Relative concerns associated with genetics and surrogacy

Maggie Kirk
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Abstract
Assisted reproductive technologies, incorporating artificial insemination and in-vitro fertilization techniques, are widely practised across Europe. Concern about surrogacy prompted the UK Government to commission a review and consultation on surrogacy arrangements. The ensuing document was concerned primarily with the questions of payment to the surrogate, and the regulation of agencies involved in surrogacy arrangements. This author feels that more fundamental issues should first be debated by both health professionals and society. Genetic aspects of surrogacy merit special attention, particularly regarding the genetic contribution to parenthood and the ownership and use of genetic information. Health professionals need to be fully aware of the ethical implications of advances in genetics and technology when they are applied to assisted reproduction.

The involvement of a third party in the human reproductive process by donation of genetic material is not new. Artificial insemination of sperm by donor has been with us for some considerable time, with the first known instance of its use occurring over 100 years ago (Daniels and Lewis, 1996). The implementation of in-vitro fertilization (IVF) techniques, announced with the birth of Louise Brown in 1978, paved the way for more sophisticated procedures, and there are now a number of techniques in use, including oocyte and embryo donation, as well as 'womb donation' via surrogacy arrangements.

While those techniques utilizing IVF procedures require intervention by specialist health practitioners, technological assistance is not necessary for all processes, and some companies offering reproductive services may be accessed via the Internet. One such company, following an introductory consultation, and on receipt of an appropriate medical certificate, will send sperm samples to the client’s home (Figure 1).

Assisted reproductive technologies (ARTs) are now widely practised, with 516 centres across Europe accounting for 60% of the world ART centres (Schenker, 1997). Further technical advances offer even greater possibilities for the diagnosis and treatment of reproductive disorders. However, there is often a considerable lag between such discoveries and their implementation in clinical practice; Levinson et al (1995) attribute this partly to the rapid pace of discovery, and partly to caution exercised by health professionals and regulatory bodies in approving their use.

There is also an apparent delay between clinical implementation and formulation of appropriate legislation or regulation. Although there have been various committees of enquiry (Committee of Inquiry into Human Fertilisation and Embryology, resulting in the Warnock Report, 1984) and the passage of legislation such as the Surrogacy Arrangements Act 1985 and the Human Fertilisation and Embryology Act 1990, currently the majority of countries in Europe do not have established legislation pertaining to various aspects of ART practice (Schenker, 1997).
Pacific Reproductive Services

Selecting A Sperm Bank
The Insemination Experience
The Donor Screening Process
Selecting Your Sperm Donor
Becoming A Sperm Donor
Our Donor Profiles
Bulletin And FAQ
Alternative Parenting Resources
PRS Advice Line

Pacific Reproductive Services (PRS) believes that children born of donor insemination have a right to information about their biological lineage upon adulthood. We offer our clients a higher percentage of willing-to-be-known donors than any other sperm bank. While it is more difficult to recruit these donors, we remain committed to providing our children, upon adulthood, with the option of receiving information about their biological heritage.

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Public and professional response to issues surrounding the use of ART has indicated a growing concern, with media coverage of surrogacy arrangements in particular often appearing hostile (Bromham, 1995; Cotton, 1997). In light of this, the UK health ministers commissioned a team of experts to review various aspects of surrogacy. The subsequent consultation paper, published in October 1997, invited comments on two aspects of surrogacy, namely payments to surrogate mothers and the regulation of surrogacy arrangements (Brazier et al, 1997).

This author feels that such a document was premature, in that it effectively excludes discussion on the more fundamental question concerning society’s acceptance of surrogacy arrangements, and that there are more immediate issues that should be fully discussed first. One such issue is the part that inheritance plays in parenthood, and the dilemmas that may arise as a result of confusion over control of, and access to, the information contained in the genes carried by the gametes and baby at the centre of the surrogacy arrangement. This article explores some of these genetic aspects of surrogacy.

New choices: new dilemmas?
One reason behind the present concern expressed by professionals and public alike, about ART, is perhaps a fundamental uncertainty as to how far we should be prepared to go in applying new technologies and in accepting the choices they offer. These choices arise as a result of advances both in reproductive technologies, particularly those involving IVF techniques, and in human genetics, largely following the launch of the Human Genome Project.

The Human Genome Project aims to map and sequence the entire human genetic make-up. This project is broadening out understanding of the role that genes play in health, disease and even behaviours, and providing ever-increasing scope for testing for those genes, not only in the rarer, serious genetic conditions such as cystic fibrosis or sickle-cell disease, which impact on early childhood development, but also in common disorders that have a significant genetic component, such as diabetes, heart disease, Alzheimer’s disease, and some cancers. Thus more and more information about ourselves and our offspring (both potential and actual) is becoming available (Kirk, 1997).

It is expected that one of the major applications of the advances in genetics and technology will be in detecting the genetic status of the fetus, initially utilizing the techniques currently available, namely amniocentesis, chorionic villus sampling (CVS) and pre-implantation genetic diagnosis (PGD). On the basis of the outcome of such tests, decisions may be made as to whether or not to continue with the pregnancy (Green and Statham, 1996).

The most commonly used of these tests is amniocentesis, where amniotic fluid is withdrawn during the second trimester of pregnancy to obtain fetal cells for culture in the genetics laboratory. CVS can be carried out in the first trimester. Here, biopsy of the chorion (which is genetically identical to the fetus) provides cells that can be analysed directly (Green and Statham, 1996). PGD is associated with IVF techniques, where one or two cells of the pre-embryo are isolated and tested. Embryos subsequently found to have a genetic disorder may not then be transferred to the uterus (Wood-Harper and Harris, 1996).

Both amniocentesis and CVS pose some risk to the developing fetus and so are restricted to pregnancies considered to be at higher risk of a genetic disorder, while PGD is reliant on IVF techniques and is not widely available. In the near future, new techniques such as direct sampling of fetal cells from maternal blood could be implemented, with no associated risk to the fetus (Green and Statham, 1996). Implementation of such low-risk techniques combined with the knowledge and technology to detect, from one blood sample, a vast range of genes causing or contributing to
disease (and even non-disease characteristics such as intelligence) could have major implications for prenatal genetic diagnosis and reproductive decision-making. Genetic screening of all pregnancies, rather than testing only those at risk of a specific gene defect, could become routine, providing couples with a quantity of information about the genetic status of their baby.

The convergence of clinical genetics research and the reproductive technologies offers powerful choices, particularly for couples at risk of conceiving a baby affected by a genetic disorder, or for those with reduced or absent fertility as a result of a genetic disorder (e.g. Turner’s syndrome) or uterine abnormality. The more traditional choices previously available to such couples have involved ‘taking the chance’ of having an affected child, or, if available, undergoing prenatal testing. Assistance by a third party was restricted to artificial insemination (which may have been inappropriate) or trying to adopt a child. Now they have further choices of utilizing not only donor sperm, but also donor eggs, or donor embryos, and donor wombs, through IVF techniques and surrogacy arrangements. The potential for genetic screening of these donor gametes or embryos, utilizing some of the techniques mentioned, could further widen possible choices.

But these choices also bring dilemmas - there is a burden associated with the choice. This is perhaps greatest when the applied technology incorporates genetics and surrogacy.

**Surrogacy: the present position**

Brazier et al (1997) define surrogacy as:

‘The practice whereby one woman (the surrogate mother) carries a child for another person(s) (the commissioning couple) as the result of an agreement prior to conception that the child should be handed over to that person after birth.’

Two categories of surrogacy may be identified (Table 1).

<table>
<thead>
<tr>
<th>Table 1. The two categories of surrogacy</th>
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<tr>
<td>Partial surrogacy</td>
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<tr>
<td>Full or gestational surrogacy</td>
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The current legislation regarding surrogacy arrangements is covered by the Surrogacy Arrangements Act 1985, amended by the Human Fertilisation and Embryology Act 1990. The law makes it a criminal offence to make surrogacy arrangements on a commercial basis, and bans advertisements relating to surrogacy. The 1990 Act made further provision for *married* couples whereby, under certain conditions (including that at least one of the applicants is the genetic parent), such commissioning couples may be treated in law as the parents of the child without having to go through the adoption process, with the consent of the surrogate mother. The Act acknowledges that surrogacy contracts are unenforceable in the courts, and that the surrogate mother cannot be forced to hand over the child. The ‘birth mother’ is thus to be treated as the mother of the child. If new legislation is introduced in the wake of the review of surrogacy arrangements, this situation may alter.
What are the issues?

Parenthood and the genetic contribution

The fundamental problem appears to be that the new technologies allow a child to be created by means that do not constitute traditional family units, and challenge the concept of motherhood, questioning the contribution of the genetic, physiological and emotional components. Blyth (1991) goes so far as to state that surrogacy ‘subverts ideology of the family … reducing the role of the surrogate mother to that of a breeding machine.’. He argues that a predetermined arrangement to hand over the baby undermines beliefs about the strength of the mother-child bond, with an arrangement made on a commercial basis in particular being considered to ‘violate the dignity of motherhood by encouraging women to be paid for bearing a child by proxy’.

Before the development of IVF, the only person who could possibly be a child’s genetic mother was the gestational mother. Gestational surrogacy has created the situation where one child has two mothers. Certainly, assisted reproduction had demarcated the constituent parts of the parenting function, so it is now possible to distinguish between:

• The genetic mother
• The genetic father
• The birth mother
• The husband of the birth mother (who may be the legal father)
• The social mother
• The social father.

Interrelations between these are also possible, e.g. the birth mother could be the ‘genetic’ grandmother. The possibility of step-parents or foster parents may further complicate the issues.

In looking for a way forward for fair and acceptable application of ART in surrogacy arrangements, we need to obtain a balance between the rights and wishes of the genetic parents and the birth mother that does not devalue either; there is a risk that the present high profile being given to genetics may obscure and dehumanize the role of the birth mother. We need to recognize the contribution of both genes and the uterine environment to motherhood, as well as the emotional bond that develops during pregnancy, otherwise we are in danger of reducing the fetus to a genetic product and the gestational mother to a human incubator, or fetal container (and what arguments will we be left with when babies can be reared entirely in vitro, by ectogenesis?)

Ownership and use of genetic information

The fundamental question is who owns the genetic material, i.e. the gametes or embryo, ‘contained’ in the baby? Related to this first issue is then the question of who ‘directs’ the pregnancy, in relation to obtaining genetic information and making decisions based upon it. Or, to put it another way, who assumes the rights and responsibilities of rearing the embryo to term and then beyond into childhood?

This issue is gaining a higher profile as more information is becoming available about our genes and the contribution they make to health, disease and behaviours. As testing becomes more widely available, the issue of who owns the genetic information about an individual, or has access to it, becomes more pertinent, particularly in relation to the following:

1. Genetic testing or screening of the fetus may also reveal the genetic status of the parents, as the fetus receives half of its genes from its mother and half from its father. The parents may not wish this information to be made available to the gestational mother, or they may not wish to know it themselves.

2. The genetic information about potential donors that could become available to commissioning couples may be subject to abuse. With an increasing range of gene tests becoming available, donors could be screened not only to reassure commissioning parents that they do not carry
deleterious genes, but also perhaps to indicate the presence of genes associated with particular characteristics, e.g. reading ability or sporting prowess. Choosing a donor for partial surrogacy on the basis of the gene profile of the surrogate may be construed as eugenics, and possibly facilitates exploitation of the surrogate. Donors perceived as having more desirable genetic profiles may command a higher fee if one is offered, and may tempt donors to try to conceal information that could result in their rejection. The establishment of ‘genetic supermarkets’ in these circumstances becomes less of a science-fiction scenario. One company advertising reproductive services on the Internet offers more detailed information about their sperm donors than is usual, with in-depth profiles being available for an additional fee (Figure 2).

3. There is also the potential for conflict between the genetic parents and the birth/legal parents in relation to:

- Whether the baby should undergo prenatal testing, and what tests should be undertaken. Currently the birth (surrogate) mother has ‘control’ over the pregnancy, and her consent is required for prenatal tests. However, the commissioning couple in a commercial surrogacy arrangement may require tests to be undertaken against the wishes of the surrogate mother. If legislation is introduced to support their legal status in relation to the pregnancy, the surrogate mother may be forced to agree to testing. The implications of this are worrying, and such situations as could potentially arise would surely be unacceptable to health professionals involved in prenatal testing and antenatal care.

This issue is likely to become more problematic particularly as more tests become available for the common disorders of later life, where perhaps there is more ambivalence as to what constitutes acceptable grounds for termination of pregnancy on the basis of detected genetic disorder. The issue of gene testing for late onset disorders is itself the subject of a consultation by the Government Advisory Committee on Genetic Testing (ACGT, 1997) who acknowledges that the situation of prenatal testing is complex - without the added complication of surrogacy arrangements.

- Subsequent decisions made on the basis of the outcome of such tests. Commissioning parents, for example, may not wish for pregnancy to be continued following diagnosis of genetic disorder in the fetus, whereas the surrogate may feel that termination of pregnancy is inappropriate for a particular disorder. Again, could a change in legislation force her to comply with their wishes?

There is thus clearly a need for all parties to be fully informed. If agencies are to be permitted to mediate in surrogacy arrangements, whether fully informed consent of both parties can be ensured other than through regulation is open to question. If this is the case, then evidence of this needs to be made available.

**Implications for health professionals**

The role of nurses in informing and supporting couples seeking treatment for fertility problems is outlined by Denton (1998). She urges nurses to contribute to raising public awareness about such problems, and to encourage more people to donate eggs and sperm cells. However, all professionals - nurses, midwives and social workers - involved in assisted conception services, directly or indirectly, need to be fully aware of the implications for those involved. Their education needs to embrace not only genetics and reproductive technologies, but also applied ethics. Furthermore, ongoing professional updating is essential for such fast-moving fields.

Lützén (1997) acknowledges that nurses are encountering new ethical problems as a result of the psychosocial impact of advances in medical technology, including genetics. She feels that nurses are showing an increased awareness of the ethical impacts of these advancements. Indeed, Daniels
and Lewis (1996) note that health professionals in New Zealand have called for regulation, or at least clear national guidelines on semen provision, because of growing concerns about difficult ethical decisions related to assisted conceptions. It is to be hoped that one outcome of the response to the consultation paper (Brazier et al., 1997) is that clear guidelines are issued for nurses and midwives working in the relevant field in this country.

Figure 2 Information about donors: current practice (reproduced with permission).

<table>
<thead>
<tr>
<th>Pacific Reproductive Services</th>
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<tr>
<td><strong>Donor Profiles</strong></td>
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<tr>
<td>Pacific Reproductive Services offers clients a higher percentage of willing-to-be-known donors than any other sperm bank. While it is more difficult to recruit these donors, we remain committed to providing our children, upon adulthood, with the option of receiving information about their biological heritage.</td>
</tr>
<tr>
<td>The following are the current donors’ profiles. You may call Pacific Reproductive Services to receive a free donor profile booklet containing more detailed information for each donor. Additional information includes: personality, hobbies, work, education, habits, medical history, family history and blood type. Registered clients can also receive in-depth profiles for each donor at an additional $15 each.</td>
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<thead>
<tr>
<th>Donor Number: (Limited supply)</th>
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<tbody>
<tr>
<td><strong>Willing To Be Known?</strong> No</td>
</tr>
<tr>
<td><strong>Ethnicity:</strong> Swedish/Italian-American</td>
</tr>
<tr>
<td><strong>Height:</strong> 6’1”</td>
</tr>
<tr>
<td><strong>Weight:</strong> 156</td>
</tr>
<tr>
<td><strong>Eyes:</strong> Blue</td>
</tr>
<tr>
<td><strong>Hair:</strong> Blonde</td>
</tr>
<tr>
<td><strong>Build:</strong> Tall and lanky</td>
</tr>
<tr>
<td><strong>Face:</strong> Cute face, striking blue eyes.</td>
</tr>
<tr>
<td><strong>Complexion:</strong> Fair</td>
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<th>Donor Number: (Limited supply)</th>
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<tbody>
<tr>
<td><strong>Willing To Be Known?</strong> Yes</td>
</tr>
<tr>
<td><strong>Ethnicity:</strong> African-American &amp; Caucasian (Irish)</td>
</tr>
<tr>
<td><strong>Height:</strong> 5’6”</td>
</tr>
<tr>
<td><strong>Weight:</strong> 143</td>
</tr>
<tr>
<td><strong>Eyes:</strong> Brown</td>
</tr>
<tr>
<td><strong>Hair:</strong> Reddish-Brown</td>
</tr>
<tr>
<td><strong>Build:</strong> Small build, trim and very muscular</td>
</tr>
<tr>
<td><strong>Face:</strong> Strong jaw, freckled, boyish face</td>
</tr>
<tr>
<td><strong>Complexion:</strong> Light brown</td>
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<table>
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<tr>
<th>Donor Number: (Limited supply)</th>
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<tbody>
<tr>
<td><strong>Willing To Be Known?</strong> No</td>
</tr>
<tr>
<td><strong>Ethnicity:</strong> Swedish/Irish/West European</td>
</tr>
<tr>
<td><strong>Height:</strong> 6’0”</td>
</tr>
<tr>
<td><strong>Weight:</strong> 150</td>
</tr>
<tr>
<td><strong>Eyes:</strong> Brown</td>
</tr>
<tr>
<td><strong>Hair:</strong> Blonde, thick, straight</td>
</tr>
<tr>
<td><strong>Build:</strong> Tall and wiry</td>
</tr>
<tr>
<td><strong>Face:</strong> Attractive, slender, nice eyes, straight nose</td>
</tr>
<tr>
<td><strong>Complexion:</strong> Medium</td>
</tr>
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Conclusions
There is still much uncertainty about the application of new genetic knowledge to clinical practice. When this is considered alongside the area of legal and ethical uncertainty that is offered by the application of ART to surrogacy, an ethical minefield is created.

Bromham (1992) felt that attempts to establish guidelines or laws for the practice of surrogacy resulted in paradox. The rights of the genetic patient are set against the rights of the gestational parent, with any legislative guidelines being unenforceable. Wider access to services via the Internet further confounds the practical application of legislation within national boundaries.

Reproductive decision-making is becoming increasingly more complex; surrogacy arrangements may become increasingly less attractive as a result. A simple preconception contract becomes more of a remote possibility, in reality becoming more inadequate and inappropriate, failing to address the complex physical and emotional situations of all involved and perhaps masking the inequalities between parties with respect to the risks and benefits and this facilitating exploitation. Through all of this, we have to attempt to develop a framework for gestational surrogacy that not only satisfies both ‘parents’ but also is in the child’s best interests, is acceptable to society, and goes some way to addressing the issues that may arise from the application of future technological advances (Figure 3).

Surrogacy, and the genetic issues pertaining to it, need to be debated by society, as well as by scientists, concerned professionals in health and social care, and ethicists. While the opportunity to comment on the consultation document prepared by Professor Brazier and her team is welcome, the author questions what attempts have been made, and what attempts should be made, to canvass public opinion and to facilitate public participation in decision-making on a policy issue of such fundamental importance to society. Finally, it may be worth reflecting on Wilkie’s words (Wilkie, 1994), as he dwelt on the moral implications of the new genetics:

‘... the real world is wider and more complicated, and human relationships are downright messier, than the abstractions contemplated in either laboratory or philosophy seminar.’

Figure 3  Gestational surrogacy
Key points

- Assisted reproductive technologies (ARTs) are widely practised, with access to some services gained via the Internet.
- A recent review and consultation document published in response to concern over surrogacy arrangements failed to address more fundamental questions about surrogacy.
- Clinical genetics research and ART offer powerful choices in reproductive decision-making, but also create ethical dilemmas.
- Issues of ownership and use of genetic information may create problems in surrogacy arrangements, particularly in relation to prenatal testing and eugenics.
- Health professionals need to be aware of the ethical implications of the applications of genetics and technology to assisted reproduction.

Any views expressed by the author are her own and do not necessarily reflect those of the University of Glamorgan.

Thanks are due to Dr Rachel Iredale for her helpful comments on the manuscript.


