

## **Assessing Child Welfare under the Human Fertilisation and Embryology Act 2008: A Case Study in Medicalization?**

### **Authors**

Dr Ellie Lee (for correspondence), Reader in Social Policy, School of Social Policy, Sociology and Social Research (SSPSSR), Cornwallis NE, University of Kent, Canterbury CT2 7NY, 01227 827526, [E.J.Lee@kent.ac.uk](mailto:E.J.Lee@kent.ac.uk)

Dr Jan Macvarish, Research Fellow, Centre for Health Services Studies (CHSS), SSPSSR, University of Kent, Canterbury

Sally Sheldon, Professor of Law, Kent Law School, University of Kent, Canterbury

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**Abstract**

This article reports findings from a study of interviews with 66 members of staff working in assisted conception clinics in the UK about their experience of making 'welfare of the child' (WOC) assessments pre-conception. This aspect of the provision of infertility treatment services is obligatory under section 13(5) of the Human Fertilisation and Embryology Act. This provision was amended in 2008 and the primary aim of the study was to find out how this change had impacted on practice. In describing what we found, we also make a contribution to scholarship about the medicalization of reproduction. Section 13(5) has often been discussed as a prime example of medicalization, as it gives clinics power to grant or deny access to infertility treatment on wide ranging 'child welfare' grounds, encompassing far more than purely clinical considerations. Yet while such medicalization may be entrenched in the law, our findings suggest this power is used in a very 'light touch' way, with clinics explicitly directed by the Human Fertilisation and Embryology Authority that they should operate with a presumption to treat. Further, while our interviewees offered near-universal support for the need to consider child welfare before offering treatment, this is now justified by concerns which focus not on family form (e.g. the need for a father figure) but more on the quality of interactions and relationships between parents and children. In this light, and by virtue of the fact that a wide variety of clinic staff share the gatekeeping role with doctors, we suggest that the concept of medicalization may offer a rather blunt tool for understanding a far more complex reality.

## Introduction

The current UK law regulating assisted reproduction dates from 1990, when treatment services involving donated gametes or the *ex utero* creation of embryos came under statutory control. The Human Fertilisation and Embryology Act 1990 (hereafter the 1990 Act) established a statutory body the Human Fertilisation and Embryology Authority (hereafter the HFEA), to regulate this sector of health care provision through, among other things, developing a Code of Practice (COP) and ensuring compliance through a system of licensing and clinic inspections.

This paper is concerned with just one part of these regulations, concerning 'Welfare of the Child' (WOC) assessments. The original wording of the 1990 Act provided for these as follows:

s.13(5) A woman shall not be provided with [infertility] treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for a father), and of any other child who may be affected by the birth.

Successive iterations of the COP since the early 1990s have provided guidance on how clinics should interpret this subsection in practice.

While the regulation of assisted conception attracted controversy since long before the inception of the regulatory framework noted above, s.13(5) became a particular focus of debate and criticism through the 1990s and this century. At the most extreme, it has been argued not just that it is discriminatory to require the infertile (and not the fertile) to be

screened for their suitability for parenthood, but further that the very idea of using the idea of the welfare of a child yet to be born to argue against his or her conception is nonsensical (Jackson 2002, 2008).

Most frequently, criticism of s.13(5) focussed on two main areas. The first concerned the practical difficulties posed in obtaining information to demonstrate that clinics had 'taken into account' the 'welfare of the child' pre-conception and clinic staff's lack of training to carry out such investigations. For example, it was asked, did seeking the opinion of prospective patients' GPs, as was originally suggested by the COP, constitute a reliable or fair way of doing so? Who could provide such information to clinics about the future welfare of a child? Further, had multiple individual clinics each with their own systems for carrying out 'welfare checks' generated unequal access to treatment across the UK (Blyth and Cameron 1998, Jackson 2001)?

The second criticism was that s.13(5) was discriminatory towards those who are not physically, but socially, infertile: single and lesbian women (Douglas 1993, Blyth 1995, Blyth et al 2008). In this regard, s.13(5) appeared importantly out of step with other legal provisions introduced to recognise same sex couples (most notably the Civil Partnership Act (2004) and the Adoption and Children Act (2002)). Indeed, even before 2008, the HFEA had amended its guidance to clinics explicitly to emphasise that they must take care not to 'discriminate' against any prospective patients (see generally McCandless and Sheldon 2010).

In 2008, s.13(5) was amended as part of a broader reform process. Powerful arguments in favour of simply deleting the section altogether, which had gained some traction not just in academic work (Jackson 2002, 2008), but also in earlier Parliamentary consideration of the

issues (House of Commons Science and Technology Committee 2005), fell by the wayside. Rather, the focus centred squarely on the exact form of words which should be used to replace the phrase 'the need of that child for a father' with concerns about discrimination coming to dominate the Parliamentary debates (McCandless and Sheldon 2010).

After lengthy discussion, the following new wording was agreed:

S.13(5) A woman shall not be provided with [infertility] 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 (our emphasis).

Following the reform, the COP was also revised, *inter alia*, to provide 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 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 (HFEA 2009, para 8.11, our emphasis).

The COP thus, since 2009, explicitly places the burden of proof on those who would seek to refuse a woman access to treatment: those seeking to make use of assisted reproduction are to be 'presumed' to be 'supportive parents' unless, there are good grounds for believing a

child who may be born will be 'at risk'. The WOC assessment involves identifying whether there are grounds for suspecting that the child to be born will be at risk of 'significant harm or neglect' (HFEA 2009, para 8.3), to be determined by reference to a list of 'risk factors'. Factors to be considered include past or current circumstances that may lead to any child experiencing serious physical or psychological harm or neglect; past or current circumstances that are likely to lead to an inability to care throughout childhood for any child who may be born; mental or physical conditions; and drug or alcohol abuse.

The reform of s.13(5) was clearly considered highly significant by policy makers: revision of this one phrase took over eight of only eighty hours of Parliamentary time available to debate an Act that runs to over one hundred pages long. The changes were also accompanied by extensive media debate, with the question of the deletion of the phrase, 'need for the father', proving particularly controversial (McCandless and Sheldon 2010). In the light of this level of interest, the study reported here sought to find out how these changes impacted upon clinical practice, drawing upon interviews with those working most directly with the new regulations: clinic staff.

The overarching questions that informed interviews were:

1. *Who, if anyone, will s.13(5) henceforth serve to exclude from treatment?*
2. *How do clinics decide who should be treated?*
3. *In the view of clinic staff, have the changes made to the welfare clause solved the problems previously associated with it?*

In order to respond to these questions, we asked staff to describe how WOC assessments are performed at their clinic and to give their opinions both on the legal requirement to

undertake the assessment and on the effects of the 2008 reforms. In setting out some answers to these questions below, we provide the first account of WOC assessments in practice since 2008. Before discussing our methodology and findings, however, we first consider what we consider to be the most interesting aspect of the new regulatory framework from a sociological perspective. This is the combination of what can be considered to be a 'light touch' approach to regulation in the form of 'risk assessment' within what has been described as a 'medicalized' framework of assessment for suitability for parenthood.

### **Medicalization and risk assessment**

As noted above, in its original formulation s.13(5) required consideration of the child's welfare, including the 'need for a father' before regulated treatment services could be offered. As a result, s.13(5), more clearly than any other part of the 1990 Act, has been taken to express anxieties about the potentially disruptive role of assisted reproduction with regard to family formation (Tizzard 1998). In support of this view, commentators have referred to the Warnock Report, which preceded and informed the 1990 Act:

...many believe that the interests of the child dictate that it should be born into a home where there is a loving, stable, heterosexual relationship and that, therefore, *the deliberate creation of a child for a woman who is not a partner in such a relationship is morally wrong* ... we believe that as a general rule it is better for children to be born into a two-parent family, with both father and mother, although we recognise that it is impossible to predict with any certainty how lasting such a relationship will be (Warnock 1984, para 2.11, our emphasis).

While an attempt to restrict treatment to married, heterosexual couples had been only narrowly defeated in the House of Lords (House of Lords 1990), the 1990 Act did not translate Warnock's moral objection into a ban on treating anyone other than stable heterosexual couples. Rather, Parliament voted to leave the legal responsibility for making 'welfare of the child' assessments to clinics, thus ascribing to them the task of 'making social judgements that go beyond the purely medical' (Millns 1995). As Tizzard noted of s13(5):

Never before have doctors been in a position where they are making such far-reaching judgements about the individual or couple sitting before them. And never before have doctors been in a position to make decisions that are *patently not medical ones* (1998, p191, our emphasis).

In this sense, s.13(5) has been seen as an example of the medicalization, the 'process through which nonmedical problems become defined and treated as medical problems' (Conrad 2007, p4. See also Conrad and Schneider 1980, Conrad 1992, Sheldon 1997, Lee 2004). The archetypal example of childbirth illustrates how the concept 'medicalization' has played out in the area of reproduction, with the medical profession's increasing control of pregnancy and childbirth in the twentieth century castigated as far outstripping what is clinically necessary to ensure the health of women and children (Graham and Oakley 1981, Doyle 1994). Most forms of infertility treatment services involve procedures, often technically complex ones, which require medical involvement. However, while the likelihood of success and the clinical merits and dis-merits of particular procedures are medical issues requiring doctors' input, the question of *which sorts of people* should be permitted to undergo treatment and become parents to a child, involves considerations of a quite different order, particularly if understood as a means of promoting or protecting a particular model of the family (as headed by a heterosexual couple). It is this legally mandated



gatekeeping role, and the way that it stretches our understanding of medical competence to include making decisions which are non-medical, that has led the commentators above to describe s.13(5) as involving medicalization.

As we noted earlier, while the 1990 Act imposes clinical scrutiny as a prerequisite to accessing treatment services, the accompanying COP provides additional guidance as to how this should operate in practice, instructing clinics to presume that 'all prospective parents will be supportive parents, in the absence of any reasonable cause for concern'. This appears to reflect a view that in-depth scrutiny of prospective parents pre-conception *vis a vis* their parenting abilities is unnecessary in almost all cases. As noted, the COP uses the notion of 'risk assessment' to indicate the sorts of things that might give 'reasonable' cause for concern, citing the threat of 'significant harm', a phrase that has its origins in the Children Act 1989, where it is used as the threshold for state intervention in cases of child abuse and neglect. While this creates a discursive connection between the WOC assessment and 'child protection', the recommended method for assessing risk is entirely unlike that used in child protection. The COP suggests it may take place through use of a 'tick box' form, completed by prospective patients themselves (regardless of what sort of treatment they are seeking), giving answers to the following questions (HFEA 2008):

- 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?

The voluminous literature on the 'risk society', detailing the growing reach of 'risk assessment' is too extensive to discuss here. It is, however, interesting to contrast the process described above with other instances where the term 'risk' or 'at risk' is used as part of a process of expanding and extending the remit of regulation and oversight by professionals (Parton 2006). Unusually, in the context of s.13(5), the introduction of the 'risk assessment' has sought to encourage *restraint* of oversight, with the pro-forma 'tick list' form, produced for clinics by the HFEA, intended to make this a speedy and uncomplicated process.

This move towards restraint builds on a trajectory towards restricting the scope of WOC assessments that was already in place prior to 2008. Following an earlier consultation on the operation of the assessments (HFEA 2005), the HFEA had introduced a number of changes to the COP (HFEA 2007), the most significant of which was the presumption in favour of providing treatment to those who requested it, to operate unless there was evidence that any child born to an individual or couple (or any existing child of their family) would face a risk of serious medical, physical or psychological harm. This advice was then carried forward into the current edition of the COP (2009), issued after the reforms to the law.

In sum, s.13(5) has been described as a case of the medicalization of reproduction in that the law imposes specific responsibility on clinics to decide who can and cannot be treated,

despite the fact that these decisions do not turn on clinical considerations. The COP risk assessment process can be seen as a mechanism for restraining the operation of discretion in this context, specifically seeking to ensure that it is not used discriminatorily. In what follows below, we aim to demonstrate how neither the imposition of clinical responsibility foreseen in s.13(5), nor the attempts to contain it foreseen in the COP, have translated in any straightforward way into the practice of clinics. Rather, clinic staff's responses to s.13(5) are complex and underpin welfare assessment practices which involve a far wider range of staff than just clinicians. Indeed, given an enhanced focus on emotional and psychological factors in these processes, particular weight has been given to the role of counsellors. In light of these findings, we end by suggesting, it is difficult to sustain the idea that these processes involve any straightforward 'medicalization'.

To discuss these points, after providing a brief account of our methods, we move on to draw out three core findings. First, the ambiguity of WOC assessments: our findings point to a combination of a very low number of refusals to treat emerging from current WOC procedures (and indeed a widespread of ethos of working with patients to help overcome any obstacles to treatment) with near ubiquitous support for taking child welfare into account. Second, developments in attitudes towards treatment of lesbian couples and single women, and third concerns regarding donated gamete recipients, who emerged as a group seen as having special needs and requiring special treatment. We end with some brief conclusions about both what the study identified and the concept 'medicalization' in this context.

## **Methods**

Our methodology was designed primarily to take account of the inherent difficulties involved in seeking to generate comprehensive and detailed information from busy medical professionals, and the time and financial constraints associated with obtaining ethical and Research and Development (R&D) approvals for research in NHS settings. For these reasons, face-to-face interviewing at a sample of clinics was selected as the way to collect data rather than a postal questionnaire to all clinics.

A target sample size of 20 clinics (approximately a quarter of the 77 clinics licensed in the UK to carry out IVF treatment) was judged sufficient. Discussion with Advisory Group members and within the research team led to the identification of 47 clinics as possible research sites, from the list of all HFEA-approved clinics in the UK. Desk research into the profiles of these 47 clinics assessed the size of clinic; the range of services offered; the balance of NHS and private patients; the reputation regarding liberal or a more restrictive approach to accepting patients for treatment, and the location of the clinic. Following further discussion with the Advisory Group, this group of 47 was reduced to 44 clinics to approach with an 'in principle' request that they consider participating in the study and interviews were, in the end, conducted at 20 clinics.

Fifteen clinics were NHS-funded and 5 were privately-funded. The categories 'NHS' and 'Private' denote the status of the clinic as part of the National Health Service or a private business; however, most NHS clinics treat a substantial number of self-funded patients, and some private clinics have contracts to provide NHS-funded treatments. The final sample included clinics in all regions of the United Kingdom, and ranged in size from the smallest to the largest type of centre (determined by number of cycles per year according to HFEA 2009 figures). Ethics approval was granted in May 2011 by the Oxford REC B committee and we also obtained consent from the R&D office of each NHS research site.

Our original aim was, at each clinic, to interview the lead clinician (also usually the ‘person responsible’, within the terms of the 1990 Act, for supervising all licensed activities, hereafter PR), along with three other members of staff. Following discussions with AG members, we decided to include nurses, counsellors and embryologists, as members of clinic staff who have ‘input’ into WOC assessments, thus ensuring that we gained a complete picture of how WOC assessments work. This reflects the fact that, in practice, there is no one individual with sole responsibility for the assessment process, and assessment was not done only by those with medical training. For example, counsellors, who are employed by clinics primarily to provide therapeutic counselling where desired by patients, and who do not usually have a background in medicine, often play a central role in WOC assessments. While it was not always practically possible to interview the intended four staff at each clinic, we did complete interviews with more than one member of staff. The participant profile is as indicated in Table 1.

<b>CLINIC</b>	<b>Interviewees</b>	<b>Total</b>
1	Doctor/PR; Embryologist; Nurse; Counsellor	4
2	Doctor; Nurse (PR was unavailable)	2
3	Doctor/PR; Nurse; Counsellor	3
4	Doctor 1 /PR; Doctor 2; Counsellor; Embryologist	4
5	Doctor 1/PR; Doctor 2; Embryologist; Nurse	4
6	Doctor/PR; Nurse; Embryologist 1; Embryologist 2; Counsellor	5
7	Doctor 1/PR; Doctor 2; Embryologist; Counsellor	4
8	Scientific Director/PR; Counsellor; Nurse	3
9	Nurse; Senior Nurse; Embryologist (PR was unavailable)	3

10	Doctor/PR; Nurse; Embryologist; Counsellor	4
11	Doctor 1/PR; Doctor 2; Doctor 3; Nurse	4
12	Embryologist/PR; Embryologist; Doctor; Nurse; Counsellor	5
13	Senior Embryologist; Nurse (PR was unavailable)	2
14	Counsellor; Scientific Director; Nurse (PR was unavailable)	3
15	Doctor/PR; Nurse; Embryologist	3
16	Doctor/PR; Nurse; Nurse Manager	3
17	Doctor/PR; Counsellor	2
18	Doctor/PR; Embryologist; Nurse; Counsellor	4
19	Doctor/PR; Nurse	2
20	Scientific Director/PR; Counsellor	2
<b>TOTAL</b>		<b>66</b>

**Table 1: Professional profile of interviewees**

The interviews were recorded on a digital recorder for later transcription and Nvivo (version 9) was used to support the analysis of transcribed interviews. Data analysis was conducted in two stages; first the transcripts of two key informants were selected from each clinic to gather factual information about the WOC assessment process. Stage two of the analysis was a thematic reading of responses to our questions about changes to the regulatory framework. The interviews raised a range of issues, only some of which can be discussed here, but the key areas identified by the study are as follows.

### **Refusals to treat and ambiguities of WOC assessment**

Given the amount of Parliamentary time invested in discussing the welfare clause, it is interesting to know how often the welfare assessment results in a refusal to treat patients, or even in any further investigation of them. In the table below, we therefore give the numbers of 'cases of concern' respondents indicated their clinic dealt with each year

(requiring further investigation following the risk assessment process undergone by all prospective patients).

We provide this information alongside an indication of clinic size to give a sense of proportion. Clinic size is indicated by the number of treatment cycles provided annually, where 'treatment' means methods used to fertilize an egg *ex utero*, which are *In Vitro* Fertilisation (IVF) and Intra Cytoplasmic Sperm Injection (ICSI) (and which, because they involve the ex-utero fertilisation of an egg, are regulated by the HFE Act). Treatment cycle numbers reflect each single attempt at creating a pregnancy rather than patients treated, as this is the way that data is collected within the sector.

<b>Number of cases of welfare of the child concern in a year</b>	<b>Number of clinics and clinic size (by annual number of cycles of IVF and ICSI)</b>
0-5	11 clinics (4=< 500 cycles, 5=<1000 cycles and 2=1500-2000 cycles)
5-10	4 clinics (1=<500 cycles, 2=800-1100 cycles, 1=1800 cycles)
10-15	3 clinics (1=400 cycles, 1=600 cycles and 1=730 cycles)
30-60	2 clinics (2=2000-2500 cycles)

**Table 2: Number of 'cases of concern' generated through WOC assessment**

While there is no straightforward correlation between the size of clinic and number of cases generated (reflecting distinct practices in different clinics), as would be expected, this shows the largest number of cases of concern occurring in the two largest clinics. However, in all cases, set against the size of the clinics, numbers of cases of concern are low. Clinics reported that these cases, which would trigger further investigation, typically related to

mental illness (including depression), transmissible or inherited illness, physical illness or disability and drugs and alcohol. Only 10 clinics reported dealing with cases involving 'violence in the family environment' and 11 had encountered 'convictions for harming children' (both categories used on the HFEA risk assessment form).

Where 'welfare of the child concerns' did emerge, treatment could not be granted until further information about the patient's current or previous medical or social circumstances had been obtained to rule out 'risk of significant harm or neglect'. The following, which strongly reflects the ethos of the COP discussed above, represents the typical approach:

*I think the way we work is there's a presumption to treat and...we have to give the patient as much chance as we can to put their sort of side across...obviously if something is found...there are occasions we turn down but it probably is only one or two a year, I would say. (Embryologist)*

Further, for the majority of interviewees, most of the welfare concerns that had emerged had been minor and easily resolvable through a little more information, provided most often by the patients themselves or their GPs. Occasionally, further investigations involved consulting specialists with expertise in a particular medical condition or in drug or alcohol abuse, or social workers or probation officers who had professional contact with the patient. Further information might also be obtained from a clinic counsellor, who might conduct an assessment session with the patient to gather further information, or patients might be the subject of further discussion at a clinic multi-disciplinary team meeting. Finally, in a very small number of clinics, independent social workers might be called upon to make a fresh assessment of the patient.



Hence, the overall picture is of a strong practical endorsement of the COP's 'presumption to treat', with a very small number of cases where there is 'cause for concern' resulting from the general WOC risk assessment of all prospective patients. Resulting refusals to treat were rarer still: seven clinics estimated that in an average year there would be no refusals on welfare grounds, two clinics said refusals happened only once every couple of years, eight clinics estimated one to two refusals per year, two clinics said three to four, and only one clinic said over seven. All staff had examples of 'extreme cases', but these were often drawn from a number of years back or from cases that they had heard discussed without being directly involved themselves.

The rarity of refusals meant that there were no 'typical' cases: all were, by their nature, complex and idiosyncratic, and some staff reported struggling to resolve the small number encountered. One clinic thus described frustration concerning the case of a male patient in his late twenties, who disclosed that he had received a conviction for sexually assaulting a young child when he was a teenager. The clinic was willing to treat him and his partner but considered that they needed an 'all-clear' from the social services that he no longer posed a risk to children before proceeding. However, social services would not provide a judgement prior to any pregnancy being achieved or a child being born. In the end, despite the clinic's wish to proceed, the couple did not receive treatment.

Thus, while all clinics had refused treatment to patients, overall, such decisions were very unusual. The clear picture is one of clinics working hard to try to find ways to overcome any obstacles to providing treatment. This appears confirmed by another finding: that the outcome where 'welfare' concerns were raised appeared to be deferrals of treatment, which might occur while further investigations were made, or while a patient sought to change their behaviour, for example by limiting their alcohol consumption.

How new is this picture of WOC assessments? While it is certainly different from that emerging from early research (Douglas 1993), our respondents told us that changes to their practice pre-dated 2008. Many thought that the new COP (2009) did not have significant implications for practice, because there was already a presumption to provide treatment:

*I think it was already the way we were seeing things (Counsellor)*

*I think perhaps it has been made more prominent after the recent changes but, you know, one...has always to work on the principle that people are innocent until proven otherwise (Doctor).*

This doctor thought the new guidance had, however, legitimated what he considered to be a more positive approach towards new patients:

*I'm not sure it [the new regulations] solved any welfare of the child problems, but it solved logistical paperwork, not being able to proceed with treatment until the GP had sent the letter back so yes, it made management of the couple's treatment easier. I also felt much more comfortable philosophically with.... you go into this wanting to treat someone, as your default position. I think that's a far healthier situation to be in than to take on some type of state assessor of suitability to be parents (PR).*

This strong endorsement of the presumption to treat should not be taken, however, as implying a view that the WOC assessment was considered to be a mere formality. While most staff reported that the vast majority of patients were 'normal' and should be treated,

this view clearly co-existed with an often overtly expressed sense that it was very important to be alert to 'welfare of the child' concerns, with the responsibility for maintaining such vigilance shared amongst all clinic staff.

In this sense, we found that although the mainstay of the formal WOC assessment process was the use of a form (most usually that designed by the HFEA or a version of it), the culture of most clinics was such that *all* staff involved in face-to-face contact with patients (including, for example, reception and administrative staff and laboratory staff who might deal with patients either at the clinic or over the telephone) might 'input' into welfare of the child assessments, whether or not they were responsible for checking the WOC form or taking patient histories. If patients were upset or angry, for example, or revealed information about their circumstances deemed to have significance, either prior to or during treatment, staff were encouraged to report this to another member of the team.

The study detected, in particular, a view that vigilance was necessary because 'you can never really know': the spectre of the child abuser as a person hardly ever encountered, but whose threat nevertheless creates a powerful rationale for pre-emptive action, influenced staff perceptions. As one nurse put it:

*I think the obligation for our clinic is to look into the welfare of any child that might be born...you wouldn't want to bring a child into a relationship where the child was at any danger of child abuse or sexual abuse...[A]nything...that sets those alarm bells going would be something that we wouldn't want to risk.*

These concerns sometimes led staff to consider checks and filters beyond those currently required:

*We all have to be CRB checked...is it too much to ask the patient to be CRB checked?*

*Is that too far?...I don't have the answer but it's just something that concerned us.*

(Nurse)

However, the imaginative power of being on guard against 'the paedophile' coexisted with an awareness of the impossibility of knowing who was, and who was not a potentially risky parent.

*Who is going to be honest about having been arrested as a paedophile ten years ago? They're going to hope that they're going to get away with it aren't they? It's very much taking what they say on trust... (Counsellor)*

The low number of refusals to treat on WOC grounds was seen as reflecting the fact that assisted conception is a normal, everyday part of medical care, sought by normal, everyday people who want to be parents. However, neither this view, nor the kinds of criticisms of s.13(5) noted in the introduction, nor even the fact that the end result of a process that adds costs to treatment is a handful of people being refused treatment on highly unusual grounds (which, in many cases, would come to light without the WOC assessment) led clinic staff to reject the need for welfare assessment. On the contrary, the need for such assessment was overwhelmingly endorsed.

### **The 'socially infertile'**

In the introduction we noted that a strong motivation driving legal reform had been a desire to end discrimination against the socially infertile. Same-sex female couples and single

women were treated by all but one of the clinics (which provided a very limited range of services, not running to use of donated gametes). Even where staff had their own concerns about treating single or lesbian women, they made a strong distinction between their personal views and their professional obligations. While some clinics allowed staff to 'opt out' of treating certain patients on grounds of conscience, there were no recent examples of staff taking up such an option.

Within this overall picture, there nonetheless remained circumstances that provoked concern: for example, treatment of single women was considered completely unproblematic at some clinics but, in others, single women still attracted particular scrutiny regarding their suitability as future parents. Indeed, compared to previous research, a notable finding of this study was a bifurcation in attitudes towards single women and lesbian couples (with the latter viewed by many as model patients).

In terms of lesbian couples, there was some variation in the way they were discussed, with a few interviewees noting the need for patients to discuss 'role models' or 'male role models' with a counsellor, reflecting some continuity with previous concerns about the 'need for a father':

*I think they go into how people feel about the genetics of it, that it's not genetically your child, and we do quite a few same sex couple, so the need of a father figure is gone into, so it is still all discussed. I think we ask people to think around all these subjects. (Nurse)*

However, the main emphasis was on 'not discriminating':

*We've never discriminated against same-sex and you mustn't. It implies that relationships are less valid. (Doctor)*

Further, lesbian patients were frequently represented as 'ideal patients'. In general, treating lesbians was seen as straightforward, with some respondents keen to point out how 'good' lesbian patients could be as parents because they were seen as 'well-prepared' for parenthood: fully aware of the facts and consequences, equipped with strong support networks, and open and honest in discussions with clinic staff:

*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)*

Complications associated with lesbian couples tended to be seen as relating to the donation of gametes rather than the sexuality of parents (a point discussed further below):

*They get implications counselling, not because they're same-sex but because they're using donor sperm. (PR)*

*Interviewer: So they'll be using donated gametes, do they have to go to counselling?*

*Respondent: In exactly the same way as a heterosexual couple [using donated gametes]. There's no discrimination at all. (Doctor)*

The discussion of single women patients had a rather different tone. While single women were accepted for treatment at all but the one clinic which did not offer donor insemination, there were varying opinions about this and their treatment was more contentious. Some staff felt that single women should be treated like any other patient:

*Interviewer: And do single women trigger any different assessment process?*

*Respondent: No, not really. Not unless they're... you know, not unless they're a single woman with an issue, if that makes sense? (Embryologist)*

However, some clinics were still thinking in terms of the pre-2008 framework, despite the change in the law:

*We've always treated single women as well...and obviously it's something that's talked about with them about whatever male figure there may be....I think it is important that they are aware of...the differences...and the different relationships that might develop and the communication, I think, is often different with men and women for a child...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. (PR)*

A minority of interviewees worried about other issues: the costs of childcare, the level of support needed from family or friends, or the demands a child might place on the mother, sometimes also expressing vaguer concerns that a particular single woman was rather odd and her personal circumstances were not conducive to raising a child. These counsellors (from different clinics) 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?*

*We're looking at why? Why do it on your own? 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.*

This PR felt uncomfortable with what they saw as a sense of entitlement amongst some single women:

*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.*

In so far as interviewees were able to explain what they thought 'supportive parenting' might mean, a notable finding was the meaning given to it in discussion of single women. This terminology seemed to be interpreted by some as requiring 'supported parenting' with women seeking treatment on their own requiring additional assessment to establish that they had in place 'networks of support'. In this way, the single woman was viewed by some as problematic as a prospective patient, even if not posing any risk of serious harm to her child:



*We've all become a lot more accepting of these things...I think the studies so far say single people are fine if they have a support network and the children are fine, but not if they're under pressure. (PR)*

A key finding of our research, in line with the conclusions of Blyth *et al* (2008), is a continued trajectory toward the disappearance of 'group' exclusions by clinics relating to perceptions of desirable family form. Practices in relation to the socially infertile appeared overall (though not entirely) to reflect the removal of 'the need for a father' from the law. However, neither did we find that such 'group' concerns have entirely vanished. While lesbian parents were frequently praised as ideal parents, single women continued to cause clinics some concern, although this was now more typically discussed in terms of their motivations for seeking single parenthood than in terms of the child's need for a father. Further, and rather more markedly, one group of prospective patients was talked about quite differently as requiring particular consideration: donor gamete recipients (with this group obviously including lesbian and single women).

### **Recipients of donated gametes**

Patients who need to use donated gametes are a minority: in 2010, just over 5,000 cycles used donor sperm, just over 1,500 donor eggs and 325 donor embryos (HFEA 2012). This area has been the subject of sustained debate and significant reform in recent years, with the removal of anonymity for donors for conceptions occurring after 1 April 2005 under the Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004/1511. While we have no space here to explore the extensive discussions of a child's right to information regarding his or her genetic inheritance and the dominance of

ideas that access to such information is in a child's best interests (see Haimes and Weiner 2001), these discussions do form an important backdrop to one final finding of our study.

Notably, ideas about child welfare which have been dominant in this context, appear to have contributed to a widespread misperception that there is a legal requirement that patients using donated gametes must be treated differently, with all but one clinics seeing such patients as needing to undergo at least one session of what was generally termed 'implications counselling'. Such counselling was sometimes framed as being 'mandatory' or 'compulsory', despite the fact that the HFE Act and HFEA's COP determine that while the *provision* of counselling is mandatory, the *take-up* of counselling by patients is not. As one doctor explained:

*If any couple are receiving or donating any gametes then we make it a condition of their treatment that they should receive counselling.*

Others described such counselling as 'routine' or 'automatic', rather than an aspect of treatment patients may choose:

*All patients are advised to see the counsellor for support while they're going through treatment but patients using donor gametes, whether it's eggs or sperm, automatically see the counsellor. We try to make it almost a routine thing as part of their routine care to see the counsellor. (Nurse Manager)*

All clinics with such 'compulsory' implications counselling required lesbian couples and single women to go for at least one session, due to their need for donated gametes. Most

respondents stated explicitly that the need for counselling was derived solely from the use of donated gametes, not to deal with any perceived issues specific to lesbian parents.

Thus, insofar as staff discussed a patient group as treated differently, differentiation was not mainly by merit of the form of family the child would grow up in, but was rather by merit of the nature of the treatment to be received. While this aspect of treatment has no formal relation to WOC assessment, it did appear that the need for counselling in this situation reflected broad ideas of what it means to take 'the welfare of the child' seriously. While not going so far as to implement the recommendations of the Donor Conception Network that 'donor procedures [...] be restricted to people giving an advance undertaking that they would tell their child about his or her conception' (Blyth et al 2008, p32), current practices might nonetheless be seen as reflecting broadly similar sensibilities. The purpose of such counselling was described as providing an opportunity for patients to consider a number of issues that could potentially arise from the use of donated gametes, to emphasise the importance of communicating the circumstances of conception to the child and to discuss with them how to go about managing this process.

### **Discussion and conclusions**

This study aimed to provide the first account of the workings of WOC assessments in clinics following the 2008 reforms. In sociological terms, it hoped to generate insights about the operation in practice of an arguably very distinctive kind of regulation, that has been criticised for undue medicalization and yet which has simultaneously sought to limit the exercise of medical 'overreach' and associated unwarranted denials of access to medical treatment.

Our interviews indicate, on the one hand, the strength of the imperative to limit such 'overreach'. They found a generalised and strong acceptance of the presumption to treat, with very few patients denied treatment. Very notably, we found a marked break with early research into s.13(5): the association between *moralised* concerns about family form and welfare assessments has not only weakened but has been replaced by a dominant ethos of 'non-discrimination'. Staff in all roles communicated a belief in the idea that there should be 'no discrimination' against particular groups of patients on the grounds of gender, race, sexual orientation, disability, religious belief or age. This ethos was expressed most clearly in the way interviewees talked about lesbian patients, with any idea of refusing to treat on the grounds of sexuality having diminished to the point of non-existence.

At the same time, however, the study detected a general acceptance, again holding true for all categories of staff, that clinics *ought* to assess *all* prospective patients as future parents, with the method of risk assessment broadly welcomed as more simple and easier to administer than previous systems. The fact that this might now appear, on the face of it, to be a box-ticking procedure did not mean that it was seen as unimportant or a mere formality: not a single interviewee argued for abolishing the WOC assessment. In so far as there were differing views about the general idea of assessment, these turned not on whether the assessment was important but on whether it was *possible* reliably to assess the welfare of a child yet to be conceived. The idea that 'you never know' was widespread. In so far as the 'unknown' was named, it was through reference to the danger of giving treatment to a paedophile.

The continued need for a system of WOC assessment emerged as underwritten by more or less strongly expressed concerns about *interactions and relationships* between parents and children. This was apparent in the way some respondents discussed single women seeking

treatment where, despite the move towards a non-discriminatory approach regarding sexuality and marital status, single women appeared still to be regarded by some as potentially problematic patients and parents, less because of the child's perceived 'need for a father', but more on the grounds of their motivations for, and ability to cope with, parenthood. There seems in this area to be a residual paternalism (considered by some an inherent by-product of medicalization (Sheldon 1997)) in the construction of single women as particularly vulnerable and in need of support.

'Welfare concerns' of this kind were most clearly and coherently expressed, however, in relation to treatment using donor gametes. No interviewees contested the idea that there was a particular need for counselling of those using these procedures, and some – nurses and counsellors especially – were strong advocates of this practice. It was deemed essential that patients were encouraged, primarily through counselling, to take seriously the future child's need to know the circumstances of his or her conception and to consider how best to go about this.

In the light of this finding, we suggest that the concept of 'medicalization' may offer a somewhat blunt tool for capturing the complex realities of current service provision. The use of this term reflects the continued gatekeeping role for clinics, prescribed in law, regarding access to treatment. While in most cases, the 'person responsible' for ensuring compliance with the legislation is the lead clinician, it is nonetheless noteworthy that practical input into welfare assessments is not restricted to medical professionals but is shared by all clinic staff, including those with administrative and counselling roles. Our research found a widespread sense of ownership of the assessment process. We also found that the focus of welfare concerns is now less on questions of family form (with, for example, very few comments made about the existence of male role models) and is far more squarely focused on

emotional and psychological factors and the quality of future parent/child relationships. Specifically, in this regard: in so far as single women continue to attract attention, this was due to concerns regarding their motivation in seeking treatment alone. The patient group which are now seen most in need of particular attention are those using donated gametes, who were broadly seen as in need of professional support, provided through counselling.

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