

Assisted reproductive technologies and equity of access issues

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In Australia and other countries, certain groups of women have traditionally been denied access to assisted reproductive technologies (ARTs). These typically are single heterosexual women, lesbians, poor women, and those whose ability to rear children is questioned, particularly women with certain disabilities or who are older. The arguments used to justify selection of women for ARTs are most often based on issues such as scarcity of resources, and absence of infertility (in lesbians and single women), or on social concerns: that it “goes against nature”; particular women might not make good mothers; unconventional families are not socially acceptable; or that children of older mothers might be orphaned at an early age. The social, medical, legal, and ethical reasoning that has traditionally promoted this lack of equity in access to ARTs, and whether the criteria used for client deselection are ethically appropriate in any particular case, are explored by this review. In addition, the issues of distribution and just “gatekeeping” practices associated with these sensitive medical services are examined.

any, significant difference in physical development or psychological wellbeing in IVF children as compared to non-IVF children.^{3–6}

The symbiotic relationship between medical advances and social values is well established. Technologies such as IVF and other ARTs inevitably provide normative challenges as they widen the scope of reproductive options and contest the traditional notions of motherhood, pregnancy, and childbirth. Inevitably, new technologies and capabilities prompt medical and legal discourses, usually representative of the dominant power groups within society, which may act to either encourage or discourage consequential social adjustment. Throughout history there have been numerous examples of initial intense public resistance to new medical treatments and procedures that later become commonplace and manifestly socially acceptable. The introduction of the IVF procedure for heterosexual, infertile couples is a modern example of this type of initial resistance, prompted by fear of the unknown, followed by relatively swift social adaptation.^{1–7}

An appreciation of the relationship between procreative freedom and professional agency is necessary to understand why and how women make their particular reproductive choices. The options made available to, or withheld from, women are determined centrally by the medical profession with reference to legal issues and social values.

The fact that the vast majority of IVF services are private can sometimes allow the operators to use their own paternalistic forms of discretion in patient selection and, in effect, in USA at least, legally allows them to set their own criteria for client selection or deselection.⁸ In Australia, access to ART programmes may be restricted by legislation or specific codes of practice in some states, which, in turn, may be inconsistent with the Commonwealth Sex Discrimination Act (CSDA). In such cases of legal conflict, state law prevails and ART programmes may seek exemption from the CSDA by application to the Human Rights and Equal Opportunity Commission.⁹

Indeed, it is only in recent times that the provision of established common medical services, public or private, has appreciably diverged

Although many think of assisted reproduction as a recent development, the first recorded case of medical assistance, in the normally private act of procreation, occurred nearly one hundred and twenty years ago in Philadelphia when a doctor used sperm, donated by a medical student, to inseminate a woman whose husband was sterile. When the successful case was published in a medical journal, the public was outraged.¹ Today, as well as artificial insemination by donor (AID), there are numerous other artificial reproductive technology (ART) procedures available and it has been estimated that around 300 000 babies have been born worldwide as a result of ARTs.^{1–2}

Many of the initial objections to *in vitro* fertilisation (IVF) technology were based on fears and assumptions that the physical and/or psychosocial development of children born as a result of these technologies would be impaired by the artificial way in which they had been conceived. There was a perceived anticipation of increase in potential for aberrant parental bonding as well as an expectation of probable social stigmatisation of IVF offspring. The vast majority of studies undertaken to investigate these concerns have, however, found very little, if

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Abbreviations: AID, artificial insemination by donor; ART, assisted reproductive technology; CSDA, Commonwealth Sex Discrimination Act; IVF, *in vitro* fertilisation; NHMRC, National Health and Medical Research Council

from a paternalistic delivery model to one that respects the client as an autonomous agent capable of making medical decisions (if provided with appropriate information) based on personal values and beliefs. Autonomy has been defined as “freedom from external constraint and the presence of critical mental capacities such as understanding, intending, and voluntary decision making capacity”.¹⁰ The concept of respect for autonomy is based on the Kantian notion of humans as “ends in themselves” capable of the determination of their own destinies. This, in turn, implies that each individual has autonomy based rights that require a morally appropriate response from others. In medical service provision, however, exceptions to the demand for respect for autonomy are deemed acceptable when “an individual’s choices endanger the public health, potentially harm another party, or involve a scarce resource for which a patient cannot pay”.¹⁰

The predominance of white, middle class, able bodied women living as heterosexual couples is evident across private IVF clientele. This is, in part, due to the “out of pocket” costs to the client associated with the procedure, which in Australia is between AUD\$1200 and AUD\$2800 (depending on level of private health insurance) for one basic IVF cycle; pregnancy success may require several cycles.^{11 12} In the USA, non-Hispanic white women are twice as likely as Hispanic women, and four times as likely as black women, to have used ARTs. Age, income, and education level are also positively correlated with use of infertility services.¹³ Some might interpret this to suggest that ART services are increasingly used by older, professional women because they more often choose to delay childbearing to benefit their own professional advancement. It is known, however, that those in the lowest socioeconomic groups actually have higher infertility rates because of poverty, poor nutrition, and increased rates of infectious diseases and sexually transmitted diseases such as chlamydia.⁸

The cost of ongoing research and development associated with artificial reproductive technologies is significant and it has often been noted that funds are allocated to this lucrative field of medical treatment to the detriment of less financially profitable projects such as screening and treatment for sexually transmitted diseases that could effectively reduce the rising rate of infertility. Thus, a majority of poorer, less educated women suffer a double loss with respect to reproductive medical services as their health needs are ignored because of preferential attention to consumer demand from a selected minority of advantaged women.¹⁴

“Procreative liberty”, as defined by Robertson,⁸ is the widely accepted fundamental individual right to either have or avoid having children. This entails reproductive freedom as a negative personal right, meaning that the person “violates no moral duty in making a procreative choice and other persons have a duty not to interfere with that choice”.⁸ Thus, the ideal of “procreative liberty” for some women often cannot be realised unless they “qualify” or have the necessary means to access all available treatments for infertility. It is a valid interpretation to suggest that denial of procreative choice equates to denial of basic personal respect and dignity. Individuals or couples that experience infertility often experience guilt, low self esteem, disappointment, depression, increased rates of relationship conflict, and sexual dysfunction.⁸ When the 1948 Charter of the United Nations endorsed the democratic ideal that “men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family” and that “the family is the natural and fundamental group unit of society and is entitled to protection by society and the state” in Article 16 of the Universal Declaration of Human Rights, it

signified the wide acceptance that the family unit is central to human existence and dignity.¹⁵

The Report of the Committee of Enquiry into Human Fertilisation and Embryology (known as the Warnock Report) in the UK acknowledged the stress suffered by those who are childless, even if they have intentionally chosen this state, because of the importance that society places on the family unit as a valued institution. The report concluded that whether child-bearing is considered a “wish” or a “need” is irrelevant, as medicine no longer only deals with preservation of life but addresses any bodily malfunction.¹⁶ Thus, it is not unreasonable to acknowledge that it is the state of childlessness that is of grave concern for many women and men as opposed to merely the actual cause of infertility.

The Warnock report concluded with a recommendation that a statutory licensing authority be established to regulate reproductive technologies and licence ART service providers. As a result, the UK Human Fertilisation and Embryology Act 1990 code of practice clearly states that licensed centres providing ART services “**must** also take into account the welfare of any child who may be born...as a result of treatment (including the need of that child for a father)” before providing a woman with such treatment. The act also notes that “centres should avoid adopting any policy or criteria which may appear arbitrary or discriminatory”.^{17 18} There is no recommendation or reference, however, to an appropriate agent or the necessary standardised methods of assessment required to facilitate this process. By default, ART medical professionals have accepted this role but whether this is an acceptable situation is a debatable issue. There has been little, if any, open resistance by doctors to assuming this extraordinary role of social and psychological evaluator.

“Welfare” is a broad notion comprising both material and psychosocial wellbeing; however, it is widely accepted that the most important aspects of a child’s welfare are those that pertain to “stability and security, the loving and understanding care and guidance, the warmth and compassionate relationships that are the essential for the full development of the child’s own character, personality and talents”.¹⁸

In Australia, the individual states control ART services, with three states having enacted legislation (Victoria 1995, West Australia 1991, and South Australia 1988) to control the procedures involved, while the remaining states and territories have traditionally adhered to the NHMRC (National Health and Medical Research Council) guidelines supplementary note 4.¹⁹ The latter guidelines, for many years, referred to the fact that “IVF should only be available to people within an accepted family relationship” but failed to provide a definition of this concept. In 1996, the NHMRC replaced supplementary note 4 (SN4) with a revised version, entitled *Ethical guidelines on assisted reproductive technology*, which omits reference to “accepted family relationships” but effectively ignores access issues by failing to address them at all, recommending that they be addressed by complementary ART legislation in all states and territories. Over eight years later, however, none of the remaining four Australian states and territories has enacted legislation and thus, by default, their ART services still refer to the 1996 NHMRC guidelines, which are currently under review.²⁰ In addition, the introduction to the guidelines includes a reference to the impact of social values, citing the need for “a serious regard for the long term welfare” of any children who may be born as a result of ARTs. As opposed to advocating equity of access this manoeuvre can be interpreted as tacit endorsement of the status quo effectively promoted by the initial guidelines.²

Hitherto, legal regulation of reproductive technologies has occurred belatedly in response to the challenges to social and cultural norms that these new capabilities instigate.²¹ Thus far, the most common initial legal response has been to form

regulations that reinforce and protect the traditional patterns of procreation, thereby promoting the very narrow opinion of the “appropriate” family unit as being composed of children with heterosexual parents who are married or have been in a stable de facto cohabiting relationship for at least five years. A recent legal decision in Queensland upheld the right of a fertility service doctor to refuse AID unless the requesting woman could provide written consent to the procedure from her male partner. Stuhmcke notes that, in this way, the law acts to limit the possibility of social change by controlling the medical advances that may enable such change.^{2 22}

Steinberg’s study of attitudes held by ART medical staff found that there was a common belief that, inherent in their medical responsibilities, IVF professionals were obliged to use their “common sense” about facilitation of “appropriate” reproduction and in the judgement of parenting ability. The vast majority of respondents admitted that they would refuse to treat women who were neither married nor living in a long term heterosexual relationship out of concern for the potential child’s need to have an appropriate family unit that included both male and female parents.¹⁴ This provides confirmation that many ART medical professionals feel entitled to exercise power over the reproductive autonomy of their referred potential clients, denying some women freedom of procreative choice by electing to reinforce entrenched ideologies about the family unit and sexuality.^{2 23}

Social learning theory views human development in terms of the child’s tuition experiences based on their prime models within family, peer, gender, and culture groups. There is much evidence that psychosocial influences of families and peers affect children’s self esteem, beliefs, aspirations, and levels of self regulation, which, in turn, causally affect their emotional, moral, and academic development.²⁴ It has traditionally been assumed that it is important for children to have both male and female role models, within the primary family unit, for healthy psychosocial development. Psychological studies of children raised in family units with homosexual parents have, however, found no significant negative impact on cognitive development and function, emotional adjustment, gender identity or behaviour when compared with children of heterosexual couples or single mothers.^{2 5 22 25}

With the failure rate of modern marriages approaching 40–50% in many countries which also have the highest number of ART services, a significant number of families have minimal or no contact with a father figure and there are obviously no guarantees that heterosexual couples will remain married or as a couple throughout their offspring’s childhood.^{2 5 18 26} Thus, it would constitute an inappropriate discrimination to exclude lesbian, single heterosexual, or postmenopausal women from access to ARTs because of concern for the welfare of their potential offspring.

Around twenty five per cent of children in Western societies are currently being raised in homes that do not include both a mother and a father for a variety of reasons. Today, the definition of family is often not restricted to a biological characterisation but may be broadened to encompass those committed relationships between individuals that fulfil the functions of a family. Apart from law and custom, subjective intention can also define family and, using this method of determination, a homosexual couple, in a stable relationship, caring for a child or children, functions as a family.^{26 27} The clinical importance of embracing a wider definition of family has also been recognised as crucial for good medical practice by family physicians.²⁸

At present, homosexual couples who seek the assistance of ART services necessarily request the use of donor gametes. Thus the question of whether offspring are psychologically harmed by collaborative reproduction or by lack of

knowledge or contact with a genetic parent might be considered. Concerns raised about the lack of knowledge of, and contact with, a genetic parent have been well debated and studied with respect to artificial insemination by donor (AID), but have not proven to be a deterrent to the provision of this service to heterosexual couples. Ethically, there should be no difference in consideration of this issue in the case of homosexual couples.

The claim of non-qualification due to absence of medical infertility is routinely used as a reason to deny ART services to lesbian women. Yet, fertile heterosexual couples who are at high risk for having a child with some specific genetic disorders are currently not only able, but encouraged, to access IVF services to increase, as far as possible, their likelihood of a producing a healthy baby by using pre-implantation genetic diagnosis to select embryos without the condition. Some ART units have specifically annotated this latter category of client as an exception to the requirement for infertility and it is sometimes claimed that these fertile couples have a “legitimate” medical need for ART services.²⁹ On the other hand, as Pearn highlighted, because neither member of a lesbian couple can produce sperm, they could be considered to be technically infertile and thus qualify to access donor sperm in the same manner as a heterosexual couple in which the male partner is unable to produce enough healthy sperm to achieve conception naturally.²⁵ Although it is feasible for lesbians to obtain private sperm donation and self inseminate, the potential health risks combined with the possibility of future demands for paternal involvement in child rearing decisions or access make anonymous donation via ART services preferable.²

In 1997, the Queensland Anti-Discrimination Tribunal found that a lesbian who was refused access to donor sperm insemination by a clinic had been treated as “less than the equal of a heterosexual woman”.³⁰ Also, more recently, the decision of the Court of Appeal of the Supreme Court of Queensland, in *JM v QFG (Queensland Fertility Group)*, helped to maintain limitation of access to ART through the legal sanctioning of a restricted medical definition of infertility. The decision was based on the finding that “the refusal was not due to her lesbianism but rather due to her not complying with the definition of ‘infertility’ stated by the clinic”.^{22 31} The 1996 Supreme Court of South Australia decision, in *Pearce v South Australian Health Commission*, held that the Reproductive Technology Act’s limitation of access to ART services to married couples is inconsistent with the provisions of the Sex Discrimination Act, making this limitation constitutionally invalid.³² Although single women are now able to access ART in South Australia, the Sex Discrimination Act does not protect women from discrimination associated with sexual preference. It does, however, signify the beginning of hope for further legal sanction of “alternative” family units.²

As a result of a legal challenge in 2000, an amendment was made to the Infertility Treatment Act 1997, which directed that women who were not married or in a heterosexual de facto relationship should not be treated unless they were medically assessed as “clinically infertile”. Thus, this medical diagnosis, in its narrowest form, has become the basic test for eligibility, with non-clinical or “social” factors theoretically excluded from the process, for a subset of potential recipients of ART services, whereas the wider application of “otherwise being unlikely to become pregnant” applies to women who are married or in de facto relationship.^{33 34} In 2001, an Australian Government social policy research paper examined, in detail, the main arguments, based on the issue of medical legitimacy, which have been routinely used against extending ART services to lesbians and single women and were able to “with some degree of confidence, conclude that these leading reasons for denying socially infertile women

access to ART on medical grounds have not sufficiently made their case".²⁹

As Pearn notes, it is unreasonable to expect doctors to be "mechanistic agents of State policy" and conscientious objectors who have sound personal or religious convictions must be allowed to refrain from the provision of ethically sensitive services such as abortion and some ART practices.²⁵ This needs to be balanced, however, by restraint from judgmental or negative behaviour toward the client seeking these services. Although the suggestion that homosexual doctors should develop specialised "alternative" ART services to provide lesbians with access to reproductive procedures denied elsewhere might appear to be supportive, it simply promotes further marginalisation of this minority group and, therefore, is inappropriate. A recent position statement launched by the Australian Medical Association (AMA) notes the high social status held by doctors in this culture and indicates that, therefore, they "have a role to play in promoting acceptance of sexual and gender diversity".³⁵

It is interesting to note that much resistance to provision of ART services to lesbians focuses on concern for just distribution of scarce resources. International estimates identify lesbian sexual identity in around 0.8% of women, although estimates as high as four to 10% have also been suggested. However, these higher estimates usually include women who identify themselves as bisexual or merely report same sex attraction or sexual experience.³⁶ A recent epidemiological study specifically designed to estimate the incidence of lesbian identity in a single county in the USA determined an incidence of 1.87% of the adult female population.³⁷ As only a proportion of individuals who identify themselves as lesbians are anticipated to request access to ART services, this indicates that the actual impact on resource utilisation is unlikely to be significant enough to warrant such vehement resistance and suggests that the actual motivation for prohibition is more likely to be discriminatory homophobia or heterosexism.

Postmenopausal women require donated ova to achieve IVF pregnancies. In the past, excess ova harvested after hormonal stimulation of young women undergoing IVF were donated in significant numbers. Improved techniques, including embryo freezing, have, however, reduced the number of excess ova available for donation.³⁸ Recent legislation in Victoria, which is likely to be repeated in other Australian states, has given offspring of donor gametes the right to request identifying information about their donor biological parent once they reach 18 years of age.³⁹ This change is expected to impact negatively on the number of anonymous sperm donors and suggests that donated gametes will become an increasingly scarce resource.

The allocation of scarce medical resources is often an ethically contentious problem. The scarcity argument is applied to a number of varied services in medicine today and different units devise their own methods of assessment of potential recipients to determine the allocation of their particular scarce resource. Transplant units routinely allocate scarce donor organs to waiting recipients who will be the lucky few among many on a long waiting list. Many potential recipients die waiting. In part, the transplant coordinators' decisions are determined by the imperative to closely match donor and recipient tissue by immune system compatibility, however, some ethical guidelines are still necessary.

Considerations of medical and social utility are often appealed to as part of the decision making process. It is accepted within the discipline of transplant medicine that psychosocial and lifestyle criteria should be considered by coordinators for patient selection or rejection for organ transplant. Order of priority is usually based on a perception of how deserving potential recipients are, informed by their

demonstrated compliance with general health advice. Higher level compliance is assumed to be an indicator of potential to care appropriately for the transplanted organ and, therefore, predictive of a more successful long term outcome.⁴⁰ In parallel terms of medical utility in the case of ART services, lesbian women are expected to achieve the same rate of pregnancy success from AID and general childrearing success as heterosexual women. In terms of social utility, it is impossible to make generalised claims about discernible difference between the contributions to society's welfare of lesbians and heterosexual women or that of either's offspring.

On consideration of medical utility, it would be unjust to assess recipient priority based on age alone because the medical fact remains that pregnancy success rate is most strongly correlated with the age of ova, donated or otherwise. Also, it is doubtful that large numbers of postmenopausal women are likely to inundate IVF services.⁴² If older women are discriminated against, the remaining option of negotiation with private donors, who are known or related to the recipient, would circumvent competition for anonymously donated ova but may provoke regrettable familial or interpersonal stresses. A desire for just process must be counterbalanced against the concern that consumer demand for the right to procreative choice via new technologies might create pressures for young and underprivileged women to undergo invasive procedures associated with some long term health risks in order to sell gametes or act as surrogate mothers.

Another point of resistance to allowing postmenopausal women access to ART services is the claim that older women might not have the energy and patience to cope with babies when they are in their fifties and teenagers when they are in mid to late sixties. It is salient to note that older women have, since time immemorial, played an important role in child-rearing, including being the sole carer for their grandchildren if they become orphaned or the children's parents are physically or mentally incapacitated or otherwise rendered incapable of parenting. Nor has there ever been any strong condemnation of men aged fifty or older becoming fathers, which is a regular event. A study of assisted reproductive technology clinics in the USA determined that although most clinics set age limits for women, most do not do so for men.⁴³ Additionally, although the average age of menopause remains around 52, life expectancy has increased dramatically over the twentieth century, more so for women than for men. It is also true that some women have borne babies naturally in their mid to late fifties prior to the advent of ART services. These facts indicate that expressed concerns about whether older women will survive long enough to properly care for their children are logically tenuous.⁴⁴

The argument against postmenopausal childbearing based on the belief that this state in older women goes "against nature" is contrived, as it conveniently ignores the fact that, at present, it is socially and medically perfectly acceptable to create a temporary or permanent "against nature" infertile state in young women with the use of contraceptives or surgery. It is also considered appropriate for older women to "defy nature" by using hormone replacement therapy to postpone the untoward effects of menopause.⁴⁵ As Singer also notes, if the descriptive view of what is natural (nature untouched by human intervention) is employed, then all of medicine goes against nature. Alternatively, the teleological view (that human nature involves exercising human capacities) also indicates that pregnancy resulting from ART technology is natural because it is a result of the exercise of current human capacity.⁴⁶

Very much in the realm of non-natural, researchers at the University of Pennsylvania have now created artificial ova

from mouse embryonic stem cells and believe that the process will be just as simple using human stem cells. Obviously, this will force society to further rethink philosophical ideas of parenthood but could negate some of the current ethical and legal dilemmas associated with the use of donor gametes. This technology would, theoretically, make it easier for postmenopausal women to access IVF services and could enable homosexual couples to have offspring genetically related to both same sex parents.⁴⁷ Similarly, although researchers claim to be developing the artificial uterus specifically to improve survival chances for premature newborn infants, this technology may, in the future, provide a reproductive option to couples or individuals that will be equally feasible for postmenopausal women, women who have undergone hysterectomy, and male homosexual couples.⁴⁸

Even though there is occasional evidence of incremental adjustment in medical and legal discourse towards accommodation of non-traditional concepts of the family unit and parenting, much resistance still persists. One only needs to be reminded of the fear of stigmatisation that accompanied the advent of the first births of "test tube babies", which failed to materialise, to hope that equity of access to ARTs can and will exist in the future and also that non-standard families become a welcomed and accepted part of the social, medical, and legal fabric of life.

On the other hand, issues raised in the debate about access to ARTs are inextricably entwined with other debates, such as those to do with feminist issues, reproductive politics, public health policy and funding as well as the ethics of future human reproductive potentials such as cloning, artificial ova, and artificial wombs. As Van Dyck notes, the public debate of ARTs is often restricted to doctors, scientists, religious groups, politicians, and a few feminists who have strong cultural authority in Western societies. Many groups, however, such as the poor, the elderly, the uneducated, and ethnic minorities, have an equal right to participate in the debate but have neither opportunity nor appropriate skills to effectively present their views.⁴⁹ It is noteworthy that these latter groups are the same ones who are commonly barred access to ARTs by the more powerful parties.

In the absence of universally accepted psychological or other criteria for adequate parenting, medical ART gatekeepers often fall back on traditional unfounded beliefs and socially accepted biases to justify deselection of particular individuals. There is a great deal of variability in the processing of perceived ethical challenges and most ART services have no openly available information or written policy regarding their exclusion criteria. Some IVF units request the support of staff psychologists or psychiatrists in decisions to exclude applicants for treatment on the basis of sexual orientation, marital status, or personal beliefs. Increasingly, these professionals are refusing to allow an inappropriate inference of assumed mental health problems related to personal, innocuous lifestyle preferences and are reminding IVF practitioners that these are, instead, ethical and moral questions.⁴⁹

According to Stern's study of ART services in the US, many use various professionals, including nurses, mental health providers, and laboratory staff to make access decisions but only 31% of the clinics use ethics committees and there is no requirement for such committees to include individuals who hold formal qualifications in ethics. As Seal notes: "Social and 'ethical' decisions about the suitability of the individual to be treated based on class, race or lifestyle are unacceptable".⁵⁰ To ensure equity of access to reproductive services and just distribution of medical resources, it is imperative that ART clinics should provide valid, defensible policies that encourage deliberation of ethically contentious cases with

consistency and fairness.⁴³ Such policies must be determined, with reference to law, by ethics committees, which include members who represent the underserved and minority groups whose needs otherwise remain unrecognised.

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