



# AUSTRALIAN CATHOLIC BISHOPS CONFERENCE

## Bishops Commission for Family, Youth and Life

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Dear Sir/Madam

### **Draft Ethical guidelines on the use of assisted reproductive technology in clinical practice and research (Parts A and B)**

This submission is from the Australian Catholic Bishops Conference (ACBC) as prepared by the Bishops Commission for Family, Youth and Life (BCFYL).

The ACBC is a permanent institution of the Catholic Church in Australia and the instrumentality used by the Australian Catholic Bishops to act nationally and address issues of national significance.

The BCFYL is one of a number of commissions established by the ACBC to address important issues both within the Church and in the broader Australian community. The BCFYL has responsibility for life issues, including assisted reproductive technology.

The ACBC appreciates the opportunity to make a submission on the *Ethical Guidelines for the Clinical Practice of ART* (the ART Guidelines).

Consistent with introductory comments to its 30 April 2014 submission on Part A of the guidelines, the ACBC makes this submission noting that:

- Many couples face great pain and sadness associated with infertility and struggle to have a child. Many of us know and love people who are in this position. There is a natural and commendable desire to bear children, but Assisted Reproductive

Technology (ART) is not in their best interests because it raises issues affecting the dignity of each of the participants<sup>1</sup>;

- Human beings have inherent dignity and their rights as people must be respected including their right to life from the moment that the first cell of the human zygote is formed by whatever means it comes to be<sup>2</sup>;
- A logical ethical sequence of this dignity is that the life of each human embryo is to be considered inviolable;
- ART may involve the discarding of human embryos;
- ART may involve the formation of an embryo by a laboratory procedure replacing the personal, life giving nature of the intimate expression of love through marital intercourse between husband and wife with a technical procedure<sup>3</sup>;
- The interests of children are paramount and this is a principle upheld in international law to which Australia is a signatory<sup>4</sup>. Children have a right to an identity and family relations<sup>5</sup>, and as far as possible, the right to know and be cared for by<sup>6</sup>, and maintain personal relations and direct contact with, both natural parents.<sup>7</sup> The origins of a child in the laboratory, where the child may be considered “spare” and never have a relationship to parents and a family, places the child at risk in his or her origins as a laboratory product subject to quality control and domination<sup>8</sup>, including selection and destruction. Further, the use of donor gametes threatens the above rights of the child to inherit his or her relationship to natural parents;
- On the same basis, the relationship between a parent and a child requires an awareness that it has a life-long character, and that each parent – just like the child – has a right and responsibility to know, in as far as is possible, their child or children, and that such a right cannot be discretely put aside with the promise of anonymity or for the purposes of economic or social expediency;
- The ACBC, therefore, is critical of the provision of ART services because of these significant ethical concerns and the violation of the human dignity and rights of the child as an embryo and as a child born or to be born. Nevertheless, given these

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<sup>1</sup> Congregation for the Doctrine of the Faith, *Donum Vitae: Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation: Replies to Certain Questions of the Day*. 22 February 1987, #5; Instruction *Dignitas Personae* on Certain Bioethical Questions, 20 June 2008, #16.

<sup>2</sup> Instruction *Dignitas Personae* on Certain Bioethical Questions, 20 June 2008, #4, 6.

<sup>3</sup> Instruction *Dignitas Personae* on Certain Bioethical Questions, 20 June 2008, #16; Catholic Health Australia, *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*. Catholic Health Australia, 2001. #2.1.

<sup>4</sup> UN *Convention on the Rights of the Child* Art. 21

<http://www.ohchr.org/en/professionalinterest/pages/crc.aspx>

<sup>5</sup> *Ibid.* Art. 8

<sup>6</sup> *Ibid.* Art. 7

<sup>7</sup> *Ibid.* Art. 9

<sup>8</sup> *Dignitas Personae* 2008, # 17 and *Donum Vitae* 1987, II, B, # 5

services exist, the ACBC wishes to contribute to the discussion over ethical boundaries to protect the child and his or her parents from harm;

- Where there are issues of such ethical importance, it is important to have guidelines that effectively guide ART practitioners, their patients and clients, and those who own and operate ART services. There is a danger in a deregulated environment that some will advocate leaving these serious issues to the market. ART is not an issue that can be safely left to either market forces or good will;
- The danger with guidelines is that to an administrator, ethics can seem just another administrative process or an obstruction to overcome so as to meet the objectives of their organisation. Guidelines must also educate administrators on the serious ethical issues involved and there must be systems in place to ensure that they meet their obligations to monitor compliance with those guidelines.

Noting these comments, the ACBC has detailed in the attachment its response to the consultation on the ART Guidelines.

Yours sincerely

Most Rev Peter A Comensoli  
Bishop of Broken Bay  
For the Bishops Commission for Family, Youth and Life

## 2. Ethical principles in the clinical practice of ART

### 2.1 Human rights, ethical principles and values

Among the principles and values listed in this section, the key concept missing is human dignity, the dignity unique to human beings and the basis of all human rights. This human dignity is possessed by each and every human being, irrespective of their age, sex, race, abilities, or any other quality. Since human life is continuous from conception to natural death, the inherent dignity and right to life of every person must be respected from the moment that the first cell of the human zygote is formed by whatever means it comes to be.<sup>9</sup> The practice of ART clearly compromises the human dignity of people in the earliest stage of their development.

The document acknowledges that ‘respect’ is to be shown to all people involved in ART procedures, including those born as a result of ART. However, the nature of ART is that it tips the balance of respect away from people born as a result of ART to the intending parents.

ART presumes that ‘respect’ is owed to the human person born as a result of ART regardless of the procedure by which that person was conceived. We share the commitment to respect for each individual human person, from conception until natural death, yet urge that this respect for the persons conceived must also be manifest in the manner by which they are conceived (i.e. by the process of conception itself). If respect is not inherent in the manner by which a person is conceived and if conception is treated merely as a mechanical means of production, then respect is denied to the child conceived at the very origin of their life.

In this context, one important concept that would help ensure respect for the people conceived as a result of ART is the principle of anticipated consent. In considering the needs of children who will be conceived by ART, “... the principle of ‘anticipated consent’ requires that, when a person seriously affected by a decision cannot give consent, we must ask whether we can reasonably anticipate that he or she would consent if able to do so. If not, it is unethical to proceed.”<sup>10</sup>

Consent is another important principle not mentioned, but worthy of inclusion.

The *Code of Ethical Standards for Catholic Health and Aged Care in Australia* gives extensive advice on consent, including:

“Research depends upon a partnership between participants and researchers with a view to meeting the needs of future beneficiaries. Researchers must, therefore, seek the adequately informed and freely given consent of potential research subjects. Each person must be informed of the risks and benefits involved in participating in the research. Participants must be free to withdraw at any time.

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<sup>9</sup> Instruction *Dignitas Personae* on Certain Bioethical Questions, 20 June 2008, #4, 6.

<sup>10</sup> Tobin, B, Donor-conceived people: are they entitled to identifying information about their biological parents? *Bioethics Outlook*, 24(1) 2013: 6.

Researchers, in particular those conducting clinical trials, have a responsibility to ensure that participants understand they are enrolled in a research project. Reimbursements should not be so large as to become unwarranted inducements.”

“When a potential research participant is in a dependent position in relation to the researcher, for example, as the patient of a doctor-researcher, there is need for extra diligence in the obtaining of consent to ensure that the patient can distinguish between the procedures of the research trial and those needed for his or her care. Patients should be assured that their health care needs will be met, without discrimination, even if they choose not to participate in, or to withdraw from, a research project.”<sup>11</sup>

### **3. Application of ethical principles in the clinical practice of ART**

This section includes the comment that “the nature of ART raises a number of particular ethical issues and dilemmas.”

In response, we point out Gleeson’s valid argument that “... we should refrain from generating these dilemmas in the first place. Once the conception of a child is removed from the sexual embrace of husband and wife, once third parties and technologies dominate the context of conception, we are bound to encounter competing claims which cannot all be met.”<sup>12</sup>

#### **3.1 ART activities must be conducted in a way that shows respect to all involved**

The document states that human “embryos warrant serious moral consideration” rather than respect. Given the concept of serious moral consideration was not detailed in the ethical principles and values discussed in 2.1, it is not clear what these words mean. The same words are used in other sections of the draft guidelines and appear to mean that ethically troubling actions can be recognised but not restricted. It would be useful to have this point clarified. The presumption should be that in the case of human beings from the beginning of their lives, “serious moral consideration” requires nothing less than respect for human dignity that is due to every human being, in particular the right to life and the right to not be used as a means to an end.

#### **3.2 Decision-making in the clinical practice of ART must be undertaken in a manner that protects from harm each individual or couple involved in ART activities and any persons who would be born**

This section refers to the use of human embryos and says their use should include consideration of the person who might be born, but does not mention any consideration of the human embryo. The “serious moral consideration” in 3.1 must include any practical considerations of harm to the embryo. There is mention of limiting the number of

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<sup>11</sup> *Code of Ethical Standards for Catholic Health and Aged Care in Australia*. Catholic Health Australia, 2001. #6.5, 6.6, 6.7.

<sup>12</sup> Gleeson, G, Ethical issues in reproductive technology: some Catholic insights. *Bioethics Outlook*, 9(1) 1998: 11.

embryos used “to those likely to be needed” but apart from this consideration, the wants of the commissioning individual or couple are given priority.

A consequence of this is to repeat the problem identified by G Gleeson in 3.0: a creation of competing claims which otherwise is unnecessary.

There is mention of “serious consideration” being given to the wellbeing of the person to be born as a result of ART, but no detail of the nature of that consideration. This is where it would be useful to detail the principle of anticipated consent, mentioned in comments on 2.1.

### **3.3 Decision-making in the clinical practice of ART must recognise and take into account the biological connections and social relationships that exist or may be formed**

We do not know what significance a person might place on their biological connections, but that is precisely why we should be careful to not sever those connections. The claim these connections might have “no significance” seems very unlikely. Recent Australian history, in various cultural contexts, has attempted to address previous generations’ mistakes in the severance of the relationship and contact between parents and children, and it would be counter-intuitive to replicate the mistakes of the past in the area of bio-medical reproductive technology. This point is also discussed in 5.8.

### **3.4 Decision-making about ART activities must recognise and respect the autonomy of each individual or couple involved**

Autonomy and consent are key concepts mentioned here which are not detailed in 2.1.

The focus of this section should be on the common good, which balances the rights of all, more than on individual rights. ART cannot be just about the wants of adults, but must also consider the good of the individuals conceived and that of our nation.

Valid consent is a difficult concept that is about more than obtaining a signature on a form. It must also consider that people may be acting out of feelings of obligation or because they are in difficult social circumstances.<sup>13</sup> The ACBC has provided a further comment on the issue of consent in 2.1.

### **3.5 Processes and policies for determining an individual’s or couple’s eligibility to access ART services must be just, equitable and respectful of the inherent dignity and of the equal and inalienable rights of all persons**

It would be reasonable to give preference to the biological parents of any child conceived by ART in recognition of the fact children have a right to an identity and family relations<sup>14</sup>,

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<sup>13</sup> Dickenson, DL, Regulating (or not) reproductive medicine: an alternative to letting the market decide. *Indian Journal of Medical Ethics*, VIII(3) 2011: 178.

<sup>14</sup> UN Convention on the Rights of the Child Art. 21, 8.  
<http://www.ohchr.org/en/professionalinterest/pages/crc.aspx> Ibid.

and as far as possible, the right to know and be cared for by<sup>15</sup>, and maintain personal relations and direct contact with both natural parents.<sup>16</sup>

### **3.6 Donation of gametes or embryos or the provision of surrogacy services is an act of altruism and solidarity that provides significant benefits to those requiring assisted conception**

The donation of gametes or embryos is presented here as an unquestioned positive because of the benefits to those who wish to have assisted conception. The heading refers to those people “requiring assisted conception”. The word “require” implies an imperative, but this is a want, however strong and understandable, but not a need.

The donations of gametes or human embryos in fact initiate extra complications into the lives of any children born from these donations. As noted in 3.5, children have a right to know and be cared for by their natural parents. For those children not brought up by their natural parents who wish to know their genetic origins, they must work hard to establish and maintain contact with their genetic parents as well as their social parents.

The ACBC agrees there should not be payments for the donation of gametes or embryos. The Conference agrees there could be compensation for donors for documented expenses that are directly relevant to the donation. It suggests the standard should be the level of expense documentation required by the Australian Taxation Office in relation to documenting work related expenses. This is covered in more detail in 5.4.

### **4.1 Provide and discuss all relevant information – General requirements**

The reference to “all relevant information” is imprecise and allows the provider of ART to choose what it considers relevant. Natural bias means that information is unlikely to reflect negatively on the ART provider.

The NHMRC should have more prescriptive requirements that all ART providers publish standard statistical information to inform people considering accessing ART about the likelihood of achieving a live birth with the assistance of the particular ART clinic.

It is a matter of deep concern that it is very difficult for those considering IVF as an option to know what their chances of conception are with and without the intervention. The clinics’ advice to clients can differ remarkably from the information they make available to governments. Thus for instance it is not uncommon to have success rates provided in misleading ways in terms of clinical pregnancies rather than live births and for results to be exaggerated. As a matter of contrast, the information required by statute law to be kept in the state of Victoria, for instance, shows the last completed cycles recorded for the 2009-10 year. In that year in Victoria there were:

- 7330 women treated with IVF (inc. ICSI)
- 50,249 embryos formed (eggs fert.)
- 2208 Clinical pregnancies (elev. HCG)

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<sup>15</sup> Ibid. Art. 7

<sup>16</sup> Ibid. Art. 9

- 1700 confinements (gave birth)
- 1855 babies born
- 23% of women treated gave birth
- 3.5% of embryos survived to birth.<sup>17</sup>

Thus despite one of the leading teams, Melbourne IVF, claiming, “we would expect that 85% of couples will conceive within six months of trying to get pregnant”<sup>18</sup>, in fact 77% of women treated in the most recently assessed period did not achieve the birth of a child and 96.5% of embryos did not survive to be born.

These figures are not generally known to women or their partners when they make decisions to undergo treatment. Nor is it generally made known what proportion would conceive naturally.

Further, a Monash University study, published in the *Australian and New Zealand Journal of Obstetrics and Gynaecology* (2013)<sup>19</sup>, examined the rates of unexpected conception in Australian women who had a first child through assisted reproductive technology (ART). The study of 236 women who had a baby through assisted reproductive treatments found 33 per cent of them conceived a second child naturally within two years of their first birth. Those involved in assisting women with fertility awareness report natural pregnancy rates of above 50% in women who had been trying unsuccessfully for more than 12 months.<sup>20</sup>

#### **4.4 Provide counselling services – Specific situations**

The ability of a person to find information about their gamete donor parent is often frustrated because “... research suggests that most heterosexual parents who conceive via donor conception never tell their children.”<sup>21</sup>

Lucy Paplinska who made the documentary, *Sperm Donors Anonymous* says “a lot of people focus on starting a family but they don't think about what happens when that child grows up or what the child might want.”<sup>22</sup> The important issue of being honest with children about their origins needs to be thoroughly explored with social parents before there is agreement to go ahead with ART.

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<sup>17</sup> [www.varta.org.au/annualreports](http://www.varta.org.au/annualreports)

<sup>18</sup> <http://mivf.com.au/about-fertility/how-to-get-pregnant>

<sup>19</sup> Wynter, K., et al. (2013), Spontaneous conceptions within two years of having a first infant with assisted conception. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 53: 471–476.

<sup>20</sup> An unpublished retrospective study undertaken by the Ovulation Method Research and Reference Centre of Australia Inc. noted that of couples who had been trying unsuccessfully for more than 12 months, over 54% conceived within an average of less than five months after learning fertility awareness.

<sup>21</sup> Power, J, Secrets and lies: why donor-conceived children need to know their origins. *The Conversation*, 3 July 2015. See: <http://theconversation.com/secrets-and-lies-why-donor-conceived-children-need-to-know-their-origins-44015>

<sup>22</sup> Kalina, P, ABC documentary Sperm Donors Anonymous lifts the lid on donor conception. *The Sydney Morning Herald*, 13 August 2015. See: <http://www.smh.com.au/entertainment/tv-and-radio/abc-documentary-sperm-donors-anonymous-lifts-the-lid-on-donor-conception-20150807-girwzwm.html>



### **5.3 Limit the number of persons born from a single donor**

The guidelines are very vague on the “putative” limit. Consideration should be given to the rights of those receiving the donated gametes to know whether other children have already been conceived through the use of the donor’s gametes. This would be considered by many to be a significant “risk factor” in the use of donor gametes.

### **5.4 Provide reimbursement of verifiable out-of-pocket expenses**

The ACBC supports the requirement that donation of gametes must be altruistic. The ACBC does not support allowing direct or indirect inducements, such as a monetary payment for human gametes and only supports compensation for donors for documented expenses that are directly relevant to the donation. The standard should be the level of expense documentation required by the Australian Taxation Office in relation to documenting work related expenses. The matter of inducements for participation in research was addressed in detail by the Australian Health Ethics Committee in a document which suggested questions for Human Research Ethics Committees to ask in relation to separating reimbursement from offering a financial incentive or inducement.<sup>23</sup>

The issues involved in paying for human eggs are also related to a document the NHMRC produced entitled “The commercialization of human tissue and human tissue products” in 2011. The document referred to several issues including:

- the danger that payments would adversely affect the social capital and community benefit involved in altruistic donation for transplantation to the blood, bone-marrow and eye banks;
- creation of perverse incentives leading to vendors acting in ways in which they would not have acted without the inducement, including, for instance, not providing important information such as information about risk activities for infection, or poor people being exploited;
- the genomic significance of tissue or tissue products being sold which contain genetic information thus affecting not only the donor but also family members, especially if the genomic significance involves a unique value;
- the commodification of the donor’s body in parts being bought and sold, which many of those who submitted to that enquiry thought involved a loss of respect for human dignity.<sup>24</sup>

All of these matters are significant in relation to women being paid for egg donation over and above the reimbursement of documented expenses incurred in the provision of their eggs.

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<sup>23</sup> Using the National Statement 1: Payments to Participants in Research, Particularly Clinical Trials. NHMRC, October 2009.

<sup>24</sup> NHMRC Ethics and the exchange and commercialisation of products derived from human tissue - background and issues 2011 pp 27ff

In any case, the donation of gametes is different to the donation of human tissue generally. The commodification of the bodies of the women involved is a crucial ethical issue. As Pope John Paul II expressed it, donating tissue is not just a matter of giving away something that belongs to us but of giving something of ourselves, for "... the human body cannot be considered as a mere complex of tissues, organs and functions ... rather it is a constitutive part of the person who manifests and expresses himself through it".<sup>25</sup> He went on to say, "any procedure which tends to commercialize human organs or to consider them as items of exchange or trade must be considered morally unacceptable because to use the body as an "object" is to violate the dignity of the human person."<sup>26</sup>

Allowing inducements would mean treating the human body and hence the person as a mere commodity, undermining the existing social capital in existing systems of donation that depend on altruism and a commitment to the common good, and exploiting the poor who lack alternative ways of earning an income. Individuals and the common good are best protected by maintaining the existing prohibitions on trading in human eggs.

The medical team involved in living organ donation have a special responsibility to ensure the safety of the donor and, in general, that has proved to be the case in Australia. The opposite, however, has proven to be true when organs are traded rather than given altruistically and this is a strong reason for opposing trade in human tissue. Further, allowing the trade in human ova allows and even encourages disadvantaged women in need of cash to sell their ova at risk to their own health. Where women are short of money, they are not exercising the choice freely to donate their ova.<sup>27</sup> In fact, to allow women to have true informed consent to donating their ova, inducements must continue to be banned.<sup>28</sup>

### **5.8 Provide persons born from donated gametes with information about the gamete donor**

This is an appropriate approach to ensuring the children of gamete donors can make contact with their natural parents.

The ACBC submits the biological link between gamete donors and the children who result is of profound significance, which is the reason these links must be recognised and respected in the ART Guidelines.

Tobin points out "... the primary point is not the usefulness of this information but access to it being a moral right. That is to say, the idea that one is entitled to know one's biological parents should be understood primarily as a (moral) right to know the truth

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<sup>25</sup> Pope John Paul II [address](#) to the 18th International Congress of the Transplantation Society 2000

<sup>26</sup> Ibid.

<sup>27</sup> George, K, What about the women? Ethical and policy aspects of egg supply for cloning research. *Reproductive BioMedicine Online*, Vol 15(2), page 132.

<sup>28</sup> Rao, R, Coercion, Commercialisation, and Commodification: The Ethics of Compensation for Egg Donors in Stem Cell Research. *Berkeley Technology Law Journal*, Vol. 21(3), February 2014. Page 1059.

about one's conception as a (or, perhaps, the) fundamental aspect of knowledge of one's own identity."<sup>29</sup>

This is about more than ensuring donor-conceived people have access to records and contact details for their biological parents. It is ensuring that the technology is never used so as to prevent a child not only knowing the identity of his or her biological parents, and ensuring a right to be identified as the natural child of a biological parent, in addition to having social parents, and to have access to that parent even if the law has arranged that he or she cannot make an inheritance claim.

The falsification of a birth certificate so that it does not contain the names of biological parents is a great wrong to the child. This is creating a whole new stolen generation of children dispossessed of their connectedness, personal, biological and cultural to their natural parents and family. It also raises issues about consanguinity; they may unwittingly have children by someone who is in fact a half sibling. The link is even more relevant to children who are conceived using two donated gametes (or donated embryo) and therefore will not be raised by either of their biological parents.

The connections between people and their biological families are so important because:

“... genetic relationship goes to our deepest roots of who we are and to whom we bond. One only has to look at one of the primary uses of the internet – genealogical research – to see how important it is to most of us to know who we come from. And those bonds are not just to parents, but also to brothers and sisters and other genetic relatives. We have ethical obligations to heed these sentiments.”<sup>30</sup>

It should be noted that it is not just a matter of genetics. A child dispossessed of a relationship to a genetic parent, may also be brought up in a totally different culture and feel quite unfamiliar with those who do not share his or her genetic, racial or cultural background. That is not such an issue if the child knows from the outset and is encouraged to form cultural links. However, deception or suppression of information and falsification of records or not keeping accurate records makes it very difficult for the child to later trace his or her family and cultural inheritance.

These genetic relationships are confused by ART as rather than parents being biological, gestational and nurturing, these roles may be split between a number of people:

“Psychologists often refer to the issue of genealogical bewilderment as children, perhaps later in life, seek to discover their origins and to identify their own identity in circumstances in which the genetic parents may be completely unknown to them or become known to them at a later stage. The relationship between a child

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<sup>29</sup> Tobin, B, Donor-conceived people: are they entitled to identifying information about their biological parents? *Bioethics Outlook*, 24(1) 2013: 6.

<sup>30</sup> Somerville, M, Dispossessed and forgotten: the new class of genetic orphans. *Mercatornet*, 18 September 2007.

and his or her parents is complex. So much of our sense of identity is based upon that relationship. When it is fragmented, that can be hurtful and confusing.”<sup>31</sup>

In considering the needs of children who will be conceived by ART, “... the principle of ‘anticipated consent’ requires that, when a person seriously affected by a decision cannot give informed consent, we must ask whether we can reasonably anticipate that he or she would consent if able to do so. If not, it is unethical to proceed.”<sup>32</sup>

The frequent frustration that has been expressed by people tracing their natural parents highlights the fact that they would not have consented to decisions being made not in their interests but the interest of their parents and the clinics. That issue is now even more complicated with the increasing use of surrogacy arrangements. A child’s connection to the mother who conceived and nurtured him in the womb is of great significance. For most of the first year she was his mother. Forever she remains the woman who sacrificed herself for him as his birth mother. She may or may not be genetically connected, but she will always be his mother. She will always have the biological and spiritual connection of having been so intimately connected with the child within her body.

## **Surrogacy**

### **8.7 Do not practice, promote or recommend commercial surrogacy**

The ACBC supports the ban on commercial surrogacy for a range of reasons, including the fact that women who act as surrogates might be exploited given the likely difference in income between the commissioning parents and the woman.<sup>33</sup>

There is clear evidence with regard to overseas commercial surrogacy that the women providing the service are financially disadvantaged and exploited. Melinda Tankard Reist wrote of Thai surrogate mothers “... eliminated from the children’s history, treated as nothing more than disposable uteruses. The physical, emotional, spiritual bonds between mother and child that develop during a pregnancy are rendered null and void by a monetary transaction.”<sup>34</sup>

In India, “the poor, illiterate women of rural background are often persuaded in such deals by their spouse or middlemen for earning easy money.”<sup>35</sup>

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<sup>31</sup> Associate Professor Nicholas Tonti-Filippini, Submission No.2 to the NSW Parliamentary Inquiry into Inclusion of Donor Details on the Register of Births, 18 November 2011.

<sup>32</sup> Tobin, B, Donor-conceived people: Are they entitled to identifying information about their biological parents? *Bioethics Outlook*, Vol.24(1), page 6.

<sup>33</sup> Tieu, MM, Altruistic surrogacy: the necessary objectification of surrogate mothers. *J Med Ethics* 2009; 35: 174.

<sup>34</sup> Reist, MT, Overseas Surrogacy: Wombs for rent but no room for birth mothers. *The Age*, 16 February 2014.

<sup>35</sup> Saxena, P et al, Surrogacy: Ethical and Legal Issues. *Indian Journal of Community Medicine*, Vol.37(4), Oct-Dec 2012, pp211-213.

Women in commercial surrogacy in Australia would have better conditions, but there is no doubt that ultimately they would, in the main, be disadvantaged women who would have few rights with regard to the children they bear.

No-one should profit from surrogacy. Now that almost all ART clinics in Australia are owned by for-profit entities, the charging of fees for providing ART procedures to achieve pregnancy in a woman in a surrogacy arrangement must continue to be prohibited. Otherwise the ban on commercial surrogacy is easily avoided.

### **8.8 Assess the ethical acceptability of non-commercial surrogacy**

The ACBC opposes surrogacy, whether it is commercial or not. Surrogacy raises a number of ethical issues:

- The welfare of the child is not the objective with surrogacy as it is with adoption, because the desires of the infertile couple are given priority;<sup>36</sup>
- Surrogacy gives priority to the childless woman or commissioning parents over the woman who is the gestational surrogate by objectifying her as a womb;<sup>37</sup>
- The surrogate mother must attempt to hide her emotional connection with the child from others, suppress her emotions to herself, and control any love for the unborn child when she surrenders the child she has carried for nine months. This has proven not to be possible for some women;<sup>38</sup>
- The act of surrogacy denies the child the right to be conceived, carried, born and brought up by his or her genetic parents. It sets up, to the detriment of families, a division between the physical, psychological and moral elements that constitute those families.<sup>39</sup>
- It overlooks the difficulty of full consent given the women are likely to be related to the commissioning couple in the case of altruistic surrogacy.<sup>40</sup> There is a possibility of emotional blackmail;
- It requires a woman to deny many of the significant, integral parts of the experience of pregnancy.<sup>41</sup>

All forms of surrogacy should be prohibited.

### **8.10 Obtain consent from all relevant parties**

The ACBC has provided comments on consent in 2.1.

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<sup>36</sup> Tieu, MM, Altruistic surrogacy: the necessary objectification of surrogate mothers. *J Med Ethics* 2009; 35: 172.

<sup>37</sup> Tieu, MM, Altruistic surrogacy: the necessary objectification of surrogate mothers. *J Med Ethics* 2009; 35: 173.

<sup>38</sup> Tieu, MM, Altruistic surrogacy: the necessary objectification of surrogate mothers. *J Med Ethics* 2009; 35: 172. Byrne, M, Surrogacy: some ethical issues. *Bioethics Outlook*, 9(1) 1998: 15.

<sup>39</sup> Tonti-Filippini, N, 2013. Pages 106-107.

<sup>40</sup> Byrne, M, Surrogacy: some ethical issues. *Bioethics Outlook*, 9(1) 1998: 16.

<sup>41</sup> Byrne, M, Surrogacy: some ethical issues. *Bioethics Outlook*, 9(1) 1998: 16.

In the context of surrogacy, the ACBC endorses the comments of Dickenson, who says “the language of choice and consent ... is insufficient, and even misleading. Instead, the communitarian view argues, we must also consider the possibility that disadvantaged economic or social circumstances lie behind women’s ostensible consent.”<sup>42</sup>

## **8.12 Provide persons born with information about the surrogate**

### **Preimplantation genetic testing**

The language in the introduction to this section gives the impression preimplantation genetic testing (PGT) is an established and reliable technology. Victorian Assisted Reproductive Technology Authority (VARTA) figures for the 2012-3 year indicate a live birth rate of less than 4% per treatment cycle and an embryo survival rate of less than 6 per thousand following PGT. Again, ART clinics should be required to publish comparable, accessible data on the practical success of this technique in terms that interest them, such as live births.

The introduction also claims PGT is used to “prevent conditions that would seriously harm the person who would be born.” That is not correct. For the most part, PGT is used to ensure human embryos that do not test well are discarded.

King quotes Axel Kahn saying “Part of the individuality and dignity of a person probably lies in the uniqueness and the unpredictability surrounding his or her development. As a result, the uncertainty of the great lottery of heredity constitutes the principal protection for human beings against biological predeterminism imposed by third parties, including parents. One of the blessings of the relationship between parents and their children is their inevitable difference, which results in parents loving their children for what they are, rather than endeavouring to make them what they want.”<sup>43</sup>

## **8.13 Assess the ethical acceptability of PGT to select against a serious genetic condition**

The use of PGT to select against genetic conditions should be banned.

A community that devotes significant time and money to PGT to ensure people with a disability are not born is one that has a continued prejudice against people who have a disability.<sup>44</sup> The eugenic nature of PGT is one of the factors that helps to continue the prejudice against people who have a disability. People who need acceptance and sometimes assistance are seen as their disability rather than as human beings.<sup>45</sup> PGT is not an acceptable response to possible genetic conditions.

The comment that context is important to assessing genetic conditions as serious or non-serious is an important one. A condition may be rendered more serious in a social sense because of the lack of support available to parents with children with a particular genetic

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<sup>42</sup> Dickenson, DL, Regulating (or not) reproductive medicine: an alternative to letting the market decide. *Indian Journal of Medical Ethics*, VIII(3) 2011: 178.

<sup>43</sup> King, D, Preimplantation genetic diagnosis and the ‘new’ eugenics. *J Med Ethics* 1999; 25: 180

<sup>44</sup> King, D, Preimplantation genetic diagnosis and the ‘new’ eugenics. *J Med Ethics* 1999; 25: 181

<sup>45</sup> King, D, Preimplantation genetic diagnosis and the ‘new’ eugenics. *J Med Ethics* 1999; 25: 181

condition. Medicine should not reinforce that social issue by ensuring fewer children with that condition are born, but campaign to change social attitudes and the support available to people who have a disability.

#### **8.14 Assess the ethical acceptability of PGT to select an embryo with compatible tissue for a sibling**

Using “... PGT for the purposes of tissue typing an embryo for subsequent stem cell therapy for a sibling ...” is not ethically acceptable, because it presumes that the particular human embryo will be chosen not for itself, but at least in part for its value as a source of tissue to help a sibling. This treats the child as a commodity, not as a person with human dignity, and contradicts concerns raised elsewhere in the document regarding the commodification of persons.

#### **8.15 Provide relevant information and counselling and access to a genetic counsellor**

It would be useful for parents who may have a child with a genetic condition or disability to be referred to people who are actually living with the condition, or parents who have children with the condition. This would help alleviate fears and provide the basis of a support group.<sup>46</sup>

#### **Posthumous use of stored gametes and embryos and the collection and use of gametes from persons who are deceased or dying**

#### **8.16 Respect the wishes of the person for whom the gametes or embryos were stored**

The ACBC does not support the use of gametes from those who are deceased. Such an action invariably involves an intention to conceive a child knowing that the child will not be nurtured by one of his or her parents. Such an action cannot be seen as in the best interests of the child but only serves the interest of the adult parent. To use donated gametes from a person who has died would violate the child’s right to know and to have access to his or her natural parents. This right is recognised by the UN Convention on the Rights of the Child. It is possible that such choices will have very negative effects upon the child conceived in these circumstances, including upon the relationship between the child and the surviving parent.

### **Appendix 3**

#### **3a Sex selection for non-medical purposes**

The ACBC believes that sex selection for non-medical purposes is gravely wrong. As a form of prenatal preimplantation diagnosis, sex selection is directed toward the “qualitative selection and consequent destruction of embryos”<sup>47</sup> and is therefore expressive of a eugenic mentality.<sup>48</sup> Further, within this process the human embryo is

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<sup>46</sup> King, D, Preimplantation genetic diagnosis and the ‘new’ eugenics. *J Med Ethics* 1999; 25: 178

<sup>47</sup> *Dignitas Personae*, no.22.

<sup>48</sup> *Ibid.*

treated in such a way that is subject to alteration and discrimination,<sup>49</sup> thereby violating the dignity due to all human life, from conception to natural death.

“Dignity belongs equally to every single human being, irrespective of his parents’ desires, his social condition, educational formation or level of physical development. If at other times in history, while the concept and requirements of human dignity were accepted in general, discrimination was practiced on the basis of race, religion or social condition, today there is a no less serious and unjust form of discrimination which leads to the non-recognition of the ethical and legal status of human beings suffering from serious diseases or disabilities. It is forgotten that sick and disabled people are not some separate category of humanity; in fact, sickness and disability are part of the human condition and affect every individual, even when there is no direct experience of it. Such discrimination is immoral and must therefore be considered legally unacceptable, just as there is a duty to eliminate cultural, economic and social barriers which undermine the full recognition and protection of disabled or ill people.”<sup>50</sup>

Sex-selection for non-medical purposes has demonstrated the following disadvantages to families, society and the wellbeing of children:

- The promotion of gender discrimination through sex-selection is “inherently sexist.”<sup>51</sup>
- The threat to the universality of human rights and the resulting effect of legitimising sex selection in countries where the gender ratio is severely imbalanced.<sup>52</sup>

In cases where sex selection is used for ‘family balancing’: it is discriminatory towards families that consist only of children of the one gender, and promotes a belief that these families are ‘less desirable’ than families of children of both genders.<sup>53</sup>

The ACBC objects to the disposing of any human embryos, whether that be for sex-selection for medical or non-medical purposes. That is because such actions would instrumentalise human embryos, treating them as part of a production process where they can be kept or disposed of subject to arbitrary judgements.<sup>54</sup> This of course does not respect the embryos’ inherent human dignity.

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<sup>49</sup> Ibid.

<sup>50</sup> Ibid.

<sup>51</sup> Lisa Marie Sternke, “Ethical Considerations of Nonmedical Preconception Gender selection Research” in *Online Journal of Health Ethics Vol.6, Issue 1, Art.3*, July 2010

<http://aquila.usm.edu/cgi/viewcontent.cgi?article=1063&context=ojhe> , p.6.

<sup>52</sup> Blyth, Eric, Frith, Lucy and Crawshaw, Marilyn (2008) “Ethical objections to sex selection for nonmedical reasons.” *Reproductive BioMedicine Online*, 16 (Supple). pp. 41-45,

<http://eprints.hud.ac.uk/5406/1/BlythEthical.pdf> at 43.

<sup>53</sup> Blyth, Eric, Frith, Lucy and Crawshaw, Marilyn (2008) “Ethical objections to sex selection for nonmedical reasons.” *Reproductive BioMedicine Online*, 16 (Supple). pp. 41-45,

<http://eprints.hud.ac.uk/5406/1/BlythEthical.pdf> at 43.

<sup>54</sup> Velez, J, An Ethical Comparison between In-Vitro Fertilisation and NaProTechnology. *The Linacre Quarterly*, Vol. 79(1), page 61.



Sex selection is counter to the ideal that the love of parents should be unconditional. Children should be valued, whether born or not, whatever their sex, race, health, ability or age. Allowing sex selection for non-medical reasons would endorse a practice that undermines the value of parental love.<sup>55</sup> Moreover, there is no guarantee that a child selected on the basis of the sex desired by the parents will actually grow up meeting the parents' expectations for that sex and gender. What will happen if the parents' expectations for their "boy" or "girl" are not fulfilled by their child? In such cases, the "ability of parents to choose what sort of children they are going to have could lead to them being less willing to tolerate their children's shortcomings, and the child's self-esteem could be adversely affected, undermining the unconditional acceptance of a child."<sup>56</sup>

Additionally, what must also be considered is: "What fate might await a child where sex selection fails? Or one who develops a 'wrong gender' identity after their parents have gone to the effort and expense of sex selection?"<sup>57</sup>

The use of ART for sex selection clearly involves using not only the discarded embryos, but even the embryos accepted, as a means to an end.

This disapproval of sex-selection is shared by the Australian people. One Australian opinion survey on this issue found "seven percent of respondents approve or strongly approve the use of IVF for sex selection, 24% neither approve nor disapprove, and 69% disapprove or strongly disapprove."<sup>58</sup> A second survey of Australians found similar results with 73% saying "social gender selection" should not be allowed.<sup>59</sup>

Kippen et al hypothesised that, based on opinion data, "... widespread use of sex-selective technology could lead to a preponderance of first-born boys; where a preference is expressed, Australians tend to prefer first-born sons over first-born daughters."<sup>60</sup> Whether or not Australian culture would be as male preferring as some other cultures does not seem to have been resolved on the basis of evidence. The pressure appears to be for sex selection for the purpose of what is called "family balancing" in which a couple who already have a child or children of one gender want a child of the other gender. As noted above, there is no guarantee that the child "selected" to balance family gender expectations will actually meet those expectation. Moreover, no child should be expected to meet any such expectations.

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<sup>55</sup> Tobin, B, Why the Australian Health Ethics Committee should continue to prohibit sex-selection for non-medical reasons. Unpublished paper, 2015.

<sup>56</sup> Blyth, Eric, Frith, Lucy and Crawshaw, Marilyn (2008) "Ethical objections to sex selection for nonmedical reasons." *Reproductive BioMedicine Online*, 16 (Supple). pp. 41-45, <http://eprints.hud.ac.uk/5406/1/BlythEthical.pdf> at 43.

<sup>57</sup> Blyth, Eric, Frith, Lucy and Crawshaw, Marilyn (2008) "Ethical objections to sex selection for nonmedical reasons." *Reproductive BioMedicine Online*, 16 (Supple). pp. 41-45, <http://eprints.hud.ac.uk/5406/1/BlythEthical.pdf> at 43.

<sup>58</sup> Kippen, R et al, Australian attitudes toward sex-selection technology. *Fertility and Sterility*, Vol 95(5), April 2011, page 1825.

<sup>59</sup> Kovacs, G, McCrann, J, Levine, M and Morgan, G, The Australian Community Does Not Support Gender Selection by IVF for Social Reasons. *International Journal of Reproductive Medicine*, Vol 2013.

<sup>60</sup> Kippen, R et al, Australian attitudes toward sex-selection technology. *Fertility and Sterility*, Vol 95(5), April 2011, page 1826.

This issue was addressed in a case in Melbourne in which a couple had already aborted several male pregnancies in their desire to have a daughter and sought access to IVF for the purpose. The Victorian Civil and Administrative Tribunal (VCAT) addressed the issue on appeal after the matter was dealt with negatively by the Patient Review Panel established under the ART Act 2008. On appeal VCAT found “arguments based on completion of family, replacement of a child, or family balance do not advance the welfare or interests of a child born to fulfil that end.” The tribunal rejected the application.<sup>61</sup>

### **3b Compensation of Australian women for the reproductive effort and risks associated with donating their eggs**

The buying and selling of the most intimate and personal of human activities – the procreation of a child – is ethically unacceptable and must continue to be rejected. The existence of this ‘trade’ in human gametes in overseas countries is a tragic sign of the continued inequality and exploitation suffered by many women in our world. Financial compensation for egg donation will only continue to draw the neediest and most economically and socially disadvantaged women into the ‘market’ for reproductive ‘parts’.

As new reproductive ‘markets’ open up in the global economy, women are becoming both the consumers and the consumed. The dignity of women is violated, because the generation of a child is not simply a biological function which can be ‘outsourced’ to another in return for financial compensation, but a profoundly intimate relationship involving her whole person.

Payment of egg donors violates the dignity of the child by treating him or her as a commodity. Many women share these ethical concerns, as well as concerns about the risks to their health and fertility involved in egg donation.

The United Kingdom’s Human Fertilisation and Embryology Authority (HFEA) also found that financial inducement was not a significant factor influencing the supply of human eggs:

“In the HFEA’s own previous SEED review, women surveyed put lack of financial inducement at the very bottom of the list of reasons why they did not wish to donate eggs. At the top came justifiable concerns about the uncertainty of evidence concerning risks of ovarian hyperstimulation.”<sup>62</sup>

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<sup>61</sup> JS and LS v Patient Review Panel (Health and Privacy) [2011] VCAT 856  
[http://docs.health.vic.gov.au/docs/doc/61EEBF4FD349D1F8CA257AB5001916FE/\\$FILE/JS%20and%20LS%20v%20Patient%20Review%20Panel%20\(Health%20and%20Privacy\)%20\[2011\]%20VCAT%20856.pdf](http://docs.health.vic.gov.au/docs/doc/61EEBF4FD349D1F8CA257AB5001916FE/$FILE/JS%20and%20LS%20v%20Patient%20Review%20Panel%20(Health%20and%20Privacy)%20[2011]%20VCAT%20856.pdf)

<sup>62</sup> Dickenson, DL, Regulating (or not) reproductive medicine: an alternative to letting the market decide. *Indian Journal of Medical Ethics*, VIII(3) 2011: 176.

Regardless of the level of 'demand' for children, we must maintain the prohibition on the buying and selling of reproductive 'goods' and recognise it as a grave violation of human dignity:

"To treat parts of the body as fungible objects is to treat the provider not as an autonomous member of the kingdom of ends, but merely as a means ... Even if the seller of tissue voluntarily consents to treat her own body in this fashion, it is still wrong for any would-be buyer to treat her in this fashion, because it is inherently degrading."<sup>63</sup>

### **3c Establishment of an Australian donor egg bank**

For obvious reasons, we would not support establishment of a donor bank – which would only compound the numerous ethical problems with ART already noted.

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<sup>63</sup> Dickenson, DL, Regulating (or not) reproductive medicine: an alternative to letting the market decide. *Indian Journal of Medical Ethics*, VIII(3) 2011: 178.