



Women's Health West

Response to Position Paper 1

of the Victorian Law Reform Commission Enquiry 'Assisted Reproduction and Adoption: Should the Current Eligibility Criteria in Victoria be Changed?'

INTRODUCTION

ABOUT WOMEN'S HEALTH WEST

Women's Health West is the women's health service for the Western Metropolitan Region of Victoria. Established in 1988, Women's Health West's services include research, health promotion, community development and advocacy around issues of women's health, safety and wellbeing. Since 1994, the agency has also hosted the region's largest family violence support and prevention program.

Women's Health West works from a social model of health, regarding health as determined by not just physiology, but by a wide range of social, cultural and economic issues including poverty, isolation, sexual and family violence, and discrimination on the basis of gender, sexuality, ethnicity, ability and other factors. Discrimination is not just present in social attitudes, but embedded in institutions including health, community and legal services, and in Victorian law itself.

OUR WORK WITH WOMEN

Women's Health West uses community development models to work with marginalised women in a range of communities in our research and health promotion work. These communities are identified through our consultative research as being at greater risk of poor health outcomes. They include, for example, women from various Culturally and Linguistically Diverse (CALD) communities, Indigenous women, women with disabilities (including women affected by mental illness), socially and geographically isolated young mothers, and lesbian/same-sex attracted women.

In our health needs analysis for the Western Metropolitan Region, *Beyond Symptoms*, Women's Health West found that lesbians/same-sex attracted women were "not at greater risk of reduced health outcomes because they are lesbian, but rather because they face discrimination, stigmatisation and a dominant culture that vilifies them or renders them invisible." (WHW 2002) Our work with this community to date has included a health forum, organised with the aims of providing often isolated women with a safe place to meet, discuss issues and access health information, and of informing Women's Health West and other services about the health needs of this diverse community. We have also been involved in a working group for a project by Absolutely Women's Health to produce a health promotion resource, *Pride and Joy*, for single/lesbian/same-sex attracted women who are prospective parents.

Women's Health West has identified lesbian/same-sex attracted women from CALD backgrounds as a priority focus for future health promotion work, along with the need to focus on providing sensitive support services to women in same-sex relationships who are affected by family violence.

ABOUT THIS SUBMISSION

This submission follows another made by Women's Health West in June 2004, in response to the VLRC's initial Consultation Paper for this Enquiry. In it we will address key questions, as requested by the Commission, as well as providing responses to a number of the Interim Recommendations contained in Position Paper 1.

KEY QUESTIONS

1. Do the Commission's recommendations adequately protect children from unacceptable risks?

While Women's Health West welcomes the Commission's intention in seeking to protect children from unacceptable risks, we have concerns about an approach which empowers institutions to bar some people from treatment, and thus from parenthood. We are also concerned about how such regulations may be enacted in clinical practice. Please refer to our discussion under Interim Recommendation 2.

2. Do the Commission's recommendations leave sufficient room for clinic discretion in the majority of cases?

As indicated, Women's Health West has questions about the whole approach of regulating around people's 'fitness' to parent. However, we are aware that at least some clinics already 'turn away' some people seeking treatment, and have done so for some years. We welcome increased transparency in the practice of clinics, including the right of appeal for people who have been excluded from treatment due to the 'concerns' of practitioners. We are specifically concerned about the wording of Interim Recommendation 2, that a doctor or counsellor may embark of a course of action which may result in a person/couple being excluded from treatment on the basis not only of 'physical or mental health' but also of 'some other concern' – we argue that this is too vague and gives too much leeway to the practitioner.

We are aware of the argument that decisions around ART, like decisions around abortion, should remain 'between a woman and her doctor' with a minimum of regulation. However, we do not see that such focus on the right to privacy necessarily leads to recognition of other rights, for example to freedom from discrimination. Doctors and other practitioners do not make treatment decisions solely on medical grounds – they are influenced by their own personal values and beliefs about children, parenting and family. Thus we have seen different clinics, even different doctors, taking differing approaches to treating single women and lesbians under the current laws, for example in deciding whether or not to offer the new service allowed by the ITA of freezing and screening known donor sperm for self-insemination.

Therefore Women's Health West welcomes the Commission's recommendations which explicitly prohibit discrimination on the grounds of sexuality or marital status in the provision of ART, and recommends that this approach be broadened to prohibit discrimination on grounds including ability, family structure, race, culture, personal beliefs etc.

3. Are the situations where a presumption against treatment applies appropriate? Should the presumptions be expanded or restricted?

Please see our discussion under Recommendations 2 and 4.

4. What steps should clinics take to find out whether a prospective patient falls into one of categories where there is a presumption against treatment?

Please see our discussion under Recommendation 16.

5. What categories of people should be appointed to the ITA review panel and ethics committee?

Please refer to the relevant discussion points below.

6. Should the legislation impose requirements about the proportion of men and women on the review panel and ethics committee?

Yes, we believe this would be useful, and recommend that they should both comprise at least 50% women.

7. Should posthumous use of gametes and embryos be permitted, and if so in what circumstances?

Yes, where express consent has been given.

8. If a person is permitted to use the gametes of his/her deceased partner in a treatment procedures, should there be a period of time within which the gametes must be used?

No, however the person should be encouraged to explore the issues and implications through counselling.

9. Should there be a transitional provision to deal with cases where gametes or embryos of a deceased person are already in storage, but the person did not express his/her intentions about posthumous use, and the surviving partner wishes to use the gametes or embryos in a treatment procedure?

Women's Health West does not have the expertise to answer this question, however notes that where legislation in other jurisdictions allows this to occur, there should be consistency in the law, or at least no barrier to the export of gametes from Victoria to other states or countries.

10. Do you have any other comments about the interim recommendations?

Please see our discussion points below, including our response to Recommendations 1 and 17.

RESPONSE TO INTERIM RECOMMENDATIONS AND ISSUES RAISED

INTERIM RECOMMENDATION 1

The Infertility Treatment Act should set out principles to guide the administration of the Act, and the carrying out of activities regulated by the Act. These principles are:

- the health and wellbeing of children born as a result of the use of assisted reproductive technology (ART) must be given priority in decisions concerning the use of such technologies;
- at no time should the use of reproductive technologies be for the purpose of exploiting (in trade or otherwise) either the reproductive capabilities of men and women or the children resulting from the use of ART;
- all children born as a result of the use of donated gametes have a right to information about their genetic parents;
- the health and wellbeing of people undergoing ART procedures must be protected at all times;
- people seeking to undergo assisted reproductive procedures must not be discriminated against on the basis of their sexual orientation, marital status, race or religion.

PROTECTING RIGHTS AS WELL AS HEALTH AND WELLBEING

Women's Health West supports the overall intentions behind the above principles, in particular that the health and wellbeing of children born as a result of ART should remain to the *Infertility Treatment Act* and the *Adoption Act*. We also understand the prioritising of the 'health and wellbeing' of children to imply that services must be provided to maximise the health and safety of children born as a result of any form of assisted reproduction, including both clinic services and home-based 'self-insemination'.

We argue that this principle should be extended to a broader guarantee of the rights of children born through ART, including to information about their genetic parentage, and to freedom from discrimination be protected. That is, all necessary legislation should be amended to provide protection against discrimination on the basis of sexual orientation, family formation and the sexual orientation of a person's parents. We also believe that laws or practices guaranteeing a child's right to information about their genetic parents should be broadened to facilitate contact between gamete donors and children produced through such donation early than age 18 if this is the wish, and in the best interests of the child, and the donor consents. We are very concerned by recent revelations that gamete donors may be allowed under current law to contact children born using their donated gamete after the children have turned 18. We strongly recommend that the volition for contact rest solely with children, and that the relevant part of the Act be urgently amended.

EXTENDING ANTI-DISCRIMINATION

We particularly welcome the principle that there should be no discrimination against those seeking ART. Women's Health West supports the statement in Section 2.36 (p 11) that "the elimination of discrimination in this area will also promote the health and wellbeing of children born to single women and people in same sex relationships in a direct way, by allowing more women to have access access to the benefits and safe guards offered through the licensed clinic system." This principle should include but not be limited to the categories mentioned. In particular, Women's Health West has criticisms about some of the directions mooted in Position Paper 1 about exclusions from treatment on the basis of concerns about mental health issues (which also raises questions about other forms of disability). This is discussed further below.

THE SURROGACY QUESTION

With regards to the second principle above, while we strongly agree that ART should not be used for “exploitation” (in the sense of exploitative use) of the reproductive capacities of men or women, or children resulting from ART, we raise the question of whether this implies that there will never be any form of surrogacy, commercial or ‘altruistic’, allowed under the *Act*. We look forward to the opportunity to respond to the Commission’s Position Paper 3 on surrogacy, meanwhile offering some initial thoughts for the Commission’s consideration.

Women’s Health West supports a feminist position that women’s reproductive capabilities should not be exploited, however, the issue of surrogacy is live in the community and should be opened up for debate, and various options for regulating surrogacy explored. For example, while there are some who would take a feminist position against commercial surrogacy as exploitative *per se*, there are others who would argue the opposite feminist position that women’s agency in choosing to engage in surrogacy should be respected, and women not automatically regarded as ‘victims’ in surrogacy arrangements. A similar debate between feminists exists on the issue of sex work.

Surrogacy, like sex work, is essentially a victimless crime. Like any victimless crime, to outlaw surrogacy (whether commercial surrogacy only, or any form of surrogacy) is to simply drive it underground, where exploitation of the parties involved is much more likely (the analogy with sex work still holds). Thus Women’s Health West argues that it is much better to legalise and regulate all forms of surrogacy to protect those involved from exploitation.

It may be that the Commission would recommend legalization of ‘altruistic’ surrogacy only. However, Women’s Health West would argue that while acting as a surrogate is clearly a profoundly altruistic act (including for those engaged in commercial surrogacy in other jurisdictions), there is also an argument women should be adequately compensated for their ‘labour’ (throughout the whole process) should they do so, and that allowing only ‘altruistic’ surrogacy may encourage exploitation in a more hidden form, and/or institutionalize discrimination against those who do not have someone in their lives willing to act as a surrogate for them without any monetary compensation.

Another impact of prohibiting surrogacy in Victoria is the exclusion of various categories of people from a form of ART they require to have children: heterosexual couples, single and lesbian women who cannot carry a baby to term, and gay men who wish to become primary parents of their own biological children. While gay men’s right to become parents is not a priority for Women’s Health West as a women’s health service, we believe that the prohibition on surrogacy is effectively a form of discrimination against men seeking ART on the basis of their sexual orientation, as surrogacy is the only form of ART which would allow gay men to become parents.

At present, the only option for gay men (who are also excluded from adoption, including overseas adoption – an effective ban which the federal government seems determined to strengthen) is to seek commercial surrogacy services overseas, at an extraordinarily prohibitive cost (\$AUD150,000+). Apart from issues of exclusion this raises, we also have concerns arising from the fact that the majority of surrogacy services use anonymous egg donors. While ongoing contact with the surrogate is often possible and encouraged, children born as a result of such services can never have access to information about their genetic parentage – a direct contradiction of the principles outlined above, and of the longstanding intention of Victorian law.

THE DONOR GAMETE SHORTAGE

We also note that the current ban on any form of compensation for gamete (sperm or egg) donation may well be contributing to an extreme shortage of donor gametes – witness the contrast with the availability of donor gametes (both sperm and eggs) in US jurisdictions which allow compensation of donors. One impact of the current shortage of gametes is concern about the numbers of half-siblings being born into a relatively tight-knit lesbian community. Another concern is that the lack of supply effectively pushes up the ‘price’ for donor insemination services, excluding many people from accessing them (and forcing them into potentially less ‘safe’ forms of self-insemination). It also means in practice that some clinics are reluctant to use scarce donor sperm for less interventionist donor insemination, and will push donor insemination clients into more

interventionist treatment such as IVF before this has been shown to be medically indicated, for example after two cycles of donor insemination rather than a standard six cycles.

INTERIM RECOMMENDATION 2

- If, before a woman undergoes treatment, a doctor or counsellor believes that any child that might be born as a result of a treatment procedure may be at risk of physical abuse, sexual abuse, emotional/psychological abuse, or neglect because of:
 - (a) an ongoing problem concerning the physical or mental health of the person seeking treatment or that of his or her partner (if any); or
 - (b) some other concern the doctor or counsellor has about the person seeking treatment or his or her partner (if any);
- the doctor or counsellor must seek advice about whether or not to proceed with a treatment procedure from a clinical ethics committee within a relevant hospital, which must include a child development expert, a psychologist or psychiatrist with expertise in the prediction of risk of harm to children and a doctor with experience in ART.

INCREASING TRANSPARENCY

As a family violence support service, Women's Health West supports the Commission's intention in focusing on the health and wellbeing of children born as a result of ART. We note that according to media reports (*Herald Sun*, 14 May 05, p 20) clinics like Melbourne IVF have already "turned away" up to three or four patients seeking treatment each year for at least the past five years on the grounds of mental health issues or criminal convictions, and understand that this has occurred through a panel similar to that recommended by the Commission. Therefore if the approach of empowering institutions to exclude people from treatment is to be taken, we welcome any recommendations which increase transparency and accountability of those making such decisions, and of the institutionalisation of the right of appeal for those excluded from treatment. Further responses to the proposed model are outlined below.

LEGISLATING ON PARENTHOOD

However, Women's Health West has grave concerns about the whole approach of legislating to empower institutions to exclude people from treatment, and thus from parenthood. Australia has a shameful history of empowering people (usually white heterosexual men) and institutions (government, churches, welfare and health institutions) to determine who should and should not be a parent. We see this in historical and ongoing practices including forced removal of children from Indigenous families, the history of lesbian and gay parents losing custody of their children through the courts, and removal of children from parents with psychiatric, physical an/or intellectual disabilities and/or forced sterilisation of such women. All of these practices were undoubtedly based on 'good intentions' by those who made laws or regulations to allow them, or who administered and carried them out. Nonetheless, they have resulted in serious, and in some cases, ongoing abuse of human rights, as well as serious lasting harm to children and families.

Similarly, we are certain that the Commission's recommendations – to allow exclusion on the basis of 'concerns' arising from a person's mental or physical health, of 'other concerns' (a worryingly vague criterion), of conviction for sexual offences, violent offences or of ever having had children removed – arise from very good intentions. However, we have serious concerns about how some of these 'criteria' may be interpreted in practice (see below), and more importantly about the potential for them to be misused or widened through regulation or legislative change by current or future policy-makers who may be keen on these Interim Recommendations, and less keen on those Interim Recommendations recommending removal of discrimination on the grounds of sexuality or marital status, or any other grounds. As we saw at last year's federal election, and the recent WA state election, the conservative side of politics is determined to increase barriers to equality for same-sex couples, including in relation to their families, as well as to 'roll back' progressive laws where they exist.

Women's Health West argues that the whole approach of regulating to allow exclusion from parenthood smacks uncomfortably of the past and continuing policies discussed above, and of eugenicist debates openly supported by some Australian lawmakers up until the mid-1940s. To legislate 'parenting criteria' on any grounds, we argue, is to open the door to further institutionalisation of discrimination – perhaps once again against same-sex couples, for example, by future legislators with more homophobic notions of what makes a family. We do not accept the Commission's argument that such a problematic approach is justified by the fact that public monies are involved, or that some children may be at risk. Thus while Women's Health West might agree that there is a benefit in stopping a serious sex offender, for example, from using public monies to become a parent, we cannot agree that this justifies such an approach with such potential for misinterpretation and human rights abuse.

SPECIFIC CONCERNS ABOUT THE MODEL

Despite our position on the overall approach, we believe it is important that we respond to the model proposed. Women's Health West appreciates that the Commission is interested in creating a formal system that implements "a decision-making process that is transparent, procedurally fair and consistent." To this end we concur with the statement in Section 2.59 (p 17) that, in regards to Interim Recommendation 4, "priority to be given to the health and wellbeing of children, but recognises that decisions to exclude people from treatment should be subject to proper review and consideration".

We also support the statement in Section 2.46 (p 14) that "the proposed process will ensure that decisions about access to treatment are not based on discriminatory assumptions about parenting capacity of particular groups of people (e.g. people with a psychiatric condition)". However, we are concerned that the processes suggested in Position Paper 1 may, despite this statement, in effect institutionalise further discrimination against people on the basis of disability, including intellectual disability and/or mental illness. We express concern about the extreme inadequacy of parenting and other supports and welfare provisions for parents with mental health or psychological concerns, and strongly recommend that advocates are available to support people throughout any process, such as going before a clinic ethics committee, or the ITA review panel.

Women's Health West is also aware that institutionalised discrimination including homophobia (including by fertility services, refer to the discussion under Interim Recommendation 19) is an ongoing concern for many in the community, and of the need to ensure that this does not continue directly or indirectly by giving power to practitioners and panels to exclude people from treatment. We are concerned by anecdotal experience in jurisdictions such as the UK and New Zealand that despite non-discriminatory laws, some doctors are excluding people from treatment on the basis of personal homophobic beliefs about the "best interests of children". We strongly recommend all measures to guard against such outcomes, including that the Terms of Reference of any panels and briefings to doctors/counsellors clearly state that homophobia, sexism, racism and religious bias as well as other forms of discrimination e.g. on the basis of ability including psychiatric illness, are unacceptable, unlawful and discriminatory and should bear no relevance on the discussion or decisions of the committee.

INTERIM RECOMMENDATION 3

Where a clinical ethics committee decides that a person or couple should not be treated:

- (a) the person or couple may apply to the ITA review panel to have the decision reviewed; and
- (b) a clinic must not treat that person or couple unless the committee's decision is reviewed by the ITA review panel, and the panel decides there is no barrier to treatment or decides that subject to compliance with certain conditions there is no barrier to treatment.

Despite our position on the overall approach, Women's Health West welcomes transparency, fairness, openness and accountability in all processes to determine exclusion or otherwise from treatment if this is the approach taken by the Commission, and subsequently by the Victorian

Government. We also suggest that there be provisions for an advocate to be available, in particular where the concerns raised are in regard to the mental or physical health of a person/couple seeking treatment. Importantly, this advocate (and any other supports made available) should be separate from the counselors, doctors and other practitioners who could potentially have been involved in raising the 'concerns' which led to the person/couple being excluded from treatment.

ISSUE

There is a substantial body of research on the parental factors which place children at risk of harm. This information should be taken into account when assessing whether a person is eligible for treatment. This will require clinics to put in place procedures to identify whether any of the proposed risk factors are present. The commission would welcome advice about the best way of doing this.

INTERIM RECOMMENDATION 4

A licensee should not treat a person without the approval of the ITA review panel where the person seeking treatment and/or his/her spouse or partner (if any):

- (a) has had charges proven against them in Victoria or elsewhere for a serious sexual offence; or
- (b) has been declared a serious violent offender under the Crimes Act 1958 (Vic) or any equivalent law of the Commonwealth or any place outside Victoria (whether or not in Australia); or
- (c) has had a child protection order (but not an interim protection order) made in respect of one or more children in their care under a child welfare law of Victoria or any equivalent law of the Commonwealth or any place outside Victoria (whether or not in Australia).

If the exclusionary approach is to be taken, Women's Health West does not have particular concerns about Interim Recommendation 4(a). However, we question whether some violent offences (Interim Recommendation 4(b)) are actually relevant to a person's capacity to be a good parent. We also raise concerns about the automatic assumption that having had a child removed at some time in the past means that person can never be a good parent. As is raised by the Commission in its discussion, there should be consideration of the currency and circumstances of the child removal. For example, a woman may have had a child removed because of the actions of a violent ex-partner, but now be in a healthy relationship. Acknowledgement and consideration should also be given to the history of child welfare authorities in what many argue is over-monitoring and interference in the lives of particular groups in society – for example Indigenous families, parents with psychiatric and/or intellectual disabilities, and homeless/poor families – and whether this is relevant to a particular woman/couple's history.

INTERIM RECOMMENDATIONS 5 - 10

5. The Infertility Treatment Authority should establish a review panel to decide whether or not a person is eligible for treatment where:

- (a) one of the presumptions against treatment in Interim Recommendation 4 applies to a person or his/her partner (if any); or
- (b) a person or couple has applied for review of a clinical ethics committee recommendation that they not be treated because of a concern about the health and wellbeing of any child that might be born as a result of a treatment procedure.

6. The purpose of the ITA review panel will be to consider whether or not a person (or couple) who:

- (a) meets the criteria in recommendation 4 (a, b or c); or
- (b) has been refused treatment by a clinical ethics committee pursuant to recommendation 2 and has made an appeal to the panel, may or may not proceed with treatment.

7. The review panel must give the person or couple who may be denied treatment the opportunity to explain why they should be allowed to proceed with treatment.

8. If the review panel decides that a person should not be treated, a clinic must not treat that person or couple.
9. If the review panel decides that a person should not be treated unless he/she (or partner) meet certain conditions, a clinic must not treat that person (or couple) until those conditions have been met.
10. Where the review panel decides there is no barrier to treatment, or there is no barrier to treatment once certain conditions have been met, the decision of the panel must be conveyed to the clinic and to the person (or couple) seeking treatment. In such circumstances a clinic will not be compelled to treat the person (or couple).

As stated above, Women's Health West welcomes recognition of the right of appeal and opportunity for review of clinic ethics committee decisions, and suggests that advocacy be made available to the person or couple seeking treatment to enable them to best represent their own interests. In addition, we have concerns about a process which requires a person/couple to 'defend' their right to treatment, rather than putting the burden of proof on the institution which seeks to exclude them from treatment. We suggest that other supports such as counselors should be made available to a person/couple going through the process, however these counselors should not be those who are attached to the clinic and thus empowered to raise concerns which might lead to a person/couple being excluded from treatment.

ISSUE

2.60 The commission has developed a tentative model for the composition of the review panel and the factors that should be taken into account when a case comes before it. We seek your views and comments about these suggestions.

2.61 We suggest the membership of the review panel comprise a:

- child development expert;
- person with expertise in the clinical medical practice of ART;
- member of the Infertility Treatment Authority;
- person with expertise in psychology or psychiatry;
- person with expertise in a relevant area of law;
- person with knowledge of the ethics of clinical medical practice;
- person with understanding of the concerns of people with ongoing disability or illness; and
- layperson sitting in the capacity of a community representative.

We also seek comments about whether the legislation should impose requirements about the proportion of men and women on the panel, as is the case for the South Australian Council on Reproductive Technology.⁵⁰

If the exclusionary approach is to be taken, Women's Health West largely supports the above composition for the panel and the suggestion that it comprise at least 50% women. However, we recommend that more than one community representative sit on the panel, as different sections of the community may often represent differing views on a complex issue (for example, parents groups, children produced through ART, gay and lesbian groups, religious institutions).

We also suggest that there should be open acknowledgement of the past history and ongoing existence of institutionalised homophobia and other forms of discrimination in many Victorian services and institutions, and of the need for those involved in the review panel to be aware of personal belief systems they may hold, for example that some family structures are more valid than others. We strongly recommend all measures to guard against direct or indirect discrimination, including that the terms of reference of any panels and briefings to doctors/counsellors clearly state that homophobia, sexism, racism and religious bias as well as

other forms of discrimination e.g. on the basis of ability including psychiatric illness, are unacceptable, unlawful and discriminatory and should bear no relevance to the discussion or decisions of the committee.

INTERIM RECOMMENDATIONS 11 – 13

11. The requirement that a woman who undergoes a treatment procedure be 'married and living with her husband on a genuine domestic basis', or 'living with a man in a de facto relationship' should be removed.
12. The Act should otherwise be amended to recognise that some people to whom the Act applies will be married or in a heterosexual de facto relationship, some will be in a same-sex relationship and others will not have a partner.
13. 'Partner' should be defined in section 3 to include a spouse or 'domestic partner'.⁵⁷

Women's Health West strongly supports the above recommendations, and the removal of all forms of discrimination in both the regulation and practice of ART. Women's Health West advocates equality under the law and that legislation regulating access to ART and adoption should apply equally to all groups and individuals in Victoria, regardless of sexuality, marital status, ability, race, ethnic background or belief system.

Women's Health West supports the Commission's statements in Section 2.65 and Section 2.68 that:

- after reviewing the social research on outcomes for children born to and raised in a diversity of family types, "this research does not support the view that marital status requirement should be retained to safeguard the health and welfare of children", and
- "...the marital status requirement is not only inconsistent with the principal of non-discrimination, but it also bears no relationship to the health and wellbeing of children...".

As stated in our original submission (June 2004), laws discriminating against those wishing to create families do not stop them from doing so. They simply make it much harder to do so, putting at risk the health, wellbeing and rights of all involved (including children born to such families). Such laws also reinforce negative social attitudes that cause further harm to the health and wellbeing of children and families. Thus, Women's Health West supports the Commission's statement in Section 2.66 (p 19) that "laws reinforcing social attitudes which stigmatise non-nuclear families may have a negative effect on children born to single women or women in lesbian relationships."

INTERIM RECOMMENDATION 14 and 15

14. Before a woman undergoes a treatment procedure a doctor must be satisfied that the woman is:

- (a) in the circumstances in which she finds herself, unlikely to become pregnant other than by a treatment procedure; or
- (b) unlikely to be able to carry a pregnancy or give birth to a child without a treatment procedure; or
- (c) likely to transmit a genetic abnormality or a disease to a person born as a result of a pregnancy conceived other than by a treatment procedure (including where the woman's partner is the carrier of the genetic abnormality or disease which is likely to be passed on to a child conceived other than by a treatment procedure).

For the purpose of (a), the doctor may be satisfied that a woman is unlikely to become pregnant other than by a treatment procedure if she does not have a male partner.

For the purpose of (c), the doctor must seek advice from another doctor who has specialist qualifications in human genetics or infectious diseases.

15. Where a woman does not satisfy these requirements she may apply to the ITA review panel, which may authorise the clinic to provide the treatment procedure. In deciding such applications the review panel should have regard to the guiding principles of the Act.

Women's Health West strongly supports the above recommendations. As argued in our original submission, Women's Health West believes that the definition of "unlikely to become pregnant" should be broadened to include anyone who has need of ART to conceive and bear a healthy child. This may be for medical reasons, such as infertility, or for any other reasons, including being a single woman, in a same-sex relationship, or being a heterosexual couple who are unwilling to have penetrative sexual intercourse that might lead to conception.

With regards to Recommendation 15, Women's Health West acknowledges that the proposal of establishing the ITA review panel (as outlined in Section 2.61 (p 18)) may be necessary to arbitrate such decisions.

INTERIM RECOMMENDATION 16

Where an approved doctor, scientist, counsellor or the Infertility Treatment Authority considers that a new development in treatment or a new use of treatment raises ethical concerns, the matter must be referred to the ITA ethics committee for advice. In reaching a decision, the ITA ethics committee must consult with clinics and may choose to undertake further public consultation.

ISSUE

2.80 The commission has developed a tentative model for the composition of the ITA ethics committee. We seek your views and comments about these suggestions.

2.81 We suggest that the membership of the review panel comprise:

- the Chairperson of the ITA;
- a person with knowledge of the ethics of clinical practice;
- a person who has expertise in law;
- a person who has experience in public health;
- a person who has experience in social research;
- a person who has experience in the clinical medical practice of assisted reproduction;
- a person who has experience in nursing or allied health practices;
- a person with understanding of health consumer issues;
- a person with understanding of the concerns of people with a disability;
- a person with expertise in philosophy and applied ethics; and
- a layperson sitting in the capacity of a community representative.

Women's Health West welcomes the Commission's acknowledgement that future changes in reproductive technologies and in the community's use of them cannot be accurately predicted. We welcome the institution of an open, consultative process for making decision on such issues, stressing that the committee's deliberations must be based on firm principles of non-discrimination, and on upholding the rights, health and wellbeing of all parties involved, including of any children born as a result of treatment. In terms of the make-up of the committee, we suggest that there should be more capacity for community representation, in particular where different sections of the 'community' might represent different perspectives on an issue.

Importantly, there should be open acknowledgement of the past history and ongoing existence of institutionalised homophobia and other forms of discrimination in many Victorian services and institutions, and of the need for those involved in processes to be aware of personal belief systems they may hold, for example that some family structures are more valid than others. As concluded

by the Commission and shown in research reviewed for the Occasional Papers produced by the Commission as part of this Enquiry, there is no evidence that, for example, children of same-sex parents are in any way disadvantaged in terms of emotional or intellectual development, or in gender and sexual identity. Please refer to the discussion under Interim Recommendations 2 to 10.

ISSUE

We would be particularly interested in your thoughts on what steps clinics should take to find out whether a prospective patient falls into one of the categories where there is a presumption against treatment.

If the exclusionary approach is taken, the person/couple seeking treatment could be required to undergo a police check, and a check of whether the person/couple have had a child permanently removed from their care by welfare authorities. We do not believe that either should automatically exclude a person/couple from treatment, as the circumstances at the time, and changes since then should be taken into account. Please refer to our discussion above.

Another possibility is that the counselling process explore a range of issues including the wellbeing of potential children, as it is more likely during this process that issue might emerge rather than in a medical consultation. This would require additional training for counsellors in a range of relevant issues. Where concerns are in regard to whether a person has an intellectual disability, or is affected by mental illness, for example, there should be the capacity for that person/couple to have an advocate present should the matter be referred to a committee for a decision on whether that person/couple will be excluded from treatment.

Importantly, if a counsellor is empowered to raise 'concerns' that might lead to a person/couple being excluded from treatment, the impact that this has on the counselling relationship should be acknowledged. The proposed model would strengthen the counsellor's role as a 'gatekeeper', a person with the power to influence whether a person/couple is 'worthy' of treatment/parenthood – a fact that must be disclosed by the counsellor at the outset of counselling. This then means that the counsellor cannot provide a completely confidential environment for a person/couple to explore potential issues without concern as to the potential consequences for that person/couple's access to treatment.

INTERIM RECOMMENDATION 17

If access to artificial insemination is extended to single women and women in same-sex relationships, clinics should no longer store sperm from screened donors for the purposes of providing it to women to self-inseminate.

Women's Health West does not support this recommendation. We are aware from our contact with community members and advocacy groups that although many single women and women in same-sex relationships would clearly prefer 'artificial insemination' (using either clinic donor sperm, or sperm from a known donor) as an option for attempting conception, there will continue to be many women who would prefer conception to be as 'non-medicalised' as possible, and who will therefore attempt conception through self-insemination. All efforts must be made to maximise safety for those making such a choice, and any children born as a result.

Like heterosexual couples, many same-sex couples would prefer conception of their children to be part of the intimate, private realm if possible. The current practice of storage and screening of known donor sperm for the purpose of self-insemination as allowed under ITA guidelines has provided a good option for women to do this in a way that maximises safety of the prospective birth mother and prospective child, as well as providing clinic services such as counselling for all parties involved, including the donor. We believe there would be much greater take-up of this option if more clinics were to offer it, and if clinics openly advertised it as one of the services available.

Rather than ending the practice of providing known donor sperm for self-insemination, Women's Health West would rather it be extended to providing clinic donor sperm for the purpose of self-inseminations, as is the case in many other jurisdictions, in particular the US. We are aware that due to the extreme ongoing shortage of donor sperm clinics would be most reluctant to offer such as service, however we see no medical reason not to do so.

In addition, we argue that clinical services such as counselling and other supports should be offered to women using self-insemination, even if they do not wish to store sperm for screening. We are aware of clinics in NSW that offer workshops for women interested in self-insemination which advise on health and safety issues and correct self-insemination techniques. Counselling and consent processes are important for all parties involved, including the prospective parent/s, known donor/s and their partners if they have one. Counselling should be given by counsellors trained in and sensitive to all the issues relevant to diverse family formations, aimed at establishing that all parties had explored the issues involved not only about the outcome (i.e. the child and their roles in her/his life) but also the likely process.

There is an urgent need for people in the community to receive such health information and support – a need that for a long time has been primarily met by volunteer community groups such as Prospective Lesbian Parents, Maybebaby (a mixed gay and lesbian group) and Gay Dads Victoria (a new group for current and prospective gay fathers). More recently this has been augmented by occasional forums and the 'Pride and Joy' publication by Absolutely Women's Health. However it is also the responsibility of fertility clinics and other health services to provide this kind of health information and support to those wishing to become parents.

INTERIM RECOMMENDATION 18

Section 7(1) of the Act should be amended to read:

- 1) A person may only carry out artificial insemination of another woman using sperm from a man who is not the husband of the woman at a place other than a hospital or centre licensed for the carrying out of donor insemination if he or she:
 - a) is a doctor approved under Part 8 to carry out donor insemination; and
 - b) is satisfied that the requirements of Divisions 2, 3 and 4 and section 36 (ie the counselling, consent and information provisions of the Act) have been met.
- 2) It is not an offence for a woman or her spouse or domestic partner (if any) to carry out artificial insemination of that woman.

As stated above, Women's Health West argues that the law should recognise the reality that some women will continue to choose self-insemination as a way to attempt conception, and that every effort must be made to provide services and supports that minimise the risk to all parties involved, including any potential children. As argued in our original submission, self-insemination should not be treated as a criminal offence, regardless of who performs the insemination, as this potentially increases the health risk to birth mother and child by discouraging GPs and other health providers from providing support or referral.

As a feminist women's health service, Women's Health West argues that legislation that supports increased medical control over reproduction at the expense of women's control over low technology procedures ignores feminist arguments for women's control over reproductive decision-making. It also increases risk to parties involved, given that women will continue to want to perform self-insemination. A law that cannot be policed and is not universally supported is, in effect, a victimless crime, and leads to potential for corruption and exploitation where individuals seek alternatives outside the law.

Women's Health West believes that health service providers be encouraged to support women who are self-inseminating with appropriate testing, and referral for services including counselling, donor insemination, investigation of possible fertility issues, instruction on correct techniques for self-insemination, storage and screening of donor sperm.

INTERIM RECOMMENDATION 19

Donors should not be allowed to specify qualities or characteristics of the unknown recipients of their donated gametes and embryos.

Women's Health West strongly welcomes this recommendation, believing that the practice of allowing people donating gametes to unknown recipients to exclude potential recipients on the basis of sexuality or marital status is repugnant, and anathema to the principles outlined in Interim Recommendation 1. We argue that such an institutionalisation of discrimination on any other basis, such as for example ethnicity or religion, would never have been contemplated by clinics. We offer the current existence of such practices by a number of clinics as evidence of ongoing institutionalised homophobia within Victorian health services, even within those clinics that currently offer other services to single women and same-sex couples.

ISSUE

Regarding the exclusion of certain groups from donating to clinics, in particular gay men.

4.21 Changes in clinic practices appear to have met these concerns. The ITA advised clinics on 20 September 2001 that the recruitment of homosexual men is not automatically excluded under Victorian legislation. The ITA received advice from the Director of Public Health, Professor John Catford, that the Health Act 1958 does not indicate that a 'yes' answer to the question on the Tissue/Semen Donation Statement requires the person to refrain from donating until their health status is ascertained. Professor Catford advised the ITA that this 'is a matter for risk assessment by the medical practitioner or other person dealing with tissue donation'. It is therefore at the discretion of the doctor to accept donors even if they say yes to some aspects of the Tissue/Semen Donation Statement. The directive also leaves to the discretion of the doctor a decision about any person who admits to having injected non-prescribed drugs.

4.22 It has not been clear to people wishing to access clinical services that a clinic may accept donors who answer 'yes' to some questions on the Lifestyle Declaration. In light of the confusion regarding the criteria for eligibility to donate, particularly in relation to gay men but also to people who have ever injected non-prescribed drugs, the commission recommends the Tissue/Semen Donation Statement be reviewed and clinics provide information to people seeking to donate about the way clinics use answers to questions in the statement.

Women's Health West welcomes the information that current laws do not actually exclude donors such as gay men, even if the majority of clinic practice to date has in effect done so. As stated in our previous submission, the effect of this is to greatly reduce the number of donors to clinics, exacerbating problems such as the birth of half-siblings to a number of women in the tight-knit lesbian community. Women's Health West believes that donors should be screened out on the basis of high-risk activities, rather than effectively by sexual identity. High-risk activities could be initially ascertained using a statement of risk behaviours, rather than the existing lifestyle declaration.

We also welcome any processes that would clarify clinics' obligations under the law, including their capacity to accept donations for anonymous use from gay men and from people who may have injected non-prescribed drugs. This would be consistent with existing practices and principles, in particular around universal precautions, where treatment is not refused to particular sections of the community, but universal precautions taken to minimise risk.

ISSUE

4.23 The commission has received advice that the current state of knowledge of HIV and HCV detection supports the reduction of the six-month quarantine period prescribed in the Health Act.101 The commission therefore recommends the Department of Human Services and the Infertility Treatment Authority seek advice on the quarantine period which should apply to donated gametes.

Women's Health West supports that the requirement for a six-month quarantine of donor gametes be reduced to a period that is medically justified.

INTERIM RECOMMENDATIONS 20 - 26

20. Where people have expressly consented to the use of their gametes to treat their partner or an unknown recipient after their death, the clinic should be able to use those gametes in a treatment procedure after the person has died.

21. Where a person has died leaving express written instructions that his/her gametes are not to be used in a reproductive treatment procedure, then the clinic may not use those gametes.

22. Clinics should ensure that people's wishes about posthumous use of their gametes are recorded. This should apply to donors and to people who are involved in treatment programs.

23. Clinics should contact all people whose gametes are already in storage to ascertain their wishes with respect to posthumous use.

24. Donors who do not consent to posthumous use of gametes should be advised to make arrangements for the clinic to be notified if they die.

25. Where a person involved in a treatment procedure has expressly consented to his/her partner using an embryo created from his/her gametes and the gametes of another person, or to the donation of the embryo to another person after his/her death, the clinic may use that embryo after the person has died in the ways stipulated in the consent.

26. Where an embryo has been created from donated gametes, with the consent of the donor, the clinic may use that embryo in a treatment procedure after the donor's death.

Yes, we support recommendation 20 where express consent exists. Unknown recipients of gametes donated by donors who have since died should be advised of this, and encouraged to explore any issues that may arise from this in counseling, e.g. what the implications may be for potential children born from such donated gametes. We support recommendations 21 to 26, and also recommend that issues which may arise from such decisions be explored in counseling with potential recipients of such gametes, whether they are the partner of someone who has died, or an unknown recipient.