Report For
2001 Edith Cowan Western Australian Women's Fellowship

THE ROLE OF INFERTILITY COUNSELLORS AND PSYCHOSOCIAL ISSUES IN FERTILITY TREATMENT CENTRES IN THE UK AND USA

By

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EXECUTIVE SUMMARY

Introduction

This report provides an outline of the study undertaken as part of the 2001 Edith Cowan Western Australian Women's Fellowship, from August to October 2002. The study involved visiting fertility treatment centres in the UK and USA that employed infertility counsellors as integral members of the team; examining the role of support groups in fertility clinics and the selection process of those involved in third party reproduction as well attending the American Society of Reproductive Medicine Conference in Seattle, Washington, USA.

Background

There are approximately 1 in 6 couples in Australia facing infertility and it is usually the women that bear the largest impact of infertility and its treatment. Despite the cause of infertility, it is women who are required to undergo treatment due to the technologies available. Many women report the experience of infertility diagnosis, treatment and outcomes as intensely invasive, isolating and highly stress-inducing with relatively few couples achieving their desired outcome of creating a family. This study examines overseas strategies that could impact positively upon these women's experiences both professionally and systemically, so that they are not left as 'battle scarred' as often indicated.

Main Findings

Where the counsellor is an integral clinic member, more effective and proactive psychosocial support to consumers and staff is provided. In addition, the informal availability normalizes access to counselling and contributes to the longer-term adjustment of consumers who face infertility treatment.

The importance of collecting more comprehensive information on donors in order to assist recipients in donor selection, as well as the availability of more detailed personal and health information for future donor offspring.

Surrogacy is the only option available for some women/couples who want a family. Selection, preparation and appropriate matching of surrogates with intending parents is essential for the welfare of the child, as is a legal structure which allows for transferring of parentage to intending parents, and the protection of surrogates is imperative in the longer adjustment of all parties concerned.

SUMMARY OF FINDINGS

ISSUE	USA	UK	WA
1. Service Provision by infertility counsellors	Employed as a permanent member by the clinic; available formally and informally	Employed as a permanent member by the clinic; available formally and informally	Employed on a sessional basis by the clinic; available formally only
2. Screening of Egg Donors using psychological testing	Psychological testing and clinical interviews are used	Clinical interviews only	Clinical interviews only. In cases of known donation then counselling of all parties is mandatory as well as 6 month cooling off period.
3. Best Interests of the Child	Primary focus is on the adults. However, some clinics are beginning to address the needs of potential children.	Primary focus is on the welfare of the child, underpinned by legislation. GPs are specifically consulted by the IVF specialist.	Primary focus, is both on the welfare of the parents and the child, underpinned by legislation. The treating specialist has ultimate authority to grant treatment.
4. Egg Donors - payment	Egg donor are paid	Egg donors are reimbursed for expenses	Egg donors are reimbursed for expenses
5. Sperm Donors - payment	Paid; choice about being identified or anonymous	Reimbursed for expenses; anonymous donation only (except in cases of known donation)	Reimbursed for expenses; anonymous donation only (except in cases of known donation)
6. Donor Information	Recipients can choose to have a donor who has agreed to be identified. ******************** Comprehensive history of donor is available to recipients even if donor is anonymous; photos can also be provided.	Only anonymous donation is permitted unless the donor is already known to the recipients ******************** Donor information is not very comprehensive.	Only anonymous donation is permitted unless the recipients already know the donor. ******************** Donor information is not very comprehensive.
7. Surrogacy	Commercial surrogacy permitted with legally binding contracts.	Altruistic surrogacy possible, but commissioning parents must provide surrogate. Commercial surrogacy possible but discouraged.	IVF surrogacy not permitted, unless consumers go interstate or overseas.
8. Self-Help Groups/Support Groups	Offered on ongoing basis by the counsellor as an essential part of clinic support for consumers. Mandatory attendance for surrogates. Seen as important in the decision making process for consumers. National self-help groups with local chapters offer educational sessions and psycho- therapeutic groups.	Psychotherapeutic groups conducted by counsellor in the clinic (as need identified); Infertility nurses offer ongoing support groups in the clinic. Self-help groups operate throughout the country with particular focus eg Pink Parenting for gay and lesbian parents who use ART.	Self help groups are available in the community. Clinic support groups are not offered on ongoing basis.
9. Options for Consumers	Little regulation; greater number of options provided consumers have financial means; such as surrogacy or adoption	Highly regulated; However, consumers have greater options available outside the UK due to geographic proximity to other countries.	Highly regulated; consumers have less options due to geographic isolation and cost and little access to alternative forms of family formation such as adoption.

Policy Implications and Recommendations

As a result of this fellowship, there are 3 major areas that I would recommend being reviewed in Western Australia, these include:

1. A review of the current situation in relation to surrogacy, with a view to consideration being given to legislative change in WA. This should enable access to Assisted Reproductive Technology (ART) treatment for surrogacy and provisions for transferring parentage to commissioning parents as well as legal protection for the surrogates.
2. That the WA Reproductive Technology Council seek to review the quality and quantity of donor information currently being collected in WA in order to meet the needs of recipient parents and potential donor offspring.
3. That the WA Reproductive Technology Council encourage the Fertility Treatment Centres to review their employment practice of infertility counsellors with a view to employing them as integral members of staff.

This report and recommendations will be sent to the WA Reproductive Technology Council (Council). The Council has responsibility for the implementation of *the Human Reproductive Technology Act 1991* (HRT Act) and its subsidiary legislation. In 1999 the Select Parliamentary Committee report of its review of the HRT Act made a number of recommendations. One of these was that legislation be drafted to provide for surrogacy arrangements and to clarify the legal status of surrogate children and their commissioning parents as a matter of urgency.

Research Proposal

I have 18 years experience working with the psychosocial aspects of reproductive health. I have been involved in the area of Assisted Reproductive Technology (ART) firstly as an infertility counsellor since 1993 and as the women's interest representative on the WA Reproductive Technology Council since 1997. I have observed and learnt of many of the experiences from women who have pursued ART treatment.

For many who had not achieved their goal of a baby, and at times even when they had, their resounding message was 'had I known what it was going to be like I may never have chosen to undergo the treatment'. Words women used to describe their experiences included 'abusive', 'discarded as damaged goods', a sense of 'abandonment' [from the fertility clinic] and essentially having emerged 'scarred' and at times 'embittered' by the experience.

Many of the women to whom I listened suggested they had little preparation for what they were about to embark on before entering treatment. Although they had been given information this did not match their experience. Hearing these many stories left me wondering how I could positively impact upon these women's experiences both professionally and systemically so that they were not left 'battle scarred'.

I believed that if couples could be made more aware of what was involved and therefore be more prepared intellectually, psychologically and emotionally that they could make better decisions for themselves. I thought that if counselling and peer support were part of the psychosocial preparation for entering treatment then this would assist in the longer-term adjustment of couples following assisted conception treatment regardless of the outcome. My goal for the Fellowship was to visit fertility centres in the USA and UK where they had successfully integrated the role of the professional counsellor and peer support.

Background

There are approximately 1 in 6 couples in Australia facing infertility and it is usually the women that bear the largest impact of infertility and its treatment [1,2]. Medical practitioners define infertility as the inability to conceive following 12 months of regular unprotected sexual intercourse for those aged less than 35 years and 6 months for those aged over 35 years. The causes of infertility vary and can include problems with the production of sperm or eggs, with the Fallopian tubes or the uterus, frequent miscarriage, as well as hormonal disorders in both men and women. It is estimated that in about 40% of infertile couples, the problem is a male factor, in about 40% it is a female one, and for the remaining 20% it is a joint problem, or the cause is unknown.

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[1] ACCESS fact sheet (1999) states "*… one in six couples of reproductive age in Australia face infertility.*"

[2] 2.Dill, Sandra - Consumer Perspectives (1999) states "*between 13% and 24% of couples who would like to have a child but are not able to, it can be a very painful experience and one difficult to manage.*"

Those women who are not able to fall pregnant or have a history of miscarriage seek Invitro Fertilisation (IVF) treatment. IVF became available in WA in the 1980s following the birth of the world's first IVF child in the UK in 1978 and the world's fourth baby being born in Melbourne in 1980. Prior to that donor insemination was practiced in cases of male factor infertility. IVF treatment in WA is only available to women of reproductive age and not if they are infertile due to age, that is a menopausal woman. In the year 2000 the average age of women in WA who commenced IVF treatment was 34.9 years and the age range spanned from 20 to 50 years of age [3].

In WA, prior to IVF being available, couples were limited to either adopting a child or being involuntarily childless. With the numbers of babies being placed for adoption being extremely low, for example 4 local babies in 2002, this is no longer a real option for couples.

Despite the cause of infertility, women are the ones who are required to undergo treatment due to the technologies available. The process of IVF involves taking eggs from the woman's body, fertilising them with the sperm in a laboratory and then replaced into the woman's for development. The treatment involves taking fertility drugs (with their various side effects), regular blood tests, anaesthetics, ultrasounds or laparoscopies and injections all coupled with regular visits to the clinic. Then if no pregnancy results they need to make the decision of whether to do it all again as well as facing the grief of not achieving a pregnancy or facing a miscarriage.

Many women report the experience of infertility diagnosis, treatment and outcomes as intensely invasive, isolating and highly stress-inducing with relatively few couples achieving their desired outcome of creating a family. Often women report feeling disempowered, out of control and rejected if they are not a successful statistic[4]. Furthermore on reflection it seemed that women in their pursuit of creating a family often found themselves undergoing treatment without a clear sense of decision making. Offering counselling in clinics is required within the provisions of the licensing of clinics however, relatively small numbers of women or couples facing infertility access any form of counselling or support. This seems to be due to women's own perception that accessing any form of support is a negative reflection on their capacity to cope coupled with their fear of being refused treatment if they take up counselling.

The WA Reproductive Technology Council conducted an audit on counselling in 2001 as recommended by the 1999 report by the Parliamentary Select Committee reviewing the *Human Reproductive Technology Act 1991.* A response rate of 36.3% was recorded. There were 98 female respondents and 4 males.

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[3] Reproductive Technology Council of WA – figures collected from data

[4] ACCESS fact sheet ('Emotional facts' Kay Oke ed., from Taking Charge of Your Infertility, Melbourne IVF, 1999) states "*Some people find their self-esteem is battered by the loss of a sense of control, the unfamiliar experience of failure, the loss of privacy and loss of an overall sense of personal mastery.*"

The audit ascertained that:

- 75 of the 105 respondents had accessed counselling, of which three-quarters had *only one* session of counselling through the clinic; and
- approximately 30% of respondents were unaware of the service; or were unaware that counselling was paid for in the overall fee or were unable to utilise services at the times it was available[5].

In terms of recommended changes, 51 respondents wanted the clinic to promote the importance of counselling.

I therefore noted that if counselling and psychosocial support were offered as routine practice in clinics, women would feel less stigma and would be more willing to access counseling at various critical times throughout their treatment. Consequently I was interested to visit clinics where the infertility counsellor and peer supports were an essential part of the preparation and ongoing support for those accessing fertility treatment.

Methodology

The following table shows the UK and USA organisations/Infertility Counsellors selected for the study and the reason for selection. For further information pertaining to the individuals contacted and their role within their respective organisation, see Appendix 6.

Organisation	**Specialty/Reason for Selection**
UK	
St Mary's Hospital, Manchester	• First Major public clinic in UK. Established 1982 • Support groups conducted by Infertility Nurses. Psycho-therapeutic groups run quarterly by Infertility Counsellor
Dept Social Policy & Social Work, University of York	• Founding member of British Infertility Counsellors Association (BICA) • Extensive Infertility Counselling experience • Reviewing "Issues in Donor Anonymity in UK"
Linda Greenaway, Brighton, West Sussex	• Independent Infertility and Surrogacy Counsellor • Surrogacy assessment
Hammersmith Hospital, London	• Counselling available for all issues during treatment and for following 12 months • Chair of Social/Ethical Dilemmas committee for clinic • Developing guidelines for those approaching register for information in 2007
Homerton Hospital, East London	• Consensus Team Decision Making model
Bourn Hall Clinic, Cambridge	• Surrogate assessment • World's First IVF baby born at Bourn Hall
USA	
Pennsylvania Reproductive Associates Institute for Fertility	• Psycho-educational session for all IVF patients • Conducts support groups for egg donor recipients/egg donors
The Sperm Bank of California (TSBC) Berkeley, California	• Specialising in Identity Release Donors • Preparing offspring for receiving information on donor identity

[5] Audit of counselling services for people undergoing treatment for infertility - WA Reproductive Technology Council 2001

Donor Egg Recipients & Donors San Francisco, California	• Psychological testing for Egg Donors • Clinical Interviews • Experience in 'Telling Issues' with donor offspring
Centre for Surrogate Parenting (CSP), Los Angeles	• 20 years experience in surrogacy • Commissioning parent selection and matching surrogates • Supervises other counsellors
Elaine R Gordon (CSP), LA	• Conducts Surrogate Support Group meetings • One to One support for surrogates
RESOLVE Support Group, LA	• Psychotherapeutic groups for Infertile couples
Surrogate Parenting Services, Orange County, California	• Conducts Surrogate Support Group meetings • One to One support for surrogates
American Society of Reproductive Medicine (ASRM), Seattle, Washington	• Male & Female Sexual Dysfunction - What Every Practitioner Needs to Know: State of the Art Treatment Approaches by Sheryl Kingsberg PhD & Bill Petok PhD
American Society of Reproductive Medicine (ASRM)	• Conference Proceedings, "Health, Hope & Humanity in a Brave New World", Seattle, Washington (see Appendix 3)

Each of the above organisations/Infertility Counsellors were asked to respond to a structured set of questions. These questions are included in Appendix 5.

GOALS OF THE STUDY

1. ***How best to integrate and promote counselling services and self-help support for those diagnosed with infertility or needing to access Assisted Reproductive Technology in a manner that is perceived as facilitative and supportive rather than as threatening.***

The fertility treatment centres I visited in the USA and UK the mental health professional/infertility counsellor was an integral part of the team. This applied to both private and public clinics. It was openly acknowledged that the psychosocial functioning of those seeking treatment was integral to their capacity to cope with this extremely invasive and demanding treatment. There was a commitment and provision made by the centres to include the infertility counsellor as part of the team.

In all clinics the counsellor was always seen on at least one occasion by all patients seeking treatment for assisted conception. As the counsellor was part of the team they were able to follow up with patients following a failed cycle or miscarriage. This model of practice normalised the contact with the counsellor and conveyed to the patient that engaging in ART treatment was highly stressful and that accessing some form of support was acceptable and in fact health promoting. Counsellors were employed as a regular staff member and had the opportunity to not only be available to clients on a more informal basis but to offer support to staff as well who also had to deal with the constant cycle of grief and loss.

The Hammersmith Clinic in London practiced a model that I thought particularly worthwhile. Clients were able to access counselling on any matters impacting

their lives while they were undergoing ART treatment. Furthermore, this service was available for up to 12 months post treatment. The infertility counsellor at this clinic also fulfilled the role of coordinating and chairing the ethical and social dilemmas meeting on a 6 weekly basis. This provided a forum for clinical, nursing, administration, embryology and counselling staff to explore their views and to reflect on their practice in this complex and evolving technology.

Self Help/Support Groups

The use of support groups varied across clinics I visited. In the UK some fertility clinics offered ongoing support groups and at one particular centre the infertility nurses conducted ongoing groups while the counsellor offered psychotherapeutic groups several times throughout the year.

There were national self-help groups in the UK such as ISSUE, CHILD, PINK PARENTING, and ACE BABIES, which offered support groups in various geographic locations throughout the country. The ISSUE self-help group also offered a national telephone advice line staffed by a trained nurse and evening telephone counselling service.

In the USA, the infertility counsellor conducted ongoing support groups at the Philadelphia clinics as an integral part of the treatment for those engaged in third party reproduction such as recipients of egg donation. One group I attended included people attending for the first time and those who attended regularly throughout their treatment. The consensus from the group members was that this was such an important source of support as most family, friends and even partners (who were not present) were not able to understand their unique experiences, fears and anxieties.

The Los Angeles chapter of the national support group RESOLVE offered ongoing therapeutic groups via the services of a very experienced infertility counsellor. These were closed groups that met weekly for a designated number of weeks throughout the year. The counsellor I met with had conducted these groups for many years and had noticed that with the advent of the Internet there seemed to be less demand for these groups. In the surrogacy program ongoing support groups were mandatory for surrogates to attend and were seen as pivotal to their longer-term adjustment.

Conclusion

As ascertained overseas, where counsellors are employed on a permanent full time or part time basis, this model of practice has enabled the counsellor to provide more effective psychosocial support to consumers and staff. Having counsellors available informally has normalized access to their services. Counsellors have also been able to be proactive in addressing psychosocial issues for consumers and for staff.

Clinics in WA are required to offer counselling by an approved counsellor within the provisions of the *Human Reproductive Technology Act 1991 a*s part of their

licence to operate as an infertility treatment centre. However, there is no guidance on how this should be carried out. Currently in WA approved counsellors are employed as sessional staff at clinics, which limits their involvement with the clients, and the clinic staff.

In WA support groups are conducted by self help groups and are not part of the role provided by counsellors within the clinics.

Recommendation: To assist health professionals and fertility centres with the positive integration and promotion of psychosocial supports for women through the employment of infertility counsellors as integral members of the clinic.

2. ***To develop 'Best Practice' Psychosocial Guidelines which will assist Infertility Counsellors working with women and couples. These could be incorporated in the direction and guidelines for Infertility Counsellors approved under the WA Human Reproductive Technology Act.***

As a result of my overseas study I have observed and collected information about procedures and issues that can enhance infertility counsellors work with consumers of assisted reproductive technology. These are addressed in the sections under surrogates, egg donors and sperm donors as well as in Appendix 3 reporting on the ASRM conference proceedings.

In my new role as Executive Officer for the WA Reproductive Technology Council I have been coordinating the development of best practice psychosocial guidelines for approved counsellors utilizing some of the material I gathered overseas. This material is being incorporated into a resource to equip counsellors working in this field. As well as psychosocial guidelines, it will include the various state and national legislative requirements relevant to the field of assisted reproductive technology.

Recommendation: To provide Approved Counsellors with a resource of psychosocial guidelines and relevant legislative requirements.

COMPARATIVE ANALYSIS

Counsellors in fertility treatment centres operated as an integral part of the clinic team and consequently were available formally and informally for patients and staff. However, the extent of support available in some clinics during and for up to 12 months after treatment was unexpected.

There were variations in the provision of support groups. In clinics that offered third party reproduction such as donor egg, and donor embryo, the support groups were seen as important in the decision making process and in the support they provided to patients. Many consumers commented that they were able to

discuss their concerns more intimately with each other than they could with family or friends. I had expected to find support groups to be conducted by counsellors only. However, in several clinics the infertility nurses who came to know the patients very closely also conducted ongoing support groups while counsellors in these clinics conducted psychotherapeutic groups.

As counsellors were employed on a permanent basis they were able to provide valuable staff training, conduct research on the psychosocial aspects of treatment and report on findings at conferences. Generally I observed more of a collaborative approach between the multi-disciplinary team members as they worked alongside each other.

In the UK as in Western Australia there is legislation that regulates the provision of ART treatment with the welfare of the child being a primary consideration. However, in the UK, the GP of those seeking fertility treatment is asked to comment on whether *there is any reason that the couple should not be able to access ART treatment.* This mechanism is designed to fill any gaps in information especially in relation to the welfare of future offspring. This is not the practice in Australia and I am aware there can be a lack of history on a couple especially in relation to any past parenting.

SIMILARITIES AND DIFFERENCES TO WESTERN AUSTRALIA

The similarities between the situation in WA and overseas includes the professional isolation of infertility counsellors, and a relative difficulty in accessing professional training in this area of work. However, there is more psycho-social research taking place at the university level. In the UK there is a process of accreditation under way in order to gain greater credibility for infertility counsellors but it seems both expensive and onerous to undertake.

From the consumer perspective in the USA and UK there is greater opportunity for fertility treatment tourism, so that consumers have more choice in terms of treatment options. Furthermore, adoption of babies is a real option for the infertile in the USA and UK, which is not the case in Australia. As assisted conception in WA is heavily regulated consumers can feel less empowered and less in control of their choices. In the USA especially it is more culturally acceptable to access counselling and clinics actively promote this.

In the USA all the treatment is conducted privately and consumers require private health insurance, otherwise the cost of ART treatment is prohibitive for the majority of people. In the UK inequities exist in accessing ART treatment depending on geographic location, which is referred to as the “postcode lottery”. Each local health authority decides how much funding is allocated to infertility treatment. As there is a 3-year wait for ART treatment in the public health system, seventy five percent (75%) of treatment takes place in the private system in the UK. In Australia although the majority of treatment is conducted through private clinics rebates are available for aspects of treatment through Medicare. However, consumers do require private health insurance to meet the costs of treatment.

There is limited availability of public patient treatment in Australia and there is a considerable waiting period involved which varies across the country.

Surrogacy
IVF surrogacy is readily available both in the UK and USA while this is not the case in Australia even though there is increasing pressure being brought to bear. At present in Australia, IVF surrogacy is available in the ACT and NSW if the intending parents are able to provide their own surrogate.

The lack of legal framework for transferring parentage in surrogacy arrangements has contributed to many problems for families in Australia. In the UK, IVF Surrogacy is available on a limited basis through the public health system to women with particular health considerations such as having had an hysterectomy; those born without a uterus; those with serious illnesses and multiple pregnancy losses. Furthermore the intending parents must provide their own surrogate.

Generally practices vary widely across clinics in the UK even though more clinics are getting involved in IVF surrogacy. There are also commercial surrogacy enterprises in the UK that locate surrogates for intending parents. Two of the counsellors involved in surrogacy programs I had contact with in the UK both conducted assessment visits with the intended parents and the surrogate in their own homes and factored in a minimum 3 month waiting period after the initial assessment. In cases of traditional surrogacy arrangements this waiting period is more difficult to impose. In the UK and in the USA, the intending parents meet the cost of counselling.

The Los Angeles based surrogacy centre offered a very comprehensive model of operation. The centre has been in existence for some 20 years. Screening & support of surrogates is seen as an ongoing process and psychological testing is performed on surrogates and egg donors. Even though there are formalised assessment and screening procedures once surrogates are matched with the intending parents attending monthly support groups is mandatory.

Another source of screening and support occurs by the centre in employing two peer counsellors, one of whom liaises with the intending parents and was herself a commissioning parent and the other liaises with the surrogates and herself has been a surrogate on two occasions.

All surrogates are required to have at least one child before being considered for the program. In both programs I visited separate legal representation and contracts for the intending parents and surrogates are pivotal to the success of the arrangements. Contact between couples is encouraged throughout the pregnancy and one centre even specified weekly contact.
The idea of “matching” intended parents with surrogates was seen as vital to the long-term adjustment for the surrogate. Even though the surrogate received payment, some form of concrete and meaningful acknowledgment by the

intended parents once the baby was handed over was considered extremely personally significant for the surrogate. Some form of ongoing contact between the couples was also highly desirable and an important issue in the matching stage. However, contact was not always possible as many intending parents were from out of state or other countries such as Australia. After the birth of more than 900 babies there have been 3 'unsuccessful' arrangements in total. This is where the intended parents did not take the child for various reasons. I thought that this was a remarkable outcome for such a program.

Egg Donors/Recipients

Prospective egg donors undergo psychological testing and interviews as part of the selection in the USA. This is not the case in WA. The clinical interview follows the testing and provides the counsellor the opportunity to pursue particular issues highlighted in the testing. The psychological testing is performed as an objective measurement, which is perceived to offer some protection against medico-legal litigation. Counsellors stated that it is easier to reject unsuitable donors using an objective measurement.

Blood group matching is also offered to recipients based on their intention of whether they will disclose the facts about their conception to their children. This is not practiced in Australia and would be actively discouraged as generally the rights of offspring to know their true biological heritage is safeguarded in various ways. For instance in WA one of the reasons that the Reproductive Technology Register were established 1993 was as a source of information for future offspring.

At one clinic in the USA I noted that recipients aged in their late 40's were advised that multiple births at their age would be an indication to others that they had received donor eggs. Therefore they would need to be prepared to deal with this should they not wish to disclose this information to others. Whether the donor was anonymous or known the recipients had access to a detailed history of the donor and sometimes even a photograph. In Australia the information available on anonymous donors is very limited and would certainly not involve a photo.

As in Australia, consumers of ART were asked to consider the issues of multiple births, selective pregnancy reduction and the future of surplus embryos after the completion of their family. However, I noted that consumers had the opportunity to reflect on this before starting treatment with both the counsellor and the infertility nurse. I thought that this was a particularly useful strategy otherwise these important issues can get lost in the flood of new information with which consumers are confronted.

Unlike the situation in Australia donors are paid and the amount varies with the centres and whether they have donated before. In lesbian couples, known donation can occur from the fertile partner to the infertile partner who wants to carry the child. I am not aware of this practice in Australia. In all cases of

donation whether altruistic or paid there seemed to be agreement amongst the infertility counsellors in the USA that it is important for the egg donors to be held in high regard by the recipients whether known or anonymous. It was important for the donors to be acknowledged by the recipients in some meaningful concrete way. I am not aware that this practice is observed in Australia.

Sperm Donors

Having visited The Sperm Bank of California (TSBC) I was impressed with the comprehensive health information gathered from sperm donors together with the high level of commitment demanded. This criterion was developed by TSBC and not subject to legislative requirements. They allowed sperm donors to decide whether they wanted to be an identity-release donor or not. Identity-release donors are willing to become known to the recipients or offspring. To date 70% were identity-release donors and 80% of recipients wanted identity-release donors. Each donor was permitted to donate up to 10 families and up to 5 families in each state. There had been a total of 1200 births since 1982. There were 800 families and 10% were on the family contact list. To date 25 families out of 90 had matched with other families who had used the same donor.

TSBC was conducting focus groups to prepare donors, recipients and offspring for the identity-release program. TSBC also kept in close contact with donors and constantly updated the personal details database. Payment was made for donation and used as leverage for compliance to the program. For example 6 months after their last sperm donation, the donor received a $200 exit bonus if they completed the exit blood test requirement. TSBC is showing forethought and leadership in terms of considering the future needs of offspring.

There is a great deal that can be done in WA to ensure better preparation of sperm donors in meeting the information and contact needs of future offspring and recipients. The launch of the WA Voluntary Register (Information about Donation in Assisted Reproduction) in November 2002 by the WA Department of Health was certainly a step in the right direction.

POLICY IMPLICATIONS AND RECOMMENDATIONS

As a result of this fellowship I have identified three areas that I would recommend being reviewed in WA. These include:

- reviewing the current situation in relation to policy development in surrogacy;
- reviewing the data collected on donor information with a view to making it more comprehensive in order to assist recipients in selecting a donor and also to meet the needs of future offspring;
- reviewing fertility treatment clinics' employment practices of infertility counsellors with a view to including them as integral team members.

1. Surrogacy

Surrogacy is taking place in WA without a legal framework. Currently, IVF surrogacy is prohibited in WA. In March 1991, Australia's Health and Social Welfare ministers agreed to support uniform legislation to control surrogate motherhood. However, since then, 5 States have established surrogacy legislation each with a different perspective. In WA legal parentage remains unresolved with the child legally belonging to the birth parents while being raised by the commissioning parents who have either provided both the egg and sperm or just the sperm. In 1999 the WA Parliamentary Select Committee on the *Human Reproductive Technology Act 1991* included surrogacy as one of their terms of reference. The Committee made seven recommendations in relation to surrogacy, which were supported by Cabinet.

There are cases of women and couples in WA and Australia for whom surrogacy remains the only option for creating their own biological family. Couples can only access IVF surrogacy in the ACT and NSW if they have their own surrogate or commercially in the USA if they have the financial means. Some Australians are accessing surrogacy services overseas. These overseas services support the case for women to access surrogacy in their own country as they recognise the cost and the travel are extra burdens these couples have to confront. Some of these women have been born without a uterus; or have difficulty achieving or maintaining a pregnancy; or have required a hysterectomy some while undergoing Assisted Reproductive Treatment (ART) treatment and have embryos in storage (whom they consider as their children). These women's only hope of using these embryos is through a surrogacy arrangement.

Recommendation

I support the review of the current surrogacy situation with a view to legislative changes in WA. This would enable access to ART treatment for surrogacy and provisions for transferring parentage to commissioning parents as well as legal protection for the surrogates.

2.Donor Information

(a) Recipient Perspective

There is a need for the collection of more comprehensive information on donors to assist recipients in donor selection as well as more detailed personal and health information for future donor offspring.

In WA recipients are expected to select donors in the process of hoping to create their own families from very scant donor information. In the Pennsylvania and California clinics that I visited the collection of personal and health information is very comprehensive and it is made available to the prospective recipients. One particular sperm bank collects a four-generation health history on its potential donors. In WA recipients are finding the task of donor selection quite overwhelming when they are given so little information upon which to base their selection.

2.Donor Information
(b) Offspring Perspective

There has been much discussion in recent times about the rights of offspring to access information about their genetic heritage and conflicting tensions between rights of parents, donors and offspring. However, the WA Parliamentary Select Committee in their report tabled in 1999 recommended that offspring be able to access identifying information about their donor once they reached 16. My concern relates to how much meaningful information will be available for offspring once they can access information from the register? As parents are being encouraged towards openness and telling children about their conception the system needs to support them in making available the necessary resources to meet the needs of their children.

Recommendation
I recommend that WA Reproductive Technology Council seek to review the quality and quantity of donor information currently being collected in WA in order to better meet the needs of recipient parents and potential donor offspring.

3. Employment of Infertility Counsellors as integral members of Fertility Treatment Centres.

In WA currently infertility counsellors are employed on a sessional basis. This practice limits their availability to patients and to the professional staff. As an integral member of the fertility treatment centre the counsellor could contribute to the greater acceptance and normalisation of the psychosocial impact of ART treatment; provide greater access to a counsellor by both consumers and staff; provide increased follow up of consumers; provide leadership in psychosocial and ethical issues at clinical meetings, and provide greater visibility of the counsellor as a member of the multidisciplinary team.

Recommendation
I recommend that the WA Reproductive Technology Council encourage the Fertility Treatment Centres to review their employment practice of infertility counsellors with a view to employing them as integral members of staff.

This report and recommendations will be sent to the WA Reproductive Technology Council (Council). The Council has already supported action on recommendations

two and three.
In terms of recommendation one to review the current situation in relation to policy development in surrogacy the Council may wish to consider following this up with the Commissioner for Health and the Minister for Health. As the Parliamentary Select Committee's report was tabled in the Legislative Assembly in April 1999 and made seven recommendations in relation to surrogacy. In November 1999, Cabinet approved the start of policy development to inform the subsequent development of legislation regulating surrogacy. Cabinet supported the recommendations of the Parliamentary Select Committee, and approved policy development. In 2000 a policy officer was appointed with a view to developing a policy on surrogacy.

OVERALL CONCLUSION

What Has Happened Since The Fellowship?

On my return to WA I had anticipated being able to influence policy and decision-making through the various roles I held. These included being the women's interest representative on the WA Reproductive Technology Council (RTC); member of the RTC Counselling Committee; approved counsellor employed by a private fertility clinic; trainer/educator of health professionals; member of the professional infertility counsellors' organisation, ANZICA, and as a member of the WA Approved Infertility Counsellors group.

However, in February 2003, within two months of my return to Perth I was offered a short-term contract as Senior Policy Officer/Executive Officer of the RTC until the job was advertised. Subsequently I was successful in gaining a 2-year contract. This fellowship contributed significantly in having the confidence to undertake this challenging position. This position has enabled me to more directly achieve the goals I had set as part of the fellowship. Furthermore, while in this position I have received regular requests from consumers regarding the availability of surrogacy in WA. Some of these women have been aware of the recommendations for surrogacy made by Parliamentary Select Committee in their report tabled in Parliament in April 1999. In terms of the other two recommendations, I have been able to progress these in my role.

The fellowship has provided a very worthwhile mechanism to review and compare practices in addressing psychosocial issues in ART treatment between WA and the countries visited. It has enabled me to develop contacts with colleagues internationally, which has served to better meet the needs of WA consumers. On a professional level it has provided an opportunity for me to contribute more directly in this very specialist and highly contentious area of reproductive technology with its challenging psychosocial, ethical and moral dilemmas. I anticipate that the findings from the study will continue to impact positively in the field well into the future.

APPENDIX 1: GLOSSARY OF TERMS

ANZICA - Australian and New Zealand Infertility Counsellors Association - professional organisation recognised by infertility licensing authorities. Infertility counsellors are required to be eligible for membership of ANZICA.

Approved Counsellor - Approved Counsellors who assist people seeking infertility treatment need to have a knowledge and understanding of the complex issues involved. For this reason the Western Australian Reproductive Technology Council recognises some counsellors as 'Approved Counsellors' under the *Human Reproductive Technology Act 1991* (Act). In Western Australia all fertility clinics are licensed under the Act, and must provide access to counselling to all people undergoing IVF treatment, with some counselling being provided at no extra cost in the overall treatment fee. There is currently an entitlement to counselling at the rate of one hour per IVF treatment cycle, plus one additional hour when the decision is made to withdraw from further IVF treatment.

Assisted Reproductive Technology (ART) - Several procedures employed to bring about conception without sexual intercourse, including IUI, IVF and GIFT.

Artificial Insemination (AI) - Placing sperm into the vagina, uterus or fallopian tubes through artificial means instead of by coitus - usually injected through a catheter or cannula after being washed. This procedure is used for both donor (AID) and husband's (AIH) sperm. This technique is used to overcome sexual performance problems, to circumvent sperm-mucus interaction problems, to maximize the potential for poor semen, and for using donor sperm.

Best Interests of the Child/Welfare of the Child - Increasingly the impact of ART treatments are being considered from the perspective of those being created from the outcome of treatment. Greater consideration is being placed on minimising the negative consequences including physical, social, psychological, ethical/moral.

Best Practice Guidelines - a set of guidelines developed to assist professionals in their practice. These have been developed from the accumulated wisdom of professional practitioners in a particular discipline such as infertility counselling.

Donor Egg - Eggs donated by one woman to another.

Donor Insemination - Artificial insemination with donor sperm. See Artificial Insemination, Intrauterine Insemination

Donor Insemination is the procedure whereby semen from a donor is inserted into a woman's cervix/uterus with the intention of her becoming pregnant. The treatment has been used for many years and has a high success rate up to 8.5% per month and 40% over a six month course of treatment.

Approximately one in 25 males are unable to father children. Indications for D.I. include the male partner:

i) being azoospermic (no sperm at all);
ii) very oligospermic (very few sperm);
iii) having hereditary disorders

Egg (Oocyte) - The female reproductive cell.

Egg Donation - The act of donating eggs to someone else for use in attempting pregnancy through in vitro fertilization.

Egg Donor - A women who contracts to donate eggs to an infertile couple for in vitro fertilization.

Egg Retrieval - A procedure used to obtain eggs from ovarian follicles for use in several ARTs including in vitro fertilization, GIFT, and ZIFT. The procedure may be performed during laparoscopy or by using a long needle and ultrasound to locate the follicle in the ovary.

Embryo Disposition – Following IVF treatment couples can end up with excess embryos and they need to decide what to do with these embryos. The options available 1) to maintain frozen embryos for future use by the couple; 2) to discard the remaining embryos; 3) to donate embryos for research purposes; or 4) to donate embryos to infertile couples either anonymously or to known recipients identified by the donors.

Embryo Transfer (ET) - Placing an egg fertilized outside the womb into a woman's uterus or fallopian tube.

Fertility Treatment - Any method or procedure used to enhance fertility or increase the likelihood of pregnancy, such as ovulation induction treatment and microsurgery to repair damaged fallopian tubes. The goal of fertility treatment is to help couples have a child.

Fertilization - The combining of the genetic material carried by sperm and egg to create an embryo. Normally occurs inside the fallopian tube (in vivo) but may also occur in a petri dish (in vitro).

Frozen Embryo Transfer (FET) - A procedure where frozen embryos are thawed and then placed into the uterus.

Gamete - A reproductive cell: Sperm in men, the egg in women.

Gamete Intra Fallopian Transfer (Gift) is a modification of the classic IVF technique where, instead of fertilisation occurring in the laboratory, it occurs within the fallopian tube, the normal site of fertilisation. Only women who have at least one normal fallopian tube can be considered for treatment by GIFT since the fertilisation takes place in the tubes. There must also be a sufficient number of normal, healthy sperm to allow this method to be used.
The aim is to place two, or in some instances three eggs and a prepared sample of sperm into the fallopian tubes, allowing fertilisation to occur naturally. As conception occurs within the body there are fewer objections on religious or moral grounds as compared to the IVF programme.

Gestational Host/Carrier - A woman who contracts to carry a pregnancy for someone else. The host is not the biological mother of the baby being carried. See Surrogacy

Infertility (IF) - Infertility is defined as unable to conceive following 12 months of regular unprotected sexual intercourse for those less than 35 years and 6 months for those over 35 years. Or the inability to carry a pregnancy to term.

In Vitro Fertilization - Literally means "in glass." Fertilization takes place outside the body in a small glass dish. See appendix 2 on IVF Procedures.

Insemination refers to the placement of semen into the cervix or uterus in an attempt to achieve pregnancy, using semen from the male partner or from a donor.

Intrauterine insemination (IUI) is intended to give sperm better access to the egg following ovulation. It is often recommended when a male factor is identified as a cause of infertility. If ovulation problems are also a factor for the couple, or if the couple has unexplained infertility, IUI may be combined with ovulation induction to achieve pregnancy.

Ovary - The female gonad; produces eggs and female hormones.

Ovulation - The release of the egg (ovum) from the ovarian follicle.

Ovulation Induction - Medical treatment performed to initiate ovulation.

Psycho-social – psychological and social factors that can affect individuals. In the context of infertility issues includes reproductive health history (eg infertility, pregnancies, abortions), sexual history, relationship history (marital, family, social supports), stressors, and loss and grief issues.

Selective Reduction/Foetal Reduction - When a multiple pregnancy is diagnosed, and particularly that of triplets or more, the doctor may suggest that the patient considers a foetal reduction (also called selective or embryo reduction). This entails the reduction of one or more embryos in the early weeks of pregnancy and the procedure is done in order to give the remaining embryo(s) a better chance to develop into healthy babies

Sperm - The microscopic cell that carries the male's genetic information to the female's egg; the male reproductive cell; the male gamete.

Sperm Bank - A place where sperm are kept frozen in liquid nitrogen for later use in artificial insemination.

Surrogacy Arrangement - involves the:

Birth mother: the woman who will carry and give birth to the child

Birth father: the husband of the birth mother

Commissioning/intending parents: the persons who intend to bring up the child born to the birth mother.

Surrogacy/Altruistic - in this arrangement the surrogate is not paid but may be recompensed for agreed upon expenses by the intending parents.

Surrogacy/Commercial - in this arrangement the surrogate is paid by the intending/commissioning parents to carry a baby to term for them.

Surrogate - A woman who agrees to become pregnant (for instance using artificially insemination or an IVF procedure) and carries to term a baby for another person or couple. This term may be used for a woman who is the biological mother of the baby she is carrying, or for a woman who carries a foetus that is not genetically hers.

Telling Issues/Telling Children About Their Method Of Conception.
Most parents of a child conceived by Donor Insemination or In Vitro Fertilisation have, at some stage, wondered whether or not to tell their child of his or her means of conception.
It is a complex and sensitive issue and touches on feelings about infertility and the emotional pain associated with it. It is also connected to whether or not you have told others about how your child was conceived.

Termination - The ending of a pregnancy by choice by induced labour (resulting in a live birth or stillbirth) or abortion.

Third Party Reproduction - Where couples are assisted in forming their families using a known or anonymous donor (egg, sperm or embryo) or a surrogate.

Unexplained infertility - Unexplained infertility is a diagnosis of exclusion, once a couple have both been evaluated. The reasons for infertility are unable to be determined. Approximately 10 to 15 percent of couples will receive the diagnosis of unexplained infertility.

APPENDIX 2: IVF PROCEDURES

In Vitro Fertilisation (IVF) is the process where eggs are taken from the woman's body, fertilised in a laboratory with the sperm and incubated, then replaced into the woman's body for development.
The basic stages involved in the IVF procedure are detailed below;
The IVF treatment involves five main stages:
a) Growth and maturation of several eggs
b) Exact timing of the collection of these eggs
c) Egg Collection
d) Fertilisation of the eggs invitro.
e) The transfer of the embryo back into the woman.

Medication Fertility drugs are used to stimulate the ovaries to develop a number of eggs in the cycle. This is because the normal cycle usually only produces one egg, and pregnancy rates in IVF/GIFT are better if a number of eggs can be collected.

Monitoring Egg Development The eggs (or Ova) develop in follicles, which are like little cysts or bags containing fluid. These follicles produce increasing amounts of oestradiol (an oestrogen hormone) as they grow. The size of the follicles can be measured by ultrasound, although the eggs themselves are much too small to see.

Blood Tests Blood is taken at intervals from about day 8 of the cycle to measure oestradiol levels. This has to be done between 7.30am and 9.00am so that the results are available the same day at the clinic. Closer to ovulation, further blood tests may be required outside of office hours

Ultrasound Examinations Patients have vaginal ultrasound examinations to measure the size, number and development of follicles growing. Sound waves are used to produce pictures of the growing follicles, so that they may be counted and measured. The number of eggs collected may differ from the number of follicles seen on ultrasound. These scans are done at the clinic*.*

Timing Of Ovum Aspiration This is undertaken via a laparoscopy or an ultrasound guided pick-up about 36 hours after the HCG injection. The oestradiol levels (from the blood tests) and the number and the size of the follicles (from the ultrasound) are together used to assess the maturity of the eggs and the right time for egg collection.

HCG Injections HCG (human chorionic gonadotrophin) is a hormone, which performs the function of LH, triggering the final maturation of the eggs and ovulation. This is given by injection 34-36 hours before the operation is planned. A second injection may be given.

Ovum Pick-Up (Egg Collection) This is most commonly done using a vaginal ultrasound probe under a general anaesthetic, although intravenous sedation can be used as an alternative, depending on the patient's preference. In certain circumstances the collection may be done laparoscopically, in which case a general anaesthetic is used. The follicles are visualised, and the fluid inside them is sucked through a needle and tubing into a test tube. The eggs are then put in the incubator Patients may be nauseous or sleepy following this procedure.

Sperm collection occurs 1-8 hours after the ovum/egg pick-up operation. Three days abstinence from intercourse is necessary prior to ovum pick-up. The sperm sample is produced by masturbation at the clinic.

Events In The Laboratory The sperm sample is prepared and put with the eggs (insemination), shortly after collection. Some patients may have their eggs matured for up to 24 hours before being inseminated. The eggs are kept in tubes in an incubator until next inspected 12-18 hours later. At this time they are checked under the microscope to determine whether fertilisation has occurred. At about 36-48 hours after fertilisation, the embryos will be transferred to the uterus.

Embryo Replacement Patients are informed of progress daily. Transfer usually takes place around 2 days after pick-up. No more than 2-3 embryos will be replaced because of the risk of multiple pregnancies. Usually no anaesthetic is required and the procedure takes approximately 15 minutes. After transfer confinement to bed rest for ½ hour is required and then sitting in a chair. The patient is required to remain in hospital for 4 hours.

Surplus Eggs Some patients have more than two or three ova/eggs retrieved. They are asked what they their preference regarding the excess ova. One option is to attempt to inseminate the excess eggs and freeze all embryos suitable for transfer in a later cycle, should pregnancy not occur initially. Another option is to donate these extra eggs to women who cannot produce their own eggs, or finally these extra eggs can be destroyed. A combination of these choices is also possible ie fertilise half of the excess eggs and freeze all suitable embryos; and donate the other half of the excess eggs. Embryos, which are no longer wanted, can be donated or destroyed. They can remain in storage for a maximum of three years.

Discharge From Hospital Patients stay in hospital for about four (4) hours after the transfer. They can resume normal activities but to avoid strenuous activities until the pregnancy has been diagnosed. No sexual intercourse must occur for four (4) days after the egg collection.

Pregnancy Blood Test To maintain progesterone level either pessaries or injections may be required. Other blood tests, specific to the patient's cycle may be ordered by your doctor. Menstruation does not necessarily mean that a pregnancy is not developing. Blood tests are continued until a final outcome is known. The blood test taken approximately two weeks after the egg collection will detect whether the pregnancy hormone (HCG) is present and check the blood progesterone level. If the pregnancy hormone is detected it is too early to know whether there is a healthy continuing pregnancy. Further blood tests and an ultrasound examination are needed. Multiple pregnancy (twins or triplets) is more common with IVF than with natural conception, because of the practice of transferring more than one embryo/ova.

Repeat In-Vitro Fertilisation Attempts
If pregnancy is not achieved then a repeat attempt can be made approximately 1-3 months later, depending on findings at the most recent treatment cycle

Vaginismus - is an involuntary spasm of the muscles surrounding the vagina that closes the vagina thus limiting or preventing sexual penetration.

APPENDIX 3: THE 58TH ANNUAL MEETING OF THE AMERICAN SOCIETY FOR REPRODUCTIVE MEDICINE (ASRM) HELD IN OCTOBER 2002, SEATTLE, WASHINGTON, USA.

Being a delegate at this conference provided a unique opportunity to meet with policy makers from other countries such as Canada who are interested in implementing legislation and sharing information learnt from the WA experience. The following are brief outlines of the seminars and workshops I attended highlighting the salient issues.

Male & Female Sexual Dysfunction - What Every Practitioner Needs To Know: State of the ART Treatment Approaches – 2 day workshop prior to the conference for Mental Health professionals.
Sexual dysfunction can be both the cause of infertility and its outcome. For example erectile dysfunction & male orgasmic disorders can lead to male factor infertility while female pain problems & vaginismus can lead to female factor infertility. Extensive infertility treatment can impact negatively on sexual functioning through such procedures as timed intercourse and timely and efficient ejaculation being the goal of sex.
Clinical procedures also contribute to sexual difficulties through constant invasion of privacy. A variety of interventions can assist in the prevention or remedy of sexual difficulties with those facing infertility if reproductive health care providers are more prepared and aware of these issues.

Preparing for Third Party Families & the First Generation of Offspring & Telling Issues
In general there has been little done to assist health professionals and parents in meeting the future needs of offspring. This is becoming clear and will continue to become more apparent as the offspring reach adulthood. One very important issue raised in my discussions with colleagues about telling offspring of their assisted conception especially where third party reproduction is involved is that telling is not enough. One particular colleague in the USA observed that there tended to be a view held that "If you give enough information then everything will be OK?" Her point was that we certainly require information but we also must be vigilant about the individual needs of offspring. Some of these will have the need to have access to more than information. They will want to have contact with the donor and in some places such as WA this is not at this stage possible. This highlighted the need as health professionals to continuing lobbying for the best interests of offspring and to ensuring that systems that already exist within the WA legislation are enforced. For instance there are provisions for donors to provide a personal biography about themselves for the register. However, since 1993 when legislation came into being no personal data has been lodged by donors. Further discourses, education and a multidisciplinary approach are very much needed to the meet the emerging need of this growing population.

Multiple Pregnancy Reduction
This issue it was highlighted required consideration prior to couples undergoing fertility treatments and not just on one occasion. The best practice I observed was at one of the USA fertility treatment centres I visited where both the infertility counsellor and the fertility nurse raised this issue very thoroughly with patients prior to them embarking on treatment. There has been an attempt to address this issue in WA by not allowing more than 2 embryos to be put back in IVF treatment.

Decision making Regarding Embryo Disposition
The optimum model for addressing this issue also required counselling prior to IVF treatment and also at the termination of treatment. This is a complex area in which couples in WA are facing great difficulty deciding. Some of the issues centre on the ability to give informed consent when embryos are a theoretical notion as opposed to when they have become a reality especially following the birth of offspring. Couples tend to have greater moral dilemmas about the status of the embryo once they have been created. Another complexity, which impedes the decision-making process, is that couples can differ in their view of the status of the embryo.

Controversial Issues in ART
These included the Status of Embryos; Disputes over Embryos between Couples & between Recipients and Clinics; Adoption of Embryos; Frozen Embryos - what to do?; Disposition of Embryos - rights of egg & sperm donors? When is Egg-Sharing Coercive?
Some of these issues are the subjects of discourse in WA by the Reproductive Technology Council especially with the increasing number of frozen embryos where their owners are delaying difficult decision-making.

Is It Ethical to Pay for Gametes?
This seminar explored the ethical issues in paying for gametes. It included some of the following issues: Is Altruism the paramount paradigm?; What is the impact on those children created of altruism versus payment?; Does coercion mask Altruism?; Is it exploitative to expect donation without remuneration?; What about Reimbursement of Expenses? - What expenses should be permitted? Is it appropriate to set a level of reimbursement? Are expenses a euphemism for payment? Is payment to donors a least worse option.

Anticipating the Future in Reproductive Medicine: Where Do We Go From Here, How Far Do We Go and How Can We Be Ready?
This seminar raised more questions than it attempted to answer. Some of the issues raised included: *'If it is possible is it Right?,' 'Gender Selection for non-medical indications', 'the tension between the best interests of the child versus parental rights,' 'freezing eggs or embryos for later use - do we create embryos that will never be used?' 'the use of ART in couples with severe disabilities or HIV?'*
Some suggestions that were made in terms of *How Can We Be Ready?* Included developing guidelines, clarification of our own values, greater collaboration and research.

APPENDIX 4: FACTS ABOUT INFERTILITY

Source ACCESS fact sheet (From 'Emotional facts' Kay Oke ed., from Taking Charge of Your Infertility, Melbourne IVF, 1999)

Some infertility facts:

- A couple is regarded as infertile when they have not conceived after 12 months of regular unprotected sexual intercourse.
- Approximately 15% (one in six people) of Australian couples of reproductive age have a fertility problem.
- Infertility is not just a female problem.
- In about 40% of infertile couples, the problem is a male factor, in about 40% it is a female one, and for the remaining 20% it is a joint problem, or the cause is unknown ("idiopathic").
- The causes of infertility are many and varied.
- They include problems with the production of sperm or eggs, with the Fallopian tubes or the uterus, endometriosis, frequent miscarriage, as well as hormonal and autoimmune (antibody) disorders in both men and women.
- Treatments for infertility are many and varied.
- Treatments include surgery on the Fallopian tubes to fix blockages, hormone treatments for men and women, insemination of the woman with donor sperm or sometimes her partner's sperm, IVF and related treatments such as GIFT. Some people try natural treatments, such as herbs, acupuncture and meditation. Some couples will opt to create a family by adoption; others choose to remain without children.
- Just relaxing" or taking a holiday does not cure "infertility". For 80% of couples there is a proven medical cause. "Unexplained" infertility is just that - it means that we're not yet able to find the cause. There is no evidence to suggest that stress causes infertility. There is plenty of evidence, however, that infertility causes stress.
- How long does it "normally" take to become pregnant?
  Three out of five couples conceive within six months of trying; one in four take between six months and a year. For the rest, conception takes more than a year, which means that there may be a problem.

When infertility can't be treated with drugs or surgery, assisted reproduction may be an option. Depending on the problem, there are a number of techniques to help infertile couples conceive.

The best known is In Vitro Fertilisation (IVF) where a woman is given drugs to help her produce more than one egg. The eggs are then removed under local anaesthetic and put with the woman's partner's sperm into a special container in the laboratory where - hopefully - the eggs will be fertilised. If this happens, one or more embryos are implanted in the woman's uterus so that a normal pregnancy can occur. But because techniques like IVF are expensive and can be stressful, they are usually considered as a last resort.

There is some evidence however that infertility and treatment can also have some negative effects. Some people find their self-esteem is battered by the loss of a sense of control, the unfamiliar experience of failure, the loss of privacy and loss of an overall sense of personal mastery. Unfairly, some people experience infertility as a judgement and believe that perhaps they were never 'supposed' to become a parent.

APPENDIX 5: STRUCTURED QUESTIONNAIRE

1. Role of Infertility Counsellor within Clinic; limitations of role
2. Experience/Length of Service/Private/Public Clinic
3. ART Services offered such as Donor; Surrogacy/ main client group
4. Role of Support Groups in Client Support
5. Main Issues for Patients
6. Main Issues for Counsellor
7. Guidelines/Questionnaires used for providing counselling
8. Donor Offspring -Telling Issues
9. Professional supports for Counsellor
10. Resources/Literature
11. Other specific issues

APPENDIX 6: CENTRES SELECTED

Country	Organisation	Role	Specialty/Reason for Selection
UK Manchester	• Jennifer Dunlop St Mary's Hospital, Manchester	• Infertility Counsellor • Vice Chair, British Infertility Counsellors Association (BICA)	• First Major public clinic in UK, since 1982 • Support groups conducted by Infertility Nurses, psycho-therapeutic groups run quarterly by Infertility Counsellor
York	• Marilyn Crawshaw - Dept Social Policy & Social Work - University of York	• Lecturer/ Researcher • Inspector for UK Regulator (HFEA)	• Founding member of BICA • Extensive Infertility Counselling experience • Reviewing "Issues in Donor Anonymity in UK"
Brighton, West Sussex	• Linda Greenaway - Surrogacy Counsellor Brighton, West Sussex	• Independent Infertility Counsellor	• Surrogacy assessment
London	• Jennifer Hunt - Hammersmith Hospital, London	• Infertility Counsellor since 1984	• Counselling available for all issues during treatment and upto 12 months post treatment; • Chair of Social/Ethical Dilemmas committee for clinic • Developing guidelines for those approaching Register for information in 2007
London	• Christa Drennan - Homerton Hospital, East London	• Infertility Counsellor	• Consensus Team Decision Making model
Cambridge	Tiim Appleton - Bourn Hall Clinic, Cambridge	• Infertility Counsellor	• Surrogate assessment • World's First IVF baby born at Bourn Hall

USA Philadelphia	• Andrea Braverman - Director of Psychological Services Pennsylvania Reproductive Associates Institute for Fertility	• Infertility Counsellor	• Psycho-educational session for all IVF patients • Conducts support groups for egg donor recipients/egg donors
Berkeley, Northern California	• Alice Ruby - The Sperm Bank of California (TSBC)	• Executive Officer	• Specialising in Identity Release Donors • Preparing offspring for receiving information on donor identity
San Francisco, Northern California	• Jean Benward - Consultant to IVF program - Donor Egg Recipients & Donors	• Infertility Counsellor	• Psychological testing for Egg Donors • Clinical Interviews • Experience in 'Telling Issues' with donor offspring
Los Angeles	• Hilary Hanafin - • Centre for Surrogate Parenting (CSP)	• Director Psychological Services	• 20 years experience in Surrogacy • Surrogacy Assessment • Commissioning parent selection • Matching surrogates • Supervises other counsellors
Los Angeles	• Elaine R Gordon (CSP)	• Infertility Counsellor	• Conducts Surrogate Support Group meetings • One to One support for surrogates
Los Angeles	• Carol Leiber Wilkins - RESOLVE Support Group Counsellor	• Infertility Counsellor	• Psychotherapeutic groups for Infertile couples
Orange County, Southern California	• Christie Montgomery - Surrogate Parenting Services -	• Director	• Surrogate experience 13 years ago
Orange County, Southern California	• Ellen Speyer - Surrogate Parenting Services	• Infertility Counsellor	• Conducts Surrogate Support Group meetings • One to One support for surrogates

Seattle, Washington	• American Society of Reproductive Medicine (ASRM) - Mental Health Professionals Pre-Conference Program	• Postgraduate Course	• Male & Female Sexual Dysfunction - *What Every Practitioner Needs to Know: State of the Art Treatment Approaches* by Sheryl Kingsberg PhD & Bill Petok PhD
Seattle, Washington	• American Society of Reproductive Medicine (ASRM) Conference "*Health, Hope & Humanity in a Brave New World*"	• Annual Conference	• Conference Proceedings (see Appendix 3)