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# **‘Supportive Parenting’, Responsibility and Regulation: the Welfare Assessment under the reformed Human Fertilisation and Embryology Act (1990)**

**Sally Sheldon\*, Ellie Lee\*\* and Jan Macvarish\*\*\***

## **Abstract:**

Section 13(5) of the Human Fertilisation and Embryology Act 1990 imposes a requirement on fertility clinics in the UK that, before offering regulated treatment services, they must take account of the welfare of any child who may be born as a result of the treatment and any other child affected by that birth. This paper presents the findings of an empirical study examining how controversial reform of this section in 2008 has impacted (or failed to impact) upon practice. It suggests that while the broad values underpinning section 13(5) appear well-embedded in the ways in which clinic staff engage with the ethical issues raised by their work, there is little evidence to suggest that practice has been influenced by the new wording of the legislation and accompanying guidance. Regulation does not operate in a vacuum and a complex picture emerged regarding the implementation of section 13(5), particularly in the light of the interaction of the statutory norm with other factors, such as NHS funding criteria and professional norms around counselling. This combines to imply a higher level of ongoing attention to likely parenting ability – particularly that of single women – than might be expected from a reading of the statute and guidance alone.

## **Key words:**

Welfare of the child; Section 13(5); Human Fertilisation and Embryology Act (1990); Counselling; Regulation; Parenting; Parenthood; Single Women.

## Introduction

The reform of the UK's Human Fertilisation and Embryology Act (1990) after almost twenty years in operation provoked prolonged, sometimes heated debate.<sup>1</sup> The 1990 Act had represented an attempt to offer a framework for responsible science, harnessing the promise of assisted reproductive

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<sup>1</sup> The Act establishes a regulatory regime for embryo research and for those infertility treatment services which involve creation of embryos outside of a woman's body and/or use of any gametes other than her own and those of her partner. For consideration of the debates relating to s.13(5), see e.g. J. McCandless and S. Sheldon, "No Father Required"? The Welfare Assessment in the Human Fertilisation and Embryology Act (2008)' (2010) 18(3) Feminist Legal Studies 201.

technologies and embryo research, whilst containing them within acceptable moral boundaries.<sup>2</sup> One dominant theme in the anxiety provoked by the new technologies was the likely impact on the traditional family and the 1990 Act reflected a desire to protect and entrench a model of 'heterosexual, preferably married, parents.'<sup>3</sup> Section 13(5), the 'welfare clause', was a major plank in this project and one which has proved controversial since the moment of its inception. The provision represented a compromise measure, which imposed a requirement that, before offering regulated treatment services, clinics must take account of the welfare of any child who may be born as a result of the treatment (including the need of that child for a father) and of any other child who may be affected by the birth.<sup>4</sup> Reform of section 13(5) became a key focus of parliamentary and media attention and the eventual replacement of the wording envisaging the need of that child 'for a father' with the need for 'supportive parenting' represented the outcome of lengthy consideration.

Taking section 13(5) as its focus, this paper presents the findings of an empirical study examining how this highly controversial change to legislation impacted (or failed to impact) upon practice. It suggests that while the broad values underpinning section 13(5) appear well-embedded in clinic staff's engagement with the ethical issues raised by their work, there is little evidence to suggest that the way in which discretion is exercised is influenced by such changes to the wording of statute or specific detailed guidance regarding the finer points of its interpretation. Further, a complex picture emerged regarding the implementation of section 13(5), with a higher level of ongoing scrutiny regarding

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<sup>2</sup> M. Mulkey, *The Embryo Research Debate: Science and the Politics of Reproduction* (Cambridge: Cambridge University Press, 1997).

<sup>3</sup> J. Dewar, 'The Normal Chaos of Family Law' (1998) 61 MLR 467, 482.

<sup>4</sup> See generally R.G. Lee and D. Morgan, *Human Fertilisation and Embryology: Regulating the Reproduction Revolution* (Oxford: Blackstone Press, 2001), chapter 6.

motivation for parenthood and future parenting ability than might be expected, with – in some clinics, at least – this scrutiny particularly focused on single women. In this regard it is important to remember that regulation does not operate in a vacuum. Professional practice is rather determined by a broad range of influences including the ‘residue’ of earlier legal provisions, institutional pressures, professional cultures, the individual’s own broader moral views and emotional reactions, and economic constraints.<sup>5</sup> Our research thus offers a case study of how statutory norms will interact with other factors in practice, sometimes producing unintended results.

We begin by providing some brief background to the relevant law and summarising the process leading to reform, before giving more information about our study. We then move on to discuss our findings, first, regarding how the broad values underpinning the legislation have been accepted and applied and, second, how the regulatory framework interacts with other competing norms. The issue of whether single women and lesbian couples should be accepted for treatment has been a key focus in the history of section 13(5) and we end with specific consideration of how these groups fare under the new legislation.

## 1 The reform process and new law

### The reform process

The origins of the 1990 Act lie in a report produced by a Committee of Inquiry, chaired by Mary (now Baroness) Warnock in 1984.<sup>6</sup> Some twenty years on, while recognised as ‘a tribute to the foresight of its

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<sup>5</sup> See generally: J. Black, ‘New Institutionalism and Naturalism in Socio-Legal Analysis: Institutional Approaches to Regulatory Decision Making’ (1997) 19 *Law & Policy* 51, at 51-2.

<sup>6</sup> *Report of the Committee of Inquiry into Human Fertilisation and Embryology*, Report Cm 9314 (1984).

creators’,<sup>7</sup> the Act was nonetheless widely accepted to be in need of updating and further ‘future proofing’. Notably for current purposes, reform provided an opportunity to revise it in the light of changing social and familial norms, bringing same-sex and single parents more effectively within the statutory framework, while nonetheless continuing to privilege a two-parent model of parenting.<sup>8</sup> The vehicle for reform, the Human Fertilisation and Embryology Act 2008, was the product of significant consultation, review and discussion including over eighty hours of parliamentary debate.<sup>9</sup>

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<sup>7</sup> Department of Health, *Review of the Human Fertilisation and Embryology Act: A Public Consultation* (2005).

<sup>8</sup> On the continued privileging of a two-parent model within the legislation, see further J McCandless and S Sheldon, ‘The Human Fertilisation and Embryology Act (2008) and the Tenacity of the Sexual Family Model’ (2010) 73(2) *Modern Law Review* 175 and J McCandless ‘The Role of Sexual Partnership in UK Family Law: the Case of Legal Parenthood’ in D Cutas and S Chan (eds) *Families – Beyond the Nuclear Ideal* (London, Bloomsbury Academic, 2012).

<sup>9</sup> Hansard Society, *Online Consultation on Human Reproductive Technologies and the Law, Commissioned by the Science & Technology Select Committee (Summary Report)* (2004); House of Commons Science & Technology Committee, *Human Reproductive Technologies and the Law* (Fifth Report of Session 2004-5. HC 7-1) (2005). See further: HM Government, *Government Response to the Report from the HC Science & Technology Committee* (2005); Department of Health, *Review of the Human Fertilisation and Embryology Act: a Public Consultation* (2005); Department of Health, *Review of the Human Fertilisation and Embryology Act: Proposals for Revised Legislation*, Report Cm 6989 (2006); House of Lords, House of Commons Joint Committee on the Human Tissue and Embryos (Draft) Bill, Vol 1: Report, Session 2006-07, HL Paper 169-I, HC Paper 630-I (July 2007) and Vol II: Evidence, Session 2006-07, HL Paper 169-II, HC Paper 630-II (July 2007). See also HM Government, *Government Response to the Report from the Joint Committee on the Human Tissue and Embryos (Draft) Bill*, Report Cm 7209 (2007).

Consideration of the welfare clause occupied a very substantial and, arguably, wholly disproportionate amount of this time,<sup>10</sup> with the proposal that the 'need for a father' should be deleted from the legislation criticised as an attack on the family, fatherhood and traditional male roles in modern Britain.<sup>11</sup> Parliament was presented with a 'veritable banquet of options'<sup>12</sup> for what wording might replace it, including the need for 'a father and a mother',<sup>13</sup> 'support by a father and a mother',<sup>14</sup> 'supportive parenting and the advantages of having a father and a mother',<sup>15</sup> 'supportive parenting and a father or male role model',<sup>16</sup> 'supportive parenting and family life'<sup>17</sup> and 'the advantages of

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<sup>10</sup> See McCandless and Sheldon, above n 8, for more detail and for a contrast with discussion of the parenthood 'status provisions' (ss. 33-47), which have significantly more impact in practice yet received around one tenth of the time for debate in Parliament and considerably less attention in the consultation and committee processes noted above.

<sup>11</sup> See generally, McCandless and Sheldon, above n 1, for a fuller account of this aspect of the reform process and reporting of it.

<sup>12</sup> Per Lord Warner, HL Debs vol 698 col 71 21 January 2008.

<sup>13</sup> Amendment 56, tabled by Iain Duncan Smith, David Taylor, Claire Curtis-Thomas, Johan Gummer, Michael Ancram and Geraldine Smith.

<sup>14</sup> Amendment 108A, tabled by Baronesses Deech and O'Caithan and Lord Lloyd of Berwick.

<sup>15</sup> Amendment 108C, tabled by Lord Northbourne, Baroness Butler-Sloss and the Earl of Listowel.

<sup>16</sup> Amendment 58, tabled by Mark Simmonds and Andrew Lansley.

<sup>17</sup> Amendment 108B, tabled by Lord Northbourne, Baroness Butler-Sloss and the Earl of Listowel.

having a father and a mother'.<sup>18</sup> After protracted debate, the Government's proposal that 'the need for a father' be replaced by 'the need for supportive parenting' was enshrined in the final text of the legislation.<sup>19</sup>

Recognising the limitations of statute as a way of regulating such a complex and fast-moving field and the problem of 'speaking from the past' while 'purporting to govern the future',<sup>20</sup> the 1990 Act had established a regulatory body, the Human Fertilisation and Embryology Authority (HFEA), and charged it with issuing and regularly updating a Code of Practice. The Code's guidance on how section 13(5) should be understood provides an interesting example of the greater flexibility of non-statutory regulation in keeping up with evolving social mores, involving what one recent account describes as 'law-making by interpretative elaboration'.<sup>21</sup> The Code had evolved in interesting and significant ways

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<sup>18</sup> Amendment 101A, tabled by Baroness Deech and Baroness Butler-Sloss.

<sup>19</sup> Amendment 108, tabled by Lord Darzi on behalf of the Government.

<sup>20</sup> Julia Black argues that written norms have two central features which make them particularly problematic regulatory instruments: their temporal aspect (they speak from the past or present but purport to govern the future) and their linguistic aspect (they require interpretation). J Black 'Regulatory Conversations' (2002) 29(1) JLS 163, 172.

<sup>21</sup> J Montgomery, C Jones and H Biggs, 'Hidden Law-Making in the Province of Medical Jurisprudence' (2014) 77(3) MLR 343, 349-51.



before the changes introduced in 2008.<sup>22</sup> For example, the first edition of the Code, published in 1991, had advised that where the child would have no legal father:

Centres are required to have regard to the child's need for a father and should pay particular attention to the prospective mother's ability to meet the child's needs throughout his or her childhood, and where appropriate whether there is anyone else within the prospective mother's family and social circle who is willing and able to share the responsibility for meeting those needs and for bringing up, maintaining and caring for the child.<sup>23</sup>

At that time, clinics were obliged to satisfy themselves that the woman's General Practitioner knew of no reason why she should not be offered treatment; and while her GP should only be approached with her consent, a refusal would be taken into account in considering whether or not to treat her.<sup>24</sup>

Over subsequent years, section 13(5) came increasingly to be viewed as out of step with attitudes towards same-sex couples,<sup>25</sup> and later editions of the Code saw a marked relaxation of these requirements. By 2007, when the legislation came to be reconsidered by Parliament, the Code had already moved towards an explicit presumption in favour of providing treatment to those who request it, with clinics advised to contact GPs and other relevant agencies only where the information gathered

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<sup>22</sup> See generally McCandless and Sheldon, above n 1; E. Blyth, 'The United Kingdom's Human Fertilisation and Embryology Act 1990 and the Welfare of the Child: a Critique' (1995) 3 *The International Journal of Children's Rights* 417-438; Montgomery et al, *ibid.*

<sup>23</sup> HFEA *Code of Practice* (1st Edition, 1991), para 3.16.

<sup>24</sup> *ibid*, para 3.19.

<sup>25</sup> As reflected in a range of legal reforms, e.g. Civil Partnership Act 2004; Adoption and Children Act 2002.

from patients gave grounds to suggest that there might be a risk of serious harm to the child, or where information gathered was incomplete, inconsistent, or deception was suspected.<sup>26</sup> Treatment should be refused only if the centre concluded that the child to be born or any existing child of the family 'is likely to experience serious physical, psychological or medical harm or where the treatment centre is unable to obtain sufficient further information to conclude that there is no significant risk'.<sup>27</sup> For the first time, this (seventh) edition of the Code also provided that a patient's refusal for her GP to be contacted should not itself be grounds for refusing treatment<sup>28</sup> and, explicitly, that 'patients should not be unfairly discriminated against on grounds of gender, race, disability, sexual orientation, religious belief or age'.<sup>29</sup> Combined, this set of changes represented a significant restacking of the decks in favour of the possibility of offering treatment, foreshadowing the legislative reform. The repeated attention paid to this provision across successive editions of the Code of Practice also demonstrates the HFEA's awareness of the sensitivities associated with section 13(5) and a sustained concern with influencing its interpretation.

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<sup>26</sup> HFEA, *Code of Practice* (7th Edition, 2007) para G.3.3.3.

<sup>27</sup> *ibid*, para G.3.4.5.

<sup>28</sup> *ibid*, para G.3.4.4.

<sup>29</sup> *ibid*, para G.3.3.2. The explicit reference to sexual orientation is significant. The 6th Edition of the Code had stated merely that those seeking treatment 'are entitled to a fair assessment', which should be conducted 'with skill and care' and due regard 'to the wishes and sensitivities of all involved' HFEA, *Code of Practice* (6th Edition, 2003), para 3.12.

The reform process has been extensively considered elsewhere.<sup>30</sup> For our purposes, it suffices to note that the significant attention paid to section 13(5) throughout suggests that Parliament, like the media, identified it as a key issue and, further, that at least some Parliamentarians attached sufficient weight to its exact wording to justify expending significant time and energy on its reform. This raises the question of whether this level of attention in any way correlates with the impact of the reform in practice, and this was one of the questions that inspired our research.

### The current law

Section 13(5), as amended, now reads:

A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for supportive parenting), and of any other child who may be affected by the birth.

A new, eighth, edition of the Code of Practice was issued the year after the legislation was passed.<sup>31</sup> This maintained a presumption in favour of treatment, giving the following definition of ‘supportive parenting’:

Supportive parenting is a commitment to the health, well-being and development of the child. It is presumed that all prospective parents will be supportive parents, 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

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<sup>30</sup> See generally, the special issue of *New Genetics and Society* (2013, 32(2)) on the reform process and the new legislation. On debates regarding the reform of section 13(5) specifically, see e.g. McCandless and Sheldon, above n 1.

<sup>31</sup> HFEA *Code of Practice* (8th Edition, 2009).

or neglect. 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>32</sup>

The potential for tension between the key values of the need to take account of child welfare, on the one hand, and the avoidance of discrimination, on the other, is thus mediated through a risk analysis process. Prospective parents should henceforth be assumed to be 'supportive' and accepted for treatment unless clinics are aware of factors likely to cause a risk of 'significant harm or neglect'.<sup>33</sup> The Code provides a non-exhaustive list of such risk factors, which include: any aspects of the patient's (or, if she has one, her partner's) past or current circumstances that may lead to a child experiencing 'serious physical or psychological harm or neglect' (e.g. previous convictions relating to harming children); or past or current circumstances likely to lead to an inability to care throughout childhood for any such child (e.g. mental or physical conditions or drug abuse).<sup>34</sup> The draft Code of Practice, as

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<sup>32</sup> *ibid*, para 8.11. This definition differs in subtle and interesting ways from that which was suggested in Parliament, see McCandless and Sheldon, above n 1, 217-18.

<sup>33</sup> *ibid*, para 8.10.

<sup>34</sup> *ibid*. This translates into the following list of questions on the standard HFEA 'Welfare of the Child: patient history' form, which was used in many clinics in our sample: 1 Do you have any previous convictions relating to harming children? 2 Have any child protection measures been taken regarding your children? 3 Is there any serious violence or discord within your family environment? 4 Do you have any mental or physical conditions? 5 To your knowledge, is your child at increased risk of any transmissible or inherited disorders? 6 Do you have any drug or alcohol problems? 7 Are there any other aspects of your life or medical history which may pose a risk of serious harm to any child you might have or anything which might impair your ability to care for such a child?

put out for consultation, had envisaged including reference in this list to wider family and social networks. However, in order to avoid the risk of discriminating against 'lesbian couples, single women, orphans and recent immigrants, who may not have a wider family or social network',<sup>35</sup> this factor was relegated in the final version, to be considered only where one of the other risk factors had triggered concern (thus becoming more likely to gain relevance not as a cause for concern in its own right but as a way of alleviating concerns raised by other factors). This provides a clear example of the strength of the HFEA's concern to avoid discrimination in access to treatment services.

## 2 The study

Our study sought to assess how this change to the legislation and Code of Practice was received by clinic staff and, from their perspective, how it had affected clinical practice. A researcher visited twenty clinics (just over one quarter of the 77 licensed to carry out IVF), a sample large enough to capture the range of existing practice. It included clinics of all sizes, from all regions of the UK and

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<sup>35</sup> HFEA, *Consultation Report: Code of Practice 8<sup>th</sup> Edition and Revised Consent Forms* (2009), para 3.9. The definition of 'supportive parenting' contained in the Code was similarly amended to delete the word 'sustained' from the original requirement contained in the draft, for a '*sustained* commitment to the health, wellbeing and development of the child'. The deletion reflected a concern that the clause not be read as mandating the exclusion of patients who had 'a serious medical condition or terminal illness'. This sits in some tension with some cases we were told about, see below, particularly the cases described in the text accompanying nn 48 and 56.

located within and outside the NHS.<sup>36</sup> Our sample was constructed to reflect the fact that, in practice, welfare assessment is not treated as the sole responsibility of any one person, with interviews conducted with an average of three members of staff at each clinic, typically including the lead clinician, who was also generally the Person Responsible (PR) under the legislation,<sup>37</sup> and two further members of staff with different professional backgrounds, including nurses, counsellors and embryologists. Interviews were recorded, transcribed and analysed with the support of NVivo.<sup>38</sup>

Our interest in conducting the study was raised by the amount of time that Parliament had spent on this issue, combined with our knowledge that the initial introduction of section 13(5) was found to have made very little difference to clinical practice in the early 1990s.<sup>39</sup> We were also interested to gain a better impression of practice in this area. A number of studies into section 13(5) were carried

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<sup>36</sup> Clinic size was determined by the number of cycles of treatment performed per year. In practice, the distinction between NHS and privately funded clinics blurred, with most NHS clinics treating self-funded patients and some private clinics holding NHS contracts.

<sup>37</sup> Under the 1990 Act, each clinic must have a named 'person responsible', under whose supervision the activities authorised by a licence are conducted. A list of the PR's responsibilities are set out in s.17.

<sup>38</sup> For a more detailed account of our methodology and a detailed breakdown of the categories of professional interviewed at each clinic, see 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(4) *Sociology of Health & Illness* 500.

<sup>39</sup> E.g. G. Douglas, *Access to Assisted Reproduction: Legal and other criteria for eligibility. Report of a survey funded by the Nuffield Foundation* (1992). G. Douglas, 'Assisted Reproduction and the Welfare of the Child' (1993) 46(2) CLP 53.

out in the early years following its introduction but no significant empirical research had been done on it since the 1990s.<sup>40</sup> As such, we aimed to provide new insights into how the legislation was working some twenty years after its introduction, in a context where infertility treatment services had become a broadly accepted means of achieving parenthood and far more liberal attitudes pertained towards same-sex families. This study of mature, well-embedded regulation would also allow us to offer a more general investigation of the regulation of professional practice in this area, providing a close analysis of how statutory regulation interacts with a range of other institutional, professional and other influences. Our study was timed to allow the changes to the law to be sufficiently recent for their impact to be fresh in the minds of staff.<sup>41</sup>

### 3 General responses to s. 13(5)

Our research confirmed that, in general terms, the welfare assessment provision was well received by clinic staff, who shared a strong commitment to the values underpinning it (which we take to be a

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<sup>40</sup> Douglas (1992, 1993), *ibid*; Blyth, n 22; E. Blyth and C. Cameron, 'The Welfare of the Child: An Emerging Issue in the Regulation of Assisted Conception' (1998) 13(9) *Human Reproduction* 2339; B.A Lieberman, P. Matson, and F. Hamer, 'The Human Fertilisation and Embryology Act: How Well is it Functioning?' (1994) 9(9) *Human Reproduction* 1779; S.E. Mumford, E. Corrigan, and M.G.R. Hull, 'Access to Assisted Conception: A Framework of Regulation.' (1998) 13(9) *Human Reproduction* 2349; J.C. Patel and M.H. Johnson, 'A Survey of the Effectiveness of the Assessment of the Welfare of the Child in UK In-Vitro Fertilization Units.' (1998) 13(3) *Human Reproduction* 776; D. Savas and S. Treece 'Fertility Clinics: One Code of Practice?' (1998) 3 *Med L Int* 243; D. Steinberg *Bodies in Glass: Genetics, Eugenics Embryo Ethics* (Manchester: Manchester University Press, 1998).

<sup>41</sup> The coming into effect of the 2008 Act was staged, with the revised s. 13(5) in force from October 2009. Our interviews were conducted from July 2011 to September 2012.

concern for the welfare of the child, tempered with a desire avoid discrimination in deciding who to treat).<sup>42</sup> We also found strong (though less unequivocal) support for the ‘presumption to treat’. Indeed, for many, the 2008 reforms represented a case of the law changing to reflect clinical practice rather than vice versa. However, while the broad ethos of section 13(5), and particularly the importance of the welfare of the future child, fitted well with clinic workers’ own normative commitments, we found no evidence that the changes to the regulatory framework had made any difference to decision-making regarding access to treatment.

### A strong consensus in support of the welfare assessment

Black has noted that regulation is only fully effective if it is ‘institutionalized’, becoming part of the internal morality of the organization.<sup>43</sup> In this sense, section 13(5) and the associated guidance is working well, with a widespread and significant level of shared normative commitment to the broad values underpinning the regulation (which, as noted earlier, we take to be a commitment to child welfare and non-discrimination). The following comment was typical:

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<sup>42</sup> Identifying the values that underpin the 1990 Act is less straightforward than might be assumed, with the legislation criticised by one leading commentator as suffering from a ‘lack of conceptual depth’, see: M. Brazier, ‘Regulating the Reproduction Business?’ (1999) 7 Med L Rev 166. However, along with consent, the welfare of the child appears to have been accepted as constituting one of the ‘twin pillars’ supporting the Human Fertilisation and Embryology Act 1990: see *U v Centre for Reproductive Medicine* [2002] EWCA Civ 565 at para [24], *Leeds Teaching Hospital NHS Trust v A and others* [2003] EWCA 259 (QB) at para [20], and *Natallie Evans v Amicus Healthcare Ltd and Others* [2004] EWCA (Civ) 727 at para [21]. Further, as discussed above, the need to avoid discrimination was clearly a motivating concern for the provisions elaborated in the Code of Practice.

<sup>43</sup> Black (2002), above n 19, at 79.



We have a responsibility to the couples that are seeking treatment, to any children born as a result of treatment and we also have a responsibility to society as a whole, particularly when we're accessing public funding for patients. If we have concerns, then I think it's our responsibility to raise those, just as we would if we saw something, an incident happening in the street (PR).

While clinic staff told us that the vast majority of patients gave no cause for concern, this sat in some tension with this strong sense of responsibility for children created with their assistance, a level of uneasiness regarding future parenting ability, and a sense that 'you can never know'. The fear of providing treatment to a paedophile played an important role in creating a rationale for pre-emptive action despite the fact that only a couple of staff in our study had encountered patients with any record of sexual offences and none used the term 'paedophile' to describe a prospective patient that he or she had encountered.<sup>44</sup>

This high level of support for the welfare assessment process contrasts with the academic literature on section 13(5), which has been far more equivocal. For example, Jackson has argued that the provision is unjust (because only infertile people must prove their fitness to parent prior to conception), meaningless (because clinicians have insufficient information to make robust welfare assessments) and inconsistent with existing legal principle (appearing to offer a unique instance of law

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<sup>44</sup> Here, clinic staff may simply be reflecting the kinds of concerns which resonate in popular opinion. See S. Cohen, *Folk Devils and Moral Panics* (London: Routledge, 3<sup>rd</sup> edition, 1972/2002) listing 'Child Abuse, Satanic Rituals and the Paedophile Register' as one of seven familiar clusters of social identity to which objects of moral panic typically belong.

aiming to protect a child's welfare by denying it existence).<sup>45</sup> Our respondents were keenly aware of these concerns:

We're assessing parents before they've become parents, so just basically because they have got an infertility problem, where any other parents don't have this sort of type of assessment [...] It's difficult. An old boss of mine always used to say, any life is better than, you know, no life at all (embryologist).

I honestly think that we probably [...] capture I don't know, five, ten per cent of the actual risk and the argument that the patient groups always used to make when this was a big issue was, well, you know,

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<sup>45</sup> E. Jackson 'Conception and the Irrelevance of the Welfare Principle' (2002) 65(2) MLR 176. Similarly, in 2005, a House of Commons Committee proposed that section 13(5) might simply be removed from the face of the legislation: HC Science & Technology Committee. 2005. *Human Reproductive Technologies and the Law* (Fifth Report of Session 2004-5. HC 7-I, Report), [107], recommending that: 'Doctors should minimise the risks to any child conceived from treatment within the constraints of available knowledge but this should be encouraged through the promotion of good medical practice not legislation.' On the idea that someone can be harmed by being brought into life, see Derek Parfit's discussion of the 'non-identity problem': D. Parfit, *Reasons and Persons* (Oxford: OUP, 1984) ch 16. Many bioethicists accept that someone can only be harmed by being brought into existence if s/he has a life that is 'not worth living', a condition that will be only rarely met: see e.g. A. Buchanan, D. Brock, N. Daniels and D. Wikler, *From Chance to Choice: Genetics and Justice* (Cambridge: CUP, 2000), 236; and J. Harris, *Clones, Genes and Immortality: Ethics and the Genetic Revolution* (Oxford: Oxford University Press, 1992), chapter 4. On the issue of inconsistency with legal principle, it should be noted that in the leading case, Stephenson LJ did implicitly accept the possibility of a wrongful life claim, when he noted that a court would hold that it was better to be born except in extreme cases of mental and physical disability, see *McKay and Another v Essex Area Health Authority* [1982] 1 QB 1166, at 1182. As an illustration of what such an extreme case might look like, he cited *Croke (A Minor) v Wiseman* [1982] 1 WLR 71, where the child suffered from severe spastic quadriplegia following medical negligence when he was 21 months old.

'you can have a natural conception and nobody's checking on the welfare of the child [...] what gives you the right to check?' And I think to a certain degree that [...] there might be something to that. You know, maybe we shouldn't actually be checking because we can't guarantee that we're getting everybody (PR).

However, at no clinic did a fairly widespread scepticism regarding the usefulness of the welfare checklist form,<sup>46</sup> which is a central part of the assessment process across the sector, translate into more general rejection of the need for assessment per se. Rather, welfare assessment was taken seriously as an active, shared professional responsibility of all staff involved in face-to-face contact with patients, including laboratory, reception and administrative staff, regardless of legal formalities and regardless of whether or not they were responsible for checking the form or taking patient histories. If patients revealed significant information, either prior to or during treatment, all staff were encouraged to report this.

While the Person Responsible was ultimately responsible for pushing towards a resolution of welfare issues, multidisciplinary team meetings also played a very important role (and one which has grown significantly since earlier studies of section 13(5)).<sup>47</sup> These were used in a large number of clinics to gather opinions and facilitate the building of consensus.

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<sup>46</sup> eg, 'I feel this is a very weak tool, truthfully. I think that we had been...it's been watered down enormously and it's now something which given it now happens once patients are within the system and at a decision point, it's true, but still within the system it's much more difficult to say no to people' (doctor).

<sup>47</sup> Notably, our findings suggest a significant departure from the practice described by Douglas in the early 1990s, that it 'may frequently come down to the personal whim of the clinician in charge as to whether a person is lucky enough to be accepted for treatment in a particular clinic' (1993), above n 39, 69. She found that in 42 clinics (of the 66 who responded) the final decision to treat was taken by a medical person, compared to only 13 clinics

I feel confident because it's a group of people and so we try and make a consensus decision but I don't think any person will have hold of the real truth [...] but if we reach a consensus in which we all have a say, it's the best way, isn't it? Rather than a unilateral decision where someone would decide based, you know, on their subjective beliefs (embryologist).

I tried to encourage that we discussed patient cases as well as clinical issues at those team meetings because I think it's really important to a) make everybody aware if there are issues that need to be addressed and b) you know, to get everyone's view on those. It's not just up to one or two or three people. There was one case in the past where we did have quite mixed views as to whether it was acceptable to treat a couple when the male partner had terminal cancer and I know that the clinician had very strong views. I felt very strongly the other way and to discuss it at a team meeting like that, I think it's really beneficial because it just makes you, you know, look at maybe other aspects that you hadn't considered (nurse).<sup>48</sup>

This use of multidisciplinary team meetings demonstrates a strong sense of shared responsibility for, and some anxiety regarding, future parenting, with greater security found in joint decision-making. Meetings included doctors, nurses and, often, laboratory, reception and administrative staff. Perhaps anomalously, given the significant role that we describe for them below, counsellors tended not to be present unless they were presenting the findings of an assessment session. This reflects the fact that

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where the decision was taken by a team and two where the decision was taken by their ethics committee: (1992), above n 39, 22. It is possible that this shift reflects more general developments in health care, with reduced power for doctors and an increase in shared decision-making.

<sup>48</sup> It is interesting to note the controversy provoked by this case, given that the female partner would still be available to care for a future child.

most counsellors were not full-time clinic employees and, further, that the team meetings would cover a wide range of issues which were unrelated to welfare concerns. The involvement of ethics committees was generally regarded as something to be avoided, other than in exceptional cases, as it could delay the process of approval or refusal.<sup>49</sup>

Given the early research on section 13(5),<sup>50</sup> we were not surprised that clinic staff reported the new law to have made little difference to their practice. Indeed, one general criticism that has been made of the regulatory framework is precisely that it is too responsive to clinicians, with the HFEA said to be risking regulatory capture.<sup>51</sup> Above, we noted that changes to the Code of Practice had prefigured the reform of statute and clinic staff told us (often approvingly) that changes in each were predated by an evolution in practice, with regulation 'falling into line'.<sup>52</sup>

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<sup>49</sup> Again this is a departure from Douglas's finding that, while not all clinics had ethics committees, those that did, found them 'extremely helpful' in resolving problems and sharing the burden of responsibility for taking on, or declining to treat, a particular patient (1992), *ibid*, 9.

<sup>50</sup> See particularly, Douglas, *ibid*.

<sup>51</sup> One of the criticisms that has long and frequently been made of the HFEA is that it is unduly influenced by scientists working in the field, see Lee and Morgan, above n 4, 8. On the possibility that the HFEA has been subject to regulatory capture, see D. Morgan, 'Ethics, Economics and the Exotic: The Early Career of the HFEA' (2004) 12 *Health Care Analysis* 7 and T. Callus, 'Ensuring Operational Compliance and Ethical Responsibility in the Regulation of ART: the HFEA, Past, Present, and Future' (2011) 3(1) *Law, Innovation and Technology* 85.

<sup>52</sup> It should also be noted that all stake-holders, including clinics, had the possibility to comment on – and thus to influence the contents of – the draft Code, which was put out for consultation.

I think [the Eighth] Code of Practice caught up with what was happening in clinics, so [...] clinics led the way and there then became a change in the Code of Practice to really reflect what people were saying in the clinics [...] I think that's quite a good reflection on the law that we have, that it's not too bad a law (PR).

I think it did happen in parallel and society has moved and there's more acceptance of single women having treatment and there is more acceptance of same-sex couples having treatment, so that change in the welfare of the child just came to mirror what is happening in society, so [the reform] was not to introduce change, but to mirror the change that has already happened (doctor).

In general, we found a strong agreement on the need for welfare assessment prior to treatment being offered. Further, while occasional disagreements between different respondents did emerge regarding the outcome in a particular case, there was a strong, shared sense of how conflicts might be addressed through multidisciplinary team meetings, and a significant reliance on the role of counsellors to conduct further investigations. This role became particularly important in dealing with 'difficult cases' and in supporting patients using donated gametes and we return to this below.

### Strong support for the presumption to treat

While clinic staff were united in their commitment to the need for welfare assessment, they were generally also strongly in favour of the 'presumption to treat' principle, which has been enshrined in the Code of Practice since 2007. Again here, the law was commonly seen as following what already happened in practice or as forming part of a broader cultural shift, making single women and lesbian couples more likely to request treatment, more confident that they would be greeted positively and, thus, more likely that clinics could offer the treatment services that they wished to provide.

The proof of clinics' adherence to the presumption to treat went well beyond frequent formal expressions of support, being clearly reflected in the practices described below and very low reported rate of refusals of treatment.<sup>53</sup> Of course, our data on refusal rates tells us nothing about attrition along the path to a final decision: some patients are unlikely to be referred to a clinic at all, while others may self-screen or drop out following a request to address an underlying issue (e.g. to give up smoking) before treatment can commence. This enhances the significance of the gatekeeping function: many who would not receive treatment will recognise the gate as impassable and simply not arrive at it. Nonetheless, it is noteworthy that no clinic had referred more than a small percentage of patients for further investigation and vanishingly few patients were refused treatment altogether. This low exclusion rate reflects a very strong ethos across the sector of working with patients to overcome perceived obstacles to treatment. Drug or alcohol abuse, mental health issues, a disability, or a previous conviction involving a child were typically not insuperable barriers but rather served as prompts for staff to make efforts (sometimes considerable ones) to find the evidence that would alleviate concerns. One interviewee told us that there were few refusals as the clinic would investigate and then try to 'support [the patient] as much as possible and see how we can treat them' (nurse). Another described this as giving the patient 'as much chance as we can to put their sort of side across' (embryologist).

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<sup>53</sup> Few clinics record such data in one place and information was therefore gathered through the interviews, with the two – four responses from each clinic compared to check the broad accuracy of figures reported to us. Our interviewees reported the following number of refusals to treat on welfare grounds at their clinic each year: seven clinics stated no refusals; two reported less than one refusal per year; eight reported one or two refusals each year; two said three or four refusals each year; and just one clinic suggested a number higher than this, noting an average of seven refusals each year. For a breakdown of these figures by clinic size and figures regarding the numbers referred for further investigation see: Lee et al, above n 38.

Where concerns could not be immediately addressed, this would not inevitably result in an outright refusal. One respondent gave the example of deferring treatment until a man had successfully completed an anger management course. Another told us about a patient who was a heavy drinker:

[We said] 'go away, try and sort yourself out', basically. 'Do a few more sperm samples for us, you know, see if things improve.' You know, that kind of thing rather than, not just a flat, I don't think they would completely, flat refuse someone, I think it's a case of explaining why this isn't [...] the right time to help with a child and see if you can sort that situation out rather than just kicking someone out the door (nurse).

Where specific concerns based on a medical or psychiatric condition needed to be investigated, GPs or other specialists involved in the care of the patient were contacted. Where concerns related to the treatment of existing children, convictions or ongoing criminal issues, then social services, probation officers, the police or a patient's lawyer had been approached for further information regarding, for example, the details of a crime or to satisfy the clinic that a patient's behaviour towards an adult victim need not be read as an indication that he or she posed a risk towards children. A small number of clinics had asked patients with a criminal conviction to acquire a Criminal Records Bureau (CRB) check.<sup>54</sup> We also found some instances of the continuation of practices entrenched during the operation of earlier editions of the Code of Practice. For example, one clinic still routinely contacted

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<sup>54</sup> Since our research was conducted, the Disclosure and Barring Service has been formed, merging the functions of the Criminal Records Bureau (CRB) and the Independent Safeguarding Authority (ISA). The 'CRB check' has thus now been replaced by a 'DBS check'.



patients' GPs specifically to request confirmation that there were no welfare concerns.<sup>55</sup> In at least some cases, this appeared not reflect ignorance of the new rules but rather an active resistance to them: while some clinics had seen the GP checks as a waste of time, for example, others told us that the GP was a very valuable source of information.

In their efforts to secure the reassurance that would allow treatment to proceed, many staff expressed frustration with the lack of further support from other agencies, including the HFEA. For example, one clinic reported the case of a male patient who, with his partner, was requesting treatment some twelve years after having committed a sexual assault against an 18-month-old child, while he was still in his teens:

The big difficulty we have [...] is that when you actually ask for a social services assessment, they – certainly locally – will not provide that until there's actually a pregnancy that's achieved. There can be social services involvement because of concern about a parent with a previous child that's been neglected or whatever but the social services involvement will not happen until a pregnancy's been achieved, whereas in actual fact what we could do with is exactly that same assessment but prior to achieving a pregnancy. So in a way you're in a Catch 22 (doctor).

Another reported struggling to assess whether a couple with significant disabilities would cope with a child:

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<sup>55</sup> A larger number routinely contacted GPs primarily to inform them that the patient was presenting for treatment but also including a final paragraph in the letter which asked about welfare concerns (with no response now taken to indicate that there was no problem in proceeding to treatment).

they're involved with social services, so I wrote to social services [...] and they wrote back and said, 'Well it's not our remit. We can tell you what we've done' but they won't tell me anything about whether or not they think they could manage a child in their house. I just think that's really disappointing [...] I can't go to their home and see whether it's OK. You know, will they get or have they got, will they get the support? I find it frustrating, the social services link, I have to say, for pre-conception concerns (doctor).

Particularly in the case of single, disabled women, their chances of receiving treatment were relatively slim,<sup>56</sup> with one doctor telling us that it was important to avoid making 'a whole lot of child carers', given what is known about the 'pressures that are on teenage kids to look after their disabled parents.'<sup>57</sup>

The support for the 'presumption to treat' was thus strong, however it was not unequivocal. Some staff felt that the balance had tipped too far in the patient's favour, creating inappropriate, consumerist expectations (a point to which we return below),<sup>58</sup> while others suggested that it imposed

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<sup>56</sup> This issue was also dealt with in one episode of the BBC Radio 4 programme, *Inside the Ethics Committee*, which revealed considerable ambivalence among clinic staff regarding provision of treatment to a woman with a severe disability. See 'Assisted Conception and Disability': <http://www.bbc.co.uk/programmes/b037vb3f> (last visited 28 February 2014).

<sup>57</sup> On which, see J. Aldridge and S. Becker 'Punishing Children for Caring: The Hidden Cost of Young Carers' (1993) 7 *Children & Society* 376.

<sup>58</sup> See n 84 and text of accompanying paragraph.

too high a threshold, making it difficult to justify further investigation where staff had hunches that something was 'not right':

it turns the whole thing around from the way it used to be, to making the assumption that you will treat everybody unless you've a really good reason not to, and it puts the responsibility on us to set what we think would be the reasons for that, which isn't bad in itself but it's simply that [...] the way that it's now being phrased is that it's very much, there's really no reason not to treat anybody and the tone seems to be very much [...] that the firmness which would have been there before has gone and the support you might get from the HFEA in terms of a challenge is going to be probably non-existent and I think it's those kind of things that you realise [...] their view is you should treat everybody [...] That's not quite what they would say because they would say, 'no, no, no, it's, you know, serious harm'. But [...] 'serious harm' is a very major thing to try to define, whereas [...] a discomfort or an uncertainty you might have, or unhappiness you might have ... well that's not enough (doctor).

In sum, it can be said that the broad values underpinning the revised section and accompanying guidance are well-embedded and widely accepted, though in 'hard cases' clinic staff inevitably still struggled to balance the rights and interests of prospective parents alongside a concern for the welfare of the future child. While a sense of the importance of non-discrimination was widespread, we found ongoing concerns regarding the quality of parenting likely to be provided by certain kinds of patient (including notably, as we consider below, single women).<sup>59</sup> Significantly, a presumption in favour of treatment has not translated into an assumption that scrutiny is generally unnecessary or can be

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<sup>59</sup> While we have no space here to expand on this point, it is worth noting that this concern for future parenting ability also relates in interesting ways to what has been described as the 'professionalisation' and 'psychologisation' of family life, where expert opinion gains significance in the management of parent-child relationships, with a need to manage the emotional and psychological development of children in their relationship with their parents, see e.g. E. Lee, J. Bristow, C. Faircloth and J. Macvarish, *Parenting Culture Studies* (Palgrave Macmillan, 2014); F. Furedi, *Therapy Culture, Cultivating Vulnerability in and Uncertain Age* (London: Routledge, 2003).

performed in a perfunctory, 'tick box' manner. Here, a sense that most people are 'normal' was nonetheless accompanied by a generalised unease regarding the possibility of treating someone who turned out to be a seriously inadequate parent or, in the worst eventuality, a paedophile.

On the basis of our interviews, we might suggest a slight divergence between the HFEA – which appears to place proportionately greater weight on a desire to avoid any hint of discrimination – and clinic staff, whose gaze is more tightly trained on child welfare. While this is no more than a difference of emphasis, our research also suggests that the attempt to resolve such issues by subtle changes to the wording in the Code of Practice is unlikely to succeed. Notably, as we discuss below, the term 'supportive parenting' was neither widely used nor well understood by clinic staff, notwithstanding detailed HFEA guidance on how it should be interpreted. If seriously concerned to influence practice, the HFEA might be advised to consider the suggestion made by several of our respondents: to devise a forum where advice could be sought or views shared regarding specific 'hard cases'. In addition to providing support to clinics, this would allow for pooling of experience across the sector.

We also noted a significant belief amongst interviewees that the law was following clinical practice rather than vice versa. This is a particularly interesting finding given that the regulatory framework introduced in 1990 replaced an earlier system of self-regulation, where clinicians' role in developing standards and guidelines was foregrounded. Our findings on this point would suggest a close congruity between these two models of regulation, with dynamic interaction between the regulator and regulated rather than a top-down process of development of guidelines.

#### **4 Interaction of legal and other norms**

The above findings demonstrate a reasonably close fit between the existing law and practice, with the regulation largely welcomed as supporting and, indeed, following clinical practice. However, the fine

detail within this broad brushstroke picture is more complicated. Professional practice is influenced by a range of influences, including not just regulation but also the moral views and emotional reactions of clinic staff, economic constraints and incentives, NHS rationing criteria, and other professional norms (here, most notably around counselling). These coexist and interrelate in complex ways. Here, we first deal briefly with the former factors, before moving on to deal in more detail with the two latter, which emerged as particularly significant. Each of these factors complicates the claim that the reform has resulted in a straightforward decrease in scrutiny of patients' future parenting ability.

### Staff's moral views and emotional reactions

First, clinic staff are not automatons: they have their own moral views, cultural beliefs, and emotional reactions (sometimes strong ones) to patients.<sup>60</sup> In one case:

it was going to be serious risk to the patient's life if she were to conceive and the ethics committee argued that it was her choice and my view was well, if she was going – this is going to sound terrible – if she were going to kill herself, that would be her choice but she couldn't ask us to do it for her. And my concern is then for – apart from the fact she had an existing child [...] whose welfare was a major issue – then we have all the staff at the clinic who would have been involved had she died because we had agreed to treat her [...] We said, 'we feel yes, there is an element of patient choice but it is also our choice and we're saying no, we don't want to put her to this risk' (PR).

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<sup>60</sup> On the importance of taking account of the emotions of those charged with interpreting and applying regulation, see: B. Lange, 'The Emotional Dimension in Legal Regulation' (2002) 29 JLS 197.

This also illustrates the extent to which different kinds of concerns (not to harm the patient, to protect the welfare of an existing child, and to avoid negative emotional impact on staff) can become entwined. In another case, treatment was refused because of the staff's unease regarding the polygamous relationship of the couple requesting treatment, the issues that the periodic absence of the father presented for child welfare, and the woman's reported distress regarding the relationship:

a man who was Sudanese or Saudi or something was coming with a person we thought was his wife but it also became clear from comments that she had made to the nurses that he had another wife and that was a real barrier. [... We told them] 'Your social norms and ours are different. In this country, you know, having two wives is not legal or having two people is just not something we can accept and, you know, you need to be committed to this person,' and we felt that we wouldn't progress with treatment until that had been resolved [....] We're giving this couple a child between them and yet if this man is not committed to her and is going to spend six months of his life off with somebody else, given that we have this framework which was to think about the welfare of the child, I don't think that's a good way to bring up the child; to have a father who won't be around most of the time or even half the time (doctor).

Staff are also inevitably concerned with the feelings and views of their colleagues and another decision against treatment was reported as motivated primarily by the conflict that a case was causing within the multidisciplinary team:

'The chap had been convicted – it was exposing himself to children, as I recall, [...] so therefore a risk and was on the register, but it was a spent offence from many years before. The clinician felt that very compassionate idea that [...] he'd done his kind of punishment and [...] he was going to go on to treat

but it was actually a member of nursing staff who kind of blew the whistle anonymously through an anonymous letter [...] My view was that ... that child protection, child abuse or risk is not about doing your sentence, it's a life-long risk and that was a huge issue [...] They contacted the GP and then the ethics committee wanted more information and I think he gave permission ... I think he gave permission for probation to be contacted but I don't think we got that far because ethics said, 'We're not happy about this'... it was more because of the conflict it was causing in the clinical team that they decided not to treat' (counsellor).

Our respondents' emotional reactions to the patients they encountered are apparent in many of the other comments reported in this paper. Staff frequently noted their own feelings as something to be managed or overcome. For example, the doctor who told us about the polygamy case reported worrying about whether the refusal of treatment was racist or culturally insensitive. The obvious, but nonetheless crucial, point here is that regulation is interpreted and applied by real people, with their own normative commitments, cultural beliefs and emotional reactions to the clients that they see and, further, that these people are embedded in working relationships that have their own complex dynamics.<sup>61</sup>

### Economic constraints and incentives

Second, in addition to being part of the health service, assisted reproduction is big business.<sup>62</sup> Where a patient is refused treatment on welfare grounds, this may also represent turning away income.

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<sup>61</sup> *ibid.*

<sup>62</sup> M. Brazier, 'Regulating the Reproduction Business' (1999) 7 *Med L Rev* 166, 176–7; Lee and Morgan, above n 4 at 164.

Perhaps unsurprisingly, no clinic told us about someone that they had decided to treat for monetary reasons in the face of serious welfare concerns but we did hear suspicions that some other clinics were less professional and were inappropriately influenced by financial considerations in their assessment practices:

We've heard of cases in other clinics where people have been treated and you wouldn't possibly have treated them, and if we've turned people down here, we know that they've gone on elsewhere and accessed treatment [...] I think because assisted conception is a business, it does make it harder because, you know, you're turning business away and especially if you know the clinic down the road will treat them whatever, but I think as a clinic, you have to have integrity and you have to have standards (PR).

Financial considerations also play an obvious role in determining the extent to which clinics are able to follow the Code of Practice: for example, below we note that few clinics complied with the recommendation to use different personnel for welfare assessment and counselling, with one telling us specifically that they had drastically reduced the number of counsellors in the clinic for financial reasons.<sup>63</sup>

### Eligibility for NHS funding

Third, we found some seepage between the welfare assessment and assessment for NHS funding eligibility. At the time we conducted our research, a non-mandatory guideline issued by the National Institute for Health and Clinical Excellence (as it then was) recommended that three cycles of IVF

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<sup>63</sup> See further below. One PR told us that 'purely through cost', whereas formerly the clinic had four counsellors, now there was just one who worked part-time.



treatment should be provided to infertile couples who had an identified cause for their fertility problems or who had infertility of three years' duration and where the female partner was aged from 23-39.<sup>64</sup> Primary Care Trusts then developed their own funding criteria, which frequently introduced further restrictions.<sup>65</sup> Typically, PCT criteria did not reflect purely clinical factors but might include, for example, relationship status, the age of the father, whether anyone in the family smokes, existing children in the family (with variation as to the relevance of whether such a child is still living at home,

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<sup>64</sup> See NICE (2004) *CG11: Fertility: Assessment and Treatment for People with Fertility Problems*. Since we completed our research, the NICE guideline has been updated, see: NICE (2013) *CG156: Fertility Assessment and Treatment for People with Fertility Problems*, available at <http://www.nice.org.uk/nicemedia/live/14078/62769/62769.pdf> (last visited 28 February 2014). The new guideline, *inter alia*, retains the recommendation for three cycles of treatment for women of 39 and under; reduces the requirement for infertility from three to two years before treatment is recommended; and introduces a recommendation that women between 40-42 should be treated in some circumstances. Since 2013, while retaining the same acronym, NICE has been renamed as the National Institute for Health and Care Excellence. NICE's general duties and functions are now set out in the Health and Social Care Act (2012), Part 8.

<sup>65</sup> Department of Health, *PCT Survey – Provision of IVF in England 2007* (2008), available at: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_085665](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085665) (last visited 28 February 2014). Since we completed our research, Clinical Commissioning Groups have taken over responsibility for purchasing infertility treatment services, generally relying on broadly similar eligibility criteria. See National Infertility Awareness Campaign (2014) *Assisted Conception Needs Assisted Implementation: a Report into the Status of NHS Fertility Services in England*, available at: <http://www.infertilitynetworkuk.com/uploaded/NIAC/Assisted%20Conception%20Needs%20Assisted%20Implementation.pdf> (last visited 28 February 2014), which found that the majority of Clinical Commissioning Groups do not yet fund fertility services to the level expected by NICE. The findings of our research regarding the possible distorting effects on the welfare assessment of additional restrictions introduced by funders thus retain relevance.

is under 16, or is adopted) and whether infertility results from sterilisation.<sup>66</sup> Some eligibility criteria (such as maternal age) had both clinical and non-clinical dimensions and others were arguably justified by the fact that funding for treatment services is a severely limited resource and ought thus to be allocated where it meets the most pressing need or can achieve the greatest good. However, the criteria can sometimes appear arbitrary,<sup>67</sup> and restricting access to treatment on non-clinical grounds risks appearing inconsistent with the heavy emphasis on non-discrimination that characterises the regulatory framework described above.

Our study focused on the welfare assessment process rather than the broader issue of how patients seeking treatment might be filtered out over the course of the entire journey to obtaining treatment. Notably, those who fail to meet relevant funding criteria are likely never to reach a clinic. What was interesting for our purposes, however, was the extent to which a separation is consistently maintained between welfare assessment and consideration of funding eligibility.<sup>68</sup> Where seepage between these

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<sup>66</sup> *Ibid.*

<sup>67</sup> R. Kennedy, C. Kingsland, A. Rutherford, M. Hamilton, W. Ledger, 'Implementation of the NICE Guideline – Recommendations from the British Fertility Society for National Criteria for NHS funding of Assisted Conception' (2006) 9(3) *Human Fertility* 181.

<sup>68</sup> See also Douglas's (1993) early study of the operation of the 1990 Act, above, n 39, 64: '[c]learly funding is a problem in the NHS and there may be a wish to channel available treatments to those deemed most in need ... value judgements play a part in rationing healthcare resources. It seems that patients who do not fit the standard model of a heterosexual couple in a stable relationship may be regarded as less justified and less well qualified to be parents and so not entitled to take up scarce resources ... Similarly women over a certain age may be excluded not just because they are less likely to succeed in treatment but also because it may be felt to be inappropriate to create 'elderly' parents.'

processes occurs, regardless of what clinic staff had told us regarding a presumption to treat and light touch welfare assessment, consideration of funding eligibility reintroduces some elements of scrutiny that are no longer carried out in the name of child welfare.

First, while the risk analysis mandated by section 13(5) does not suggest that a woman must be in a relationship in order to receive treatment, many PCTs required that patients should have been in a relationship for about two years as a condition of funding. Such rules presented difficulties for clinics, as they were required to determine whether patients presenting as a couple, were in fact a 'couple in a stable relationship' and a perceived lack of stability was sometimes described as a welfare concern. Concerns were typically referred to the counsellor but assessing stability is not easy and might involve a detailed scrutiny of a relationship.

Now I've had to talk with my colleagues sometimes – my counselling colleagues – and say, 'How do you define a couple?' And, you know, a social worker said to me, she said, 'well I think it's whether they actually eat at the same table.' And then somebody else said, 'Well it's whether they share a bed,' but they're not ... that wouldn't tell you that they're a couple, would it? Somebody said, 'do they share a TV licence?' You know, you could have a girlfriend and a boyfriend (and I've had this before), a girlfriend and a boyfriend who've been together quite long term, don't actually live in the same house. She lives with her parents, he lives with his parents because it's just easier for their benefits and if they ... and when I said to them, 'well surely having a child together, it is better a supportive, stable relationship for you to actually share a place together', and they said, 'well when I get pregnant, then we'll be found a place together', so yes, you could say it's financial. But is that for us to say that they're not a couple? They've been in a long term relationship but they don't actually live together. I mean some clinics [...] do say they have to have the same address (counsellor).

Women who attended the clinic with more than one partner over time provoked particular concerns. For example, one woman who presented with four different partners over a number years, never

achieved the two year 'stable' relationship that would render her eligible for NHS treatment at the point that she arrived at the top of the waiting list. The interviewee who described this case was clear, however, that the 'instability' in her personal life made it equally impossible to accept her as a self-funding client, notwithstanding the fact that she could have been accepted for (self-funded) treatment were she single.

Further, a desire to establish their eligibility for funding could sometimes lead patients to attempt to deceive clinics about their circumstances. If discovered, this could then become cause for broader concern, with deception as a factor that potentially triggers the need for further investigation of a woman or couple under the Code of Practice.<sup>69</sup>

[The criterion is that they must] live together for a year [...] unless they've got a [very good] reason behind it. So as soon – I think it's the smell a rat sort of law of thumb – as soon as you think, hold on a minute, what they're telling us doesn't match ... [that raises an issue of] trust because there's a trust relationship and, you know, they expect to trust us to do things right and we kind of expect them to tell the truth because [...] how can you trust somebody who's basically lying to you (PR)?

Secondly, many PCTs restricted treatment to couples who had no children (or none together). Although past conceptions and births are significant to a medical assessment of currently infertile patients, again the precise significance of questions about existing children was not always clear. Having existing children living elsewhere could be taken as an indicator of children having been taken into care or residence being awarded to another parent. Again, there was some blurring in the interviewees' narratives as to whether this question was required for funding purposes or for the welfare of the child assessment. For example, this counsellor explained the presence of questions

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<sup>69</sup> HFEA (2009), above n 31, para 8.13.

regarding length of cohabitation and existence of other children on the clinic's welfare assessment form in this way, also revealing an important gendered difference in how responses were interpreted:

They are 'welfare of the child' questions because, you know, the recommendation is that we treat people who are in a stable relationship [...] If they have any children, it's not automatically a 'welfare of the child' but if they are not living with them then you know it could be highlighting issues, why haven't they got custody of the children? I think here we're aware that there might be a difference between men and women because if a man answers, 'yes I have children but they are living with their mother', we don't assume there is any issue, but if it's a woman who has children under the age of 14 who are not living with her, then we may assume that there may be issues (counsellor).

Thirdly, it was not always clear whether questions relating to parental age or smoking in the family reflected clinical factors, funding eligibility or child welfare concerns, with the following extracts showing the extent to which these factors were sometimes entwined in staff's narratives.

Interviewer: Does the age of either parent ever get discussed as a welfare concern?

Respondent: Yes it does, because we have NHS criteria, we have upper age limits for parents and lower age limits as well, so I think if there was a very big mismatch, we might have some concerns (PR).

Respondent: when they come through for a licensed treatment, there's another form that [the woman and her partner] sign which is a no-smoking agreement and they actually get told that if we think they're smoking, we can do a smokaliser test on them. And we can stop treatment if we think that's the case.

Interviewer: And that's all to do with funding?

Respondent: Yes, and also the effect to the child – the unborn child and smoking – I mean we're not dealing with a foetus as such but they've got to stop at this stage.

Interviewer: But is it a welfare of the child issue, rather than about the effectiveness of treatment?

Respondent: I think it is a mixture.

Interviewer: And can you see people being refused treatment because of smoking?

Respondent: They have been, yes. [...] Anybody who has said on their history that they are smoking or anybody that we think is smoking, we just don't call them up and we say to them: 'we can't call you up until you've stopped' (nurse).

Patients who required, but were ineligible for, NHS funding were unlikely even to arrive at the clinic. However, funding eligibility criteria nonetheless played a significant role in clinics, in suggesting an enhanced need for scrutiny of patients' circumstances. The potential for a blurring of boundaries between funding eligibility and welfare concerns was exacerbated where clinics had modified the standard HFEA welfare assessment form to include questions relating to other purposes. Four clinics included questions on the form regarding length of current relationship and whether a couple both lived at the same address and, where they did not, requesting explanation. Interviewees were not always clear whether this was due to funding requirements, a clinic's own protocols, or welfare concerns. In one of these clinics, the form also asked about any children born in this or a previous relationship and where any minor children currently lived. At the time of our visit, this clinic's welfare form was being updated to include further questions about alcohol and anti-depressant use.<sup>70</sup>

Finally, this seepage may operate in both directions: it is possible that a clinic's reluctance to treat certain groups might impact on PCT (or now CCG) funding criteria. One doctor told us that the local PCT's decision to fund same-sex couples but not single women was 'partly because we felt very uncomfortable treating single women and they're happy to take any reason not to treat people anyway.'

## Counselling

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<sup>70</sup> It is not known whether updates on the draft that we were shown were formally adopted at this clinic.

While the degree to which counsellors were routinely involved in the welfare of the child assessment varied considerably, a heavy reliance on counsellors represented an important shared strategy for investigating 'hard cases' and, potentially, resolving disagreements. Further, in the most clearly sustained departure that we found from the requirements of the regulatory framework, patients seeking treatment involving donated gametes or surrogacy were widely and strongly regarded as facing a complex set of issues, with counselling vital to their successful negotiation. Here, counselling tended to be described as being mandatory, with many interviewees stating an erroneous view that it was legally required.<sup>71</sup> In those clinics that were aware that there was no legal requirement for counselling, the large majority noted that it was nonetheless a requirement imposed by the clinic, with others describing how, while implications counselling was not strictly obligatory, patients seeking donated gametes would be made 'more of an offer they can't refuse' to undergo it. At the one clinic in our sample of twenty where counselling was neither a formal nor *de facto* requirement, this was a source of marked regret for one interviewee:

[Patients are] pretty strongly invited, to have counselling – implications counselling – but if they say they do not want it, they tick that they've been invited to do it. But they don't have to and that's a great concern for me because the folk who are probably are most resistant to the clinical implications are the ones who probably will say, 'we don't want to' and their fear level will be high for some reason, you know, and that could probably be well supported or helped in a counselling session (counsellor).

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<sup>71</sup> ss.13 and 13A of the 1990 Act merely provide that patients must be offered a 'suitable *opportunity* to receive proper counselling'. The Code of Practice is equally clear that the decision of whether to accept the counselling belongs to patients, stating that 'the centre should allow enough time before treatment starts for patients to consider the offer and to take up the opportunity of counselling *if they so choose*', *ibid*, para 3.2. The emphasis in each case is ours. See further, Blyth, n 22.

Almost all patients using donated gametes are thus invited to discuss the issue of how to inform a future child of the circumstances of his or her conception. While some clinic staff were categorical that there could be no slippage between this implications counselling and the welfare assessment, others were less clear.<sup>72</sup> For example, this respondent suggested that a discussion about disclosure was a 'doorway' into further exploration of the couple's suitability for treatment:

So the doorway in is before we start just going, 'Mmm, I wonder if they're quite normal,' [...] just by having the conversation of, 'So are you going to tell them?' [...] Now obviously we can't force them. There's no law [...] but certainly a flag's going up if someone's saying no, or there is a difference in the couple, so that says something else, doesn't it? That's like the parenting styles are very different and that could become conflict. So yeah, automatically that's welfare of the child concerns. I wouldn't say in itself the fact that the child isn't going to be told, although I think one could make an argument to say that is [...] the welfare of the child is not being considered appropriately (PR).

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<sup>72</sup> Douglas's early study of the operation of the welfare clause equally found evidence of slippage between counselling and welfare assessment, see (1993), above n 39, 66-7. Further, our findings suggest that counselling may have achieved a significantly enhanced status in clinics since her research was carried out. While counselling was not a central focus of her study and the questions that she asked were not restricted to counselling for those seeking donated gametes, she noted that most clinics would not refuse treatment to patients who refused to undergo implications counselling (1992), n 39, 21-2, suggesting that counselling had not yet achieved the widespread status of a requirement, as we found. A 1990 report had similarly found that prior to the introduction of the 1990 Act, notwithstanding the Interim Licensing Authority's recommendation that clinics should offer access to appropriately trained counselling staff, there was 'very little specific counselling' available and that which existed was typically done informally by the consultant. See ILA Guidelines, para 13(g) and H Harman, *Trying for a Baby: a Report on the Adequacy of NHS Infertility Services* (1990), both cited in Lee and Morgan, n 4, 182.



In earlier editions of the Code of Practice, the prospective parents' ability to tell the child about the circumstances of conception was routinely considered as part of the welfare checklist of factors that clinicians must consider before accepting someone for treatment. It was only in 2007 that this was specifically taken out of this list, with a separate paragraph inserted to recommend that all prospective parents be advised of the need to tell their children.<sup>73</sup> As such, the above response may reflect the residue of earlier working practices. Equally, however, broader popular debates have placed a heavy emphasis on the child's 'right to know' the circumstances of his or her conception, with this frequently cast as essential for a child's welfare.<sup>74</sup> Clinic staff were keenly aware of and, in many instances, are

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<sup>73</sup> HFEA, n. 26. This was given additional weight in the reforms, which introduced a new s.13(6C) to the Act, providing that information must be given to those making use of donated gametes about '(a) the importance of informing any resulting child at an early age that the child results from the gametes of a person who is not a parent of the child, and (b) suitable methods of informing such a child of that fact.'

<sup>74</sup> D. Gurnham and J. Miola, 'Reproduction, Rights, and the Welfare Interests of Children: the Times They Aren't A-Changin'' (2012) 23 KLJ 29. See also Nuffield Council on Bioethics, *Donor conception: Ethical Aspects of Information Sharing* (2013), available at <http://www.nuffieldbioethics.org/donor-conception>, which argues that openness about donor conception is important in so far as it improves family relationships and adds to the well-being both of parents and of donor-conceived people. See further E. Blyth, M. Crawshaw, L. Frith, and C. Jones, 'Donor-conceived People's Views and Experiences of their Genetic Origins: A Critical Analysis of the Research Evidence' (2010) 19(4) *Journal of Law and Medicine* 769 for an overview of empirical research relating to donor anonymity, finding that it consistently reports that most donor-conceived people have an interest in securing information about their genetic and biographical heritage. For an older review, explicitly arguing that children's welfare is harmed by withholding this information see A. McWhinnie, 'Gamete Donation and Anonymity' (2001) 16(5) *Human Reproduction* 807. Smart notes that this emerging consensus is relatively recent, with a prevailing view in earlier times being that it was better for secrets to be kept and the integrity of the nuclear family to be thus protected, see: C. Smart, *Personal Life: New Directions in Sociological Thinking* (Cambridge: Polity, 2007), 122-32. McWhinnie likewise notes that at the time of publishing her paper (in 2001), the dominant clinical

actively involved in these discussions. As such, it is not surprising to find interviewees discussing disclosure as a matter of child welfare notwithstanding the tension between this view and the rather narrower understanding of welfare given in the regulatory framework.

Further, despite advice in the Code of Practice that any counselling should be kept quite distinct from processes of welfare assessment,<sup>75</sup> only a small number of the clinics in our sample were able to provide more than one counsellor to enforce a clear distinction between therapeutic and implications counselling, on the one hand, and assessment counselling, on the other. This exacerbated tensions in the counsellor's role, with a range of views expressed regarding how easily these could be managed in practice. Further, a number of interviewees raised more general issues regarding a lack of clarity in the role of counsellors.<sup>76</sup>

I think we use counselling sometimes inappropriately as a profession in that we use it as an assessment exercise, so I'll say to [the counsellor], 'I'm really worried about this couple. Can you see them?' And

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practice was to favour the anonymity of donors and to prioritise the privacy of couples receiving treatment, *ibid*, 807.

<sup>75</sup> HFEA, 2009, above n 31, para 3.7 provides that: '[t]he provision of counselling should be clearly distinguished from: (a) the assessment of a person's suitability to receive treatment, or to store or donate their gametes or embryos; (b) the provision of information before obtaining consent or providing treatment, and (c) the normal relationship between clinical staff and patients or donors.'

<sup>76</sup> This was also noted as a problem by Douglas, who noted that just over a third of the clinics in her sample routinely used the counsellor as a source of information in the welfare assessment. This, she argued, was problematic, as while the Code of Practice 'appears to assume that counselling can be distinguished from assessment ... patients do not always see it like this' 1993, above n 39, 66.

actually that's not what counselling is all about. Counselling is there for the benefit of the couple whereas I'm using it ... to make a psychological evaluation of whether I think this couple are bonkers or not (PR).

This expansion in the role of the counsellor, and the reliance on counsellors in dealing with 'hard cases', might also reflect a strategy for dealing with anxiety around future parenting ability noted above.

## 5 Lesbian couples and single women seeking treatment

The provision of treatment services to lesbian couples and single women has been a major focus of concern throughout the life of the legislation and, as such, clinics' current practice in this area is of particular interest. In the early debates around IVF, lesbian couples and single women were typically conflated as raising the same potential problem: lack of suitable male role models for their children.<sup>77</sup> Some two decades on, a very different picture has emerged, with clinics telling us that they had 'become much more comfortable treating both lesbian couples and single women and not putting them through any special hoops' (PR). Just one clinic in our sample of 20 had a welfare of the child protocol that still considered the treatment of single women and of patients in lesbian and gay relationships to 'merit careful consideration'. This clinic was still routinely referring requests for treatment from single women to its ethics committee and had only recently discontinued this practice for lesbian couples. However, notwithstanding the fact that many interviewees talked about the need

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<sup>77</sup> D. Cooper and D. Herman, 'Getting the Family Right: Legislating Heterosexuality in Britain, 1986-1991' (1991-1992) 10 Can J Fam L 41.

to avoid discrimination, heightened scrutiny of single women was still relatively common in our sample.

### Lesbian couples

While we found a few lingering concerns regarding lesbian couples (again bearing the imprint of the former legislative provision), these were uncommon and the following two responses were, thus, untypical:

Where the child would have no legal father you are expected to have ... you need to check out somebody's attitude to men. Is there going to be a balanced attitude to men? That's the only thing I'll check out with a lesbian. But if you've got a rip-roaring lesbian couple who are so anti-men [...] I came across one a couple of years ago [and] one of them was very, very anti-men. It was bloody ridiculous and of course it came out that she'd been abused (counsellor).

One of the risks is that they ... that they can become isolated in their relationship because they're a lesbian couple [and] don't get out and about and meet people or have no people or friends or share experience with people, so it's as much checking that they've got people around them, I think, and that they're not ... they're not stuck. Actually, I think the couples that we've seen have been very straightforward from the point of view of treating them and much less difficult to deal with from that point of view, and that discussion point of view, than single women, for instance, because they know where they're going, they know what they need, they know where to go to (doctor).

Far more commonly, as the second respondent above ends by suggesting, lesbian couples were now seen as raising no particular issues at all and, indeed, were more frequently referred to as ideal patients, who were generally very well informed, equipped with strong support networks and

prepared to be open and honest in discussions with clinic staff. The following responses, reflecting this homonormative ideal,<sup>78</sup> were far more typical of the way that staff talked about lesbian couples:

In reality, actually lesbian couples are very well thought out often before they come. There still is an awful lot they have to think about, but ... they're often a joy to work with because they really do think about the child and managing difference because they're already managing difference in the fact that their sexuality is different so they're often very, very well thought out but there's still a lot of stuff we need to discuss (counsellor).

If you look at Susan Golombok's work, the stuff that comes out is lesbian women couples do the best parenting. Heterosexual couples do the next best but single women struggle (counsellor).

### Single women

Single women seeking treatment provoked a more complex and varied set of reactions. The need 'not to discriminate' was frequently voiced and, in some clinics, providing treatment for single women raised no particular concerns. In others, however, they attracted particular scrutiny for a range of reasons. First, for a few interviewees, concerns lingered regarding the importance of a suitable male role model.

I mean having only one parent is probably not a healthy thing for a child so having only a man or a woman as being the parent is probably not healthy. And having, you know, deliberately allowing it to be so that women can have children without there even to be a man within that relationship to act as the male figure, I just feel is an unhelpful, unhealthy way to behave and it does reflect the society that we live in, the [...] more liberalism that this country exists within. It wouldn't be my morals. But, you

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<sup>78</sup> On the concept of homonormativity, see generally, L. Duggan, *The Twilight of Equality? Neoliberalism, Cultural Politics and the Attack on Democracy* (Boston: Beacon Press, 2003).

know, we do recognise and would not withhold treatment from same-sex couples but at the moment we don't treat single women. I will still have some anxieties about the lack of a male in that sort of child's life (doctor).<sup>79</sup>

**Commented [S1]:** Jan: is this footnote right? I'm just wondering how they treat lesbian couples if they don't do DI?

Second, and more prevalent, were a range of worries regarding whether single women had thought through the financial implications of having a child, the level of support needed from family and friends and their own ability to cope.<sup>80</sup> The subtle change made to the Code of Practice following consultation, whereby a need to talk about broader support networks was not required as a part of the routine welfare assessment but was triggered only on the basis of another concern being raised during that process, appeared not to have informed the practice at these clinics.

[We discuss] whether or not they're isolated in their relationship or whether they've got supportive friends, whether they've got family round about, and those kind of things, so that they're supported enough (doctor).

[Single women] have to see the counsellor. She has to look at whether they've got their coping mechanisms, to make sure they've got support mechanisms and things like that (nurse).

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<sup>79</sup> The treatment of single women at this clinic was not possible in any case, as it did not offer donor insemination services.

<sup>80</sup> While we have no space here to develop this point, the concern that women may not have adequately thought through their choices resonates with a broader literature on medical paternalism with regard to women's medical decision making. Specifically on the issue of women's irrationality in the context of accessing infertility treatment services, see L. Koch, 'IVF – A Rational Choice?' (1990) 3 *Reproductive and Genetic Engineering: International Journal of Feminist Analysis* 235.

This raises the possibility that some women who do not have a male partner will be, as Blyth et al put it, ‘counselled out’,<sup>81</sup> deciding not to proceed with treatment in the light of their discussions with clinic staff. For example, one counsellor told us:

I really want them to find out the actual practical realities of childcare costs and, after two sessions with me, this girl who was adamant she had to be treated next month, sort of dropped out because she said she just can't afford to do it, she hadn't thought about this, that, the other.

In discussing single women's ability to cope, the idea of ‘supportive parenting’ often took on its own, very different meaning from that provided in the Code of Practice.<sup>82</sup> We noted above, that the reform

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<sup>81</sup> The possibility of ‘counselling out’ is raised by E. Blyth, V. Burr, and A. Farrand ‘Welfare of the Child Assessments in Assisted Conception: a Social Constructionist Perspective’ (2008) 26(1): *Journal of Reproductive and Infant Psychology* 31, 32. They note that the potential for counselling to perform this dissuasive function was intended by at least one parliamentarian active in the introduction of the 1990 Act: Lord Mackay told Parliament that: ‘[w]ith the child and welfare amendments we have just discussed there is a likelihood that through counselling and discussion with those responsible for treatment [women without a 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’ (ibid).

<sup>82</sup> Notwithstanding the fact that an abbreviated version of the Code's definition is given in the HFEA ‘Welfare of the Child: patient history form’, which was widely in use in clinics. The first question to be answered by the clinic staff asks: ‘[i]s there any concern that the prospective parents may not be supportive parents (ie, that they show a lack of commitment to the health, well being and development of the prospective child)?’ Emphasising that questions of support networks should only become relevant where a concern has been raised through one of the risk factors listed above, the form then asks ‘If **yes**, please specify if and how the wider family and social networks within which the child will be raised have been taken into account’ (emphasis in original). The form is available at: [http://www.hfea.gov.uk/docs/Welfare\\_of\\_the\\_child\\_Aug\\_2010.pdf](http://www.hfea.gov.uk/docs/Welfare_of_the_child_Aug_2010.pdf) (last visited on 28 February 2014).

of the law appeared to have had no clear impact on practice. Specifically, it is noteworthy that the term 'supportive parenting' was not cited as a significant point of reference in decision making and, where it was used, it was understood in quite different ways from that intended by the legislator and regulator. Insofar as respondents had any view on what was meant by the term (and many did not), the clearest opinion was that it applied particularly to same-sex couples and single women, perhaps because it was considered as a direct replacement for the old wording that explicitly categorised these two groups as requiring additional input regarding their future parenting:<sup>83</sup>

I'm not sure what supportive parenting is. I think a male figure that, that a child might relate to because [...] I think it is important that they are aware of the, the differences and the different relationships that might develop and the communication, I think, is often different with men and women for a child. Maybe 'supportive parenting' is not the right word [... Or] maybe it is the right word because I don't know what other term there would be but it's upbringing of the child, isn't it, and recognising that if ... if it's a single woman or a same-sex couple that, that to give a child an all-round life experience and whatever else that they need to be aware of the role of men in society and relationships, I guess (PR).

I must admit I don't use that [term], but I would certainly use the word 'support': 'is this child going to be well supported by friends and are you going to be supported by friends and relatives? What would happen if you were ill? Who would then support the child and would help them go to school? What happens if you find you're in an accident and you lost a leg?' You know, 'what if, what if, what if?' (doctor).

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<sup>83</sup> Interestingly, this was also the case for Phil Willis MP (now Lord Willis), who played a very significant role in the reform process, and who suggested that he thought most MPs understood 'supportive parenting' as a 'modern way of talking about the traditional family'. See McCandless and Sheldon, above n 1, 216.



It thus emerged as relatively common for *supportive* parenting to be interpreted as requiring *supported* parenting, with single women requiring additional, careful assessment to establish that they had in place 'networks of support'.

Third, concerns were expressed by a number of clinic staff regarding single women's motivation for seeking sole parenthood, with this sometimes being framed in terms of an anxiety regarding whether the woman's single status itself might reflect some broader issue with her ability to form relationships.

These counsellors commented:

If they haven't had a serious relationship for a number of years, I will sort of wonder why. You know, is there a commitment issue? You know, a baby is for life, like the dog is for life, not just for Christmas. And what does a child mean for them? Why do they want a child?

You have to look at motivation for having children. We have had cases where a single woman has been motivated to come to us to have a child because, not for the sake of having a child, but really it's transpired that they would move into better social housing if they had a child and things like that, you know, so it's looking at the motivation.

Finally, while the 'presumption to treat' principle resonated strongly with practice, it was nonetheless subject to ambivalence. It is noteworthy that, notwithstanding a clear liberalisation of attitudes, worries regarding a 'sense of entitlement' and consumerist attitude to treatment were particularly expressed regarding single women and the clearest illustrations of it that we were given involved, respectively, a same-sex couple and two single women. Here, insofar as lesbian patients were not merely seeking the alleviation of social infertility but were approaching the clinic in an apparently more 'consumerist' way, they fell short of the homonormative ideal: we were told of staff discomfort regarding one female couple requesting simultaneous pregnancies. This reflects an ambiguity long present in this area and captured in the idea of infertility 'treatment services': while our interviews revealed that staff recognised social infertility as creating a real need and were happy to offer *treatment* for it, the above example reflects a concern regarding the provision of a *service* to

enable patients to build a family in the way, and at the time, that they chose. Further, two of our respondents told us of planned 'virgin births',<sup>84</sup> each of which raised serious concerns for the staff involved. One explained:

[Needing to prove 'serious harm'] is very strong, isn't it? We had a patient who was a virgin, who wrote to us to have treatment and she'd identified the man that she wanted to be the father. She hadn't actually spoken to that man's wife. We never even got as far as treating this woman [...] What sort of impression are you giving to give to a 14/15 year old [child born following treatment] who's discovering their sexuality [...] if you are a virgin, you know? I appreciate that might not be 'serious harm' in terms of physical abuse but it's not a healthy attitude to sexuality (nurse).

Finally, it is also worth noting one important consequence of the consensus that all patients making use of donated gametes should receive counselling: while single women and lesbian couples may no longer raise widespread concerns regarding 'family form', it would thus be exceptional for them not to be required to undergo counselling (along with others intending to conceive via donation). In this sense, these groups are automatically included within the cohort of patients who continue to attract a higher level of scrutiny and support, albeit again for different and more complex reasons than a concern with the lack of a suitable 'father figure' in the social family unit.

In her study of the early implementation of s.13(5), Douglas found that treatment decisions were made on the basis of appropriate family form, often reflecting the 'personal whim of the clinician in charge' and limiting treatment to 'those people we, as a society, think are worthy of parenthood' (primarily on the basis of relationship status).<sup>85</sup> Some twenty years on, our study has revealed a very

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<sup>84</sup> This provides an interesting echo of concerns widely voiced at the time of the introduction of the 1990 Act, see: Cooper and Herman, above n 77.

<sup>85</sup> G. Douglas (1993), above n. 39, 69 and 55. See also Douglas (1992), n 39; Blyth, Burr and Farrand above n 81.

different picture, with a rejection of group exclusions, a larger number of clinic staff involved in treatment decisions, and a sustained focus on considerations of child welfare and future parenting ability. Single women nonetheless continue to be perceived as a problematic group within this process. While a desire to avoid discrimination was clear, it is not possible to legislate away staff's emotional reactions to patients and the values which they bring to their work, which will, inevitably, also reflect working practices developed under earlier law. This results in a more subtle and nuanced problematisation of single women, involving not a group exclusion but the occasional emergence of one or more of a set of concerns regarding support mechanisms, ability to cope, motivation for parenting, ability to sustain a loving relationship, likely quality of future parenting given these other factors, and an occasional poorly defined sense of there simply being something 'a bit odd' about the woman seeking sole parenthood. Further, as noted above, women who presented as being in a series of relationships or a relationship that was not 'stable' were seen as particularly problematic. These rather different grounds for concern bolstered a need for greater scrutiny and underpinned acceptance of the specific expertise of counsellors in the assessment process.

## Conclusion

Earlier studies have suggested that regulation is only fully effective where it is 'institutionalized', becoming part of the internal morality of an organization.<sup>86</sup> While many of our interviewees were unhappy about specific aspects of the welfare assessment process, all took it seriously as a significant shared professional responsibility, representing far more than a form-filling, 'tick-box' exercise. In this sense, section 13(5) can be claimed as a significant success, with a shared 'regulatory community'

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<sup>86</sup> See generally, J. Black, above n 20, 182.

operating at a 'deep level'.<sup>87</sup> Clinic staff share both a strong normative commitment to the values underpinning the legislation and a collective vision of how conflicts and trade-offs between those values should be addressed. Notably, this involves a key role for the Person Responsible in driving welfare assessment decisions, the exchange of views and building of consensus in multidisciplinary team meetings, and a central role for counsellors in investigating and managing complex cases. Across the sector, we equally found an important shared frustration at the lack of external support (from the HFEA, social services and other agencies) that might allow treatment to proceed in 'hard cases'. This is far from the picture of clinicians operating on a 'personal whim' described in the early 1990s.<sup>88</sup>

Within this broad brushstroke, a complex picture emerged regarding the application of law in practice, with important limits to its influence on decision-making. Written norms cannot serve directly to translate even the clearest of Parliamentary intentions into practice: they require interpretation by human beings who are influenced by a range of other factors, including personal morality, emotional reactions, economic constraints, other competing norms, and the residue of practices and beliefs developed under earlier regulation. And while the removal of the 'need for a father' from the law may have been heard as imposing a requirement 'not to discriminate', Parliament's intention is significantly less clear in the term chosen to replace it. Indeed, it is possible that 'supportive parenting' came to be adopted precisely because of its ability to mean different things to different people.<sup>89</sup>

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<sup>87</sup> *ibid*, 178.

<sup>88</sup> As suggested by Douglas, n 85.

<sup>89</sup> The differences in the definition given by the Government and the understanding of MPs involved in the reform is explored in McCandless and Sheldon, above n 1. They contrast the views of two parliamentarians, who had each been very active in the discussions leading to reform. As noted above, while Phil Willis, MP (chair of the pre-legislative scrutiny committee which examined the draft legislation) suggested that most MPs

Certainly, for our interviewees, the term was either not used or was understood in ways that sharply diverged from the definition provided in the Code of Practice. Notwithstanding the very significant Parliamentary time devoted to revision of section 13(5), then, this specific change to its wording appears to have had no real impact on clinical practice. Rather, the most significant changes to the Code of Practice's guidance on section 13(5) predated the 2008 reform, and a number of our interviewees suggested that both statute and Code had changed in line with clinical practice, rather than vice versa. None reported any significant change to their own practice as a result of the reform.

The fact that our respondents believed that the evolution of clinical practice had prefigured, and perhaps even driven, legal reform is also interesting. The HFEA replaced an earlier, self-regulatory body, with practitioners having been amongst the most vocal of those calling for regulation to be put on a statutory basis.<sup>90</sup> The 1990 Act clearly made a significant difference to the sanctions available to the regulatory body, albeit that these are seldom used.<sup>91</sup> However, in terms of drivers of change to

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understood this phrase as a 'modern way of talking about the traditional family', this understanding was strongly rejected by Baroness Ruth Deech (a former chair of the HFEA as well as a very active participant in debates around the reform). Deech noted: 'the [word] "supportive" was an indication that you were no longer going to need two-parents let alone a father and a mother ... "Supportive parenting" is absolutely rubbish...what does it mean?'

<sup>90</sup> The Voluntary Licensing Authority was set up in 1985 by the MRC and RCOG. It later changed its name to the Interim Licensing Authority as a way of signalling the need for statutory body to take over its work. The VLA issued a code of practice, invited all centres to submit for licensing, committed to visit each centre before a license was granted, and reported to the MRC and RCOG, see: VLA (1986) *First Report of the Voluntary Licensing Authority* (London, VLA, 1986).

<sup>91</sup> Lee and Morgan note that this is not necessarily a bad thing, citing Stanley de Smith's comment that one should not judge a watchdog by the number of people that it bites, n 4, 142.

the regulation, differences between the operation of the earlier, self-regulatory model and the current statutory one may be subtle at times, with a strong role for professional practice also present in driving the evolution of regulatory norms in the context of the latter. The picture that emerges is one of a continual dialogue between the regulator and the regulated, with law in this context closely dependent on scientific opinion and clinical understandings of best practice.<sup>92</sup>

We found some evidence in support of the view that, in balancing the competing values within the legislation, the HFEA's stance might be characterised by a more pronounced focus on non-discrimination, with clinic staff placing proportionately greater weight on the welfare of the child. However, this is no more than a difference of emphasis. The most marked wrinkles in the implementation of the regulation rather emerged where it was most clearly in tension with, or was competing for attention alongside, other influences. Law does not operate within a vacuum and where the welfare assessment functions alongside assessment for NHS funding eligibility, then it would be surprising if there is no interaction between the two processes. The more intrusive lines of questioning no longer routinely required under the welfare assessment remain widespread where there is a need to assess for NHS funding eligibility. And we found a common lack of clarity regarding whether questions were asked in order to address welfare or funding eligibility concerns and some seepage of information obtained in one context being treated as relevant in the other. Further, such seepage is inevitably exacerbated where clinics do not have different staff to provide counselling and to perform the welfare assessment, as recommended by the HFEA, yet many clinics rely heavily on the same counsellor or counsellors to perform multiple functions.

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<sup>92</sup> Lee and Morgan, *ibid*, 141.

Debate regarding section 13(5) has historically been dominated by concerns regarding the deliberate creation of ‘fatherless families’. While we found a very small number of instances where lesbian couples were thought still to merit greater scrutiny than heterosexual ones, this was exceptional. Rather, those lesbian couples who have taken on the homonormative ideals of carefully planned parenthood, with responsibilities shared in a stable relationship and a solid support network, are seen as particularly good – indeed, for some, the very best – patients. Further, with it impossible to deny the involvement of a third party to a future child, lesbian couples are more likely to conform to dominant norms around the need for transparency regarding the circumstances of conception.

A more complex picture emerged around single women, with lingering concerns in some clinics regarding the lack of a suitable male role model for their children, and – more commonly – issues raised regarding their ability (financial and otherwise) to cope with a child and their motivation for parenting. Specific concerns were expressed regarding women who, over time, presented with more than one partner and who were thus felt not to offer a ‘stable’ family life for a child. Single women and lesbian couples will, by virtue of the treatments sought, invariably attract a higher level of attention than many other patients, given that they (like some heterosexual couples) will almost certainly be expected to undergo implications counselling before being offered donated gametes. Making such counselling mandatory or presenting it as ‘an offer that they can’t refuse’ was the most clearly sustained departure that we found between clinical practice, on the one hand, and the letter and spirit of the revised regulatory framework, on the other. This deviation was underpinned by a powerful shared sense of the complex issues raised by gamete donation and the idea that the responsible parent is one who chooses to disclose to her or his children at an appropriate time and in an appropriate way, a view that has become a near orthodoxy within the sector. Further, we found some instances of an unwillingness to disclose being treated as a welfare concern.

In sum, our analysis suggests that while access to infertility treatment services has become less restricted over the lifetime of the 1990 Act (with most of this evolution taking place prior to the 2008

reforms), patients seeking infertility treatment services are still subject to a level of scrutiny, with power operating through the clinical encounter in subtle and complex ways. This is not primarily through refusals to treat certain groups, though awareness of the possibility of refusal will almost certainly have a chilling effect on who presents for treatment and may potentially impact on what information patients are willing to share. At the extreme, patients may even be ‘counselled out’ of the treatment process. Beyond this, scrutiny operates through ideas of appropriate parenting deployed by clinic staff who share a keen sense of responsibility for the future child to be born as a result of their intervention. While this might sometimes appear to go beyond the strictures of the regulation, law does not merely leave open a space for such scrutiny: it mandates it. Rather than attempting to restrict access to treatment services to certain categories of patient, section 13(5) explicitly relies on the deployment of clinical discretion as a way of mediating political tension around the threat that reproductive technologies pose to the ‘traditional family’ and acceptable parenting.<sup>93</sup> Where discretion is left to be exercised at the clinical level, it should not come as a surprise if that discretion is so exercised, nor that the precise manner of such exercise is not susceptible to precise regulatory control.

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<sup>93</sup> An amendment seeking to criminalise the treatment of unmarried women, introduced by Lady Saltoun of Abernethy, only narrowly failed in the House of Lords: HL Deb vol 515 col 787 6 Feb 1990.