The pre-conception welfare principle: a critical analysis

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ABSTRACT

This article explores the functioning of the pre-conception welfare principle (PCWP) which is located at the core of the framework regulating human assisted reproductive technologies (ARTs). First, it queries how the borders of child welfare have been defined by judge-made law in cases involving wrongful life or withholding/withdrawing treatment from severely sick children. Second, it conducts a chronological and comparative legislative assessment of the development of the regulation of child welfare in the context of the PCWP. It questions how the PCWP is applied in the regulation of ARTs and demonstrates the departure in practice from benchmark standards of objectivity, transparency and contextual-sensitivity that are identifiable in the judicial approach. This article concludes that the regulatory approach to assessing the PCWP is regressive. It is neither fair nor justified and hence, it should not be used.

ARTICLE HISTORY Received 23 June 2017; Accepted 16 August 2017

KEYWORDS Child welfare; human fertilisation and embryology; pre-conception welfare principle; regulation; pre-implantation genetic diagnosis; harm diagnosis

1. Introduction

The birth of Louise Brown in 1978 changed the landscape of reproductive medicine irrevocably. What was taken as an emergent area of medicine was ‘singled out as special, as a part of medicine of such particular social concern and significance that the state should have a direct stake in its evolution’.[[2]](#footnote-3) Almost four decades later, human assisted reproductive technologies and embryo research (ARTs) are subject to intense regulation in the United Kingdom (UK).[[3]](#footnote-4) The Human Fertilisation and Embryology Act 1990 (HFE Act 1990) was the first cornerstone in the legislative framework, regulating the creation, use and keeping of embryos or gametes outside of the human body. While some commentators have praised the legislation as standing the ‘test of time’,[[4]](#footnote-5) others have criticised its ‘paternalistic structure…as outdated’,[[5]](#footnote-6) and some have labelled it ‘a textbook example of regulatory disconnection’.[[6]](#footnote-7) In 2004, given emerging technologies and the rapid advances in the development of human embryology, legislative reform began. The HFE Act 1990 was amended in 2008 (HFE Act 2008),[[7]](#footnote-8) resulting in a consolidated Human Fertilisation and Embryology Act (as amended) (hereinafter the HFE Act).

The main purpose of this article is to explore the inclusion and application of one provision located at the core of the framework, the pre-conception welfare principle (PCWP). It provides Parliament and the regulator - the Human Fertilisation and Embryology Authority (HFEA) - with the scope to set out the boundaries for what are deemed to be acceptable ARTs, acceptable reproductive choices, and to gate-keep which individuals gain access to treatment.[[8]](#footnote-9) It is located at section 13(5) of the HFE Act and mandates that prior to offering licensed treatment a clinic must take into account the welfare of any child who may be born as a result and of any other child who may be affected. The considerations undertaken are theoretical, given that they relate to a future child born if treatment is successful, or to any extant child who could be affected by the birth of a future sibling. Thus, given that it occupies such a fundamental role in the framework with unparalleled regulatory strength, it is crucial to reflect on the development of the PCWP, examine its inclusion in the HFE Act 1990, and explore the basis on which it was retained in 2008, albeit in an amended form. Some commentators have already argued it is a haphazard and disingenuous sort of child protection,[[9]](#footnote-10) while others claim its application to the selection of embryos is problematic.[[10]](#footnote-11) Whichever the preferred analysis, given its impact on reproductive choice and the potential to impact on the regulation of innovation in science and human embryology, unpacking the function of the PCWP is crucial.

The first part of the article examines the judicial approach to child welfare appraisals in the healthcare context relating to existing children, focusing in particular on case law on wrongful life and that involving the withdrawal or withholding of life sustaining treatment from severely sick children. It will be demonstrated that the paradigmatic common law position on wrongful life and withdrawal of life prolonging treatment provides an equitable legal foundation for a child welfare appraisal which necessitates an exploration into the health and existence of a child in a state of ill-health. By examining aspects of leading judgments, a sense of judicial pragmatism emerges as regards the deconstruction of medical and genetic harm. This pragmatism is highlighted to acknowledge the evolution of judge-made law given the development of a contextual assessment of child welfare based on a balance sheet method and to then compare this to the regulatory framework governing the PCWP.

The second part of the article traces the legislative development of the PCWP, arguing that the law has departed from benchmark standards of objectivity, transparency and contextual-sensitivity which are identifiable components of the judicial approach to a welfare appraisal. In order to substantiate this argument, this critique separates the PCWP framework into two categories of harm-based regulation. One concerns the familial aspects of the PCWP, while the other concerns the medical aspects of the PCWP. The latter, it will be shown, is most directly relevant to the judicial approach to child welfare appraisals outlined in Part I involving considerations of medical harm. Part II will focus on the application of the PCWP in relation to the use of in vitro fertilisation (IVF) and pre-implantation genetic diagnosis (PGD), as these technologies can determine whether a child is born and in what state of health. PGD is considered an acceptable ART because it detects embryos affected by a genetic condition or abnormality and enables the selection of genetically healthy embryos for implantation. This creates a nexus between the PCWP and the provisions regulating PGD, in the HFE Act[[11]](#footnote-12) and the Code of Practice (CoP).[[12]](#footnote-13) This hybrid regulatory approach will be scrutinised in order to reveal the misconceptions and inconsistencies in the current PCWP framework. However, it is also relevant to the former familial aspects of the PCWP given the benchmark standards that are lacking when the PCWP is assessed in the context of access to ARTs.

This consideration of the regulatory approach to the PCWP in Part II is relevant for two reasons. First, an important analogy can be drawn regarding the use of the PCWP in the regulation of PGD and the judicial case law concerning a child’s best interests when the assessments both focus on the existence and non-existence of a child in a state of ill-health. Second, the overall comparison of the two approaches exemplifies the identified benchmark standards are lacking in the regulation of the PCWP. It will be argued that far from achieving conceptual clarity, the PCWP is a nebulous concept which should not be used to justify state intervention in ARTs. It is suggested that the PCWP should be abolished. Space does not permit a full exploration of an alternative model of regulation but - if there must be a preconception welfare test - it is suggested that the law must be transparent and display a stronger commitment to context.

## 2. The judicial approach to child welfare

The Children Act 1989 (CA 1989) is the primary Act that legislates for born children in England and Wales; it provides what is deemed to be the strongest form of a child welfare principle for an existing child in need of safeguarding.[[13]](#footnote-14) In child law, in effect, ‘children’s welfare trumps and outweighs all other considerations; no other interests or values may affect the decision; children’s interests are the only ones that count’.[[14]](#footnote-15) It mandates the court and any other party to proceedings to account for a list of statutory welfare factors when making enquiries to safeguard a child.[[15]](#footnote-16)

In the context of medical law, a judicial appraisal of child welfare for a born child is generally triggered when a conflict arises between parents and healthcare professionals. The first task is for the court to establish its jurisdiction in the case and thereafter, explore the challenges faced by the healthcare professionals in medical decision-making. On the face of it, the process of a welfare appraisal seems relatively uncontroversial. However, a review of precedent reveals that this is far from the case. Welfare appraisals conducted by judges who have been tasked to determine a claim for wrongful life, or determine whether life prolonging medical treatment for a severely sick child can be withdrawn, unveil the comparative conundrum of a child’s existence and non-existence within an assessment. To what extent the law intervenes in withholding or withdrawing life[[16]](#footnote-17) prolonging treatment in order to alleviate the burdens of severe illness demonstrates the fine ‘balance between the pain of prolonged life and the finality of death’ [[17]](#footnote-18) which the courts have resolved. These cases involve both establishing a concept of health and the construction of quantified legal harms as the appraisals question a child’s existence in a state of ill-health. Over time therefore, the concept of welfare has become an evolving product of judge-made law. The following two sections shed some light on the jurisprudence of a child’s best interests. First, in relation to wrongful life claims, it is clear that the judges believe that life is better than no life and life is, to that extent, in a child’s best interests. Second, in cases involving the withholding or withdrawing of life-sustaining treatment, we see the development of a judicial approach that is responsive to context, objective and transparent.

## *Wrongful life*

In the seminal case of *McKay v Essex Area Health Authority*[[18]](#footnote-19) in 1982the plaintiff child, Mary McKay, claimed her actionable injury was life itself. During pregnancy her mother had wrongly been informed that she had not been infected with rubella. As result of the negligent misdiagnosis she had not been advised of the consequences of the infection in relation to the foetus nor had she been given the option of a termination, which she claimed she would have accepted. Mary was born severely disabled as a consequence of the infection. The Court of Appeal dismissed her claim for wrongful life. It held that no action lay where the thrust of the claim was that but for a defendant’s negligence the child would never have been born. Of particular significance, Stephenson LJ remarked, ‘If a court had to decide whether it were better to enter into life maimed or halt than not to enter it at all, it would, I think, be bound to say it was better in all cases of mental and physical disability, except possibly those extreme cases’.[[19]](#footnote-20) While observing a lack of evidence on the extent of suffering experienced, Stephenson LJ stated it ‘[c]ould not be suggested that the quality of her life is such that she is certainly better dead*,* or would herself wish that she had not been born or should now die’.[[20]](#footnote-21) Ackner LJ took this further by considering the theoretical application of the Congenital Disabilities (Civil Liability) Act 1976 (CD Act 1976)[[21]](#footnote-22) – which came into force a year after Mary McKay was born – and stated there was no comparison to make, in law, between existence and non-existence:

Her complaint is that she was allowed to be born at all, given the existence of her pre-natal injuries. How then are her damages to be assessed? Not by awarding compensation for her pain, suffering and loss of amenities attributable to the disabilities, since these were already in existence before the doctor was consulted. She cannot say that, but for his negligence, she would have been born without her disabilities. What the doctor is blamed for is causing or *permitting* her to be born at all. Thus the compensation must be based on a comparison between the value of non-existence (the doctor’s alleged negligence having deprived her of this) and the value of her existence in a disabled state. But how can a court begin to evaluate non-existence, ‘the undiscovered country from whose bourn no traveller returns?’ No comparison is possible and therefore no damage can be established which a court should recognise.[[22]](#footnote-23)

The effect of the judgment not only barred any claim for wrongful life where a child is harmed in utero before birth[[23]](#footnote-24) but, crucially, the Court of Appeal ruled it impossible to quantify a level of damages representative of the difference between a disabled child’s existence versus her non-existence.[[24]](#footnote-25) In deeming ‘…Life – whether experienced with or without major physical handicap is more precious than non-life’,[[25]](#footnote-26) the court pronounced a life with defects can never be an injury cognisable at law for three distinct reasons. First, that it would undermine the sanctity of human life in a public policy capacity if a doctor owed a duty of care to a child to ensure she did not exist. Second, if such actions did succeed then doctors may be burdened with a duty to encourage or persuade women to terminate life *in utero.*[[26]](#footnote-27) Third, that life, however disabled, had to be better than no life.

For more than thirty years since *McKay* the common law position on wrongful life remains intact. Rosamund Scott[[27]](#footnote-28) criticises the anomalous legal position created by the ruling, claiming it is inequitable, because of a child’s inability to claim wrongful life when conceived naturally when disability is erroneously not detected, in contrast to a child’s ability to claim damages as a result of negligent embryo selection by PGD.[[28]](#footnote-29) But despite the anomaly, there is a clear and identifiable logic in the judicial rejection of life as a quantifiable damage. First, it opposed a negative endorsement of a harmed or disabled life being considered as damaging, wrongful, unworthwhile or a life not worth living.[[29]](#footnote-30) Second, it was a positive premise for devising law and public policy surrounding the value of life. Arguably, then, the approach in *McKay*, highlighting that life is more precious than non-life, raises questions about the coherence of the PCWP to the extent that the latter presupposes that non-life might be the better option.

* 1. ***Withholding treatment***

Cases that are concerned with providing, withholding or withdrawing of life sustaining treatment from an existing seriously ill or severely disabled child reveal an alternative judicial approach towards adjudicating contextual issues on child welfare including an analysis of harm. The case law demonstrates the many dimensions of judicial analysis of child welfare when quality of life decisions surrounding medical treatment in this context are considered. If a child is living in a harmed state because of a medical or genetic condition then sometimes a very difficult question arises as to whether she should continue to live in that harmed state or whether treatment should be withdrawn. By invoking a normative concept of harm - a life perhaps ‘not worth living’ - judges deal with the possibility and legality of withholding or withdrawing life sustaining treatment from a severely ill child, inevitably resulting in death. The welfare considerations which influence an answer to the question of withdrawing treatment are revealed in the contextually-sensitive judicial reasoning. The approach is factual and evidence based, and requires where possible that equal weight be given to the wishes, beliefs and feelings of the parents involved. It demands a collection of multi-agency medical evidence,[[30]](#footnote-31) collating and dissecting it during the proceedings to enable well-reasoned and informed decision-making in every case. The approach is to construct a ‘balance sheet’, weighing the respective benefits and burdens of sustaining treatment or not.[[31]](#footnote-32) It requires balancing the competing interests where there is pain and suffering, against the prospect of withdrawing treatment and ending life to end the suffering.[[32]](#footnote-33) Thus, in practice, the common law’s paradigmatic position on child welfare is a product of its own objective judicial reasoning.

In *McKay*, Stephenson LJ cited[[33]](#footnote-34) the 1981 case of *Re B (A Minor) (Wardship: Medical Treatment),*[[34]](#footnote-35) in which the Court of Appeal was asked to determine whether a child born with Down’s syndrome (a genetic condition which can be detected by PGD) who was suffering with an intestinal obstruction should undergo invasive surgery or not. The parents refused to authorise the surgery on religious grounds. Without the surgery the baby would die. By balancing the burdens of his condition set against any experience of pleasure in existing, the procedure was judged to be in the child’s ‘best interests’ and the court gave consent to the surgery. More recent case law demonstrates that the court remains reluctant to deem a child’s life to be a ‘pitiful existence’.[[35]](#footnote-36) In order to justify a decision to stop treatment, on what is framed as a best interest’s analysis,[[36]](#footnote-37) the court conducts an exhaustive consideration of all available evidence, medical and otherwise. Thorpe LJ in *Re A*[[37]](#footnote-38) set out a pragmatic approach to a welfare appraisal in a case concerning the sterilization of a male who lacked capacity in the following way:

[t]here can be no doubt in my mind that the evaluation of best interests is akin to a welfare appraisal.…Pending the enactment of a checklist or other statutory direction it seems to me that the first instance judge with the responsibility to make an evaluation of the best interests of a claimant lacking capacity should draw up a balance sheet. The first entry should be of any factor or factors of actual benefit… Then on the other sheet the judge should write any counterbalancing dis-benefits to the applicant. An obvious instance in this case would be the apprehension, the risk and discomfort inherent in the operation. Then the judge should enter on each sheet the potential gains and losses in each instance making some estimate of the extent of the possibility that the gain or loss might accrue. At the end of that exercise the judge should be better placed to strike a balance between the sum of the certain and possible gains against the sum of certain and possible losses. Obviously, only if the account is in relatively significant credit will the judge conclude that the application is likely to advance the best interests of the claimant.[[38]](#footnote-39)

Ward LJ in *Re A (Minors) (Conjoined Twins: Separation)*[[39]](#footnote-40) considered that ‘every life has an equal inherent value. Life is worthwhile in itself whatever the diminution in one’s capacity to enjoy it’.[[40]](#footnote-41) In addition, the court made clear that while parents have parental responsibility to give consent to undergo treatment, overriding control is vested in the court to exercise objective and independent judgement in a child’s best interests.[[41]](#footnote-42) In *Portsmouth NHS Trust v Wyatt and another*[[42]](#footnote-43) the conflict concerned whether a baby born prematurely at 26 weeks should be ventilated or not if she succumbed to infection. Wall LJ set out ‘intellectual milestones’[[43]](#footnote-44) for judges to consider in cases where medical treatment is identified as required, but has been refused. While advocating for paramountcy of child welfare the Court of Appeal held that the best interests of a child in the context of withholding medical treatment were not to be determined by a strongly subjective test of whether the child’s life would be intolerable if treated. It held that although there is a strong presumption in favour of a course of action which will prolong life, the presumption is also not irrebuttable[[44]](#footnote-45) and the child’s best interests should be broadly interpreted including balancing medical, emotional and other welfare factors.[[45]](#footnote-46) These intellectual milestones were then elaborated upon in *An NHS Trust v MB (A Child) (represented by CAFCASS as Guardian ad Litem)* [[46]](#footnote-47)when Holman J stated that, if a dispute arose between the treating doctors and parents, and the parties asked the court to make a decision, then it is the role and duty of the court to exercise its own independent and objective judgment. He described the best interests test in the widest sense – although he conceded it is impossible to weigh mathematically – to include every kind of consideration capable of impacting on the decision, non-exhaustively including medical, emotional, sensory and even instinctive considerations.[[47]](#footnote-48)

The law has also confirmed that continued life in a state of ill-health is sometimes judged not to be in the interests of a born child according to the balancing exercise. In *Kings College Hospital NHS Foundation Trust v Y and MH[[48]](#footnote-49)* MacDonald J rebutted the ‘strong presumption in favour of a course of action that will prolong life, a strong presumption that flows from the recognition and acknowledgement of the sanctity of life’[[49]](#footnote-50) given the ‘very considerable and weighty factors on the other side of the welfare balance sheet’.[[50]](#footnote-51) In his reasoning he applied a perspective on welfare by carefully recounting the medical evidence, particularly noting the stark neurological deterioration of Y,[[51]](#footnote-52) which allowed him to depart from the dominant rule at law that errs toward the prolongation of life. In this case, given the risk of Y being kept in a permanent vegetative state, MacDonald J determined that re-intubation and intensive ventilation could not be said to be in the patient’s best interests.[[52]](#footnote-53) Importantly, the judgment signalled that the legality of withholding treatment is contingent on the highest degree of analysis of the evidence and welfare considerations. It demonstrates that the contemporary judicial approach is contextually sensitive. Moreover, it reinforces the need for a transparent method of welfare determination. Given that such cases are inherently complex and demand interpretation of the evidence, information and opinion from multiple disciplines, the parents or interested parties, in a mixed objective and individualistic sense, the law is able to conclude that continued existence in a harmed state is not congruent with the welfare of a child.

The highly publicised case of *Great Ormond Street Hospital v Yates and Gard*[[53]](#footnote-54)goes further still, demonstrating that judicial standards of objectivity, contextual sensitivity and transparency can extend beyond the conventional balance sheet approach when alternative therapeutic treatments are an option to explore. Charlie Gard was born in August 2016 and suffered from a rare inherited mitochondrial disease,[[54]](#footnote-55) he had severe progressive muscle weakness and could not move his arms or legs or breathe unaided. In February 2017 the NHS Foundation Trust for Great Ormond Street Hospital for Children (GOSH) issued an application to the High Court seeking a declaration that it was lawful and in Charlie’s best interests for artificial ventilation to be withdrawn and that he receive only palliative care. A second declaration sought was for Charlie not to undergo alternative deoxynucleoside therapy in America—Charlie’s parents wished to take him to America to receive this treatment in the hope of ameliorating the disease. In the High Court, Francis J stated that ‘although the parents have parental responsibility, overriding control is by law vested in the court exercising its independent and objective judgement in the child’s best interests’.[[55]](#footnote-56) The intellectual milestones from *Wyatt v. Portsmouth NHS Trust*[[56]](#footnote-57) were recounted and over three days Francis J heard evidence from the healthcare professionals treating Charlie, further evidence given by four other UK doctors from whom the hospital sought a second opinion and evidence from a fifth doctor instructed by the parents. In evidence, it was suggested that alternative therapy would not only be futile but might well cause pain, thus prolonging suffering and increasing distress to Charlie.[[57]](#footnote-58) Following an astute analysis of the medical evidence Francis J granted the applications brought by GOSH.

The parent’s appealed the decision on five grounds, two of which will be briefly outlined for the purposes of this discussion.[[58]](#footnote-59) For ground one, they sought to distinguish two types of cases concerning medical treatment of severely sick children. They argued their case was distinct from the norm given there was a viable alternative treatment option available. The central issue was whether the parents’ preferred treatment option would be likely to cause ‘significant harm’[[59]](#footnote-60) to Charlie and it arose from the judgment of Baker J in *Re King*[[60]](#footnote-61) (which focused on a disagreement between the parents and healthcare professionals treating Ashya King - a five year old boy suffering from a serious form of brain cancer – as to the type of radiotherapy to be administered).[[61]](#footnote-62) Charlie’s parents relied on Article 8 of the European Convention on Human Rights (the Convention) to suggest that in the absence of significant harm their parental rights had been interfered with unjustifiably. McFarlane LJ reflected - as per *Re King* – that the court may not ‘interfere with a decision by parents in the exercise of their parental rights and responsibilities with regard to their child’s medical treatment, save where there is a risk the parents’ proposed course of action may cause significant harm’.[[62]](#footnote-63) In essence, before the Court of Appeal it was argued that ‘absent a finding that a course of action preferred by the parents would be likely to cause their child significant harm, it was neither necessary nor proportionate for the state to override the parents legitimate choice of treatment’.[[63]](#footnote-64) For ground two, the parents asserted that Francis J had erred in relying on a best interests test alone and not conducting an assessment according to the conventional balance sheet approach. But, after a proclaimed ‘100 percent, child focused, court-led evaluation’[[64]](#footnote-65) the Court of Appeal unanimously dismissed the parents’ appeal.

At the very outset, McFarlane LJ disagreed with the alleged failure of Francis J to correctly attribute weight by not drawing a balance sheet. He declared it was not a conventional balance sheet case given ‘that all of the evidence, including the opinion of the parents, led to the sad conclusion that it would be in his best interests now to withdraw treatment’.[[65]](#footnote-66) Given the absence of any benefit from the alternative therapeutic treatment, whose prospects of success were said to be ‘effectively zero’,[[66]](#footnote-67) a balance sheet was rendered unarguable.[[67]](#footnote-68) In addition, McFarlane LJ determined that the creation of a new category of case going beyond the category of significant harm outlined in *Re King* was neither necessary nor appropriate in Charlie’s case.[[68]](#footnote-69) The court concluded that the factual basis for the submissions was undermined and the question of a distinction between cases did not arise. Nevertheless, it stated:

It must follow from that unanimous professional and expert evidence that to move Charlie to America and expose him to treatment over there would be likely to expose him to continued pain, suffering and distress.[[69]](#footnote-70)

Thus, the incontrovertible consequence was that travelling to America to try alternative therapy was not found to be in Charlie’s best interests.

The Supreme Court similarly declined to grant permission to appeal on the basis that no arguable point of law had been identified.[[70]](#footnote-71) Lady Hale addressed the issue of an assessment of best interests given that Charlie’s parents argued it was not the right legal test to undertake. The parents claimed ‘that parents and parents alone are the judges of their child’s best interests’.[[71]](#footnote-72) Lady Hale stated it was not arguable that the UK courts lacked jurisdiction to make a ruling and make a determination by conducting a best interests evaluation. She reiterated that a child’s rights must be the paramount consideration and that the domestic law of the UK accorded with Articles 2 and 8 of the Convention.[[72]](#footnote-73) Before the European Court of Human Rights (ECtHR) Charlie’s parents argued an unjustifiable infringement of Article 2 (right to life), Article 5 (right to liberty and security) Article 6 (right to a fair trial) and Article 8 (right to respect for private and family life), on the basis that blocking access to alternative treatment deprived Charlie of his liberty and furthermore, the domestic court decisions amounted to an unfair and disproportionate interference in their parental rights. By a majority the ECtHR endorsed the domestic approach, declaring the application inadmissible. It stated:

[E]xamining the decisions taken by the domestic courts…the Court recalls that they were meticulous and thorough, ensured that all those concerned were represented throughout; heard extensive and high quality expert-evidence; accorded weight to all the arguments raised; and were reviewed at three levels of jurisdiction with clear and extensive reasoning giving relevant and sufficient support for their conclusions at all three levels.[[73]](#footnote-74)

Recounting the process of a welfare appraisal in such complex cases is of relevance here for two reasons. The first, which is legally straightforward, reflects the conceptualisations of a majority culture about the limited circumstances in which the law is permitted to make such fundamental decisions involving existence. Only in extreme cases and with extreme caution can the state involve itself in such matters. The second involves the role of the parents and their power to make decisions about their child’s life-affecting medical treatment, because the judgments signal something interesting regarding residual paternalism in a welfare assessment. Dependent upon the parents withdrawal of consent to treat or request for treatment to continue, judges often uphold the contrary view according to the evidence from healthcare professionals. Judicial deference to medical evidence and opinion often conflicts with the more emotive submissions made by parents regarding familial aspects of a child’s welfare, their bond with the child and their parental urge to do what they feel is best. The important part of the process, however, is either the balance sheet analysis or a methodical examination of the evidence when a balancing exercise cannot be undertaken given the facts (as in the case of Charlie Gard above). The overarching purpose is to ensure the appraisals are unique and uncircumscribed. The judicial exercise demonstrably balances welfare considerations by taking into account multiple perspectives. There is no judgment or assertion that the child should never have existed in the state of ill-health and no clear definitive line between a right and wrong decision on a child’s continued existence in a state of ill-health. Overall, the judicial approach demonstrates that the role of the law is to collate the evidence, to be independent, avoid presupposition and provide transparent child focused decision-making in welfare appraisals. Most importantly, the role is not premised in any notion of bias and despite the outcome sometimes being contrary to the parents’ wishes, the sanctity of human life is preserved, including those lives that start out medically harmed.

1. **The legislative development of the pre-conception welfare principle**

In this part of this article the legislative development of the PCWP will be traced in five sections. First, the focus is on the initial inclusion of the PCWP in the legislation and its growth as a key regulatory principle in the ART setting. This leads onto a discussion of, secondly, the House of Commons Science and Technology Select Committee’s recommendations (during the process of reforming the legislation); then, thirdly, the HFEA’s pubic consultation at much the same time; and, fourthly, the restatement of the PCWP in the HFE Act 2008. Finally, the overarching approach conducted by the HFEA in regulating the PCWP is critically examined.

* 1. ***The Warnock Report and the HFE Act 1990***

The development of the current framework regulating ARTs traces back to the publication of the Warnock Report (the Warnock Report).[[74]](#footnote-75) In 1982, under Dame Mary Warnock, a Committee of Inquiry debated a range of moral, legal and ethical issues in the field of infertility and made recommendations on a model of regulation for fertility treatments and embryo research. Although, at that time, PGD was not available to use, it is clear – and will be shown – that despite the connection of key issues surrounding welfare, both the Committee and Parliament were uninfluenced by the judicial approach to child welfare appraisals when the legislation was crafted. Miola described it as ‘the defining report of its decade’.[[75]](#footnote-76) Given its gradualist approach to regulation it has underpinned both HFE Acts, resulting in the consolidated HFE Act.[[76]](#footnote-77) Yet despite the Committee’s commitment to covering a range of fundamental ethical topics, the need for a PCWP is not explicitly mentioned within the 103 pages. Instead, focus was placed on ‘the primacy of the interests of the child and on *upholding family values*’.[[77]](#footnote-78)

The PCWP was also not included within the 1987 White Paper preceding the HFE Act 1990.[[78]](#footnote-79) It was only by virtue of debate in the House of Lords during the committee stage of the HFE Bill on whether treatment should be provided to lesbians or unmarried couples that the need to include a welfare principle was raised.[[79]](#footnote-80) Emily Jackson, a staunch opponent of the principle, observed that its inclusion was ‘neither challenged nor defended…it was simply assumed to be self-evidently true that their future children’s welfare ought to be taken into account before a couple is offered assistance with conception’.[[80]](#footnote-81) This view is perhaps exemplified by Lord Clyde’s later claim that the inclusion of such a principle in the legislation resulted in his mind being ‘substantially set at rest’.[[81]](#footnote-82) When the HFE Act 1990 came into force it devoted little space to the PCWP, occupying only subsection 13(5):

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 (including the need of that child for a father), and of any other child who may be affected by the birth.

Importantly, during the 1990 debates the inclusion of the PCWP within the legislation was unconnected to the health of future children. PGD was not a reproductive technology available in clinics at that time. The Warnock Report described the use of embryo biopsy to detect genetic conditions as ‘potentially useful’[[82]](#footnote-83) but it was not anticipated that PGD would become a feasible method of detecting abnormal embryos for some considerable time. For that reason the HFE Act 1990 did not include provisions for embryo testing. This means that the PCWP was not inspired by a concept of health or prevention of medical harm, and it was not included with the benevolent motivations one might assume. Its central welfare focus was dissimilar to the aspects divulged in *McKay*, *Re B* and *Wyatt,* where health and medical harm connected to welfare considerations were scrutinised. Actually, the PCWP was included for two reasons. First, it alleviated Parliamentary fears of the unknown in ARTs that even Dr. Robert Edwards (who successfully pioneered IVF with Dr. Patrick Steptoe) had declared were ‘based on the pessimistic assumption that the worst will happen’.[[83]](#footnote-84) Second, it was aimed at restricting who may gain access to ARTs in accordance with the Warnock nuclear family model.

Given the lack of debate in the House of Lords surrounding the necessity of the PCWP’s inclusion during the early legislative stages, the principle lacked an ethical underpinning. But by being drafted in broad terms it did create an assurance for their Lordships that the potential capabilities of ARTs would not go beyond the preferred parameters of what had been deemed acceptable by the Warnock Committee. It also simultaneously created the impression that an important socio-ethical principle had been included in the legislation with child safeguarding objectives. This then entails a further assumption that its inclusion was consequent to thorough consideration and careful drafting. In reality however, its centrality in the law was to assert control over individuals’ reproductive autonomy, and restrict innovation, rather than promote and resolve a welfare concern for an un-conceived child.

Notwithstanding the bias supporting its inclusion and the lack of a definition in the statute, the status of the PCWP has developed with judicial scrutiny and academic commentary. In *Evans v Amicus Healthcare Ltd,[[84]](#footnote-85)* a case in which the court determined the fate of stored embryos created by a couple who had since separated, Wall J confirmed that upon a combined reading of the HFE Act 1990 and the CoP,[[85]](#footnote-86) the principle was considered to be ‘a twin pillar of the Act’[[86]](#footnote-87), alongside consent to treatment. Further still, he claimed it had become one ‘of the most important principles’[[87]](#footnote-88) underlying the legislation. Likewise, it established strength in its application before the Grand Chamber of the ECtHR in case law concerning serving prisoners’ access to artificial insemination (AI). In *Dickson and Another v United Kingdom* the court accepted that child welfare considerations were legitimate considerations to undertake in circumstances which involved a non-serving prisoner, who would be 51 years of age when her partner would be eligible for release from prison, requested to receive AI.[[88]](#footnote-89)

Interestingly, when focus shifts towards treatment of post-menopausal women, the PCWP is also located at the forefront of socio-ethical critique by attracting debate over a woman’s reproductive responsibility.[[89]](#footnote-90) The fact that there is debate over whether or not post-menopausal women should gain access to ARTs reveals an important feature about what the PCWP demands and its widespread social impact. When the reproductive freedoms and broader implications of becoming an older parent are balanced against the welfare of a theoretical child, there emerges a form of social conscience to the PCWP.[[90]](#footnote-91) Those who object to the treatment of older women often rely on a welfare argument, suggesting that older women with deteriorating health and mobility who seek treatment are reproductively irresponsible - despite the high variables in age, mobility, parental ability and the social acceptance of grandparents raising children. It is also argued that child welfare would be diminished not only by parental limitations but also the likelihood of the child experiencing the death of her mother at a younger than average age.[[91]](#footnote-92) But the use of a welfare argument in this context gives little regard to the fact that older men retain biological ability to naturally reproduce and are less likely to be scrutinised for fathering a child at an older age than their female equivalents. In addition, a child conceived naturally by parents of any age could encounter limitations in their childhood owing to a multitude of external factors, such as parental death, illness or disability, or substandard parenting. The possibilities are infinite. Perhaps the irony lost in this aspect of the debate is that the menopause itself no longer signals the end of a woman’s ability to gestate,[[92]](#footnote-93) yet the welfare of a theoretical child can do.

The crucial point here is this, as the capabilities of human fertilisation and embryology developed the PCWP acquired a powerful, probative and confusing regulatory value. While on the one hand, the laws regulating ARTs are said to engage Article 8 rights to a private and family life,[[93]](#footnote-94) on the other hand, access to treatment is not available on request and can be denied on the basis of a failed PCWP assessment.[[94]](#footnote-95) From the outset the PCWP affected the determination of parentage and it remains the case that theoretical considerations can preclude an individuals’ ability to embark on their private reproductive path.

The original wording of the PCWP also attracted opposition. A body of legal literature examines the principle’s ‘unashamedly discriminatory’[[95]](#footnote-96) nature towards unmarried, single women and gay couples, due to the prerequisite need for a father.[[96]](#footnote-97) Following the relaxation of social attitudes towards ‘unconventional’ families, and given the advances in science and embryology, it was no surprise that in 2004 the UK government announced it would review the HFE Act 1990.[[97]](#footnote-98) By doing so it demonstrated it was responsive to the proposition that regulation was no longer ‘up-to-date in light of changing social and familial norms’.[[98]](#footnote-99) The PCWP was central to the debates on the parenting provision given the preoccupation with parental eligibility.[[99]](#footnote-100) Subsequently, two individual processes began to explore the function of the PCWP and debated child welfare issues during 2004 and 2005. First in June 2004, the House of Commons Science and Technology Select Committee (HCSTC)[[100]](#footnote-101) conducted a review of the 1990 Act, reporting in March 2005. This was followed by the HFEA consultation during the same period specifically on the PCWP, entitled ‘Tomorrow’s Children’, reporting January 2005.[[101]](#footnote-102)

## *The House of Commons Science and Technology Select Committee Inquiry into Human Reproductive Technologies and the Law*

A large proportion of the Committee’s criticism levied toward the HFE Act 1990 centred on the welfare of the child provisions and the then proposed abolition of donor anonymity, both of which later received the government’s continued support in terms of retention and abolition respectively. The basis of the Committee’s recommendation for the abolition of the PCWP in its then form was as follows:

The welfare of the child provision discriminates against the infertile and some sections of society, is impossible to implement and is of questionable practical value in protecting the interests of children born as a result of assisted reproduction. We recognise that there will be difficult cases but these should be resolved by recourse to local clinical ethics committees. The welfare of the child provision has enabled the HFEA and clinics to make judgements that are more properly made by patients in consultation with their doctor. It should be abolished in its current form. The minimum threshold principle should apply but should specify that this threshold should be the risk of unpreventable and significant harm. Doctors should minimise the risks to any child conceived from treatment within the constraints of available knowledge but this should be encouraged through the promotion of good medical practice not legislation.[[102]](#footnote-103)

This approach to reframing the PCWP reveals the same pragmatism and situated assessment adopted in the judicial approach to welfare appraisals in the previous discussion. The proposed ‘minimum threshold principle’ specifies the risk of unpreventable and significant harm, which if used would simultaneously empower the individuals receiving treatment and the healthcare practitioners treating them to engage in dialogue surrounding decision-making and relevant welfare concerns. In addition, by acknowledging that a scenario could arise in which child welfare risks were present - in difficult cases - the Committee recommended the engagement of existing agencies to protect children from harm, akin to the duties enforced in existing child law.[[103]](#footnote-104) According to the Committee, ‘if there is reason to believe that children born as a result of assisted reproduction are at an increased risk then healthcare professionals can alert social services at an early stage’.[[104]](#footnote-105) While the Committee’s advocated solution to deregulating the PCWP was pragmatic and realistic, it was not adopted. The government responded to the recommendation by stating that: ‘[a]ttempting to frame these matters in national legislation and guidance which pays due regard to both individual circumstances and the need for objectivity and fairness is extremely difficult’.[[105]](#footnote-106) Aside from the modest amendment to the parenthood terminology, there was no attempt to contextually reframe the PCWP, despite the countervailing public interest in transparent regulation of reproductive rights.

## *HFEA Review: Tomorrow’s Children*

In January 2005 the HFEA commenced a public consultation on the PCWP. Its sole focus was the PCWP*,* highlighting the inconsistency in which clinics approached the welfare assessment given the unsatisfactory state of regulation. The HFEA declared it was ‘not within the powers of the HFEA to amend the welfare section in the HFE Act’[[106]](#footnote-107) and carefully made clear that the consultation was not intended to solicit suggestions on how the legislation might be amended,[[107]](#footnote-108) but instead set out a range of different approaches to account for a future child’s welfare.[[108]](#footnote-109) First, the approach adopted could be ‘the maximum welfare principle’, which, specifically influenced by child law and adoption proceedings, places the child’s welfare as paramount and above all other concerns. This approach places significant responsibility on clinics to ensure any ‘child born has a good chance of a living a happy and fulfilled life and is not disadvantaged in any foreseeable way…places the burden of proof upon the prospective parents to demonstrate their competence’.[[109]](#footnote-110) Second, the ‘reasonable welfare approach’, noted to reflect a position of compromise between the welfare of a future child and prospective parents’ reproductive liberty. It states that the provision of ARTs is acceptable when the child born will have a reasonably happy life. This option would require clinics providing treatment services to satisfy themselves that any child born would have ‘at least an adequate future, cared for by a “good enough” family. The reasonable welfare principle takes a relatively thorough approach to the welfare of the child, whilst also attaching some importance to the autonomy of the prospective parents.’[[110]](#footnote-111) Or third, ‘the minimum threshold principle’ - which was chosen by the HCSTC in its review - placed greater importance upon parental autonomy and reproductive liberty rather than a future child’s welfare save for cases of ‘high risk of serious harm’.[[111]](#footnote-112) Its declared emphasis was to protect children from serious harm and suggested ‘[D]octors should withhold treatment, thereby preventing a child from coming into existence, only where the quality of the child’s life would fall below a minimum threshold of acceptability.’[[112]](#footnote-113) In addition, the document proposed the possibility of the organisation of welfare linked risk factors into three main groups: medical, physical, and psychological and social harm.[[113]](#footnote-114)

Despite what appears to be a genuine attempt, from a practical perspective, to offer some clarification on an ill-defined area of regulation, the consultation failed to deliver on how best to regulate the PCWP and question the underlying value of making this assessment in a pre-conception context. In practical terms, nothing was gained from the review that was not already known or suspected concerning the unsatisfactory regulatory framework at the clinical level. Even in respect of the ‘reasonable threshold’, representing the compromise position, it conceded the difficulty in determining ‘exactly what this approach might mean in practice’.[[114]](#footnote-115) In addition, neither of the thresholds was ever implemented. What it did do successfully, however, was to demonstrate that the HFEA were suggesting an air of regulatory discontent but that it would not get heavily embroiled in a contentious aspect of regulation. Whether its lack of philosophical direction ‘was actually ever part of its brief’ [[115]](#footnote-116) is a valid point in the HFEA’s defence but, by not committing to any of the three approaches, the consultation begs the question of how much influence the HFEA has on public policy, and the regulation and determination of the PCWP located at the core of framework. By adopting the non-committal approach the HFEA was certain to avoid any controversy that would have flowed should it have agreed with the HCSTC recommendation of abolition or recommend the lesser ‘reasonable welfare’ threshold. Instead, it focussed on a risk based model of regulation, providing threshold criteria with a strong emphasis on medical conditions that might affect a child born and a narrow determination of welfare.

Moreover, the review is disappointing because of how conservative and superficial it was. It lacks a commitment to contextualise any socio-medical ethics underpinning the PCWP. It fails to address what the principle is regulating, and why it is necessary. It also fails to address why, and how, child welfare is theoretically assessed. By not committing to an approach the HFEA simply kept in tune with the UK government and Parliament and avoided clarifying what components support or negate the PCWP’s position in regulation. A question which could have been addressed was what, if any, practical value the PCWP holds. By failing to conduct a comprehensive review which offered critical conclusions or recommendations, it could be argued that perhaps the HFEA is ill-equipped to regulate such a thorny issue. This is troubling given that the PCWP is a central tenet to much debate on the provision of ARTs. If the HFEA deliberately adopted an avoidant approach in order to prevent legislative disharmony with Parliament then it has failed to conduct its principal responsibility as the sector’s regulator.[[116]](#footnote-117)

Following the review, the HFEA introduced key changes to the seventh edition of its CoP by removing some vague and subjective questions from the child welfare assessment of the medical and social history of prospective parents.[[117]](#footnote-118) The deletions from the sixth edition included the ability to provide a stable environment[[118]](#footnote-119) and provide for the needs of a child,[[119]](#footnote-120) the risk of harm to children including multiple births[[120]](#footnote-121) and asking the GP if s/he knows of any reason why patient(s) might not be suitable for treatment.[[121]](#footnote-122) The changes also removed obtaining the patients’ consent to make enquiries of their GPs and consent to approach ‘any individuals, agencies or authorities for such further information as the centre deems to be required’.[[122]](#footnote-123) The statutory responsibility for conducting the assessments remained with the clinics, although the multidisciplinary assessment noted in the sixth edition of the CoP as the expectation of centres to ‘take into account views from the staff who have had involvement with the prospective parents’[[123]](#footnote-124) was also removed. The HFEA claimed such changes would allow for an improved system while being keenly focused ‘on the risk factors that could lead to serious harm…whilst still protecting children’s interests’.[[124]](#footnote-125)

## *The HFE Act 2008 amendment*

After four years of a reform process the HFE Act 2008 received royal assent.[[125]](#footnote-126) In part, its enactment introduced important changes in respect of same sex or single parent families’ ability to access ARTs. The amendment of the preferred family form was a welcome change and the capacity for reproductive choice was extended to accommodate the unconventional family.[[126]](#footnote-127) In effect, the PCWP side stepped the pro-family ideology advanced by the Warnock Committee and their Lordships that treatment services should be provided only ‘for the married, mortgaged and middle-classes’.[[127]](#footnote-128) In practical terms, the amendment to section 13(5) replaced *‘the need of that child for a father’* from the original wording for *‘including the need of that child for supportive parenting’.*[[128]](#footnote-129) Subsequent to the amendment the HFEA revised its CoP in 2009 to include a definition of supportive parenting, thus extending the dynamics of regulated parenthood.

As regards the functional transparency of the PCWP no improvement is recognisable in the legislation. Given that eight hours (within a total of eighty) were spent in Parliament discussing the welfare of the child clause that is perhaps quite surprising.[[129]](#footnote-130) The HFE Act still does not contain a definition of preconception welfare and there are no legislative ‘intellectual milestones’ on which to base an approach to a welfare appraisal. There is no statutory guidance similar to that attached to the paramountcy principle in child law despite its own contextual success in practice. This means, on a practical level, that the margins of interpretation of the PCWP are as wide as they are long. It indicates that regulatory flexibility is more important than conceptualising a central provision in the framework. This supports the view that the regulatory framework has two distinct roles, one in practice and one on paper. On paper, the PCWP takes centre stage in the statute and has a universal effect on the supply of ARTs in the UK. In practice, its engagement and application fundamentally affects who gains access to treatment and their permitted reproductive choices within that process. The responsibility of providing regulation falls to the HFEA, it regulates the PCWP according to its CoP and how this translates in practice at the clinic level will now be discussed.

## *The HFEA approach to regulating the pre-conception welfare principle*

Since its inception in 1991 the HFEA has regulated fertility clinics providing licensed fertility treatment services.[[130]](#footnote-131) Within successive editions of its CoP the HFEA has regulated the PCWP according to the assessment it devises internally.[[131]](#footnote-132) In practical terms then, it offers the only available insight into the approach for determining pre-conception welfare. In the absence of the ‘factors to take into account during the assessment process’[[132]](#footnote-133) contained in the CoP, the interpretation of the statutory PCWP would have to be founded purely on individualistic application by clinicians. Among the eight available editions of the CoP, a concentration on and evolution of risk-based and harm-based regulation is also identifiable. In particular, the emphasis and use of a harm threshold in the assessment criteria has developed in the CoP regulating both the PCWP[[133]](#footnote-134) and the restrictions on embryo testing.[[134]](#footnote-135)

The CoP reinforces the statutory wording of the PCWP and states that no treatment services regulated by the HFEA may be provided unless account has been taken of the welfare of any child and any other child who may be affected by the birth.[[135]](#footnote-136) Centres should have documented procedures to ‘assess each patient and their partner (if they have one) to decide whether there is a risk of significant harm or neglect to any child’.[[136]](#footnote-137) The current guidance states centres should take a medical and social history from each patient and their partner (if applicable)[[137]](#footnote-138) with reference to the factors contained at 8.10 of the CoP:

These factors include any aspects of:

a) past or current circumstances that may lead to any child mentioned above experiencing serious physical or psychological harm or neglect, for example:

i) previous convictions relating to harming children

ii) child protection measures taken regarding existing children, or

iii) violence or serious discord in the family environment

b) past or current circumstances that are likely to lead to an inability to care throughout childhood  for any child who may be born, or that are already seriously impairing the care of any existing child of the family, for example:

i) mental or physical conditions

ii) drug or alcohol abuse

iii) medical history, where the medical history indicates that any child who may be born is likely to suffer from a serious medical condition, or

iv) circumstances that the centre considers likely to cause serious harm to any child mentioned above.

This broad harm-based framework separates risks to welfare into two categories: those related to familial harm between 8.10(a)(i) – (iii) and (b)(i)-(ii) and those related to medical or genetic harm between 8.10(b)(iii) – (iv). At first blush this approach provides two main benefits. First, that the framework is non-prescriptive given that it allows for wide margins of interpretation. Second, the PCWP is broadly permissive.[[138]](#footnote-139) But these are both false benefits. The presumption to treat individuals is rebuttable provided any of the criteria in the assessment are engaged. And in practical terms the regulatory model is ill-suited for resolving a theoretical concern over welfare given that the determination of the familial harm criteria is largely intuitive, individualistic and grounded in notions of bias. In addition, the assessment perpetuates a significant person-affecting role that clinic staff undertake when deciding who gains access to treatment.

Isabel Karpin has argued that a ‘regulatory system based on assessments of risk and benefit to future possible children at the preconception stage has the potential to lead to narrow and discriminatory assessments of health and create burdens on those who are least able to meet them’.[[139]](#footnote-140) Writing in 1998 Julie Tizzard observed the staff conducting the assessments are forced to make value judgements which are patently not just medical ones.[[140]](#footnote-141) Almost two decades later and the approach is unimproved. On the contrary, it denotes a new method of regulated paternalism in ARTs which derives solely from the statutory PCWP. Notably, the approach is inconsistent with the world of natural conception given that fertile individuals do not undergo a preconception assessment.[[141]](#footnote-142) Take for an example, a single woman who discovers she is pregnant after spending one night with a stranger and chooses to embrace motherhood alone. She is not subjected to external scrutiny regarding her capabilities in raising a child. Yet a single woman deliberately planning to become a parent via gamete donation is subjected to an examination of her suitability as a parent and even her ‘wider family and social networks’ could be scrutinised.[[142]](#footnote-143) While the practical assessment displays key influences from the paramountcy principle in the CA 1989 framework – which is responsive to risk and places the welfare of the born child before any other parties[[143]](#footnote-144) - the factors contained between 8.10 (a) (i) – (iii) and (b) (i)-(ii) are symbolically important. They erroneously validate an idealised family environment and represent the preconditions of the ‘ideal parents’ who evade the criteria set out by the HFEA.

Subjectivity - as opposed to objectivity - is a key feature of this potentially prejudicial assessment of individuals seeking treatment. This raises a legitimate concern of inconsistent application of the criteria if the staff conducting the assessment interpret the principle by apportioning different weight to the risk factors or grounding their assessment in intuition. It relies on the speculation of risk to theoretical children in the same terms that child protection laws measure and respond to actual risk to existing children. But it fails to explicitly distinguish the key difference between the preconceived and born child, and it fails to accord the weight to be attached to the risk factors. Regulating the PCWP in this way is disproportionately unbalanced against the individuals seeking access to treatment. Given that there is no empirical evidence available to suggest that individuals seeking access to ARTs present more of a risk to future children than those who conceive naturally, this aspect of the assessment inadvertently facilitates discrimination.

The disclosure or presence of mental or physical conditions,[[144]](#footnote-145) or drug or alcohol problems,[[145]](#footnote-146) is also problematic given the scope for bias. An individual’s honest disclosure of depression, perhaps previous post-natal depression, or a prior drug or alcohol addiction, can impact on her (and her partner’s) ability to access treatment services.[[146]](#footnote-147) But the risk factors simply serve to mandate a further assessment and prediction of parental competence. They are akin to the factors contained in the CA 1989 assessment which determine welfare by inspecting the environment a born child is living in and judging the capabilities of the people responsible for the child’s care.[[147]](#footnote-148) The crucial difference between the two welfare appraisals is that the PCWP assessment takes place preconception, when the assessed harm does not require legal remedy because it has not occurred and is, at its highest, a speculative risk. In that sense, the law is anticipatory, in that it preemptively judges the risks to welfare. But in reality such prenatal risks exist in every case of natural conception. In the unfortunate circumstances when familial harm or the significant risk of harm to a child is identified, the law is reactionary. Consequently, it negates the need for a familial welfare assessment which does not meet the standards of objectivity required for better regulation.

Perhaps most striking, and what exemplifies the risk of discrimination, are the risk factors included between 8.10 a (i)-(iii) signifying future harm based on past events. This includes the disclosure of previous convictions which could significantly impact the welfare assessment.[[148]](#footnote-149) Public attitudes towards criminal offending are highly variable and public perceptions of crimes, sentencing and punitive sanctions can differ according to the facts of each case, the individuals involved, the media coverage and political regimes in power.[[149]](#footnote-150) In determining child welfare by reference to previous convictions the HFEA targets individuals seeking treatment. Because it ignores that a criminal antecedent history does not automatically negate an individual’s ability as a potential parent; this reveals the discriminatory undertone of the PCWP.

The question then arises as to the grounds on which patients are being refused access to treatment. How effective and forceful is the regulation of the PCWP in practice? A report entitled *Assessing Child Welfare under the Human Fertilisation and Embryology Act: The New Law*[[150]](#footnote-151) revealed that while the number of presenting risky parents remained low, clinic staff reported confusion in resolving difficult cases and expressed concerns regarding their role in the process of assessing the PCWP.[[151]](#footnote-152) The report contains examples of ‘hard cases’, for example, one clinic’s refusal to treat a couple as the male partner had a spent conviction for a violent crime (not committed against a child) recorded against him.[[152]](#footnote-153) The refusal was justified on the grounds that no formal psychiatric diagnosis had been established during the criminal proceedings. This then lead to the assumption that a child’s welfare could be jeopardised given the male’s background.[[153]](#footnote-154) The gravity of that refusal should not be underestimated. It shows the heavy hand of state intervention in real terms, resulting in the complete removal of the male’s reproductive freedom to genetically father a child with his partner. Consider for a moment the stark contrast to the Grand Chamber’s decision in *Dickson and Another v UK,* when the incarcerated male and his partner gained access to AI after successfully challenging a refusal based on their Article 8 right to private and family life.[[154]](#footnote-155) This hard case illustrates the harsh reality of the PCWP assessment. The law does not mandate that a defendant in criminal proceedings should undergo a psychiatric assessment following a violent conviction. Moreover, the law would not prevent contact between a parent and a child if a father had previously been violent to the child’s mother. Thus, the refusal to treat the male in this example based on welfare grounds is misleading. In truth, the refusal was likely grounded on a discriminatory attitude towards ex-offenders and an inability to recognise a process of social rehabilitation. The example demonstrates an ingrained social bias surrounding criminal antecedents and an explicit failure in the current regulatory model to conduct familial welfare appraisals transparently and fairly.

The section of the welfare assessment contained in 8.10 (b) (iii)-(iv) denotes the genetic harm threshold within the PCWP. It connects the principle to the express provisions regulating PGD in the amended HFE Act. This includes activities that may be licensed under Schedule 2 Paragraph 1ZA of the HFE Act for ‘establishing whether the embryo has a gene, chromosome or mitochondrial abnormality that may affected its capacity to result in a live birth’ and section 13(9) which specifically states:

(9) 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) 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.

This statutory provision – which validates the policy on embryo testing promulgated by the HFEA prior to the HFE Act 2008 - regulates the scope for reproductive choice by imposing restrictions on preference selection between embryos affected and unaffected by genetic conditions. This creates a nexus between the PCWP and section 13(9). But the limited detail contained in the CoP welfare assessment at 8.10(b) (iii)-(iv) is as far as the genetic harm threshold is explored within the ambit of PCWP. Additional guidance is provided in the CoP specifically for embryo testing and sex selection which then links to broader welfare considerations connected to genetic health.[[155]](#footnote-156)

First, the guidance recites the statutory framework for embryo testing, interpreting the mandatory requirements as ‘a particular risk that the embryo to be tested may have a genetic, mitochondrial or chromosomal abnormality, and the Authority is satisfied that a person with the abnormality will have or develop a serious disability, illness or medical condition’.[[156]](#footnote-157) It specifies that PGD should be considered only where there is a significant risk of a serious genetic condition being present in an embryo.[[157]](#footnote-158) In addition, the seriousness should be discussed between the individuals and the recommended multidisciplinary team including ‘reproductive specialists, embryologists, clinical geneticists, genetic counsellors, cytogeneticists and molecular geneticists’.[[158]](#footnote-159) It continues at 10.9 stating:

The centre should consider the following factors when deciding if PGD is appropriate in particular cases:

(a) the views of the people seeking treatment in relation to the condition to be avoided, including their previous reproductive experience

(b) the likely degree of suffering associated with the condition;

(c) the availability of effective therapy, now and in the future;

(d) the speed of degeneration in progressive disorders;

(e) the extent of any intellectual impairment;

(f) the social support available; and

(g) the family circumstances of the people seeking treatment.

This includes providing information for those seeking PGD on the condition being tested for,[[159]](#footnote-160) the likely impact of the condition on those affected and the family,[[160]](#footnote-161) information about treatment and social support[[161]](#footnote-162) and testimony of people living with the condition.[[162]](#footnote-163) On its face, the factors are broad welfare considerations. It is self-evident that the PCWP is utilised in the HFE Act and the CoP to justify using PGD and the restrictions on embryo selection because both are premised on genetic harm prevention. The regulatory message is clear: avoid genetic harm and you maximise child welfare. But the guidance is flawed. It does not provide a protocol for conducting a welfare assessment of genetic harm, because the HFEA has already determined the outcome according to its own harm threshold assessment. It does so via its centralised list of approved genetic conditions which have been deemed serious enough to warrant genetic testing.[[163]](#footnote-164) There are currently over three hundred and fifty genetic conditions contained on the HFEA authorised list. Further still, the restriction on embryo selection set out in section 13(9) limits the scope for a contested welfare appraisal. Given that section 13(9) imposes a direct restriction on preferential embryo selection, the factors contained in the guidance have been included in disingenuous terms as, in reality, they would rarely would be considered. A reader of the guidance would be right to assume that these factors are routinely considered in each case. But in practice, these factors only serve to substantiate that assumption of a routine welfare assessment of genetic harm when in reality, they are redundant and provide a false impression of a contextually-sensitive and objective assessment. Thus, the factors to consider in the CoP at 10.9 above have no practical impact as long as an unaffected genetically healthy embryo is available for selection. Reproductive choice is not a feature in this regulatory framework unless there are no un-affected embryos to select from.[[164]](#footnote-165) Likewise, the multi-disciplinary team noted at 10.6 will have little effect on the process of embryo selection given the statutory restriction on preference. Only when embryos affected by genetic conditions are available for selection and implantation does an assessment of welfare affected by genetic harm come into play. And even in those circumstances the unpleasant hierarchical regulatory method – which hinges on almost ranking the available embryos according to the genetic data retrieved - is far from contextually-sensitive.

When one reconsiders the judicial approach to analogous welfare appraisals discussed in the first part of this article – primarily the approach conducted by Thorpe LJ in *Re A* and his pragmatic balance sheet,[[165]](#footnote-166) as well as the intellectual milestones outlined in both *Wyatt* and *An NHS Trust v MB (A Child)*[[166]](#footnote-167), and the full exploration of alternative therapeutic treatment in the case of *Great Ormond Street Hospital v Yates and Gard[[167]](#footnote-168)* - the current regulatory provisions for PGD fall far below the benchmark standards of transparent, objective and just regulation. The ethico-legal dilemma of adjudicating between a harmed existence versus no existence highlights the significant departure in practice from the expected standards of transparent and fair regulation. It can be argued, therefore, that the PCWP has evolved into an exploitable regulatory device, it has manifested into a form of regulatory control over individuals receiving treatment which does not acknowledge the hallmarks of a democratic society. It is a regressive regulatory approach which is neither fair nor justified and hence, it should not be used.

1. **Conclusion**

Controversial as such a suggestion may sound; my argument is first that the PCWP does not meet the requisite standards expected of a contemporary model regulating ARTs in the UK. Standards of objectivity, transparency and contextual-sensitivity are prerequisites in the regulation of such a powerful statutory provision. Regrettably, Parliament foreclosed the possibility of the PCWP ever being regulated in a way that balances the competing interests of a future child and the individuals seeking treatment because of one clear failure. It never explored what the principle would demand in practice. Parliament’s avoidant approach resulted in a narrow understanding of the principle at the regulatory level and thus, a misunderstanding of how best to regulate it in practice. Thus, the target of my critique is not only the erroneous interpretation and application of the law, but also the law itself.

The judicially created, and child-focused, balance sheet approach to conducting child welfare appraisals for severely sick children was examined in Part I of this article. The extent of judicial energy spent determining the issue of welfare, and all that it entails, demonstrates how contentious and difficult conceptualising child welfare is in practice. Tracing the judicial development of the substantive idea of child welfare also emphasises the need for objectivity and a strong commitment to context within a welfare assessment. My examination of the judicial approach to welfare appraisals served as a meaningful comparator of these benchmark standards. By illustrating a consistency in judicial logic, combined with the reliance on judge-made intellectual milestones and the need for a contextual view of the evidence demanded by the balance sheet approach, this article argues that the judicial approach to welfare appraisals is an equitable method.

Part II of the article examined the development of the PCWP and highlights its departure in practice from the benchmark standards of judicial regulation. The tensions in the normative framework regulating the PCWP were explored via the familial and genetic harm thresholds. The engagement of the PCWP and the familial harm assessment enforces a pro-family ideology that perpetuates legislative supremacy over individuals who wish to become parents. In simple terms, it is an extended version of regulated parenthood. The harsh reality of this regulatory approach is the invisible psycho-social hurdle it imposes in front of individuals to overcome before they gain access to treatment. Far from an objective and contextual assessment, the engagement of the PCWP’s familial harm assessment necessitates that individuals persuade the powers that be, that in spite of this arbitrary criteria positing their perceived flaws, they deserve to receive treatment.

To highlight my concerns about the problematic application of the PCWP and its connection to genetic harm, this article focused on the guidance provided in the CoP on embryo testing and selection. The core concern is that there is no scope for a pragmatic exploration of medical evidence, equivalent to that conducted in judicial law-making, which would allow for a reasoned welfare assessment prior to embryo selection. Individuals undergoing PGD are not awarded with the power of decision-making according to the current criteria. Given the departure from the same benchmark standards in the judicial approach, the overall view of this framework is quite troubling. An analysis of the regulatory framework governing the PCWP, genetic harm threshold and PGD presents quite a different picture. In complex cases involving the detection of serious genetic harm, a transparent, contextual and reciprocal doctor-patient appraisal of pre-selection welfare could be a valid regulatory replacement. This model would balance the reproductive choices of individuals, whilst relying on expert medical advice and an ethical judgement from the healthcare professionals to refuse to grant treatment in exceptional cases.[[168]](#footnote-169)

Overall, this analysis demands an important check on the power of the over-zealous state and calls for abolition of the current PCWP. It is essential that the law adopts a more objective and contextual approach to assessing theoretical harms to future children who may be born as a result of ARTs. Much more needs to be done by Parliament and the HFEA to justify the restrictions and impositions on reproductive choice, and there is much to be learned from the way that judges approach questions concerning child welfare.

1. \* Liverpool Law School [↑](#footnote-ref-2)
2. Margaret Brazier, ‘Regulating the Reproduction Business?’ (1999) *Medical Law Review* 166. [↑](#footnote-ref-3)
3. Litigation has brought about legislative change in terms of the Human Reproductive Cloning Act 2001, the Human Fertilisation and Embryology (Deceased Fathers) Act 2003, the Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004, and the Human Fertilisation and Embryology (Quality and Safety for Human Application) Regulations 2007. [↑](#footnote-ref-4)
4. Emily Jackson, ‘The Human Fertilisation and Embryology Bill’, *Expert Review of Obstetrics & Gynecology,* 3: 429. [↑](#footnote-ref-5)
5. Margaret Brazier and Emma Cave, *Medicine, Patients and the Law* (Penguin 4th edition, 2007) 316. [↑](#footnote-ref-6)
6. Roger Brownsword. *Rights, Regulation and the Technological Revolution* (Oxford University Press, 2008) 297. [↑](#footnote-ref-7)
7. Human Fertilisation and Embryology Act 2008. [↑](#footnote-ref-8)
8. David Gurnham and Jose Miola, ‘Reproduction, Rights, and the Welfare Interests of Children: The Times Aren’t a Changin’ (2012) 23 *King’s Law Journal* 29; Sally Sheldon and Stephen Wilkinson, ‘Selecting Saviour Siblings’ (2004) 12 *Medical Law Review* 137; Tom Campbell and Laura Cabrera., ‘The weak moral basis for strong PGD regulation’ in Sheila McLean and Sarah Elliston (eds), *Regulating Pre-Implantation Genetic Diagnosis. A Comparative and Theoretical Analysis* (Routledge: 2013), 17; Emily Jackson ‘Conception and the Irrelevance of the Welfare Principle’ (2002) 65 *Modern Law Review*176. [↑](#footnote-ref-9)
9. Jackson (n 7). [↑](#footnote-ref-10)
10. Sarah Elliston, ‘The welfare of the child principle and the use of PGD: selecting for disability’ in Sheila McLean and Sarah Elliston (eds) *Regulating Pre-Implantation Genetic Diagnosis. A Comparative and Theoretical Analysis* (Routledge: 2013) 89, 123. [↑](#footnote-ref-11)
11. HFE Act s.13 (9) and (10). [↑](#footnote-ref-12)
12. CoP, 8th edition, 2009. [↑](#footnote-ref-13)
13. No single piece of legislation covers child protection in the UK. In accordance with the inherent jurisdiction of the Court the best interests of the child is the prime concern. The best interests of the child is also the primary consideration in decisions taken affecting a child in accordance with Article 3 of the United Nations Convention on the Rights of the Child (The UK signed the convention in April 1990, ratified it December 1991 and it came into force January 1992). [↑](#footnote-ref-14)
14. Helen Reece, ‘The Paramountcy Principle: Consensus or Construct?’ (1996) 49 *Current Legal Problems* 267. [↑](#footnote-ref-15)
15. Section 1(1) of the legislation states that when a court determines any question with respect to the upbringing of a child or the administration of a child’s property the child’s welfare shall be the court’s paramount consideration. [↑](#footnote-ref-16)
16. *Re C (A Minor)(Wardship: Medical Treatment)* [1989] 2 All ER 782, CA; *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 930, CA; *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 All ER 906, CA. [↑](#footnote-ref-17)
17. Margaret Brazier and Emma Cave, *Medicine, Patients and the Law*, 6th edition (Manchester University Press, 2016) 443. [↑](#footnote-ref-18)
18. [1982] QB 1166 CA. [↑](#footnote-ref-19)
19. Ibid, 1182. [↑](#footnote-ref-20)
20. Ibid, 1180. [↑](#footnote-ref-21)
21. The Congenital Disabilities (Civil Liability) Act 1976 section 1 (1) states: ‘If a child is born disabled as the result of such an occurrence before its birth as is mentioned in subsection (2) below, and a person (other than the child’s own mother) is under this section answerable to the child in respect of the occurrence, the child’s disabilities are to be regarded as damage resulting from the wrongful act of that person and actionable accordingly at the suit of the child’. Such disabilities are considered ‘damage’ as a result of the actions of the third party. [↑](#footnote-ref-22)
22. Ibid, (n 17) 1189. [↑](#footnote-ref-23)
23. In England if a child is injured before birth by a defendant whose conduct caused the child’s disability then there is an action and claim for compensation in wrongful disability. [↑](#footnote-ref-24)
24. Ibid, (n17) 782, 787, 790. [↑](#footnote-ref-25)
25. Ibid, 771, 782. [↑](#footnote-ref-26)
26. Ibid, 797. [↑](#footnote-ref-27)
27. Rosamund Scott, ‘Reconsidering “Wrongful Life” in England after Thirty Years: Legislative Mistakes and Unjustifiable Anomalies’ (2013) 72 *Cambridge Law Journal* 115. [↑](#footnote-ref-28)
28. When the HFE Act 1990 was enacted CD 1976 section 1 was extended by s. 1A to cover infertility treatments where (a)a child carried by a woman as the result of the placing in her of an embryo or of sperm and eggs or her artificial insemination is born disabled, (b)the disability results from an act or omission in the course of the selection, or the keeping or use outside the body, of the embryo carried by her or of the gametes used to bring about the creation of the embryo, and (c) a person is under this section answerable to the child in respect of the act or omission, the child’s disabilities are to be regarded as damage resulting from the wrongful act of that person and actionable accordingly at the suit of the child. [↑](#footnote-ref-29)
29. Jonathon Glover, *Choosing Children: Genes, Disability and Design* (Oxford, 2006), 60; Julian Savulescu, ‘Is there a right not to be born? Reproductive decision-making, Options and the Right to Information’ (2002) 28 *Journal of Medical Ethics*, 65. [↑](#footnote-ref-30)
30. Courts will obtain information from the Children and Family Court Advisory and Support Service (Cafcass) in each case. In addition to Local Authority intervention and referral to the Royal College of Pediatrics and Child Health, *Making Decisions to Limit Treatment in Life-limiting and Life Threatening Conditions in Children: A framework for Practice*, (March 2015) (RCPCH, 2015). [↑](#footnote-ref-31)
31. *Re MB* [1997] 2 F.L.R. 426, 439. [↑](#footnote-ref-32)
32. *Re C (A Minor) (Wardship: Medical Treatment)* [1989] 2 All ER 782, CA; *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 930, CA; *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 All ER 906, CA; See, Tony Sheldon, ‘Court Awards Damages to Disabled Child for Having Been Born’ (2003) 326 *British Medical Journal*, 784. [↑](#footnote-ref-33)
33. *McKay* (n 17), 1166. [↑](#footnote-ref-34)
34. [1981] 1 WLR 1421. [↑](#footnote-ref-35)
35. *Re K (A Child) (Withdrawal of Treatment)* [2006] EWHC 1007 (Fam)*,* 57. [↑](#footnote-ref-36)
36. Ibid, [44-47]; *Re L (A Minor)* [2005] 1 FLR 491 [12-13] (Dame Butler Sloss); Re J (A Minor) (Wardship: Medical Treatment) [1991] Fam 33, 47 (Lord Donaldson). [↑](#footnote-ref-37)
37. [2000] 1FLR 449. [↑](#footnote-ref-38)
38. Ibid, 560. [↑](#footnote-ref-39)
39. [2000] 4 All ER 961 CA. [↑](#footnote-ref-40)
40. Ibid, 1002. Their Lordships relied on the doctrine of necessity to justify the separation of the twins - leading to the inevitable loss of Mary’s life – the analysis of evidence and welfare factors contributed to the decision that a deliberate act was a justified one despite the grave and fatal consequences. The judicial reasoning in this case has been criticised. See, John Harris, ‘Human beings, persons and conjoined twins: an ethical analysis of the judgement in Re A’ (2001) 9 *Medical Law Review* 221. [↑](#footnote-ref-41)
41. *Re A (Children) (Conjoined Twins: Surgical Separation)* [2000] 2 WLR 480. [↑](#footnote-ref-42)
42. [2005] EWCA Civ 1181. [↑](#footnote-ref-43)
43. Ibid, 90-91. [↑](#footnote-ref-44)
44. This wording was expressed by Lord Donaldson in *Re J (A minor) (Wardship: medical treatment)* [1991] Fam 33, para 46. The Court has since conceded the sanctity of human life is not absolute; see *Airedale N.H.S. Trust v Bland* [1993] A.C.789, on withdrawal of artificial nutrition and hydration from a patient in a persistent vegetative state. [↑](#footnote-ref-45)
45. *Portsmouth NHS Trust* (n 41), 87. [↑](#footnote-ref-46)
46. [2006] 2 FLR 319. [↑](#footnote-ref-47)
47. Ibid, 88 – 105. [↑](#footnote-ref-48)
48. [2015] EWHC 1966 (Fam). [↑](#footnote-ref-49)
49. Ibid, 35. [↑](#footnote-ref-50)
50. Ibid, 48. [↑](#footnote-ref-51)
51. Ibid, 50 – 57. [↑](#footnote-ref-52)
52. Ibid, 55. [↑](#footnote-ref-53)
53. *Constance Yates, Christopher Gard v Great Ormond Street Hospital for Children NHS Foundation Trust, Charles Gard (A Child, by his Guardian)* [2017] EWCA Civ 410. [↑](#footnote-ref-54)
54. Infantile onset encephalomyopathy mitochondrial DNA depletion syndrome (MDDS). [↑](#footnote-ref-55)
55. *Constance Yates, Christopher Gard v Great Ormond Street Hospital for Children NHS Foundation Trust, Charles Gard (A Child, By his Guardian)* [2017] EWHC 972 (Fam), 11. [↑](#footnote-ref-56)
56. [2005] EWCA Civ 1181, 90-91. [↑](#footnote-ref-57)
57. [2017] EWHC 972 (Fam), 49 and 83. [↑](#footnote-ref-58)
58. Grounds 1, 2 and 4 (asserting significant harm, no jurisdiction and a breach of Articles 2, 5 and 8 of the European Convention on Human Rights) were granted permission to appeal. Grounds 3 and 5 (asserting a judicial error on the conventional best interest’s evaluation and procedural unfairness on the parents and their legal team surrounding disclosure of documents) were refused permission to appeal. [↑](#footnote-ref-59)
59. Significant harm is the key element within the threshold criteria in the CA 1989 s.31 (providing any local authority with the power to intervene in the ordinary care of a child). Significant risk of serious harm is one of the elements contained in the threshold criteria regulating PGD in the HFE Act 1990 (as amended) s. 13 (9) and the PCWP assessment in the CoP 8th edn, 2009. [↑](#footnote-ref-60)
60. *Portsmouth City Council v Naghmeh King, Brett King, Southampton Hospital Trust, Ashya King (by his children's guardian, John Mellor)* [2014] EWHC 2964 (Fam). This case involved a choice between two types of radiotherapy to treat a child’s brain tumour. The parents disagreed with the treatment plan proposed by the hospital and removed the child so that he could be treated in Spain. [↑](#footnote-ref-61)
61. Ibid, 5. [↑](#footnote-ref-62)
62. [2017] EWCA Civ 410, 54. [↑](#footnote-ref-63)
63. Ibid, 82. [↑](#footnote-ref-64)
64. Ibid, 118. [↑](#footnote-ref-65)
65. Ibid, 48. [↑](#footnote-ref-66)
66. Ibid, 113. [↑](#footnote-ref-67)
67. Ibid, 47-48. [↑](#footnote-ref-68)
68. Ibid, 113. [↑](#footnote-ref-69)
69. Ibid, 114. [↑](#footnote-ref-70)
70. Permission to appeal hearing in the matter of Charlie Gard, 8 June 2017; <https://www.supremecourt.uk/news/permission-to-appeal-hearing-in-the-matter-of-charlie-gard.html> (Accessed online 10.07.17). Judgement of the UK Supreme Court in the case of Charlie Gard, 19 June 2017; <https://www.supremecourt.uk/cases/docs/charlie-gard-190617.pdf> (Accessed online 13.07.17). [↑](#footnote-ref-71)
71. Ibid, 8 June 2017. [↑](#footnote-ref-72)
72. Ibid. [↑](#footnote-ref-73)
73. *Gard and Others v. The United Kingdom* (Application No 39793/17) ECHR (2017), 124. [↑](#footnote-ref-74)
74. Report of the Committee of Inquiry into Human Fertilisation and Embryology (HMSO; London, 1984). [↑](#footnote-ref-75)
75. Jose Miola, *Medical Ethics and Medical Law. A symbiotic relationship* (Hart Publishing, 2007) 187. [↑](#footnote-ref-76)
76. Gulam Bahadur, ‘Parliamentary proposals for liberal approaches to assisted conception’ (2005) 11 *Reproductive Biomedicine Online*, 177, 178. (accessed [www.rbmonline/Article/1884](http://www.rbmonline/Article/1884) on 21.01.15). [↑](#footnote-ref-77)
77. Warnock Report (n 73) para 3 (my emphasis). [↑](#footnote-ref-78)
78. White Paper, *Human Fertilisation and Embryology: A Framework for Legislation*, 1987, Cm259. [↑](#footnote-ref-79)
79. Lords Hansard, 07 December 1989 (Lady Saltoun), Col 1090; (1990) 06 Feb, Col 787. [↑](#footnote-ref-80)
80. Jackson (n 7), 177. [↑](#footnote-ref-81)
81. Lords Hansard, 5 December 1996 (Lord Clyde) Col 812. [↑](#footnote-ref-82)
82. Warnock Report (n 73), 12.13. [↑](#footnote-ref-83)
83. Robert Edwards and Patrick Steptoe, *A Matter of Life: The sensational story of the world’s first test-tube baby*, (Hutchinson & Co, 1980) 107. [↑](#footnote-ref-84)
84. [2003] EWHC 2161 (Fam). [↑](#footnote-ref-85)
85. CoP 6th edn, 2003. [↑](#footnote-ref-86)
86. *Evans* (n 83), 23. [↑](#footnote-ref-87)
87. Ibid, 37. [↑](#footnote-ref-88)
88. (2007) 46 EHRR 41 and also *The Queen on the Application of Mellor v Secretary of State for the Home Department* [2001] 3 WLR 533. See also, Helen Codd,‘Prisoners’ access to fertility services’ in Kirsty Horsey (eds), *Revisiting the Regulation of Human Fertilisation and Embryology* (Routledge, 2015), 50. [↑](#footnote-ref-89)
89. Anna Smajdor, ‘Time to put a stop to menopausal mothers?’ *Bionews* (2010) 543; ‘German Woman Aged 65 Gives Birth to Quadruplets after IVF Treatment’ *The Guardian* (2015) 23 May; Margaret Brazier, ‘Liberty, Responsibility Maternity’ (1990) 52 *Current Legal Problems,* 359. [↑](#footnote-ref-90)
90. Sarah Bosley, ‘Can couples in their 70’s have children?’ *The Guardian* (13.05.16) (last accessed 10.06.16) <https://www.theguardian.com/society/2016/may/13/should-couples-in-their-70s-be-able-to-have-ivf> ); Jo Macfarlane, ‘Woman, 59, becomes oldest person to be offered IVF treatment by British clinic’ 17.01.10 Mail Online (last accessed 10.06.16) <http://www.dailymail.co.uk/news/article-1243839/Woman-60-oldest-person-given-IVF-treatment-British-clinic.html> ). [↑](#footnote-ref-91)
91. Jones B. Oldest woman to give birth dies, leaving twins. USA Today. July 15, 2009. <http://www.usatoday.com/news/world/2009-07-15-spain-oldest-woman-birth_N.htm>. (Accessed online 10.01.16) [↑](#footnote-ref-92)
92. The National Institute for Health and Care Excellence (NICE), ‘Fertility Problems: assessment and treatment’ (2013), in which it recommends women under 43 years of age should be offered treatment. Any decision regarding treatment funded by the NHS in England is made by Clinical Commissioning Groups. [↑](#footnote-ref-93)
93. *Evans* (n 83), 71. [↑](#footnote-ref-94)
94. Ms Evans took her case to the ECtHR and lost in the European court of first instance and the Grand Chamber, [2006] 1 FCR 585 (ECtHR) and [2009] 46 EHRR 34. [↑](#footnote-ref-95)
95. Gurnham and Miola (n 7), 29; Jackson (n 7). [↑](#footnote-ref-96)
96. John Harris, ‘Rights and reproductive choice’ in John Harris and Soren Holm (eds) *The Future of Human Reproduction: Ethics, Choice and Regulation*, (Clarendon, 1998) 5; Jackson (n 7). [↑](#footnote-ref-97)
97. House of Commons Science and Technology Committee, *Human Reproductive Technologies and the Law,* Fifth Report of Session 2004-05, Volume 1, 136. [↑](#footnote-ref-98)
98. Julie McCandless and Sally Sheldon, ‘No Father Required? The Welfare Assessment in the Human Fertilisation and Embryology Act 2008’ (2010) 18 *Feminist Legal Studies* 201. [↑](#footnote-ref-99)
99. Julie McCandless and Sally Sheldon ‘The Human Fertilisation and Embryology Act 2008 and the tenacity of the sexual family form’ (2010) 73 *Modern Law Review* 175. [↑](#footnote-ref-100)
100. HCSTC (04-05) (n 96). [↑](#footnote-ref-101)
101. The Human Fertilisation and Embryology Authority, ‘Tomorrow’s Children: A consultation on guidance to licensed fertility clinics on taking into account the welfare of children to be born of assisted conception treatment’ (2005). [↑](#footnote-ref-102)
102. HCSTC (04-05) (n 96), 107. [↑](#footnote-ref-103)
103. LA’s have a duty to investigate if there is reasonable cause to suspect that a child is suffering, or is likely to suffer significant harm. Harm is defined as ill-treatment, including sexual abuse and non-physical forms of ill-treatment, or the impairment of health (physical or mental) or impairment of development, including physical, intellectual, emotional, social and behavioural. See CA 1989, sections 17, 31(2) and 47. Also, the Children Act 2004 s. 11. [↑](#footnote-ref-104)
104. HCSTC (04-05) (n 96), 103. [↑](#footnote-ref-105)
105. Department of Health, *Report on the Review of the Human Fertilisation and Embryology Act: A public consultation* (London: Stationary Office, August 2005) 39 - 40. [↑](#footnote-ref-106)
106. HFEA (n 100), 02, 1.1. [↑](#footnote-ref-107)
107. Ibid. [↑](#footnote-ref-108)
108. Ibid, 07, 2.4. [↑](#footnote-ref-109)
109. Ibid. [↑](#footnote-ref-110)
110. Ibid. [↑](#footnote-ref-111)
111. Ibid. [↑](#footnote-ref-112)
112. Ibid. [↑](#footnote-ref-113)
113. Ibid, 11, 3.3. [↑](#footnote-ref-114)
114. Ibid, 07, 2.4. [↑](#footnote-ref-115)
115. Brazier (n 1), 174. [↑](#footnote-ref-116)
116. The HFE Act 1990 s. 25 (1) tasked the HFEA to provide guidance on the proper conduct of activities carried out in pursuance of a licence under the Act. [↑](#footnote-ref-117)
117. CoP, 6th ed, 3.20. [↑](#footnote-ref-118)
118. Ibid, 3.12 (ii). [↑](#footnote-ref-119)
119. Ibid, 3.12 (iv). [↑](#footnote-ref-120)
120. Ibid, 3.12 (v). [↑](#footnote-ref-121)
121. Ibid, 3.20 (iii). [↑](#footnote-ref-122)
122. Ibid, 3.10 (i)-(iv). [↑](#footnote-ref-123)
123. Ibid, 3.21. [↑](#footnote-ref-124)
124. HFEA (2005) ‘Improved welfare checks system will be better, fairer and clearer for fertility patients, GPs and clinics’, Press release, 2 November 2005 (London: HFEA). [↑](#footnote-ref-125)
125. November 13 2008. [↑](#footnote-ref-126)
126. HFE Act 2008 part 2; McCandless and Sheldon (n 97) and (n 98), 20; Eric Blyth, ‘Conceptions of welfare’ in Kirsty Horsey and Hazel Biggs (eds) *Human Fertilisation and embryology: Reproducing regulation (*Routledge-Cavendish), 17. [↑](#footnote-ref-127)
127. Robert Lee and Derek Morgan, *Human fertilisation and Embryology: Regulating the Reproductive Revolution* (Blackstone, 2001), 164. [↑](#footnote-ref-128)
128. The definition of supportive parenting is included in the 8th edition of the CoP at para 8.11. It states there is a prescribed presumption in law that supportive parenting will be provided by the prospective parent(s), unless there are justifiable grounds for suspecting the contrary. [↑](#footnote-ref-129)
129. Julie McCandless ‘Cinderella and her cruel sisters: parenthood, welfare and gender in the Human Fertilisation and Embryology Act 2008’ (2013) 32 *New Genetics and Society* 136. [↑](#footnote-ref-130)
130. HFEA 1990 s. 8 details the general functions of the HFEA. [↑](#footnote-ref-131)
131. Section 25 (1) of the HFE Act 1990 states the HFEA ‘shall maintain a code of practice giving guidance about the proper conduct of activities carried on in pursuance of a licence under this Act and the proper discharge of the functions of the person responsible and other persons to whom the licence applies’. [↑](#footnote-ref-132)
132. CoP 8th ed, 2009, 8.10. [↑](#footnote-ref-133)
133. The 8th edition of the CoP has been revised in April 2010, April 2011, October 2011, April 2012, October 2013, October 2014, April 2015, October 2015, July 2016 and May 2017. [↑](#footnote-ref-134)
134. CoP, 8th edn 2009, 10. [↑](#footnote-ref-135)
135. Ibid, 8.2. [↑](#footnote-ref-136)
136. Ibid, 8.3. [↑](#footnote-ref-137)
137. Ibid, 8.9. [↑](#footnote-ref-138)
138. It is noted within the CoP that there is a prescribed presumption in favour of providing treatment but clinics should refuse treatment if any child born or any existing child is likely to be at risk of significant harm or neglect, or if it cannot obtain enough information to conclude there is no significant risk, 8.11 and 8.15 – 8.17. [↑](#footnote-ref-139)
139. Isabel Karpin, The ‘health’ of preconceived human embryos, in Jeff Nisker and others (eds), *The Healthy Embryo: Social, Biomedical, Legal and Philosophical Perspectives* (Cambridge University Press, 2010), 149. [↑](#footnote-ref-140)
140. Julie Tizzard, ‘Reproductive Technology: new ethical dilemmas and old moral prejudices’ in Ellie Lee (ed) *Abortion Law and Politics Today* (Macmillan Press, 1998). [↑](#footnote-ref-141)
141. Jackson (n 7); McCandless (ns 97, 98, and 128); John Harris (n 95). [↑](#footnote-ref-142)
142. CoP, 8th 2009, 8.11. [↑](#footnote-ref-143)
143. In particular, the CA 1989 section 1 (3) (e) and (f). [↑](#footnote-ref-144)
144. The welfare assessment which is conducted by clinics can be located online at <http://www.hfea.gov.uk/docs/WelfareofthechildformV2.pdf>. (accessed online 14.05.15), 2.4. [↑](#footnote-ref-145)
145. Ibid, 2.6. [↑](#footnote-ref-146)
146. CoP 8th 2009, 8.10 (b)(i) – (ii). [↑](#footnote-ref-147)
147. CA 1989 section 1 (3). [↑](#footnote-ref-148)
148. Ibid, 8.10 (a)(i); This is arguably analogous to a risk assessment conducted by the police in respect of detainees in custody , see Police and Criminal Evidence Act 1984, Code of Practice Part C. [↑](#footnote-ref-149)
149. Carol McNaughton and others, ‘Attitudes to Sentencing Sexual Offences’ Sentencing Council Research Series 01/12 (March 2012); Jessica Jacobson, A Kirby and Mike Hough, ‘Public attitudes to the sentencing of drug offences’ Sentencing Council Research Series 01/11 (March 2011). [↑](#footnote-ref-150)
150. Ellie Lee, Jan Macvarish and Sally Sheldon, *Assessing Child Welfare under the Human Fertilisation and Embryology Act: The New Law* (2012) University of Kent (E.S.R.C) Full Report. [↑](#footnote-ref-151)
151. Ibid, 5. [↑](#footnote-ref-152)
152. A spent conviction is a conviction which, under the terms of Rehabilitation of Offenders Act 1974, does not need to be disclosed after a specified amount of time. The Act aims to rehabilitate offenders by not making their past mistakes affect their lives. [↑](#footnote-ref-153)
153. Lee, Macvarish and Sheldon (n 149), 8. [↑](#footnote-ref-154)
154. (2007) 46 EHRR 41, 78. [↑](#footnote-ref-155)
155. CoP, 8th 2009, 10. [↑](#footnote-ref-156)
156. Ibid, 10, p 96. The guidance also elaborates on gender related serious disability which due to space is outside of the scope of this article. [↑](#footnote-ref-157)
157. Ibid, 10.6. [↑](#footnote-ref-158)
158. Ibid,10.2. [↑](#footnote-ref-159)
159. Ibid, 10.16 (a). [↑](#footnote-ref-160)
160. Ibid, 10.16 (b). [↑](#footnote-ref-161)
161. Ibid, 10.16 (c). [↑](#footnote-ref-162)
162. Ibid, 10.16( d). [↑](#footnote-ref-163)
163. The HFEA provide a centralised list of genetic conditions which are authorised to be tested for by PGD. This can be found at <http://guide.hfea.gov.uk/pgd/> (last accessed 19.06.17). [↑](#footnote-ref-164)
164. Marleen Eikkholt, ‘Procreative autonomy and the Human Fertilisation and Embryology Act 2008: Does a coherent conception underpin UK law?’ (2011) 11 *Medical Law International* 93. [↑](#footnote-ref-165)
165. (n 36). [↑](#footnote-ref-166)
166. *Wyatt* (n 41) and *An NHS Trust v MB* (n 45).

 [↑](#footnote-ref-167)
167. (ns 52, 54, 69, and 72). [↑](#footnote-ref-168)
168. Section 38 of the HFE Act includes a conscientious objection clause, which states that no person who has a conscientious objection to participating in any activity governed by this Act shall be under any duty, however arising, to do so. [↑](#footnote-ref-169)