

Living and Dying with a Disability in Debtor Society: Why Context Matters in Assisted Suicide Debates

Brian Brock,¹ University of Aberdeen, 24 April 2018 FINAL SUBMITTED VERSION

Abstract:

Economic rationalities are a central component of the malignant social positioning of people with all sorts of disability and mental health issues today. This paper traces the role of economic rationality in positioning some lives today as not really worth living. This widespread willingness of the general populace in western liberal democracies to map their political relations in economic terms is historically novel in the west, and is one of the more noteworthy marks the transition points into, and out of, Christendom. The paper examines the impact of the rise of the cultural settlement called Christendom for social outsiders, suggesting that they provide illuminating contrasts with some of the characteristic practices and moral assumptions of our contemporary western liberal democracies. The conclusion of the paper is that a society without a working account of mercy and forgiveness will find it difficult conceptually to explicate practices associated with valuing human lives which are considered non-contributors within accounts of political life grounded in economic rationalities.

Keywords: value of life, disability, euthanasia, Christian theology, eugenics

To allow the cultural backdrop within which contemporary debates about assisted suicide and euthanasia to be thrown into sharper relief it is sometimes useful to zoom out to overview the trajectory of Christianity in the west over two millennia. This change in perspective allows the moral baseline within which debates about appropriate end of life care are taking place to emerge to view. This in turn allows greater critical purchase on the reality that people with various disabilities are systematically disparaged in modern liberal societies, despite the congratulatory tone with which those societies assess their humanity toward people with disabilities. If we take actual practice more seriously than self-congratulatory rhetoric, then the rise of understandings of political relations viewed

¹ The author would like to dedicate this essay to David Braine (1940 – 17 February, 2017).

primarily in financial terms does not bode well for serious and evenhanded critical analysis of the ethical and legal questions surrounding the legalization of euthanasia. Surveying larger trends in the moral landscape of the west over the last 2000 years allows several tipping points to emerge that press hard questions about the moral presuppositions characteristic of the overarching ethos of modern liberal societies. This step back is an exercise designed to give us enough distance from our present that we can find the intellectual space critically to analyze it.

My suggestion in this paper is that the horizon of finance is one of the central components of what John Swinton has called the “malignant social positioning” of people with all sorts of disability and mental health issues today (Swinton 2017, quoting Sabat 2006). My aim is to get to grips with how we subtly and structurally position some lives today as really not worth living. My opening suggestion is that one of the most pervasive ways we do so is to suggest that some lives incur costs that in the final analysis are not really defensible. I will open by looking at what the rise of what we call Christendom meant for social outsiders, the practices toward such lives that were characteristic of the first Christians. I will then compare some of the characteristic practices and moral assumptions of our contemporary western liberal democracies, focusing first on practices of prenatal testing and them more briefly on work and wider healthcare practices.

Dependency as Debt

Friedrich Nietzsche was at the height of his analytical powers when he unleashed his most devastating critique of Christian morality in the 1887 book, *On the Genealogy of Morality*. The aim of this work was to reveal Christianity as nothing more than a carefully crafted system of thought whereby the weak and materially powerless of the world had managed to gain control over the noble and worldly powerful by means of a crafty moral sleight of hand. In it he drew attention to the fact that the German word *Schuld* means both “guilt” and “debt” (Nietzsche 2014, 251). Through the door left ajar by the polyvalence of the word *Schuld* Christians, and Jews before them, had been able to turn *financial* debt into a *metaphysical* debt system that facilitated those without money, the “poor in spirit,” along with the humble and meek, to capture the moral high ground. This first century Jew who had had his life snuffed out by the powerful nobles and judges of his time somehow

managed to persuade a whole society of unbelievable claims like, “Blessed are the meek, for they will inherit the earth.” (Matthew 5:5)

Nietzsche examined guilt and debt near modern Christendom’s height, and the social anthropologist David Graeber thought it worth revisiting 120 years later as this culture unravels. What he finds remarkable about ancient societies when compared with 21st century liberal secular society is the universality of the ancient awareness that money is always and only a culturally constructed cipher for social obligations. In Almost all ancient cultures it is presumed that human beings owe their existence to more powerful agencies that have come before; a creator-god or some other creative power, to the ancestors who have bequeathed laws and language by way of our parents. Ancient peoples thus had a lively sense that our social and material debts dwarf the accounts kept by humanly devised systems of coin and accounting. Only within this primitive universe could radical debt forgiveness (as pictured, for instance, in the Jubilee laws of Leviticus 25) be thinkable (Graeber 2011, 67-68). Only because they believed in the possibility of such radical debt forgiveness could the gospel writers present Jesus’s life and works as an embodiment of Israel’s understanding of jubilee. In cancelling every conceivable form of humanly accounted debt Jesus is understood to be reestablishing the human relationship to its true source, the Creator, and so to other creatures. Only a God to whom every human debtor is infinitely indebted could demand and accomplish the erasure of all accrued forms of social indebtedness (Wagenfuhr 2016, 151-196).

Graeber compares ancient and non-western understandings of debt in order to highlight the violence embedded in contemporary western accounts of money. In banning God from politics modern secular liberals seem to have generated a new myth, of primordial debt—debt that *cannot* be escaped or forgiven. Our culture would quickly begin to totter if the inescapability of student fees, house mortgages, credit card debts, corporate debt and the debts of sovereign nations began to be seriously questioned (as attempted in the global Occupy movement that took off in earnest during 2011, and which was forcibly suppressed soon after). Debt has become a permanent state, an index of individual and collective distance from an unreachable utopia of debt freedom that we are nevertheless condemned eternally to chase. We fear debt, and we desire to escape from the constraints it puts on us, but we don’t really believe it can be escaped. Modern, liberal members of rapidly

dechristianizing late-capitalist globalizing societies are becoming permanently ensnared in *Schuld*.

This cursory sketch of the processes by which our contemporary world has come to assume the inviolability of financial debt as the basic matrix of our communion is intended to draw attention to what is inexorably becoming the moral baseline of modern developed societies. Whether one finds Graber's narrative of debt persuasive or not, it seems very hard to doubt that in what has come to be called "austerity Britain" people who receive any form of public benefit acutely feel the moral presumption that they are a net drain on the public purse, a status that it is assumed they really ought to appreciate (an assumption conveniently forgetting that institutions like road maintenance and public schooling are massive public benefit programs). To be disabled (whether physically, mentally, or through mental ill health) in our societies is thus to be constantly faced with a debtor status. How can we justify so many teachers in special schools when we are cutting music programs in mainstream schools? By what right do disabled people get free public schooling to the age of 21 when everyone else only gets it up to 18? Why should people with various disabilities get benefit payments instead of a job? In 2005 a deputy mayor in Swindon, Wiltshire, provoked outrage when he proposed in an open council meeting to send the children in a £3,000 a week care home "to the guillotine" as a resource reallocation proposal (Mirror 2005). Though undoubtedly crossing the sensitivity line about what sort of things can be said in public, the more salient point to note is that that such comments would be unthinkable if those who dared utter them were not able to assume widespread agreement about the moral baseline of modern developed societies. Only on such a basis could much more well-known figures like Richard Dawkins feel free to express opinions like the one he did in 2014, that it would be morally indefensible for the mother of a Down's syndrome child to knowingly *not* abort, given the drain on the public purse implicated in such an irresponsible course of action (Guardian, 2014). As 2017 drew to a close one of the most powerful members of British Prime Minister Theresa May's government, Philip Hammond, the Chancellor of the Exchequer, suggested in a Treasury Select Committee meeting that current sluggish productivity reflected, in part, rising numbers of disabled people in the workplace (Slawson 2017).

Such statements stand within a stream of modern thinking whose interest in the worth of disabled lives has direct and obvious roots in modern eugenics movements (Jones 2016). Though the survival of these types of belief beggars belief in a post-holocaust moral climate, only in the late modern west have Christians arisen outspokenly defending medically assisted suicide, for the first time in Christian history. I wish to augment and broaden this story in two ways. First, by looking at the longer arc of the Christian west, specifically, the characteristic ethos of the patristic period, and second, by highlighting the force of economic thinking as the eugenic foundations of this modern movement subtly shift toward the economic domain. Putting the proposal of this paper simply, if the euthanizing of people with disabilities was countenanced among some Christians for the first time in modernity on eugenic grounds, it is beginning to be thinkable for many more Christians today on the economic grounds that have become the dominant ethical matrix of modern liberal public morality.

Entering and exiting Christendom

I hope that these opening observations will sensitize us to the moral implications of encroachments of a monetized account of the citizen's relation to the body politic. My main claim in this paper is that it is the widespread willingness of the general populace to map their political relations in economic terms that most obviously marks the transition point into, and out of, Christendom. For our purposes I define Christendom as that period in which the vast majority of the populace assume that the Christian creeds were to be understood as being a literally true account of reality, at least in public. This is a low level historical claim of the type commonly made in assuming today that religious beliefs are marginal private beliefs about reality that cannot be invoked in public discourse to dispute the basic atheistic presumption that the cosmos is essentially governed by natural laws.

It is the shifts in *moral* presumptions that I take to be more important. I want to look at some moral characteristics of the early Christians' response to their own era's public morality during the first 400 years of the Common Era, the centuries between the life of Jesus Christ and the Emperor Constantine's conversion and subsequent decriminalization of Christianity. In the context of late antique morality, by following what they understood to be Christ's message and example, early Christian theologians thus give testimony in their context to a decidedly counter-cultural attitude towards human life from beginning to end.

By looking back, I hope to suggest that their situation may be becoming much closer to that of Christians today than it has been during the last millennia in the Christian west.

A first thing that we can say is that not only were many of the very earliest Christians slaves, but they were also well aware that they were subject to being killed by the state for their beliefs. From the time up Christ until the legal toleration of Christianity in 313, Christianity had been treated as a minority sect looked upon with suspicion for its rejection of the ancestral and national gods, a suspicion which drove spasms of persecution, up to and including executions and being sent to the gladiatorial games. For this reason in this period the martyrs came to have a central role in Christian self-identity, and much Christian writing takes the form of apologia, writings which defend Christianity as non-threatening to the powers that be. Those who were being exterminated and persecuted by the state and its citizens and who followed a God-man who had been executed by those same authorities soon developed a deep sympathy for all marginalized human lives that crystallized in what might be called the “rule of human solidarity”. Among the people who confessed that every human being was “one for whom Christ died” (1 Corinthians 8:11), a blanket rejection of killing people considered non-contributors to the household or city came to be one of the most widely known characteristic of this growing sect.

A well-known practice that flowed from this rejection of killing among Christians was the rescuing of abandoned infants, both disabled and healthy, which as far as we can tell arose among the very earliest converts. The earliest Christians apparently understood their total rejection of infanticide and thus the repudiation of the routine destruction of disfigured infants to be a rejection of the independent powers of the pantheon of gods and demons. In Greek and Roman antiquity the head of the household had absolute legal rights of life and death over his newborn children, and considered it part of his duty as an overseer of the domestic economy to kill (by exposure or any other means) both the healthy and the deformed when conditions indicated it. In both Classical Greece and Rome disfiguring conditions had generally been understood as caused by supernatural powers that needed to be exorcised and purified for the benefit of society as a whole. Sources such as Plato’s *Republic*, Aristotle’s *Politics*, and Soranus’ *Treatise on Gynecology* reveal that in classical antiquity the care of defective newborns was not even classified as one of the tasks of the doctor. Citizens of the Greco-Roman world prioritized the needs of the collectives of which

they were part when considering whether or not to accept a newborn into life. They considered themselves to be discharging a sacred responsibility to protect their own household and then their city against the ill effects associated with such children, which were typically understood as ominous warning signs of the displeasure of the gods (Caspary, 2012).

The salient point is that in Greek and Roman antiquity a person's value was largely defined in social terms, calibrated by reference to his or her potential to contribute both materially and through acquired virtues to the good of the family and society. Martyrdom was important in forming the early Christian identity in helping them to see how any prioritization of the good of the polis over individual human lives was always prone to end in killing. Christianity thus marked a turning point in late antiquity in holding every human life to have intrinsic value. If we look more closely at how this "rule of human solidarity" began to be formulated we immediately notice its radical scope. In North Africa, Tertullian (c. 160 – c. 220 AD) worked hard to persuade both Christians and non-Christians that the "games", the gladiatorial shows, were something Christians avoided. "[T]he man who when he sees a quarrel on the streets coming to blows will try to quiet it or expresses his strong disapproval, will in the stadium applaud fights far more dangerous; that he who shudders at the body of a man who died by nature's law the common death of all, will, in the amphitheater, gaze down with most tolerant eyes on the bodies of men mangled, torn in pieces, defiled with their own blood (Tertullian 1931, XXI). Even earlier, while some of the New Testament documents were still being written, Christians were rewriting the Old Testament Decalogue for the benefit of gentile converts. One gloss on the command "thou shalt not commit murder" was presented it as a blanket refusal of abortion and infanticide: "you will not murder offspring by means of abortion and you will not kill having been born" (Milavec 2003, 2:2). Before 200 CE this refusal had become so widespread that in an apologetic text Tertullian could defend Christians by holding up the whole Christian community for public scrutiny as nowhere being guilty of murder, including abortion (Tertullian 1950, 9:25). It is therefore most accurate to say that their root concern was to oppose the universally held worth-calculus of the ancient world which assumed that the worth of a human life rested with judgments made by rulers of the family or the state about which lives could be expected to contribute something to the community.

The logic also extended to the ways in which they approached death. The only deaths which were worth attending to were those of heroes in general, whether great statesmen or soldiers. For such characters suicide or a death on the battlefield could be understood as a noble act, but one which had nothing to do with medicine, which was devoted to healing.

The ancient doctor was an observer rather than a therapist. In the [ancient Greek] medical texts no mention is made of the doctor's task to relieve the suffering of those who are fatally ill. Palliative care to ensure a gentle death was not a major concern of ancient medicine (Van Hoof 2004, 980).

And the notion of a "good death", a peaceful death undergone without pain was, by the late antique period, understood within the same moral calculus that justified infanticide, "as a socially meaningful end, in which the do-operative values of the city-state were demonstrated" (Van Hoof 2004, 979). The morally relevant point is that the worth of life in the ancient world was a measure of the perceived contribution of any given individual to the polis, and these judgments were foundational for ancient Greco-Roman understandings of the licit taking of life of both infants and adults. While Christians did occasionally draw on the language of "good death" (euthanasia) to describe martyrdom (Van Hoof 2004, 976), they quite strictly rule out the intentional taking of one's own life and any courting of martyrdom. Christians could glory in being martyred, but definitively could not seek it, because their lives were not theirs to take (Augustine 1998, I.16-20).

Given this backdrop, it is important for Christians today to attend very closely to the gradual re-ascendency of accounts of political relations in which a cost-benefit ratio is taken to be legitimate to apply to human lives. This re-emergence of the financialized matrix for the assessing of human life is especially unsettling in no longer being linked, as it was for in Greco-Roman society, with a thick account of the communal good. To jettison *both* the belief in the infinite worth of every human life *and* the belief that the good life is intrinsically social (a chief characteristic of modern neoliberal capitalism) is to unleash a fluctuating instability in valuation exactly of the sort on display in a stock market. If human value is finally grounded in being wanted, the only option left to groups of whose condition threatens to drop their value into negative territory in the eyes of the populace at large is to mount a publicity campaign to defend those sorts of life as worth the cost of keeping around.

Failure to attend to this wider cultural-moral landscape dooms those interested in assisted suicide and euthanasia to lose sight of the wood for the trees of ethical arguments and the intellectual work of clarifying key concepts. The great danger of the discourse of ethics is that if it proceeds without exposing our desires and presuppositions to deep critical investigation, it will inevitably ensnare us more deeply in our conceptual and practical aporias. Thus we dare not imagine ourselves to be on anything like a level playing field as we are “clarifying concepts and arguments” surrounding the legalization of euthanasia for those with disabilities and mental illness. What then do we know about the lives being lived by people labelled disabled in today’s debtor society?

Debtors at the beginning of life

It is by now well-documented that many pregnant women in highly medicalized western societies feel strong, sometimes coercive resistance to their decisions not to abort what has been diagnosed as an “affected” fetus. Here the proximity of actual and felt vulnerability is particularly apparent. Liesa Whitaker, who has a form of dwarfism, relates her experience of prenatal genetic testing in terms only slightly more stark than that of many women.

I remember sitting in the [genetic specialist’s] rooms listening as he explained that there was a 25 percent chance that our child could still inherit the dominant achondroplasia gene and the dominant psuedoachondroplasia gene—a combination that they had never seen before anywhere in the world. They had no idea of what effect this would have on the baby... Having told us this the specialist offered us an abortion. He asked us to think about whether we wanted to bring another dwarf baby into the world. It was something I hadn’t even thought of. This was our child! Why would we not want her? Why would the world not accept our child? (Reist 2006, cf. Burcham 2016)

The science of prenatal testing is reaching its maturity with the development of a non-invasive blood test which can detect genetic conditions such as Down’s syndrome cheaply and safely. Just as it now seems perverse not to test pregnant woman for conditions that are potentially catastrophic for the health of the child, such as for toxoplasmosis, AIDS or hepatitis, it will soon seem nonsensical not to check if our nascent children have genetic defects (Lakia’s 2011, Groskop 2016). We have now been living in this world for at least 20

years, a fact that has some rather gut-churning implications as Stacy Simplican points out. In the United States alone, if an average of 90 percent of the children conceived with Down's Syndrome have been aborted, we are talking about one million missing people—and that is to leave aside all those aborted after misdiagnosis, not to mention other genetic conditions (Simplican 2015, 10).

Because we have accepted the moral case that this state of affairs can be said to be characteristic of a humane society, it will be hard for modern states that face mounting healthcare costs not to strongly encourage routine fetal testing, and increasingly difficult for parents to resist submitting to it. Who, after all, would willingly choose the hardship, financial challenges and social stigma associated with raising a disabled child? With the advent of painless genetic testing which is embedded in the standard prenatal care regimen offers to young parents as a matter of routine, every new parent will begin life with their children having had to make a choice about whether to continue or abort each pregnancy.

It is at this point that public moral discussions are typically ensnared by the individualism that is built into the dominant moral languages of consent and choice. The decision to end a life is by no means an individual affair in our society, no matter how much it is defended in individualist terms. As Fox and Swayze have observed, much contemporary philosophical ethics displays an individualistic bias that comes at the expense of broader social perspectives. This problem is especially pronounced in bioethics, a discourse that grew out of a focus on the doctor patient relationship and the decisions made by individual patients about given treatments. In such cases the contexts framing medical decision-making were often understood to be marginally relevant at best (Fox and Swayze 2008, 185-187). This is why looking at the moral language around prenatal testing can help us to see the dynamics of the moral language that is being used to make ending the lives of adults thinkable. Consider how many people are involved in the ending of nascent human lives. Medical researchers develop diagnostic tests. Legislators, acting on the advice of managers, accountants, lawyers, and physicians, legislate permissible modes of policing the boundary of human life. Genetic counselors explain and validate the notion of borders to parents who often have ambivalent feelings about bearing a disabled child. And at the end stands the techniques of violence wielded by the medical practitioners who perform abortions.

We can now see why it is morally crucial to notice the social context in which we discuss prenatal testing, the social and institutional structures that make our world hospitable to some and inhospitable to others. The ways social orders shape what can be admitted as a thinkable moral question must be made part of our moral calculus, suggests Judith Butler. Otherwise the form taken by contemporary moral debates becomes unintelligible.

“Decisions to extend life *for* humans or animals and decisions to curtail life are both notoriously controversial precisely because there is no consensus on when and where decision should enter the scene” (Butler 2009, 20). We are bodies from conception, but in the context of modern developed societies we kill some bodies without grieving them, most obviously those of animals and human fetuses. The question this raises is what it means to *recognize* a life, a body as worthy of our grief. Butler is pushing against the intellectual and emotional evasions built into the language of “personhood” with which we usually negotiate these questions. “Personhood” is a superficial conceptual apparatus for parsing the problem of recognizability in resting wholly on a testable cognitive criterion. Only when a body has cognitive capacity is it legitimately grieveable, and otherwise the passage of bodies into and out of existence is morally irrelevant. The only morally relevant passage made by bodies is across a threshold of cognition, from which point those lives may be, in some cases, legitimately grieveable (Butler 2009, 4-7).

The questionable foundations of modern Christian defenses of euthanasia began precisely with what Butler is calling the non-grieveable status of human life deemed to lack cognitive capacity. As David Jones has noted, Joseph Fletcher was arguably one of the most important self-identified Christians in the post-world war English speaking world to defend the legalization of euthanasia, and his whole position began with precisely this designation of some (disabled) lives as non-grieveable. Striking the very same notes as Dawkins in 2014, Fletcher had this to say to a father of a child born with Down’s syndrome.

People...have no reason to feel guilty about putting a Down’s syndrome baby away, whether it’s ‘put away’ in the sense of hidden in a sanitarium or in a more responsible lethal sense. It is sad; yes. Dreadful. But it carries no guilt. True guilt arises only from an offense against a person, and a Down’s is not a person. There is no cause for remorse, even though, certainly, there is for regret. Guilt over a decision to end an idiocy would be a false guilt ... There is far more reason for real

guilt in keeping alive a Down's or other kind of idiot, out of a false idea of obligation or duty, while at the same time feeling no obligation at all to save that money and emotion for a living, learning child (Jones 2016, 336; citing Fletcher 1968).

My suggestion is that while the eugenic account of "worthless life" that is stated outright in this passage has been muted in recent decades, the transparency of the economic rationale which gives it its political teeth has not. A society that at least feels the moral taint of eugenic language can keep its conscience clean by using economic arguments to achieve the same result since economics is assumed to be a morally neutral science.

Here I am distinguishing between those *legal* frameworks that assume it problematic to criminalize abortion and the embrace in policy and practice the *moral permissibility* or even *desirability* of selective abortion on the grounds of disability. Selective abortion destroys human community at its foundations by setting up a criterion against which every human life must justify itself before being granted the right to enter human society. Just as we have to rethink what it might mean to be human were we to eliminate dying, so too must we face the full conceptual and ethical implications of moving from an understanding of welcome receipt of all nascent human life to a conditional acceptance based on our definitions of human lives worth living. Screening is by definition a screening *out* of those considered defective and a burden. It is never solely a parent's choice to bar the gates to an individual life: such denials can only be carried out by a whole social order. Perceptual regimes that render some lives and deaths ungrievable are not simply individual beliefs but must be collectively accepted, whether explicitly or tacitly. All such regimes constitute enacted denials of every human being's right not to be attacked, a denial with direct political implications in the sphere of prenatal medicine.

Some have protested that testing and aborting fetuses with genetic anomalies is not necessarily a judgment about citizens currently living with those conditions. Addressing these objections, Hans Reinders concludes that it is very difficult to make strong claims about the benefits of screening out the disabled from judgments about the perceived negative impact of the living disabled on society. To "test" implies "selections" resting not only judgments on the health of the human genome, but also on the quality of life of disabled persons who already exist (Reinders 2000, ch. 4; Reinders 2007). A fundamental sample bias is built into our moral decision-making under such conditions, one that is deeply

pejorative against people with disabilities. Empirical studies confirm that, when faced with a diagnosis of genetic anomaly, virtually every mother or couple draws on anecdotal experiences and accounts of the lives of the disabled and their caregivers in deciding whether or not to abort (Thomas, 2017, 107-142, Rapp 2000, chs. 3, 6). Bringing these questions to end of life debates, Elizabeth Schlitz has nicely encapsulated the moral momentum that the focus on individual choice elides. "If a person without a disability decides to commit suicide, society considers that an irrational choice that should *not* be respected; society intervenes to prevent the free exercise of that choice. However, if a person with a disability makes the same choice, it is seen as entirely rational and something that should be supported" (Schlitz, 2018, p*). And here again the sample bias reappears, since, for instance, those who make a living will are forced to imagine a future state that they have not experienced but which they imagine to be not worth living.

None of the foregoing should be taken as a suggestion that the technologies of prenatal medicine are somehow suspect. Christians can and should welcome the fact that technologies developed to aid screening can now be used in the service of care. The essential ethical insight to grasp, however, is that there is a vast difference between using those technologies to care for children in the joyous receipt of a divine gift, and deploying them as an expression of the ideologies of risk avoidance and cost reduction. From a theological perspective, prenatal testing is built on the assertion that in order not to take on more than we can bear, we must choose who we will accept into the human community. John Swinton explains.

Neo-liberal capitalism offers a picture of human beings as fundamentally individual beings who choose to join together to form societies, the primary purpose of which is to attain the greatest benefits for the largest number of individuals. In other words, the individual *precedes* the community. ... Thus we begin with individuation, separation, and distancing and move towards unity and relationship, a unity and relationship that is *optional, tentative, and dependent* on the child fulfilling certain criteria... (Swinton 2007, 200).

The marketers, political spin-doctors and MBA-trained pastors who are so influential in neo-liberal societies are deeply invested in an account of freedom that rests, finally, in the supremacy of choice. In such a landscape prenatal testing is one more mechanism serving

the worship of freedom defined as “choice”, in this case a choice about whether or not to incur the “labor” and “expense” of receiving this singular life. It therefore sounds nicely like the many other praises we sing of the techniques that can save individuals and families from “accidents” that will destroy the lives we have imagined for ourselves.

As we exit the time of Christendom it is now the mother who is given the legal right and with it the responsibility to assess whether a given life will be contribution or a drain rather than the *paterfamilias* as it was when the Christian era began. When Christians arrived on the scene, the question of life and death was organized by a twofold question: “What does this person give to the society?” and “Given what they give to us, how much can we afford to invest in caring for them?” It should therefore not be entirely surprising that these are once again becoming the matrix within which western societies assess disabled lives at beginning and end.

Debtors in the middle of life

So much for the beginning of life in our debtor society. What about life after birth?

There is recent evidence that in the UK, at least, decreasing numbers of people with learning disabilities were finding paid employment. Over the four year span up to 2015 the number employed in England had dropped, “from 7.1% to 6% - fewer than 10,000 people in real, fully paid jobs” (Fox 2015). Public discourse about these questions of employment are often also very often couched in terms of the public funding that is being poured into making transport infrastructure accessible (Taylor, 2017). In light of these trends, Philip Hammond’s 2017 appeal to rising employment among disabled people as an explanation of stagnating national productivity and employment statistics appears as the transparent scapegoating it is.

Now and again stories like these do prick the social conscience. In response to a scandalous case of mistreatment in the Winterbourne View home for learning impaired people uncovered by the BBC in 2011 (BBC 2012), the then British Prime Minister David Cameron convened a wide-ranging special inquiry into the state of care given to learning impaired people in the UK. Its findings were released in March 2013 as the *Confidential Inquiry into premature deaths of people with learning disabilities*, the CIPOLD report (Heslop 2013). The question was not whether or not any given healthcare worker was discriminating, but

whether the infrastructures and working patterns of the National Health Service (NHS) is discriminatory in disproportionately disadvantaging a specific subgroup of patients. A research team from the University of Bristol comprehensively studied two years' worth of mortality statistics for a population of over 1.6 million people in the southwest of England (Heslop 2013, 12, 20). Their aim was to build a picture of the incidence of premature or preventable deaths among mentally disabled people. The CIPOLD authors are keen to stress that the conclusions of their report are by no means new findings, but are all the more disturbing in reiterating criticisms that appeared in earlier official government reports. They comment:

Valuing People in 2001 committed the government to exploring the feasibility of establishing a Confidential Inquiry into mortality among people with a learning disability. *Treat Me Right* in 2004 concluded that a Confidential Inquiry into the deaths of people with learning disabilities would not only identify the causes of death, but would also be a powerful lever for improvement in the delivery of health services. A Disability Rights Commission report in 2006 considered it 'alarming' that little or nothing had been done to implement the recommendations of Mencap's *Treat Me Right* report by those with the power to do so. A Disability Rights Commission report in 2007 criticised the lack of strategic change and prioritisation that had taken place following its report the previous year, calling it 'quite literally a matter of life and death'. *Death by Indifference* described the circumstances surrounding the deaths of six people with learning disabilities while they were in the care of the NHS. It suggested that people with learning disabilities, their families and carers were facing 'institutional discrimination' in healthcare services. *Healthcare for All* is the report of the Michael Inquiry, which was established to learn lessons from the six cases highlighted in the Mencap report. It reported evidence of 'a significant level of avoidable suffering and a high likelihood that there are deaths occurring which could be avoided'. It recommended the establishment of a learning disabilities Public Health Observatory, and a time-limited Confidential Inquiry into premature deaths of people with learning disabilities 'to provide evidence for clinical and professional staff on the extent of the problem and guidance on prevention'. (Heslop 2013, 12).

Despite this history of official internal criticism, the CIPOLD report one again concluded that mentally disabled people still die much earlier and more unexpectedly than the majority population (Heslop 2013, 28). They also found that, statistically speaking, the more severe one's mental disability the more likely one would be to die younger, and from a preventable death. Broader analysis revealed in addition that people with learning disabilities were statistically underweight (a contributor to early death), suffered from more preventable conditions than the general population (such as pressure sores or acid reflux) and were unlikely to have had regular health checks or health plans. After examining 247 deaths of people with learning disabilities during the two year window of the study, the commission found that the majority of what they called premature or preventable deaths were not caused by carers overlooking or ignoring the distress of an ill person (Heslop 2013, 4). The fatal problems arose when medical professionals failed to offer a timely and accurate diagnosis and/or a workable treatment plan (Heslop 2013, 56). For the minority of individuals who had been given integrated health plans, the commission found that the use actually made of these "personalized health plans" was more often to hold patients to account for self-care than for the purpose for which they were originally designed—to coordinate disjointed healthcare provision. Most importantly, "reasonable adjustments" to the normal ways of providing healthcare for those with special needs were rarely and certainly not routinely made, meaning that a whole range of practical barriers often derailed effective diagnosis and treatment.

Without "reasonable adjustments" to routine protocols being made, procedures like the preventative screening that is offered to all patients when they reach a certain age can easily become too unwieldy for staff or carers or too distressing for patients. Similar problems emerge when doctors prescribe complex treatment regimens or assume that everyone is capable of keeping up with difficult hospital checkup appointment schedules (Heslop 2013, 63-66). In many cases mentally disabled people's "social care providers appeared to be neither equipped nor resourced to chase up appointments or monitor [the person's] progress through so many different systems, and there was no one else to do this on [his or her] behalf" (Heslop 2013, 65) In addition to these hurdles, many people with learning difficulties and their carers were often unaware of the services that might be available to ameliorate some of these difficulties (Heslop 2013, 102).

We can now see in a more rounded way how, at least in southern England, the culture of hospitals is configured in a manner that assumes that the “average” patient can be counted on to present their own symptoms and deal with the waiting, discomfort and logistics it takes to secure their own care. The system as a whole is geared toward the statistically normal patient, and if an individual’s specific mental disability makes the system threatening or inaccessible the evidence suggests that the statistical outliers will simply be ignored, solidifying their invisibility as appropriate recipients of the routine healthcare statutorily due to every citizen of the modern nation state. It would simply be “too expensive” to do things otherwise.

Among those people with disabilities who are capable of expressing it, the social pressures and public assumptions just described very understandably can yield a clear awareness of the moral burden that disability represents when finances have become the moral baseline of our understanding of political community. While negotiating his own terminal illness in 2010, the Australian bioethicist Nicholas Tonti-Filippini wrote this in response to the Voluntary Euthanasia Bill that was at that time being proposed in South Australia.

As a chronically ill person I know well what it is to feel that one is a burden to others, to both family and community, how isolating illness and disability can be, and how difficult it is to maintain hope in the circumstances of illness, disability and severe pain, especially chronic pain.

For several years, until I objected, I received from my health insurer a letter that tells me how much it costs the fund to maintain my health care. I dreaded receiving that letter and the psychological reasoning that would seem to have motivated it. Each year I was reminded how much of a burden I am to my community. The fear of being a burden is a major risk to the survival of those who are chronically ill. If euthanasia were lawful, that sense of burden would be greatly increased for there would be even greater moral pressure to relinquish one’s hold on a burdensome life. Seriously ill people do not need euthanasia. We need better provision of palliative care services aimed at managing symptoms and maximising function, especially as we approach death. Rather than help to die, the cause of dignity would be more greatly helped if more was done to help people live more fully with the dying process (Cook 2010).

Killing and Cost Saving

It is little wonder that it is people who have been dependent for long periods of their life on the care of others who most often perceive the legalization of euthanasia as a threatening prospect, given the contours of the malignant social positioning of people with disabilities as financial drains in our debtor societies. David Braine was a philosopher at the University of Aberdeen whose spine was severely injured in a car accident. In 2013, after 33 years as a quadriplegic, mounted a stage in his electric wheelchair and with obviously laborious effort made his views publically known about the assisted suicide bill being proposed at that time by the MSP Margot McDonald (Black 2013). After remarking on several legal and conceptual problems in the bill, he made it clear that his main concern was deeper. In much the way I have been suggesting, he pointed out that deeper question is not, "What does a good bill look like?" but "What is the moral context in which we are considering such laws?" And his answer to *that* question clearly indicated the importance of his experiences as a precariously balanced member of our debtor society.

I have a huge fear of going into hospital with the danger of hospital infections, pressure sores, and of "do not resuscitate" orders, but up until recently I have had a general confidence that doctors, nurses and auxiliary and paramedical workers will not take part in attempts to kill their patients. My psychosis in 1986 had to do with fears of doctors and others wanting to kill me, arising from auditory hallucinations in a situation of sleeplessness. It is vital that people like myself can have confidence in doctors and nurses in the setting of general practice and the home, and this confidence must not be weakened. This is what makes the unqualified protection of the law vital (Braine 2013).

It now seems more than likely that within our current moral landscape the legalization of euthanasia should be understood as a policy designed by and for the creditors, those who Nietzsche hope would regain their social standing, those with physical power and social capital. Euthanasia, which is invariably presented in public discourse today as relieving the suffering of the weak, now looks uncannily like a policy organized by those still in the possession of the larger measure of their physical and mental powers and who wish to secure them according to the moral parameters by which they are living their lives.

And yet as those who have not yet lived life in care or with a disability argue for the right to die they push forward public policies that increase the social debt, and thus the fear, of those who have been assigned the place of the most highly indebted in our modern, liberal, debtor societies. Anecdotal evidence is beginning to make it clear that make it more that contemporary euthanasia bills are not actually geared toward the problems and pains of the most vulnerable. Canada provides the most recent example, where, as one Canadian doctor and regulator of the practice in Canada, Madeline Li, has observed, most of the people who actually avail themselves of medically assisted dying are people who have been used to being in control. “It wouldn’t shock anyone to learn that these are often doctors, lawyers, captains of industry, very successful businesspeople. These are the people that always get what they want” (Hune-Brown 2017, 16). Given this Canadian moral context—which appears to be a classic case of the moral profile we have seen in medical ethics more generally in which the individualistic moral standpoint is emphasized to the exclusion of moral evaluation of institutional structures of medical care—that one Canadian maternity doctor can understand her work of helping women give birth as essentially like what she labels the “choreographing of death” of assisting suicide (Shore 2017). In a world where having a child is wholly a matter of choice, as is the setting in which one has it, why should not the medical professional who understands their role as giving patients what they want not help people realize the death of their choice? In a world in which ending lives has been understood individualistically and within which assessing lives within a matrix of affordability has become routine, why should we be surprised when this rationale is applied in end of life debates?

From a theological perspective, this is where this “cost saving” understanding of our political relations becomes most objectionable. As problematic as the legalization and institutionalization of killing might be, it is the lives that we formally condemn people to live by legalizing end of life killing that are most unjust.

Conclusion: Debt and the weapon of fear

Bernd Wannewetsch has suggested that, “the prophetic ministry of the Christian Church entails not only contributing to existing debates, but also learning to read those debates crucially with a view to their underlying yet unexplained assumptions, narrowness of parameters, overlooked questions and tabooed zones” (Wannewetsch 2011, 428). He has

further proposed that modern debates about euthanasia reflect the final evaporation of the distinction between spiritual death and physical death that was one of the defining characteristics of the Christian tradition. For Christians the idea of spiritual death as a death defeated by Christ allowed physical death to be shorn of its overweening psychological power. “It was precisely this relatively relaxed attitude—which kept equal distance from the antique pagan veneration of death as the single most definitive qualifier of a human life (as reflected in the ideal of a heroic death), and from the modern pagan abhorring of death as dirty, indecent, and in total opposition to life—that allowed for a genuine attitude of caring to develop toward the dying” (Wannenwetsch 2011, 437). In a world where no debts have been or can be forgiven, a wide range of practices currently considered humane will become difficult to narrate—precisely because they rest on merciful gratuity. It was as people who knew themselves as forgiven and redeemed to an extent they could never replay that the Christians of the patristic era were able to resist the Greco-Roman matrix for assessing the worth of human lives. The same remains true in any social world in which the idea of forgiveness is lost and human life is made to justify its existence before some law of performance.

In this paper my aim has been to illustrate why we must understand the claim that it is immoral for humans to kill their own as a theological claim. Christians may, and I have proposed should hold that killing and mutilation of human beings is against Jesus’ teaching and example, however inconsistently Christians have adhered to them. I have suggested that one of the prime markers of the transitioning of the developed west into a post-Christian world is the widespread conceivability of justifications of killing human beings. I have been pressing the question of how seriously we take the lives of those who are socially marginalized in order to raise the question of what this might mean if (when) the majority in post-Christian societies assume that it is humane or even morally incumbent to kill people with disabilities as a matter of routine. I have attempted to press the Christian church to face both the promise and the task demanded by a post-Christian context by offering at least a tentative account of how we might be losing the sense that if and when people commit suicide it is a failure and a loss, never a “happy release”.

My assumption as I have done so has been that the early Christians were right: the teaching and example of Jesus Christ points ineradicably to the insightfulness of the early Christian

formulation of the principle of universal human solidarity. What those Christians saw and put into costly practice was a pro-life policy of the most sweeping variety. In this paper, however, I have tried to show how the western world is “coming of age” and moving beyond this naive and apparently too expensive form of human solidarity. I have been trying to suggest that in those countries where euthanasia is legalized, the Christians within them should be prepared to find themselves once again facing questions in this domain not dissimilar to those faced by the earliest Christians. And as we slowly edge toward this cultural transition it is important to explicitly articulate the moral premises of the discussion that are systematically elided in most of the arguments in the public sphere today.

This alternative path will come with a new suite of ethical questions. One of the most obvious is to follow the cues left by the Christians of the patristic period by asking seriously and practically about the lives thrown away by our societies. This suggests a church engaging much more conscientiously in practices of adoption and fostering (Swinton and Brock 2018), as well as accompanying people carrying “unviable” children to term (Cobb, 2014) or those with intellectual impairments as they negotiate medical and care systems, and beyond that to become their friends.

These are new forms of attention and lines of ethical questioning that will lead Christians into alternate life-paths on which they will no doubt meet others who have arrived on them by other routes. One such fellow traveler is the philosopher Licia Carlson, who nicely articulates how this rejection of the moral baseline of the debtor society reshapes the most important moral questions.

Rather than simply conflating disability and suffering, we can ask, How have these particular forms of attention to suffering precluded the analysis of and response to *other* causes of suffering? To what extent does emphasizing prevention, elimination, and cure of intellectual disabilities divert attention and resources away from the many ways in which persons with intellectual disabilities and their families suffer at the hands of a society that devalues them, economically disadvantages them, and subjects them to social stigma and discrimination? How will suffering be increased in promoting practices that are purportedly aimed at eliminating it? And to what extent does the tragic portrait of the inevitable life of suffering obscure other dimensions of disabled existence? (Carlson 2010, 176-177)

As viewed from the standpoint of Christian theology that has oriented my treatment here, Carlson is absolutely right: the question is not “Are we for or against euthanasia?”. The real question is: “What do we expect from human life?”

If human beings are never “accidents”, then instructing people that they have a choice and how to make it is an induction into an anti-doxology that refuses to praise the Trinitarian creator for fertility and new life. When we are beginning to countenance discussions about human beings as burdens, even admitting the idea that we have the *right* to screen out those who don’t belong with us, we have begun to sing anti-doxologies. What such thoughts cannot be is a singing with the psalmist that “The right hand of the Lord does valiantly” (Ps. 118:16). A different song has been struck up: “we must act to save ourselves from ‘them’ or be drowned.”

Bibliography

Augustine (1998). *The City of God against the Pagans*. R W Dyson ed. Cambridge: Cambridge University Press.

Burcham, P (2016). War Against the Weak: Genetic Counselling and the New Eugenics. *ABC Religion and Ethics*. 28 Nov.

<http://www.abc.net.au/religion/articles/2016/11/28/4583274.htm> accessed 19 Dec. 2017.

BBC (2012). Timeline: Winterbourne View abuse scandal. 10 December.

<http://www.bbc.co.uk/news/uk-england-bristol-20078999> accessed 19 Dec. 2017.

Black, A (2013). MSP Margo MacDonald launches new assisted suicide bill. *BBC Scotland*. 14 November, <http://www.bbc.co.uk/news/uk-scotland-scotland-politics-24927805> accessed 19 Dec. 2017.

Braine, D (2013). Paper against Euthanasia Bill. Delivered in the Salvation Army Citadel, Aberdeen. Unpublished manuscript.

Butler, J (2009). *Frames of War: When Is Life Grievable?* London: Verso.

Carlson, L (2010). *The Faces of Intellectual Disability: Philosophical Reflections*. Bloomington: Indiana University Press.

Caspary, A (2012). The Patristic Era: Early Christian Attitudes toward the Disfigured Outcast. In B Brock and J Swinton eds., *Disability in the Christian Tradition: A Reader*. Grand Rapids: Eerdmans, 24-64.

Michael C (2010). A dying bioethicist warns of the peril of euthanasia. *Mercatornet*, Nov 23. <https://www.mercatornet.com/careful/view/8335/> accessed 19 Dec. 2017

Cobb, A D (2014). *Loving Samuel: Suffering, Dependence and the Calling of Love*. Eugene: Cascade.

Fletcher, J (1968). The Right to Die. *The Atlantic Monthly*. April, 59-64.

Fox, N (2015). Learning disability employment rate “unacceptable”. *BBC News*, 4 December. <http://www.bbc.co.uk/news/disability-35005362>. accessed 19 Dec. 2017

Fox, R C and J P Swazey (2008). *Observing Bioethics*. Oxford: Oxford University Press.

Graeber, D (2011). *Debt: The First 5,000 Years*. Brooklyn: Melville House.

Groskop, V (2016). Sally Phillips: Do we really want a world without Down’s syndrome? *Guardian*. 1 October, <https://www.theguardian.com/lifeandstyle/2016/oct/01/do-we-really-want-a-world-without-downs-syndrome-ds-prenatal-test> accessed 01/12/17.

Guardian (2014). Richard Dawkins apologises for causing storm with Down's syndrome tweet. 21 August. <https://www.theguardian.com/science/2014/aug/21/richard-dawkins-apologises-downs-syndrome-tweet> accessed 01/12/17.

Heslop, P, P Blair, P Fleming, M Hoghton, A Marriott and L Russ (2013). *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)*, final report. Bristol: Norah Fry Research Centre.

Hune-Brown, N (2017). How to End a Life. *Toronto Life*, 23 May. <https://torontolife.com/city/life/doctors-assist-suicide-like-end-life/>. accessed 19 Dec. 2017

Jones, D A (2016). Apostles of Suicide: Theological Precedent for Christian support of “Assisted Dying”. *Studies in Christian Ethics* 29:3, 331-338.

Laika's (2011). A New Safe Blood Test to Diagnose Down Syndrome. *Laika's MedLibLog*. 14 March, <https://laikaspoetnik.wordpress.com/2011/03/14/a-new-safe-blood-test-to-diagnose-down-syndrome/> accessed 19 Dec. 2017

Milavec, A ed. and trans (2003). *The Didache: Text, Translation, Analysis and Commentary* Collegeville: Liturgical Press.

Mirror, The (2005). Tory deputy mayor: Best thing for disabled children is the guillotine. 24 September. <http://www.mirror.co.uk/news/uk-news/tory-deputy-mayor-owen-lister-558677> accessed 01/12/17

Nietzsche, F (2014). *On the Genealogy of Morality*, Adrian Del Caro trans. Stanford: Stanford University Press.

Rapp, R (2000). *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. New York: Routledge.

Reinders, H (2007). Life's Goodness: On Disability, Genetics and "Choice". In *Theology, Disability and the New Genetics: Why Science Needs the Church*. J Swinton and B Brock eds. London: T&T Clark, 163-181.

Reinders, H (2000). *The Future of the Disabled in Liberal Society: An Ethical Analysis*. Notre Dame: University of Notre Dame Press.

Reist, M T (2006). *Defiant Birth: Women Who Resist Medical Eugenics*. North Melbourne: Spinifex.

Sabat, S R (2006). Mind, Meaning and Personhood in Dementia: The Effects of Positioning. In J C Hughes, S J Louw and S R Sabat eds., *Dementia: Mind, Meaning and the Person*. Oxford: Oxford University Press, 287-302.

Schlitz, E (2018). Contradictory Disability Rights Laws: Who Gets Help to Thrive, and Who Gets Help to Die? *Journal of Religion and Disability* *this current special issue

Shore, R (2017). Circle of Life: Former Victoria maternity doctor now helps terminally ill end their suffering. *Vancouver Sun*. 17 February. <http://vancouversun.com/news/local-news/circle-of-life-former-victoria-maternity-doctor-now-helps-terminally-ill-end-their-suffering> accessed 19 Dec. 2017

- Simplican, S (2015). *The Capacity Contract: Intellectual Disability and the Question of Citizenship*. Minneapolis: University of Minnesota Press.
- Slawson, Nicola. Philip Hammond causes storm with remarks about disabled workers. *The Guardian*. 7 December 2017. <https://www.theguardian.com/politics/2017/dec/07/philip-hammond-causes-storm-with-remarks-about-disabled-workers> accessed 19 December 2017.
- Swinton, J (2017). Response to Adam McInturf. *The Syndicate*, 26 June, <https://syndicate.network/symposia/theology/becoming-friends-time/> accessed 19 Dec. 2017.
- Swinton, J and B Brock eds. (2018). *A Graceful Embrace: Theological Reflections on Adopting Children*. Leiden: Brill.
- Swinton, J (2007). *Raging with Compassion: Pastoral Responses to the Problem of Evil*. Grand Rapids: Eerdmans.
- Taylor, A (2017). Disability employment: The challenge of getting to work in a wheelchair. *BBC News*. 30 November. <http://www.bbc.co.uk/news/uk-42181276> accessed 19 Dec. 2017.
- Tertullian (1950). *Apology*. In *Apologetical Works*, R Arbesmann, EJ Daily and EA Quain trans., Fathers of the Church, vol. 10. Washington DC: Catholic University of America Press.
- Tertullian (1931). *De Spectaculis*. In TR Glover and Gerald Rendall trans, *Tertullian: Apology, de Spectaculis, Minucius Felix*. Cambridge, Mass.: Harvard University Press.
- Thomas, G M (2017). *Down's Syndrome Screening and Reproductive Politics: Care, Choice, and Disability in the Prenatal Clinic*. Abingdon: Routledge.
- Van Hooff, A J L (2004). Ancient euthanasia: "good death" and the doctor in the graeco-Roman world. *Social science & medicine*. 58:5, 975-985.
- Wagenfuhr, G P (2016). *Plundering Egypt: A Subversive Christian Ethic of Economy*. Eugene: Cascade.
- Wannenwetsch, B (2011). From *Ars Moriendi* to Assisted Suicide: Bonhoefferian Explorations into Cultures of Death and Dying. *Studies in Christian Ethics*. 24:4, 428-440.