clinical decision to withhold treatment based on a patient’s best interests would fulfil positive obligation under article 2.⁴⁶² This approach seems somewhat contrary to the burgeoning importance accorded earlier to judicial role.⁴⁶³

As Grubb observes:

‘satisfying the Bolam test in reaching a ‘best interests’ determination will be convention-compliant’.⁴⁶⁴

Furthermore, the President’s conclusion regarding Article 3 also displays Bolam-like phraseology, with overtones of beneficence negating infringement and requiring the patient to be *aware* of any inhuman or degrading treatment for violation to occur.⁴⁶⁵ This need for subjective perception is criticised by Mason *at al* as incorrect in its interpretation of European jurisprudence.⁴⁶⁶ On this basis, human rights provisions seem to lack the patient-oriented influence on best interests that might have been

⁴⁵⁸ Application of dignity is easier where a patient is competent. The decision *Re B* (adult: refusal of medical treatment) [2002] 2 All ER 449 confirms that a competent patient may request cessation of treatment, that mental capacity is the issue (not consequences), and that seriously disabled patients have this right. Much of the judgment focuses on capacity, reiterating the right of competent patients to give no reasons for refusal (*ibid* 456). However, as M. Stauch observes the Court’s ‘extended and anxious enquiry into Ms B’s reasons’ may mean that the competent patient refusing for no reason ‘may be a legal oxymoron’, *Commentary, J. Med. Eth.* [2002] 28, 232, 233. However, the need to be certain about competence was evinced by *Re AK* (medical treatment: consent) [2001] 1 FLR 129, where a patient with motor neurone disease was limited to communicating with movement of one eyelid. These cases contrast with *active* assistance to end life, which was declined as acceptable by the ECHR in *Pretty v UK* [2002] 2 FLR 45.

⁴⁵⁹ [2001] 1 All ER 801.

⁴⁶⁰ Schedule 1, HRA (1998).

⁴⁶¹ Above, 810(c).

⁴⁶² *Ibid*, 811(d).

⁴⁶³ In *Re F* [2000] above, and *Re SL* [2000] above.

⁴⁶⁴ See A. Grubb, *Commentary, Med. L. Rev.* 8 [2000] 342, 346.

⁴⁶⁵ *Ibid* 814(d-f).

⁴⁶⁶ (2002) above, paragraph 17.28.

anticipated. Rather, best interests continues as a sweeping justificatory reason endorsing medical perspective regarding IcP treatment.

Indeed, further consideration of human rights in the context of treatment withdrawal seems unlikely in view of *Re G* (adult incompetent: withdrawal of treatment).⁴⁶⁷ There the President declared withdrawal from a female patient with profound (anoxic) brain damage 'lawful' without reference to human rights. Drawing simply on the above decision, she concluded that G be allowed to 'die with dignity'. Judicial reference to family consultation makes it likely that familial views (if they concur with medical views) are influential. Additionally, 'unreserved' acceptance of the evidence of only one expert witness raises concern about courts 'rubber-stamping' medical views.⁴⁶⁸ Under the O.S. Practice Direction,⁴⁶⁹ all discontinuance of a.n.h. from p.v.s. patients must come before the court. However, on a strict reading this might not apply to non-p.v.s. states and, together with judicial 'rubber-stamping', this is of concern in view on medical misdiagnosis of p.v.s., and debate about medical guidelines. The latter was considered in *NHS Trust A v H*.⁴⁷⁰ Guidelines by the Royal College of Physicians exclude certain clinical features from diagnosis of p.v.s., including nystagmus response (rapid, involuntary eye movements) to ice water testing, 'tracking' moving objects with the eyes, or responding to 'menace' threat.⁴⁷¹ Whereas, an international working party on vegetative state do include 'tracking' and some response to stimulation within *some* types of vegetative state and also some types of profound brain damage.⁴⁷² In *NHS Trust A v H*,⁴⁷³ the latter guidelines were preferred, admitting H's visual tracking and response to menace as possible p.v.s. (H had suffered a brain haemorrhage eight years earlier). This allowed Bland, and *NHS Trust A v M*; *NHS Trust B v H*, to be followed. This decision continues the expansion of treatment withdrawal cases

⁴⁶⁷ [2001] 65 BMLR 65.

⁴⁶⁸ Similar to the Frenchay case, above.

⁴⁶⁹ Endorsed [2002] above.

⁴⁷⁰ [2001] 2 FLR 501.

⁴⁷¹ Published in *Journal of the Royal College of Physicians of London*, vol. 31(3) (1997), reproduced in P. Walsh (ed.), *The vegetative state: persisting problems in law and regulation* (1999), King's College, London, 71.

⁴⁷² International Working Party report on the Vegetative State (1996), reproduced in R. Francis and C. Johnston's *Medical Treatment: Decisions and the Law* (2001), Reed Elsevier (UK) Ltd, Butterworths, London, 288.

⁴⁷³ Above.

regarding adults based less in diagnosis than in 'futility' (absence of any prospect of recovery).⁴⁷⁴ Human rights regarding minors were highlighted dramatically in the context of surgical separation of conjoined twins.

2.3.4.3 Re A (Conjoined twins: medical treatment)⁴⁷⁵

The facts of this case were well publicised at the time. A hospital sought judicial permission to separate conjoined twins joined at the abdomen. Each twin had her own brain, heart, lungs and limbs, but the weaker twin (Mary) was incapable of sustaining her own circulation and was dependent on the heart/lung action of her sister (Jodie). Mary was also severely brain damaged and her capacity to experience pain not determinable. Without surgical separation, both twins would die within a few months. If separated, Mary would die immediately, while Jodie may have a relatively normal life. The twins' parents objected to surgical separation on religious grounds and because of anticipated difficulties about caring for Jodie in their home community (Malta) where healthcare was limited. At first instance, Johnson J authorised separation as being in the best interests of both twins. The Court of Appeal's further support for surgery has raised wealth of academic consideration. There has been widespread criticism of the complexity and **inconsistency** of the Court's views both within individual judgments and between them.⁴⁷⁶ Uniacke rightly suggests that some of this confusion derives from the legacy of Bland, regarding classification of withdrawal as an 'omission'.⁴⁷⁷ However, criticism extends beyond complexity.

In the Court of Appeal, only Robert Walker LJ concurred with the first instance view of surgery being in the best interests of *both* twins.⁴⁷⁸ In contrast, Ward LJ, having

⁴⁷⁴ In effect, the previous distinct approaches regarding minors and adults have merged into a human rights/futility approach.

⁴⁷⁵ [2001] 1 FLR 1.

⁴⁷⁶ See: J. Harris, Human beings, persons and conjoined twins: An ethical analysis of the judgment in Re A, Med. L. Rev. 9 [2001] 221; M. Freeman outlines extensive inconsistencies in Whose life is it anyway? Med. L. Rev. 9 [2001] 259, 274-275; S. Sheldon and S. Wilkinson, 'On the sharpest horns of a dilemma': Re A (conjoined twins) Med. L. Rev. 9 [2001] 201, 203; and B. Hewson, Killing off Mary: was the Court of Appeal right? Med. L. Rev. 9 [2001] 281, 291 and 292 where the similarities and differences are tabulated.

⁴⁷⁷ S. Uniacke, Was Mary's death murder? Med. L. Rev. 9 [2001] 208, 209. The deficiencies of the Bland decision are considered above, and my own earlier papers, above.

⁴⁷⁸ Above, 118(E) and 119(D). Walker LJ's approach has been adopted since by the Supreme Court of Queensland regarding conjoined twins: Queensland v Nolan [2001] QSC 174. However, as Grubb

separated out the questions of (a) consideration of best interests and (b) evaluation of lawfulness,⁴⁷⁹ perceived a conflict of interests; Jodie's favouring separation (in view of her positive prognosis),⁴⁸⁰ while separation for Mary would bring her no advantage (merely hastening her inevitable death).⁴⁸¹ On this **conflict** of interests *paramountcy* was unhelpful, because the interests of *both* twins could not be 'paramount'. However, Jodie's interests were found to prevail expressly by Brooke LJ,⁴⁸² and implicitly by Ward LJ:

'[g]iven the conflict of duty, I can see no other way of dealing with it than by choosing the lesser of the two evils and so finding the least detrimental alternative'.⁴⁸³

In essence, this reflects the moral quandary situation outlined earlier in chapter 1, employing Benn's 'thresholds in two dimensions'.⁴⁸⁴ The situation parallels Appendix 3 hereto, where either choice of action seems untenable (failing to support the interests of one or other twin), yet we cannot make *no* decision (as to do so would favour Mary's interests by default).⁴⁸⁵ Hence, arguably, the only solution is to 'make the best of a bad job' by choosing a solution we would not (prior to this decision) have considered acceptable. Harris criticises Ward LJ's approach of 'least detriment' as inconsistent with the earlier-posed ineliminable value of each life.⁴⁸⁶ Relatedly, Mason suggests Ward LJ's approach

'started on deontological premises but had to be, effectively, rescued by way of consequentialist ethics'.⁴⁸⁷

While less than ideal, the resort to consequentialism is understandable. The majority of the Court was, at least, honest enough to recognise a conflict of interests. Had the issue been surgical intervention on the twins as individual neonates, the cases would

highlights, in his commentary thereon (10 Med. L. Rev. [2002] 100), the requirement (under the Queensland Criminal Code exception for *bona fide* and reasonable medical treatment, s282) requires some 'benefit' (accruing to the weaker twin) be found in surgery and this demands of an approach like Walker LJ's absence of conflicting interests (above, 101-102).

⁴⁷⁹ Ibid 35(D-E).

⁴⁸⁰ Ibid 37-38.

⁴⁸¹ Ibid 39(F-H) and 46(G). See also Brooke LJ, *ibid* 99(D-E).

⁴⁸² Ibid 99(D-E).

⁴⁸³ Above, 49(C), drawing on *Birmingham County Council v H* (No. 2) [1993] 1 FLR 883.

⁴⁸⁴ Above.

⁴⁸⁵ Indeed, even Walker LJ, who found no conflict of interests acknowledged duality of duty on the part of HCPs, and that doing nothing was not an option, above 113(H).

⁴⁸⁶ See J. Harris, above, 228.

⁴⁸⁷ J.K. Mason, *Conjoined twins: a diagnostic conundrum*, ELR 5 (2001) 226, 231.

surely have invited different decisions based on each twin's (differing) best interests. However, having talked themselves into this (albeit honest) conflict of interests the Court still had to make a decision. Criticism of the utilitarian approach surely lies in the fact the Court were making a relative **quality of life** decision based on each twin's prospects, yet denying so doing. This is particularly apparent in the Court's distinction between *sanctity* and *quality* of life, and attempt to value not 'life' but worthwhileness of 'treatment', and/or capacity to *exercise* right to life.⁴⁸⁸ This distinction is untenable; an individual's value of life is surely dependent in part on his/her capacity to exercise it. It may still be assessed as *value to the subject*, but cannot be divorced from ability to participate in benefits or experience detriments of living.⁴⁸⁹ As Harris argues

'we cannot address the question of the best interests of treatment independently of our assessment of whether or not the continuation of life that the treatment affords is of value to the subject of that life'.⁴⁹⁰

In terms of **interest attribution**, considerable criticism is (rightly) directed at Robert Walker LJ's minority view that remaining conjoined would deprive the twins of their bodily integrity and dignity,⁴⁹¹ whereas separation would restore it to Mary.⁴⁹² As several authors comment, restoration of bodily integrity at the cost of life is a heavy price.⁴⁹³ Indeed, as Hewson suggests

'the principle of autonomy...points to leaving the twins intact, not to separating them'.⁴⁹⁴

Furthermore, the Court was willing to authorise invasion of Mary's bodily integrity by way of surgery. Watt characterises this 'mutilation' as the

'bad means to the good end of saving her twin sister's life'.⁴⁹⁵

Judicial assessment admitted Jodie as an interest-holder (all three judges unanimously found surgery in her best interests), while Mary was characterised as

⁴⁸⁸ Ibid 53-54 and 102(D).

⁴⁸⁹ Certain interests may be attributable to individuals *despite* inability to exercise them, see Chapters 3 and 7, below.

⁴⁹⁰ Above, 225. See also M. Freeman, above, 278

⁴⁹¹ Above, 118(E).

⁴⁹² Ibid 119(E).

⁴⁹³ See: H. Watt, Conjoined twins: separation as mutilation, *Med. L. Rev.* 9 [2001] 237, 239; J. Harris, above, 226; J.K. Mason, above, 234; and M. Freeman, above, 279.

⁴⁹⁴ B. Hewson, above, 297.

⁴⁹⁵ Above, 243 and 245.

'pitiable' and having no 'best health interests'.⁴⁹⁶ The prospect of leaving the twins conjoined never seemed considered as a realistic possibility. Yet, arguably, given that some hospitals might not have even brought the matter for judicial determination, the parental wish to leave the twins conjoined was really an alternative perception of best interests.

Hewson suggests that the resort to judicial intervention is due to a contemporary society's risk-avoidance.⁴⁹⁷ However, this thesis argues for better risk assessment; we cannot achieve this without limiting the **roles** of others involved to some extent, to being significant but not determinative factors. While the Court acknowledged the importance of parental views, it reserved its authority to determine welfare,⁴⁹⁸ construing **welfare** as synonymous with best interests,⁴⁹⁹ (framing the meaning of welfare as taking account of all relevant interests, needs, risks and benefits and weighing those to decide).⁵⁰⁰ The respective roles of court and parent are contentious. And, it is questionable in this case whether the Court really did *weigh* the issues regarding *both* twins without an agenda of utilitarian preservation of (at least one) life. While some authors argue in favour of parental autonomy, Freeman reminds us that best interests is about the *child*.⁵⁰¹ While he acknowledges the views of Goldstein, Freud, Goldstein and Solnit,⁵⁰² and of Friedman Ross,⁵⁰³ both based in the importance and delicate balance of the family unit, he argues that

'there are dangers in putting the intimate family beyond scrutiny' [and] '[t]here are more important rights to confer upon children than the right to autonomous parents'.⁵⁰⁴

This thesis argues for recognition of relationship as a part (sometimes an important part) of individual interests, but the emphasis is on the *individual*. *S/he owns* the interests, and we should be careful to treat children as individuals worthy of respect in their own right, even in the context of dependency on parents and others for

⁴⁹⁶ See Walker LJ, above 115(G-H), and Ward LJ, *ibid* 39(G).

⁴⁹⁷ Above, 285.

⁴⁹⁸ Above, 49-53.

⁴⁹⁹ See Walker LJ, *ibid* 102-102.

⁵⁰⁰ *Ibid* 39(C-E).

⁵⁰¹ Above, 262.

⁵⁰² *Best interests of the child* (1996) Free Press. See Freeman's discussion, above, 264-267.

⁵⁰³ *Children, families and health care decision-making* (1998) Clarendon Press. See Freeman, above, 267-270.

⁵⁰⁴ Freeman, *ibid*, 279.

protection and care. For this reason we should not underestimate the importance of children's interests as the primary concern under Article 3(1) of the UN Convention on the Rights of Children, and to the rights of maturing minors to have their views heard and considered under Article 12(1).⁵⁰⁵ The Court's decision in the instant case to overrule the sincere parental view, which could have been an equally justifiable view of best interests, seems to reinforce judicial drive towards preserving life wherever possible (unless medical evidence is divided *per* the mother's views in *Re T* (a minor)).⁵⁰⁶

Much of *Re A* focuses on **criminal** law.⁵⁰⁷ Pressure to avert criminal intention was intense with regard to interpreting the **HRA 1998**. The Court's unanimous view of non-contravention of Article 2 (right to life) was located variously in: the European Commission's decision in *Paton v UK*, which justified a judicial 'balancing act';⁵⁰⁸ the 'unintentional' nature of resulting death (not being the intended purpose of surgery);⁵⁰⁹ and the limited application of Article 2 'intention' to action where death *is* the purpose (whereas this case remained governed by existing common law).⁵¹⁰ Further, Brooke LJ dismissed contravention of Article 3 because use of general anaesthetic would negate any inhumane or degrading aspect to surgery, and that any interference with Mary's Article 8 rights was justifiable as the welfare principle warranted preference for Jodie's interests.⁵¹¹ The human rights provisions received scant attention in the judgments and their impact in medical treatment decisions is already beginning to look minimal.

However the confused judgments of *Re A* indicate the need for exploration of issues underlying decisions for IcPs. The disparity highlights the need for better

⁵⁰⁵ This is supported by Article 14(2) of the same Convention, which casts the parental role as providing direction in light of the child's evolving capacities. See also J. Loughrey, *Medical decision making and the Human Rights Act 1998*, *Med. Law* (2001) 20, 493, 503 regarding the limitations placed on Article 8 protection such that it may not jeopardise a child's health and development. The views of mature minors can be strongly held and insightful in terms of his/her own relationship with self, see for example *Re M* (medical treatment: consent) [1999] 2 FLR 1097 where a 15 year-old girl's refusal of a heart transplant was overruled by Johnson J, despite M's concerns that she would 'feel different with someone else's heart' and would 'rather die than have the transplant' (see also the report in the *Scotsman* 16.7.99, 5 cols 1-4).

⁵⁰⁶ [1997] above.

⁵⁰⁷ See Uniacke, above.

⁵⁰⁸ (1980) 3 EHRR 408. See Ward LJ, above, 61-62.

⁵⁰⁹ See Brooke LJ *ibid* 97(D-F).

⁵¹⁰ See Walker LJ, *ibid* 117(A-B).

understanding of concepts involved. In this regard, Sheldon and Wilkinson suggest that what

‘is clear...is the futility of any approach which attempts to make sense of this decision (and, indeed, health care law in general) without a thorough understanding of its ethical underpinnings’.⁵¹²

The remainder of this thesis explores some of these elements underlying best interests, such as the notion of interests, autonomy, welfare, respect, and individuality, as a means to reshaping best interests as a more structured framework that better protects patients’ fundamental stakes in life. Before doing so, however, it is important to stress why the recent reassessment of best interests is insufficient.

2.4 The legacy of critical battles

2.4.1 Why redefinition is not enough

The very need for redefinition indicates the unsatisfactory state of best interests that had developed by the early 1990s. Recent attempts at redefining best interests – predominantly by the Court of Appeal – focus on capacity, relationship, risk, extension of admissible interests and more open address of conflict. Undoubtedly, these refinements were much needed. However, **deconstruction** of best interests case law thus far has revealed persisting lacunae:

- clear **jurisdiction** is still lacking regarding adults. Although a welfare-type jurisdiction is posited in *Re F (Adult: court’s jurisdiction)*,⁵¹³ wherefrom it derives its authority is uncertain given earlier loss of *parens patriae*.⁵¹⁴ Indeed, even in this case, the declaratory scope is something of a stop-gap, as *per curiam* the need for a structured, defined framework to protect vulnerable ICPs is reiterated;
- **roles** of respective parties remain questionable: parental views regarding minors often hold little sway short of being also medically qualified;⁵¹⁵ the

⁵¹¹ Above, 97-98.

⁵¹² Above, 204.

⁵¹³ [2000] 55 BMLR 81.

⁵¹⁴ See *Re F* [1989] above.

⁵¹⁵ E.g. *Re T* [1997] above.

views of IcPs are insufficiently sought; judicial role regarding adults is still in a state of flux; and the views of those emotionally closest to IcPs are ambiguously dismissed yet referenced. Additionally, despite recent retrenchment from heavy emphasis on medical opinion, decisions such as *Re Y* raise undermine the confidence in admitting a role for family members if the benefit to the patient may be so remote.⁵¹⁶ There seems to remain a drive towards judicial assessment of best interests promoting medical efficacy – even if that is not directly therapeutic to the patient.⁵¹⁷ While all or any such input from third parties is not necessarily unwarranted, the point here is that it is at present entirely inconsistent;

- assessment of patient **capacity** also remains heavily medical, and ample scope remains for it to be undermined by factors commonly present in the healthcare context (e.g. pain and environmental stress). Too few safeguards presently exist to protect patient capacity, despite *Re MB/St. George's* guidelines, and patients may still be classed 'incompetent' due to irrationality or risk-related standards,⁵¹⁸
- **relationship** is used inconsistently, its admission or rejection seeming to vary with objective.⁵¹⁹ Indeed, factual relationship was at its closest in the conjoined twins case, yet the Court individuated the twins and the only reference to their relationship was regarding 'parasitic' use of the other's resources;
- some useful areas of redefinition have occurred, such as broadening the range of admissible interests, but these are employed to ambivalent **purpose**, sometimes benefiting others perhaps more than the IcP,⁵²⁰ while denied at other times despite obvious direct benefits to an IcP's quality of

⁵¹⁶ [1996] above.

⁵¹⁷ Medical impracticality is also imported into best interests, see *Re D* [1998] above.

⁵¹⁸ *Re B (Adult: refusal of medical treatment)* [2002] above, acts as a *caveat* to *assuming* incompetence, but the existing guidelines still require that only complex capacity decisions be raised in court.

⁵¹⁹ E.g. in *Re T*, above, mother and child were deemed 'as one', yet in *Re MM* [2000] above, the parent/child relationship was deemed less important despite the prospect of similar care difficulties when the family would return to a remote area of Russia (where the child would be highly dependent on the parents).

⁵²⁰ E.g. *Re Y*, above.

life.⁵²¹ A clear purposeful objective should be axiomatic in focusing what *best* serves an IcP's *interests*;

- **tenuous distinctions** flow from redefinition in aspects such as 'risk' in sterilisation. The contrast between the decisions of the case law suggests that application of criteria varies with gender, and consequences still dominate. Hence, while 'risk' may rightly be used to limit (inappropriate) intervention, an inappropriately limited vision of risk is also being used to create short-sighted differences of application;
- best interests still lacks **definition**. Fundamentally, courts employ terms such as 'interests', 'dignity' and 'bodily integrity' without fully exploring their meaning. Graduated changes have occurred, shifting withdrawal of treatment from a 'futility' to a 'quality of life' standard without elucidating on the meaning or significance thereof.⁵²² Additionally, relevance of underlying ethical values of autonomy, welfare and respect remain obscure. The result is a mandate for approving medical opinion, vaguely justified on 'best interests'. Yet the observer is little wiser about how that individual's best interests are comprised. Rather, to be a useful decision or justificatory tool, best interests should be transparent and understandable;
- although redefinition seems to reformulate a more **autonomy-oriented** model of best interests, the problem remains that best interests come about because the autonomy model of self-determinative decision-making breaks down in the face of incapacity. Certainly, best interests has been overly paternalistic, and a shift to include autonomy elements is welcome. However, best interests should be a *combination* of **residual autonomy** (identified through past and present patient views) and protection of his/her **welfare**. This might be better termed **patient-focused decision-making** and is developed in the remainder of this thesis through an approach of *respecting IcPs*;

⁵²¹ E.g. Re A (male sterilisation), above.

⁵²² Mason *et al* raise a similar observation (2002) above paragraph 16.50.

- the HRA (1998) has made relatively little pragmatic difference to treatment decisions. Article 2 has been sidestepped regarding withdrawal of treatment and even surgical invasion (in the twins' case) does not infringe the right to life. Article 3 has been effectively negated where medical treatment is concerned, and judicial consideration hints more at fitting **human rights** into existing law than of altering domestic law to meet individual rights and interests. Its influence on roles (of parents, individuals and those emotionally closest) under Article 8, and the decision process under Article 6, remain to be tested in the treatment context;⁵²³
- although the expansion of certain IcP situations (such as sterilisation) now has limits, the application of best interests overall continues to expand in healthcare decisions. Beyond those areas already mentioned are decisions relating to withdrawal of treatment from non-p.v.s. adults,⁵²⁴ treatment for anorexia,⁵²⁵ diagnostic testing,⁵²⁶ and decisions about transplantation.⁵²⁷ Hence, the range of potential battlegrounds continues to **develop**. Redefinition merely indicates the pressing need for more thorough reformulation of best interests and IcP decision-making.⁵²⁸

Use of best interests as a justificatory mechanism across this increasing range is understandable, reflecting its inherent **flexibility**. However, its expansion and development continues without a full exploration of best interests **conceptually**. Hence, distinctions are made piecemeal and the **content** accorded to best interests becomes increasingly disparate. Obscure decision **purpose** and inconsistent attribution of **roles** create inconsistent application. Under-exposition of influential **values** (welfare, quality of life, autonomy, and medical ethics) causes vagueness in the justificatory **role** and **process** of best interests.

⁵²³ The normative value of these articles is considered in Chapters 6-8, below.

⁵²⁴ E.g. Re R (adult: medical treatment) [1996] 2 FLR 99, Re D (medical treatment) [1998] 1 FLR 411, Re H (adult: incompetent) [1998] 2 FLR 36 and Re G (adult incompetent: withdrawal of treatment) [2001] 65 BMLR 65.

⁵²⁵ Re C (Detention: medical treatment) [1997] above.

⁵²⁶ Re C (HIV test) [1999] above.

⁵²⁷ Re T [1997] above, and Re M [1999] above.

Despite development and redefinition, best interests still lacks substance, consistency, and clarity. This weakens its efficacy, turning it from panacea to placebo. Piecemeal redefinition creates questionably distinct borderline cases and redraws only limited, accessible aspects, or risks wider changes lacking substantive jurisdictional/precedential authority. Meanwhile, contextual expansion continues apace. Mere redefinition is not enough. Best interests needs to be more radically reconstructed. If this mechanism is to serve properly the interests of IcPs, we must be clearer about the nature and validity of decision goals. In its current incarnation best interests sometimes **fails** fundamentally **to protect** the interests of IcPs. Treatment decisions are about human interests. To determine an individual's *best interests* soundly, we must be honest and open about the issues and sub-strata values informing those human interests. We must better understand **what is at stake, on behalf of whom, and how conflict can be soundly resolved**. We must set gateways that respect IcPs – recognising both (a) their limitations (and need for assistance) and (b) the individual importance of their participation in decisions about treatment that impact *their* life.

2.4.2 The impetus for radical reconstruction

A number of proposals for reconstruction have been mooted over some years in England and Wales. The **Law Commission's** views were reported in 1995,⁵²⁹ expressly favouring a best interests test but including an element of substituted judgment.⁵³⁰ While best interests was described as meaning more than non-negligent action towards the incapacitated person,⁵³¹ further focus is on proposed inclusion of more autonomy-oriented factors for consideration in best interests evaluation. These include ascertainable past and present views of the patient (including perception by appropriate others), patient participation, and minimisation of disruption to patient freedom.⁵³²

⁵²⁸ Especially as redefinition has emanated from a relatively small pool of judges, particularly: Dame Butler-Sloss (P) in *Re T* [1996], *St George's, Re A* [2000], and *Re SL* [2000], and Thorpe LJ in *Re C* [1994] and *Re SL* [2000] all above.

⁵²⁹ *Mental Incapacity (1995) Law Com No. 231*, HMSO, London.

⁵³⁰ *Ibid*, para. 3.25

⁵³¹ *Ibid*, para. 3.27.

⁵³² *Ibid*, para. 3.28-3.37.

Subsequent **consultation**, in 1997,⁵³³ has now culminated in a **policy statement**, which the Government formulated in 1999.⁵³⁴ The policy position picks up three key principles from earlier consultation (capacity, best interests, and a general authority to act reasonably), and provides for new Continuing Power of Attorney, appointment of a manager regarding welfare and/or healthcare issues, and modernises the judicial framework through a Court of Protection empowered to resolve certain disputes.⁵³⁵ Regarding best interests, the Government endorses the Law Commission's views on relevant factors,⁵³⁶ and identifies two additional factors: foreseeable likelihood of the patient recovering capacity, and the need to avoid undue influence on patient views.⁵³⁷ The general authority to act reasonably would be based also on reasonable belief that action is in the patient's best interests,⁵³⁸ and that certain decisions may not be taken on behalf of an ICP.⁵³⁹ The Court of Protection would have jurisdiction to approve/refuse treatment,⁵⁴⁰ and some 'serious' treatment decisions (such as withdrawal of a.n.h.), or where a patient has made an advance statement, would require court approval.⁵⁴¹

The provision of suitable jurisdiction and clarification of relevant factors would be valuable changes and are clearly oriented to taking more account of autonomy-based input to decisions. However, the proposals have remained unactioned, in policy form, since 1999. And, they say relatively little anyway about best interests. Its presence is profligate therein, but its meaning (beyond four factors) remains unexplored, and the document is silent about underlying values or address of conflict. Rather, disputes would remain subject to judicial resolution. While the court should rightly remain in this role (initially or on appeal), it is not apparent that enactment of this policy (if it happens) would furnish much in terms of the ICP

⁵³³ Who decides? Making decisions on behalf of mentally incapacitated adults (1997) Cm 3803.

⁵³⁴ Making decisions (1999) Cm 4465. The Lord Chancellor's Department has also issued a consultation paper and series of leaflets providing current guidance on: consent and refusal of treatment, establishing and evidencing best interests, capacity assessment, how decisions are made, and protection from abuse, *inter alia*. While this guidance is valuable in the interim it is, of course, no substitute for reform (Making decisions: Helping people who have difficulty deciding for themselves (April 2002)).

⁵³⁵ However, it declines to address at present the position on Advance Directives and advocacy.

⁵³⁶ Outlined above.

⁵³⁷ (1999), para. 1.12.

⁵³⁸ *Ibid*, para. 1.16.

⁵³⁹ *Ibid*, para. 1.23.

⁵⁴⁰ *Ibid*, para. 3.7.

decision *process*. In short, the policy is a step in the right direction, but does not go anywhere near far enough. Furthermore, overhaul of best interests is not just about injecting some autonomy-based elements, it is about understanding *both* aspects of best interests (autonomy *and* welfare), and applying them more constructively to best protect *all* of a patient's relevant interests.

A different range of 'best interests' factors is supported by the **BMA Guidelines** on Withholding and Withdrawing Life-prolonging Treatment.⁵⁴² While these include the views of patients (and any evidence of his/her views available from persons closest to the patient), of appointed proxies (in Scotland), and parents views regarding minors, the focus is understandably on more clinical aspects such as sentience to pain, awareness, likely improvement, and invasiveness of any treatment. Being posited as indicators of a person's 'overall health benefit' these are important indicators of a patient's **best medical interests**. However, this thesis argues that medical interests are only one element of a person's interests overall. Thus, while the policy document in England and Wales reflects certain (much-needed) recognition of residual autonomy, the BMA guidelines represent factors influencing a patient's medical welfare. Yet, neither satisfactorily embraces both autonomy *and* welfare interests in their full *breadth* (or *depth*, i.e. how to use them in best interests determination). Admittedly, as Mason *et al* suggest:

[a]s a vague concept, best interests permits of a wide-ranging discretion even when, as the English proposals would have it, the test is tempered by 'factors' to be taken into account'.⁵⁴³

However, even under the existing **Adults with Incapacity (Scotland) Act 2000** which eschews use of 'best interests', factors in determining whether to intervene are not dissimilar to the autonomy-oriented English proposals regarding best interests. The views of the primary carer, guardian, or other persons the Sheriff directs, or those having an interest in the adult's welfare should be considered.⁵⁴⁴ Relatedly, the authority for treatment under s47 frames its scope (and implicit purpose) as

⁵⁴¹ *Ibid*, para. 3.8.

⁵⁴² (2001) BMJ Books, London, paragraph 18.1.

⁵⁴³ (2002) above, paragraph 10.37.

⁵⁴⁴ S1(4).

‘what is reasonable in the circumstances...to safeguard or promote the physical or mental health of the adult’.⁵⁴⁵

This reflects the meaning attributed to best interests in *Re F*,⁵⁴⁶ and is equally broad, providing ample scope for clinical discretion. The absence of best interests from the Scottish approach seems perhaps, therefore, to be one of form rather than substance. Certainly, the legislation has usefully clarified roles and responsibilities of parties involved in care and treatment of incapacitated adults. However, where disagreement occurs amongst those involved, ultimate recourse must be made to the Court of Session. Hence, the protection of vulnerable ICPs may not be as much improved as it initially appears – rather the procedures have been clarified.

Furthermore, as Laurie and Mason highlight, *withdrawal* of treatment surely could not be construed as safeguarding or promoting the patient’s health.⁵⁴⁷ On this basis, they argue that Law Hospital remains the relevant authority on withdrawal of treatment from p.v.s. patients.⁵⁴⁸ In this regard best interests therefore presumably endures even in Scotland.

None of the considered approaches reconstruct best interests (or treatment decisions for incapacitated adults) satisfactorily. They fail to address the lacunae outlined above in any comprehensive manner. While they include valuable aspects, they do not go far enough to constitute a thorough investigation of relevant issues and values, or to break with existing traditions in finding more dynamic solutions to ICP decisions. Best interests is retained and preferred herein for its scope for emphasising **impact** on the patient’s interests; it could represent an important expression of *purpose* and *focus* upon the incapacitated **patient**.

Best interests could be used **positively** and **flexibly**, provided it is used carefully and with **understanding of its complexities**. Sound **reconstruction** requires the development of a **strategic framework** that admits **decision purpose**, appropriate **roles**, and comprehensive **content** and provides for ancillary ‘**gateway**’ **issues** such as capacity. The framework must also accord suitable **authority** and

⁵⁴⁵ S47(2).

⁵⁴⁶ [1989] above.

⁵⁴⁷ See G.T. Laurie and J.K. Mason, Negative treatment of vulnerable patients: euthanasia by any other name? [2000] *Juridical Rev.* 159

⁵⁴⁸ *Ibid*, 177.

responsibilities. In essence, successful reconstruction requires clarification of decision process (including address of conflict) in determining 'best', and exposition of 'interests' – the interrelationships of factors and function must be explored as normative components. This thesis proceeds with further **deconstruction**, of 'interests' (Chapter 3), and the influential values of autonomy (Chapter 4) and welfare (including quality of life and personhood in Chapter 5). This enables fuller understanding of complexities. Chapters 6 to 8 then **reconstruct** a new **developmental framework** for best interests under the auspices of **respect**, through responsible, informed proxy choice.

CHAPTER THREE

INTERESTS AND INTERESTED PARTIES

Chapter 3 - Interests and interested parties

Let us start with a simple distinction. The decision mechanism is 'best interests', but 'best' is separable from 'interests'. 'Interests' may be used *descriptively*, to represent important factors in an IcP treatment decision, and/or to *justify* why those factors are important to that patient. However, interests may be a catalyst for conflict, such that an individual's various interests may seem equally justified yet mutually exclusive. A competent individual may trade-off conflict by reference to his/her underlying values. Where autonomy is compromised choice falls to responsible others, who seek the 'best' decision in the IcP's 'interests'. Hence, 'best' concerns the *process* of deciding; how we balance opposing factors to derive the optimal course of action. In short, how we resolve conflict.

Locating 'best' is contentious, being subject to infinite opinions about ranking which is inevitably value-laden.¹ 'Best' is the most intractable aspect of best interests; no ranking satisfies all commentators. Derivation of best is addressed later.² Deconstruction of 'interests' in this chapter considers what an interest is, and prerequisites for possession, and highlights underlying values, interest role and objects. It concludes with a connected interest concept related to interested parties.

3.1 Definition of 'interest'

What do we mean by 'interests'? 'Interest' has descriptive meaning enabling us to know an interest when we see one, and normative significance that acknowledges the importance of having interests and influencing who may possess them. So, how might we define an interest? A dictionary definition offers wide interpretation.³ From this wide range, certainly IcPs might have '**concerns**' about things '**important**' to them, but these broad interpretations need refinement to have real meaning in this context. Additionally, IcPs can experience a '**state**', or '**feeling**', of interest (being '*interested in X*'). In effect, 'feeling' could describe the relationship

¹ 'Ranking' connotes the relative weights, accorded by a decision-maker, to factors and/or interests.

² See particularly Chapter 8, below.

³ New Shorter Oxford English Dictionary, (ed. L Brown) (1993) Clarendon Press, Oxford, vol. 1, 1393, col. 2 describes an interest variously as: a share, concern or right; a (financial) stake; a benefit or advantage; a thing of concern or importance (to someone); a cause or principle; and a state of feeling. 'In the interest(s) of' is defined as being 'on the side of...out of consideration for, to the advantage or benefit of'.

between an IcP and his/her interests, but this is limited by the extent to which an IcP is able to conceptualise feelings. A **state** may represent the position brought about through promotion/negation of interests. Thus, an IcP might have an interest in a *state of good health* or *sexual freedom*, or maintaining a *state of dignity*. But, this does not give meaning to the interest itself.⁴ The notion of '**benefit**' is familiar in the IcP and best interests context.⁵ However, benefits (and opposing detriments) represent the *effect* of an action upon interests, namely how an action serves an interest.

Relatedly, Benn suggests that

'[a] person's interests are, in one sense, those things which would be to his advantage'.⁶

He considers an '**advantage**' as being perceived to make an individual 'better-off'.⁷ While this is inviting in the healthcare context, because of its obvious association with 'well-being', there is synonymy between 'advantage' and 'benefit'. Both essentially pertain to the *effect* of an action. It is a state of resulting gain or loss. To be advantageous, an action must yield 'better' results than an alternative. Thus, 'advantage' relates to 'best' rather than 'interests'.

Interests can also be construed in terms of rights and powers. Hohfeld offered an early evaluation of interrelationships between rights, liberties, and powers.⁸ A full evaluation of rights is not warranted here, but recent accounts define **rights** in ways relevant to the medico-legal context. Feinberg suggests that

'[t]o have a right is to have a claim *to* something and *against* someone'.⁹

He ultimately concludes rights to be 'valid claims' through their

⁴ S.I. Benn, above, 266, distinguishes 'states' from 'powers', 'interests', 'rights' and 'objects' in relation to privacy, and notes that a state may be subject to *conditions* (i.e. circumstances or events necessary to bring it about).

⁵ See chapters 1 and 2, above.

⁶ S.I. Benn, above, 105.

⁷ *Ibid.*

⁸ W. Hohfeld, *Fundamental legal conceptions* (1923) Yale U. P. New Haven.

⁹ J. Feinberg (1974), *The rights of animals and unborn generations* (in W.T. Blackstone's (ed.), *Philosophy and environmental crisis* (1974) Univ. of Georgia Press, Athens, 43). In another context, around the same time, he develops this in terms of duty: '[l]egal claim-rights are necessarily the grounds of other people's duties toward the right-holder. A legal right is a claim to performance, either action or forbearance...It is also a claim against the state to recognition and enforcement', *Social philosophy* (1973) Social Philosophy (1973) Prentice Hall, Englewood Cliffs, 58.

'justifi[cation] within a system of rules'.¹⁰

What relationship exists, between rights and interests? Raz suggests all rights to be based on interests,¹¹ but *caveats* that

'[a]n interest is sufficient to base a right on if and only if there is a sound argument of which the conclusion is that a certain right exists and among its non-redundant premisses is a statement of some interest of the right-holder, the other premisses supplying grounds for attributing to it the required importance, or for holding it to be relevant to a particular person or class of persons so that they rather than others are obligated to the right-holder'.¹²

In other words, a right is created only where (i) an interest is asserted, and (ii) that interest is sufficiently important to constitute a right *or* it raises a corresponding duty in identifiable other(s). But, rights and interests are not synonymous.¹³ Rather, a right has protection of an interest as its objective.¹⁴ The importance of rights is now consolidated in the Human Rights Act (1998), which protects the fundamental rights of individuals, and these are attributable to IcPs despite the disempowering effects of incapacity. The language of rights therefore cannot be avoided, but for present purposes and as will be argued below an alternative perspective may prove to be more helpful in our conceptualisation of what we mean by best interests.

Power concerns ability to access and give effect to one's entitlements.¹⁵ Lack of power renders patients vulnerable.¹⁶ Although IcPs do not necessarily lose their interests, nor their entitlement to claim protection of those interests or give waiver regarding them (i.e. rights), incapacity may rob them of the power to exercise those rights for themselves. As this power falls to the proxy, an IcP's interests are vulnerable in direct proportion to degree of power accorded to the proxy. Thus, power relationships necessarily fall to be considered in the treatment decision process. However, power itself says nothing about the meaning of interests from the

¹⁰ Ibid, 67.

¹¹ J. Raz, *The morality of freedom* (1986) Clarendon, 191.

¹² Ibid, 181.

¹³ Feinberg sees rights as closely affective - but distinct from - interests, *Harm to others*, above, 34.

¹⁴ However, Raz highlights that rights may serve a person's individual interests, yet be against his/her interests overall, above, 180.

¹⁵ See Benn, above, 266.

¹⁶ G. Dworkin, writing on proxy representation of incapacitated patients, cites Mill: '[h]uman beings are only secure from evil at the hands of others in proportion as they have the power of being, and are, self-protecting', *The theory and practice of autonomy* (1988) Cambridge U.P., Cambridge, 93, (J.S. Mill, *Considerations on representative government*, in H. Pitkin's *Representation* (1969) Atherton, New York, 180-1).

perspective of the IcP. Indeed, as has been shown none of the above concepts adequately describe the essence of interests. Rather, it is submitted, that an interest for the purposes of this thesis should be perceived as a 'stake'.

3.1.1 Interests as 'stakes'

Feinberg draws on commercial-legal use of 'interest',¹⁷ and applies it to criminal law, such that an individual's interests are

'a miscellaneous collection, consist[ing] of all those things in which one has a stake'.¹⁸

Feinberg additionally construes stakes as

'the amount risked...a person has a stake in *X*...when he stands to gain or lose depending on the nature or condition of *X*'.¹⁹

If we apply this to IcPs, a patient could have a stake in: good health; freedom from unwarranted invasion; quality of life, freedom to choose within the extent of his/her capacity; and so on. The IcP's 'interests' would encompass a collection of such stakes.

However, Feinberg's fundamental concern is with prohibition of criminal harm, making the relationship of 'risk' and 'interests' vital; risk of harm to an individual's interests warrants prohibition of an action. Certainly, the risk of harm is also important regarding IcPs, but we can consider this as the impact of a treatment option on a patient's interests, rather than definitive of the interests themselves. Frey acknowledges Feinberg's view of 'harm' as

'an injury to something in which [a person]... has a genuine stake'.²⁰

He (Frey) progresses this interpretation of interests to represent an individual's

'vital concerns in respect of what happens to them and theirs'.²¹

¹⁷ J. Feinberg, *Harm to others, The moral limits of the criminal law*, Vol. 1 (1984) Oxford U.P. Inc., New York, 33, suggests a person owning stock in a company has an interest as a 'stake in its well-being'.

¹⁸ *Ibid*, 34.

¹⁹ *Ibid* 33-34. Relatedly, T. Regan, *The moral basis of vegetarianism*, *Canadian Journal of Philosophy*, Vol. V, No. 2 (1975) 181, employs the word 'interest' to denote a 'certain class of acts or states which have the common characteristic of 'being for or against' (citing R.B. Perry, *Realms of value* (1954) Harvard U.P., Cambridge, Massachusetts, 7).

²⁰ R.G. Frey, *Interests and rights, The case against animals* (1980) Clarendon Press, Oxford, 146, n5, citing J. Feinberg (1973) above, 26.

²¹ R.G. Frey, *ibid*, 146, n5.

What constitutes a 'vital' concern is unclear, but Frey argues that such 'vital concerns' survive entry to coma. Being independent of consciousness, vitality seems, therefore, to connote fundamental importance to the individual.

Further support for stakes as types of concern is available in Partridge's denial of 'posthumous interests'.²² Discussing Feinberg's view of objective fulfilment of interests, Partridge suggests that

'while it is true that interests are, or may be, fulfilled by objective events and circumstances, these objective conditions are "interests" only insofar as they matter to someone. Take away the personal concern or "stake", say by death, and what remain are mere pointless happenings and conditions, not "interests"'.²³

Objectivity of interests, and capacity for interests to 'survive' are considered below. For present purposes, Partridge's view evinces that although interests broadly involve 'concerns' or 'stakes', their significance as *interests* arises through an element of '**individuality**' attaching to them.²⁴

If we incorporate Frey's view of interests as vital concerns, and Partridge's requirement for interest-concerns to be personal to the individual, we can identify interests as 'stakes' that form a smaller sub-group of concerns. They are elevated to 'stakes' by virtue of one's active, or significant, personal involvement with them. In essence, a stake is a '**concern-plus**'; the 'plus' accruing from the investment, involvement, or engagement that we make in certain of our concerns. Indeed, this accords also with the business context from which Feinberg derived stakes. Commercially, a 'stakeholder' denotes a party whose involvement (in a company, product or market) arises through his/her financial or labour investment, active involvement as a seller/buyer, or regulatory influence. This is equally applicable to human decision-making. Each of us invests time, effort and/or money in our life objectives and goals - in those concerns that matter most to us, such as relationships, career, health, or even just in getting by day-to-day. Our investment raises the status of a concern to a 'stake'. These stakes then influence our decisions about our life's

²² E. Partridge, Posthumous interests and posthumous respect, *Ethics*, 91 (1980-1981) 243.

²³ *Ibid*, 247.

²⁴ See Partridge, *ibid*, 264, who also acknowledges his concurrence with Feinberg's view (1974) above, 61, of an interest concept based 'on the capacity of certain beings to experience "awareness, expectation, belief, desire, aim and purpose"'.

direction and purpose. Indeed, even in relation to 'public interest' this can be regarded as those 'stakes' with which a society is concerned or invests through legal regulation or moral involvement.

Incapacity need not negate stakeholder status. Incompetent patients may still hold stakes in health, relationships, goals and experiences - despite incapacity. Interpreting an interest as a stake - a concern in which an IcP has some personal investment - provides a working notion of 'interest'.

As treatment decisions involve fundamental interests (e.g. life, bodily integrity, dignity) a proxy must exercise power carefully to uphold IcP rights, protect interests, to waive entitlement only where necessary, and to compel others to fulfil their duties. However, this goal is attainable only once we recognise the distinction between interests, rights, and powers. This enables an IcP's *interests* to be recognised and protected despite incapacity. For example:

- a **p.v.s. patient** has an *interest* (i.e. a *stake*) in maintaining a dignified *state* (it may be a *condition* that s/he be biologically alive). However, s/he lacks *power* to *claim* promotion of his/her interest. But, s/he does retain the *right* to dignified existence, and a proxy can be *empowered* to *claim* on the patient's behalf;
- an **incapax patient** has an *interest* in a *state* of relationship. It may be an appropriate *condition* that she be protected from pregnancy. Her legal incompetence denies her the *power* to consent, and she cannot *claim* protective measures herself. But, she does not lose the *right* to sexual freedom, as her *ancillary right* (to judicial intervention) *empowers* the court to promote her *interest*.

3.1.2 Investments and identity

On a daily basis we **invest** in our lives. Some investments are sub-conscious choices, others are conscious. While many choices are positive, not all investments are; we may invest in things negative/harmful to us in the short or long run through poor decision-making, or abuse (e.g. drugs, relationships, violence, or illness). Or,

may invest in things through necessity rather than choice, for example doing a job we hate in order to support our family. But, of itself, this indicates the importance of family in our concerns. Each individual's investments are personal indicating what matters most to that person. However, investment and interest are not synonymous; interests should not be construed *only* as things in which we invest. Rather, investment should encourage us to look further at the significance of that concern; to determine whether it amounts to a stake, because the personal quality of investments makes the uniqueness of the person. To an extent they represent individual **identity**. A decision about an ICP's treatment should have **integrity** with his/her investments and identity. However, individuals change and grow. Thus, Dworkin interprets integrity as reflecting investment, and as

'mark[ing]...conviction, of commitment, not just past choice'.²⁵

The interrelationships between identity, integrity, investments and interests are also apparent in Benn's view that interests are

'not merely objects or objectives to which the subject addresses himself; they provide the strands of his identity over time, through which he is able to see continuity of meaning and pattern in what he is and does'.²⁶

Identity adds a gloss to the idea of an interest as a stake. It indicates why stakes are important to individuals. Stakes reflect important concerns in which we invest, these stakes make up our interests, and our collective interests represent our individual uniqueness. In this sense, identity may be relevant to the *composition* and *objective* of best interests.

An interest cannot be *defined* unequivocally,²⁷ because as Frey suggests:

'[r]eliance upon definition in this way obviates the necessity...to cite the necessary and sufficient conditions for a being to have interests'.²⁸

Rather, 'interest' is used to connote conceptual threads that create the conditions surrounding the term; the interests *concept* is a more robust notion reflecting different parameters in which 'interests' are identified and attributed. Hence, we

²⁵ R. Dworkin, *Life's Dominion, An argument about abortion and euthanasia* (1993) Harper-Collins, London, 206.

²⁶ S.I. Benn, above, 106-107. Temporal issues are considered below, Chapter 7.

²⁷ Although philosophers develop conceptual accounts of interests, they decline to simply define: see, for example, J. Feinberg, *Freedom and Fulfillment* (1992) Princeton U.P., New Jersey, 4.

must establish the structure woven around interests, lending it conceptual meaning. To aid conceptual understanding, the remainder of this chapter considers: when an interest may arise (**gateways**); the value and role interests serves (**purpose**); what we have interests in (**objects**); and who may hold interests (**subjects**).

3.2 Gateways to interests

3.2.1 Needs and desires

3.2.1.1 Why do needs and desires matter?

Where do interests come from? We need to identify sources of interests as a gateway to interest ownership. Having identified interests as stakes, an obvious source of *concerns-plus* is our **desires**. Desires represent what we *want*; the positive experiences, or things, that contribute to our individual notion of a 'good life'. However, other types of 'want' arise from '**needs**'.

Certainly, interests may arise from desires as reflections of our stakes.²⁹ Relatedly, Regan employs '*interests*' to connote *experiential* preferences:

'liking-disliking, loving-hating, hoping-fearing, desiring-avoiding'.³⁰

Tooley's view of *rights* (protecting interests) is based on capacity to *experience* desires:

"A has a right to X" is roughly synonymous with "A is the sort of thing that is a subject of experiences and other mental states, A is capable of desiring X, and if A does desire X, then others are under a prima facie obligation to refrain from actions that would deprive him of it".³¹

Thus, a relationship may exist between desires and interests, and between interests and experiential capacity (and/or capacity for certain mental states). Additionally, Frey draws on Feinberg's early work to substantiate a relationship between beliefs, desires and interests.³² However, desires and value judgment implicitly import reflectivity:

²⁸ R.G. Frey, above, 53, criticising the syllogism about interest possession from the argument of L. Nelson, *A System of Ethics*, trans. N. Guterman (1956) Yale U.P., New Haven, 139.

²⁹ *Pace* Frey, above.

³⁰ T. Regan, above, 192.

³¹ M. Tooley, *Abortion and Infanticide* (1983) Clarendon Press, Oxford, 45.

³² See Frey, above, 55, drawing from J. Feinberg (1974), above.

'[i]nterests are compounded out of *desires* and *aims*, both of which presuppose something like *belief*, or cognitive awareness'.³³

Importation of requisite mental states invokes a barrier to interest possession, and raises issues about where to set the threshold. Desire-derived interests can exclude IcPs. Harris identifies certain defects as diminishing autonomy because they affect choice, desire and belief.³⁴ Young minors, p.v.s. patients, and severely intellectually disabled adults could be incapable of forming any significant beliefs (on Frey's approach) and possessing self-consciousness. Consequently, if desires are the *exclusive* generator of interests, *pace* Frey, this excludes not only inanimate objects and animals but also many IcPs.

This should be contrasted with interests as they relate to needs. Frey's distinction concludes that needs do not require consciousness.³⁵ As reflective capacity is not a prerequisite to needs, all patients might have needs, irrespective of incapacity. In contrast, desires being based in belief/cognitive awareness

'presuppose...at least rudimentary cognitive equipment'.³⁶

Tooley also advocates a cognition requirement in the context of the right to life:

'having a right to life presupposes that one is capable of desiring to continue existing as a subject of experiences and other mental states. This in turn presupposes both that one has the concept of such a continuing entity and that one believes that one is oneself such an entity. So an entity that lacks such a consciousness of itself as a continuing subject of mental states does not have a right to life'.³⁷

Further, Benn acknowledges the effect of this regarding incapable humans:

'[a]s with all theories that understand desires as intentional...it requires a desirer to be able to identify the object of desire by forming a belief about it. This condition is generally met by human adults; however, it seems inconsistent with our intuition that infants have desires. While we say of a newborn that it wants to be fed, it would be odd to claim that it believes it would enjoy it'.³⁸

³³ Feinberg, *ibid*, 52.

³⁴ I.e. defects in self-control, reasoning, information, and stability J. Harris, *The value of life, An introduction to medical ethics* (1985) Routledge & Kegan Paul, London, 196-199.

³⁵ See Frey, above, 82.

³⁶ J. Feinberg (1974) above, 52.

³⁷ M. Tooley, above, 49, cited by Frey, above, 109.

³⁸ Above, 37.

Where incapacity severely limits cognitive ability this could undermine desire-based interest possession. Cognitive capacity spans a wide range, but five useful examples can be made:

- (A) a self-conscious patient, capable of reflection;
- (B) a 6/7 year old child without mental impairment;
- (C) a severely mentally-impaired patient, with infant-like linguistics and no reflective capacity;
- (D) a patient in low cognitive awareness, capable of sensing pain but lacking self-consciousness;
- (E) a permanently unconscious patient, without response to pain stimuli, but biologically alive.

On Frey's high-level requirement regarding desires, only patient (A) would certainly meet the threshold, because patients (B)-(E) lack reflective and/or linguistic capacity. Further, only patients (A) and (B) would meet even his self-consciousness requirement for possession of 'simple desires'. However, on a purely needs-based assessment all of the above patients can easily be attributed with interests in any decision-making process relating to their welfare.

In truth, Frey's desire-based argument is about **personhood** as a means to delineating subjects of moral importance. While Frey draws on Feinberg's requirement for cognition (embodied in a 'conative life'), he omits to address Feinberg's view about what amount to conations,³⁹ namely:

'conscious wishes, desires, and hopes; or urges and impulses; or unconscious drives, aims and goals; or latent tendencies, direction of growth, and natural fulfillments'.⁴⁰

These mental states lower the entry level for personhood: 'urges and impulses' are considerably less demanding than 'beliefs', and patients (A), (B) and (C) arguably could be regarded as having a conative life. However, Feinberg's view is ambivalent,

³⁹ See Frey, above, 45.

⁴⁰ Feinberg, (1974) above, 49.

as he later employs his requisite states cumulatively, denying such status to 'human vegetables', fetuses and newborns.⁴¹

Relatedly, Harris bases personhood in 'reflective self-consciousness'.⁴² On a strict application only patients (A) and (B) would be 'persons', while patient (C) would fall within Harris' safety measure that

'the presence of language is definitive evidence that the beings who possess it are persons'.⁴³

Personhood is problematic regarding IcPs because it excludes the very young, the insensate, and the severely mentally impaired, with the result that they are not provided with moral protection. Only Tooley expressly acknowledges the logical extremes of demanding requisite mental states,⁴⁴ concluding that adult animals may have a right to life,⁴⁵ while a newborn baby has no more right to life than a newborn kitten, as both lack any concept of a continuing self.⁴⁶

Once again, the point can be made that on a basic needs-based approach all of these problems disappear for the IcPs. But, is it necessary to adopt an either/or approach? That is, while 'needs' may be all encompassing, it does not follow that IcPs have no 'desires' in any of the senses discussed above. Indeed, it is submitted that a dual approach considering both needs and desires is most appropriate when dealing with IcPs. This is because most, if not all, IcPs can express some forms of desire in one way or another - it is a means of input which, as has already been argued, should equally be weighed in any balance to decide what should be done with, or for, an IcP.

It should be noted that Feinberg distinguishes two different senses of 'need':

'[t]o say that *A* needs *X* may be to say either: (1) *X* is necessary to the achievement of one of *A*'s goals, or to the performance of one of its functions, or (2) *X* is good for *A*; its lack would harm *A* or be injurious or detrimental to him'.⁴⁷

⁴¹ See *ibid*, 60-64. However, Feinberg finds other reasons to treat these beings as having rights, modifying his position in later work.

⁴² Harris, *above*, 18-19

⁴³ *Ibid*. Harris considers language to mean something more than mere parroting/smiles/growls, *ibid*, n20. This would exclude patients (D) and (E).

⁴⁴ M. Tooley, *above*, 64-65.

⁴⁵ *Ibid*, 65.

⁴⁶ *Ibid*, 63.

⁴⁷ Feinberg (1974) *above*, 53.

However, Feinberg associates only (2), above, (which he labels 'need') with interests:

'[t]he first sort...is value-neutral...whereas the second kind...commits its maker to a value judgment about what is good or bad for *A* in the long run, that is, about what is in *A*'s interests'.⁴⁸

It is in this second sense that needs and interests deriving from them are used in this thesis. The attribution of a value judgment should not only be acknowledged but also embraced in the decision-making process involving ICPs.

3.2.1.2 Relating interests to needs and desires

In later work,⁴⁹ Feinberg refines his identification of interests: *ulterior* interests concerning ultimate, reflective goals; and *welfare* interests, which are 'the necessary means to his more ultimate goals'.⁵⁰ Feinberg evaluates the relationship between the two as close but non-mandatory: an individual may have an interest without having knowledge of it, or s/he may want something contrary to his/her interest.⁵¹ Feinberg concludes that welfare interests are objectively identifiable, irrespective of belief.⁵² This explains why we perceive incapacitated humans still to possess interests. Patients (A)-(D) (above) could possess 'welfare' interests in health, freedom from pain, tolerable environment and relationships. Patient (E) might possess an (objective) welfare interest only in continuance of life (such as it is).⁵³ In contrast, ulterior goals demand reflectivity and, additionally, relevant wants must be realistic,⁵⁴ ends in themselves,⁵⁵ and 'capable of promotion by human effort'.⁵⁶ This accords with having realistic scope for individual investment; investment making it a stake, rather than a mere passing or instrumental want (neither of which give rise to interests).⁵⁷

⁴⁸ Ibid 53-54.

⁴⁹ See, especially *Harm to Others*, above, 38-45.

⁵⁰ Ibid, 37.

⁵¹ See *ibid*, 38.

⁵² Ibid, 42. These might equally be termed 'commonly human interests'.

⁵³ However, 'surviving' interests are considered below, Chapter 7.

⁵⁴ I.e. more than an unattainable wish, *ibid* 42-43.

⁵⁵ I.e. not mere means to other ends, *ibid*.

⁵⁶ I.e. the individual can do something to promote it, *ibid*, 44.

⁵⁷ See *ibid*, 56-61.

To **include IcPs** it is submitted that desires should be sufficient,⁵⁸ but not necessary,⁵⁹ to interest attribution, as 'common' interests may also apply despite incapacity. A purely desire-based source of interests completely closes the gate on best interests, whereas purely needs-based interests can render possession of interests meaningless. Feinberg's delineation of welfare and ulterior interests enables controlled expansion of interest sources that includes IcPs appropriately as interest-holders. Applied to IcPs, ulterior interests may be held in proportion to residual capacity (as reflective capacity and belief are unnecessary, merely requiring the 'want' as a realistic, promotable end). Furthermore, even in severe incapacity, IcPs can have welfare interests, requiring no sophisticated mental state.

3.3 Purposive interests

The purpose of interests concerns the objective that we seek when employing interests.

3.3.1 The goal of interests

Interests operate to achieve valuable ends, that is, ends that are of inherent value. Understanding these values aids our conceptual understanding of interests by contextualising it. Two values dominate healthcare choices: autonomy and welfare. Each is considered later in this thesis.⁶⁰ Here, it is intended merely to introduce the relationship between value and interest. In essence, value is used in a justificatory way in decision-making; a decision-maker may appeal to a particular value to substantiate the importance of certain interests. Different values may support different treatment actions. But, as value systems are individualistic, there may be no definitively 'right' attribution of value, only a 'supportable' one. Because values lie at a high level of abstraction they gain practical application only through interests. Our values shape our interests, and our interests serve our values. The relationship is one of appeal and support. A value supports recognition of an interest by (1) encouraging us to assess the importance of the value, and (2) requiring consideration of the extent to which an interest serves that value. Some associations are axiomatic: an interest in freedom from pain appeals to, and is supported by, quality of life (life

⁵⁸ I.e. desires *can* give rise to interests.

⁵⁹ I.e. that *only* desires can give rise to interests.

is manifestly better if pain-free). Alternatively, an interest in bodily integrity serves, and is supported by, the value of autonomy because bodily integrity concerns control over one's person.

Beyond these examples, the interest/value relationship is far more complex. One may appeal to, and derive support from, both values simultaneously. For example, our interest in continued life serves our existence as autonomous agents *and* furthers experiences comprising good quality of life. Moreover, appeal may be indirect, where an interest in dignity serves our autonomy and quality of life through perception by family/friends. Indeed, autonomy itself is one facet of good quality of life. Hence, the value/value, and interest/value, relationships are not discrete, but a series of complex interrelationships of mutual support and (sometimes) conflict.

While judicial appeal may presently be made to autonomy and welfare, this thesis argues that these values are not yet employed to full and proper effect. Vague, justificatory allusion to value is insufficient. Patient well-being is the overall decision **purpose**; treatment choice strives to achieve this end. In view of the complex interrelationships between values and interests, seeking to promote *purely* (subjective) self-determination *or* (objective) welfare, risks over-simplification and poor evaluation of contribution to an ICP's overall well-being. As Dworkin suggests

'[t]here is an intellectual error...whenever autonomy has been defended as crucial or fundamental...the notion is elevated to a higher status than it deserves...although it is important to respect the autonomy of others, it is also important to respect their welfare, or their liberty, or their rationality'.⁶¹

In contrast, Feinberg believes that where conflict occurs between self-determination and (objective) well-being,

'[h]e has a sovereign right to choose in a manner we think, plausibly enough, to be foolish, provided only that the choices are truly voluntary'.⁶²

However, Feinberg's qualification of 'voluntariness' does not deem incompetent persons 'voluntary'.⁶³ Further, he places voluntariness on a sliding scale

⁶⁰ Autonomy in Chapter 4, and welfare in Chapter 5.

⁶¹ G. Dworkin, above, 32.

⁶² J. Feinberg, *Harm to self, The moral limits of the criminal law*, Vol. 3 (1986) Oxford U.P. Inc., New York, 61.

⁶³ See *ibid*, 106.

commensurate with degree and irrevocability of harm.⁶⁴ Buchanan and Brock suggest that these limitations effectively encompass balancing of self-determination and well-being.⁶⁵ Where autonomy is compromised, it invites welfare to step into the breach. But, this can give rise to excessive paternalism. In truth, every life combines both autonomy and welfare, and sometimes requires compromise between the two. Transparency of any compromise is crucial where another person's well-being is the decision's prime focus. *Aliter*, a decision stands unjustified and its purpose unveiled. How then do interests serve a goal of patient well-being?

3.3.2 The role of interests

Interests are a tangible means of assessing a treatment option's impact and the dis/service of desirable values.

3.3.2.1 Impact assessment

Feinberg makes a detailed analysis of the meaning of 'harm'.⁶⁶ Relevant to this context, he suggests 'harm' to be

'the thwarting, setting back, or defeating of an interest'.⁶⁷

He distinguishes this from 'wronging', which is

'indefensible...conduct [which] violates the other's right'.⁶⁸

However, Feinberg further distinguishes between a state of harm and a harmful act,⁶⁹ and distinguishes 'harms' from other states which, while unpleasant or undesirable, he considers do not amount to 'harm'.⁷⁰ Effectively, this excludes *de minimis* hurts.

Impact (harm/benefit) is inescapably relevant. It allows decision-makers to speculate about relative values through concrete evaluation of the consequences of particular decision on certain identified interests. However, our perception of

⁶⁴ See *ibid*, 118-121.

⁶⁵ A.E. Buchanan and D.W. Brock, *Deciding for others, The ethics of surrogate decision making* (1990) Cambridge U.P. 45.

⁶⁶ See particularly *Harm to others*, above, 32-35.

⁶⁷ *Ibid*, 33. This is gauged by 'whether that interest is in a worse condition than it would otherwise have been in had the invasion [of the interest] not occurred at all', *ibid*, 34.

⁶⁸ *Ibid*, 34. Feinberg argues that although wronging often invades an interest, it does not necessarily set it back; an interest-holder may *benefit*, or a person's interest may be set back without being wronged because invasion is justifiable or he has consented, *ibid* 34-35.

⁶⁹ See Feinberg, *Freedom and Fulfillment*, above, 6: states of harm may accrue from natural (non-acted) events.

harm/benefit may influence the types of interest open to harm. As Childress suggests:

'[t]he object of harm is always an *interest*...But there are both broad and narrow definitions of "harm" according to the range of interests involved. In a narrow definition, harm is viewed as damage to physical and perhaps mental interests, which are distinguished from other interests. In a broad definition, various interests are included, such as life, health, property, familial relations, privacy and liberty. Harm is damage to any of those interests'.⁷¹

Arguably, the relationship between harm (or benefit) and interests is symbiotic; the range of interests admitted has equal implications for scope of impact. Thus, in ICP decisions, it is important that we are clear about which interests an ICP may possess because this shapes our perception of impact, thereby influencing conflict resolution. Harm and benefit have increased ethical significance in healthcare through non-maleficence and beneficence, respectively.⁷² Furthermore, existing judicial assessments of impact include:

- *harmful* pain/suffering, coupled with lack of long-term *benefit* justifying withdrawal of treatment from severely defective neonates,⁷³ and adults in low cognitive awareness states;⁷⁴
- *harm* to a pregnant woman's physical health, and assumed *psychological harm* predicated on natal death, justifying enforced Caesarean;⁷⁵
- psychological *benefit* to a patient's relationship interests justifying invading her bodily integrity interest, thereby benefiting another;⁷⁶

⁷⁰ See Feinberg, Harm to others, above, 45-51.

⁷¹ J.F. Childress, Who should decide? Paternalism in health care (1982) Oxford U.P. New York, 108, citing J. Feinberg. Childress adopts a broad definition.

⁷² Harm-avoidance has prime importance; *primum non nocere* ('first do no harm'). However, the subjects of non-maleficence and beneficence may differ: moral agents may exercise non-maleficence to all persons (i.e. refrain from harming anyone), but cannot logically accord beneficence to all persons (i.e. it is not humanly possible to positively benefit everyone). See Beauchamp and Childress, Principles of biomedical ethics (1994) Oxford U.P. Inc., New York, 262.

⁷³ E.g. Re C (A minor)(Wardship: medical treatment) [1989] 2 All ER 782; Re C (A baby) [1996] 2 FLR 43; Re C (A minor)(Medical treatment) [1998] 1 FLR 384; A National Health Service (NHS) Trust v D [2000] 2 FCR 577.

⁷⁴ Discussed above, Chapter 2.

⁷⁵ E.g. Norfolk & Norwich Healthcare (NHS) Trust v W [1996] 2 FLR 613.

⁷⁶ E.g. Re Y [1996] 2 FLR 787.

- however, *benefit* to a patient's interest in continued life may not justify invading his self-determination interest.⁷⁷

Criticisms already raised indicate that the balance of harm/benefit is not always sound.⁷⁸ Moreover, range and possession of interests strongly influences what we perceive as a decision's *purpose*, and exerts a direct effect on how we choose to balance conflicting impact on interest *objects*. Further, the degree of impact varies at different stages of an IcP's life, and during different mental states, and some impacts remain contentious, such as the relevance of impact on persons other than the IcP. However, prior to further consideration of interests, an important distinction must be outlined regarding the role of interests.

3.3.2.2 'In', 'against' and 'not in/against' interests

'**In interests**' denotes impact of an action as *beneficial*, promoting a patient's interests and contributing to his/her overall well-being. We can view impact as a harm-benefit continuum, an action '*in X's interests*' lying to the 'benefit' end of the continuum.⁷⁹ In contrast, where an action's effect is detrimental to a patient's interests, diminishing well-being, it is '**against his/her interests**'; lying towards the harmful end of the continuum. In IcP treatment decisions, we clearly seek a course of action '*in*' the patient's interests,⁸⁰ rather than '*against*' them. A further position warrants distinction: '**neither in nor against**' interests is highlighted by Gillon in relation to best interests, such that:

'[i]t is not in my best interests if Jones rather than Smith wins a prize - but neither is it against my best interests'.⁸¹

On a theoretical level this distinction represents a point on the continuum where an action's impact is neutral, having no impact at all on a person's interests. This distinction appears significant in treatment withdrawal from p.v.s. patients. In Bland, the House of Lords concluded continued prolongation of life to be '*not in*' his interests; it could not benefit him by enabling recovery, nor harm him (as he was

⁷⁷ E.g. Re C [1994] 1 WLR 290.

⁷⁸ Above, Chapter 2.

⁷⁹ Feinberg outlines a harm-benefit continuum, see Harm to others, above, 137-138, diagrams 1 and 2.

⁸⁰ This need not preclude withdrawing life-sustaining treatment, however. Arguably, where maintaining life is futile or harmful to the IcP, and the patient has only a very limited range of interests, death may be '*in*' his/her interests, as it frees the patient from pain/suffering/bodily invasion.

insensate and unaware). If so, then pvs is an exceptional neutral state,⁸² where either action (withdrawing or continuing treatment) is 'not relevant' to patient well-being. On this view, death might be what Feinberg would term a 'non-benefit'.⁸³ By corollary, death could equally be a 'non-harm' so far as a p.v.s. patient is concerned. Being already in a form of living death, his/her biological death might seem to make little difference to the patient. However, some value still seemed to be placed on Anthony Bland's life, in the sense that allowing him to die still required justification. The Law Lords posited justification less in interests than in the idea of life being of no further benefit to Bland, and continued intervention amounting to a source of indignity and harm. While this is correct in terms of impact, the very recognition of such impact implicitly imports interests. An impact cannot occur unless there are interests to be so affected. Rather, it is submitted that the impact is better explained in terms of our valuing 'life' in a wider sense (i.e. more than biological). It is the loss of *experiential* life, and the consequent wholly negative impact of continued biological life on remaining non-experiential interests (such as bodily integrity) that provides the justification for allowing Bland to die.⁸⁴ However, account should also be taken of the patient's subjective interests. This argument is developed in Chapters 5 and 7, below.

Thus, at this point, two objections may be raised to the idea of an action being *neither in nor against* an IcP's interests. First, nil effect upon interests depends on the interest concept. Adopting a broad concept would attribute even p.v.s. patients with some residual interests. Given that a treatment decision concerns an IcP personally, (not third party interests as in Gillon's Smith/Jones example),⁸⁵ it is unlikely to have *no* effect at all. Second, the addition of the superlative 'best' appears to commit us to an either/or situation; treatment being either optimal or non-optimal. On this basis, the theoretical distinction between '*neither in nor against*' and '*against*' interests becomes a distinction without difference; both represent non-optimal

⁸¹ R. Gillon, [1998], above, 75, in an editorial response to my published paper on p.v.s., above.

⁸² Exceptional because every other IcP, even in low cognitive-awareness states, has (albeit limited) interests.

⁸³ See Feinberg, Harm to others, above, 139.

⁸⁴ See also R. Dworkin's view of Bland's experiential interests, discussed below.

⁸⁵ Certainly, a treatment decision concerning patients X and Y *could* be neutral regarding patient Z's interests.

actions.⁸⁶ However, if our aim is to achieve the best outcome possible in terms of engaging in the best possible decisional process - rather than the best outcome in terms of an aspirational, and often unattainable, optimal decision - then we are no longer in an either/or situation, but can weigh all factors in the balance, their degree of influence varying depending on where they fall on the continuum of impact. It is submitted that this is the better approach, and this process is developed in Chapter 8.

3.3.2.3 Interest sets

Interest sets substantiate the relationship between interests and value. They represent a collective identity of stakes, grouped according to their role in a person's life. Grouping interests within a classification illuminates associations between particular interests, and between interests and interest-holders. The nature of interests may be explored through 'welfare/ulterior',⁸⁷ and 'experiential/critical' interests.⁸⁸

3.3.2.3.1 Welfare and ulterior interests

Feinberg's **classification** of welfare and ulterior interests has been outlined briefly earlier. He views welfare interests as 'minimal but nonultimate goods'.⁸⁹ These include: continuance of life; physical health; integrity and functioning of one's body; absence of pain and suffering; minimal intellectual acuity; emotional stability; absence of groundless anxieties; social capacity; minimal income; tolerable environment and freedom from coercion.⁹⁰ Thus, 'welfare' interests represent the basics of life that most of us take for granted. These provide the necessary stability for development of individualistic desires; they are facilitative.⁹¹ Feinberg rightly acknowledges that such interests are necessary but not sufficient for a good life.⁹² Yet, their absence fundamentally undermines an individual's capacity for achievement of 'ulterior' interests, which are:

⁸⁶ Both objections are raised in my response letter (re. Gillon's editorial), above [1999] 59.

⁸⁷ Per Feinberg, above.

⁸⁸ Per R. Dworkin, below.

⁸⁹ Harm to others, above, 37.

⁹⁰ See *ibid.*

⁹¹ See J. Feinberg, *ibid.*

⁹² *Ibid.*

'a person's more ultimate goals and aspirations...such aims as producing good novels or works of art, solving a crucial scientific problem...successfully raising a family...achieving [in] sport...[or] ameliorating human suffering'.⁹³

Ulterior interests are valued subjectively as contributing to an individual's conception of a 'good' life. Feinberg's distinction is useful because:

- it supports the view that interests arise from both needs and desires. Reflective capacity is not a prerequisite to welfare interests, but is crucial to ulterior interests;
- the groupings account for the fundamental quality of certain interests, which have both intrinsic and facilitative value (i.e. welfare interests);
- Feinberg's posited relationship between welfare and ulterior interests reinforces the complex nature of an individual's interests. Indeed,

'[w]hen [welfare interests]...are blocked or damaged, a person is very seriously harmed indeed, for in that case his more ultimate aspirations are defeated too'.⁹⁴

Thus, both interest groups serve a common goal of individual well-being. But, the role of each group differs: welfare interests being stakes in participative existence, and ulterior interests serving reflective choice.

Feinberg clearly finds welfare interests under common **ownership**, being

'of a kind shared by nearly all his fellows, in the necessary means to his more ultimate goals'.⁹⁵

Welfare interests (such as health, life, tolerable environment and economic sufficiency) are important to many people. We can attribute them as objectively valuable, whereas ulterior interests are highly subjective and a matter of choice for individual value. Welfare interests could be seen as springing from objectively identifiable needs, while ulterior interests arise from subjective desires. However, this is overly simplistic because welfare interests may be desired as well as needed, and may be subjectively perceived. Pragmatically, the issue is one of possession; it is more useful to regard welfare interests as *commonly owned* by persons generally as

⁹³ See Feinberg, *ibid*, 37.

⁹⁴ J. Feinberg, *ibid*.

⁹⁵ *Ibid*.

this does not create spurious classes attributing only needs to IcPs and desire-based interests to competent individuals.

However, contrasting welfare with ulterior interests shows why incapacity is so threatening to interests. **Incapacity**, which may accrue through lack of 'intellectual acuity', 'emotional instability', compulsive anxiety, or 'coercion',⁹⁶ interferes with a patient's integrity and functioning, undermining the stable minimums of welfare interests. Additionally, illness damages welfare interests themselves by threatening life, causing pain, damaging relationships, or making for intolerable physical environment. Incapacity and illness harm a patient's welfare interests and, therefore, can seriously invade a patient's ulterior interests, eventually diminishing the value of the patient's autonomy and quality of life. Proxy treatment decisions seek to restore these values where possible.

But, in many cases conflict occurs within and between interest groups. A series of examples is useful:

- where a patient suffers severe intellectual impairment, focus may be limited to improving basic welfare goals, such as reducing pain, improving environment, and enabling physical functioning, while minimising harm to bodily integrity;
- in a severe situation, such as low cognitive awareness, all hope of restoring autonomy value is gone, and welfare interests become yet more restricted. Our choice may be limited to: (1) withdrawing treatment (defeating an interest in continued life but promoting an interest in freedom from pain); or, (2) continuing treatment (which may cause pain but promotes continued life). Thus, while all welfare interests may be *owned* by IcPs, realistically the degree of incapacity may limit a patient's range of welfare interests;
- in relation to neonates and young minors a temporal aspect is added; the patient's welfare interests may develop over time. Where incapacity is severe, and life expectancy short, this development is precluded, restricting focus to fundamental welfare. However, where a patient is

curable,⁹⁷ a conflict arises between his/her *immediate welfare* interests and *longer-term ulterior* interests. Here, the patient's current condition sets back his/her welfare interest (in health), yet curability means that his/her long-term ulterior interests need not automatically be thwarted. Thus, giving treatment may: (1) set back some current and long-term welfare interests (i.e. freedom from pain and commitment to further procedures/medication); while, (2) promoting other welfare interests (particularly continued life that facilitates ulterior interest development). In contrast, withholding treatment simultaneously: (1) promotes current welfare interests (in bodily integrity and freedom from pain); while (2) thwarting a longer-term welfare interests of continued life (thereby defeating development of ulterior interests). Either action causes conflict. Ultimate choice turns upon the decision-maker's perceived combination of value commitments.

An alternative grouping of interests throws a different light on the role of interests.

3.3.2.4 Experiential and critical interests

Dworkin considers the nature of interests in the context of life/death decisions. He defines **experiential** interests as things

‘we like the experience of doing...the value of these experiences...depends precisely on the fact that we do find them pleasurable or exciting *as experiences*’.⁹⁸

These may be basic day-to-day interests, but they are *subjective* and based in capacity for sense. This admits a broader range of interest-holders than basing interests in cognition.⁹⁹

In contrast, Dworkin regards **critical** interests as

‘interests that it does make their life genuinely better to satisfy, interests they would be mistaken, and genuinely worse off, if they did not

⁹⁶ On Feinberg's view, discussed above.

⁹⁷ E.g. Re T [1996] 1 All ER 906.

⁹⁸ R. Dworkin, *Life's dominion, An argument about abortion and euthanasia* (1993) HarperCollinsPublishers, 201. Dworkin's examples include watching football, walking, listening to music, or working, *ibid*.

⁹⁹ Animals could possess experiential interests through capacity for pain/pleasure.

recognize...[t]hey represent critical judgments rather than just experiential preferences'.¹⁰⁰

Critical interests are value-based judgments about what makes life good. In a sense they are similar to Feinberg's ulterior interests, both concerning aims or (reflective) valuable ends. However, critical interests need not be profound, nor mandate reflective lives as more valuable.¹⁰¹ Rather, they concern

'what is...aspirational, within most lives'.¹⁰²

In other words, what *persons generally* consider to give meaning to life. Dworkin believes the distinction explains

'why we think that mind-changing drugs...produce long-lasting pleasure and contentment [to the user] are not in their victims' interests: we mean they are not in their *critical* interests'.¹⁰³

Thus, he considers that a subject may be mistaken about what is (objectively) important in life.¹⁰⁴ But, he suggests that critical interests

'seem very much to depend on his personality',¹⁰⁵

and our view of a 'good' life occurs as

'a direct response to our own specific circumstances of place, culture and capacity'.¹⁰⁶

This offers an important inference: the subjective/objective balance of critical interests might shift in response, say, to a diminution in capacity. This is endorsed by Dworkin's ultimate argument favouring decisions regarding IcPs made in sight of *individual integrity*.¹⁰⁷ Thus, in essence, **Dworkin's conceptualisation finds life's value to consist both in pleasurable experiences *and* things contributing to life in a broader, more meaningful way.**

Courts presently take account of experiential and critical interests in **IcP** decisions. Experiential interests are clearly recognised regarding severely defective neonates by

¹⁰⁰ Above, 201-202. Dworkin's examples include relationships, which people believe to be good, and that people *should* want them, *ibid*, 202.

¹⁰¹ *Ibid*.

¹⁰² *Ibid*.

¹⁰³ *Ibid*.

¹⁰⁴ *Ibid*, 206.

¹⁰⁵ *Ibid*.

¹⁰⁶ *Ibid*.

¹⁰⁷ He connects integrity with time, encompassing a patient's subjective view of his critical interests and a HCP's objective view of them. See *ibid*, 258-259, fn20.

reference to pain and suffering, which may prevail over an (objectively) critical interest in continued life.¹⁰⁸ However, experiential interests are also used as a prerequisite to interest possession. In the p.v.s. context, Dworkin highlights that

'[s]everal opinions in the House of Lords decision in the *Bland* case...simply assumed that only experiential interests can matter...and therefore had no difficulty in deciding that it could be neither in *nor* against Anthony Bland's interests that his life support be discontinued'.¹⁰⁹

Critical interests were not considered in the absence of experiential capacity. Arguably, in p.v.s. an *objective critical interest* might signify death being in the patient's interest, because continued life serves neither quality of life nor autonomy. Alternatively, recognising a *subjective critical interest* could admit the patient's former views as relevant. In short, the decision-maker's position on relative importance of experiential and critical interests depends on the value that s/he seeks to promote. While Feinberg's classification identifies interest sources, Dworkin's experiential/critical distinction acknowledges the contribution interests make to an individual's life, being

'two kinds of reasons people have for wanting their lives to go one way rather than another'.¹¹⁰

In particular, by according importance to a patient's experiences we can respect *individuality* despite lack of reflective capacity.

3.3.2.5 Objective/subjective perceptions of interests

Benn groups interests specifically on an objective/subjective basis. He distinguishes between

'perceived interests, what...[a person]...believes would make him better off, from his real interests, the conditions under which he really would be better off, whether he believes it or not'.¹¹¹

In essence, **perceived interests** comprise a subject's own view of his/her interests (whether welfare or ulterior, experiential or critical). Perception requires capacity for cognition. In contrast, Benn considers **real interests** to consist in factual conditions;

¹⁰⁸ However, regarding mature minors courts impose a negative treatment experience (by authorising treatment contrary to patient wishes), because of an (objective) critical interest in continued life enabling development of full, subjective reflection.

¹⁰⁹ Above, 208.

¹¹⁰ *Ibid*, 201.

these interests would, *in fact*, bring advantage/benefit to a person irrespective of his/her perception. This allows for interest possession even where a subject is mistaken, or in denial, or unable to perceive his/her interests or any impact on them. However, surety of advantage can be difficult to ascertain, certainly in application to treatment decisions where the result is contingent on, say, an operation proceeding smoothly or a treatment's efficacy. Additionally, overall gain/loss can be difficult to determine. Thus, even Benn's 'real' interests comprise a set of *objective beliefs* about another individual's interests.

The subjective perceptions of a **competent** patient about his/her interests prevail over any objective view (no matter how 'real'), due to dominance of the autonomy value. However, the same is not true for the **incompetent** patient, where commitment to perceived interests diminishes with incapacity, which increases patient susceptibility to mistake or misunderstanding. The present threshold for admission of perceived interests is high; evinced by the few cases according importance to an IcP's subjective views.¹¹² Soft paternalism in relation to IcPs tends to warrant invocation of an (objective) quality of life value where a patient's (subjective) autonomy is diminished.

However, incapaces may perceive interests in some aspects of their life, but not others. For example, an incapax may be able to perceive a relationship as subjectively valuable, but be unable to understand the complex possibility of harm. This thesis argues that: (1) significance may still be accorded to an IcP's perceptions if s/he has requisite understanding of the *particular aspect* in question; and (2) perceptions and beliefs change over time, an IcP may have had relevant perceptions previously,¹¹³ or may develop them in future.¹¹⁴ On this basis, perceived beliefs are not an 'all-or-nothing', 'now-or-never' concept. The role of objectivity and subjectivity vary regarding different *aspects* of life, and over *time*. Subjectivity may have a role regarding 'incompetent' patients.¹¹⁵

¹¹¹ S.I. Benn, above, 105.

¹¹² E.g. Re C [1994] 1 WLR 290, St George's case [1998] 2 FLR 728. In contrast, numerous IcP cases endorse an objective (medical) view of IcP interests, see *supra* Chapter 2.

¹¹³ E.g. a p.v.s. patient may have held complex beliefs about his/her life and interests.

¹¹⁴ E.g. a neonate/infant may develop beliefs in time.

¹¹⁵ Developed in Chapters 4 and 6-8.

In summary, the subjective/objective balance plays an important three-way role: it reflects value balance; locates decision-making perspective; and influences subjective input. However, subjective/objective perspective should not dictate *possession* of interests. Hence, a distinction should be made between *having*, *taking*, and *knowing* of an interest.

3.3.2.6 Taking, having and knowing

The distinction between *having* an interest, *knowing* of it and *taking* an interest is important regarding IcPs. Incapacity may impair cognitive capacity (which diminishes an IcP's ability to *know* of an interest), or it may inhibit capacity to *exercise* cognition (i.e. *take* an interest). However, it is submitted, even incapacitated patients may still be interest-holders (i.e. *have* interests).

Knowing of an interest accrues from *beliefs about possession*, and it has already been argued that some interests are objectively identifiable independent of a patient's beliefs.¹¹⁶ In essence, an interest may be objectively held (and harmed/benefited), despite subjective unawareness.

Taking an interest concerns engagement; a person takes an interest if s/he considers it or exercises it.¹¹⁷ An IcP could *have* interests (that a proxy should engage with), despite inability actively to *take* any interest. Frey, for example, suggests that a comatose patient may be attributed with a commonly human interest in good health despite inability to take an interest in it.¹¹⁸ He rightly concludes that it is

'a mistake always to conflate having an interest with taking an interest, a distinction which it seems especially important to observe in comatose cases...[where] it does not follow - and I am inclined to think it dangerous to think otherwise - that she does not have an interest in what happens to her'.¹¹⁹

Incapacity clearly may disable a patient from *taking* an interest. However, in proxy decisions an IcP *has* an interest in *X*, which the proxy *takes* on the patient's behalf, by recognising, considering and weighing it.

¹¹⁶ I.e. 'welfare', commonly human, (genuine) 'critical', and 'real' interests.

¹¹⁷ Frey, above, 157.

¹¹⁸ Ibid.

¹¹⁹ Ibid, 157.

Inability to *take* an interest may limit the range of interests that an IcP has. A defective, sentient neonate has interests in freedom from pain and bodily integrity, but where treatment is futile, and life expectancy short, s/he has no opportunity to develop ulterior/subjective interests. In other words, because s/he will never be able to *take* an interest it becomes unrealistic to attribute possession of such interests. Thus, while taking and having should not be simply conflated, we must accept that *permanent* inability to *take* interest may preclude attribution.

Frey's view of the 'comatose' individual runs contrary to the current judicial position on p.v.s., which negates interest possession due to inability to take or know of - experience – one's interests. On Frey's account, a p.v.s. patient's permanent inability to *take* an interest would not preclude possession. This is surely the better view. For example, if a p.v.s. patient were subjected to sexual assault this should amount to an invasion of an interest in bodily integrity, despite the patient neither *knowing* of, or *taking*, an interest in bodily integrity because s/he should still have interests meriting respect and protection through human status or possession prior to entry to p.v.s. Yet, the current conflation of interest possession and knowledge of, or engagement with, one's interests would deny any such infringement. Brock and Buchanan also acknowledge the distinction in terms of 'surviving interests'.¹²⁰ Thus, even in extreme incapacity, *having* interests should be independent of *taking/knowing* of them. A further distinction must be raised regarding the functionality of interests, clarifying interests-overall and single-interest terminology.

3.3.2.7 '*Interest in*' contrasted with '*in interests*'

Fundamentally, a distinction should be made between: (1) having an '*interest in*' something, and (2) that which is '*in [someone's] interests*'. First, an individual may have an interest 'in' a particular value or outcome. This is a matter of the *object* of the process, that is, what is the interest aimed at protecting? Thus, I might have an interest *in* a good quality of life or in autonomous decision-making. This is to be contrasted with identifying that certain things may be *in* my interests. Here the focus is me, that is, I am the *subject* of attention, and the purpose is to act in my (overall) interests. Here the question is the overall *impact* on my interests of seeking to meet

¹²⁰Above, 163.

certain objects in which I might have an interest. Hence, for clarity this thesis adopts the following terminology:

- an ICP may have an **interest in** (singular) a particular object, such as bodily integrity;
- where several interest objects are relevant, an ICP can cumulatively possess **interests in** (plural) them;
- however, both differ from impact; an action may be **in the ICP's interests** (overall),¹²¹ or **against an ICP's interests** (overall).¹²²

The **objects** that a patient has *interest(s) in* may be objective (i.e. from the 'common' or 'welfare' groups), or subjective (i.e. ulterior, experiential, or subjectively critical). Furthermore, either classification (*interest[s] in* the particular, and *in interests* overall) may be perceived subjectively or objectively.

Thus, 'interest(s)' serve a variety of **roles**. They represent the single interest 'objects' in which a patient has a stake. These objects may be common to persons generally, or individualistic. They may also be basic and facilitative, or ulterior goals and aspirations, and may be mutually supportive or conflicting. In contrast, *in* (or *against*, or *neither in nor against*) *a patient's interests* refers to an action's impact on a patient's interests overall; whether an action cumulatively improves or impairs his/her overall well-being. Impact may be perceived subjectively or objectively, but the latter dominates regarding ICPs.

3.4 Objects of interests

3.4.1 Nature of objects

'**Objects**' describe those things an ICP has an **interest in**, that is, the particular things in which a stake resides.¹²³ Applied to ICPs, objects might include 'dignity', 'freedom from pain', and 'bodily integrity'. Recognition of an interest object triggers a certain normative response:

¹²¹ I.e. promotes the ICP's interests in an overall sense.

¹²² I.e. harms the patient's interests overall.

¹²³ See also Benn, above, 267.

'it signals the sort of behaviour which is appropriate to the object'.¹²⁴

This might mean in relation to an ICP's dignity that our actions should not subject him/her to inhuman behaviour, ridicule, or degrading treatment. However, objects also offer the substance of an ICP's interests and have formed a central judicial focus thus far, both expressly and implicitly. For example:

- referring to a 'life full of pain' implicitly accepts an ICP's interest in *freedom from pain*;
- requirement of judicial sanction recognises the gravity of invading an ICP's interest in *bodily integrity*;
- referring to the effect of continued treatment on an ICP's family/nursing staff alludes to a patient's interest in *dignity*;
- identifying an ICP's enjoyment of relationships/affection accords significance to his/her interest in *sexual freedom*; and,
- reference to futility infers a patient's interest in *continued life* may have ceased.

Objects often represent the sub-text of judgments; express reference to factors alluding, in a vaguely justificatory way, to an ICP's interest objects. Recent redefinition more willingly includes interest objects expressly. But, it is far from clear how these objects fit together, or how relative weightings are attributed. In other words, doubts remain about *why* - and *to what extent* - interest objects are important for an individual patient.

Certainly, relevant objects may include things in which the patient *takes* a subjective interest (e.g. religion), or *objectively has* an interest (e.g. good health), or that arise from *needs* (e.g. freedom from pain). Further, objects may be *facilitative* (contributing to welfare, thereby facilitating ulterior goals), or *ends* in themselves (e.g. cessation of interest in life). However, the **range** of ICP objects has been too constricted.

¹²⁴ Ibid.

3.4.2 Range

The range of IcP interests is potentially broad, including: health, care; freedom from pain; bodily integrity; dignity; privacy; reputation; relationships (including well-being of family/friends); being heard; psychological well-being; and, ultimately, quality of death. IcPs are people, with likes and dislikes, views and responses, drives, values and concerns. Admittedly, incapacity may rob them of reflectivity, and may deprive them of (objectively) 'well-thought-out' reasons. But, nevertheless many have (or previously had, or may develop) personal, subjective responses. At present, little space is allowed for IcPs' subjectively valued objects, because the practical range of interest objects is limited by:

- imposition of reflective capacity as a **gateway**. At present, a patient is either (1) 'competent' to decide, whereby subjectivity dominates, or (2) 'incompetent', requiring little account of his/her subjective views. This dictates non-acceptance of certain interest objects. For example, the interest in privacy may be overlooked regarding IcPs,¹²⁵ or the impact of enforced treatment on psychological health ignored.¹²⁶ In reality, incapacity is a matter of degree (even though competency is a threshold) and the relevance of subjective interest objects should vary with that degree;
- the way interest **function** is viewed means that some of the distinctions outlined are not considered by courts.¹²⁷ Thus, some interests are not recognised with objective input only being favoured, or limiting interests to experiential possession. Further, how we perceive harm may cause rejection of certain objects, such as an interest in quality of death,¹²⁸ or an interest in relationship;
- **conflict** of objects across the range appears likely to increase with the breadth of admissible interests. However, the answer lies in

¹²⁵ Indeed, D. Carson argues that little scope is given for incapax patients to develop relationships due to lack of patient privacy in institutions, *The sexuality of people with learning difficulties* (1989) J. Soc. Welf. Law, 355, 360.

¹²⁶ Discussed above, chapter 2.

¹²⁷ E.g.: objective/subjective; 'in'/'not in'/'against'; 'interests in' cf. 'in interests'; and 'having' contrasted with 'taking/knowing' of an interest.

¹²⁸ Namely, that people can have a death relatively free from pain/prolonged suffering.

understanding the role of objects decisions. Where decisions focus on specific, low-level object conflict, inconsistency occurs and the means and reasons for resolution are obscured. Conflict at object level really represents higher-level value conflict, as interest objects serve higher values. Thus, we could expand the range of relevant interest objects provided that: we set *gateways* appropriate to interest possession by IcPs;¹²⁹ we acknowledge that, while these interest objects give content to IcP interests, they are representations of interest *function*, serving particular values; we are aware of the complex *inter-connections* of interest objects;¹³⁰ and we are clear about *value*, resolving our conflicting role commitments to different values in order to support relative weightings at object level. Hence, sound resolution of conflict derives from appeal to value.¹³¹

How can objects, purpose and values be usefully represented? One relevant representation is available in the form of Feinberg's 'interest network'.

3.5 Subjects

3.5.1 Individuals

3.5.1.1 Interest networks

Feinberg proffers interest networks as a means to identify relative degrees of ulteriority regarding instrumental wants,¹³² welfare interests,¹³³ and focal aims.¹³⁴ His diagrammatic network represents complex interrelationships between the three classifications in 'self-regenerative' fulfilment:¹³⁵

¹²⁹ Considered further, below, Chapter 4 and paragraph 7.2.

¹³⁰ I.e. interest groupings, perspective, and impact.

¹³¹ See Chapters 4-8, below.

¹³² Harm to others, above, 55-61, i.e. wants that are 'linked up, either as a means or as necessary conditions, to the advancement of more ulterior goals'.

¹³³ I.e. necessary but barely sufficient interests for 'good life', *ibid*, 57.

¹³⁴ I.e. ulterior goals, *ibid*, 59-60.

¹³⁵ See *ibid*, 61, diagram 4.

'new interests regularly emerging from old ones to be advanced harmoniously with their progenitors'.¹³⁶

Feinberg's reference to 'harmonious advancement' alludes to a drive towards what is in a person's (overall) interests.¹³⁷ Thus, Feinberg's network (in the context of criminal prohibition of harm) provides an image of connected interests, some facilitative, some necessary, and some ultimate ends, which represent a person's stakes and fuel one another.

The conceptual strength of his network lies in representing the relativity of interests. It allows us to see the complex **interrelationships** within an individual's interests, and exposes the creative and conflicting nature of interests. In application to ICPs, an interest network could encourage us to stand back from the interest concept, enabling us to see:

- **single interest objects** as inherently valuable (in the *particular*), and in relation to other interests (as part of the *cumulative* impetus);
- that some interests are necessary means to others, their value being mainly **facilitative**. For example, an interest of an incapax in avoiding pregnancy (i.e. maintaining good physical and mental health) valuably *facilitates* her ulterior interest in relationship. The nature of some interests is to serve other parts of a patient's interest network. The decision-maker must be aware of the potential to undermine such facilitation to those connected parts of the network (this explains why invasion of fundamental interests, such as withdrawing life-sustaining treatment or imposing medical intervention against an ICP's will, needs to be clearly and substantially justified);
- the mutual **support and conflict** of interests, which may be *direct*,¹³⁸ or *indirect*.¹³⁹ As our interest objects do not exist discretely, promoting/setting back one has a ripple effect regarding others.

¹³⁶ Ibid, 61.

¹³⁷ Ibid. 55.

¹³⁸ E.g. promoting an ICP's interest in health, yet conflicting with his/her interest in bodily integrity.

¹³⁹ Arising from knock-on effects of invading one interest to secure another. For example, promoting a mature minor's interest in health may (directly) conflict with his/her bodily integrity, and may

It is apparent from this application that while conflict does not make interests less valuable within a network, we must be clear-sighted about the (direct or indirect) **extent of any conflict** on the *overall* impact. Furthermore, an interest network suggests interests to be **dynamic**; certain interests generating others, and enabling interest objects to change over time in response to circumstance. These issues of conflict resolution and interest ascertainment as a process are developed in due course.¹⁴⁰

Impact is an important aspect of decision-making regarding interests, concerning the effect an action has upon an ICP's stakes. Certain impacts may be allied to **single** interests, such as *promoting*, *thwarting* (i.e. preventing or blocking furtherance),¹⁴¹ *setting back* (i.e. reversing progress),¹⁴² or damaging an interest object. However, *benefit* and *harm* can be used to express **cumulative** impact on an interest network overall. *Benefit* can represent positive advantage to an ICP's interests overall. This is the prime objective of best interests - to benefit or bring gain to an ICP's cumulative interests. In this sense, an action that *benefits* an ICP is *in* his/her interests overall, because: (1) it serves existing interests; and (2) it enables his/her future interests to develop where possible. *Harm* is damage to, or diminution of, an ICP's overall interest network, comprising actions *against* an ICP's interests. An action might alternatively be *impact-neutral*, where a patient's overall interest network is neither benefited nor harmed. This impact would be '*neither in nor against*' a patient's interests, and has been employed in treatment withdrawal from p.v.s. patients.¹⁴³ However, this impact would virtually never occur if interests were construed as inclusive and wide-ranging.

Evaluating impact on a network is difficult, requiring assessment of: (1) the importance of impacts on *single* interests; (2) connective impact - *support* or *conflict* of single impacts relative to one another; (3) where conflict is irresolvable, impacts must be *set-off* (i.e. a negative impact accepted in order to promote another interest); and (4) a choice made about what *best* serves decision purpose overall. Assessing

(indirectly) impair interests served by bodily integrity, namely psychological health, or future capacity for decision-making.

¹⁴⁰ Below, Chapter 8.

¹⁴¹ See Feinberg, Harm to others, above, 53.

¹⁴² *Ibid.*

relative importance and overall impact almost invariably involves balancing and paramountcy – that is, some form of value preferencing. Such preferencing requires points of reference, and recognition of IcP input and individuality could make a significant additional contribution to the existing position. However, the welfare of IcPs is also important, particularly where no IcP input is, has been or will ever be available. Balancing represents the final part of the decision process and is considered later.¹⁴⁴ It is sufficient here to note that value preference is inevitable in proxy decisions because conflict requires some choice of compromise to be made.

Some undesirable impact(s) are often the price to be paid for positive gains. A decision-maker seeks an action most beneficial to a patient's interests, *on balance*. But, attributing importance - weighing - is no simple task. For, as Feinberg notes:

[i]t is impossible to prepare a detailed manual with the exact "weights" of all human interests'.¹⁴⁵

However, some guiding features are identifiable. In the harm context, Feinberg advocates an initial reference to (1) likelihood of harm occurring,¹⁴⁶ and (2) degree of resultant harm.¹⁴⁷ Relatedly, in risk evaluation in healthcare, Carson argues risk should reference how probable and extensive any harmful consequences of non/treatment are likely to be for the patient.¹⁴⁸ Beyond this Feinberg proffers three criteria for assessing relative importance: '**vitality**' (i.e. how important or 'vital' the interest in terms of the whole network);¹⁴⁹ '**degree of reinforcement**',¹⁵⁰ (i.e. the more an interest is reinforced by other interests the greater its importance); and the '**inherent moral quality**' of the interest. Vitality and reinforcement essentially identify interrelationships of interest objects within networks.¹⁵¹ Rather, *balancing* lies in value, but inherent moral value is always contentious. Relatedly, Benn

¹⁴³ See discussion of Bland, *supra*, chapter 2.

¹⁴⁴ Balancing builds on the concept of interests adopted and the values that are deemed important. Relevant values are considered in Chapters 4 and 5. Subsequent chapters then embrace values under 'respect' for IcPs, and balancing within the decision process is developed in Chapter 8.

¹⁴⁵ Harm to others, above, 203. Indeed, even if possible to do so certainty would be gained at the expense of flexibility.

¹⁴⁶ See *ibid*, 204.

¹⁴⁷ A 'total thwarting' being more serious than invasion to 'small degree', *ibid*.

¹⁴⁸ D. Carson, Risk-taking policies (1988) *J. Soc. & Welf. Law*, 328.

¹⁴⁹ The greater the harm to the interest network, the more important it is. See Feinberg, above, 204-205.

¹⁵⁰ See *ibid*, 205.

considers value in resolving conflicting role commitments. *Prima facie*, Benn's diagrammatic representation of roles, locating action options and applying *Pareto* curves to identify the 'best' overall action, appears to offer a solution to balancing through 'trade-off'.¹⁵² However, because IcP decisions often involve minimum threshold values, no amount of trading-off may present an acceptable solution. In hard cases Benn suggests that we must 'make the best of a bad job'.¹⁵³ And, where the need for a decision is inescapable,¹⁵⁴ yet no option offers satisfactory impact, a decision-maker must find the next-best option.¹⁵⁵ Ultimately, this requires a value judgment about what is important and how well treatment options fulfil those values. This might involve according paramountcy to certain interests; choosing which value should dominate. But, every individual has a different value system - different ideas about what is important. One decision will rarely please everyone. However, the alternative of adopting a 'reasonable' or 'rational' position may lack individuality.

Traditionally, in the UK, 'best interests' inclines to objectivity, regarding quality of life paramount where autonomy is undermined. In the USA substituted judgment standards prevail, proffering subjective patient views despite incapacity. Choice of objective (and decision mechanism) is, therefore, a judicial policy preference based on relative commitment to autonomy or quality of life.

Whether balancing conflict, or according paramountcy, decision-makers are compelled to appeal to value. The seemingly irresolvable nature of IcP decisions and gravity of impact encourages seeking of higher abstracted values to help justify our choice of 'best' impact. Appeals to value are explored in due course.¹⁵⁶ However, interest content (and impact on it) is also influenced by whose input is admitted.

¹⁵¹ This amounts only to mapping (i.e. descriptive identification), which this thesis regards as a part of the process prior to weighing.

¹⁵² Outlined, Chapter 1 above.

¹⁵³ See S.I. Benn, above, 59-64.

¹⁵⁴ I.e. because harm will occur if a decision is not taken.

¹⁵⁵ Certainly, this was Ward LJ's approach in the recent conjoined twins decision, above, Chapter 2.

¹⁵⁶ Autonomy in Chapter 4, welfare in Chapter 5 and respect in chapters 6-8.

3.5.2 Interested parties

Whose input to the decision is warranted, and why? Overt emphasis in decisions is on the incompetent patient as the *subject* of interests, but redefinitional aspects of relationship recognition suggest some admission of relevance of other parties.¹⁵⁷

The IcP clearly has interests, but his/her input is presently very limited wherever a finding of incompetence is made. However, the 'incompetent patient' classification may comprise a broad range of patients and conditions, ranging from mild to severe and temporary to permanent. It is submitted that incompetence need not negate all relevance of patient input. For, IcPs are not all equally *in*competent. Incapacity varies in **degree and nature**, and **duration**. Thus, some IcPs may be able to give views and information about some aspects of a decision, or at certain times.¹⁵⁸

In addition, other **sources of input** include: *clinicians*; the *judiciary*; *State* or *society*; the patient's *family*; and those persons *emotionally closest* to the patient (i.e. partner/spouse/friends). The input of these parties contains a value judgment based on recognition of relationship. Some are presently more readily admitted than others. The normative value of such recognition is discussed later.¹⁵⁹ However, relevance here relates to a particular type of interest that can be promoted through relationship recognition.

Frey considers that an individual's 'vital concerns' may include concerns about the well-being of 'them and theirs', namely his/her family and those with whom s/he shares his/her life.¹⁶⁰ Further, *Feinberg* develops a classification of '*self-regarding*' interests (which relate to one's own ulterior interests), and '*other-regarding*' interests (which focus on well-being of others).¹⁶¹ Although both groups are subjective, the classification evinces that a person's interests in self and others are closely allied. *Feinberg* identifies **self-regarding** interests as: (1) direct (promoting only the individual's self-regarding ulterior interests); and (2) indirect (promoting only his/her self-regarding ulterior interests by means of promoting well-being of others).¹⁶²

¹⁵⁷ See *supra*, Chapter 2. This is also growing relevance in the Adults with Incapacity (Scotland) Act 2000 and proposed English reform, see above, paragraph 2.4.2.

¹⁵⁸ Scope for patient input also depends on construction of competence, considered below, Chapter 4.

¹⁵⁹ Below, Chapter 6.

¹⁶⁰ Above, 146, n5.

¹⁶¹ See *Harm to others*, above, 70-79. J.S. Mill originates the interrelationship of interests between persons, see *On Liberty* (1859), reprinted Penguin Books Ltd, London (1974), Chapter IV.

¹⁶² Above, 74, diagram 1.

Clearly, healthcare decisions concern *direct* self-regarding interests, for example in acknowledging advance directives and refusal of treatment by competent patients.¹⁶³ Courts do also occasionally employ indirect self-regard on an ICP's behalf; for example in *Re Y* an *indirect* psychological benefit Y was identified through her resulting continued familial relationship.¹⁶⁴

In contrast, **other-regarding** interests are

[a]cts that directly promote the actor's...desires for the well-being of others, at least partly as an end in itself.¹⁶⁵

In essence, we can view other-regarding interests as areas of overlap in the interest networks of individuals. Other-regarding interests account for human capacities of compassion; concern for others' well-being for their sakes,¹⁶⁶ and because we have an interest in being compassionate - as it reflects our part in humanity. Other-regarding interests are difficult to attribute to **ICPs** because they are subjectively reflective. Certainly, mature minors or mildly intellectually disabled patients may appreciate the interests of others, as may any competent patient prior to incapacity. But, the courts have approached other-regarding interests cautiously. In *Re T*, the mother's responsibilities and care commitments were emphasised as part of assessment of C's interests, and might be framed as an other-regarding interest of C. However, other-regarding interests are more likely to be *about* ICPs than owned by them. Feinberg gives an example akin to *Re T* in reverse; that a mother has an other-regarding interest about her infant's well-being, at least partly for the infant's sake.¹⁶⁷ In short, realistic scope for attributing self and other-regarding interests to ICPs may be limited to previously-competent, or mildly incompetent patients. However, recognising relationship could permit the interests of others in the patient more openly. In *Re Y* the court could have simply acknowledged that Y's sister had an interest in Y's donation because of the benefit it would bring her (the sister), and to Y's family. This more realistic interpretation appears to contradict well-established Kantian views that (human) persons should not be a means to an end. However, suffusing

¹⁶³ However, arguably no patient's interests are *entirely* self-regarding, as no person exists in isolation.

¹⁶⁴ Arguably, however, the underlying motivation for authorising Y's donation could lie in the interests of others in Y.

¹⁶⁵ Feinberg, Harm to others, above, 74, Diagram 1. This is akin to Frey's concern about the well-being of others.

¹⁶⁶ But not in a purely altruistic sense, Feinberg, *ibid*, 74 diagram 1, and 75.

contentious issues regarding interested parties in dubious conceptions of an IcP's interests (rather than those of others) only clouds best interests. This thesis argues that the relationships between IcPs and those emotionally close to them *are* important. Those emotionally closest to us are concerned about our life and well-being. Life is full of relationships - for both competent *and* incompetent persons - and ignoring them is shortsighted. Rather, we could usefully regard mutual stakes to arise from them within certain overlapping areas of an IcP's interest network.¹⁶⁸ Again, a balance must be struck, admitting input and consideration of all network areas, and interested parties, yet sifting this information with the interest-holder (IcP) clearly in sight as owner of his/her network.

3.6 Concluding interests and interested parties: A connected concept

This chapter has sought to deconstruct the interest concept to explore the nature of interests, the purpose they serve, and to whom they belong. Deconstruction was needed as decided cases fail to elucidate these issues clearly, often failing to define a decision's purpose, or how interests serve that purpose, and positing conflicting interest objects. The interest concept has been shown to be more than mere definition, being constructed from additional features woven around it. Varying the features alters the concept, and would create different outcomes on application to IcP decisions. These surrounding features include:

- **gateways**, such as reflective capacity and sources from which interests derive (i.e. needs and desires). This dictates who may possess interests and when;
- **functional** issues, including: (1) the *goal* or *purpose* of the decision that interests serve. This *value* has been construed as patient well-being, and is discussed further below;¹⁶⁹ and (2) the *role* of interests (i.e. how interests serve or detract from that purpose). This depends, in part, on acceptance of certain distinctions, perception of 'harm' and 'benefit', and the types of interests admitted;

¹⁶⁷ See *ibid*, 75.

¹⁶⁸ See further, Chapter 6.

¹⁶⁹ Below, Chapter 5.

- **content** represented in interest objects and how those interests relate to one another; and
- **subjects** of interests, in terms of attribution of interests and input of interested parties to the decision.

Acknowledging the connections between elements allows us to understand that conflict manifest in content, or in interest attribution, may be more symptomatic of fundamental value conflict. Judicial and medical focus on interest objects has occluded the importance of value, making justificatory reasoning hard to trace and conflict resolution unclear. It becomes difficult to ascertain: (1) which interests and values conflict; (2) how we might set-off that conflict when reconciliation is impossible; and (3) why that position is justifiable in terms of the patient's interests overall. Unsurprisingly, a confused image of 'best' and 'interests' has accrued from IcP decisions thus far.

We must recognise conceptual connections if IcP decision-making is to improve. Conceptual features - gateway, goal, role, content and subject - are inter-dependent. Each contributes to a decision, and only by recognising their connectedness can we develop understandable, traceable, and justified reasons for treatment decisions.

Interest networks have been identified to represent connections between objects, role, and an IcP's relationships.¹⁷⁰ Networking interests can translate the theoretical interest concept into a manageable framework because it encourages a proxy to take account of a full range of an individual's interests, to consider how those interests interact, and to focus on impact in terms of decision purpose. Because the networks of individuals differ, their purposes may differ.¹⁷¹ Ultimately, conflicts of interest may be unavoidable. A value judgement about relative harms and benefits may be needed to locate 'best'. This chapter has argued that the broad aim of IcP treatment

¹⁷⁰ The term 'interest network' is drawn from Joel Feinberg's work, but is then developed here in relation to IcPs to include zones and relationships of mutuality, see below, chapter 6.

¹⁷¹ E.g. in withdrawal of treatment from a defective neonate his/her commonly-valued critical interests are predominantly future-oriented and contingent on likelihood of development, combined with actual, experiential interests regarding current/foreseeable pain. By contrast, a p.v.s. patient's interests are essentially backward-looking, ulterior interests concerning self and those emotionally-closest. Experiential interests are non-existent, and future interests limited to any deemed 'surviving' (see Chapter 7 below). Hence, the two patients' networks differ radically, as does purpose of present/future well-being.

decisions is to secure patient well-being. In so doing we should take account of all relevant interests and relate them to purpose. We should be aware of how we use interests and be prepared to address conflict. Further, we should acknowledge an IcP's relationships, admit relevant input, and consider interests and issues from a rounded perspective (i.e. objectively and subjectively).

We may not reconcile every interest conflict, but an informed, enlightened decision-maker is better able to choose reflectively to promote an IcP's well-being. This eventual choice must be justifiable, and this depends on (1) clear expression of conceptual understanding; and (2) appropriate appeal to value and informed perspective. Based on the conceptual understanding herein, remaining chapters evaluate autonomy and patient perspective,¹⁷² and explore the significance of welfare and quality of life.¹⁷³ Ultimately, the value of respect for persons is proffered and developed as a desirable synthesis.

¹⁷² Chapter 4.

¹⁷³ Chapter 5.

CHAPTER FOUR

APPEAL TO VALUE:

AUTONOMY - A PATIENT'S PERSPECTIVE

Chapter 4 Appeal to value: Autonomy – A patient's perspective

Appeals to value have an important role in best interests. Beyond retrospective justification, value can proactively inform and represent **purpose** in IcP decisions. Positively connecting value purpose with interest function would clarify the relative importance of the various interests within a patient's network. This exploration of appeal to value considers how our (implicit or express) choice of value reflects perspective. Both factors – value promoted and perspective adopted – influence which interests we admit and how we resolve conflict. Initially this chapter focuses on the meaning of 'autonomy' and its value in healthcare. Incapacity causes a breakdown in the effectiveness of an autonomy model. In this regard two issues are identified as central to autonomy and patient perspective in IcP decisions: competence construction; and the choice of decision mechanism, both considered in the latter part of this chapter.

4.1 Defining autonomy

4.1.1 The nature of autonomy

Autonomy represents self-determination: deriving literally from the Greek terms for self (*autos*) and rule or law (*nomos*).¹ In relation to individual autonomy, Feinberg identifies 'four closely related meanings':

'[i]t can refer either to the *capacity* to govern oneself, which of course is a matter of degree; or to the *actual condition* of self-government and its associated virtues; or to an *ideal of character* derived from that conception; or...to the *sovereign authority* to govern oneself, which is absolute within one's own moral boundaries'.²

If we apply Feinberg's approach to the IcP context then autonomy concerns:

- the ability to make choices (capacity), usually gauged against a minimum threshold level of 'competence';
- the opportunity to exercise capacity (i.e. absence of inhibitive conditions of interference, impairment, influence or self-control);

- limitation to, and acceptance of, the individual's role as a member of a community (the ideal of autonomy); and
- clarity between the concept of autonomy, and the significance accorded to choice, under what Feinberg terms 'sovereignty' (autonomy as a right).³

In essence, therefore, patient capacity and its exercise represent the underlying foundations of autonomous decision-making.

Hence, the prize for being recognised as autonomous individuals is, as Dworkin simply identifies, in having

'a right to make important decisions defining their own lives for themselves'.⁴

However, autonomy is not always attainable given prevailing conditions. In Beauchamp and Childress' view there are three requisite conditions for an 'autonomous' decision: it must be (1) intentional; (2) made with understanding; and (3) made without controlling influence (by others).⁵ These conditions substantiate the abstract idea of self-determination and have parity with Feinberg's more generalised view of capacity and conditions of self-government. Combining the two, Feinberg's capacity relates to one's ability to *understand* and *intend*, which must be exercised in actual conditions *free from interference*. Patient capacity is, therefore, fundamental to autonomous treatment decisions. Capacity for choice is an important part of this and unavoidably engages issues of reflectivity and preference.

But, clearly, autonomy is not merely about being free to choose,⁶ but about choice based on *understanding* and *deliberate intent*. However, a dichotomy exists

¹ See, for example, T.L. Beauchamp and J.F. Childress, *Principles of biomedical ethics* (1994) Oxford University Press, Inc., New York, 120, R. Gillon, *Philosophical Medical Ethics* (1986) John Wiley & Sons (BMJ) 60, and J. Feinberg, *Harm to self*, above, 27.

² Feinberg, *ibid*, 28.

³ See more fully, *ibid* 28-51.

⁴ R. Dworkin, *Life's Dominion*, above, 222. Relatedly, Buchanan and Brock, above, 36-37, construe self-determination as 'a person's interest in making significant decisions about his or her own life'.

⁵ Above, 123; Beauchamp and Childress require a 'substantial degree of understanding and freedom', because they acknowledge that realistically 'people's actions are rarely, if ever, fully autonomous'.

⁶ G. Dworkin differentiates autonomy from liberty and/or power because the latter two are 'necessary conditions' for individuality, see *Theory and Practice of Autonomy*, Cambridge U.P., Cambridge (1988) 108.

regarding the need for *deliberation* (or reflection) upon one's preferences in the choice process. Dworkin suggests that

'[a]utonomy is a second-order capacity to reflect critically upon one's first-order preferences and desires, and the ability either to identify with these or to change them...By exercising such a capacity we define our nature, give meaning and coherence to our lives, and take responsibility for the kind of person we are'.⁷

However, any demand for reflective capacity raises the level of the autonomy concept. Beauchamp and Childress argue that few choosers would be autonomous under such a standard, and that

'[n]o theory of autonomy is acceptable if it presents an ideal beyond the reach of normal choosers'.⁸

On this basis, any inclusion of reflective capacity must be set at a reasonably attainable level. Certainly, however, autonomy is important in its subjective role. An appeal to autonomy seeks to promote subjective preferences; autonomy is used to *justify* allowing a *patient's* evaluation of what makes *his* life 'good' to prevail.

To some extent, this debate about the nature of autonomy may seem arid in terms of IcPs because their autonomy is compromised. Thus, while an IcP may be able to form preferences, incapacity inhibits his/her reflectivity and raises doubts about, or denies entirely, his/her autonomy. Undoubtedly, some patients cannot meet prerequisite mental thresholds, and lack sufficient capacity for autonomous choice. Alternatively, some patients have capacity for autonomy but are unable to exercise it, their freedom to choose suffering such interference that their actual choice is not autonomous. Appealing to autonomy in such circumstances seems less valuable, because the preference it would facilitate would not be truly autonomous. Promoting a non-autonomous preference may harm, rather than promote, an (incompetent) patient's interests. Thus, where a patient is incompetent, why do we even need to consider autonomy? In essence, because: 1) capacity for autonomous choice determines *who makes a treatment decision* (patient or proxy); and 2) *patient perspective* may be warranted even where a person is non-autonomous. To understand these issues, we must first recognise why autonomy is so valuable.

⁷ G. Dworkin, *ibid.*

⁸ Above, 123.

4.1.2 The value of autonomy in healthcare

4.1.2.1 Why is autonomy a 'good thing' in healthcare?

Dworkin recognises autonomy as personifying *individuality*:

'[w]hat makes an individual the particular person he is is his life-plan, his projects. In pursuing autonomy, one shapes one's life, one constructs its meaning. The autonomous person gives meaning to his life'.⁹

Facilitation of individual preference is important in healthcare decisions because every individual's value system is unique and personal to him/her. Medical treatment may affect many aspects of life, including the continuance of life itself. Individuals respond differently to those effects based on their own personal value systems. This means that in making a decision a patient accords importance to certain things in his/her life, assesses the relative weight of beneficial effects, and trades-off conflicting values where necessary. The resulting individual preference, or choice, is subjective.

In the healthcare context, recent decades have witnessed a burgeoning significance for autonomy paralleled by a departure from 'doctor knows best' philosophy. Rather, many patients seek more information and involvement in their treatment (including decisions), and more HCPs are willing to involve patients.

In essence, **autonomy** is valuable because it **empowers patients**. It lends credence to the principle that persons should not be treated as a means to an end, rather that they are ends in themselves.¹⁰ It enables patients to refuse treatment, irrespective of the resulting benefits (of treatment) to themselves or others. Recognising autonomy allows an individual to live his/her *own* life, in his/her *own* way. Particular importance has flowed from this in terms of incapacitated patients. As Mason *et al* suggest autonomy has

'enhanced the freedom of those whose vulnerability, physical or mental, may have exposed them to insensitive treatment or even to exploitation; it has imparted dignity to the lives of those who might, otherwise, have felt themselves to be powerless in the face of the articulate and the professional'.¹¹

⁹ G. Dworkin, above, 31.

¹⁰ An approach evolved in the work of Immanuel Kant.

¹¹ (2002) above, paragraph 1.16. However, they also remind us that: 'the acceptance of autonomy as the benchmark of the good has led us to ignore other values, and this may have negative effects'

In the medical context the value of autonomy has evolved as **consent**. Because treatment invariably invades a person's bodily integrity, it is self-governance of one's body that autonomy is invoked to support. Where a patient is competent, the power to give/withhold consent is rightly his/hers; the patient's perspective should dominate because individual autonomy is so fundamentally valuable. Anything less would be an imposition:

'because my body *is* me, failure to respect my wishes concerning my body is a particularly insulting denial of autonomy'.¹²

Interests act as the vehicle by which the relationship between *autonomy and consent* connects. Consent protects particular interest objects, for example the patient's interest in his/her physical and psychological integrity. This interest in personal integrity serves the valuable purpose of self-determination/autonomy.

However, the state of being autonomous is distinct from requiring *respect* for autonomy. Respect for autonomy is the means by which patient perspective is protected. In other words, respect for autonomy is owed *by* others *to* the (competent) patient. This raises the purposive question: why should we allow our actions (of respect or paternalism) to be dictated solely by the fact that the individual is in an autonomous state? Dworkin considers two possible reasons for respecting individual autonomy: the 'evidentiary view'; and the 'integrity view'.¹³ He suggests the evidentiary view to be that:

'we should respect the decisions that people make for themselves...because each person generally knows what is in his own best interests better than anyone else'.¹⁴

However, that view quickly encounters difficulties.¹⁵ Dworkin's integrity view explains more successfully why we respect autonomy. He argues that autonomy

(*ibid*), and that autonomy must be qualified by: 'the legitimate interests and expectations of others'; 'economic constraints'; the 'sensitivities' of other autonomous agents; and 'the needs of society as a whole' (*ibid*).

¹² G. Dworkin, above, 113.

¹³ R. Dworkin, *Life's Dominion*, above, 222-225.

¹⁴ *Ibid*, 223, citing Buchanan *et al*, *Surrogate decision-making for elderly individuals who are incompetent or of questionable competence*, November 1985, report for Office of Technology Assessment.

¹⁵ As Dworkin points out, *ibid* 223, even competent individuals do not always act in ways that promote their own best interests. Autonomy goes beyond mere subjective knowledge of one's own best interests; autonomy is about the right to make one's own decision – whether that decision promotes one's best, or indeed, worst interests.

protects the capacity of people to live a distinct, individual life, and to choose whether to pursue overall integrity in that life. On this basis, the integrity view of autonomy

‘does not assume that competent people have consistent values or always make consistent choices, or that they always lead structured, reflective lives. It recognizes that people often make choices that reflect weakness, indecision, caprice, or plain irrationality’.¹⁶

In effect the integrity view recognises the worth of choice *and* individuality – irrespective of outcome.

Admittedly, not all commentators value autonomy so highly. Gert, Culver, and Clouser identify a persisting problem with using autonomy as an action guide:

‘the basic difficulty with autonomy, is knowing whether the actions and choices one is concerned with are autonomous’.¹⁷

In short, this amounts to disagreement about the *conditions* that are necessary to give rise to autonomous decision-making, and/or whether a patient is deciding autonomously under those conditions. Nowhere is this more contentious than in the face of incapacity.

4.1.2.2 Incapacity – a breakdown in the autonomy model

Potentially, incapacity represents a breakdown in the autonomy model of decision-making. While a patient’s views about his/her interests may ordinarily be accepted as the dominant model, the compromise exerted by incapacity shifts the balance from a subjective to an objective perspective. Incapacity diminishes autonomy in a number of ways. Harris identifies four ‘defects’ with this effect: defects in control;¹⁸ defects in reasoning;¹⁹ defects in information;²⁰ and defects in stability.²¹ However, he highlights that autonomy (and any diminution by defect)

¹⁶ R. Dworkin, *ibid*, 224.

¹⁷ B. Gert, C.M. Culver, K.D. Clouser, *Bioethics, A return to fundamentals* (1997) Oxford U.P., New York, 78.

¹⁸ E.g. addiction, see J. Harris, *The value of life*, above, 196.

¹⁹ E.g. parroting the views of others, prejudice, or invalid inference, where the defect undermines capacity for choice, see *ibid*, 197-198.

²⁰ E.g. where incomplete or false information is given or received, *ibid*, 198.

²¹ However, as people learn and change over time, shifting preferences should not necessarily be equated with instability undermining autonomy, see *ibid*, 198-199.

'is a matter of degree [and] does not make it any the less worth striving for, nor does it make it any the less important to have as much of it as possible...[o]ne will be autonomous simply to the extent that one's decisions are one's own, unfettered by others and suffering as little from the various defects as possible'.²²

However, the breakdown in the autonomy model may be only *partial*, and patient perspective could still be relevant if we recognise its importance. This thesis argues that, even though incapacity compromises autonomy, an appeal to autonomy may still be relevant for two reasons. First, in one sense, autonomy is already respected by decision-makers beyond patient incapacity. A decision-maker's need to *justify* interference or imposition upon the patient's bodily integrity (by way of *necessity* or *benefit to the patient him/herself*) arises because the patient's individuality is still recognised. We consider autonomy to be so important it may be bypassed only if justified in its *effect on the individual's interests*. By contrast, if respect for autonomy were truly irrelevant then decision-makers would feel no need to justify treatment, and could treat incompetent patients however they wished. Second, adopting Dworkin's integrity view, the relevance of autonomy to ICPs turns on his/her degree of capacity. If we accept that *competent* individuals may make irrational or inadvisable choices, then we should not demand more of the *less competent*. Thus, as Dworkin suggests:

'[w]hen a mildly demented person's choices are reasonably stable, reasonably continuous with the general character of his prior life, and inconsistent and self-defeating only to the rough degree that the choices of fully competent people are, he can be seen as still in charge of his life, and he has a right to autonomy for that reason'.²³

Hence, for some (mildly) incompetent patients, autonomy may still have value. Additionally, it is submitted, even regarding more severe patients the *individuality* that autonomy embodies may still be important within best interests. In this context, **individuality** means the uniqueness of the ICP's personality and circumstance. And, we may well find considerable direction and value from a consideration of the patient's individuality. With regard to the connected concept outlined earlier, values are the highest abstracted level of contribution to a person's well-being. Consideration at this level helps to universalise the particular, and to explore a

²² Harris, *ibid*, 200.

²³ R. Dworkin, above, 225.

proposed course of action in relation to the overall purpose of a treatment decision. In essence, values inform decisions in two ways: values throw up potential factors for consideration (interest objects), and offer guidance about how we may resolve conflict between factors (by reference to decision purpose). Both elements are identified earlier as influential in the content and function of best interests; autonomy can still be a window to patient perspective. Standing in an ICP's shoes could offer different factors for consideration, and help to clarify the decision's purpose in light of this individual's interests. Thus, autonomy framed as *individuality* may be valuable even where a patient is obviously non-autonomous in the sense of not being able to make his/her own choices.

Relatedly, Cox White identifies relationship between value structures and best interests:

[d]ifferent people make different choices, choices that provide them with value structures that define their personalities and provide the basis for principled action...Value structures, as collections of values, long-term goals, and beliefs, are an indication of an individual's best interests'.²⁴

Cox White rightly considers only competent patients to be suitably placed to choose autonomously.²⁵ However, not all patients are equally *incompetent*; incapacity is a matter of degree. Hence, once again it is not obvious that autonomy holds no value for all 'incompetent' patients, even if in order to experience its value we need to reframe it as 'patient perspective'. On this basis attention may now turn to the two issues identified earlier as fundamental to autonomy (and perspective) in the ICP context: (1) whom we deem 'competent' and 'incompetent' (determining location of decision-making authority), which clearly depends on how we construct competence; and (2) the locating of 'patient perspective' in alternative decision mechanisms.

²⁴ B. Cox White, *Competence to Consent* (1994) Georgetown University Press, Washington D.C., 15.

²⁵ See *ibid*, 17-18.

4.2 Construction of competence

4.2.1 Aspects of competence

The current position on competence is questionable regarding both adults and minors.²⁶ A commitment to autonomy and patient perspective demands sound construction of competence, because competence is the gateway to self-determination or best interests. However, Cox White rightly suggests that, while

‘[a]greement is widespread that competence ought to be assessed in terms of capacities (abilities)...[c]urrently no consensus exists about what capacities – and in what number or to what degree – constitute competence to consent’.²⁷

The contestable aspects of competence comprise: what patients must be competent about (*task/general*); the nature of understanding (its *meaning* and whether *ability/actual* understanding should be required); and how the marker for competence should be set (*threshold/degree*). Each is considered in turn.

4.2.1.1 General and task-specific competence

In the particular context of medical decision-making:

‘[c]ompetence is always competence *for some task* – competence *to do something*. The concern here is with competence to perform the task of making a decision. Hence competence is to be understood as *decision-making capacity*...Thus competence is decision-relative, not global’.²⁸

However, some dissent exists. Dworkin considers that, because task-specific competence varies ‘even among ordinary non-demented people’, in reference to autonomy

‘[competence] means the more diffuse and general ability...to act out of a genuine preference or character or conviction or a sense of self...[because] it is no kindness to allow a person to take decisions against his own interests in order to protect a capacity he does not and cannot have’.²⁹

But, why does it matter which sense of competence is adopted? First, because it affects who is ‘competent’. A patient may be competent regarding his/her life in general, yet incompetent regarding the specific task of treatment decision. The reverse may also be true; a patient may be competent for a specific decision, despite

²⁶ See Chapter 2, above.

²⁷ Cox White, above, Introduction xii-xiii.

²⁸ Buchanan and Brock, above, 18.

his/her incompetence for many other aspects. Ultimately, therefore, the sense attributed to competence may determine who makes the decision.³⁰ Second, adopting task-specificity allows the threshold of competence to shift according to the task.³¹

While full evaluation of the nature of competence is beyond the scope herein, it is submitted a focus on task-specificity is merited for a number of reasons:

- it mirrors the **variance** of capacities relevant for differing decisions. A general sense of competence is too blunt for accurate competence assessment; a refined tool is needed for accuracy;
- it **minimises arbitrary** drawing of **thresholds**. Relating requisite competence levels to a particular situation tailors competence assessment to individuals, by making fewer assumptions based on (inaccurate) generalisations;
- task-specificity reflects the **reality** and **complexity** of competence. As Gert, Culver, Clouser argue:

‘[i]t is true that some persons (for example, the unconscious) are globally “incompetent”, in that they do not have the ability to do anything. But there is no one who is globally “competent”; that is, there is no one who has the ability to perform all mental and physical tasks’;³²

Cox White refines her definition of competence in terms of task-orientation:

‘[a] person is competent for the task of giving a free and informed consent if (1) he is generally informable and cognitively capable of performing the actions involved in making a decision, (2) he knows that decision making requires these tasks, (3) he knows how to perform these tasks, and (4) given his situation, we can reasonably expect him to be able to make decisions’.³³

As this thesis is concerned with deciding for *incapacitated* patients (rather than informed consent) it is more useful to approach competence issues from the direction of impairment and its impact. Here, remaining issues are considered as: (1) impact

²⁹ R. Dworkin, above, 225-226.

³⁰ See Cox White, above, 61-62.

³¹ As Beauchamp and Childress suggest (above 136, citing D. Wikler, *Paternalism and the mildly retarded*, *Philosophy & Public Affairs*, 8 Summer (1979) 377): ‘[f]or practical and policy reasons, we need threshold levels...below which a person with a certain level of abilities is incompetent...[w]here we draw the line will depend on the particular tasks involved’.

³² Above, 132.

³³ Above, 50.

of *cognitive/affective impairment on ability for, or actual, understanding* (akin to informability through cognitive capacity and ability to decide); and (2) *competence thresholds and degrees of capacity* (reflecting evidential issues).

4.2.1.2 Understanding

Understanding is broadly defined by Beauchamp and Childress as:

‘acquir[ing] pertinent information and justified, relevant beliefs about the nature and consequences of one’s actions’.³⁴

Refinement in the context of competence distinguishes ‘understanding’ from ‘appreciating’:

“‘[u]nderstand’ refers to a patient’s general comprehension of the information presented...We take “appreciate” to refer to a patient’s knowledge that the information she has “understood” does in fact apply to her in the present situation’.³⁵

While much work has been done on *how* ICPs understand information – and we shall return to this briefly below – for the purposes of this thesis the most important distinction to be made is that between *ability* to understand and *actual* understanding.

An intellectually disabled patient may be *able* (cognitively) to understand relevant information, but s/he might not *actually* understand. For, ability is attributable to the patient alone, while actual understanding is influenced by factors such as environment, information presentation, and the degree of patient inclusion in the decision process. Roth, Meisel and Lidz characterise the two as tests:

‘[w]hat matters in...[ability to understand] is that the patient is able to comprehend the elements that are presumed...to be an important part of treatment decision making’,³⁶ [while actual understanding involves] ‘directly ascertain[ing] whether he or she has in fact understood’.³⁷

The designation is important because:

‘[a]bility to understand is the least demanding...since the question is whether the patient is *capable* of understanding...whereas if...[the test] is based on

³⁴ Above, 157. See also, *ibid*, 136.

³⁵ Gert, Culver and Clouser, above, 132-133.

³⁶ L.H. Roth, A. Meisel, C.W. Lidz, Tests of competency to consent to treatment, *Am. J. Psychiatry* 134:3 (1977) 279, 281.

³⁷ *Ibid*, 282.

actual understanding she is incompetent until she makes the intellectual effort to understand, and indeed succeeds in that effort'.³⁸

Additionally, ability allows patients to make autonomous but (objectively) inadvisable choices.³⁹ However, as Gunn *et al* acknowledge:

'the reality [is] that ability to understand cannot be determined unless actual understanding is assessed. The latter can be assessed'.⁴⁰

This may account for the mixed messages apparent in existing common law decisions. Assessing *ability* requires a culture shift that sometimes affronts our intuitive response inhibiting irrational behaviour. Unwise choices raise doubts about a person's competency, which s/he must then disprove. This has the effect of setting a more demanding threshold for refusal.⁴¹ Combined with presence of some incapacity (such as intellectual disability or mental illness) it may become virtually impossible for an IcP refusing treatment to evince this higher requisite level of showing *ability* through a test for *actual* understanding. Furthermore, impairment often undermines at least some of the abilities perceived as necessary to understanding. For, understanding is associated with high-level functions.⁴² Cox White suggests that:

'cognitive competence applies to the capacities of attention and perception, language usage (fluency, articulation, and comprehension), memory, and cognition itself (intelligence, calculation, insight and judgment, manipulation of data, and abstract thinking).⁴³

By definition, IcPs have impairments limiting these abilities, thereby restricting receipt or processing of information, or expression of requisite functions. But it should not be presumed to *preclude* competence. For, **competence is a complex of ability and facility**. This is perhaps clearest in relation to children's competence, where Alderson identifies a relevant combination of inner and outer aspects:

³⁸ M.A. Jones and K. Keywood, Assessing the patient's competence to consent to medical treatment, *Med. Law Int'l* (1996) Vol.2, 107, 113.

³⁹ Because '[t]his approach permits unwise choices, since the weight which the patient places upon the information or how that information is used is not of relevance': M. Gunn, The meaning of incapacity, *Med. L. Rev.* 2 [1994] 8, 18.

⁴⁰ M.J. Gunn, J.G. Wong, I.C.H. Clare and A.J. Holland, decision-making capacity, *Med. L. Rev.* 7 [1999] 269, 304.

⁴¹ Jones and Keywood suggest that: '[i]t is where patients are refusing treatment that questions of competence tend to arise...[i]n these circumstances the courts have tended to raise the hurdle by requiring at least actual understanding of the issues', above, 140.

⁴² Buchanan and Brock, above 23, suggest competence requires 'possession of various linguistic, conceptual and cognitive abilities' for receiving and comprehending information.

'[c]ompetence has more to do with qualities, experiences and perceptions. It is affected by the child's inner qualities (abilities, memories, confidence) and by outer influences (the nature and circumstances of the decision, its salience to the child's concerns, the adults' expectations and information, their support and respect for the child)'.⁴⁴

Hence, ability should be regarded as a blend of *individual qualities* (even though limited or impaired) and *opportunities* (created by supportive others) for those qualities to be maximised. Incapacity should not be instantly conflated with inability. And *ability* is the preferable criterion because it better reflects the qualitative nature (accessible through a supportive approach) of capacity, rather than the defensive rigidity imported by requiring actual understanding. Admittedly, however, *ability* is difficult to gauge. We must be clear, therefore, about *what* a patient should be able to comprehend and to what *degree*. Considerable work has been carried out on the difference between, for example, cognitive and affective abilities.⁴⁵ The reader is referred to the relevant literature and to its importance in terms of appreciating the complexities of incapacity and responding to the actual needs of individual IcPs. However, for the purposes of this work we need only note two essential points:

- decision-makers and those who inform them must understand *how* IcPs understand in order to meet communication deficits, and this includes the possibility, of course, that there may be no understanding whatsoever. Communication, after all, is a two-way deal; we cannot hope to assess an impaired patient's ability unless we provide suitable opportunities for him/her to display it. Normative guidance can be drawn from Alderson's views on children's competence development:

'[c]ompetence develops through relationships, which nourish yet restrict it'.⁴⁶

⁴³ Above, 117.

⁴⁴ P. Alderson, *Children's consent to surgery* (1993) Open University Press, Buckingham, 193. Furthermore, actual understanding requires patients to justify their right to autonomy, to articulate and evince actual thought processes, and potentially precludes the right of unwise choice. This latter aspect is destructive to the importance of making one's life one's own.

⁴⁵ See, for example: Gunn, above, 18-20 and 22-24; Cox White, above, 117-144; Beauchamp and Childress, above, 157-162; Buchanan and Brock, above, 23-25; and A. Rudnick, *Depression and competence to refuse psychiatric treatment*, *J. Med. Eth.* [2002] 28, 151.

⁴⁶ P. Alderson, above, 193.

For many IcPs the development of relationships as a means to communicating treatment information may be important; their feelings of security established through relationship may provide a better environment for cultivating understanding. By contrast, poor communication creates confusion for all parties.⁴⁷ In communication with children, Alderson concludes that

‘[w]illing uncertainty is perhaps the best guide during dilemmas, when the adults and children concerned work together towards the least harmful decision’.⁴⁸

This approach could equally guide our communication efforts with patients generally – particularly those that are incapacitated. Given our uncertainty about their capacity, willingness to communicate with them and provide a supportive, informative environment is the most positive means of assessing their ability to understand. Furthermore, even if a patient proves ‘incompetent’, relating with him/her may supply us with valuable information about him/her as an *individual*. It also provides IcPs with an opportunity to feel heard and involved;

- the focus for decision-makers – in light of this evidence – must be to *maximise* the IcP’s ability to understand and so to participate as fully as possible in the decision-making process. Competency is a gateway to decision-making authority. But, it need not entirely preclude patient involvement. We could still maximise a patient’s capacity by permitting input where some ability is present. This is herein termed ‘**input**’. If an (incompetent) patient can understand information, relate to it, and experience his/her feelings about how its impact, but cannot choose due to phobia, we could still take account of how s/he relates to, and experiences it, to provide input to a proxy decision. Alternatively, where a patient is unable to relate information to self (for example in anorexia), we could instead ascertain his/her feelings about it by discussing the de/merits of treatments in a hypothetical context. Alternatively, where a person is unable to function in a sufficiently complex way to deal with

⁴⁷ E.g. Alderson, *ibid.*

relevant issues (for example, through intellectual disability), we should still hear their views because, although simplistic, they may be strongly held. Ignoring them may seem valid because they are not fully autonomous, but to do so fails to respect them as persons. Maximising patient capacity is about more than pure autonomy. A humane response to ICPs requires us to allow people to input to their own treatment decisions as *one source* within that decision. Rather than worshipping autonomy the important thing in respect is that **a person is heard**. Respect is developed later in this thesis,⁴⁹ but its starting point is maximising individual patient capacity. First and foremost this means *listening* to patients – whichever side of the competence line they fall and whatever the difficulties of expression. To make better proxy decisions, we must listen more, assume less, and be prepared to inform ourselves from a wider range of sources. The patient's feelings matter – whatever their status as a decision-maker.

4.2.1.3 Evidencing competence: threshold or degree?

Competence is about determining decision-making authority. Capacity is about wider issues based on listening, communicating and maximising a person's participatory abilities. **Capacity is a matter of degree**. Individual capacities reside at any of an infinite number of positions along a continuum. Each of us may hold a different position for varying types of decision.⁵⁰ However, we could acknowledge capacity as a strength by attributing weight to capacitated input where possible. Admitting input and encouraging patients to participate in the decision process values individuality (a form of autonomy), and is particularly valuable in 'grey competence' where a patient's capacity borderlines the threshold (such as mature minors or temporary occlusion by pain/environment). Allowing input is part of *respecting a person as s/he is*, and engages us (as proxies) with information we might otherwise overlook.

⁴⁸ Ibid, 194.

⁴⁹ Chapters 6-8.

⁵⁰ Gunn, above 14, describes such a continuum as 'rang[ing] from full capacity at one end to full incapacity at the other end'.

However, a degree approach to legal *competence* fails as a mechanism. Ultimately a choice is required between patient or proxy determination because there is no halfway house in attributing decision-making authority. A patient is either competent to self-determine or not; s/he falls to one side of the line, or the other.

The essentially **functional** purpose of competence creates the need for threshold status, its aim being:

‘to divide persons into classes and not to place persons at various points on a continuum of abilities’.⁵¹

As a gateway mechanism,⁵² competence

‘expresses an all or nothing concept’.⁵³

One either is, or is not, competent to make one’s own decision without interference. Undoubtedly, the setting of thresholds is problematic. Cox White identifies a danger of thresholds being set for ‘bureaucratic convenience’,⁵⁴ and that their designation is time-consuming and arbitrary.⁵⁵ However, these issues are not avoided by degree competence either.⁵⁶ An intermediate level of threshold is required, to allow people to run their own lives through choice, while also protecting the vulnerable through a proxy.⁵⁷ An issue also arises regarding variance of any threshold.⁵⁸ The positioning of a competence threshold is developed in reconstructing best interests, below.⁵⁹ But, in essence, adopting a ‘functional’ standard allows a consistent threshold level, yet permits *natural variance* in individual decisions through complexity of information concerned.

⁵¹ Beauchamp and Childress, above, 136. Also, Buchanan and Brock, above, 27.

⁵² See also Beauchamp and Childress, *ibid* 132.

⁵³ J. Feinberg, Harm to Self, above, 28, citing the work of H. Kelsen, General theory of law and state, translated by Anders Wedberg, (1945) Harvard U.P., Cambridge, Massachusetts, 90-92.

⁵⁴ Above, 99.

⁵⁵ *Ibid*.

⁵⁶ As every individual must still be professionally assessed.

⁵⁷ See also Gunn *et al*, above, 293, regarding the dangers of setting thresholds too low.

⁵⁸ Gunn, above, 14, suggests it preferable to ‘set a definition which does not vary with the medical treatment in question nor does its level vary’. This contrasts with current judicial approaches requiring increased capacity correlative to gravity of decision (or consequences), see *Re T (Adult: refusal of treatment)* [1992] above. However, Gunn acknowledges, *ibid*, that: ‘some treatments are easier to understand or appreciate than others’.

⁵⁹ See Chapters 7 and 8, below.

In summary, the standard proffered herein is a **composite** of **task-specificity**, based on an **ability to understand and use information**.⁶⁰ **Using** information concerns ability to **relate information to self, engage with it, and choose**. The individual should be able to perform these elements at 'functional' level, which need not be sophisticated, merely basic provided that it pertains to all four aspects (understanding, relating, engaging, and choosing). Lack of ability in any of these four renders a patient 'incompetent', and a proxy should decide.⁶¹ However, two points merit reiteration: 1) careful communication is warranted using clear and appropriate language (or other means), and effortful understanding of their forms of expression; and 2) even where a patient lacks the functional ability for competence, his/her *input* may still be relevant. His/her degree of capacity may still offer personal feelings and perspective to be considered.⁶² Admitting incompetent patients' views, where expressed, maximises patient capacity through input. Respect demands listening – truly attending – to what IcPs have to say.⁶³

4.2.2 Additional issues – creeping incompetence

'Creeping incompetence' may arise through importation of **rationality** and/or **asymmetry**. Use of **time** can also influence competence construction. The informal presence of these criteria sometimes causes inappropriate findings of 'incompetence'.

4.2.2.1 Rationality

Rationality is sometimes used informally.⁶⁴ However, there are good reasons why rationality should not form part of competence. Practically, there are problems in:

⁶⁰ This terminology is also employed by the Law Commission, Mental Incapacity (1995) Report No. 231, above, paragraphs 3.14-3.16.

⁶¹ However, a presumption of competence should remain in force regarding adult patients; competence assessment only comes into play if there is reasonable doubt about a person's competence.

⁶² See also Buchanan and Brock, above, 27.

⁶³ See also, P. Alderson, above, 163, who suggests regarding children that 'sincere attempts to listen can sometimes remove the deadlock'.

⁶⁴ See Jones and Keywood, above, 112: 'even where formally the test of competence is based on the patient's understanding, the unreasonableness or irrationality of the outcome may strongly influence the court's assessment of the patient's understanding'. See also Gunn *et al*, above, 296; and Roth *et al*, above, 283.

'distinguishing rational from irrational reasons and drawing inferences of causation between any irrationality believed present and the valence (yes or no) of the patient's decision', [and] '[t]he patient's decision might well be the same even if his or her cognitive processes were less impaired'.⁶⁵

However, in contrast, Gert, Culver and Clouser expressly incorporate rationality fundamentally within their proposed construction of competence, defining 'competence' as

'the ability to make a rational decision'.⁶⁶

Prima facie this seems a radical normative departure. However, on closer inspection, their four definitional factors correspond closely to those already proffered herein within ability to understand, relate to, and engage with information, then to choose.⁶⁷ Hence, 'rationality' so framed adds little to a competency test, yet has ample inherent scope for misinterpretation.⁶⁸

Admittedly, irrational behaviour may indicate a need for competence assessment. Certainly there comes a point where a person's beliefs tilt the balance into incompetence.⁶⁹ But the crucial factor in this balance should be the effect on a person's ability to *function*. Competence should test a person's ability regarding the decision *process*, not outcome.⁷⁰ If we are really committed to a criterion of *ability to engage with the decision process*, then rationality should form no part of competence construction. Rather, we should assess a person's *ability* to enter a 'decision space', perceive him/herself to be there, engage with the contents of that space and choose an exit. This should not involve *us* in gauging how the contents of the space relate to the individual's value system *unless* we deem him/her unable to evaluate for him/herself. Moreover, competence should not be determined by his/her choice of exit. In reality, people may decide in ways that contradict rationality and reason, yet are still capable of making competent *choices*.

⁶⁵ Roth et al, above, 281.

⁶⁶ Above, 137.

⁶⁷ See Gert, Culver, Clouser, above 139, whose abilities for rationality include understanding, appreciation, ranking and volition (paraphrased here).

⁶⁸ See Buchanan and Brock, above, 69-70.

⁶⁹ See Gunn *et al*, above, 296.

⁷⁰ See, for example, Gunn *et al*, *ibid*, 298, citing the views of I. Kennedy, Consent: Adult, Refusal of Consent, Capacity – Commentary on Re MB Med. L. Rev. 5 [1997] 317; Buchanan and Brock, above, 70 and 82; Jones and Keywood, above, 112, citing Roth *et al*, above, 281; and Gunn, above, 16. Even attempts to define competence by testing outcome against subjective individual value systems (see

4.2.2.2 Asymmetry and decision consequences

In practice competence is relatively rarely at issue.⁷¹ But, as Gert, Culver, Clouser highlight:

‘[i]t is in cases of treatment refusals, especially those that appear to be irrational, that the question of a patient’s competence most frequently and appropriately arises’.⁷²

Asymmetry is understandable because treatment refusal raises doubts about competency, and it is then a naturally human response to seek affirmation of a person’s competence. It is appropriate that a refusal may trigger an assessment.⁷³ However, mere refusal should *not* raise the presumption of *incompetence*.⁷⁴ Furthermore, even a *consenting* patient could lack competence. Rather, it is oddity in behaviour or apparent thought processes (including refusal) that should initiate competence assessment.⁷⁵ In these circumstances it is in the interests of patients that competence be assessed, because wanton attribution of autonomy to patients suffering functional incapacity fails to respect their need for care. Focusing on ability helps to alleviate paternalistic presumption of incompetence-by-refusal.⁷⁶ However, asymmetry represents a consequence driven approach.

Consequential approaches occur as ‘risk-related’ standards. That is, the requisite threshold increases in direct proportion to seriousness of consequences. This approach appears in English law.⁷⁷ However, the problem with using risk to determine threshold level is that the relationship between consequences and risk may be ill-founded.⁷⁸ Further, a consequence-driven approach could engender

Buchanan and Brock, above, 56) encounter problems – requiring a patient to *have* a value system (see Gunn *et al*, above, 299), and precluding irrational choice in terms of that value system.

⁷¹ See Gert, Culver, Clouser, above, 142.

⁷² *Ibid*, 142-143.

⁷³ See also Buchanan and Brock, above, 82.

⁷⁴ See *ibid*, 85.

⁷⁵ See Cox White, above, 7-8.

⁷⁶ Contrast the views of Gert, Culver and Clouser, above, 144, who embrace some asymmetry, distinguishing between defects in cognitive capacity, and defects in affective and volitional capacity. They consider the former should be based on competence symmetry, while the latter two situations can render a person competent to consent but not to refuse. However, their approach relies on *rationality*, which may be influential.

⁷⁷ See *Re T* [1992] above, 796(H), and 796(E).

⁷⁸ See Chapter 2.

unattainably high competence thresholds.⁷⁹ And it is unclear why gravity of consequence should make the *standard* differ, rather than merely influencing the type or amount of information to be understood.⁸⁰ It seems more likely that our non-acceptance of negative consequences causes us to conflate refusal with a patient failing to ‘understand’.⁸¹ Rationality, asymmetry and consequence-driven standards can easily collaborate to edge the threshold level of competence ever higher. While there may be a:

‘strong societal bias in favor of treating treatable patients so long as it does not expose them to serious risks’,⁸²

a commitment to individual well-being should include commitment to subjective individuality.⁸³ Consequences do have a role in competence as one aspect of the *information* that a patient should be able to consider, such that

‘[i]t is the complexity, and not the risk, that is correlated with the understanding needed to make a decision’.⁸⁴

This contrasts with the *standard* of requisite competence required, which should remain *functional*.⁸⁵ It need not be ‘full’ or ‘substantial’, because healthcare decisions are so personal and individual that we should seek to maximise patient capacity wherever feasible. Complexity of information will bring a *natural variance* to what must be understood in different decisions,⁸⁶ but the standard (‘ability to understand and use’) should remain constant. And, the requisite level of understanding should be never more than ‘functional’.

4.2.2.3 Temporal aspects

The final element that can feed creeping incompetence is the importance of ‘time’. Assessment of competence *at the time of the decision* is integral to the existing legal

⁷⁹ Ibid.

⁸⁰ See also A. R. Maclean, Caesarean sections, competence and the illusion of autonomy, webjcli.ncl.ac.uk/1999/issue1/maclean1.html, page 5, who discusses M.R. Wicclair, Patient decision-making capacity and risk, (1991) 5 *Bioethics*, 91.

⁸¹ See Jones and Keywood, above, 140.

⁸² Roth *et al*, above, 283.

⁸³ See Buchanan and Brock, above, 50.

⁸⁴ Maclean, above, 5.

⁸⁵ I.e. a person’s ability to understand and use relevant information should be the minimum necessary to process the healthcare decision mentally and emotionally.

⁸⁶ This is also recognised by Maclean, above, 5, and Buchanan and Brock, above, 83.

approach.⁸⁷ While this accords with task-orientation, a single assessment of competence may act as a disservice to some incapacitated persons, particularly whose capacity is impaired cognitively or fluctuates.⁸⁸ Beauchamp and Childress suggest a proactive role for time:

‘[w]hen it proves too difficult at first to determine the level of competence, it is appropriate to evaluate the patient’s understanding, deliberative capacity, and coherence over time, while supplying counseling and further support and information’.⁸⁹

A longer period of assessment and delivery of information may benefit *some* patients, helping to maximise their capacity for understanding and using information.⁹⁰ For example, gradual or repeated delivery, through a variety of communication methods may aid assimilation for some patients.⁹¹ So, although competence assessment should be current, a *number of assessments*, say over a month or two, may inform us about how best to communicate information to an individual, maximising supportiveness of environment, and enabling patient capacity to be recognised.

In contrast, time might play a different role regarding patients in fluctuating mental states. Those with psychosis, anorexia or under environmental stresses may have widely varying capacity, including periods of lucidity interspersed with periods of clear incompetence. This inconsistency may cause a finding of incompetence. But, capacity of such patients could be maximised by taking account of his/her lucid views. This ‘intermittent competence’ could endure effectively through temporary

⁸⁷ See Chapter 2, above.

⁸⁸ It is noteworthy that in *Re C* [1994] above, the refusal of the patient was deemed valid for all time coming absent a fundamental change in his circumstances. This was the first judicial recognition of the legal validity of advance directives and sent a clear message to HCPs that the onus was on them to show incompetence. However, *C* was ultimately held to be competent. It is most unlikely that the same consideration of the patient’s input would be given to *IcPs* – hence the need for this consideration of temporal aspects of decision-making.

⁸⁹ Above, 134.

⁹⁰ E.g. see *J. O’Hara, Pregnancy in a severely mentally handicapped adult*, *J. Med. Eth.* [1989] 15, 197. Assessment over time, proposed herein, does not mean that historic mental history should be evidence of current mental state (as occurred inappropriately in *Norfolk & Norwich Healthcare (NHS) Trust v. W* [1996] above). Note that in *Re B (Adult: refusal of medical treatment)* [2002] 2 All ER 449 *Dame Butler-Sloss* considering evidence regarding depression and psychological regression of a quadriplegic patient, emphasised that she ‘could not see how’ *Ms B’s* ‘difficult and traumatic childhood...should affect any future choice [by the patient]’.

⁹¹ On variation of patient capacity see *Gunn et al*, above, 280, Figure 1.

incompetence.⁹² It is simply a temporally-compressed version of an Advance Directive, provided that material circumstances are as anticipated. Gert, Culver and Clouser take an opposing view:

‘[t]he ability to make a rational decision of a certain kind is, like all abilities, usually a relatively stable attribute of a person, not something that quickly comes and goes’.⁹³

However, while ability is *usually* stable for most patients, for a few others it is not. A genuine commitment to maximising patient capacity requires that, at the very least, we hear his/her lucid views, discuss their relevance to periods of fluctuation, and consider whether his/her position is held consistently enough to constitute functional competence. If not, then the (lucid) views may still act as informative input.

Buchanan and Brock identify two important consequences flowing from intermittent competence: the HCP is responsible for ensuring the patient’s competence is re-evaluated appropriately, and that s/he

‘is responsible for making every reasonable effort to maximize the patient’s competence’.⁹⁴

It is submitted that this is the **most important normative guide regarding competence**. Commitment to autonomy demands **maximisation of capacity**. *This means changing our perspective to distinguish between capacity and competence, overturning assumed correlation between impaired capacity and incompetence, and carefully constructing a competence standard*. Further, we must avoid the attractions of creeping incompetence, retain a constant functional standard that varies naturally only with information complexity, and acknowledge new roles for time within competence assessment. The notion of *incompetence* is developed further later in this thesis.⁹⁵ However, we may now consider the scope for patient perspective in states of incapacity.

⁹² Beauchamp and Childress, above, 134, also use the term ‘intermittent competence’.

⁹³ Above, 137.

⁹⁴ Above, 83.

⁹⁵ See Chapter 7, below.

4.3 Locating patient perspective in enduring and proxy decisions

Where the governing role of autonomy falls because a patient fails to meet the threshold level for competence, other decision-making mechanisms come into play. Alternatives include advance directives, substituted judgment, comprehensive exclusion of designated types of treatment absent consent, and of course 'best interests'. Each is considered briefly here in terms of autonomy value. This thesis ultimately prefers a reframed approach to best interests,⁹⁶ recognising an important role for 'input' in promoting autonomy through patient perspective even where a patient is incompetent for determinative decisional authority.

4.3.1 Advance directives

Advance directives (ADs) represent subjective wishes of patients post-incapacity. The directive, made during competency, specifies how a patient wishes to be treated (including withholding treatment) in anticipated future circumstances that may include incompetence.⁹⁷ Advance directives have legal effect in English law provided that they are 'clearly established' and 'expressed in clear terms'.⁹⁸ *Prima facie*, there are obvious advantages of advance directives in respecting self-determination and protecting patients from unwanted intervention.⁹⁹ Further, they may

'relieve emotional and financial burdens that would otherwise fall on others', and thereby 'do good to others'.¹⁰⁰

ADs accord with the idea that certain interests can survive a person's incompetence (and/or death),¹⁰¹ allowing his/her autonomous choices post-incapacity to honour his/her earlier life and value structure. In short, an AD may represent the clearest indication available (or needed) of a person's views.¹⁰² Some authors go further, arguing that it has:

⁹⁶ See further chapters 6-8, below.

⁹⁷ In the USA advance directives may instruct about treatment, or appoint a proxy, see Buchanan and Brock, above, 95.

⁹⁸ For comment on procedural aspects of ADs see Kennedy and Grubb, *Principles of Medical Law*, above, 229. See also Re C [1994] above and Re AK (Medical treatment: consent) [2001] 1 FLR 129.

⁹⁹ See Buchanan and Brock, above, 99.

¹⁰⁰ Buchanan and Brock, *ibid*.

¹⁰¹ *Ibid*. The value of 'surviving interests' is developed Chapter 7, below.

¹⁰² See also D. Meyers, *The family and life and death decisions*, in Sutherland and McCall Smith (eds.), *Family Rights, Family Law and Medical Advance* (1990) Edinburgh U.P., Edinburgh, 59, 66, who describes the advance directive as 'best evidence' of the patient's desires.

'great symbolic significance, for it encompasses three human rights upon which all other rights hinge. They are the *right to life*, the *right to freedom*, and the *right to happiness* (in the sense of a good quality of life)'.¹⁰³

Seen in this way, ADs are tremendously important, facilitating both self-determination and quality of life values. If we seek to maximise individual liberty and self-responsibility,¹⁰⁴ then we should accord authority to a relevant, valid AD. However, the difficulties lie in validity and relevance. It can be problematic to ensure a person was competent, informed and uncoerced when making a directive;¹⁰⁵ it can be difficult to foresee future circumstances and therefore to set appropriate limits on the AD;¹⁰⁶ there is always the issue of unforeseen circumstances;¹⁰⁷ and severe illness or injury may cause a person to reconsider their values, such that the AD no longer accurately reflects his/her views.¹⁰⁸ Stern suggests that a schema of recording a person's preferences and values may help to resolve uncertainty about scope.¹⁰⁹ Relatedly, Meyers observes that:

'[o]ften there may only be a 'sense' of what the patient would want done based on knowledge by the family of his or her religious views, philosophy of life, internal constitution and self-image and other, rather subjective attitudes or generalized comments'.¹¹⁰

Meyers argues that this supports the need for a 'backup' standard such as 'best interests'.¹¹¹ Indeed, Peart et al illustrate the boundaries of ADs starkly in the context of women who are pregnant at the time of becoming severely incapacitated through p.v.s. or brain-stem death). Ethical dilemmas accrue about respecting a woman's autonomous AD to withdraw treatment (thereby allowing the foetus to die also) where the woman has no prospect of recovery. Peart *et al* conclude that: where an AD is specific (i.e. has foreseen and included the prospect of pregnancy), her wish

¹⁰³ V. Frosini, The "Living Will" and the right to die, *Ratio Juris* (1995), 8(3), 349, 356.

¹⁰⁴ See also D. Meyers, above, 66 on the importance of maximising freedom of choice.

¹⁰⁵ Buchanan and Brock, above, 101. K. Stern, *Advance Directives*, *Med. L.Rev.* 2 [1994] 57, 63, also highlights the dangers of undue influence and lack of informedness at the time the directive is made.

¹⁰⁶ See also, Buchanan and Brock, *ibid*, 105: formulation of qualifications may become unfeasible.

¹⁰⁷ See Stern, above, 64.

¹⁰⁸ See also, Buchanan and Brock, above, 106, who suggest a change to competence is often accompanied by changes to other capacities.

¹⁰⁹ Stern, above, 64, drawing from the work of P. Lambert, J. McIvor Gibson and P. Nathanson, *The values history: an innovation in surrogate medical decision-making*, (1990) 18 *Law, Medicine and Health Care* 202.

¹¹⁰ Meyers, above, 66, drawing from the USA case of *Cruzan v. Harmon* 760 S.W. 2d 408; *Cruzan v. Director, Missouri Dept. of Health* (U.S. Supreme Court, 25-06-90).

¹¹¹ Meyers, *ibid*, 66-67.

to withdraw treatment should be respected – autonomy should dominate;¹¹² in contrast, where her wishes are unknown (no AD in force) they advocate allowing the interests of the foetus to dominate;¹¹³ and it seems likely that they would regard this applicable also where an AD is non-specific regarding pregnancy, because this raises significant doubt.¹¹⁴ However, where doubts about ADs occur, Peart *et al* suggest that while not binding an AD may still

‘offer valuable insight into the patient’s wishes which should be respected in any decisions about treatment’.¹¹⁵

This corresponds to the position advocated herein: ADs may provide ‘input’ to inform any proxy, despite their authority limitations. Additional limitations exist where patients have never been (cognitively) competent enough to make an AD, or indeed from the many competent persons who have simply not made any formal/informal AD. Hence, pragmatically, ADs may provide excellent patient perspective, but only a limited source of solutions to decision-making authority. Thus, many decisions still necessarily fall to proxies. While ADs can be useful sources of informal patient input to future decisions, we should be wary about adopting an overly formalistic approach to ADs – for example by requiring them to be in writing, signed, with witnesses etc. – because in such an eventuality they would become wholly useless to ICPs.

4.3.2 Proxy decisions

Where autonomy fails to bind, it is the responsibility of a proxy to decide on an ICP’s behalf. In some jurisdictions proxies may be appointed by form of AD,¹¹⁶ or by relationship between proxy and patient,¹¹⁷ or by the court.¹¹⁸ Absent these jurisdictions, resort is made to declarations of lawfulness.¹¹⁹ Difficulties surrounding

¹¹² See N.S. Peart, A.V. Campbell, A.R. Manara, S.A. Renowden, and G.M. Stirrat, Maintaining a pregnancy following loss of capacity *Med. L. Rev.* 8 [2000] 275, 282-283, 284-285.

¹¹³ *Ibid* 291-292, because the ‘patient’s condition and prognosis have effectively deprived her of the sort of interests which normally underpin treatment decisions’, *ibid* 294.

¹¹⁴ See *ibid*, 279.

¹¹⁵ *Ibid*, 298.

¹¹⁶ E.g. in the U.S.A., see Buchanan and Brock, above, 95. See also Adults with Incapacity (Scotland) Act 2000, s.16.

¹¹⁷ E.g. assumed in England and Wales through parental capacity to consent to (but not refuse) treatment on behalf of a minor, see Chapter 2, above.

¹¹⁸ Sheriffs are now empowered to appoint (Adults with Incapacity (Scotland) Act 2000, s58), and the former function of tutors-dative is abolished (s.80).

¹¹⁹ In England and Wales, see Chapter 1, above.

proxy appointment include patients designating proxies who are ill-suited to determining the patient's well-being,¹²⁰ and patient voluntariness and competence at the time of appointment.¹²¹ Also, in relation to proxies' execution of duties, it is difficult procedurally to monitor whether surrogates respect patients' earlier wishes and act responsibly.¹²² However, whenever proxies do make decisions they are generally based in one of two approaches: substituted judgment or best interests. Each is considered here in terms of autonomy.

4.3.2.1 Substituted judgment and other comparative alternatives

4.3.2.1.1 Substituted judgment standard

The substituted judgment standard imposes a responsibility on a proxy:

‘to choose as the patient would choose if the patient were competent and aware of the medical options and of the facts about his or her condition, including the fact that he or she is incompetent’.¹²³

In essence, it seeks to determine the decision fully from the patient's perspective through the proxy and is commonly used in the U.S.A.¹²⁴ Gostin argues that substituted judgment:

‘forces the proxy decision maker to search for the patient's views, and to respect those views, before making treatment decisions’.¹²⁵

Prima facie, it replicates as closely as possible what a patient's own choice would be. Indeed, it is argued herein that determining patient perspective (through his/her views and values) is extremely valuable within the decision process.¹²⁶ However, as the sole decision-making tool, substituted judgement is fraught with difficulty. We should not underestimate the difficulty of standing in the shoes of another; the elusiveness of preference and choice is magnified when trying to gauge how another person would decide. This need not deter us, but we should be aware of the

¹²⁰ See Buchanan and Brock, above, 102.

¹²¹ See Stern, above, 64.

¹²² See Beauchamp and Childress, above, 177.

¹²³ Buchanan and Brock, above, 94.

¹²⁴ See *ibid*, 113, discussing *Re Quinlan* (1976) 70 N.J. 10, 355 A.2d.647 and *Superintendent of Belchertown State School v. Saikewicz* (1977) 373 Mass. 728, 38, 370 N.E.2d. 417.

¹²⁵ L. Gostin, in C. Dyer's (ed.) *Doctors, patients and the law* (1992) Blackwell Scientific Publications, Oxford, 84.

magnitude of the task the impossibility of fully replicating another's decision process. Further, Buchanan and Brock argue that substituted judgment fails when: there is insufficient evidence of what the patient would choose;¹²⁷ or the patient has *never been* competent.¹²⁸ They suggest that lack of evidential base brings the standards of substituted judgment and what they term 'basic interests' closer; the latter becoming increasingly important in correlation to diminution of the former.¹²⁹ These pragmatic limits support the submission in this thesis that, while an IcP's views are important to proxy informedness, they should form part of a wider decision perspective such as best interests.

Nowhere is the role of proxies as substitute decision-makers more emotive than in the context of parents and children. In Israel, an interesting concept of 'parental competence' has recently arisen in determining a child's best interests within custody.¹³⁰ Generally, courts are reluctant to hand absolute authority to parents. Mason *et al* highlight American and Canadian judicial approaches countenancing strongly against such parental scope.¹³¹ Further, they observe that little sensitivity to parental cultural and religious mores has been accorded in the UK.¹³²

In the context of consent, this is really about 'parental or family autonomy', and tensions lie in the divergence between the close parent/child relationship and provisions protecting the minor *as an individual*.¹³³ A minor's individual rights are strengthened by the Children Act (1989), the Human Rights Act (1998) and the UN Convention on the Rights of the Child (1989).¹³⁴ While the English courts have

¹²⁶ See Chapters 6-8, below. It is also clear that incapacitated individuals should be treated equally: see C. McKay, Legal competency as the basis for human rights, SCOLAG (1994) 108, col.2 highlighting Article 1 of the UN Declaration on Rights of Mentally Retarded Persons,

¹²⁷ Above, 113.

¹²⁸ *Ibid*, 114-115, (e.g. due to lifelong cognitive impairment).

¹²⁹ *Ibid*, 119-120.

¹³⁰ See M. Zaki, Parental competency assessment: approaches and issues, *Med. Law* (2000) 19, 1.

¹³¹ Mason *et al*, above, paragraph 10.19, whereby children should not be made 'martyrs' by parental choice, and the family not permitted to inhibit the court's *parens patriae* jurisdiction (paragraph 10.20).

¹³² *Ibid*, paragraph 10.21. However, see *Re T* [1997] above.

¹³³ Highlighted in *Re C (HIV Test)* [1999] above, 1021, where Butler-Sloss LJ reflected that: 'the space...in which parental decisions are final, undoubtedly exists, but it exists subject to s 1(1) of the Children Act'. Parental autonomy was overridden where objectively enforceable (i.e. HIV testing), but acceded to in the less enforceable private context (of breastfeeding).

¹³⁴ Cited by Wilson J. at first instance in *Re C (HIV test)*, above.

rejected subsuming a child's rights under those of the parents,¹³⁵ the Irish Supreme Court has recently taken a different view,¹³⁶ according weight to parental views and authority. Laurie construes this decision to posit a (rebuttable) constitutional presumption that determination of a child's welfare is found in familial authority.¹³⁷ But he argues that this is not always in a child's best interests,¹³⁸ and the decision may fail to strike an appropriate balance of parental rights, children's rights, and parental responsibilities.¹³⁹ Minors should be protected, and indeed respected.¹⁴⁰ However some role for the family is merited by Article 8 (Schedule 1, HRA 1998).¹⁴¹ In essence, the familial right to be heard accrues from relationship and could equally apply regarding incapacitated adults. Some consider familial involvement in proxy decisions to be rightly occurring.¹⁴² However, family autonomy is in contrast to familial involvement, and raises concerns of possible misrepresentation.¹⁴³

Additionally, it could overlook the emotional impact of a patient's incapacity and illness upon the family. The family may *not* be best placed to uphold an ICP's wishes and preferences because of its own emotional pain. As Stern observes:

'the family member may find it difficult to place the patient's own interests above those of the family and other carers. Problems might arise where there are antagonistic family relations...or...there is no family or carers to whom such a decision can be referred'.¹⁴⁴

Hence, placing an expectation of decision-making authority upon a family (or those emotionally closest to an ICP) may be too burdensome. The demands upon a proxy decision-maker are onerous and, other than a formalised appointee, it is a dangerous imposition to require a substituted judgment from an emotionally-involved proxy. If made as an advance appointment and the appointee still feels able to act responsibly,

¹³⁵ See A. Downie, *Re C (HIV test)*, *The limits of parental autonomy* CFLQ 12(2) [2000] 197, 201.

¹³⁶ See *North Western Health Board v W(H)* [2001] IESC 70, 8 Nov. 2001.

¹³⁷ G.T. Laurie, *Better to hesitate at the threshold of compulsion: PKU testing and the concept of family autonomy in Eire*, *J. Med. Eth.* [2002] 28, 136.

¹³⁸ *Ibid*, 137 col.2.

¹³⁹ *Ibid*, col.3.

¹⁴⁰ On the importance of respecting children's views see P. Alderson (1993) above.

¹⁴¹ See R. Clayton and H. Tomlinson, *The law of human rights*, Vol.1 (2000) Oxford U.P., Oxford, paragraph 13.129: any interference with family life through care proceedings must involve parents in the process to the extent of protecting their interests.

¹⁴² See Meyers, above, 63-64.

¹⁴³ See Buchanan and Brock, above, 121.

¹⁴⁴ Stern, above, 69.

it seems reasonable that s/he should be allowed to do so. For, this approach acknowledges the importance of an ICP's chosen relationships within his/her interest network. Further, *involvement* of family/partners/close friends can be a valuable source of *input* to a proxy decision. However, the notion that we can hope to emulate a patient's decision is unrealistic, and his/her ascertainable views are advocated only as a part (albeit an important one) of the proxy's decision. Hence, a best interests standard is preferred to pure substituted judgment. Input from a patient's relationships of mutuality is merited, but not to the extent of supporting 'family autonomy' – regarding minors or adults. Rather, we should seek a rounded view that takes account of patient perspective and maximises individuality, but keeps a pragmatic eye on the whole landscape of a person's interests. Autonomy is important, but to decide compassionately and responsibly we must acknowledge that autonomy is not all.

4.3.2.1.2 Other comparators

Interesting, additional comparators have occurred recently in proxy decision-making. The Scottish approach to incapacitated persons is now contained in the **Adults with Incapacity (Scotland) Act 2000**. Scope for guardianship is a major theme, and an appointed guardian may have power to consent to medical treatment as a proxy.¹⁴⁵ *Prima facie*, this guardianship supports autonomy, particularly as s/he must be consulted.¹⁴⁶ *Aliter*, s47 will not confer authority for treatment to a medical practitioner.¹⁴⁷ While his appears commendably protective of autonomy, certain qualifications under s50 limit the proxy guardian's role somewhat. While subsections (3) to (6) provide for appeals in the event of disagreement about

¹⁴⁵ S. 64(1) and, implicitly, s.50 (subject to exceptions in s. 64(2) prohibiting consent to certain types of treatment for mental disorder and detention in a mental hospital against the patient's will, and additional safeguards now required regarding certain types of treatment, contained in supplementary provisions to the Act).

¹⁴⁶ S.50(2), provided it is reasonable so to do (s.50(2)(c)).

¹⁴⁷ S.47 authorises treatment reasonable in the circumstances to safeguard or promote the physical or mental health of the adult, bearing remarkable similarity to the *ratio* of Re F [1989] above. However, 'best interests' is not used in the Act. Alternatively, if an application for determination has been made (s.49), that application must be determined (s.49(2)).

proposed treatment,¹⁴⁸ s.50 (5) authorises treatment proceeding on the basis of certification by a nominated medical practitioner:

‘notwithstanding the disagreement with the guardian, welfare attorney, or person authorised under the intervention order’.¹⁴⁹

In effect, the guardian is empowered by one part of the Act and disempowered by another. The Scottish approach is an improvement on the existing common law position of England and Wales, as the role of treatment proxies is recognised and their rights and responsibilities clarified. However, the Act remains disappointing in terms of autonomy because of the limitations outlined and persisting dominance of medical opinion. Furthermore, the definition of ‘incapable’ is too broad, and lacks emphasis on our duty to communicate with IcPs and maximise their capacity.¹⁵⁰ However, the Act does set out a general principle of wide consultation with the IcP, nearest relative, primary carer, any appointee, and any other person judicially directed.¹⁵¹ This at least facilitates *input* as a useful source of information.

A different approach to autonomy is highlighted in German law, regarding sterilisation of incapable persons, through a notion known as ‘**natural will**’.¹⁵² Little interprets this to mean that:

‘a person who is incompetent to consent to an operation is still regarded as “competent” to refuse the sterilisation, if by her natural will, she manifests that opposition’.¹⁵³

In essence, this is asymmetry reversed; an IcP under German law may *refuse* treatment to which s/he is regarded *unable to consent*. This radical approach protects subjective bodily integrity despite lack of traditionally self-determinative capacity. Little suggests that the provisions acknowledge that

¹⁴⁸ Indeed, ultimately, ‘any person having an interest in the personal welfare of the adult, may apply to the Court of Session for a determination as to whether the proposed treatment should be given or not’, s50(6).

¹⁴⁹ S.50(5). A right of appeal still lies to the Court of Session, s.50(6). Further provision to treat in situations of life-saving necessity is made by s.50(7).

¹⁵⁰ See s.1(6).

¹⁵¹ S.1(4).

¹⁵² See G.B. Little, Comparing German and English law on non-consensual sterilisation: a difference in approach, *Med. L.Rev.* 5 [1997], 269, 285-287.

¹⁵³ *Ibid*, 285, drawing on the work of A. Jurgens, D. Kroger, R. Marschner and P. Winterstein, *Das neue Betreuungsrecht. Eine systematische Gesamtdarstellung* (2nd ed.) (1992), Munich at 58 m.n. 216. Little suggests, above, 285, that opposition may be shown by words, gesture, mimic or defensive posture is an expression of the ward’s natural will...[it] does not therefore require any insight into the consequences of a refusal’.

‘even for the most helpless and dependent individual there remains always a residual autonomy, which third parties cannot disregard’.¹⁵⁴

While this thesis promotes residual autonomy and maximisation of patient capacity, is the German approach really protecting individuality? Certainly, it takes account of an IcP’s preferences, but this preference may lack significant understanding. Nor is autonomy clearly served if refraining from sterilisation deprives an IcP of his/her sexuality. Little notes that the German courts support the sexuality rights of the intellectually disabled.¹⁵⁵ In combination, this seems to create an invidious position in German law that could commonly result in pregnancy.¹⁵⁶ While the German approach seeks to respect individual ‘autonomy’, it is doubtful whether it truly respects the person because a rounded, balanced view of the whole person is lost.

Certainly, some jurisdictions adopt a similar stance to certain treatments.¹⁵⁷ Canada more stringently imposes an effective **blanket ban** on non-consensual surgical sterilisation.¹⁵⁸ However, defensive approaches to difficult and sensitive situations serve no one well. The flexibility of best interests has much to offer, provided it is used with common sense, reflection and consideration.¹⁵⁹ Better that IcPs can access all the treatment options available to competent persons, provided best interests is used judiciously.

4.3.2.2 Preferring best interests

Best interests is the preferred standard because of its flexibility; it is amenable to change and adaptation to the uniqueness of individual situations. The way competence is structured and the position on advance directives and input significantly influences the degree of value accorded to autonomy within best interests. It is imperative to understand that the thrust of this thesis sees autonomy as comprising two (often related) elements, namely choice and individuality. The trend

¹⁵⁴ Ibid, 286.

¹⁵⁵ See *ibid*, 287, referencing a decision of the BayObLG of 15 January 1997.

¹⁵⁶ Which has a significantly greater impact on bodily integrity than does non-voluntary sterilisation.

¹⁵⁷ Indeed, in England and Wales electro-convulsive therapy for mental disorder is restricted to consent (albeit by non-competent patients), and under the new Scottish provisions, above, there is scope for certain treatments to be specified by the Scottish Ministers as restricted to certain specified circumstances, see s.48 of Adults with Incapacity (Scotland) Act 2000.

¹⁵⁸ *Re Eve* (1986) 2 SCR 388; (1981) 115 DLR (3d) 283.

¹⁵⁹ Compare *Re B (a minor)(wardship: sterilisation)* [1987] 2 All ER 206, which adopted a best interests approach to the very same question as occurred in *Re Eve*, above.

to date has focused on the former and this has meant that autonomy ceases to have meaning for IcPs. However, if one adopts a broader view of autonomy to include individuality – in the sense of seeking and respecting varying forms of input from the IcP to the decision process – then autonomy retains a valuable residual role in treatment decisions concerning such patients. More particularly, the focus herein seeks to add value to the existing approach to best interests in three ways:

- by recognising **individuality**, even where a person is incompetent we should – wherever possible – maximise a patient’s ability and opportunity for understanding with a view to their having input (but not determination) of the treatment decision. Individuality offers a representation of a patient’s perspective; we can still recognise and respect a person *as an individual* whether competent or not;
- by seeking **informedness** as a proxy we can better understand the identity of the person upon whose behalf we decide, enabling a decision of greater integrity with the IcP. Informedness comes from broadening the range of information sources (‘input’) to include the patient’s views/wishes,¹⁶⁰ ‘investments’ (of time, attention, energy, if any) s/he has made, and the views of those persons emotionally closest to him/her;¹⁶¹
- by adopting a **rounded perspective**, that combines both objective and subjective viewpoints. Best interests is normatively capable of encompassing both perspectives, by looking at the *whole* individual and the full contextual situation.

Respect is the value proffered by this thesis to facilitate the above three elements, and admit autonomy to what has, traditionally, been a welfare-oriented standard. In essence, the best way to avoid harming any person is to respect him/her. The aim of decision-making should be to respect the person. Admitting autonomy as valuable within best interests is essential. However, respect for persons also embraces the

¹⁶⁰ Supported by the Adults with Incapacity (Scotland) Act (2000), s.4(a); and the English Law Commission, Mental Incapacity (1995) above, paragraph 3.28.

¹⁶¹ See in this regard: *ibid*, s.4(b); *ibid*, 3.28, respectively.

value of welfare – which has traditionally functioned as a focus of best interests and is considered next.

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CHAPTER FIVE

APPEAL TO VALUE: WELFARE VIA QUALITY OF LIFE - A CLINICAL/COMMUNITY PERSPECTIVE

Chapter 5 Appeal to value: Welfare via quality of life – A clinical/community perspective

Choice of value greatly influences our assessment of best interests, and reflects decision-making perspective. Both factors – value and perspective – also impact on our approach to conflict resolution. While autonomy is important, it breaks down to some degree in the face of incapacity. **Welfare** often fills this gap, couched as ‘quality of life’, ‘well-being’, or ‘harm avoidance’. It also often represents a clinical and/or community perspective on what is ‘good’ for an incapacitated individual. None of these roles are definitively ‘good’ or ‘bad’, but merit attention because of their differences. Initially, this chapter focuses on the meaning of ‘welfare’, its value in healthcare, and its connection with interests and perspective. From this overview, two contentious aspects are identified and explored: construction of ‘life’ in proxy decisions, and the role of personhood in interest attribution and welfare derivation.

5.1 Defining welfare

5.1.1 The meaning of welfare

‘Welfare interests’ are considered earlier.¹ However, *welfare* is relatively unexplored, perhaps because it need not be used in a ‘technical’ way; Harris interprets welfare to mean

‘what it usually means, ‘the state or condition of doing or being well’...which will include things like happiness, health and living standards’.²

Indeed, its literal roots seem self-evident; ‘welfare’ is a state of ‘faring well’, a state many of us easily recognise through our own experiences. Is there any need to shape it further - given that we know it when we see it? If we are to make a state of ‘doing or being well’ attainable, then we need to know its substance. This raises nebulous possibilities; ‘well-being’ for one person is not necessarily so for another. Feinberg’s definition of welfare interests perceives them as facilitative of other (chosen)

¹ Chapter 3, above.

² J. Harris, *The value of life, An introduction to medical ethics* (1985) Routledge and Kegan Paul, London, 193, quoting from the Shorter Oxford English Dictionary.

interests that add further well-being.³ For Feinberg, therefore, welfare interests are the foundation, but not the entire structure, of well-being.⁴ Rather, it is the combination of basic welfare *and other* interests that comprise well-being in a more complete sense. Hence, 'welfare' can appear synonymous with 'well-being', but sometimes 'welfare' references quite a specific range of minimal 'goods' that are commonly human. The significance of this is twofold:

- while we should seek well-being in the fuller sense, medical treatment often seeks to restore welfare in the 'minimal good' sense, lost through pain, threat to life, or curtailment of social, functional, or experiential life;
- 'minimal good' welfare is important and can complement autonomy; together they comprise a person's 'well-being'.⁵

We can define welfare, therefore, as comprising **a range of fundamental factors contributing to well-being**. Action taken in the name of **welfare** may *promote* well-being, or *prevent* harm from accruing. Thus, welfare is a powerful supportive value, *expressly recognising the purpose of an action*.

5.1.2 The meaning of welfare in healthcare decisions

Illness or incapacity can erode facilitative welfare which, in turn, inhibits other autonomous interests, and so diminishes overall well-being. Patient well-being lies at the core of healthcare.⁶ For, healthcare professionals seek to improve the lives of others, to make them 'fare better'. In terms of mentally incapacitated persons, Harris perceives the responsibility of harm prevention as falling to society.⁷ HCPs are members of society with the specialist knowledge and means actively to achieve this. Welfare, in its ethical guise of beneficence and non-maleficence, accounts for a clinical/community perspective on treatment. Nowhere is welfare a more appropriate objective than in an IcP situation. An incapacitated person still needs alleviation of

³ Paraphrasing from J. Feinberg's Harm to others, above, 37, welfare interests include: continued life, physical health, physical functionality, minimal intellectual acuity, emotional stability, social engagement, minimal financial security, tolerable environment, and freedom from interference.

⁴ Ibid.

⁵ Developed in Chapters 6-8, below.

⁶ See Buchanan and Brock, above, 29.

⁷ See Harris, above, 217-218.

pain/suffering/harm, and promotion of ‘good’ (positive) experiences – irrespective of incapacity. As a goal, welfare provides a focus for proxies in taking up decision responsibility. This is its meaning in IcP treatment decisions.

However, exercise of responsibility involves judgment; an assessment of what contributes to welfare. The assessable standard developed for gauging welfare impact in healthcare is ‘quality of life’. Although contentious, it is part of welfare’s meaning regarding IcPs because

‘ “quality of life” is unavoidable...A vital part of the treatment decision rests on the issue of whether the proposed measures can restore the patient to a way of living he or she would be likely to consider of reasonable “quality”, despite any side effects or disadvantages of treatment’.⁸

A proxy must judge the impact of any treatment option on an IcP’s life; in short, whether and how an option contributes to a person’s welfare – measured by the degree of improvement/harm on the quality of that life. Quality of life has drawn a bad press because it has been wrongly construed as an external judgment of how valuable that incapacitated person is. This is confusing and inappropriate. Rather, as Beauchamp and Childress suggest:

‘ “quality of life judgements” are not about the social worth of individuals, but about the value of the life for the person who must live it. The value of life is primarily...the value it has for that person’.⁹

If we look to quality of life judgments in terms of a purposeful welfare objective, and acknowledge the individuality of ‘life’, there is nothing to fear from a responsible, qualitative assessment. Further, best interests is the connective element:

‘[b]est interests judgments are one way to focus attention on this point, rather than on the value the person’s life has for other persons. Accepting a best interests standard...is tantamount to acknowledging that we have to decide in marginal cases what a patient’s welfare interests are at the moment’.¹⁰

This chapter seeks to develop welfare as a purposeful objective in best interests decisions for IcPs.

⁸ BMA, Withholding or withdrawing life-prolonging medical treatment (2001) above, paragraph 1.2.

⁹ Above, 180.

¹⁰ Beauchamp and Childress, *ibid.* Buchanan and Brock, above, 123, also identify a relationship between quality of life, best interests and ‘life’, such that mere benefit does not evince best interests because the latter depends upon the expected character of life for the individual.

5.2 The value of welfare in healthcare

5.2.1 Why is welfare a 'good thing' in healthcare?

Welfare plays a two-way role in healthcare: (1) as a *beneficent aim* of treatment, and (2) as a *justificatory reason* to which appeal is sometimes made regarding a particular treatment action. These two are mutually supportive mirror images, providing 'good reasons' for treatment based on its contribution to a patient's well-being, applicable to both competent and incompetent patients.

Undoubtedly, the impetus to improve the lives of others is at its strongest in healthcare. Promoting welfare is an action generally born out of kindness, care and humanity.¹¹ Medical treatment generally seeks to restore, maintain, improve, or minimise deterioration of a patient's health and quality of life through welfare as a *treatment objective*. A competent patient can make his/her own assessment of welfare in relation to interests, based on information about treatment options and awareness of other (non-medical) values in his/her life. However, treatment decisions for incompetent patients rely on assessments of welfare made by others on the patient's behalf. While an IcP's life and interests may be more limited, we should still seek directly to promote his/her welfare interests, thereby facilitating his/her other life goals. In short, *treatment decisions should support a person to become more of him/herself; to enable his/her individual life to become fuller in the ways s/he is able to choose, and to meet his/her ongoing needs*. Welfare as a treatment objective is about **enabling an IcP's well-being**. By attending to a patient's welfare we can help to equip them with the basis for building other aspects of life.

This function may then be employed as a *justificatory reason* for treatment choice, supporting adoption of a particular course of action. Such justificatory use is not inherently problematic, but its use in healthcare has previously brought it into direct conflict with autonomy regarding competent patients. Welfare has previously been proffered as a contentious justification for 'hard' paternalistic behaviour, where a competent patient's views might be overruled in the name of their welfare. The heightened role for autonomy within medical ethics, and legal protection of

¹¹ See also Beauchamp and Childress, above, 260.

autonomous choice, now ensure that this is unlikely to persist. In contrast, the role of welfare regarding incompetent patients had been simply assumed appropriate (to the total exclusion of any residual autonomy). Undoubtedly, welfare has a valuable justificatory role in proxy decisions for IcPs, and willingness to justify choice of treatment, and balance of interests, is an important part of due process.¹² Moreover, because incapacity diminishes autonomy, welfare becomes a key factor in determining overall well-being for IcPs. But, this thesis argues that the proper, valuable role for welfare lies in its relationship with interests and perspective, and its consideration along with any residual capacity that an IcP retains.

5.2.2 Welfare, interests and clinical/community perspective

Welfare supports important individual interests that form the foundations of good quality of life.¹³ And, Feinberg rightly characterises 'welfare interests' as facilitative of ulterior interests. But, surely welfare interests are also ends in themselves; valuable 'goods' forming part of the quality of life day-to-day. Essentially, they are the framework of good quality of life, and ulterior or critical interests add the substance. However, the underlying structure remains no less important because it is unseen. Our awareness of these important underlying interests often arises only when they become negatively impacted through illness, impairing our welfare. This may happen whether or not we are competent. However, the relative importance of welfare within overall quality of life lies in its connection with **interests**, and interests vary with the nature and degree of mental incapacity. Persons temporarily incapacitated retain many ulterior interests (which are merely temporarily suspended), and those with developing capacity (such as mature minors) have scope for future ulteriority. Others with more severe incapacity have a diminution in ulteriority. This is accompanied, however, by durable welfare interests that adopt a greater proportional importance in individual quality of life.¹⁴ It is clear, therefore, that welfare is important to almost all patients, but its *facilitative* role is less

¹² Intensified by the Human Rights Act (1998); reasons for decisions should be made available under Article 6 (Schedule 1 HRA 1998).

¹³ E.g. avoidance of pain/suffering, a safe and supportive environment, and freedom from harm/interference.

¹⁴ Interestingly, in extreme incapacity (such as p.v.s.) welfare interests may diminish due to the patient's (non-experiential) insensate state, while some ulterior interests (such as dignity) arguably endure, see Chapter 7, below.

extensive for some, depending on the extent to which incapacity inhibits other (non-welfare) interests. This is not a judgment about how valuable people are. Rather, it is a simple recognition that individual lives are composed differently. We should assess and acknowledge what contributes to good quality of life *for that individual*.

Beyond interests, welfare can provide valuable *perspective* in proxy decisions. Welfare can provide a balancing objectivity. Competent patients may (autonomously) choose against their (objectively perceived) welfare interests. However, decisions regarding incapacitated patients are, by definition, 'imperfect' insofar as the 'best' option (i.e. autonomous patient choice) is unavailable. Here, we must look to objective welfare assessment alongside any (previously held) subjective views and/or current input to make the best assessment we can of an individual's overall well-being. Welfare represents an objective perspective (framed clinically or by the community view of human welfare) that should be heard in all decisions – even where a patient is competent. For, the objective welfare perspective is as important to informedness as individual subjectivity. Furthermore, in IcP decisions – where subjective input may be evidentially very limited – an objective view becomes increasingly important as a substantial base for decision. Hard paternalism has given a welfare bad name.¹⁵ Yet, clinical perspective is an essential element of information regarding a patient's personal, medical welfare. And, welfare has been common currency of IcP healthcare decisions in the U.K.¹⁶ On one hand, this *is* the rightful role for welfare because of its increased importance where a person is unable to determine matters for him or herself; **welfare is a valuable objective**. However, its overriding dominance has previously sold IcPs short of subjective input. Welfare is important to informedness in every healthcare decision, but no value should dominate to the occlusion of all others. *Good decision-making is about balance*. 'Quality of life' is about assessing balance within an individual life. To understand what makes a person 'fare well', we must evaluate what makes life 'good' and what it means to have their life.

¹⁵ See Harris, above, 193: '[a]n initial problem is that concern for the welfare of others is compatible both with paternalism and with moralism'.

¹⁶ In the USA welfare is rejected regarding IcPs in favour of 'substituted judgment'.

5.3 'Life'

Well-being exists only in the context of a life. How we view 'life' and its meaning influences the content of 'welfare'. To assess welfare impact we must ascertain what might be considered valuable in life.

5.3.1 What do we mean by 'life'?

Life can be regarded as a biological state, at some cellular level. However, Warren suggests that 'living' refers to:

'organisms, rather than to their component cells, organs, or tissues – although these are also alive'.¹⁷

In short, 'life' is a collective of biological components constituting a 'being'.¹⁸ Even on a biological level, however, beginning and ending of 'life' is contentious.¹⁹ For, coming into being and dying are parts of a process that can be difficult to discern. The nature of being alive was raised in the recent conjoined twins case.²⁰ In the wealth of commentary thereon, Mason raises an interesting distinction in terms of biological life. He argues that the weaker twin (Mary) may never have acquired 'alive' status,²¹ and confusion may exist

'between the concepts of somatic life and death and cellular life and death. I have no doubt that Mary's cells were alive by virtue of the fact that they were oxygenated, albeit "artificially"...Equally...the majority of the medical opinion must be interpreted as showing that her soma was dead in that it had never been alive'.²²

Thus, life can be difficult to define (or its present/absence to diagnose) – even at a purely biological level.

Furthermore, life as a *process* is never static. Our body is in a constant state of change. Sometimes that change is at odds with our intuitive sense of 'living'; in

¹⁷ M.A. Warren, *Moral status, Obligations to persons and other living things* (1997) Oxford U.P. Inc., New York, 25.

¹⁸ Characteristics of personhood are considered below.

¹⁹ As R. Dworkin observes (*Life's Dominion*, above, 21): '[s]cientists disagree about exactly when the biological life of any animal begins, but it seems undeniable that a human embryo is an identifiable living organism at least by the time it is implanted in a womb...[and] that the cells that compose an implanted embryo already contain biological codes that will govern its later physical development'. But, he continues that: 'it does not follow...that a fetus also has rights or interests...[t]hat is plainly a further question, and it is in large part a moral rather than a biological one' (ibid 22).

²⁰ *Re A (Children) (conjoined twins: surgical separation)* [2000] above.

²¹ Under the Births and Deaths Registration Act (1953).

²² J.K. Mason, *Conjoined twins: A diagnostic conundrum*, E.L.R. Vol. 5 (2001) 226, 233.

p.v.s the body persists in its vital biological functions of breathing and beating heart without intervention, but higher-brain function is permanently lost. Yet, arguably this does not amount to 'life', but a suspended stage of life's process. Recognition of the tragic absence of any *meaningful* life in p.v.s. stems not from lack of biological aliveness, but from some notion beyond biological. In short, 'life' is more than a biological state.

5.3.1.1 Contribution beyond the biological

Rachels distinguishes *biological* from *biographical* life, the latter being

'the sum of one's aspirations, decisions, activities, projects and human relationships'.²³

The meaning of a life – and its quality – is shaped as much by these elements as by biological existence. Biological life is effectively a vehicle for the valuable process of biographical living. The nomenclature is correct; biographical aspects tell the story of individuality. Relatedly, Feinberg refers to capacity for 'conative life', arguing that interests accrue from conations.²⁴ In essence, conative life imports some *volitional* or *purposeful* focus to life. It is submitted that biography and/or conation reflect the value of *engaging* or *participating* in one's life. Any realistic quality of life assessment must gauge welfare in terms of this purposeful nature of life as well as biological status. However, exclusive focus on biographical life as the *only* source of life value could feasibly exclude severely damaged neonates, long-term coma patients, and perhaps even severely disabled adults from having quality of life worth protecting. Alone, this produces harsh results based on diagnostic classification rather than individual assessment.²⁵

But, biographical life is important to good quality of life assessment, recognising impact on 'aspirations, activities, projects and relationships',²⁶ not just in respect of

²³ See J. Rachels, *The End of Life, Euthanasia and morality* (1986) Oxford U.P., Oxford. 5.

²⁴ J. Feinberg, *The rights of animals and unborn generations* (1974) above, 49. He construes conative life to consist in conscious wishes, desires or hopes, urges and impulses, drives, aims and goals, and growth, *inter alia*, *ibid*.

²⁵ Rachels, above 26, endorses protection of biographical life because: 'there is nothing important about being alive except that it enables one to have a [biographical] life'. Further, *ibid*, 32, he doubts whether such babies 'have any prospect of a life in the biographical sense', and that killing a long-term coma patient would have 'no effect whatever on her [biographical] life' as 'her life was already over; it ended when she entered the coma'.

²⁶ *Per* Rachels, above.

(biological) health. At the extremes of life, acknowledging prospective absence of any biographical life can aid our understanding of the negligible quality of life for a patient in p.v.s. or of a severely defective neonate.²⁷ This is not because that person is not valuable as an individual, but merely because of the lack of *participation* in life through activities, relationships or experiences.

Biological and biographical lives are inter-dependent and mutually supportive. Good quality of life flows from presence of both aspects in some combination. The lives of most incapacitated persons do have this combination. For example, a mature minor's aspirations may lend direction to life, a young minor's activities form a significant part of daily life, the intellectually disabled person's familial or intimate relationships add to his/her quality of life, the anorectic patient may have projects s/he strives to fulfil, the schizophrenic person may wish for particular experiences, and the mother in labour may desire to fulfil her parental role. All of these biographical aspects can be impacted by illness (*and/or treatment*) interfering with biological life. Admittedly, certain IcPs, such as p.v.s. patients and/or long-term, severe, steady-state patients may lack biographical life. However, the p.v.s. patient has previously had a biographical life that can still inform us about him/her as an individual. And, although the severe, steady-state patient may have never even had such a life - making biography for him/her seem meaningless - there is still an element of biography discernible in individuality of circumstance, such as his/her care environment and family whose concern for the patient is unique to him/her. **To assess how a treatment option contributes to, or detracts from, an IcP's welfare we must look at its effect on biographical qualities.**

Often the impact of medical intervention on both biological and biographical aspects differs. Traditional emphasis on medical opinion has inclined weighting of quality of life to the biological. But, just as competent patients are able to take account of impact on 'life' in a wider sense of relationships, personal goals and experiences, so good proxy decisions should consider impact on an IcP's 'combined' life. It is submitted that, for almost all IcPs, we should value their being *alive* and *being* alive.

²⁷ In the severely defective neonate, the biological prognosis may be so bad that the necessary physical vehicle is absent, precluding development of any biographical life. Whereas, the p.v.s. patient's biological life may be durable but the biology is undermined (through damage to the higher cerebral cortex), precluding any further biographical life.

5.3.2 Life value

5.3.2.1 What is valuable?

Fundamentally, the very existence of life - being *alive* - is valuable. The Human Rights Act (1998) already protects biological life, but it also offers significant *normative* guidelines for the appropriate treatment of fellow human beings. Under Article 2 signatory States have an obligation to protect everyone's right to life from intentional deprivation.²⁸ It even extends to a positive obligation.²⁹ In *X v FRG* this obligation was sufficient to override concurrent obligations under Article 3 towards a prisoner, such that force-feeding was authorised to be in his 'best interests'.³⁰ Thus, protection of (biological) life under Article 2 may dominate other Article 2 rights, supporting the idea that being *alive* is an essential vehicle for exercising other protected aspects of life.³¹

However, it is also clear that while the right to biological life is fundamental, it is not absolute.³² In circumstances of futility the *right* to life might not be infringed by withdrawal of medical treatment. As Maclean argues:

'it cannot be a breach of a person's right to fail to perform an action that would, in any event, be futile'.³³

However, 'futility' draws criticism of 'value judgement'.³⁴ But value judgement is not inherently 'bad', rather it is inevitable in hard cases and *responsibility* in making such judgments is key.³⁵ However, Maclean rightly suggests that the physiological sense, which the European Commission has identified with futility,³⁶ could preclude withdrawal of assisted nutrition and hydration (a.n.h) from p.v.s. patients. For, a.n.h.

²⁸ Article 2, paragraph 1, (Schedule 1, HRA 1998), subject only to certain exceptions (Article 2, Paragraph 2). 'Deprivation' does not require an 'intention to kill': *Stewart v UK* 39 DR 162 (1984).

²⁹ See *Osman v UK* (2000) 29 EHRR 245, but 'reasonable' measures will suffice (*ibid*, 306). The effect of this is such that placing a prisoner suffering from psychosis in hospital care under daily medical supervision was enough to prevent breach of Article 2, despite inadequate maintenance of records and absence of psychiatric referral (*Keenan v UK* (2001) 33 EHRR 38).

³⁰ (1984) 7 EHRR 152.

³¹ However, other interests such as privacy and family life may endure beyond biological death - and 'being *alive*' may incorporate '*having been alive*' in that regard, see Chapter 7, below.

³² See Clayton and Tomlinson (2000) above, 353.

³³ See A. Maclean, *Crossing the Rubicon on the human rights ferry* (2001) MLR 64(5), 775, 782.

³⁴ Maclean, *ibid* 783, citing R.D. Truog, A.S. Brett and J. Frader, *The problem with futility* (1992) 326 *New Eng. J Med.* 1560.

³⁵ See Chapter 8, below.

³⁶ Accepted in *LCB v UK* (1998) 27 EHRR 212.

would achieve its aim of sustaining biological life;³⁷ hence it is not technically 'futile'. He argues further that an alternative (non-physiological) means is therefore needed to warrant a finding of 'futility', such as 'benefit' or 'purpose'.³⁸ Indeed, benefit does go beyond biological/physiological. Treatment decisions impact not only medical interests but also personal, relationship and societal interests. Benefit (or harm) accrues to 'life' in this wider sense. And, its absence in situations of futility is important. When life in a broader, non-physiological sense is harshly impacted, this must also be taken into account in making individual quality of life judgments.

Paraphrasing Mason, McCall Smith and Laurie, the medically intended use of 'futility' (identified by Jecker and Pearlman)³⁹ construes as futile treatment that would be: useless or ineffective; fails to offer minimum quality of life; can't achieve patient goals; or provides no reasonable chance of survival.⁴⁰ Such futility pertains to absence of treatment purpose in either biological or biographical senses. Inevitably, this may involve a value judgment. As Mason *et al* identify, across these four possibilities, *two* characterisations of futility:

'the *effect* of a treatment – which is no more than an alteration in some bodily function – and...the *benefit* of a treatment – which is something that can be appreciated by the patient'.⁴¹

They proceed to distinguish between physiological futility (based on purely medical grounds) and normative futility (involving a value judgment which is the prerogative of the patient or a surrogate).⁴² When treatment is normatively futile – meaning there is no purposeful benefit – we should consider withdrawing (biological/physiological) support. Admittedly, this requires a value judgment. But, provided that judgment is informed, considered, and follows requirements of due process, an individual's 'right

³⁷ See Maclean, above, 783.

³⁸ E.g. See H. Brody, *The Healer's Power* (1992) Yale University Press, New Haven, 177. Brody frames futility as failure to produce any benefit, and/or to promote any reasonable purpose of treatment (because likelihood or magnitude of any benefit is too small, or relative harm too great). Again, Maclean criticises this approach as 'based in value judgment', above, 783-784.

³⁹ See N.S. Jecker and R.A. Pearlman, *Medical futility: who decides?* (1992) 152 *Arch. Intern. Med.* 1140.

⁴⁰ (2002) above, paragraph 16.8.

⁴¹ *Ibid*, paragraph 16.9, citing L.J. Schneiderman and N.S. Jecker, *Futility in Practice* (1993) 153 *Arch. Intern. Med.* 437.

⁴² *Ibid*, citing R.M. Veatch and C.M. Spicer, *Futile care: Physicians should not be allowed to refuse to treat*, in T.L. Beauchamp and R.M. Veatch's *Ethical issues in death and dying* (1996), 392.

to life' will have been accorded appropriate importance. **In essence, withdrawal of treatment may be warranted because we value life in a sense that is more than purely biological.** Far from undervaluing 'life', we arrive at this point by valuing 'life' highly in its individual biographical and biological senses; 'life' means both being *alive*, and *being* alive.

Indeed, through Articles 3, 8, and 12 of the ECHR some fundamental aspects of *being* alive are effected. In the context of medical intervention, Article 3 promotes dignity and bodily integrity,⁴³ Article 8 individual and familial privacy, and Article 12 protects a right of relationship. In addition Article 14 requires non-discriminatory enjoyment of these rights. So, incapacity should not negate these rights, the spirit of which pertains to 'life' in its wider sense of individuality, relationship, personal choice, and aspiration.⁴⁴ Hence, there is value in the *process and experience of living a life* (as well as simply being *alive*). Human rights legislation merely reflects underlying values fundamental within philosophy, medicine, and amongst persons. As Harris observes:

'[w]hile to many just staying alive may be the most important consideration, and while they may even wish to continue to live even at appalling cost in terms of pain, disability and so on...they of course prefer to live worthwhile lives. So that while any life might be better than no life, people generally expect medical care of concern itself not simply with preventing death but with restoring worthwhile existence'.⁴⁵

The notion of 'whole life' within a best interests framework is developed in the remainder of this thesis by relating 'combined life' to interests and time in the context of individuality. All that need be reiterated here is that **in considering welfare we should evaluate *impact* (benefit/detriment) accruing to an incapacitated individual's biographical aspects of life – in addition to the biological effect.**

5.3.2.2 *How do we value life?*

The value of life accrues in different ways:

⁴³ Loughrey (2001) above, 500, highlights: 'medically necessary treatment will not breach Article 3 and...established principles of medicine will usually be decisive of medical necessity' (*Herczegfalvy v Austria* (1992) 15 EHRR 437 para. 82).

'[s]omething is *instrumentally* important if its value depends on its usefulness...[s]omething is *subjectively* valuable only to people who happen to desire it...[s]omething is *intrinsically* valuable...if its value is *independent* of what people happen to enjoy or want or need or what is good for them'.⁴⁶

Dworkin rightly suggests human life to be valuable in all three ways.⁴⁷

Instrumental value of life is often seen as inappropriately treating persons as means rather than ends.⁴⁸ But, arguably, this is

'an evocative way of articulating the complaint that one has been treated as a mere thing, as an object, as having no intrinsic value, or as lacking the distinctive human capacities. However, the language of instrumentalization is pretty elastic and, at its broadest, it simply conveys the complaint that one feels that one has been 'used' or exploited'.⁴⁹

Rather, a person's life may serve the lives of others without any hint of exploitation but because we choose it as part of *our* (biographical) life. Most of us are constantly relating to other people and functioning within small teams or within wider society – *and we choose this*.⁵⁰ Instrumental value is part of the story of a life that merits acknowledgement. Indeed, instrumental value may form part of **subjective** life value (considered below).

Dworkin's main focus, however, is **intrinsic** life value, being sacred or inviolable.⁵¹ He regards this value as based in *process*,⁵² supporting the approach already outlined that *being* alive (in the sense of *experiencing the process of living* one's life) is a fundamental part of life's importance. Admittedly, not all ICPs are able to *experience* their lives; permanently insensate individuals are unable to experience even their day-to-day life. Yet, intuitively we still may feel that their life bears some intrinsic value, which is apparent in our experiencing decisions to withdraw treatment from

⁴⁴ These aspects might be summed up as 'human dignity': for a definition of dignity, see D. Beyleveld and R. Brownsword, *Human dignity in bioethics and biolaw* (2001) Oxford U.P., Oxford, 18.

⁴⁵ Harris, above, 99-100.

⁴⁶ R. Dworkin, above, 71.

⁴⁷ *Ibid.*, 72. He defines instrumental value as 'how much...being alive serves the interests of others', subjective value as 'how much *he* wants to be alive or how much being alive is good for him', and intrinsic value within the very state of being 'because – and therefore only once – it exists', see *ibid.* 72-74.

⁴⁸ In terms of Kant's Categorical Imperative.

⁴⁹ Beyleveld and Brownsword, above, 17.

⁵⁰ See also, Warren, above, 98. It is submitted that, despite incapacity the fact remains ICPs do relate to others, therefore their life may have instrumental value in the most positive sense; they matter to others, and contribute to the quality of lives of their families and emotionally-closest others.

⁵¹ Above, 73.

⁵² *Ibid.*, 78.

them as dilemmas. This may be a recognition of intrinsic value in biological life as well, or a manifestation of the scope for intrinsic value of a person's life to be experienced *by others* (where a person's own experiential capacity is lost). However, most IcPs are capable of experiencing their lives, and Dworkin's interpretation of intrinsic life value accounts for two important features of 'well-being':

- that we should be (biologically) able (so far as is possible) to experience this (biographical) process – being physiologically well enough to participate in life's process. Any treatment decision made in the name of welfare must contribute towards this state, and 'benefit' may accrue from enabling/restoring a person's capacity for participation; and
- that we should be free to live our life – free from interference in our choices about (biographical) content of life's process.⁵³

These may be termed welfare and autonomy respectively, and are developed as 'respect' in the remaining chapters hereof. For present purposes, it is submitted that the potent intrinsic value of life lies in accepting its combined nature. Whether we call this 'human dignity', 'combined life', or 'whole life' matters less than its spirit. As Dworkin concludes:

'[t]he idea that each individual human life is inviolable is therefore rooted...in two combined and intersecting bases of the sacred: natural *and* human creation'.⁵⁴

5.3.2.3 Whose value?

Having established what is valuable and how we as humans value it, there remains the issue of *who attributes that value*. In essence, this is an objective/subjective debate. In ideal circumstances a quality of life evaluation (and the impact of any treatment decision upon it) would be made by the individual concerned. *Every person is an expert in his/her own life*. For, part of the value of living is experiential, and the subject is the only person experiencing his/her individual life in *all* its aspects. Many subjective choices are made in anticipation of the added value we

⁵³ This accords with Beyleveld and Brownsword's view on 'dignity', which incorporates freedom and support, see above, 18.

perceive an action will bring. Because life is a unique experience, less controversy surrounds an individual subjectively choosing what is valuable in his/her life, than does an objective judgment about it. As Dworkin suggests, **subjective** life value is about its '*personal value*'.⁵⁵ Thus, if we believe life value to be partly experiential then, by corollary, freedom to choose one's experience is fundamental.

As proxies we might seek to assess impact on an IcP's life in terms of *zoë* and *bios* - traditional Greek terminology which Dworkin highlights: *zoë*, meaning physical or biological life, and *bios* meaning

'a life as *lived*, as made up of the actions, decisions, motives, and events that compose what we now call a biography'.⁵⁶

But from whose perspective do we make this assessment? Any assumption that we might want to judge IcPs as 'worthless' or 'less valuable' is misplaced. It underestimates our humanity; we recognise our own humanity in, and through, others. In respecting the (combined) value of another's life we respect our own life. Indeed, Dworkin suggests that:

'the most powerful reason we have for wanting others to respect the intrinsic value of human life – in the way we think that value demands respect – is not concern for our own or other people's interests at all, but just concern for the value itself'.⁵⁷

On this basis, whether deciding about our own subjective life, or the life of another, we are making a judgment about the value of life itself. Thus, quality of life judgments are rarely so trite as to be about social worth. They are about personal impact first and foremost and, perhaps at a subconscious level, a reflection on the nature of being human. Indeed, we should guard against any extension of the discussion into the realms of social worth.

In proxy decisions, the prime focus is the impact on an IcP's life, and Buchanan and Brock seemingly promote subjectivity, that is:

'the value or quality of an individual's life *to that individual*, regardless of how society or would-be calculators of social utility evaluate it'.⁵⁸

⁵⁴ R. Dworkin, above, 83.

⁵⁵ Ibid, 73.

⁵⁶ R. Dworkin, *ibid*, 82-83.

⁵⁷ Ibid, 167.

⁵⁸ Above, 124.

It is submitted that we *should* try to establish impact subjectively as far as possible in order to allow life experience to be maximally personal and unique. Furthermore, the value of *participation* should extend to an ICP's involvement in his/her treatment decision where achievable in terms of 'input'. However, it is unrealistic to assume that even as a highly informed proxy we could evaluate impact on an ICP's quality of life wholly subjectively. We simply cannot step into his/her shoes or draw the inferences and conclusions that s/he would.⁵⁹ Rather, we must allow for a proxy to exercise his/her responsibility; seeking to benefit the patient's life, acknowledging the patient's subjective perspective on his/her life value where possible, but accepting that an objective perspective is *also* warranted in determining welfare. Objectivity incorporates clinical perspective on an ICP's medical needs, together with societal influence about which values are acceptable across the community, and scope to act from compassionate concern for another human being in need of our care and protection. It has been argued herein that life is a combination of the biological and biographical. It is submitted that welfare too must be assessed from a *combined viewpoint*. To understand fully what would benefit a person we must: (1) be aware of their **objective** needs (which they may be unable to recognise and act upon due to incapacity);⁶⁰ yet (2) act with compassion and respect for their **subjective** views. This is *protective* rather than paternalistic. It is respectful because we act in sight of individuality, yet in accordance with humanity; essentially providing the conditions of freedom and support that characterise human dignity.

While notions of welfare, life and quality of life have been explored, there remains one issue that connects these issues with respect for persons; personhood.

5.4 'Personhood'

A contentious area, over many years, concerns the question of whether and to whom we attribute moral rights and worth. People disagree over the classification used *because* its end point is attribution of moral *status* and, in turn, this acts as a means of

⁵⁹ For this reason a pure substituted judgment standard is rejected herein.

⁶⁰ These needs include a person's clinical need for treatment, which contributes to his/her physical and psychological health, freedom from pain, suitable care environment, and relationship needs. In other words, those things that objectively can be seen to contribute to his/her welfare interests. See discussion of interests deriving from needs (contrasted with desires), particularly Feinberg's welfare interests, Chapter 3, above. These are determinable by reference to input from HCPs, carers, and those emotionally closest to an ICP.

establishing the type of *moral duties* we owe to them. Personhood acts as a form of *gateway* to moral status, determining who possesses 'life' in a valuable sense, and is consequently hotly debated at the 'edges' of life.⁶¹ This is particularly poignant regarding incapacitated persons where their incapacity often impinges upon their ability to fulfil their biographical lives. Although some sort of identifying classification must be set,⁶² the fundamental danger is that rigid application of personhood criteria often excludes these patients and contradicts our compulsive moral intuition. In particular, because those who do not meet the requisite criteria - 'non-persons' - are owed different (often lesser) moral duties by others. Thus, groups of 'exceptions' are often created in order to protect IcPs who fail to meet the criteria. It is submitted that incapacitated humans merit our respect and we should bear these individuals in mind when setting any such criteria. Ultimately, we cannot permit personhood to create a stumbling block to treating these patients respectfully. For, if the personhood concept works against our moral intuition and compassion as humans, then the criteria are functionally (morally) questionable. With this in mind, how should we frame the criteria for attributing moral worth? What terminology best represents classes of individuals to whom we owe moral duties? Three varying possibilities are identified from relevant literature: **human organisms**; **persons**; and **human beings**.

5.4.1 Requisite biological states

Should biological existence be enough to merit moral status? If we adopt a '**human organism**' approach then it would be so.⁶³ A human organism represents the collection of cells, DNA, and physiological systems of human biological constitution. Certainly, some form of biological existence is needed for attribution of

⁶¹ Harris, above, 8, summarises the question as: 'when does life begin to have that special value we believe attaches to human life and when does it cease to have that value?'

⁶² *Aliter*, we would owe such extensive duties to all organisms that it becomes practically impossible to fulfil.

⁶³ See: M. Lockwood who defines a living human organism as 'a (complete) living organism of the species *Homo Sapiens*', *Moral dilemmas in modern medicine* (1984) Oxford U.P., Oxford, 10; and H. Watt who Relatedly describes such an organism as 'a living, self-organising whole', *Conjoined twins: separation as mutilation*, *Med. L. Rev.* 9 [2001] 237, 238

moral worth in any substantially meaningful way. Watt places heavy emphasis on the significance of the physical body in attributing interests to individuals:

‘[w]e are bodily beings, not purely spiritual beings or a series of thoughts. We all experience ourselves as bodily beings at times when we are conscious. We also know that there are times when we go on existing despite not being conscious – for example, when we are asleep or in a coma. The human moral subject is not reducible to his or her experiences, which come and go; rather, it is the underlying bodily being who is the subject of interests and rights’.⁶⁴

It was argued earlier that the physical body acts as a *vehicle* for other aspects of *being*, such as cognition, emotion and spirit. Clearly, the issue of assessing an individual’s quality of life for purposes of treatment does not even arise if no physical person exists. The human organism as a functioning (or dysfunctioning) whole is fundamental. Whenever we recognise the value of biological life we are – in effect – honouring the notion of human organism. But, while the human organism is important, its employment as the sole definitive criterion for accrediting moral worth raises two problems: 1) where does the definition of ‘living human organism’ begin and end?; and 2) is it really appropriate (given that it takes no real account of any intrinsic value of biographical life)?

In terms of the beginning of life, the ‘living human organism’ definition has scope, *prima facie*, to attribute moral value from the moment of conception, based on the combining of cells capable of forming something programmed for human status. However, development of a whole human organism from fertilisation is not a foregone conclusion. Harris rightly concludes that:

‘[l]ife, then, is a continuum and the emergence of the individual occurs gradually...[a]ll that can safely be said of the fertilised egg is that it is live human tissue’.⁶⁵

It is surely the ample scope for misconstruing life’s beginning at cellular stage that causes the qualifications ‘whole’ or ‘complete’ to be added to ‘human organism’. *Aliter*, (if a human organism need simply be ‘living’ to merit moral value) then abortion – or even contraception – could be prohibited. Such a position on

⁶⁴ Watt, *ibid.*

⁶⁵ See Harris, above, 11-12.

contraception has been legally tested recently and found untenable.⁶⁶ Further, the problem with any construction that prohibits abortion through such early attribution of moral status is its creation of conflict with freedom and autonomy – also valued as part of human dignity – of another whole living organism who is already *living* a life. It is this conflict, as much as any definitional weakness, that inhibits pragmatic use of early-life moral status.

Certainly, foetal life is accorded some legal status prior to birth.⁶⁷ In England and Wales the current legal time limit for termination of pregnancy (on ‘therapeutic and social’ grounds⁶⁸) is set at 24 weeks.⁶⁹ As a foetus may be capable of being born alive (and surviving with medical assistance) at this developmental stage this appears pragmatic.⁷⁰ But, perhaps the transition to morally protected status at 24 weeks (by virtue of biological capacity to be born alive) is something of a red herring. Is such choice really about the moral status of biological human organisms (or even sentience to pain), or is it equally about loss of a chance; that terminating an embryo or foetus ends all opportunity for it to *live* a life? It is submitted that it is our recognition of human life as more-than-biological that fuels our concerns about terminating an individual’s life at any of its stages. Thus, the intensity of issues increases as a pregnancy proceeds not only because of sentience, but also because potential to *live* a life becomes more real.⁷¹ Certainly, in part, we attribute moral status on the basis of being, or having potential to become a living (whole) human organism. However, a physical collection of cells is not the whole story; we manifest respect also in our perception of life as more-than-biological, recognising

⁶⁶ See *The Queen on the application of Smeaton on behalf of the Society for the Protection of Unborn Children v Sec. State for Health (Schering Health Care Ltd and Family Planning Asscn as interested parties)* [2002] EWHC 610 (Admin.), reported by C. Bridge, *Fam. Law* 32 [2002] 664.

⁶⁷ This is considered below paragraph 5.4.3.

⁶⁸ See Mason *et al* (2002) above, paragraph 5.7.

⁶⁹ See the Abortion Act 1967, as amended by the Human Fertilisation and Embryology Act 1990 (s37). This is only one of four possible grounds for abortion, and the only one to be temporally limited, see Mason *et al*, *ibid*.

⁷⁰ However, little consensus exists. Beyleveld and Brownsword, above, 32, identify a distinction in the Convention on Human Rights and Biomedicine (1996): ‘Article 1 brokers a clear compromise: while those signatories who cannot agree that the *conceptus* is a bearer of human *rights* are to be allowed to persist with this belief, all signatories are required to accept that, in the name of human *dignity*, the *conceptus* is a protected entity’, *ibid* 32. Hence, while the embryo or foetus must be treated with some respect as a living human organism, its moral status is not protected *as of right* (to life) until some later point designated by society through domestic provisions.

⁷¹ Relatedly, we feel the loss of a child or young person keenly because death totally frustrates their (biographical) living yet to be done (see also R. Dworkin, above, 84-85).

the participatory element in the process of *living*. We can still respect biographical life both before biological life has started,⁷² and after biological life has ended.⁷³ Biological life as a human organism is important to moral status, but this does not mean that we should always protect or perpetuate it. For, we also attribute moral status on the basis of life *as lived*. This biographical sense of life, involving mental, emotional and spiritual capacities, may be represented as belonging to 'persons'.

5.4.2 Requisite mental states

In the treatment context, the ethical tenets of medicine become applicable once an individual's moral status as a 'person' is established. As Harris observes, this means that

'[o]nce this threshold is crossed, no individual is more of a person or more valuable than any other. This concept of the person sets out to identify which individuals and which forms of life have the sort of value and importance that makes appropriate and justifies our according to them the same concern, respect and protections as we grant to one another'.⁷⁴

Strictly speaking, if an individual does not meet the requirements of personhood then we need not accord him/her the same moral status.

However, the term 'person' connotes possession of certain mental capacities beyond the merely physiological:

'[p]ersonhood is a psychological concept, not a biological one. It is a being's mental and behavioural capacities that make it a person, not the shape of its body, the microstructure of its chromosomes, or any other strictly physiological characteristic'.⁷⁵

The origins of modern philosophical use of the term 'person' derive from Locke's seventeenth century writings.⁷⁶ Singer highlights the connection between these origins and current use of personhood in medical ethics.⁷⁷ Relatedly, Harris defines 'persons' as

⁷² I.e. by respecting the biographical life of a pregnant woman up until a foetus reaches a stage of having a 'real prospect' of biological (and potential biographical) existence.

⁷³ I.e. in how we treat a corpse, and in acknowledging the durability of a deceased's wishes and views.

⁷⁴ Harris, above, 18.

⁷⁵ Warren, above, 93-94.

⁷⁶ Based on reasoning, reflective capacity and some form of self-consciousness over time, see J. Locke, *Essay on Human Understanding* (1690), Book II, Chapter 9.

⁷⁷ P. Singer, *Rethinking life and death, The collapse of our traditional ethics* (1994) Oxford U.P., Oxford, 180.

‘beings capable of valuing their own lives’,⁷⁸ and argues that ‘[i]n order to value its own life a being would have to be *aware* that it has a life to value. This would at the very least require something like Locke’s conception of *self-consciousness*...[which] is not simple awareness, rather it is awareness of awareness’.⁷⁹

A need for self-consciousness imports certain requisite capacities.⁸⁰ Characterisation through experience and self-awareness posits personhood firmly within a concept of biographical life.⁸¹ However, these capacities are also based in biological function such as the physiology for cognitive function, which enables us to ‘think’ or ‘believe’. Hence, ironically, recognising moral status under personhood also depends upon a combination of biology and biography.

Some of the difficulties of requiring reflective capacity in terms of incapacitated patients are considered earlier.⁸² Essentially, tying moral status to personhood makes it impossible for some incapacitated humans to be included. Certain groups of IcPs such as neonates, infants, those with severe intellectual disability, severe mental illness, low cognitive awareness states, or p.v.s. are simply excluded from meriting moral status. Some authors overcome exclusion of the first two groups (neonates and infants) by adding ‘ability to acquire’ (self-consciousness) into the criteria.⁸³ This allows for attribution of moral status where current absence of self-awareness is purely developmental. However, it fails to relieve the pressure for severely damaged babies and children, whose developmental capacity may be non-existent or whose expected short lifespan will preclude any real opportunity for such development. Further, it does not address the other excluded groups at all.

Why does this matter? Why can’t we simply accept that incapacitated humans do not have the same moral status as those with full capacity for self-consciousness? Certainly, some do accept that difference.⁸⁴ And, to an extent, differentials in moral

⁷⁸ Harris, above, 16-17.

⁷⁹ Ibid, 18.

⁸⁰ Lockwood, above, 10, suggests that ‘[a] person is a being that is conscious, in the sense of having the capacity for conscious thought and experiences, but not only that: it must have the capacity for reflective consciousness and self-consciousness. It must have, or at any rate have the ability to acquire, a concept of itself, as a being with a past and a future’.

⁸¹ Harris also adopts an association between personhood and biographical life: Human beings, persons and conjoined twins: An ethical analysis of the judgment in *Re A*, *Med. L. Rev.* 9 [2001], 221, 234.

⁸² Chapter 3, above.

⁸³ See, for example, Lockwood, above.

⁸⁴ E.g. Harris [2001] above, 233.

status *are* acceptable in terms of our focus (as moral agents).⁸⁵ Traditionally, however, moral rights were based in moral agency; only those that had full moral agency might be accorded reciprocal moral (and legal) rights.⁸⁶ However, moral agency as a key is diminishing:

‘in so far as very young children, foetuses, the dead, and members of the human biological species who are apparently not agents are granted rights under the human rights instruments, this claim [of rights-bearers as moral agents] is challenged’.⁸⁷

Beyleveld and Brownsword acknowledge that human rights are now being extended to some of these groups.⁸⁸ But, even assuming that moral agency is no longer the appropriate criterion for moral status, a problem persists with attribution of different moral status based on ‘personhood’. Given that the purpose of determining moral status is to establish what our moral obligations are towards an individual, the exclusiveness of personhood engenders anomaly. Arguably, some higher animals could constitute (self-conscious) ‘persons’,⁸⁹ yet many incapacitated humans would not. This is where intuitive moral discomfort for many observers begins, because it means according more significant moral duties to animals than to incapacitated humans. While some might not regard this problematic, it is submitted that *many* people do feel an intuitive dis-ease about that position.⁹⁰ Surely, we owe moral duties to IcPs. Why? Because, fundamentally, as human beings we have compassion for their human plight. We acknowledge that: (a) there is some value in their biological lives to consider; and (b) some of these individuals also have some sort of biographical life. It may be minimal (i.e. for severely intellectually disabled adults), short (i.e. for severely disabled neonates), unpredictably transient (in the mentally ill), or past (i.e. for p.v.s. patients). However, *it remains part of the story of*

⁸⁵ E.g. regarding a doomed, severely damaged infant our main concern may be short-lived sentience-welfare, whereas our prime concern regarding a temporarily incapacitated adult may be to protect his/her autonomy.

⁸⁶ Implicit in Kant’s attribution of full moral status only to ‘rational moral agents’. See Warren, above, 101-102.

⁸⁷ Beyleveld and Brownsword, above, 80.

⁸⁸ *Ibid.*, 80-81.

⁸⁹ See: Singer, above, 172-183; and T. Regan, Frey on interests and animal rights, *Philosophical Quarterly*, 27 (1977) 335; cf. R.G. Frey, above, Chapter VII.

⁹⁰ Perhaps partly because it amounts to the type of objective ‘social worth’ quality of life judgment rejected above. This is not to suggest that moral duties are not also owed to animals. But, the duties owed to IcPs may be differently founded; ‘personhood’ can protect some animals, but we need an additional criterion regarding IcPs.

that individual's life. And, it is part of what identifies a person as a valuable individual. Additionally, these individuals do still have interests that could be infringed, such as privacy, dignity or bodily integrity.⁹¹ As compassionate humans we do, and should, feel offended by such invasions. Treating these individuals as being of no significant moral status affronts our moral intuitions.⁹² This is why personhood as a sole criterion is unsuitable; these individuals fall through the gap, and end up being included as 'special exceptions' to the personhood rule. Harris makes an interesting distinction between 'non-human persons',⁹³ and 'human non-persons',⁹⁴ and suggests that this explains why we perceive variance in the right to life between full persons (with full moral status) and, say, the foetus (whose full moral status is yet to come into being) or the p.v.s. patient (where it has essentially gone). However, ultimately this distinction makes no difference to the insufficiencies of personhood as the sole base for moral status; personhood is simply too demanding. Some humans cannot meet it, yet surely their life still merits our respect. This does not mean that we must always treat them, or keep them alive indefinitely, but simply that we should see them as morally important individuals to whom we owe consideration, care and compassion. Further, these individuals should be allowed a role centre-stage, not as marginalised 'exceptions'. Personhood fails to admit this to them.

5.4.3 Incapacitated individuals

We have seen that the term 'human organism' (potentially) attributes moral status to all forms of humanity (however undeveloped), and a person's life would cease to have any significant moral value only on physiological death. In short, it 'organism' values only biological life. But, it is submitted, a person's biography is also valuable and durable. Although we cling to our memories of another's life for fear that, with biological death, they might be lost, in truth their legacy persists. Indeed, our moral qualms about ending the lives of p.v.s. patients are eased, not by reference to any suffering of their physical bodies (as they are insentient), but in recognising and

⁹¹ Indeed, some patients in coma states have been raped during incapacity.

⁹² See also Frey, discussed above, Chapter 3.

⁹³ Harris [2001] above, 233, regards 'non-human persons' to include: animals (real/fictional) and disembodied/non-human entities such as 'gods, demigods, ghosts, extraterrestrials, angels and devils'.

releasing the lost prospect of any future biographical life. We acknowledge that they can no longer *live* in a more-than-biological sense. In these various ways we *do*, instinctively, recognise and value life in a combined sense. And, our moral intuitions matter; we should listen to them because they offer guidance. However, a sole personhood criterion, raises attribution of moral status unacceptably high and inaccessible to many IcPs, and creates contradictory results for our moral intuition. Rather, IcPs should have moral status because of their *being human* – in terms of their physiology *and* biography. Certainly, their lives may be very different, seeming diminished even, but their uniquely individual ‘stories’ still consist in their relationships (however rudimentary) and experiences of daily (and/or historical or future) life. It is argued here that ‘**human being**’ is a definition capable of including these individuals, and connecting with both biological and biographical life values.

How, then, might we define a ‘human being’? Watt conflates the meaning of a *human being* with *living human organism* in arguing that we are ‘bodily beings’.⁹⁵ However, arguably this overlooks the *biographical nature* of *being*. Lockwood differentiates between human organisms, persons and beings,⁹⁶ but his definition appears somewhat tautological.⁹⁷ However, if we seek a term that encompasses both being *alive* (biologically) and *being alive* (biographically), then ‘human being’ can fulfil this attributive role. For, ‘**human being**’ recognises that **individuals are members of the human species, in a state of being alive, and being in the process of a uniquely individual life of relationships, experiences and circumstances.** In essence, it accepts that the unique combination of biological and biographical is enough to warrant moral status; whatever the proportions of that combination.⁹⁸

The three elements of this proffered definition require clarification in terms of IcPs. **Membership of the human species** is fairly self-evident. It is intended to admit ‘human non-persons’ (including IcPs) to the core of moral status rather than squeezing their inclusion in at the margins. Its purpose is *not* to exclude ‘non-human

⁹⁴ Harris, *ibid*, includes zygotes, embryos, ‘brain-dead’ and PVS individuals, and anencephalic infants as ‘human non-persons or humans who are not fully fledged persons’.

⁹⁵ Watt, *above*, 237.

⁹⁶ Lockwood, *above*, 10.

⁹⁷ ‘Human being’ representing ‘whatever it is that you and I essentially are, what we can neither become nor cease to be, without ceasing to exist’, *ibid* 13.

⁹⁸ Considered further, *below*.

persons'⁹⁹ from moral status, but pragmatically no single definition will cover all. Hence, the moral status of 'human beings' should be *additional* to any status that society might choose to accord to 'non-human persons'.¹⁰⁰ Even patients in extreme states of incapacity remain identifiable as members of that species known as 'human'.

The second element '**in a state of being alive**' admittedly raises some of the problems outlined earlier regarding beginning of life. A state of being alive essentially can be construed as being in (biological) existence. However, this raises issues about foetal interests, as a foetus is in existence, yet his/her moral status is contentious. While debate about abortion is extensive,¹⁰¹ and beyond the parameters of this paper, attribution of foetal moral status is relevant because it raises conflict in the situation where a pregnant woman (whose competence is in question) refuses intervention, thereby threatening the life of her unborn baby. In certain regards foetal moral status is recognised. This morality is effected through the legal provisions regarding abortion,¹⁰² and recognition of injury caused *in utero*.¹⁰³ However, in both cases arguably this recognition occurs through the medium of the mother. This explains the apparent conundrum comprising absence of foetal right to life prior to 24 weeks (when termination can occur for a variety of maternal welfare reasons), yet that potential 'right to life' - to use a value-laden term - can be destroyed by actions of other individuals (outside the mother). This integral/external approach also accounts for judicial reluctance to recognise foetal interests actionable against the mother.¹⁰⁴ However, beyond 24 weeks of pregnancy abortion is

⁹⁹ 'Human non-persons' and 'non-human persons' are terms employed by Harris [2001] above.

¹⁰⁰ Hence, this approach is not speciesist because it does not purport humanness to be the *only* criterion for moral status candidacy.

¹⁰¹ Regarding abortion the reader is referred to the works of: R. Dworkin; Tooley; Singer; and Harris (1985) all above.

¹⁰² See above paragraph 5.4.1.

¹⁰³ See Attorney-General's Reference (No. 3 of 1994) [1996] QB 581, where the respondent stabbed his pregnant girlfriend in the stomach and she (some days later) delivered a premature baby who died after 120 days. While the Court of Appeal held that the requisite intent for murder or manslaughter could be shown through the doctrine of transferred malice (being directed at the mother and, prior to birth, the foetus being viewed 'an integral part of the mother', *ibid* 598), the House of Lords emphasised that mother and foetus were distinct, but declining to accord personhood status to the foetus, [1997] 3 All ER 936, for discussion see Mason *et al* (2002) above, paragraphs 5.34-5.37.

¹⁰⁴ See *Re F (in utero)* [1988] 2 All ER 193 where the Court of Appeal refused to make a wardship order regarding a foetus, due to lack of individual foetal personality and inapplicability of paramountcy of foetal interests when conflicting with the mother's legal interests. Also, in *Winnipeg Child and Family Services (Northwest Area) v G (DF)* [1997] 2 SCR 925 the Supreme Court of

permitted only for serious welfare reasons; implicitly the foetus seems then to acquire an interest in being born contrary to the 'integral' approach outlined. This could be regarded as an exception, but realistically the extent of any foetal interests still may not trump maternal welfare if termination is needed to protect the woman's health or other legitimate reasons.¹⁰⁵

While it is dangerous to derive the normative from the descriptive, this description highlights the moral difficulties involved in maternal-foetal conflict. Essentially, this is a problem of 'potentiality'. Undoubtedly, *potential* for life comes about at some point *in utero*, and a foetus can be attributed with immediate (welfare) and potential (ulterior) interests once it is born *into being*. The potentiality problem arises where we ask whether potential interests include *an interest actually to be born*, particularly where that conflicts with maternal autonomy. Ultimately there is no single right answer; it is a policy choice based on preferred moral position. However, it is submitted that, as life is a *process*, the birth process could be the point at which the right to, and value of, life become 'real' rather than potential. From the twenty-fourth week of pregnancy onwards it may be possible for a foetus to survive if born. Hence, from this point we might attribute to the foetus an '*interest in the birth process*' (subject to the mother's welfare). This is not necessarily synonymous with a 'right to life'. '*Interest in the birth process*' would essentially mean according to the foetus *a moral interest in attempting to realise its potentiality, but that is all*. The birth process is hazardous and, if a foetus presents in a manner requiring intervention, its potentiality (for being born alive) may be jeopardised if the (competent) mother exercises autonomy by refusing intervention. In essence, the birth process is the point at which the reality of foetal potentiality is *realised*. The being has progressed from foetus to neonate and possesses individuality independent of the mother.¹⁰⁶ This should be protected in the same way that any human being is

Canada refused to uphold an order to detain a pregnant woman addicted to solvent abuse in order to protect her foetus because of the 'unique relationship' between mother and foetus (as not separable).

¹⁰⁵ Such termination may be carried for reasons of; risk of grave permanent injury to the pregnant woman; that continuance of pregnancy carries greater risk to the woman's life than does termination; or foetal abnormality, (Abortion Act 1967, as amended). For discussion see Mason et al (2002) above, paragraph 5.7.

¹⁰⁶ Clearly, a neonate has an independent existence that means decisions can then be taken about the quality of life of that individual. Relatedly, Mason et al (2002) above, paragraph 5.51 (referring to a parliamentary speech by A. Widdicombe (Official Reports (HC) 24 April 1990, vol. 171, col. 192)) suggest it is 'illogical to distinguish in legal terms between abandonment of the newborn infant and

valued. *Crystallisation*, then, is a point of transition where the potential becomes real. However, if a competent pregnant woman refuses intervention needed by the foetus, difficult as we may find it, arguably we should refrain from intervening because: 1) the woman is already *in being* and should be respected as a valuable individual capable of autonomy; and 2) the foetus has had its interest in attempting the birth process, but during that process has failed to progress sufficiently to make its potential become real. Further, we have no more justification to invade the competent woman's body to remove and allow life to the foetus, than to invade her body against her will in order to remove a kidney and give life to another existing human being. To do so would diminish one of the very aspects of life we value – freedom. Even if it serves the woman's welfare, we still should not intervene because autonomy should hold the balance of power in this situation. Admittedly, this may seem harsh, but the conflict in this situation is acute and views will differ about its correctness – whatever the position adopted.

What about a mother who is incompetent? Our natural inclination seems then to shift to intervention in the interests of foetus and/or mother because incompetence alters the value balance – we can take account of a greater relative proportion of the woman's welfare. However, it is still debatable whether we should intervene purely in the potential interests of her foetus. Peart *et al* explore this issue, initially in the context of two American cases and one known case in the UK where women became incapacitated during pregnancy,¹⁰⁷ and they raise interesting distinctions based on classification of the pregnant woman's prognosis.¹⁰⁸ Where the woman has a *chance of recovery* Peart *et al* suggest that

'[i]n the absence of evidence to the contrary, it is presumed that her interests are best served by whatever treatment would be best for both her and her unborn child'.¹⁰⁹

Where there is *no chance of the woman's recovery*, they argue that

abandonment of the living abortus'. On the approach adopted herein, it could be said that the living abortus has managed – against the odds – to survive the birth process and its interests have 'crystallised' meriting protection of life value.

¹⁰⁷ [2001] above, see also earlier discussion by J.J. Finnerty, C.A. Chisholm, H. Chapple, I.S. Login and J.V. Pinkerton, Cerebral arteriovenous malformation in pregnancy: presentation and neurologic, obstetric and ethical significance (1999) 181(2) *American Journal of Obstetrics and Gynaecology* 296.

¹⁰⁸ Above, 275.

¹⁰⁹ *Ibid*, 287-288, including Caesarean section if clinically warranted.

‘maintaining life support in these circumstances is neither in the woman’s best interests nor against her best interests. It is a-therapeutic, because she has no real interests’.¹¹⁰

They conclude, on this basis, that proceeding with the pregnancy to birth does not conflict with her interests.¹¹¹ Under the third prognosis, *brain stem death*, they observe that because the foetus is alive but the woman is not,¹¹² (despite non-crystallisation of interests until live birth):¹¹³

‘the benefit to the foetus of continuing treatment surely outweighs any harm to the cadaver’.¹¹⁴

In essence, the first situation recognises the ‘integral’ nature of the woman and child; their mutual welfare being bound up in a joint outcome. The second recognises that where no conflict exists (because her biographical life has ceased), the foetus’ interest in the birth process gains stronger moral status. And, in the final scenario the moral status of the foetus’ potentiality outweighs the woman’s because even her biological status has gone.¹¹⁵ The views of Peart *et al* essentially acknowledge that circumstances alter cases. And, surely, that is vitally important in all cases of incapacity; every individual should be regarded as valuable and have their unique interests, views and needs fully considered. This is the end-point to which attribution of moral status should drive. Furthermore, the views of Peart *et al* do not contradict those offered herein. It remains feasible that interests crystallise upon birth, prior to which there may be an interest in the birth process, rather than in life itself. This interest in process may simply become stronger or weaker depending on the circumstances of the pregnant woman’s incapacity. Once born, however, an individual is then in a state of being alive.

However, being alive is not all there is to *being human*. The final criterion in the definition is **being in the process of a unique individual life**. This refers to experiences and relationships present in an individual’s life (even at a simple level), and to more complex goals present in varying degree. This is about *being alive* –

¹¹⁰ Ibid, 290.

¹¹¹ Ibid, 291.

¹¹² Ibid, 292.

¹¹³ Ibid, 293.

¹¹⁴ Ibid, 297.

whatever that may mean for different individuals. It bears some resonance with ‘personhood’ – acknowledging that humans *participate* in life rather than merely existing as organisms – but does not make the same demands for self-consciousness. Rather, it emphasises capacity to *engage with* one’s life (i.e. to interact with one’s experiences, other people, and circumstances, even in very simple ways such as response to touch, experience of pain, simple likes and dislikes etc.) as an important part of what it is to *be human*. It does not require that individuals be any particular way, or have any requisite mental capacities other than a capacity to participate in the process of life – however rudimentary or simple for them, or however complex their goals and objectives. In terms of wholly insensate patients, they may previously have been able to participate and this means that they *are* still in the *process* of their lives, but account must be taken of their prospective total inability to participate further. The only group of incapacitated patients who might be excluded on this definition are those who have never been participatory in any way; the utterly and permanently insensate neonate for example (perhaps the nearest example thus far has been the position of Mary in the recent conjoined twins case). While such a patient meets the criteria of *membership of the human species*, and the *state of being alive*, s/he arguably fails the criterion of *being in the process of life* in a participatory or engaged manner. This is an extreme example that sits on the farthest margin between the status of a ‘human organism’ and a ‘human being’. However, by surviving the birth process, his/her interests have crystallised. Moreover, rather than exclude the individual from moral status in such a marginal case, it is surely better to err on the side of caution by admitting moral status, and taking account of the patient’s permanent and total incapacity to participate at the stage of quality of life evaluation (perhaps warranting treatment withdrawal to allow biological life to end). For, our quality of life judgment could justifiably conclude that the value of *being* is so diminished that continued biological life no longer holds real value to that individual other than mere existence. Despite this one marginal scenario that may require an exceptional admission, the term *human being* is preferred herein because it

¹¹⁵ This might differ if the woman was known to have held conflicting views. Peart *et al*, above, 297, do acknowledge ‘some force’ in the view that interests may extend beyond a lifetime, and posit application of their harm/benefit approach where her wishes are unknown.

does embrace *most* incapacitated patients without difficulty,¹¹⁶ and embodies both the biological (i.e. *species membership* and the state of being *alive*) and biographical (i.e. *engagement* with the *process of living*) values of life.

Many debates about moral status have traditionally revolved around de/merits of maintaining or ending life. But IcP treatment decisions may also be about impact on quality of life in non-life-threatening situations. The purpose of using **human being** as a designate of moral status is to ensure recognition of both the biological and biographical values, and to secure a middle path between the biological fundamentalism of 'organism' and the exclusivity of 'personhood'. It is submitted that the scope for status of all IcPs as *human beings* merits our **respecting** them as individuals, at all times and in all degrees of their incapacity. This means taking them into account as *individuals*, recognising their interests *over time*, admitting their subjective involvement and *input*, improving proxy *informedness*, and according them *dignity* in the way we address conflict. Ultimately, respect requires us to act with humane responsibility as proxies. This in no way inhibits making quality of life judgements that might result in biological life ending, but it accords to incapacitated patients **equal status and dignity in considering their well-being**.¹¹⁷ Respect is the key; an ethic that openly embraces both autonomy and welfare and allows that combination to adapt to individuality. Respect therefore forms the basis for best interests reconstruction in remaining chapters.

¹¹⁶ For example, many severely defective neonates do experience life to some degree (even if based on sentience and minimal relationship with parents), and some have a 'personality' of sorts. In this (albeit basic) experiential sense they are *engaged* in their individual life. Whereas, in the context of p.v.s., patients *have previously* engaged with their life. Thus, most incapacitated patients *are* or *have been human beings*.

¹¹⁷ As Freeman suggests [2001] above, 279, regarding the conjoined twins decision: 'it was...in the best interests of both twins that they be separated. The decision is one which upholds dignity; the right of Jodie to live with dignity, the right of Mary to die with dignity. Perhaps even the right of Mary to confer life upon her sister'.

CHAPTER SIX

RESPECT FOR PERSONS - A SYNTHESIS

Chapter 6 Respect for persons – A synthesis

While ‘rights’ (in the guise of autonomy), and ‘responsibilities’ (particularly beneficence), are of value regarding incapacitated persons, it is apparent from the previous two chapters that - alone – neither satisfactorily resolves these difficult decisions. Respect is a concept enjoying a revival under the currency of human rights discourse. The notion of respecting persons could reinvigorate the rather sterile debates of rights and duties. Respect can embrace the significance of both autonomy *and* professional responsibility as a **synthesis**. ‘Synthesis’ imports a *dynamic* melding; making something more than its constituent parts. This is needed if we are to achieve better decisions for IcPs. This dynamic allows inherent conflicts to be resolved in a more balanced, transparent and realistic way. This chapter explores this potential.

6.1 Defining respect for persons

6.1.1 General definition

What do we mean by ‘respect’? One simple dictionary definition refers to respect as:

‘[d]eferential esteem felt or shown towards a person, thing, or quality’.¹

In other words, respect concerns acting in a way that acknowledges the other as valuable and worthy of being heard and considered.

The term ‘respect’ is express in the European Convention on Human Rights, conferring rights to have one’s private and family life respected, and respect for freedom of conscience, thought and religion.² This does not prevent interference with those aspects absolutely. In a sense ‘respect’ is used both as enabling the right and qualifying it; conferring a right to have one’s views treated as valuable and worthy of consideration. Clayton and Tomlinson highlight that:

‘the notion of ‘respect’ (and its requirements)...vary considerably from case to case’.³

However, it is clear that respect in human rights law can encompass both negative (i.e. refraining from interference) and positive obligations (to act) upon states.⁴ In

¹ New Shorter Oxford English Dictionary (1993) 2565, col.2.

² Articles 8 and 9, respectively (Human Rights Act (1998), Schedule 1).

terms of healthcare, however, respect seems to extend beyond a purely 'rights-oriented' approach.

Harris' definition of respect reflects mutuality. He suggests that to respect a person we must exhibit:

'(1) concern for their welfare, and (2) respect for their wishes'.⁵

These clearly parallel values of welfare and autonomy, respectively.⁶ The importance of respect lies in the conscious choice to meld both of these principles. Accepting their joint value within any single context, rather than as separate and divisive norms, reminds us to engage with both elements and to resolve conflict where we can. Furthermore, Harris' specific approach pinpoints welfare and patient wishes as core issues. This contrasts with vaguer appeals to beneficence or autonomy, which are open to wider interpretation. He also specifies conflict resolution by according lexical priority to respecting patient wishes,⁷ and develops this weighting further by then defining a 'point of transition' at which paternalistic intervention loses its justification.⁸

In practical application Harris' approach has **limits regarding IcPs** as it remains heavily dependent on knowing the patient's wishes. Hence, problems persist where an IcP is unable to give (and has not previously given) any view. Harris acknowledges four 'defects' that may diminish autonomy:

'(1) defects in the individual's ability to control either her desires or her actions or both; (2) defects in the individual's reasoning; (3) defect in the information available to the individual, upon which she bases her choice; (4) defects in the stability of the individual's own desires'.⁹

Clearly many incapacitated patients would fall into these categories. Hence, while Harris' definition helps specificity, acceptance of conflict and lexical priority, the

³ Clayton and Tomlinson, above, 820, citing *Abdulaziz, Cabales and Balkandali v. U.K.* (1985) 7 EHRR 471, paragraph 67.

⁴ See Clayton and Tomlinson, *ibid.* 820-824. See also: *X and Y v. The Netherlands* (1985) 8 EHRR 235 (criminal legal provisions as a deterrent to sexual assault on an intellectually disabled girl); and *B. v. France* (1992) 16 EHRR 1 (re-registration of gender following reassignment surgery).

⁵ Harris (1985) above, 193.

⁶ See *ibid.* 194-5.

⁷ J. Harris, 'Professional responsibility and consent to treatment' in Hirsch and Harris, *Consent and the Incompetent patient*, *Ethics Law and Medicine* (1988) Gaskell, 37-47, 42.

⁸ This occurs where 'paternalistic interference...operates to frustrate the exercise of choices', Harris, *ibid.* 43.

⁹ Harris (1985) above, 196.

'defect' classification still causes us to view incapacitated patients as ideal subjects for paternalistic intervention. But, respect for persons has scope to go further, and must do so if a genuine synthesis is sought regarding IcPs.

6.1.2 A new take on an old theme

The new approach, proffered herein, aims to strengthen the synthesis of respect by embracing autonomy and welfare, reconsidering the impact of attributing moral status, and developing issues outlined earlier on interests, competence, purpose, and temporal aspects. It is submitted that an approach is needed that derives support from ethical bases, which is geared specifically to incompetent patients. The argument proposed herein can be characterised by beliefs about IcP decisions that have evolved from consideration in foregoing chapters:

- some **conflict** within a patient's interests (*intra-interest conflict*) is unavoidable; balancing is necessary in many cases;
- **no uniquely 'right'** ethical solution may exist, merely an acceptable one;
- incapacitated patients should be **protected** from harmful consequences of medical treatment as far as is possible;
- an incapacitated patient may still have **capacity** in degree, intermittently, or regarding some aspects of life;
- a proxy decision-maker is a morally responsible agent, and should be prepared to **justify** a treatment decision, including expressing its purpose - 'incompetence' does not exonerate a need for justification;
- due consideration should be given to the '**whole**' circumstances of the incapacitated patient (including their in/capacities, across their lifetime where appropriate, and in terms of their broader interests).

This chapter starts to develop a revised ethic of respect for IcPs flowing from these beliefs and taking into account the philosophical, ethical and legal issues already raised. The ideas raised as a revised concept of respect can be summarised in a shorthanded form using an acronym for 'respect'. In essence, to respect an IcP, a

proxy should Respond Empathically to the Subject's Personality, Experiences, Capacity and Truth. Empathic response refers to the need for a proxy to decide compassionately.¹⁰ The subjective elements of the decision lie in recognising an incapacitated person's personality, experiences and residual capacity.¹¹ Truth recognises the need for objectivity to be added to the proxy decision to balance overall perspective on interests and issues. The starting point for this 'new take' lies in picking up the 'old theme', by accepting the relevance of autonomy (subjectivity) and (objective) paternalism.

6.1.2.1 Embracing autonomy and defects of incapacity

The concept of autonomy is considered above (Chapter 4). Here, we are concerned with its relevance to respect. The issue is one of being autonomous *enough* for the treatment decision in hand. We all suffer Harris' defects to some degree,¹² yet might not accept being disrespected. A balance must also be struck regarding people suffering significant impairment. Incapacitated individuals are more susceptible to Harris' autonomy defects. Hence, a woman in labour, with a phobia of needles, may well have a control defect fulfilling Harris' definition:

'the illness has such extreme effects on the individual's ability to control his life...[that] preferences expressed while so comprehensively out of control must not be regarded as the genuine preferences of the individual'.¹³

Thus, while she desires that her baby be delivered safely (her 'genuine' preference), she refuses an injection (her 'expressed' preference) due to phobia. Alternatively, we can see that the mature minor, on the cusp of autonomy, might suffer from Harris' second category defect in reasoning if s/he blindly accepts the views of others, infers invalidly from one premise to an unrelated conclusion, or vitiates his/her reasons by prejudice.¹⁴ Harris' third defect could occur regarding the

¹⁰ Chapter 8, below.

¹¹ Considered below, Chapter 7. Subjective experience in the form of relationship is discussed in this chapter.

¹² See also Harris (1985) above, 200.

¹³ Ibid, 196.

¹⁴ Harris includes as a defect decision-making based on 'received opinion' or 'gut reaction', *ibid.* 197. But surely, a decision according with medical advice is one taken on 'received opinion', and a decision based on 'gut reaction' is taken in awareness of the values lying at an individual's very core. Thus, it seems Harris' approach is heavily oriented to respecting logic.

intellectually disabled adult labouring under cognitive management of information to the extent of deficiency.¹⁵

Where these defects occur, Harris considers that the patient may fail to be 'maximally autonomous', and paternalistic interference aimed at securing his/her welfare may be justified.¹⁶ Hence, on application to incapacitated patients, respect really flows from the *caveats* that Harris places upon 'defect' categories,¹⁷ including task-specificity.¹⁸

These *caveats* are important. But, to respect incapacitated individuals we should go further:

- we should recognise that a proxy decision-maker may equally be subject to autonomy defects. If a proxy fails to evaluate an ICP's interests – including his/her preferences – across the full network, then the proxy may fail to identify the genuine decision purpose (a defect in control). Alternatively, failing to consider all relevant risks and benefits could amount to defective reasoning. Relatedly, gender assumptions may be based in prejudicial beliefs.¹⁹ Furthermore, proxy decisions taken without knowledge or admittance of an ICP's lifestyle, preferences, values and relationships are defective in information. **Thus, to respect incapacitated patients it is vital that any proxy is maximally autonomous, and as free from Harris' defects in autonomy as is possible;**
- we should acknowledge that 'autonomy' is not synonymous with 'input'. Exercise of autonomy is based on competence thresholds, whereas, input is based in capacity. Allowing an incapacitated individual to be genuinely heard respects that individual and can reduce conflict. To

¹⁵ However, this also depends on how, and how much, information is presented to such patients.

¹⁶ Harris, above, 200-201.

¹⁷ Namely, 'that the illness was such that none of the individual's choices could be taken as genuine, or that this particular choice could not be so taken' (ibid. 196); that 'the defects undermine or tend to undermine the agent's capacity to make choices' (ibid. 198); and that defects in information 'can happen of course by others deliberately deceiving him...or knowingly giving only partial information, or...by negligence or sheer mischance' (ibid. 198).

¹⁸ The defect must inhibit ability regarding a particular decision, ibid, 210.

¹⁹ E.g. about the greater acceptability of sterilising female intellectually disabled patients.

respect an IcP we must allow them involvement in decisions about their life, and permit input from other significant persons. This helps to maximise the proxy's autonomy and recognises that respect endures beyond simple autonomous/non-autonomous distinctions;

- as irrationality is part of human nature, logic should not have an absolute right of dominance. IcPs have no less right to irrationality than competent persons. Admittedly, it may be difficult to identify when a choice is simply (acceptably) irrational rather than substantially defective, but we should not assume from irrationality that reasoning is defective.

6.1.2.2 Autonomy as a process

Interestingly, Harris does not include his fourth category defect (instability) as justifying paternalistic intervention. The reasons for this are unclear from the text. However, his recognition of Mill's position,²⁰ and his emphasis that having our autonomy respected may result in different – but nonetheless autonomous – decisions over a lifetime,²¹ indicate understanding of autonomy as an organic, developing process. This author concurs with his approach. Each individual is a unique product of his/her own experiences. These experiences are not externalised, subject to judgment of validity by others. Rather, the decisions we make in the light of our experiences reflect the essence of the individual in that moment. And, deciding in the present moment is the most any individual can ever do. On this basis, if only the patient's stability is in doubt, it is arguable that the 'point of transition', whereupon paternalism becomes justified, has not been reached.

To act respectfully in the context of incapacity we must recognise autonomy as a process that relates not only to the patient, but also to the proxy. And, that patient incompetence does not justify ignoring input. We must also be clear about how to act when autonomy is significantly compromised. Harris pragmatically resorts to

²⁰ I.e. '[s]elf-determination improves not with time but with practice, and that one's later decisions only have a chance of being more self-determined than one's earlier ones if one is permitted to make the earlier ones and learn from them', Harris, *ibid* 199, describing Mill's view.

welfare.²² But, we need to clarify the pressures of paternalism that have so long dogged the notion of welfare.

6.1.2.3 Accepting paternalism

Many debates in medical ethics focus on the head-on collision between autonomy and beneficence in so-called 'hard paternalism'. Meanwhile, acceptability has been assumed of (soft) paternalism.²³ On a strict definition of 'paternalism' this position may be warranted.²⁴ However, focusing on the 'more interesting' problem of hard paternalism is unfortunate because: (1) it contributes to an assumption that where autonomy is compromised medical intervention is defensible automatically, provided that it seeks to prevent harm or promote benefit. Consequently, IcP interests in the wider sense are overlooked, and ethical acceptability reduced to an unquestioned appeal to principle; and (2) it blurs the edges of paternalism and welfare. Welfare is a valuable objective in an IcP treatment decision, and a significant part of respect, whereas 'paternalism' primes the situation for conflict; importing dominance of medical opinion.

6.1.2.3.1 Paternalistic or parental?

Accepted notions of paternalism are of little assistance in seeking ethically acceptable solutions to decisions for incapacitated patients. Issues geared to justify overruling competent patients are insufficiently focused to handle the multifarious considerations arising within an IcP's interests. A purely 'principled' approach,²⁵ or a 'common morality' approach,²⁶ tends to classify incapacitated patient situations as 'exceptions' or 'special cases'. That approach is too blunt to do justice to incapacitated individuals. What is the alternative? The context of these decisions is, at a basic level, *parental*; that is, in the sense of seeking a decision that **protects** the IcP's interests. It is imperative that this protective responsibility is acknowledged, as

²¹ 'Autonomy is the running of one's own life according to one's own lights. The fact that these lights change colour and intensity over time is no evidence at all that the later lights are either better or more 'one's own' than the earlier ones. They're just different', Harris, *ibid* 199.

²² *Ibid*, 202.

²³ E.g.: R. Carter, *Justifying paternalism*, *Canadian Journal of Philosophy*, vol. VII, No. 1 (1977) 133, 143; Beauchamp and Childress, *above*, 277; and even Feinberg, *Harm to Self*, *above*, 14.

²⁴ I.e. it may be impossible to act paternalistically towards a patient who cannot hold/express a view.

²⁵ See Beauchamp and Childress, *above*.

²⁶ See Gert, Culver and Clouser, *above*.

these patients are undoubtedly some of the most vulnerable individuals in society. It is our **responsibility** to act protectively towards them. A treatment decision may seriously impact the incapacitated patient's life, and any proxy holds a powerful position in that regard. However, even adopting the context as 'parental' contains dangers; it is easy for many parents to ignore the autonomy even of their mature children. Hence, the relationship of IcP and proxy is better seen as slightly more distant, and objective, guardianship.

However, the importance of embracing autonomy as part of respectful decision-making means that, in making a protective decision, it is essential that the IcP's views and preferences are also acknowledged and considered where possible. Aliter, a decision-maker may act for objectively 'good reasons', yet still fail to respect the IcP. Hence, the context must be one of **respect**. Furthermore, the justification for the eventual decision should be at least as stringent, perhaps even more so, than the perceived need for justification in 'hard' paternalism. In hard paternalism we are justifying overruling a competent patient who has been able to express their view, and the disagreement is really about ranking of priorities. But, an IcP's input may be very limited, or even absent. It is submitted that this *heightens* the importance of acting compassionately and openly on the basis of full information. In short, we should take *extra* care to ensure our actions are respectful, as respect is too easily overlooked in relation to such patients.

6.1.2.4 Moral status revisited

The fundamental aspects of 'respect' are considered above. However, the inescapable focus is respect *for persons*. True respect for persons should extend beyond autonomy, beneficence or personhood. Harris argues that respect is

'the starting point of morality...because it involves recognising that other people matter and so also that how they live their lives, and the quality of their lives, matters as well'.²⁷

The importance of respecting incapacitated individuals is apparent in this statement; rather than shying away from 'difficult' issues surrounding 'quality of life' and individuality; respect can be *based* upon it. Fundamentally, this is the reason that

²⁷ Above, 192.

'personhood' should not be a stumbling block to respecting incapacitated patients. Their status as **human beings**, as individuals whose life (past, present or future) is the only one they have, merits that we treat them with respect. It is that simple. If we choose respect as our guiding ethic, then recognising others as individuals with dignity and compassion is all that is required. It need be no more complex than acting responsibly within a clear framework, and acknowledging the individual as valuable.

6.1.3 Seeking a synthesis - A balanced ethic for incapable patients

To redefine respect in terms of incapacitated patients we need to release limiting notions of autonomy and welfare, and momentarily reflect upon the purpose behind respect. What is the objective of respect? Richardson's perception that it concerns respect for self-conscious life merely returns us to personhood issues.²⁸ Rather, if we acknowledge our intuitive response (that all incapable patients merit admission as morally significant by virtue of their being, having been, or having potential to be human beings),²⁹ we can access the core of respect; that through it we explicitly **acknowledge our respect for humanity**. Thus, we **respect each individual** that comprises part of humanity, and **by respecting others we respect ourselves**, because we accept and experience our own intuitive moral commitment to valuing every individual. In this light, respect represents a formal moral recognition of individual worth. In view of this purpose, three objectives emerge. Respect for human beings should:

- be impartial, considering each individual **equally**;
- actively recognise **value in life** (both intrinsically and as elements valued within one's own life);

²⁸ H.S. Richardson, Specifying norms as a way to resolve concrete ethical problems, *Philosophy & Public Affairs*, 19 (1990) 279, 304.

²⁹ The only possible exception is the neonate born wholly and permanently insensate, who may not even have potential to develop engagement with the process of living. This is considered above, Chapter 5, and the conclusion drawn that such marginal cases should err on the side of caution by admitting moral status, particularly as diagnosis of sentience to pain, and response to touch can be difficult to gauge. Account can be taken of the patient's total, permanent incapacity within the subsequent quality of life judgment.

- function **responsibly in the name of common humanity**, such that each moral agent gives respect to - and receives reciprocal respect from - others with regard to moral norms.

These objectives give direction to respecting *incapable* individuals. The remainder of this chapter gives substantive content to the first of these goals, drawing from earlier consideration of interests and relating respect to interests and the dynamic of using interest networks. The second objective (life value) is considered in Chapter 7, while the third objective of common humanity is the focus of ethical acceptability and legal representation in Chapter 8.

6.2 Equality of the individual

Respect requires recognition of individuality, including the combination of experiences, beliefs and values comprising an individual life. Treating human beings equally does not mean ignoring incapacity, but rather acknowledging individuality – of which incapacity is a part. Respect means respecting *this* individual whomever, and however, s/he is.

6.2.1 Relating interests to respect – persisting and prevailing interests

Interests represent the stakes a person holds in life (Chapter 3, above). Some are commonly held (representing welfare), others highly individual (representing preferences). By recognising fully an individual's interests we express our respect. Interests give content and meaning to respect; the range of admissible interests is fundamental.

6.2.1.1 Range: prevailing and persisting interests

The range of interests may include broad, but definable, common interests: good physical and psychological health, care, a safe environment, freedom from pain, freedom of choice, bodily integrity, privacy, dignity, relationships, quality of life and being heard. These elements represent a secure base – from which an individual can function to develop subjective interests, which s/he chooses through reflective preference. The variance in the latter is infinite in range and highly individualistic in

combination. Herein lies individual uniqueness. To respect the individual requires us to admit the range of both interest types. This does not mean that we can *serve* every interest, or know the inner corners of another's mind. But, respect lies in acknowledging individuality,³⁰ acknowledging that s/he exists, in a unique life, as an individual – irrespective of incompetence. This requires us to open ourselves to:

- the **full range of potentially relevant common interests**; we should not assume, for example, that because an individual is not conscious of their own dignity or bodily integrity, that our behaviour need not acknowledge those interests which are part of common humanity. Failure to respect these traits in others also fails to accord importance to those interests within common humanity. We can frame these as '**prevailing interests**', forming an umbrella of interests that shields every human being and facilitates his/her fulfilment of potential. Such interests are often embodied in national constitutions as legally enforceable 'rights', possessed equally and impartially. Regarding IcPs, particularly those institutionalised, certain overarching protective interests (such as privacy and dignity) and interests in self-expression are easily overlooked because his/her capacity to exercise them is diminished. This can falsely increase the significance of other interests, and risks a distorted and unequal perspective.³¹ Recognising every individual as valuable requires that these prevailing, protective rights be universally applied. The enactment of the Human Rights Act (1998) now attributes to every citizen the rights and freedoms embodied therein.³² Hence, decision-makers must consider more explicitly the interests of incapable patients in terms of those rights and freedoms,³³ and
- recognise the **contribution of subjective preferences** to individual uniqueness. Many IcPs do currently, or have previously, held views

³⁰ Individuality being part of autonomy, along with choice.

³¹ Certainly differences in judicial approach can be seen from Bland, above, contrasted with Re a Ward, above. In the latter the Irish Constitutional interests, outlined by Denham J, made clear that the patient still possessed these interests despite her near-p.v.s. state. No explicit framework is attributable in the English case where the patient's possession of interests was effectively dismissed.

³² In reference to the Convention (1950), Article 1.

about the content, nature and purpose of their life. These contribute to individual identity. For example: the intellectually disabled individual has a preference about whether, and with whom, s/he wishes sexual involvement; the p.v.s. patient has lived his/her earlier life in a unique way; the pregnant woman in labour still holds her own set of beliefs – who are we to deem her beliefs invalid simply because they seem illogical to us. However, beyond express preferences lie investments – expression by action. It has already been highlighted that we invest in our lives in a wide variety of ways (Chapter 3, above). These investments comprise part of individual identity. They may usefully indicate stakes we hold in life, and investments made pre-incapacity may be valuably admitted post-incapacity; current incompetence need not negate an individual's previous investments. Life is a continuum, a process, and past investments can mark the way to informing us about this individual now. Admittedly, people do change; their investments and choices do not remain static. However, some investments (and preferences) endure. If we can identify these then we know more about the individual whom we seek to respect. Such interests, personal to the individual, '**persist**' within his/her identity despite incapacity. To respect subjective preference we must listen to action-statements individuals make during their lives. Hearing the uniqueness of others informs us better about who the individual is, or has been. We have nothing to fear from listening - perhaps we are simply afraid it may challenge us to derogate from decisions based on assumption, prejudice and questionable categorisation of incapacitated patients.

6.2.1.2 Range and Equality

We need not accept all we discover as relevant, but respect requires that we discover who the individual is. This entails openness and consideration of all potential interests. The decision-maker is responsible for ascertaining the shape, and detail, of an ICP's interest network. Equality flows from this in two ways:

³³ The 1998 Act is discussed comprehensively in J. Wadham and H. Mountfield's Blackstones Guide

- in identifying interests relevant to the patient's network each interest is considered equally in terms of (i) how the interest relates to the particular patient, and (ii) how that interest relates to other interests in the individual's network;
- the purpose of mapping interests is to facilitate decisions on the dual basis of: (i) current circumstances, objectively understood; and (ii) integrity of the incapacitated individual. This ensures that patients' interests are not lost to general situational categories. We respect the incapable patient through a combined objective assessment (of present and foreseeable circumstances), and evaluation of impact on his/her subjective interest network.

Range is the starting point for this equal consideration. Inequality lies in arbitrary selectivity. Hence, we must perceive honestly the full range of impacts; blinkered acknowledgement of benefits and harms perpetuates inequality.

6.2.1.3 Interest sets and respect

The value of interest sets in understanding the concept of interests is considered earlier. Because of their conceptual nature, set groupings remind us *why* single interest objects are important. Fundamentally, the sets reflect a respect ethic. Those groups offered by Feinberg,³⁴ and by Dworkin,³⁵ seem to reflect Harris' approach to respecting persons; evincing the combination of objective welfare and subjective preference that comprises a 'life'.

6.2.1.3.1 Interest sets embracing autonomy

Interest sets support **individuality** by helping to focus our attention on how interest objects contribute to an ICP's life.³⁶ Hence, a single interest may impact a patient's various interest sets in a number of ways. We should seek to identify and consider

to the Human Rights Act 1998, (1999) Blackstone Press Ltd, London.

³⁴ I.e. 'welfare' and 'ulterior' interests.

³⁵ I.e. 'experiential' and 'critical' interests (subdivided to 'subjective critical' and 'genuine critical').

³⁶ E.g. the intellectually disabled person's interest in relationship/sexual freedom could contribute to: his/her 'ulterior' interests (having a valuable relationship, and being permitted to make choose such relationships); and his/her 'experiential' interests - intimate contact contributing to his/her day-to-day experiences in life.

all potential impacts regarding this incapacitated individual – only then can our decision to be truly informed. Furthermore, evaluating impacts under the umbrella of interest sets sharpens our focus, by constantly filtering through the decision-maker's mind the question: *what is the objective here; how important is this interest in X to this individual's overall network?* This awareness keeps the individual, and the bigger picture, in mind as the decision process evolves.

Sets also remind us that input need not equate with autonomy. Benn's 'perceived' and 'real' interest groupings reflect location of decision-making power,³⁷ which may necessarily be placed in a proxy regarding IcPs. However, while a proxy views the objective 'reality' of the situation, s/he should take account of the IcP's perceptions because admitting this input is part of 'becoming informed', and 'knowing' the individual s/he seeks to respect. Benn's sets remind the decision-maker that different perceptions may exist, and should be heard.

The specifically autonomy-oriented groupings further remind us of the importance of individuality; that we are all entitled to live our life by our own experiences, ulterior goals, and values derived through subjective critical reflection – however irrational the outcome. Even where capacity for reflectivity is significantly impaired, experiential interests remain important. Most IcPs still have day-to-day experiences that comprise their individual life. Indeed, arguably, the very open nature of some intellectually disabled patients and maturing minors may intensify, rather than diminish, their daily experience of themselves and their life. In effect, they may invest more heavily in their daily experiences. Such intensity need not determine a decision, but we should be aware of its validity for that individual. Additionally, awareness of an IcP's 'ulterior' goals facilitates direction and purpose in our proxy decision, by recognising that their subjectively 'critical' views (even as 'preferences', or previously-held opinions) can inform us about how a treatment option might impact an individual in an unexpected way. By acknowledging that IcPs are entitled to autonomy-oriented experiential and subjective values we may better respect the individual as s/he is.

³⁷ Above, Chapter 3.

6.2.1.3.2 Interest sets assisting guardianship

Interest groupings can also help us to fulfil good respectful guardianship. 'Welfare', 'genuine critical', and 'real' interest groupings emphasise the *protective* responsibility important in respecting incapable individuals. Awareness of welfare-oriented groupings encourages us to look at both harms and benefits. For example, an intellectually disabled adult's interest in intimate relationship may benefit his/her psychological well-being, and the genuine critical interest of an opportunity to mature in a relationship. On the other hand, his/her welfare interests also demand protection of physical health from sexually transmitted disease, or from any potential abuse of power in the relationship.³⁸ Thus welfare-oriented groupings remind decision-makers of the 'reality' and responsibilities of respectful, protective guardianship.

Interestingly, autonomy-oriented interest sets also serve guardianship. The personal quality of 'ulterior', 'experiential' and 'perceived' interests reminds us that an important characteristic of a respectful guardian is to act compassionately, seeing clearly the individual concerned. Protection is important, of course, but protection must be measured with equal compassion for genuine respect to result. Excessive protection actually makes for a poor guardian who substitutes his own values for those of the ICP. Compassion is an important linking characteristic; it connects care (and welfare), to recognition of the individual subject (and his/her experiences, perceptions and preferences). An informed, compassionate decision-maker is fundamental to good decision-making.

6.2.1.3.3 Interest sets and equality

The juxtaposition of collective groupings is useful, highlighting the inevitability of conflict, and the need to see the whole picture. Each interest must be given equal consideration (though not necessarily equal weighting). The occurrence of some interests in more than one grouping may signify their importance or reinforcement within a patient's interest network. Furthermore, juxtaposition emphasises that all lives comprise a combination of common,³⁹ and personal,⁴⁰ interests. The degree

³⁸ See X and Y v. Netherlands, above.

³⁹ I.e. 'welfare', 'genuine critical', or 'real' interests.

⁴⁰ I.e. 'experiential', 'subjective critical', 'perceived' interests.

may vary individually, but the significance of both endures. In this regard we can ensure equality for ICPs; by recognising that they too have a 'combined' life, its combination being as individual as yours or mine. Equality is not about evaluating what life is 'worth' – a concept that any assessment of another's life too often founders upon. Even in assessments involving quality of life evaluation, we can treat ICPs equally provided that we respect their individuality. If we inform ourselves fully about the individual, admit his/her input and act with focused, protective, compassionate guardianship then we will act respectfully in the ICP's 'best interests'. Interest sets are merely a practical marker of concept that aids our focus. Even in situations laden with conflicting intra-patient interests, we can act respectfully. Conflict and support is part of the human condition - for ICPs no less than those with capacity. Sometimes the most we can do is acknowledge conflict, be informed, and make the best decision we can with clear purpose and reasoning. In respecting the incapable individual in this way we respect ourselves.

Thus far, this chapter has established the nature of respect for ICPs, the need for openness to the full range of interests and impacts, and the value of conceptual groupings to link interests with the overarching ethic of respect. Emphasis throughout has been on individuality. The remainder of this section considers how we can gather and use information about the individual in a respectful treatment decision.

6.2.1.4 Inputs; recognising relationship, respecting individuals

To understand how an ICP's interests may be impacted we need information about the individual. The range of potential sources of input is outlined earlier, concluding that admittance of input depends upon recognising relationship. This thesis argues, however, that recognition of incapacitated individuals' relationships is currently too limited; to respect ICPs we must expand our view.

6.2.1.4.1 The reality of relationships

Relationships are a significant part of human life. An individual's relationships contribute to the quality and content of his/her life. They are investments of time, energy, emotion and self that we make in mutual reciprocation. Relationships

represent part of a human being's experiences as an individual.⁴¹ They may even represent part of his/her identity because relationships engender roles.⁴² No single role embodies the whole of someone's identity; rather identity consists in the individual him/herself, *plus* a combination of these roles. For each individual the exact combination of self and roles (including role in society/community) is unique. If we make a proxy treatment decision without awareness of an individual's significant relationships then we base the decision on a limited view. These relationships need not dominate a decision, but we should be willing to consider input from them and impact upon them.

Furthermore, relationships are real for almost **all** incapable patients. Even the p.v.s. patient has previously *had* relationships that form part of his/her life and which may be regarded as *persisting* (in the minds of those significant others). Severely defective neonates may have a very simplistic relationship or bond with parents. The only possible exception is the wholly insensate neonate, whose capacity for engagement with others may be completely absent. This could be considered only from the perspective of admitting the parents' interest in the baby. However, this is a marginal case. Other examples of relationship might include:

- regarding minors, parents invest love and affection in raising that child and making a commitment to his/her future care through to maturity. The relationship is so strong that a child depends upon the parents for his/her very survival, and any treatment decision about the child's life is certain to impact child, parents and their relationship;
- the relationships between adult partners, and between friends, are based on mutual investments of time and energy in practical daily life and across the lifetime of the relationship itself. These mutual investments form part of our shared, critical interests. Interest networks overlap in these areas of shared mutuality. It is unrealistic simply to disconnect an individual's interests from this overlap where one suffers incapacity. An incapacitated individual may be able currently to interact in significant relationships, or will become so enabled (e.g. if temporarily

⁴¹ Experiences being a fundamental element of the R.E.S.P.E.C.T. acronym outlined earlier.

incompetent), or has been able to do so previously.⁴³ Hence, a treatment decision may draw insight from these relationships, and will almost certainly impact upon them;

- relationships exist in time: formerly-competent patients *have had* relationships; other patients, such as young minors may not yet have attained competence, but do currently have relationships and may develop a wealth of relationships in the future; even severely defective neonates might have a very rudimentary mutual relationship with their parents (perhaps through response to touch), and certainly the parents have extensive concerns for their baby; transiently-competent patients relate to others when not in a dissociative state; adolescent patients (with emerging competence) clearly have similar relationships to all other young adults; while intellectually disabled patients (with capacity in some aspects of life) may have relationships with carers, family, friends, and perhaps intimate others.

This is the reality of relationships. It is human nature to relate, and relationships can be a central element of what makes life 'good'. Although relationships serve critical/subjective interests, autonomy is not a prerequisite to relationship; relationships may be as real in an IcP's life as yours, or mine. Ignoring that reality leads to being misinformed about an IcP's interests.

6.2.1.4.2 Respect via relationship interests

If we accept relationship as important, then how does relationship associate with respect? The answer lies in interests. Or, more specifically, in the input available from mutual others to assist identification of IcP interests, and to the impact of a treatment decision on those interests; relationship points the way to input and impact. *Respect* depends on *admitting* all relevant input, and *considering* all relevant impacts. Some relationships are more easily admitted than others: the clinical relationship is obviously important to our degree of informedness; also input from, and impact on, parents regarding treatment of minors is often willingly considered; and the patient's

⁴² I.e. it is part of an individual's identity that s/he is a parent, partner, friend, or son/daughter.

⁴³ And that former relationship persists in the hearts and minds of those significant others.

relationship with State and society may be acknowledged by the moral/legal context of the decision. However, more contentious – and less accepted - relationships lie in the personal sphere. Where a benefit from a personal relationship can be ascertained to flow to the patient (say, if it contributes to his/her quality of life) this may reduce contention and increase acceptability. However, the reciprocity of relationships means that the other person also enjoys or benefits from his/her relationship with the IcP. Admitting this as input is more contentious due to fears of self-interest. The interests of those emotionally close to an IcP may be classified, in Feinberg's terms, as 'indirectly self-regarding'.

However, by classifying relationship as based on mutuality, a fuller and more balanced perspective is offered. **Mutual** interests are reciprocal stakes that arise quite naturally from the love, affection or esteem flowing between an IcP and those emotionally closest to him/her. Although they arise naturally, these interests are a matter of individuality meriting a proxy's consideration rather than presumption.⁴⁴ Relationship is set to receive growing attention judicially. The advent of the Human Rights Act (1998) imports a responsibility on the domestic courts to determine issues in ways that comply with the European Convention on Human Rights and Fundamental Freedoms (1950). Of particular relevance is Article 8, which protects respect for private and family life, and the right to marry and found a family enshrined in Article 12. The European Court of Human Rights has construed the notion of 'family life' widely, expressly recognising a variety of familial relationships as subject to protection from unjustified interference (considered below). Relatedly, the recognition of a right to marry is express acknowledgement of the choice of individuals to formalise their relationship.⁴⁵ Hence, any proposed reconstruction of best interests must take account of the significant role of relationship. Furthermore, overtly recognising relationship-derived interests reflects the core value of individuality in a patient's interest network (and its overlap with the networks of others).

⁴⁴ E.g. in *Re Y*, above, Y's relationship with her sister appeared relatively weak, and would barely amount to one of 'mutuality'. However, Y's relationship with her mother was clearly stronger and mutual. Whether this should influence the decision about Y as a donor depends on how the indirect impact (through Y's sister's illness/death severely impacting their mother) could impinge on Y's

Undoubtedly, there are risks in recognising relationship. There is some foundation in fears that the self-serving characteristics of human nature risk abusing mutuality interests; exposing ICPs to deliberate or inadvertent selfishness of others. But, this is likely to be rare, and harm may result equally from ignoring the importance of a person's relationships.⁴⁶ Balance may be further encouraged by placing decision authority with a 'disinterested' third party.⁴⁷ Additionally, mutual interests would accrue from establishing a personal relationship 'significant' within a patient's interest network – they may be just one of a number of interests, and not all relationships would have significant mutuality. The alternative (i.e. excluding input from personal relationships) is an attenuated perspective that could be ill-informed. It fails to respect the incapable individual, because it fails to accredit to him aspects of life significant to human beings generally.

6.2.1.4.3 Relationships; identify and inform

Four relationships are potentially relevant: 'individual relationship with self'; 'mutual relationships'; 'clinical relationship'; and 'community/State relationship'. Relationships also give rise to interests. Interests are grouped herein as 'personal medical'; 'personal non-medical' (of which a sub-group are 'social'); and 'contextual'. The connections between these relationships and the interests they create are represented in Appendix 4, hereto, and developed within the text.

6.2.1.4.3.1 'Individual relationship with self'

This relationship concerns how an individual engages with his/her own life, reflecting personal perspective on the meaning and content of life and subjective value of life for that individual. Incapacity can inhibit relationship with self (through lack of self-awareness). However, most patients with incapacity still have subjective goals or experiential preferences that can represent this relationship and found interests. The interests arising from this personal connection might be termed '**personal non-medical**' and are highly individualistic, embracing experiential and

relationship with her mother. Indirect impact *could* be relevant, but its significance should require supporting evidence, and caution about the degree of indirectness.

⁴⁵ 'Marriage' under Article 12 has been narrowly construed.

⁴⁶ See also Buchanan and Brock, above, 134.

⁴⁷ 'Disinterested' being construed by Feinberg as 'unbiased and impartial', Harm to others, above, 76.

ulterior goals in day-to-day life or in the longer term. Their subjectivity makes them harder to discern, particularly in ICPs, but they represent the essence of individual uniqueness. It seems natural for a competent, self-determining patient to take account of a treatment's impact on his/her broader 'well being' in this sense. A proxy should also seek to construe the impact on an ICP's personal non-medical interests wherever possible, in order to achieve an improved, holistic assessment of impact on the individual's network.

6.2.1.4.3.2 'Mutual relationships'

Mutual relationships embrace those relationships in which we engage with others, such as spouses, partners or friends and family with whom we have close ties; in other words, emotionally-closest others. Human rights law now recognises the importance of many of these relationships, and the scope for admittance of *de facto* 'familial' relationships is relatively wide,⁴⁸ in relation to decisions that might interfere with 'family life'.⁴⁹ This gives rise to a recognisable interest regarding parents and children,⁵⁰ which appears potentially relevant to decisions about treatment of minors.⁵¹ However, it is submitted that the approach to relationship should go beyond the current parameters of the European Court's position on it.⁵²

Relationships of mutuality give rise to what might be termed '**social interests**', which some authors use to mean the incapacitated individual's personal interests in

⁴⁸ 'Family life' may be attributed to: married couples (*Abdulaziz, Cabales and Balkandali v UK* (1985) 7 EHRR 471); cohabitantes with children (*X, Y and Z v UK* (1997) 24 EHRR 143); parents not resident with children (*A and A v Netherlands* (1992) 72 DR 118); adoptive parents/children (*X v Belgium and Netherlands* (1975) 7 DR 75, E Comm HR); and, sometimes, children's relationships with aunts (*Marckx v Belgium* (1979) 2 EHRR 330, uncles (*Boyle v UK* (1994) 19 EHRR 179 cf. *X and Y v UK* (1971) 12 DR 32, E Comm HR), grandparents (*Marckx*, above); also adult siblings (e.g. *Nasri v France* (1995) 21 EHRR 458). For discussion Clayton and Tomlinson, above, paragraphs 13.89-13.110.

⁴⁹ Where 'family life' is established, Article 8 seeks to protect: 'the right to live together so that family relationships can develop naturally and that members of the family can enjoy one another's company', Clayton and Tomlinson, above, paragraph 13.90.

⁵⁰ Parents must be consulted as part of any decision process regarding taking a child into Local Authority care: *W v UK* (1987) 10 EHRR 29.

⁵¹ As such decisions have scope to interfere with 'family life'. However, protecting a child's health might amount to a 'justified' interference (Article 8(2)), provided it is necessary, proportionate and in the child's best interests (*Gribler v UK* (1988) 10 EHRR 546).

⁵² While the Court has upheld the rights of relationship for homosexuals in terms of non-interference in 'private life' under Article 8 (see *Dudgeon v UK* (1981) 4 EHRR 149), exclusion of homosexual and lesbian relationships from parental status in 'family life' (Article 8), or 'marriage' under Article

the wider (non-medical) sense.⁵³ However, 'social interests' deriving from mutual relationships are really a sub-group of an IcP's 'personal non-medical' interests, simply reflecting the overlap of part of the IcP's interest network with that of another significant person's.

It is submitted that any reconstruction of best interests should take account of an IcP's mutual relationships accruing from a grouping of '*emotionally closest*' others. This is capable of admitting any relevant, significant relationship. Relationships of mutuality are significant investments that individuals make in their lives. To ignore such investment surely disrespects the individual. Interests arising from mutual relationships could include: dignity;⁵⁴ privacy;⁵⁵ or concern of an IcP for the well being of mutual others;⁵⁶ and the reciprocal concern of those mutual others towards the IcP. Admitting this sub-group of 'personal non-medical interests' is fundamental to our understanding the identity of the IcP. The two relationships already considered (with self and with mutual others) together create an IcP's 'personal non-medical' interests. A third relationship adds to personal interests.

6.2.1.4.3.3 'Clinical relationship'

The function of this relationship is to inform proxies about the patient's current health situation, his/her competence, and prognosis. The clinical relationship gives rise to an IcP's '**personal medical interests**'. These comprise common interests such as the right to life, freedom from pain, and an interest in good health. Impact on these interests may be determined by the objectively assessable gain/detriment to an IcP's health, flowing from a predominantly medical evaluation of risks and benefits. Traditionally, best interests decisions promote heavily these medical interests, sometimes to the exclusion of other personal interests.⁵⁷ However, there is no apparent reason why this relationship should inform beyond medical aspects into

12 (see Clayton and Tomlinson, above, paragraphs 13.84-13.87) jeopardises the role of relationship in these cases.

⁵³ See N. Cica, above.

⁵⁴ E.g. dignity of the severely incapacitated may be perceived only through the eyes of others; acknowledging relationship allows enduring dignity even of p.v.s. patients.

⁵⁵ Article 8 protects 'private life', including the maintenance of personal relationships, see G.T. Laurie, Genetic privacy, A challenge to medico-legal norms (2002) Cambridge U.P., Cambridge, 249.

⁵⁶ E.g. the physical/mental health, emotional stability, or happiness of that significant other.

⁵⁷ See Cica, above, 195.

moral/legal decision-making about how best to respect an individual. The clinical/IcP relationship informs us about an IcP's 'personal medical interests' but '**personal interests**' are formed by a combination of medical *and non-medical* interests. Hence, all three relationships (self, mutual and clinical) should be taken as sources of input regarding personal interests. The combined personal interests comprise the principal representation of an individual's identity and stakes. However, all three relationships outlined are set against a contextual background.

6.2.1.4.3.4 'Community and State relationships'

Community/State relationships form the contextual framework in which decisions are made. They relate to incapacitated individuals by ensuring that IcPs are treated respectfully and in accordance with their human rights.⁵⁸ Two contexts are identifiable:

- *societal context*, embodies the moral context of the treatment decision, including society generally, and/or the views of recognised groups (such as those representing clinicians, patients or other sectors of society). The societal context can only reflect the mores of a society within a median band of current values;
- *State context* embraces due legal process, and entitlement to common rights, such as human rights.⁵⁹ Treatment decisions may push at the boundaries of the State context as an impetus for legal reform but, until reform is enacted, treatment decisions must remain within the boundaries of existing criminal and civil law.

Contextual frameworks invariably involve certain value judgments: societally, about moral and ethical propriety, and recognition of representative groups; while the State's responsibility lies in structuring due process, and willingness to reform. An individual's interests may arise from relationships with Community and State through his/her interaction with the decision-making process and exercise of human rights. This contextual environment also provides a forum for conflict resolution where, say, the views of those emotionally closest to the patient are contradictory, or

⁵⁸ See e.g. *X and Y v Netherlands* (1985) 8 EHRR 235.

contradict the clinical view, or contradict the community.⁶⁰ A judicial (or quasi-judicial) forum can represent an impartial, unbiased, informed observer. This forum's role would be to identify and relate to an IcP's interests in the widest sense, resolve conflicts, and achieve the best decisions it could for the individual, within the parameters of a framework that reflects the State position on moral/ethical issues.

Excluding any of the four relationships outlined from an IcP's interest network would fail to respect that individual. Each relationship group offers information enabling a proxy to understand an individual, his/her present situation, and explore all relevant impacts on interests. Deny these sources of input and we deny the incapacitated individual. Hence, it is axiomatic that these relationships are acknowledged. Once we identify an individual, and sources of input, we then need to determine what to do with the information we acquire about his/her interests. At this point, networks and perspective become important.

6.2.1.5 Network and perspective

The value of conceiving an IcP's interests as a form of interest network is outlined earlier.⁶¹ A network performs an important function of respect. Where the range of interests and inputs *inform* the decision-maker, a network *describes* an incapable individual's interests. Description is as important as identification because it is a prerequisite to assessing impact. We cannot take account of something that we cannot describe. Further, we must be able to show due consideration.⁶² Clear description is fundamental to express consideration.

6.2.1.5.1 Networks: interests and incapable individuals

A network is a structure on which we can hang relevant interests. A network is a collation of an individual's interest objects.⁶³ A network is an individual description of the IcP we seek to respect. It expresses his/her individuality and mutuality. It is

⁵⁹ E.g. the right to a fair hearing (article 6) and non-discrimination (Article 14).

⁶⁰ As Clayton and Tomlinson, above, paragraph 13.114, suggest regarding interference with 'family life': '[it] requires a fair balance that has to be struck between the general interests of the community and the interests of the individual'.

⁶¹ Chapter 3, above, drawing on the work of Joel Feinberg.

⁶² Due process is increasingly important in human rights – showing due process can indicate an action 'justified' within a margin of appreciation.

not temporally constrained, and can therefore take into account who s/he has been, or may yet become.

The network need not be literally drawn. But it can be carried as a conceptual framework in the awareness of the decision-maker as s/he gathers information and locates its relevance other interests. It is a valuable reminder to adopt a wide, flexible view directed to a clear purpose for this incapacitated individual, and the network accepts the inevitability of conflict and support between interests. The network concept also emphasises individuality; that the *IcP* matters most. By permitting (commonly human) 'prevailing' interests, and having the scope for (personal) 'persisting' interests, a network admits of common welfare goals and individual preferences, thereby according with an ethic of respect.

The network structure allows for inter-interest conflict and support. This reflects the reality that no single interest is 'all good' or 'all bad' in terms of a patient's interests overall. In effect, interests pull and push at one another, but a network concept encourages us to view the network as a whole, and permits the idea too that interests change over time. This reflects the human condition; our lives are not static, our experiences change our values, and we do not hold interests in isolation. However, the structure endures and is flexible enough to accommodate this growth. Hence, a network can be important expression of an individual's interests and identity. How may we respect that?

6.2.1.5.2 Networks: respecting *IcPs*

Primarily, we should be aware that the individual we seek to respect is the **whole** of that network; we do him/her a disservice if we attenuate our focus to certain elements. A decision-maker's role is, therefore:

- to take stock of the broad network as representing the incapacitated individual;
- acknowledge areas of mutuality;

⁶³ Objects are based on stakes, drawn from a potential range of interests and identified by input, investment or commonality.

- note connections (and their directional flow) between interest objects, and take a balanced view of impacts upon them;
- to be aware of network flexibility – it is rarely static, reflecting the nature of human beings whose identity alters and adapts;
- to be aware of how the perceptions of the network vary depending on zonal awareness. That is, our perception of an individual's network depends from which direction we are viewing. Thus, viewed from a clinician's perspective, an IcP's interests may appear differently than from a patient's perspective. The proxy must be aware of the limitations of any single perspective, and be prepared to consider all relevant viewpoints, thereby evaluating information and impact in all network zones;
- and, finally, to negotiate the best path s/he can across the network to an identified purpose, bearing in mind that the network always *belongs* to the incapacitated individual.

Respect, it is submitted, flows from this approach. The framework forms a realistic combination of protective care and admission of individuality - despite incapacity. Decisions may be difficult; a network reflects only the diversity, complexity and contradiction of the human condition. A proxy must make decisions despite this. However, a network approach opens up what is involved in these decisions. Much depends, however, on perspective.

6.2.1.5.3 Respecting individuals through perspective

Let us imagine the IcP's interest network as a three-dimensional landscape, comprising small structures (representing interest objects – nodes on the network) that are interconnected by paths (representing access between nodes). Where access is blocked, due to conflict, a hill is created by pressure. Imagine entering this landscape and scanning across the network's panorama. From our stance we have a clear view of the immediate zone around us. Into the far distance, objects (interests) are less distinct. However, where a conflict-hill occurs, we can see the near slope but not the far side of it. If the hill is big enough to seize our attention, it may

completely obscure our view of distant areas and objects. In short, our single perspective is limited and unsighted in relation to some areas of the patient's interest network. A decision made purely from this perspective may seem perfectly justified in terms of the immediate zone, yet could be appallingly unjustified from other zonal perspectives. Hence, it is axiomatic that our perception must admit the genuine breadth and depth of an interest network.

It is easy to allow our view to be obstructed and, indeed, to forget the existence of anything on the other side. However, the informed decision-maker is aware of more distant zones – even when the view is obstructed from the current vantage point. This *awareness* is key; durable awareness engenders respectful decision-making. Recognising present perspective permits clarity about why an interest is regarded significant, and whether this is motivated by concern for the individual, concerns for mutuality, or for context. It offers respect through honesty and transparency, and precludes dressing-up contextually motivated decisions as individually oriented.

Further, what is herein termed 'zonal awareness' incorporates *belief* in the existence of the other zones of the network, even when unsighted. This respects IcPs by acknowledging their importance as whole individuals, within the lives of others, and as part of society. A proxy should be willing to survey the problem and process from multiple perspectives. This respects the IcP by ensuring all relevant inputs are heard, and a fuller, three-dimensional view is taken. Zonal belief acts as a prompt to view all angles, and to be willing to justify the choice of dominant perspective (if any). Coupled with acceptance that the landscapes of incapable patients are hilly (i.e. full of conflict), and a willingness to examine connecting paths (i.e. impacts) to progress to the (purpose-oriented) far side of the landscape, the zonally-aware proxy has a realistic prospect of making an informed and soundly evaluated decision. Seeing the whole landscape network of the individual (with all its zones), and deciding with integrity for that is maximally respectful.

For example, in a decision whether to sterilise an intellectually disabled adult male, our attention as a proxy may be caught initially by an interest object of bodily integrity; we do not wish to invade his bodily integrity unless to do so benefits him. His interest in sexual freedom and relationship is also a valid object in his network.

But the possibility of his causing pregnancy creates conflict between the two interest objects of bodily integrity and sexual freedom. If we remain static in our perspective this conflict may be all that we see, and our focal point remains the original (bodily integrity). However, if we change our position and survey the network from, say, the perspective of others with whom he might have a relationship, then we discover that the scope for mutuality (of network overlap) with those others is currently significantly limited by protecting his bodily integrity. In effect, this other side of the conflict-hill is obscured in our first perspective. Moreover, this interest in relationship and sexual intimacy is supported by an additional interest object of quality of life. Hence, by changing perspective our awareness of other zones of importance in a patient's network becomes enhanced. We could also consider further perspectives, such as the *clinician's* view of what is involved in surgical sterilisation, and the views from the patient's *care environment* (which may offer more information about the connection between his interest in sexual relationship and his quality of life). It is equally important that we consider the network from the *patient's* point of view, and admit input from him as a means to understanding his feelings about relationships for him. The network is simply a useful, adaptable reminder that our evaluative stance should be as full and extensive as possible.

This chapter has related interests to individuality and respect. Networks have been proffered as a descriptive means of expressing that relationship. However, to respect IcPs it is surely essential that we see them as whole individuals – despite incapacity. To genuinely acknowledge IcPs we must look, it is submitted, at 'whole life' 'over time', considered next.

CHAPTER SEVEN

RESPECT - A SYNTHESIS: RECOGNISING LIFE VALUE

Chapter 7 Respect – A synthesis: Recognising life value

Respecting individuality requires acknowledgement of the components of an individual's life; the values, experiences, and beliefs that make that life uniquely his/hers. The importance of recognising 'whole life' is considered first in this chapter. The second section argues that, to decide respectfully, we should look beyond an individual's current incapacity to view his/her life more broadly 'over time' to gain a better understanding of the individual and his/her life values. 'Whole life' 'over time' is really about becoming as informed as we can be, thereby improving the achievable degree of respect.

7.1 'Whole life'

What makes up a life? The possibilities are infinite. Some aspects have already been outlined (Chapters 4 and 5, above). Genuine respect acknowledges the value of an individual. Individuality is about the *whole* person, cognisance of whom is identifiable from his/her *whole life*. Any failure to recognise an ICP's whole life risks making a decision from ignorance rather than information. Every life is unique in its blend, and we must respect its breadth in order to evaluate the depth - the weighty significance - of its most important elements.

Incorporating a broad sense of 'life' (i.e. biological and biographical) permits an individual's identity, and what is important to him/her, to be comprehensively ascertained. A proxy who is well informed in these regards should be more able to resolve conflict, because the individual's values act as heuristic rules of interpretation. This enables objective and subjective perspectives to be combined. In so doing, we give effect to the notion of residual autonomy,¹ while recognising the simultaneous need for welfare to be assessed too. To see an individual's life as a 'whole', we need to be aware of the connectedness within that life, and the unbreachable connection it has with the individual. Even in the face of complete incapacity that life still belongs to that individual, and we may act only as a respectful caretaker of it. This demands, fundamentally, that we acknowledge that 'life' extends beyond the biological.

¹ I.e. we seek to access any remaining pockets of patient capacity that may be brought to bear on the treatment decision.

7.1.1 Making life 'whole' – beyond the biological

The notion of life being a 'combination' of 'biological' and 'biographical' aspects is made by Rachels.² It is argued earlier that respectful assessments of 'quality of life' should take account of 'life' in both senses because they are interdependent and mutually beneficial. Thus, establishing a biographical life requires a biological existence, and our biological existence is lent greater significance through our biographical life. On this basis, any assessment of the impact upon a person's life should encompass combined senses. Hence, the impact of a treatment option should take account of the benefit/detriment flowing to both biological life (e.g. physical health) and biographical life (e.g. ulterior goals, capacity to engage in valued relationships and experiential interests).

In terms of quality of life, impact can be gauged by how an action improves or diminishes the quality of an individual's biological and biographical life. To some extent this depends on his/her existing quality of life, which can vary considerably between individuals. Hence, a person who is a severely physically incapacitated person may still have a good quality of biographical life, provided that his/her (diminished) quality of biological life is still physically comfortable enough to allow focus on ulterior interests or engagement in relationships and so forth. Equally, a person with no incapacity may have excellent quality of biological life, yet a poor or non-existent biographical life. Thus, the quality of a competent person's 'combined life' can be seen to be based on *a sufficient quality of biological existence to support the quality of biographical life that s/he chooses*. For, even where poor quality of life exists - in one or other sense - the overall quality of the individual's life depends, to some degree, on the combined quality, and whether the diminution in one is sufficiently compensated by the other.

It is not dissimilar for those with mental incapacity. The needs they seek to fulfil in life are of the same type as for competent persons. Admittedly, the content of an ICP's biographical life may differ in degree – s/he may take pleasure in 'small' things that competent persons might overlook or take for granted. But, the importance of those things to the individual is what counts; it is the contribution to his/her

² See above, Chapter 5 where R. Dworkin's emphasised distinction between physical life ('*zoë*') and life as lived ('*bios*') is also considered.

biographical life that matters. Moreover, some needs are essentially the same. For example, the contribution an IcP's relationships make to his/her life may be just the same as those of mentally competent persons; it is merely the nature of engagement that varies. Furthermore, the biological needs of many IcPs clearly replicate those of competent persons; seeking freedom from pain and good physical health is just as important and perhaps achievable. Hence, quality of combined life holds good for human beings generally, whether physically and mentally able or incapacitated. The point at which this appears to break down is where a person is totally and permanently insensate. In a situation such as p.v.s. the patient's biographical life appears presently non-existent. However, his/her *past* biographical life surely can be admitted as a guide to his/her individuality (and views) in the present. Certainly, the absence of any *prospect* of biographical life is something that we must consider in a quality of life assessment. But, arguably, some biographical aspects of his/her life may endure incapacity and remain attributable. Surviving interests are considered further below. Admittedly, the totally and permanently insensate neonate's life is even more limited to biological elements. However, even there, some (albeit minimal) biography can be found in the uniqueness of circumstance that attaches to every individual, in terms of a parental or family bond with the child (despite non-reciprocity), who cares for him/her, and how s/he is cared for. Thus, we should *seek* to locate relevant past biography, and consider the prospects for its future development. However, it may be that in cases of severe incapacity from birth the biographical element is limited to evaluating uniqueness of circumstance (as the totality of individuality).

However, for many IcPs good quality of life is grounded in having sufficient biological quality of life to support and enable the quality of biographical life that s/he can achieve. Together these amount to good quality of life in a combined sense. The starting point of this is to admit interests in their widest sense, embracing the groupings outlined earlier and including relationship as a valuable element. However, the fundamental concept of *combined life* needs to go further. It is argued herein that respecting persons requires that a proxy recognises an IcP's 'whole life', 'over time'. Impact is assessable by the effect on quality of life, but quality of life is often seen as a welfare-oriented concept. Hence, quality of life has the potential to

draw us towards respecting welfare of IcPs, rather than respecting their life in true combination. It is submitted that a better term of recognition and respect is that of 'whole life'. This is definable in terms of the full breadth of that life being uniquely connected with that individual: that the 'combined life' that we recognise is the 'whole' context for that individual's engagement with life's experiences and relationships. The diminution of a person's mental capacity is, too easily, assumed to preclude his/her ulterior goals or biographical existence. In some cases such a reduction will occur,³ but in other cases the incapacity may have been always present,⁴ or may be purely temporary,⁵ or may simply result in different, but no less important, biographical interests.⁶ By keeping in mind that this is the whole of this individual's life, we are reminded that the **combination** of his/her life at any given time is uniquely individual. Hence, while 'welfare' may incorporate quality of life in its combined sense, the role for autonomy remains, in recognition that that life is still wholly individualistic in its combination and is inherently attached to the incapacitated individual. Respectful proxy decisions should consider both of these welfare and autonomy values.

To respect an IcP's 'whole life' we must recognise that – despite his/her incapacity – the individual's life remains entirely his/hers; unique in its combination and quality, unique in its combination of biological situation and biographical engagement. We cannot perfect an IcP's life by curing their incapacity, or even curing any physical health problems – any more than we can for competent patients. We must be realistic about this. Life 'happens' to people both with and without capacity; it has trials and tribulations for all of us. But we can offer to *respect* an IcP by acknowledging the wholeness of life for that individual. However impeded a life might seem to an objective observer, it is still the entirety of life, and it is still unique, for that human being. This is not an argument based on vitalism or sanctity of life. This author is not advocating that treatment should never be withdrawn.⁷ Rather, simply that incapacitated individuals have a combined life, just like the rest

³ For example, in severe incapacity situations, such as p.v.s. However, if we look at whole life, over time, even this need not totally inhibit recognition of life value.

⁴ E.g. in intellectually disability through say Downs' syndrome.

⁵ E.g. where phobia inhibits treatment.

⁶ Illness may cause an individual's personal priorities to change.

of us, that embodies the whole of who they are. It belongs to them wholly and regardless of incapacity. We can honour this by permitting respect for that whole, unique life to be the aim of our decision as proxy. The import of biological and biographical aspects is important to that wholeness. To make a compassionate decision it is imperative that we see an ICP's life in its fullest, widest sense. This requires admission of all that may be relevant to this individual, and recognition of a life in its unique blend of elements. Furthermore, the investments s/he makes can offer valuable information about his/her personal, unique, individual combination, and we need to identify these useful investments as markers that point the way to individuality.

7.1.2 Making life whole: investing in individuality

Investments provide information about some of the stakes that an individual holds in his/her life. Acknowledging these investments enhances proxy informedness, enabling an ICP's individuality to be better respected within the decision. The nature of investment is considered above (Chapter 3). In short, investments include both simple and complex choices about where an individual engages energy and focus. Investments are part of his/her subjective 'experiences' within life. Acknowledging these experiences is an important part of the respect concept posited here.⁸ Investments may, objectively, benefit or harm an individual, but they remain a subjective focus, by his/her conscious attention or sub-conscious action.⁹ Dworkin attributes the very value we accord to life itself as lying in the 'complex creative investment it represents'.¹⁰ The complexity is further increased by the impact of death or illness 'frustrating our investments'.¹¹ Clearly, throughout our lifetime our investments vary: predominantly biological in early life, shifting to heavily biographical during the main part of adult life, which may steadily decline towards the end of life, becoming biologically focused again. Considered in this way, evaluation of treatment options should have affinity with the previous choices and

⁷ That would be an assessment based on a narrowly biological view of life – quite the reverse of the combined approach promoted here.

⁸ Part of the R.E.S.P.E.C.T. acronym outlined in Chapter 6, above.

⁹ A person may *have* an interest through sub-conscious actions, despite not consciously *taking* an interest in that object, nor even necessarily *knowing* (in the sense of acknowledging) of it.

¹⁰ R. Dworkin, above, 84.

human input that a person has made,¹² and should be aware of the scope for future investment in life experiences and relationships. By acknowledging previous investments, and being aware s/he may yet make other investments, we allow the individual's life in its whole sense to be considered. The alternative of limiting our evaluation to a current snapshot restricts our view of the individual; we recognise less individuality by operating from limited information.

However, investments are not definitive. Rather, they are indicative markers of objects that should be considered in assessing an IcP's unique combination of interests. An investment can be seen as a valuable pointer to an individual's interest network: a potential node within the network capable of interacting with other interests in an individual life. In essence, an interest network should reflect the most important investments that an individual makes. Admittedly, the investments we make change over time. We might not make the same investments later in our lives, or with the benefit of hindsight. However, this is part of the fullness of life; that our individuality evolves as a product of our experiences; experiences that each of us interprets uniquely. As proxy decision-makers we cannot aspire to interpret the experiences of another human being as s/he would.¹³ However, we can still respect individuality by identifying, considering and acknowledging the investments s/he currently makes, has made previously, and/or has scope to make in the future.¹⁴ Aliter, if we ignore those investments we also ignore the identity of the IcP – how may we decide respectfully if we do not know about the individual upon whose behalf we decide?

7.1.3 Returns on investment; integrity with identity

The 'return' on recognising individual investments is better decision-making. But this return is only accessible if we employ the information discovered in a manageable, connected way in the decision process. Networks provide the

¹¹ R. Dworkin, *ibid*, 87, whose approach to evaluating degree of frustration (by death or illness) of a person's life investment looks both forward and back in time.

¹² See *ibid*.

¹³ This forms part of the reason for rejecting a pure substituted judgment approach herein.

¹⁴ It is not intended to attribute life value purely in proportion to investments in life. As human beings we can all be regarded as having some 'commonly human' investments in welfare interests that should be respected. Rather, investments are a source of *further* information about the identity of an incapacitated individual, enabling our decision to have more integrity with his/her values.

framework for managing information, enabling us to act with **respect** by seeking a decision that has *integrity* with individual identity.

If we are to be aware of the whole of an ICP's network, and to be able to evaluate impact in terms of his/her whole life, then we must look at *all* relevant investments. Undoubtedly, conflicts will occur in the investments an individual makes. For example, in choosing to become and remain pregnant a woman makes an investment in the life of her foetus. Even if her choice is made unwillingly, it is still a choice, albeit perhaps made in subconscious acquiescence. Having made that investment, she may then choose against obstetric intervention, despite a need for it in order to deliver the baby safely. This too is a choice. Both choices are represented by investment, yet the two investments contradict each other. Both investments are relevant to a decision about intervention because to acknowledge the woman's whole life we must consider all relevant investments.

But, we must also acknowledge that a person's life is a work in progress, a journey of acquired experiences. This does not mean that a later decision should always supersede an earlier one, merely that we must allow every individual where possible to travel his/her own journey. Ultimately, therefore, we respect a person only by allowing them to make their own decisions where able. In the example, the decision authority would still come down to issues of competence. However, respecting her whole individual life involves us acknowledging her early investment (in getting pregnant) by addressing that choice with her, and encouraging her to evaluate its relevance in the later choice that she is now making. Where her competence is in serious doubt, we can still respect her by acknowledging both investments. This would mean ensuring that her (incompetent) refusal has been clearly listened to and acknowledged, because sometimes simply feeling genuinely heard may diffuse conflict or even alter a person's current perspective.¹⁵ This is not about paying patronising lip-service to autonomy, or adopting any type of retrospective 'thank-you' test. Rather, it is about genuinely acknowledging that an individual's life consists of **all** his/her investments - even those that apparently conflict. Our very act

¹⁵ In contrast, by riding roughshod over a person's (in/competent) choice we resist hearing his/her current investment. Our resistance may actually encourage that person to persist further, becoming even more vociferous in their vain attempt to be heard.

of acknowledgement, or of encouraging the individual to acknowledge the whole of his/her investments, may alter the stance that the individual adopts in relation to them, *because s/he feels recognised and respected* in the decision process.

However, ultimately we may still have to make a difficult proxy decision – in the earlier example, either to let the competent woman lose her life or that of her child, or to overrule the protestations of an incompetent woman and offer support to help her come to terms with our choice. But respect flows from acknowledging her life in its whole sense, through her various investments.¹⁶ Of course, the competence threshold is a crucial gateway that determines who makes the decision. However, as a proxy, we should not decide without giving serious consideration to the whole of a person's investments - even an incompetent individual's investments – within their life. Respect is achieved through the giving of that consideration. But, genuine respect reaches beyond current incapacity; 'whole life' is incomplete in according life value unless it is allied to time.

7.2 'Over time' – temporal issues

Seeking a respectful approach warrants reconsidering time in relation to IcPs because it is a potentially valuable source of information that is mostly overlooked. Indeed, incompetence and incapacity tend to be the 'poor relations' of competency. Incompetence is relatively unconsidered as an issue because 'soft' paternalism is often assumed an acceptable solution to decisions for this group of patients. This thesis offers a reclassification of 'incompetence' as a starting point for temporal assessment. The idea of temporal interests is then introduced, together with the notion of an 'ascertained' interest network representing life's value to an individual. Conclusions are then drawn about the character of a genuinely informed decision-maker.

¹⁶ A similar example occurs where an individual refuses life-saving treatment for, say, religious reasons. We must acknowledge that his/her religion (one investment) may be such a fundamental part of that individual's life that s/he values it above all other investments. If we ignore this, we ignore the identity of the individual whose 'best interests' we seek to serve.

7.2.1 Competence over time – reclassifying *incompetence*

The normative construction of competence is considered earlier,¹⁷ and reconstruction proffered in the concluding chapter.¹⁸ Clearly, the construction of competence significantly influences who meets the requisite standard for decision-making authority. However, this thesis argues that input from an incompetent patient may still be relevant: his/her views should still be heard where s/he could express them. For example, while an intellectually disabled person may be unable to weigh up the issues in surgical sterilisation, s/he may be able to offer views about pursuing a sexual relationship. By hearing this input a proxy could better understand the significance and meaning of that relationship which, in turn, influences assessment of risk of pregnancy and the need for contraception. This example supports the argument proposed in this paragraph: ‘*incompetence*’ is complex and demands consideration if we are to accord genuine respect to legally incompetent patients. Recognising competence over time is a means of acknowledging residual capacity of IcPs. Residual capacity is a reflection of subjectivity that can be accorded importance within the RESPECT acronym already outlined. The input that an IcP may offer flows from his/her ‘residual autonomy’. This residue is enhanced by recognising temporality – looking beyond the ‘here and now’ of ‘*incompetence*’.

By attributing to person a ‘lifetime line’ (considered below), and raising awareness of incompetence within the time context, we can credit capacity and/or input where it is due. We all have lives beyond the present moment. When our ability to live effectively within that moment is diminished, by incapacity, our identity remains defined by the rest of life before incompetence and life yet to come. Thus, the decision-maker should recognise this temporal extension as part of acknowledging ‘identity’. **This may mean that an individual’s views prior to incompetence, or during lucid intervals, comprise relevant input.** However, this is *not* about manipulating a person’s past mental history or present inconsistency to generate a finding of incompetence. Nor it is about diminishing the authority of an advance directive now in terms of its future authority. For, even competent persons can only make a decision in the present based on their past experience and estimate of future circumstances. This does not make that decision invalid just because they might

¹⁷ Chapter 4, above.

think differently at some future point or with benefit of hindsight. That is part of the *process* of living and gaining our life's experiences. Rather, it must be emphasised this is simply about *enabling* patients who are under some degree of incapacity to have *input* (wherever possible) by viewing competency in a longer time frame.

To achieve this change we must first consider the nature of incompetence. This thesis submits a new classification of incompetence that connects time with incapacity. It aims to perceive ICPs in the context of their 'lifetime competence'. This then acts as a guide to possible input, possession of interests, and the directive purpose of their interest network. Viewing incompetence in this way allows us to recognise scope for residual input, and permits identity to endure a phase of incompetence enabling more integrity to be attainable in proxy decisions. Incompetence can be classified into three basic groupings: temporal variance; degree variance; and mixed incompetencies.

7.2.1.1 Temporal variance

This concerns individuals whose competence, when seen over time, is at variance with his/her current incompetence. Temporal variation occurs in three forms: **previously competent**; **never-been competent**; and/or **transiently competent**. In all three situations, the patient is deemed 'incompetent' because s/he fails to meet the threshold *at the time of the treatment decision*. However, this does not mean that s/he has always been, or will always be, unable to meet it. By looking to his/her *competence at other times* we may be able to glean input about his/her views and identity, and acquire guidance about interests that persist beyond incompetence.

7.2.1.1.1 Previously-competent

This recognises that the person has been competent earlier in his/her life, but is not competent now. Some previously-competent individuals may regain competence in future (perhaps contingent on a restorative treatment decision made now), while others will remain incompetent. For example, a patient currently incompetent due to concussion resulting from trauma *was previously* competent and may be expected to *regain* competence on recovery - his/her incompetence may be purely temporary. In

¹⁸ See below, Chapter 8.

contrast a p.v.s. patient has also *been previously competent*, but *will not* regain competence again in the future - his/her incompetence is permanent. The *aim* of the proxy decision in both cases is to secure the patient's well-being, but the *objectives* vary with the type of incompetence. For the temporarily incompetent patient, the objective is to restore competence. Whereas, for the p.v.s. patient the objective could be to make a decision about future treatment that has integrity with his/her life. However, despite the differences in objective, both patients were *previously* competent and have a past life of subjective interests, which are assessable as input to the current decision.¹⁹ By acknowledging previous competence and admitting former subjective interests, the proxy is better informed about the individual upon whose behalf he decides. Respect demands integrity. Integrity requires awareness of identity. Previous competence can illuminate identity.

7.2.1.1.2 Never-been competent

In contrast to the first category some patients have never met the minimum threshold for competence; they have not been 'competent' at any point in life. This category may also be subdivided to two groups. While both subdivisions start from the same point of never-having-been competent, a distinction again arises on forward projection between patients who (i) may *become* competent, and (ii) will *never become* competent. For example, a neonate, infant or young child has never been competent, and is incompetent currently. However, s/he may be expected gradually to develop competence in the future (group (i) above). Meanwhile, a neonate or infant suffering from severe mental and/or physical impairment may never become competent in the future, because his/her capacity for cognitive development is so severely undermined, or his/her life expectancy short (group (ii) above). In either case, we may look to current personality to provide relevant subjective input and combine this with common interests to determine the decision. However, any scope for development of future subjective capacity is limited to group (i) patients. What effect does this have? It may influence the range of the patient's forward-looking interest network. Group (i) patients are likely to have a heavier predominance of welfare-oriented focus, and less critical or ulterior scope. Indeed, severe impairment

¹⁹ I.e. experiential, ulterior or critical interests.

may significantly limit experiential capacity and/or capacity to form relationships.²⁰ This does not determine the value of his/her life (in the sense of being 'less' or 'more' valuable), but may locate its combination balance as predominantly biological, rather than biographical. Hence, the 'best' treatment achievable may focus, legitimately and respectfully, on biological objectives.

7.2.1.1.3 Transient

The competence of this group of patients fluctuates. They may be seen to drift in and out of incompetence, with this transience making it hard to rely upon their views in determining the treatment decision. Transiently competent patients could be regarded as including those suffering from mental illness, such as schizophrenia, psychoses, delusions, and perhaps anorexia. These patients may well have been competent previously, and may regain competence in the future (though this may be contingent on the treatment decision at hand, say, in administering anti-psychotic drugs). Admittedly, transience makes assessing subjective patient views difficult. However, merely dismissing a patient's previously-competent views or his/her views expressed during lucid periods, fails to respect him/her as an individual. Whereas, if we admit a patient's input, through either his/her previous or intermittently lucid views (when the patient is generally 'well'), the decision-maker is able to accord more integrity with that (transiently competent) input during the patient's periods of illness. Respect flows from this acknowledgement and admittance of input. We recognise individuality by seeing the IcP as a whole and allowing for transient incompetence within that, rather than the transient incompetence being projected as the whole of the individual.

Awareness that competence varies over time moves us closer to realistic acceptance of ourselves and others as transient, variable creatures - a clearer acknowledgement of human identity and the variance of personality (and individuality) within that collective identity.

However, the nature of incompetence also varies beyond time, through degree (considered next) and combination (considered below).

²⁰ This does not preclude totally any significance for such relationships and interests, but it may influence the relative balance of interest groupings held

7.2.1.2 Degree variance

It has already been argued that IcPs may often have some *residual autonomy* that should be taken into account and respected in any proxy decision.²¹ In essence, because in/capacity is a matter of degree (whereas competence requires setting of a threshold) some 'incompetent' patients may still have a significant degree of capacity. It has been argued herein that these individuals should be permitted input to a decision about their treatment insofar as we can admit their views and concerns, because to do so contributes to our informedness as proxies and respects them by ensuring that their views are heard and considered. These patients form groups that might be termed '**semi-competent**', whereby they are competent in some aspects of their lives but not in others (e.g. intellectually disabled patients who may have some cognitive or affective impairment that limits their competence for some decisions in their lives, but not others). Additionally, patients such as mature minors who may be 'Gillick-competent' or in the process of developing competence, form a further group of degree variance. We can describe them as having '**emerging**' competence. While it is unnecessary to reconsider these classifications further here, it is emphasised that there should be a *general responsibility* on proxies to **maximise the capacity and input of IcPs** wherever possible. For, it is integral to respect that we enable them as individuals to participate in decisions about them to the fullest extent they can achieve. Thus far we have seen how incapacity may vary in time and degree. However, complexity increases where variance occurs in mixed combinations.

7.2.1.3 Mixed incompetencies

The final reclassification of incompetence recognises that the groups already considered are not mutually exclusive. Variation may occur in more than one dimension, causing incompetency to be 'mixed' in one of two ways:

- *between subjects*, that is, where the treatment decision directly affects more than one person. For example, a competent mother refusing life-saving treatment on behalf of her infant, mixes (1) her own current competency with (2) the infant who has never been competent, and

whose future competence depends on the prognosis (and the decision). More contentiously, where a pregnant woman is refusing obstetric intervention due to incapacity, such as phobia, thereby endangering the foetus, this combines: (1) her temporary incompetence (including previous competence and scope for its restoration); and (2) the fetus who has never been competent, and whose future competence is contingent on being born. These situations demand yet more of a proxy's commitment to respect, because by respecting the individuality of one subject we fear disrespecting the individuality of the other. However, simply through recognising temporal aspects of incompetence, the proxy begins to accord respect. Both individuals are at different stages of temporal incompetence, and at different stages of their respective lifetime lines.²² Provided all relevant input is gathered we can acknowledge residual autonomy by really listening to what the woman is expressing in her refusal. Further, we can genuinely engage with the issues by making a clear and full assessment of interests, including the welfare interests of both parties. In this way we are acknowledging the *whole* lives (including temporal and degree incompetence) as far as *time* will allow. This may not provide any 'easy' answer to resolving conflict therein. But, through this process we offer the respect to both subjects that is the maximal aim in these situations;

- *combining time and degree variation regarding one subject*, that is, where a patient's incompetence imports both temporal and degree dimensions. For example, a maturing minor suffering from anorexia has (1) transient competence, depending upon the intensity of anorexic compulsions at any given time, and (2) emerging competence, in the sense that his/her competence is also in the process of degree development. We can also interpret the incompetence of other individuals in both dimensions. Hence, an intellectually disabled adult's competence may be described in terms of degree variation - namely the

²¹ In Chapters 2 and 4, above.

²² Lifetime lines are discussed below.

s/he is semi-competent – and temporally as ‘never having been’ nor ‘likely to become’ fully competent.

The purpose of classifying incompetence by time and degree is to evince incompetence as a complex issue. It is not a simple or all-inclusive category. Certainly, a threshold must be drawn for the pragmatic attribution of decision-making authority. However, below that threshold an IcP is not ‘totally’ incompetent for all time and all purposes. Rather, variance can support individuality of subject even in proxy decisions. Variance over time may warrant input from an IcP’s previous subjective views, or that we acknowledge his/her anticipated future capacity as a good reason for delaying the decision where possible, or minimising the permanence of any impact. Relatedly, transience variation may drive us to seek to ascertain his/her views during lucidity and give effect to those. Alternatively, degree variance may encourage acceptance of an IcP’s input to some aspects of the decision, or attributing more significance to his/her emerging competence than occurs at present.

It is *not* intended for this classification of incompetence to be used simplistically to categorise patients with certain illnesses as ‘incompetent’. Rather the classification is intended to support an argument for better acknowledgement of residual capacity as decision *input*. The present branding of all IcPs as a vague generic class is disrespectful. ‘Incompetent’ persons vary as individuals just as much as those who are ‘competent’. The issues of incompetence are just as complex. Incompetence is a state of infinitely diverse combinations, feelings, beliefs and choices. And, as a state, it fluctuates in degree and over time. If we are to act with the respect posited herein, by viewing IcPs holistically through their lifetime to identify individuality, then we must look beyond current incompetence to locate markers that enable us to know the individual we seek to respect. This is no threat to competence thresholds, for this reclassification of incompetence is about seeing beyond the present moment in order to admit useful input – not to dictate decision-making authority.²³

Recognising the complexity of incompetence is a starting point to understanding the temporal issues involved in reconstructing best interests. Viewing an incompetent

patient's whole life, over time, is a means of actively recognising individual values. It is through our active efforts to do this, and to be compassionately informed, that we respect the human being. In short, it is through our actions and acceptance that we accord respect to another. We can do no more. Having raised awareness of temporal variance in incompetence, we now must progress to understanding how *interests* may vary over a lifetime.

7.2.2 Developing temporal interests

The further relevance of time pertains both to the 'life' and 'interests' of an individual. Each is considered in turn.

7.2.2.1 Lifetime line

Every individual's life is a continuum. Its continuity is manifest in its relentless consistency: a person's life belongs to him/her throughout, and there are no breaks in it – a person cannot step in or out of life temporarily, nor choose to experience only certain parts of it. Even in the face of incapacity (through physical or mental illness, substance abuse, or abdication of self-responsibility), it remains a fact that that period of incapacity is only part of the continuous whole. It is the continuity – the wholeness of it – that contributes to individuality; the unique combination of aspects makes all of those aspects part of his/her journey. The experiences acquired on that journey assist the person incrementally in developing his/her identity over a lifetime.

We can usefully represent an individual's life as a line flowing through time. It flows from biological conception, through the physicality of birth, the physical and emotional development of childhood and adolescence, the experiential development of adulthood (including life events, illness, personal growth, and older age), to death and beyond (including the legacies of ourselves left in the hearts and minds of others). Conscious recognition of an incapacitated individual's life in terms of a lifetime line usefully positions any current healthcare decision as an event in the context of that life as a whole. It reminds the proxy that the IcP is a unique

²³ Allowing an incompetent, non-autonomous patient to make his/her own treatment decision would be disrespectful because it fails to fulfil the welfare aspect of respect. This is not intended here.

individual and that any current decision must consider carefully any future impact and the degree of accordance with past individual investment. Seeing the decision as merely a point (albeit an important one) on the line also reminds us that incapacity is only a state - some patients may have been, or may again become, competent.

A decision of integrity requires knowledge of identity. Broadening the view to encompass lifetime context, of which the present decision is only a part, enhances the view of an individual's identity. However, some pragmatic temporal limits are necessary in order to make this approach workable. *Aliter*, interest attribution and the flow of identity become unmanageable and unhelpful to the decision process. So, where should we set temporal limits? Interests are attributable to individuals. An individual lifetime line could begin from the moment of conception, but a foetus' capacity to engage with the world is contingent on birth.²⁴ In essence, we can regard the interests of a foetus as being future-located until they crystallise into actual interests, based upon a capacity to engage with individual life, upon being born. At the opposite end of a lifetime line, the situation differs by virtue of a life of engagement and experiences that has already taken place.²⁵ It is important that a proxy acknowledges these individual experiences, and interests flowing from them. It is argued herein that such interests may persist beyond entry into severe incapacity states such as p.v.s. (or perhaps even death). The reader is referred to Appendix 5, which represents the lifetime line diagrammatically as a solid line between the times of birth and death, during which it meanders through experiences and crosses the lines of other individuals through mutual relationship. The period between conception and birth can be represented as a dotted line of potentiality, which becomes solid upon birth (recognising crystallisation of capacity for individual engagement in life). Relatedly, an intermittent broken line can represent the period post-mortem, where an individual can no longer exercise his own interests, but interests may still be attributable in recognition of investments made during life, and the experiential memories that remains in the lives of mutual others.

²⁴ Considered above, chapter 5.

²⁵ This need not be a 'lifetime' however, as a healthcare crisis can occur at any point in a person's life, from neonatal stages through to old age. However, life experiences and events accumulate, as do relationships of mutuality. There is no hard and fast rule here; the lives of some individuals may touch many others in a very short space of time, while some persons live long but very independently.

Certain stages identifiable on a lifetime line are associated with temporal incompetence. Regarding 'previously-competent' IcPs, these individuals have attained a stage of adult competence from which we can evaluate investments and identity. For those individuals whose competence can be restored the incapacity stage will be relatively short within their lifetime line. For others where competence cannot be restored (such as p.v.s. patients), the post-capacity stage becomes commensurate with the remainder of their (potentially lengthy) lifetime, until death brings about the post-mortem stage. Where young children are concerned ('never been' competent), some will emerge from their pre-capacity stage, developing capacity gradually, while those suffering impairment may live through various stages of incapacity for much of their lifetime. Severely damaged individuals may never emerge into a capacity stage. Meanwhile, patients with certain mental illnesses ('transiently competent') have a variety of stages of capacity, post-capacity (i.e. incompetent), and post-incapacity (i.e. return to competence) stages. Other individuals, such as those that are intellectually disabled, may remain in a relatively consistent state of semi-competence throughout their lifetime. The stages in their life will pertain to limited intellectual and emotional development in an overall context of incapacity throughout their lifetime.

Hence, a 'lifetime line' is a means of setting the complexities of incompetence in the context of an individual lifetime, acknowledging the various stages, end-points (at its extremes of birth and death), the contingency that may exist before birth, and the legacy that may exist post-incapacity or post-mortem. Further, it reminds us that a treatment decision is made only at one moment in an individual's life, though its impact may extend thereafter. Hence, the proxy has a responsibility to act with integrity towards the individual's broader context of a lifetime. Having set the proxy decision in its 'life' context, we still need to resolve attribution of interests temporally. Where lifetime line is about perspective, temporal interests are about the stakes belonging to an individual that are susceptible to impact by a proxy decision. The attribution of current interests is considered earlier,²⁶ as is the attribution of

Neither is wrong nor right - merely different. But each comprises part of individual life and merits respect. The notion of 'life over time' acts as an aide-memoire of 'whole perspective' for the proxy.

²⁶ Chapter 3, above.

interests *in utero*.²⁷ The remaining contentious issue lies in whether interests can 'survive' beyond entry to permanent incapacity.

7.2.2.2 Can interests 'survive'?

The issue of attributing interests to IcPs who suffer total, permanent loss of capacity severely taxes best interests. However, this thesis contends that respect surely demands respect for the individual now because s/he is already in the process of a life, and his/her prior existence can provide input that assists us in knowing more about them as an individual for whom we must now decide.

The interest concept strongly influences which interests are recognised, to whom, and which values are served.²⁸ However, interests are not static; some endure through a lifetime, while others are fluidly changing during our lifetime experience. The degree to which interests are accepted in a temporal context has important implications for attribution, and for the subjective/objective content. In turn, this influences *how* we might effect 'respect'. The most severe challenge comes from permanent insentience. Hence, this is the focus of this section, arguing that a non-temporal view of interests is too attenuated, and drawing on philosophical debate about 'posthumous interests' to provide a temporally enlightened perspective on IcP interests.

7.2.2.2.1 Interests from the past – defining 'surviving interests'

The 'nil' prognosis of p.v.s. tests the interest concept to its limits. The patient's permanent state of suspense renders his/her life a matter of indifference to him/her in the present.²⁹ Indeed, any forward-looking interest in continued life arguably has also gone because the individual exists merely as a shell, unable to engage (even in the smallest way) in life.³⁰ *Prima facie*, this permanent and total incapacity denies any attributable interests due to an absence of experiential, subjective critical, ulterior, or even welfare interests (due to insentience), either currently or

²⁷ Chapter 5, above.

²⁸ See Chapter 3, above.

²⁹ The term 'indifference' was used in the Bland decision, discussed above, Chapter 2.

³⁰ If, in contrast, a possibility of some future recovery exists then we could regard a person's interests as temporarily 'suspended', but not entirely lost.

prospectively. However, there remains a possibility of interest attribution through the notion of interests 'surviving' entry to p.v.s.

In this regard, Buchanan and Brock suggest that:

'the interests of persons [who were once self-determining] can survive not only incompetence and the loss of personhood, but death itself. Because of the values and preferences an individual now has, he or she may have an interest in the coming to be of certain states of affairs in the future. In some cases the state of affairs in question is not expected to come about until after death'.³¹

Further, that we should look not only at experiential interests, but also those interests

'whose formation presupposed capacities that he or she no longer has but whose satisfaction or thwarting will depend upon events yet to transpire...the application of the best interests principle...requires consideration of both sets of interests'.³²

In essence, this means that a person's interests at any given time can relate to states (or events) occurring later. Applied to incapacitated individuals this would warrant considering any past subjective (critical or ulterior) interests that, then, related to future states/events that have now manifested. In other words, if a patient - while competent - was concerned for the future welfare of mutual others, then that interest may endure his/her subsequent incapacity.

Further support for interest durability can be found in Frey's work. He raises three significant points. First, he concurs with Feinberg's view that

'an interest is something a person always possesses in some condition, something that can grow and flourish or diminish and decay, but which can rarely be totally lost'.³³

This could support a valuable shift in the burden of interest possession; moving from an onus on *proving* interest durability to *disproving* it. Frey then develops his general observation by specifically relating it to incapacitated persons in the context of pain:

'it is an important fact in our thinking about people that the stake they have in the concerns of life is not lost through, for instance, having suffered damage to their nervous system'.³⁴

³¹ Above, 162-163.

³² Ibid, 163-164.

³³ Frey, above, 146, n5, citing J. Feinberg, *Social philosophy*, above, 26.

³⁴ R.G. Frey, *ibid.*

Finally, he suggests that interests should be attributed to these individuals (i.e. beyond insentience) because:

'(i)...the individuals in such cases have vital concerns in respect of what happens to them and theirs, (ii)...these vital concerns represent interests they have, (iii)...these concerns are things in which they have an interest in spite of the fact that they are things in which they cannot take an interest, and (iv)...these interests do not simply vanish the moment an individual...steps upon an anti-personnel mine or lapses into coma'.³⁵

Hence, Frey clearly considers these 'vital concerns' to be markers of interests capable of surviving incapacity. He grounds his attribution of such interests in membership of the human race. This thesis concurs with this in essence; that we feel driven intuitively to respect individuals (even in the way we treat their body posthumously) *because* they have once existed as human beings. But such membership should not be conflated with 'personhood' – which demands reflective capacity and results in Frey's creation of 'special exceptions' for neonates and the severely impaired. Simply 'being' in life, as a human interaction with the world should be sufficient to merit attribution of durable interests. Indeed, this would require respect even of those who are permanently incapacitated from birth. Their worth derives from their status as human beings *simpliciter*.

7.2.2.2.2 Parity with posthumous interests

Other authors, such as Feinberg, expressly use the term 'surviving interests' in the context of a person's death.³⁶ Although p.v.s. patients are biologically alive,³⁷ this approach is relevant because, as Buchanan and Brock argue:

'[i]f interests can survive death, then *a fortiori* they can survive permanent unconsciousness, loss of personal identity, and less extensive departures from competence'.³⁸

Feinberg argues that some interests 'survive' death insofar as they might still be affected by posthumous events/actions. Hence, he concludes that death

'does not prevent us from referring now, in the present tense, to his interests, if they are still capable of being blocked or fulfilled'.³⁹

³⁵ Ibid.

³⁶ See Harm to others, above, 83-89.

³⁷ In p.v.s. the part of the brain controlling functions such as breathing and heartbeat is intact, while higher brain function (concerning consciousness and thought process) is irretrievably damaged. Thus, the patient still breathes unaided, but does not sense pain, or have conscious response to stimuli.

³⁸ Above, 163.

In other words, some interests may still be harmed or promoted after one's death. The examples Feinberg offers all relate to an individual's relationships, which is a limited potential range.⁴⁰ However, the idea of impact persisting was acknowledged historically by Aristotle, who perceived the dead to be affected by the impact of actions on others, but not in an experiential sense.⁴¹ It is submitted that, while a dead person cannot *experience* harm directly, it is surely possible for those things a person leaves behind as a marker of self, such as reputation,⁴² life's work, or achievements, to be harmed. Certainly, we have long recognised a person's wishes in the form of testamentary disposition, and protected a deceased person's property through the mechanism of trusts. Permitting protectable interests in material objects to survive death, while denying a surviving interest in one's identity, lacks respect for the individual as a whole. However, the purpose of establishing that some interests may survive incapacity is to contribute to the proxy decision process. This process has, at its core, an action of 'ascertainment' of an individual's interests by an informed decision-maker. The remainder of this chapter is about applying this action to the whole, incapacitated individual that we can identify. This involves developing the idea of temporal identity outlined towards an ascertainment process within an interest network. Finally, the role of the informed decision-maker will be explained.

7.2.3 Ascertainment

To say that an ICP's interests have been 'ascertained' means that due consideration and process have been accorded to attributing interests to the individual. Assuming that a suitable interest structure and value acknowledgement is in place, ascertainment involves a process of determining the identity of the individual to

³⁹ Harm to others, above, 83.

⁴⁰ Feinberg's examples include: an individual's concerns about well-being of others, maintaining reputation, and the way in which others remember that individual, see *ibid*, 86. This latter example, he regards as an interest in oneself, while the others concern other people. However, while Feinberg sees many self-regarding interests as defeated by death, he acknowledges that not all are defeated because some events 'can harm my interests by forcing nonfulfillment of goals in which I had placed a great stake', see *ibid*, 87.

⁴¹ '[I]t appears that the dead are affected to some extent by the good fortunes of those whom they love, and similarly by their misfortunes; but that the effects are not of such a kind or so great as to make the happy unhappy, or to produce any other such result', *The Nichomachean Ethics*, Book I, Chapter xi.

⁴² While English law does not currently recognise libel in relation to a dead subject, but a duty of confidence may persist legally beyond death of the subject, see *Re C (adult patient: publicity)* [1996] 2 FLR 251, discussed by Mason *et al* (2002) paragraphs 8.68-8.69.

whom interests attach and employing interests in his/her network. We need to know *who* we are dealing with in order to identify *which* interests are relevant.

7.2.3.1 Ascertaining the individual

To act respectfully we must allow IcPs to be attributed with their interests as an individual. The proxy is merely a caretaker who carries out an evaluation exercise that the IcP is unable to do for him/herself. Allowing the unique association (between an IcP and his/her interests) to endure requires a proxy to ascertain *who* the interest-bearer is, as this enables a proxy to act with better understanding. We must ascertain the *identity* of the IcP in order to make a decision that has integrity with that individual.

Identity is part of the continuum notion already outlined. Our identity persists beyond our physical/mental state because it is such a potent projection of individuality.⁴³ However, identity is a complex subject, which has received considerable philosophical attention in relation to the notion, existence and persistence of self.⁴⁴ Debate has centred upon ideas of divided self, and the degree of psychological continuity needed to establish continuing identity between two different selves.⁴⁵

Clearly identity relates conceptually to time. This essentially accords with the 'life as a continuum' idea proffered earlier. However, because identity imports some requirement of self-consciousness or mental activity as a base for identity, this creates problems regarding IcPs.

⁴³ Indeed, Benn's reasons for respecting persons post-mortem are founded not in the notion of surviving interests, but in the important connection between subjectivity and identity, because: '[h]is projects are an exteriorization of himself, projections, indeed, of himself into the world; his identity as a person, qualifying for respect not only from others but also from himself, depends on his sense that they are indeed his own, informed by interests which together constitute him an intentional agent with an enduring nature, not simply a stream of experiences', S.I. Benn, above, 107.

⁴⁴ Early examples are found in the seventeenth century writings of John Locke. A more recent evaluation is D. Parfit's 'Personal Identity', in Honderich and Burnyeat's (eds.) *Philosophy As It Is*, (1979) Penguin, 186.

⁴⁵ See, for example: Parfit, *ibid*; M. Lockwood, *Identity Matters*, in K.W.M. Fulford, G.R. Gillett and J.M. Soskice's (eds.), *Medicine and moral reasoning* (1994) Cambridge U.P., Cambridge, 60; Buchanan and Brock, above, 165-189, discussing the relevance of personal identity to advance directives; and G.R. Gillett, *Why let people die?*, *J. Med. Eth.* (1986) 12, 83

7.2.3.1.1 Identity and incompetent patients

Because this thesis focuses on decision-making for IcPs, a theoretical consideration of the nature of identity would be a diversion. Any discussion of identity must be limited, therefore, to the context of patients with impaired (or undeveloped) cognitive/affective capacity. Identity is based on consciousness of self and this is a matter of degree. Incapacitated patients span a range of self-consciousness. For example, if we apply the varying approaches of Gillett,⁴⁶ contrasted with Lockwood,⁴⁷ to IcPs:

- a woman in labour refusing intervention, but borderline incompetent, is plainly aware of herself and her identity persists despite incompetence;
- the competent mature minor has a concept of self and identity - even though the wisdom of his/her decision may be questionable;
- an intellectually disabled patient's position is more tenuous. Disability may impair capacity for mental function (in terms of Lockwood's interpretation of identity), and/or sense of self (in Gillett's terms). On a strict interpretation, *severe* impairment could deny the patient an identity. However, if a patient has subjective life history, character, and/or some enjoyment of life, s/he may still be a candidate for identity on Gillett's view;
- patients suffering mental illness may have problems central to their identity. For example, s/he may be delusional about his/her identity,⁴⁸ while anorexic patients' views of self differ drastically from an objective observer's. Although these patients have capacity for mental function, their perception of self may be distorted by their mental illness;
- an infant patient may meet Lockwood's view of identity if s/he has the requisite brain hardware for mental function, but could fail Gillett's view as s/he can only fulfil the character criterion at that stage. However, as identity is temporally-related, a future identity could be attributed to an

⁴⁶ Based in life history, character and sense of self (1986) above, 85.

⁴⁷ Based in organisation of the brain to sustain mental processes (1994) above, 72.

⁴⁸ E.g. in Re C [1994] above, the patient had grandiose delusions believing himself to be a medical consultant.

infant if s/he presently has capacity to develop a sense of self and subjective life history later on;

- a severely defective neonate may lack the brain facility required by Lockwood, both currently and in the future. Relatedly, s/he may lack capacity ever to develop any of Gillett's features of identity. It is difficult to attribute 'identity' to such neonates, even on a temporally related view;
- perhaps the most extreme examples, however, are p.v.s. patients, who fail Lockwood's criterion, and no longer possess capacity for subjective life, sense of self, or enjoyment of life posited by Gillett. Certainly, the p.v.s. patient has, currently and prospectively, lost even his/her character. On this basis, the identity of the p.v.s. patient seems lost permanently on entry to p.v.s.

On a straight application of these recognised identity criteria to IcPs the results are hit-and-miss. The potential of a mildly impaired infant transpires to have stronger force for identity than does a patient in p.v.s. Yet, the latter may have already lived forty years of unimpaired self-consciousness; this seems intuitively wrong. Meanwhile, the patient suffering delusions of paranoid schizophrenia has identity – but do we acknowledge his/her (distorted) subjectively perceived identity, or the objective reality? And, even regarding severely impaired adults and infants, are we really prepared to hold that they have no identity to consider? If we do so, we ignore the importance of the individual's relationships of mutuality, and make an overly literal interpretation of individuality being based on *awareness* of identity. Any individual may be unaware of aspects of their own identity, but this does not mean objectively that those aspects are any less part of his/her identity.⁴⁹ Identity theory cannot be enough if, in practical application, it unrealistically results in humans treating other (incapacitated) humans inappropriately.

Furthermore, any straight association between identity and interests fails. For, while many IcPs might lack identity in pure philosophical terms, they do clearly have

interests to be considered. In these cases, a subject exists despite lacking narrowly defined identity. Thus, identity's value - its accepted persistence through time - seems useful, but its theoretical base tends to be too narrow when applied to incapacity. A less restricted, more robust representation of an individual is needed if it is to be workable in respecting IcPs. This is developed here as respecting 'personality', rather than pure identity, as part of individuality.

7.2.3.1.2 Respecting personality through time

The real issue is respecting (incapacitated) individuals. It has already been argued that even severely incapacitated individuals (such as those in p.v.s.) may be attributed with interests that should influence our actions. This is supportable by respecting who that individual *has been*, despite his/her incapacity being permanent prospectively. This practically durable form of individuality accords with the views of Buchanan and Brock regarding identity:

'a person's prudential concern that is expressed in an advance directive can extend beyond the bounds of personal identity to the fate of the human body in which the person once "resided"'.⁵⁰

Personality is an element of individuality,⁵¹ and more inclusive than identity. Personality is simply about the character and uniqueness of the individual. Moreover, it need make no reference to psychological continuity personality could be perceived by others, rather than by the IcP. Hence, personality is not necessarily lost when incapacity strikes. Indeed, as Benn concludes:

'[m]ortality is not wholly fatal to personality so long as such an idea of the dead person remains in the awareness of the living...Understood in this way...the known wishes of a person now dead can still constitute reasons for action for the living'.⁵²

If Benn's view is correct then an individual's (ante-mortem) personality may survive his/her death, for it is still attributable (post-mortem), through his/her (ante-mortem)

⁴⁹ Relatedly, surely competent persons are not any less identifiable as individuals when they are unaware (e.g. when sleeping), or their perception of themselves is distorted (e.g. through dreams while sleeping, or strong emotion while in waking state).

⁵⁰ Above, 185. This accounts for our inclination to accord respect to the dead. As Benn, above 253, suggests: 'we accord the corpse a kind of dignity, by virtue of what it has been...under the aspect of humanity'.

⁵¹ Individuality comprising: biography, needs, preferences, relationships of mutuality, and uniqueness of circumstance.

⁵² Benn, above, 254-255.

relationships with others. On this basis, *a fortiori*, ante-incapacity personality could survive even severe incompetence and remain attributable to a post-incapacity individual, his/her personality persisting in the minds of others.⁵³ Personality perceived through mutuality does not require self-consciousness and need not be complex. Acknowledging personality could be as simple as recognising an IcP's (basic) dis/likes, such as Baby C's liking for her forehead to be stroked.⁵⁴

Certainly personality develops naturally through time. Hence, a neonate has very limited personality, but this develops (subject to the extent of any impairment) as s/he becomes an infant, a young minor, a mature minor and towards adulthood. S/he gains personal, subjective interests as personality develops. We look instinctively to the future capacity of incapacitated minors to develop as individuals and engage in their lives. In essence, we seek to respect IcPs (and individual personality) through time - in terms of what *has been*, what *is*, and what *may become*. The role of interests is to represent stakes and values a person *had*, currently *has*, or to facilitate their development in the future. Thus, although 'pure identity' sets unachievable requirements of psychological continuity regarding IcPs, a broader, robust idea of personality allows us to recognise the individual to whom interests belong. It should be noted that personality is not regarded here as a prerequisite to accrediting respect; rather, as has been outlined above (Chapter 5), respect is merited to IcPs based on their status as *human beings*. Rather, personality is an *additional* source of information about *how* we can respect a particular IcP. It tells us more about whom that individual is as a means of the proxy knowing him/her better. Acknowledging individuality is essential to 'ascertaining' interests; pragmatically we need to let in the idea that individual personality endures incapacity. We must respect personality wherever it exists. Admittedly, personality may not be identifiable in all IcPs (e.g. the permanently insensate neonate),⁵⁵ but for most IcPs it is an access point to information about the individual upon whose behalf a proxy decides.

⁵³ This allows us to view an individual's former wishes, feelings and stakes as exterior representations of his/her personality that endure. Personality is an aspect of subjectivity in the earlier identified acronym of R.E.S.P.E.C.T.

⁵⁴ *Re C (a baby)* [1996] 2 FLR 43.

⁵⁵ Though we may still respect them as human beings and attribute them with commonly-human interests.

7.2.3.2 Employment within network

The final important element of ‘ascertaining’ interests lies in the dynamics of the process; employing interests in individual networks. Interest networks are considered earlier (Chapter 3). ‘Ascertaining’ can be summarised as mapping information and interests within the network frame. This extends beyond identification of (single) interest objects. Ascertaining concerns the following threefold relationships of interests:

- *how* interests interrelate - helping to identify conflict and support within the network overall. Interrelationships are pathways connecting (or veering away from) various nodes. Ultimately, the degree to which interests are mutually supportive, or in conflict, may influence a decision’s weighting; promoting one interest may ‘feed’ others it supports, strengthening the potency of that interest;
- the *purpose* to which interest relationships are directed - it is imperative that purpose is made clear through objectives; the overall aim may be to respect the (incapacitated) individual, but different objectives gear this to the particular situation.⁵⁶ Objectives provide a focus for an individual’s various interests and his/her mutual relationships;
- *areas of overlap* between an IcP’s interest network and the networks of others - acknowledging relationships of mutuality. It is important to keep the decision process real, and most individuals have relationships that may be impacted by a healthcare decision. The flow is two-way; *input* may flow into a decision *from* mutual others, and *impact* may flow from it *to* others. To ignore this reality isolates an IcP inappropriately, because choice to engage in relationships is part of individuality.

In summary, only once the interest concept is soundly and broadly structured, the personality of the subject recognised, and the interests employed in a network can we

⁵⁶ E.g., in a sterilisation decision, respect may be achieved through specific objectives of providing reliable contraception, with minimum bodily infringement, and avoidance of irreversible consequences.

consider the individual's interests 'ascertained'. We should seek to achieve this 'ascertainment' in every proxy decision if it is to be genuinely respectful.⁵⁷

7.2.4 Informed decision maker

The process of ascertaining interests is a central part of 'informing' the decision-maker. It is axiomatic in this synthesis of **respect** that a proxy is *informed*. This involves: comprehensive awareness of issues surrounding interests, competence and input; knowledge about the incapacitated individual; address of preliminary issues, and establishing directive purpose of the decision through respectful individual objectives; and employment of this information in a decision process made with clarity and compassion. **An 'informed' decision-maker is fundamental to this proposed reconstruction of best interests.** A proxy decision that has integrity with the IcP – one that resonates with his/her unique life – must be made from a position of informedness. Informedness is achieved by *ascertaining* interests, and *actively deciding* in the light of those ascertained interests. It remains to consider the role of the decision-maker in choosing actively, with integrity.

7.2.4.1 Decision-maker's role: deciding with integrity for individuality

Ascertained interests are only given real value if a proxy chooses in a way that has integrity with those interests. This demands obvious qualities in the proxy such as non-bias and the willingness to set aside one's own values.⁵⁸ Further, it is submitted, to respect an incapacitated patient we must acknowledge his/her whole life, over time, as a basis of interests and as a means to integrity with individuality in its fullest sense. The role of the informed decision-maker combines objectivity,⁵⁹ and the individual's subjectivity.⁶⁰ Dworkin's views on integrity also support a combined

⁵⁷ It is acknowledged that this desirable position may be unattainable in emergency situations, where the objective could be to stabilise the situation to permit full evaluation. However, 'emergency' status must not be abused; too many situations previously have been inappropriately classed as 'emergencies'.

⁵⁸ Impartiality is now an even more important element of judicial determination of civil rights by Article 6 ECHR (Schedule 1, HRA (1998)).

⁵⁹ Shorthanded herein as 'Truth' in the RESPECT acronym – acknowledging the objectively real circumstances and welfare interests involved.

⁶⁰ Shorthanded in the acronym as 'Subjective Personality, Experiences and Capacity'.

objective/subjective approach,⁶¹ and its being forward and backward looking. Thus, he suggest that

'[i]ntegrity...is the mark of conviction, of commitment, not just past choice; it also reflects investment, the idea that the value of a life lies in part *in* its integrity'.⁶²

Commitment to integrity can be seen as raising a rebuttable presumption that subjective past investments and future commitments (that a patient has formed ante-incapacity) should be recognised and related to the treatment decision post-incapacity. Thus, a patient's subjective stakes form durable interests influencing a decision beyond incapacity, while (objectively) the decision-maker is still able to address current and foreseeable circumstances and take into account other stakes attributable to the IcP (despite his/her unawareness). By considering a patient's subjective interests over time, acknowledging relevant current and future (objective) interests, and seeking to resolve (or choose between) conflicts of interest, the complexity of the interest network (and an individual's 'whole' life) can be honoured.

Hence, the integrity responsibility of an informed proxy is to decide objectively, but with compassion for the individual. In fulfilling this responsibility, s/he must have awareness of, and respect for, the *enduring* nature of personality (as a significant part of *individuality*) and ascertainable interests. The process of respectful decision-making, thus far, can now be concluded as comprising:

- awareness of preliminaries, such as *competence*, and *interest construction*, *wholeness* of **individuality** (which incorporates the IcP's ascertainable *personality*, individual *needs* and *circumstances*, and *relationships of mutuality*) and *temporal* aspects;
- acknowledgement of the **aim** (of respecting IcPs);

⁶¹ See above, Chapter 3.

⁶² R Dworkin, above, 206. Currently, imbalance exists in English law: absence of future commitments in p.v.s. causes lack of interest attribution; the patient's (*past*) *personality* being dismissed as irrelevant. Also, reluctance to recognise the *current* and *past* (*subjective*) views of pregnant women refusing obstetric intervention contrasts with judicial/medical willingness regarding *objective* interests looking ahead to safe delivery (the potential *harm* to her *subjective*, *critical* interests resulting from enforced intervention is ignored). Further: while courts (rightly) attribute *current* welfare and *future objectively critical* interests to neonates, they are less willing to consider past, current and future *subjectively critical* interests of mature minors who refuse treatment.

- derivation of **objectives** for each incapacitated individual;
- **ascertainment** of his/her interests; and
- evaluation of **impact**: assessing how well each treatment option serves ascertained interests in terms of objectives.

The informed decision-maker must be fully 'present', that is, in a state of informedness and engagement throughout each stage if a decision is to have integrity and respect for its subject. Ultimately, however, hard cases will demand choices. Respect requires choice to be made *responsibly in the name of common humanity*.

CHAPTER EIGHT

RESPECT - A SYNTHESIS: RESPONSIBILITY IN THE NAME OF COMMON HUMANITY

Chapter 8 Respect – A synthesis: Responsibility in the name of common humanity

A proxy has to perform nothing short of alchemy, creating the ‘best’ decision from fragments of information and perceived resultant impacts. The proxy role is an immensely powerful, yet onerous, responsibility that must be exercised insightfully. *Responsibility in the name of common humanity* is proffered herein as **a willingness to resolve difficulties and conflicts regarding the treatment of an incapacitated person with a compassionate, benevolent and unbiased regard for their welfare and individuality as a fellow human being.**¹ This amounts to a responsible action even if a perfect decision outcome is unachievable. Humanity is the common bond between all parties in the decision; incapacitated patient, emotionally closest mutual others, advocate representatives, healthcare professionals, wider society, and informed proxy. Respect demands simple recognition of an IcP’s humanity in common with our own (including our human limits of ‘best efforts’). The need to act reflectively is gathering strength through the Human Rights Act (1998), which reinforces equal attribution for fundamental rights to all individuals by virtue of being citizens of signatory States. Improved decision-making for IcPs must embrace ethical and legal issues. This concluding chapter proffers a legal process designed to encourage better proxy decision-making, by way of a route of clear ethical evaluation. Fulfilling ethical acceptability is considered first, legal objectives are then set, and finally a means of legally representing the respect for persons ethic is outlined.

8.1 Respect for persons: ethically acceptable?

8.1.1 Drawing from principles

The value of ethical principle governing medical action is long established and durable. In laymen’s language too, founding decisions ‘on principle’ is common, and principles provide a useful starting point for ethical acceptability. The principled approach in medicine is expounded strongly by Beauchamp and Childress,² and has dominated medical ethics in recent years.

¹ This is represented as Responding Empathetically in the R.E.S.P.E.C.T. acronym already outlined.

² Above.

Beauchamp and Childress' approach offers four normative principles (respect for autonomy, nonmaleficence, beneficence and justice) in a justificatory model that employs deductive and inductive reasoning towards a theory of coherence. Coherence is based on Rawls' notion of 'reflective equilibrium',³ and produces 'considered judgments' that are applied paradigmatically. Any resulting incoherence is subject to further reflection, and action guides (normative rules) are adjusted appropriately through 'specification'. Beauchamp and Childress offer a simple example of the need for specification where a rule that 'doctors should put their patients interests first' conflicts with rules against deception (in the event of a patient needing diagnosis/treatment which is affordable only by falsifying information on insurance forms).⁴ They suggest that conflicting rules

'are not categorical demands, and they stand in need of specification to give fuller, more concrete moral advice to physicians'.⁵

Thus, specification concerns increasing the *content* of rules in order to improve our understanding of their *conditions* of application in relation to particular situations. Beauchamp and Childress conclude that

'[s]pecification is a way of resolving problems through deliberation, but no proposed specification is justified without a showing of coherence. All moral norms are, in principle, subject to such revision, specification and justification'.⁶

The objective of specifying to overcome conflict is framed, therefore, within the process of working towards a 'coherent moral judgment'.⁷

The principled approach has value. It offers relative certainty; and the ethical principles which might apply are relatively easily recognised in any given situation. Furthermore, by seeking some sort of integration, through specification (and reflective equilibrium), conflict between principles can (theoretically) be resolved. Further, the scope for decision-making to be traced (through principles, rules, sub-rules, and particular applications and exceptions) appeals to our human desire to

³ J. Rawls, *A theory of justice* (1971) Harvard U.P., Cambridge, Massachusetts.

⁴ *Ibid.*, 29.

⁵ *Ibid.*

⁶ *Ibid.*, 30.

⁷ See Beauchamp and Childress, above, 13-40.

classify and catalogue. *Prima facie*, therefore, individual decisions are justifiable, which is an important facet of ethical acceptability. Justification enables independent observers to recognise *why* a decision is made as it is. However, while principles justify, do they make for justice? Are 'good' (just) decisions generated by pure principlism?

The principled approach is heavily criticised by Gert, Culver, and Clouser who coin the term 'principlism'.⁸ Fundamentally, they argue that principlism fails to recognise the public nature of morality, fails to distinguish between moral imperatives and ideals, and lacks lexical ranking (therefore failing to offer true action guides). Further, they consider that autonomy as a centrepiece is unclear, and that principlism lacks a mechanism for conflict resolution.

This thesis does not seek to consider ethical theory *per se*, but rather to explore how these theories might facilitate better decisions at a practical level. The most significant criticism on applying principlism to IcPs is that doubts arise about its capacity to resolve conflict. The immense scope for conflict within an incapacitated person's interests has already been emphasised. *Prima facie*, specification of normative rules seems an attractive means of clarifying application in IcP decisions. Indeed, Richardson develops specification as an effective way of resolving conflict,⁹ arguing that specification learns from conflict by seeking qualification, tailoring specification to the issue being addressed and articulating its rationale.¹⁰ In effect, specification is regarded as a form of (reflective) refinement of principles and rules.¹¹

Undoubtedly, *reflectivity* about application of principles to cases is a valuable to any decision process, and developing clarity about the meaning of rules employed is also useful. However, does increasing specification really resolve conflict? This is doubtful, as specification tells us little about any *means* of weighing competing issues or trading-off conflicting commitments. Rather, what specification might create is an increasing range of qualifications and exceptions. Rather than aiding our application this could generate further scope for conflict. Arguably, the specification

⁸ Bioethics, A return to fundamentals, above.

⁹ H.S. Richardson, Specifying norms as a way to resolve concrete ethical problems, *Philosophy and Public Affairs*, 19 (1990) 279.

¹⁰ *Ibid*, 308.

¹¹ See *ibid*, 309-310.

offered as part of a principled approach to conflict resolution still leaves hard cases that too often would fall into the 'exception' category; hard cases are the norm in 'best interests' situations. Moreover, the use of qualification could persistently attenuate our focus to concentrate on finer and finer distinctions between aspects in a particular decision. In relation to IcP decisions, this may result in excessive focus on interest objects (and the conflict therein), which has already been identified as an unhelpful focus in existing best interests decisions. In essence, our attention may be engaged by defining and refining *norms*, rather than focusing on the *individual* concerned. It is submitted that, in order to resolve conflict between their interests (and between our commitments to values), it is better to take a *broader* perspective aimed at understanding *more* about who that person is. Hence, the principled approach alone seems to offer too limited a perspective to respond robustly to some of the conflicting pressures endemic in IcP decisions.

However, the principled approach does have some obvious parity with a respect ethic. The four principles of non-maleficence, beneficence, autonomy and justice are not so different from respect for persons. *Non-maleficence* and *beneficence* can be subsumed within 'welfare', while '*autonomy*' is acknowledged as an important part of respect, and *justice* can be seen as 'due process'. Indeed, most ethical theories seek to empower the individual, minimise harm where possible, and ensure some kind of framework of application. But, resolution through *integration* of all relevant norms is not always possible; sometimes we must rely on an informed moral agent to decide as best s/he can *despite* persisting conflict.

8.1.2 Accepting conflict – a strategy for resolution

Conflict in IcP decisions is inevitable. Every individual experiences mixed feelings, and we make trades-off daily about choices serving, or even acting against, our own interests. The choices in medical treatment can be stark, and incorporate potential for conflict at a profound level. Hence, any approach to decision-making must address conflict successfully in order to be ethically acceptable.

8.1.2.1 Increasing specification?

Although the principled approach seeks to handle conflict by increasing specification towards 'coherence', such coherence is realistically unachievable regarding most IcPs. While some coherence may be attainable between cases through careful specification,¹² this approach risks developing a series of relatively isolated 'exceptions' rather than any normative convergence. Admittedly, *being* specific – in the sense of clarity – helps decision-making. Delineating norms clearly aids our understanding of a broad normative value, and illustrates and invites reflection upon its strengths and weaknesses. However, as a real strategy for conflict resolution that task is simply beyond the means of specification. For, endless specification hits a point of 'diminishing returns' where, rather than contributing to coherence, specification detracts from it. Our efforts to specify become so diverse and divisive that they render overall reflection unmanageable. Relevant norms become lost, disappearing under a mass of further specification. This occludes their original purpose, creating an excess of exceptions. Thus, while specific use of language and purpose is a valuable aid to clarity, endless specification in response to conflict is not the answer.¹³

In addition, the quest for overall coherence could invite over-zealous attempts to make a case 'fit' the general pattern, causing individual injustice and making any 'coherence' superficial and forced. In addition, many conflicts occur *within* an individual's set of interests, where 'coherence' is impossible – no amount of specification will resolve conflict between a person's interests in good health and bodily integrity if beneficial treatment involves invading bodily integrity. Thus, while coherence may be theoretically desirable, in pragmatic terms it seems unattainable. Better we forsake our overblown claims to coherence and rather take the blow of conflict 'on the chin'. We can do this by recognising its omnipresence yet still making an informed choice based on justified reasons. Ultimately, the issue is one of balance.

¹² Via factual distinctions being made clear and drawing the *ratio* of cases narrowly.

¹³ Indeed, Beauchamp and Childress, above, 31, recognise the limits/weaknesses of specification in terms of: continued conflict from competing specifications; inevitability of moral conflict; and potential persistence of dogma/bias etc.

8.1.2.2 An alternative: Respect for human beings

Respect embraces balance at its core. By incorporating both autonomy and welfare as constituent values it presses for acknowledgement of both, despite their possible *prima facie* conflict. **Respect accepts the tension-filled complexity of being human.** Pragmatically, sometimes the ‘best’ we can hope for is an informed, justifiable balance between tense issues. Indeed, even Beauchamp and Childress are driven to acknowledge that in some cases

‘some intuitive judgments and subjective weightings are unavoidable, just as they are everywhere in life’.¹⁴

This author concurs that balancing is a combination of normative reflection - that is, making use of principled consideration to its useful extent - and thereafter relying on an intuitive (and empathic) response to the situation. This is developed further below. The starting point for this approach is **perspective**. To establish an informed (intuitive) balance position it is paramount that the decision-maker adopts a broad view of the issues. This ensures that any conflict is raised not in minutiae, but in relevance to the whole context and purpose of the decision.

Employing respect as the guiding ethic does not dissolve conflict – it does not seek to do so. Rather, it embraces tension. It allows us to acknowledge these tensions as part of individual (and commonly human) experience. It encourages us to accept our responsibility; a proxy is no magician able to spirit difficulties away, but rather an alchemist seeking resolution through responsible awareness. Ultimately, balancing comes down to responsible choice. And respect for persons empowers us as decision-makers; because it demands of us, yet allows for our human limitations. To respect another we must fulfil demanding requirements of informedness, and possess the requisite qualities of a compassionate decision-maker. Yet, our own limits are acknowledged; that the ‘best’ we can do is to decide respectfully, through the process outlined herein, and choosing to balance issues responsibly.

¹⁴ Ibid, 36. Certainly, the principled approach raises valuable elements of ethical acceptability: the importance of reflectivity; the combination of deductive and inductive analysis; clarity; and the significance of justification.

8.1.2.3 Accepting conflict

What, then, is it that we must accept about conflict? First, **that conflict is unavoidable** in IcP decisions. It pervades them at all levels: from conflicting specific objectives,¹⁵ through conflict within the overall interests of an individual,¹⁶ to conflict between interest objects.¹⁷ Further conflicts may arise beyond the individual regarding other stakeholders, such as those emotionally closest to the IcP and healthcare professionals involved. The impact of a decision flows beyond the individual due to mutuality, and the simple fact that s/he is a member of wider society. The role of a decision-maker is analogous to an alchemist, creating a valuable outcome from relatively base elements. Respect is no 'golden elixir' that can relieve the pain of the decision. But, in contrast to singular polarity (heavily oriented to either autonomy or welfare as a panacea), respect for individuals at least acknowledges conflict at its essence because it embodies both potentially polar values (autonomy and welfare). This reminds us that the most a proxy can do is respect the individual by realistically experiencing his/her own commitment to both values.¹⁸

Secondly, **acceptance involves directness in approach**. To *accept* something we should face it squarely and openly. It is submitted that this requires us:

- to acknowledge the real scope for conflict in medical treatment decisions, and its exacerbation in proxy decisions where we also face our own dilemmas about deciding on another's behalf;
- to evaluate the impact of conflicting aspects honestly and in a manner as free from bias as possible,¹⁹ this requires awareness of our own

¹⁵ E.g. trying to prevent pregnancy in an intellectually disabled woman, while simultaneously avoiding invading the integrity of her body or relationships.

¹⁶ E.g. whereby a woman's experiential interests may be enhanced by her intimate relationships, yet jeopardised by risk to her mental or physical well-being resulting from any pregnancy.

¹⁷ E.g. her interest in relationship cannot be served easily without diminishing her interest in bodily integrity.

¹⁸ Which brings this argument full circle to the discussion in Chapter 1, above, about the inherent conflict in dual role commitment offered by Benn.

¹⁹ Freedom from bias is now important as legal right (Article 6 ECHR, Schedule 1 HRA (1998)). Individuals have a right to have civil (and criminal) matters determined by an independent and impartial court (or legal tribunal). Impartiality is rebuttably presumed, but - if raised - requires that an adjudicator be free from undue influence (*Zand v. Austria* (1978) 15 D.R. 70), and have objective non-familiarity with those involved (see *Pullar v. UK* (1996) SCCR 755).

preferences and emotional bias to enable us to identify them as ours - rather than projecting them onto an ICP; and

- to remain open about trade-off and be willing to explain why we arrived at a particular conclusion. This is part of transparent responsible choice, which includes helping others to understand our decision process.

There is risk attached to directness. Being open and direct compels us to acknowledge - to ourselves and others - that we may not have all the answers and that we are human and fallible. It also reflects the reality that proxy decisions may not be definitively 'right' (or 'wrong'), and therefore challenges the assumption that a 'best' outcome is realisable. The conventional conception of best interests sets an impossibly high hurdle, and sets the decision-maker up to fail if s/he fails to produce an 'optimal' outcome. The alternative analysis proposed here requires merely that we make the best decision we can through informed, compassionate and responsible choice. The imperative is to make the effort to arrive at the best decision. This is 'all' that we can do, but it is 'enough' because it characterises human compassion.

8.1.2.4 Resolving conflict

So how does this help to resolve conflict? Conflict resolution is the core difficulty in best interests decisions and resolution starts with the genuine acceptance of conflict already outlined. But, beyond acceptance, resolving conflict is about the dynamics of balancing. Debate about whether a decision is 'best' is really about 'ranking', that is, the relative importance of interests and impacts involved. Complete consensus is not possible on this issue; we live in a pluralistic society where we justifiably feel entitled to our own opinion, and we struggle vociferously against imposition by others. Individuality will always give rise to argument about ranking of values, interests and impacts. Indeed, therein lies the spirit of individuality. However, it opens us to difference of opinion about the 'rightness' of any balance position adopted.

The strategy for resolution lies in accepting that we *cannot* prove our chosen ranking to be 'right' within such a pluralistic value system. However, by corollary, neither can our ranking be 'wrong' *provided* that we have acted respectfully. This is based

on an underlying belief that **deciding respectfully is enough**. While this is open to criticism that ‘best’ should mean *better than all other* possible decisions in the circumstances, it is submitted that if we think this realistically provable or achievable then we delude ourselves. Such a position is simply a mirror image of positing consensus/coherence. This belief is not borne from any sense of failure, rather from a simple recognition that a middle way (whereby we recognise our conflicting commitments and the subject’s conflicting interests) can achieve sound balance. For, by seeing issues from a rounded perspective, and setting aside our own bias, we choose an informed balance point. The capacity to inform ourselves is part of the beauty of being human; we can step in and out of another’s perspective and refine our own view on the basis of information received. This is similar to the reflective equilibrium proffered by Rawls, and applied to the principled approach by Richardson.²⁰ This thesis seeks to marry the valuable aspects of these approaches, and to go further by deepening the connection with temporal and holistic aspects considered earlier, to create a workable process for proxy decisions. The strategy for conflict resolution proffered here lies simply in a genuinely informed decision-maker making an ‘integrity’ decision. This means that: (1) s/he soundly ascertains the individual’s interests;²¹ and (2) fulfils his/her role responsibly in accordance with ‘common humanity’, which is explored in the remainder of this chapter.

Respect provides an umbrella that shelters this process from the harshness of unrealities brought about by polar needs to be proven ‘right’, or to show that the decision is ‘best’, which in turn implies that it is unquestionably ‘right’. Respect for persons aids conflict resolution by providing an environment where the human strengths and limitations of both the proxy and subject are taken into account, and where a balance is justifiable because it is genuinely ‘informed’ and made in the spirit of respect, embracing values of compassion and individuality. Acting compassionately from a position of informed respect is an important part of what it is to be human. This is ‘enough’ because it is *all* that can be achieved – not in the sense of *merely all*, but in the sense that its achievement is *everything* that can reasonably and realistically be expected.

²⁰ Above.

²¹ *Per* Chapter 7, above.

8.1.2.5 Respecting humanity: recognising commonality and individuality

Respecting humanity combines recognition of both commonality and individuality. The case for **individuality** is outlined earlier, based on its vital role and the unique association between an IcP and the interests comprising his/her whole life.²² Recognising **commonality**, at a simple level, is about recognising interests common among humans. Commonly human interests include welfare interests (the minima of comfort and security that facilitate development of other interests), and also critical interests held by humans generally such as interests in dignity, privacy, reputation or raising a family. However, commonality is also about acknowledging common *experience*. This extends beyond interests to recognise context. 'Common experience' denotes persons living their individual lives as part of a social structure. This structure may be an immediate group with whom we share relationships of mutuality,²³ and/or the wider societal group or, at its broadest, as part of humanity. Commonality enables us to share the experiences of others, thereby extending our own experience; allowing it to become common amongst us. Compassion flows from commonality; we can have compassion and respect for another's experience through recognition of our own individuality as part of wider human experience.²⁴

Why is commonality important to IcP decisions? Because to respect persons we must acknowledge what it is to be human. To respect an IcP we must recognise who that person is and what is their experience. This is a combination of individual identity and aspects of shared common humanity. Failure to acknowledge individuality ignores the subject's identity, while failure to acknowledge commonality ignores the context in which an individual lives his/her (uniquely blended) life, and ignores the role s/he plays in relation to other persons. Additionally, conflict is a significant part of common human experience. Recognising individuality within the context of common humanity may help to abate conflict by admitting that a balance position may be individualistic within a range of

²² Chapter 7, above.

²³ I.e. our 'emotionally closest others': partners, friends, family etc.

²⁴ Indeed, even the permanently insensate p.v.s. patient has shared common experiences in the past, and the totally insensate neonate shares in the common status of being human, which imports certain commonly held welfare interests. Further, the experience of others (in caring for and treating these patients) extends the common experience of compassion amongst HCPs and families.

commonly human experience. This obviates a need to evince 'rightness' or 'wrongness',²⁵ such that it will be substantially acceptable if made through a process of respect, informedness and individual responsibility within the commonly human context.

8.1.3 Willingness to justify; degree and strength of justification

As part of individual responsibility, a proxy must be willing to justify the balance point s/he adopts. *Strength* of justification depends on the degree to which a proxy's reasons for that choice are clearly acceptable within the commonly human range. This implies that a checklist of factors can be developed against which any particular decision can be judged. We return to this below, for it has especial significance in the realm of legal regulation of the decision-making process. Perhaps even more important, however, is the proxy's willingness to justify his/her choice with *reasons why* s/he believes it acceptable. For, proxy decisions come down to individual responsibility. In essence, a proxy must be prepared to show informedness and reflectivity to evince his/her respect for the incapacitated individual, and that the proxy has actively sought to make a well-rounded decision of integrity. If so, the proxy has fulfilled his/her role and the IcP has been properly respected as an individual. Certainly, the legal framework should set guidance for proxies regarding the substance of the decision in terms of what a proxy should consider, information sources, evaluation and decision process. Departure from guidance is permissible - as even extensive guidance will not cover every individual circumstance and we must ultimately trust the proxy. However, any such departure should require the proxy to justify his/her chosen position. Hence, respect for IcPs lies both in process and justification.

8.1.3.1 Justification: a prospective process

We often regard justification as retrospective defence of our actions. This still applies in best interests decisions; we should be able to offer good and sufficient reasons (i.e. defence) for having made a particular decision. However, justification

²⁵ A decision could only be 'wrong' if it lay in extreme polarity at the edges of common human experience. E.g. an idiosyncratic position that is extreme in disrespecting the common experience - but such a position would also fail on grounds of bias, narrow perspective, lack of informedness etc.

can be more proactive in resolving ethical dilemmas. By testing a theoretical action guide (a norm) in application, we re-evaluate our perception/belief about whether that norm is really justified. In essence, theory and experience inform one another in terms of establishing degree of justification.²⁶ We adjust our beliefs and norms by experiencing how 'just' they are in practice. While reflective equilibrium is important to Beauchamp and Childress' principled approach, it raises potential criticism as an intuitive element that is too nebulous. Beauchamp and Childress preempt this by incorporating De Grazia's argument that

'the good and sufficient reasons that one offers in an act of balancing can be viewed as a specification of norms that incorporates one's reasons',²⁷

and by formulating five minimal conditions that

'must be met to justify infringing one *prima facie* norm in order to adhere to another'.²⁸

However, as Holm rightly observes, Beauchamp and Childress' conditions are 'totally uncontroversial'.²⁹ The conditions merely reiterate that our choice of balance should cause as little harm (to the patient) as possible, and adding that our assessment of success must be realistic and our infringement (or choice of non/intervention) minimal. Furthermore, Beauchamp and Childress retain a *caveat* that these conditions are not absolute.³⁰

While specification and conditions clarify norms, they still cannot posit *which* norm should be followed when conflict occurs. While reflection is also valuable, the bare fact remains that ultimately balance has to be struck in states of conflict. The problem of balancing is considered below. However, thus far we can acknowledge that:

²⁶ Relatedly, Beauchamp and Childress, above, regard justification as involving deductive and inductive reasoning and develop Rawls' reflective equilibrium to facilitate 'considered judgments'.

²⁷ Ibid, 34, discussing D. De Grazia: Moving Forward in Bioethical Theory: Theories, Cases and Specified Principlism, *Journal of Medicine and Philosophy* 17 (1992) 511.

²⁸ Beauchamp and Childress, above, 34. Paraphrasing, these conditions concern whether: the overriding norm evinces better reasons to act; the justifying moral objective has a realistic prospect of success; no morally preferable alternative exists; that this is the least infringing effective alternative; and that negative effects of infringement are minimised.

²⁹ S. Holm, *Not Just Autonomy: The principles of American Biomedical Ethics*, in J. Harris (ed.), *Bioethics*, Oxford University Press (2001) 494, 504.

³⁰ Scope is retained therefore for a further range of 'exceptions' where outcomes are counter-intuitive.

- justification may play an inductive, reflective function. A proxy may test conflicting norms at various levels of abstraction to determine their degree of justification, which then further inform the decision process;
- to be ethically 'justifiable' a proxy should be willing to: (1) offer reasons for the decision, and (2) show those reasons to be soundly considered.

Much depends, however, on the framing of 'justification'.

8.1.3.2 Recognising justification

If a decision meets the above two criteria it is *potentially* justifiable. But how do we decide whether a decision *is* justified? Certainly, this depends partly on balancing. But it also depends which features we attribute to 'justification'. If we base justification only in our full concurrence with a decision, we are likely to be frequently disappointed. Justification surely is a matter of degree. The work of Gert, Culver and Clouser characterises justification in this way, violation (of a norm) ranging from being '*strongly justified*' (if all impartial rational persons would agree that less harm flows from allowing the violation), to '*unjustified*' (if all impartial rational persons would not allow the violation), through '*weakly justified*' (if impartial rational persons would disagree about the estimate of harm flowing from violation).³¹ In application to the real world of treatment decisions, a consensus of evaluation seems unlikely. Contentious IcP decisions are unlikely to fall in the strongly or weakly justified categories – as a strong degree of consensus posited between IRPs (impartial, rational persons) is probably rare. Most would fall as 'weakly justified' interventions.³² So, in a sense, simply recognising justification as a matter of degree does not resolve how we determine that degree. But the approach of Gert *et al* does raise our awareness of the nature of justification because, by reinforcing justification as degree, we can acknowledge that:

³¹ See Gert *et al*, above, 40-41. In determining how justified a violation may be, they propose a normative standard of an 'impartial rational person'. Rationality' can be contentious. However, they define *irrationality* as: 'act[ing] in a way that one knows (justifiably believes), or should know, will significantly increase the probability that oneself, or those one cares for, will suffer death, pain, disability, loss of freedom or loss of pleasure; and one does not have an adequate reason for so acting. Any intentional action that is not irrational is rational' (*ibid*, 26). Arguably rationality in this public sense is relatively unproblematic; an IRP merely being an unbiased, disinterested decision-maker who avoids unjustified harm.

- moral agents may disagree about whether an action is 'justified';
- realistically many decisions may fall in the (broad) range of 'weakly justified' (and that may be all we can evince);
- disagreement about the degree of justification arises from 1) differences in ranking of benefits/harms, and/or 2) differences in estimated consequences of allowing a violation.³³ In essence, these are both about difference in assessment of impact.

Beyond this, decision-making comes down to balance. Disagreement *will* occur about how issues are ranked and balance struck. Indeed, it is possible to posit, in addition to the approach of Gert *et al*, that a further preferable option is available to us, namely, **recognition of the scope for legitimate disagreement**. This thesis argues for this option because it acknowledges that consensus is frequently unrealistic and even less frequently possible. Rather, we should strive for a state of legitimate disagreement wherein it is accepted that while a particular outcome might not satisfy all parties, it is none the less reasonably and responsibly arrived at. In this sense, then, it is justified. Of course, the question arises, what is 'legitimate'? But this can be settled in large part by reference to the commonly accepted ethical frameworks that can help by setting out an environment that expresses our moral beliefs about what it is to be part of common humanity. So long as decisions are taken within these frameworks there is less scope for legitimate disagreement. Illegitimate disagreement can, then, be disregarded. The framework offered here is that of respect for human beings, as already outlined - a framework that few could legitimately challenge.

8.1.4 No unique solution; best achievable decision

A reasonably and responsibly arrived at balance point may be the 'best' a proxy believes achievable, but pluralism and the nature of justification preclude its being proven 'best' definitively. Hence, 'best interests' is something of a misnomer. Gert,

³² It is unclear why Gert *et al* do not classify such decisions as weakly *unjustified*, rather than weakly justified.

³³ See Gert *et al*, above, 40.

Culver and Clouser, in positing 'common morality' as a 'justified moral system', argue that:

'[i]t is not useful but dangerous to provide a system that can be applied mechanically to arrive at the correct solution to a moral problem; not all moral problems have unique correct solutions. Common morality only provides a framework for dealing with moral problems in a way that will be acceptable to all who are involved; this justified moral system does not provide a unique right answer to every moral question'.³⁴

The valuable point we can derive from this is that there **may be no uniquely 'right' answer to some moral dilemmas**. We tend to talk freely of a solution being 'in a person's best interests', yet more realistically we must accept a proxy's limits. Further pressure is applied by '*best*'; the superlative implies that the 'right' or 'most right' answer to the dilemma is found. Realistically, this is excessively demanding. If we adopt the 'no unique right solution' proposition, then IcP situations can be seen more pragmatically as decisions where no perfect moral answer may be attainable. Rather, a proxy should create **a soundly justified moral solution that seeks to promote the IcP's interests overall**. This is both the maximum a proxy can hope to achieve and the minimum that an IcP can expect. Some commentators may find this unsatisfactory – that 'best' should mean that we could prove it better than all other solutions. But, we must be realistic if we are to improve decisions for incapacitated individuals. Respect and realism are not mutually exclusive. Rather, they are close cousins; if we act unrealistically then we act disrespectfully. Ignoring reality – that these are decisions where the alternatives may seem entirely at odds and equally awful – does the IcP no favour. Furthermore, perceiving a super-level of 'right' decision-making as attainable heaps pressure on the decision-maker, potentially inhibiting rather than encouraging, good clear decision-making and willingness to justify. Indeed, even a competent, autonomous person can only choose an option *s/he believes (at the time) to be 'best' for him/herself*. Only time will tell whether it really was 'best'; 'best' is only determinable retrospectively. **We cannot set a task for proxies that is beyond the reach even of autonomous individuals.**

Certainly, a proxy could – and should – act from a position of informedness and compassion. Further, *s/he* can identify clearly a treatment decision's aim(s) and

³⁴ Ibid, 34.

objectives, and ascertain carefully a patient's interests (including relationship-based ones) and inter-connections. Ensuring due process is followed is another part of honouring an incapacitated individual. But, beyond this the decision becomes the responsibility of the proxy. Impact assessment and foresight of consequences will vary between different decision-makers. The balancing process where conflict occurs is indefinable. In short, we have to trust the decision-maker at this point of the process. We must have faith in his/her self-responsibility as s/he considers information compassionately, evaluates impacts in terms of objectives, and ultimately chooses the option s/he believes best serves the overall interest stakes of the incapacitated individual. To some this may seem unsatisfactory, nebulous even, as a process. But it is disrespectful, to incapacitated subject and compassionate proxy alike, to posit any means of deriving balance that is formulaic, or focused on retrospective, external justification. Better to allow a proxy to do all s/he can to fulfil his/her role, and ensure an environment where an incapacitated individual's interests are ascertained thoroughly and caringly. This is the 'best achievable' decision. For, it allows a proxy to fulfil his/her responsibilities in a humane and respectful way. Responsibility and respect go hand-in-hand; to respect the IcP we must trust in the process and, ultimately, the decision-maker. If we feel unable or uneasy about doing so then we are failing due to breakdowns in the process, or in selecting suitable proxies. It is better to correct those elements than to develop an ethical system that is unachievable in practice, or one that produces intuitively unjust results.³⁵

8.1.5 A balanced ethic

8.1.5.1 The need to balance

The need to balance norms where conflict occurs is inherent in moral decision-making.³⁶ But problems arise in the balancing process. Fundamentally, in balancing conflicting norms (or interests) at any level of abstraction, the crux question is how may a proxy justifiably assign relative weights to those norms/interests? On one hand, even if it were humanly possible to assign totally objective weightings,

³⁵ Indicated by an excess of 'exceptions'.

³⁶ See for example, Beauchamp and Childress, above, 33, citing W.D. Ross, *The right and the good*, (1930) and *The foundations of ethics* (1939) both Clarendon Press, Oxford; Buchanan and Brock, above, 41 and 123; Benn, above, 59-64; Feinberg, *Harm to Self*, above, 25.

decisions so founded would draw criticism for being purely formulaic or utilitarian. Arguably, this lacks common humanity, and disrespects individualism and pluralistic value of life. Alternatively, introducing subjectivity into the process risks criticism of arbitrariness and *ad hoc* decisions that fundamentally lack consistency. This is equally disrespectful. Yet, balancing dilemmas require resolution. In a sense there is 'no answer' to the balancing dilemma, because no answer will satisfy all viewpoints. However, the mechanistic net benefit approach and the formless *ad hoc* approach are both polar extremes. The achievable 'best' probably lies in a 'middle way', combining objective consistency with subjective, responsible reflectivity that is part of the value of human capacity. In short, adopting some sort of 'reflective equilibrium'.³⁷

However, far from rejecting intuition as part of decision-making, perhaps we could wisely embrace it as a means to reflective balancing. The approach preferred herein is '*responsibility in the name of common humanity*', and it is proffered very much as a *process*. Decision-making *is* a process, and balancing a further process within it. In 'best interest' treatment decisions, it is submitted that three stages embody the decision process: network identification; informedness; and realistic consideration. **Network identification** is the stage that determines an incapacitated patient's various interests, interrelationships between those interests, and areas of overlap with mutual others. **Informedness** is the stage of a proxy fully informing him/herself about who the subject is, his/her wishes, personality, investments, and relationships. It aims to ensure that a proxy knows the subject as well as s/he reasonably can to engender a decision that has integrity with identity. In practice, network identification and informedness would occur in conjunction, each facilitating the other. Together they provide the *means* to act compassionately and respectfully. The third stage is about so acting.

8.1.5.1.1 'Realistic consideration'

In acting as a responsible and humane moral agent in the decision-making process one cannot (and should not) detach oneself from that process nor attempt to take a totally objective stance. Compassion is part of what makes us human and connects

³⁷ Posited by Rawls and employed by Beauchamp and Childress.

individuals together across barriers of language, geography and religion. It is one of the most valuable facets of our humanity. We should embrace our capacity for compassion, enabling us to envisage an interest network from the patient's perspective wherever possible, yet combining this with his/her objectively identifiable needs. This **combined approach** does not engender arbitrary/*ad hoc* decisions driven uncontrollably by emotion, or totally objective decisions that lack respect or empathy for the subject. Rather, it adopts a middle way, allowing objective responsible choice to be made from an enlightened compassionate understanding of the patient's issues and interests. But, this path requires that we **trust ourselves as responsible moral agents**; that we are capable of having compassion for another, without compromising our capacity for philosophically sound, legally astute and ethically justifiable decisions. 'Realistic consideration' seeks to create this blend.

It begins from a premiss that all human beings merit respect.³⁸ This avoids the encumbrance of 'personhood' status, accords with our intuitive inclination to treat even severely incapacitated individual respectfully, and averts development of numerous exceptions when personhood criteria produce intuitively harsh results. From this premiss, scope for justification lies in the evaluative process. This is based in a suitable legal environment that encourages clear aims/objectives, factors for consideration, rights of fair representation, and that selects the appropriate people as proxies. Beyond this environment, evaluation is about balancing. And balancing comes down to a matter of trust; trusting the proxy to strike a soundly reflective balance point on an ICP's behalf. Far from weakening a decision it requires an informed decision-maker to shoulder his/her responsibility. S/he must actively trust his/her own judgment – even if that judgment involves an intuitive element. This, it is submitted, is '*realistic*' because having an emotional, or instinctive, response to a situation is part of the human condition. Trust and intuition are not something to be feared or eradicated from decision-making unless we are afraid to trust ourselves, or we have placed decision-making power with the wrong person. Trust is not about blind faith. Rather we can trust in a principle, a process, and/or the qualities of an

³⁸ *Per* Chapters 5 and 7, above.

individual.³⁹ And all of these should be in place in proxy decisions. Admittedly, intuition is often rejected as an unjustifiable way of deciding. Perhaps this is because it has been treated philosophically as separate from reasoning.⁴⁰ Yet, intuition about a choice may surely arise at *any* point in a reflective process. Certainly, it may arise instantly, but also by gravitating instinctively towards a choice that feels 'right'. However, more importantly in a **combined approach** we may experience an inexplicable resistance (at a non-conscious level) to an option by feeling reluctant to choose it. Once we let this resistance into our conscious mind, it frees us to eliminate that option, and return to consider other options more openly. This often seems to occur in ethical approaches where 'counter-intuitive' results accrue, despite a carefully constructed ethical system. These cases are then promptly developed as an 'exception' to the general rule. The problem is that many 'exceptions' involve incapacitated patients; we clearly do already have intuitive responses from a humane perspective about such individuals. It is submitted that better decisions flow from embracing this intuition openly and treating it as valuable, rather than creating endless exceptions in denial of our own human capacity.⁴¹

Notwithstanding, this thesis does *not* advocate making *purely* intuitive decisions. It is emphasised that a firm framework must be established, and proxies carefully selected and expected to reason about impacts on interests *so far as is possible*. Any advocated role for intuition is merely as a means to resolving conflict when reasoning runs out. It is a relatively small percentage of the whole decision process. Certainly, it is difficult to explain and justify an intuitive element of decision-making to an impartial observer. But, it is submitted, admitting it in a combined approach merely makes express a facility that we do already frequently employ but often deny. Surely, doctors making choices of conscience about not carrying out treatments against their own beliefs are making an intuitive response; they feel an action is not 'right' for them. Or, in resource allocation situations, if two patients are very evenly matched in rational terms, on what basis does an HCP choose to allocate? Perhaps

³⁹ See generally, O. O'Neill, *Autonomy and trust in bioethics* (2002) Cambridge U.P.

⁴⁰ Intuition is defined (New Shorter Oxford English Dictionary (1993) Clarendon Press, Oxford, 1407, col.1) as '[i]mmmediate apprehension by the mind without the intervention of reasoning, direct or immediate insight'.

⁴¹ See also Gert et al, above, 3: 'moral theory should be firmly based on and tested by clear moral intuitions', such that moral theory and moral experience are mutually supportive.

s/he intuitively recognises that one patient will fight harder to recover than the other. Judges also surely act from intuition when meting out equity; we trust their instinctive perception of justice and fairness. Of course, these decisions are informed by logical reasoning, but in finely balanced decisions what pushes a decision-maker to choose one course rather than another? Surely, it is in intuitive *sense*, a *sense* that our self-responsibility drives us towards. Intuition informs beliefs. Beliefs, in turn, inform responsible choice. Mill acknowledged intuition as locating 'truths':

'[t]ruths are known to us in two ways: some are known directly, and of themselves; some through the medium of other truths. The former are the subject of Intuition...the latter of Inference'.⁴²

Further, he accorded importance to intuitions within a *process*:

'[t]he truths known by intuition are the original premises from which all others are inferred'.⁴³

This view acknowledges that reason alone is not enough – it is based in some intuitive truths that are 'just known'. In effect, these are fundamental beliefs that inform our reasoning through a process of application and sifting to test the veracity of beliefs against outcomes. This process is exemplified too in the work of Leibniz:

'[t]he human mind is analogous to a sieve: the process of thinking consists in shaking it until all the subtlest items pass through. Meanwhile, as they pass through, Reason acts as an inspector snatching out whatever seems useful'.⁴⁴

From this, Ross, writing on Leibniz, concludes that:

'he could not altogether eliminate the need for judgement and intuition, since the combinatory art was only a method for generating all the possible combinations of a set of concepts. It could not tell you *how* to analyse complex concepts into simples, nor could it tell you which combinations to prefer'.⁴⁵

These scholarly perspectives on intuition elevate awareness that, however sound or extensive our (logical) reasoning, as human beings we cannot escape our faculty for intuitively known beliefs that we experience at a fundamental level. Our need to

⁴² See 'Introduction', J.S. Mill, *A system of logic* (1884) Longman.

⁴³ Mill, *ibid.*

⁴⁴ Leibniz. Cited in *Opuscles et fragments inedits de Leibniz*, Louis Couturat (ed.) (1903) Paris, 170. The approach of Leibniz is succinctly summarised by G.M. Ross in *Leibniz* (1984), Oxford University Press (Past Masters) also published (2000) on University of Leeds Electronic Text Centre's website: www.etext.leeds.ac.uk. Ross construes Leibniz' central idea to be that 'the logic of discovery and that of judgement should be perfectly complementary. Since judgements of truth were always *analytic*, symmetry suggested that the process of discovery should be *synthetic*, or *combinatorial*', *ibid.*, 61.

respect others is perhaps one such intuitive truth. If we trust ourselves as open, responsible decision-makers we will – in cases of severe dilemma when the support of reasoning runs out – be capable of balancing issues to align with this truth.

The parameters of this thesis do not permit debate about intuition in logic theory. However, it is submitted that intuitive sense can be a valuable element of judging the relative weights of impacts in IcP treatment decisions.⁴⁶ In truth it probably already does play a part, but is unacknowledged. Intuitive sense can enlighten and inform the reflective process by inductively feeding back into evaluation of options against interests. Further, it can allow a proxy to ‘arrive at’ a decision where conflicting obligations seem evenly matched. Indeed, where logic and reason fail to produce a result, a sense of intuition may be the only tool left in the decision-maker’s kit.⁴⁷ And no set of criteria can provide *reasons for all seasons*. At the point where a dilemma is intensely balanced a proxy must trust his/her own intuition to provide a ‘sense’ of responsible choice. To restrict a proxy from employing this intuitive sense actually fails to respect him/her (as it manifests our lack of trust in our decision-makers). And, it risks injustice to a subject, because we are not allowing a decision-maker to discharge his/her responsibilities in accordance with common humanity. Admittedly, use of intuition might seem to diminish the transparency or accountability for a particular decision. However, it need not do so provided that the proxy is simply honest about employing intuition regarding certain aspects of his/her decision. Moreover, intuition is advocated here only in *addition* to reasoning and reasons would be required to justify choice insofar as they were available.

In summary, realistic consideration requires a firm framework and criteria for consideration, but it also requires that we choose decision-makers who have the right qualities to engage (and be fully present)⁴⁸ in the decision process. Certainly, we can

⁴⁵ G.M. Ross, *ibid.* 61.

⁴⁶ Indeed, perhaps it best mimics the decision-making of some individuals who arrive at an autonomous decision through sub-conscious ‘knowing’, rather than logical conscious evaluation.

⁴⁷ Some ethical authors regard non-logic based characteristics as valuable. E.g. in virtue theory Beauchamp (Principlism and its alleged competitors, in J. Harris (ed.), *Bioethics*, above, 491-2) highlights that Annette Baier considers ‘sympathy, virtue, and various emotional capacities at least as fundamental in the moral life as the categories of rationality, obligation, justice and rights. She argues that moral philosophy should broaden its scope to consider virtues of caring, loving, trusting, gentleness, and the like’, (A. Baier, *Moral Prejudices* (1994) Harvard University Press, Cambridge, Massachusetts).

⁴⁸ See further below.

train selected proxies in addressing the reflective process generally. And, through reflection, s/he may be able to identify the weightings of some impacts and interests relatively easily in terms of the whole network, enabling a filtering-out of less important aspects. But, when it comes to finely balanced impacts (or options, interests, or obligations), balance is not necessarily a measurable exercise. In short, we can no more tell someone how to 'balance' conflicting issues, than tell them how to balance (successfully) on a tightrope, bicycle, or skates. It is simply something that one acquires through practice, experience, informedness (in an information-based context), and ultimately by using one's senses responsibly. The proxy must combine the structured framework and interest network (i.e. recognising common humanity), with his/her own experience and intuition to find a balance point (i.e. self-responsibility). In short, to trust and respect both the incapacitated patient and the proxy, we must *allow* the decision-maker to act responsibly. This may not engender a uniquely 'right' outcome, but it will create a soundly reasoned, considered, and developed decision. We can expect no more, and should do no less.

8.1.5.2 Justification

How, then, is this synthesised ethic of respect ethically justified? Its justification derives from embracing a series of features that create acceptability. No apology is made for this approach being a 'middle way', because the alternative polar extremes of autonomy or (soft) paternalism are unhelpfully unattainable or lacking in individuality. Rather, this synthesised respect and combined approach to balancing offer a realistic tenor of what is achievable and valuable. The respectful decision process offered herein embodies the following important features:

- **a structured environment** for decision-making. This incorporates clear role definition and factors for consideration being made explicit at the outset. The overarching ethic of respect should embrace both autonomy and welfare, together with additional features facilitating respect across temporal and individual limitations. The aims and objectives of a decision should be clearly set out as a directive purpose. A compassionate proxy, who is open to becoming informed, must be available and s/he should 'ascertain' an IcP's interest network to ensure

the fullest understanding possible prior to making a decision. In sum, this structure facilitates consistency, clarity, and careful, informed decision-making, while still allowing a proxy the flexibility to decide responsibly;

- **openness** regarding both input to, and output from, the decision process. This includes the proxy's openness to identifying the subject's individuality by admitting a wide range of potentially relevant information sources. Further, s/he should be open and transparent about the features considered important to the decision, how interests are impacted, and the reasons for choosing as s/he does. The role of intuition, as an element of decision process should be openly acknowledged in finely balanced, difficult cases;
- **fullness**, of the range of interests an incapacitated individual may possess; IcPs are not deprived of commonly human, or personal individual, interests purely due to incapacity. Fullness also corresponds to the degree of consideration given to an individual's interests; that his/her network should be fully considered and the gravity of the proxy's responsibility recognised. Both of these aspects contribute to a person's interests being fully ascertained;
- **acceptance** of premisses that: 1) all human beings merit respect by virtue of being part of common humanity (and that this accords with our intuitive inclination to treat other humans with respect); 2) all human beings possess interests of some sort; 3) that the incapacitated individual is of central importance in the decision and a proxy must try to perceive interests from the subject's viewpoint as well as from an objective stance. This provides a fuller perspective; 4) conflict between interests and moral commitments is inevitable in many cases; and 5) as decision-makers we are only human. We cannot achieve a perfect decision, nor make any better quality decision (that is definitively and uniquely justifiable as 'the right decision') than we are able to make for ourselves.

Acceptance of these issues encourages us to keep proxy decisions realistically achievable;

- **informedness** accrues in three respects. We need a proxy to be informed about: 1) *background issues*, such as: philosophical conceptions of interests, moral and ethical awareness, the role of self-responsibility, the nature of the 'human condition', and recognition that societal/cultural issues also influence on an individual's interest network. This provides insight to 'commonly human' interests; 2) the *individual subject* through his/her investments, choices, identity/personality, and relationships of mutuality, all of which may give rise to 'personal, non-medical' interests; 3) *objective information* about prognosis and treatment options ('personal, medical' interests); and 4) their *own role* as the decision-making authority in the case, together with the framework within which the decision is to be made, and need for reflective reasoning and use of intuition as part of engagement with the process;
- **focused engagement** of the proxy in his/her role is extremely important. If a proxy fails to engage in the decision process in a focused way then the decision will be correspondingly poor. By 'focused engagement' it is meant that the proxy is *fully present* in his/her information gathering and, particularly, the evaluation stage of the process. Being psychologically fully present means an absence of distractions, and being effortful to involve oneself in addressing information and issues. It also requires awareness of one's own state of involvement (and a willingness to take breaks from the process when necessary, and ask for clarification/confirmation of understanding if appropriate). It means too having awareness of one's own biases, and wisdom to distinguish those from one's genuine intuition regarding the IcP. Most importantly, it demands listening actively to available information and being willing to act with the IcP's interests genuinely at the heart of the decision. This, in turn, requires commitment to openness. Although these are stringent demands a proxy would not be acting responsibly without such awareness, presence and commitment. We must demand a proxy's full

presence within his/her role because, in essence, respect for others comes from making oneself *fully available to genuine contact* with that other (or in this case with his/her interests) during periods of engagement;

- **willingness** to offer reasons for the decision wherever they are available, and to be honest about the significance of using an intuitive sense where reasoning runs out.

These features provide the necessary ethical justification in this approach. Openness and full involvement within a carefully constructed framework are the most that we can demand of *any* decision-maker (proxy or otherwise). If these elements are fulfilled then we can be reasonably sure that the incapacitated individual's interests have been fully acknowledged and considered, and that the ultimate decision is a justifiable one. Furthermore, the process should not be purely deductive, but reflective; the process of **engagement and re-engagement** is important. This allows a distillation to occur, enabling principal issues and conflicts to emerge gradually, and allowing our *sense* of intuition to become more informed through re-engagement. Hence, the decision *develops*.

How justified must a decision be? Well, proxy decisions are deemed here to consist in acting self-responsibly, in common with another human being. Hence, it is submitted if we were able to explain our decision process to the incapacitated patient, and could expect him/her to understand how, and why, we arrived at that choice based on his/her ascertained interests, and for him/her to accept the decision as a reasonable one, then we can consider the decision 'sufficiently justified'. The individual is of utmost importance in the decision, but it is enough that s/he could understand our decision process (if capacity could be momentarily restored) – even if s/he might not arrive at exactly the same choice. For, we cannot hope to emulate the refined decision a person might make for him/herself from a position of capacity. But, by actively engaging in the process outlined, security of justified decision-making should flow from the proxy's combination of self-responsibility and compassion. Trust and respect are mutually creative. If we trust ourselves, we feel able to respect others. In turn, feeling respected, others are encouraged to trust us. Hence, mutual trust and respect can develop. In IcP decisions we must trust the

proxy to uphold the ethic of respect and engage in the process, and we must trust in the individuality of the patient and inputs from others. By so doing, **an alliance of trust and respect may evolve**. The only question remaining is how we can translate this synthesised ethic of respect for persons into a legally achievable framework.

8.2 Respect for human beings: legally representing the synthesis

Which objectives should the law provide in seeking to respect incapacitated patients? And, how can those objectives be created and supported by a legal framework? This final section makes clear *what* the law needs to effect, and proffers guidelines for *how* we may bring about these objectives.

The purpose of deconstructing and reconstructing best interests has been to improve ‘best interests’ decisions for incapacitated patients. It is outlined earlier that consistency is an important factor in improvement. It has been argued that internal consistency – in the form of integrity with an individual’s interests – is of central importance. Additionally, consistency between cases is important, but less in terms of outcome than in consistent decision process.⁴⁹ These concluding paragraphs seek to offer the essence and detail of this process.

The objectives of the process are divisible to three levels: the high-level normative **aim**; **preliminary objectives**, which must form part of the framework before a process is actioned; and **purposeful objectives** that give effect to the essence of the process. In each case, *objectives* are set out, and the *means* of achieving them expressed as bullet points. It is intended that these bullet points could form the basis of *guidelines*, by means of a Practice Direction or similar instrument, which would allow significant change without the formality of wholesale legislative reform. This enables the most valuable elements of the ‘best interests’ mechanism (such as flexibility and sensitivity to individual circumstances) to be retained. Yet, the guidelines also provide a more structured base, and introduce more radical changes to the current approach where they are most needed. Guidelines permit a focused, creative approach to best interests without losing its essence.

⁴⁹ Because individuality may bring some variance at outcome level.

8.2.1 Preferred overarching aim

The overarching aim of reconstructed ‘best interests’ in proxy decision-making is to **treat the incapacitated individual with respect and compassion**. Respect is the purpose to which interests are employed. The nature of this respect has been outlined already as comprising a synthesis of autonomy and welfare, together with an expanded interpretation of ‘interests’, relevance of individuality, and admittance of temporal aspects. In short, we must look at the *whole person, over time*. This includes acknowledging residual competence where possible and relationships of mutuality. The aim provides a focal point for viewing the interests, connections and impacts within an individual’s network. It is the reason why we seek to evaluate these elements. We carry out this evaluation by asking ourselves: *what is in this person’s best interests?* This question connects the interest network with the respect ethic. Furthermore, genuine engagement in seeking that which is *in* his/her cumulative interests is a *proactive* dynamic. It demands excellent information gathering, honest evaluation of harms/benefits, clear interest attribution and focus on the goal. Engendering this overarching aim of respect and compassion has its foundations in the **environment** for decision-making. An appropriate environment consists of: a suitable *decision framework*; an ‘*enabled*’ proxy; and appropriate procedural *representation*.

8.2.1.1 Decision framework

It is submitted that the decision-making framework should consist of:

- a decision forum akin to a quasi-judicial tribunal, and a non-adversarial approach to healthcare decisions for incapacitated patients. This provides a clear locus for decision-making, without the formalities of seeking court orders, and allows the flexibility of best interests to be retained enabling individual circumstances to be considered. Further, a more inquisitorial approach seeks to reduce conflict from the outset;
- a single proxy would sit in any one case. Fundamentally, this accords with the importance of self-responsibility advocated herein. It is submitted that full responsibility encourages a proxy to step up to that responsibility. By corollary, it diminishes scope for hiding behind an

organisational, consensus-oriented or anonymous policy decision. In addition, it meets the criteria regarding judicial forums posited by Stern, namely that expense and delay should be minimised,⁵⁰

- the proxy should be drawn from a register of approved decision-makers, selected because they possess appropriate qualities. This pre-selected register offers expediency in appointing a proxy to any given case. Clearly, good selection criteria are crucial, and the proxies concerned need to be unbiased, without vested interest and able to take a broad perspective.⁵¹
- the proxy represents the decision-making authority in the judicial forum. However, the purpose of employing a forum is to minimise formalities and maximise understanding of the incapacitated individual. This in no way means, however, that a decision should be lightly taken. But, what is sought is a form of therapeutic alliance.⁵² The preferred idea is of all parties involved in an IcP decision being able to sit down around a table, offer their input, make their representations, and for the proxy to have access to this (and more, by being able to request further information where s/he requires). This provides the 'informed' element in the decision. But, decision-making authority rests clearly with the proxy, and s/he chooses compassionately and responsibly in the light of that information. Far from being naïve or ideological, this process brings an element of common sense to proceedings by ensuring, first and foremost, that all parties feel heard; a fundamental way of minimising conflict right from the start of the process.

⁵⁰ See K. Stern, *Advance Directives*, *Med. L. Rev.* 2 [1994] 57, 69-70.

⁵¹ The inquisitorial proxy's role is akin to that of a tribunal chairman - s/he must seek *all* relevant perspectives/input and be unbiased about evidential sources.

⁵² See H. Teff, *Reasonable Care*, *Legal perspectives on the doctor/patient relationship* (1994) Clarendon Press, Oxford, 117-128 who discusses the merits of 'collaborative autonomy' regarding competent patients.

8.2.1.2 'Enabling' a proxy

While framework is a starting point, a proxy must be enabled to fulfil his/her role. S/he must have the power to ascertain interests and to *make a treatment decision*.⁵³

This requires:

- a form of protective jurisdiction regarding legally incompetent minors and adults. The jurisdiction should empower a proxy to consent/refuse or choose between healthcare options on behalf of such incapacitated patients;
- it matters less whether this protective jurisdiction follows the form of historic *parens patriae*, or a modern equivalent,⁵⁴ than its substance being *protective of the IcP*, and enabling the proxy to obtain *all relevant information*, and to *decide actively and responsibly*. To allow a proxy to make the 'best' decision in the individual circumstances, the jurisdiction should be broad and relatively free from restrictions. Any restrictions that are placed upon it should be for the additional protection of the incapacitated individual;
- the jurisdiction should enable a proxy to appoint an Advocate-Guardian, whose responsibility is to speak in advocacy for an IcP to ensure that the latter's views and perspective are presented in health and care decisions.

Legislative provisions may be required to create the framework and permit jurisdictional aspects to be put in place. It is axiomatic that any quasi-judicial forum must be appropriately constituted, and that any jurisdiction must be legally sound. *Aliter*, the framework structure is unstable, and the proxy disempowered. Legislative procedures, conforming to the requirements of domestic public law and European Human Rights provisions, are the best means of achieving this satisfactorily, but the parameters of this thesis inhibit further discussion of these public law matters. However, it is important that any new decision-making process conforms to human rights law. It is this *process* that is of greater interest to our overarching aim in the 'best interests' context.

⁵³ In contrast to merely declaring lawfulness, see Chapter 2, above.

8.2.1.3 Process: procedure and representation

Vital aspects of process, procedure and representation are outlined in turn:

- any decision-making **process** must conform to Article 6 of the European Convention on Human Rights (Schedule 1, HRA (1998)). This provides citizens with a right to have civil and criminal matters determined by way of fair and public hearing, within a reasonable time, by an independent and impartial tribunal established by law. It is a moot point whether a judicial forum would be '*determining civil rights*',⁵⁴ but it is good practice (and ethically warranted as part of 'respect') that the decision process should conform to Article 6 provisions because fairness and respect are close allies. Furthermore, Article 6 would seem to apply to 'any tribunal' in which legal proceedings may be brought;⁵⁶
- Article 6 incorporates an over-riding fairness requirement,⁵⁷ regarding the process as a whole.⁵⁸ The process herein can be summarised as one of 'ascertaining' interests and making the 'best achievable decision' based on that ascertainment. Clearly, this process overall must accord with Article 6, which means that the structure of the process must provide for: an ICP's right to a hearing; that the hearing should be subject to public scrutiny;⁵⁹ within a reasonable time;⁶⁰ by an independent and impartial tribunal. In essence, therefore, to comply with these objectives any proxy decision process must be accessible, transparent, efficient, and

⁵⁴ Such as the more specific responsibilities conferred by the Adults with Incapacity (Scotland) Act 2000 to courts (s2-5), the public guardian (s6-7), and the Mental Welfare Commission (s9).

⁵⁵ Proceedings must be 'determinative' to be subject to Article 6, and some proceedings (such as interim applications) do not amount to 'determination' (see Clayton and Tomlinson, above, paragraph 11.315). However, the combined effect of Articles 6 and 8 is to extend procedural requirements where the issue is respect for family life (see *ibid*, paragraph 13.119). As most cases fall within 'family law', these decisions seem likely to be matters of determining civil rights/obligations, see *ibid*, paragraph 11.364.

⁵⁶ See Clayton and Tomlinson, *ibid*, paragraph 11.324, (and paragraph 11.363: the GMC procedure has been held by the Commission to comply with Article 6, see *Stefan v UK* (1997) 25 EHRR CD130, and *Wickramsinghe v UK* [1998] EHRLR 338).

⁵⁷ See A. Brown, *Law Basics, Human Rights* (2000) W. Green/Sweet & Maxwell, Edinburgh, 40.

⁵⁸ See *Asch v Austria* (1993) 15 EHRR 597, discussed *ibid*, 41.

⁵⁹ To ensure open administration of justice, but anonymity may be retained where necessary (Article 6(1)).

⁶⁰ Reasonableness comes down to particular circumstances, see *Konig v Germany* (1980) 2 EHRR 170. The duty is upon States to construct their judicial systems to achieve this, see A. Brown, above, 48-49, discussing *Caillot v France* (1999).

independent, respectively. It is submitted that this is achievable here within the procedural and representation provisions proffered below. However, as a further safeguard, a right of appeal to a court should be included. If any interested party objects to an individual proxy decision, it should be possible to appeal to a court for judicial determination.⁶¹ Importantly, the right to a court accorded under Article 6 seems to propel 'best interests' decision-making away from reliance on Bolam. As Maclean highlights:

'[a]ny judicial refusal to review the doctor's opinion concerning the patient's best interests would arguably breach Article 6'.⁶²

Indeed, the pressures of Article 6 may be greater. As Clayton and Tomlinson suggest:

'it is arguable that the obligation to ensure effective access to the court means that the court will have to address the issue of the patient's best interests directly'.⁶³

If so, this is a welcome gift of clarity and responsibility. Good practice demands that any tribunal proxy also gather up this responsibility willingly. The 'ascertainment and decision' process is given effect through the fundamentals of procedure and representation;

- the **procedure** should be inquisitorial in character. An appointed proxy should act as a compassionate inquirer into an IcP's stakes, relationships and individuality. The purpose of gathering this information is to establish an individual's interests - his/her stakes in life;
- to respect an IcP a proxy should seek to ascertain any of an individual's relevant views to the extent that they can be communicated. This opportunity is important as a means to finding the subject's personality in order to understand how a treatment decision might affect him/her. If

⁶¹ The right of appeal is an important safeguard. It is retained under the new Scottish legislation, see s50(3) and s50(7) of the Adults with Incapacity (Scotland) Act 2000. Furthermore, Article 6 ECHR also provides for judicial review of tribunal decisions.

⁶² A. Maclean (2001) above, 788.

⁶³ Above, paragraph 11.367.

necessary, the proxy should go to the IcP for this part of the procedure.⁶⁴

Where a person has been competent previously, any formal Advance Directive should be considered, or any relevant informal statement heard;

- if we are to ensure the individual patient is represented throughout the process, then the views of any Advocate-Guardian should be established and considered;⁶⁵
- additionally, to address the reality of individual lives, the proxy should consider any role or relevance for the views of others with whom an IcP has a relationship of mutuality;⁶⁶
- the inquisitorial procedure is geared towards gathering information about the stakes that make up an IcP's life, and establishing the identity of the individual upon whose behalf a decision is made. This information stage is crucial to respect. The quality of a proxy's understanding, evaluation and balancing are directly correlative to his/her degree of informedness;
- beyond this informedness, the procedure is one of a proxy sifting and assimilating what s/he has heard: (a) to ascertain the incapacitated individual's interest network (within an awareness of the contextual framework of State and society), and (b) to evaluate and balance impacts in working towards the best decision achievable for the individual IcP in light of that ascertained interest network. There can be no procedural guidance about this stage, because this is the point at which we must trust the proxy decision-maker's quality of compassionate respect, and trust in the process already outlined of informedness, open ascertainment and therapeutic co-operation to ensure all relevant voices have been fairly heard and considered. Ultimately, we must trust a proxy to fulfil his/her decision responsibility and allow that proxy the space so to do. *Aliter*, we undermine the scope for flexibility and individuality available to IcP's through best interests;

⁶⁴ E.g. if the incapacitated person is restricted physically from attending, or if it is conducive to respectful understanding to see an IcP in his/her own environment.

⁶⁵ The role of Advocate-Guardian is outlined below.

- procedural safeguards remain, however, in the form of a right of appeal, and the importance of **patient representation**. Each incapacitated patient should be properly represented as an individual within the process. This representation is termed herein an Advocate-Guardian (AG). While some existing legislation allows for guardianship,⁶⁷ too little emphasis is currently placed upon advocacy. A person specifically representing the IcP emphasises the central importance of the patient throughout the process. The Advocate-Guardian's role is to ensure that an IcP's views and interests are heard. An IcP might appoint an AG during some period of competence (prior to entry to incompetence, or during intermittent lucidity). Alternatively, in the absence of such competency, the proxy could appoint an AG. The Advocate-Guardian's sole focus should be the incapacitated patient; to represent the IcP's views and inform about day-to-day life for that person, yet without taking responsibility for actual decision-making. It seems advisable that an AG should be independent of close relationship with the patient in order to minimise any personal agenda. Thus, an Advocate-Guardian appointed by a proxy could be drawn from a pool of suitably trained professionals whose role is to act, in effect, like an *amicus curiae* who engages in observing and communicating with the patient to provide an additional information source. It is not his/her role to judge the patient, but rather to get to know him/her. However, it is recognised that a patient appointing during a competent period should be free to choose a representative individually, and this freedom should extend to selecting an AG from a relationship of mutuality;
- an appointed AG should always be consulted in treatment decision as a significant source of information. S/he is not involved in the *decision*, but would have the right to appeal a decision if s/he believed it contrary to an IcP's interests. In this regard, an AG constitutes an additional safeguard to an incapacitated patient's interests. An AG would be

⁶⁶ This clearly would incorporate parents in relation to children as is now required by Human Rights provisions in the context of interference with family life.

expected to spend time with a patient to get to know his/her preferences, beliefs, concerns, understanding, relationships, and lifestyle. This information s/he then offers to the forum in representing the patient. A proxy could, and should, substantiate this through personal interview with incapacitated patients where appropriate. It must be emphasised, however, that this new form for decision-making is regarded very much as a *process*. Information gathering could be a back-and-forth process. Gathering all interested parties around a table is not envisaged necessarily to be a once and for all decision. Rather, it is about gradually sifting all available information to determine the most relevant aspects. This process may involve one or several meetings, information exchanges, requests for clarification, interviews with an IcP and/or other interested parties, and consultation with professionals at all levels. While this may be laborious and time-consuming it is necessary if we really want to improve decision-making.⁶⁸ Effort is the expense of better ‘best interests’, where patients are heard, considered and respected as human beings with feelings and beliefs important to their individual lives.

8.2.2 Preferred preliminary objectives

Within the framework, certain preliminary objectives must be allowed space. Appropriate construction of these preliminary issues reinforces the strength of the framework and supports the rounded perspective of the proxy. Two preliminary objectives are identified: a) **competence** construction; and b) clear assessment of **risk**. These are identified earlier as important issues in the environs of ‘best interests’. Others may yet arise and could be embodied as ‘preliminary objectives’ if their influence in the decision process is indirect (rather than as a directly considered ‘factor’). Such objectives are ‘preliminary’ because their construction can be

⁶⁷ E.g. in the Adults with Incapacity (Scotland) Act 2000.

⁶⁸ Clearly, a genuine situation of medical emergency may prohibit such a process. As an ancillary issue, it is also recognised that it is not practical for every minor procedure to be referred through the whole process outlined herein. Hence, some general authority would need to be made to permit HCPs to carry out routine healthcare procedures (or daily care routines) for IcPs. However, if any interested party (including the IcP) objected to these procedures, then this process for determining the IcP’s best interests should be initiated.

determined *before* any decision process is actioned. An individual decision simply applies them as part of the framework.⁶⁹ The construction of preliminary objectives is consistent and applicable across the full range of incapacitated patients.

8.2.2.1 Reconstructing competence

Competence is included as a preliminary objective because it is the starting point, a gateway to the proxy decision process. It is the prerequisite assessment determining who makes a treatment decision. A finding of 'incompetence' opens the gateway for the process to become activated in an individual case. The constituent elements of competence have already been considered, and a reconstruction of *incompetence* submitted.⁷⁰ Here, it is intended to summarise the objectives considered important for any construction of competence in view of the position of incapacitated patients:

- respecting others requires that autonomy be respected wherever feasible. Autonomy is based on self-determination, and the latter requires competence. Hence, if we are to offer maximal respect then we must also maximise patient capacity. This means that we must not set the standard for competence exclusively high, nor assume that everyone suffering from incapacity is incompetent;
- competence assessment should be carefully focused. A person needs to be competent for the treatment decision at hand; s/he need not be globally competent. Global competence is unrealistically idealistic – no one is competent for *all* decisions.⁷¹ All persons (competent and incompetent) have areas of varying competency. It is respectful, therefore, to limit assessment to a real treatment decision rather than demanding elusive, hypothetical, generic competence;
- ability to understand and use information is preferable to actual understanding and use. The latter requires that a person justifies and

⁶⁹ Whereas, 'purposeful objectives' are elemental to an individual decision – they embody that process, their nature and impact differing between individual cases in response to individual purpose.

⁷⁰ Chapters 4 and 7, respectively.

⁷¹ Arguably, some patients might be *incompetent* for all decisions, however, if they are in a state of permanent, total insentience. However, if these patients have previously been competent individuals we may be able to ascertain guidance from evidence of their previously-held views.

explains his/her thought processes and could preclude unwise choice by even highly autonomous and articulate individuals, whereas ability maximises patient capacity. Understanding is cognitive, while use is about being able to relate to the information, engage with it and choose. If a person meets the ability criterion we should respect his/her competence, irrespective of the outcome of his/her decision;

- a threshold approach to the requisite standard of competence is inevitable. The standard should be realistically achievable. A 'functional' level is consistent with this, in setting ability to understand and use information at a relatively basic level, across all relevant information, such as: the need for treatment, treatment options, risks, benefits and impacts of non/treatment. Some incapacitated patients may be capable of meeting this requisite ability to understand the specific task in hand; mental illness, intellectual disability, minority, and pregnancy do not definitively preclude competence. The assessment of competence, to be respectful, must look at the individual in each case. By keeping the competence profile symmetrical, and ability functional the threshold is set to maximise patient competence. In essence, to accord competence where it is due;
- even with a functional standard, natural variance will occur. The ability to understand and use information remains consistent, but the exact nature of information varies with individual situations. Hence, *what* a person must be able to understand and use will vary for every individual. In other words, the breadth of relevant information is individual, but the depth of ability remains the same. Natural variance is part of individuality;
- 'competence' should not be equated with 'input'. While a pragmatic threshold must be set for competence as a gateway to decision authority, the *concept* of competence is degree based. We can give this meaning by acknowledging that, even where a person is not competent to make a decision, s/he may still have relevant input to the decision. Respecting

individuals means involving them in decisions on their behalf. We must listen to their views, preferences, wishes and fears.⁷² To trivialise the views of an adult woman in labour, or the concerns of a mature minor, or the preferences of an intellectually disabled person, disrespects that individual's individuality, and elevates inappropriately categorisation by situation, age or impairment. It is dangerous and arrogant to assume that we can determine what is in a patient's best interests without making ourselves properly informed about that individual and his/her interests. If a decision-maker trusts him/herself, and roles are clearly defined, s/he has nothing to fear - and much to gain - from gathering all relevant input;

- affective disorders, such as pain, stress, environment, delusion, misperception, depression and phobia can render a person incompetent. But, to do so, they must be relevant to the decision at hand,⁷³ and impose a degree of incompetence that makes the person incapable of understanding and using information.⁷⁴ This impact must also occur at the time of decision-making.⁷⁵ Affective factors are at play on every individual in the context of medical decision-making – even the most competent. It is a matter of degree whether they impact inhibitably. To determine this degree requires us to listen to an individual. Indeed, his/her views could be the same irrespective of competence. While we should treat irrationality cautiously – it may be symptomatic of incompetence - it could simply characterise individuality. A person's view may be no less strongly held simply because s/he cannot sufficiently understand (cognitively), or apply (affectively), the issues to him/herself. We must listen to individuals to find out who they are.

⁷² E.g. in affective impairment a person may be able to understand cognitively, to relate information to self and engage with it, but merely cannot choose. It is respectful that decision authority remains with a proxy – but that listening to those stages of competence that the individual can achieve enhances a proxy's informedness.

⁷³ E.g. a schizophrenic may be delusional about his/her identity, but may genuinely recognise his/her illness, need for treatment, and impacts of non/treatment.

⁷⁴ E.g. depression or physical pain may diminish, *but not necessarily preclude*, an individual's capacity to relate or engage with information, or to choose.

⁷⁵ Hence, a person's mental history of depression may be completely irrelevant to a current decision. Assessing on a historic basis disrespects the reality that people recover and change.

Failure to recognise individuality – whatever the competence status – fails to respect the him/her;

- other capacities may be relevant to competence assessment. An IQ test tells us relatively little about an IcP's capacity for understanding and using information, and even less about their relationships and interaction with environment. To maximise an individual's capacity we should make a broader assessment of his/her cognitive and affective understanding, together with functioning and capacity for expression. Even if s/he is still found incompetent to decide, a proxy decision-maker will be better informed about the individual and it provides scope for patient involvement and input;
- communication is crucial. Terminology used to impart information about need for treatment, options, and risks and benefits can significantly influence anyone's ability to understand. Tailoring communication to a suitable format does not necessitate limiting information, but does require use of simple clear language, and possibly alternative communication methods beyond purely verbal or written. Careful communication fundamentally respects the individual; it seeks to ensure that *this* person has the maximum opportunity to use their ability to understand. It does not make assumptions about a person's ability to understand based on an incapacitating condition, or on a benchmark of 'normal'. Rather, it seeks to access capacity wherever it lies;
- possession of competence and exercise of competence are different. Although a patient may *currently* be incapable of *exercising* any kind of competence (for example, due to states of delusion or unconsciousness) a straight denial of any possession of competence is shortsighted. Maximising patient capacity should recognise temporal competence.⁷⁶ The patient with delusions may be 'transiently competent', and the unconscious patient 'previously competent', respectively. This would permit their views during periods of lucidity, or prior to entry to

⁷⁶ Discussed above, Chapter 7.

incapacity to be considered. Such consideration respects another human being in his/her fullest sense, by seeing beyond the incapacitating illness to the individual;

- maximising patient capacity is not about finding the incompetent to be fictitiously competent. It is about recognising a patient's incompetence, yet enabling him/her to inform us and to be as involved in the decision as is realistically possible. To respect IcPs we must maximise patient capacity. *Aliter*, we see not the individual but the illness. In truth the illness is part of the individual as a whole – respect demands that we recognise the whole patient and decide motivated by his/her interests. Competency is a gateway determining who makes the decision, and competence requires informedness. Input from the individual (and others) informs. To offer respect, and for the sake of our competence as decision-makers, we should **maximise patient capacity**. Competence construction must fulfil this preliminary objective of respect.

8.2.2.2 Risk assessment

Risk assessment is considered earlier. Risk is important as a preliminary objective because it is the second gateway through which some treatment decisions (such as sterilisation) must pass to warrant invoking the proxy process.⁷⁷ It is essential that it is suitably framed so as the process is invoked in appropriate cases. This requires:

- distinguishing consequences flowing from a risk from the likelihood of its occurrence.⁷⁸ While the consequential events that could result from non/treatment may be serious (if they happen), the probability of their occurring may be minimal. Alternatively, the consequences may be quite mild, but are highly likely in probability terms. Any proxy must be clear whether a risk exists to such a degree that some form of treatment is 'necessary' at all.

Beyond this gateway role, risk assessment is still important:

⁷⁷ The first gateway being incompetence.

⁷⁸ See Carson, Risk-taking policies (1980) above, and Chapter 2, above.

- the approach to risk should be *balanced*. That is, a proxy should be open and even-handed about his/her assessment of the consequential harms and benefits likely to flow from various treatment options. The ‘risk’ to the patient’s interest network should be honestly assessed. As decision-makers we must ensure that we do not become affectively incompetent. We too are subject to influence by environment. It is easy to stumble into viewing a situation as (unrealistically) ‘urgent’ when caught in the hype of treatment pressures. Relatedly, it is fallacious to deem a treatment ‘necessary’ if we have failed to look seriously at viable alternatives. Acting on the basis of consequence-driven risk assessments encourages this skewing. Respect requires openness to establishing balanced information about options, risks and benefits. There is no need to manipulate information unless we are running scared of a rounded, genuine perspective. This is an important prerequisite to informedness;
- serious or grave consequences of a treatment decision simply mean that more information abounds for consideration; we (or a patient) do not have to be more *competent*, we need to be equally competent but more **informed**. We need to ensure that we have looked at *all* relevant information before making our evaluation of best interests. Of course, the consequences flowing from non/treatment are relevant. These foreseeable outcomes will significantly impact a patient’s life. However, their role is to inform our decision, not to drive it. Individual interests should drive best interests. If we are clear about what comprises an individual’s interest network, then we can more confidently assess the impact of various treatment options – and their foreseeable outcomes – upon that network. This respects individuality. Whereas, allowing consequences to drive a decision, respects generalised fears about abstract, a-contextual events.

8.2.3 Desired purposeful objectives

With the framework and preliminary objectives set, purposeful objectives can be created. The principal purpose of all proxy decisions for IcPs is **to make a sensitive,**

compassionate and just decision that has integrity with the incapacitated individual's interests. It has been established that a proxy must be informed and empowered, and act responsibly in the name of common humanity. This flows from the blend of framework and qualities outlined. It progresses from gathering the right information (outlined as factors for consideration, below) to employing it through a reflective decision process of mapping, evaluation, balancing and justification (considered below). The reader is referred to Appendices 6 and 7 hereto for example applications of this decision process in the IcP context.

8.2.3.1 Factors for consideration

A series of questions provides the basis of a checklist for a proxy to consider,⁷⁹ aimed at securing all relevant information. In other words, it provides a series of **prompts to informedness**. The answers to these questions would contribute information about decision-making authority, the individual subject, his/her relevant interests, the input of mutual others, decision purpose, treatment options and impact.

1. **Competence** - This is a threshold device aimed at identifying decision-making authority. The guidelines regarding competence assessment are outlined above (as a preliminary objective). Ultimate assessment should lie within the remit of the proxy, but this must be based on information provided by medical and/or psychiatric assessment, the views available from an Advocate-Guardian, and any other source the proxy finds relevant. The proxy's assessment is preferred as s/he is in effect an objective observer able to take account of a wide range of information about the patient's capacity. The fundamental questions to address are:

- Is this person competent to make his/her own treatment decision?
- Is there any advance directive (formal or informal)?
- What capacity does s/he have? To what extent can s/he understand and use (relate to, engage with and choose) information? Does s/he have capacity in some aspects of life but not others?

⁷⁹ The value of asking a series of questions is based on Gert, Culver, Clouser's approach to identifying 'morally relevant features', above, 38.

- Could the patient's competence be maximised by supportive communication methods, or evaluation over a period of time?

2. **Establishing individuality** - this is about input, circumstances, relationships and personality:

- Can the patient offer input, despite incompetence (i.e. based on the reconstruction of incompetence)? If so, what is this input?
- What is the Advocate-Guardian's understanding of the individual patient's views?
- What is the patient's position within his/her lifetime line? How does this relate to any past, transient, or future competence and/or views?
- What can we discover about the patient's personality? Who *is* this person on whose behalf a respectful decision is to be made?
- With whom does s/he have relationships of mutuality?
- Which circumstances are uniquely involved with this patient's situation?

3. **Establishing interests** - which interests are at stake?

- What commonly human interests might this patient have?
- Which human rights laws are relevant to this patient's treatment circumstances?
- What matters to this IcP in (a) daily life (preferences and choices), (b) longer-term goals/values, and (c) in the context of the decision at hand?
- What does this individual need in clinical terms? What would improve his/her well being - both medical and non-medical?
- Which of his/her interests endure incapacity?
- Which interests, identified and attributed to this IcP, conflict with each other? Which support one another?

4. **Establishing input** - input should be *reassessed* once the patient's interests have been initially established in order to ensure that all influential sources of input are

considered, such as the individual IcP, emotionally closest others, carers, HCPs, and the Advocate-Guardian.

- With whom does this patient share mutually important relationships? To whom is s/he emotionally close? What input can these people offer?
- What medical input has been provided? What else do we need to know about (e.g. additional information on risks/benefits, prognoses etc)?
- Do we need to consult further with any of the above interested parties (including the IcP)?

5. **Establishing decisional purpose and treatment options** - to clarify what we are trying to achieve and what is realistically achievable:

- What is the purpose of this decision for this particular individual?
- Are any requisite preliminary risk factors (such as the need for a 'real' risk to exist) fulfilled?
- What is the range of treatment options available?

6. **Establishing impact** on interests and individual(s):

- How could each treatment option benefit the IcP's identified interests? How likely are these benefits to occur?
- How could each treatment option harm his/her identified interests? How likely are these harms to occur?
- How would the treatment options impact the lives of mutual others?

7. The decision-maker should then assess his/her current position in terms of **informedness**:

- Am I as informed as I can be about:
 - (a) this patient as an individual;
 - (b) his/her personal medical interests;
 - (c) his/her personal non-medical interests;
 - (d) his/her stakes in life;

- (e) his/her views and preferences;
- (f) his/her relevant relationships;
- (g) his/her needs.

If so, then the proxy is equipped to make a decision that involves reflective evaluation, balancing and intuition (if necessary). In other words, to use this information within the decision process.

The remaining purposeful objectives embody the **decision process**. This process consists of *mapping* the patient's individual network, *evaluation* (in terms of autonomy and welfare (i.e. respect) and progressive ascertainment), to reach a *balance* point that offers a *justifiable* decision about treatment choice for this individual patient. Each is considered in turn and guidelines proffered.

8.2.3.2 Individuality of interest network

Respect must acknowledge individuality through the human right to have privacy and relationships respected. Actively representing such respect is termed herein 'mapping'. This is about a proxy **describing** a person's interests. '**Mapping**' is the part of the dynamic that assesses relevance of interests to an individual. Representing an individual's interests as a network valuably clarifies the function of, and interrelationships between, various interest objects. A network image provides a mental inner framework, against which a proxy can 'map' (i.e. locate) single interests, while keeping sight of the overall aim. Mapping need not focus on detailed minute analysis of every knock-on effect, as this would be unworkable and generate indecision. Nor is mapping, of itself, a conflict resolution strategy. Rather, mapping focuses on individuality, reminding a proxy:

- to consider the factors outlined, looking to a broad range of *potentially* relevant interests in order to identify *those important for this individual*.⁸⁰ The network highlights that different interests facilitate (and create) one another. The individuality of any network also

⁸⁰ The process of mapping a network should safeguard against arbitrary, premature value judgments about assumed non/relevance.

encourages respect for interests important to that individual, rather than on generic interest-type;

- s/he should take account of relevant interests in terms of: (1) the importance of the interest itself within the network; and (2) the connections flowing from it to other interests;
- that life is a continuum; an essentially individualistic process, that sometimes overlaps mutually with lives of others, but a process during which each grows through personal interpretation of experiences. A proxy should acknowledge the uniqueness of the individual as an ongoing, unfinished creation that changes with the developing blend of his/her experiences. Describing interests as a network raises awareness of the instant decision in the broader life context, and encourages ownership of decision impact to remain with an individual;
- that a proxy should determine the *shape* of a patient's network, establishing areas of importance for that individual, including overlaps with networks of mutual others;
- that objects in the network should be employed *towards* identifying an option in the patient's interests (the purpose), rather than vice versa.

8.2.3.3 Autonomy where it is due - The issue of input

As part of the **evaluative** stage of the process, there are two component objectives of respect: promotion of autonomy and welfare. It should be a purposeful objective to *credit an individual with autonomy wherever it is due*. In essence, to *maximise autonomy* by:

- adopting a reconstruction of 'competence' as a gateway to decision-making authority;
- seeking all sources of relevant input establishing who this individual is;
- acknowledging an IcP's significant relationships;
- acknowledging an IcP's relationship with self – with his/her own life;

- maintaining awareness of individual uniqueness that merits respect;
- actively ascertaining his/her network;
- recognising and taking into account 'whole life, over time'. We should hold this individual in esteem in an individually tailored decision;
- recognising the full range of subjective interests, prevailing common interests, temporally persisting interests, and an individual's ulterior, critical and experiential interests.

8.2.3.4 The welfare aspect of common humanity

Also part of the **evaluative** stage, an ICP's welfare forms a purposeful objective. A proxy should *seek to enhance or restore a patient's well-being, and act in a protective role towards the patient*. This means:

- recognising that an ICP's status as a human being commands equal respect;
- attributing commonly prevailing interests, welfare interests, and genuine critical interests;
- valuing objective input about a patient's prognosis;
- assessing the patient's relationship with State and society, and with HCPs;
- acting compassionately towards an ICP as a fellow human being in need of care;
- accepting conflict/support where it occurs;
- recognising one's own limitations, acting responsibly and engaging with the process.

8.2.3.5 Ascertainment

Ascertainment ensures that an individual receives due consideration and process. It is a fundamental part of **evaluation**, achievable by:

- ascertaining whom an individual is; discovering his/her personality, current temporal position in life, and how his/her personality has endured in relation to incapacity (or how it may yet develop). It is about accepting (with an open mind) his/her preferences, choices of relationship, and establishing a picture of who this unique individual is/has been/may become;
- accrediting possession of interests to incapacitated individuals (by allowing interests to be conceptually durable through time). It is about determining which interests have endured as part of this IcP's network. Further, it is about the interrelationships of those various interests; acknowledging conflict and support within the network, and the pathways and pressures created within it;
- determining impact of treatment options upon the network. A treatment option may support, block, or damage single interest objects in a network. The impact of each option should be considered across the whole individual network; identifying pressures created or relieved, extent to which any purpose is achieved, and the effect on areas of overlap (with networks of mutual others);

The ascertainment process is a gradual one of gathering information, accrediting its importance to the individual, and evaluating impact. Assessing and reassessing in a sifting progression towards overall aim.

8.2.3.6 Balancing

Beyond dynamic and framework, proxy decisions come down to **balancing** of any issues of conflict within an individual network. No hard-and-fast rules can apply, and a combination of logic and intuition is advocated:

- a combined approach melds awareness and understanding of subjective issues with human compassion. The former derives from informedness, the latter from trust;
- we must trust the proxies with whom we place responsibility. Further, those proxies must trust their own capacity to engage fully and genuinely

with the decision process and, where necessary, to trust their intuitive response;

- intuition is valuable *as an addition to* logical evaluation. It can support the reflective process, inductively feeding a proxy's gradual evaluation and sifting of information;
- we must allow a proxy to exercise his/her responsibility; the act of balancing is the most fundamental aspect of this responsibility. If we feel uneasy about trusting a proxy to fulfil this, we could be appointing the wrong proxies, or we have an insubstantial framework. If a proxy can act with R.E.S.P.E.C.T.,⁸¹ then this is as much as any human being deciding on another's behalf can achieve.

8.2.3.7 Justification

Conflict between interests is inevitable and is best acknowledged and the adopted position justified. But, respect demands realism and if we seek to justify 'best' as a 'uniquely right solution' then we will be disappointed for reasons already outlined in this chapter.

In view of these limits, a proxy should be willing to justify his/her treatment choice by showing that s/he has decided:

- *within the structured environment*, addressing factors outlined and any relevant domestic and European legal provisions;
- *openly*, having regard to subjective input and personality, making express the issues and interests arising, and the reasons for the eventual choice (including any role of intuition);
- in full *recognition* of an IcP's broad range of *interests*;
- *respectfully*, accepting that all IcPs possess interests, and that both subject and proxy are valuable human beings, but with limited human capacities;

⁸¹ I.e. acting responsibly by Responding Empathetically to the Subject's Personality, Experiences, Capacity and Truth.

- from a state of *informedness* about background understanding of issues raised herein, and through available evidence of a subject's 'personal medical', 'personal non-medical' stakes, and his/her personality and individuality;
- through *focused engagement* – genuinely listening to all information involved, and acting as a beneficent inquisitor to the process; and
- with *willingness* to discuss reasons, decision process and making him/herself available to any appeals process.

Any decision statement should make all of these justificatory points available as part of transparency. If a proxy has actively engaged with the process then his/her decision is sufficiently justified. A **decision report** should detail: assessment of a person's capacity and competence, sources of input, medical prognoses, evidence of the subject's individuality, which issues are deemed important, relationships of mutuality, the patient's views, the involvement of an Advocate-Guardian, identified interests, areas of conflict/support, how treatment options are foreseen to impact identified interests, reasons for ultimate choice and areas of compliance with law.

But, the key factor above all else is **respect**. Clear respect for the subject, throughout the process, will create a proxy decision that is *justified enough*.

8.2.4 Improvements, weaknesses, and the 'best' way forward

The time has come to close the historical chapter of anachronistic, misunderstood labelling of legally incompetent individual. Incapacitated human beings are, primarily, individuals. They warrant the same degree of respect as any other individual. But, these vulnerable human beings are also in need of our care, compassion and help from time to time. When illness strikes them – as anyone – they need access to suitable treatment and care. When medical treatment could improve their quality of life it should be considered – as any competent person would consider for him/herself. The legal framework should be in place to enable this to happen. Previously, the dysfunction that incapacity causes within the autonomy model of decision-making has compelled the courts in England and Wales to resort

to the beneficence offered by 'best interests'.⁸² However, a purely welfare-oriented approach to best interests decisions risks disrespecting a patient's residual autonomy that may have existed previously, or exists transiently, or may exist in the future. Furthermore, conflicts remain about how 'best' to 'benefit' the patient.

However, the ethic of **respecting persons** offers **improvement**. It embraces both beneficence *and* autonomy. In addition, it encourages focus upon the value of all individuals – whatever their capacity. And, we can adapt the respect for persons approach to suit incapacitated individuals. By adopting the concept of 'interest' proffered herein, and the idea of reflecting upon an individual's life in its broadest and temporally unconstrained senses, we can accept an IcP's residual autonomy while attending to his/her welfare needs in a uniquely tailored combination. In essence, we can both acknowledge and support the individual because autonomy and welfare become more malleable. Each value retains its own integral role, yet allows for the importance of the other, under an umbrella of purpose known as 'respect'.

It is submitted that the approach put forward in this thesis would create a form of decision-making for IcPs that aims to secure their well-being through a well-rounded perspective. This approach recognises both common human experience and individuality. It is focused, yet aware of the wider context. It is realistic, yet strives to attain philosophical and ethical objectives. By seeking the *best achievable decision based on an individual's ascertained interests*, we can offer a genuine respect towards *all* incapacitated human beings. And, in respecting the individual, we respect ourselves as part of common humanity. The approach adopted herein aims to retain the valued flexibility inherent in 'best interests'. However, in so doing, we must provide more guidance than has previously existed. We can do this by creating an outer framework comprising a judicial forum, and an inner framework of process and role. We can choose our decision-makers with specific qualities in mind, and educate them to become informed, to act responsibly and compassionately. And, we can give guidance about the factors that might be involved and should be considered. But, beyond this, we must trust in the proxies we appoint, trust in the process, and permit the flexibility of best interests to adapt to

⁸² Scotland has previously focused that beneficent principle through a proxy decision-maker – a 'tutor-dative'.

new cases and advances in medical technology. We must trust in our human capacity for both compassion and invention.

Certainly, **weaknesses** will still exist. Using the term 'best interests' is perhaps something of a misnomer if no choice can be proven 'better than all others'. And, not all commentators will be satisfied by anything less than that. Ideally, we feel we ought to be able to say definitively that we made the 'best' choice. But, pragmatically, life is simply not this predictable or quantifiable. We can make a choice with someone's best interests genuinely in our heart at the time, but we cannot prove it is the best of all options. Perhaps an alternative term could be used, but with respect as the underlying ethic, the name of the tool seems to matter less than the motivation and care with which it is used.

A further potential weakness lies in the time and effort involved in gathering information from so many sources, and mapping and ascertaining an interest network for each individual subject. Admittedly, this could be seen as pragmatically inhibitive. However, this is what determining 'best interests' surely should be setting out to achieve. While commentators could argue about nomenclature and justifiability, none of that is significant in any case if the job is not done properly. No apology is made for such a heavy onus on finding out about the incapacitated individual. *S/he should* be the effortful focus of a decision-maker's attention, and we cannot aspire to doing what is 'best' for him/her if we do not know who s/he is and what interests s/he has. These individual subjects are unfortunate to suffer their incapacity. The rest of us, as competent proxies, mutual others, Advocate-Guardians, carers and members of society are in the fortunate position of having enough capacity to share with others. Our capacity can help to compensate their lack of capacity provided it is used carefully. Far from being an extravagance of time or energy to attain a state of informedness, it is a gift we are able to share by evaluating another's interests and well-being on their decision-making behalf. Full consideration and respectful choice should be the gifts that we offer in return for our involvement.

One final weakness could be considered to exist in the balancing process. Balancing is inherently difficult to pin down. Of itself, balancing requires a balance of

establishing guidance while allowing flexibility. Intuition has been included here as a decision-making tool to use when (logical) reasoning fails to provide a clear answer. Some might regard the use of intuition as a weakness. Admittedly, were the parameters of this paper more extensive, further development of this area could be valuable, simply in view of the contentiousness of its use in decision-making. However, it has been included within the balancing armoury because it is believed significant. Indeed, it may be present already in medical and legal decision-making (such as in resource allocation and equity, respectively). Furthermore, some may regard intuition as a strength rather than a weakness. It may not fit the traditionally patriarchal, logic-oriented models of decision-making to which we are accustomed. However, it could form part of a new wave of more compassionate, instinctive and emotion-based approaches to decisions and choice that is perhaps beginning to emerge in the twenty-first century. Further research into gender and generational issues in decision-making might usefully illuminate this aspect, as might psychological analyses of decision motivation. Unfortunately, these approaches lie beyond the limitations of this present thesis.

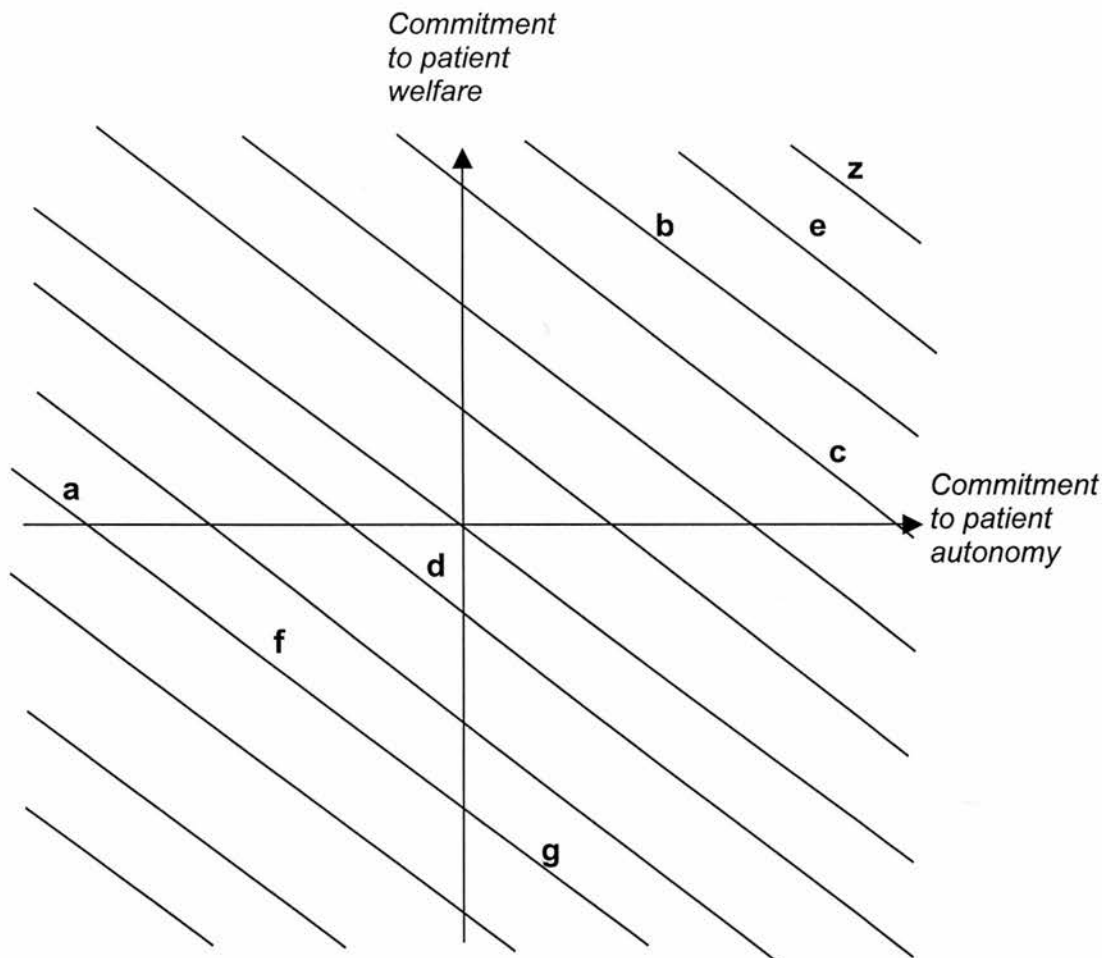
While acknowledging this scope for further development, it is submitted that the approach proffered herein is still a **valuable way forward**. It has clarified the existing meaning of best interests, identified dysfunction in its application through caselaw, explored the characteristics of 'interests', considered underlying ethical values, and developed a reconstruction of the legal framework based on the preferred ethic of respect. In total, rethinking how we structure the interest concept, the value or purpose to which it is employed, and the roles within the decision can contribute significantly to creating the *right environment* for attributing interests where they are due. With an enlightened structure and purpose there is scope for relevant interests to be better identified and their significance to the individual evaluated. But, according genuine respect requires a weighty emphasis on recognising individuality; to act with sound judgment we must ascertain clearly not only interests and purpose, but the individual to whom they belong. It is anticipated that the '**best achievable decision based on ascertained interests**' would provide a more robust and compassionate approach to many decisions for incapacitated patients. It is philosophically supportable, ethically acceptable, and traceable within individual

decisions; **a reconstructed process by way of ethical evaluation.** A new form of 'best interests' that can be '*many* things to *many* incapacitated patients'. But, more importantly, **respects all human beings by allowing them individuality as part of humanity.**

APPENDICES

Appendix 1 - Interpretation of Benn's figure 2, here applied to the decision whether to sterilise and incapax patient

This serves a descriptive function herein representing duality of proxy commitment.



Options:

- a** - sterilise regardless
- b** - sterilise, on balance of evidence
- c** - don't sterilise, on balance of evidence
- d** - delay decision until later/patient older
- e** - use alternative, reversible contraceptive methods
- f** - preclude patient permanently from sexual relationships
- g** - do nothing, i.e. run the risk of pregnancy
- z** - a combined solution of (c) and (e)

Factors influencing positioning:

- a** - protects from pregnancy, but lacks sound assessment of overall welfare (i.e. some commitment to welfare); ignores patient's integrity and potential interests in having children (i.e. lacks commitment to autonomy)
- b** - protects from pregnancy, facilitates quality of life through sexual relationship, (i.e. good commitment to welfare); necessarily invades bodily integrity, precludes

any interest in having children, but does consider these issues (i.e. limited commitment to autonomy), risks sexual assault going unnoticed (i.e. undermines commitment to welfare)

c - may not protect from pregnancy, does not make patient more vulnerable to sexual assault (i.e. limited commitment to welfare); does not invade bodily integrity, does not have irreversible consequences, may limit or preclude sexual activity (i.e. some commitment to autonomy)

d - may not protect from pregnancy, may/may not permit sexual activity, but leaves option of sterilisation open (i.e. limited commitment to welfare); does not invade bodily integrity, not irreversible, but really fails to address patient's interests now (i.e. limited commitment to autonomy)

e - offers significant protection from pregnancy, but may increase vulnerability to assault (i.e. some commitment to welfare); limits invasion of bodily integrity (depending on method), reversible, facilitates sexual relationships (i.e. good commitment to autonomy)

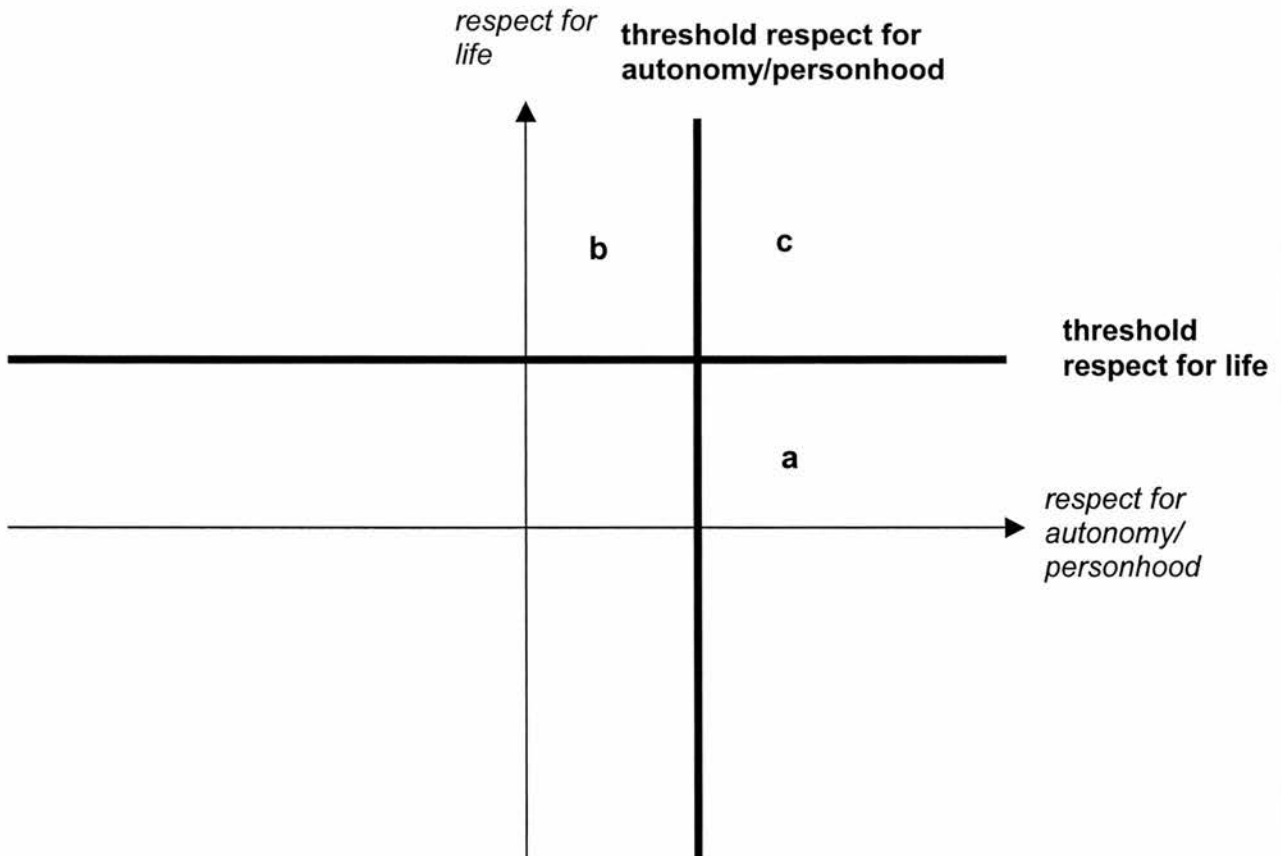
f - protects bodily integrity, reversible, ignores any potential interest in having children (i.e. reasonable commitment to autonomy); protects from pregnancy, minimises vulnerability to assault, but very poor commitment to patient's quality of life and (i.e. lacks significant commitment to welfare);

g - permits sexual relations, but fundamentally fails to protect from pregnancy, minimises vulnerability to assault (i.e. limited commitment to welfare); protects bodily integrity (in the short-term), reversible, (i.e. some commitment to autonomy)

z - provides best elements of (e) by protecting from pregnancy, and facilitating sexual relationships, but may create some vulnerability to assault (i.e. some commitment to welfare); also best elements of (c) minimising invasiveness of bodily integrity and reversible, (i.e. good commitment to autonomy). This combination may offer 'best' overall commitment to the two roles, reflected in its positioning on right uppermost curve, but is often unavailable in sterilisation decisions due to unsuitability of alternative contraceptive methods for the incapax patient.

In summary, by considering the extent to which various treatment options commit to each role, these options can be plotted relative to the two axes, and to one another. Certain options (*a*, *f* and *g*) on the outer negative sectors of the graph appear untenable because they profoundly fail to commit to either axis value. Options *c* and *d* show limited commitment to both roles. The most tenable options sit in the positive quarter and, of these, the most northerly, then easterly would be regarded (on Benn's approach) to represent the option with the highest commitment level to *both* axis values. However, arguably as a means of conflict resolution this creates bias towards the value on the vertical (*y*) axis as a priority. The curves always run from upper left to lower right because the relationship between the two axis values is inverse; as commitment to one value increases, commitment to the other value diminishes.

Appendix 2 - Interpretation of Benn's figure 4, applied to a decision whether to withdraw treatment from a pvs patient



Options:

- a** - no instructions from the patient, withdraw treatment, allow the patient to die
- b** - no instructions from the patient, continue the patient, maintain life
- c** - patient has left explicit instructions, which do not contravene decision-maker's commitments

Factors influencing positioning:

a - meets the threshold for autonomy by respecting the nature of personhood, but falls below the threshold for respecting life because withdrawal will result in the patient's certain death

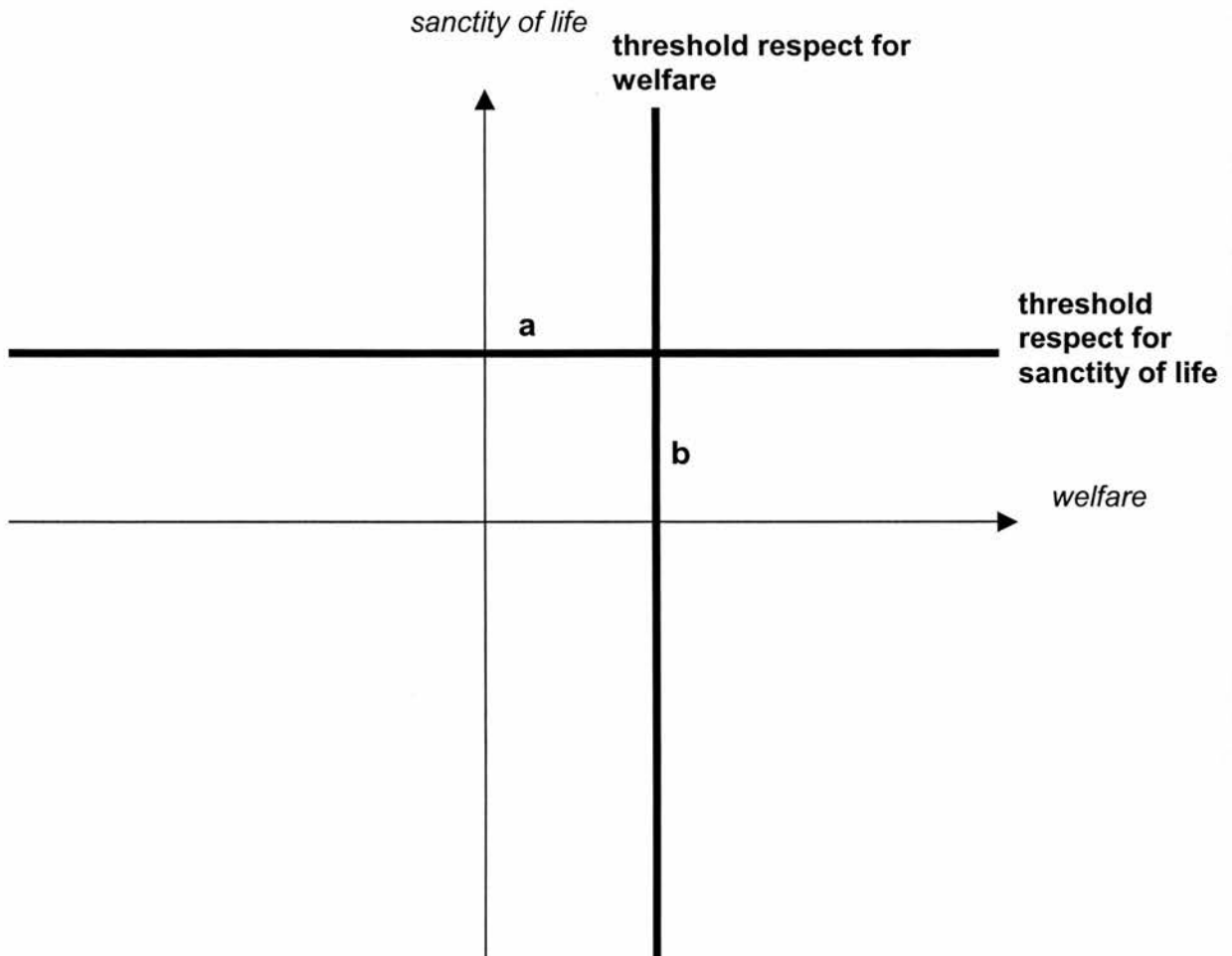
b - falls below the threshold for respecting autonomy because continuance of treatment disregards the nature of personhood and maintains the patient in a state less than a 'person', but meets the threshold for respecting life by not causing the patient's death

c - desirable rational decision location, attainable only if the patient leaves explicit instructions which do not contravene the decision-maker's commitment to respecting

life and respecting autonomy - essentially an unattainable position in most pvs scenarios due to absence of patient instructions

In summary, withdrawing alimentation will certainly mean ending the patient's life - which falls below the threshold for respecting life (position (a)). However, maintaining the patient's existence disrespects autonomy/personhood (position (b)). Thus, neither option sufficiently meets the decision-maker's role commitments. Hence, no rational decision position is available to us. The only rationally acceptable position would be (c) - if the patient had left a valid Advance Directive that did not contravene the decision-maker's minimum commitments to both values.

Appendix 3 - Interpretation of Benn's figure 5, applied to a decision whether to withdraw treatment from a severely defective neonate



Options:

- a** - continue therapeutic treatment
- b** - withdraw therapeutic treatment, maintain palliative care only

Factors influencing positioning:

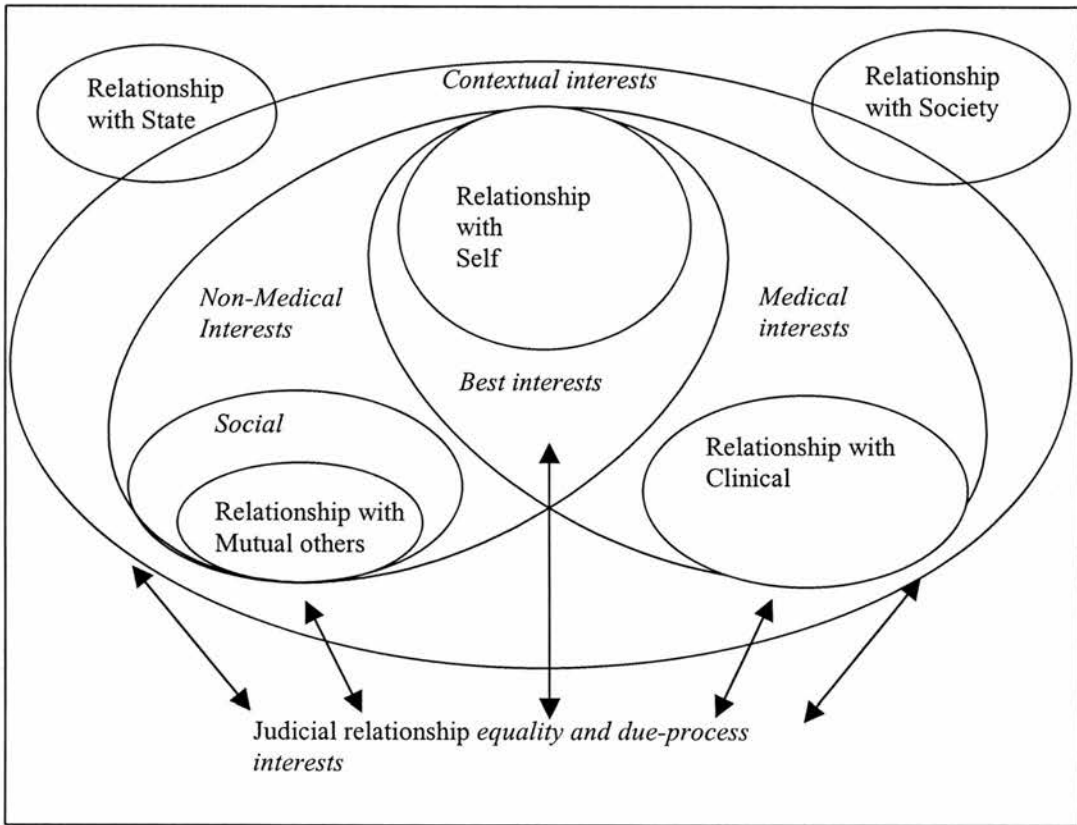
a - meets the threshold for sanctity of life because the decision does not shorten the neonate's life, but falls below the threshold respect for welfare because continuance will cause pain and/or very poor quality of life

b - falls below the threshold for sanctity of life because withdrawal of therapeutic treatment will result in the neonate's death, but meets the welfare threshold by minimising the duration of pain, and avoiding poor quality of life in the longer-term

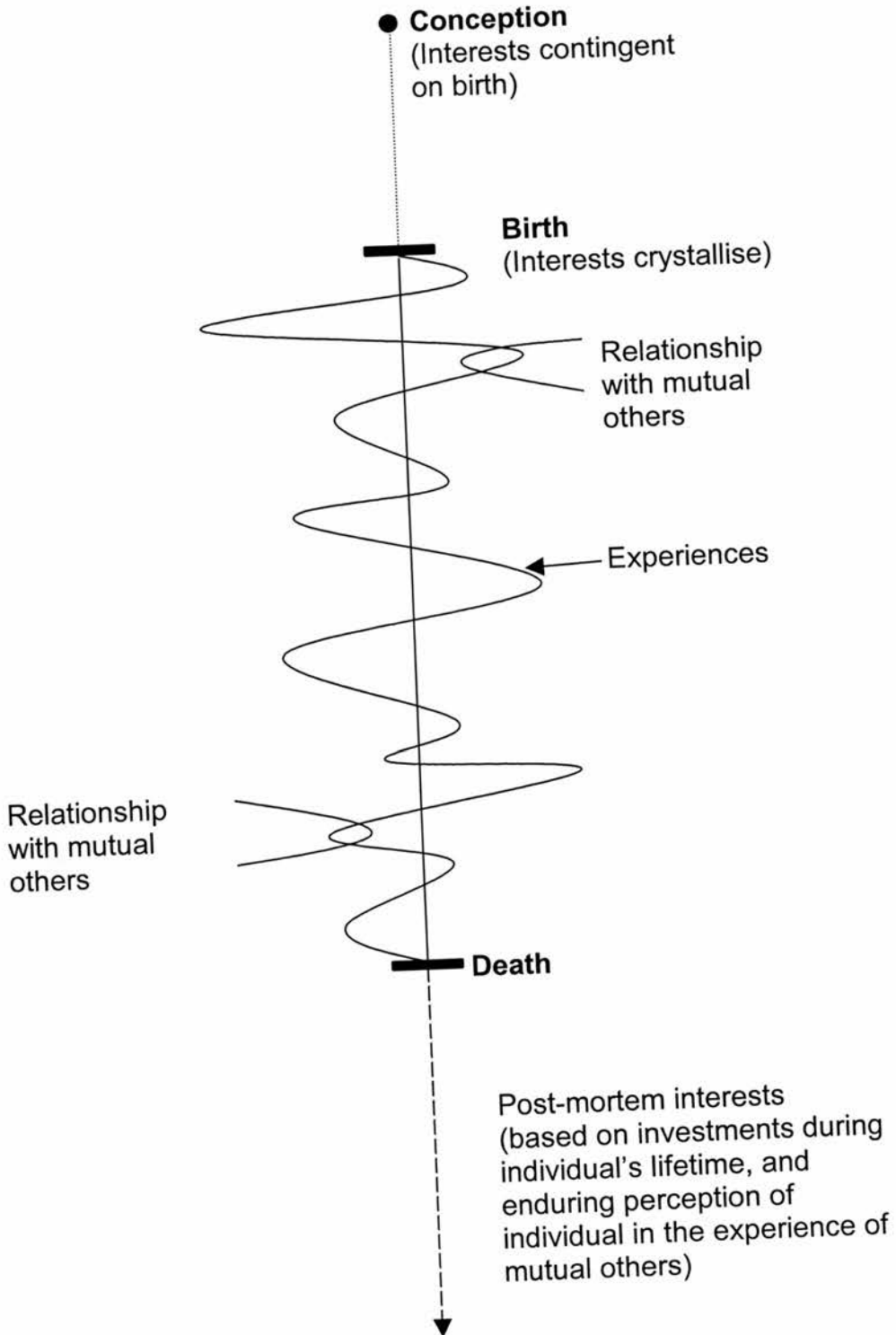
In this situation, no desirable rational decision location is attainable; the only two possible options result in harm of some sort ensuing. A subthreshold choice therefore becomes necessary.

In summary, this situation involves different conflicting values: 'sanctity of life' and 'welfare' (i.e. avoidance of suffering). Available options include (a) continuing therapeutic treatment (which may delay/avoid the neonate's death, but will prolong pain and poor quality of life), or (b) maintaining palliative care only (accelerating the neonate's death, but minimising pain and suffering). Option (a) meets the sanctity of life threshold but fails the welfare threshold. Option (b) meets the welfare threshold but fails the sanctity threshold. Either decision is 'wrong', therefore, in either condemning the baby to a limited life full of pain, or condemning him/her to death.

Appendix 4 - Relating relationships of individuals to interest groupings



Appendix 5: Lifetime Line



Appendix 6: Application of reconstructed best interests decision process to Re Y

This appendix seeks to evince how the reconstruction of best interests, proposed by this thesis, might function in application to the existing case Re Y (Mental Incapacity: Bone Marrow Transplant) [1996], above, as a means to highlighting how analysis would differ.

Additional information would be needed for a full proxy analysis of Y's interests, including medical information on the risks/probabilities involved in the procedures, evidence of relationships, and about Y as an individual. But, a brief overview can be given here and differences highlighted, as much by the variance in questions raised (contrasting with earlier formulations of best interests), as by the answers (which would depend on further information):

The **overarching aim** of the decision would be to treat Y with respect and compassion.

In establishing Y's **individuality**:

- Y's severe intellectual impairment would mean that she was not competent to self-determine, had never been able to make an advance directive, and that her capacity seemed minimal (being able to understand her own needs, but not those of others). However, a supportive environment might enable us to gain input from Y, or to better understand her level and deficiencies in capacity, for example while Y did not appear to understand what was said to her about her sister's situation, Y made most of her own communication through signs - could this be employed to improve her understanding/input?
- An Advocate-Guardian could be appointed to Y to gain more information about her as an individual. While we know that she had always been incompetent and would remain so, we know little about her personality (only that she had a cheerful disposition). The AG would seek information about how Y interacted with her environment, her family, her carers, and the content of her daily life (preferences, likes/dislikes etc), and individual circumstances as a means for us to know Y better;

- The relevance of Y's relationships in the context of her broader life would be an important part of identifying Y as an individual in the context of this decision. It seems that Y's relationship with her (plaintiff) sister was not strong - we can construe the overlap in their interest networks as minimal. In contrast, her close, affectionate relationship with her mother would represent a significant area of overlap in Y's interest network. We should also be aware of the mother's interest network overlapping with the sister's - this is the *indirect* area of relationship interest regarding Y, and that certain circumstances existed (i.e. the mother's poor state of health, exacerbated by anxiety over the plaintiff sister), but again these exist *indirectly* in relation to Y's network, being located in the overlap between the mother's and sister's networks.

This awareness of relative interest networks is the beginning of **mapping** Y's interests. It raises a particularly important question in the context of this decision:

- Should mutuality be regarded as the whole of Y's interest network? We return to the answer, below.
- To map Y's interest network we must set aside, for now, her relationship interests to consider the potential range of other interests attributable to Y as human being. Further information about Y's daily life/preferences/capacity for communication (using her methods) would facilitate our understanding of her life *as an individual*, both its biological and biographical content (albeit that the latter may be limited). This would enable us to understand her needs as an individual on a day-to-day basis. Certainly, we can attribute her with some *commonly human, prevailing* interests in bodily integrity, dignity, health, and freedom from pain. These interests should be protected, and we can identify that Y has a *need* to be protected from unjustified invasion;
- However, Y also has a *subjective, persisting* interest in her relationship with her mother by virtue of the investment of engagement that Y makes in so relating. This relationship contributes to Y's well-being (it is not clear whether Y has capacity to experience this in an other-regarding sense - for her mother's well-being). But, because this is a relationship of mutuality, we

can identify that the mother has an interest in Y (for Y's sake, and for her own enjoyment of engaging with Y);

- Further, Article 8 (HRA 1998, Schedule 1) raises an interest belonging to the family in ensuring that they are considered within a decision process that may interfere with family life. This *supports* the family's interest in Y. But, at this point an important distinction should be made: the (other-regarding) interests of the mother (or family) in Y should not be equiparated with the mother's/family's self-related interests *via* Y. In other, words, while a relationship of mutuality would contribute to the well-being of each, ultimate self-related interest *through* an IcP says nothing about concern for the IcP (as the interests pertain wholly to the other people). Thus, the *indirect* areas of overlap outlined earlier arguably should not form part of Y's interest network because they are served *via* Y, rather than in *mutuality* with Y;
- Such indirect interests (relating to the mother and sister rather than Y) effectively conflict with Y's *commonly human* interests and need for protection from unjust intervention. Further, they also overshadow Y's *persisting subjective* interest in her relationship of mutuality with her mother. It seems in the actual decided case that what effectively happened was that, rather than the mutual relationship between Y and her mother being an area of overlap in the two networks, the relationship was regarded as the *whole* of Y's interest network. However, in answer to the question raised at the outset of mapping, surely Y's *whole* range of interests as an individual should form the majority of her interest network (i.e. her commonly human and subjective interests *as an individual*), with her maternal relationship forming only one part of the network in overlap;

At this stage, having mapped Y's interests, **additional input** might be needed in order to make an evaluation:

- Particular input would be required about the nature and significance of the familial relationships. An AG could perhaps obtain this information through observation and communication with the IcP. The proxy could secure further information direct from the family members. The questions that this information should be directed to address are how Y's acting/not acting as a

donor would realistically be likely to impact (i) Y's relationship with her mother, and (ii) Y's relationship with her sister/family unit.

- Additional input would also be needed from medical experts about the position regarding alternative donors (i.e. the statistical effect of using a non-sibling donor, success rates, availability, testing), which was dismissed somewhat perfunctorily in the actual case.

By this point in **evaluation** we can identify:

- *decision purpose*: the case is unusual insofar as the proposed medical procedure served no diagnostic, prophylactic, or curative purpose for Y directly. Rather, the case required a *decision* about whether Y should make a contribution to the health of her sister (and mother);
- However, having established Y's interest network as extending beyond mutual relationships, the *decision purpose* that best interests should serve is to support and protect Y as an individual, that is, to protect and support her full range of interests (including her relationships). Thus, while we can experience compassion for the family's situation as a whole, we must focus primarily on our concerns for Y's interests (of which her familial relationships are only a part);
- The range of *treatment options* are identifiable as (1) authorising the donation procedure, (2) not authorising the donation procedure, and/or (3) advocating seeking other donors;
- The *impact* of these options in terms of Y's mapped interests would be determined from fuller information. However, at a simplistic level, *authorizing the procedure* would benefit Y's persisting interest in her continued relationship with her mother (thereby supporting her relationships in terms of purpose), but could harm her commonly human interests (in bodily integrity, possibly her health, etc.) and we do not know how she might respond to what is involved in carrying out the procedures (she may/may not experience them as traumatic). In contrast, *not authorising* the procedure, benefits Y's commonly human interests (protects her welfare interests), does not impact her personality (as there is no procedure to respond to), but might damage her relationship with her mother. Assessment could, therefore, turn

on the likelihood of this damage happening and the degree of importance that this relationship interest serves in Y's whole interest network. However, it must be said relationships should not be based in one individual having to act in certain ways in order for the other to continuing relating to them, and there is no reason to think that Y's not acting as a donor would *necessarily* damage her mother's relationship with her (which remained unelucidated in the actual case). Thus, in terms of decision purpose, not authorising the procedure would protect Y's interests, but may/may not support her relationships. The final option of *seeking other donors* was given minimal consideration the actual decision, yet is the option that best protects Y's interests (protecting her commonly human interests, not affecting her persisting relationship interests), while minimising damage to the family's interests as a unit.

Thus, on **balance**, the preferred option based on a reconstructed analysis of Y's best interests is **not to authorise** the donation procedure. Evaluation has taken account of Y's *commonly human* interests, and her *subjective* interests in mutual relationships, and concludes that the absence of any benefit to Y's health, bodily integrity, dignity, and freedom from pain is not outweighed by the benefit that may (or may not) accrue to her mutual relationships, particularly as this benefit is to some degree indirect. If the procedure were authorised it would support Y's relationships to the exclusion of her other interests and, it is submitted, would be *unjustified* in terms of her individual interest network identified herein. And, while the potential pressures on Y's relationships are acknowledged, we must respect Y as a whole individual (of which her membership of her family unit is only one part).

Appendix 7: Application of reconstructed best interests decision process to Bland

This appendix seeks to evince how the reconstruction of best interests, proposed herein, might function in application to the existing case *Airedale NHS Trust v Bland* [1993], above, as a means of highlighting how analysis could differ.

Additional information would be needed for a full proxy analysis of Bland's interests, including more information about Anthony Bland's personality (pre-incapacity), and his mutual relationships. But a brief overview here can provide an example of the different reasoning that might result.

The **overarching aim** of the decision would be to treat Anthony Bland with respect and compassion.

In establishing Bland's **individuality**:

- We can conclude that Anthony Bland was clearly unable to self-determine, and would remain so. However, he had been previously-competent. No advance directive had been made by him, but his previous life might provide indicators of input to the decision;
- Appointment of an AG could enable information to be sought from those emotionally closest to Anthony Bland to gain a clearer impression of his personality (we know only that he was 'sensitive and willing' and his father's belief that Anthony would not wish 'to be left like he is', above, 826). An AG might identify further information to confirm this perceived personal view. In essence, we could seek to know more about how Bland interacted with life, and his choices and investments, prior to incapacity as a means of better knowing him as an individual, and identifying his interests;
- Bland's pre-incapacity relationships with those emotionally closest to him may also inform us about what mattered to him; how important were those relationships in his life? Would he be concerned (if he were able to know of his situation) for the effect now on his family and friends? In which areas might Bland's interest network have overlapped with the networks of others?

This initiates **mapping** of Bland's interest network:

- If information regarding Bland's relationships of mutuality warranted it, he could be attributed with a *subjective* interest in the well-being of those mutual others. Moreover, on this reconstructed account of best interests, such an interest could endure Bland's entry to incapacity as a *persisting* interest in his network;
- Additionally, if information about his life, prior to p.v.s., were to furnish *personal* interests, such as his former views on existence in such states, religious beliefs (or secular beliefs about the life/death cycle), the importance of life to him/her in biological and biographical senses, or strongly held views on ancillary issues (e.g. tissue donation), then these aspects may also *persist*. For, such aspects contribute to making him the individual he was (pre-p.v.s.), and should not be merely abandoned due to current (permanent) incapacity. This information may help us to resolve conflict, for example, if he would not wish to 'live' long-term in p.v.s. then we might attribute him with a significant interest in the importance of biographical life as valuable;
- We can attribute Bland with some *commonly human, prevailing* interests in dignity, and bodily integrity. There is no reason why these interests should not endure his incapacity, as commonly human interests are not dependent on being able to know of them, or take an interest in them. Further, we could also attribute Bland with a *commonly human, prevailing* interest in (biological) life which remains part of his network despite incapacity;
- However, we should also acknowledge that other *commonly human* interests are affected to an extreme degree by permanent insentience. Thus, certain *welfare* interests are rendered irrelevant to Bland, such as freedom from pain (as he has no sentience), tolerable environment (as he does not experience it), and non-interference with choice (as he has no prospect of making even simple choices). Moreover, his *subjective* interest in participating in his (biographical) life is permanently lost to him, other than in terms of reputation and how he is remembered by others;
- In terms of how these interests *support and conflict* with one another, Bland's persisting concern for those emotionally closest others with whom he had

mutual relationships, and remembrance by them, would be supported by his enduring interests in bodily integrity and dignity. And, both would be supported by his loss (prospectively) of any experiential participation in biographical life. However, conflict occurs between these interests and his remaining commonly human interest in (biological) life, particularly if he might have had a subjective interest in 'not wanting to live in such a state';

We may need to reconsider **input** at this stage to see if we are fully informed about Anthony Bland as an individual; could more information about his personality, relationships, present circumstances or previous interaction with life help us to resolve the conflicting aspects, or further reinforce the supporting aspects, of his interest network?

By this stage of **evaluation**, we can posit that:

- *Decision purpose* is an assessment of Anthony Bland's *quality of life*. Although he may be subject to intermittent infections, his biological life could be sustainable for some time. Whereas, his scope to participate and experience his own life biographically has ceased. A decision is required about which aspect is most important in terms of his interest network;
- The *treatment options* are simple, either: (1) to withdraw a.n.h. from him thereby allowing him to die, or (2) to continue providing a.n.h. thereby sustaining his life, as it is, for the foreseeable future;
- The *impact* of these options in terms of Bland's mapped interest network would benefit from fuller information about him as an individual. However, *withdrawing treatment* would have a positive impact on his prevailing, commonly human interests of dignity and bodily integrity (given the invasive nature of support care and a.n.h.), it could have positive integrity with his subjective biographical life (pre-incapacity). It could have a mixed impact regarding his interests of mutuality: it may relieve his family of their emotional distress, which accords with his enduring other-regarding concerns for his family's well-being, and with their other-regarding concerns for him; yet, his death will create grief among his emotionally-closest which would be likely to also concern him if he were able to consider it. However, beyond this, the only overtly negative impact on Bland's network is of

withdrawal ending his interest in biological life. In contrast, *continuing treatment* clearly benefits biological life (to the extent that it is valuable). But, this is the only positive impact it brings. Continuance would invade Bland's prevailing interests in bodily integrity and dignity. It could have little integrity with his pre-incapacity biographical life, in terms of the active life and relationships that he valued. Further, it would continue to impact negatively the lives and experience of those emotionally closest to him, whose memory of him could become dominated by the continued invasiveness of treatment. Hence, no benefit would accrue to Bland in terms of his biographical life by continuing treatment.

Thus, **on balance**, the preferred option based on a reconstructed analysis of Anthony Bland's interests would be to **withdraw treatment**. Evaluation has taken into account Anthony Bland's *current*, commonly human interests in dignity and bodily integrity, his *enduring* interests in terms of his personality and past investments in engaging with life and with mutual others, and the total *prospective* absence of any participatory biographical life. It has been shown that he *has* these relevant interests to consider, but his total incapacity precludes him engaging with, experiencing or participating in his life in any biographical way, and this outweighs his continued interest in biological life. His only engagement with living would be in the sense of continued invasive treatment that impacts negatively on his dignity and bodily integrity. In short, the quality of Bland's biographical life would be prospectively so poor, that it is more respectful to accord integrity to his pre-incapacity biography and recognise the negative impact of treatment on his current interests. It is therefore *in* his best interests to withdraw treatment and allowing his (biological) life to end.

Appendix 8

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Applying best interests to persistent vegetative state - a principled distortion ?

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Abstract

"Best interests" is widely accepted as the appropriate foundation principle for medico-legal decisions concerning treatment withdrawal from patients in persistent vegetative state (PVS). Its application appears to progress logically from earlier use regarding legally incompetent patients. This author argues, however, that such confidence in the relevance of the principle of best interests to PVS is misplaced, and that current construction in this context is questionable on four specific grounds. Furthermore, it is argued that the resulting legal inconsistency is distorting both the principle itself and, more particularly, individual patient interests.

Editor's note

This paper won the 1997 UK Forum Essay Competition, organized in collaboration with the *Journal of Medical Ethics*.

(*Journal of Medical Ethics* 1998;24:86-92)

Keywords: Persistent vegetative state; "best interests"; legal decisions

A contextual introduction

Patients in persistent vegetative state, being incognizant, incapacitated and insensate, pose difficulties for both law and medicine. Burgeoning legal support for patient autonomy and self-determination falters on confronting patients previously possessed of such interests, but now permanently unable to express them. Incurability, coupled with potentially indefinite continued existence, raises questions of withdrawing "treatment" from a *non-terminal* patient. This involves medical professionals in action diametrically opposed to the very life-sustaining aims of "treatment". Nevertheless, a decision is needed.

Few would dispute the PVS patient's lack of legal capacity, ie the patient's inability to exercise his/her own rights, particularly the right of self-determination and, indeed, his/her unawareness of the very need for any decision. With relative ease, we can therefore conclude that the patient fails to meet the requisite "competency threshold" of consent. However, such rights are not lost simply because the patient cannot

personally exercise them - proceeding to treat may still be unlawful unless it is "justified". The chronic nature of PVS means that the situation can no longer be characterised as an "emergency" (justifying intervention as "necessary"). Without consent, continuing treatment could therefore invade privacy and constitute an illegal battery, whilst ceasing treatment may not fulfil ethical and legal duties towards the patient. Thus, some form of authorisation of the continuance (or withdrawal) is required, and this decision necessarily falls to others. "Best interests", being an established and beneficent solution, seems a safe and uncontentious route to take. Paradoxically though, PVS may involve the most contentious treatment-outcome of all consent decisions, namely the death of the patient. The relevant decision-making device must therefore withstand the closest and most critical scrutiny.

Certainly the application of "best interests" to PVS decisions is espoused at the highest levels of legal authority. Its current standing as "the law" within the United Kingdom and Ireland is unquestionable. However, doubts arise regarding the *way* in which it is applied to PVS. Are the foundations of the principle as soundly reasoned as we might expect? Is this new application a legally consistent development? Does closer inspection reveal structural weakness? This author believes that there are fundamental grounds for concern and that distortion, rather than development, is occurring. Before substantiating these claims though, it is worth considering from where "best interests" has sprung.

"Best interests" at source

"Best interests" constitutes something of a panacea in medico-legal decision-making - invoked in the treatment of severely disabled infants,¹ sterilisation of incompetent adults,² and as a "fall-back" where consent is defective.³ A principle's gradual levitation to such multi-functional status draws it inexorably away from contextual application, to more-generalised formulation. *Airedale NHS Trust v Bland*⁴ witnessed this shift by way of heavy cross-contextual reliance

upon Re F (a mental patient: sterilisation),² where *lawful* treatment of incompetent patients was equated with treatment in patient "best interests", ie that which sought: "...to save their lives or to ensure improvement or prevent deterioration in their physical or mental health".⁵

The court deemed such evaluation to be within the remit of "Bolam",⁶ thereby effectively requiring "a responsible body of medical opinion" so to construe it. In its entirety, this formulation comprises one of the most explicit formulations of "best interests" to date.

Further support for applying "best interests" to PVS derives from its earlier application to life/death decisions on withholding treatment (Re J (a minor) (wardship: medical treatment)).¹ Here, however, a different formulation involved more overt weighing of "benefits" and "burdens" and minimal reference to "Bolam", thus rendering Re J a more individualistic, "quality-of-life" decision than Re F.

The difficulty in extending "best interests" to PVS decisions lies essentially in the apparent similarity to other non-treatment cases. Like Re J, PVS concerns withdrawing/withholding life-sustaining treatment, but regarding an adult unable to express any consent - like Re F. The disparity of formulation, coupled with high profile, and emotive overtones of "ending life", meant that applying best interests to PVS - though perhaps logical - was never going to be easy.

Best interests in PVS - current aspects

Construction of "best interests" in recent UK and Irish PVS cases, essentially seeks to steer something of a middle course between the generalised and individualistic formulations and permits identification of three component elements: jurisdiction; medical involvement; and classification of interest.

JURISDICTION

Both the Scots Court of Session⁷ and the Irish Supreme Court⁸ are empowered with *parens patriae* jurisdiction, enabling them to exercise a role akin to guardianship, in respect of incompetent adults. This effectively imbues these courts with a power to consent on the patient's behalf. This contrasts sharply with the English courts, where its absence limits jurisdiction to a power to declare a treatment decision "lawful",⁹ ie stating that deciding to cease (or, indeed, continue) treatment will not contravene civil or criminal law.

The wider scope of the Scots and Irish courts facilitates a broad perspective, and "weighing" of the various factors involved (analogous to the Re J

formulation involving wardship). Whereas the more restrictive jurisdiction of the English courts centres the decision upon questions of infringing legal "duties", drawing the focus away from patient need towards more generalised principles (more akin to a Re F formulation). This is not to say that such jurisdictional limits are totally distinct, nor inflexible, merely that each may predispose "best interests" to a particular type of formulation.

MEDICAL INVOLVEMENT

Medical involvement in "best interests" invokes aspects of both Re F and Re J. Thus, in Bland,⁴ continued application of "Bolam", renders medical opinion fundamental to "best interests", a role which is similarly emphasised in the Scots decision of Law Hospital NHS Trust v Lord Advocate.⁷ Such emphasis clearly simulates the Re F construction. However, by contrast, most of the PVS decisions also make reference to other individualistic facets of medical evaluation such as: benefits and burdens of treatment¹⁰; likely effect upon prognosis,¹¹ and invasiveness of treatment to bodily integrity¹⁰ - all essentially more representative of the "balancing" approach so evident in Re J.

It thus seems that, not only is there *considerable* medical input in determining best interests in PVS, but also that this input is then utilised in a mixed construction of formal general principle and informal individualistic balancing.

CLASSIFICATION OF "INTEREST"

The PVS context appears to have spawned a new classification of "interest", and consequent restructuring of "best interests". In previous contexts, identifying the optimal ("best") implicitly required deriving "net benefits", which Buchanan and Brock succinctly explain as: "... assigning different weights to the [treatment] options to reflect the relative importance of the various interests ... then subtracting costs or 'disbenefits' ...".¹²

In Re J such assessment was made openly by the court, whereas in Re F evaluation fell to the medical professionals, whose decision could be judicially verified as "lawful". However, in PVS, continued "treatment" confers only extremely limited "benefits" (such as maintaining the *status quo*), or "burdens" (such as treatment hazards). This lack of input to the "net benefit" equation results in PVS patients' interests being classified as "none", and a consequent denial of any need for weighing.¹³ This rather radical classificatory departure demands - not surprisingly - an alternative formulation of "best", which has ultimately resulted in inverting the formula to consider

whether continued alimentation is “not in the patient’s best interests”.¹⁴

Essentially then, current application of “best interests” to PVS comprises a mixture of previous formulations (and terminology), together with a new classification designed to address the peculiarities of PVS. This may be construed as a principled development, and heavy judicial emphasis on “patient interests” in PVS decisions means that the relevance of “best interests” is undoubtedly firmly established. However, construction of principle is really a secondary step in the decision-making process. Initially let us clarify the objective of that process.

“True” objective

Essentially, we must initially ask: what is the purpose of making this treatment decision? Existing formulations focus upon whether we should treat so as to “prolong life”^{14 15} - a construction which avoids the emotive nature of “causing the patient to die”, and pre-empts suggestions of euthanistic overtones. However, formulating sound legal principle requires honesty of objective and no matter how euphemistically phrased, or finely distinguished, the inevitable consequence of withdrawing alimentation from a PVS patient is *death*. This is simply a fact which, if one is honest, renders the decision one of life-or-death choice. The true objective should therefore be: *to establish whether artificial nutrition and hydration should be withdrawn (or withheld) from a patient in persistent vegetative state, such that the patient will die*. This is not to comment upon the moral or ethical correctness of so doing. It is merely a more truthful statement of the ultimate objective of the decision, which then enables us to seek the most appropriate principle to attain it justly and compassionately.

What is being suggested is that “best interests”, as currently formulated, fails to address this “true” objective, thereby distorting both interests and principle - a claim which must now be substantiated.

The distortion of a principle?

Despite “best interests” value in other medico-legal areas, doubts concerning its construction in PVS decisions are founded on four specific grounds: delusory objective; illogicality; medicalisation, and range of “interests”.

DELUSORY OBJECTIVE

Current construction seeks to constrain “best interests” within strictly delineated parameters. This, in itself, may be no bad thing. However, the

means used to achieve this are less well founded, insofar as suggested substantive conceptual distinction often transpires - on closer inspection - to be merely semantic, and delusory as to true objective. Recurrent judicial distinction between “letting die” and “euthanasia” is a prime example.¹⁶ Judicial motivation for avoiding “slippery slopes” may well be valid, but in terms of PVS this distinction is negligible, as withdrawing “treatment” results in the death of a patient who is not “terminally”, but rather “chronically”, ill. Thus we are not merely “letting” an already imminent death occur. The choice of a particular label, and use of supporting terminology such as “natural death”, whilst suggestive of a more remote, less direct consequence, lying only on the very periphery of our sphere of influence, cannot change the character of the event. In truth, as McLean suggests: “... the actual decision, however reached, is a decision for or against death. We are, in its purest form, considering euthanasia”.¹⁷

Further judicial semantics skirt this by construing euthanasia as requiring positive, direct action. But as Mason and Mulligan indicate, this constitutes “... a very limited definition of euthanasia”.¹⁸

These semantic distinctions are similarly paralleled in promoting “ceasing to prolong life” as differing from “terminating life”,¹⁹ and devolves from Re J. However, withholding reventilation where death is already imminent (through cessation of breathing, as would occur in Re J) possesses a natural, preliminary factor such that “ceasing to prolong” and “terminating” may be distinct. This is simply not apparent in PVS - where the death only becomes imminent as a result of withdrawing or withholding the life-sustaining treatment, thus it is difficult to see how “not prolonging” differs substantially from “ending”, when life would not otherwise cease. Craig suggests that such semantic juggling arises from the vagaries of English criminal law,²⁰ whilst Mason and Laurie emphasise the designation of “cause of death” as a factor.²¹ Whatever the origin, the effect of such fine distinction implicitly suggests “not extending” to be somehow more legally, morally and ethically acceptable than “ending”. This exemplifies judicial delusion as to the decision’s true objective and consequences.

This delusion is supported by further semantics categorising withdrawal of treatment as an “omission” rather than an “act”,²² thereby averting problems of criminal liability, and facilitating a shift of focus towards “duty” and Bolam-relevance. Such distinction is therefore, perhaps, a means to an end rather than substantive in itself and, indeed, its suitability in the PVS context was doubted by Lord Mustill in Bland.²³

In totality, it therefore seems that the current formulation of "best interests" is derived from a number of semantic distinctions. These distinctions, though seemingly "substantial", are - on closer inspection - euphemistic at best. Realistically, they perhaps represent delusion as to the true objective of the decision, and comprise a practical means of circumventing the contentiousness of outcome - ie the patient's death. However, this semantic juggling merely creates inherent inconsistency within the principle itself, which results - ultimately - in a disservice to the individual patient.

ILLOGICALITY

The delusion extends beyond semantics though, to more fundamental illogicality. This arises from the particular difficulties of making a life/death decision, without encountering a problematic valuation of "death" - an unknown concept - or risking intimation of euthanasia. In addition, the generally relevant factors do not possess the same significance in PVS as they have in previous contexts. The patient feels no pain, hazards are few, benefit is minimal, prognosis unalterable, and treatment "futile". This lack of "input" renders weighing of tangible, measurable "interests" near impossible, and has led the courts to conclude (apparently logically) that the patient really has "no interests", thereby denying the need to "weigh" the potentially contentious issues. Such a multiplicity of problems does not, however, justify distorting or misapplying legal principle, yet this is exactly what occurs in seeking to derive "best interests" from "none". Irrespective of whether we believe that the PVS patient does or does not retain interests,²⁴ once we declare "no" interest then surely "best" becomes superfluous - no pool exists from which to draw the "best". The derivation is, therefore, simply not logical, yet this seems overlooked in judgments thus far.

It would be logical to justify withdrawal by saying that the patient has "no interests" and therefore no claim on treatment. Alternatively recognising "minimal" (ie *some*) interests, in PVS (or particularly near-PVS) patients, would enable determination of "best interests". However, no logic lies within mixing the two. Such confusion probably arises from judicial reluctance to classify withdrawal of treatment in PVS as a "quality of life" decision,¹⁴ whilst seeking simultaneously to use a principle evolved from exactly that type of case. Such inconsistency is, however, both inappropriate and unnecessary. A treatment decision in the context of PVS surely requires evaluation of "quality of life" - even if only to establish an answer of "nil" or "minimal". Brock and Bucha-

nan suggest that evaluating "interest" "...depends upon how it affects that patient's life ...", thereby rendering "quality of life" judgments unavoidable.¹² If so, then "best interests" in PVS cases *either* should involve "quality of life" (together with recognition of *some* interests), and current construction is therefore incorrect, *OR* the decision *not* being a "quality of life" one, (the patient having *no* interests to assess), "best interests" is inapplicable.

Furthermore, it is difficult to see how "best" *cannot* involve comparative evaluation, ie weighing, of some sort. McLean rightly identifies a fear factor involved in acknowledging that "...there may be conditions which make death preferable to life",²⁵ and judicial concern has been voiced in categorising one life as "...intrinsically worth less than another".²⁶ Such judicial fears are misplaced however, as they misconstrue "quality of life" as comprising an (offensive) external valuation, rather than an (inoffensive) valuation of that life to that individual. (Brock and Buchanan appropriately term the former a "social" sense and the latter an "intrapersonal" sense²⁷). This judicial misinterpretation fundamentally distorts the evaluative character of "best interests". A valid assessment of intrapersonal "quality of life" (requiring explicit consideration of the patient's likely wishes and feelings, similar to Re J) would, in fact, represent a protection rather than derogation of patient "interests".

Judicial conclusions of "no interests" and "no weighing", combined with marked reluctance to suggest death as being "in the patient's best interests", ultimately result in reversed construction. Thus courts have seen fit to indicate what is "*not* in best interests",¹⁴ to the effect that: where treatment is futile, and the PVS patient no longer has any interest in being kept alive, then it is *not* in his best interests to have his life artificially prolonged - consequently duty to treat ceases and withdrawal is lawful. This eventual construction remains, however, illogical in several respects. Primarily, the derivation of "best" from "none" is questionable. Furthermore, the accepted negative construction of "*not* in best interests to prolong life" is logically no different from the refuted construction that "it is *in* this patient's best interests to die" - the two are merely mirror images of the same equation, possessing the same outcome, by way of the same passive route. In addition, despite denying the relevance of "quality of life", judgments still refer to "invasiveness" and "futility" of treatment²⁸ - suggesting *informal* weighing of burdens/benefits. Current construction of "best interests" is therefore inherently illogical, and distorts previous formulations. It is also questionable

whether we are any longer deciding "in" the patient's "best interests", rather than implementing solutions "not in" those interests - a contortion running a gamut of inappropriate possibilities.

Finally, we may doubt whether "best interests" was ever a logically analogous application in PVS decisions. Despite superficial similarity to both Re J and Re F there is, after all, one fundamental *dis*-similarity. Both of those cases concerned patients who had never been legally competent - in stark contrast with most PVS patients. "Best interests" may therefore even be a "misapplication" in this context, causing patients' previous wishes to be under-valued. An alternative principle might, therefore, have been warranted and avoided the need for contortion. However, at present, "best interests" still prevail.

MEDICALISATION

The inherent medicalisation within the Re F formulation (commented upon by the Law Commission)²⁹ is similarly apparent in Bland,⁴ despite the Bolam standard finding disfavour in its original negligence context in recent years.³⁰ Accepting a "responsible body of medical opinion" as evincing "best interests" essentially subjugates patient interests to professional duty and, whilst reliance upon medical evidence is necessary, it should remain purely evidential - not determinative. Importation of Bolam into PVS decisions insupportably abrogates the decision, thereby failing to protect those individuals *most* in need of court protection regarding the ultimate decision: life or death. Although its invocation was not universally embraced, (doubts being cast by the Court of Appeal, and subsequently Lord Mustill, in Bland),³¹ the Scottish courts appear to have similarly accepted medicalisation as a foundation for "best interests".¹³ By contrast though, the Irish courts retain a more patient-oriented, individualistic approach, deeming the judge the ultimate decision-maker.³² Subsequent attempts by English law to reserve final authority to the court, though explicitly expressed in Frenchay Healthcare NHS Trust v S,³³ implicitly lack substance - in view of the alarming speed, lack of full investigation and weighty emphasis on medical evidence apparent in that case.

The danger in medicalisation is its denial of the patient's previous, and continuing, *non*-medical interests. In addition, the minimisation of judicial involvement in this new legal area, concerning decisions laden with ethical and social implications, is highly questionable and risks courts merely "rubber-stamping" medical decisions. Once combined with judicial willingness to categorise artificial hydration and nutrition as

"medical treatment",³⁴ and contrasted with judicial *unwillingness* to countenance alternative patient-oriented tests,³⁵ the distortion becomes yet more exaggerated. How might this distorted principle cope with circumstances yet to arise? What if all family members (rather than just one - as in Re G³⁶) oppose withdrawal? Or if strong evidence of "patient wishes" contradicts medical opinion? Could courts justifiably construe the interests of a near-PVS adult as "none" thereby denying any "balancing", when Re J would be more closely analogous? Reliance on medical opinion, and British Medical Association guidelines,³⁷ is no substitute for clear judicial guidelines founded on sound, consistent principle. This begs the serious question: just whose interests are currently being served?

LIMITATION OF RANGE OF INTERESTS

Medicalisation admits only a narrow conception of "interests". A broader perspective, seeking "best interests" in totality, might view medical best interests as just one segment, others perhaps comprising: "personal" interests, incorporating non-medical aspects such as religious belief; "familial" interests, admitting views of those emotionally closest to the patient; and even "societal" interests, considering a decision's effect upon society or other, similarly placed patients, potentially including the issue of resource allocation.

Undoubtedly the non-individualistic interests are contentious but, before rejecting them out of hand, it should be borne in mind that they may already play an *unofficial* role in PVS decisions. Judgments are, after all, sprinkled with references to *familial* opinion,³⁸ and "indignity"³⁹ - a state which is perceived by those associated with the patient, whilst the repeated distinction from "euthanasia" surely indicates evaluation of potential *social* implications.

So, where does this current construction, of formal medical interests and informal non-individual interests, leave the actual PVS patient? Where are his personal, non-medical interests incorporated? The short answer is that they are not - a result of imputing "no interests", or even "no relevant personality",⁴⁰ to PVS patients. However, in Re J,¹ concerning withholding reventilation from a severely brain-damaged baby, the Court of Appeal did view the patient's perspective as being relevant to "quality of life" - itself an element weighed in determining "best interests". Thus, the court emphasised that "quality of life" should be viewed "... from the assumed point of view of the patient ...", and that "... the test must be whether the child in question, if capable of exercising sound judgment, would consider the

life tolerable".⁴¹ The irony of this is, of course, that in the PVS context "best interests" takes no account of a genuine, previously existing personality. However, a *non-existent* opinion is imputed regarding a severely disabled baby who has never actually possessed competence, opinions, or beliefs.¹ This distorts, beyond recognition, the very thing supposedly sought, i.e. the "interests" of that individual PVS patient.

We cannot conclude from this, however, that "best interests" is completely inapplicable to PVS, but rather that its current construction is inappropriate. Would it not be preferable to adopt the broader perspective, enabling other interests to be formally incorporated and permitting proper relevance to the patient's *non-medical* interests? Although a PVS patient appears to have no current or future interest in living, this does not automatically equate to "no interests". Interests deriving from his previous personality are surely still attributable to him, and potentially relevant. These "subsisting interests" include religious beliefs, former opinion as to his present situation, feelings towards his family, and perhaps even beneficence towards others (for example, strong personal belief in organ donation). By adopting a fuller, rounder view of "*interests*" a truer picture of the whole individual is formed, providing a firmer basis for formulating "*best*" interests. Its invocation would require us to turn the Bland decision upon its head, and to go beyond "Re J individualism" in making explicit which interests are relevant. So far only one judgment (by Denham J) has even approached this, by identifying and applying fifteen "factors" in determining "best interests".⁴² These included, for example, the patient's life history and previously expressed views; the family/carer's view; privacy, dignity and autonomy; and the "common good" involved in protecting life. Until this clearer-visioned, non-delusory approach is adopted, both principle and "interests" seem set for distortion.

In conclusion...

Medico-legal decision-making faces difficulties in addressing persistent vegetative state (PVS) due to the condition's chronic nature, potentially contentious outcome, and intrinsic patient incapacity. Law has tried to address these difficulties using the beneficent solution of "best interests". This is a valuable decision-making device in areas such as emergency treatment and (perhaps) treatment of patients who have never been competent. However, its relevance to PVS decisions - and patients previously possessed of competence and opinions - is less readily apparent. Dismissing its applicability out of hand is overly simplistic though, and

untested in terms of viable alternatives. "Best interests" should, therefore, be seen as *potentially* relevant, but needing careful formulation.

Whilst the judgments correctly identify the PVS situation as a product of technological and medical advances,⁴³ they fail to acknowledge that this novel situation may warrant a more innovative legal approach to "best interests". Earlier formulations of "best interests" have varied considerably and are essentially contextual in construction.^{1,2} Judicial attempts to "fit" PVS into these formulations have distorted the concept of "best interests", resulting in an illogical mixed interpretation. In addition, denying that the patient still possesses any real interests distorts the focus of the decision. This has been exacerbated by judicial delusion regarding the true nature of treatment withdrawal in PVS, perhaps due to fears of confronting the all-too-real life/death issues involved.

Judgments are peppered with semantic distinctions, which are dubiously founded, lend nothing to clarity and, indeed, the very need to invoke such distinctions is a telling criticism in itself. Denying PVS to be a "quality of life" decision is also highly questionable, (virtually non-existent quality of life surely must be a major factor in the decision), and is at odds with its central relevance in previous constructions of best interests. The related disinclination to openly "weigh" relevant factors contradicts the very essence of *best* interests itself. Thus, the path of "best interests" is now effectively strewn with interpretational debris.

Furthermore, judicial use of "*best interests*" has persisted, despite simultaneously declaring PVS patients to possess "*no*" interests at all. This approach lies far beyond this author's understanding of logic as, even setting aside problems of linguistic vagueness and viewing from a purely logical perspective, it is difficult to see how "something" may be derived from "nothing".

Meanwhile, overly heavy reliance upon medical determination of PVS patients' "best interests" causes other relevant interests - such as individual, personal (non-medical) interests - to be displaced entirely.

This current, contorted approach is doing no one any favours: PVS patients are ill-protected; the burden on medical opinion is heavy, and the law is on course for castigation when case circumstances arise such as to highlight weaknesses. It may well be that a reformulation of "best interests" to comprise elements outlined by Denham J, or perhaps those of the Law Commission,⁴⁴ could provide a better reasoned, more productive approach. Alternatively, hierarchical structuring of decision-making "devices" could primarily

emphasise patients' wishes, and use "best interests" only in a fall-back capacity.⁴⁵ Whichever the preferred solution, the essential focus must lie with the interests of the individual patient, admitting other interests only where relevant. Any such development will however require a preliminary step of honesty - as to issues and objective.

Admittedly, the PVS patient may well be legally incompetent, physically insensate and ultimately incurable. However, we would do well to remember that the decision to withhold nutrition is the "ultimate" one of life or death, and - no matter how beneficent or "right" the outcome - it should not consist in a legal formulation which is illogical, or inimical to that patient's former and subsisting interests. Otherwise it is, by definition, most certainly not in his "best interests".

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Letters

Best interests in persistent vegetative state

SIR

While I agree with several points raised in your recent editorial¹ on my paper, Applying best interests to persistent vegetative state - a principled distortion?,² I must respond to a number of other issues which you raise. I agree unreservedly with your caveat that both doctors and judges must act within the law. My paper, however, sought to expose that the paradox for the court in the Bland case³ lay in struggling to attain: 1) a morally "right" outcome (withdrawal of life-prolonging treatment (LPT)); while at the same time 2) remaining within the bounds of the current law. As the current law stands it permits allowing patients to die in certain circumstances, whilst prohibiting intentional killing. We should not believe, however, that this state of affairs compels us to accept it as the best we could hope for. Changes to the law may be justified if sufficient moral support exists for making such changes. Although medical ethics, as a discipline, places considerable reliance on moral values, the relationship of law and morality has been traditionally fraught. This latter tension is reflected in the strained semantics of the persistent vegetative state (PVS) decisions. Thus, far from condoning any flouting of the criminal law, I submit that we, as decision makers, need to embrace more honestly the moral content of LPT withdrawal decisions, if decisions are to be clearer and more consistent.

Your editorial suggests that my article implicitly equates "not in" a patient's best interests with "against" best interests. I accept that this is the effect of my approach. However, I adopt this position on the basis that any further distinction regarding best interests is ineffective. While your pro-

posed three categories of "in"; "not in" (presumably neutral); and "against" a patient's best interests are viable regarding "interests" as such, I would argue that the addition of the superlative "best" seeks the optimal action for the patient. This absolutist tone creates an either/or situation, such that an action can only be "in" or "not in" the patient's "best interests". Any further distinction, such as actions which are "not in" or are "against" a patient's best interests, merely represents examples from the same category; namely a non-optimal solution. It is therefore a distinction without difference. Furthermore, while your Smith/Jones example is warranted regarding the patient's interest in other patients' treatment, the LPT decision in PVS obviously relates to the patient personally. Thus, the decision/outcome can never be neutral to that patient's interests, and therefore must fall to one side or other of the "best interests" line.

With regard to my argument that the decisions are founded upon a "delusory objective", (ie that non-treatment is sought rather than the death of the patient), I agree with your suggestion that "...any action is properly described in part by the intentions of the agent...". Certainly, for example, English law's distinction between murder (where death or serious injury is intended) and manslaughter (where such intention is absent) would support your view. However, as a lawyer, I must dispute your conclusion that a patient's death is not "intended" when it is merely "...foreseen as inevitable". Several years of debate in English criminal law have concluded that where an agent foresees death to be the "virtually certain" consequence of his or her actions he or she may be inferred to possess criminal "intention".⁴ Thus, a doctor knowing death to be the virtually certain result of withdrawing LPT from a PVS patient could legally "intend" that death. The House of Lords' denial of

such criminality on the basis that a doctor is under no duty to maintain the patient's life, may (commendably) reflect judicial recognition of such medical action as both morally supportable and ethically sound. However, the complex semantic juggling needed to achieve this moral recognition suggests that medical law is being contorted to bridge the gap between criminal law and modern morality in LPT situations.

Relatedly, your suggested test of a doctor's/judge's true intention (ie his reaction to the patient waking and asking for food) I find unhelpful as, by definition, a PVS patient's consciousness and communication have ceased and the possibility is therefore extremely remote. Contemplating such unlikely events regarding PVS patients is not the answer to establishing doctors' intentions. This is the task of legal and medical professionals and commentators. Open examination and recognition of realistic consequences of decisions is the initial step in providing acceptable solutions to these difficult cases.

With regard to my argument that it is illogical to derive "best interests" from "no interests", I agree entirely with your suggestion that finding the alternative of "no best interests" may be logical where a patient has "no interests". In PVS cases the courts have been compelled to use this approach because the test offered by earlier cases,⁵ namely seeking what is in best interests, seems to offer nothing to weigh in the balance. On this view, "no interests/not in best interests" therefore provides the only logical solution. However, this is premised on the view that only the patient's experiential interests matter. Yet, patients arguably do possess interests beyond the purely experiential.⁶ And, if such interests are deemed to persist beyond entry to PVS,⁷ then merely construing "no interests/not in best interests" is inappropriate, and we must revert to the original construc-

tion of seeking what is in the PVS patient's best interests.

Finally I would emphasise my principal argument which focuses on the need for clear decision making in PVS, LPT decisions. Existing judgments do not - and cannot - deliver this until relevant criminal, civil, medical, ethical and moral issues are openly debated. Undoubtedly all concerned - doctors, family, nursing staff, lawyers and judiciary - seek the best outcome for the patient. However, the appropriate mechanistic tools are needed to allow decisions to be taken with that objective in mind. Recent judicial semantics and reconstructions show that, in England and Scotland at least, courts are not suitably equipped. A broader, empowered judicial function is therefore needed. Open debate of these issues is the essential first step towards meeting the genuine best interests of patients in this tragic, highly personal situation.

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Appendix 10

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Re S (Medical Treatment: Adult Sterilisation) Retrenching on risk – revising the lawful boundaries of sterilisation

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Making decisions for others is a risky business. We fear making the wrong decision. Yet medical treatment and what we might term 'life management' of intellectually disabled people frequently necessitate difficult decisions being made on their behalf. Such decisions are not only risky in terms of getting it wrong, but also risk driven. The decision-maker must assess the risks associated with each option in arriving at the optimal solution. This involves identifying the relevant range of risk factors, and evaluating their impact on the *incapax*, which is inherently problematic in terms of accuracy and attribution of value. However, the recent case of *Re S (Medical Treatment: Adult Sterilisation)*² has confronted risk head-on in the context of proposed prophylactic sterilisation of an intellectually disabled woman. This commentary argues that *Re S* represents a retrenchment from the previously expansive boundaries of lawful sterilisation, based on a re-evaluation of risk. In calling for a more extensive redefinition this commentary also proffers a more realistic two-stage approach to risk assessment.

RE S: REAL RETRENCHMENT?

Re S concerned a vulnerable 22-year-old intellectually disabled woman, who was not sexually active. Pregnancy could, therefore, only result from sexual assault. The High Court's unexpected refusal to authorise sterilisation was clearly posited in 'risk'. In overtly assessing the risk of pregnancy, Johnson J gave detailed consideration to S's daily routine, supervisor/client ratio, tactile behaviour, respite care supervision, and need for supervision generally. This focus on supervision and degree of care had been previously highlighted in *Re LC (Medical Treatment: Sterilisation)*³ where the High Court had similarly refused authorisation partly based on evidence that existing levels of care and supervision 'would effectively eliminate the risk of sexual abuse to L'.⁴ In *Re S*, while acknowledging the irony of overriding the wishes of parents *because of* their responsible supervision, Johnson J emphasised the need for 'identifiable consistency' and thus felt 'driven' to find parity of circumstance with *Re LC*.

Although both *Re S* and *Re LC* adopt a similar approach, the tenor of *Re S* is altogether broader. Johnson J considered the impact of the decision regarding the family unit, the Children Act 1989 and the European Convention for the Protection of Human Rights and Fundamental Freedoms. While admitting the relevance of parental opinion, the ultimate balancing exercise was reserved to the court alone. Broader risk factors were acknowledged, including, most importantly, the risk and seriousness of sexual assault itself (as opposed to resultant pregnancy). Furthermore, Johnson J set new temporal limits on risk assessment. He cautioned that 'speculation as to future risk must be based on circumstances as they presently exist or can be reasonably foreseen to exist'.⁵ Restricting risk to foreseeability enabled the requisite degree of risk to be redefined as 'identifiable rather than speculative'.⁶

¹ The author wishes to thank Dr Graeme T. Laurie and the anonymous referee for their valuable comments on earlier drafts of this commentary, and also the British Academy (Humanities Research Board) for its continued support. The usual disclaimer applies.

² [1998] 1 FLR 944.

³ [1997] 2 FLR 258 (decided in 1993).

⁴ *Ibid.*, at p 260F.

⁵ [1998] 1 FLR 944, at p 947A-B.

⁶ *Ibid.*, at p 949E.

Why retrench?

We might wonder why retrenchment was necessary, as two relevant House of Lords' decisions already existed in *Re B (A Minor) (Wardship: Sterilisation)*,⁷ and *Re F (Mental Patient: Sterilisation)*.⁸ Indeed, *Re B* was based on relatively restricted grounds insofar as the ward showed normal sexual drive, while possessing no understanding of the causal connection between intercourse and pregnancy. However, these limits were subsequently eroded by shifting judicial criteria. In *Re F* the House of Lords combined welfare with necessity, but invoked the *Bolam* standard in determining best interests and, by so doing, ignored the broader philosophical, social, moral and personal aspects of the decision. The cumulative effect was thus: (1) to establish a loose formulation of best interests; and (2) to load the best interests equation with heavy medical bias. Absence of mandatory court involvement simultaneously relaxed procedural steps.

This facilitated further expansion during the following four years, through to the high water mark of *Re HG (Specific Issue Order: Sterilisation)*.⁹ This persistent boundary extension witnessed the downgrading of factual criteria regarding sexual activity (for example *Re W (Mental Patient) (Sterilisation)*¹⁰ and *Re HG*¹¹) and supervision (*Re HG*), together with the admission of increasingly remote, future-oriented aspects (*Re W*¹²). This factual downgrading facilitated approval of sterilisation based on best interests. Legal criteria were simultaneously loosened – moving from necessity and welfare (*Re F*¹³) to vague assessments of 'interests overall' (*Re HG*¹⁴), and shifting from paramountcy (*Re F*¹⁵) to taking account of others' interests (*Re HG*¹⁶). Procedures were relaxed regarding therapeutic sterilisations (*Re E (A Minor) (Medical Treatment)*¹⁷ and *Re GF (Medical Treatment)*¹⁸). The net effect was the seemingly limitless expansion of lawful boundaries, to the point where even *de minimis* risk of pregnancy – where the patient was not, nor would become, sexually active – would translate into an 'overwhelming' reason for sterilising (see *Re HG*¹⁹).

Re S has stemmed this tide. Although any right of reproduction was denied – as in *Re B* and *Re F*²⁰ – Johnson J acknowledged the special character of contraceptive sterilisation, together with dangers inherent in leaving sterilisation decisions to immediate carers. Ultimately, the abuse issue founded the refusal, *Re S* being distinguished from *Re B*²¹ in terms of S's lack of sexual awareness. However, *Re S* represented a turning point in a wider sense, by compelling courts to focus on risk.

New limits (Re S)

Revising the requisite degree of risk to 'identifiable rather than speculative'²² effectively resurrects the limits of sterilisation. Indeed, it reflects the language adopted in *Re D*, where

⁷ [1987] 2 All ER 206.

⁸ [1990] 2 AC 1, sub nom *F v West Berkshire Health Authority* [1989] 2 All ER 545.

⁹ [1993] 1 FLR 587.

¹⁰ [1993] 1 FLR 381.

¹¹ [1993] 1 FLR 587.

¹² [1993] 1 FLR 381.

¹³ [1989] 2 All ER 545.

¹⁴ [1993] 1 FLR 587.

¹⁵ [1989] 2 All ER 545.

¹⁶ [1993] 1 FLR 587.

¹⁷ [1991] 7 BMLR 117.

¹⁸ [1992] 1 FLR 293.

¹⁹ [1993] 1 FLR 587.

²⁰ But in contrast to *Re D (A Minor) (Wardship: Sterilisation)* [1976] 1 All ER 326, at p 332H where Heilbron J clearly characterised such sterilisation as violating a woman's right to reproduce. However, unlike S, D was likely later to develop sufficient intellectual capacity to enable her to make her own choice.

²¹ [1987] 2 All ER 206.

²² [1998] 1 FLR 944, at p 949E.

Heilbron J similarly focused upon the ward's absence of sexual interest, lack of opportunity for sexual activity and high degree of supervision, in concluding the need for contraception was 'premature'.²³ The return by *Re S* to 'identifiable risk' also corresponds with an earlier Practice Note of the Official Solicitor,²⁴ requiring a real danger, as opposed to mere chance, of pregnancy.²⁵ While the decision still clearly (and rightly) depends on factual circumstances, 'identifiable risk' suggests that any purely *de minimis* degree of risk will not suffice. Hence, risk has been brought sharply into focus, and into line, with accepted policy approaches to foreseeability and remoteness.

The motivation for this approach is apparent towards the end of Johnson J's judgment, 'if in the circumstances of this case the court were to declare sterilisation to be lawful, then it is difficult to envisage any factual situation in which that relief would be refused'.²⁶ This clearly indicates judicial discomfort with previous expansiveness, and a perceived need for more restrictive boundaries. Johnson J, in the final paragraph of his judgment, clearly reserved responsibility for deciding whether to sterilise to the court, restricting boundaries further by halting procedural relaxations.

Admittedly, as first instance decisions, both *Re S* and *Re LC* could be dismissed as renegade judgments.²⁷ However, their very unexpectedness – after more than five years of seemingly unstoppable expansion – suggests that the pendulum is swinging back. There are now limits. The boundaries have been revised and retrenchment is becoming a reality. In this process the key factor is risk, and it is to a consideration of its assessment that we now turn.

THE RISK MECHANISM

So, why was retrenchment based on risk? The short answer is that expanded lawful boundaries meant that risk was the only control factor left open to the court. Determining best interests had been all but handed to the medical profession so that, once *any* risk of pregnancy was identified, sterilisation was lawful wherever a 'responsible body of medical opinion' believed it to be in the patient's best interests. Thus the court could effect a limit only by deeming the risk unproven. However, *Re S* (and *Re LC*) represent a more fundamental shift in how risk, as a mechanism, is viewed, assessed, and its impact interpreted.

Evaluating 'risk'

Carson, discussing risk assessment within health care generally, advocates a distinction between two identifiable variables: consequence and likelihood.²⁸ He argues that risk assessment should consider all relevant factors in terms of both of these variables. In other words: (1) what will happen if the foreseen risk actually transpires; and (2) what is the likelihood of that risk occurring? He believes that in assessing risk we are susceptible to irrationality about both variables, tending to emphasise harm rather than benefit, and unrealistically anticipating a worst-case scenario as virtually certain.²⁹

On this basis, the expansive sterilisation decisions clearly evidence poor risk assessment in confusing risk (of pregnancy occurring) with consequence (of resulting trauma). The resulting approach becomes consequence driven, subjugating particular risks to others. For example, the psychological harm of sterilisation became less important than the perceived major psychological harm from pregnancy/birth. It thus becomes compelling to see sterilisation as 'necessary' and clearly in the patient's best interests. In reality, the risk assessment was being skewed. Focusing predominantly on the ultimate harm of pregnancy/birth trauma obscures a

²³ [1976] 1 All ER 326, at pp 333J–334A.

²⁴ *Practice Direction – Practice Note – Official Solicitor: Sterilisation* (May 1993) [1993] 2 FLR 222.

²⁵ See G. B. Little, 'Comparing German and English law on non-consensual sterilisation: A difference in approach' (1997) 5 *Medical Law Review* 269, at pp 283–285.

²⁶ [1998] 1 FLR 944, at p 949F.

²⁷ Similarly, G. B. Little (op cit, n 25, at p 289), writing prior to *Re S*, observes that the *Re LC* judgment differs from the general pattern of sterilisation cases.

²⁸ D. Carson, 'Risk-taking policies' (1988) *Journal of Social & Welfare Law* 328, see particularly pp 328–329.

²⁹ *Ibid.*, at p 329 and p 330, respectively.

clear view of the range of relevant risk factors, the harm or benefit accruing from them, and the likelihood of these harms/benefits actually occurring.

Retrenchment and the 'risk mechanism'

The recent retrenchment shifts this focus. In effect, it deconstructs the existing risk mechanism. Instead of focusing on *ultimate* harm/consequence, assessment reconsiders earlier stages to assess what might be termed *intermediate* harm, namely the risk of pregnancy occurring in the first place. This permits clearer perspective, and more accurate evaluation, of factors cumulatively influencing risk. Thus the courts were able to admit risk factors previously ignored, such as the risks involved in operating, and so reconstruct a more justifiable risk assessment.

More importantly, in *Re S*, the court accepted, for the first time, the significance of the *risk agent*. Assessment thereby starts from the first level of the mechanism, by determining the realistic source of potential risk. This facilitates a broader view of risk factors and injects likelihood as a vital element. *Supporting risk factors*, such as degree of care/supervision, capacity to consent to sexual intercourse, and surgical risks, are also admissible within general rules of foreseeability. Together they help to determine whether risk of pregnancy is realistic, or simply too remote to warrant surgical intervention.

This evinces a substantial judicial shift. The risk mechanism is being viewed in a more complete sense. If the risk of becoming pregnant is virtually nil, then the consequences become irrelevant. In other words, ultimate harm is irrelevant because the risk of intermediate harm occurring is non-existent. Furthermore, the *court* is responsible for determining whether intermediate harm is a real risk or not.

Staging risk assessment

It is submitted that risk assessment regarding sterilisation of the intellectually disabled should incorporate two distinct stages:

- (1) identifying whether a cumulative³⁰ risk of pregnancy really exists, by determining the likelihood of a pregnancy occurring, and by which agent; then,
- (2) considering the likelihood of further harms/benefits accruing from:
 - (a) the process of pregnancy/birth/separation/parenting;
 - (b) surgical sterilisation; and
 - (c) alternative methods of contraception.

Re S goes part way to promoting this two-stage approach, by distinguishing respective stages and broadening the range of admissible factors. Effectively, lawful boundaries have been revised and redrawn using the risk mechanism. However, risk re-evaluation is in its infancy. While the risk equation is now in better order, the range of relevant factors is far from complete. English courts still tend to adopt a one-sided perspective regarding certain factors. For example, the ability of intellectually disabled patients to form relationships is often denied. Statistical risks, painful side-effects, and the potentially substantial psychological impact (ie distress and low self-esteem) resulting from surgical sterilisation are often trivialised. Furthermore, while the patient's personal inviolability is recognised regarding inability to consent and the need for court involvement, that inviolability is often forgotten regarding both surgery and sexual assault. This raises questions, respectively, whether the sterilisation would be performed forcibly in the event of patient objection, and whether vulnerability to sexual assault is implicitly accepted.

In addition, Carson identifies several difficulties surrounding the sexuality of the intellectually disabled generally. These include, for example, the difficulty of their securing

³⁰ G. B. Little (op cit, n 25, at p 277) also identifies the German legislative approach to sterilisation as requiring 'cumulative' fulfilment. However, those requirements extend beyond assessing risk of a pregnancy occurring and therefore comprise a different decision-making model than is proposed here.

privacy in which to develop relationships,³¹ the particular implications of general social constructs of male responsibility for contraception, and the additional difficulties in countering risks of sexually transmitted disease.³² These factors, which surely merit consideration if our aim is to protect the patient from the potential harms of sexual activity, remain entirely unconsidered within sterilisation decisions thus far. Furthermore, adopting alternative communication methods³³ and/or developing a patient's social skills may represent important alternatives prior to resorting to sterilisation. A patient's low IQ is not necessarily commensurate with an inability to understand enough to consent, and/or cope with pregnancy.³⁴ However, current legal emphasis upon IQ values tends to preclude realistic evaluation of a patient's broader social capacity.

One common thread is ascertainable among these unconsidered factors. It pertains to the intellectually disabled patient's *personal non-medical interests* including, for example, sexuality, privacy, bodily integrity and social development. The early expansive sterilisation decisions failed to consider particular (non-medical) risk factors. Thus, within stage two of assessment, medical interests predominated. This permitted an unofficial distinction to exist between medical interests – which weighed heavily – and what Cica terms the patient's 'social interests'.³⁵ These social (or personal non-medical) interests were too often left aside. In retrenching on risk, *Re S* has undoubtedly altered prospective case outcomes – foregone conclusions are now rendered unpredictable. Furthermore, the court tentatively acknowledged patient interests in a broader, non-medical sense. However, more substantial recognition of such interests, and admittance of associated risk factors, remains a matter for speculation.

RISK – CURIOSITY OR CATALYST?

The precedential value of *Re S* begs the question whether focusing on risk is a catalyst for change, or merely a curiosity – a very specific exception to the generally expansive rule. Let us consider each in turn.

Curiosity?

There are a number of reasons why *Re S* and *Re LC* may yet prove mere curiosities.³⁶ These include:

- the status of the retrenchment decisions, in that they are first instance decisions compared with earlier House of Lords' decisions;
- the particular circumstances of the retrenchment cases, notably the very high degrees of care or supervision in both *Re S* and *Re LC*;
- the intellectually disabled woman's absence of sexual drive, making criminal assault the only potential risk agent. This could limit the cases to their facts;
- the continuing influence of medical opinion, which could render judicial supervision insignificant in circumstances not strictly analogous to *Re S* or *Re LC*;
- the very limited admission of patient social interests or supporting risk factors.

Catalyst?

These cases do, however, possess potential for catalytic change. The recent retrenchment effectively protects personal, non-medical interests by the back door. While this currently

³¹ D. Carson, 'The sexuality of people with learning difficulties' (1989) *Journal of Social and Welfare Law* 355, at p 360.

³² *Ibid.*, at pp 363–364.

³³ For example, see generally J. O'Hara, 'Pregnancy in a severely mentally handicapped adult' (1989) 15 *Journal of Medical Ethics* 197, at pp 197–199.

³⁴ See *op cit.*, n 31, at pp 367–371. See also J. P. M. Denekens, H. Nys and H. Stuer, 'Sterilisation of incompetent mentally handicapped persons: a model for decision-making' (1999) 25 *Journal of Medical Ethics* 237, at p 239.

³⁵ N. Cica, 'Sterilising the Intellectually Disabled: The approach of the High Court of Australia in *Department of Health v JWB and SMB*' (1993) 1 *Medical Law Review* 186, at p 195.

³⁶ G. B. Little (*op cit.*, n 25, at p 289) also regards the *Re LC* judgment as a 'curious case'.

focuses on protection from sexual assault, the relevant interest is 'bodily integrity'. This interest could equally apply where a patient is sexually active but risk of pregnancy does not, on balance, justify invasive surgical sterilisation because of, for example, reduced patient fertility, or male responsibility for contraception.

This more radical shift towards protecting social interests would require assessing a wider range of risk factors than traditionally – or even recently – admitted in England. That depends upon courts accepting the broader personal/social/ethical context of sterilisation decisions. This, in turn, requires recognition of issues which are still problematic for society, the legislature and the courts, such as the sexuality of intellectually disabled people, sexually transmitted disease, male responsibility, and personal development of the intellectually disabled.

Such changes are not impossible. Society's attitudes do change. The law develops to reflect appropriate changes. The recent retrenchment recognises that lawful boundaries need revising, and that a patient's social interests raise factors which ought to be relevant to the decision. Furthermore, the decisions show judicial desire to reclaim the court's role as final arbiter. Theoretically this trend could continue to develop. If so, it is to be encouraged. 'Best interests' surely suggests, to the layman at least, taking an active decision about the proactive welfare of the intellectually disabled patient – a decision taken in full sight of all factors and circumstances. Continued development would move closer to this. In its wake it would leave only a series of decisions by default – predominantly negative decisions based on a limited, medically oriented agenda and inaccurate risk assessment.

Alternative approaches?

On the face of it, the retrenched position appears now to replicate the Australian approach accruing from *Secretary, Dept of Health and Community Services (NT) v JWB and SMB*,³⁷ and *Re L & M, Director-General Department of Family Services and Aboriginal and Islander Affairs*.³⁸ *JWB*³⁹ set out the parameters of sterilisation decisions, within which *Re L & M*⁴⁰ then developed guidelines. Similar boundaries in Australia and England seem to result, particularly comparing *Re L & M*⁴¹ and *Re S*⁴² in relation to: parity of language/principle; refusal (to sterilise) based on insufficient risk; and mutual imposition of court involvement. However, the means used to arrive at those boundaries creates a significant difference. The logical, traceable Australian approach remains more accessible to future sterilisation decisions because the Australian Family Court adopts a wider agenda in terms of: accepting a wider context; recognising the importance of personal inviolability; and admitting a broad sweep of evidence regarding both medical and social interests.

Hence, while Australian boundaries are clearly demarcated, courts still have ample room to manoeuvre. Where future cases raise different issues, the range of risk factors is capable of developing to encompass them. This perspective engenders highly individualised decisions within tighter, justifiable boundaries. In contrast, the English High Court was able to retrench only on narrow grounds pertaining to risk in particular circumstances. Furthermore, the traditional weight of medical evidence in England may still be overwhelming, once identifiable risk of pregnancy exists.

³⁷ (1992) 66 ALJR 300.

³⁸ (1993) 17 Family LR 357.

³⁹ (1992) 66 ALJR 300.

⁴⁰ (1993) 17 Family LR 357.

⁴¹ *Ibid.*

⁴² [1998] 1 FLR 944.

Further developments: Re X (Adult Sterilisation)⁴³

The recent decision of *Re X* serves to indicate the potential limits of *Re S*. The two cases display important factual distinctions,⁴⁴ and X's apparent interest in (and possible history of) sexual activity effectively shifted her situation across the risk boundary. Thus Holman J agreed with both the consultant psychiatrist and the Official Solicitor that there existed 'a real risk that X will have a relationship with a sexual ingredient and may become pregnant'.⁴⁵ Holman J clearly delineated relevant issues in addressing a logical series of questions regarding X's capacity, risk of pregnancy, risk of consequent harm, and risks associated with an alternative contraceptive method. This delineation, together with willingness to implement a 'real risk' criterion, suggests that the requirement that a risk be 'identifiable' is tentatively taking root and a revised approach is being adopted.

However, despite this apparent recognition of boundary changes resulting from *Re S*, the *Re X* judgment ultimately exposes the limits of retrenchment. Once a 'real risk' had been identified, judicial emphasis turned to focus solidly upon prevention of consequential harm (from pregnancy), limited evaluation of alternatives, and heavy reliance on medical evidence. Indeed, in contrast to *Re S*,⁴⁶ Holman J drew attention to particular precedential aspects of *Re F* regarding the need for care and the lawful acceptability of a responsible body of medical opinion.⁴⁷

Hence, in terms of this author's suggested two-stage approach, the first stage (cumulative risk) was fulfilled by virtue of a foreseeable risk agent (X's male friend), and supporting risk factors (X's opportunity for, and interest in, sexual activity). The second stage, however, received only partial consideration in the *Re X* judgment, where reliance on medical assessment of consequential harm, and a limited consideration of alternatives still predominated.⁴⁸ Imbalance within the harm/benefit perspective⁴⁹ seems, therefore, to persist. Despite redrawing certain boundaries, *Re S* may yet prove a curiosity – its role restricted to initial identification of the existence of risk. In England any development of the *Re S* approach beyond this first stage of risk assessment remains, therefore, a matter for conjecture.⁵⁰

DEFINING NEW BOUNDARIES

Realistically, sterilisation benefits some intellectually disabled patients, yet is an unnecessary imposition on others. A more radical overhaul of this area is needed if boundaries are to be appropriately set. Incompetent patients merit coherent, active decision-making on their behalf, in full sight of all associated harms and benefits. After all, this is no more than we, as legally competent decision-makers, would expect in making the 'right' decision for ourselves.

⁴³ [1998] 2 FLR 1124.

⁴⁴ *Ibid.*, at p 1127. The factual differences arising regarding X concerned: her desire for physical contact with men; her potential enjoyment of a sexual relationship; her degree of independence; her friendship with a particular male, to whom she regarded herself 'engaged'; her previous history of some sexual activity; and her expressed desire to 'have a baby'.

⁴⁵ *Ibid.*, at p 1127C–D.

⁴⁶ In *Re S* [1998] 1 FLR 944 no reliance upon the *Bolam* standard was apparent. See commentary by A. Grubb, 'Incompetent adult (sterilisation): Best interests and the risk of pregnancy' (1998) 6 *Medical Law Review* 354, at pp 354–356.

⁴⁷ [1989] 2 All ER 545, at p 567A and p 571H, per Lords Goff and Jauncey, respectively.

⁴⁸ For example, as neither the contraceptive pill nor the possibility of male responsibility for contraception were mentioned, it is not clear whether these alternatives were unsuitable or simply unconsidered in *Re X* [1998] 2 FLR 1124.

⁴⁹ In terms of Carson's harm/benefit analysis, *op cit*, n 28, at pp 328–330.

⁵⁰ In addition, Holman J's reference to X's inability to make 'any sensible, informed decision for herself' (author's emphasis) suggests that some degree of rationality is required. If so, this would exceed the requirements for overtly competent patients, who may refuse treatment whether acting sensibly or not: *Re T (Adult: Refusal of Treatment)* [1992] 3 WLR 782, particularly at p 799B–C.

Some kind of statutory intervention is probably required for this to be achieved.⁵¹ Any statutory proposal requires certainty of direction. That direction should make it clear that those new boundaries require:

- (1) broader context and range (of relevant risk factors) to be recognised;
- (2) acceptance that a more accurate, visible assessment method based on (but not limited to) a two-stage approach, is warranted; and
- (3) that the assessment process should take account of risk agent, relevant primary and supporting risk factors, and resultant impact on the patient's medical and personal (non-medical) interests.

Only then will risk be assessed individually and fully, and the interests of intellectually disabled patients regarding their sexuality be suitably protected.

⁵¹ Other authors also recognise the need for legislation. See, for example, J. P. M. Denekens et al (op cit, n 34, at p 240) who, in complete contrast to the present author, adopt a family-based decision-making model. Interestingly, however, several of the issues perceived as relevant find mutual support, for example multidisciplinary input, patient involvement, patient fertility, and the need for sexual education and consideration of alternative contraceptive methods.

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