

## CHOOSING DEAFNESS? A LIBERAL EXPLORATION OF THE LEGAL PROHIBITION ON SELECTION FOR DISABILITY IN ENGLAND AND WALES.

**ABSTRACT** - This paper concerns the insertion into English and Welsh law of a prohibition on selection for disability in one's offspring for social reasons via the use of assisted reproductive technologies. It explores the changes in law that have occurred since the 2008 HFEA Act and subjects to philosophical scrutiny, from a liberal perspective of the limits of law, the reasons that have been given within legal and policy documents for its insertion.

**KEYWORDS** – Assisted Reproductive Technologies, HFEA 2008, Liberalism, The Non-Identity Problem, Reproductive Autonomy, Wrongful Disability.

### I. INTRODUCTION

In January 2004 the UK government announced a review of the Human Fertilisation and Embryology Act 1990<sup>1</sup> – the primary piece of legislation regulating the practices of artificial reproduction and embryo research in England and Wales – with the primary aim of updating the law in order “to keep pace with new avenues of scientific research and... reflect wider change in our society”.<sup>2</sup> Four years later, and after a great deal of debate and discussion the Human Fertilisation and Embryology Act 2008 – which provided 127 pages of amendments for a document which originally contained only 39 pages – received royal assent. Such amendments have, to a large degree, constituted a liberalising force. The Act, for example, now recognises both members of same sex couples as the legal parents of children conceived via donated gametes, and has replaced the ‘need for a father’ provision present in the 1990 Act with a more inclusive gender-neutral provision regarding a child’s need for ‘supportive parenting.’

Yet, while many changes have been met with approval by groups that the 1990 Act might have been seen to ignore or devalue, and some have even criticised those responsible for the legislative changes for having taken an ‘extreme libertarian approach’,<sup>3</sup> not all of such changes should be viewed as so liberalising. Elliston notes that “in one area the HFEA 2008 has taken a uniquely restrictive step...[seeking] for the first time in the UK to make it impermissible at least in certain circumstances, to choose to try to have children that are known to have particular genetic constitutions”<sup>4</sup> where prospective parents require/seek access to ARTs such as Pre-implantation Genetic Diagnosis (PGD) and In Vitro Fertilisation (IVF). Such restrictions apply generally to any and all forms of pre-implantation selection of which the purpose is not to avoid the birth of a child with a gene, chromosome or mitochondrion abnormality; to select embryos with tissue types compatible with existing siblings with serious medical conditions that can be treated with umbilical cord blood stem cells, bone marrow, or other tissue; or to determine, in

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<sup>1</sup> Hereafter to be referred to as the Act or where specification is required the 1990 Act, the 2008 Act or the amended Act.

<sup>2</sup> HC Deb, 12 May 2008, c1066.

<sup>3</sup> Science and Technology Select Committee, *Inquiry into Human Reproductive Technologies and the Law* (HC 2004-05 491), pp. 4-5.

<sup>4</sup> S. Elliston (2012) 'The Welfare of the Child Principle and the Use of PGD: Selecting for Disability', in S Elliston and S Mclean (eds.), *Regulating Pre-Implantation Genetic Diagnosis*, Oxford: Routledge, pp. 136-137.

cases where uncertainty has arisen, the parentage of embryos before implantation.<sup>5</sup> They also apply specifically to two particular types of selection: sex selection for social reasons via PGD<sup>6</sup> or gamete selection<sup>7</sup>, and the comparatively rare practice of deliberately selecting for disability in one's offspring using the same means.<sup>8</sup> As a result, those who perform PGD or utilise other selective reproductive technologies without a licence/outside the terms of a licence are now guilty of a criminal offence punishable by a prison sentence of up to two years and/or a fine.

This paper concerns the second of the specific restrictions noted above: the insertion into English and Welsh law of a prohibition on the use of ARTs for the purpose of selecting *for* disability. In order to provide context for readers I begin by providing an account of the desire itself and examples of some who have been shown to hold such a desire. A comparison of how a request to select for disability in one's offspring would have been met prior to the 2008 amendments with how such a request is now met is then made. This is done in order to show the reader firstly *how* the law has changed and secondly to bring together the reasons given in legal and policy documents for this change. Such reasons are then subjected to philosophical scrutiny from the perspective of a *liberal account of the limits of law*. Once it is explained why these reasons are inadequate, other possible arguments in favour of a prohibition against selection for disability are then explored.

## II. LAW AND POLICY REGARDING SELECTION FOR DISABILITY

In the last 60 years, since the *Abortion Act* 1967 decriminalised termination for reasons of foetal abnormality<sup>9</sup>, and pre-natal screening techniques were developed such as Amniocentesis in the late 1950s; Chorionic Villus Sampling (CVS) in the 1970s; IVF and PGD in the 1980's; and maternal blood screening in the 2000s reproductive choice has increased dramatically for prospective parents who are willing and able to access such technologies and techniques.

These technologies have, for the most part, been used to help potential parents conceive and give birth to children free from genetic disease and disability or to make adequate preparations for the birth of a child who may have complex medical and/or social needs. In recent years however, it has become apparent that some prospective parents harbour a desire to select for traits in their offspring which are widely viewed to be deleterious. The most publicised example of this is likely that of Duchesneau and McCullough, a profoundly deaf couple from the USA who, in the early 2000s, successfully ensured the birth of two congenitally deaf children via a fifth-generation deaf sperm donor and artificial insemination.<sup>10</sup>

Such cases, however, are not isolated, and a number of surveys and anecdotal studies published in the last few years show that for deaf persons, especially those identifying as culturally deaf (Deaf), a desire for a deaf child is not as uncommon as many would assume. For example, one study undertaken at a 'Deaf Nation' conference showed that 29% of respondents gave a positive answer to the question of whether they would prefer to parent deaf children.<sup>11</sup> Indeed, despite a widespread distrust of pre-implantation and pre-natal genetic diagnosis within

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<sup>5</sup> Human Fertilisation and Embryology Act 1990 (as amended by the Human Fertilisation and Embryology Act 2008), Sch. 2.3.1ZA. s. (1).

<sup>6</sup> *ibid*, Sch. 2, S.3, para 1ZC(3).

<sup>7</sup> *ibid*, Sch. 2. S. 4. Para 1A.

<sup>8</sup> *ibid*, s.13(9).

<sup>9</sup> Abortion Act, 1967, s. 1(d).

<sup>10</sup> M. Spriggs (2002) 'Lesbian Couple Create a Child Who Is Deaf Like Them', *Journal of Medical Ethics*, 28 (5) p. 275.

<sup>11</sup> A. Middleton, J. Hewison, and R. Mueller (1998) 'Attitudes of Deaf Adults toward Genetic Testing for Hereditary Deafness', *American Journal of Human Genetics*, 63, p. 1175.

the deaf community,<sup>12</sup> the idea of employing ARTs to increase the likelihood of the birth of a deaf child has also been met with enthusiasm by some deaf persons, with a small number of respondents to another survey noting they would consider aborting a foetus if it was discovered it could hear.<sup>13</sup> That such is the case is also evidenced by a study of the practices of United States IVF clinics showed 3% of the 190 clinics involved had received requests for, and provided PGD to, prospective parents who wished to select for disability in their offspring.<sup>14</sup> Indeed, when the 2008 amendments to the HFE Act regarding selection for disability were proposed a deaf artist and broadcaster appeared on the BBC's *Today* programme<sup>15</sup> and in various newspapers expressing his disappointment at the fact that he and his wife would be unable to use PGD to select for deafness should they require IVF in the future.<sup>16</sup>

Desires like this are also *not* confined to the deaf community. A 2006 article in the *New York Times* reported the stories of two women with Achondroplasia who, when undergoing genetic testing during their pregnancies to ensure their foetuses were not subject to a fatal double dose of the Achondroplasia gene, expressed a desire for a child who was 'little' like them. Indeed, one noted that were IVF and PGD less invasive procedures she would be willing to use such technologies to secure the birth of a child with Achondroplasia.<sup>17</sup>

It should be noted too that despite a lack of evidence it is possible that persons with other disabilities may express similar desires. This seems especially likely for those with conditions around which a strong culture, based on a shared experience of the world, has developed and for those whose disabilities are relatively easily (and often) compensated for by society or who have learned to accept and embrace their disabilities as either a neutral or positive characteristic. Indeed, it is not beyond the realms of possibility that certain non-disabled individuals may express a desire to select for disability in virtue of their association of that disability with characteristics they view to be desirable. Hearing persons may, for example, wish to have deaf children if most of their family are deaf and individuals who view that children with Down's Syndrome are invariably bundles of joy ready to furnish those around them with unconditional love, may, given this romantic-but-faulty belief, wish to select for it. Given this, the question of how a request to select for disability would have been met prior to the 2008 act and how such a request will be met now will be addressed.

### *III.I. Selecting for disability prior to the 2008 amendments: The HFEA and the Welfare Principle.*

In England and Wales, the activities of fertility clinics in relation to the use and storage of embryos and gametes are regulated by the Human Fertilisation and Embryology Authority. A

<sup>12</sup> *ibid.*, p. 1176.

<sup>13</sup> C. Dennis (2004) 'Genetics: Deaf by Design', *Nature*, 431(7011), p. 895.

<sup>14</sup> S. Baruch, D. Kaufman, and K. L. Hudson (2008) 'Genetic Testing of Embryos: Practices and Perspectives of Us in Vitro Fertilization Clinics', *Fertility and sterility*, 89 (5), p. 1058.

<sup>15</sup> *Today* (10 March 2008) (Radio Programme, BBC), audio download available at [http://www.bbc.co.uk/radio4/today/listenagain/listenagain\\_20080310.shtml](http://www.bbc.co.uk/radio4/today/listenagain/listenagain_20080310.shtml), [last accessed 10 November 2013].

<sup>16</sup> D. Lawson (2008), 'Of Course a Deaf Couple Want a Deaf Child', *Independent*, 11 March 2008, sec. Voices., available at <http://www.independent.co.uk/voices/commentators/dominic-lawson/dominic-lawson-of-course-a-deaf-couple-want-a-deaf-child-794001.html>, [last accessed 10 November 2013]; A. O'Hagan, 'Some 'Gifts' One Is Better Off Without', *The Telegraph* 2008, available at [http://www.telegraph.co.uk/comment/columnists/andrew\\_o\\_hagan/3555996/Some-gifts-one-is-better-off-without.html](http://www.telegraph.co.uk/comment/columnists/andrew_o_hagan/3555996/Some-gifts-one-is-better-off-without.html), [last accessed 10 November 2013].

<sup>17</sup> D. M. Sanghavi, (2006) 'Wanting Babies Like Themselves, Some Parents Choose Genetic Defects', *New York Times*, 5 December 2006., available at [http://www.nytimes.com/2006/12/05/health/05essa.html?ref=science&\\_r=0](http://www.nytimes.com/2006/12/05/health/05essa.html?ref=science&_r=0), [last accessed 10 November 2013].

fertility clinic may only offer fertility treatments licensed by the HFEA and the kinds of fertility treatments the HFEA may license are limited to those that fulfil licensing conditions set out in the HFE Act. Clinics found to have licensed the use of ARTs for any purposes other than those outlined as acceptable in the 2008 Act may lose their license to perform genetic testing. Indeed, persons found guilty of such an offence are liable on conviction to be imprisoned “for a term not exceeding two years or a fine or both, and... on summary conviction, to imprisonment for a term not exceeding six months or a fine not exceeding the statutory maximum or both”.<sup>18</sup> Despite this, until the 2008 amendments the HFEA actually had a great deal of discretionary power when deciding which fertility treatments to license as the licensing conditions for fertility treatment, set out in sections 12-15 of the 1990 Act were rather vague, providing no statutory prohibitions. Indeed, they contained only one provision of relevance to HFEA decisions regarding the circumstances and purposes for which it would provide fertility treatment to couples requesting it.

This provision is known as ‘The Welfare of The Child Provision’ and is derived from and viewed to constitute an extension of a principle that has, over the last century, become an increasingly dominant feature in both family and criminal law in England and Wales: the Welfare Principle (WP).<sup>19</sup> In its most simple form WP consists in a requirement that the welfare of children be taken into account by the courts in scenarios where their interests will be affected by its decision. It can be found in a number of statutes with slight variations in terms of strength between them,<sup>20</sup> but is usually understood in the way it is set out in the Children Act (1989), which provides: “when a court determines any question with respect to – (a) the upbringing of a child; or (b) the administration of a child’s property or the application of any income arising from it, the child’s welfare shall be the courts paramount consideration”.<sup>21</sup>

Within the HFE Acts the welfare of the child provision is slightly less strict, requiring that before licensing any kind of fertility treatment account – as opposed to paramount consideration – is taken of both the welfare of the child who may be born and any other child who may be affected by the birth. It is expressed as follows:

A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment...and of any other child who may be affected by the birth.<sup>22</sup>

Provided it could be shown that account had been taken of the welfare of children affected by a decision to provide fertility treatment, the HFEA was therefore relatively unconstrained in the kinds of activities it could choose to license, especially as nowhere within the 1990 Act – or indeed any legal documents containing a version of WP – can be found a definition of what constitutes child welfare.

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<sup>18</sup> Human Fertilisation and Embryology Act, 1990, s. 41(4).

<sup>19</sup> HL Deb, 6 March 1990, col. 1100.

<sup>20</sup> Jackson explores the differences in strength between versions of WP set out in The Children Act 1989, The Adoption Act 1976 and The Child Support Act 1991, in her paper ‘Conception and The Welfare Principle’, noting that the principle can be seen in its strongest form in s. 1 of The Children Act where the welfare of the child is held to be the paramount consideration of the courts, in a slightly weaker form in The Adoption Act 1976 where it is held to be the courts first but, by implication, not only, consideration and in a weaker form still in the Child Support Act 1991 where Child support officers are required only to have regard to the welfare of any children who might be affected by their decisions. It should be noted however that The Adoption Act 1976 is no longer in force, having been replaced by the Adoption and Children Act 2002 within which a version of WP still exists, but a version which is identical to that found in the Children Act 1989. See: E. Jackson (2002) ‘Conception and The Irrelevance of The Welfare Principle’ *The Modern Law Review*, 65 (2), pp. 176-203.

<sup>21</sup> Children Act, 1989, s.1 (1).

<sup>22</sup> Human Fertilisation and Embryology Act, 1990, s.13 (5).

Within the Children Act 1989 and the Adoption and Children Act 2002 however, a set of factors is included which the court and other relevant authorities are directed to have regard, all of which are noted by Barlow to “have been commonly used to identify a child’s *needs* and to determine... the best way to meet them”.<sup>23,24</sup> These factors were not included in the 1990 Act and the HFEA was thus left to determine the kinds of activities that may and may not engage the WP. Yet, while the WP was open to HFEA interpretation, HFEA understanding of the demands of the principle was broader than it might have been. Since the first edition of the Code it was held that any disease or disability might well engage s. 13. Thus, in order to properly take account of the welfare of the child it was noted: “centres should bear in mind... any risk of harm to the child or children who might be born, including the risk of inherited disorders”.<sup>25</sup> This was further expanded in later versions of the Code, which by the 7<sup>th</sup> edition read:

In order to take into account the welfare of the child, the centre should consider factors... likely to cause serious physical, psychological or medical harm, either to the child to be born or to any existing child of the family. These factors include... any aspect of the patient’s (or, where applicable, their partner’s) medical history which means that the child to be born is likely to suffer from a serious medical condition.<sup>26</sup>

Those who might have requested the use of ARTs to select for disability would thus have been highly unlikely to have their request granted prior to the 2008 Act where it could be demonstrated that the condition selected for was of sufficient gravity to be classed as a ‘serious medical condition.’ Testing embryos for some particular disability and then selecting for the condition may well have been viewed to violate the welfare provision, as understood in the Codes. Of course, as s.13 of the 1990 act required only that the welfare of children created be taken into account when determining whether to license a treatment, the HFEA could also have concluded that despite threats to the welfare interests of the child created, these would be outweighed by the interests of his potential parents.

As the Codes became longer and more detailed the likelihood anyone would be permitted to use ARTs to ensure the birth of a deaf child became smaller still. For example, since 1998 it had been HFEA policy to refuse donations of gametes from those with genetic diseases or other “deleterious recessively inherited” genetic conditions.<sup>27</sup> In 2003 when policy regarding the use of PGD was first given it was noted that PGD should *only* be used to test for genetic abnormalities where there is “a significant risk of a serious genetic condition being present in the embryo”<sup>28</sup>, and when it is known that one or more members of a couple possess a high likelihood of transmitting a genetic condition onto their offspring. Indeed, the code states that in such cases “all reasonable steps should be taken to prevent the transmission of serious genetic disorders”.<sup>29</sup> Thus, although the Code had held since the 6<sup>th</sup> edition that HFEA licensing committees must, when deciding whether or not to license PGD, consider “the unique circumstances of those seeking treatment, rather than the fact that they carry a particular genetic condition”<sup>30</sup> – and thus the possibility that potential parents might, in line with social constructionist accounts of disability, argue that the disability should not be considered serious–

<sup>23</sup> A. Barlow (1991) *The Children Act 1989: The Private Law*, London: Fourmat Publishing, p. 10.

<sup>24</sup> Such factors include the requirement that the courts take into account the child’s wishes regarding their decision (should he have any), what his needs may be (whether they be physical, emotional and/or educational), how a change in his circumstances might affect him and whether it would be better for him should no change occur, his age, sex, background and other characteristics, any harm he has suffered as well as any harm he may suffer as a result of their decision.

<sup>25</sup> HFEA, *Code of Practice*, 1<sup>st</sup> ed. (London, HFEA, 1990), para. 3.14.

<sup>26</sup> HFEA, *Code of Practice*, 7<sup>th</sup> ed. (R.4), (London, HFEA, 2008), para. G.3.3.2.

<sup>27</sup> HFEA, *Code of Practice*, 4<sup>th</sup> ed. (London, HFEA, 1998), para. 3.59-60.

<sup>28</sup> HFEA, *Code of Practice*, 6<sup>th</sup> ed. (London, HFEA, 2003), para. 14.22.

<sup>29</sup> HFEA, *Code of Practice*, 6<sup>th</sup> ed. (London, HFEA, 2003), para. 4.10.

<sup>30</sup> HFEA, *Code of Practice*, 6<sup>th</sup> ed. (London, HFEA, 2003), para. 14.20.

the HFEA had *never* licensed the use of PGD for the purpose screening in *any specific genetic traits for social reasons*. Indeed, since the 3<sup>rd</sup> edition of the Code it was noted too that they would refuse to license other forms of social selection such as sex selection and allow for the possibility of screening or selecting of embryo's in only a very small handful of circumstances.<sup>31</sup>

### *II.II. Selection for Disability and The HFE Act 2008*

Since the HFE Act 2008 the law governing the activities of fertility clinics in England and Wales has tightened greatly. Where there were once only instructions to take into account the welfare of those who might be born through fertility treatment, far stricter legislative provisions governing the purposes for which PGD and other means of selection may be used in fertility treatment are now in place. The Act provides an exhaustive list of the purposes for which PGD may be licensed and while accepted purposes include the testing of embryos in order to discover whether they have a “gene, chromosome or mitochondrion abnormality... a gender related serious physical or mental disability... a gender related serious illness... or any other gender related serious medical condition”,<sup>32</sup> selecting for disability after such testing reveals a positive diagnosis is now prohibited. In relation to the selection of donors and donor gametes the same rules apply. The licensing conditions now state that when determining: “the persons who are to provide gametes...the woman from whom an embryo is to be taken... [and] which of two or more embryos to place in a woman”<sup>33</sup> “persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that the person with the abnormality will have or develop – (a) a serious physical or mental disability, (b) a serious illness, or (c) any other serious medical condition, *must not be preferred* to those that are not known to have such an abnormality”.<sup>34</sup>

The HFEA thus no longer possesses the discretion that made a positive response to a prospective parent's request for disability selection prior to the 2008 Act a very slim possibility. For while there still exist some technical loopholes in the law<sup>35</sup> – such as where testing reveals all embryos to be affected, only affected embryos are viable, or all embryos are implanted – potential parents would not be able to *select* affected embryos even if it can be successfully argued that to do so would not violate the WP (which is still present in the 2008 legislation). This is so as if *PGD is licensed* to test for a particular condition it is licensed on the basis that the condition is classified as serious rather than trivial, where a determination of seriousness is made after consideration of medical and social factors such as “the likely degree of suffering associated with the condition... the availability of effective therapy now, and in the future, the speed of degeneration in progressive disorders... the extent of any intellectual impairment...

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<sup>31</sup> These were summarised by the Department of Health as follows: to avoid the transmission of inherited disorders and diseases; to avoid sex linked diseases; to screen out chromosomal abnormalities to increase likelihood of live birth; or in order that the child created via fertility treatment was able to become a tissue donor for a seriously ill sibling. See: Department Of Health (2005), *Review of the Human Fertilisation and Embryology Act: A Public Consultation*, p. 39.

<sup>32</sup> Human Fertilisation Act 1990 (as amended by the Human Fertilisation and Embryology Act 2008), Sch. 2.3.1ZA, s.(1).

<sup>33</sup> *ibid*, s.13(8)

<sup>34</sup> *ibid*, s.13(9).

<sup>35</sup> Elliston notes in her 2012 paper (op. cit. note 4) that it may be possible for couples to circumvent the 2008 amendments in order to select for implantation an embryo that has a known disability after PGD by creating only one embryo at a time such that the embryo selected cannot be said to have been ‘preferred to other available embryo’s’ where such a preference is judged to have occurred when one embryo from one particular IVF batch is preferred as opposed to all of the embryo’s available to a woman for implantation ( which would include all spare IVF embryos/embryo’s available via embryo adoption schemes).

the social support available”.<sup>36</sup> Thus, those who wish to select for disability cannot argue that the condition they desire to test for should not be considered a serious medical condition, disease or disability by reference, for example, to social constructivist accounts of disability. For, if this were so the use of PGD to test for it would be prohibited just as is sex selection by provisions banning the use of embryo testing for anything other than the purposes specified in schedule 2 of the amended Act.

### III. WHY PROHIBIT SUCH SELECTION?

As can be seen in the previous section, the HFE Act 2008 has significantly changed the possible outcomes of requests regarding the use of ARTs to select for disability. For, while it was unlikely under the 1990 Act that the HFEA would approve such requests, the legislative provisions inherent in the 2008 Act have now made such selection virtually impossible. Some might view this development to be uninteresting given the small number of individuals who are and will, in the future, be affected by it. However, the question of whether any legislative change can be justified in accordance with the principles underpinning our legal system should be of interest to any jurist regardless of the number of individuals affected. I now turn to the question of the justifications that have been given for the legislative change just outlined.

While there are numerous accounts of the purposes, functions and limits of the law to which we might possibly appeal as providing justification or condemnation of a legal prohibition on selection for disability, a treatment of all such accounts cannot be attempted in this paper. Instead, it will be assumed that within broadly liberal democracies such as England and Wales a liberal framework for law is appropriate. As such, whether a prohibition can be justified will be determined in accordance with those principles agreed upon as providing adequate reason for the prohibition of activities in a liberal society.

#### *III.I. What Might Justify A Prohibition on Selection for Disability in A Liberal Society?*

While there is no one version of liberalism to which all who subscribe to a broadly liberal framework for society will agree, certain fundamental ideas are common to the most prevalent accounts. These include a commitment to moral individualism, the basic equality of persons and the belief that there should be a distinction between public and private morality. Thus, regardless of the extra content one adds, the primary job of any liberal state should be seen as to work out the terms under which persons, who naturally differ and disagree in their fundamental religious, philosophical and moral convictions can live together in peaceful political association in a way that both preserves and enlarges freedoms by accommodating these fundamental differences instead of reducing them by the legal enforcement of agreement.<sup>37</sup>

In his four volume series *The Moral Limits of The Criminal Law* Feinberg identified four broad candidates to which we might appeal when attempting to provide justification for state imposition on individual liberty: harms to others, offence to others, harms to self and legal moralism. However, as Feinberg noted only the first two of these and, perhaps to some limited extent, the third,<sup>38</sup> may be seen, in a liberal state as providing good reason for prohibition.

<sup>36</sup> HFEA Code of Practice, 8<sup>th</sup> edition (R4), s. 10.7.

<sup>37</sup> C. Larmore (1996), *The Morals of Modernity*, Cambridge: Cambridge University Press, pp. 121-127

<sup>38</sup> Dworkin, for example suggests that ‘soft paternalism’ can be justified in a liberal state in cases when our current and irrationally held desires are denied in order to preserve those desires we would deem rational if we were thinking clearly as in the case of forcing motorcyclists to wear helmets and Feinberg suggests that the state may be justified in temporarily curtailing our liberty or in order to establish the voluntariness of a preference. See: G. Dworkin (1972), ‘Paternalism’, *The Monist*, 56 (1),

Arguments falling into the fourth category should however, be wholly rejected as “there are some disagreements about the good life and ultimate values that we do not have to settle in order to decide collectively how we will pursue justice and the common good”.<sup>39,40</sup> As such it is held that the criminal law should be concerned only with what Feinberg termed ‘Legislative Evils’, defined as “reasonably foreseeable or preventable consequences of human beings’ actions or omissions.”<sup>41</sup>

It is therefore prudent, before examining the reasons that have been given within legal and policy documents for a prohibition on selection for disability, to briefly sketch an account of what it means for some action to cause harm or offence to others in a legally admissible sense.

Generally, when we state that some particular person (x) has been harmed by some event or action (y) we use the term to mean that x’s interests – defined as distinguishable components of his wellbeing – have been set back, thwarted or defeated as a result of the action or event in question. Counterfactually then, we are claiming that x is worse off than he otherwise would have been had y not occurred.<sup>42</sup> Therefore, x is harmed when struck unawares by lightning or by some person (z) with a broken bottle because both events cause x to experience something he has an interest in avoiding: significant and unwanted pain. When we state that x is harmed by y in a sense that may justify our legislating against it, however, we utilise the concept of harm slightly differently. We cannot, after all, prohibit lightning and would not condone z’s striking x with the bottle if it turned out that by some fluke z’s act had actually benefited x on balance.<sup>43</sup> This is because the legal sense of harm involves a normative component: an account of moral responsibility. Thus, when we claim that x is harmed in a legally admissible sense we claim not just a harm but also a wrong: a deliberate or negligent and unjustifiable violation or invasion of x’s interests.

#### III.IV. *What Does This Mean for Selective Reproduction?*

For a liberal government to be justified in prohibiting some action it must therefore be shown that the act in question will not only cause or be likely to cause harm/offence to some identifiable party but that it is unjustifiable. Thus, when it comes to questions of what we should and should not allow prospective parents to do within the arena of reproduction, the liberal approach offers a clear account of the limits of reproductive freedom: persons should be formally free to choose whether they wish to procreate, with whom they wish to procreate, when they wish to do so, how many children they wish to have and what kinds of children they wish to have,<sup>44</sup> provided that their choices do not cause unjustifiable harm or offence to others.

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pp. 64-84; J. Feinberg (1989), *The Moral Limits of The Criminal Law Volume 3: Harm To Self*, Oxford: Oxford University Press.

<sup>39</sup> T. Nagel (2006) ‘Progressive but Not Liberal’, *The New York Review Of Books*, 25<sup>th</sup> May 2006, available at <http://www.nybooks.com/articles/archives/2006/may/25/progressive-but-not-liberal/>, [last accessed 10 November 2013].

<sup>40</sup> Such disagreements will be those regarding actions in which the liberty of one does not impinge upon the interests of others and thus causes no harm or offence to any party or can be shown to satisfy the *volenti* maxim.

<sup>41</sup> J. Feinberg (1990), *The Moral Limits of the Criminal Law Volume 4: Harmless Wrongdoing*, Oxford: Oxford University Press, p. 18.

<sup>42</sup> J. Feinberg (1987), *The Moral Limits of the Criminal Law Volume 1: Harm to Others*, Oxford: Oxford University Press, p. 34.

<sup>43</sup> Such is of course, unlikely but possible. It could be the case, for example, that y’s striking x with the bottle could lead to doctors discovering while x was in hospital for his injuries that he has a brain tumour that while currently operable would, left untreated, have killed him within the next few weeks and that thus while y did indeed cause great harm to x by his actions, he also saved his life.

<sup>44</sup> A. Buchanan et al. (2000), *From Chance to Choice: Genetics and Justice*, New York: Cambridge University Press, pp. 209-211.



Certain moral criticisms that we might, in a philosophical arena, level against practices such as selection for disability cannot – in good conscience at least – be used in a liberal society to justify a legal prohibition. This is so because, while available to each of us when it comes to the formulation of our own private moral codes, such arguments are incompatible with the basic liberal principles of non-perfectionism and reasonable pluralism that are required in the sphere of public morality. These arguments are easily identifiable and tend to fall into one of two camps.

The first type of argument consists in the denial that the state should only concern itself with the consequences of human beings' acts and omissions in favour of a broader account of the limits of the criminal law. According to such an account certain actions are held to be inherently wrong in virtue of their contravening some universal and, supposedly, undeniable moral principle or right. On such accounts, those who wish to select for disability might be charged with the possession of a faulty desire, of committing a category error in treating their prospective children as objects of desire or of wronging, but not harming their child, by violating some right on their part 'to be born perfect' or with 'at least an average chance of living a good life', among other things.

Arguments falling into the second camp however, retain the liberal focus on consequences but widen those consequences of relevance when determining the moral status of a particular action to encompass not only harms determined by reference to their impact on the interests of some particular person but also an impersonal account of harm (such as when it is claimed that to select for disability would harm 'the world' by lowering total net or average happiness).<sup>45</sup>

### *III.V. What reasons have been given in legal and policy documents as providing justification for this prohibition?*

With these restrictions in mind let us now turn to the reasons that have been given as to why it was HFEA policy prior to the 2008 amendments to refuse to license PGD for selection for disability. The answer to this question is not hard to locate and can be found in HFEA's concern that to select for disability in one's offspring might engage the welfare provision of the licensing conditions of the 1990 Act given that the code also holds that the risk of inherited disease or disability is a risk of serious harm. This concern can be found in *all* versions of the HFEA Codes of Practice<sup>46</sup> yet nowhere within such documents or other relevant documents is it expanded to explain exactly *how* this type of selection should be viewed as possibly causing serious harm to the child created and thus as being contrary to the welfare of the child provision.

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<sup>45</sup> For those unfamiliar with the notion of impersonal harm an account of both impersonal total and average harms as well as their implications can be found in Part IV of D. Parfit (1984), *Reasons and Persons*, Oxford: Clarendon Press. For examples of moral arguments for a duty to select against disability in one's offspring based upon notions of impersonal harm see: J. Harris (1998), *Clones, Genes and Immortality: Ethics and the Genetic Revolution*, Oxford: Oxford University Press, p. 111; J. Savulescu (2001) 'Procreative Beneficence: Why We Should Select the Best Children', *Bioethics*, 15(5), p. 418; J. Savulescu & G. Kahane (2009), 'The Moral Obligation to Create Children with the Best Chance of the Best Life', *Bioethics*, 23/5, p. 277.

<sup>46</sup> See: HFEA, *Code of Practice*, 1<sup>st</sup> ed. (London, HFEA, 1990), para. 3.14(d); HFEA, *Code of Practice*, 2<sup>nd</sup> ed. (London, HFEA, 1993), para. 3.16(d); HFEA, *Code of Practice*, 3<sup>rd</sup> ed. (London, HFEA, 1995), para. 3.17(f); HFEA, *Code of Practice*, 4<sup>th</sup> ed. (London, HFEA, 1998), para. 3.17(g); HFEA, *Code of Practice*, 5<sup>th</sup> ed. (London, HFEA, 2001), para. 3.13(g); HFEA, *Code of Practice*, 6<sup>th</sup> ed. (London, HFEA, 2003), para. 3.12(v)(a); HFEA, *Code of Practice*, 7<sup>th</sup> ed. (R4) (London, HFEA, 2008), para. G.3.3.2.(c); HFEA, *Code of Practice*, 8<sup>th</sup> ed. (R4) (London, HFEA, 2012), para. 8.10.(b)(iii).

The first discussion of whether selection for disability should be prohibited within the HFE Act can be found in the HCSTC report on Human Reproductive Technologies and The Law. In a subsection of the ‘Selection and Screening’ section entitled ‘undesirable characteristics’ they summarised their position on the matter in the following rather ambivalent paragraph:

We can imagine that many clinicians would balk at the idea of selecting, for example, a deaf child using PGD, but we do not feel that the creation of a child with reduced life opportunities is sufficient grounds for regulatory intervention, else we might logically deny poor people IVF. Professor Tom Shakespeare told us that PGD should not be allowed to select out “minor or trivial” conditions such as restricted growth or deafness. On this basis, it is difficult to argue that they should not be selected rather than deselected. A more challenging but unlikely scenario would be the desire to select a child who would suffer obvious discomfort (rather than disadvantage), or worse. In this area there needs to be further debate.<sup>47</sup>

The DoH in their *Review of the HFE Act: a Public Consultation* also took an interest in the question of selection for disability, noting the existence of a “commonly expressed concern... that techniques used to screen out disabilities or impairments could also be used for screening in”.<sup>48</sup> In the report the case of Duchesneau and McCullough was outlined (although not by name) as an example of the desire of some to select for disability in their offspring: “there has been a well-publicised case in the United States, of a deaf couple who wished to select a deaf donor so that the resulting child would also be deaf, and therefore share more closely the parents’ experience of the world.”<sup>49</sup> It was also noted that “The House of Commons Science and Technology Committee considered this issue and concluded that the desire to select a child who would suffer obvious discomfort or worse was an area needing further debate”.<sup>50</sup> A question (no. 32) regarding this matter was thus inserted in the document: “Do you think that there should be a prohibition on deliberately screening in, or selecting for impairments or disabilities – as opposed to screening out, or selecting embryos free from diseases?”<sup>51</sup>

After the consultation closed People Science and Policy collected and summarised the arguments put forward in the 535 replies sent in by organisations, medical and legal professionals and individual members of the public.<sup>52</sup> A summary of responses to question 32 was outlined in S.5.3:

Those respondents who wanted to see screening in or selecting for impairments banned did so because they saw it as *against the best interests of the child and reflecting the parents’ needs as opposed to the child’s*... There were also responses in favour of allowing screening in or selecting for impairments. Some arguments put forward related to *freedom of choice* and the *rights of adults to make choices*... Some responses felt that the answer was not clear-cut and there may be circumstances when screening in might be desirable because ‘the basic classification of disabilities and impairments is not straightforward.’ *The regulator was felt to be the relevant organisation in these cases ... but the HFEA response said that they would like parliamentary guidance.*<sup>53</sup>

Despite large variations in the content of the responses to the consultation document the DoH proposals for revised legislation largely ignored what can only be described as a state of split opinion on the matter of selecting for disability among respondents to the consultation document. After “carefully considering a full range of viewpoints, suggestions and proposals”

<sup>47</sup> House of Commons Science and Technology Select Committee, *op. cit.* note 3, p. 66.

<sup>48</sup> Department of Health, *op. cit.* note 31, s. 5.13.

<sup>49</sup> *ibid*

<sup>50</sup> *ibid*

<sup>51</sup> *ibid.* Annex B, Q. 27.

<sup>52</sup> People Science and Policy (On behalf of the Department of Health), (2006) ‘Report on the Consultation on the Review of the Human Fertilisation and Embryology Act 1990’, s.1.2.

<sup>53</sup> *ibid.* s.5.3.

and balancing “competing claims of reproductive liberty and responsibility”<sup>54</sup> the DoH seemed convinced by the arguments of those who wanted to see screening in for impairments banned and published the following recommendation regarding selection for disability: “the government will propose that the law is changed to include explicit criteria for the testing of embryos... Deliberately screening in a disease or disorder will be prohibited”.<sup>55</sup>

Such was indeed the case and in May 2007 the Human Tissues and Embryos (Draft) Bill was published containing as part of the Conditions of Licensing for Treatment (s.21) the following:

- (8) In determining –
- (a) The persons who are to provide gametes for use in pursuance of the licence in a case where consent is required under paragraph 5 of Schedule 3 for the use in question,
  - (b) The woman from whom an embryo is to be taken for use in pursuance of the licence, in a case where her consent is required under paragraph 7 of Schedule 3 for the use of the embryo, or
  - (c) Which of two or more embryos to place in a woman,

persons or embryos that are known to have a gene, chromosome or *mitochondrion* abnormality involving a significant risk that a person with the abnormality will have or develop a serious physical or mental disability, a serious illness or any other serious medical condition must not be preferred to those that are not known to have such an abnormality.<sup>56</sup>

In May 2007 the Joint Committee on the Human Tissue and Embryos (Draft) Bill was appointed by a motion in the Houses of Commons and Lords with “terms of reference to consider and report on any draft Human Tissue and Embryos Bill presented to both Houses by a Minister of the Crown”<sup>57</sup> by the 25<sup>th</sup> of July 2007. Their consideration of the matter of selection for disability was however, limited to nothing more than a description of the proposed changes to the act<sup>58</sup>. No further mention was made of selection for disability or the rather serious lack of discussion regarding possible justifications for this proposed restriction of liberty in the government response to the joint committee report and by December 2007 when the Bill was introduced to the House of Lords the question of why it was imperative to ensure that selection for disability was prohibited had still not been answered.

Indeed, there is no evidence of sustained and reasoned discussion of this point within either the Lords or Commons Hansard. This is not, however, to say that the prohibition was ignored as selection for disability was mentioned in both Houses discussions of the Bill. Baroness Deech noted during a discussion regarding the parameters for screening and selecting embryos that “I hope your lordships will be pleased that the deliberate choice of an embryo that is, for example, likely to be deaf will be prevented”.<sup>59</sup> Earl Howe, too noted, in a rather stirring monologue:

New Subsections (9), (10) and (11) of Clause 14, which would amend Section 13 of the Act, focus upon pre-implantation genetic diagnosis and take us to a particular aspect of that issue which, but for these provisions, many of us might not otherwise have thought much about. They explicitly prohibit embryos being selected with a view to increasing the chance of having a child with a serious disability or medical condition. Consciously to wish such a disability or condition on a child may seem extraordinary, but there have been well-documented cases where parents who are disabled in

<sup>54</sup> Department of Health (2006), *Review of the Human Fertilisation and Embryology Act: Proposals for revised legislation* (CM6989), London: Department of Health, foreword.

<sup>55</sup> *ibid*, s. 2.43.

<sup>56</sup> Department of Health (2007), *Human Tissue and Embryos (Draft) Bill*, London: Department of Health, s. 21(4).

<sup>57</sup> Joint Committee on the Human Tissue and Embryos (Draft) Bill (2007), *Human Tissue and Embryos Draft Bill Volume I Report*, London: Her Majesty’s Stationery Office, s.1.

<sup>58</sup> *ibid*, app. 3, p. 88.

<sup>59</sup> HL Deb, 19 November 2007, col. 673.

a particular way have expressed a desire to have a child with the same disability. I find that idea repellent because it ignores one of the issues central to any IVF procedure, namely, the future welfare of the child. Therefore, I wholly support a ban on that type of embryo selection. The techniques available to diagnose the presence of genetic conditions in any embryo should be used, if they are used at all, to reduce the risk of a child being born with a serious handicap and to reduce the risk of suffering.<sup>60</sup>

This was to be the end of the Lords discussions on the matter and Commons discussions also failed to provide any explanation of justifications for the prohibition. Indeed, while the Commons Hansard shows that officials within the Department of Health had made contact with several Deaf organisations that had publicly criticised section 14 of the new bill,<sup>61</sup><sup>62</sup> the only mention of selection for disability was in a summary of the Bill's proposals regarding PGD.

#### IV. HARM TO THE CHILD

As can be seen above, the main justifications advanced in legal and policy documents in favour of prohibiting selection for disability in the UK have been based upon the notion that those who would use ARTs for such purposes would cause harm to the child created and thus fail to take into account WP as it has been expressed in both HFE Acts. Should this be the case a prohibition on such selection would be justifiable in accordance with liberal principles. However, it has also been observed that there has been very little, if any, real discussion within legal and policy documents of *how exactly* selection for disability might be seen to harm those children created as a result of such selection.

##### *IV.II. Child Welfare, PGD and The Non-Identity Problem.*

It is, in general, rather hard to find anyone with broadly liberal sensibilities willing to criticise the insertion of a *welfare principle* into the laws governing matters relating to children. Indeed, those arguments that do withstand scrutiny tend not to attack the spirit of such a principle as it is currently understood: the view that “children, being vulnerable, impressionable and dependent, must be protected from harm and given every opportunity to become successful adults”.<sup>63</sup> Instead, such arguments tend to bring into question whether actual versions of the principle can be said to embody that spirit. They thus focus on whether the principle is too strong or requires too much from judges and other legal figures who are expected to balance numerous conflicting factors such as the child's wishes; the child's current and future interests; and predicting the outcomes for the child of various different arrangements.

That such is the case, however, is understandable. For, regardless of one's opinion on the matters above, it is a common feature of all *reasonable* religious, philosophical and political doctrines that persons are fundamentally equal, and must thus be treated with equal concern and respect. That someone has not reached majority is little reason to ignore their interests or treat such interests as of only secondary importance and steps must thus be taken to ensure that the interests of those who might easily be ignored are taken into account. The WP and principles like it serve this purpose by forcing the court and other legal bodies to take notice of the interests “the person whose voice may be the quietest both literally and metaphorically... who has the

<sup>60</sup> HL Deb, 21 January 2008, col. 23.

<sup>61</sup> Such groups included the Royal National Institute for the Deaf, the British Deaf Association, Islington Deaf Campaign and the Stop Eugenics group.

<sup>62</sup> HC Deb, 2 April 2008, col. 1098W.

<sup>63</sup> S. Gilmore (2001), 'A Critical Perspective on the Welfare Principle', in LA Long and J Roche (eds.), *The Law and Social Work: Contemporary Issues for Practice* (1 edn.; Basingstoke: Palgrave Macmillan), p. 6.

least control over whether the issue arrives before the court or in the way that it does... the person with whom the court is least able to empathise”,<sup>64</sup> the child.

With almost universal support for the inclusion of the WP in the laws governing decisions relating to *children* it is unsurprising that when it was suggested that the principle be included in the laws governing the use of ARTs such a suggestion was met with resounding approval. Jackson, for example, notes that the inclusion of the principle was “greatly welcomed by every peer who expressed an opinion”<sup>65</sup> when section 13(5) of the HFE Act 1990 was debated in parliament. It does seem intuitively to make sense that if we are concerned with ensuring the welfare of children once they are born we should be concerned too with taking steps to ensure that welfare prior to their birth. Yet, that it has been used to justify limiting the purposes for which ARTs may be licensed seems to be a step too far. This is because there is a crucial difference between taking into account the welfare of a particular extant/future child when making decisions that will impact *his* welfare, as in custody disputes and adoption hearings, and attempting to do the same when deciding whether to license the use of PGD for a specific purpose.

This difference hinges upon the fact that while in former cases there is an actual child whose welfare may be affected by a court’s decision or protected by a particular piece of legislation, decisions made regarding the kinds of fertility activities to license seem to affect the identities, as opposed to the welfare of those children created. This problem is often termed ‘the wrongful handicap conundrum’ and is a variation of a problem in philosophy known as ‘the non-identity problem’ which essentially states that in cases where a child “could not have existed otherwise than in his suboptimal state... he has not been harmed by being born in his damaged state”<sup>66</sup> unless his life will be less than one worth living.

Parfit illustrates this point well with a thought experiment where he asks us to imagine two women, A and B. A is in the early stages of pregnancy and has been told by her doctor that unless she takes the pill he has just given her, the child she is carrying will develop a serious and painful disability. B is not yet pregnant but plans to become so soon. The doctor tells B she has a rare and bizarre medical condition which means that should she conceive now her child will be born with a disability similar to that which A’s child will have should A not take the pill. He notes however, that if B waits three months she will be able to conceive a healthy child. Both women are thus faced with a choice: A must choose whether or not to take the pill and B must decide whether or not to wait to conceive.

Parfit suggests that the majority of us intuit that both A and B should, *ceteris paribus*, act in such a way so as to ensure they give birth to a healthy child: A should take the pill and B should wait to conceive and should they not make these decisions they would act wrongly. If A and B choose not to prevent disability in their offspring, they are viewed to harm their child because a child born without a painful disability is likely to have a far better life than a child born with one. In the case of A, Parfit notes that our intuition that she should take the pill in order to ensure the birth of a healthy child is in line with a commitment to harm prevention, since, if A does not take the pill, once born, her child might claim that in failing to prevent his disability, at very little personal cost, she has greatly harmed him. He could, after all, have been born without his disability. In B’s case however, harm-based accounts of wrong give B no moral reason to choose to conceive now or to wait, based on the interest of her child. For, although we might *feel* that B should wait, she has no reason to do so if we are to focus only upon whether her child would be harmed. If B heeds the doctor’s advice and waits for three months to conceive, the result will be a different child from that she would have conceived

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<sup>64</sup> *Ibid*, p. 5.

<sup>65</sup> E. Jackson, *op. cit.* note 20, p. 180.

<sup>66</sup> D. S. Davis (2001), *Genetic Dilemmas: Reproductive Technology, Parental Choices and Children's Futures*, London: Routledge, p. 35.

three months prior because our coming into existence depends upon both the timing and manner of our conception. Thus, while A's child would have a claim to having been harmed should A choose not take the pill as she would be made worse off by A's choice, B's child would not be harmed should B prove impatient. For, although he might prefer not to be disabled he cannot claim he has been harmed by her choice as to prefer that she had waited to conceive would be to prefer non-existence, an irrational preference, if his life is worth living.<sup>6768</sup>

A decision regarding whether to select an embryo or gamete donor based on their possession of certain disabling genetic traits is a decision more akin to B's than A's. Just as B's decision will lead to the coming into existence of different persons, selection for a disabling genetic trait such as deafness will change, not the capacities of a particular possible person, but who it is that will come to exist. Should a pair of prospective parents deliberately create a deaf child via PGD and IVF, such a child could not exist without her disability. She may not complain that she has been harmed by the negligence or cruelty of her parents unless her life is so bad that existence is harmful. Thus, provided we are willing to accept that most disabilities, deafness included, do not render one's lives less than worth living and that a life lived is a more desirable prospect than a life never lived at all<sup>69</sup>, we can conclude that her parents would not harm her by bringing her into existence.

#### IV.III. A Right to An Open Future?

Some however, have argued that to appeal to a violation of the interests of the child created by such forms of selection need not fall into the trap of the wrongful handicap conundrum. Davis proposes that rather than view the ethical challenge posed by selection for disability as a conflict between the liberal requirements both to respect autonomy and to prevent harm we should instead "recast it as a conflict between respecting parental autonomy and the child's potential autonomy".<sup>70</sup> She does so by applying an argument of Feinberg's concerning children's rights, known as the Open Future Argument (OFA) to the prenatal context, arguing that those who deliberately create impaired children violate the child's "rights in trust".<sup>71</sup>

Feinberg derives a child's possession of such rights from the rights adults in liberal societies possess to choose their own paths in life. As a corollary of such rights, Feinberg suggests children possess a similar type of right that requires we not close off certain key

<sup>67</sup> D. Parfit (2006), 'Rights, Interests and Possible People', in P. Singer & H. Kuhse. (eds.), *Bioethics: An Anthology*, 2nd edn, Oxford: Blackwell, pp. 88-90.

<sup>68</sup> It should be noted that dependent on the theory of personal identity to which we subscribe the conclusions of the non-identity problem may not pose an insurmountable obstacle to determinations of prenatal harm in cases such as that of B. If, for example we subscribe not to a biological or psychological criterion of personal identity, according to which our identities are fixed by our being a particular numerical entity or being psychologically connected to past and future versions of ourselves, but instead, to a placeholder account, according to which certain morally relevant aspects of our identities are fixed by the relationships in which we stand to others, the non-identity problem may not hold. This question has been explored in some depth in the paper: N. J. Williams (2013), 'Possible Persons and The Problem of Prenatal Harm', *The Journal of Ethics*, 17 (4), pp. 355-385. Yet, regardless, it should be noted that English and Welsh law tends to determine both claims to harm and moral responsibility in accordance with biological and psychological accounts of personal identity, rather than placeholder accounts.

<sup>69</sup> There are those who suggest otherwise such as Benatar who, as an anti-natalist argues that this 'cheerful belief' is grossly misinformed and that coming into existence is always a serious harm. See D. Benatar (1997), 'Why it is better never to come into existence' *American Philosophical Quarterly*, 34 (3), pp. 345-355.

<sup>70</sup> D. S. Davis (1997b), 'Genetic Dilemmas and the Child's Right to an Open Future', *Rutgers Law Journal*, 28, p. 562.

<sup>71</sup> see D. S. Davis, (1997C) 'Genetic Dilemmas and the Child's Right to an Open Future', *The Hastings Center Report*, 27 (2), pp. 7-15; D. S. Davis, *op. cit.* note 66.

choices they may wish to make when adults while they are still children.<sup>72</sup> Such “rights in trust” protect children from decisions they themselves may make concerning their futures, such as deciding to drop out of school early as their future career plans as dancers or rock stars do not require much schooling and from parental beliefs and practices that may conflict with their future autonomy. They require that parents refrain from making serious and final commitments on their children’s behalf, waiting “until the child grows to maturity and is legally capable of making them himself”.<sup>73</sup> An embodiment of these rights can be seen in the right of the state to act as *parens patriae* that has been used by the courts in cases such as in *Re O*<sup>74</sup>, *Re S*<sup>75</sup>, *Re R*<sup>76</sup>, *Re A*<sup>77</sup> and *An NHS Trust v SR*<sup>78</sup>. In such cases parental decisions to deny life-saving medical treatment for their offspring on the basis of religious/spiritual beliefs have been overruled on the grounds that such children were not yet capable of forming their own religious convictions and that their parents choices would ensure they would not live long enough to do so.

A less stark, and consequently more fitting, example for the case of selection for disability can be found in the case of *Wisconsin vs. Yoder*.<sup>79</sup> Here, members of an Amish community won the right to withdraw their children from school at the age of fourteen as opposed to the state requirement of sixteen. Their request was granted after they managed to persuade the court of two things: first, that sending their children to school past the age of fourteen was antithetical to their religion and could potentially destroy the Amish way of life as “higher learning tends to develop values they reject as influences that alienate man from God”,<sup>80</sup> and second, that as education’s value is assessed by its ability to prepare children for life:

[i]t is one thing to say that compulsory education for a year or two beyond the eighth grade may be necessary when its goal is the preparation of the child for life in modern society as the majority live, but it is quite another if the goal of education be viewed as the preparation of a child for life in the separated agrarian community that is the keystone of the Amish faith.<sup>81</sup>

While the courts found in favour of the Amish, they did so by begging the question “against anyone who suggests that some Amish children might freely and even wisely decide to enter the modern world if given the choice”.<sup>82</sup> Although Feinberg agreed with the ruling, noting that in the modern world the difference between eight and ten years of education is relatively trivial and likely to make little difference to the prospects of any particular individual<sup>83</sup>, others, also committed to the OFA, disagree. Davis, for example, argues that “if Wisconsin had good reasons for settling on high school graduation or age sixteen as the legal minimum to which children are entitled, then the Amish children were entitled to that minimum as well, despite their parents’ objections”.<sup>84</sup>

Davis proposes that as in *Wisconsin vs. Yoder*, those who deliberately seek to create disabled children impinge upon their child’s right to an open future. She suggests that such individuals wilfully narrow their child’s future range of options so considerably that “liberalism requires us to intervene to support that child’s future ability to make her own choices about

<sup>72</sup> J. Feinberg (1992), 'The Child's Right to an Open Future', in J. Feinberg (ed.), *Freedom and Fulfilment: Philosophical Essays*, Princeton: Princeton University Press, pp. 76-78.

<sup>73</sup> *ibid.*, p. 80.

<sup>74</sup> *Re O (A Minor) (Medical Treatment)* [1993] 2 F.L.R. 149.

<sup>75</sup> *Re S (A Minor) (Medical Treatment)* [1993] 1 F.L.R. 377.

<sup>76</sup> *Re R (A Minor) (Blood Transfusion)* [1993] 2 F.L.R. 757.

<sup>77</sup> *Re A (Children) (Conjoined Twins: Medical Treatment) (2)* [2001] 1 F.L.R. 267.

<sup>78</sup> *An NHS Trust v SR* [2013] 1 F.L.R. 1297

<sup>79</sup> *Wisconsin v. Yoder*, 406 U.S. 205 (1972)

<sup>80</sup> D. S. Davis, *op. cit.* note 66, p. 26.

<sup>81</sup> J. Feinberg, *op. cit.* note 72, p. 84.

<sup>82</sup> *ibid.*, p. 86.

<sup>83</sup> *ibid.*

<sup>84</sup> D. S. Davis, *op. cit.* note 66, p. 27.

which of the many diverse visions of life she wishes to embrace".<sup>85</sup> According to Davis' reading of the OFA, a liberal state is justified in prohibiting prospective parents from selecting for disability in their offspring as permitting it would allow prospective parents too much control over their offspring's futures.

Yet, while this reading of the OFA does sit well with the current legal status of selection for disability, questions do remain. How open, for example, must a child's future be and at what level of expected openness may a parent violate their child's right to an open future? No person can have a *truly* open future and in the process of helping their children fulfil their potential parents *will necessarily* close off certain future options to their children. A parent of a gifted child musician may, for example, forego ensuring she develop a complement of rounded talents to help her fulfil her dreams. Similarly, the child of a parent who places a great deal of import on a balanced education and fostering independence will never have the option of doing a great many things that involve intense and focused training from an early age. Those who subscribe to such an application of the OFA might feasibly reply to such an objection by stating that the parental decisions in the cases above are of insufficient gravity to invoke the OFA. Thus, such individuals would claim that parents should be free to shape their children's futures and limit certain opportunities in order to open the door to others, but that such freedoms are limited. Consequently, while parents should be free to spend or refrain from spending thousands of pounds on musical instruction, dance classes, and tennis coaching this does not mean they should be free to deny them their education, or, by the same token, a particular ability, such as hearing in the case of selection for deafness. This line of thought is understandable as it *is* the case with lives, just as it is with coats or shoes, that we are more likely to find one that fits when we are provided with a large number of choices<sup>86</sup>

We must, however, question whether Davis' application of the OFA to the pre-natal case is coherent. After all, one cannot harm someone by bringing them into existence when their life will, on balance, be one worth living. When looking to the OFA to determine whether a particular parental action is justified the answer is found by looking to its effects on that child's future. Amish parents may be criticised for a decision to remove their child from school at fourteen because that child, if she chooses to leave the Amish community, will be disadvantaged by that decision. She would have a legitimate complaint against her parents as they saw fit only to provide her with the education necessary to follow their chosen path for her. The case of selection against disability however, is different. A child who is deaf, for example, is likely to have a less open future than a hearing child, and may well be born at a disadvantage. However, unlike the Amish child she would not have a legitimate complaint as she could not be born hearing. Deafness is a condition of her existence and her right to an open future is one that may only exist within her genetic limitations.

This does not mean that her parents cannot be charged with violating her right to an open future by denying her opportunities to hear *after her birth by deliberately failing to provide her with hearing aids, adequate language therapy, or a cochlear implant*. In such circumstances their child *may* have a legitimate complaint, but this is an *altogether different issue* that although may influence parental decisions regarding selection for deafness may not be addressed fully here. Either way, it seems that by itself the OFA can offer no reason to avoid disability in our offspring but could possibly render the decision to select a child with a 'curable' disability self-defeating.<sup>87</sup>

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<sup>85</sup> D. S. Davis, *op. cit.* note 71, p. 11.

<sup>86</sup> J. S. Mill (1989), *On Liberty and Other Writings*, ed. S. Collini, Cambridge: Cambridge University Press, p. 67.

<sup>87</sup> This is couched in hypothetical terms for the debate concerning cochlear implants and open future arguments is far from straightforward. A deaf child with a cochlear implant or a hearing aid is still a deaf child with an experience of the world entirely distinct from a hearing child. For an insight into this lively debate see: D. S. Davis (1997a), 'Cochlear Implants and the Claims of Culture? A Response to



## V. HARM OR OFFENCE TO OTHERS?

During the Lords debates on the HFE Bill, Earl Howe attempted to define a serious disease or disability and thus of whether it should be prevented as something to be assessed, not from the point of view of the NHS or a prospective parent or indeed the interests of any other interested parties, but from “the point of view of the child when they are born”.<sup>88</sup> However, as explained in the previous section it cannot be shown that the practice of selection for disability causes harm to the interests, whether current or future of the child created.

As such, despite Earl Howe’s protestations it seems that a prohibition on such selection may be justified in accordance with liberal principles only by appeals to harms and offenses other than those already appealed to within existing legal and policy documents: those which selection for disability may impose on the interests of others than the child created. In this section the question of whether decisions to create impaired offspring might be said to cause unjustifiable harm or offense to others to such an extent that it constitutes reason enough for prohibition will be explored.<sup>89</sup>

### *V.II. Harm to Others: Resources and The Cost of Care.*

By far the most likely candidate for an attempt to justify a blanket prohibition on selection for disability by reference to the harms that such selection might impose on others is based upon the fact that in countries with advanced public healthcare and social welfare systems such as England and Wales, persons with disabilities tend to place a heavy burden on society’s shared resources. Thus, if, by prohibiting deliberate selection of disabling traits, we could lessen this burden and make available more and better resources to already extant persons who need them there seems good reason to implement such a prohibition.

The issue, however, is not so simple. For, while those with disabilities do tend to withdraw more from and contribute less towards the social pot than other ‘healthy’ members of society the reasons given for this differ greatly depending upon whether one views the disvalue of particular inabilities/disabilities to be inherent, or exherent, a product, not of biological limitation, but the structure of society. On the former view, it is understandable that a desirable way to combat the burdens of disability is to prevent the births of those who would be disabled. On the latter view however, disability is held to be socially constructed with many of the disadvantages normally associated with impairments attributed “not to the physical, cognitive, or emotional characteristics of individuals, but to the failure to account for everyone when designing physical, economic and social institutions”.<sup>90</sup> Thus, in choosing how to construct our societies we choose who will and will not be disabled. This point is well made as society *is* designed to cater for the majority of the populous and thus *does* place barriers to the participation of those who depart from societal norms.

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Lane and Grodin', *Kennedy Institute Of Ethics Journal*, 7 (3), pp. 253-8; and P. Kermit (2009), 'Cochlear Implants, Linguistic Rights and 'Open Future' Arguments. ', in K. Kristiansen and S. Vehmas (eds.), *Arguing About Disability*, London: Routledge, pp. 137-153.

<sup>88</sup> HL Deb, 21 January 2008, vol. 698, cols 24-25.

<sup>89</sup> It should be noted that within this section two additional potential claims to harm are not addressed. These include harms to parents themselves, and in cases where those who would select for disability in their offspring, harms to their existing children (and other dependents). Such arguments, however, are considered in some detail in my paper: N. J. Williams (2016), 'Harms to Others and The Selection Against Disability View', *The Journal of Medicine and Philosophy*, 42 (2), pp. 154-183.

<sup>90</sup> A. Asch (2003), 'Disability equality and prenatal testing: contradictory or compatible?' *Florida State University Law Review*, 30 (2), p. 319.

Those who subscribe to the latter view – often termed social or minority group views – suggest that in many cases what is needed is not a “cure” for the inabilities certain disabled persons have but instead a cure for the institutions allowing inabilities to be disabilities.<sup>91</sup> Those unable to walk – so the argument goes – need wheelchairs and wheelchair accessible buildings, those who are D/deaf require adaptations to the environment which make lack of hearing inconsequential in their daily lives and those who view those with inabilities to be incapable of work that is not ruled out by their inabilities need education. Such a definition of disability is thus tied to notions of social justice, to the idea that in a liberal, pluralist society, justice requires that we “arrange society so as to accommodate and facilitate a maximally plural range of views and ways of living”.<sup>92</sup>

Certainly, to alter the arrangements of society in this way would require increased spending of common resources, which seems to lend support to the argument that perhaps we should prevent the birth of the disabled to lessen the strain on our already stretched resources. Yet, as only a small percentage of disabled persons are born disabled and the majority become disabled later in life<sup>93</sup> it is questionable as to whether any money would actually be saved. One might therefore note that the money society spends on increasing access to disabled persons to healthcare and society would likely not be reduced unless we abandon our commitment to equality or choose “a campaign of eliminating disabled people in addition to preventing the births of those who would be disabled”.<sup>94</sup> Thus, while those with disabilities may have a claim to being harmed by the attitudes of non-disabled persons towards their inabilities and the structure of society it is unlikely that those who would be affected negatively by the decision to select for disability would have a justifiable claim to being harmed by such a choice.

### *V.III. Might Allowing Selection for Disability Cause Harm to Those with Disabilities?*

Another possible justification for a prohibition on selection for disability is based on the idea that to allow some individuals to select for disability in their offspring may result in an unwillingness on the part of non-disabled members of society to provide support to persons with disabilities for which certain couples have deliberately chosen in their offspring. Such a criticism focuses upon the relationships between different members of society, and commonly held intuitions regarding the limits of what justice may require of us both in an individual sense and within our social institutions. While justice may require that we compensate for inequalities of birth and natural endowments and that the better off make *some* sacrifices in order to elevate the position of the worst-off,<sup>95</sup> people are generally more willing to provide compensation to others for inequalities in terms of welfare, opportunity and resources when such inequalities are held to be the result of brute luck as opposed to considered choices. This can be seen easily when one considers the decision of the NHS Blood and Transplant Service to use pictures and videos of sick children, wholesome looking families and athletes in their attempts to get people to sign up to the organ donor register or to donate blood instead of images and videos of alcoholics requiring liver transplants and gang members with knife wounds.

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<sup>91</sup> See, for example: R. Amundson (1992), ‘Disability, Handicap and the Environment’ *Journal of Social Philosophy*, 23 (1), pp. 105-119 & A. Asch, *op. cit.* note 90, pp. 315-342.

<sup>92</sup> S. N. Glackin (2010), ‘Tolerance and illness: the politics of medical and psychiatric classification’, *Journal of Medicine and Philosophy*, 35 (4), p. 11.

<sup>93</sup> According to the 2015/16 Family Resources Survey, while there are over ten million disabled persons living in the UK, children with disabilities are likely to amount to around 7% of the total population and those over state pension age make up around 44% of the number. See: Department For Work and Pensions (2017), *Family Resources Survey*, London: Department for Work and Pensions, p. 1.

<sup>94</sup> A. Asch (1999), ‘Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy’, *American Journal of Public Health*, 89 (11), p. 1652.

<sup>95</sup> J. Rawls (1971), *A Theory of Justice*, Revised edn.; Cambridge MA: Harvard University Press, p. 86.

Sandel, for example, speaking of genetic testing in general, has suggested that the availability of such technologies has resulted in an “explosion of responsibility for our own fate and that of our children [that] may diminish our sense of solidarity with those less fortunate than ourselves”,<sup>96</sup> and that as a result of this we may feel less willing provide support for such persons. Taken at face value such an argument is faced with a patent flaw, noted by Kamm and Fox which is that “it makes no sense to hold a designer child morally responsible for the natural tendencies with which she is born, since it would be either her parents or reproductive physicians who chose or manipulated those characteristics prenatally, and she could not have done anything herself, before she was born, to have made her genetic characteristics come out any different”.<sup>97</sup> Yet to read the argument in this manner would lack charity and miss the subtlety of the claim, which is not that people would be *right* to be less willing to provide support, but that regardless of the rightness/wrongness of their attribution of responsibility, they would still be more inclined to do so.

Such a claim is evidenced in peoples’ willingness to take pride in their appearance despite the fact that they have played no more of a part in its creation than had their beauty been crafted by a plastic surgeon.<sup>98</sup> Politically, one can also see such sentiments in affirmative action and intergenerational reparations for historic injustices in which people are held to be “accountable for the wrongs of their ancestors or the groups to which they belonged”,<sup>99</sup> not just because they benefit from those wrongs, which is a valid reason for reparation, but because persons are representatives of family lines, generations can be tied together (although as time passes relations are viewed to become weaker) and as such their relation is viewed to be morally relevant. Yet, while such is the case, that persons seem to attribute responsibility for things beyond their control seems less to be an issue for philosophy or law and more of an issue for education, requiring concerted attempts to remove this fiction.

## VI. CONCLUSION

Within this paper the legal prohibition for selection for disability in England and Wales was examined and explored. The reasons provided in legal and policy documents for this prohibition were also outlined and subjected to philosophical scrutiny. Liberal approaches regarding the purposes, functions and limits of the law were explored and it was suggested after Feinberg that the criminal law should be concerned only with ‘legislative evils’, which were defined as reasonably foreseeable or preventable consequences of human beings’ actions or omissions. As such, in order for a liberal government to be justified in prohibiting the practice selection for disability it must be shown that the act in question will, or be liable to, cause harm or offence to others by deliberately and/or negligently and unjustifiably violating, setting back or thwarting their interests.

The reasons given within legal and policy documents for the prohibition were then outlined and it was noted that such reasons, where, indeed, they have been given, have focused on the idea that to allow selection for disability would cause harm to the child created. By reference to the non-identity problem it was shown that such arguments do not stand up to philosophical scrutiny. For, in cases where a child could not exist otherwise than with his disability he cannot be harmed by being born with a disability unless his life can be shown to be one that is less than one worth living. The question of whether a child’s future autonomy might be violated by

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<sup>96</sup> M. J. Sandel (2007), *The Case Against Perfection: ethics in the age of genetic engineering*, Cambridge MA: Belknap Press, p. 89.

<sup>97</sup> D. Fox (2007), ‘Silver spoons and golden genes: genetic engineering and the egalitarian ethos’, *American Journal of Law and Medicine*, 33 (4), p. 599

<sup>98</sup> R. Dworkin (2000), *Sovereign Virtue. The Theory and Practice of Equality*, Cambridge: Harvard University Press, p. 445.

<sup>99</sup> *ibid*, p. 603.

such selection was also examined and it was found that while convincing when applied to extant children such arguments lack coherence when applied to cases of pre-natal selection. It was thus suggested that within a liberal society only those reasons focussing on the harms and offences that such selection may cause to already extant persons are liable to offer good reason to prohibit selection for disability. Yet, while it was noted that those with disabilities do tend to command more societal resources than others it was shown, by appeals to social constructionist accounts of disability that although those with disabilities may have a claim to being harmed by the attitudes of non-disabled persons towards their inabilities and the structure of society it is unlikely that those who would be affected negatively by the decision to select for disability would have a justifiable claim to being harmed by such a choice.

It is thus suggested that within a liberal society no good reason can be found for the prohibition of selection for disability and that the insertion into English and Welsh Law of such legislation represents an unfortunate and misguided encroachment by the state into what should be seen as a matter of private morality. For, while many of us may question the wisdom of a desire to select for disability in one's offspring these very differences of opinion regarding what it is that constitutes the good life were what the liberal political order was designed to accommodate. However, while such is the case, whether or not those who seek to deliberately create disabled offspring should be helped to do so requires further debate as, indeed, does the question of whether the prohibition of selection for other purposes should be lifted or remain in place.

#### **ACKNOWLEDGMENTS:**

I wish to thank members of the Reproductive Donation team at Lancaster University and Kings College London, the Centre For Social Ethics and Policy at the University of Manchester, and the Wellcome Trust and the Arts and Humanities Research Council for their support, without which this article would never have been written.

Special thanks are also due to Stephen Wilkinson, Rebecca Bennett, Iain Brassington and Hazel Biggs, all of whom have read and provided detailed comments on previous versions of this paper, and to Natasha Hammond-Browning and Claire Lougarre who organized the event upon which this special issue is based.

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