FINRRAGE (Australia)

Feminist International Network of Resistance to Reproductive and Genetic Engineering

Submission

On Draft Guidelines on assisted reproductive technology

General Comment

Since its inception in 1984, FINRRAGE International and FINRRAGE (Australia) have consistently opposed reproductive technologies and genetic engineering. We argue that these technologies are not in women's - and society's at large - best interest. Given their short- and long-term adverse effects (many still unknown), as well as their persistent abysmal failure rate they should not in any way be supported by public funds. We strongly believe that there is no 'right' to a child, therefore there can not be a 'right' to assisted reproductive technologies (ART).

Nevertheless, we comment on these Draft Guidelines - as FINRRAGE (Australia) has consistently commented on documents from other regulatory bodies over the last 10 years (see previous submissions to the NBCC), because the promoters of ART continue - and indeed escalate - their experimentation on women's bodies. Through this escalation they are moving closer to taking the control of reproduction away from women. Indeed, ART promoters' desire to create 'perfect children' for 'the common good' under the guise of alleviating pain and suffering, is profoundly disturbing. For these reasons FINRRAGE (Australia) contends that the strongest possible regulations must be in place to prevent ART promoters from further escalation of their eugenic ideology. Much of ART experimentation appears to take place out of sheer curiosity to see if it can be done. This does not bode well for the future lives of human beings that are 'other', that is who deviate from what is considered the norm. We believe that it is the responsibility of the NH&MRC to anticipate such further escalation of experimentation and to make sure that it will not harm people already now disadvantaged in Australia.

Unfortunately however, we do not believe that the ART Draft Guidelines fulfil this mandate. As we will comment below in some detail, they lack a comprehensive understanding of the magnitude of the human experimentation in process and retreat to individualistic and libertarian solutions. Furthermore, even where some socially responsible principles are proposed (eg as in the section on informed consent), the Draft Guidelines have no inbuilt mechanisms to enforce ART promoters' to comply with the regulations. For these reasons we believe that the Draft Guidelines should be radically changed (not just amended!).

We are also very displeased to see that once again regulation of research on human oocytes - and indeed ovaries - rates no special mention in the NH&MRC Draft Guidelines. Given current 'cutting edge' research with maturing immature eggs, egg freezing and ovary transplantation (eg at the Monash Infertility Centre), we must insist that this area be covered in any regulatory Guidelines. As we've said in earlier FINRRAGE (Australia) submissions, once egg cells can be matured or as easily frozen as sperm, this removes the necessity for involving a real live woman in the process. Embryos could be manufactured without a man's and woman's consent and implanted into an artificial womb. As we've been saying for years, this would be the ultimate removal of babymaking from women. We hasten to add that this is <u>not</u> science fiction (nor are we scare mongering!) but that recent research along all of these lines is in process (eg on the artificial womb in Japan). We need

immediate regulations so that unethical applications of these technologies can be prevented. For once, the technologists must not be ahead of the ethicists!

In what follows we offer comments on some of the Sections of the Draft Guidelines.

Governing Principles
I. Respect for, and protection of, the interests, rights, dignity and welfare of all the individuals involved in ART, in particular those of any children who may be born as a result of the technology and also those of the couples (and in particular, the women) who undergo the procedures.
Considering the experimental and dangerous nature of ARTs, the basic premise of the Draft Guidelines asking to maintain 'respect' for, and protection of, 'dignity' of children born of ART and 'couples' is rhetorical. Put differently, it is not grounded in the bodily and emotional ART experiences of women - much more so than couples - and their children, neither as individuals or as members of their respective social groups. Unfortunately, the Governing Principles set the tone for much of the Draft Guidelines. They are removed from the disturbing ART reality as it is experienced by women and do not encompass the broader framework of how these technologies are interfering with who is 'allowed' to have children, in which ways, and what sort of children. In other words, they are nice words without demanding social responsibility of ART proponents.

I.i. As an aside, talking about the children first instead if considering the women who remain the main actors in 'making babies' - even in ART! - again does not bode well for the rest of the Guidelines...

Of course FINRRAGE (Australia) does recognise the importance to safeguard children born from ART. Therefore, benevolent words such as 'protection', 'rights' and 'dignity' in the governing principles ignore the fundamental problem of who will inform the children born as a result of ART that they are in fact 'donor children'. From the adoption experience we have learnt that concealing information about a child's biological origins is detrimental to the child's well being. Therefore some form of identification about specific ART procedures and gamete donors must be mandatory and not just left to individuals to decide who they will tell.

I.ii Whilst we agree with the principles expressed in b), c) and d) we query that it is possible to make truly autonomous decisions. Saying this we do not deny that women have agency and are fully capable of making their own decisions. Rather we are pointing to the persisting social pressures on a woman to become a mother, the often painful stigma of infertility, and, importantly, ART promoters' well documented failure to fully inform the women and their partners of short and long term effects of suggested procedures, especially as a lot of them consist of escalating medical experimentation for which human guinea pigs are necessary.

II. The principle of social justice and promotion of the common good
We take particular issue with the suggestion that ART relates to social justice and 'the promotion of the common good'. We are talking here about expanding technological fantasies for the select few deemed suitable to be 'proper' parents (eg heterosexual married, affluent couples). The obligations of society to protect its vulnerable members contradicts the principles of 'the common good'. In the desire to manufacture perfect children, the right of existence and livelihood is denied to human beings with disabilities. Indeed with reference to a) society has

an obligation to protect its vulnerable members but FINRRAGE (Australia) strongly believes that in the context of ART this will mean stopping these technologies as they explicitly harm its most vulnerable members eg women and children.

With regard to b) we restate what we have said above in the general comments which is as there is no right to a child, there is no right to public access to ART, let alone a right to receive state funding.

With regard to c) whilst we applaud these very nice words - the right of public access to information about ART - how does the NH&MRC propose to enforce this? Over the last ten years one of the biggest obstacles to resistance to these technologies has been the promoters' consistent misrepresentation of the dangers to women and the subsequent misrepresentation of ARTs in the media.

III. The principle of protection of the human subjects of experimentation

FINRRAGE (Australia) finds it quite unacceptable that under this magnanimous heading, the first point (a) refers to embryos. This is not just semantics: embryos don't plop from heaven but are extracted from a woman's ovary after she has been subjected to the perils of fertility drugs and the following extraction process - again not without dangers. We also query the word 'normally' in relation to therapeutic experimentation. We are appalled that the NH&MRC would agree to even the possibility that embryos might be created for experimental purposes alone. While for us an embryo does not represent an unborn child, it nevertheless has the potential to grow into a human being. In our view there will never be justification for experimenting on embryos. Given the ongoing development of the artificial womb (see, for example, recent reports from Japan), such loose wording might even endorse the placement of embryos into an artificial womb thereby removing further control from women.

With regard to b) - risks and harms permissible in standard medical research- we wish to reiterate FINRRAGE (Australia)s position that infertility is not a disease. Therefore any comparison between medical research aimed at curing disease and medical experimentation into vulnerable peoples' fertility problems is inappropriate.

Section 1 Regulation and review issues
1.1 In the Australian states where legislation is enacted there is a high degree of non compliance such as, for example in Victoria where the donor registers remain worryingly empty. For any regulation to work there must be strong enforcement mechanisms which seem absent here.

1.3 FINRRAGE (Australia) refers to recent experiences with an approved ethics committee of the family planning centre in Victoria which endorsed RU 486 trials where the consent form failed to inform the trial participants of potential short and long term adverse effects of the RU 486 and the prostaglandin component. It follows from this experience that Institutional Ethics Committees should not be left in charge of approving such projects as it is in their best interests both financially and in terms of 'cutting edge' research to have this research carried out in their institution.

1.5 After years of 'voluntary' compilation of data from ART programs for Paul Lancaster's Perinatal Statistic Reports it is astonishing to find in these Guidelines

nothing more than a weak suggestion that this practice should be maintained. At the very least the NH&MRC should demand mandatory reporting and subsequent deregistering of individual and/or clinics when failing to comply. This does not of course cover ART at private clinics who are exempt from NH&MRC Guidelines which puts in question the value of NH&MRC Guidelines in the first place.

Section 2 Eligibility of ART
2.1 a) Whilst FINRRAGE (Australia) does not support the notion that there is a right to a child - and a right to ART - we nonetheless consider it important not to restrict the definition of 'stable' and 'supportive environment' for a prospective child to a heterosexual married couple. Therefore while not endorsing ARTs in general - and wishing them greatly reduced and even stopped wherever possible - we still believe that as long as they are offered, ARTs should be open to de facto couples and lesbian women who have a strong commitment to raising a child. Similarly, clinics must not discriminate between affluent and poor people and, importantly, must not reject people with disabilities who want to have a child but do not wish to have their own disabilities screened out!

b) What does the NH&MRC define as a 'grave hereditary disease'?? This is one of the passages which fills us with great concern for its implied laissez-faire attitude which of course hands over power to ART stake holders.

Lastly, the comment about ARTs only being used when there is a reasonable chance of pregnancy is laughable. Despite statistical acrobatics offered by ART personnel these technologies continue to fail in 80 to 90% (or more) of cases to deliver a healthy live baby per attempt. Following the Draft Guidelines own advice, ART should cease to be offered!

2.3. The age restriction for donated oocytes between 18 and 50 seems quite arbitrary. Conversely if an age restriction needs to apply, where is the age restriction for donated sperm???

Section 3 Surrogacy
This is one of the weakest sections of the Draft Guidelines. By deferring to existing State Guidelines, the NH&MRC fails to take leadership in prohibiting a practice that, as US birth mother Elizabeth Kane put it, 'transfers the pain from one woman to another'. Whether for love or money, so-called surrogacy exploits (and physically endangers) the birth mother. Moreover, a child born of a so-called surrogacy arrangement has to live with the burden of being a 'bank card baby' or else the product of love that is so selfless that the birth mother is reduced to a 'suitcase' in the process. Specifically, the recent glorification of IVF surrogacy by ART specialists where supposedly the birth mother experiences no attachment to the growing foetus/baby, negates nine months of the most intimate of all relationships.

For all these reasons FINRRAGE (Australia) feels strongly that all forms of surrogacy should be prohibited.

Section 4 Informed decision-making
4.1 and 4.2 Of all the sections in the draft guidelines the section of information giving is clear and carefully thought through. However, how does the NH&MRC propose to ensure that these guidelines with respect to informed decision-making are strictly followed? Again, what is lacking here are enforcement mechanisms.

FINRRAGE (Australia) has concerns that given the medical culture which is shrouded in secrecy, information on treatment risks that are said to 'upset' patients will continue to be withheld.

4.3 We fully endorse the separation of screening and assessment from counselling. However we suggest it be made more explicit that counselling should be provided independently of the institution involved in ARTs. Pioneered in Germany by FINRRAGE members Ute Winkler and Traute Schönenberg already in the 80s (See Klein, 1989, Infertility) counselling for infertility away from any pressures associated with medical treatment results in a high level of acceptance of involuntary childlessness (as well as a significant number of 'natural' pregnancies).

Section 5 Consent
5.1 and 5.2. We welcome the suggestion that the medical practitioners are responsible for fully informing ART participants but, given our comments above, doubt - based on previous experiences - that this will happen without major re-education of the medical profession as well as heavy punishments if they do not comply. Moreover we believe that as principal stake holders they have every interest in encouraging customers to enter their programs. We therefore strongly recommend that independent bodies such as women's health centres provide the information as they are removed from the places where ARTs are actually performed.

Re: 5.2. We take issue with the very patronising suggestion that a woman embarking on ART procedures should seek her partner's consent. We believe that since the potential child will be part of a woman's body for 40 weeks - and very often years thereafter - it is her decision and she does not need anyone else's permission.

Re: 5.4. What is missing here is a reference to the potential problems arising after a couple's separation (a very frequent event in ART programs given its stressful nature) in relation to the stored embryos. Embryos, having the potential to grow into future human beings, are not commodities to be owned. However if the embryos are not destroyed (as would be our preferred solution), we strongly recommend that the final decision about their fate remain with the woman. We argue this based on a woman's pivotal role in pregnancy as notwithstanding artificial wombs (!) an embryo can only develop as part of a woman's body. As the recommendations stand now, they bestow false equity to both parties.

Re: 5.5. Posthumous use of embryos. We reject the false equity embedded in the recommendation that each surviving partner has the right to make decisions re the embryos. This implies that a man could decide to have an embryo implanted into a so-called surrogate woman's body which FINRRAGE opposes on principle. This is a very real possibility given well known family pressures on women to carry a pregnancy for another family member; it can easily be seen how to carry the embryo of a deceased sister could be perceived as the ultimate gift of love!

Re: 5.6. Consent relating to donation completely contradicts suggestions made in 5.5. It is obvious that donors are relinquishing all rights from the moment they make a donation: they do not have a say in the fate of their egg cells/ sperm. Importantly however, this also completely contradicts the current change of legislation in the ACT re IVF surrogacy which will bestow all rights on the commissioning/donor couples thereby removing them from the birth mother). It's

really a case of having one's cake and eat it as well!

The picture gets even more messy because in 18 years' time egg and sperm donors can be contacted by their children (which we strongly support) who may be very angry with them (eg for having created them outside their own body). Gamete donors must be informed about such potential difficulties: such information may convince them not to enter 'donation' arrangements. Again we strongly suggest that ART regulators must learn from the adoption experience where such unfortunate events take place frequently and create much anger, misery and guilt among all parties. Moreover, such information must be provided by an independent body as specified above, and not ART providers.

Re: 5.8 The recommendation to vary or withdraw consent is not well thought out. You cannot withdraw consent once the embryo has been implanted because the partner has decided that this pregnancy is not a good idea! Women seeking ART for infertility do not want to be faced with the ludicrous and painful decision of having an unwanted abortion. FINRRAGE (Australia) strongly recommends that all (four) parties involved may not change or vary consent when the gametes or embryos have been used.

Section 6 Counselling and role of the clinic counsellor
Re: 6.1 As previously stated counselling should be provided independently from the institution or clinic providing the service for obvious ethical reasons.

Section 7 Research, monitoring and dissemination of results
FINRRAGE (Australia) strongly supports that short and long term health status and psycho-social effects of ART on participants be investigated, documented and distributed to them the wider public. It is extremely important that women have access to this information so that their decisions to participate are informed of the disadvantages.

Section 8 Research on embryos
Re 8.1 If the intention of the NH&MRC guidelines is to generate embryos solely for therapeutic purposes then there is no scientific reason why research should be permitted up to 14 days. In fact it could be argued that the maximum research should be permitted up to the date of implantation which is up to day 5. Allowing embryo experimentation up to day 14 is another instance of giving ART researchers green light.

Re: 8.5 The word 'currently' must be deleted from this sentence. Here again the weaknesses of the Guidelines are glaringly obvious.

Section 9 Genetic diagnosis, therapy and selection
9.1 The recommendation that genetic diagnosis on pre 14 day embryos is only acceptable when there is a substantial risk of grave hereditary disease or disability is extremely offensive and is nothing short of eugenics. Who defines substantial risk? This recommendation has the potential to openly eliminate certain unwanted groups in society usually referred to as 'other'.

Section 10 Sources of gametes and embryos for research
Re: 10.3 Gametes from human foetuses. FINRRAGE (Australia) takes extraordinary exception to this point. In fact we find it unbelievable that a document issued by the NH&MRC would even suggest such a procedure. (And are we taking here about

dead or live foetuses???) This conjures up ugly dreams of IVF researchers' having access to thousands of egg cells with which to create embryos and then, with or without so-called surrogate mothers/artificial wombs go on to create parentless children. We strongly suggest that deriving gametes from a foetus is added to section 17 Prohibited, unacceptable practices.

Section 11 Clinical issues
11.1 The clinically accepted maximum number of embryos to be transferred should be restricted to no more than two and not left open to the specifications in the code of practice of the accrediting body. Such loose recommendations would leave the practice wide open to abuse. Transferring more than two embryos places impossible decisions on the pregnant woman: she may have to decide whether to keep for instance five embryos with the risk of losing one or all of them, or be forced to undergo selective foetal reduction. Either way, she has to live with guilt for the rest of her life (and possibly severe health damage). This is <u>not</u> in the best interests of women or the children that may be born of such ill thought out practices.

Section 13 Record keeping and access to information
Re: 13.2 Information about eggs or sperm donors must be accessible to any child born of ARTs. The donor too should have the possibility of identifying what happened with their egg cells/sperm. (Of course an agreed upon protocol would have to be observed.) Relevant non-identifying medical, social and demographic information should be recorded on a central register and be accessible to the child(ren) and the donor(s).

Re 13.4 The question of access to information is crucial. FINRRAGE (Australia) supports 13.4.1 and 13.4.2. However, parents must be required to disclose information about the child's conception. We suggest again that we must use what we have learnt from the adoption experience, which is that telling children only when they have grown up about their adoption, often proves to be very detrimental. Adoption processes have shown a host of difficulties experienced such as lack of trust and/or the feeling that children have been deceived. 80-90% of adopted children want to know their origins; therefore it is imperative that this information be told to donor children born from ART.

Re 13.6.2 FINRRAGE takes issue with this - there should be <u>no</u> publication of results that identify any individual.

Re 13.6.4 Again words such as 'the common good' fail to make women visible in all of this. Post treatment follow-up and data linkage studies must include women's consent prior to using information about them in a study.

Re 13.6.5 To use data without women's consent should be prohibited.

Section 14 Quality assurance and risk management
Although quality assurance programs are necessary, this section does not state how they will be evaluated or who will evaluate them. This section lacks vigour and enforcement mechanisms.

Section 17 Prohibited/unacceptable practices
We agree with the procedures listed but would like to add that deriving gametes from foetuses' must be added to this list.