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A 'Healthy Baby': The double imperative of preimplantation genetic diagnosis

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Biographical notes:

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Abstract:

This paper reports from a study exploring the social processes, meanings and institutions that frame and produce 'ethical problems' and clinical dilemmas for practitioners, scientists and others working in the specialty of preimplantation genetic diagnosis (PGD). A major topic in the data was that, in contrast to IVF, the aim of PGD is to transfer to the woman's womb only those embryos likely to be unaffected by serious genetic disorders; that is, to produce 'healthy babies'. Staff described the complex processes through which embryos in each treatment cycle must meet a double imperative: they must be judged viable by embryologists <u>and</u> 'unaffected' by geneticists. In this paper, we focus on some of the ethical, social, and occupational issues for staff ensuing from PGD's double imperative. (125 words)

Keywords: genetics, PGD, ethics, embryology

Introduction:

This paper reports from a 31 month <u>study</u> that aimed to explore the social processes, meanings and institutions that frame and produce ethical issues and clinical dilemmas for practitioners, scientists and others working in the specialty of preimplantation genetic diagnosis (PGD). The aim of this <u>paper</u> is to focus on a major topic from our data, the double imperative of PGD,

highlighting some of the ethical, social and occupational issues for staff ensuing from PGD's double imperative.

PGD brings together in vitro fertilisation (IVF) technology with clinical genetics, necessitating close working relationships between specialist teams of embryology and genetics staff. Staff who participated in our study described the complex processes through which embryos in each treatment cycle must meet a double imperative: they must be judged viable by embryologists <u>and</u> 'unaffected' by geneticists. Viewed from this perspective, it might appear that we focus here on that interface in a narrowly constituted sense and refer only to embryologists and genetics scientists. However, the complex mixture of clinical and scientific staff made up from the disciplines of nursing, obstetrics and gynaecology, sonography, embryology, molecular and cyto-genetics could be characterised differently for other purposes, for example clinical and laboratory staff could be seen as two teams or collectively as the 'PGD team'. For this paper, we will refer to embryology and genetics 'teams' to reflect their broader constitution, but wish to make it clear from the outset that although this does reflect the way in which some of the staff who participated in our study often represented themselves, it was not exclusively so and we have chosen to work with that representation in the knowledge that others co-exist.

The treatment goal of practitioners in PGD is to produce a 'healthy baby', in contrast to IVF, which does not involve selection of embryos on a genetic basis. It is important to stress that although IVF embryos are selected on the

basis of their morphology and development in vitro, this is to select the embryo most likely to implant and establish a successful pregnancy. In that sense the aim is to select a 'healthy' embryo, but embryologists do not claim to be selecting embryos that will become 'healthy' children and adults. Once a pregnancy is established, couples who have used IVF must rely on prenatal diagnosis if they wish to establish that their future child is likely to be unaffected by a serious genetic condition. It has been argued that one of the key advantages of PGD is that it allows women/couples to avoid repeated termination of pregnancies following pre-natal diagnosis of genetic disease, which may have serious and long-term effects on women/couples (Lavery et al, 2002). PGD offers women/couples who are at risk of having a child with a serious genetic condition the option of having their embryos tested before implantation and therefore pregnancy, with the aim of avoiding the implantation of affected embryos. This is done so that they can try to avoid having a child with a serious disease or disability, thus the term 'healthy baby' has longer-term significance in PGD. PGD can also help women/couples who have experienced repeated miscarriage due to chromosome rearrangements such as reciprocal translocation (Braude, Pickering, Flinter & Ogilvie, 2002; Soini et al, 2006).

PGD is currently offered in about eight centres in the UK, which must be licensed by the Human Fertilisation & Embryology Authority. IVF technology is used to create embryos in the laboratory, from which one or two cells can be tested at three days post fertilisation for specific genetic disorders. The embryos are also assessed according to the usual standards for IVF to select

those that seem most likely to be viable and to implant successfully in the woman's womb. After genetic testing, unaffected embryos that also meet embryological criteria for suitability can then be transferred to the woman, where they may successfully implant, or frozen for later use. Embryos that have not been selected for transfer to the woman's womb for implantation are either allowed to perish or donated for research. The important feature of PGD that makes it unique in reproductive technology and that we focus on in this paper is that it requires the collaboration of assisted conception teams and geneticists, and of course specialised technologies to achieve the double imperative of PGD.

Through this and other publications from the study, we contribute to the national and international social science and ethics literature on PGD which highlights the clinical, ethical and policy dilemmas implicit in this area, from the perspective of staff, patients and 'publics' (eg Krones & Richter, 2004; Roberts & Franklin, 2004; Watt, 2004; Zeiler, 2004; Kalfoglou, Scott and Hudson, 2005; Meister, Finck, Stobel-Richter, Schmutzer, and Brahler, 2005; Ehrich, Williams, Scott, Sandall and Farsides, 2006; Krones, Schluter, Neuwohner, El Ansari, Wissner, and Richter, 2006; Franklin & Roberts, 2006). This paper also adds to the growing number of anthropological and sociological studies which explore the ways in which clinical/ethical issues are discussed and acted upon in clinical settings (Chambliss, 1996; Casper, 1998; Williams, Alderson and Farsides, 2002a,b,c; Williams, Sandall, Lewando-Hundt, Heyman, and Spencer, 2005). More broadly, this paper contributes to the literature on the sociology of biomedical ethics (De Vries & Conrad, 1998;

Zussman, 2000; Haimes, 2002). Rather than presenting ethical reasoning in the disembodied ways often characteristic of philosophical bioethics, our approach shifts the focus from what <u>should</u> be happening, to what <u>is</u> happening (Haimes, 2002; Hedgecoe, 2004; Haimes & Luce, 2006; Wainwright, Williams, Michael, Farsides and Cribb, 2006).

Study aim and methods

The aim of the study from which this paper reports was to explore the social processes, meanings and institutions that frame and produce 'ethical problems' and clinical dilemmas for practitioners, scientists and others working in the specialty of preimplantation genetic diagnosis (PGD).

The study, 'Facilitating Choice, Framing Choice', used ethnographic methods including observation, interviews and ethics discussion groups (EDGs) with staff from two Assisted Conception Units (ACU) in the UK offering PGD and IVF. (Our research also included 'stakeholder' interviews with representatives from religious, activist and patient groups, but these are not reported on here.) The study was funded from January 2005 to July 2007. Our multidisciplinary team was comprised of two social scientists, a midwife/social scientist, a moral philosopher, an ethical and legal expert, and a clinician.

Following Ethics Committee approval, the study focused on two sites, both Assisted Conception Units (ACU) in teaching hospitals in England, which offer a mixture of National Health Service (NHS), privately, 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.

Interviews were conducted by the authors (the majority by the main researcher, KE). Participants were recruited following explanations of the research and informal follow-up approaches from the researchers. Interviewees were selected using purposive sampling to include members of all the professional disciplines involved in PGD in the settings studied, including nursing, obstetrics and gynaecology, sonography, embryology, molecular and cyto-genetics, and administration. The interviews were conducted as 'guided conversations' (Lofland & Lofland, 1984), lasting between one and two hours. Open-ended questions and an informal interview schedule were used, with topics such as the status of the embryo; staff experiences of working in a multi-disciplinary environment; and the opportunities and dilemmas associated with PGD as a new technology.

Observations took place in the clinic (including consultations), laboratories, and staff meetings throughout the period of research. Observations in the clinic were almost all carried out by the main researcher. Both authors observed in the laboratories, and at staff meetings which occurred at roughly six week intervals.

The EDG groups were made up of staff who had been interviewed, as well as a small number of staff who were interested in the study but had not been

interviewed. The EDGs were facilitated by a moral philosopher specialising in medical ethics (Alderson, Farsides and Williams, 2002) who was also a coapplicant for the study. To ensure that the EDGs were relevant for staff, the topics for each individual EDG were generated from a content analysis of the interviews. EDGs were specifically tailored to those participants taking part by addressing the issues and examples they had provided in their earlier interviews and their own suggestions for topics that could usefully be discussed in the groups (Alderson et al, 2002). The groups lasted two hours each, and all of the discussions were tape-recorded and transcribed.

Aim and methods for this paper

The aim of this paper is to focus on a major topic from our data, the double imperative of PGD, highlighting some of the ethical, social and occupational issues for staff ensuing from PGD's double imperative.

Transcripts of the interviews and EDGs were analysed using a modified version of the framework approach (Ritchie and Spencer, 1994). Sections of the transcripts relating to topics such as the aims of PGD, choosing embryos and inter-disciplinary working were grouped together and analysed for content. The topic for this paper was chosen to convey what is most unique about PGD and what effects certain features of PGD have on social and ethical aspects of the work for staff. Pertinent sections of the transcripts addressing how the embryos are tested, who is responsible for the different procedures, and how decisions are made across the two teams, were

examined and analysed broadly within a 'social studies of science' perspective.

Study numbers are used to protect anonymity, and for the same reason reference to occupations is in general terms rather than specific job titles, so for example the category of 'counsellor' could include specialist genetics counsellors who provide genetics information or counsellors who work with women/couples primarily in relation to emotional issues. We present quotes selected from the interviews and the EDGs not to argue for their generalisability but to illustrate the views of staff in particular roles. Although there were some differences in the way assisted conception and PGD procedures were carried out in the two sites, we have not described these in detail as this would compromise the confidentiality we have maintained in presenting our findings.

We wish to stress that the views presented here pertain to the medical and wider cultural, historical and legal context in which they occurred. Our findings are therefore limited and we do not make claims as to their generalisability to other sites within the UK or to settings outside the UK. We were also aware of the possible effects that our own role as researchers may have had in generating the focus on particular topics such as potential conflicts between teams and professions, and in the setting up of the EDGs in a particular format, which provided opportunities for staff to explore potentially challenging topics. Brief telephone-based evaluations of the groups, in which

each participant commented on the experience, highlighted appreciation of the perspicacity and high level of trust generated in the EDGs.

Results

This paper reports on one of the major topics from our study: the double imperative of PGD. We draw here on 41 staff interviews, and seven ethics discussion groups from our two study sites, generated between May and December 2005, and March and July 2006, and observations throughout the period from May 2005 to May 2007. We present staff views and discussion grouped into four themes: 'healthy', not 'designer' babies; bringing together two 'tribes'; separation and sharing of accountability and control; and choices and chances.

'Healthy', not 'designer' babies

The first theme addresses contrasts staff made between the purposes of PGD and IVF treatment:

> Doctor 11: Couples with certain conditions are given the opportunity [through PGD] to have a healthy child. And the majority of those don't know they've even got that condition until they've had a child. So I can understand they might want to have a healthy child, and they should be given that opportunity. IVF is different. It's not being done for that purpose, it's being done because they can't have children in the normal way.

The aim of PGD is not only to 'produce parents' (Thomson 2005) since many PGD patients have already become parents; the intention is to produce a 'healthy baby' (and 'parents of a healthy baby'). The aim of PGD was also defined in terms of what it is not: staff in both units criticised the popular press and other media portrayals of PGD as giving women/couples a 'consumerist' opportunity to select embryos for particular features of their future offspring. Instead they had a considerable sympathy with women/couples in relation to what they saw as the misrepresentation of the goal of PGD:

> Genetics scientist 8: It's not about designer babies, it's just helping people to have normal, healthy children… all they want is a nice healthy baby.

This reflects Franklin and Roberts' (2006) report of the views of women and couples who decide to try PGD because they feel it is their only hope of having a child unaffected by a serious genetic condition. They regard themselves as being forced to do extraordinary things to achieve what they feel is a very ordinary goal in life. It is interesting that in both of the quotes above, normality is referred to, in terms of the 'normal' way of having children, or 'normal, healthy children'. The question of what constitutes 'normality', other than the absence of a serious disease, was discussed in some of the EDGs in relation to the criteria for PGD of 'seriousness'.   Although staff recognised that in some instances, for example late onset or low penetrance conditions, offering PGD could contribute to changing conceptions of normality, staff find it hard to argue against women/couples' own conclusions

about what constitutes seriousness in the context of supporting individual autonomy and choice (Williams et al 2007). This also allowed staff to distance themselves to some extent from being implicated for their possible contribution to changing concepts of normality that might follow from increasing selection and decreasing levels in the criteria for seriousness.

Thompson (2005) argues (drawing on Foucault and Goffman) that the variously instrumentalised and embodied procedures used in assisted conception clinics are both 'normalising' techniques and 'epistemically normative'. They are normalising, in the sense that they incorporate new techniques, knowledge, instruments and patients into existing procedures and objects of the clinic (2005:80), and 'normative' in the sense that routinised skills are often used to separate diagnostically the normal from the abnormal (2005:81). In some ways it could be argued that PGD is only a refinement in technological methods that already exist to help women/couples avoid having a child with a serious condition, which has already become normalised to a large extent through prenatal diagnosis (PND). However the ability to test the embryo before implantation has been seen as offering an ethically preferable alternative, mainly because it allows women to avoid termination of a pregnancy in which the fetus is found to be affected by a serious genetic condition. In this respect, the ethical advantage of PGD could be seen as giving further impetus to the normalisation of this use of genetic technology. This ethical advantage may also contribute to the acceptability of a normative delineation between 'healthy' and 'affected' children as an effect of PGD.

Bringing together two 'tribes'

A key feature of PGD is that it demands the coordination and staging of tasks from two fields: embryology and genetics. This has significant implications for the social and occupational organisation of work in the clinic.

> Nurse 1: I think one of the things that really strikes me about working in PGD is, obviously the team is made up of people from Genetics and people from ACU. And we have a different way of looking at things. Of course we do. We come from completely different backgrounds.

> Doctor 11: …there does become a bit of 'them and us', isn't it? The nurses say this about the doctors and the doctors say this about the embryologists. And I think it's because we don't fully understand each other's roles. And it's interesting, what [another participant] is saying is really fascinating, I suddenly thought, 'You know, you don't have nearly as much personal contact with patients as we do, so you don't have nearly as much feeling about them as we have.'

Like all relationships between 'tribes', sometimes the close interdisciplinary relationship between the teams that PGD brings together can seem like a kind of dance, and sometimes it can include conflict, or the feeling that different practices and perspectives mean staff are living in 'different worlds'.

> Genetics scientist 39: I mean it's a fight between us and the embryologist. This happens every time, because [her] prime directive

is pregnancy, and my prime directive is a normal pregnancy. These people [clients] are not necessarily infertile. They have waited years and years for PGD so that they could try and guarantee a normal child. And where [name of embryologist] is coming from is the people that [she] generally sees can't have babies… So it's two different outlooks.

Genetics scientist 46: In comparison to ACU staff, we are more research scientists… after you've done a PhD, you think in a different way anyway … in IVF clinic, you just follow protocol. … not just our IVF unit, but any IVF unit. They've got their clinical work, they've got to do ABC and that's it, whereas we don't do it like that, scientists don't do it like that. So, so it's, it's two different worlds.

In another EDG, the participants discussed who makes the decisions about which embryos to select for transfer, and the controversial issue of sex selection for social reasons (currently illegal in the UK) that can overlap with avoiding a sex-linked condition. It became clear that, in contrast to how the genetics team view the decision as one which necessarily involves the parents, one of the embryologists was accustomed to thinking of the choice as a purely clinical one depending only on morphology:

Embryologist 33: Our goal is to get them pregnant regardless of the sex, because I mean, even if you go down all the PGD and had a sex selection or whatever, ultimately you're not guaranteed a pregnancy … Normal IVF patients go through and they show up at transfer and we

say, 'These two are the best, they're the ones we're putting back today.'

This range of comments illustrates differences of perspective in terms of professional roles, relating to clients, and who should be responsible for making decisions about embryo selection. Looking at it another way, one of the clinicians in our study has said that for PGD to be successful an embryologist must 'get into bed' with a geneticist. Ideally the design of the whole service should reflect the need for close working relationships between teams of people, techniques and clinical systems. However, it cannot be taken for granted that they will all share the same worldviews, work goals, or working practices. We have addressed this in other papers reporting from this study, dealing with ethical issues such as how staff feel about the destruction of embryos compared to termination of affected pregnancies (Ehrich et al 2007a), and to what extent they can support the philosophy of patient choice (Ehrich, Williams, Farsides, Sandall and Scott, 2007b). We have also suggested (Ehrich, Williams and Farsides 2008) that sharing overarching work goals (e.g. to help women/couples produce a 'healthy baby') across the teams may help to achieve a workable tension that facilitates cooperative relations, even when personal and more micro-level work goals potentially produce conflict between actors. Renegotiation of professional relationships in these various ways was a striking feature of the teams we studied seeking to achieve the double imperative of PGD.

Another concept that is helpful here is one we have used elsewhere (Williams, Wainwright, Ehrich and Michael 2008) in relation to embryos moving from the social world of PGD to that of embryonic stem cell science. The notion of 'boundary objects' describes the shared understandings and the collective actions which help to manage and unite related but different social worlds. As Star and Griesemer (1989) state, boundary objects can have different meanings in different social worlds because they are sufficiently 'plastic' and can adapt to local needs, yet 'their structure is common enough to more than one world to make them recognizable, a means of translation' (Star and Griesemer 1989, p.393). Fujimura(1992, p. 173) argues that boundary objects emerge through processes of work when elements of the work of groups coincide, and Clarke (2005) suggests that the use of this concept can allow social scientists to study and analyse the different participants in a social world 'through their distinctive relations with and discourses about the specific boundary object in question.' (Clarke 2005, p.51). We think this concept applies equally well to the translation of embryos from IVF to PGD, since in many ways they are produced through processes of work involving the two groups of staff and retain important structures in common, yet they have different meanings in the two different social worlds. Therefore embryos under conditions of the double imperative act as boundary objects at a point of translation, helping to manage and unite the social worlds of IVF and PGD.

Separation and sharing of accountability and control

The double imperative of PGD has further ethical and social implications for professionals involved because of the separation and sharing of technical,

clinical and regulatory aspects of accountability and control. One example of this is that embryologists remove the cell(s) for testing the embryo and then the cells may be prepared for, or transferred directly to, the genetics scientists. The biopsy and handover are extremely skilled and critical procedures and the teams follow strict protocols to allow each team to have control over particular parts of the process. At the same time, supporting their common goal on the overarching level, the teams depend on each other in numerous ways, including all aspects of the care and handling, labelling and storage of embryos and cells; maintaining the correct air quality and temperature of the environment and chemical composition of cell culture mediums; and the genetic testing of the biopsied cells.

Efforts were made in both of our study sites to support cooperation between teams because of the serious consequences of any technical failures and the mutual dependence and accountability of the two teams,. A practical need for this arose because at various times the teams at both sites have been located in different buildings, at distances requiring over 20 minutes walk or taxi rides, and the transport of embryos between them. The teams at our two sites had different histories in this respect: the teams at one site had moved closer together, and the teams at the other site had moved further apart. Instances of cooperation between teams were observed in staff meetings, for example in discussions dealing with communication issues (who needs to inform which colleagues of which information at what points in time); the sharing of empathy with the clinical and emotional experiences of women/couples; or the arrangement of meetings at times and places that allowed members of the

teams to meet together. Discussion of potential or actual conflicts due to the more fundamental differences in aims of IVF and PGD were occasionally observed in team meetings, and were also addressed in the EDGs. In these situations, separation and sharing of aspects of accountability and control were a feature of potential conflict, whether on the more pragmatic level or on the level of considering ethical dimensions and differences of outlook.

A salient example concerned the fluctuation in success rates, a common situation in all assisted conception units compounded because success rates are difficult to quantify, and vary depending on factors including different measuring methods used by clinics, the age of the woman and whether the embryos used are fresh or frozen (Thompson, 2005). In the ACUs we studied, when the success rates rose, there were celebrations, for example sharing cakes and sweets. When there were dips in pregnancy rates, it was important for the teams to investigate possible causes, and natural at times to seek reasons and place accountability outside their own immediate team. The organisations as a whole are affected in various ways by successful pregnancy and birth rates and these have important effects on how the teams are judged by peers, patients and regulators, which in turn serve financial and institutionally strategic purposes. The double imperative of PGD plays out tensions between the scientific and clinical prestige of doing PGD as an innovative health technology and the reputation of the clinic for achieving successful pregnancies.

The constant (re)negotiation of the social order in and between the teams can also be seen in group discussions about the ethics of particular cases (what stand should we agree on for this case, for what reasons, how does this relate to our broader policies), and in forming strategies for how work is presented publicly. All of these instances of fluid movement between separation and sharing of accountability for tasks, decisions and public perception can be seen as ways in which the 'technology' of PGD is performed, interpreted and represented. Different forms of sharing and separation of accountability, tensions between micro, team and organisational level goals, and the dynamic and emergent representations of PGD can be seen as predictable characteristics of a constantly evolving technology (Grint and Woolgar, 1997).

Choices and chances

Finally, there is the question of how PGD contributes to the range of choices available to women/couples with a known genetic condition who want to start or increase their family. Prior to PGD, a number of options were available to women or couples wishing to avoid having children affected by serious genetic conditions, including the use of donor gametes, adoption, or using prenatal testing and termination of affected pregnancies. For people who also have difficulty conceiving, the IVF part of PGD could be thought of as an opportunity for some people to have a greater chance of pregnancy because, for one reason, it can produce more embryos than in a natural cycle. However, compared to IVF or trying 'naturally' and using PND, PGD may significantly reduce fertile women's/couple's chances of having what is sometimes referred to as 'a take home baby' (Franklin and Roberts, 2006).

This is because the complex coordination of a number of <u>things</u> of different kinds together with highly specialised technical, clinical, ethical, legal and social processes and bodies of knowledge most often result in no embryos meeting PGD's double imperative.

> Nurse 1: I think that 13/14 [translocation of chromosomes] is quite a good example, you know, if a couple has no fertility issues, is able to get spontaneously pregnant without too much of a problem,   […] then I don't know that we really are doing them favour by hampering that fertility … I don't think, I think quite often they get in to this system, simple thing – you know, maybe they've had miscarriages, whatever, translocation diagnosed, 'Oh well they must have PGD'.   Well actually that's not true. It's not a 'must have PGD' – they have a range of options of which PGD is one. And actually, for the vast majority of couples who are fertile in that sort of situation – it works for some of the reciprocals as well, PGD is not necessarily going to help them, it's going to hinder them in terms of their chance of getting pregnant.

Thus although PGD offers a further option for some women/couples, at the same time it makes the process of decision making between choices more complex. In this sense PGD increases some choices but also reduces certain chances.

Staff who participated in our study from different occupational groups and from both sites expressed the view that many public and academic opinions of

PGD rest on an overestimation of the degree of choice possible between embryos in each PGD treatment cycle. Talk of 'designer babies' and selecting embryos as if there were a vast pool to choose from caused frustration amongst staff. They often explained that when selecting suitable embryos for transfer in PGD, there is a very narrow degree of 'choice' because there are so few embryos that are assessed as viable embryologically and genetically unaffected.

Genetics scientist 39: We are hardly, hardly ever in the position where there are two embryos which are genetically normal and embryologically good looking… So I haven't faced this dilemma yet. I haven't really had the choice.

Genetics scientist 38: The whole point is that, and a lot of people don't know this, don't realise, that… you very rapidly run out of embryos… it needs to be said again and again.

From this point of view, both choices and chances are perceived as scarce, but we suggest that this may be a taken-for-granted perception of staff who no longer see the production of this narrowed down choice as very complex because of their everyday embeddedness in the technology of PGD. Women/couples who participated in Franklin and Roberts' ethnography of PGD (2006) often expressed their belief that PGD had become the only way for them to have a healthy child so their experience was that they had no other choice. Alternative possibilities, such as adoption, or not having

children, may not be considered and instead the goal of having a genetically related 'healthy' child using complex technological intervention comes to be perceived as the only 'choice'. Expression of the feeling that there is not much room for choice in both of these senses can be seen as indicators of normalisation. We argue that the normalisation of these two versions of limited choice is socially significant and part of the gradual, incremental and taken-for-granted acceptance of PGD as a new reproductive technology.

DISCUSSION

In this paper we focus on a major topic from our data, the double imperative of PGD, highlighting some of the ethical, social and occupational issues for staff that ensue from PGD's double imperative. Decisions about the selection of embryos to meet the double imperative of PGD take place in 'a crowded room – a room filled with individual assumptions, organizational contexts, and social, cultural and political constructs' (Todd 1989:131). What is more, interactions between the people providing and receiving assistance with conception and genetic diagnosis are infused with meanings reaching back and forth in time. Focusing on the double imperative of PGD has led us to consider specifically how the technologies of IVF and PGD came about, the significance of their different origins, and the social organisation of the combined technologies brought together to achieve the double imperative of PGD.

In PGD, decisions about the future possible existence of each embryo are made on the basis of their morphology up to five days post fertilisation, and

the testing of one or two cells removed from the embryo at three days. The biopsied cells have no future purpose other than to be tested, yet the fate of the embryo from which they were removed will follow on from the testing of each cell. This means that one can consider the biopsied cell as a synechdote for an 'affected' embryo, and therefore the cutting short of the potential for a future person with a serious genetic condition; or alternatively, an 'unaffected' embryo as the potential for a successful pregnancy, the hope for a future 'healthy child', the future parenting of this possible child, and the existence and life of a new and 'healthy' human being. All of these possibilities can be seen as being reduced to the embryologist's assessment of the embryos at three to five days, joined by the geneticists' testing of one or two biopsied cells.

PGD entails a workable tension between the various occupational and personal work goals of staff (see Ehrich, Williams and Farsides, 2008), and competing ideals in treatment (to produce a baby, not to produce particular babies). For ACU staff whose primary orientation is to help create life, the goal of PGD may be problematic. For example, embryos that might have developed into successful pregnancies are not used for transfer to the woman if the genetic diagnosis indicates the child would be at high risk of a serious genetic condition, but in some cases this may mean allowing a 'normal' embryo to perish, such as when selection is only possible through identifying the sex of the embryo. This is notwithstanding the situation in which IVF staff contribute to the overarching purpose of PGD. To fulfil the aim of PGD, embryology and genetics teams in particular must take account of and

engage with technical, scientific and ethical aspects of the other team to deliver the treatment, even though these may sometimes conflict with their own personal or team work goals (see also Ehrich, Williams and Farsides, 2008; Ehrich, Farsides, Williams and Scott, 2007a). An agreement must be reached between the two teams on each embryo as to its expected ability to lead to a successful pregnancy and develop into a 'healthy baby', based on their combined expertise and judgement. PGD therefore departs in important ways from IVF and involves the staff in additional personal, occupational, political and ethical considerations about the nature of their work.

The coming together of IVF and genetics technologies, expertise, staff, and various human substances, and the culmination of processes that lead to deciding which embryos to transfer to the woman's body also stands for another much larger set of 'things': PGD entails the coordination of medical and scientific knowledge, skill, decision-making, regulation and so on, all of which are infused with ethical, cultural and social values, practices, knowledge, beliefs, and aims. In a broad sense, the emphasis on the morphology of the embryo stands for the aims of embryologists (and assisted conception generally) to help create life, whereas the additional emphasis in PGD on the results of genetic tests stands for the prevention of certain forms of life (see Franklin and Roberts, 2006, on the 'born and made' distinction) and both positions are supported by their own social and ethical arguments. The embryo selected for transfer after PGD could stand for the achievement of these two simultaneous goals (which for some people are contradictory). Building on our previous work on the two social worlds of PGD and embryonic

stem cell science (Williams et al 2008), and following Fujimura's point that boundary objects can both enable and disable particular social actions (Fujimura 1992, p 204), we argue that embryos as boundary objects enable some futures in IVF and disable certain futures in PGD, as well as articulating common and different processes in the two social worlds.

These findings resonate with Casper's (1998) work on fetal surgery, in which she argues that the interests of the fetus and the mother are reflected in the joint work of different medical and scientific specialties, and constructions of the fetus as work object vary depending on their different work goals. Further, in a similar way to Casper's argument that fetal surgery creates a new subject, the 'fetal patient', we suggest that the coming together of medical and scientific specialties in PGD could also be considered as creating both a new hybrid field, and a new hybrid subject, the PGD embryo standing for a future 'healthy baby'.

In support of Thompson's (2005) argument that the variously instrumentalised and embodied procedures used in assisted reproduction are both 'normalising' techniques and 'epistemically normative', we suggest that PGD as a technology for producing 'healthy' babies helps to normalise the desire of parents to avoid having a child with serious genetic disease, and may contribute to a changing normative delineation between 'healthy' and 'affected' children. The procedures, professional knowledge and techniques of PGD can also be seen as constituting a further gradual, incremental (but perhaps not yet publicly taken for granted) normative effect in this sense.

However, rather than seeing this as an effect of 'technology' on 'society', we are interested in how professionals position PGD socially and ethically as indications of its broader interpretation and representation, lending authority to certain ways of seeing things, people, and relationships according to particular, but changing, views of normality. It could be claimed that PGD translates the purpose of IVF (for some clients and professionals), because the aim of PGD is to prevent the birth of children with serious genetic conditions, whereas in IVF the aim is to achieve a successful pregnancy and any attempt to ensure the baby is 'healthy' in terms of serious conditions must rely on prenatal testing. However in both IVF and PGD, staff share a similar view of embryos in terms of the <u>scarcity value</u> of embryos that develop into successful pregnancies and 'healthy babies'. Staff in our study placed an emphasis on the fact that most embryos do not develop into successful pregnancies, and therefore the idea that people could select between a range of embryos, in the way that those who compare PGD to eugenic practices envisage, does not match their experience.

One could argue that a technology's capacity and capability always rely on its interpretation, and the point is to analyse how persuasive certain accounts may be (Foucault 1980, Grint and Woolgar 1997). Taking this stance one might claim that our knowledge of a technology such as PGD is constructed by the more powerful and collective elements of our society that represent PGD as a technology that prevents suffering, distress, illness and disability, and that this has won out over efforts to construct it differently, for example as a 'weapon of destruction' (Quintavalle, 2006). Grint and Woolgar (1997) argue

that the nature and characteristics of a technology and its capacities are crucial matters to investigate because they are representations of our <u>social</u> capacities and capabilities. In contrast to debates polarising 'technology' and 'the social', they argue that the two tendencies (technology and the social) are both aspects of a negotiated order, so that technologies are continually (re)interpreted and (re)constituted. Thus people, various systems, forms of training, configurations of the 'users' (clients are constituted as 'appropriate' users of PGD and 'educated' as part of that process), the division of occupational roles and other social arrangements and relations are all part of this emergent 'technology'.

PGD, like IVF, can be seen as a performed community of social relations that continually adapts to new technological and social developments. However, like other biotechnologies, PGD and IVF are comprised not only of Petri dishes, microscopes and so on, but also of people, practices, and social relations, and these are not so reliably translated or reversed. In contrast to a view that once a technology has been designed it carries political and historical features that lock in aspects of those social arrangements, we agree with Grint and Woolgar (1997) that this underestimates the significance of actors' continuing interpretations and uses of the technology. Because the techniques of IVF and genetic diagnosis were originally created for quite different purposes than that to which their combination is employed in PGD, it should not be surprising that the social significance originally adhering to them as separate technologies (in the broader sense) persists and therefore we could conceptualise the performance in which the teams and possibly its

'users' act in terms of emergent, contingent and therefore unstable relations as a predictable effect of an emergent technology.

In conclusion, we have explored in this paper a major topic in our study of PGD – the double imperative it imposes on embryos before implantation – and some of the ethical, social and occupational issues that ensue from this double imperative for staff working in this field. We consider that thinking of the embryo as a boundary object in IVF and PGD, or thinking of the PGD embryo as a new hybrid subject, and subject to predictable forms of social relations characteristic of emergent technologies, are useful tools with which to analyse the social and ethical dilemmas and conflicts that arise in PGD but have also been the subject of our programme of study of developments in reproductive technology including the status of the fetus, fetal surgery, prenatal diagnosis and PGD (Williams 2005; Williams 2006; Williams, Alderson & Farsides 2002a,b,c; Williams,Sandall, Lewando-Hundt, Heyman & Spencer 2005, Ehrich, Williams & Farsides 2008, Ehrich, Farsides,Williams & Scott 2007) and stem cell science (Wainwright et al 2006, Williams et al 2008). As a hybrid, emergent technology, PGD enables some futures but also disables certain futures. It provides, for some women/couples as well as staff, an ethically preferable alternative to previous means of trying to ensure the long-term health of a baby in families who are at high risk of having a baby with a serious genetic condition, and therefore may contribute to normalisation of the desire to prevent the birth of such children. The emphasis of both teams on the scarcity of embryos that will develop into a successful pregnancy and a 'healthy baby' stand in contrast to the idea of eugenic

selection from an abundance of embryos. Despite some differences between the two teams in terms of work goals and important practical issues, the double imperative of PGD serves to unite them in emphasising the scarcity value of embryos that are likely to produce a 'healthy baby'.

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