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## ACCESS OF SINGLE WOMEN TO FERTILITY TREATMENT: A CASE OF INCIDENTAL DISCRIMINATION?

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### SUMMARY

The purpose of this article is to evaluate the extent to which single women have access to publicly-funded fertility treatment. It claims that, despite the fact that great progress has been made in removing gender inequalities in the area of assisted reproduction in England and Wales in recent years, there are points in the regulatory framework that still allow for discrimination against single women. The paper builds on recent studies concerning the reforms brought about by the Human Fertilisation and Embryology Act 2008 (HFEA 2008). However, it focuses on publicly-funded treatment, thus directing scholarly attention away from the controversies over the amended s 13(5) HFEA 1990. It argues that the primary reason for remaining inequalities can be traced back to: a) the limitations of the current legislative framework, b) the ambiguities inherent in the regulatory framework, which in the context of publicly-funded fertility treatment is determined by the NICE clinical guidelines and CCGs and Health Boards' resource allocation policies, and c) the remaining confusion about the relationship between 'welfare of the child' assessments and eligibility criteria in NHS rationing decisions. The paper argues that the current regulation does not go far enough in acknowledging the inability of single women to conceive naturally, but at the same time that it struggles to address the fluidity of contemporary familial relationships. The analysis presents an opportunity to contribute to debates about the role of law in shaping the scope of reproductive autonomy, gender equality, and social justice.

**KEYWORDS:** Access to treatment, discrimination, IVF treatment, NICE guidelines, single women, welfare of the child

## I. INTRODUCTION

The purpose of this article is to evaluate the legal position of single women in the context of publicly-funded fertility treatment in England and Wales. For the purposes of this article the term ‘single women’ refers to women without a partner receiving treatment.<sup>1</sup> The 2008 amendments to the Human Fertilisation and Embryology Act 1990 (HFEA 1990) aimed at bringing the Act into line with the fast-progressing advances in reproductive medicine, the deep social changes affecting ‘traditional family’ structures, and the strengthening of human rights and anti-discrimination laws with regard to sex, gender, and sexual orientation.<sup>2</sup> A series of amendments concerning the ‘welfare of the child’ principle, parenthood, gamete donation, and surrogacy aimed at securing access to services providing assisted reproduction techniques (ART)<sup>3</sup> for same-sex couples and single women. One of the most controversial debates involved the amendment of s 13 (5) HFE Act 1990,<sup>4</sup> replacing the ‘need for a father’ with the ‘need for supporting parenting’ in the welfare of the child assessments. In order to align NHS practice with these changes and with advances in reproductive medicine, in 2013 NICE issued new fertility guidelines.<sup>5</sup> Two years later and almost six years after the relevant provisions of the HFEA 2008 entered into force in October 2009 the issue remains highly controversial.

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<sup>1</sup> The term has not been defined by the Human Fertilisation and Embryology Authority, but the proposed definition was adopted in its recent responses to FOI requests discussed later in the paper.

<sup>2</sup> Human Rights Act 1998, Adoption and Children Act 2002, Civil Partnership Act 2004 and later also the Equality Act 2010.

<sup>3</sup> Fertility treatment falls into 3 main types: (1) medical treatment (2) surgical treatment and (3) assisted reproduction techniques (ART) which includes any treatment that deals with means of conception other than vaginal intercourse, such as intrauterine insemination (IUI), intracytoplasmic sperm injection (ICSI), or *in vitro* fertilisation (IVF). It is the third type of ART treatment that constitutes the main focus of this analysis.

<sup>4</sup> Hansard Reports, HC Deb 12 May 2008, vol 475, cols 1063-1171 <<http://services.parliament.uk/bills/2007-08/humanfertilisationandembryologyhl/stages.html>> **All internet resources accessed on 23 April 2015.**

<sup>5</sup> NICE, ‘CG156 Fertility: Assessment and treatment for people with fertility problems’ (London: National Institute for Health and Care Excellence 2013) <<https://www.nice.org.uk/guidance/cg156/resources/updated-nice-guidelines-revise-treatment-recommendations-for-people-with-fertility-problems>>.

On the one hand, it has been generally accepted that the 2008 reforms have removed all discriminatory provisions from the legislation.<sup>6</sup> Others believe that the Act has simply aligned the existing law with an already liberal medical practice and in this respect it is a display of powerful yet merely symbolic imagery.<sup>7</sup> Nevertheless, as the number of NHS clinics providing fertility treatment to persons defined as ‘contextually’<sup>8</sup> or ‘socially’<sup>9</sup> infertile has been on the rise, media reports about the preferential treatment of these patients over heterosexual couples have increased.<sup>10</sup> This criticism of NHS practices has been further supported by politicians across the political spectrum.<sup>11</sup> On the other hand, the regulation and practice of fertility treatment seem far more complex. Recent studies suggest that there is a divergence between attitudes towards lesbian patients, who are perceived as ‘ideal patients’, and single female patients whose abilities to become parents are often questioned.<sup>12</sup> Nevertheless, to date relatively little attention has been paid specifically to the legal situation of single women in the context of fertility treatment. Their reproductive rights are usually analysed as part of broader investigations of the welfare of the child principle stipulated in s 13 (5) HFEA 1990 or discussions of the rights of same-sex couples.<sup>13</sup> This seems particularly

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<sup>6</sup> Secretary of State for Health, *Post-Legislative Assessment of the Human Fertilisation and Embryology Act 2008* (Cm 8823) (London: DH, 2014). Also: Antony Blackburn-Starza, ‘UK Human Fertilisation and Embryology Act receives Royal Assent’, *Bionews* 484, 17 Nov 2008.

<sup>7</sup> J. McCandless and S. Sheldon ‘“No Father Required”? The Welfare Assessment in the Human Fertilisation and Embryology Act 2008’ (2010) 18 *Feminist Legal Studies* 3, 201-225, 219.

<sup>8</sup> R. Deech and A. Smajdor *From IVF to immortality: controversy in the era of reproductive technology* (Oxford: Oxford University Press, 2007), 172. Also: A. Smajdor, D. Cutas, Will artificial gametes end infertility? *Health Care Analysis*, 29 November 2013, 1-14, 8 <<http://www.ncbi.nlm.nih.gov/pubmed/24293033>>.

<sup>9</sup> E. Lee, J. Macvarish and S. Sheldon ‘Assessing child welfare under the Human Fertilisation and Embryology Act 2008: a case study in medicalisation?’ (2014) 36 *Sociology of Health & Illness* 4, 500–515, 510.

<sup>10</sup> S. Adams, S. Rainey and M. Beckford, ‘Single women being offered IVF on the NHS’, *The Telegraph*, 24 October 2011, <<http://www.telegraph.co.uk/women/womens-health/8844762/Single-women-being-offered-IVF-on-the-NHS.html>>.

<sup>11</sup> *Ibidem*.

<sup>12</sup> E. Lee et al. (2014), *op.cit.* n. 9, 515.

<sup>13</sup> M. Stanworth, ‘Reproductive technologies and the deconstruction of motherhood’, in: M. Stanworth (ed.) *Reproductive technologies: Gender, motherhood and medicine* (Cambridge: Polity Press, 1987), 10–35; Cooper, Davina, and Herman ‘Getting ‘the family right’: Legislating heterosexuality in Britain, 1986–1991’ (1991) 10 *Canadian Journal of Family Law*, 41–78; S. Millns ‘Making social judgments that go beyond the purely medical: The reproductive revolution and access to fertility treatment services’, in: J. Bridgeman, and S. Millns (eds) *Law and body politics: Regulating the female body* (Dartmouth: Aldershot, 1995), 79–104. S. Sheldon ‘Fragmenting fatherhood: The regulation of reproductive technologies’ (2005) 68 *Modern Law Review*, 523–553. C. Jones *Why donor insemination requires developments in family law: The need for new definitions of*

unfortunate in light of data recently released by the Office of National Statistics, according to which 57% of conceptions that occurred in 2012 happened outside marriage or civil partnership.<sup>14</sup> The paper aims to address this gap, setting out the following argument.

Despite the fact that great progress has been made in removing sex and gender inequalities in the area of assisted reproduction in England and Wales in recent years, there are junctures in the legislative and regulatory framework that still allow for discrimination against single women in practice. The paper builds on recent studies which reveal continuing stigmatisation of single women stemming from traditional ideas about parenting enduring in the HFEA 2008.<sup>15</sup> However, it extends such studies by evaluating the broader legislative context comprising human rights and anti-discrimination laws which fail to provide adequate protection to single women seeking fertility treatment. Within this remit, the emphasis on publicly-funded (NHS) treatment is important, because it helps redirect scholarly attention away from well-established debates about the welfare of the child principle<sup>16</sup>, to the analysis of other, equally important, normative factors determining access to fertility treatment for single women who cannot afford private treatment. Arguably, these women constitute one of the most vulnerable groups of patients in the area of assisted reproduction, because they usually have to face not only their infertility, but also the lack of financial resources alone.

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*parenthood* (Edwin Mellen Press, 2007); S. Golombok and S. Badger 'Children raised in mother-headed families from infancy: a follow-up of children of lesbian and single heterosexual mothers, at early adulthood' (2010) 25 *Human Reproduction*, 1150–157. R. Harding *Regulating sexuality: Legal consciousness in lesbian and gay lives* (London: Routledge, 2010).

<sup>14</sup> In 2013 conceptions outside of a marriage/civil partnership accounted for 57% of all conceptions in England and Wales, compared with 55% in 2003 and 45% in 1993. Although this data include informal relationships as well as single women (single women do not feature as a separate category), it is fair to assume that the number of conceptions in this group is also growing respectively. See: Office for National Statistics, Conceptions in England and Wales 2012, Statistical Bulletin 24 Feb 2015 [http://www.ons.gov.uk/ons/dcp171778\\_396674.pdf](http://www.ons.gov.uk/ons/dcp171778_396674.pdf) >

<sup>15</sup> J. McCandless and S. Sheldon, The Human Fertilisation and Embryology Act (2008) and the Tenacity of the Sexual Family Form (2010) 73 *Modern Law Review* 2, 175-207; E. Lee. J. Macvarish and S. Sheldon 'Assessing child welfare under the human fertilisation and embryology act: the new law' (2012) 19 *Journal of Fertility Counselling* 3, 20-25.

<sup>16</sup> G. Douglas 'Assisted Conception and the Welfare of the child' (1993) *Current Legal Problems* 53; S. Golombok, 'New families, old values: Considerations regarding the welfare of the child' (1998) 13 *Human Reproduction* 9, 104-109; E. Jackson 'Conception and the Irrelevance of the Welfare Principle' (2002) 65 *Modern Law Review*, 176-203; E. Jackson 'Re-thinking the pre-conception welfare principle', in: K. Horsey and H. Biggs, *Human Fertilisation and Embryology: Reproducing Regulation* (London -New York: Routledge Cavendish, 2007), 47-67.

Furthermore, the problems concerning access to ART services become much more transparent in the context of the NHS system, which is subject to acute financial pressures. In this respect, it draws attention to the fact that the gaps in legislation are further exacerbated by the jurisprudential reluctance to recognise the right to access fertility treatment in the context of resource allocation decisions.

Against this backdrop, the paper proposes that the primary reason for remaining inequalities can be traced back to the ambiguities inherent in the regulatory framework, which in the context of publicly-funded fertility treatment is determined by the NICE clinical guidelines and CCGs and Health Boards' resource allocation policies. It argues that the recent quest for equality and human rights has paradoxically resulted in a 'regulatory silence' in the NICE fertility guidelines which overlook single women as a separate group of patients with their own specific needs. It also suggests that the regulation does not go far enough in acknowledging single women's impossibility to conceive naturally, but at the same time that it struggles to address the fluidity of contemporary familial relationships. Finally, the paper highlights the importance of persisting misconceptions about the relationship between 'welfare of the child' assessments and eligibility criteria in the NHS for the rationing decisions determining the access of single women to fertility treatment.

To elucidate the position of single women in this complex normative framework the paper uses several strategies. The first is doctrinal in its nature, focusing on legal analysis of statutes and relevant case law concerning the rights of single women in the context of fertility treatment. The second is a detailed examination of policy documents that regulate access to publicly-funded fertility treatment, in particular the NICE clinical fertility guidelines. The third involves analysis of empirical data derived from three sources: a) statistics provided by governmental and non-governmental bodies, including the Office for National Statistics and Fertility Fairness, b) responses to Freedom of Information (FOI) requests available on the

HFEA website, and c) a small pilot study based on FOI requests concerning the provision of NHS-funded ART services for single women, the details of which are provided later in the paper. This combination of approaches provides a wealth of information supporting the argument presented in this paper and gives insight into this underexplored area of law and medical practice. The paper takes forward the recent studies concerning the HFEA 2008 amendments, contributes to debates about the role of law in shaping the scope of reproductive autonomy, gender equality, and social justice, and sets directions for future research enhancing the understanding of reproductive rights of single women in contemporary society.

## **II. RIGHTS OF SINGLE WOMEN IN THE CONTEXT OF FERTILITY TREATMENT – LEGISLATIVE FRAMEWORK**

### ***A. The right to access fertility treatment***

The access of single women to fertility treatment is determined by the HFEA 1990, as amended by the HFEA 2008, which regulates the provision of assisted reproduction services in the UK. Despite common misconceptions empirical and theoretical studies have often pointed out that the original HFEA 1990 contained no explicit statutory prohibition of fertility treatment of any competent patients.<sup>17</sup> Therefore, single, lesbian or older women were all able to lawfully receive ART services even prior to the 2008 amendments. At the same time, however, it has been convincingly argued that until the reform of 2008 there was a presumption *against* their treatment. The presumption was inextricably linked with the ‘welfare of the child’ principle set out in s 13 (5) HFEA 1990, which required fertility clinics

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<sup>17</sup> The article provides a comprehensive summary of the recent developments of the Welfare of the Child principle. See: J. McCandless and S. Sheldon (2010), *op. cit.* 7. See also: E. Blyth, V. Burr and A. Farrand. ‘Welfare of the child assessments in assisted conception: A social constructionist perspective’, (2008) 26 *Journal of Reproductive and Infant Psychology* 1, 31–43.

to consider the ‘need for a father’ when considering patients for treatment.<sup>18</sup> As demonstrated in early parliamentary debates about the HFEA 1990 there was a clear expectation that fertility clinics were to discourage women who did not have a male partner from seeking assisted reproduction services.<sup>19</sup> After the adoption of the Act in 1990 the Conservative Government at the time continued to pursue an agenda based upon the promotion of traditional family values, reflecting widespread beliefs about the correlation between lone parenthood and social and economic problems. Initially the HFEA drew heavily on the government’s emphasis on parenting competence and the suitability of those seeking assisted conception services.<sup>20</sup> It was impossible to deny that the original text of s 13(5) invited an interpretation tilted toward a refusal of single motherhood and a desire to link women to men to form what Martha Fineman called the ‘sexual family’.<sup>21</sup> Despite a gradual shift towards an increasingly liberal interpretation of the HFEA 1990 developed by the HFEA at the start of the new millennium<sup>22</sup>, which meant that fertility clinics rarely refused treatment of same sex couples and single women on the ‘welfare of the child’ grounds, proponents of changes highlighted the need to remove from the HFEA 1990 any in-built discrimination that placed an additional hurdle before some people because of their sexual orientation or relationship

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<sup>18</sup> Human Fertilisation and embryology Authority 1990, Ch. 37, 1st November 1990 and Human Fertilisation and embryology Authority 2008, Ch. 22, 13 November 2008.

<sup>19</sup> Lord Ashbourne, HL Debs, Vol 515, Col 767 (6 February 1990), David Wilshire, HC Debs Vol 174, Cols 1024–1025 (20 June 1990). Also: Lord Mackay explicitly stated that ‘there is a likelihood that through counselling and discussion with those responsible for treatment [women without a male partner] may be dissuaded from having children once they have fully considered the implications of the environment into which their child would be born or its future welfare.’ See: Lord Mackay (Lord Chancellor), Official Report. House of Lords, 6 March 1990, para 1098

<sup>20</sup> Paras 3.13 – 3.16 of the HFEA’s Code of Practice had remained virtually unchanged between 1992 and 2003. HFEA Code of practice, 1<sup>st</sup>-5<sup>th</sup> ed. London: HFEA (1991, 1993, 1995, 1998, 2001, 2003).

<sup>21</sup> M. Fineman, *The neutered mother, the sexual family and other twentieth century tragedies* (New York: Routledge 1995).

<sup>22</sup> The 6<sup>th</sup> edition of the HFEA Code of Practice, published in 2003 stipulated that in situations when there is no legal father, clinics were required to assess the prospective mother’s ability, and that of others in the family or social circle who will share responsibility for the child, to meet the child’s needs. Although the provision had not specifically stipulated treatment of gay and single women, it had in fact allowed for such cases to be considered by IVF clinics. See: HFEA Code of Practice, London 2003-2006, para. 3.14.

status.<sup>23</sup> According to those supporting the 2008 amendments, the argument was ‘about individuals having the right to be considered objectively for IVF treatment’.<sup>24</sup> There was a clear concern that unjustified distinctions between gay and heterosexual or married and unmarried couples would constitute a breach of the right to respect for private life without discrimination (as protected by Article 8 and Article 14 ECHR). Therefore, the removal of the gender specific reference to the ‘need for a father’ was considered a human rights enhancing measure.<sup>25</sup> It is worth noting that at the early stages of the HFE reform process, the need to protect single women seeking fertility treatment featured quite strongly in the debates. The Royal College of Obstetricians and Gynaecologists (RCOG) argued that the requirement for a father discriminated against single women ‘who may have the financial and emotional facilities to cope with a child on their own or with other support systems, who may need to use donor insemination to conceive safely’.<sup>26</sup> The then Labour Government followed this reasoning. Emphasising that patients’ safety could be compromised if some groups of women were encouraged to seek treatment privately,<sup>27</sup> it decided to support changes which, after heated debates,<sup>28</sup> replaced the ‘need for a father’ with ‘the need for supporting parenting’ in s 13 (5). The new 2009 Code of Practice defined supportive parenting as ‘a

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<sup>23</sup> E. Blyth, ‘The United Kingdom’s Human Fertilisation and Embryology Act 1990 and the welfare of the child: A critique’ (1995) 9 *International Journal of Children’s Rights*, 417–438. See also: E. Blyth et al., (2008) *op. cit.*, n.17; E. Jackson (2007) *op. cit.*, n. 16; L. Saffron, Minutes of Evidence taken before the House of Commons Science and Technology Select Committee: Human Reproductive Technologies and the Law. 30th June. Ev. 43. In: House of Commons Science and Technology Committee ‘Human Reproductive Technologies and the Law’ Fifth Report of Session 2004–05. Vol II: Oral and written evidence (London, 2005) <<http://www.publications.parliament.uk/pa/cm200405/cmselect/cmsctech/7/7ii.pdf>. >

<sup>24</sup> Norman Lamb, HC Deb 12 May 2008, vol 475, col 1090 < <http://services.parliament.uk/bills/2007-08/humanfertilisationandembryologyhl/stages.html>>.

<sup>25</sup> Joint House of Lords and House of Commons Committee On Human Rights - Fifteenth Report, Part 4: Human Fertilisation and Embryology Bill, 18 March 2008, para. 4.17: <<http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/81/8107.htm#note170>>.

<sup>26</sup> House of Commons Science and Technology Committee. *Human reproductive technologies and the law* (Fifth report of session 2004–2005, HC papers 7-I and 7-II), London: HMSO, Vol I, para 99; See also: Joint Committee 2007 House of Lords, House of Commons Joint Committee on the Human Tissue and Embryos (Draft) Bill, Vol I: Report (Session 2006–2007, HL paper 169-I, HC paper 630-II), London: HMSO, para. 243.

<sup>27</sup> Department of Health, Review of the Human Fertilisation and Embryology Act: Proposals for Revised Legislation (Cm 6989) (London: HMSO 2006). The term ‘private treatment’ meant self-arranged donor insemination, rather than privately funded treatment.

<sup>28</sup> Hansard Reports *op. cit.* n. 4.

commitment to the health, well-being and development of the child'<sup>29</sup> and contained a clear presumption against detailed welfare of the child assessment. It provided that – ‘in the absence of any reasonable cause for concern that any child who may be born, or any other child, may be at risk of significant harm or neglect’ – all prospective parents should be viewed as supportive parents and that ‘where centres have concern as to whether this commitment exists, they may wish to take account of wider family and social networks within which the child will be raised.’<sup>30</sup>

Regrettably, the impact of these legislative and regulatory changes on the access of single women to fertility treatment in general has so far been rather ambivalent. A post-legislative assessment of the HFEA 2008 published by the Government in March 2014 found compliance with the revised requirement of supportive parenting irrespective of the sex of the parents.<sup>31</sup> These findings have been partly corroborated by the most recent and relevant study evaluating the implementation of the HFEA 2008 and the operation of s 13(5) in clinical practice, conducted by Ellie Lee, Jan Macvarish, and Sally Sheldon. Their research confirmed that the changes introduced by the HFE Act 2008 had little impact on the provision of fertility services.<sup>32</sup> Before as well as after the reform, women denied treatment in one clinic were able to access it elsewhere in the country. Differences in patient experience and the potential for discrimination have been reduced due to common procedures for welfare of the child assessments established by the HFEA (before and after 2008).

At the same time, however, Lee et al.’s analysis identified areas where the operationalization of the principle is still problematic. Although no evidence was found of general ‘group discrimination’ based on sexuality or relationship status, the study found

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<sup>29</sup> HFEA, 8<sup>th</sup> Code of Practice (London: HFEA 2009), para 8.11

<sup>30</sup> *Ibidem*.

<sup>31</sup> Secretary of State for Health, Post-legislative Assessment of the Human Fertilisation and Embryology Act 2008 (Cm 8823, March 2014), paragraph 30.

<sup>32</sup> E. Lee, et al. (2014), *op. cit.*, n. 9; E. Lee, J. Macvarish and S. Sheldon (2012) *op. cit.* n. 15.

‘bifurcation’ in attitudes towards lesbian patients, and single female patients. Interviews with fertility counsellors revealed peculiar prejudice and an interesting hierarchy between different groups of patients. While lesbian couples are perceived as ‘ideal patients’ and the best parents, better than heterosexual couples, the treatment of single women was commonly more contentious. Their ability to access fertility treatment was sometimes perceived as problematic in regards to their motivations for having a child, their ability to provide for it, and the strength of their support networks.<sup>33</sup> Because single women are seen as struggling individuals emotionally unable to commit to a stable relationship, they occasionally, seem to be subject to additional assessment aiming to establish the existence of sufficient family and friend support systems.<sup>34</sup> These attitudes might stem from the fact that, as argued by McCandless and Sheldon with regard to the HFEA 2008, ‘the sexual family ideal has retained a significant hold...[which] can be seen in: the ongoing significance of the formally recognised adult couple; law’s continued adherence to a two-parent model; what we describe as ‘parental dimorphism’ (which, within the two-parent model, allows only for one mother plus one father or female parent); and the notion that the couple must be (at least potentially) in a sexual relationship.’<sup>35</sup> The acceptance of the notion that the child has two – and only two – “real” parents has proved a somewhat unifying article of faith for the Act 2008. Although not specifically excluded, single-parenthood may prove just as objectionable as more than two-parent parenthood, given the expectations laid out by the current legal parenthood provisions.<sup>36</sup> Therefore, it is fair to conclude that despite celebrated legislative reforms and considerable changes in medical practice, single women are still denied standing equal to other groups of patients seeking fertility treatment and were discrimination to occur, they

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<sup>33</sup> E. Lee, et al. (2012), *ibidem*.

<sup>34</sup> E. Lee, et al. (2014), *op. cit.*, n. 9.

<sup>35</sup> J. McCandless and S. Sheldon (2010) *op. cit.* 15, 188.

<sup>36</sup> J. McCandless, ‘Cinderella and her cruel sisters: parenthood, welfare and gender in the Human Fertilisation and Embryology Act 2008’, (2013) 32 *New Genetics Society* 2, 135-153, 147.

would enjoy a lower level of protection. This disparity is exacerbated and particularly visible in the context of *publicly-funded* fertility treatment.<sup>37</sup>

### ***B. The right to publicly-funded fertility treatment***

The HFEA 1990 does not distinguish between privately- and publicly-funded treatments. In fact, the issue of funding remains entirely beyond the scope of the Act and the regulatory powers of the HFEA, leaving open the question of whether single women have a right to NHS-funded fertility treatment. The answer to this question, which concerns resource allocation in healthcare, is determined by the Government, the NHS, and its arms-length bodies, whose decisions are scrutinised by courts. It is well-known that the English judiciary has historically been very reluctant to intervene in decisions which involve rationing in the NHS. They have confirmed on many occasions that the duty to provide treatment is not absolute. As noted by Lord Bingham ‘in a perfect world any treatment which a patient... sought would be provided if doctors were willing to give it, no matter how much it costs’ but that would mean ‘shutting one’s eyes to the real world.’<sup>38</sup> The statutory duty under the NHS Act 2006 is not to provide, but to *promote* a comprehensive health service.<sup>39</sup> This duty is considered to be very far from a duty to ensure that the service was comprehensive that may never, for human, financial, and other resource reasons, be achievable.<sup>40</sup> Therefore, as long as the Secretary of State for Health (and bodies with delegated powers) pays ‘due regard’ to this obligation, the incomprehensiveness of the services provided will not be tantamount to illegality,<sup>41</sup> which, along with irrationality and procedural impropriety, could be seen as

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<sup>37</sup> For a detailed discussion see: J. McCandless and S. Sheldon (2010), *op.cit.*, n. 16. See also: E. Blyth, ‘Conceptions of Welfare’ in: K. Horsey and H. Biggs (2007) *op. cit.* 16; Blyth et al. (2008), *op.cit.*, n.17.

<sup>38</sup> *R v Cambridge Health Authority, ex p B (a minor)* [1995] EWCA Civ 49

<sup>39</sup> According to s 3 of the NHS Act 2006, the Secretary of State for Health has a duty to provide healthcare services to patients to such extent as he considers necessary to meet all reasonable requirements.

<sup>40</sup> *R v North and East Devon Health Authority, ex p Coughlan* [2000] 2 WLR 622.

<sup>41</sup> *Ibidem.*

continuing *Wednesbury* grounds for judicial review.<sup>42</sup> Additionally, because the NHS Act 2006 does not foresee any penalty or sanction for breach of duties stipulated in the Act, the courts have accepted that there is no cause of action for any member of the public affected by such breach.<sup>43</sup> Furthermore, even in most severe cases concerning life-saving treatment<sup>44</sup>, cancer treatment<sup>45</sup>, or artificial nutrition and hydration<sup>46</sup> courts usually refrain from interfering with rationing decisions taken by health care professionals. Finally, as the Human Rights Act 1998 had remarkably little impact on the provision of health services in the UK, the courts will remain unwilling to bring human rights law into such cases unless a decision is clearly irrational.<sup>47</sup> In short, courts will not intervene except in the most serious of cases of human rights violations. Consequently, it is generally accepted that there will always be types of medical care which the NHS will offer free of charge only in very exceptional circumstances, including counselling, psychotherapy, dental treatment, optometry, and last but not least assisted reproduction, which used to be seen more as a ‘lifestyle enhancement’ rather than a treatment of a medical condition.<sup>48</sup> Therefore, there is very little support for a justiciable right to publicly-funded fertility treatment in English law.

Similarly, little support will come from the European Court of Human Rights which considers healthcare funding to fall almost entirely within a state’s margin of appreciation. Admittedly, a broad right to reproductive autonomy derived from Art. 8 (right to private life), 12 (right to family), and/or 14 (non-discrimination) of the ECHR is well established in the

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<sup>42</sup> K. Syrett *Law, Legitimacy and the Rationing of Health Care* (Cambridge: Cambridge University Press, 2007), 166-7.

<sup>43</sup> *Re HIV Hemophiliac Litigation* (1990) 41 BMLR 171.

<sup>44</sup> *R v Cambridge Health Authority, ex p B* (a minor) [1995] EWCA Civ 49, *R v Central Birmingham Health Authority; ex p Collier* (unreported, Court of Appeal, 6 January 1988),

<sup>45</sup> *R v North Derbyshire HA ex p Fisher* [1997] 8. Med LR 327.

<sup>46</sup> *R v General Medical Council & Ors, ex p Burke* [2005] EWCA Civ 1003

<sup>47</sup> L. Riley, Access to NHS-funded IVF treatment in England and Wales, in: K. Horsey (2007), *op.cit.* 16, 83-108, 101-104.

<sup>48</sup> S. Redmayne and R. Klein ‘Rationing in practice: The case of in vitro fertilisation’ (1993) 3306 *British Medical Journal* 1521; A. Plomer, I. Smith, and N. Martin-Clement, ‘Rationing policies on access to in vitro fertilisation in the NHS, UK’. (1999) 7 *Reproductive Health Matters*, 60–70.

jurisprudence of the ECtHR.<sup>49</sup> Its justification, existence, and scope have been discussed extensively in literature.<sup>50</sup> The right entails reproductive freedom as a negative personal right to either have or avoid having children (free from state's intervention). For some women it often cannot be realised unless they have the necessary means to access all available treatments for infertility.<sup>51</sup> Nevertheless, the corresponding state obligation to protect these rights does not automatically encompass a duty to fund assisted reproduction services. For, it is one thing to allow and guarantee a safe use of a new technology; it is another to fund all requested treatment. It seems inevitable that the needs of some patients will remain unsatisfied. The Strasbourg Court has been particularly wary of attempts to establish a positive obligation under Article 8 in the area of the provision of state benefits. It has repeatedly argued that questions about how much money should be allocated by the state on competing areas of public expenditure, and how the sums allocated to each area should be applied, are perceived as matters which lie essentially in the political domain.<sup>52</sup>

### ***C. The right not to be discriminated against in accessing publicly-funded fertility treatment***

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<sup>49</sup> *Evans v UK* [2008], *Dickson v UK* [2007], *Vo v France* (Application no. 53924/00) [2004] 40 EHRR 12, *RR v Poland* (Application no. 27617/04) [2011] 53 EHRR 31.

<sup>50</sup> M. A. Warren 'Does distributive justice require universal access to assisted reproduction?' in: R. Rhodes, BP. Battin, and A. Silvers (eds.) *Medicine and Social Justice: Essays on the Distribution of Health Care* (New York: Oxford University Press, 2002), 426-437; J. Harris 'Rights and reproductive choice.' in: J. Harris and S. Holm S (eds.) *The Future of Human Reproduction: Ethics, Choice, and Regulation* (Oxford: Clarendon Press, 1998), 5-37; MM. Peterson Assisted reproductive technologies and equity of access issues (2005) 31 *Journal of Medical Ethics*, 280-285.

<sup>51</sup> It might be interesting to note that in *Artavia Murillo et al. ("In Vitro Fertilization") v Costa Rica* [2012] (IACtHR, IVF Decision, 28 November 2012) the Inter-American Court of Human Rights, relying on the Convention on the Rights of Persons with Disabilities 2006, concluded that infertility is a disability necessitating access to treatment. The Court held that infertility as a medical condition constitutes a functional limitation to those suffering from it, and is a recognised medical infirmity therefore requiring infertile individuals to be protected under rights of disabled individuals, including access to techniques that could help them overcome their condition.

<sup>52</sup> *Pentiacova and Others v Moldova* (Application No. 14462/03) [2005], 40 EHRR 23; *Scialacqua v. Italy* [1998] 26 EHRR 164, *Osman v. UK* [1998] 29 EHRR 245; *Taylor and Others v UK* [1994] 79 DR 127; *McDonald v UK* (Application No. 4241/12) [2014].

As mentioned earlier, the HRA 1998 has been of little assistance to single women seeking NHS-funded treatment on the basis of Art. 3, Art. 8, or Art. 12 ECHR. This assertion extends to the protection offered by Art.14 ECHR, which stipulates the enjoyment of convention rights without discrimination on any ground. The right cannot be engaged because it only applies to ‘rights and freedoms set forth in the convention’ and no positive right to fertility treatment has been inferred from the ECHR.<sup>53</sup> Furthermore, single women seeking assisted reproduction services would be precluded from claiming discrimination under the Equality Act 2010.<sup>54</sup> Although a detailed analysis of equality legislation exceeds the scope of this paper, a couple of comments are due. The Act is based on the notion of ‘protected characteristics’ which include sex, sexual orientation, marital status, as well as pregnancy and maternity. In order to establish a claim on the basis of direct discrimination a single woman who has not been granted fertility treatment would be required to compare her less favourable treatment with a comparator who is in materially similar circumstances. However, this is where problems occur. Founding a claim on marital status would not be allowed, because the Act offers protection only to those married or in civil partnership (not to single persons). The same obstacles would be encountered if the single woman sought comparison with pregnant women, as it has been recently demonstrated the courts perceive IVF and pregnancy are two distinct categories.<sup>55</sup> It would be equally difficult to claim discrimination on the basis of sex or sexual orientation, because it is the lack of partner which is the issue rather than gender or sexual orientation - it is fair to assume that lesbian single women or indeed single men<sup>56</sup> would encounter similar obstacles. Consequently, it would also be very difficult indeed for the single woman to claim indirect discrimination, i.e. that the policy of insisting on

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<sup>53</sup> *Balkandali v United Kingdom* (1985) 7 EHRR 471.

<sup>54</sup> Equality Act 2010, c. 15, <<http://www.legislation.gov.uk/ukpga/2010/15/contents>>

<sup>55</sup> Court of Justice of the EU, Case C-167/12 *C. D. v S. T.* and Case C-363/12 *Z. v A Government Department and the Board of Management of a Community School*, 18 March 2014.

<sup>56</sup> The issue of access of single men to IVF treatment certainly deserves scholarly attention in a separate paper. Unlike pregnancy – where the courts have accepted there is no need for a male comparator (as there *is* no male equivalent) during the protected period – a comparison (albeit irrelevant) would be possible.

supporting parenting appears neutral, but puts single women at a disadvantaged position and is not objectively justified. For, the difficulties in accessing treatment occur not because of patient's sex or gender, but because of her relationship status (other than marriage or civil partnership).<sup>57</sup> Moreover, even if her claim were to be considered admissible in principle, the NHS would be able to argue that limited access to treatment is objectively justified by the legitimate aim of providing efficient and equitable health care.<sup>58</sup> Finally, the single woman could attempt to claim a breach of the Public Sector Equality Duty, which requires public bodies to have 'due regard' to equality in the planning and commissioning of healthcare services, to ensure that patients have equitable access to healthcare services and to ensure equal treatment when receiving healthcare services.<sup>59</sup> However, the fact that the duty is limited to having *only* 'due regard' and that it again arises only with regard to protected characteristics suggest that it is highly unlikely that such a claim would be successful.<sup>60</sup> In sum, it is fair to conclude that the legal protection of single women against discrimination in fertility treatment is overall weak and insufficient. The above analysis clearly demonstrates that this is generally true for the statutory provisions and common law principles that determine single women's access to NHS fertility treatment. Statistical data concerning access to fertility treatment in the UK seem to lend credibility to this interpretation.

#### ***D. Data concerning access of single women to NHS treatment***

The limitations in the protection of single women offered by the legislative framework seem to correlate with the data retrieved from the HFEA responses to Freedom of Information

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<sup>57</sup> See: B. Hepple, *Equality: The Legal Framework* (Oxford: Hart Publishing, 2014).

<sup>58</sup> This would essentially be considered a resource allocation issue, discussed below. See: K. Syrett 'Opening Eyes to the Reality of Scarce Health Care Resources? *R v Swindon NHS Primary Care Trust and another, ex p Rogers* [2006] EWCA Civ 392' (2006) *Public Law*, 664-73.

<sup>59</sup> S 149 Equality Act 2010 read in conjunction with the Health and Social Care Act 2012.

<sup>60</sup> *R (Brown) v Secretary of State for Work and Pensions* [2008] EWHC 3158 (Admin), *R (Eisai) v National Institute for Clinical Excellence & Others* [2007].

(FOI) requests and the HFEA register data, all available on the HFEA website.<sup>61</sup> The data show a still relatively small number of single women undergoing fertility treatment in England and Wales. Admittedly, the analysis of statistical evidence confirms a gradual yet consistent rise in the number of single women undergoing fertility treatment, i.e. IVF treatment or donor insemination (DI). For instance in 2006 there were 574 registered IVF treatment cycles and 705 DI treatment cycles, bringing the overall number to 1279.<sup>62</sup> This number rose to 1685 of IVF and DI treatment cycles in 2012.<sup>63</sup> The number of women registered as not having a partner at UK licensed clinics between 2011 and 2012 rose from 702 to 845<sup>64</sup>. However, it is important to bear in mind that the above data include both publicly and privately funded treatment, and that the exact number of single women provided with NHS treatment is hard to determine.<sup>65</sup> In the last five years the HFEA has refused to provide this information under section 22 FOIA on the basis that the requested data were likely to be misleading for the patients and the general public. It decided that the public interest in ensuring access to accurate and verified information outweighed the public interest in disclosure. Despite the HFEA's promise, these data have not been published, yet.<sup>66</sup> Nevertheless, the number of single women seeking NHS treatment could probably be inferred from two facts: a) that until 2013 the NICE guidelines precluded women over the age of 38

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<sup>61</sup> Although the details of the requests are not provided, the relevant information extracted from these responses was used in this analysis.

<sup>62</sup> HFEA, A long term analysis of the HFEA Register data 1991-2006, 11 July 2007, <[http://www.hfea.gov.uk/docs/Latest\\_long\\_term\\_data\\_analysis\\_report\\_91-06.pdf](http://www.hfea.gov.uk/docs/Latest_long_term_data_analysis_report_91-06.pdf)>

<sup>63</sup> HFEA, A reply to a Freedom of Information Act Request F-2013-00276 - Single women undergoing treatment with donor sperm for the first time, 22 November 2013, <<http://www.hfea.gov.uk/8543.html>>

<sup>64</sup> HFEA, A reply to a Freedom of Information Act Request F-2014-00213 - Numbers of single women registering with UK clinics and live births, 19 August 2014 <<http://www.hfea.gov.uk/9138.html>>. On this basis it can be assumed that more single women are offered fertility services respectively in England and Wales.

<sup>65</sup> The only available data concern the overall split between privately and publicly funded IVF and DI treatment cycles. According to the HFEA Reports on fertility treatment between 2011 and 2013 the proportion of privately and publicly funded cycles was respectively and approximately 60% to 40%. These figures do not distinguish between heterosexual and homosexual couples, and single women. Interestingly, the number of NHS funded DI cycles has been declining from 18.9% in 2010 to 16.4% in 2013. These figures refer to the UK as a whole, but it is fair to assume that they will be similar in England and Wales. See: [http://www.hfea.gov.uk/docs/HFEA\\_Fertility\\_Trends\\_and\\_Figures\\_2011\\_-\\_Annual\\_Register\\_Report.pdf](http://www.hfea.gov.uk/docs/HFEA_Fertility_Trends_and_Figures_2011_-_Annual_Register_Report.pdf) and [http://www.hfea.gov.uk/docs/HFEA\\_Fertility\\_Trends\\_and\\_Figures\\_2013.pdf](http://www.hfea.gov.uk/docs/HFEA_Fertility_Trends_and_Figures_2013.pdf).

<sup>66</sup> HFEA, A reply to a Freedom of Information Act Request F-2013-00203 - IVF treatment on the NHS for single women in the last five years, 24 July 2013, <<http://www.hfea.gov.uk/8516.html>>.

from NHS treatment<sup>67</sup>, and b) that the average age for single women seeking treatment is 40 years old<sup>68</sup>. On this basis, it is fair to assume that most of the treatments reported by the HFEA have been privately funded.

Within the NHS the numbers of single women receiving treatment at different fertility clinics across England and Wales will inevitably vary substantially, not least because of the now well-publicised 'post-code lottery' in fertility treatment.<sup>69</sup> A survey published by the Department of Health in March 2009<sup>70</sup> found that 30% of PCTs were adhering fully to NICE guidelines by offering three full cycles of treatment with only 2% not funding IVF. However, by 2014 this trend has been reversing. In 2013 only 23% of CCGs were still offering three cycles recommended by NICE<sup>71</sup> and by 2014 only 18% of CCGs provide the three cycles nationally recommended. Worryingly these figures show a notable reduction from the previous year in the number of CCGs who commission the recommended three cycles.<sup>72</sup> Although the numbers refer to treatment cycles in general, they are symptomatic of a trend that will inevitably affect single women.

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<sup>67</sup> NICE Press Release, 19 Feb 2013, <http://www.nice.org.uk/guidance/cg156/resources/updated-nice-guidelines-revise-treatment-recommendations-for-people-with-fertility-problems>

<sup>68</sup> HFEA, A reply to a Freedom of Information Act Request F-2014-00105 - The average age of single women being treated with IVF in 2012, 30 April 2014, <http://www.hfea.gov.uk/8943.html>

<sup>69</sup> NICE Press Release, NICE calls for an end to postcode lottery of IVF treatment, 23 Oct 2014, <https://www.nice.org.uk/news/article/nice-calls-for-an-end-to-postcode-lottery-of-ivf-treatment>; Ch. Cooper, NHS must end IVF 'postcode lottery' – watchdog says, *The Independent*, 23 Oct 2014 <http://www.independent.co.uk/life-style/health-and-families/health-news/nhs-must-end-ivf-postcode-lottery-watchdog-says-9811944.html>; C. Jones, The IVF postcode lottery that's stopping women from becoming mums, *The Daily Mirror*, 29 Oct 2014, <http://www.mirror.co.uk/lifestyle/health/ivf-postcode-lottery-that-stopping-4532868>; D. Ferguson, IVF and the NHS: the parents navigating fertility's postcode lottery, *The Guardian*, 10 May 2014; <http://www.theguardian.com/money/2014/may/10/ivf-nhs-fertility-postcode-lottery-cut-costs>;

<sup>70</sup> 152 Primary Care Trusts and Health Authorities responded to the survey. See: Department of Health (2009) *Primary Care Trust survey – provision of IVF in England 2008*, London: DH.

<sup>71</sup> Of 198 CCGs offering IVF to patients, 49% funded one cycle of treatment. 24% funded two cycles of treatment and only 24% funded three cycles. 'It is now nearly 10 years since the original NICE guideline was published and yet we are still facing a situation whereby the level of service is determined by postcode. Sutton and Merton, along with the CCGs covering the former North Yorkshire and York PCT, have all chosen to follow the policy of their predecessor PCTs and are consequently offering no funding for IVF. One very positive finding is that three areas identified as non-funders in 2011 (Stockport, Warrington and North Staffordshire), are now offering funding to eligible couples.' See: Fertility Fairness ((previously) National Infertility Awareness Campaign (NIAC)) *A report into the status of NHS fertility services in England* (London, 2014) <<http://www.infertilitynetworkuk.com/uploaded/NIAC/Assisted%20Conception%20Needs%20Assisted%20Implementation.pdf>>.

<sup>72</sup> Fertility Fairness (2014), *ibidem*.

To try to determine whether this decreasing trend has had a deferential impact on single women, a small pilot study has been undertaken focusing on the practices of NHS health care providers. As part of the study FOI requests were sent to 14 CCGs and Health Boards selected based on provision and size (7 CCGs in England<sup>73</sup> and 7 Health Boards in Wales<sup>74</sup>). The requests contained three questions, concerning: a) the number of single women who have received fertility treatment (IUI, IVF, ICSI) each year from 2008-2014; b) the number of single women who applied for treatment; c) the grounds on which any women were the denied treatment. Responses were received by 3 CCGs from England and 1 Health Board from Wales. These data suggest divergence in medical practices across the country. Perhaps more importantly, the data reveal a rather ambiguous picture. While according to data provided by the Welsh Fertility Institute, only 4 single women received publicly-funded IVF treatment last year<sup>75</sup>, responses from service providers in England revealed that a number of CCGs does not offer NHS fertility treatment to single women at all. For instance, in Hull CCG single women fall outside the scope of policy for assisted reproductive techniques.<sup>76</sup> While most CCGs do not hold separate information about the number of single women receiving treatment<sup>77</sup>, Manchester does not provide treatment to ‘single women who are not in partnership’.<sup>78</sup> The latter suggests that there might still be some definitional confusion about the term ‘single women’, with some clinics using it to describe (gay or

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<sup>73</sup> CCGs include: London - Tower Hamlets CCG, East of England – Cambridgeshire CCG, North East – Hull CCG, North West – Central Manchester CCG, South West - Bristol CCG, East Midlands – Nottingham City CCG, West Midlands - Birmingham Central CCG.

<sup>74</sup> Health Boards include: Abertawe Bro Morgannwg University Health Board, Aneurin Bevan Health Board (does not provide IVF treatment), Betsi Cadwaladr University Health Board, Cardiff & Vale University Health Board, Cwm Taf Health Board, Hywel Dda Health Board, Powys Teaching Health Board. However, as fertility treatment in Wales is governed by the Welsh Health Specialised Services Committee (WHSSC), which also sets additional local eligibility criteria for access to fertility treatment, most Health Boards referred the question to the WHSSC.

<sup>75</sup> Cardiff and Vale University Health Board (Welsh Fertility Institute), A response to a FOIA request received on 8 July 2014. It is important to note that the small number refers only to IVF treatments (i.e. it is possible that the number of single women receiving IUI has been higher. Cardiff & Vale University Health Board (Wales Fertility Institute) was the only HB to hold separate data about single women.

<sup>76</sup> Hull CCG, A response to FOI request - HU 287 received on 1 August 2014.

<sup>77</sup> Cambridge CCG, A response to FOIA request SF/sb/2014 – FOI 76 received on 15 July 2014.

<sup>78</sup> NHS Manchester (Primary Care Trust), NHS Funded Treatment of Subfertility Eligibility Criteria, June 2011, para. 5.4: ‘NHSM will not fund fertility treatment for single women who are not in a partnership.’

heterosexual) patients who are in informal relationships (as opposed to those who are married or in civil partnerships). This in turn indicates lack of transparency with regard to single women undergoing fertility treatment in England and Wales. Overall, the analysis of empirical data questions the optimistic picture painted in the post-legislative assessment and the scope of access to fertility treatment of single women. It also calls for more detailed investigation of the reasons why one particular group of patients has not benefited fully from the 2008 reforms. The following part of the paper concentrates on the recommendations stipulated in the NICE guidelines and their interaction with eligibility criteria to fertility treatment set out by CCGs' and Health Boards. . It suggests that the differences in CCGs' and Health Boards' practices and the restrictions in the access of single women to NHS fertility treatment have two main causes. First, it is the ambiguity intrinsic in the NICE guideline even after the recent the changes adopted in 2013.<sup>79</sup> Second, it is the incoherency and tension between different values embedded in the regulatory framework of publicly-funded ART services.

### **III. THE IMPACT OF NICE GUIDELINES ON SINGLE WOMEN'S REFERRAL FOR ART TREATMENT**

#### ***A. General eligibility criteria for fertility treatment***

The NICE 'fertility' guideline offers advice on assisting people of reproductive age who have problems conceiving. As one of NICE's major roles is to identify clinically- and cost-effective services which should be funded by the NHS, the guideline outlines eligibility criteria for access to fertility treatment for individual patients. Healthcare professionals in the NHS are expected to take NICE recommendations fully into account when exercising their

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<sup>79</sup> NICE (2013), *op.cit.*, n.5.

professional judgement, although the guidelines do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of each patient.<sup>80</sup> As confirmed by recent case law<sup>81</sup>, CCGs hold obligations in public law to have regard to the NICE guidance and are required to provide clear reasons for any policy choosing not to follow its recommendations. The same applies to health care professionals. Although formally the NICE instruments are not legally binding, failing to comply with their recommendations might have far-reaching implications for health care providers and individual health care professionals. It has been recently highlighted by courts that they might be used to support appeals against rationing decisions and judicial review claims.<sup>82</sup> Furthermore, although NICE powers do not extend beyond England, clinical guidelines continue to apply in Wales on the basis of an agreement with the Welsh Assembly Government.<sup>83</sup> NICE guidelines are subsequently implemented or modified by CCGs in England and Health Boards in Wales according to local needs and available resources.

According to the latest NICE guideline published in February 2013 fertility treatment should be offered to patients who have problems conceiving.<sup>84</sup> New provisions recommend that a woman of reproductive age, who has not conceived after 1 year of unprotected vaginal sexual intercourse, in the absence of any known cause of infertility, should be offered clinical assessment and investigation along with her partner. However, earlier referral for specialist consultation to discuss the options for attempting conception should be offered where: a) the woman is aged 36 years or over, b) there is a known clinical cause of infertility or a history of

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<sup>80</sup> NICE, Clinical Guidelines < <https://www.nice.org.uk/About/What-we-do/Our-Programmes/NICE-guidance/NICE-guidelines/NICE-clinical-guidelines>>.

<sup>81</sup> *R v Thanet Clinical Commissioning Group, ex p. Rose* [2014] EWHC 1182 (Admin) (15 April 2014)

<sup>82</sup> *Ibidem*.

<sup>83</sup> Welsh Assembly Government, The National Institute for Clinical Excellence – new relationship with Wales, 21/03/2005, WHC (2005) 22 <http://www.wales.nhs.uk/sites3/page.cfm?orgid=465&pid=5396>.

<sup>84</sup> NICE (2013), *op.cit.*, n. 5.

predisposing factors for infertility.<sup>85</sup> As far as assisted reproduction techniques are concerned, paragraph 1.9.1.1 of the guideline provides that IUI – which is much less demanding than IVF – should be considered as an option for some groups of patients before they are referred for IVF treatment. These groups include same-sex couples and people who are unable, or would find it very difficult to have vaginal intercourse because of a clinically diagnosed physical disability or psychosexual problem.<sup>86</sup> When IUI fails, the number of publicly-funded IVF cycles offered to a woman patient will be determined by her age. In women aged under 40 years who have not conceived after 2 years of regular unprotected intercourse or 12 cycles of artificial insemination (where 6 or more are by IUI), 3 full cycles of IVF will be offered with or without ICSI.<sup>87</sup>

#### *B. The effects of the NICE regulatory silence on single women*

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<sup>85</sup> This guidance is also repeated in the draft NICE Quality Standards published on 23 October 2014 <<http://www.nice.org.uk/guidance/qs73>>.

<sup>86</sup> NICE (2013), *op.cit.*, n. 5, para. 1.9.1.1.

<sup>87</sup> *Ibidem*, para.1.11.1.3-8.

Prima facie, the above recommendations seem quite straightforward and easy to implement. The main principle on which the guidance is based is that patients unable to conceive within a certain period of time are eligible for fertility treatment (including IUI, IVF and/or ICSI). The adoption of medical criteria as the basis for referral seems in conformity with the anti-discrimination laws and human rights standards, as it does not differentiate on the basis of sexual orientation or relationship status and as such it treats all women equally. One might thus wonder whether, and if so how, could the NICE guideline contribute to the aforementioned discrepancies between different CCGs and Health Boards in their policy-making practices which have the potential to exclude single women from fertility treatment. Are the reasons intrinsic to the guideline or, as most studies suggest, external to the regulatory provisions?

First of all, the NICE guideline does not specifically mention single women. Although a casuistic approach is not necessarily always an effective method of regulating professional conduct, in this particular case the omission is potentially problematic. The NICE guideline suggests that fertility treatment is offered only to women with diagnosed or suspected infertility issues or those in same-sex relationships. Unlike same-sex couples single women are not enumerated among patient groups which should be considered as potential candidates for the initial treatment of IUI, unless they suffer from specific medical problems rendering it impossible for them to engage in vaginal sex.<sup>88</sup> This would suggest that they are required to fulfil the condition of having 1-year period of unprotected sex before they can be referred for fertility treatment. If one were to depict the rationale behind this principle, it would appear to run as follows: at least theoretically, single women have the ability to procreate naturally, without the need for assisted reproduction services. Most assisted reproduction techniques are very onerous and should not be recommended unnecessarily. Natural conception will always

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<sup>88</sup> *Ibidem.*

be the preferred means of reproduction, as it is far less burdensome and expensive. Therefore, single women will be able to first try to conceive naturally before turning to assisted reproduction. Consequently, they will also be able to provide evidence of unsuccessful attempts to conceive. This kind of reasoning would suggest that whenever the regulators intend to include single women into the equation, they have heterosexual women in mind. This could explain why the NICE guideline does not mention single women among groups which should be automatically offered IUI.

In the abstract, this conceptualisation of ART services is correct and it is probably fair to assume that some (or perhaps most) single women will wish and manage to conceive without medical assistance. However, this assumption seems to contain a flaw which does not take into account important tendencies in contemporary society. The conception rate among women over 35 has been rising since 1990, and the conception rate for women aged over 40 has more than doubled from 6.6 to 14 conceptions per 1,000 women.<sup>89</sup> These women have consistently avoided motherhood for some time and if they decide to start a family on their own that choice is most probably a conscious one. They might choose not to engage in unstable relationships in order to conceive. The availability of assisted reproduction services has changed the understanding of reproductive decisions, providing additional options to large groups of society, and enabling a shift from chance to choice.<sup>90</sup> Consequently, many single women will exercise this choice and decide to use donor insemination as a more informed, transparent, and safer way of starting a family. This has been indeed confirmed in interviews conducted by Susanna Graham, in which getting pregnant through casual sex was

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<sup>89</sup> This number excludes teenage mothers in the UK. The UK has still the highest rate of teenage pregnancies in (western) Europe and. See: Office for National Statistics, Conceptions in England and Wales 2012, *Statistical Bulletin*, 25 Feb 2014 <[http://www.ons.gov.uk/ons/dcp171778\\_353922.pdf](http://www.ons.gov.uk/ons/dcp171778_353922.pdf)>. See also: *BBC News*, 'Teen pregnancy rate 'lower still'' 25 Feb 2014 <<http://www.bbc.co.uk/news/health-26338540>>. In 2013 only 2.6% of people under 20 years old conceived within marriage or civil partnership. Public Health England, Conception Statistics 2013, Census 2001, National report for England and Wales (C21) <http://www.lho.org.uk/viewResource.aspx?id=8453>.

<sup>90</sup> J. Habermas *The Future of Human Nature* (Cambridge: Polity Press, 2003).

dismissed on health safety and moral grounds.<sup>91</sup> Alternatively single women might come to an arrangement to use a sperm of a friend.<sup>92</sup> This is exactly the reason why they might not be able to meet the requirement of the 1-year period of unprotected intercourse, designed to indicate infertility. This latter condition is by definition, impossible to fulfil, unless we assume – or indeed require – that single women engage in random sexual relationships in order to establish their infertility.<sup>93</sup> Any expectation to engage in unprotected sex with ‘strangers’ would pose a considerable risk to their health and could potentially violate human dignity and the right to private life of these women. It is, thus, highly improbable that NICE, an arms-length body of the NHS, would ever intend to impose this kind of requirement and pressure on its citizens. However, even if, for the sake of argument, such interpretation were plausible (hypothetically a single woman could have been in a relationship which dissolved prior to her seeking treatment) the requirement poses further difficulties, as the guideline does not specify what kind of evidence should be submitted to substantiate her inability to conceive during the 1-year period.<sup>94</sup> There are two possible interpretative approaches to the provision setting the 1-year requirement that could lead to very different outcomes.

A restrictive literal interpretation of the guidelines could result in practices preventing single women from accessing IVF treatment, as it would be impossible for them to meet the 1-year period criterion. There will of course be cases where the patient is diagnosed with a condition potentially affecting fertility *prior to or independently of* considerations about procreation (e.g. cancers, infections, hormonal imbalance, etc...). However, to limit access to

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<sup>91</sup> S. Graham, ‘Single women negotiating relatedness’, in: T. Freeman, S. Graham, F. Ebtehaj, M. Richards (eds), *Relatedness in Assisted Reproduction* (Cambridge: Cambridge University Press 2014).

<sup>92</sup> At the same time, admittedly, the media have recently reported on ‘dating’ sites, where would-be sperm donors offer their services to would-be parents. E. Jackson, ‘The internet is a dangerous wild west of DIY-assisted conception’, *The Guardian*, 29 April 2013, <<http://www.theguardian.com/commentisfree/2013/apr/29/internet-wild-west-diy-assisted-conception>>.

Nevertheless, this reflects the growing acceptability of single parenthood, because many of these women decide to raise the children on their own.

<sup>93</sup> A more stable relationship would most probably result in a situation where the woman is treated together with her partner, thus losing her ‘single’ relationship status.

<sup>94</sup> The evidential difficulties are equally problematic in case of heterosexual couples, as it is not clear what evidence would be expected to substantiate claims of a 2-year period of unprotected intercourse.

ART services only to patients already diagnosed with health problems would prevent all those who suffer from unexplained infertility from receiving treatment. As the number of patients with unexplained subfertility is constantly rising, such interpretation could have serious consequences for access to treatment in particular for single women.<sup>95</sup> As the age for making reproductive decisions increases and the number of unexplained infertility cases grows it is likely that many single women, who have not yet attempted to conceive, will not be aware of any fertility problems. As fertility declines with age, more and more women will face such difficulties. Therefore, to employ a restrictive interpretation of NICE guidelines would drastically limit the number of single women eligible for NHS treatment. In addition, a reading like this would be *contra legem* as it threatens to thwart the objectives of the HFEA 2008, which aimed at removing the obstacles encountered by single women in their access to treatment.

Therefore, a teleological approach focused on achieving the purpose of the amended HFEA 1990 seems more appropriate. Such an approach could accommodate two different interpretations. One would be to employ a form of legal fiction with regard to the burden of proof and accept verbal statements from women about their failed attempts to conceive without the need to obtain any additional evidence. It seems unlikely that local CCGs and Health Boards would issue policies officially sanctioning referrals based on such premises. However, evidence suggests that some CCGs are already employing this method grounding their referral practices solely in patients' history provided by them.<sup>96</sup> Another more transparent way to achieve the aims of the amended HFEA 1990 would be to explicitly acknowledge that medical reasons do not constitute relevant grounds for access to treatment

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<sup>95</sup> According to the HFEA Annual Register Report 2011 out of 14551 reasons provided to justify IVF treatment 4433 have been unexplained. See: HFEA *Fertility treatment in 2011 trends and figures - Annual Register Report* (London: HFEA2011). This correlates roughly with the data provided by NICE in 2013, which estimates the number of unexplained infertility to around 25% or all reasons for referral to treatment. See: NICE (2013) *op.cit.*, n. 5.

<sup>96</sup> Cambridge CCG, A response to FOIA requests SF/sb/2014 – FOI 76: 'A patient's history is all that is requested for compliance in the absence of specific tests.' 15 July 2014.

of single women, who like gay women, are ‘socially infertile’. *Per analogiam*, if single women wish to conceive a child using donor insemination, they should be referred to a fertility clinic without the need to fulfil the 1-year requirement. This interpretation would mean that NHS funded IVF treatment could be open to single women: a) diagnosed with infertility, b) unaware of any fertility issues who nevertheless suffer from lower fertility (established as a result of the initial investigation), and perhaps more importantly c) women without any fertility issues (regardless of their sexual orientation) who have made a reproductive decision to start a family. This outcome seems to fall squarely within the principles of the HFEA 2008 amendments, which aimed at bringing the law on assisted reproduction in line with equality legislation and changing human rights standards, and confirming the provision of treatment to both, biologically and contextually infertile. It seems that the recent Quality Standards (QS) issued by NICE in October 2014 and aiming at improvements in clinical practice in the area of fertility treatment follow the broader interpretation proposed above.<sup>97</sup> However, the real impact of these standards remains to be seen. At the same time, the problem discussed above does not exhaust the obstacles arising before single women seeking treatment. Although individual provisions of the NICE guideline do not expressly discriminate against this group of patients, the guideline does allow for situations where discrimination might incidentally occur.

### *C. The case of incidental discrimination of single women resulting from regulatory silence*

The HFEA 2008 has been praised for removing in-built discriminatory provisions which put same sex couples seeking fertility treatment in a disadvantageous position. However, it might not have been equally successful in addressing other forms of family relationships and the

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<sup>97</sup> NICE (2014), *op.cit.*, n. 85.

fluidity of contemporary relationships.<sup>98</sup> If the relationship breaks up at an early stage of the referral process, both partners can seek treatment individually. If a similar situation arose, a woman coming out of a relationship would have little difficulties providing evidence of her infertility. Therefore, a break up could be beneficial from a referral point of view, because – should a teleological interpretation be employed – the woman would not have to comply with the 1-2 year waiting period. However, it is possible to imagine a reverse situation, which has not been anticipated in the amended HFEA 1990 and which could expose single women to additional complications. Let us imagine a hypothetical scenario, in which a single woman forms a relationship in the midst of fertility treatment and the new partner is willing to undergo fertility treatment with her. The scenario might seem less farfetched if one takes into account the length of fertility treatment from the initial consultation to successful conception, including long waiting lists. The legal situation of this woman changes dramatically and this change gives rise to several questions concerning access to treatment of *new* partners entering the treatment later in the process. What are the consequences for the single woman in terms of her eligibility for treatment? Can the new partner enter the treatment and if so, at which point? If he does, can he be treated as a partner or perhaps as a known donor?

The attempt to address these questions reveals an interesting regulatory conundrum. This woman might be doubly disadvantaged in the process of referral to treatment. First, as established by the studies by Lee et al. mentioned earlier, she might experience hostility during welfare of the child assessment. Second, once in a relationship, she might be subject to unfavourable rules concerning 1-2 year waiting period imposed on couples. Admittedly, such situations will occur very rarely and it therefore might be understandable that the Act does not contain specific provisions in this respect – it would be unreasonable to expect the legislator to regulate every eventuality of life. Nevertheless, this omission will inevitably shift

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<sup>98</sup> J. McCandless, *op. cit.* n. 36; J. McCandless and S. Sheldon, *op. cit.* n. 9.

the burden of decision-making on the medical staff in fertility clinics. They will be looking to professional and regulatory sources for guidance. However, neither the NICE guideline, nor even the HFEA COP, foresees a situation where the single women willing to undergo fertility treatment begins a relationship amidst the referral process. A lacuna at this level of the lower regulatory structure might be more problematic, as it creates ambivalence which can have adverse consequences for single women willing to start a relationship. The question, arises whether women in similar situation should be: a) refused treatment because of her changed relationship status (referred back to her GP for a new referral as a couple), b) 'put on hold' for 1-2 years to demonstrate infertility without the need of a new referral, or c) treated together with her partner, either as a sperm donor or her partner.

The first and the last option lie on the opposite ends of the spectrum. Bearing in mind that at least 29% CCGs require couples to spend three years attempting to conceive, rather than the recommended two years, and that at least 3% of CCGs – require couples to wait one to two years even when there is a diagnosed cause of infertility<sup>99</sup>, the first two options seem to disadvantage the woman in a new relationship. Taking into consideration these lengthy and complex procedures, the woman could lose several years in the process and become ineligible for treatment because of her age. Therefore, perhaps the least controversial solution would be to require the new couple to meet the 1-2-year requirement for medical reasons, but without the need to seek new referral. Although unfortunate for the woman seeking treatment, this could be justified in situations where neither partner is aware of any fertility problems, as it allows for the possibility to conceive naturally.<sup>100</sup> However, the same requirement would be

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<sup>99</sup> As it is highly improbable, if not impossible, that these couples will conceive naturally, this period seems to constitute nothing more than an enforced waiting list and a means to limit access to treatment. See: Fertility Fairness (2014), *op.cit.*, n. 71.

<sup>100</sup> As argued earlier, in contrast to same-sex couples and single women, heterosexual couples who are unaware of any fertility problems might still be able to conceive within 1-2 years of unprotected intercourse. Therefore, the argument that the 1-2 year waiting period requirement discriminates against heterosexual couples, in comparison to same-sex couples and single women is unsubstantiated. Such claims seem even less defensible in

unwarranted, if either of them had been already diagnosed with subfertility. If health problems have already been established, a waiting period creates unnecessary psychological burden for the woman, who although originally admitted for treatment, would be disadvantaged by the change in her relationship status. It is important to note that the double bias would not be against the newly-formed heterosexual couple, but against the single woman who has entered a relationship. Although empirical research on single women in fertility treatment has not yet addressed this particular issue, it is fair to assume that such women would be forced to leave NHS and seek treatment privately. Those in their late 30s, who could not afford this option would risk becoming ineligible for treatment.

The bias would be particularly obvious if the requirement to stay in a relationship for 2 years was to be imposed as part of the welfare of the child assessment aiming to prove the stability of the relationship. Formally, such assessments should be independent from rationing decisions, because the HFEA 1990 does not determine funding issues. However, anecdotal evidence suggests that there are instances where medical staff evaluating patients' eligibility presents the 2-year waiting period for heterosexual couples as part of the 'welfare of the child' assessment, a period to confirm the stability of the relationship.<sup>101</sup> It is likely that in such cases welfare of the child assessment is used as a rationing tool. This is highly problematic in light of the 8<sup>th</sup> HFEA COP, according to which: a) such assessment should only be undertaken in exceptional circumstances; b) the stability of relationship does not constitute part of the welfare of the child assessment or a condition to access treatment. If this was indeed the case, it would be hard to justify imposing such condition on heterosexual couples, but not on gay couples. However, if one were to apply the requirement consistently

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the context of NICE provisions that allow for this period to be shortened in cases where either one or both partners have already been diagnosed with fertility problems. See: NICE (2013), *op.cit.*, n. 5.

<sup>101</sup> The HFEA does not publish details of the exact assessment procedure that each clinic requires, so the evidence remains anecdotal on this. See: L. Riley, *op.cit.*, n., 82. A case illustrating the ambiguities of the eligibility assessment process occurred at the Cardiff & Vale University Hospital on the 3<sup>rd</sup> July 2013. The couple decided to seek treatment privately due to women's age. For ethical reasons (i.e. couple's wish to remain anonymous) the names of the parties involved cannot be disclosed.

to couples, then single women would be the clear beneficiaries of such regulation (as reported by the media) unless they were expected to provide evidence of a stable family network during a period of 2 years. A refusal to access treatment on this ground would be a convoluted rationing decision raising serious questions about the powers of commissioning bodies.

This scenario illustrates further shortcomings in the regulatory framework of publicly-funded fertility treatment so often praised for its sensitivity to changing social and family structures. It reveals areas where incidental discrimination of single women can occur due to the fact that (in particular heterosexual) single women have been too readily subsumed in the NICE guidelines under the wider notion of the ‘contextually infertile’ without due regard to the specificities of their situation. This in conjunction with the existing preconceptions towards single women can lead to further hurdles experienced by this group of patients. More importantly, however, the situations discussed above draw attention to much broader tensions between different rationales and values governing the system of NHS-funded ART services.

#### **IV. SINGLE WOMEN IN LIGHT OF GENERAL PRINCIPLES GOVERNING ACCESS TO ART**

##### ***A. Competing rationales of the publicly funded ART regulatory framework***

At the centre of the 2008 reforms was the recognition that the reproductive rights of same-sex couples and single women have the same standing as those of heterosexual couples. Single women were to be treated similarly to same-sex couples, because both groups were seen as ‘socially infertile’ and because their access to treatment required a modification of the welfare of the child principle. It seems peculiar at first that the aim to protect single women – so clearly articulated during Parliamentary debates – gets completely lost within the NHS context. However, the reasons become more transparent if one realises the fundamental

tension between different values and objectives governing NICE and local commissioning bodies.

NICE was established to ensure that ‘access to the NHS will be based on need and need alone’.<sup>102</sup> Hence, the NICE guidelines, so far as they affect resource allocation in the NHS, are based on a premise that treatment should be distributed on the basis of scientific, clinical, and financial efficiency and go to those with the biggest *clinical* needs.<sup>103</sup> These needs are established on the basis of scientific evidence, risk-benefit analysis and cost-effectiveness calculations. Finally, CCGs and Health Boards face the difficult task to interpret these normative documents in a way which reconciles the two rationales in face of rising financial pressures in the NHS. The conundrum entails finding a way to address simultaneously three challenges: a) to allow publicly-funded treatment for individuals who are fertile, but unable to conceive because of their particular life circumstances; b) to retain the basic principle (a myth?) that resource allocation and rationing decisions concerning fertility treatment are taken on purely clinical grounds; and c) to ensure that resource allocation policies and rationing decisions are taken in a non-discriminatory and equitable manner. Two questions arise in this context: 1) Is there a way to reconcile the tension between different rationale underlying the regulatory framework of fertility treatment? 2) How much latitude do CCGs and Health Boards have in diverging from the NICE guidelines in setting eligibility criteria limiting single women’s access to treatment? 3) How important is the (mis)understanding of the relationship between welfare of the child assessments and social eligibility criteria to provide single women with equitable access to fertility treatment?

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<sup>102</sup> Department of Health, *op.cit.*, n. 70.

<sup>103</sup> Department of Health, ‘The Government keeps its promise for fairer, faster, treatment for patients, the new National Institute for Clinical Excellence opens for business’. Press release, 31 March 1999, DoH Ref No. 1999/0193. The principle of equitable healthcare based on needs is also engrained in the Health and Social Care Act 2012 and the NHS Act 2006.

Although the regulatory framework of ART rests on the basic assumption that assisted reproduction services should be offered to those suffering from infertility, it is also clear that patients in perfect reproductive health might be eligible for treatment. As noted by Deech and Smajdor, a healthy woman may be eligible for treatment with IVF as ‘contextually infertile’, because her partner has fertility problems.<sup>104</sup> Moreover, unexplained infertility is extremely common. One of the ‘diagnoses’ of infertility is simply a failure to conceive after a certain period of having unprotected sex. Often, there may be no identifiable medical cause at all, but this does not mean that patients are denied treatment. This reasoning applies to single woman and people in same-sex partnerships.<sup>105</sup> The principle of non-discrimination on the basis of sexual orientation and the principle that rationing decisions should be based on clinical needs are reconciled through the broad conceptualisation of infertility and the acknowledgment that the inability to have children can have profound psychological (mental health) implications.<sup>106</sup> However, following this line of reasoning, it could be argued that in England and Wales fertility treatment is/should be open to all those who – for whatever reason – cannot conceive children naturally. This by no means a controversial statement. However, this widely accepted conclusion puts enormous financial pressure on the already stretched health care resources. Therefore, CCGs and Health Boards set out additional criteria limiting access to fertility treatment. So far, the task to establish objectively justified and non-discriminatory conditions has proved very difficult, if not impossible. It is in this area that the biggest differences between CCGs and Health Boards usually occur. They interpret differently clinical factors recommended by NICE and set a wide array of non-clinical

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<sup>104</sup> R. Deech and A. Smajdor, *op.cit.*, n. 8, 172.

<sup>105</sup> *Ibidem*,

<sup>106</sup> The conceptualisation of infertility as an illness has been discussed in the context of the medicalization of society, e.g. G. Becker and R. D. Nachtigall, Eager for medicalisation: the social production of infertility as a disease, 14 *Sociology of Health & Illness* 4 1992, 456-471; R. Tong, ‘Ethics, Infertility and Public Health’, in M. Boylan (ed), *Medical Ethics* 2<sup>nd</sup> edition, (Wiley Blackwell 2014), 13-30. These, albeit fascinating, discussions fall beyond the scope of this paper. At the moment demonstrating mental health problems as a result of infertility does not form part of eligibility assessment.

criteria. This is where the question about the margin of appreciation (scope of authority) of commissioning bodies comes into focus.

### ***B. The CCGs' powers to set eligibility criteria***

In addition to the statutory obligations of s. 13 (5) HFEA 1990, local commissioning bodies impose their own social criteria for treatment to enable prioritisation in the allocation of fertility treatment. They usually choose between the following non-medical factors: a) no children from current or previous relationship (very common) sometimes including foster or adopted children, b) no children living with couple, c), non-smoking, d) no previous sterilisation in either partner, e) stable (2 year) relationship, f) age restrictions on female and/or male, g) BMI 20-25, h) registration with local GP for a minimum of three years.<sup>107</sup>

Some of these criteria can be seen as derived from the NICE guideline, which advises doctors to inform the patients about the potential negative influence on fertility of factors such as smoking, alcohol consumption, body weight, or occupation. It might be argued that they are used as selection criteria because the treatment should be offered to those who have the best chance to conceive and in those cases where the treatment will be most effective.<sup>108</sup>

However, as the wording of these provisions is much less prescriptive, it is not clear whether, and if so to what extent, they should be treated by fertility clinics as eligibility criteria for treatment. Additionally, these factors should be distinguished from other criteria imposed by the commissioning bodies which are completely unrelated to fertility or health. These include length of the relationship, stability/extent/composition of family networks, or existing children of one partner or adopted/foster children living with patients seeking treatment. These factors are not mentioned by NICE at all and it is not clear how they have made their way into CCGs' policies. The most probable explanation would be that the need for a

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<sup>107</sup> Department of Health (2009), *op.cit.*, n.70.

<sup>108</sup> Another important criterion falling within this category would be age.

biologically and/or genetically related child has been confused with psychological need for a child (and the presence of (any) children in the family is seen as satisfying the need for parenthood and thus a factor excluding from treatment). There is no basis for this in the national NICE guideline and yet 81% CCGs deny treatment on these grounds.<sup>109</sup> This is truly astonishing in light of the fact that from the start the primary purpose of reproductive medicine has been to enable patients have biologically and/or genetically linked offspring. The importance of this need has been not only recognised through the adoption of the HFEA 1990, but also confirmed in human rights case law.<sup>110</sup>

The widespread and divergent use of clinical and non-clinical factors, illustrating the well-known problem of post-code lottery, has been heavily criticised by Fertility Fairness and the Infertility Network UK.<sup>111</sup> Their report called for a mandatory and definite list of access criteria produced by NICE and NHS England to remove the existing differences. As a response to the wide-spread criticism NICE issued Quality Standards (QS) aiming at reducing the existing variation between different CCGs and Health Boards and harmonising clinical practice. This initiative, supported by the main charities involved in the area of reproductive health, needs to be seen as a vital step in securing equitable access to health care. As such it should also improve the access of single women to fertility treatment. However, although a step in the right direction, it is questionable whether it will solve the problems identified in the aforementioned study by Lee et al., which highlighted the ambivalent relationship between welfare of the child assessments, NHS funding criteria, and individual clinic protocols.<sup>112</sup> Furthermore, it is doubtful that the NICE QS will manage to reconcile the

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<sup>109</sup> Fertility Fairness (2014), *op.cit.*, n. 71. See also: Fertility Fairness Survey (2014) <<http://www.fertilityfairness.co.uk/nhs-fertility-services/ivf-provision-in-england/>>.

<sup>110</sup> *Evans v. the United Kingdom* (App. No.6339/05) ('the right to respect the decision to become a parent in a genetic sense') [2008] 46 EHRR 34; *Dickson v UK* (App. No. 44362/04) [2007] All ER (D) 59 (Dec), *S. H. and Others v. Austria* (App. No. 57813/00) [2010] 52 EHRR 6.

<sup>111</sup> Fertility Fairness (2014), *op.cit.*, n.71.

<sup>112</sup> The study found that in some clinics, there is a porous boundary between the clinic's role in assessing prospective patients' compliance with funding criteria established by former PCTs and its role in performing the

competing rationales and broader lack of coherency between different elements of the regulatory framework. This lack of coherence is paradigmatic of the tension between resource allocation and the right to access treatment and as such it exceeds the scope of this paper. However, a few remarks of a general nature are worth noting here.

Despite all the difficulties outlined above, it is still relevant to consider the possibility of the right of single women to access ART services. For, it would seem incorrect to suggest that single women lack any legal protection should they seek fertility treatment. Although it is very difficult to argue the existence of a right to fertility treatment, interpreted as an absolute right to demand access to ART services and protected by effective remedy, a suggestion that there is a right to be considered for treatment without discrimination seems very plausible and should be easily accepted. At the individual level it has become apparent that once the condition is recognised as illness, the commissioning body must consider individual's condition before refusing to fund treatment.<sup>113</sup> In this respect, despite ongoing debates about the definition of disease and health needs, the status of infertility as an illness has been officially approved both, at the international level by the WHO (in a non-hierarchical list of diseases), and at the national level by NICE. As illustrated in the statements issued recently by the latter aiming at harmonising the diverse commissioning practices, a wide consensus is forming that commissioning bodies should acknowledge that a clear decision has been made by Parliament, the Government, and NICE to fund fertility treatment from public resources.<sup>114</sup> Commissioners in England and Wales have a duty to take this statutory decision into account when they design their rationing policies. It is also important to note that the NHS Constitution also emphasises the patient's right to treatments

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welfare of the child assessment. For example, welfare of the child assessment forms sometimes included questions related to smoking, Body Mass Index (BMI), relationship stability, age, and existing children. However, these tended to be rationalised by staff on medical or rationing grounds. See: Lee et al. (2014), *op.cit.*, n. 9.

<sup>113</sup> *R v North West Lancashire Health Authority, ex p A, D, and G* [2001] 1 WLR 977.

<sup>114</sup> V. Whitehead, 'Commissioning decisions reveal the trivialisation of infertility', *BioNews* 772, 22 September 2014 <[http://www.bionews.org.uk/page.asp?obj\\_id=454560&PPID=454613&sid=813](http://www.bionews.org.uk/page.asp?obj_id=454560&PPID=454613&sid=813)>.

that have been recommended by NICE for use in the NHS, if recommended by the doctor as clinically appropriate.<sup>115</sup> Despite highlighting the sensitive issue of resource allocation, the use of rights-based language might have modest, yet important consequences. First, it can help shift the burden of proof from patients to the CCGs, so that a restriction of the right needs to be objectively justified by the commissioning body. Therefore, second, it might gradually help limit the need to argue the existence of exceptional circumstances in order to receive treatment. The authority of the CCGs and Health Boards in drafting access to treatment criteria might be broad, but it is not unlimited.

The courts can still intervene in rationing decisions, if they are persuaded: a) that the decision-making process is flawed (procedural injustice)<sup>116</sup>, b) where a blanket policy is pursued, without considering each case individually, c) the real reason behind a decision is not transparent (financial consideration rather than clinical decision)<sup>117</sup>, or d) the promise to offer particular services is broken<sup>118</sup>. It can thus be assumed that the courts support transparency especially that it is now also required by the NHS Constitution.<sup>119</sup> Furthermore, as demonstrated in the case of *Condliff*, the courts expressed a clear preference for clinical over social/non-clinical criteria in rationing decisions.<sup>120</sup> The claimant argued that the commissioning policy, which led to him being denied treatment, violated his right to private life, because it did not take into account social factors. Although the court rejected his claims, it applauded the fact that the resource allocating policy of the commissioning body was based on the comparative assessment of clinical needs because it was intentionally non-discriminatory. The circumstances in *Condliff* cannot be easily applied to single women

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<sup>115</sup> Department of Health (2013) *The NHS Constitution*, 26 March 2013, London: DH.

<sup>116</sup> *R v West Sussex Primary Care Trust, ex p Ross* [2008] EWHC 2252 (Admin).

<sup>117</sup> *R v Swindon NHS Primary Care Trust and another, ex p Rogers* [2006] EWCA Civ 392. Cf.

<sup>118</sup> *R. v. North and East Devon HA, ex p Coughlan* [1999] EWCA Civ 1871

<sup>119</sup> NHS Constitution, *op.cit.*, n. 115.

<sup>120</sup> A morbidly obese man has lost his appeal against his local Primary Care Trust's (PCT's) refusal to fund his anti-obesity surgery. See: *Condliff, R (on the application of) v North Staffordshire Primary Care Trust* [2011] EWCA Civ 910.

seeking access to ART services, who might not suffer from a clinical condition. However, there are aspects of the decision, which are relevant to the current discussion. First, the judgment in *Condliff* showed that courts are prepared to accept differences between various commissioning bodies as long as rationing decisions are based on non-discriminatory and objective criteria. This certainly brings into question the acceptability of the non-medical criteria used by CCGs and Health Boards in drafting policies concerning access to ART services, such as the stability of a relationship and/or the support family network. Second, at the heart of Condliff's claim was an attempt to tackle postcode lottery and more importantly to introduce human rights to resource allocation considerations. Regardless of the final outcome of the case, it is becoming clear that as a result of the Human Rights Act 1998 rationing decisions are now expected to be made with regard to due process requirements and to claims to equality and proportionality. This expectation seems to coincide with the obligations imposed by the Health and Social Care Act 2012 on the Secretary of State to 'have regard to the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service'.<sup>121</sup> Despite the fact that establishing a breach of statutory duty has been an ineffective alternative to judicial review, the introduction of this duty in addition to existing obligations should not go unnoticed. Even if the provision does not open a new litigation route for single women, it requires all the delegated bodies exercising healthcare functions to take their situation into account when drafting and implementing policies concerning fertility treatment and delivering ART services.

## V. CONCLUSIONS

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<sup>121</sup> S 1(c) of the Health Service Act 2006 as amended by S 4 of the Health and Social Care Act 2010.

The purpose of this paper was to provide a preliminary analysis and identify potential gaps and inconsistencies in the regulatory framework surrounding the access of single women to publicly funded fertility treatment.. In particular the study focused on the rights of single women stipulated in the statutory framework, including the HFEA 1990 (as amended by the HFEA 2008), the Equality Act 2010, and the NHS Act 2006 and eligibility criteria for fertility treatment set out in the 2013 NICE clinical guidelines. . The analysis revealed that although formally the legal framework has substantially improved the situation of single women in recent years and removed much of pre-existing biases against them, they are still exposed to prejudice and potential (accidental) discrimination. The paper drew on recent studies showing that negative attitudes concerning single women still persist among medical staff and it has been argued that these assertions stem from the ambiguity inherent in the welfare of the child assessment stemming from the amended s 13 (5) HFEA 1990. It also highlighted the inadequacies of the currently equality legislation, which does not include the state of 'being single' in its protected characteristics.

However, this paper has demonstrated that the reasons for potential discrimination against single women originate in the regulatory framework of assisted reproduction services, which fails to provide adequate protection to single women seeking publicly funded fertility treatment. The paper found that the primary reason for remaining inequalities can be attributed to the ambiguities inherent in the regulatory framework, which in the context of publicly-funded fertility treatment is determined by the NICE clinical guidelines and CCGs and Health Boards' resource allocation policies. In particular, the paper revealed ambiguities, inconsistencies, and gaps in the NICE guidelines that might adversely affect single women's access to treatment. It has been argued that although as a matter of principle casuistic approaches to regulation should be avoided, in this particular instance addressing single women expressly would improve their legal standing as fertility patients and send a powerful

message to CCGs and Health Boards responsible for resource allocation and health care professionals taking individual rationing decisions. Furthermore, the paper has identified an area where neither the amended HFEA 1990 nor the NICE guideline take fully into account the fluidity and dynamics of contemporary relationships.

Finally, the paper also exposed surprising serious gaps in the understanding of the position of single women in fertility treatment. First, the number of single women undergoing publicly-funded treatment remains unknown, not least because of definitional ambiguities that persist in defining 'single women'. Second, it is not clear why the subsequent HFEA Codes of Practice have not been successful in changing professional attitudes towards single women. Third, despite numerous studies of NICE regulatory practices, the implementation of guidelines continues to pose significant obstacles. This lack of knowledge reveals that, despite their vulnerability in the context of the NHS fertility treatment, single women remain a silent, excluded, and even absent group of patients.

Therefore, further studies are required to investigate the legal and societal standing of single women in the context of fertility treatment. Such studies should analyse the factors taken into account by clinicians when they determine the eligibility of patients according to clinical guidelines. They should also aim to investigate how health care professionals view discrimination/non-discrimination of single women seeking access to ARTs and to what extent the regulatory framework is responsible for their attitudes. Finally, further research should aim to determine local practices of commissioning bodies and health care professionals, involved in the decision making process concerning access to IVF treatment. Only through such a comprehensive analysis of the complex socio-legal realities can the situation of single women be improved.

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