

Cover Sheet

To reference this article, please use the following citation:

Ehrich, K., Williams, C., Scott, R., Sandall, J. and Farsides, B. (2006). Social welfare, genetic welfare? Boundary-work in the IVF/PGD clinic. *Social Science & Medicine*. Vol 63, No. 5, pp. 1213-1224.

Social welfare, genetic welfare? Boundary-work in the IVF/PGD clinic

Authors: Kathryn Ehrich, Clare Williams, Rosamund Scott, Jane Sandall, and Bobbie Farsides

King's College London

Abstract

Through the lens of the 'welfare of the child' assessment, this paper explores how staff working in the area of in vitro fertilisation and preimplantation genetic diagnosis (IVF/PGD) balance reflexive relations of legitimacy and accountability between the public and private spheres, and between medicine, the citizen and the state. The wider research of which this analysis is a part uses multiple methods to study two National Health Service Assisted Conception Units in England. Research methods used included observation clinics and interviews with staff from a range of disciplines. We illustrate how the staff reveal tensions between their views that the welfare of the child assessment can be seen as intrusive and discriminatory, and on the other hand that medical intervention in reproduction should be socially and professionally accountable. These tensions can be understood sociologically in terms of a gradual movement from socially based solutions to fertility problems and disabilities, towards a biomedical, and arguably genetically oriented worldview of such problems. Rather than being viewed as discrete, these two orientations should be seen as indicating an emergent direction of travel along a continuum, with elements of both being present in the accounts. We argue that consideration of the welfare of the child involves staff in ethical boundary-work across the two orientations and between the accountabilities and responsibilities of healthcare professionals, individuals and the state.

Keywords

UK, Genetics, Professional ambivalence, Boundary-work, In vitro fertilisation, Preimplantation genetic diagnosis.

Introduction

New genetic technologies intensify long-standing contrasts between the public and private spheres. Policy in this area brings public interests to bear on the private and interpersonal characteristics of genetic information and intervention. Conversely, it is argued that, 'genetics, particularly when combined with new reproductive technology, seems to bring the private into the public arena' (Parker, 2000, p. 160), and that a coherent ethical approach to challenges raised by the 'new genetics' must balance the moral status of the individual with the communitarian, interpersonal dimensions of the world in which we live.

Kerr and Cunningham-Burley (2000, p. 285) argue that reflexive modernity, characterised by 'tensions between reflexivity and objectivity; doubt and certainty; choice and coercion; and change and convention', is more manifest in lay responses to

science, technology and institutions of the new genetics than it is a feature of professional rhetoric in this field. Powerful professional institutional efforts to assert cognitive authority and distance from a eugenic past, combined with a stress on individual choices, may be seen as deflecting fundamental questions about the values embedded in the new human genetics. Yet as Kerr (2004, p. 163) states, there is a relative lack of literature on professional practice in this area, and, 'a tendency to black box professionals' roles, alongside the genes, knowledge and technologies with which they work', resulting in a lack of knowledge about professional uncertainty and ambivalence.

In the UK, public attention has recently been drawn to the role of reproductive healthcare professionals in relation to their statutory obligation to consider the welfare of children they help to create. The more socially oriented literature dealing with the welfare of the child has tended towards theoretical argument, such as ethical debates contrasting deontological versus consequentialist positions and considering what might be a minimum threshold criterion for children's welfare (Langdridge, 2000); or considering preimplantation genetic diagnosis (PGD) in the light of existing research on family structures and children's psychological health (Golombok, 1998). However, there is very little literature reporting the views and experiences of staff working within this regulatory context.

Through the lens of the 'welfare of the child' assessment, this paper explores how staff working in the fields of in vitro fertilisation (IVF) and PGD balance reflexive relations of legitimacy and accountability between the public and private spheres, and between medicine, the citizen and the state. We illustrate how the staff in our study revealed tensions between their views that the welfare of the child assessment can be seen as intrusive and discriminatory, and on the other hand that medical intervention in reproduction should be socially and professionally accountable. We argue that this tension can be understood sociologically in terms of a gradual movement from socially based solutions to fertility problems and disabilities, towards a biomedical, and arguably genetically oriented worldview of such problems. Rather than seeing these two orientations as discrete, they should be seen as indicating an emergent direction of travel, with elements of both being present in the accounts. We will argue that the ability to respect, contain and operate across the two orientations both as an individual and as part of a team is a form of ethical boundary-work.

In the study on which this paper reports, we are particularly interested in social and ethical issues pertaining to PGD, but in some cases, these issues include or overlap with considerations relating to IVF. In this paper, the main distinction is that although consideration for the welfare of the child is already an established principle in relation to adoption and assisted conception, the introduction of PGD has led to new ethical and social questions that extend or counter those posed previously. These new questions can lead to ambivalent feelings and dilemmas for staff, perhaps especially for those who see themselves primarily as working in the field of infertility rather than genetics (Krones et al., 2006). For instance, PGD can extend some of the issues raised by IVF, such as the sense of accountability staff feel for their assistance in conception, but it challenges other assumptions because PGD allows people to make new kinds of choices that IVF does not. Even having these choices can be seen by some as controversial, not least because of what 'choosing' (through PGD) implies for the parent-child relationship (Watt, 2004). As many of the staff we interviewed worked across the areas of IVF and

PGD, their comments often apply to both PGD and IVF, but where there are important implications to be drawn from the distinction, we highlight them.

The paper begins with a brief explanation of the clinical background and UK policy context. The key interlinking theoretical concepts drawn upon for the paper will then be introduced, followed by a description of our methods. The main section of the paper presents the experiences of staff in relation to their role in mediating legitimacy and accountability between a variety of audiences and contexts.

Clinical background and policy context

PGD can be offered to couples who are at risk of having a child with a serious genetic condition, or in some cases, to couples who have experienced repeated miscarriage due to chromosome rearrangements such as reciprocal translocation (Braude, Pickering, Ginter, & Ogalvie, 2002). IVF is used to create embryos in the laboratory, from which one or two cells can be tested for specific genetic disorders. Currently in the UK, up to two unaffected embryos can then be transferred to the woman, where they may successfully implant. PGD is offered in about eight centres in the UK, which must be licensed by the Human Fertilisation and Embryology Authority (HFEA).

In the UK, the Human Fertilisation and Embryology Act 1990 requires that account must be taken of the welfare of any child who may be born as a result of IVF and PGD, and this assessment must be undertaken before treatment is offered. Although there is variation in the policies and practice of individual units, the assessment is expected to take into account a variety of medical and social factors, including the woman or couple's commitment to raise children, and the ability to provide a stable environment; immediate and family medical histories; and age, health and ability to provide for child's needs. It should also assess the risk of harm to children including multiple births, neglect or abuse and the effect of a new baby or babies upon any existing child of the family. Assessment must include enquiries to the general practitioners (GPs) of prospective parents and may necessitate approaches to authorities for any further information required. Unsatisfactory responses or refusal to give consent for such enquiries can be taken into consideration in the decision of whether or not to provide treatment (HFEA, 2003).

The HFEA is currently reviewing its Code of Practice and has carried out a consultation to assess public and professional views of this statutory requirement and how such assessments should be made (HFEA, 2005). Concurrently, the Human Fertility & Embryology Act is itself under review. In 2005, The House of Commons Science & Technology Committee (2005) published a controversial majority report which amongst other recommendations, sought to reallocate the responsibilities of the HFEA, and to abolish welfare of the child assessments. The Committee Chairman, Dr. Ian Gibson MP argued that: "we should strip this provision from the HFE Act and stop the state making subjective judgements about people's private lives" (Gibson, 2005). These comments allude to themes that have been widely rehearsed in these debates, such as the balance between reproductive freedom and the interests of the state and society.

Key theoretical concepts

'Social welfare' and 'genetic welfare' worldviews

We propose that the reviews by the UK government and the HFEA of the welfare of the child requirement reflect shifting social and ethical perspectives that can be understood in terms of an emerging transition from social welfare towards more biomedical, and ultimately genetic welfare worldviews, exemplified by Miringoff's (1991) comparison of the development of two views of disability over recent years:

one a social vision seeking to reconstitute the environment in order to accommodate the special needs of social groups, the other a genetic vision seeking to excise or biologically refashion the problem (p. xiv).

In the social welfare worldview described by Miringoff, she states that:

societies provide for their population's welfare through legislation and public policy...seeking to ensure equity and to improve human life by alterations in the social environment through organizational and institutional change (1991, p. xiv).

Problems are perceived as embedded in society and solutions to problems such as infertility, or having children with serious and life-threatening disorders, are typically located in the social structure. In this worldview, the family and community are responsible for ensuring that children and families are adequately cared for within a socially mediated framework of accountability. Consideration for the welfare of the child has its roots in adoption and social work practice (Blyth, 1999), which could be conceptualised as an example of social welfare par excellence. We argue that the contemporary practice of considering the welfare of the child in assessing couples for fertility treatment means that some element of social mediation and accountability is retained.

In the genetic welfare worldview, solutions to some reproductive problems are envisaged and sought at the genetic level, entailing medical and biological intervention. The rising significance of genetic intervention may tilt choices and perceived solutions in this direction. Miringoff argues that new technologies not only alter our medical and scientific abilities in relation to reproductive and genetic disorders as forms of disability, but also our vision. Disillusionment with social engineering gives way to the appeal of 'new genetic interventions...[which] appear to reduce the unwieldy nature of social issues to the relative clarity of genetic defect' (1991, p. 8). Within this worldview, PGD might be seen as offering an intervention that not only mitigates a couple's reproductive genetic disorder, enabling them to have a healthy child, but also offers the hope of carrying forward that solution to reduce the chances of their 'family line' being affected by the condition. If reproduction and disability become increasingly the province of medical science, ethical questions can be posed in terms of the accountability of scientists and clinicians. If the genetic welfare worldview prevails, where might the accountability for these solutions lie—with individual citizens, within families, the broader community, healthcare professionals, the state?

Petersen (2002) situates the current emphasis on genetic knowledge in the context of the post-welfare era, characterised by a radical redefinition of citizenship rights and responsibilities; a winding back of state provision of social services; and an emphasis on sovereign citizens, who are expected, indeed obliged to take greater responsibility for managing their own relationship to health risks (Bunton & Petersen, 2005; Polzer, 2005; Rose, 2002). In this context, 'genetic literacy', and the rapid integration of genetic technologies in prevention strategies, has increased public awareness of genetically

related risk and more individuals have 'begun to identify themselves, as being 'at risk' or as victims of a genetic disease or disability, or as carriers of a genetic defect' (Petersen, 2002, p. 180). Petersen also agrees with the views of Foucauldian scholars such as Rose (1999) that:

the governance of populations is achieved not so much through repression but through the active participation of 'free' subjects; that is, subjects who are able to exercise their agency without coercion from an external authority (Petersen, 2002, p. 182).

Further, others such as Beck-Gernsheim (2000, pp. 131–2) argue that although avoiding the birth of a handicapped child might once have been seen in terms of freedom of choice and basic rights, there are signs that in gradual steps, it may be seen increasingly as a matter of individual 'responsibility', through new developments in technology. Such 'freedoms', or responsibilities, depend on complex means and social practices to produce genetic literacy, and actual decisions are constrained by social and economic contexts. As Shakespeare (1999) points out, it is ironic that just as the disabled people's movement has emerged as a significant player in many western societies, there has been a revival of genetic intervention into human reproduction, which, he argues, can be seen as essentially eugenic, despite ritual disclaimers. Crucially, the apprehension and fulfilment of these increasing freedoms or obligations—to develop awareness and take individual responsibility for genetic risk—depends on professional actors who engage in the production of public genetic knowledge and facilitate genetic choices and intervention (Williams, Alderson, & Farsides, 2002). Regulatory processes in genetic services, such as the welfare of the child assessment, can thus be seen as a boundary where individual autonomy, medical practice and state authority meet in particular contexts.

Ethical boundary-work

In this paper, we apply the concept of ethical boundary-work to describe the work of staff as they straddle a number of conflicting positions relating to the new genetic technologies and ethical aspects of their work. Boundary-work is employed by Gieryn to highlight the negotiated character of science, and is defined as:

The discursive attribution of selected qualities to scientists, scientific methods and scientific claims for the purpose of drawing a rhetorical boundary between science and some less authoritative residual 'non-science'.(Gieryn, 1999, pp. 4–5)

Gieryn (1999) argues that the demarcation of science from non-science allows scientists to defend their intellectual territory and maintain an image of expertise, authority and credibility. Kerr and Cunningham-Burley (1997) draw on Gieryn's (1983) concept of boundary-work as flexible, historically situated and sometimes ambiguous, in their exploration of how health professionals working in genetics discussed their roles in terms of responsibility and the social implications of their work. Building on Gieryn's concept of boundary-work (Gieryn (1983) and Gieryn (1999)), Wainwright, Williams, Farsides, Michael, and Cribb (in press) introduce the notion of 'ethical boundary-work' to describe the shifting context of scientific work. They claim that science has become a more complex process which has resulted in the performance of ethical boundary-work, with the scientists they interviewed presenting themselves as ethical, as well as expert, actors. For example, scientists drew complex boundaries between responsibility and 'non-responsibility', where the bulk of responsibility for ensuring their ethical

accountability in relation to their work on stem cells was placed with regulatory bodies such as the HFEA.

In summary then, this paper focuses on the welfare of the child assessment to explore how staff working in PGD perform ethical boundary-work in reflexive relations of accountability between the public and private spheres, and between medicine, the citizen and the state. We locate these multiple boundaries conceptually in terms of shifts between 'social welfare' and 'genetic welfare'.

Methods

The ongoing project from which this paper reports explores what actual and potential ethical, social, clinical and legal dilemmas genetic developments and new reproductive technologies pose for practitioners, scientists, policy makers and others working in the area of PGD. Although there have been a number of studies on the experiences and views of women/couples undergoing PGD and/or IVF (Becker, 2000; Franklin, 1997; Franklin, Roberts, Braude, & Rutherford, 2003), there is a lack of research on the views of staff and policy makers, so this research focuses specifically on their experiences and views.

The project uses multiple methods to study two sites (only one of which is used here), both Assisted Conception Units in teaching hospitals in England which offer a mixture of National Health Service (NHS), private or 'self-funded' NHS treatment. The clinics provide a range of services including IVF to women and couples who need fertility treatment, and PGD, which requires many of the same procedures and technologies.

Following Ethics Committee approval, our research includes observation in clinics; interviews with staff from a range of disciplines including nursing, obstetrics and gynaecology, radiography, embryology, molecular and cyto-genetics, and administration; and ethics discussion groups facilitated by a specialist in medical ethics. This paper draws on the 16 staff interviews from the first study site, generated between May and July 2005. Participants were recruited following explanations of the research and informal follow-up approaches from the researchers, and include staff from each of the disciplines working in the clinic. The interviews are conducted as 'guided conversations' (Lofland & Lofland, 1984), and last between 1 and 2 hours. Open-ended questions and an informal interview schedule are used, with themes including views on treatment eligibility for PGD; views about the genetic conditions that should be tested for; and the efficacy of regulatory systems such as the HFEA. Transcripts were analysed for this paper using a modified version of the framework approach (Ritchie & Spencer, 1994). Sections of the interview transcripts relating to topics such as welfare of the child, regulation and accountability were selected and examined to produce a framework of themes. Accounts were then grouped together to discern the similarities and differences between them. This framework will form part of the larger framework for analysis and coding of the complete data set when all data have been collected.

Themes

Staff views and experiences of fulfilling the welfare of the child assessment required by the current HFE Act are grouped into three themes: professional responsibility and accountability for medical intervention; welfare of the child assessment as a form of discrimination and intrusion; and working on the boundaries of social accountability.

Professional responsibility and accountability for intervention

The first theme of professional accountability for their medical intervention appeared in many participants' comments. This sense of accountability was not purely for their medical, scientific and technological skills, as might be envisaged within the genetic worldview. Staff from a range of disciplines expressed a heightened sense of professional accountability which incorporated a feeling of social responsibility for the consequences of their intervention and the instrumental role they play in family creation:

It's like they wouldn't exist without you—so you're involved in the existence of something, so you have to be responsible for making sure that that existence is as nice an existence as possible (Scientist 2).

This sense of responsibility and accountability for their interventions included direct references to the relationship between their professional actions and effects in the public sphere:

We should try and have as good a standard as possible for that child. I don't think you should say that anything goes just because anything goes in society. That doesn't make it right...sometimes parents can't be responsible because they're in a situation where they're incapable of being responsible, because of their problems in their lives, so somebody has to be responsible for them...and these Acts, that's why they're there in the first place after all...There's so much in the papers now about degeneration of the youth culture and all that kind of stuff. Well, why are you going to make it even worse? (Scientist 2).

Participants concurred on many aspects of patients' background or circumstances which in extreme cases would make them reluctant to offer treatment, for example, a history of child abuse. However, they did not always express the same views on what a 'good' standard of parenting should be:

There are people that have psychiatric problems, which I have less of a problem with... there are some other aspects of it, say they may drink more than the recommended units each week or smoke drugs—which doesn't—again some people would find that unacceptable to bring a child in to that sort of a household, whereas I would think that that would not necessarily be a reason not to have children. That wouldn't be my—you wouldn't say, 'no you're not going to be a suitable parent' (Embryologist 15).

In relation to the HFEA and the Welfare of the Child assessment, some aspects were seen as outdated or no longer necessary:

I think that the basis of some of their regulation might be a little bit outmoded now, and some of what they impose on us here, some of what it imposes on us makes some practice quite difficult. Things that they expect us to do Welfare of the Child on—we might decide it wasn't particularly necessary (Doctor 11).

These comments demonstrate that staff feel a sense of responsibility and accountability for their intervention, but that at the same time they can hold ambivalent feelings about some of the ethical judgements they have to make in practice. This form of ambivalence could indicate a wish to maintain professional authority in terms of their medical

intervention, and a disinclination to claim such authority in the social sphere. In short, some staff questioned the professional basis for this aspect of their work:

Who are we to sit in judgment anyway? (Nurse 13).

Despite the difficulties in reconciling these conflicting views, most of the staff held the view that some form of regulation, including assessment of the welfare of the child, should be retained. One reason was that it provided reassurance that their work takes place within a regulatory framework:

Obviously, whilst the average couple in the street want to have a child, then there's no laws against it. But then they don't use the intervention of a third party and actually to let me sleep at night, I'm quite glad, that, at least on a very basic level, that the welfare of the child aspect is there... I think we are intervening, so I think there should be some sort of check (Embryologist 15).

A further reason given was that against the tide of 'patient choice' and demand, regulation provided some protection of their ability to exercise clinical judgement:

It does worry me that we're moving towards a situation where, to say no to anybody in any circumstances, is becoming difficult (Nurse 1).

A key function of regulation is that it was seen to represent approval from a broad social and ethical consensus:

I think we're very fortunate in the UK having the HFEA. I think they do a remarkable job...So, yes, I mean I support the HFEA 100%. I think we need something like that. They're a reasonable bunch of people. And it's a good idea anyway that they draw from different sectors of society as well, lay people, clergy, medics, scientists (Scientist 3).

I think the HFEA is good in Great Britain in stopping maverick behaviour that might happen in other countries. And I like the fact that it has some element of public consultation, so it allows the public who are, who we're treating, to have some voice in what we can do for them. So, I like the fact that they regulate people who might otherwise behave not necessarily in the best interests of the patient (Doctor 11).

So although the overt purpose of the welfare of the child assessment is to assess the capacity of potential parents to ensure the best possible welfare of the child, for many staff, it is closely bound up with their own sense of professional accountability. In some ways, this requirement can be seen as providing legitimation of medical/professional judgement in the social sphere, because it represents a social consensus that authorises such judgements as part of their role.

This section illustrates how staff are engaged in complex ethical boundary-work which involves mediating between the interests of medicine developing new scientific techniques and genetic knowledge; the state's interest in the children and families created; and the public, both as patients who wish to avoid having children with serious genetic conditions, and in terms of social attitudes towards the creation of children and parental accountability. As with the scientists interviewed by Wainwright et al. (in press), staff allocated various aspects of responsibility for ethical standards to the HFEA.

However, in contrast, the clinical work of PGD directly involves staff in carrying out a regulatory role, so ethics could not be wholly devolved to outside authorities. We argue that some of the perceived risks attending the implications of genetic aspects of the staff's work are underwritten by retaining professional safeguards linked to regulation. This serves to contain some of the ambivalence and anxiety generated and also provides continuity with a social welfare worldview.

Welfare of the child assessment as a form of discrimination and intrusion

Even though most staff supported some form of regulation which protects both potential children and themselves against possible consequences that might follow their intervention, they also expressed concerns that the welfare of the child assessment might be seen as putting the woman or couple through a hurdle too far:

What I've heard from quite a few couples is that... if there was another way, then they would have done it, because it seems quite traumatic, particularly on the lady, to have all the drugs and to go through all the processes. And I don't imagine that any of them take it lightly. So to then say, 'Oh we're going to have to screen you for, to make sure you're going to be suitable parents for this little embryo that we're putting money into'—seems a bit churlish really (Scientist 9).

A stronger version of this view, also expressed by many of the staff, was that the welfare of the child assessment amounted to discrimination of couples needing reproductive assistance, including PGD couples:

If someone can have a child, no one actually—they don't have to go to their doctor and say—'Do you think I'm going to be alright to be a parent? Will you give me permission to start trying to procreate now?' [... It is] very, very discriminatory against infertile people, that you're—to make them go through this test of their ability to parent before they've even started a child, and at a time when it's actually probably quite stressful for them... suddenly someone says to them, 'Well actually we've got to find out if you're okay to be a parent, we've got to get all this information from your doctor' (Embryologist 5).

Of note here is the reasoning that people are being discriminated against because they are infertile. Most women or couples requesting PGD are not infertile, but need IVF because the technology is required for embryo biopsy. However, whether or not these women/couples are fertile is for some staff not significant to their argument about discrimination, because the distinction they object to is between 'normal' reproduction, which is not regulated, and assisted reproduction, which is:

I personally can't see any difference between somebody having IVF treatment to conceive a child and somebody conceiving a child normally. And there shouldn't really be restrictions. Why should you be penalised? (Administrator 12).

A related issue was that many staff thought the assessment constituted an invasion of privacy:

Unfortunately the people that tend to come back with issues raised on the welfare of the child assessment tend to then have to undergo quite a—it can be quite an intense and invasive privacy process in trying to unravel the truth behind the issues the GP raises ... Quite often...there's something in the notes saying, I don't

know, saying, 'Child fostered', 'Son fostered 1984'—or something like that. And the next step will be for one of the counselling team to see that couple or that person... to talk to them about that and find out more about it. I don't necessarily think that's the right way to move forward (Nurse 1).

The feeling that the assessment is discriminatory and invasive of privacy could appear contradictory to the comments in favour of regulation of some kind articulated in the first theme, but it was usually stated in terms of staff being positioned in an inherently problematic position between competing priorities. For staff, the ensuing ethical boundary-work entails reconciling the two positions in practice:

I can see why people want to consider the welfare of the child and I think it's important to do so. But it's also—we don't put everybody on the Pill or pass out condoms and say, 'Okay, if you're not going to use these, then we need to fill in this questionnaire about you'—so it is an inequality (Counsellor 10).

Summarising this second theme, it can be seen that staff feel concerned that women or couples requiring fertility treatment are being discriminated against through the welfare of the child assessment. They see it as unfair that their patients have to go through an evaluation that does not apply to most other people wanting to have a baby, yet as we saw in the first theme, they are reassured that regulation is in place that includes this assessment. Their clinical orientation toward women or couples requesting PGD may be to view them as patients for whom the emphasis is on genetic technology and intervention to avoid the effects of particular conditions. However, many of the participants expressed substantial ambivalence over aspects that could be seen as belonging to a social welfare worldview, the example given here being that they feel it is inequitable and intrusive to treat prospective parents differently in this way. This theme demonstrates another aspect of the ethical boundary-work staff undertake as they simultaneously hold aspects of both the social and genetic welfare worldviews, despite the contradictions this appears to contain.

Working on the boundaries of social accountability

The third theme expands on some of the issues touched upon in the first theme of professional accountability, and explores how staff can feel positioned on various boundaries in relation to social accountability. One position is working on behalf of medicine and society in relation to individual citizens:

If you're seen to be helping couples that are deemed socially unacceptable to be parents, then that's going to give IVF a bad name. So it's a slightly society based drive to deprive people that are deemed inappropriate parents from being parents (Doctor 6).

However, some of the staff did not wish to be portrayed as so distinctly outside of the public sphere:

Sometimes scientists are portrayed as the ones that push it, but in fact you often find that they're the ones that are more cautious and that it's public opinion that is pushing for change (Scientist 2).

In this quote, the scientist attempts to establish some distance from the notion of scientists pushing for change, arguing that it is often the public who do so. At the same

time, this statement may be seen as questioning particular representations of scientists, and the boundary-work here appears to be concerned with the portrayal of scientists as in a separate, conflicting category to the public. This example supports Gieryn's (1999) portrayal of scientists as defending their intellectual territory and authority, through maintaining a boundary between themselves and the 'non-science' public.

Many of the staff commented that they did not like to be associated with representations of science as racing ahead of public consensus on how genetic technologies should be employed in medicine:

I think a lot of what we do is portrayed atrociously by the media and there are big anti-assisted conception and embryo screening movements, for whatever reason, at the moment. And I think you do get a lot of positive coverage, but I think there's a lot of sensationalism (Embryologist 15).

I think if the medical field start making decisions about what's okay and what's appropriate without considering social consensus, we're going to alienate the general public, and if you alienate the public, you create animosity and disdain for what you're doing almost. And I think that will be a terrible thing to happen, because in the UK it does seem to me that the public is considered...The medical benefit is for the general public, so I think we do have to work together... (Counsellor 10).

These comments can be seen as occupying and at the same time questioning a boundary between social and genetic welfare. There is medical benefit to be derived from their work, but the genetics aspects can alienate the public, and in this sense, a boundary is perceived. However, staff question this by pointing out that 'the medical benefit is for the general public'. This leads them to engage in the work of reassurance, avoiding the alienation and animosity of the public and working 'together' to demonstrate that staff are concerned with public opinion and benefit, not just with their own world of 'science'.

In the next quote a more reflexive position in relation to boundary-work is illustrated. When people need assistance to create a child, medical assistance becomes something more than technical help—it becomes something staff have to account for. However, this participant questions in whose interests the welfare of the child assessment operates:

...they're coming to you for the assistance. And it feels like our input to give them something, we have to account for. I think that's mainly what we're hiding behind by using the welfare of the child. But... is that to alleviate our conscience or theirs? Maybe ours. To say that you've actually vetted this person to say, yes they're okay for us to treat them... So we feel happy in doing what we've done, so we don't have the guilt. I think that's what that's for... There's always room for guilt really, I think, because you haven't got the ultimate control really (Nurse 13).

According to the social welfare worldview, it would be the parents and the community who would ideally be held most accountable for the welfare of children, with structural support and regulation of transgressions and failures. The long-term involvement of all those parties is implied. In the genetic worldview, medical intervention in the creation of children might be seen by some as technical assistance, which carries familiar implications for upholding professional standards of clinical judgement, but not a long-term commitment. The nurse's comment indicates that this transition is not complete.

There is a sense of unease: the nurse speaks of alleviating 'our conscience', and guilt. While having an instrumental role in the creation of a child, healthcare staff will not be able to have a long-term involvement and control over that child's future, so there is room for some doubt and perhaps for some guilt in the future. In this sense, a kind of temporal boundary-work is entailed. The work of PGD staff allows them to offer genetic, biomedical solutions to childlessness and/or serious conditions through a limited time intervention. However, the welfare of the child assessment ties staff to the social welfare worldview in which families are still perceived to belong to, and to be created in the context of implications for the longer-term past and future, and potentially for a lifetime.

In this theme, staff expand on some of the elements of their comments on professional accountability, expressing a wish not to be seen as outside a more general social framework of accountability. In this sense, they are keen to have their work understood as ethically acceptable to the public, and this, as Kerr and Cunningham-Burley (2000) argue, can be seen as part of a professional institutional reflexivity. The potential for social judgement of their work extends into the future because their intervention may have unforeseen social repercussions for their patients and for the society they themselves will live in. This supports Wainwright et al.'s (in press) observation of stem cell scientists, 'incorporating ethical acceptability into the heart of the scientific work'. However, in contrast to stem cell scientists, PGD practitioners are directly involved in the clinical application of one of the regulatory aspects of their work. Their comments suggest this may entail a further reflexive turn in the performance of ethics attached to medical science. Working in this relatively new and controversial area of medical science means that they are engaged both in reassuring the public and themselves, as members of families and as citizens, that this effort is going to result in, and be understood as a public good.

Discussion and conclusion

Our interviews with staff in one IVF/PGD service show how, within the UK context, the welfare of the child assessment raises questions that can be conceptualised in terms of staff engaging in ethical boundary-work (Wainwright et al., submitted), where the liberty of individuals to pursue reproductive autonomy meets ethical regulation and rationing of scarce resources; and where individual and professional accountability meet public concerns.

We argue that a number of forms of ethical boundary-work can be located in terms of shifts between social and genetic welfare worldviews. In the social welfare worldview, there is a focus on the social environment of the potential child, including social attitudes to disability, and parenting abilities to provide a good enough environment. From this perspective, many participants in our study felt it was a form of discrimination to treat potential parents differently according to their physical reproductive capacities. In contrast, the genetic welfare perspective focuses on the child's and the family's medical future, and the benefits or harms to them of medical, reproductive, and especially genetic, intervention. From the genetic welfare worldview, staff are heavily invested in the work of genetic intervention through providing the means of selection, but they want to be seen as delivering the benefits of this to the public, their patients and future children, not just to the world of science.

The welfare of the child assessment and its recent review also highlight temporal aspects in that this work can be seen as marking significant developments in an emergent

transition from social to genetic reproductive solutions. Looking at these shifts historically, we could describe our gaze through the lens of the welfare of the child assessment as moving from a focus on parenting capabilities and environment in adoption cases, to questions within the 'new genetics' being more oriented towards patient autonomy and medical non-maleficence. Solutions to reproductive problems then 'progress' through medical techniques including assisted reproductive technologies, particularly PGD. We argue that staff in this field are working at a key point in time in the trajectory between these two worldviews envisaged by Miringoff (1991).

In such a sample, one should not be surprised to find that staff are inclined to be very sympathetic to the genetic end of the welfare spectrum and through their work they are committed to ensuring that, where possible, couples do not have to fall back on solutions from the social end of the spectrum. The form of technological intervention they are able to offer patients could be seen almost entirely in terms of medical progress, as the potential benefits are currently in relation to what would generally be perceived as 'serious' conditions, albeit that the nature or definition of 'serious' has not been defined. Yet our informants can also be seen as engaged in working on the boundary between the genetic and social welfare worldviews, because they expressed limits as to what are acceptable forms of intervention. Their commitment to medical progress is tempered by their consciousness of being personally implicated by their interventions in the creation of human beings, and all of our long-term social, as well as medical, futures.

Participants expressed a heightened sense of responsibility for the consequences of their subsequent intervention in terms that closely support Widdows and MacCallum's (2002) view of the significance staff place on the instrumental role they play in family creation in the context of adoption and embryo donation:

...social criteria are thought important in order to safeguard the welfare of the child. This responsibility stems from the necessity of third party involvement in these methods of family creation [...] This instrumental role in family creation makes third parties (and society, insofar as these practitioners are society's representatives) responsible for the child's welfare in a way that they are not responsible in natural conception. (p. 142)

Clearly, responsibility for intervention using PGD does fit this argument. But are we moving into new expectations because of the increasing possibilities for intervention of the third party? Are parents becoming less the focus for social scrutiny, and is our gaze turning more to those who intervene, and the technologies they employ? In his discussion of PGD and the welfare of the child, Lavery (2004) contrasts the parents' interests in terms of autonomy, with the obligation of clinics to consider the medical welfare of children born as a result of PGD. The splitting and apportioning of interests in this way might give the impression that the most significant risks concern the medical effects and possible implications of the treatment, whilst less emphasis is placed on assessment of the child's social environment. Might this be another example, or effect, of the genetic worldview coming to displace or overshadow a social welfare worldview? We could also consider how, within the history of eugenics, the current emphasis away from state towards individual decision making could be seen as cutting across the social to genetic shift.

The distinction referred to between patients undergoing assisted conception as opposed to PGD distinguishes types of justification for the treatment. Some staff are committed

to their work in assisted conception because it allows couples to have children who might not otherwise be able to have them at all. In contrast, for some staff, PGD specifically offers couples the hope of having children who are not affected by particular conditions, which introduces a different set of motivations, ethical issues and reasons for regulation. Whilst 'natural' reproduction appears to sit easily with concepts of social welfare, traditional family formation and responsibilities for children, PGD focuses on individual families and genetic intervention to reduce the risk of particular conditions. We suggest that the spectrum ranging from 'natural' reproduction to technologically assisted reproduction, to reproductive assistance which involves genetic testing and specification, can be overlaid with the spectrum of concepts of welfare gradually shifting from a social orientation towards genetic orientation.

In conclusion, staff are engaged in ethical boundary-work between the accountabilities and responsibilities of healthcare professionals, individuals and the state, and consideration of the welfare of the child requires staff to operate in and between these spheres. The emergence of genetic welfare has been supported by the legitimacy that medicine offers to genetic and reproductive technologies (Petersen, 2002, p. 52), but intervention implies accountability in new ways that increasingly expand into the social future. Future developments in the regulation of fertility pose further potential challenges. Could welfare of the child considerations become even more important in the light of such developments? For example, if, as seems possible, it eventually becomes legal in the UK to select the sex of embryos for social reasons, what would be the implications for assessing the welfare of the child? Sex selection can be achieved through less technologically difficult means than PGD, but can the same welfare of the child criteria be applied to prospective parents if they request intervention for other social characteristics, or for less, rather than more serious medical conditions? Will such developments lead us further towards a genetic welfare worldview, and what new forms of ethical boundary-work might such developments require of staff working in this area?

Acknowledgements

The Wellcome Trust Biomedical Ethics Programme, who funded the project 'Facilitating choice, framing choice: the experience of staff working in preimplantation genetic diagnosis' (no. 074935).

References

- Beck-Gernsheim, E. (2000) Health and responsibility: From social change to technological change and vice versa. In: B. Adam, B.U. Beck and J. Van Loon, Editors, *The risk society and beyond*, Sage, London, pp. 63–77.
- Becker, G. (2000) *The elusive embryo: How women and men approach new reproductive technologies*, University of California Press, Berkeley, CA.
- Blyth, E. (1999) The social work role in assisted conception, *British Journal of Social Work* 29, pp. 727–740.
- Braude, P., Pickering, S., Gliner, F. and Ogalvie, C. (2002) Preimplantation genetic diagnosis, *National Review of Genetics* 3, pp. 941–953.
- Bunton, R. and Petersen, A. (2005) *Genetic governance: Health, risk and ethics in the biotech era*, Routledge, London.

Franklin, S. (1997) *Embodied progress: A cultural account of assisted conception*, Routledge, London.

Franklin, S., Roberts, C., Braude, P., & Rutherford, T. (2003). Definitions of genetic knowledge in the context of preimplantation diagnosis: an ethnographic study. End of Award Report (ESRC ref L218252036), Lancaster University.

Gibson, I. (2005). Science and Technology report opens debate on assisted reproduction laws. In *BioNews*, 29 March. Published on the BioNews website and downloaded on 27 April 2005: <http://www.bionews.org.uk/commentary.lasso?storyid=2499>.

Gieryn, T.F. (1983) Boundary-work and the demarcation of science from non-science: Strains and interests in professional ideologies of scientists, *American Sociological Review* 48, pp. 781–795.

Gieryn, T.F. (1999) *Cultural boundaries of science: Credibility on the line*, Chicago University Press, Chicago.

Golombok, S. (1998) New families, old values: Considerations regarding the welfare of the child, *Human Reproduction* 13, pp. 2342–2347.

House of Commons Science & Technology Committee. (2005) *Inquiry into Human Reproductive Technologies and the Law*. HC 491, 24 March.

Human Fertilisation and Embryology Authority (HFEA) (2003) *Code of practice (6th ed.)*, HFEA, London.

Human Fertilisation and Embryology Authority (HFEA) (2005) *Tomorrow's children: A consultation on guidance to licensed fertility clinics on taking in account the welfare of children to be born of assisted conception treatment*, HFEA, London.

Kerr, A. (2004) *Genetics and Society: A sociology of disease*, Routledge, London.

Kerr, A. and Cunningham-Burley, S. (1997) The new genetics: Professionals' discursive boundaries, *Sociological Review* 45, pp. 279–303.

Kerr, A. and Cunningham-Burley, S. (2000) A. Kerr and S. Cunningham-Burley, On ambivalence and risk: Reflexive modernity and the new human genetics, *Sociology* 34, pp. 283–304.

Krones, T., Schuter, E., Neuwohner, E., El Ansari, S., Wissner, T. and Richter, G. (in press). What is the preimplantation embryo? *Social Science & Medicine*.

Langdrige, D. (2000) The welfare of the child: Problems of indeterminacy and deontology, *Human Reproduction* 15, pp. 502–504.

Lavery, S. (2004) Preimplantation genetic diagnosis and the welfare of the child, *Human Fertility* 7, pp. 295–300.

Lofland, J. and Lofland, L. (1984) *Analysing social settings: A guide to qualitative observation and analysis*, Wadsworth, Belmont.

Miringoff, M-L. (1991) *The social costs of genetic welfare*, Rutgers University Press, New Jersey.

Parker, M. (2000) Public deliberation and private choice in genetics and reproduction, *Journal of Medical Ethics* 26, pp. 160–165.

Petersen, A. (2002). Facilitating autonomy: The discourse of genetic counselling and the new genetic citizens. In Petersen, A. and Bunton, R. (Eds.), *The new genetics and the public's health* (pp. 135–158 and pp. 180–207). London: Routledge.

Polzer, J. (2005) Choice as responsibility: Genetic testing as citizenship through familial obligation and the management of risk. In: R. Bunton and A. Petersen, Editors, *Genetic governance: Health, risk and ethics in the biotech era*, Routledge, London, pp. 79–92.

Ritchie, J. and Spencer, L. (1994) Qualitative data analysis for applied policy research. In: A. Bryman and R.G. Burgess, Editors, *Analysing qualitative data*, Routledge, London, pp. 173–194.

Rose, H. (2002) Building genethics from below. In: G. Bendelow et al., Editors, *Gender, health & healing*, Routledge, London, pp. 49–67.

Rose, N. (1999) *Powers of freedom: Reframing political thought*, Cambridge University Press, Cambridge.

Shakespeare, T. (1999) 'Losing the plot'? Medical and activist discourses of contemporary genetics and disability, *Sociology of Health & Illness* 21 (5), pp. 669–688.

Wainwright, S., Williams, C., Farsides, B., Michael, M., & Cribb, A. (submitted) Ethical boundary-work in the stem cell laboratory. In: *Sociology of health and illness monograph: The view from here: bioethics and the social sciences*.

Watt, H. (2004) Preimplantation genetic diagnosis: Choosing the "Good Enough" child, *Health Care Analysis* 12, pp. 51–60.

Widdows, H. and MacCallum, F. (2002) Disparities in parenting criteria: An exploration of the issues, focusing on adoption and embryo donation, *Journal of Medical Ethics* 28, pp. 139–142.

Williams, C., Alderson, P. and Farsides, B. (2002) Too many choices? Hospital and community staff reflect on the future of prenatal screening, *Social Science & Medicine* 55, pp. 743–753.