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PUBLIC BIOETHICS AND THE GRATUITY OF LIFE: JOANNA JEPSON'S WITNESS AGAINST NEGATIVE EUGENICS*

Amy Laura Hall

Abstract

In 2002, then Cambridge student Joanna Jepson initiated a legal, ecclesial, and media conversation on selective termination for disability. Making herself available in a way that is vulnerable, palpable, and effective, Jepson has used subtle rhetorical skill to question the ways certain lives are appraised as precious or expendable. The now Revd Jepson's witness may adumbrate a boundary past which the task of truly public bioethics becomes precarious. While ethicists may persuasively argue in the public square against positive eugenics — against selectively breeding or genetically enhancing conception — opposition to negative eugenics — against the elimination of 'unfit' lives — stretches the bounds of apologetics. The theological bioethicist may be called to gesture toward the Whence? and the Whither?, even if the purveyors of public bioethics find this an objectionable undertaking.

Introduction

In October of 2002, while a student at Ridley Hall, Cambridge, Joanna Jepson read the national abortion statistics for the previous year, noting with concern ten abortions due to a diagnosis of cleft palate, in one instance after the legal boundary of twenty-four weeks.¹ This

* I am grateful for the happy opportunity to present this paper at the opening of the 2004 Annual Conference of the Society for the Study of Christian Ethics. The conference, entitled 'Public Theology and Bioethics', was held at Wycliffe Hall, Oxford. Participants were terribly helpful, and David Clough, in particular, asked crucial questions prior. Daniel Rhodes searched for press articles. Hearty thanks finally to Douglas Johnson, who searched for press articles, offered suggestions, read multiple drafts, and edited the citations.

¹ Angela Levin, 'I'm Living Proof We Shouldn't Abort Babies for Their Looks', *Daily Mail* (London), 25 November 2003, p. 45.

struck her as a dubious interpretation of the law, in part due to her own childhood with a facial disfigurement. A 1990 amendment to the 1967 Abortion Act had addressed the relevant question. After intense debate, both Houses agreed in 1990 that a physician might perform an abortion in the third trimester (after the point of extra-uterine viability) only if there is 'a substantial risk that the child, if born, would suffer from such physical or mental abnormalities as to be seriously handicapped'.² (Up to 1990, the firm legal limit for abortion was twenty-eight weeks.) Arguing that a facial abnormality is hardly a serious handicap, Ms Jepson proceeded to press the West Mercia police to investigate. After consulting the Royal College of Obstetricians and Gynaecologists, the police chose not to wage a full investigation; Ms Jepson then appealed to the High Court in London. In April of 2004, after the High Court preliminarily decided to hear the case, the West Mercia police announced a new investigation.³ The relevant target of the investigation is the physician who performed the abortion, who faces a fine of £5,000 to life in prison if convicted.⁴

I have followed the British public's reaction to Jepson's case with interest, for the form of this episode carries import across the Atlantic. The now Reverend Jepson's witness has occurred alongside a conversation in the US over biotechnological reproduction, prompted in part by the sequencing of the human genome and by the President's Council on Bioethics. I have come to suspect that Revd Jepson's case against the selective reduction of incipient or fully formed persons with disabilities adumbrates a boundary past which the task of truly public bioethics becomes precarious. (Here I mean to evoke the etymology of that word.) While ethicists may persuasively argue in the public square against positive eugenics — selectively breeding or genetically enhancing conception — the opposition to negative eugenics — the elimination of 'unfit' lives — stretches the bounds of apologetics.

There remains a generalised sense in the US that parents should not pursue through science a 'better than normal' son or daughter. When opposing pre-natal or paediatric enhancements, a public bioethicist may appeal to a palatably diluted sense of fairness or to a Judeo-

² For more on the case and related legal history see John Finnis, 'We Warned Them, They Mocked Us, Now We've Been Proved Right', *Sunday Telegraph* (London), 7 December 2003, p. 27.

³ Jonathan Brown, 'Police to Investigate Cleft Palate Late Abortion Case', *The Independent* (London), 17 April 2004, p. 2.

⁴ Apparently Joanna Jepson's argument during the oral hearing of the case went beyond her initial claim that cleft palate falls outside the purview of the 1990 disability clause. A *Solicitors Journal* article (Barbara Hewson, 'Abortion Law in the Dock', 12 December 2003, p. 1408) reports that Jepson suggested that the 1990 clause is in violation of the European Convention on Human Rights. As the relevant ante-natal tests slide further down the gestation period toward conception, the issue of extra-uterine viability, on which the claim against the 1990 clause would presumably stand, will become irrelevant.

Christian sense of 'natural' procreation and gain a hearing. To question the routine practices of discarding or terminating incipient life due to the discovery of an 'abnormal' or 'sub-normal' genetic trait is more difficult. Negative eugenics may call less for a publicly plausible moral argument than for a publicly embodied witness. (Here I will elaborate from a suggestion by Dutch bioethicist Hans Reinders, in his book *The Future of the Disabled in Liberal Society*.)⁵ The task of persuading parents to eschew in-vitro genetic diagnosis and embryo disposal, or to refuse ante-natal testing and selective termination, may require at least as much a gesticulation as an argument. The theological bioethicist may be called to gesture toward the Whence? and the Whither?, even if the purveyors of public bioethics find this an objectionable undertaking, either insignificant or even perhaps as dangerous.⁶

First, I will discuss the parameters of public opposition to reproductive biotechnology in the US, drawing on the work of Michael Sandel, William McKibben, and the Bioethics Council chaired by Leon Kass. I will suggest that these parameters limit claims against negative eugenics. Second, I will discuss in more detail the tensions apparent in the coverage of Joanna Jepson's appearance — her face, body, clothes, and demeanour — as well as of her family and her legal case. Almost without exception, those writing to defend her do so on grounds that undermine the most compelling aspect of her incarnate witness — the life of her younger brother, Alastair. (To her notable credit, Revd Jepson resists the computations by which the media reckon her worthy.) This leads me to a more provocative twist on the suspicion I named regarding apologetics and public bioethics. In order effectively to challenge the idea that some children are ill-conceived, one may need to gesticulate not merely to a Whence? and to a Whither? but to a particular Whence and a particular Whither — to the moment which was the life of a servant and saviour.

This is a suspicion, not a hermetically tight argument. I do not believe that Joanna Jepson's story requires this conclusion, but plausibly intimates it. Her witness and the media battle may serve not so much a litmus test, but a significant question to trouble over as one proceeds with 'public' bioethics.

Public Bioethics in the US

Given an abiding commitment to individual freedom, Yankees are reticent to discuss restrictions on reproduction. What is more, as

⁵ Hans Reinders, *The Future of the Disabled in Liberal Society* (Notre Dame, IN: University of Notre Dame Press, 2000).

⁶ This last sentence echoes Karl Barth's concern that apologetic ethicists succeed only inasmuch as one assumes 'that theological ethics must be measured against a general ethics'. See 'Ethics as a Task of the Doctrine of God', *Church Dogmatics* II/2 (Edinburgh: T&T Clark, 1957), p. 521.

medical advances become part of daily domesticity (with advertisements in parenting and women's magazines), it becomes increasingly difficult to judge private, consumer choices as matters for public debate. Finally, the promises of scientifically perfected reproduction are embedded in a national dream as old as Benjamin Franklin — through human ingenuity, each generation may remake itself in a democratic meritocracy. Arguments for individual freedom, consumer privacy and parental initiative continue largely to dominate bioethics in the US.

Carefully marketed medicine now encourages parents to manipulate offspring at the pre- and post-natal level to meet expectations. Some bioethicists worry that such advances may unravel society on the micro-scale. If parents within the decision-making classes become capable of precision-tuning their offspring to navigate the demands of a highly competitive and aesthetically homogenous culture, parents who do not follow suit, whether for economic or religious reasons, may be seen as irresponsible and, ultimately, left to their own devices. This could bring an unprecedented rift between 'well-planned' and 'ill-designed' families. In response, some advocate for public funding, to allow every prospective parent to choose accordingly. Rayna Rapp, in her book *Testing Women, Testing the Fetus*,⁷ argues that individual women may navigate the new terrain of biotechnology if granted free access to all procedures. Others suspect, however, that simple, distributive justice is insufficient. So to embrace technological innovation and parental freedom may undermine vital notions of collective responsibility towards dependent life.

This is Michael Sandel's concern. A chair at Harvard, Sandel's early book *Liberalism and the Limits of Justice* argued for a 'deeper understanding of community than liberalism allows', in particular the version of Harvard philosopher John Rawls.⁸ Serving on the President's Council, Sandel published this spring an influential cover article, 'The Case against Perfection', in *The Atlantic Monthly*.⁹ While William McKibben and Leon Kass refer to the prospect of biotechnology diminishing human agency, Sandel argues that enhancement therapies 'represent a kind of hyperagency — a Promethean aspiration to remake nature, including human nature, to serve our purposes and satisfy our desires'. He continues, 'what the drive to mastery misses and may even destroy is an appreciation of the gifted character of human powers and achievements'.¹⁰ Drawing at length from the work of moral theologian (and Council member) William F. May, Sandel suggests that parenthood involves an 'openness

⁷ Rayna Rapp, *Testing Women, Testing the Fetus* (New York: Routledge, 1999).

⁸ Michael Sandel, *Liberalism and the Limits of Justice* (Cambridge: Cambridge University Press, 1982).

⁹ Michael Sandel, 'The Case against Perfection', *The Atlantic Monthly* 293/3 (April 2004), pp. 51–62.

¹⁰ Sandel, 'The Case against Perfection', p. 54.

to the unbidden'. This 'resonant phrase' evokes 'the mystery of birth', and highlights the 'humility and enlarged human sympathies' that characterise parenthood rightly construed.¹¹ Broadening the purview to consider society at large, the 'liberal eugenics' of widely distributed enhancement therapies would 'represent the one-sided triumph of wilfulness over giftedness, of dominion over reverence, of moulding over beholding'.¹² Acknowledging his use of theological concepts, Sandel re-frames the 'moral stakes' in 'secular terms':

If bioengineering made the myth of the 'self-made man' come true, it would be difficult to view our talents as gifts for which we are indebted, rather than as achievements for which we are responsible. This would transform three key features of our moral landscape: humility, responsibility, and solidarity.¹³

Sandel concludes that a 'lively sense of the contingency of our gifts' keeps a meritocracy like the US from 'sliding into smug assumptions' about the division between rich and poor. 'The meritocracy, less chastened by chance, would become harder, less forgiving', and 'perfect genetic control would erode the actual solidarity that arises when men and women reflect on the contingency of their talents and fortunes'.¹⁴

Whereas Sandel evokes the 'contingency of our gifts', Bill McKibben draws on the nature of physical endeavours; the operative metaphor in his latest book is running. Scholar-in-residence at Middlebury College, Bill McKibben is a teacher and environmentalist, and the author of a widely read treatise on global depredation, *The End of Nature*.¹⁵ In the last few years, McKibben has written on 'designer babies' and related questions for major magazines, including *The Christian Century*. His book *Enough: Staying Human in an Engineered Age* is a key text for lefties suspicious about unfettered biotech.¹⁶

Much of McKibben's thought involves the meaning of the natural world, a meaning 'offering us a doorway into a deeper world'.¹⁷ One way to peer into such a 'doorway' is through a state of 'joyful absorption' in such endeavours as running and rock climbing, through which you may come to 'know yourself better'.¹⁸ These exertions also tie generations through time:

¹¹ Sandel, 'The Case against Perfection', p. 57.

¹² Sandel, 'The Case against Perfection', p. 60.

¹³ Sandel, 'The Case against Perfection', p. 60.

¹⁴ Sandel, 'The Case against Perfection', p. 62.

¹⁵ Bill McKibben, *The End of Nature* (New York: Anchor Books, 2nd edn, 1999 [1st edn, 1989]).

¹⁶ Bill McKibben, *Enough: Staying Human in an Engineered Age* (New York: Henry Holt, 2003).

¹⁷ McKibben, *Enough*, p. 46.

¹⁸ McKibben, *Enough*, p. 53.

My love of running, somehow [connects] me to that moment six million years ago when my kind ventured out of the forests and onto the savannas, discovering that bipedal locomotion aided greatly in the hunt ... We are, by and large, the same people, more closely genetically related to one another than we may be to our engineered grandchildren.¹⁹

With genetic engineering, 'connection starts to vanish'.²⁰ In the face of this disconnect with a primordial genetic heritage, it is time to say 'Enough', for, McKibben concludes, 'We're [already] capable of the further transformations necessary to redeem the world'.²¹

McKibben thus attempts to foreclose positive eugenics, but what about the elimination of those who cannot achieve bipedal locomotion? According to McKibben, an important distinction in the future will be 'legitimate and illegitimate uses' of selection.²² One must discern the difference between conditions that warrant elimination and those to be overcome through patience and the type of physiological effort evident in the best of sports. Almost in passing, McKibben refers to a contrast between Down's syndrome and obesity.²³

Leon Kass has had the disadvantage of serving on George Bush's administration. In spite of its parentage, the President's Bioethics Council gives an exceptional model for civic bioethics in the US. Concerned with the cultivation of 'wisdom', that being a key word in his oeuvre, Leon Kass has overseen an invaluable collection of conversations and published documents. One indispensable teaching text is an extended report entitled 'Beyond Therapy: Biotechnology and the Pursuit of Happiness'; the relevant chapter is entitled 'Better Children'.²⁴

The chapter begins by asking, 'What father or mother does not dream of a good life for his or her child?' and continues to inquire 'What exactly is a good or a better child?' 'Is it a child who is more able and talented? If so, able in what and talented how?' 'More obedient or more independent? More sensitive or more enduring? More daring or more measured?'²⁵ The document thus invites conversation about the measure of a good child. The text also speaks to the tension between, on the one hand, the work of shaping that is, ineluctably, parenthood, and, on the other, the responsibility to protect childhood

¹⁹ McKibben, *Enough*, pp. 61–62.

²⁰ McKibben, *Enough*, p. 62.

²¹ McKibben, *Enough*, p. 114.

²² McKibben, *Enough*, p. 136.

²³ McKibben, *Enough*, p. 136. Here, McKibben is in agreement with Francis Fukuyama, who also makes a distinction between enhancement through germline manipulation and 'choosing from the possibilities that nature presents' with standard in-vitro fertilization.

²⁴ 'Beyond Therapy: Biotechnology and the Pursuit of Happiness'. A Report by the President's Council on Bioethics (Washington, DC, October 2003).

²⁵ 'Beyond Therapy', pp. 27–28.

as 'that stage of life justly celebrated as most innocent, open, fresh, playful, wondering'.²⁶ In pursuit of the right balance, parents face unprecedented options of 'screening out', 'choosing in' and 'fixing up'.²⁷ ('Screening out' involves selective discard and termination; 'choosing in' involves selection for particular gametes and embryos; 'fixing up' involves genetic enhancements beyond the natural norm.) The chapter focuses in on 'choosing in' and 'fixing up', primarily because prospective parents are unlikely to use 'screening out' in order, as the document puts it, 'to land a "better" — and not just a disease free — baby'.²⁸ The aim of the document is, after all, to consider the pursuit of a 'beyond therapy'.

There is reason to pause with this early distinction. Is the primary problem the pursuit of 'better than normal children' generally? Or, is there a more fundamental problem with the pursuit of a child 'better' than the child born by chance? Couples do use 'screening out' in order to secure a 'better' baby than the terminated foetus or the randomly implanted embryo. The Council notes that 'prenatal diagnosis adopts a novel approach to preventive medicine' by 'eliminating the prospective patient before he can be born', and warns that 'children born with defects that could have been diagnosed *in utero* may no longer be looked upon as "Nature's mistakes" but as parental failings'.²⁹ Yet the primary focus of the chapter is the pursuit of 'better' children and leaves largely unquestioned the distinction between 'therapeutic' abortion and the biotechnological enhancements that move 'beyond therapy'. The main target for criticism is the biotechnological pursuit of a child who is 'better' than the norm. The possibility that a child with an overt disability or difference is hardly 'Nature's mistake' is beyond the purview of the conversation.

The influence of Council members and theologians William F. May and Gilbert Meilaender is salient in the chapter, but, due to its public nature, the document must (as did Sandel) 'secularise' what were originally theological insights. The resources from which someone might draw in order to decline 'screening out' are only implicit in the opening set of questions, as the chapter implies multiple, potentially conflicting, answers to the question, 'What are children for?' To choose to bring to term a child who will never 'flourish' in a way that fits with classical rationality or the aesthetics of symmetry is to choose largely outside the norms of civic discourse. To put the same issue in Bill McKibben's terms, accepting a child whose 'genetic heritage' marks him/her as notably different from the 'naturally' occurring norm is to think differently about nature and life itself. For Christians, it is to draw on the truth that, *pace* McKibben, mere humanity (in whatever

²⁶ 'Beyond Therapy', p. 28.

²⁷ 'Beyond Therapy', p. 33.

²⁸ 'Beyond Therapy', p. 34.

²⁹ 'Beyond Therapy', p. 37.

form) is incapable of 'the further transformations necessary to redeem the world'.³⁰

Bill McKibben and the Council go well beyond the standard, American shtick that justifies unfettered reproductive control, and one must not be overly scrupulous towards one's allies. Having said this, I suspect that Michael Sandel comes closer to making moral room for an argument against negative eugenics by pointing toward the 'giftedness of life'. The depth of this notion is weakened by the limits of public, secular discourse in the US.

This brings me seriously to consider the work of Joanna Jepson.

*The 'Stunning' but 'Pushy' 'Girl of the Cloth'*³¹

The contrast between academic argument and incarnate witness is salient in the shift to Joanna Jepson. With no apparent irony, the media has placed Revd Jepson under the microscope of modern aesthetics. (Would a grown man in Great Britain ever be a 'boy of the cloth'? Has anyone read a detailed description of a bishop's mischievously sparkling eyes and lovely, St Nicholas-style beard?) Granted, this young woman is beautiful. Her smile is infectious, and her countenance uncommonly winsome, but the media's focus on her post-surgical appearance is indicative of the problem she seeks to underscore. The extent to which the press has yielded to a simple, 'Wouldn't you rather court than abort this young woman?', reveals much about the measured calculations and evaluations of human life that Joanna Jepson contests. Yet, then again, her vulnerability to description is intertwined with the potency of her message. Revd Jepson's experience as an untouchable, and her present work as a curate, a daughter, and an older sister, are intrinsically part of the reportable newspaper story. She has made herself public and available in a way that is palpable and effective, and she has pitched the aesthetic judgments back to her interlocutors, using subtle rhetorical (cricket-like) skill to question the ways certain lives are appraised as precious or expendable.

Even some of the brief articles about this case give a description of Joanna Jepson, and two key pieces dwell for some time. 'I'm living proof we shouldn't abort babies for their looks', reads the headline of a *Daily Mail* story that begins: 'Few could deny from looking at this photograph that Joanna Jepson is a stunning young woman. The twenty-seven-year-old Anglican curate has fair hair, a peachy complexion, smoky gray eyes that light up when she smiles and a dazzling sense of style.'³² Another piece tells us about the chocolate

³⁰ McKibben, *Enough*, p. 114.

³¹ Levin, 'I'm Living Proof', p. 45; Carol Sarler, 'To Boldly Go . . . : Abortion Crusade Can't Be for the Love of God', *The Express*, 21 April 2004, p. 13; 'Girl of the Cloth', *Sunday Times* (London), photograph caption, 20 November 2004, p. 2.

³² Levin, 'I'm Living Proof', p. 45.

bar she prefers, the fashionable scarves and jumpers strewn on her couch, and the popularity among her friends indicated by her busy cell-phone.³³ The most illuminating (and possibly influential) essay is by ultra-cool *Times* writer Jasper Gerard, entitled 'Holy War on the Beauty Fascists'.³⁴ Here is the boy reporter's opening paragraph:

If *Vogue* made vicars, they would look like this: long blonde locks, slim with perfectly manicured nails. Instead of that clammy Church of England handshake, the twenty-seven-year-old Cambridge graduate shoots mischievous smiles with bulging green eyes ... Vicar of Dibley she ain't. She looks more like a vicar out of a fashion shoot.³⁵

He continues a bit later on, 'For all her sharply expressed arguments, her every sentence seems to cry out: Would it have been right to abort me? And the answer, even to those wary of Christian anti-abortionists, is no'.³⁶ This essay evinces overtly what other writers covering the curate's case have sought to do with more subtlety — to situate her argument within the ugly duckling narrative. One should not too hastily destroy a cygnet, because she may, through the miracle of modern surgery, become a swan.

Yet, Jepson has managed to resist this spinning of her story, in a myriad of ways. For one, she reveals the superficiality and capriciousness of the aesthetic gaze and gauge by contrasting the ways she was perceived before and then after surgery. *Pace* Jasper Gerard, her every sentence in these newspaper reports cries out as a different sort of challenge: 'Would you have paid me heed prior to my surgery?' As Gerard concludes his piece to argue that 'some of the unlikeliest lives can be very beautiful', we suspect not.³⁷ This inconsistency leads to a second way that Jepson re-frames her witness. She delicately brings the reporter's presupposed set of aesthetic inquiries and economic standards to bear on the life of Alastair, her brother, who has Down's syndrome.

Once again, the *Sunday Times* interview overtly names the assumptions implicit in many of the other articles, as Gerard asks: 'Perhaps we have gone too far, but isn't it in our nature to desire beauty?' and 'So what's wrong with wanting aesthetically appealing children?' and, yet again, 'Perhaps parents seeking to produce perfect physical specimens are merely being responsible?'³⁸ At precisely this

³³ Elizabeth Day, 'The Law Is Saying There Are Reasons Why I Shouldn't Be Alive. I Look at My Life and Think: That's Rubbish', *Sunday Telegraph* (London), 23 November 2003, p. 22.

³⁴ Jasper Gerard, 'Holy War on the Beauty Fascists', *Sunday Times* (London), 7 December 2003, p. 5.

³⁵ Gerard, 'Holy War', p. 5.

³⁶ Gerard, 'Holy War', p. 5.

³⁷ Gerard, 'Holy War', p. 5.

³⁸ Gerard, 'Holy War', p. 5.

point, Jepson brings up Alastair, whose worth cannot be plotted along the coordinates of aesthetics and economics. The relevant segment is worth quoting at length:

Gerard: But is his life as rich as the brother who might have been born a year later if he had been aborted?

Jepson: Most who get married are not beautiful people, and they are still very happy.

Gerard: But if a healthy baby is born in place of a disabled one, is that so bad?

Jepson: It's not a disability. It's a stigma. We pursue happiness to the extent of making pain and suffering taboo. There needs to be maturity in accepting there will be suffering in this life.

Gerard: Now she is giving me a sermon. [I would add here, indeed, she is.]

Gerard [continues]: Sure, happiness can be shallow; but can she really claim her suffering was good?

Jepson: Yes, absolutely. It's made me who I am, aware of other people.

To reject your child is to take quite a disposable view.

Gerard: True; but for those who believe only in 'this life', it is asking a lot to regard suffering as a virtue.³⁹

Gerard (rather sleazily) moves quickly on to inquire about her interest in men, but the collision has occurred. As Jepson discusses Alastair, she begins to speak in a different tongue, a language that most of the reporters covering her case find vaguely foreign. As she employs the words 'happiness' and 'suffering', she intimates that Alastair's life, her life before surgery, the ordinary marriage of the average British pensioner, are all worthy in ways that do not compute. Jepson's most provocative claim is that the value of each life is, in a fundamental way, not up for appraisal. Notably, Jepson does not suggest that each life is generally, vaguely meaningful — the value towards which she gestures is neither purely general nor indescribable — but that value is unconditional. This is the standard by which she suggests we judge the abortion at issue. To reject your child — to 'have a go' at another child who might be 'up to scratch' — is to 'take a quite disposable view'.

For those who believe only in 'this life', as Jasper Gerard puts it, the Jepson narrative primarily remains that of the previously inauspicious and long-suffering cygnet. By this version, Jepson's past is redeemed by her observably beautiful present. The outrageous cruelty she endured before her surgery is rendered meaningful by the perceptible results of the surgery itself. This is even evident in the

³⁹ Gerard, 'Holy War', p. 5.

very sympathetic, extended report by Elizabeth Day in the *Sunday Telegraph*.⁴⁰ Day begins her piece by contrasting two photographs, one of the adolescent Joanna, with an awkward half-smile, and another, post-surgery, in which she 'is laughing through long, blonde hair' has 'high cheekbones, shining eyes, and even features'.⁴¹ Day makes symbolic note of Jepson's post-surgical ability to laugh freely, without shame. However, again, Jepson manoeuvres towards a more complicated question.

So I thought, if you play this argument [for cleft-palate abortions] through, the law is saying there are good reasons why I shouldn't be alive. And I look at my life and I think, 'That's rubbish'. Even if I hadn't had my surgery, even if I'd chosen to stay the way I looked before, that's no good reason for me not to be alive.⁴²

And, again, regarding Alastair —

My brother is amazing. He loves taking photos. He takes these fantastic pictures of people that everyone else ignores — like the dustbin men, the postman, or the workmen in the street. Somehow, these people are important to Alastair, and I would never have seen that unless he had given me his take on the world.⁴³

The contrast between the pre and post-surgical Joanna itself contrasts with this photographic example, the before and after images with which Day begins the piece speaking somehow less to the point at hand than the referenced photographs showing Alastair's 'take on the world'. In this as in many other articles, Revd Jepson comments on the National Health System's recent decision to offer all women screening for Down's syndrome, the most common reason given for late-term abortion. She intimates that, with such measures for assessing pre-natal life, Alastair's 'take on the world' — his sense that dustbin men in the street are worthy of sustained attention — will become even less a part of daily life. Jepson does not suggest with easy sentimentality that life with Down's syndrome is uniquely charmed, enabling Down's syndrome people to note what others would not. But Alastair's 'take on the world' is a perspective significantly at risk as a people become more intent ante-natally to assess lives for future promise.

Joanna Jepson's person and her stories dig underneath the continuum of merit by which certain conditions appear 'trivial' and others gravely burdensome, and many of her detractors have noted this with alarm. As Barbara Hewson writes forebodingly to *Solicitor's Journal*, 'there can be no legal logic in limiting the protection of Article 2 to cleft palate cases ... If Article 2 applies to cleft palate cases, then why not

⁴⁰ Day, 'The Law Is Saying'.

⁴¹ Day, 'The Law Is Saying', p. 22.

⁴² Day, 'The Law Is Saying', p. 22.

⁴³ Day, 'The Law Is Saying', p. 22.

to Down's syndrome?⁴⁴ Derisively referring to Revd Jepson's 'cute dog collar', Carol Sarler of *The Express* writes, 'if you asked her for a list of circumstances under which she would approve of abortion, that list would be pretty short'.⁴⁵ One staff writer for the *Birmingham Post* and *Evening Mail* warns that Jepson is in league with 'the men and women who would force birth on the damaged, the distressed, and the pitifully young'.⁴⁶

For many in the vocal opposition, Jepson stands for a cruel and judgmental version of Christianity — a Christianity with no relevance in a public conversation about a matter as individual and intimate as abortion. Writing for *The Guardian*, Ann Ferudi expresses her shock and outrage that 'opinionated outsiders with abstract moral views' would be allowed a say in a matter that involves only the aggrieved pregnant woman and her physicians.⁴⁷ Calling her a 'dangerously sinister evangelist' who is backed by 'zealots' and 'grisly churches', Carol Sarler says that Jepson's agenda cannot be 'driven by the love of any god I've heard of'.⁴⁸ Jili Hamilton's letter to *The Independent* sums up the argument clearly: 'Surely what is at stake here is individual choice ... If that's what a woman wants, who has the right to try and stop her. Interfering in the life of someone else should not be countenanced under any circumstances'.⁴⁹ Referring to Jepson's 'insufficient or misapplied sympathy', A. C. Grayling, in his *Saturday Times* piece 'The Reason of Things', calls hers a 'morally fallacious argument'.⁵⁰ Presenting Jepson's argument as a shallow assertion of her 'right' to speak out due to her own and her brother's apparent happiness, Grayling explains, with condescending patience, that '*the philosophical point at issue* is that abortion is about a conflict of interest between a person in the midst of life, with goals, relationships and

⁴⁴ Hewson, 'Abortion in the Dock', p. 1408.

⁴⁵ Sarler, 'To Boldly Go', p. 13.

⁴⁶ 'I've No Time for Vicar of Dabbling', *Evening Mail* (Birmingham), 23 April 2004. By collapsing Jepson's concern with selective termination due to a disability detected *in utero* with cases involving rape or incest, several of her detractors attempt to extend the umbrella of righteous sympathy to cover maternal choice in all cases. Writers further suggest that Jepson's interference will inflict suffering sufficient to outweigh a case against cleft-palate abortions. An editorial in *The Mirror* warns that 'this case will not solve anything but could lead to more suffering by mothers struggling to cope with an agonizing situation' ('Voice of the Daily Mirror: Abortion Is Not a Matter for the Law', *The Mirror*, 2 December 2003, p. 8). Laura Peek, writing for *The Times*, goes so far as to appeal to the emotional 'toll' the case is taking on the 'doctors and nurses' involved in the investigation, who are 'suffering from stress' ('Police Take Up Curate's Inquiry on Abortion', *The Times* [London], 17 April 2004, p. 4).

⁴⁷ Ann Ferudi, 'Trust Doctors on Abortion, Not Lawyers: Critics Have Been Too Quick to Rush to Judgment in the Cleft Palate Case', *The Guardian* (2 December 2003), p. 26.

⁴⁸ Sarler, 'To Boldly Go', p. 13.

⁴⁹ 'Letter: Legal Challenge to Late Abortions', *The Independent* (3 December 2003), p. 21.

⁵⁰ A. C. Grayling, 'The Reason of Things', *Saturday Times*, 6 December 2003, Weekend Review, p. 9.

responsibilities, and on the other hand a possible future person with none of these things' (emphasis added).⁵¹

The assumptions driving the arguments against Jepson may, I fear, be fundamentally opposed to those that compel her testimony. When faced with Grayling's 'conflict of interest between a person in the midst of life' and 'a possible future person', one might argue that the burden of responsibility falls on persons in the midst of life to adjust their 'goals, relationships, and responsibilities' in order to make way for a possible future person, even if (perhaps particularly if) that possible future person bears the mark of vulnerable need. This is a facet of Joanna Jepson's witness, but her case cannot take root apart from the 'sermon', as Jasper Gerard labelled it, about the 'maturity in accepting there will be suffering in this life'. Whereas in some schemas wisdom entails necessarily limiting one's ability to choose among a myriad of options, by another schema, maturity entails liberation from those burdens that limit one's options. A culture that elevates the latter version of maturity over the former cannot but be hostile to the interruption of unexpected, unplanned pregnancies. Those children that most conspicuously limit their parents' options will seem 'ill-conceived'. The Revd Jepson cannot gain rhetorical traction inasmuch as the British public implicitly accepts this form of thoroughgoing liberalism. I fear that she correctly predicts that the repercussions of unfettered reproductive choice go well beyond the plight of the pregnant woman and her physician. The same argument that leaves a woman alone *to* her 'choice' may leave a woman alone *with* her 'choice', bereft of both the concrete and informal sources of cultural and economic support requisite in the care of even supposedly 'normal' children.

Public Theology and the Gratitude of Life

In 1996, moral philosopher Hans Reinders received a request from the Dutch Association of Bioethics to write on the question 'Should we prevent disabled lives?' The Dutch government subsequently ran calculations, as has the British government, weighing the economic cost of testing and termination against the cost of care for those who might have been prevented. Reinders gave his own answer in *The Future of the Disabled in Liberal Society*:

Assuming that disabled people will always be among us, that the proliferation of genetic testing will strengthen the perception that the prevention of disability is a matter of responsible reproductive behavior, and that society is therefore entitled to hold people personally responsible for having a disabled child, it is not unlikely that political support for the provision of their special needs will erode ... The question of civic and social hospitality is key, but political liberalism is

⁵¹ Grayling, 'The Reason of Things', p. 9.

not ultimately capable of engendering and fostering hospitality toward people with overt, recalcitrant needs. The norms encircling the liberal axis of individual autonomy cannot easily accommodate lives dedicated to the care of perpetually dependent individuals, or admit the intrinsic value of these individuals.⁵²

Reinders concludes that to protect the future of the disabled is neither within the liberal purview nor within the limits of the practical. A thoroughly liberal society will be unable legally to restrict selective abortion. The predicament facing liberal society, then, is cultural, not political. The hope for those with recalcitrant need hinges on an abiding account of incarnate life as a gift.

The benefits bestowed by love and friendship are consequential rather than conditional, which explains why human life that is constituted by these relationships is appropriately experienced as a gift. A society that accepts responsibility for dependent others such as the mentally disabled will do so because there are sufficient people who accept [this] account as true.⁵³

The collective will for accommodating the overtly vulnerable depends on the public witness of those whose lives are intertwined with overt vulnerability. This is a fragile thread, but Reinders argues, I think persuasively, that it is the most plausible way.

Several months after his initial interview with Jepson, Jasper Gerard wrote another piece on the case for the *Sunday Times*, suggesting that those wishing to promote further legal restrictions on abortion should consider Joanna Jepson as their 'likeable spokesman'. However, he added, 'she might need to lose the dog collar: the British like their debates rational, not religious'.⁵⁴ Some of Joanna's supporters have attempted to minimise the effect of the dog collar, emphasising more obviously rational and publicly verifiable facets of the case, such as the point of extra-uterine viability of the foetus and the simplicity of surgical correction. Given that infants born at twenty-seven weeks (apparently the point at which the abortion concerned was performed) survive outside the womb at a rate of 99%, and that the procedure to correct cleft-palate is relatively simple, this case seems to many otherwise thoroughly liberal citizens to be egregious.

The *Sunday Telegraph* editorial in unequivocal support of Joanna Jepson (headline 'Joanna Fights For Us All') brings up both of these issues in the course of its argument.⁵⁵ But the editors go further, perhaps heightening the fears of Joanna's detractors, to suggest that 'even if the condition were not so remedial, it would still be an

⁵² Reinders, *Future of the Disabled*, p. 14.

⁵³ Reinders, *Future of the Disabled*, p. 17.

⁵⁴ Jasper Gerard, 'A Blurring of the Abortion Battle Lines', *Sunday Times* (London), 18 April 2004, p. 30.

⁵⁵ Editorial, *Sunday Telegraph* (London), 30 November 2003, p. 24.

utterly deplorable reason to proceed with an abortion'. Why? Would first-trimester abortion for Down's syndrome be utterly deplorable? Here, I recognise with mixed admiration and sympathy that the *Telegraph* editors must perform a precarious act of their own, given the rules for public debate. Nevertheless, the set of questions and assumptions behind the claim that selective abortion, as a form of negative eugenics, is 'utterly deplorable' may reside beyond sketched, 'rational' boundaries.

I suspect that Joanna Jepson's most important contribution to the British conversation has been to provide an embodied, religious witness to each life as an incalculable gift. More specifically, she has provided an embodied witness to particular lives as incalculable gifts — her own complicated life and the life of her brother. She has made readers privy to details of life lived in multiple ways with disability. While some might have otherwise viewed the lives of her mother, Dide, and her father, John, as akin to Job, given that two out of their three children struggled with physical need and cruelty, Joanna displays and narrates an alternative 'take' on the picture. The contrast between the named, now known family that chose life and the unnamed, largely unknown family that chose abortion is tangible. In so doing, she has opened the way for others to witness similarly. Linda Tsang interviewed Paul Conrathe, who is assisting in Joanna's case for 'Lawyer of the Week'.⁵⁶ When asked, 'Who has been the most influential person in your life?', Conrathe answers without hesitation 'Jesus Christ', and goes on to talk about his debt to his parents, who taught him 'the conviction, compassion, and humility that should characterise the Christian life'.⁵⁷ This claim might sound trite to the reader keen to detect hypocrisy, but, Conrathe later explains, almost in passing, that he runs a school and clinic for autistic children. Another example appears in the *Kent and Sussex Courier*. There, a Paddock Wood mother explains to reporter Tim Cook that there have been joys as well as difficulties in bringing up her son with cleft palate: 'There is nothing that cannot be sorted and nothing will put his life in danger or stop him from leading a normal life'.⁵⁸ Admitting that, 'when someone tells you something is wrong with your baby your whole world falls apart', Ms Pelling relates how important the British Cleft Lip and Palate Association was in preparing her to receive the life of her son.⁵⁹ Another potent testimony comes from Jonathan Bartley, whose story appeared last year in *The Guardian*:

The moment is fast approaching when we will have to explain to our son why, before he was born, amid all the uncertainty and emotional

⁵⁶ Linda Tsang, 'Lawyer of the Week', *The Times* (London), 2 March 2004, p. 10.

⁵⁷ Tsang, 'Lawyer of the Week', p. 10.

⁵⁸ Tim Cook, 'Handicap Can Be Sorted, Says Mum', *Kent and Sussex Courier* (7 May 2004), p. 9.

⁵⁹ Cook, 'Handicap Can Be Sorted'.

trauma of having a disabled child, the law was weighted against him rather than for his protection. He may take comfort from the fact that people like Joanna Jepson, standing in the Christian tradition, have been there to plead his case.⁶⁰

One point Hans Reinders makes is the importance of witness for the sake of social support. These voices may reverberate, sounding as echoes against a society that is choosing overwhelmingly against lives with disability. In a future with a 'brittle' view of children, testimonies like these may make our moral imaginations more supple.

Conclusion

It is useful in bioethics to be philosophically multi-lingual. Yet, there are times to be forthright, such as at the conclusion of an essay. I am unquestionably indebted to Søren Kierkegaard, a theologian whose understanding of incalculable debt and radical gratuity shapes my own questions in bioethics.

But, apart from this theological debt, I turn repeatedly to the possibility that what is called for in the face of popular appeal to negative eugenics, to what the President's Council has called 'screening out', is an embodied witness to the utter incalculability of all human life. There are coherent, and perhaps compelling, arguments against eugenic biotechnology drawing on normative accounts of human nature, but I suspect that Christians may now need to be explicit about the source of grace.

Civic bioethics in the US assumes that 'we the people' have founded a meritocracy — a democratic meritocracy, the presumably truest form, but a meritocracy nonetheless. Arguments against biotechnological plans to create 'better' children through the pursuit of positive eugenics may take hold — for there is sufficient suspicion that 'my' children will not be 'up to scratch' in such a competitive system, and germline interventions still seem vaguely unnatural. But fewer people are willing to argue against uses of technology that will prevent the births of children who are more overtly demanding, vulnerable, and wounded. This underlying assumption that one's worth, including the worth of each child, may be plotted on a calculable grid of economics or aesthetics, is an assumption about which Christianity has much to say. However, moral theologians may need to speak more explicitly about the underlying disproportion of all that has been created by grace *ex nihilo*. Christians may need to speak explicitly in the public sphere about the gratuitous nature of every life, held as each is by the extravagant providence of God. As a democratic meritocracy becomes increasingly overt in judging each life for its utility, Christians may

⁶⁰ 'Protecting the Disabled: Face to Faith', *The Guardian* (6 December 2003), p. 29.

become overt in our witness that each and every life is created, sustained and redeemed by Christ.⁶¹

By this reading of the task, Joanna Jepson's sermon, published in the *Sunday Telegraph* in late Advent of last year, is an essential complement to her subtle apologetics with the press. Allow me to quote her sermon (entitled 'Herod Is Not Alone in His Fear of the Helpless') at length:

For me, the essence of the story is about the weakness and vulnerability of the baby Jesus: a child laid in a manger, without a cot, surrounded by farm animals. When we strip away the commercialism, gimmickry and tinsel of Christmas 2003, this is what we are left with: the unadulterated power of God's message, His Word made flesh in the form of the raw life of a new-born baby ... At Christmas, we gather round the tree and count our blessings. But we are also challenged to have the courage to approach the manger, in all humility, and be transformed by our encounter with Christ's abject vulnerability.⁶²

Perhaps, by way of such sermons and such witness, Christians, and others who still recall the story with even vague fondness, will receive the faith, hope and love sufficient for the complicated path that is life.⁶³

⁶¹ For a fuller, theological argument, please see my entry on 'Love', entitled 'Love: A Kinship of Affliction and Redemption' for the forthcoming *Oxford Handbook of Theological Ethics*, ed. Gilbert Meilaender and William Werpehowski (New York: Oxford University Press, 2004).

⁶² *Sunday Telegraph* (London), 21 December 2003, p. 16.

⁶³ Editor's note. The author garnered resources from the British media through the electronic source *LexisNexis*. She has included all available information about articles cited and apologises for any omissions.