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ASSESSING CHILD WELFARE UNDER THE HUMAN FERTILISATION AND EMBRYOLOGY ACT: THE NEW LAW

*Summary of findings
September 2012*

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BACKGROUND AND METHODOLOGY

In 1990 the Human Fertilisation and Embryology (HFE) Act introduced an extensive legal framework for all research and treatment using human embryos in the UK. One short section of this Act placed on assisted conception services an obligation to assess ‘the welfare of the child’ (WOC) who may be born as a result of treatment pre-conception. This part of the HFE Act became the subject of research and debate in the subsequent years.

Central to the issues raised was the notion that certain patient groups were unfairly denied access to treatment since, by law, clinics were obliged to take into account ‘the need for a father’ when making welfare assessments. This (and other) criticism of welfare assessments informed a process of legal and regulatory reform, leading to changes in the late 2000s to both statute law and to the Human Fertilisation and Embryology Authority’s (HFEA) Code of Practice (COP). The former reform, highly controversially, entailed the replacement of the demand that clinics take into account ‘the need for a father’ when making welfare assessments with the obligation that they consider ‘the need for supportive parenting’.

This study, conducted by staff at the University of Kent and guided by an Advisory Group of experts in the field of assisted conception, sought to provide the first major assessment of welfare of the child (WOC) assessments under the new regulatory framework. The project combined original empirical research with library-based study and received approval from the Kent University Research Ethics Committee, from Oxfordshire REC B NHS Research Ethics Committee and, in line with NHS policy, from relevant Primary Care Trust Research and Development offices.

- We considered successive iterations of the HFEA’s COP, to trace the evolution of the welfare assessment, and analysed the published documentation surrounding the 2008 reform to the HFE Act.
- We reviewed previously published studies, mainly from the 1990s, that investigated the process by which clinicians made welfare of the child assessments.
- We conducted face-to-face interviews with (on average) three members of staff with different roles at 20 clinics in the UK (around one quarter of the total number of clinics), generating a set of interviews of a sufficient size to represent reliable, detailed data. The interviews found out about how clinic staff understand and apply the new welfare of the child guidance and, in the light of just under two years’ experience of the new system, assessed their views on the advantages and disadvantages of the new procedures.
- Our analysis compared what clinic staff told us about the effect of the new law with the stated aims of law and policy-makers.

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For further information about the study, including a more detailed account of the findings, contact Dr Ellie Lee: E.J.Lee@kent.ac.uk

KEY FINDINGS

- 1 Changes to the law, and more especially to the HFEA's Code of Practice (COP), constitute a shift to a more liberalised approach to regulation.
- 2 The HFEA's new 'risk assessment' process is generally perceived by staff to be an improvement on previous procedures, although despite the time spent discussing the welfare of the child (WOC) clause during the reform process, the new law appears to have had a relatively limited impact on clinics' previous practice.
- 3 The number of prospective patients deemed to raise 'welfare of the child concerns' remains small; very few indeed are subject to further investigation and even fewer are denied treatment.
- 4 Staff report struggling to work out how to resolve the small number of 'difficult cases' they experience.
- 5 Staff report variation in, and some concerns about, the role and place of counsellors and counselling in WOC assessments.
- 6 A low number of formal WOC cases co-exists with widespread concern about the 'welfare of the child'. This concern was expressed in the following three main ways:
 - A *bifurcation* in attitudes towards lesbian patients, and single female patients, was detected by the research; lesbian couples were represented often as 'ideal patients', while concerns were expressed about single women's motivations for having a child, their ability materially to support a child, and the strength of their support networks of family and friends;
 - The patient *group* most frequently discussed as requiring different treatment was donor gamete recipients and the view seemed to prevail that the law requires these patients to be treated differently;
 - A view that the vast majority of patients are 'normal' co-exists with a sense that 'you can never know' or 'you can never prove it'; the spectre of the paedophile shapes perceptions, as a person hardly ever encountered but whose threat nevertheless creates a powerful rationale for pre-emptive action.

SUMMARY OF FINDINGS

The following commentary summarises findings first from the library-based part of the research, and second from the interview study.

1: THE NATURE OF THE NEW REGULATORY FRAMEWORK

Changes made in the late 2000s to the 'welfare of the child' clause of the HFE Act and to the COP arose at least in part from a perceived need to address 'unfairness' or 'discrimination', most obviously highlighted in relation to those not in heterosexual relationships – lesbian couples and single women.

The introduction by the HFEA from 2007 of a 'risk assessment' process, based around the use of a short list of questions on a form that prospective patients need to answer*, can be understood as a 'liberalising' measure. In particular the following comprise an important departure from the previous approach:

- Advocacy of a 'light touch' approach, to streamline and simplify the WOC process.
- Guidance that clinics should approach treatment provision with a *presumption in favour of providing treatment to those who request it*, is an important shift. This presumption would operate except in the face of 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.
- The directive that: 'in particular, patients should not be unfairly discriminated against on grounds of gender, race, disability, sexual orientation, religious belief or age' (HFEA 2007, Code of Practice 7th Edition, para G.3.3.2).

This 'liberalising' approach from the HFEA was further reinforced after the 2008 legal reforms through COP guidance on how to interpret the phrase 'the need for supportive parenting':

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, Code of Practice 8th Edition, para 8.11, our emphasis).

* The HFEA risk assessment form asks:

- | | |
|--|---|
| <p>1 Do you have any previous convictions relating to harming children?</p> <p>2 Have any child protection measures been taken regarding your children?</p> <p>3 Is there any serious violence or discord within your family environment?</p> <p>4 Do you have any mental or physical conditions?</p> <p>5 To your knowledge, is your child at increased risk of any transmissible or inherited disorders?</p> | <p>6 Do you have any drug or alcohol problems?</p> <p>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?</p> <p>The form asks patients to provide details if 'yes' is answered to any question. Each patient (both partners in a couple, and all parties in a surrogacy arrangement) must sign the form and a second section is used by the clinic to detail any further action taken. The form can be viewed here:
www.hfea.gov.uk/docs/Welfare_of_the_child_Aug_2010.pdf</p> |
|--|---|

2: WELFARE ASSESSMENT PROCEDURES AND OUTCOMES

Variations in patient experience (and so the potential for discrimination) have been reduced as clinics generally use common procedures for WOC assessments; one half of the clinics in the study used the HFEA form and almost all of the remainder used a version of the HFEA's form.

However, some forms included questions where distinctions between welfare of the child requirements, NHS funding criteria, and individual clinic protocols, were blurred. For example, some WOC forms asked patients whether, and for how long, they had cohabited with their partner, whether they had criminal convictions (not just for harming children), whether they had any existing children, or whether they smoked. One clinic used a very different form, which asked patients about their alcohol consumption and their use of antidepressants. This was explained as an attempt to reduce the number of patients being assessed as problematic, by establishing protocols for normal levels of consumption.

Most respondents had a favourable opinion of the new simplified process as they found the forms easy to use and less time-consuming.

"I'm not sure it solved any welfare of the child problems, but it solved logistical paperwork." (Person Responsible)

The number of patients at most clinics considered to present concerns following WOC assessment is small (see Table 1).

Table 1

Number of cases of welfare of the child concern in a year	Number of clinics and clinic size (by annual number of cycles of IVF and ICSI)
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)

It appeared that a larger (unquantifiable) number did not access treatment as a result of self-exclusion or the effects of funding restrictions.

"Of course that's incredibly difficult to quantify because they just may never turn up to clinic again and therefore we wouldn't have any evidence at all to try and quantify that figure... But is there an attrition rate along the way? Probably but difficult to quantify." (Person Responsible)

Those investigated further following risk assessment do not fall into any particular category; no evidence was found of 'group discrimination' based on sexuality or relationship status and 'hard cases' are not of a general kind (see Table 2).

Table 2

Reasons for concern	Number of clinics reporting cases
Mental illness (including depression)	All
Illness: transmissible or inherited	All
Drugs/alcohol	All
Physical illness or disability	All
Violence in the family environment	10
Convictions for harming children	11

A very small number of treatment refusals result from WOC assessments (see Table 3).

Table 3

Number of refusals to treat per year on welfare of the child grounds	Number of clinics
0	7
<1	2
1-2	8
3-4	2
7	1

Some respondents commented on finding it hard to resolve 'difficult cases', especially as the general approach was to find ways to be able to treat, and reference was made to a lack of support from other agencies in doing so.

"It does work sometimes and sometimes it becomes a pain when you'll find the GP say, 'I can't provide this', or you find the social services not particularly helpful." (Person Responsible)

"We tried to get information from various sources and got nothing at all and we ended up having to say, 'Well I'm sorry, but we can't treat you because we can't get the support to say that it's OK.'" (Doctor)

Examples of 'hard cases' described by respondents are provided on page 8.

3: NEW ISSUES IN WELFARE OF THE CHILD ASSESSMENTS

A relative disappearance of 'group' exclusions by clinics relating to perceptions of desirable family form was apparent; 'single women' or 'lesbians' were not necessarily considered problematic as patient groups by any clinics, never mind *de facto* refused treatment.

"We've become much more comfortable treating both lesbian couples and single women and not putting them through any special hoops... to find out whether we thought they'd be good parents or not." (Person Responsible)

Compared to previous studies, a notable finding was the *bifurcation* in attitudes towards lesbian patients, and single female patients. The importance of an approach characterised by 'not discriminating' was more strongly expressed in relation to lesbian couples, who were indeed represented often as 'ideal patients', with 'single women' more commonly discussed as problematic in regards to their motivations for having a child, their ability materially to support a child, and the strength of their support networks of family and friends.

"In reality... 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)

"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." (Counsellor)

"[T]hey [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)

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*, namely the use of donor gametes. Some presented counselling as obligatory in this case.

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

"My understanding is that she [the counsellor] says, 'you really need to tell your children, otherwise you're carrying a lie the rest of your life.'" (Doctor)

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

Respondent: "In exactly the same way as a heterosexual couple. There's no discrimination at all." (Doctor)

Ambiguities were generally associated with the purpose and role of counselling. Respondents reported variation in, and some concerns about the role and place of, counsellors and counselling in WOC assessments.

"This [involvement in WOC assessment] is completely away from my counselling side... you use your counselling skills to elicit information to see what's going on, to see what's not being said, but the patient considers you to be kind of a judge in a sense and, really, to a certain extent you are, because you then determine whether or not something else comes of this matter." (Counsellor)

In some clinics, there appeared to be a porous boundary between the clinic's role in assessing prospective patients' compliance with Primary Care Trust (PCT) funding criteria and their role in performing the WOC assessment. For example, as noted above, WOC assessment forms sometimes included questions apparently related to funding criteria. However, requirements to screen patients for smoking, Body Mass Index (BMI), relationship stability, age, and existing children, tended to be rationalised by staff on medical or rationing grounds.

"They are WOC questions because... the recommendation is that we treat people who are in a stable relationship and the ethics committee here said it is considered a stable relationship where two partners live together for at least a year, so that's why we're asking how long they've been together." (Counsellor)

"That's a difficult one because I think obesity can be considered a welfare of the child issue if you consider the unborn child, because of the obstetric risk with overweight women." (Embryologist)

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." (Person Responsible)

Respondent: "We've changed it so that now when they come through for a licensed treatment, there's another form that they 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."

Interviewer: "So not just refused funding, but refused treatment?"

Respondent: "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." (Nurse)

4: PERCEPTIONS OF WELFARE OF THE CHILD ASSESSMENT

There is a strong awareness of an obligation to provide treatment that is non-discriminatory towards patients of particular social groups, and that there must be a presumption that treatment will be provided, including to those about whom 'welfare concerns' are raised, unless these concerns cannot be resolved through further investigation.

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

"[W]e don't really refuse many people because we will investigate, we'll get all the evidence and then depending on what it was, we would just try to support them as much as possible and see how we can treat them." (Nurse)

"[T]here's a presumption to treat... we have to give the patient as much chance as we can to put their sort of side across..."

(Embryologist)

At the same time, WOC assessment is viewed as unnecessary and illiberal by very few. Rather, while the new streamlined process is generally welcomed, this is tempered by a view that giving consideration to the 'welfare of the child' is good and necessary (if difficult to achieve) and that whatever the limitations of the formal process, it is intrinsically right for staff to take some responsibility for the future child as a 'third patient'.

"I'd say it [WOC assessment] has the same value as it had 20 years ago; a complete waste of time... the trouble is you immediately discriminate, but... I would like to think that if there was a problem, we would pick that up at consultation..."

(Person Responsible)

"I'm a big fan of light regulation and I think it's really only in there [WOC assessment] because it's in the Act... I think it is a serious issue and I think if you did have concerns about welfare of the child, it's absolutely right for it to figure into your decision making but to expect clinics to make an intelligent and a reasonable assessment for that, it's a tricky one." (Person Responsible)

"The idea behind it [WOC assessment]... is definitely right and proper... Unfortunately, I think many people do think it is a ticking-box exercise." (Doctor)

"Just because you don't have the same opportunity when it comes to natural conception, it doesn't matter. It doesn't mean that you shouldn't use the opportunity when you can influence what happens." (Doctor)

"I think 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." (Person Responsible)

The need for WOC assessments was often justified in an ambiguous way; most reported that the vast majority of patients were 'normal', but this co-existed with an often overtly expressed sense that 'you can never know' or 'you can never prove it'. The study detected the significance of the spectre of the paedophile, as a person hardly ever encountered but whose threat nevertheless creates a powerful rationale for pre-emptive action.

"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... We can't get everyone to do CRB checks."

(Counsellor)

"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."

(Nurse)

"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)

There was some confusion about the meaning of 'supportive parenting': it was taken by some to mean a new way of referring to 'need for the father', or was interpreted as 'supported parenting'.

"I'm not sure what is 'supportive parenting'... I think a male figure... that a child might relate to... but maybe supportive parenting is not the right word. 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?" (Person Responsible)

"I must admit I don't use that... 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)

Examples of 'hard cases'

A male patient in his late twenties 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, subject to an 'all-clear' from social services that he no longer posed a risk to children. The clinic was frustrated that social services would not provide a judgement prior to any pregnancy being achieved or a child being born. The couple did not receive treatment.

A male patient had a spent criminal conviction for a violent crime (not related to harming a child), but because it could not be established whether his crime had been triggered by mental illness (there had never been a psychiatric diagnosis) it was felt that treatment could not go ahead.

A clinic refused to treat a woman (rejecting the hospital ethics committee's recommendation that treatment was acceptable) on the grounds that her serious heart problem and other medical complications made fertility treatment and a possible pregnancy unacceptably high-risk, to the extent that her condition was very likely to deteriorate and she could possibly lose her life. The welfare of her existing child was considered to be the overwhelming factor in deciding to deny treatment, but it was also felt that it was unfair for clinic staff to have to provide treatment to a patient with such a poor prognosis.

For more information about this study, and the work of the Centre for Parenting Culture Studies, see:
<http://blogs.kent.ac.uk/parentingculturestudies/>

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