

# REPORT ON THE REVIEW OF THE ASSISTED REPRODUCTIVE TREATMENT ACT 1988 (SA)

Sonia Allan

2017



Sonia Allan

---

# Report on the Review of the Assisted Reproductive Treatment Act 1988 (SA)

Prepared by Dr. Sonia Allan for the Minister for Health

January 2017

---

Copyright © 2017

# **Review of the *Assisted Reproductive Treatment Act 1988***

## **Terms of Reference**

The review will evaluate the operation and effectiveness of significant changes made to the Act in 2010, which had a legislative requirement for review after five years. The changes included:

1. the replacement of the previous licensing scheme with a registration scheme for clinics providing assisted reproductive treatment (A.R.T.);
2. the dissolution of the SA Council on Reproductive Technology and its Code of Ethical Conduct;
3. the requirement that the welfare of any child born as a consequence of A.R.T. is to be treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of the Act, as well as in the provision of A.R.T.;
4. allowing for the establishment of a donor conception register;
5. amending eligibility for access to A.R.T. services—noting that such conditions relate to the circumstances in which, and to whom, A.R.T. may be provided; and
6. provisions regarding record keeping and confidentiality.

# Table of Contents:

	<b>Page</b>
Terms of Reference	<b>iv</b>
List of Figures	<b>ix</b>
List of Tables	<b>ix</b>
Case Studies	<b>ix</b>
Acknowledgements	<b>x</b>
Dedication	<b>xi</b>
Executive Summary	<b>xii</b>
Table of Findings	<b>xviii</b>
Table of Recommendations	<b>xxix</b>

<b>Chapter</b>		<b>Page</b>
<b>1</b>	<b>Introduction</b>	<b>1</b>
1.1	Background: Changes to South Australian A.R.T. Law	2
1.2	The Legislated Review	6
1.3	Reviewer Background, and Conduct of the Review	7
1.4	The Scope of the Review	9
1.5	Consultation: Call for Written Submissions	11
1.6	Consultation: Fact Sheets and Posters	12
1.7	Targeted Consultation Meetings	12
1.8	Advice to all Participants	13
1.9	Written and Oral Submissions Received	13
1.10	Parliamentary Briefings	15
1.11	Conclusion	15
<b>2</b>	<b>Oversight of Clinics and Providers of A.R.T.</b>	<b>17</b>
2.1	Introduction	18
2.2	Registration Requirements for Providers of A.R.T.	19

2.3	Registration Requirements do not apply in relation to donor insemination	21
2.4	Changes to Regulation and Oversight	25
2.5	The Regulatory Approach in South Australia	35
2.6	Review of the Operation and Effectiveness of the Act	48
2.7	Conclusion	48
<b>3</b>	<b>Paramourncy of the Welfare of the Child</b>	<b>51</b>
3.1	Introduction	52
3.2	Focus of the Review	53
3.3	Support for the Provision	53
3.4	Operationalising the Welfare of the Child Principle	55
3.5	Screening for Hereditary or Infectious Disease	56
3.6	Screening Applicants for Risk of Harm to a Child(ren)	69
3.7	Screening of Donors for Prior Criminal Convictions	93
3.8	Research on the Short and Long Term Outcomes of A.R.T.	95
3.9	Inclusion of the Word 'Health' in the Paramourncy Provision	100
3.10	Donor Conception and the Welfare Principle	100
3.11	Conclusion	101
<b>4</b>	<b>Establishment of a Donor Conception Register</b>	<b>103</b>
4.1	Introduction	104
4.2	Why is Access to Information Important?	107
4.3	South Australia: Calls for Information	119
4.4	What has Happened Since?	120
4.5	Current Practices by Clinics in South Australia	122
4.6	Past Records	126
4.7	Conclusion	159
<b>5</b>	<b>Further Matters regarding Donor Conception and Access to Information</b>	<b>161</b>
5.1	Introduction	162

5.2	Operation of the Donor Conception Register	163
5.3	Voluntary Registration on Donor Conception Register	183
5.4	Information to be Held on the Donor Conception Register	184
5.5	Notification of Donor Conceived Status, Birth Registration, and Birth Certificates	186
5.6	Responsibility for Costs related to the Register	198
5.7	Clinics and the Recording and Reporting of Information	199
5.8	Conclusion	202
<b>6</b>	<b>Access to ART</b>	<b>205</b>
6.1	Introduction	206
6.2	Changes to Previous Legislation and Regulations	207
6.3	Operation and Effectiveness of the Act in Relation to Access Provisions amended in 2010	208
6.4	Other Matters Raised in Relation to Access	215
6.5	Conclusion	228
<b>7</b>	<b>Record Keeping</b>	<b>229</b>
7.1	Introduction	230
7.2	Record Keeping – Previous Regulations	230
7.3	Record Keeping – Current Regulations	231
7.4	Operation and Effectiveness of the Act: Record Keeping	232
7.5	Conclusion	234
<b>8</b>	<b>Conclusion</b>	<b>235</b>

<b>Appendices</b>		<b>Page</b>
1	Consultation letters inviting contribution	250
2	Consultation Poster	252
3	Meetings and live consultations	253
4	Written submissions	256
5	Comments on YourSAy	260

6	HFEA Welfare of the Child Guidance	261
7	Information Regarding Past Records Concerning A.R.T. And Donor Conception Held at Queen Elizabeth Hospital	266
8	Information Regarding Past Records Concerning A.R.T. And Donor Conception Held at Adelaide University / ACN	268
9	Birth Registration Form	271
<b>INDEX</b>		273

## List of Figures:

- Figure 1: Written submissions to the review, by type (page 14)
- Figure 2: Existing and recommended elements for effective co-regulatory governance of A.R.T. (page 50)
- Figure 3: Example Donor Conception Relationships: 10 Family Limit (page 113)
- Figure 4: Recommendations for Donor Conception Register and Access to Information in South Australia (page 204)

## List of Tables:

- Table 1: Summary of changes to the *Assisted Reproductive Treatment Act 1998 (SA)* (page 3)
- Table 2: HFEA Guidance Note – Factors to be considered for the welfare of the child (page 80)
- Table 3: Donor conception register: *Assisted Reproductive Treatment Act 1988 s 15* (page 120)

## Case Studies:

Case Study 1: Damian (page 127)

Case Study 2: Tiffany (page 128)

# ACKNOWLEDGEMENTS

As the independent reviewer of the *Assisted Reproductive Treatment Act 1988 (SA)* (the Act), I gratefully acknowledge the many people who shared with me their stories, wisdom, knowledge, experience, and views. Their contributions to this review have enabled me to better understand the key issues and complexities affecting people born as a result of assisted reproductive treatment, consumers and industry in South Australia. Via submissions, meetings, and follow up discussions, they were able to inform me of how current practices do or do not meet community expectations, and what more they felt could be done to give effect to the provisions and intentions of the Act.

I thank the Honourable Jack Snelling, Minister for Health for putting his faith in me to lead the review regarding the operation and effectiveness of the Act following changes that were made in 2010. The task was a weighty one, which required consideration of the regulatory model adopted in South Australia, matters related to the paramountcy of the child born as a result of assisted reproductive treatment (A.R.T.), the establishment of a donor conception register, access to A.R.T., and record keeping. It is an honour to have been appointed to undertake it.

I acknowledge the assistance and support of Dr. Zoe Gill, Senior Policy Officer, and Ms. Samantha Parker, Policy Officer, in the Department for Health and Ageing who provided executive assistance to the review. I commend them for their attention to detail and efforts as the review proceeded. I am grateful for the contributions each of them made, and wish them well in the new positions each of them moved onto in late 2016

I also pay thanks to people within the Department for Health and Ageing including (but not limited to) Skye Jacobi, Executive Director Policy & Governance; Prue Reid, Director Legal Governance and Insurance Services; Rachel Newrick, Assistant Director, Policy and Intergovernment Relations; Lee Wightman, Principal Consultant, Policy and Intergovernment Relations; Alex Trinca, Policy Officer, Policy and Intergovernment Relations; and Simone McDonnell, Ministerial Adviser to the Minister for Health. Thank you also to Helen Paues, Registrar, Registration Branch of Consumer Business Services, who provided me with information regarding the register of Births, Deaths and Marriages.

To all of the MPs and staffers who attended the Parliamentary Briefings, and/or have followed the progress of the review, I thank you also for your interest and care in relation to the matters that were being considered, and place faith and hope in you that you will support the recommendations in this report.

I hope I have well represented the views of the many people who spoke with me. Where there is oversight or error the responsibility remains mine.

# DEDICATION

*To the many people who have accessed A.R.T. who seek to build families and put their faith in others to do so; who spoke of hope, happiness, and at times, sadness. To all those born as a result. To the donor-conceived children and adults, some of them now parents themselves, who seek information from an era in which secrecy and anonymity was the norm; who spoke of feeling hurt, fear, confusion, distrust, and a longing to be able to understand their beginnings and their kinship ties. To all of the donors of reproductive materials and the recipients, who have built families, sought information themselves, and who embrace openness. To those who have persistently called for a donor conception register to be established in South Australia. To those who work to bring the joy of family and connection into people's lives. To all these people, I dedicate this report. May the recommendations I have made see implementation if they will serve to meet your needs, resolve wrongs of the past, and improve future practices and outcomes in A.R.T.*

Sonia Allan

# EXECUTIVE SUMMARY

## Chapter One: Introduction

The review of the *Assisted Reproductive Treatment Act 1988 (SA)* was concerned with the operation and effectiveness of the Act following significant changes to it in 2010. Chapter One outlines what those changes were and the reasons and intentions of Parliament for making them. It details the scope of the review, the qualifications and experience I brought with me, and the approach I took to conducting the review. It notes the principles upon which the review was predicated, including independence, objectivity, an inclusive and rigorous methodology, and openness and transparency. Details are also given regarding the process of consultation, which included

- preparation and distribution of seven Fact Sheets and a poster that provided information about the review and called for contributions;
- the establishment of a consultation space on the YourSAy website where people could gain information, comment and lodge submissions to the review;
- the use of social media to engage with the community and draw attention to the review;
- letters of invitation sent to invite people to participate in the review;
- the collection of written submissions, and the conduct of numerous meetings in South Australia, and beyond, in which I heard the views of people who had accessed assisted reproductive treatment (A.R.T.) and donor conception, donors, donor-conceived people, academics, representatives from government agencies, fertility clinics, medical associations, law associations, consumer organisations, and support groups.

The views of the contributors to the review informed this final report and the recommendations I make to the Minister for Health.

## Chapter Two: Oversight

The discussion in Chapter Two considers the operation and effectiveness of the Act focusing upon the changes made to the South Australian regulatory approach. It details how the

current Act and regulations changed prior regulatory oversight and advice mechanisms that existed via the South Australian Council on Reproductive Technology (SACRT), and repealed the Code of Ethical Clinical Practice that contained detailed provisions governing A.R.T. The changes introduced in 2010 saw South Australia move to a 'co-regulatory' system implementing framework legislation, which stipulates registration conditions for A.R.T. providers, and requires adherence to National Health and Medical Research Council Guidelines (NHMRC Ethical Guidelines) combined with the self-regulatory Reproductive Technology Accreditation Committee (RTAC) accreditation process.

Examination of the intentions of Parliament reveal that the changes were intended to reduce what was seen as duplication in terms of regulatory oversight and ethical guidance, regulatory costs and burden, and to improve the regulation of A.R.T. practices in South Australia. Further discussion ensues in Chapter Two regarding how the co-regulatory system could be improved to give effect to the intentions of Parliament and to ensure effective oversight of, and compliance with, the Act.

## Chapter Three: Welfare of the Child

Chapter Three focuses upon section 4A of the Act which provides the welfare of any child to be born as a consequence of the provision of A.R.T. must be treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of the Act. It was the intention of parliament to maintain *and strengthen* the provision under the changes made to the Act in 2010, parliament stating that the interests of children born as a result of A.R.T. must be placed above all other parties.

In considering the welfare of the child provision in the context of the operation and effectiveness of the Act, the review was particularly concerned with

- whether there was support for the paramountcy of the child provision, and its being strengthened as part of the 2010 changes;
- how the provision was being used, and to what effect;
- what sorts of considerations were being made and/or systems put in place to uphold the provision;

- what guidance was needed, if any, as to the sorts of considerations that should or should not be made;
- whether the paramountcy of the welfare of the child principle was being upheld in practice;
- whether more needs to be done to ensure the paramountcy of the welfare of the child principle is met, and if so, what.

Recommendations are made that will support the better operationalisation of the paramountcy of the welfare of the child principle, and consistency of practice across clinics in upholding the principle.

## Chapter Four: Establishing the Donor Conception Register

Chapter Four begins with a brief history and overview of donor conception, and the changes that have occurred across various jurisdictions that have moved to provide for access to information by donor-conceived people about their donors and siblings. Such history and changes form the backdrop to discussion of the operation and effectiveness of the current Act, which in 2010, provided that the Minister may establish a donor conception register. Chapter Four notes that to date a donor conception register has not been established.

The Chapter reflects upon submissions by donors, recipients, and donor-conceived people who wish to exchange information. For more than thirty years many have called for access to identifying information in South Australia. From at least the early 2000s the former SACRT, and the South Australian Social Development Committee, also called for the establishment of the register. Current practices regarding information recording and release by clinics are examined, and their support for the donor conception register noted. The primary recommendation in this regard is that the Minister should act to establish the donor conception register as a matter of priority.

Past records and practices are also discussed. The Chapter highlights the concern that some past records are currently held in places that do not fall under the auspices of the Act, and that donor-conceived people that they relate to are not afforded the same protections as others. The call to transfer all records onto the donor conception register is made. The subsequent question of whether to provide access to information by all donor-conceived

people, regardless of when they were born is examined; alongside how to balance their interests with those who donated under a previous regime, who may wish to protect their privacy. The release of information to donor-conceived people is recommended, subject to a system that offers intermediary and support services to all parties, and the option for donors to lodge a contact veto/preference statement. The recommended system would achieve a *balancing* of the interests of donor-conceived people, who seek information, with the interests of past donors, who may wish to determine the level of contact, if any, they would be willing to have.

## Chapter Five: Further Matters Regarding Donor Conception and Access to Information

Chapter Five continues examination of matters related to donor conception that were raised via submissions and meetings during the review. In particular, it focuses upon matters related to the operation of the donor conception register and access to information, including

- where the donor conception register should be located;
- the provision of intermediary and support services;
- access to information by donor-conceived people, recipients, donors, and siblings;
- voluntary registration of information upon the register by known donors and past donors (when records do not exist);
- information to be held on the donor conception register;
- notification of donor-conceived status via an addendum to the birth certificate;
- entry of information about biological heritage on birth registration statements, and second birth certificates; and
- cost considerations regarding transferring records to the register, and the ongoing functions of the register and provision of intermediary and support services.

These matters go to the operation and effectiveness of the current Act as it provides for the establishment of a donor conception register, and requires that the paramountcy of the welfare of the child be upheld. They also serve to respect the interests of donors and recipients of A.R.T.

## Chapter Six: Access to A.R.T.

Chapter Six focuses on access to A.R.T. in South Australia. It outlines how the current law operates via the setting of ‘conditions’ for registration for clinics providing A.R.T that determine to whom, and under what circumstances, clinics may provide such treatment. This compares to the previous regime by which an extensive Code of Ethical Practice determined access requirements. The discussion examines how the 2010 amendments maintained some of the previous requirements regarding who could access A.R.T and in what circumstances—including requirements of infertility for more invasive treatments, and risk of a child being born with a serious genetic defect. The amendments also introduced a number more instances in which A.R.T could be used, such as risk that a serious disease or serious illness would be transmitted to a child conceived naturally;<sup>1</sup> illness which may in the future result in infertility;<sup>2</sup> and the posthumous use of sperm when the woman’s deceased genuine domestic partner/spouse has left written instructions prior to his death that his sperm could be used by his widow to conceive a child.<sup>3</sup> How the old and new requirements for access are working, and any adjustments that need to be made, are examined.

Other issues raised in submissions relevant to access to A.R.T. are also considered. Recommendations in relation to such things as body mass index and obesity, smoking, age related considerations, social egg freezing, social sex selection, and process issues, are made.

## Chapter Seven: Record Keeping

Chapter Seven provides information on the pre- 2010 South Australian legislative provisions regarding record keeping<sup>4</sup> and the operation and effectiveness of the Act following the 2010 changes. It notes that issues relevant to record keeping are discussed throughout the report, for example regarding donor conception, and the short and long term health outcomes for

---

<sup>1</sup> *Assisted Reproductive Treatment Act 1988 (SA)*, s 9(1)(iii).

<sup>2</sup> *Assisted Reproductive Treatment Regulations 2010 (SA)*, reg 8(1).

<sup>3</sup> *Assisted Reproductive Treatment Act 1988 (SA)*, s 9(1)(iv).

<sup>4</sup> Matters concerning confidentiality raised in the initial consultation Fact Sheet 7 ‘Record Keeping and Confidentiality’, were discussed and addressed in Chapter Four noting the changes to confidentiality provisions in 2010 were intended to facilitate transfer of records to the donor conception register.

children born as a result of A.R.T. and for recipients and donors. Further discussion of record keeping and measures that would improve record keeping and reporting relevant to A.R.T. to enhance the operation and effectiveness of the Act ensues.

## Chapter Eight: Conclusion

Chapter Eight concludes the report. It provides brief discussion of other concerns relevant to A.R.T. in South Australia, and looks to the future. It ends by summarising the recommendations I have made to make more effective the operation of the Act, by addressing issues related to the oversight and regulation of A.R.T., the paramountcy of the welfare of the child principle, establishing the donor conception register, access to A.R.T., and record keeping.

# TABLE OF FINDINGS

## Oversight of A.R.T. Clinics

1. The 2010 changes to the Act that moved from a licensing scheme to a registration scheme for clinics has met the Parliamentary intention of removing anti-competitive requirements of the previous licensing scheme. The registration scheme has not generally presented any issues or concerns in relation to the operation or effectiveness of the Act.
2. Conditions for registration may need to be revised from time to time on the basis of relevant expert advice and evidence provided to the Minister.
3. While there are currently no ‘approved health professionals’ providing assisted insemination outside of clinics in South Australia, current legislative provisions that do not require ‘approved health professionals’ to register, and therefore adhere to conditions of registration, transgresses the spirit and intentions of upholding the welfare of the child as paramount, and supporting recipients and donors alike. Not to hold medical practitioners that operate outside of the registered clinic system to the same standards as those who provide artificial insemination within that system is unsatisfactory and therefore compromises the effectiveness of the Act.
4. While it would be difficult, if not impossible, to implement effective regulation of private artificial insemination arrangements, the Minister for Health could provide community information and/or education about any ethical and/or legal implications, as well as health risks, of such arrangements. These functions may be performed by an A.R.T. Advisory Council or the person(s) in the Department for Health and Ageing responsible for supporting the Council and oversight of the Act.
5. The RTAC accreditation scheme is a valuable self-regulatory auditing process that requires quality management systems. It is respected by clinics, albeit some personnel highlight the need for better guidance and follow up. There is also a call for the Minister to engage in further oversight of A.R.T. and auditing of accreditation outcomes, compliance, and any required improvements. The lack of current reporting to, and oversight from, the Minister in this regard compromises the operation and effectiveness of the *Assisted Reproductive Treatment Act 1988 (SA)*.

6. While regulation 8(2)(a) requires that the Minister include, as a condition of registration, a requirement that the A.R.T. provider adhere to the NHMRC Ethical Guidelines, sole reliance upon the NHMRC Ethical Guidelines has raised concern. It is problematic to rely on a set of ethical guidelines to regulate A.R.T. in a state that has a legislative framework without having a uniform point of reference for guidance and interpretation of such guidelines.
7. The co-regulatory system adopted in 2010 to govern A.R.T. in South Australia complements other laws that aim to ensure best practice and standards are met not only in the practice of A.R.T., but in all areas of medicine. It requires the government and those subject to the regulation to act in a manner that mutually reinforce one another and the sharing of responsibilities between public and private partners.
8. Monitoring of compliance, and enforcement of the Act is not being adequately operationalised by the Minister. Lack of reporting to, and auditing by the Minister regarding the self-regulatory aspects of the regime also compromises the accountability and openness required for an effective co-regulatory regime.
9. It is important to ensure that the Act is effectively operationalised while not creating unnecessary regulatory burden or functions. To give effect to a co-regulatory system too much top down governance should be avoided. On the other hand, it is not acceptable to do nothing, as a co-regulatory system requires *active participation* in the regulatory system by both government and clinics.

#### Paramourncy of the welfare of the child

10. The provision in the Act that the welfare of the child born as a result of A.R.T. must be treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of the Act, is valued and supported within South Australia and should be maintained.
11. There is a call for guidance from the Minister concerning how to give the paramourncy of the welfare of the child principle more effect.

#### *Screening for heritable diseases*

12. The acceptability of pre-implantation genetic diagnosis (PGD) screening to protect the welfare of the child to be born as a result of A.R.T. may depend upon the type of

hereditary condition or disease being screened, and the reasoning behind such screening. The current South Australian view is that careful evaluation of the reasons for the use of PGD, and restricting such screening to specific diseases or illnesses of a severe nature, is fundamental to upholding the paramountcy of the welfare of the child principle. There was call for government oversight to ensure PGD was only used in circumstances aligned with these views.

13. The use of PGD to avoid the *transmission of a sex-linked disease, disorder, or illness* of particular gravity accords with the paramountcy of the welfare of the child principle. As per the use of PGD for other medical screening careful evaluation of the reasons for its use, the seriousness of the condition, and adherence to the NHMRC Ethical Guidelines, are required.

#### *Sex selection for social purposes*

14. Sex selection for *social purposes* remains controversial and is not supported by the majority of the general public.

#### *PGD for HLA typing*

15. The current operation of the Act satisfactorily upholds the paramountcy of the welfare of the child principle in relation to PGD for HLA typing.

#### *Screening donors for heritable conditions*

16. The screening of donors for heritable disease or illness is currently practiced in South Australia, and accords with the fundamental principle in the Act regarding the paramountcy of the welfare of any child to be born as a result of A.R.T. in which donor gametes are used. Such screening practices should be uniform and consistent across clinics, accord with current best practice, and be updated periodically.
17. There is a lack of consistent method in South Australia for updating health information for donors or donor-conceived people, and an absence of a central donor conception register upon which such information may be recorded/accessed. There is also an absence of guidance regarding how to approach a donor-conceived person when there is a risk to their life, health, or safety, that with knowledge they may address. This does not accord with the paramountcy of the welfare of the child principle.

### *Screening Applicants for A.R.T. Regarding Potential Risk of Harm to Children*

18. The paramountcy of the welfare of the child principle, and the involvement of third parties such as the state and health professionals in the provision of A.R.T., supports the requirement for a level of assessment of people wishing to access A.R.T. regarding any risks of physical and/or psychological harm that may exist for a child born as a result of providing treatment.
19. The removal of prior uniform requirements for screening applicants for A.R.T. for risk pursuant to the welfare principle, and the lack of guidance under the current Act and regulations, has led to inconsistent practices across clinics in South Australia. Inconsistency and some such practices do not serve to uphold the paramountcy of the welfare of the child principle.

### *Screening donors for criminal convictions*

20. The review received two submissions that called for release of information about the criminal history of donors to parents and children. A recommendation could not be made on this matter, as further research into whether there is a call for such checks, and the scope, and limits, of the paramountcy of the welfare of the child provision, is needed.

### *Research into the short and long term outcomes of A.R.T.*

21. A failure to implement a reporting system following changes to the Act in 2010 have meant that an avenue to promote research, to report on what is being done, to exchange information, and to directly inform the Minister and public about the outcomes of such research is now lacking.
22. There continues to exist a need to understand the short and longer term impacts upon children born as a result of the use of A.R.T. in relation to their health and well-being. The risks are significant in an industry that is increasingly commercialised and sometimes lacking in evidence based practice, and in which the result of their practices are children. Doing nothing fails to uphold the paramountcy of the welfare of the child principle.

### Establishment of the Donor Conception Register

23. Reasons that donor-conceived people, recipient parents, and donors wish to exchange information range from issues concerning identity, medical information, fear and risks of forming consanguineous relationships, concern for each other's well-being, and a desire for openness, honesty and equality. In many circumstances the reasons given highlight the devastating impact that not having access to information has on some people. Allowing people to suffer in this way does not accord with upholding the paramountcy of the welfare of the child principle.
24. Despite decades of discussion and calls for the establishment of a donor conception register in South Australia, including consistent recommendations being made to respective Government Ministers by their own advisory bodies; and despite the enactment of the current A.R.T. legislation in 2010 making such a register possible, a donor-conception register has not been established.
25. Dissatisfaction exists amongst donor-conceived people, recipients, and donors, as well as some providers of A.R.T. that the NHMRC Ethical Guidelines are inconsistently interpreted and are subject to change that may impact them negatively. This provides further reasons for their call for the establishment of a central donor conception register.
26. Use of the NHMRC Ethical Guidelines as the mechanism to establish the right for donor-conceived people to access their donor information is problematic. While compliance with the Guidelines is mandatory under the Act, they are written in ethical terms and are open to different interpretations. This undermines the operation and effectiveness of the Act. Reliance upon ethical guidelines is not as desirable as having an explicit provision in relevant legislation requiring information recording and release.
27. All people who made submissions to the review showed overwhelming support for the establishment of a donor conception register, and of regulations governing access to information by donor-conceived people, donors, and recipient parent(s). The Minister should act to establish the donor conception register as a matter of priority.

### *Past Records*

28. Historical A.R.T records held at the University of Adelaide/ACN and the Queen Elizabeth Hospital are not captured by the current A.R.T regulatory framework. Donor-conceived people, donors and recipients seeking to access information in those historical records

may not be accorded the rights and processes provided to people who may access information held by registered A.R.T providers. This situation has caused, and continues to cause people distress, and is unacceptable. Rectification of the situation is well overdue.

29. There is a need to centralise and to sort all past A.R.T. records held by the University of Adelaide/ACN, the Queen Elizabeth Hospital, and Repromed to enter all relevant information on the donor conception register (when established). This will preserve records that otherwise are at risk of loss. It will also make clear what information is, and is not available regarding past donor conception.
30. The situation in relation to past records related to donors, recipients, and donor-conceived people associated with Flinders Fertility is similarly confusing and distressing for some donor-conceived people, recipients, and potentially also donors. There would be benefit in centralising all A.R.T. and donor conception records for their preservation and to enable a system to be established that includes a sensitive and consistent way of addressing enquiries.
31. The contact veto/preference system, if implemented properly, with sensitivity to each person's needs, rights and interests, would enable release of information to donor-conceived people about their donors, while allowing for a donor to lodge a contact veto/preference that stipulates the level of contact he/she is willing to have (be it none; via email, letter, meeting, or otherwise). It is a lawful, and respectful way of allowing the release of identifying information concerning past donor conceptions, that requires a compromise by each party when rights to information and rights to privacy compete. In this regard, the approach is intended to *balance* competing interests when they exist, by allowing both parties some level of recognition and respect for their rights while not completely favouring either.
32. The contact veto/preference system adopted in Victoria is more effective in *balancing* the rights and interest of donor-conceived people with those of donors who wish to protect their privacy than 'consent first' systems. The latter systems weigh in favour of donors' interests/rights and may effectively amount to an information veto, which does not accord with the paramountcy of the welfare of the child principle.

## Further Matters Related to the Donor Conception Register and Access to Information

### *Operation of the Donor Conception Register*

33. The South Australian offices of Births, Deaths, and Marriages (BDM) are the most suitable location for the donor conception register in South Australia. Locating the register at BDM would enable information about donor conception to be collected, administered, and disseminated alongside other birth information, where records are also securely stored in perpetuity. Access to information concerning a person's birth, biological and legal parentage, would occur in one location. Such a measure would minimise donor-conceived people being treated differently to all other people in South Australia who seek information about their legal and/or biological parents. It would also enable utilisation of existing expertise, resources, practice and process within South Australia.
34. Donor conception register information services should be supplemented by intermediary and support services. Such services should be provided on a needs basis, and should not be mandated except as required in relation to intermediary services concerning retrospective access to information; contact vetoes/preferences; and information exchange concerning people under 18 years of age.

### *Donors – Access to information*

35. Clinics should have an obligation to actively notify a donor of gametes or embryo(s) of the birth of a child(ren) resulting from such donation, the number, age and sex of children born; and the number of recipient families that have resulted.
36. Donors should be able to contact the donor conception register to ask for non-identifying information about number, age and sex of children born as a result of their donation, and the number of recipient families.
37. Recipients of donated gametes/embryos with children under the age of 18, and donor-conceived people over the age of 18 or of sufficient maturity, should be able to register their consent on the donor conception register to the release of identifying information to donors.
38. Any request for identifying information about a person born as a result of a donor conception should not occur without the above registered consent. In all cases the donor

should be referred to the intermediary and support services provider where he/she/they may discuss further their request and engage with support services as required.

#### *Siblings – Access to Information*

39. Recipient families of donor-conceived people under the age of 18, and donor-conceived people over the age of 18 or of ‘sufficient maturity’ should be able to access from the register non-identifying information about number, age and sex of children born as a result of a shared donor/s, and the number of recipient families (including the donor’s family). They should also be able to place consent on the register to the release of identifying information to siblings.
40. Release of identifying information about a sibling should not occur without registered consent by the sibling’s parent(s) if the sibling is under 18, or by the sibling if of sufficient maturity or over the age of 18. When consent has not been registered referral of the person making the request to intermediary services should occur, where further consideration of whether is appropriate to contact the parent(s) or sibling to seek such consent may be had.

#### *Voluntary registration on the donor conception register*

41. Voluntary registration by past donors of gametes/embryos and donor-conceived people onto the donor conception register should be possible, subject to any requirements of BDM for confirmation of status.

#### *Support for Recipient Parents*

42. More could be done to operationalise and make effective the *Assisted Reproductive Treatment Act 1988* (SA) by the Minister and A.R.T. providers to ensure ongoing information and support is given to recipient parents of donated gametes or embryos about access to information, the significance of biological connection to genetic parents and siblings, and how to discuss donor-conception with their children—all of which are required pursuant to NHMRC Ethical Guidelines, and so therefore under the law.

*Notification, Birth certificates and inclusion of known donors on register*

43. Interim changes to the *Births, Deaths, and Marriages Act* provide for recording of known donor details on the birth registration statement and for the option of including such details on a second birth certificate. The intention of Parliament in making such changes was to ensure donor-conceived people have a way of knowing their genetic heritage. The changes will expire on the establishment of the donor register.
44. The current law that allows for registration of a known donor on the birth registration statement and the option of including donor details on a second birth certificate confer rights that should not be lessened by the implementation of the donor conception register.
45. While providing information for some the current law will not ensure all donor-conceived people can choose to access such information, as some will not know that they are donor-conceived. This should be addressed by ensuring notification of status once a donor-conceived person turns 18 via an addendum to their birth certificate.
46. The possibility for inclusion of any biological parent(s) on a second birth certificate should be maintained. The option for issuance of a second birth certificate should be available to all donor-conceived people once they turn 18 whether a 'known' donor or clinic based donor was used.
47. The option to include 'known' donor details on birth registration statements should remain, with further option for a 'known' donor to register his/her details upon the donor conception register subject to any verification requirements of BDM.

*Follow up on birth outcomes*

48. Consultation with the registered clinics in South Australia revealed that each clinic had a system in place for following up with recipients of donor gametes/embryos regarding birth outcomes. However, many relied upon phoning (or writing to) recipients and obstetricians, and an ability to cross-check recorded birth outcomes was not apparent. The current system could be strengthened by implementing a number of measures. This includes that the Minister should *require*
  1. specific record keeping concerning donation, treatment, pregnancy, and birth,

2. follow-up on birth outcomes following donor conception,
3. adherence to the RTAC technical bulletin 8, and
4. reporting on matters related to the use of donor-conception.

### Access to A.R.T.

#### *Infertility Requirement*

49. The Minister should amend section 9 of the *Assisted Reproductive Treatment Act 1988* (SA) in accordance with the recommendations of the South Australian Law Reform Institute following their audit of South Australian laws to identify any legislative or regulatory discrimination against individuals and families on the grounds of sexual orientation, gender, gender identity, or intersex status.

#### *Posthumous Use of Gametes*

50. The operation and effectiveness of the *Assisted Reproductive Act 1988* (SA) would be enhanced by the Minister clarifying matters related to the posthumous use of gametes. Issues raised in relation to such use highlight the need for a mechanism that enables ongoing consideration and recommendations concerning any regulatory steps needed to ensure clarity regarding what is or is not intended by the law.

#### *Factors that may impact pregnancy, maternal risks, and birth outcomes*

51. The review received submissions that body mass index (BMI) can impact A.R.T. and birth outcomes, as well as increase maternal risks. A call was made for directives to ensure uniform standards of practice and defining when treatment is acceptable. In addition a call was made for patients who have high BMI to be provided information on how to optimise pregnancy outcomes and to be directed to appropriate weight loss programs/support services. It would accord with the functions of the recommended A.R.T. Advisory Council (Recommendation 4) to consider these matters further and to provide advice to the Minister about any action that should be taken.

52. The review also received a submission that made mention of smoking as a risk factor for children, and possible consideration regarding access to A.R.T. Similarly, in relation to

smoking and its impact on A.R.T. the A.R.T. Advisory Council would be well placed to evaluate medical evidence, and to make recommendations to the Minister.

53. Age plays a significant factor in the success of A.R.T. in terms of pregnancy and birth outcomes. The continued treatment of women beyond a certain age may be unacceptable for these, and other reasons. There is a call for clearer directions regarding the South Australian requirement within the conditions for registration under the Act that presently limits access to treatment based upon 'age of menopause'. The operation and effectiveness of the Act is compromised if there is ambiguity surrounding how its requirements should be interpreted.

#### *Social Egg Freezing*

54. Recommended changes to the *Assisted Reproductive Treatment Act 1988* (SA) to remove the infertility requirement for access to A.R.T. (see Recommendation 41) will have the additional effect of allowing social egg freezing to occur in South Australia unless such practice is specifically prohibited. Although the use of social egg freezing may highlight certain social and structural issues faced by women in societies in which social egg freezing is being used (which ideally society should address), prohibiting an adult woman from deciding for herself whether she wishes to pursue egg freezing is not necessary. Women considering social egg freezing must be fully informed of the risks involved in engaging in such procedures, and the potential outcomes. Laws exist to prohibit misleading and deceptive conduct or advertising; require informed consent; and establish professional standards of care and practice for all health practitioners. There is again a role for the recommended A.R.T. Advisory Council to encourage public discussion and education concerning women's fertility, and to monitor evidence and respond with advice to the Minister, if and when required.

#### *Testing and Treatment*

55. Less invasive testing and treatment should precede more invasive testing and treatment when clinically reasonable to do so. Consideration of the order in which A.R.T. patients are subjected to certain inquiry and/or treatments should be had by the recommended

A.R.T. Advisory Council, and advice as to whether there should be any directives on the matter should be provided to the Minister.

### Record Keeping

56. The review revealed gaps in past and present record keeping practices as highlighted throughout the report on a number of important matters related to A.R.T. and donor conception practices in South Australia. There is also an absence of regulations providing guidance concerning record keeping.
57. A system of auditing and required reporting concerning data and records required to be kept by A.R.T. clinics and health professionals should be established by the Minister. This should include reporting of data and records supplied to ANZARD and/or other bodies.
58. The Minister should reflect upon the auditing/reporting of records and data relevant to the safety and quality of A.R.T. treatment; clinical practice of A.R.T.; and outcomes to inform regulatory responses and policy development concerning the practice of A.R.T. in South Australia.

## TABLE OF RECOMMENDATIONS

### Oversight of A.R.T. Clinics

1. The Minister should seek relevant expert advice and evidence on a periodic basis to ensure that conditions of registration remain current and effective.
2. The Minister should clarify the intention of section 5(2)(a) of the Act regarding health professionals providing assisted insemination who are 'approved' by the Minister. In particular the Minister should address the context to which section 5(2)(a) is intended to apply, and stipulate conditions that all such health professionals would be required to meet.
3. Clinics should, in addition to current requirements under the *Assisted Reproductive Treatment Act 1988 (SA)*, be required to provide to the Minister the Certification Body's audit report and recommendation to RTAC for the granting of a licence, including any outline of non-conformance and corrective actions required. Auditing of clinics concerning how any non-conformance has been remedied should be conducted by the Minister.

4. The Minister should establish an A.R.T. Advisory Council—whose role it is to
  - a) advise the Minister regarding medical, social, scientific, ethical, legal, and moral issues arising from A.R.T, and any necessary directives that need to be issued to clarify acceptable practice in South Australia;
  - b) monitor compliance with the Act, via receiving annual reports from clinics that include details of the RTAC audit and any recommendations for improvement, and any further reports necessary to inform the Council of action that has been taken in response;
  - c) consider the results of any inspection or audit undertaken by a suitably qualified person appointed by the Minister, and make recommendations (when necessary) concerning appropriate action to be taken by the Minister;
  - d) promote and engage in public education and forums concerning A.R.T.
  - e) promote research, and provide the Minister with information regarding any research that may inform regulation and governance of A.R.T.
  - f) report annually on the above, as well as upon outcomes of A.R.T. in South Australia, and any other matters decided by the Minister.

The Council should include at least one A.R.T. health professional, consumer representatives (for example a donor of gametes, and a recipient of A.R.T.), religious leader representatives, a person born as a result of A.R.T., a person born as the result of donor-conception, a person with legal expertise in A.R.T. and health law, a person with expertise in ethics, a person with relevant expertise in counselling, and a scientific expert(s).

5. The Minister should ensure that the A.R.T. Advisory Council is supported in its functions by an appropriate Department for Health and Ageing staff member (or members) as required, who in addition undertake functions relevant to the implementation, oversight, monitoring, and enforcement of the Act.
6. To ensure effective operation of the Act, and that the functions of the A.R.T. Advisory Council may be realised, the Minister should:
  - (1) act upon regulation 8(2)(b) to make it a condition of registration that A.R.T. providers supply an annual report to Council that includes details of the RTAC audit and any recommendations for improvement, as well as any further reports necessary to inform the Council of action that has been taken in response;
  - (2) make it a condition of registration that clinics:

- a) may be subject to auditing by a suitably qualified person appointed by the Minister from time to time for the purposes of ensuring compliance with the requirements of the Act
  - b) must adhere to directives issued by the Minister;
- (3) appoint a suitably qualified person to audit and/or inspect providers of A.R.T. from time to time, for the purposes of ensuring compliance with the requirements under the Act;
- (4) issue directives relevant to the practice of A.R.T. in South Australia as the need arises, and/or as advised by Council.
7. The Minister should ensure provision in the Act for review of its operation and effectiveness five years after the date of the report from the last review being tabled in Parliament.

#### Paramountcy of the Welfare of the Child

##### *Screening for heritable diseases*

8. The Minister should conduct audits of clinics from time to time to establish the circumstances in which pre-implantation genetic diagnosis (PGD) has been used, and adherence to the law, conditions of registration, and relevant ethical guidelines.

##### *Sex selection for social purposes*

9. In the interest of upholding the welfare of the child born as a result of A.R.T. as paramount, the Minister for Health should maintain prohibitions on *sex selection for social purposes*. A statement to this effect should be included in the conditions for registration, or via a directive.

##### *Screening of donors for heritable conditions, updating health information, disclosure*

10. The Minister for Health should provide a directive on
- (1) requirements pertaining to screening of donors of gametes and/or embryos for heritable disease, disorder or illness, and

(2) disclosure to genetic relatives when such a disease, disorder, or illness is discovered by a donor/donor-conceived person that may pose a threat to the life, health, or safety of a related person—including requirements and processes concerning:

- a. updating the clinic, and/or donor conception register of health status;
- b. notification to the person at risk;
- c. provision by the clinic to the person at risk of appropriate support services (such as genetic counselling).

#### *Screening applicants for risk of harm*

11. The Minister should develop a directive that provides for a clear and consistent risk assessment framework and process to be used by clinicians/health professionals when assessing applicants and their partners (if any) in relation to any risk they may pose to a child born as a result of providing A.R.T. Such a directive should

- (1) include criteria to be considered,
- (2) outline the process to be followed,
- (3) provide for referral to, and consultation with, external experts, authorities, agencies, and/or support services,
- (4) make it an offence for applicants to provide false information in relation to the assessment,
- (5) allow for criminal record, ANCOR and/or child protection order checks in individual cases that raise significant concern, and
- (6) require information to be given to applicants regarding avenues available to them for judicial review (as appropriate).

A form should also be developed that all providers of treatment must use on which the outcomes of the assessment must be recorded, that may be audited by the Minister from time to time.

#### *Screening donors for prior criminal history*

12. The A.R.T. Advisory Council should consider whether donors of gametes and embryos should be screened in relation to prior criminal history; and the scope, and limits, of the paramountcy of the welfare of the child principle.

*Research – promotion, regulatory responsiveness, support*

13. The Minister should re-establish the promotion of research, and reporting on research and the outcomes of A.R.T. practices, as a required function of the recommended A.R.T. Advisory Council under the *Assisted Reproductive Treatment Act 1988 (SA)*.
14. The Minister should, pursuant to sections 9 and 20 of the *Assisted Reproductive Treatment Act 1988 (SA)*, issue regulations, conditions of registration, or directives from time-to-time, informed by research on the short and long term outcomes for people born as a result of A.R.T., that may set the bounds of A.R.T. practice necessary to uphold the principle of the paramountcy of the welfare of the child.
15. The Minister should consider and act upon the government’s ability (if any) to fund and/or support independent research that may contribute to ensuring the health, welfare and safety of children who are born as a result of A.R.T. and donor conception.

*Inclusion of the word ‘health’*

16. The Minister should amend the statement of principle concerning the paramountcy of the welfare of the child within the *Assisted Reproductive Treatment Act 1988 (SA)* to include the wording that both the *health* and welfare of the child born as a result of A.R.T. is paramount.

Establishment of the Donor Conception Register

17. The Minister should exercise his powers under section 15 of the *Assisted Reproductive Treatment Act 1988 (SA)* to establish the donor conception register as a matter of priority.
18. The Minister should amend section 15 of the *Assisted Reproductive Treatment Act 1988 (SA)* to state that the Minister *must* establish the donor conception register – to ensure that the register is maintained into the future.
19. The Minister should amend section 15(8) of the *Assisted Reproductive Treatment Act 1988* to apply to A.R.T. provided both before and after the commencement of section 15 of the Act.<sup>5</sup>

---

<sup>5</sup> Such amendment would also allow for any such transfer to accord with s18(1)(aa) of the *Assisted Reproductive Treatment Act 1988 (SA)* 1988 (SA), which provides an exception to the confidentiality provisions

20. The Minister should, subsequent to amending section 15(8), act pursuant to section 15(6) of the *Assisted Reproductive Treatment Act 1988* to provide notice in writing requiring all record(s) held by any person, establishment, organisation, A.R.T. clinic or otherwise, that relate to A.R.T. and/or donor-conception in South Australia, including (but not limited to) Queen Elizabeth Hospital and Adelaide University/ACN, Repromed, and Flinders Fertility to be transferred to the donor conception register as a matter of priority.
21. The Minister should pass legislation prohibiting the destruction of any record that relates to donor conception, and the donation of gametes and/or embryos, as a matter of priority.
22. Access to identifying information by donor-conceived people about donors who donated prior to the requirements for consent to release of such information in South Australia, should be permitted pursuant to regulations (promulgated under section 15(4) of the *Assisted Reproductive Treatment Act 1988* (SA)) that establish a contact veto/preference system. Such a system should include a careful process that is supportive and respectful of all parties.

#### Further Matters Related to the Donor Conception Register and Access to Information

##### *Operation of the Donor Conception Register*

23. The Minister should develop laws and undertake any other measures necessary to enable the donor conception register to be held at the South Australian Attorney General's Department, Births, Deaths, and Marriages (BDM), allowing for recording of all data alongside all other records held on the birth register and access to information concerning a person's birth, biological and legal parentage, to occur in one location.
24. As part of the establishment of the donor conception register at BDM, the Minister should engage an agency to provide intermediary and support services, and take whatever measures necessary (in law or otherwise) to ensure that the agency be given 'trusted agency' status in relation to all donor conception records.
25. The Minister should pass regulations that provide that intermediary and support services should be provided on a needs basis, and should not be mandated except as required in

---

if disclosure of information is 'required or authorised by the Act'. Here the disclosure would be the transfer by the holders of records to the register.

relation to intermediary services concerning retrospective access to identifying information; contact vetoes/preferences; and information exchange between recipients and donors concerning people under 18 years of age.

#### *Donors – Access to Information*

26. The Minister should issue a directive that clinics must *actively* notify a donor of gametes or embryos of the birth of a child(ren) that have resulted from the donation, including the number, age and sex of children born; and the number of recipient families that have been formed as a result of the use of the donor’s gametes or embryo(s).

27. The Minister should provide in the regulations regarding inspection of the donor conception register that:

(1) donors are able to contact the donor conception register to access non-identifying information about number, age, and sex of children born as a result of their donation, and the number of recipient families;

(2) recipients of donated gametes/embryos with children under the age of 18, and donor-conceived people over the age of 18 or of sufficient maturity, should be able to register their consent on the donor conception register to the release of identifying information.

(3) that when a donor requests *identifying* information about donor-conceived offspring that release of such information can occur only with the registered consent of recipient parents (when the child is under 18) or the donor-conceived person if over 18 or of sufficient maturity.

(4) when consent has not been given a donor should be referred to the agency providing intermediary and support services, who may provide support services as required.

#### *Siblings – Access to Information*

28. The Minister should provide in the regulations regarding inspection of the donor conception register that:

1. Recipient families of donor-conceived children under the age of 18, and donor-conceived people of age 18 or sufficient maturity are able to:

a) contact the donor conception register to access non-identifying information about number, age, and sex of children born to a common donor, and the number of recipient families (including the donor's own family if any);

b) register their consent on the donor conception register to the release of identifying information to siblings.

2. when a recipient family of a child under 18, or donor-conceived person over the age of 18 or sufficient maturity requests *identifying* information about siblings that share a common donor, release of such information can occur only with the registered consent regarding a sibling who is under the age of 18.

3. when consent has not been registered, the requesting party should be referred to the agency providing intermediary and support services, who will determine whether it would be appropriate to contact the parent(s) or sibling(s) to seek such consent.

4. All cases should be made aware of the presence of support services available to them if required.

#### *Voluntary Registration*

29. The Minister in drafting regulations regarding inspection of the register, should provide that voluntary registration by past donors of gametes/embryos and donor-conceived people onto the donor conception register should be possible, subject to any requirements of BDM for confirmation of status.

#### *Information to be Held on the Register*

30. The Minister should pass regulations pursuant to section 15(2)(d) of the Act to require the recording of comprehensive identifying and non-identifying information regarding the donor on the donor conception register. This is especially important to ensure consistency across clinics, and to ensure the recording of meaningful information about a person's genetic heritage.

### *Recipient Parents - Support*

31. To ensure recipient parents of donated gametes or embryos are given information and support regarding the significance of biological connection to genetic parents and siblings, and how to discuss donor-conception with their children, within the context of the recommendations made in this report:

- (1) BDM and the support services should publicise the donor conception register and how it works;
- (2) the A.R.T. Advisory Council should exercise its functions to promote and engage in public education and forums via producing information brochures and/or running a yearly 'Time to Tell' seminar;
- (3) auditing of clinics from time-to-time should include consideration of what clinics have done to uphold their obligations under the NHMRC Ethical Guidelines<sup>6</sup> and the Act.

### *Notification, Birth certificates, and inclusion of known donors on the Register*

32. The Minister should amend the law to require an addendum to a donor-conceived person's birth certificate that will notify them at age 18 when they apply for their birth certificate of more information being held on the donor conception register about them.

33. Provision should be made to maintain recent amendments to section 46 of the *Births, Deaths and Marriages Registration Act 1996 (SA)*, for voluntary inclusion of the name of any biological parent(s) on a second birth certificate of a donor-conceived person at their request, or the request of their legal parent(s) if the donor-conceived person is under the age of 18. The provision should be strengthened to apply to births that occurred before and after the commencement of the section. The option for issuance of a second birth certificate should be available to all donor-conceived people once they turn 18 whether a 'known' donor or clinic based donor was used.

34. Section 14 amendments to the *Births Deaths and Marriages Act 1996 (SA)* that require recording of information on the birth registration statement about 'known' donors, should remain.

35. The Minister should include in any changes to the law and/or regulations provision to

---

<sup>6</sup> NHMRC Ethical Guidelines, 6.1.2.

allow known donors from arrangements outside of clinics to be recorded on the donor conception register, for the addendum to be placed on the resulting child's birth certificate, and for the option of the known donor's name to be placed on a second birth certificate, as per all donor conception arrangements, subject to meeting any BDM requirements.

36. The Minister should provide (via law/regulations/directive as necessary) for a presumption of legal parentage when an alleged 'known' donor and recipient have been in a prior relationship with each other that resulted in them having a child/ren together for whom the alleged 'donor' is considered the legal parent.

#### *Supporting the costs of the register and associated services*

37. An ongoing levy or yearly fee paid by registered clinics and A.R.T. providers should be established to support the ongoing maintenance and operation of the donor conception register, and provision of intermediary and support services. The Minister should pass any laws or regulations and/or take any other actions necessary to make this possible.
38. Responsibility for the costs related to the transfer of past records to the donor conception register should be borne by any person, establishment, organisation, A.R.T. clinic or otherwise, that currently holds records that relate to donor-conception in South Australia, unless special dispensation or agreement as to costs is granted by the Minister.

#### *Record Keeping – Donor-conception*

39. The Minister should pass regulations that require clinics to record information at the time of 1) donation (on the donor's record), 2) treatment, including whether a pregnancy has occurred and expected date of delivery (on the donor's and recipient's records), and 3) birth (on the donor's, recipients, and donor-conceived person's record). Such information should be regularly reported to the Minister, as well as relevant information being entered into the donor conception register.
40. The Minister should require, and monitor, adherence to the RTAC technical bulletin 8 concerning counselling, agreement, and reporting on matters related to the use of donor sperm, eggs, or embryos.

## Access to A.R.T.

### *Infertility Requirement*

41. The Minister should amend section 9 of the Assisted Reproductive Treatment Act 1988 (SA) to provide that a person can access A.R.T. if, in the person's circumstances, they are unlikely to become pregnant other than by an A.R.T. procedure; and include the guiding principle that people seeking to undergo such procedures must not be discriminated against on the basis of their sexual orientation, marital status or religion.

### *Posthumous use of gametes*

42. The Minister should act to clarify the law regarding the posthumous collection, use and/or transport of gametes to another state when there has not been written consent.

### *Factors affecting pregnancy, maternal risk, and birth outcomes*

43. The Minister should seek further evidence and advice from the A.R.T. Advisory Council concerning health factors that may compromise A.R.T., pregnancy and birth outcomes, and increase maternal risk, including but not limited to factors related to Body Mass Index, as well as smoking. Based on such advice the Minister should issue directives, if deemed necessary, so that consistency of practice regarding access to treatment and information in such circumstances occurs in South Australia. The A.R.T. Advisory Council may also assist to encourage public discussion and information regarding effects of such things upon fertility, maternal risks, and pregnancy and birth outcomes.
44. The Minister should clarify the age limit requirement currently contained in the conditions for registration for the *Assisted Reproductive Treatment Act 1988* (SA).

### *Tests and Treatment*

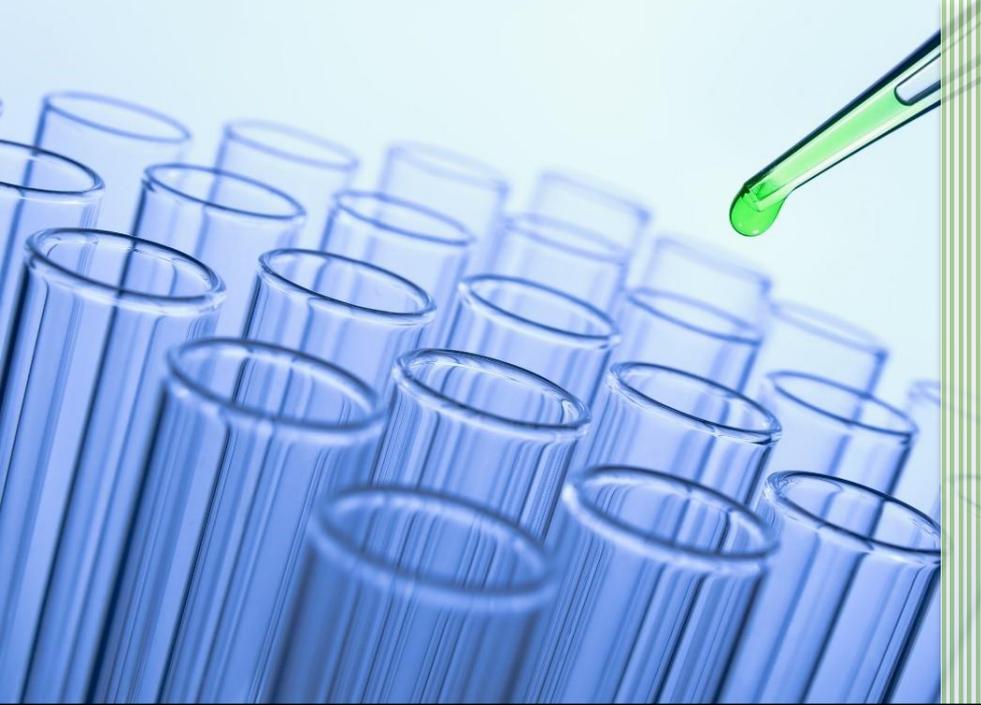
45. Consideration of the order in which patients are subjected to certain inquiry and/or treatments should be had by the recommended A.R.T. Advisory Council, and advice as to whether there should be any directives on the matter is required.

## Record Keeping

46. The Minister should issue regulations pursuant to section 16 of the *Assisted Reproductive*

*Treatment Act 1988 (SA)* concerning requirements for record keeping and documents in relation to the provision of A.R.T. and donor-conception, the length of required preservation of records, ongoing obligations concerning records should a clinic close, and responsibilities concerning records when a clinic changes hands.

47. Further to recommendations 4 and 6, the Minister should establish a system of auditing and required reporting that includes (but not limited to) reporting of data supplied to ANZARD, which may inform reflection upon clinical practice of A.R.T. and its outcomes and, regulatory responses and policy development.



# Chapter One

## Introduction

# Chapter One:

## Introduction to the Review

### 1.1 Background: Changes to South Australian A.R.T. law

On 1 September 2010, the regulation of assisted reproductive treatment (A.R.T.) in South Australia underwent significant changes. Parliament passed the Reproductive Technology (Clinical Practices) (Miscellaneous) Amendment Bill 2009 to amend the *Reproductive Technology (Clinical Practices) Act 1988 (SA)* and repeal the *Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995*. The changes were intended to ‘amend and update the *Reproductive Technology (Clinical Practices) Act 1988* to ensure that it meets the needs of South Australians requiring assisted reproductive treatment into the 21st century.’ The legislation governing A.R.T. in South Australia became known as the *Assisted Reproductive Treatment Act 1988 (SA)*.

Prior to the amendments governance of A.R.T. relied upon the South Australian Council on Reproductive Technology (SACRT), which was established under Section 10 of the previous legislation. The SACRT’s functions were to:

- a. formulate a code of ethical practice to govern artificial fertilisation procedures;
- b. provide advice to the Minister on conditions, licenses, and issues relating to reproductive technology;
- c. carry out research into the social consequences of reproductive technology;
- d. promote research and understanding of the causes of human infertility
- da. keep under review research involving human embryos;
- e. advise the Minister on any questions arising out of or in relation to, reproductive technology;
- f. promote (by the dissemination of information and other ways) informed public debate on the ethical and social issues that arise from reproductive technology;
- g. collaborate with other bodies carrying out similar functions within Australia.<sup>7</sup>

The Act and SACRT’s Code of Ethical Clinical Practice (which formed the Regulations)

---

<sup>7</sup> *Reproductive Technology (Clinical Practices) Act 1988*, s 10 (Repealed).

provided detailed information about requirements for assisted reproductive treatment in South Australia, including licence provisions, conditions for access to treatment, record keeping and confidentiality provisions.

The 2010 changes ended the oversight and functions of the SACRT, and moved to a framework style of regulation in which A.R.T. providers are registered by the Minister for Health subject to meeting certain criteria, are required to adhere to any conditions of registration set by the Minister, and are required to comply with the national self-regulatory accreditation scheme of the Reproductive Technology Accreditation Committee (RTAC)<sup>8</sup> and National Health and Medical Research Council *Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research 2004 (revised 2007)* (NHMRC Ethical Guidelines).

The 2010 changes also strengthen the stated legislative principle regarding the paramountcy of the welfare of a child born from A.R.T; amended certain eligibility criteria for accessing A.R.T. treatment; provided that the Minister for Health may establish a donor conception register; and amended record keeping and confidentiality provisions. Table 1 provides a summary of the 2010 changes to the regulation of A.R.T. in South Australia.

**Table 1: Summary of changes to the *Assisted Reproductive Treatment Act 1998 (SA)***

	Pre-2010	Post- 2010
Relevant South Australian Law	<ul style="list-style-type: none"> <li><i>The Reproductive Technology (Clinical Practices) Act 1988</i></li> <li><i>The Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995.</i></li> </ul>	<ul style="list-style-type: none"> <li>The Act was renamed <i>The Assisted Reproductive Treatment Act 1988 (SA)</i></li> <li>The Code was repealed, and replaced with <i>The Reproductive Treatment Regulations 1995</i></li> </ul>
Licensing/ Registration	<ul style="list-style-type: none"> <li>Licensing system which served to limit new providers in the area. New licenses only granted if unmet social need not met by existing licensees (seen as anti-competitive).</li> </ul>	<ul style="list-style-type: none"> <li>Registration Scheme – Clinics register with Minister pursuant to meeting RTAC accreditation, and conditions stipulated in Act and regulations.</li> </ul>
Oversight	<ul style="list-style-type: none"> <li>Reproductive Technology Accreditation Committee (RTAC) (via self-regulatory accreditation scheme)</li> </ul>	<ul style="list-style-type: none"> <li>RTAC (via self-regulatory accreditation scheme)</li> <li>SACRT dissolved</li> </ul>

<sup>8</sup> RTAC is a committee of the Fertility Society of Australia, the peak body representing all health professionals working in the fertility sector.

	Pre-2010	Post- 2010
	<ul style="list-style-type: none"> <li>• South Australian Reproductive Technology Council (SACRT)</li> <li>• Minister</li> </ul>	<ul style="list-style-type: none"> <li>• Minister</li> </ul>
Ethical Guidance	<ul style="list-style-type: none"> <li>• The <i>Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995</i></li> <li>• NHMRC Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research 2004 (revised 2007)</li> <li>• South Australian Reproductive Technology Council (SACRT)</li> </ul>	<ul style="list-style-type: none"> <li>• SACRT dissolved</li> <li>• SA Code of Ethical Clinical Practice Repealed</li> <li>• NHMRC Ethical Guidelines</li> <li>• Ethics Health Advisory Council mentioned by Parliament, but not in legislation/regulations</li> </ul>
Welfare of the Child	<ul style="list-style-type: none"> <li>• Welfare of the child prescribed as a guiding principle</li> </ul>	<ul style="list-style-type: none"> <li>• Welfare of the child provision retained and strengthened: requiring that the welfare of the child born as a result of the use of A.R.T. be considered as paramount and of fundamental importance in the application of the Act and in the provision of assisted reproductive treatment.</li> </ul>
Access to A.R.T.	<ul style="list-style-type: none"> <li>• Marital requirement (declared void in 1996 in <i>Pearce v South Australian Health Commission</i> (1996) 66 SASR 486)</li> <li>• Infertility</li> <li>• Risk of passing on genetic disease</li> <li>• Counselling requirements in Code (focus on children, outcomes and need for information)</li> <li>• ‘Screening’ - No treatment if prior offences or removal of children, or illness that would impact ability to care for children</li> <li>• Stored embryos to be destroyed if husband or wife dies, dissolve their marriage, or revoke consent</li> <li>• Welfare of the child principle</li> <li>• Appeal and review process for access to treatment decisions</li> </ul>	<ul style="list-style-type: none"> <li>• Removed marital requirement</li> <li>• Infertility</li> <li>• Risk of passing on genetic disease</li> <li>• Risk of passing on serious illness</li> <li>• Risk of future infertility of recipients</li> <li>• Posthumous use of sperm (if conditions are met)</li> <li>• A.R.T. not to be provided to woman of greater than or equal to the average age of menopause</li> <li>• Donated gametes must be destroyed after 15 years</li> <li>• Counselling provisions removed (some covered in NHMRC Ethical Guidelines).</li> <li>• No ‘screening’ criteria included</li> <li>• Welfare of the child principle strengthened</li> <li>• Removed appeal and review processes</li> </ul>

	Pre-2010	Post- 2010
Information	<ul style="list-style-type: none"> <li>• Detailed requirement for information recording about recipients and donors</li> <li>• Provisions regarding access to non-identifying records by recipients (identifying with consent)</li> <li>• Access to non-identifying information about recipients, and number and sex of children (if any), by donor</li> <li>• Recipients required to be counselled about the importance of disclosing to donor-conceived children about their status, and children's entitlement to non-identifying information about their donors (identifying with consent)</li> <li>• Provision of information to third-parties (e.g. via a register) impeded by confidentiality provisions.</li> </ul>	<ul style="list-style-type: none"> <li>• Access to non-identifying information about donor(s) and siblings possible</li> <li>• Disclosure of <i>identifying</i> information dependent upon consent</li> <li>• Provision in Act that Minister may establish a donor conception register</li> <li>• If register established provisions that: <ul style="list-style-type: none"> <li>○ enable transfer of data to the register (removing confidentiality impediment)</li> <li>○ require information to be recorded about donors/recipients/child (without register, record keeping requirements default to NHMRC Ethical Guidelines)</li> </ul> </li> </ul>
Record Keeping	<ul style="list-style-type: none"> <li>• Requirements regarding record keeping</li> <li>• Documents and records to be kept for 50 years</li> <li>• Limited protections for patients' and donors' records when clinics were closed or a licence cancelled.</li> </ul>	<ul style="list-style-type: none"> <li>• Section 16 of the Act allows for the regulations to set procedures to be followed to ensure that records are safely and appropriately stored, transferred and/or destroyed when clinics or other providers of A.R.T. cease to practice. (None currently set).</li> <li>• Conditions of registration require provision be made for transfer or destruction of records should registrant cease to provide A.R.T.</li> </ul>
Reporting	<ul style="list-style-type: none"> <li>• Annual reporting to SACRT required</li> <li>• Annual report by SACRT to Minister</li> </ul>	<ul style="list-style-type: none"> <li>• Parliament expressed intention to require clinics to provide copies of their annual national data reports to the Minister for Health, the requirements of which were to be detailed in the regulations. (Not currently operationalised).</li> </ul>

## 1.2 The Legislated Review

The law provides that the above changes to the *Reproductive Treatment Act 1988 (SA)* must be reviewed five years after the date of enactment. The Minister for Health, the Honourable Jack Snelling M.P., therefore appointed me, on 10 December 2015 to conduct the review as an independent consultant to government.

The terms of reference for the review required consideration of the operation and effectiveness of the Act in relation to:

- the replacement of the previous licensing scheme with a registration scheme for A.R.T. clinics;
- the dissolution of the SA Council on Reproductive Technology and its Code of Ethical Clinical Practice;
- the requirement that the welfare of any child born as a consequence of assisted reproductive treatment (A.R.T.) is to be treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of the Act, as well as in the provision of A.R.T.;
- provision for the establishment of a donor conception register;
- amending eligibility for access to A.R.T. services—noting that such conditions relate to the circumstances in which, and to whom, A.R.T. may be provided; and
- changes to provisions for record keeping and confidentiality.

The review was timely as a number of ethical, social, and legal issues had been raised and debated in relation to A.R.T. locally, nationally and internationally since the changes to the South Australian legislation had occurred in 2010. In particular there had been increasing public discussion of issues concerning the welfare of the child born as a result of A.R.T. and of donor conception, access to information by donor-conceived people about their donors and siblings, eligibility for assisted reproductive treatments without discrimination, sex selection for social purposes, the increasing commerciality of the A.R.T. industry, information concerning ‘success rates’, evidence based practices (or the lack thereof), and new emerging technologies. There had also been four government inquiries in Australia (one

federal, two in NSW, and one in Victoria) conducted on donor conception related issues.<sup>9</sup> In South Australia there had been a consistent call for the establishment of the donor conception register, and discussion (and some concern) about whether the regulatory model adopted in 2010 was working effectively.

The final deliverable of the review is this report, which includes discussion of issues raised with me during the review, and my findings and recommendations to the Minister for Health as to the operation and effectiveness of changes made to the Act in 2010.

## 1.3 Reviewer Background, and Conduct of the Review

To ensure openness and transparency regarding my appointment to lead the review my training and experience is noted here at the request of the Department for Health and Ageing. The principles upon which I conducted the review are also discussed.

My professional qualifications include a Bachelor of Laws (Hons), a Master of Law with Distinction (Global Health Law), and a PhD in law in which I examined the regulation of technologies that raise contentious ethical, social, and legal issues focusing on A.R.T., stem cell research, human embryo research and cloning. I also hold a Master of Public Health with merit, and a B.A. (Hons) in which I majored in psychology and education.

I have fourteen years of experience considering laws across Australia and from other jurisdictions that concern A.R.T. and emerging technologies. I have also examined the public consultation process, how we decide upon whether laws are necessary and where to draw the line between permitted and prohibited practices in areas that raise ethical, legal, and social issues, as well as how to regulate responsively in a rapidly changing field and models of regulation that most effectively achieve compliance.

---

<sup>9</sup> Senate Legal and Constitutional Affairs, Committee Inquiry into Donor Conception in Australia (2010-2011), [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Legal\\_and\\_Constitutional\\_Affairs/Completed\\_inquiries/2010-13/donorconception/index](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Completed_inquiries/2010-13/donorconception/index); NSW Law and Safety Committee: Inclusion of donor details on the Register of births (2012), <http://23.101.218.132/prod/parliament/committee.nsf/0/7E4018E851966190CA25792D0017F32F>; NSW Law and Safety Committee: Managing information related to donor conception (2013), <https://www.parliament.nsw.gov.au/committees/inquiries/Pages/inquiry-details.aspx?pk=2324#tab-reports>; Victorian Law Reform Committee, Inquiry into Access by Donor-conceived people to Information about Donors (2012), <http://www.parliament.vic.gov.au/57th-parliament/lawreform/article/1468>.

From 2003 to 2005 I worked for the Victorian Law Reform Commission on their reference on access to A.R.T. gaining invaluable experience concerning A.R.T. and associated issues, learning how to conduct public consultations, and developing an understanding of the process of law reform. I analysed submissions, conducted research, and wrote numerous briefing documents, consultation papers, and a comparative occasional paper on laws in Canada, United Kingdom, United States and Australia concerning assisted reproduction, legal parentage, surrogacy and adoption. As a legal academic and consultant I have ever since closely examined and written on such things as access to assisted reproduction, legal parentage of children born as a result of the use of A.R.T., surrogacy, posthumous use of gametes, pre-implantation genetic diagnosis, and other ethical, legal, and social issues raised by A.R.T. and emerging technologies.

I have also worked extensively on issues related to donor conception, having been struck by the experiences of donor-conceived people, their parents, and donors with whom I had come into contact. In 2011, as a result of my work on donor conception, I was awarded a Churchill Fellowship to conduct research in all countries that release information to donor-conceived people, and to bring the results of such research back to Australia. This gave me the opportunity to examine not only legislative provisions but also the implementation and practices of regulation by government agencies, clinicians, and support services in Austria, Finland, the Netherlands, Sweden, Switzerland, and the United Kingdom. I have contributed to numerous government inquiries at state and federal level in Australia. I have written extensively on information exchange between donor-conceived people, recipients, donors, and donor-siblings and refer to such research and writing within this report.

While my training and experience qualify me to lead the review, the review was conducted on the basis of **1) independence, 2) objectivity, 3) an inclusive and rigorous methodology, and 4) openness and transparency.**

To ensure independence, I was appointed as an *external* consultant to the Minister for Health independent of government. I was provided with executive support from one Senior Policy Officer, and one Policy Officer within the Department, which involved assisting me to understand policy and practice in South Australia and administrative functions relevant to the review. The policy officers also undertook their own relevant functions within the Department for Health and Ageing. Both policy officers had moved on to other positions in different government departments prior to the finalisation of this report.

Objectivity was maintained throughout the review by consulting extensively with people who are impacted by laws and practices in South Australia. This included those who have used A.R.T., donors of gametes, and those born as a result of the use of A.R.T. and donor conception. In addition, I was informed by those who work in the field of A.R.T. as well as those who have regulatory or other associated roles both in South Australia and in other jurisdictions. The consultation process gave me the opportunity to better understand the key issues, the complexities directly affecting consumers and industry, and how current practices do or do not meet community expectations. Participants were also able to reflect upon their experience and views of the operation and effectiveness of the Act since the 2010 changes, and to speak to matters regarding the regulation of A.R.T. in South Australia.

An inclusive and rigorous methodology was adopted, including thorough information gathering, and ensuring all views and submissions were analysed and considered in reaching the final recommendations.

Openness and transparency includes my acknowledging my own background (detailed above) and making clear how my experience and training has, and has not, been used to formulate the recommendations made in this report. Again, I note that while I have drawn upon such training and experience to conduct the review I have done so mindful of the need to remain objective, and to make recommendations premised upon a sound evidence base and information gathered during the review.

In addition to the above principles I have taken a comparative approach throughout, in which I have reflected upon regulation and governance, as well as practice and developments in other jurisdictions to inform matters relevant to the review. Discussion of other jurisdictions and their approach to a particular issue is provided in relevant chapters of the report.

Finally, it is noted that the review has been conducted on the basis that the fundamental principle of the South Australian legislation is that the welfare of any child born as a consequence of A.R.T. is to be treated as being of paramount importance, and is to be accepted as a fundamental principle, in respect of the operation of the Act, as well as in the provision of assisted reproductive treatment. In this regard, not only was the welfare principle evaluated in terms of its own operation and effectiveness, but it was applied to all aspects of A.R.T. covered by the review. The paramountcy of the welfare of the child principle therefore underpins all recommendations contained in this report.

## 1.4 The Scope of the Review

The terms of reference were extensive and covered a wide variety of issues related to regulation, governance and practices associated with A.R.T. and donor conception. The review did not go beyond the scope of the terms of reference.

Other legislation relevant to A.R.T. in South Australia includes the *Family Relationships Act 1975*, which refers to surrogacy and parenting; *Births, Deaths and Marriages Registration Act 1996*, which provides for registration of births; *Research Involving Human Embryos Act 2003*, which deals with the use of excess A.R.T embryos; and the *Prohibition of Human Cloning for Reproduction Act 2003*, which outlines unacceptable practices that may relate to A.R.T. These Acts were not the subject of this review. Incidental discussion of the *Births, Deaths and Marriages Registration Act 1996*, which provides for registration of births, does however occur in Chapters Four and Five in relation to the discussion concerning the establishment of a donor conception register and related matters.

The review did not cover issues related to surrogacy, research involving human embryos, or cloning, each of which fell outside of the scope of the terms of reference. The review also did not cover a small number of issues received via individual submissions that fell outside of the scope of the review, concerning an individual grievance against a clinic<sup>10</sup> and funding for A.R.T respectively.<sup>11</sup> I was sorry to hear of the experiences of the people concerned, and do hope the matters may be attended to. I have drawn them to the attention of Department for Health and Ageing. I also received a number of submissions regarding past practices of one South Australian clinic of treating women with different sperm donors. The past practices do not fall under the auspices of the current Act, however, I was very concerned for the people involved. I have contacted each individually, as well as written directly to the Minister for Health asking the issues raised be examined, and followed up separately.

The review resulted in this report, which includes discussion of the findings of the review and recommendations regarding the regulation of A.R.T. in South Australia to be considered by the Minister.

---

<sup>10</sup> Confidential, submission 76.

<sup>11</sup> Confidential, submission 13.

## 1.5 Consultation: Call for Written submissions

As part of the review of the *Assisted Reproductive Treatment Act 1988 (SA)* a three month public consultation was conducted on matters relevant to the review from 19 January 2016 to 15 April 2016. The public consultation was advertised and submissions invited in a number of ways.

Information about the review and public consultation was published on the South Australian Government SA Health website,<sup>12</sup> and on a designated consultation website known as ‘YourSAy’<sup>13</sup>—an online consultation hub where any interested party can have their say, and influence the decisions of the South Australian government. YourSAy made regular postings on social media such as Facebook and Twitter to alert the public to the review.

I also used social media to regularly ‘tweet’ and post to Facebook via my personal accounts, to raise awareness and to encourage participation in the review.

Calls for submissions were advertised in the Saturday Advertiser, local Messenger papers, and Adelaide’s Child.

More than seventy personal letters of invitation to make written submission to the review were also sent in the first month of the consultation period (see Appendix 1).

Further letters were sent in the last month of the review to bodies or associations that might have a wider reach, if a submission to the review had not yet been received, to ask them to draw attention to the review, and to encourage participation.

An email was sent out by the South Australian Department for Health and Ageing about the review to the South Australian Public sector.

Written submissions to the review were received via the YourSAy website (through an online form or comments section), email, and via the post.

<sup>12</sup>See Government of South Australia, SA Health, ‘Assisted Reproductive Treatment Legislation’, <http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/legislation/assisted+reproductive+treatment+legislation>, accessed 8 January 2017.

<sup>13</sup>YourSAy website, <http://yoursay.sa.gov.au/decisions/yoursay-engagements-review-of-the-assisted-reproductive-treatment-act-1988/about>, accessed 8 January 2017.

## 1.6 Consultation: Fact Sheets and Posters

To facilitate understanding of the focus of the review seven fact sheets were prepared for public distribution. These included Fact Sheets concerning the Act and areas of review:

- Fact Sheet 1: Introduction to the Review
- Fact Sheet 2: Paramountcy of the Welfare of the Child
- Fact Sheet 3: Registration Scheme for A.R.T. Clinics
- Fact Sheet 4: Dissolution of SA Council on Reproductive Technology, and its Code of Ethical Clinical Practice
- Fact Sheet 5: Access to Assisted Reproductive Treatment
- Fact Sheet 6: Establishment of a donor conception register
- Fact Sheet 7: Record Keeping and Confidentiality

The above Fact Sheets also posed questions intended to assist people in informing the review.

The Fact Sheets were posted on the South Australian Department for Health and Ageing website, the YourSAy website, and were also sent with each of the personal invitation letters.

The YourSAy website also provided links to

- the NHMRC Ethical Guidelines;
- the Conditions of Registration for South Australian A.R.T. registered providers;
- the Reproductive Technology Accreditation Committee Code of Practice.

A Poster was prepared for public display and distributed with many of the invitation letters above, inviting the recipient to display the poster in their rooms and to disseminate the posters to any contacts they had that might be interested in the review. Posters were also sent to the Department for Education and Child Development, the major maternity wards in South Australia, and A.R.T. clinics with a request to display at their sites (See Appendix 2).

## 1.7 Targeted Consultation Meetings

The public consultation period was followed by targeted face-to-face consultation meetings during the week of 18-22 April, 2016 and forums for donor-conceived people and consumers

respectively. Individual meetings and phone consultations were also conducted with four sperm donors, and one other donor conceived adult. Further phone consultations were conducted in May, after the above consultation period, with a relevant person about historical records held concerning donor conception at Adelaide University, and with some clinic employees who could not make the April meetings. The dates and general details of meetings and forums are further detailed in Appendix 3.

## **1.8 Advice to all Participants**

All people who participated in the review, either by making written submissions, posting comments on the YourSAy website, engaging in meetings or forums, or speaking via telephone with me, were informed that once the review was completed a report would be produced. They were told that the report would include recommendations regarding the regulation of A.R.T. in South Australia, and that their input could help shape the recommendations in the report. They were further informed that the report would be tabled in Parliament and be made publically available and the recommendations would be considered by the Minister for Health.

It was noted on all consultation materials that confidential submissions would be accepted, and that in this event the material in the submission would be used to inform the review, but the submitter would not be referred to by name. It was also noted that if submissions were not marked confidential they would be public, could be posted on the YourSAy website, and the author may be referred to by name in the report. It was stated that anonymous submissions would not be accepted to ensure that all submissions received were from identifiable people or associations. People with whom I met or spoke, gave consent to being named in the report or requested that their comments be de-identified.

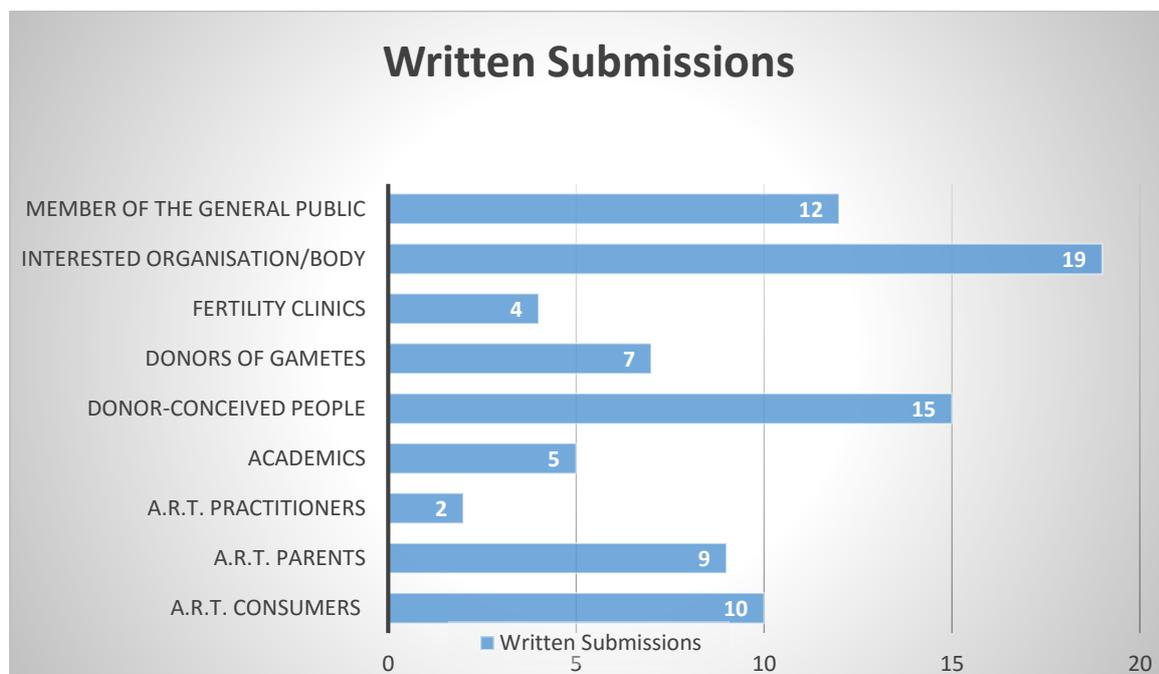
## **1.9 Written and Oral Submissions Received**

Eighty four written submissions were received during the consultation period (and for two weeks following the close of the consultation period by people/organisations who had asked for an extension). Only one submission, made by a member of the general public was

anonymous (rather than confidential), it is counted in the '84' submissions received, but was not further used as identity of the submitter could not be confirmed. All four operators of South Australian fertility clinics lodged written submissions (noting there are five registered clinics in South Australia, but two are operated by the same company, one of which is not yet operational). Each also met with the reviewer. Twenty seven of the submissions requested confidentiality as to their identity. Written submissions were numbered from 1 to 83 in the order of receipt, with the anonymous submission not being included in the numbering. All written submissions are listed in Appendix 4.

Figure 1 shows a breakdown of the types of organisations and persons who lodged written submissions to the review.

**Figure 1: Written Submissions to the Review, by type**



I also personally met or spoke with over fifty people during face-to-face consultations in relation to matters relevant to the operation and effectiveness of the *Assisted Reproductive Treatment Act 1988 (SA)*, with person/organisation type listed in Appendix 3.

Ten comments were posted on the YourSAy website, by people who wished to access A.R.T., recipients of A.R.T., donors, and donor-conceived people. The submitters of these comments are listed in Appendix 5.

In addition, I

- engaged with a number of people during the review via follow up phone calls, received follow-up emails from donor-conceived people, recipients, and donors; as well as conversed with the Western Australia Reproductive Technology Unit;
- made visits to both the NSW Ministry of Health, and Victorian Assisted Reproductive Treatment Authority—both of which were not able to make submissions to the review, but were happy to explain to me details about their functions, operation and work;
- was invited to attend a donor conception support group meeting in NSW, where I heard about a number of donor-conceived people’s experiences in that state regarding trying to access information about their donors and siblings.

## 1.10 Parliament Briefings

I conducted two briefing sessions for Members of Parliament at the beginning and end of the consultation period. The briefings were held in the South Australian Parliament House.

In the first briefing the terms of reference, the public consultation, and the focus of the review were explained. The floor was also opened for discussion with the Members of Parliament and/or their staff, and they were invited to contact me with any further questions or issues they would like attended to as part of the review. The attendees were also asked to take the matters of the review in consultation to their constituents.

In the second briefing the members and/or their representatives were informed about the results of the public consultation process and participation, and given a broad overview of what had been raised in relation to the operation and effectiveness of the *Assisted Reproductive Treatment Act 1988 (SA)*. Discussion and questions followed.

## 1.11 Conclusion

I have endeavored in the following pages to be as thorough as possible in addressing the many issues raised in the submissions to the review. Some such issues required a significant amount of in-depth analysis and discussion in order to reach a conclusion about what recommendation(s) should be made. I have included background, comparisons, research, and discussion of the results of the consultation, as a means of making clear how I have reached

my conclusions. I have stated what I have found via concluding 'Findings', as well as what action needs to be taken via 'Recommendations', in order to ensure the effective operation of the *Assisted Reproductive Treatment Act 1988* (SA).

I note that this being the first opportunity for people to raise issues concerning the changes to the Act in 2010, there was much to say about how best to refine the co-regulatory system that has been adopted; and how to implement or change provisions in the Act to better serve those born as a result of A.R.T., recipients (and their partners if any), and donors of gametes and/or embryos. Each of the different areas of the review required a number of changes, be it in relation to ensuring an active regulatory partnership between the government and clinics regarding implementing, oversight and compliance with the Act, upholding the paramountcy of the welfare of the child, establishing the donor conception register, accessing A.R.T. and/or record keeping. The discussion in the following pages reflects this, with more expansive discussion of some areas that presented challenges, or required detailed analysis of not only the steps that should be taken, but the operational considerations to be had.



# Chapter Two

## Oversight of A.R.T. Clinics and Providers of A.R.T.

# Chapter Two: Oversight of A.R.T. Clinics and Providers

## 2.1 Introduction

In South Australia, the *Assisted Reproductive Treatment Act 1988*, and *Assisted Reproductive Treatment Regulations 2010* provide for the regulation and oversight of assisted reproduction by the Minister for Health. The current Act and regulations came into effect in 2010 changing prior regulatory oversight and advice mechanisms that existed via the South Australian Council on Reproductive Technology (SACRT), and repealing the Code of Ethical Clinical Practice that contained detailed provisions governing A.R.T.

In the place of SACRT and the Code, South Australia moved to a ‘co-regulatory’ system implementing framework legislation, which stipulates registration conditions for A.R.T. providers, and requires adherence to National Health and Medical Research Council Guidelines<sup>14</sup> (NHMRC Ethical Guidelines) combined with the self-regulatory Reproductive Technology Accreditation Committee<sup>15</sup> (RTAC) accreditation process. The changes were intended to reduce what was seen as duplication in terms of regulatory oversight and ethical guidance, regulatory costs and burden, and to improve the regulation of A.R.T. practices in South Australia.

The following discussion considers the operation and effectiveness of the Act in light of the changes made to the South Australian regulatory approach. Further discussion ensues regarding how the co-regulatory system could be improved to give effect to the intentions of Parliament and to ensure effective oversight of A.R.T. in South Australia.

---

<sup>14</sup> National Health and Medical Research Council, *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research* (2004) (Updated 2007) (NHMRC Ethical Guidelines).

<sup>15</sup> The Reproductive Technology Accreditation Committee (RTAC) was established by the Fertility Society of Australia (FSA) (the peak self-regulatory body representing scientists, doctors, researchers, nurses, consumer groups, and counsellors in reproductive medicine in Australia and New Zealand) in 1986 as a committee to accredit A.R.T. clinics.

## 2.2 Registration Requirements for Providers of A.R.T

In South Australia the *Assisted Reproductive Treatment Act 1988* and the *Assisted Reproductive Treatment Regulations 2010* set out requirements for registration;<sup>16</sup> mandatory conditions for registered A.R.T providers;<sup>17</sup> powers of the Minister for Health to suspend or cancel registration;<sup>18</sup> and/or to remove a person from the register;<sup>19</sup> reinstatement provisions;<sup>20</sup> and an appeals process to enable review of any decision relating to the above.<sup>21</sup> A person (or company) must not provide assisted reproductive treatment in South Australia unless they are registered by the Minister for Health. Failure to be registered may result in a maximum penalty of \$120,000.<sup>22</sup>

To be registered an applicant must establish that he or she is a fit and proper person to be registered; holds any licence, accreditation or other qualification required by the regulations for the purposes of registration; and satisfies any other requirements prescribed by the regulations.<sup>23</sup> The 2010 regulations provide that a current RTAC license is required for the purposes of registration.<sup>24</sup>

Registered A.R.T providers must also comply with the Act, the regulations and any conditions imposed on their registration, ensure practice and research comply with any policies or guidelines issued from time to time; and submit reports to the Minister for Health on request.<sup>25</sup> Mandatory conditions for registered A.R.T. providers are placed by the Minister for Health as set out in the Act<sup>26</sup> and regulations.<sup>27</sup> Such conditions include (but are not limited to) circumstances in which assisted reproductive treatment may be provided. (For further information on access and eligibility requirements, see Chapter Six). The Minister must also

<sup>16</sup> *Assisted Reproductive Treatment Act 1988* (SA), Part 2; *Assisted Reproductive Regulations 2010* (SA), reg 6.

<sup>17</sup> *Assisted Reproductive Treatment Act 1988* (SA), s 9; *Assisted Reproductive Regulations 2010* (SA), reg 8.

<sup>18</sup> *Assisted Reproductive Treatment Act 1988* (SA), s 10.

<sup>19</sup> *Ibid*, s 11.

<sup>20</sup> *Ibid*, s 12.

<sup>21</sup> *Ibid*, s 13.

<sup>22</sup> *Ibid*, s 5.

<sup>23</sup> *Ibid*, s 6.

<sup>24</sup> *Assisted Reproductive Regulations 2010* (SA), reg 6.

<sup>25</sup> *Ibid*, reg 8(2)(b).

<sup>26</sup> *Assisted Reproductive Treatment Act 1988* (SA), s 9.

<sup>27</sup> *Assisted Reproductive Regulations 2010* (SA), reg 8.

impose a condition on registration requiring that the person comply with NHMRC Ethical Guidelines.<sup>28</sup>

The Minister may suspend or cancel registration if a person has failed to comply with or has contravened conditions of registration,<sup>29</sup> and must remove a person from the register if they no longer meet registration requirements, or have had such registration cancelled or suspended.<sup>30</sup> The Minister can also reinstate registration subject to application and approval.<sup>31</sup>

There are five registered providers in South Australia, Flinders Fertility,<sup>32</sup> which has been in existence since 1970; Repromed,<sup>33</sup> which in its current form was established in 2006; Fertility SA, established in 2011; City Fertility, established in 2011; and MyIVF, established in 2014 (which is not yet operational, and is owned by the same company as Repromed).

The review received few comments that related specifically to the current registration scheme. A medical indemnity insurer said that they were not aware of any particular issues or concerns relating to the operation of the current registration scheme. The Law Society submitted that *'the current registration scheme for clinics appears to be sufficient'*.<sup>34</sup> A.R.T. providers reported being satisfied with the registration system.

The removal of the previous licence system which included a need to demonstrate an unmet social need before any new licence could be issued, had occurred because it had been perceived as anti-competitive. Since the changes to the Act, the number of A.R.T. providers operating in South Australia has increased from two (Flinders Fertility and Repromed) to four (addition of Fertility SA and City Fertility). This has increased the geographical range of A.R.T. services in metropolitan Adelaide, especially in the Western and inner Southern suburbs particularly as City Fertility operate two A.R.T. treatment sites at Western community Hospital and Ashford.

Professors De Lacey and Tremellen however expressed their concern that entry into the market of new IVF providers 'may dilute activity to the extent that it is no longer cost-effective to provide comprehensive resource intensive treatments' and a view that 'clinical

---

<sup>28</sup> Ibid, reg 8(2)(a).

<sup>29</sup> *Assisted Reproductive Treatment Act 1988 (SA)*, s 10.

<sup>30</sup> Ibid, s 11.

<sup>31</sup> Ibid, s 12.

<sup>32</sup> Actually Flinders Reproductive Medicine, trading as Flinders Fertility; sometimes referred to in submissions as Flinders Medical Centre as this is where one of the Flinders Fertility sites is housed.

<sup>33</sup> Adelaide Fertility Centre (AFC), trading as Repromed.

<sup>34</sup> Law Society, submission 77.

outcomes tend to be superior in larger units'.<sup>35</sup> They called for further registration requirements that A.R.T. providers should demonstrate the ability to provide 'a fully comprehensive fertility service' and the 'provision of appropriate specialised clinical expertise in infertility medicine'. These suggestions do not indicate a failing of the registration scheme itself, but rather are matters that might be considered by appropriate expert advisors to the Minister as to whether condition(s) of registration should include such requirements. As such, I make no findings on these issues here.

**FINDING 1**

The 2010 changes to the Act that moved from a licensing scheme to a registration scheme for clinics has met the Parliamentary intention of removing anti-competitive requirements of the previous licensing scheme. The registration scheme has not generally presented any issues or concerns in relation to the operation or effectiveness of the Act.

**FINDING 2**

Conditions for registration may need to be revised from time to time on the basis of relevant expert advice and evidence provided to the Minister.

**RECOMMENDATION 1**

The Minister should seek relevant expert advice and evidence on a periodic basis to ensure that conditions of registration remain current and effective.

## **2.3 Registration Requirements do not apply in relation to Assisted Insemination**

The registration requirements do not apply in relation to 'assisted insemination'<sup>36</sup> – which is defined as an A.R.T. procedure that does not involve IVF or a surgical procedure.<sup>37</sup> Health professionals that provide such assisted insemination must nevertheless be 'approved by the

<sup>35</sup> DeLacey and Tremellen, submission 45.

<sup>36</sup> *Assisted Reproductive Treatment Act 1988* (SA), s 5(2)(a).

<sup>37</sup> *Ibid*, s 3.

Minister’ for the purposes of the Act.<sup>38</sup> Such approval may be conditional or unconditional<sup>39</sup>— noting any breach of a condition placed upon approval may be subject to a maximum penalty of \$120 000.<sup>40</sup> There are currently no approved health professionals in South Australia providing artificial insemination.

In addition, the approval requirements do not apply when assisted insemination is provided other than for fee or reward.<sup>41</sup> Such circumstances might include, for example, self-insemination, or the assisted insemination of a friend or partner.

The review received a number of submissions objecting to the provision that health professionals who provide assisted insemination do not have to meet the same requirements as registered clinics.<sup>42</sup> Most were concerned with the implications of having different requirements for health professionals operating outside of registered clinics upon upholding the paramountcy of the welfare of the child principle, and upon the kind of care recipients and donors of gametes might receive. For example, the Australia and New Zealand Infertility Counsellors Association (ANZICA), submitted:

*ANZICA would like to express its belief that not requiring registration in relation to assisted insemination outside of a clinic transgresses the paramountcy of the welfare of the child. A.R.T. clinics are required to comply with RTAC guidelines and auditing which includes providing Implications and Support Counselling for those involved in third party reproduction. This psycho-educational preparation provides the participants the opportunity, often the only opportunity, to give consideration to the best interests of the child and to deal with any grief and reproductive loss at not having a genetically registered child.<sup>43</sup>*

Kim Buck, a donor-conceived person, said

---

<sup>38</sup> Ibid, s 5(2)(a).

<sup>39</sup> Ibid, s 5(3).

<sup>40</sup> Ibid, s 5(5).

<sup>41</sup> Ibid, s 5(2)(b).

<sup>42</sup> Damian Adams, submission 34; Kim Buck, submission 41; Confidential, submission 68; Kylie Dempsey, submission 69; Law Society, submission 77; ANZICA, submission 82.

<sup>43</sup> ANZICA, submission 82.

*Assisted insemination provided outside of a clinic by a GP or other health professionals should be subject to the same registration requirements as that provided by clinics/providers. This would ensure that all of the protections contained within the legislation (i.e. the welfare paramountcy principle for the child resulting from ART, screening of donors for disease/illness, screening of prospective parents (if this were to be addressed in any new legislation), and satisfactory record keeping practices) would be applied transparently and fairly across all assisted reproductive treatments in South Australia.<sup>44</sup>*

**FINDING 3**

While there are currently no ‘approved health professionals’ providing assisted insemination outside of clinics in South Australia, current legislative provisions that do not require ‘approved health professionals’ to register, and therefore adhere to conditions of registration, transgresses the spirit and intentions of upholding the welfare of the child as paramount, and supporting recipients and donors alike. Not to hold medical practitioners that operate outside of the registered clinic system to the same standards as those who provide artificial insemination within that system is unsatisfactory and therefore compromises the effectiveness of the Act.

**RECOMMENDATION 2**

The Minister should clarify the intention of section 5(2)(a) of the Act regarding health professionals providing assisted insemination who are ‘approved’ by the Minister. In particular the Minister should address the context to which section 5(2)(a) is intended to apply, and stipulate conditions that all such health professionals would be required to meet.

Five submissions also expressed concern about the lack of governance regarding private arrangements.<sup>45</sup> Such submissions related to implications for children born as a result of donor arrangements regarding access to information, when relationships break down, and

<sup>44</sup> Kim Buck, submission 41.

<sup>45</sup> Confidential, submission 1; John Mayger, submission 31; Confidential, submission 68; Law Society, submission 77; WA RTC, submission 78.

the lack of control on how many times a donor may donate—and thus the number of children that may result. There was also concern for women being forced into ‘natural insemination’ (i.e. sexual intercourse).

The Law Society noted in its submission to the review that regulation of these arrangements would be difficult, if not impossible to implement, but consideration should be given to how to provide information on legal implications.<sup>46</sup> The Western Australian Reproductive Technology Council suggested that ‘[m]idwives may be well placed, through their birth notification system, to record this information and provide support or directions to appropriate resources’.<sup>47</sup> In this regard, there may also be a function for the below suggested A.R.T. Advisory Council or for the person(s) responsible for implementing and overseeing the Act within the Department for Health and Ageing to produce information that is made available to the public and/or provide community education services on the ethical, legal, and health implications (such as risks of transmitting infectious diseases) of such arrangements.

There may also be provision made (and requirements) for entering information about private arrangements that result in the birth of a child(ren) into the donor conception register once it is established<sup>48</sup> (this is further discussed in Chapter Five).

**FINDING 4**

While it would be difficult, if not impossible, to implement effective regulation of private artificial insemination arrangements, the Minister for Health could provide community information and/or education about any ethical and/or legal implications, as well as health risks, of such arrangements. These functions may be performed by an A.R.T. Advisory Council or the person(s) in the Department for Health and Ageing responsible for supporting the Council and oversight of the Act.

---

<sup>46</sup> Law Society, submission 77.

<sup>47</sup> WA RTC, submission 78.

<sup>48</sup> Confidential, submission 68.

## 2.4 Changes to Regulation and Oversight

The current Act and regulations came into effect in 2010 changing the prior licencing system to a system of registration; removing the oversight and advice mechanisms that existed via the South Australian Council on Reproductive Technology (SACRT); and repealing the Code of Ethical Clinical Practice that existed. This section considers the former SACRT and its Code of Ethical Clinical Practice, as well as what has replaced it in terms of requirements to adhere to the RTAC Accreditation Scheme and the NHMRC Ethical Guidelines.

### 2.4.1 SACRT and the former Code of Ethical Practice

SACRT was established under the former *Reproductive Technology (Clinical Practices) Act 1988* (SA). It consisted of eleven members appointed by the Governor of South Australia who were representative of a variety of views and experiences across the South Australian community. Of the eleven members five were nominated by the Minister, and one each was nominated by the Council of the University of Adelaide; the Council of the Flinders University of South Australia; the Royal Australian College of Obstetricians and Gynaecologists; the Royal Australian College of General Practitioners; the Heads of Churches in South Australia; and the Law Society of South Australia. The members appointed by the Minister tended to have expertise in paediatric health, medical law, ethics and consumer and children’s rights.

SACRT was tasked with a number of regulatory and oversight tasks, as well as providing advice to the Minister, and undertaking other tasks relevant to A.R.T. These tasks included

- a) to formulate, and keep under review, a code of ethical practice to govern the use of artificial fertilisation procedures;
- b) to advise the Minister on the conditions to be included in licences authorising artificial fertilisation procedures;
- c) to carry out research into the social consequences of reproductive technology;
- d) to promote research into the causes of human infertility (and, in doing so, to attempt to ensure that adequate attention is given to research into the causes of both female and male infertility);
- da) to keep under review research involving human embryos;

- e) to advise the Minister on any questions arising out of, or in relation to, reproductive technology;
- f) to promote (by the dissemination of information and in other ways) informed public debate on the ethical and social issues that arise from reproductive technology; and
- g) to collaborate with other bodies carrying out similar functions in Australia.<sup>49</sup>

The Code of Ethical Clinical Practice that SACRT formulated was set out as a schedule to the *Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995*. It included comprehensive coverage of issues relevant to A.R.T. including (but not limited to) matters that related to prohibited practices, eligibility for treatment, gamete donation, consent, use, storage and disposal of embryos, record keeping, selection of gametes, informing child, parents and/or donors of any hereditary diseases of the donor(s) or child(ren) born as a result of donor conception; notifying any birth defect to the Pregnancy Outcome Unit of the then Department of Human Services. Providers of A.R.T. were also required under the code to provide an annual report to the SACRT; and to provide notification of accreditation by the Reproductive Technology Accreditation Committee (RTAC) of the Fertility Society of Australia (FSA).

SACRT thus served as an ‘arms-length’ oversight and advisory body that was able to respond to ethical issues and changes in technology rapidly via the Code of Ethical Clinical Practice or issuing memorandums to clinics. The body no longer exists, and there is no equivalent in South Australia. Reporting requirements that previously existed under SACRT’s remit are not currently met by any other method or body. The Code of Ethical Practice, which carried detailed requirements for the practice of A.R.T., including extensive information and record keeping provisions, was also repealed. There is now primary reliance upon the RTAC accreditation scheme and NHMRC Ethical Guidelines.

The review received a number of submissions lamenting the dissolution of SACRT as having left a regulatory gap in South Australia, and suggesting that some sort of body should be established in its place.<sup>50</sup> Statements to the review are reflected by the following examples:

---

<sup>49</sup> *Reproductive Technology (Clinical Practices) Act 1988*, s 10 (repealed).

<sup>50</sup> Confidential, submission 4; Confidential, submission 7; AIMEE, submission 15; Lauren Burns, submission 33; Damian Adams, submission 34; Kim Buck, submission 41; Myfanwy Cummerford, submission 56; Premier’s Council for Women, submission 62; Confidential, submission 64; Confidential, submission 68; Kylie Dempsey, submission 69; Confidential, submission 80; ANZICA, submission 82; Oral submissions during consultations with clinics and consumers also included expressed views that said that there was now a gap.

1. *It is regrettable that the SACRT was dissolved as it performed many of the functions that are required and sorely absent;*<sup>51</sup>
2. *[T]here NEEDS to be an independent body to overview this;*<sup>52</sup>
3. *The dissolution of the SACRT was a mistake. I questioned this decision at that time but my concerns were dismissed. A new SACRT must be introduced, such that we have an oversight body that contains appropriate levels of expertise but that also provides annual reports for transparency and public scrutiny.*<sup>53</sup>

During face-to-face consultation one clinician said that they thought that SACRT was ‘*useful to have an umpire*’, and their view was that ‘*since SACRT has gone it is every clinic for itself and their own interpretation.*’ Another clinician said their personal view was that ‘*things are OK at the moment*’ but ‘*we need two or three people who are wise and understand.*’ He named Kathy Williams, the former executive officer of the SACRT, Gillian Lewis, who used to work on A.R.T. issues at SA Health for a long period of time,<sup>54</sup> and Andrew Dutney, an ethicist and theologian, as people who understood the background and issues, and lamented the loss of such expertise. A third clinician said that ‘*it would be good to be able to get some advice on how to interpret certain guidelines and requirements*’ and noted that possibility had disappeared with the removal of SACRT.

Hansard indicates that it was the intention of the South Australian Government, at the time of the dissolution of SACRT that an Ethics Health Advisory Council (EHAC) would be established to take over some of the functions of SACRT. However, the now existing EHAC has not fulfilled this role to any great degree.<sup>55</sup> In fact, many people in South Australia are unaware of the EHAC’s existence or functions.

Currently, in the absence of any advisory body, reliance is had on the RTAC Accreditation Scheme, and the NHMRC Ethical Guidelines. Before making any findings or recommendations in relation to the operation and effectiveness of the Act following the dissolution of SACRT, it is therefore necessary to consider these elements of governance.

---

<sup>51</sup> Myfanwy Cumberford, submission 56.

<sup>52</sup> Confidential, submission 07.

<sup>53</sup> Damian Adams, submission 34.

<sup>54</sup> Kathy Williams and Gillian Lewis were policy officers who worked on assisted reproductive technology and ethics within the Department for Health and Ageing. Due to restructuring their positions no longer existed.

<sup>55</sup> Ethics Health Advisory Council, Chair Annette Braunack-Mayer, submission to the review at the request of Sonia Allan, received via email, 29 April 2016.

### 2.4.2 The RTAC Accreditation Scheme

RTAC is a self-regulatory body charged with the responsibility of setting standards for the performance of A.R.T. through an audited Code of Practice and the granting of licences to practice A.R.T. within Australia. RTAC reports to the Fertility Society of Australia (FSA) and local state authorities where required. The RTAC code was revised in 1992, 1997, 2001, and 2005. It was rewritten in 2008, with revisions in 2010 and 2014.<sup>56</sup> The international version of the Code was released in 2015. Accreditation of A.R.T. treatment centres by RTAC requires compliance with the RTAC Code of Practice. Accreditation review is conducted as an audit by an independent Certification Body that is approved by the Joint Accreditation System of Australia and New Zealand. Following the granting of a primary licence, surveillance auditing takes place on an annual basis. Each audit includes all of the ‘Critical Criteria’ contained in the RTAC Code, and one third of the ‘Good Practice Criteria’ set out in the Code, with all areas of the ‘Good Practice Criteria’ being examined over a three year period.

‘Critical Criteria’ includes compliance with statutory and regulatory requirements, including compliance with law, policy, the RTAC Code, NHRMC Ethical Guidelines; access to competent staff (medical, scientific, nursing, and counselling); acknowledging and investigating complaints; acknowledging and investigating adverse events; ensuring gametes, embryos and patients are correctly identified and matched at all times; medication management (safe drug storage, supply and administration); minimising the incidence of multiple pregnancy; minimising the incidence of Ovarian Hyper-stimulation Syndrome; ensuring access to emergency care; data monitoring (including undertaking reviews of treatment outcomes); data reporting to the Australia and New Zealand Assisted Reproduction Database (ANZARD)<sup>57</sup>; ensuring gametes, embryos and tissues are safe for donation and use in surrogacy arrangements and ensuring appropriate counselling has been provided (which includes compliance with NHMRC Ethical Guidelines and any applicable state or territory legislation); management of risk infection transmission; ensuring treatment occurs with fully informed consent; and ensuring that doctors providing medical management and care of

---

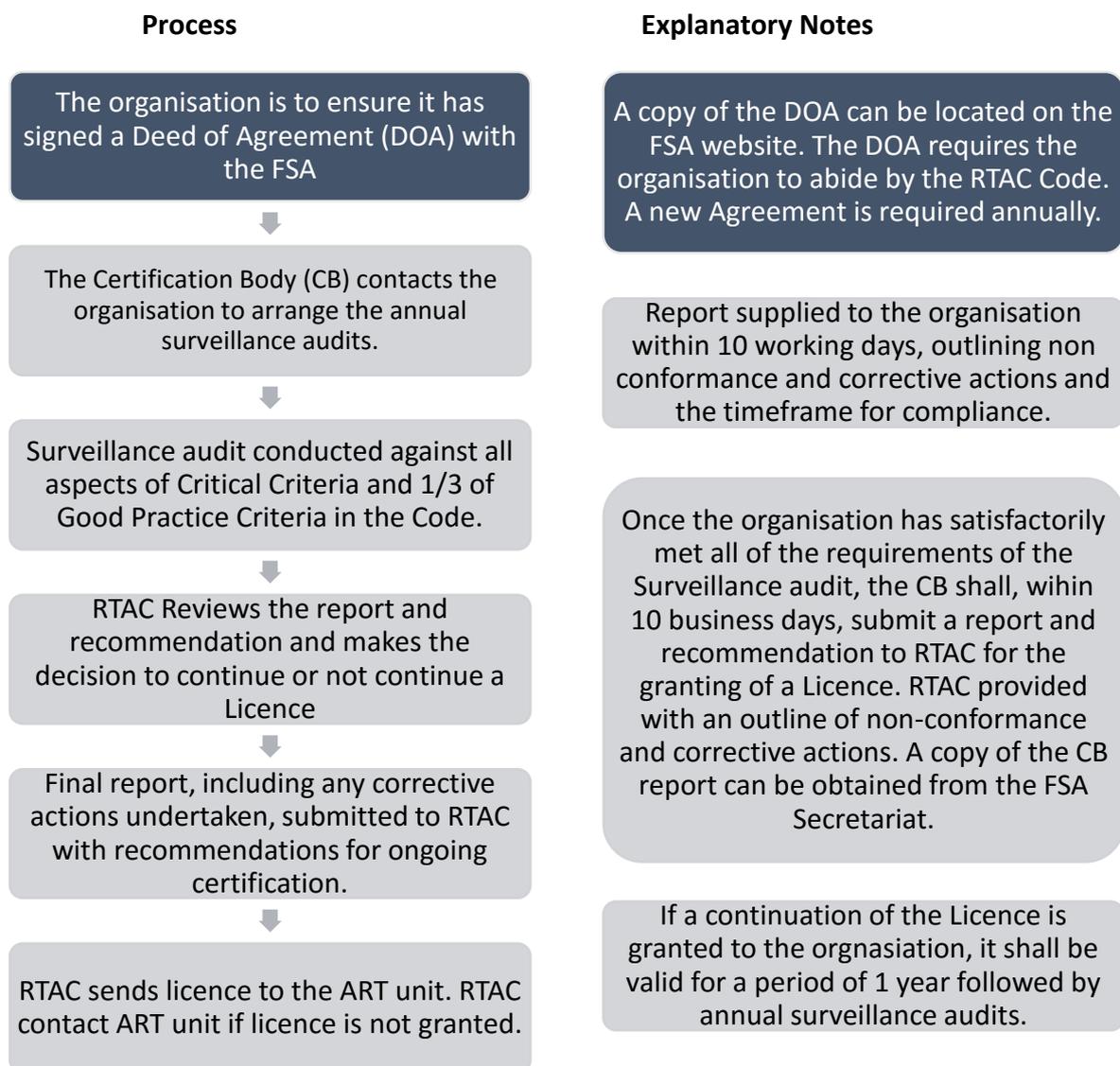
<sup>56</sup> Fertility Society of Australia, Reproductive Technology Accreditation Committee, *Code of Practice for Assisted Reproductive Technology Units* (Revised 2014).

<sup>57</sup> ANZARD was created in 2004. It is an initiative of the Fertility Society of Australia (FSA) to provide a joint data collection for both the National Perinatal Epidemiology and Statistics Unit (NPESU) and the Reproductive Technology Accreditation Committee (RTAC) of the FSA. The purpose of the ANZARD collection is to monitor the perinatal outcomes of assisted reproduction and to assess the effectiveness of ART treatments.

infertile patients comply with qualifications and training, continuing medical education, and appropriate supervision.

‘Good Practice Criteria’ includes that the organisation must have a quality management system; provide patients with information that is accurate, timely and in formats appropriate to the patient; ensure it meets the reproductive health needs of the men and women under its care; ensure safe management of cryopreserved gametes, embryos and tissues; and undertake regular stakeholder feedback.

The following flow chart depicts the yearly surveillance auditing process.<sup>58</sup>



<sup>58</sup> Content reproduced from [www.fertilitysociety.com.au/wp-content/uploads/201011201-final-rtac-scheme.pdf](http://www.fertilitysociety.com.au/wp-content/uploads/201011201-final-rtac-scheme.pdf) accessed 8 January 2017.

RTAC was invited to contribute to the review and did so. In the RTAC submission, the Chair, Keith Harrison, stated that the RTAC Accreditation system *'assures a high level of consistency, safety, reliability and efficacy'*.<sup>59</sup> He also noted that RTAC felt confident that individual states can rely on the RTAC system for accreditation and licensing purposes and confine their supervision of A.R.T. clinics to the simple registration of their activities within the state department of health. He added that there could clearly be a requirement of such registration that they supply copies of their Certifying Body Audit Certificates and their RTAC licences to the department each year upon receiving them.<sup>60</sup>

City Fertility made a written submission that was almost identical in its terms regarding the RTAC system being adequate within itself, and that clinics should supply their CB Audit certificates and RTAC licences on a yearly basis to the Department.<sup>61</sup>

During face-to-face meetings with health professionals and employees at each of the South Australian clinics it was apparent that the RTAC accreditation was taken seriously, and that the clinicians had faith in the process. This is a positive factor when considering the likelihood of regulatory compliance. However, comment was also made during face-to-face meetings concerning what the RTAC process involved and how it could be improved.<sup>62</sup> For example, personnel within clinics, in a number of different roles, commented on the *'toothlessness'* of RTAC, that the auditing process is informal compared to fiscal audits, and that there is a lack of advice and guidance about best practice and follow up concerning areas identified as needing improvement.

One staff member said that the RTAC system seems like a thorough system, but noted that the RTAC code had been reduced from a sixty page document to thirty pages, and that it is not a prescriptive document. The staff member noted it is good in respect of requirements for quality systems, but there was no follow up. His view was that clinics should have to submit the RTAC report to the Minister, and there should be some external process to check on follow up and improvements. He said that *'no-one is going to get shut down, no one in Australia is that bad, but there are operators that could lift their practices...'*

---

<sup>59</sup> RTAC, submission 44.

<sup>60</sup> Ibid.

<sup>61</sup> City Fertility, submission 63.

<sup>62</sup> Note, individual commenters on such processes were assured non-identification.

Other submissions to the review called for more transparency and arms-length oversight.<sup>63</sup> Each raised similar issues as those raised in the following example:

*...It would be a vast improvement in governance if the accreditation of ART clinics was overseen by a truly independent body, and one that provided transparency. This body could be funded by a levy on ART clinics. RTAC is currently not publicly transparent as to which clinics are in breach of particular sections of the NHMRC Ethical Guidelines, and what consequences or action plans are put in place for these clinics to become compliant. I suggest that RTAC or the relevant accreditation organisation should be compelled to provide an annual publicly available written report to the Minister for Health outlining the compliance or otherwise of ART clinics to the NHMRC ethical guidelines...<sup>64</sup>*

**FINDING 5**

The RTAC accreditation scheme is a valuable self-regulatory auditing process that requires quality management systems. It is respected by clinics, albeit some personnel highlight the need for better guidance and follow up. There is also a call for the Minister to engage in further oversight of A.R.T. and auditing of accreditation outcomes, compliance, and any required improvements. The lack of current reporting to, and oversight from, the Minister in this regard compromises the operation and effectiveness of the *Assisted Reproductive Treatment Act 1988* (SA).

**RECOMMENDATION 3**

Clinics should, in addition to current requirements under the *Assisted Reproductive Treatment Act 1988* (SA), be required to provide to the Minister the Certification Body's audit report and recommendation to RTAC for the granting of a licence, including any outline of non-conformance and corrective actions required. Auditing of clinics concerning how any non-conformance has been remedied should be conducted by the Minister.

<sup>63</sup> Damian Adams, submission 34; Kim Buck, submission 41; Lauren Burns, submission 33.

<sup>64</sup> Lauren Burns, submission 33.

### **2.4.3 National Health and Medical Research Council Guidelines**

The National Health and Medical Research Council (NHMRC) is an independent statutory agency established by the *National Health and Medical Research Council Act 1992* (Cth) (NHMRC Act).<sup>65</sup> The *NHMRC Act* provides for the NHMRC to pursue activities designed to raise the standard of individual and public health throughout Australia; foster the development of consistent health standards between the various States and Territories; foster medical research and training and public health research and training throughout Australia; and foster consideration of ethical issues relating to health.

In 2004, the NHMRC published the *Ethical guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research*.<sup>66</sup> The NHMRC Ethical Guidelines are divided into three parts: Part A provides background and introductory material; Part B provides ethical guidelines for the clinical practice of A.R.T.; and Part C relates to ethical guidelines for research, including ethical principles for research, research involving gametes, and research involving embryos. Areas currently addressed by Part B which relate to clinical practice relevant to A.R.T. include ethical principles for clinical practice of A.R.T.; use of gametes in reproductive treatment programs; use of donated embryos; storage of gametes and embryos; information giving, counselling and consent; record keeping and data reporting; sex selection; pre-implantation genetic diagnosis; surrogacy; and innovations, training and quality assurance.

The NHMRC Ethical Guidelines are not subject to the same parliamentary approval processes or debate as legislation. Review of the Guidelines, which took place in 2007 and is currently again underway, is undertaken via the appointment of a Committee, public consultation, circulation of proposed draft revisions, and further review/approval by the Australian Health Ethics Committee.

All states and territories must adhere to the NHMRC Ethical Guidelines pursuant to the above described self-regulatory accreditation system operated by the RTAC, and also in order to receive Medicare funding (public Commonwealth funding) for services. The *South Australian Assisted Reproductive Treatment Regulations 2010* also require compliance with the NHMRC Ethical Guidelines.

---

<sup>65</sup> Section 5B.

<sup>66</sup> National Health and Medical Research Council, *Ethical guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (2004), updated 2007. Hereafter, 'NHMRC Ethical Guidelines'.

The 2010 repeal of the South Australian Code of Ethical Practice, and deferral to the NHMRC Ethical Guidelines was done on the belief that this would reduce alleged redundancy, conflicts and uncertainty that were seen to exist due to both State based and national ethical guidance existing. I therefore considered how the move to reliance upon the NHMRC Ethical Guidelines has been operationalised and whether it is effective. I was informed that referral to the NHMRC Ethical Guidelines continues to result in uncertainty about what is permissible in South Australia, and there has been difficulty in obtaining guidance when this is unclear. There was also a gap when the NHMRC Ethical Guidelines did not speak to certain practices and/or were contradictory. Fertility SA noted:

*[Compliance with the guidelines] is appropriate to consider, however the guidelines are just that - a relatively loosely-held set of best practice principles that, in [the Assisted Reproductive Treatment] Act, via the conditions of registration, have been given the status of law. This has from time to time created difficulty for clinics, particularly where the guidelines are contradictory to each other, or counter to the paramountcy of the welfare of the child.<sup>67</sup>*

At time clinics sought advice from the Department for Health and Ageing, and were grateful for some advice they had received, however, they reported there is no consistent process or clarity over when such advice may be sought. There was also a lack of clarity over who may be consulted to decide upon interpretation concerning ethical issues.

I also found that most of the time clinics individually seek their own legal advice on how to interpret particular guidelines, then formulate their own respective policies. This led to differences between clinics in policies and practices concerning major ethical issues. For example, one clinic treats young children with cancer to preserve fertility, one doesn't; one clinic believes that time limit for embryo freezing is 15 years, others believe it is 10; some clinics seek the Minister's agreement to extend the time limit, others think there is no room for extension; some clinics let patients see the sex of an embryo, others don't; some are strict in terms of the definition of infertility, others are flexible; and clinics approached the age limit for access to A.R.T. differently.

---

<sup>67</sup> Fertility SA, submission 49.

*Concern about changes to NHMRC Ethical Guidelines*

Concerns were also expressed about proposed changes to the NHMRC Ethical Guidelines published in late 2015 that may introduce further inconsistencies with South Australian laws, ethics, and/or practice. For example, draft guidelines circulated in late 2015 proposed to remove the statement that the welfare ('best interests') of the child is paramount. Other issues under review include whether there should be payment for egg donation, whether sex selection for social reasons should be allowed, and whether reimbursement for loss of wages during surrogacy arrangements should be permitted (among others). Some people expressed concern to me that some such potential changes to the Guidelines may favour commercial interests and consumer demand, rather than serving the best interests of children and/or those vulnerable to exploitation.<sup>68</sup>

An important factor for the Minister is to recognise that people in South Australia were concerned that the regulation of certain issues was not being decided upon in-State. A confidential submission received during the consultation phase sums up the concerns about the current deferral to NHMRC Ethical Guidelines that were presented to the review. It said:

*We are concerned about the apparent structural deficiencies of the current arrangement, which effectively surrenders our State's sovereign policy-making capacity in this area to what appears to be a non-representative body - the NHMRC. It is not clear what accountability the NHMRC (if any) has for its decision making processes, and there seems to be a bias (even conflict) among its members towards commercial interests and powerful lobby groups. Given the extensive social ramifications of its decisions, such policy making should have social input and preferably via the mechanisms of our representative democracy.<sup>69</sup>*

The NHMRC Ethical Guidelines do not apply in South Australia to the extent that they are inconsistent with anything within the *Assisted Reproductive Treatment Act*.<sup>70</sup> However, there

---

<sup>68</sup> Consumer Forum, 21 April 2016; Confidential, submission 80.

<sup>69</sup> Confidential, submission 80.

<sup>70</sup> *Assisted Reproductive Treatment Regulations 2010* (SA), reg 8(3).

is no longer a South Australian Code of Ethical Clinical Practice or SACRT to turn to in the case that such inconsistencies exist (or are introduced), and there is also currently no other consistent source of guidance in South Australia to inform practice. If the law does not speak to certain issues, then the NHMRC Ethical Guidelines prevail.

*Concerns about Lack of Reporting and Compliance with Ethical Guidelines*

Finally, while there was general support for the 2007 version of the NHMRC Ethical Guidelines as offering some general guidance, the review also heard from a number of people who expressed concern about the lack of monitoring, transparency and reporting concerning the extent to which clinics adhere to them.<sup>71</sup> Similar issues in this regard were raised in relation to the RTAC Code of Practice discussed above.

**FINDING 6**

While regulation 8(2)(a) requires that the Minister include, as a condition of registration, a requirement that the A.R.T. provider adhere to the NHMRC Ethical Guidelines, sole reliance upon the NHMRC Ethical Guidelines has raised concern. It is problematic to rely on a set of ethical guidelines to regulate A.R.T. in a state that has a legislative framework without having a uniform point of reference for guidance and interpretation of such guidelines.

Section 2.5 explores further mechanisms that may address these issues, in a way that enhances the operation and effectiveness of the *Assisted Reproductive Treatment Act 1988* (SA) by giving effect to some of the intentions of parliament that have not yet been realised, and by strengthening the oversight and implementation of the Act.

## **2.5 The Regulatory Approach in South Australia**

The above highlights that the direct regulation of A.R.T. and associated health professionals, businesses, and practices, occurs via a ‘co-regulatory’ approach in South Australia, which combines framework legislation (which stipulates registration conditions for A.R.T. providers,

---

<sup>71</sup> Caroline Lorbach, submission 27; Damian Adams, submission 34; Kim Buck, submission 41.

and requires adherence to NHMRC Ethical Guidelines) with the self-regulatory RTAC accreditation process.

There also exists other regulatory oversight of health professionals, and businesses in South Australia relevant to A.R.T. services. These include (but are not limited to) the following:

- All health professionals are regulated under the National Registration and Accreditation Scheme (NRAS);<sup>72</sup>
- Clinics are subject to regulation as businesses, commercial providers of services, and advertisers. For example, certain conduct may be overseen or referred to bodies such as the Australian Competition and Consumer Commission (ACCC),<sup>73</sup> or the South Australian Health and Community Services Complaints Commissioner;<sup>74</sup>
- Laws that pertain to research involving human embryos and cloning, and prohibit human cloning for reproductive purposes,<sup>75</sup> as well as laws that govern the donation of human tissue,<sup>76</sup> must be followed;
- Regulation of drugs, poisons and other therapeutic goods under the *Therapeutic Goods Act 1989* (Cth) and therapeutic goods regulatory regime is relevant (for example regarding A.R.T. culture medium, medicines used in A.R.T. and so on);
- The law of negligence, contract law, corporation's law, criminal law, and anti-discrimination laws are also relevant;
- Lab, day surgery, and practice standards, governed by various internal and external standards and processes, must be adhered to.

While the above laws, regulations, and practice standards are not the focus of the review, it should be recognised that there are many facets of regulation and oversight that

---

<sup>72</sup> *Health Practitioner Regulation National Law Act 2009*. (National Law)

<sup>73</sup> For example in November 2016 the ACCC required some of Australia's major IVF clinics to change the way they advertise 'success rates' following an investigation in which the ACCC found a number had made misleading claims that focused upon pregnancy rather than birth rates, which could mislead consumers. See ACCC Media Release 'IVF 'success rates' under the microscope', MR212/16, 16 November 2016.

<sup>74</sup> The office of the South Australian Health and Community Services Complaints Commissioner (HCSCC) is a statutory office established by the *Health and Community Services Complaints Act 2004* (the Act). The HCSCC assists people – service users, carers and service providers – with complaints about health or community services in South Australia. This includes government, private and non-government health and community services.

<sup>75</sup> *Research Involving Human Embryos Act 2002* (Cth); *Prohibition on human cloning for Reproduction Act 2002* (Cth); *Research Involving Human Embryos Act 2003* (SA); *Prohibition on human cloning for Reproduction Act 2003* (SA); *Research Involving Human Embryos Regulations 2003* (SA); *Prohibition on human cloning for Reproduction Regulations 2003* (SA).

<sup>76</sup> *Transplantation and Anatomy Act 1983* (SA).

aim to ensure best practice and standards are met. There are also numerous avenues that serve to investigate and address when such practice or standards fall short.

The notion of a co-regulatory system is to implement a mode of governance in which the government and those subject to regulation act in a manner that mutually reinforce one another, and share responsibility for ensuring the best possible practice.

#### **FINDING 7**

The co-regulatory system adopted in 2010 to govern A.R.T. in South Australia complements other laws that aim to ensure best practice and standards are met not only in the practice of A.R.T., but in all areas of medicine. It requires the government and those subject to the regulation to act in a manner that mutually reinforce one another and the sharing of responsibilities between public and private partners.

### **2.5.1 Current Operation and Effectiveness of the Co-Regulatory System**

Co-regulation, which may be seen as the middle ground between traditional ‘top down’ statutory regulation and private self-regulation,<sup>77</sup> requires cooperation between the government (and its agencies) with those subject to the regulation. It may work very well in governing an area which has raised significant moral and ethical concerns such as A.R.T., and is seen as a good option for reducing regulatory burden, saving unnecessary costs from over-regulation or elaborate stand-alone statutory systems, and increasing compliance. It is also a valid way of regulating such fields as A.R.T. as it recognises that the expertise of those being regulated can inform the regulatory process *and* that risk dictates that government oversight is also necessary.<sup>78</sup> Such risks may for example, include short and long term risks to the health and well-being of children born as a result of A.R.T. and donor conception, to those people undergoing treatment, and to donors of gametes and/or embryos. There may also be other risks related to inter-generational outcomes of A.R.T., a lack of quality research and evidence regarding certain practices and outcomes, and risks associated with the ethical, legal and social issues raised by A.R.T. The increased commercial nature of A.R.T. may also pose risks to consumers—for example, in November 2016, several major IVF clinics were required to make

<sup>77</sup> Kelley Lee and Jeff Collin, *Global Change and Health* (2005), 192.

<sup>78</sup> *Ibid.*

changes to claims published on their websites about success rates following an Australian Competition and Consumer Commission investigation into potentially false or misleading representations.<sup>79</sup>

*Effective* co-regulation involves self-regulation and legislative action working together *in a manner that mutually reinforce one another*.<sup>80</sup> There is less ‘top down’ enforcement and more work done to support compliance.

While on the face of the current A.R.T. regulatory regime in South Australia there is a combination of the RTAC self-regulatory accreditation system combined with framework legislation, I found that the essential elements of an effective co-regulatory regime are lacking. This was particularly so as co-regulation implies taking self-regulation one step further in a cooperative approach to governance, rather than mere co-existence of self-regulation and statute; it involves the *sharing of responsibilities between public and private partners*.<sup>81</sup> It also implies that ‘a framework of overall objectives, basic rights, enforcement and appeal mechanisms, and conditions for monitoring compliance [are] set in the legislation...’<sup>82</sup> The organisations participating in the process must also be ‘representative, accountable and capable of following open procedures in formulating and applying agreed rules.’<sup>83</sup>

At present, in South Australia monitoring of compliance and enforcement of the Act is not being adequately operationalised by the Government. Lack of reporting to, and auditing by, the Minister regarding the self-regulatory aspects of the regime also compromises the accountability and openness required for an effective a co-regulatory regime. An analogy may be drawn to recent findings in Victoria regarding hospital safety and quality oversight, in that it was found that their Department of Health had over-relied on accreditation processes for hospitals, and did not have all the information it needed to ensure services were providing

---

<sup>79</sup> See ACCC Media Release, above n 73.

<sup>80</sup> P. Eijlander, ‘Possibilities and Constraints in the use of Self-Regulation and Co-Regulation in Legislative Policy: Experience in the Netherlands – Lessons to be Learned for the EU?’ (2005) 9(1) *Electronic Journal of Comparative Law*, <http://www.ejcl.org/91/abs91-1.html>.

<sup>81</sup> Opinion of the European Economic and Social Committee on Simplification (2002) *Official Journal of the European Communities*, 2002/c48/28, [http://eur-lex.europa.eu/LexUriServ/site/en/oj/2002/c\\_048/c\\_04820020221en01300141.pdf](http://eur-lex.europa.eu/LexUriServ/site/en/oj/2002/c_048/c_04820020221en01300141.pdf).

<sup>82</sup> *Ibid.*

<sup>83</sup> *Ibid.*

consistently safe and quality care.<sup>84</sup> The Duckett report also noted the importance of not removing funding from government regulatory functions in the name of ‘efficiency’ to such a degree to which the ability to perform core functions is lost. This is an important consideration for the Minister for Health in South Australia in relation to the current operation and effectiveness of the *Assisted Reproductive Treatment Act 1988 (SA)*.

#### **FINDING 8**

Monitoring of compliance, and enforcement of the Act is not being adequately operationalised by the Minister. Lack of reporting to, and auditing by the Minister regarding the self-regulatory aspects of the regime also compromises the accountability and openness required for an effective co-regulatory regime.

### **2.5.2 What needs to be done?**

The question thus becomes one of how to better operationalise and give effect to the regulatory system that exists in South Australia. The answer is one that requires more *active participation* by both the Minister responsible for the legislation and those being regulated. It further requires that the intentions of parliament be operationalised, rather than leaving the legislation to exist without actively implementing all that it was intended to do. This would accord with calls to address any conflicts or gaps between desired South Australian practice and the NHMRC Ethical Guidelines and to implement industry oversight.<sup>85</sup>

In considering what should occur in this regard, I took into account the intention of the South Australian Parliament in implementing the 2010 changes (including better regulation principles), submissions to the review, the South Australian political, social and economic environment, the number of registered clinics in South Australia (being four), and models of regulation in other jurisdictions. A brief outline of what occurs across other states and territories in Australia follows.

<sup>84</sup> See Stephen Duckett (Chair), Targeting zero: Supporting the Victorian hospital system to eliminate avoidable harm and strengthen quality of care. Report of the Review of Hospital Safety and Quality Assurance in Victoria. (October 2016).

<sup>85</sup> See for example of such a call, Premier’s Council for Women, submission 62.

Other Australian Jurisdictions

*New South Wales*

In NSW, legislation requires registration of clinics,<sup>86</sup> which occurs via a form being sent to the regulation and compliance unit at the Ministry of Health detailing the names and addresses relevant to those providing A.R.T. services. Regulations also set out matters to be included in a registration application, which include requirement for a statement as to whether the applicant has been convicted of contravening any A.R.T. legislation, or RTAC accreditation has been refused, suspended, cancelled or revoked; and that registered clinics must adhere to certain infection standards if they do not have RTAC accreditation.<sup>87</sup> A further oversight mechanism is available in that the Secretary may appoint any member of staff of the Department or any person who is suitably qualified for the purpose to be an inspector for the purposes of the *Assisted Reproductive Technology Act 2010* (NSW).<sup>88</sup>

The NSW legislation's primary focus is on matters related to donor conception and the recording and release of information on the donor register<sup>89</sup> or by A.R.T. providers.<sup>90</sup> Clinics may subject themselves to the RTAC accreditation scheme and adhere to NHMRC Ethical Guidelines—although there is no legislative requirement to do so.

On meeting with representatives from the NSW Ministry of Health in May 2016, there did not appear at the time to be any dedicated members of staff working on A.R.T. related matters. I was unable to establish how much time (or by whom) was spent working on such matters by staff across the department. Costs could not therefore be estimated. There are currently nineteen registered clinics in NSW<sup>91</sup> (and twenty-seven RTAC accredited locations).

*Western Australia*

In Western Australia, the *Human Reproductive Technology Act 1991* (WA) (the HRT Act) governs A.R.T. The HRT Act, among other things establishes a statutory licencing scheme, administered by the Reproductive Technology Council (RTC) and the WA Reproductive

---

<sup>86</sup> *Assisted Reproductive Technology Act 2010* (NSW), s 7.

<sup>87</sup> *Assisted Reproductive Technology Regulations 2014* (NSW), reg 8.

<sup>88</sup> *Assisted Reproductive Technology Act 2010* (NSW), Part 5.

<sup>89</sup> *Assisted Reproductive Technology Act 2010* (NSW), Part 3.

<sup>90</sup> *Assisted Reproductive Technology Act 2010* (NSW), Part 3A.

<sup>91</sup> NSW Health, <http://www.health.nsw.gov.au/art/Documents/list-registered-art-providers.pdf> accessed 8 January 2017.

Technology Unit within the Department of Health.

The licensing scheme is an example of a greater ‘top down’ regulatory oversight system than that which exists under the current South Australian system. Licenses are granted by the Commissioner of Health.<sup>92</sup> Before a practice licence (or exemption) is granted, the Commissioner must refer an application to the RTC.<sup>93</sup> Pursuant to the legislation licenses should be granted if they comply with a ‘Code of Practice’ — which is to be published by the RTC and is intended to set out guidelines and establish ethical standards required of licensees.<sup>94</sup> No such code has been drafted; instead, guidelines are contained in directions formulated by the Commissioner.<sup>95</sup> This is not disadvantageous as the use of directions allows greater flexibility than would be possible under a code.<sup>96</sup>

The RTC functions are prescribed in the HRT Act.<sup>97</sup> In addition to their licensing review functions, the RTC provides advice to the Minister for Health on issues relating to A.R.T., and the administration and enforcement of the HRT Act; provides advice to the CEO of Health on matters relating to licensing, administration and enforcement of the HRT Act; reviews any directions and guidelines and thereby regulates the proper conduct of A.R.T.; promotes research into the causes and prevention of all types of human infertility and the social and public health implications of A.R.T; promotes informed public debate on issues arising from A.R.T., and communicates and collaborates with similar bodies in Australia and overseas. The Minister for Health determines Council membership and is required to ensure that Council comprises individuals with special knowledge, skills and experience in A.R.T., members who are consumer representatives and members with expertise in public health, ethics and law.

The Assisted Reproductive Unit has three full-time staff, comprising a Manager and two Senior Policy Officers, who work on A.R.T. matters, and also provide support to the RTC. Such staff are also responsible for the operation of the central and voluntary donor registers.<sup>98</sup> The 2015-2016 RTC budget was reported to be \$62,935 with expenditure of \$60,208 for the

---

<sup>92</sup> *Human Reproductive Technology Act 1991* (WA), s 27(3).

<sup>93</sup> *Human Reproductive Technology Act 1991* (WA), s 27(1).

<sup>94</sup> *Human Reproductive Technology Act 1991* (WA), s 14.

<sup>95</sup> Western Australian, *Human Reproductive Technology Directions*, 30 November 2004, Published by authority of John A Strijk, Government Printer, State of Western Australia.

<sup>96</sup> John Seymour and Sonia Magri, *ART, Surrogacy and Legal Parentage: A Comparative Legislative Review* (2004). Occasional Paper commissioned by Victorian Law Reform Commission.

<sup>97</sup> *Human Reproductive Technology Act 1991* (WA), s 14.

<sup>98</sup> WA RTC informed me they are seeking one further staff member.

financial year.<sup>99</sup> Based on the current WA public servant award agreement,<sup>100</sup> the cost of staffing the Reproductive Technology Unit is estimated to be between \$450,000- \$500,000 per annum. There are currently eight licensed clinics operating in Western Australia, and two exempt practitioners.<sup>101</sup>

### *Victoria*

In Victoria A.R.T. is regulated pursuant to the *Assisted Reproductive Treatment Act 2008* (Vic) (the Victorian Act). The Victorian Act is prescriptive (more so than any other legislation in Australia). It, like South Australia and NSW, requires registration of A.R.T. clinics.

The Victorian Act establishes the Victorian Assisted Reproductive Authority (VARTA) whose functions are to administer the registration scheme, provide public education about treatment procedures and the best interests of children; conduct community consultation; monitor programs and activities carried out under the Act, relating to the causes and prevention of infertility, and procedures relating to treatment procedures carried out outside Victoria; keep under regular review and, if it thinks fit, to make recommendations to the Minister about its functions, operation or composition; promote research into the causes and prevention of infertility; and to approve the import or export of donor gametes or embryos.

Currently, in order to register as an A.R.T. provider in Victoria a person must hold RTAC accreditation.<sup>102</sup> VARTA may impose conditions on registration,<sup>103</sup> and may suspend registration if contravention of requirements for RTAC accreditation occurs.<sup>104</sup> The CEO of VARTA, Louise Johnson, informed me they are currently considering whether to impose conditions which provide for further auditing and inspections of clinics as they were concerned that reliance upon RTAC accreditation alone was not acceptable.

In Victoria the regulatory system also establishes a ‘Patient Review Panel’<sup>105</sup> (PRP) whose function is to consider applications from patients on a wide range of ethically complex

---

<sup>99</sup> Western Australian Reproductive Technology Council. (2016). Western Australian Reproductive Technology Council Annual Report 2015–2016. Western Australian Reproductive Technology Council, Perth, Western Australia.

<sup>100</sup> Public Service and Government Officers General Agreement 2014, 2015 WAIRC 00173.

<sup>101</sup> Reproductive Technology Council, Consumer Information, <http://www.rtc.org.au/consumer/index.html> accessed 8 January 2017.

<sup>102</sup> *Assisted Reproductive Treatment Act 2008* (Vic), s 74.

<sup>103</sup> *Assisted Reproductive Treatment Act 2008* (Vic), s 75.

<sup>104</sup> *Assisted Reproductive Treatment Act 2008* (Vic), ss 76-77.

<sup>105</sup> *Assisted Reproductive Treatment Act 2008* (Vic), Pt 9, ss 82-98.

issues, including surrogacy arrangements,<sup>106</sup> posthumous use of gametes<sup>107</sup> and failure to meet the eligibility criteria set out in the Act.<sup>108</sup> Applications to the PRP are considered by a full division of the panel consisting of the Chairperson, a Deputy Chairperson and three other members, at least one of whom has expertise in child protection. The PRP currently consists of seventeen members including the Chairperson, and three Deputy Chairpersons. Remuneration of the PRP members is unknown.

The Department of Health and Human Services employs an Assisted Reproductive Treatment Policy Manager, an Associate (legal officer) and a Project Officer who support the PRP. I did not ascertain whether these positions were full or part time. If full time the estimated costs of all three positions would be approximately \$250,000-\$300,000 per annum.

VARTA has a Chairperson, a Board, a CEO, and at June 2016 employed the equivalent of 6.7 full time staff—which include office and information management, finance and administration (2.4 FTE), communications, public health and health promotion (1.6), donor register services management and counselling (1.4), and research and scientific writing (1.3). They also have a voluntary advisory panel from whom they seek information. Their 2015-2016 expenditure reported in their Annual Report was \$991,964. (Note the donor registers (Central and Voluntary) are currently managed by staff at Births, Deaths and Marriages for which costs were not accounted in this review, but management will be moved back to VARTA in March 2017. Additional funding and staffing had been sought for when this happens.)

Total costs of the current Victorian regulatory system were estimated to be \$1.2million per annum, plus the costs of the PRP Panel and Board, as well as future costs of the donor register and associated functions. There are currently six registered clinics across seventeen treatment sites in Victoria.

### Queensland, the ACT and Tasmania

Queensland, the ACT and Tasmania do not have legislation governing A.R.T.<sup>109</sup> Instead, health professionals, clinics, and those generally practising in the area of A.R.T. may follow

---

<sup>106</sup> *Assisted Reproductive Treatment Act 2008* (Vic) s 85(a).

<sup>107</sup> *Assisted Reproductive Treatment Act 2008* (Vic) s 85(c).

<sup>108</sup> *Assisted Reproductive Treatment Act 2008* (Vic) s 85(e).

<sup>109</sup> Tasmania is however currently considering whether to establish a donor conception register. The Northern Territory also does not have legislation, however there is one Repromed clinic in the NT, which practices according to South Australian requirements.

the NHMRC Ethical Guidelines and the Reproductive Technology Accreditation Committee (RTAC) Code of Practice (the RTAC Code) as part of the a national self-regulatory scheme.

As per all other jurisdictions practitioners in Queensland, the ACT and Tasmania are governed by a number of other laws and oversight mechanisms as mentioned above.

### South Australia

During the review there was a call for further action by the Minister to address gaps that have been left by the removal of SACRT. It was also apparent that the *Assisted Reproductive Treatment Act 1988* (SA) needs to be better operationalised in terms of ensuring the government *actively participates* in the co-regulatory system established in 2010. The method of doing so needs to be proportionate to the tasks required, and the number of registered clinics in South Australia being five (with only four operating).

While discussion in Hansard regarding the changes to the Act in 2010 indicated that a specialist Ethics Health Advisory Sub-Committee was expected to advise the Minister when needed, this has not occurred, and has not proven to be the appropriate avenue to take. A sub-committee of EHAC would entail two layers of bureaucracy because the A.R.T. sub-committee would have to report through the EHAC rather than directly to the Minister. In addition, the EHAC is not generally utilised for purposes required to effectively operationalise the *Assisted Reproductive Treatment Act 1988* (SA) such as those discussed herein.

In considering what is done in other jurisdictions, it is useful to draw elements from each, but would not be suitable to replicate any one system. In making my recommendations, my aim is to ensure that the Act is effectively operationalised while not creating unnecessary regulatory burden or functions.<sup>110</sup> This is important to give effect to a co-regulatory system, because as noted above, too much top down governance should be avoided. On the other hand, it is not acceptable to do nothing, as a co-regulatory system requires *active participation* in the regulatory system by both government and clinics.<sup>111</sup> I therefore recommend that the Minister establish an A.R.T. Advisory Council—whose role it would be to

---

<sup>110</sup> The WA RTC's and VARTA's functions have informed the recommended functions of the SA A.R.T. Advisory Council however my recommendations do not mirror either approach in their entirety. Each of those states have differing regulatory requirements.

<sup>111</sup> Thus the system adopted in South Australia would not be served by mirroring approaches taken in NSW, Queensland, the ACT, and Tasmania, which involve very little or no active participation from Government.

- a) advise the Minister regarding medical, social, scientific, ethical, legal, and moral issues arising from A.R.T, and upon any necessary directives that need to be issued to clarify acceptable practice in South Australia;
- b) monitor compliance with the Act, via receiving annual reports from clinics that include details of the RTAC audit and any recommendations for improvement, and any further reports necessary to inform the Council of action that has been taken in response;
- c) consider the results of any inspection or audit undertaken by a suitably qualified person appointed by the Minister, and make recommendations (when necessary) concerning appropriate action to be taken by the Minister;
- d) promote and engage in public education and forums concerning A.R.T.
- e) promote research, and provide the Minister with information regarding any research that may inform regulation and governance of A.R.T.
- f) report annually on the above, as well as upon outcomes of A.R.T. in South Australia, and any other matters decided by the Minister.

I further recommend that the A.R.T. Advisory Council be supported in its functions by Department for Health and Ageing staff member(s) as required, who undertake functions relevant to the implementation of the Act. Such a person should be the point of contact for people who wish to seek ethical or policy guidance or raise issues regarding the Act, which may then be referred to the A.R.T. Advisory Council.<sup>112</sup>

The recommended functions of the A.R.T. Advisory Council require that the Minister act upon regulation 8(2)(b) to make it a condition of registration that the A.R.T. provider provide the requisite annual report that includes details of the RTAC audit and any recommendations for improvement, as well as any further reports necessary to inform the Council of action that has been taken in response.<sup>113</sup>

In addition, the Minister will need to make it a condition of registration that clinics may be subject to auditing by a suitably qualified person appointed by the Minister for the purposes of ensuring compliance with the requirements under the Act. The Minister should

---

<sup>112</sup> Note recommendations in Chapter Five, that the donor conception register be held at Births, Deaths, and Marriages with an external provider of search and find, intermediary and support services. The person(s) supporting the A.R.T. Advisory Council and monitoring compliance under the Act would not be responsible for maintaining the donor register. (See further Chapters Four and Five regarding the donor conception register).

<sup>113</sup> Such a need for reporting and auditing was called for by variety of stakeholders. See for example, Aimee, submission 15; Caroline Lorbach, submission 27; Lauren Burns, submission 33; Damian Adams, submission 34; Kim Buck, submission 41; Confidential, submission 68, Kylie Dempsey, submission 69.

then appoint a suitably qualified person to audit and/or inspect providers of A.R.T. from time to time, for the purposes of ensuring compliance with the requirements under the Act. Such auditing should include (but may not be limited to) inspection of treatment records, incident and complaint management registers, risk assessment forms pertaining to applicants for A.R.T. in relation to the welfare of the child, records pertaining to screening of patients, donors, and embryos for heritable disease and/or serious illness (including but not limited to the use of PGD), and/or systems in place for managing compliance with the Act. The result of any audit undertaken could then be provided to the A.R.T. Advisory Council/the Minister.

The Minister should also make it a condition of registration that clinics must adhere to directives issued by the Minister from time to time. The Minister should then issue such directives as the need arises informed by advice received from the A.R.T. Advisory Council. This will allow for responsive regulation that suits the requirements of South Australia.<sup>114</sup>

The A.R.T. Advisory Council should include at least one A.R.T. health professional, consumer representatives (a donor of gametes, and a recipient of A.R.T.), religious leader representatives, a person born as a result of A.R.T., a person born as the result of donor-conception, a person with legal expertise in A.R.T. and health law, a person with expertise in ethics, a person with relevant expertise in counselling/social work, and a scientific expert(s). It is anticipated that the Council would meet three to four times per year, noting that its functions do not replicate those of the former SACRT but rather address the gaps left in the current co-regulatory system. The aim is to improve the operation and effectiveness of the Act by creating a point for advice, reporting, and discourse about relevant issues concerning A.R.T. that will facilitate responsive regulation, and inform future practice of A.R.T.

**FINDING 9**

It is important to ensure that the Act is effectively operationalised while not creating unnecessary regulatory burden or functions. To give effect to a co-regulatory system too much top down governance should be avoided. On the other hand, it is not acceptable to do nothing, as a co-regulatory system requires *active participation* in the regulatory system by both government and clinics.

---

<sup>114</sup> This report makes further recommendations in later chapters regarding particular directives that should be issued in the short term.

**RECOMMENDATION 4**

The Minister should establish an A.R.T. Advisory Council—whose role it is to

- a) advise the Minister regarding medical, social, scientific, ethical, legal, and moral issues arising from A.R.T, and any necessary directives that need to be issued to clarify acceptable practice in South Australia;
- b) monitor compliance with the Act, via receiving annual reports from clinics that include details of the RTAC audit and any recommendations for improvement, and any further reports necessary to inform the Council of action that has been taken in response;
- c) consider the results of any inspection or audit undertaken by a suitably qualified person appointed by the Minister, and make recommendations (when necessary) concerning appropriate action to be taken by the Minister;
- d) promote and engage in public education and forums concerning A.R.T.
- e) promote research, and provide the Minister with information regarding any research that may inform regulation and governance of A.R.T.
- f) report annually on the above, as well as upon outcomes of A.R.T. in South Australia, and any other matters decided by the Minister.

The Council should include at least one A.R.T. health professional, consumer representatives (for example a donor of gametes, and a recipient of A.R.T.), religious leader representatives, a person born as a result of A.R.T., a person born as the result of donor-conception, a person with legal expertise in A.R.T. and health law, a person with expertise in ethics, a person with relevant expertise in counselling, and a scientific expert(s).

**RECOMMENDATION 5**

The Minister should ensure that the A.R.T. Advisory Council is supported in its functions by an appropriate Department for Health and Ageing staff member (or members) as required who in addition undertake functions relevant to the implementation, oversight, monitoring, and enforcement of the Act.

#### **RECOMMENDATION 6**

To ensure effective operation of the Act, and that the functions of the A.R.T. Advisory Council may be realised, the Minister should:

1. act upon regulation 8(2)(b) to make it a condition of registration that A.R.T. providers submit an annual report to Council that includes details of the RTAC audit and any recommendations for improvement, as well as any further reports necessary to inform the Council of action that has been taken in response;
2. make it a condition of registration that clinics
  - a) may be subject to auditing by a suitably qualified person appointed by the Minister from time to time for the purposes of ensuring compliance with the requirements of the Act;
  - b) must adhere to directives issued by the Minister;
3. appoint a suitably qualified person to audit and/or inspect providers of A.R.T. from time to time, for the purposes of ensuring compliance with the requirements under the Act;
4. issue directives relevant to the practice of A.R.T. in South Australia as the need arises, and/or as advised by Council.

## **2.6 Review of the Operation and Effectiveness of the Act**

It will be important to conduct another review of the operation and effectiveness of the Act in five years to assess whether the recommendations in this report have been implemented, or what has been implemented in their place (if anything) and how they are operating.

#### **RECOMMENDATION 7**

The Minister should ensure provision in the Act for review of its operation and effectiveness five years after the date of the report from the last review being tabled in Parliament.

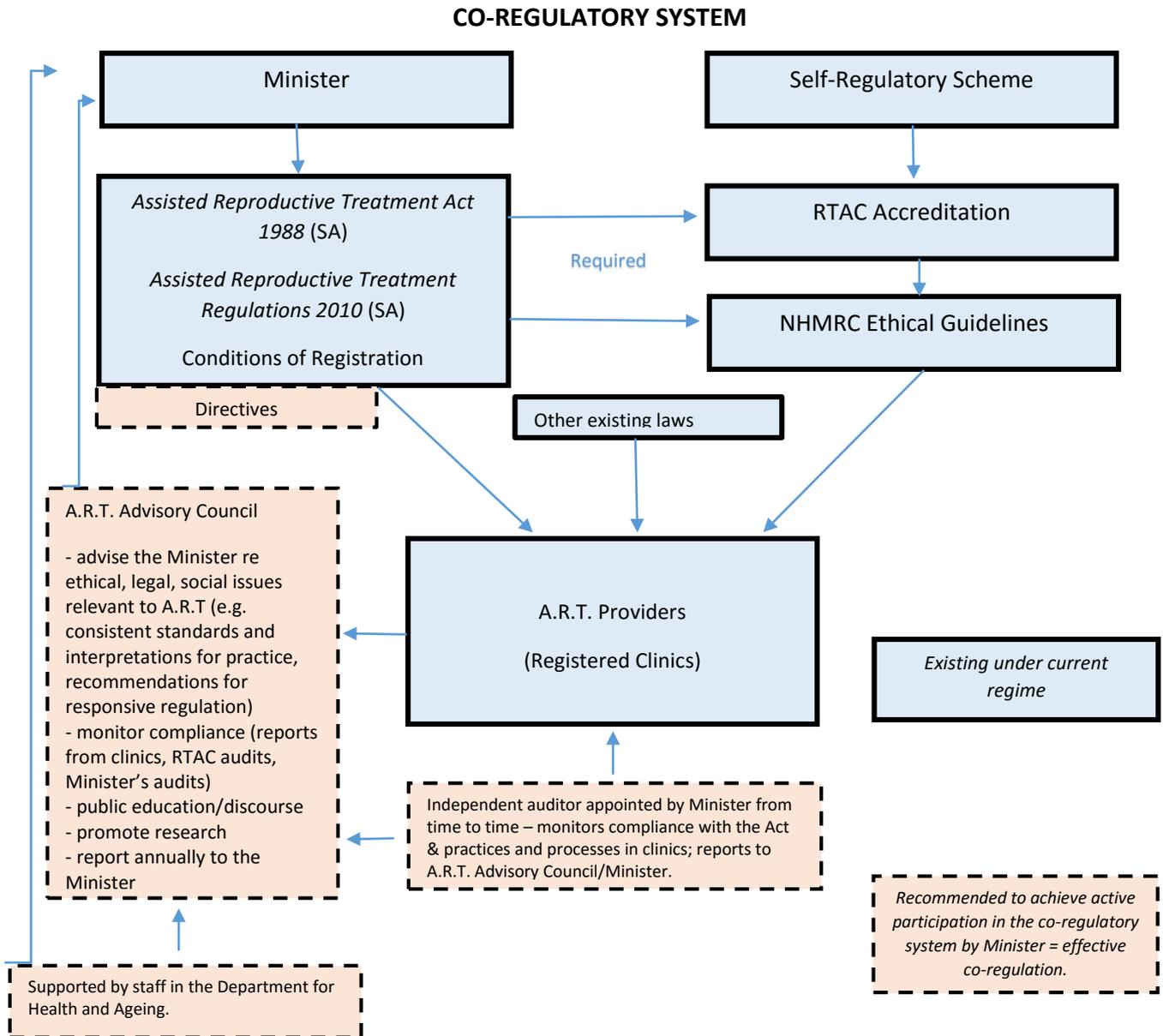
## **2.7 Conclusion**

South Australia has implemented a co-regulatory system for the governance of A.R.T. via the changes it made to the *Assisted Reproductive Treatment Act 1988 (SA)* and the *Assisted*

*Reproductive Treatment Regulations 2010 (SA)*. The system has gone a significant way to easing regulatory burden that existed pre- 2010. It is however currently lacking the necessary action by the Minister to give rise to an *effective* co-regulatory system of governance. Gaps exist in relation to regulatory oversight and monitoring, and transparency regarding the self-regulatory aspects of the system. In addition, a call for a body that enables local consultation and consideration of ethical and policy issues has been made.

The system I have recommended is thus aimed at filling the regulatory gaps, and ensuring the Act is effectively operationalised. It is proportionate to needs in South Australia and enables a ‘feedback loop’ to the Minister which would enable responsive regulation, without re-introducing unnecessary regulatory burden. It is depicted graphically in Figure 2 on the following page.

**Figure 2: Existing and recommended elements for effective co-regulatory governance of A.R.T.**





# Chapter Three

## Paramountcy of the Welfare of the Child

# Chapter Three:

## Paramountcy of the Welfare of the Child

### 3.1 Introduction

Section 4A of the *Assisted Reproductive Treatment Act 1988* (SA) (the Act) provides that:

*The welfare of any child to be born as a consequence of the provision of assisted reproductive treatment in accordance with this Act must be treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of this Act.*

This provision is commonly referred to as the ‘paramountcy of the welfare of the child principle’ and has overarching effect.

The paramountcy of the welfare of the child principle is of particular relevance to this review, given that much emphasis was placed upon it during the parliamentary debates regarding the 2010 amendments, subsequently resulting in the decision to retain *and strengthen* the provision in the amended Act. Parliament acknowledged that the welfare and/or ‘best interests’ of children is recognised as paramount internationally and domestically. Reference was made to the United Nations Convention on the Rights of the Child to which Australia is a signatory,<sup>115</sup> Australia’s family law system and agencies such as Families SA. It was seen as consistent with both international and domestic laws and practice to uphold the principle within the *Assisted Reproductive Treatment Act 1988*.

The principle that places the child’s welfare as being paramount was acknowledged in parliament as meaning that *such interests are placed above all others* including would-be-parents or medical practitioners. It was also acknowledged that the provision enshrines the welfare of the child as the fundamental principle of the Act and the guiding principle for the provision of A.R.T. generally.

---

<sup>115</sup> *United Nations Convention on the Rights of the Child*, opened for signature 20 November 1989, [1991] ATS 4 (entered into force 2 September 1990).

## 3.2 Focus of the Review

In considering the welfare of the child provision in the context of the operation and effectiveness of the Act, the review was particularly concerned with:

1. Whether there was support for the paramountcy of the child provision, and its being strengthened as part of the 2010 changes;
2. How the provision was being used, and to what effect;
3. What sorts of considerations were being made and/or systems put in place to uphold the provision;
4. What guidance was needed, if any, as to the sorts of considerations that should/should not be made;
5. Whether the paramountcy of the welfare of the child principle was being upheld in practice;
6. Whether more needs to be done to ensure the paramountcy of the welfare of the child principle is met, and if so, what.

## 3.3 Support for the Provision

Support for the paramountcy of the welfare of the child principle was explicitly given in thirty nine of the written submissions.<sup>116</sup> In other written submissions the support was implicit via, for example, expressed concern about the paramountcy provision not being upheld, and or focus upon how to give effect to the provision.<sup>117</sup>

<sup>116</sup> Confidential, submission 1; Confidential, submission 2; Confidential, submission 4; Mrs. Rosalie Dow-Schmidt, submission 6; Peter Liston, submission 9; Confidential, submission 13; Mrs. Aimee, submission 15; Confidential, submission 16; Miss Kim Pace, submission 19; Confidential, submission 20; Confidential, submission 22; Mrs. Caroline Lorbach, submission 27; Lauren Burns, submission 33; Damian Adams, submission 34; Miss Chloe Allworthy, submission 35; Dr. James Harvey, submission 38; Mrs. Danica Little, submission 40 (noting principle should extend to adult people also); Kim Buck, submission 41; Confidential, submission 43; Professors Sheryl De Lacey & Kelton Tremellon, submission 45; Fertility SA, submission 49; Marilyn Crawshaw, submission 51; Eric Blyth, submission 52; Dr. Kelly Ann, submission 55; Myfanwy Cumberford, submission 56; Professor Olga van den Akker, submission 57; Family Voice, submission 59; Natalie Parker, submission 61; Premier's Council for Women, submission 62; City Fertility, submission 63; Council for the Care of Children, submission 65; Relationships Australia, submission 66; Sandra Bevan, submission 67; Confidential, submission 68; Kylie Dempsey, submission 69; Confidential, submission 71; International Social Service Australia, submission 72; Confidential, submission 80; ANZICA, submission 82.

<sup>117</sup> For example, see Belinda Liebelt, submission 48; Ross Hunter, submission 60; Sofie Gregory, submission 70;

All people with whom I met during the face-to-face consultations expressed support for the paramountcy of the welfare of the child principle and it being seen as a fundamental principle in the provision of A.R.T. All such people agreed that the provision needed to be upheld in practice, and that giving meaning to the principle was important. This included clinicians, CEOs, nurses, administrators, and counsellors from the respective South Australian clinics; donor-conceived people; recipients of A.R.T.; donors; researchers; and staff at clinics responsible for record keeping.<sup>118</sup>

It was noted in a few submissions that the paramountcy principle, although stated in terms of the child born as a result of A.R.T., should be thought of to include the adult they will become.<sup>119</sup> This was particularly relevant to such things as the long term health and well-being of people born as a result of A.R.T., as well as access to information by donor-conceived people about their donors.

A number of submissions referred to the provision's relevance to meeting Australia's obligations under the United Nations Conventions on the Rights of the Child,<sup>120</sup> the Hague Convention on the Protection of Children,<sup>121</sup> and the *Children's Protection Act 1993 (SA)*.<sup>122</sup> The relevance of human rights was noted as also being a way to resolve issues when rights conflicted, with the view in human rights instruments that the best interests of children must be given precedence.<sup>123</sup> Human rights discourse was seen to reinforce the need for the welfare of the child to be considered paramount, above all other interests.

In contrast, one person, a donor of sperm, who had also used an egg donor to create his family through surrogacy, expressed the view that he didn't like the use of human rights discourse to 'favour children', and 'there was a need to consider everyone in the system'.<sup>124</sup>

Others stated that the welfare of prospective parent(s), women, and donors should also be considered,<sup>125</sup> although this was not seen to discount the paramountcy of the welfare

---

Ian Smith, submission 73; Robinson Research Institute, submission 74.

<sup>118</sup> See Appendix 3 for details of face-to-face consultations.

<sup>119</sup> See for example Caroline Lorbach, submission 27; and Eric Blyth, submission 52.

<sup>120</sup> Damian Adams, submission 34; Kim Buck, submission 41; Marilyn Crawshaw, submission 51; Eric Blyth, submission 52; Council for the Care of Children, submission 65; Family Voice, submission 59.

<sup>121</sup> Relationships Australia, submission 66.

<sup>122</sup> Relationships Australia, submission 66.

<sup>123</sup> Marilyn Crawshaw, submission 51; Eric Blyth, submission 52.

<sup>124</sup> Mark Dodd, oral submission, 21 April 2016.

<sup>125</sup> Confidential, submission 8; Confidential, submission 20; Dr Kelly Ann, submission 55; De Lacey & Tremellen, submission 45; Confidential, submission 68.

of the child. For example, a donor who made a submission stated:

*I agree that the resultant child (whether [donor-conceived] or not) should be of paramount importance, secondly the parents, lastly the donor and/or surrogate.<sup>126</sup>*

**FINDING 10**

The provision in the Act that the welfare of the child born as a result of A.R.T. must be treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of the Act, is valued and supported within South Australia and should be maintained.

Nevertheless, while the paramountcy provision requires the interests of the person to be born as a result of A.R.T. to be treated above all others, and its acceptance as a fundamental principle in respect of the operation of the Act was apparent, guidance was called for to give it more effect,<sup>127</sup> albeit Fertility SA said that some lack of clarity did not detract from doing one's best to uphold the provision.<sup>128</sup>

What the principle does, or should, entail is discussed below.

**FINDING 11**

There is a call for guidance from the Minister concerning how to give the paramountcy of the welfare of the child principle more effect.

### 3.4 Operationalising the Welfare of the Child Principle

The review moved to consider what was being, and or may be, considered in order to uphold the paramountcy of the welfare of the child principle, and to ensure its operationalisation and effectiveness. There were a variety of views raised in submissions regarding what

<sup>126</sup> Dr Kelly Ann, submission 55.

<sup>127</sup> DeLacey & Tremellen, submission 45; Myfanwy Cummerford, submission 56; Confidential, submission 68.

<sup>128</sup> Fertility SA, submission 49.

considerations might be had in this regard. Matters raised fell into the following categories:

- Screening for hereditary or infectious disease, disorder, or illness (discussed at 3.5);
- Screening applicants in relation to risks of harm to a person who will be born as a result of A.R.T. (discussed at 3.6);
- Screening of donors for risks of harm to a person born as a result of donor conception; (discussed at 3.7);
- Calls for long term research and follow-up on the health and welfare outcomes of people born as a result of A.R.T. (discussed at 3.8);
- Calls for inclusion of explicit reference to ‘health’ and welfare in the paramountcy provision (discussed at 3.9);
- Calls for access to information by donor-conceived people about their genetic heritage, donors and siblings (discussed in Chapter Four).

## 3.5 ‘Screening’ for Hereditary or Infectious Disease

### 3.5.1. Screening People who wish to access A.R.T.

The presence of a hereditary or infectious disease, disorder, or illness in a person (or couple) may be the reason the person or couple seek treatment in the first place. In South Australia provision of A.R.T. is permitted where people are likely to transmit a serious illness or genetic disease to their children.<sup>129</sup> Routine cycle blood tests are also carried out on all recipients of A.R.T. throughout treatment at a clinic to screen for any infectious diseases or conditions and avoid them being passed on to a child. The review did not receive any submissions on the use of A.R.T. by people in such circumstances or on screening those already accessing A.R.T. for infectious diseases. Such screening is an accepted reason for the use of A.R.T.

### 3.5.2. Screening of Embryos

Closely related to screening applicants to ensure they do not pass on certain severe hereditary disorder or disease to their offspring, is the screening of early embryos to find out if they are affected by a genetic disorder, or for the purposes of sex selection to avoid a sex-linked

<sup>129</sup> *Assisted Reproductive Treatment Act 1988* (SA) s 9(1)(c)(iii).

disorder.<sup>130</sup> Such screening is referred to as pre-implantation genetic diagnosis (PGD) or pre-implantation genetic screening (PGS) (hereafter PGD is used). As PGD is undertaken prior to any embryos being transferred to the woman who is accessing treatment, it is possible to discard any affected embryos and to select those embryos that do not have a particular condition for implantation.<sup>131</sup> There are now extensive possibilities in terms of conditions that may be screened for using PGD.<sup>132</sup>

In South Australia the *Assisted Reproductive Treatment Act 1988* (SA) permits the provision of A.R.T. ‘if there appears to be a risk that a serious genetic defect, serious disease or serious illness would be transmitted to a child conceived naturally’.<sup>133</sup> The use of PGD to screen embryos for such defect, disease or illness falls within the scope of this provision, noting that matters directly concerning PGD are also governed by the NHMRC Ethical Guidelines in South Australia.<sup>134</sup> One submission to the review noted:

*The amelioration of genetic diseases through the application of technologies such as pre-implantation genetic screening should not be overlooked when it comes to welfare of the child. Both Victorian and Western Australian Authorities, the Guidelines and case law, interpret the child’s welfare in the context of pre-implantation genetic screening.*<sup>135</sup>

Nevertheless, discussion of screening of embryos as part of upholding the paramountcy of the welfare of the child requires further detailed consideration in relation to the types of disease or disorder that may be screened, and whether PGD should be used for purposes beyond such screening—such as ‘social sex selection’.

---

<sup>130</sup> For a good discussion of the various uses of the technology, see P Braude, ‘Pre-implantation Genetic Diagnosis: Safely Born but not designed’ in S McLean and S Elliston (eds), *Regulating Pre-implantation Genetic Diagnosis: A Comparative and Theoretical Analysis*, Routledge, Oxford, 2013.

<sup>131</sup> Sonia Allan and Meredith Blake, *The Patient and the Practitioner: Health Law and Ethics in Australia* (2014) Lexis Nexis, Australia, p 391.

<sup>132</sup> See, for example, the extensive list of conditions that may be tested for using PGD that have been licensed by the United Kingdom Human Fertilisation and Embryology Authority at <http://guide.hfea.gov.uk/pgd/> (accessed 8 January 2017). (The list contains 403 different heritable conditions).

<sup>133</sup> *Assisted Reproductive Treatment Act 1988* (SA) s 9(1)(c)(iii).

<sup>134</sup> Section 9(1)(c)(iii) relates to access ART generally, while treatment decisions such as using PGD fall to the clinicians in compliance with the NHRMC Ethical Guidelines.

<sup>135</sup> Confidential, submission 68.

PGD Selection to Avoid Disability and Disease

The acceptability of PGD screening to protect the welfare of the child to be born as a result of A.R.T. may depend upon the type of disease or illness, and the reasoning behind such screening. For example, there are ongoing debates about whether the use of PGD reflects an underlying assumption that not only will those born with a disability lead a dissatisfying life, but they are unwelcome in society.<sup>136</sup> Whether provisions that enable PGD devalue the lives of people who have a disability, or value them unequally to the lives of others, is also often the subject of debate. Others have questioned whether the use of PGD for the purpose of avoiding disability means ‘society has a reduced imperative to find cures for these conditions.’<sup>137</sup>

On the other hand, for some people with severe inheritable disorders, PGD may be the only means for them to conceive a child that will survive pregnancy and result in a live birth; for others it means the child will live beyond the first few days after birth.<sup>138</sup>

Current NHMRC Ethical Guidelines provide clinics with guidance on the use of PGD, and are required to be adhered to under the *Assisted Reproductive Treatment Act 1988* (SA).<sup>139</sup> The NHMRC Ethical Guidelines expressly prohibit the use of PGD for the prevention of conditions that are not ‘seriously harmful’ to the person to be born.<sup>140</sup> The guidelines also recognise that the use of these technologies raise a number of difficult ethical issues including that what counts as a serious genetic condition is controversial; that there are different perceptions of disability; and that the practice of selecting against some forms of abnormality may threaten the status and equality of opportunity of people who have that form of abnormality.<sup>141</sup> Given the significance of these and other matters, the NHMRC Ethical Guidelines state that careful evaluation is required prior to the use of PGD.

In practice it appeared these principles were being upheld. However, during face-to-

---

<sup>136</sup> See for example, A Lippman ‘Bottom Line Genetics’ (2001) 4(2) *Community Genetics* 87-89; Ana Siltis, ‘Prenatal screening and prenatal diagnosis: contemporary practices in light of the past’ (2016) *J Med Ethics* 42:6, pp 334-339. Published Online First: 9 May 2016 doi:10.1136/medethics-2016-103623.

<sup>137</sup> R Deech and A Smajdor, *From IVF to Immortality: Controversy in the Era of Reproductive Technology*, Oxford University Press, Oxford, 2007, p 57.

<sup>138</sup> Allan and Blake, above n 131, p 392.

<sup>139</sup> *Assisted Reproductive Treatment Act 1988* (SA), s 9(1) (e) and *Assisted Reproductive Treatment Regulations 2010* (SA) reg 8(2)(a).

<sup>140</sup> National Health and Medical Research Council, *Ethical Guidelines on the use of Assisted Reproductive Technology in Clinical Practice and Research* (2007), [12.2].

<sup>141</sup> *Ibid*, [12.1].

face consultation a number of personnel working in clinics noted that there was not enough oversight occurring regarding such practices or when they are used. They called for some kind of process to ensure clinics only used PGD in circumstances that adhered to the current law and NHMRC Ethical Guidelines. It was found that at present there was no action by the government to do so, and that to better operationalise the welfare of the child principle some such action was called for.

**FINDING 12**

The acceptability of pre-implantation genetic diagnosis (PGD) screening to protect the welfare of the child to be born as a result of A.R.T. may depend upon the type of heritable condition or disease being screened, and the reasoning behind such screening. The current South Australian view is that careful evaluation of the reasons for the use of PGD, and restricting such screening to specific diseases or illnesses of a severe nature, is fundamental to upholding the paramountcy of the welfare of the child principle. There was call for government oversight to ensure PGD was only used in circumstances aligned with these views.

**RECOMMENDATION 8**

The Minister should conduct audits of clinics from time to time to establish the circumstances in which PGD has been used, and adherence to the law, conditions of registration, and relevant ethical guidelines.

PGD and sex selection

In South Australia, pursuant to the NHMRC Ethical Guidelines, PGD may also be used to screen for the sex of an embryo in order to avoid the transmission of a sex-linked disorder. When such screening occurs embryos are selected that are of a sex that will not carry the condition. Such screening is generally uncontroversial if the sex-linked disorder with which a child might be born, will be severe. The use of PGD to avoid the transmission of a sex-linked disorder is thus generally seen to be consistent with the paramountcy of the welfare of the child principle—noting that similar ‘careful evaluation’ as that regarding PGD generally is required.

Beyond sex selection for medical reasons, the use of sex selection for other reasons, such as to select an embryo of the opposite sex to those that already exist in the family

(sometimes referred to as ‘family balancing’),<sup>142</sup> or of a particular sexed child due to personal or cultural preference, has been the subject of much recent debate.

The review received two written submissions on PGD sex selection for non-medical reasons. Fertility SA submitted under the heading ‘Gender balancing for families’:

*We would also suggest consideration is given to allow couples undergoing pre-implantation genetic screening (PGS) to have access to the sex of the embryo that they may transfer. This is currently prohibited under NHMRC Ethical Guidelines, but our observation is that there is a growing demand for this information from patients.*<sup>143</sup>

This suggestion applies only to families who are already undergoing PGD/PGS for medical reasons.

Family Voice submitted:

*Sex selection by whatever means for its own sake – whether cultural or personal preference, family balancing or to “replace” a lost child – is contrary to viewing the child as a gift. It is eugenic in principle – deciding that only a child with certain characteristics is worthy to come into, or remain in existence. ...There should be no change that would allow for sex selection within the Act.*<sup>144</sup>

During oral submissions a Scientific Director of one clinic expressed concern that some clinics were using lab reports of embryos for genuine purposes but were then allowing clients to see the gender identifying information about the possible embryos that could be used in a cycle. The Scientific Director was concerned that this practice was ‘allowing sex selection through the back door’. The clinic reported that their practice was to expressly request the gender of the embryo not be provided on the lab report, but they knew of clinics that did not do this, and called for the need for clarity and hence consistency of practice.

---

<sup>142</sup> For an example of family balancing see *JS and LS v Patient Review Panel* [2011] VCAT 856.

<sup>143</sup> Fertility SA, submission 49.

<sup>144</sup> Family Voice, submission 59.

Research reveals that opponents of ‘social sex selection’ are concerned about widespread discrimination against a particular sex and long term population imbalance. Such imbalance is seen in certain regions of the world where ‘social sex selection’ is believed to have been practiced widely.<sup>145</sup> It has also been argued that ‘entry to life should not be conditional upon being a particular sex’.<sup>146</sup> Social sex selection may in addition, reinforce gender stereotyping, and or pose psychological risk to a child (person) who knows s/he has been selected for being a particular sex, particularly if s/he has a differing gender identity.<sup>147</sup> The Victorian Law Reform Commission found in 2008 that it ‘is difficult to identify ways in which the best interests of the child are served by permitting sex selection for a non-medical reason’ in the context of A.R.T.<sup>148</sup>

A joint interagency statement made by the Office of the Commissioner for Human Rights, the United Nations Population Fund, the United Nations Children’s Fund, UN Women, and the World Health Organisation in 2011, reaffirmed the commitment of UN agencies to address the multiple manifestations of gender discrimination including the problem of imbalanced sex ratios caused by sex selection, which was recognised to occur at pre-implantation phase (via sperm sorting or PGD), via abortion, or infanticide.<sup>149</sup> WHO noted further that prohibiting the use of technologies alone may be ineffective in preventing gender-biased sex selection, without broader social policies to encourage social norms that value and empower girls and women.<sup>150</sup> While not all social sex selection may prefer boys to girls, a policy that explicitly permits social sex selection may be counter to these goals.

There have been no long term studies regarding whether children born following a non-medical sex selection procedure have been harmed, or have suffered negative consequences, as a result of their parents’ choice. However, even if the selected child lived a

---

<sup>145</sup> For example, sex-ratio imbalances in favour of boy children have grown in a number of South Asian, East Asian and Central Asian countries.

<sup>146</sup> Victorian Law Reform Commission, *Assisted Reproductive Technology & Adoption: Final Report (2007)*, p 82.

<sup>147</sup> NHMRC, *Draft Ethical guidelines on the use of assisted reproductive technology in clinical practice and research: Public consultation – 2015*, p 56, available at [https://consultations.nhmrc.gov.au/public\\_consultations/assisted-reproductive-tech](https://consultations.nhmrc.gov.au/public_consultations/assisted-reproductive-tech) accessed 12 Jan 2016.

<sup>148</sup> Ibid.

<sup>149</sup> WHO, *Preventing gender-biased sex selection: an interagency statement OHCHR, UNFPA, UNICEF, UN Women and WHO*, (2011) (World Health Organization), available at <http://www.geneva.com.au/my-fertility/i-need-help/fertility-treatments/sex-selection> accessed 8 January 2017.

<sup>150</sup> Ibid, pp 7, 11-12.

favourable life within the family because of its chosen sex, the broader social implications must be considered.

A 2013 poll of Australians showed that they overwhelmingly opposed sex selection for non-medical social reasons. While 91% of people supported the use of IVF to help infertile couples, only 20% supported gender selection using PGD within IVF or for family balancing. When it came to the use of IVF only for gender selection, only 17% were in favour.<sup>151</sup>

Consideration of other jurisdictions revealed that sex selection for non-medical purposes is prohibited in numerous countries around the world.<sup>152</sup>

In Victoria, laws provide that if PGD is intended for sex selection, an application to the State's Patient Review Panel for approval is required.<sup>153</sup> The PRP must adhere to the Act's prioritising of the welfare of any child who may be born following the process. In an application made in 2010, by a couple who had three sons but had lost their daughter at birth, and wished to use sex selection to have a daughter, it was held that family balancing was 'not a sufficiently grave reason to approve a procedure that would otherwise be a criminal offence'.<sup>154</sup> The couple appealed to the Victorian Civil and Administrative Tribunal, arguing that having a daughter would improve their 'emotional wellbeing', help them complete their family and have a beneficial impact on their sons.<sup>155</sup> The Tribunal rejected these arguments stating they focused on the needs of the parents and the existing children, rather than focusing on the welfare of the future child. The application was dismissed.

In South Australia, current law does not explicitly prohibit sex selection for non-medical purposes. However, as the law stipulates that A.R.T. can only be provided in limited circumstances A.R.T. cannot be accessed solely for such purposes. The law also requires adherence to the NHMRC Ethical Guidelines under which sex selection for non-medical purposes is currently prohibited.<sup>156</sup> Should the Guidelines change to permit sex selection, the

---

<sup>151</sup> Gab Kovacs, Julian McCrann, Michele Levine, and Gary Morgan, 'The Australian Community Does Not Support Gender Selection by IVF for Social Reasons' (2013) *International Journal of Reproductive Medicine* Volume 2013, Article ID 242174, <http://dx.doi.org/10.1155/2013/242174>.

<sup>152</sup> Austria, Australia, Belarus, Bulgaria, Canada, China, Croatia, Cuba, Denmark, Egypt, Finland, France, Germany, Greece, Hungary, India, Latvia, Lebanon, Macedonia, Malaysia, Malta, Montenegro, Morocco, Netherlands, New Zealand, Norway, Oman, Romania, Russia, Saudi Arabia, Singapore, South Africa, South Korea, Sri Lanka, Sweden, Switzerland, Syria, Taiwan, Tajikistan, Thailand, Tunisia, United Arab Emirates, United Kingdom, Vietnam, Yemen.

<sup>153</sup> *Assisted Reproductive Treatment Act 2008* (Vic), s 28(2)(b).

<sup>154</sup> Cited in *JS and LS v Patient Review Panel* [2011] VCAT 856 [54].

<sup>155</sup> *JS and LS v Patient Review Panel* [2011] VCAT 856 [53], [81].

<sup>156</sup> NHMRC Ethical Guidelines (2007), [11.1] and [12.2].

position in South Australia would also change allowing social sex selection once already accessing A.R.T. for other purposes, unless the law or conditions for registration provided otherwise.

It would be inconsistent to allow social sex selection because someone is using PGD/PGS for another medical reason that is not sex-linked, but not to allow social sex selection in other circumstances. However, the evidence and arguments currently available regarding non-medical sex selection, on balance, do *not* favour its use. This is especially so as prohibitions on ‘social sex selection’ accord with concerns that the practice may negatively impact upon children. In contrast, arguments that favour social sex selection tend to focus on the adults who wish to use PGD for family balancing or, personal or cultural preferences, which does not align with placing the interests of children as paramount above all others.

#### **FINDING 13**

The use of PGD to avoid the *transmission of a sex-linked disease, disorder, or illness* of particular gravity accords with the paramountcy of the welfare of the child principle. As per the use of PGD for other medical screening careful evaluation of the reasons for its use, the seriousness of the condition, and adherence to the NHMRC Ethical Guidelines, are required.

#### **FINDING 14**

Sex selection for *social purposes* remains controversial and is not supported by the majority of the general public.

#### **RECOMMENDATION 9**

In the interest of upholding the welfare of the child born as a result of A.R.T. as paramount, the Minister for Health should maintain prohibitions on *sex selection for social purposes*. A statement to this effect should be included in the conditions for registration, or via a directive.

#### A.R.T. and PGD for human leukocyte antigen (HLA) Typing

PGD may be used together with HLA typing to create a child (commonly referred to as a ‘saviour sibling’) with a tissue type that matches that of an existing sibling who requires tissue

or organ donation, and no other suitable donor is available.<sup>157</sup> The practice is contentious as it may be seen that a child is created solely for the benefit of an existing person. Alternatively, the view may be taken that the child is being created to be loved in his or her own right as well as to assist the sibling.<sup>158</sup> Arguments abound as to whether such practice is acceptable.<sup>159</sup>

In South Australia, pursuant to section 9 of the *Assisted Reproductive Treatment Act 1988* (SA) clinics can only provide A.R.T. in limited circumstances, which do not include PGD for HLA. Should person(s) qualify to access A.R.T treatment under s9, then if PGD for HLA was being considered, the clinic must adhere to the NHMRC Ethical Guidelines. The guidelines require clinics to ‘seek advice from a clinical ethics committee’ or other appropriate agency, prior to undertaking PGD with HLA typing and restrict such use to ‘the case of siblings’.<sup>160</sup> They also require PGD for HLA typing only be conducted when the welfare and interests of the child born as a result of A.R.T. will not be adversely affected.<sup>161</sup> This accords with the South Australian paramountcy of the welfare of the child principle. There are currently no proposed amendments to the NHMRC Ethical Guidelines relevant to PGD for HLA typing that might compromise the principle.

#### **FINDING 15**

The current operation of the *Assisted Reproductive Treatment Act 1988* (SA) (1988) satisfactorily upholds the paramountcy of the welfare of the child principle in relation to PGD for HLA typing.

### **3.5.3. Medical and Genetic Screening of Donors of Sperm, Eggs, and Embryos**

Medical screening is also used in the case of donors to determine whether they may proceed to being donors of genetic material. Becoming a donor therefore, among other things,

<sup>157</sup> Note that use of A.R.T. and PGD for HLA typing are only applicable when transplantation is non-urgent and parents are of reproductive age due to the time that one must wait for the conception and birth of the ‘matched’ child. G N Samuel, et al. ‘Establishing the role of pre-implantation genetic diagnosis with human leucocyte antigen typing: what place do “saviour siblings” have in paediatric transplantation?’ (2009) 94 *Arch Dis Child* 317-320.

<sup>158</sup> J Herring, *Medical Law and Ethics*, 4<sup>th</sup> ed, Oxford University Press, Oxford, 2012, p 396. For comprehensive analysis of these issues see Malcolm K. Smith, *Saviour Siblings and the Regulation of Assisted Reproductive Technology: Harm, Ethics and Law*. (2015) Ashgate, Farnham, Surrey.

<sup>159</sup> Ibid.

<sup>160</sup> NHMRC Ethical Guidelines (2007), [12.3].

<sup>161</sup> NHMRC Ethical Guidelines (2007), [12.3.1].

includes the taking of a family medical history, and genetic and infectious disease screening and counselling. In Australia, generally karyotype (chromosome analysis) is conducted to identify any chromosomal anomalies that may affect pregnancy or the child conceived, as well as genetic testing for Cystic Fibrosis<sup>162</sup> and Thalassaemia.<sup>163</sup> Further genetic tests may be conducted if the donor belongs to certain ethnic groups (for example, Ashkenazi Jews<sup>164</sup>). Other blood and urine tests to screen for infectious diseases and conditions that might otherwise be passed on to the recipient and or child are also conducted. In the case of sperm donors, sperm quality is also checked. Donations are quarantined for a period of three to six months, and then retested, for certain infectious diseases (for example, HIV).

In many instances, therefore, screening is used as a means to prevent gametes being used that would result in heritable disease, disorder, or illness being passed on to a child born as a result of the use of A.R.T. A number of submissions to the review explicitly agreed that screening for risks of heritable disease and illness, especially in donors of genetic materials (sperm, eggs, and embryos) is acceptable, and relevant to the welfare of the child principle.<sup>165</sup> Damian Adams and Kim Buck noted such screening practices should be uniform and consistent across clinics, accord with current best practice, and be updated periodically.<sup>166</sup>

#### **FINDING 16**

The screening of donors for heritable disease or illness is currently practiced in South Australia, and accords with the fundamental principle in the Act regarding the paramountcy of the welfare of any child to be born as a result of A.R.T. in which donor gametes are used. Such screening practices should be uniform and consistent across clinics, accord with current best practice, and be updated periodically.

<sup>162</sup> Cystic Fibrosis is a genetic condition that affects many organs in the body, especially the lungs, pancreas and sweat glands. About 1 in 25 people of European Caucasian ancestry are genetic carriers of Cystic Fibrosis and are at increased risk of having a child born with Cystic Fibrosis.

<sup>163</sup> Thalassaemia is a genetic condition that can lead to serious diseases in the red blood cells. In the severe form of thalassaemia significant symptoms and death may result.

<sup>164</sup> Genetic disorders that appear more frequently in Ashkenazi Jews include, for example, Tay-Sachs Disease, Canavan, Niemann-Pick, Gaucher, Familial Dysautonomia, Bloom Syndrome, Fanconi anemia, Cystic Fibrosis and Mucopolysaccharidosis IV. Some of these diseases may be severe and may result in the early death of a child.

<sup>165</sup> Confidential, submission 68; Damian Adams, submission 34; Kim Buck, submission 41; Adnan Catakovic, City Fertility, Oral Submission 19 April 2016.

<sup>166</sup> Damian Adams, submission 34; Kim Buck, submission 41.

Late discovery of heritable disease or illness

In practice, medical and genetic testing may not encompass screening donors of gametes or embryos for all possible heritable conditions. Nor may it reveal conditions as yet unknown, or that do not appear until later in life. A donor, or a donor-conceived person, may thus later discover they have a heritable disease, even if the donor underwent screening prior to donation. This is illustrated by high profile cases such as Narelle Grech in Victoria, who died of bowel cancer in 2013;<sup>167</sup> and by the Danish sperm donor (number 7042) from Nordic Cryobank ApS who transmitted the nerve disorder Neurofibromatosis type I (NF1) to a number of donor-conceived offspring worldwide.<sup>168</sup> In both cases a number of donor-conceived siblings may also have inherited the disease.

In such circumstances, because the donor and donor-conceived person may not be in contact, it is important that any such discovery may be communicated to the clinic(s) at which the donation and/or conception took place. The clinic(s) may then take steps to cease use of any genetic materials that remain, and to consider whether any genetic relatives need to be contacted about the condition. This may be more complicated in cases in which a genetic relative is donor-conceived but does not know of such status. Nevertheless, there is support for disclosure of heritable disease or disorder when there are benefits in informing those at risk such as seeking early treatment or screening for the disease.

*Consent* to inform genetic relatives may be obtained following discussion with the person who has discovered they have the heritable condition. If consent to disclosure is not forthcoming it is lawful to disclose information to genetic relatives in some circumstances, pursuant to Commonwealth and/or state laws.

At a Commonwealth level, privacy legislation and accompanying Australian Privacy Principles (APPs),<sup>169</sup> govern how private health service providers, which would include fertility clinics, must handle, use and manage personal information. Section 16B(4) of the *Privacy Act 1988* has, since 2006, permitted the disclosure of genetic information to genetic relatives without a patient's consent, provided the health practitioner '*reasonably believes that*

---

<sup>167</sup> See Narelle Grech, Inquiry Submission to Victorian Law Reform Committee. Inquiry into access by donor-conceived people to information about donors, August 2011 5/09/2011mhtml:file://S:\Law Reform [http://www.parliament.vic.gov.au/images/stories/committees/lawrefrom/iadcpiad/submissions/DCP67 - Narelle Grech.pdf](http://www.parliament.vic.gov.au/images/stories/committees/lawrefrom/iadcpiad/submissions/DCP67_-_Narelle_Grech.pdf), accessed 8 January 2017.

<sup>168</sup> Anders Hanson, 'Danish Sperm Donor Passes Neurofibromatosis on to Five Children' (2012) *BMJ*;345:e6570.

<sup>169</sup> Contained in Schedule One of the *Privacy Act 1988* (Cth).

*disclosure is necessary to lessen or prevent a serious threat to the life, health or safety of the genetic relatives.'* Such disclosure must take place in accordance with APP 6.2(d) and the guidelines approved under s 95AA of the *Privacy Act*. Specific NHMRC guidelines set out the requirements for disclosure of genetic information in such circumstances.<sup>170</sup>

At a State level the *Health Care Act 2008* (SA) allows for disclosure of information by an officer or employee of the Department for Health and Ageing engaged in the administration of the Act, a person employed by an employing authority under the Act, and a number of other public sector health workers,<sup>171</sup> if '*the disclosure is reasonably required to lessen or prevent a serious threat to the life, health or safety of a person, or a serious threat to public health or safety*'.<sup>172</sup> The South Australian provision is more general than the Commonwealth provision as it is not limited to genetic information.

Note, the Commonwealth and South Australian laws do not mean that information *must* be disclosed, but rather that information *can be* disclosed if relevant guidelines have been followed, and a decision is made that such disclosure is warranted.

In the context of the current review, if *screening* for heritable conditions is considered as upholding the paramountcy of the welfare of the child provision, then arguably *communication* to a person born as a result of the use of A.R.T. when such screening has failed to identify a condition that is later discovered, is equally relevant to the paramountcy provision. Communication of such threats to life, health, or safety, however would require:

- a. the ability for donor-conceived people, and donors, to notify the relevant clinic(s) and/or donor conception register (if any) should a heritable condition be discovered;
- b. the ability to link donors with any donor-conceived offspring and other genetic relatives (usually up to 3<sup>rd</sup> degree) so as to be able to identify anyone who is at risk;
- c. a donor-conceived person to have knowledge of their status so that any future notification of a medical or genetic condition does not pose the added complication of revealing

---

<sup>170</sup> National Health and Medical Research Council. Use and disclosure of genetic information to a patient's genetic relatives under section 95AA of the *Privacy Act 1988* (Cth). Guidelines for health practitioners in the private sector. Canberra: NHMRC, 2014.

[http://www.nhmrc.gov.au/files\\_nhmrc/publications/attachments/pr3\\_use\\_of\\_genetic\\_information\\_s95aa\\_1\\_40311.pdf](http://www.nhmrc.gov.au/files_nhmrc/publications/attachments/pr3_use_of_genetic_information_s95aa_1_40311.pdf) accessed 8 January 2017.

<sup>171</sup> Section 93(1) of the *Health Care Act 1988* (SA) states that the disclosure provisions apply to an officer or employee of the Department engaged in the administration of the Act; a person employed by an employing authority under the Act; or a member of the staff of SAAS; or a person otherwise engaged to work at an incorporated hospital or in connection with the activities of SAAS.

<sup>172</sup> *Health Care Act 1988* (SA) s 93(3)(e).

unknown donor-conceived status; and should they discover they are carrying a heritable condition, they too can notify the clinic and register, enabling communication of the condition to the donor and any donor-siblings if required.

Unfortunately, there is currently no consistent method in South Australia for updating health information for donors or donor-conceived people, nor a central register upon which such information may be recorded/accessed. There is also an absence of guidance regarding how to approach a donor-conceived person when there is a risk to their life, health, or safety, that with knowledge they may address.

**FINDING 17**

There is a lack of consistent method in South Australia for updating health information for donors or donor-conceived people, and an absence of a central donor conception register upon which such information may be recorded/accessed. There is also an absence of guidance regarding how to approach a donor-conceived person when there is a risk to their life, health, or safety, that with knowledge they may address. This does not accord with the paramountcy of the welfare of the child principle.

**RECOMMENDATION 10**

The Minister for Health should provide a directive on

- 1) requirements pertaining to screening of donors of gametes and/or embryos for heritable disease, disorder or illness, and
- 2) disclosure to genetic relatives when such a disease, disorder, or illness is discovered by a donor/donor-conceived person that may pose a threat to the life, health, or safety of a related person—including requirements and processes concerning:
  - a. updating the clinic, and/or donor conception register (once established) of health status;
  - b. notification to the person at risk;
  - c. provision by the clinic to the person at risk of appropriate support services (such as genetic counselling).

### 3.6 Screening Applicants for Risk of Harm to a Child(ren)

The welfare of the child provision often also invokes screening applicants for A.R.T. to assess a person (or couple's) ability to provide an acceptably safe, stable, and healthy family environment for any child that may be born to them following treatment. The process of screening in this regard often draws upon an 'acute... aware[ness] of factors, that may impede a person's ability to fulfil these obligations...'<sup>173</sup> and requires consideration of whether any child born as a result of the provision of A.R.T. might be at significant risk of *physical harms*, such as physical and/or sexual abuse, neglect, family violence, and/or drug or alcohol problems; and/or *psychological harms*, such as being at risk of exposure to any of the above forms of violence, neglect or abuse, or where other family factors, such as mental illness or addiction, may affect a child's well-being.

In South Australia, some 'screening' provisions intended to protect the welfare of any child born as a result of A.R.T. were removed in 2010 when the Code of Ethical Clinical Practice was repealed. This included requirements that a person wishing to access A.R.T., and their partner (if any), sign a statutory declaration concerning whether they had prior criminal convictions, child protection orders, mental health issues, or drug use.

Under the current regime the regulations state that there is no legal obligation upon a registered provider (or anyone else) to provide A.R.T.<sup>174</sup> There is however, no further detail regarding when such refusal may occur. The Department for Health and Ageing advises via a Fact Sheet on its website that the welfare of the child provision 'allows for consideration of the suitability of a client wanting to undertake A.R.T',<sup>175</sup> but again no explanation is provided regarding what this entails. In reviewing the operation and effectiveness of the Act, submissions regarding screening for risk of harm, and whether 'suitability' screening was occurring, were considered.

<sup>173</sup> John Tobin, *The Convention on the Rights of the Child: The Rights and Best Interests of Children Conceived Through Assisted Reproduction* (2004), 24. (Victorian Law Reform Commission).

<sup>174</sup> *Assisted Reproductive Treatment Regulations 2010* (SA) reg 4.

<sup>175</sup> SA Health, Fact Sheet: Access to ART at a Registered clinic in South Australia, [http://www.sahealth.sa.gov.au/wps/wcm/connect/60b1688043a636fca671eed1a914d95/FS1\\_Access+to+AR+T.Sep+2015.pdf?MOD=AJPERES&CACHEID=60b1688043a636fca671eed1a914d95](http://www.sahealth.sa.gov.au/wps/wcm/connect/60b1688043a636fca671eed1a914d95/FS1_Access+to+AR+T.Sep+2015.pdf?MOD=AJPERES&CACHEID=60b1688043a636fca671eed1a914d95) accessed 15 December 2016.

### **3.6.1 Support for Screening for Risk of Harm to Children**

Submissions received from parents, donor-conceived people, support services, medical practitioners, A.R.T. providers, and donors called for screening for risk of physical or psychological harm to children that may be born as a result of A.R.T.<sup>176</sup> Some such submissions expressed concern about the removal of screening provisions that existed prior to 2010 and suggested that such provisions should be reinstated. For example, Relationships Australia said:

*There exist certain risks that should be screened or assessed during the application stage for people seeking ART. We believe screening provisions should be reinstated to prevent people accessing treatment who may pose a risk to the child or otherwise demonstrate the paramount interests of the child would not be upheld. This is particularly evident where there are issues of child protection, child pornography, domestic and family violence, untreated mental health and any other circumstances that present unacceptable risks to a donor conceived child.*<sup>177</sup>

Mrs. Sandra Bevin, an A.R.T. recipient said:

*The other concern I have with the Act is removing the screening requirement. I think this leaves things open to chance as how will you know if a person seeking to go through the IVF programme has a criminal record, has previously hurt children, or has had families removed through Families SA. You don't, and are really hoping for the best and leaving everything to chance... As the Act states the welfare of the child is paramount and has been strengthened...it doesn't seem to be when you see that this safety net has been removed.*<sup>178</sup>

---

<sup>176</sup> Confidential, submission 8; Confidential, submission 14; Kay, submission 18; Lauren Burns, submission 33; Damian Adams, submission 34; Kim Buck, submission 41; Professor Marilyn Crawshaw, submission 51; Professor Eric Blyth, submission 52; Myfanwy Cummerford, submission 56; Professor Olga van den Akkar, submission 57; Relationships Australia, submission 66; Sandra Bevin, submission 67; Kylie Dempsey, submission 69; Sofie Gregory, submission 70; Confidential, submission 71; International Social Services Australia, submission 72; Reece Trevenan, submission 79.

<sup>177</sup> Relationships Australia, submission 66.

<sup>178</sup> Sandra Bevan, submission No. 67.

Submissions also pointed to the lived experiences of people who had suffered abuse.

Damian Adams said:

*I am involved in numerous support groups and networks for donor-conceived people around the world. It is often regarded in the public eye that donor-conceived people must be doing well in their homes because they were wanted and their parents went to great lengths to have them. While that may be true in many cases, it does not erase the fact that there have been numerous stories told by adult donor-conceived people whereby they have been raised in abusive (physically, mentally and sexually) households. This is also certainly true for families in the general community. However, the child welfare paramountcy principle and the publicly funded nature of the treatment installs a duty of care onto the State. It is the morally and ethically correct thing to do to reintroduce screening of patients in an attempt to reduce the number of abusive incidences.<sup>179</sup>*

Lauren Burns submitted:

*This issue sounds like a theoretical concern, however I am personally friends with donor-conceived people who grew up in households where they experienced violence and sexual abuse. In some cases when their parents sought treatment they had already acquired serious criminal histories, however no questions were asked.<sup>180</sup>*

A recipient of A.R.T. said:

*My experience was that there was no psychological screening when I was a client of a reproductive clinic and personal checks were not made that have since impacted upon the welfare of my child and my mental health. Having*

---

<sup>179</sup> Damian Adams, submission 34.

<sup>180</sup> Lauren Burns, submission 33.

*psychological assessments of both parties wanting to conceive a child and the clinic offering counselling might have assisted in the development of a more positive and healthy environment for raising a child. Now, I am faced with raising a child that has had to manage shared care from age 8 months that could have been avoided with compulsory counselling and follow-up from the clinic.*<sup>181</sup>

Many submissions agreed that services should not be provided if an applicant was found to pose a risk of physical or psychological harm to any child that may be born as a result of A.R.T.<sup>182</sup>

### **3.6.2. The Involvement of Third-Parties (the State, Health Professionals)**

The involvement of third parties such as the state and health professionals led a number of people to note that paramourty of the child provision includes an obligation on such parties not to provide A.R.T., and therefore access to children, when a significant risk of harm to children may exist.<sup>183</sup> The International Social Services submitted:

*Paramourty of the welfare of the child in [A.R.T.] poses the existential dilemma of whether screening the prospective parent[s] is in a child's welfare interests, if that process results in that child not being born. However, in the case of A.R.T., prior to the screening of the applicant, the child does not exist. The child's life is being deliberately brought into being [by]... medical staff in response to an applicant's desire. Therefore, when considering a child's welfare being paramount, it seems logical that there is an obligation to screen.*<sup>184</sup>

---

<sup>181</sup> Confidential, submission 14.

<sup>182</sup> Confidential, submission 8; Confidential, submission 14; Kay, submission 18; Lauren Burns, submission 33; Damian Adams, submission 34; Kim Buck, submission 41; Professor Marilyn Crawshaw, submission 51; Professor Eric Blyth, submission 52; Myfanwy Walker, submission 56; Professor Olga van den Akkar, submission 57; Relationships Australia, submission 66; Sandra Bevin, submission 67; Kylie Dempsey, submission 69; Sofie Gregory, submission 70; Confidential, submission 71; International Social Services Australia, submission 72; Reece Trevenen, submission 79.

<sup>183</sup> Lauren Burns, submission 33; Kim Buck, submission 41; Myfanwy Walker, submission 56.

<sup>184</sup> International Social Services, submission 72.

Kim Buck said:

*Screening of potential recipient parents for violence or other criminal behaviours should be reinstated. ART is a state funded and supported treatment, which places the duty of care for children born via ART on the state. Rigorous screening occurs for prospective adoptive parents and the same protocols should equally apply for ART.*<sup>185</sup>

Similarly, Lauren Burns noted:

*This viewpoint is controversial within some sections of the community, who point out that child abuse happens to children who are naturally conceived. However I believe we should come back to the guiding principle of the Act that the welfare of any child born from ART is of paramount importance. There is a further point of difference here in that the conception of children via ART involves third parties (donors) and the financial support of the State.*<sup>186</sup>

Professor Marilyn Crawshaw also submitted that although one cannot ensure that prospective parents will not harm their offspring, and any checks need to be proportionate, the involvement of third parties such as medical practitioners in the reproductive process meant that it was not acceptable to ‘do nothing’. She emphasises that ‘a straight parallel with those conceiving without medical assistance cannot be drawn’.<sup>187</sup>

The unquestioning provision of A.R.T. to anyone who applied was not therefore seen as acceptable by a number of people who made submissions to the South Australian review.

### **3.6.3. Opposition to Screening**

In contrast, the review received a submission from a person who had been both a sperm donor and a recipient of an egg donation for surrogacy, who was opposed to screening for

---

<sup>185</sup> Kim Buck, submission 41.

<sup>186</sup> Lauren Burns, submission 33.

<sup>187</sup> Professor Marilyn Crawshaw, submission 51.

access to A.R.T.<sup>188</sup> He said he saw donor-conception as comparable to natural conception and argued that we don't screen people in the general community who wish to have children. Another submission stated the view:

*that it is not the role of legislation to screen out good prospective parents from bad prospective parents ... The law should not impose any restrictions upon individuals in the general community who wish to become parents. Indeed, [we are] of the view that it is a fundamental right of individuals to be able to have children and form families.*<sup>189</sup>

However, that submission also said that if screening was deemed necessary, it should accord with anti-discrimination laws.

#### **3.6.4. Current Clinical Practice in South Australia**

Face-to-face consultation revealed that clinics in South Australia take a varied approach to screening in relation to assessing the potential for risk of harm to future children.

A clinician at one clinic explained that although the provision for screening no longer exists under the current legislation, it was still their practice to require prospective patients and their partners to sign a declaration concerning prior convictions, child protection orders, violence, and drug use, as part of the consent process. Another clinician from that clinic noted that such a declaration opened up the possibility for a dialogue, and enabled practitioners and counsellors to explore further the issues. They said that while the situation did not arise often, there had been occasion on which refusal of treatment had been warranted due to significant concern about the risk of harm to future children. The view expressed at that clinic was that the declaration, alongside clinical judgement concerning risk, served as a 'safety net' that might not pick up everyone, but that enabled at least some protections.

At another South Australian clinic, a clinician said that he would not like to see the same screening requirements as in Victoria which require criminal record and child protection order checks, or a return to the statutory declaration. He expressed his view was that the

---

<sup>188</sup> Mark Dodd, submission 26.

<sup>189</sup> Confidential, submission 68.

police record check is just a barrier to access and doesn't stop treatment—as people could just travel to get the service, or the tribunal would order the treatment anyway. The clinician said that under the pre-2010 regime cases of concern would have been referred to the SACRT, however decisions were now made 'in-house'. He described the clinic's review process as one relying on clinical judgement, and referral to their internal medical advisory committee if deemed necessary by the clinician. He confirmed that there had been occasions, although rare, in which concern had been raised in relation to a person seeking IVF, sighting an example of a person who was intellectually impaired, and living in the country, who already had four children in her care, and for whom Families SA were involved. The clinic liaised with Families SA and ultimately it was decided that treatment could not be offered.

A counsellor at the same clinic, who had experience in working in child protection and domestic violence, said that she used a 'checklist' to provide information to applicants but this differed to conducting an assessment. She noted that there was no consistency in the state, and no recognised tool to establish what was in the best interests of the child. She was concerned that refusal to treat just meant that the person or couple would go to another clinic. She also raised that at times she felt the need to be able to call on an external body or relevant organisation to get more information or to do an assessment to consider the best interests of the child,<sup>190</sup> but at present no such system exists in South Australia.

A third clinic expressed the view that it was not their role at all to assess whether or not someone would make a suitable parent, and did not adopt 'screening' as a practice.

It was apparent that clinics in South Australia differed in their views and practices regarding whether screening to assess for risk to children should occur. They also differed regarding the criteria used (if any), who should conduct such screening, how such screening should be conducted, and what should occur if someone was identified who raised concerns about possible risk to children. There was no uniformity.

### **3.6.5. Comparison to other jurisdictions**

To inform the review, consideration was also given to practices and models implemented in some other jurisdictions as points of comparison.

---

<sup>190</sup> In discussing this the counsellor referred to a recent case in which she asked for an external assessment with a psychologist and relationship counselling for a couple applying for an embryo transfer in which the wife lives in a different country and her husband and her do not speak the same language.

Victoria

Victoria requires screening by way of criminal record and child protection order checks. There are legal presumptions against treatment when 1) a criminal record check specifies that charges have been proven against a woman or her partner for a sexual offence or violent offence;<sup>191</sup> or 2) there has been a child protection order made removing a child from the custody or guardianship of the woman or her partner.<sup>192</sup> Refusal of treatment may also occur if a registered A.R.T. provider or doctor reasonably believes that a child that may be born would be at risk of abuse or neglect.<sup>193</sup>

If there is 'presumption against treatment',<sup>194</sup> or refusal of treatment because of a reasonable belief concerning risk of abuse or neglect,<sup>195</sup> an application for review may be made to the Victorian Patient Review Panel (PRP).<sup>196</sup> Such proceedings are not open to the public and are conducted with minimum formality. Applicants do not have a right to be legally represented without leave from the PRP. Within 14 days after the hearing, the PRP must give the applicant written reasons for its decision. PRP decisions are reviewable by the Victorian Civil and Administrative Tribunal (VCAT). Research conducted in the course of the review revealed that the VCAT review process *does not* always lead to overturning of PRP decisions as was submitted to this review.<sup>197</sup>

The quasi-judicial review system adopted reflects the view of the VLRC that such a system would 'implement a fair and transparent process that enables a clinic to investigate concerns about risks to children on a case by case basis and according to identifiable and established risk factors...'<sup>198</sup> Note the VLRC had recommended a statutory declaration system

---

<sup>191</sup> *Assisted Reproductive Treatment Act 2008* (Vic), s14(1)(a).

<sup>192</sup> *Assisted Reproductive Treatment Act 2008* (Vic), s14(1)(b).

<sup>193</sup> *Ibid*, (s15(1)(c)).

<sup>194</sup> *Assisted Reproductive Treatment Act 2008* (Vic), s 14.

<sup>195</sup> *Ibid*, (s15(1)(c)).

<sup>196</sup> The Panel is established under section 82 of the *Assisted Reproductive Treatment Act 2008* (Vic) and is independent of the Department for Health and Human Services (the Department) and assisted reproductive treatment (ART) providers.

<sup>197</sup> See *TRV v Department for Health and Human Services (Human Rights)* [2015] VCAT 1188 (5 August 2015), VCAT REFERENCE NO. H68/2015, [14].

<sup>198</sup> Victorian Law Reform Commission *ART and Adoption: Final Report* (2007), 61. (Noting that it was held in *Patient Review Panel v ABY and ABZ* [2012] VSCA 264 that it was this report 'on which the provisions of the Act are clearly based...' at [91].

concerning criminal records and child protection orders; the criminal record and child protection order checks were introduced by Parliament.

Regarding what ‘identifiable and established risk factors’ may be taken into account, VCAT has stated that:

*...The following factors were identified [in the VLRC Report] as relevant factors to consider when assessing the risk of harm:*

- a. physical violence by a person or couple applying for treatment;*
- b. sexual violence by a person or couple applying for treatment;*
- c. risk of emotional abuse or neglect;*
- d. physical or psychiatric illness of a person or couple applying for treatment;*
- e. any intellectual disability of a person or couple applying for treatment;*
- f. ‘some other problem’ that raises a doctor’s concern about a person or couple’s capacity to care for their child;*
- g. previous child neglect by a person or couple necessitating the removal of a child(ren) from his or her care; and*
- h. domestic violence between the parents.*<sup>199</sup>

The Victorian ART Act does not permit the PRP to take into account factors that come within s 5(e), namely, discrimination on the basis of sexual orientation, marital status, race or religion. It is also not open to the Tribunal to take into account poverty, as this is not an ‘identifiable and established’ risk factor for harm to children. In addition, the presence of a physical or psychiatric illness, an intellectual disability or ‘some other problem’ that raises a doctor’s concern about a person’s capacity to care for a child, does not alone create a barrier to treatment.<sup>200</sup>

While clinics must comply with relevant legislation and regulations, *specific* auditing in relation to criminal record or child protection order checks, or of refusals based on other factors, does not currently take place. VARTA reported to me that it is considering including auditing provisions within its conditions for registration.

---

<sup>199</sup> *TRV v Department for Health and Human Services (Human Rights)* [2015] VCAT 1188 (5 August 2015), VCAT REFERENCE NO. H68/2015, [59]-[63]. See also *Patient Review Panel v ABY and ABZ* [2012] VSCA 264.

<sup>200</sup> *Ibid.*

The current Victorian system has not proved popular. A study conducted by DeLacey et al. revealed that although Victorian IVF counsellors saw the process where a woman (or her partner) met the criteria for a presumption against treatment as straightforward—in that they were able to inform the person(s) treatment could not be offered, and provide support if they wished to appeal to the PRP—they also experienced difficulties in relation to the system.<sup>201</sup> Counsellors reported people could be ‘quite angry and quite abusive, particularly if they feel that they've been convicted and they've paid their price’ and felt they were being unjustly punished again.<sup>202</sup> In addition, there was concern about checks revealing other crimes which did not fit the legal criteria for a presumption against treatment that were nonetheless concerning from a welfare perspective—for example, convictions for drug trafficking. While it was noted that counsellors could request a presumption against treatment in such cases, some counsellors reported considerable professional conflict in doing so, particularly as they would be named on the application.<sup>203</sup> They called for a more nuanced approach to screening for the welfare of the child.

Discussion of the system in the popular media also reports feelings ranging from dissatisfaction to anger. Imposing criminal record and child protection checks on all A.R.T. applicants has been criticised by patients and clinicians as burdensome, expensive, and discriminatory.<sup>204</sup> It has been suggested that it would make more sense to provide ‘IVF clinics access to the Australian National Child Offender Register (ANCOR), rather than presuming that everyone accessing IVF is suspect until proven otherwise’.<sup>205</sup> In addition, with thousands of couples seeking IVF treatment each year, questions have been raised, not only about the revenue that such checks must raise, but about whether the police resources are available, and should be used in such a manner.<sup>206</sup> Media reports have reported refusal regarding

---

<sup>201</sup> Sheryl L. de Lacey, Karen Peterson, and John McMillan, ‘Child interests in assisted reproductive technology: how is the welfare principle applied in practice? (2015) *Hum. Reprod.* first published online January 6, 2015 doi:10.1093/humrep/deu343.

<sup>202</sup> Ibid.

<sup>203</sup> Ibid.

<sup>204</sup> Christopher Scanlon, ‘Police Checks on IVF Patients add to the Pain’, *Sydney Morning Herald*, 27 September 2013, <http://www.smh.com.au/comment/police-checks-on-ivf-patients-add-to-the-pain-20130926-2ugs6.html> accessed 8 January 2017. Emily Bourke, ‘IVF Patients Enraged over Police Checks’ *PM ABC* 3 September 2009, <http://www.abc.net.au/pm/content/2009/s2675919.htm> accessed 8 January 2017.

<sup>205</sup> Ibid, Scanlon.

<sup>206</sup> Ibid.

overseas record checks due to a lack of resources which at times has led to significant delay or an inability to undergo treatment even when there is no criminal history.<sup>207</sup>

### New South Wales

The New South Wales health department last considered the issue of screening for risk of harm to children to be born as a result of A.R.T. in 2003, and decided not to mandate screening criteria. In its information guide on the draft legislation proposed at the time, and subsequently implemented, it said:

*It is recognised that some children will be born into families where they will suffer harm from their parents. Accordingly laws have been enacted that enable the government to intervene in the care of such children and in some cases for children to be removed from the custody of their parents and alternative arrangements to be made for their care. The role of the legislature has not been to make rules regarding classes of persons who may or may not become parents (as this is not necessarily a predictor of harm) but to make rules to safeguard the rights of individual children whose welfare has been compromised.<sup>208</sup>*

Note NSW did not go so far as to *prohibit* screening. It is unknown whether a level of clinic based screening occurs in clinics in NSW. Any refusal of treatment would have to have a sound medical basis, and not infringe anti-discrimination laws.

### The United Kingdom

The United Kingdom provides an example of a middle ground, or more nuanced approach, when compared to Victoria and New South Wales. The *Human Fertilisation and Embryology Act 1990* provides that ‘a woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment

---

<sup>207</sup> Ibid; Marianne Betts, *Herald Sun* 23 October 2013.

<sup>208</sup> New South Wales Department of Health, Consultation Draft Assisted Reproductive Technology Bill 2003 Information Guide New South Wales (2003), [4.3].

(including the need of that child for supportive parenting), and of any other child who may be affected by the birth.<sup>209</sup> This provision is also repeated in licence conditions for all A.R.T. providers. The Human Fertilisation and Embryology Authority (HFEA) then provides comprehensive guidance on the scope of the welfare of the child provision, and how it should be applied, within its Code of Practice. The HFEA also provides a form that all providers of treatment must use on which the outcomes of the assessment must be recorded, and that may be audited from time to time. The factors the HFEA requires all clinics to consider and record are noted in Table 2 below. (The HFEA guidance note is reproduced in Appendix 6.)

**Table 2: HFEA Guidance Note – Factors to be considered for the welfare of the child**

- The centre should consider factors that are likely to cause a risk of significant harm or neglect to any child who may be born or to any existing child of the family. These factors include any aspects of the patient’s or (if they have one) their partner’s:
  - a) past or current circumstances that may lead to any child mentioned above experiencing serious physical or psychological harm or neglect, for example:
    - i) previous convictions relating to harming children
    - ii) child protection measures taken regarding existing children, or
    - iii) violence or serious discord in the family environment
  - b) past or current circumstances that are likely to lead to an inability to care throughout childhood for any child who may be born, or that are already seriously impairing the care of any existing child of the family, for example:
    - i) mental or physical conditions
    - ii) drug or alcohol abuse
    - iii) medical history, where the medical history indicates that any child who may be born is likely to suffer from a serious medical condition, or
    - iv) circumstances that the centre considers likely to cause serious harm to any child mentioned above.
- When considering a child’s need for supportive parenting, centres should consider the following definition: *‘Supportive parenting is a commitment to the health, well-being and development of the child. It is presumed that all prospective parents will be supportive parents, in the absence of any reasonable cause for concern that any child who may be born, or any other child, may be at risk of significant harm or neglect. Where centres have concern as to whether this commitment exists, they may wish to take account of wider family and social networks within which the child will be raised.’*

<sup>209</sup> *Human Fertilisation and Embryology Act 1990* (UK), s 13(5). (Section 2 (1) defines “treatment services” as medical, surgical or obstetric services provided to the public or a section of the public for the purpose of assisting women to carry children.)

A study conducted by Lee et al. provides insight into the early operation of the UK regime.<sup>210</sup> They found that the number of prospective patients deemed to raise ‘welfare of the child concerns’ in the UK remains small; that very few people are subject to further investigation, and even fewer are denied treatment. Nevertheless, Lee et al. found that despite the low number of formal cases concerning a risk to the ‘welfare of a child’, there was widespread concern about the issue. They said:

*...most reported that the vast majority of patients were ‘normal’, but this co-existed with an often overtly expressed sense that ‘you can never know’ or ‘you can never prove it’. The study detected the significance of the spectre of the paedophile, as a person hardly ever encountered but whose threat nevertheless creates a powerful rationale for pre-emptive action.*

In relation to the UK screening method, some counsellors and nurses expressed concern that people may not be honest if they had a conviction for sex offending ‘ten years ago’, and questioned whether it would be possible and/or preferable to do criminal record checks. In addition, despite the defined process, some staff reported struggling to work out how to resolve the small number of ‘difficult cases’ they experienced.<sup>211</sup>

In another paper published in 2014 by the same researchers Lee et al. found that where there was concern the general approach taken was that deferral of treatment was invoked and was followed by further assessment and attempts to resolve behavioural, lifestyle

---

<sup>210</sup> Ellie Lee, Jan Macvarish, Sally Sheldon, Welfare under the Human Fertilisation and Embryology Act: The New Law - Summary of Findings (September 2012).

<sup>211</sup> Examples of such cases are provided in the study report as being 1) a male patient in his 20s who disclosed a conviction for a sexual offence against a child when a teenager. The clinic was willing to treat him and his partner, subject to social services providing an assessment that he no longer posed a risk to children. The social services would not provide a judgement prior to any pregnancy being achieved or a child being born. The couple did not receive treatment. 2) A male patient had a spent criminal conviction for a violent crime (not related to harming a child), but it could not be established whether his crime had been triggered by mental illness. Treatment did not proceed. 3) A clinic refused to treat a woman on the grounds that her serious heart problem and other medical complications made fertility treatment and a possible pregnancy unacceptably high-risk—she was very likely to deteriorate and she could possibly lose her life. The welfare of her existing child was considered to be the overwhelming factor in deciding to deny treatment, but it was also felt that it was unfair for clinic staff to have to provide treatment to a patient with such a poor prognosis.

or relationship concerns.<sup>212</sup> This was seen as a positive effect of using the welfare screening process.

In terms of justification of the system overall, Lee *et al.* found that very few interviewees saw the process as ‘unjustified’ or ‘illiberal’, reporting ‘the new streamlined process is generally welcomed, tempered by a view that giving consideration to the welfare of the child is good and necessary (if difficult to achieve).’ Further, the general view was that ‘whatever the limitations of the formal process, it is intrinsically right for staff to take some responsibility for the future child as a ‘third patient’.’<sup>213</sup>

### The United States

There is no legislation in the United States that governs access to A.R.T., or that enshrines the welfare of the child as a paramount consideration. The Ethics Committee of the American Society of Reproductive Medicine (ASRM)<sup>214</sup> in a report written in 2009, and updated in 2013, on screening in relation to the welfare of the child states:

*Although a child may not strictly speaking be “harmed” as a result of fertility procedures that made its birth possible, we think that concerns about future harm to offspring validly may be taken into account in making ethical assessments about those treatments. For some persons the potential harm to the child alone is sufficient to justify this conclusion. Others might point to the significant costs and burdens that parental unfitness imposes on the larger society. ...Fertility programs may withhold services when there are reasonable grounds for thinking that patients will not provide adequate child-rearing to offspring but are not obligated to do so.*<sup>215</sup>

Key points made by the Committee include advice that:

---

<sup>212</sup> E. Lee, J. Macvarish, and S. Sheldon ‘Assessing child welfare under the human Fertilisation and embryology Act 2008: a case study in medicalization’ (2014) 36 *Social Health Illn* 500-515.

<sup>213</sup> Lee, above n 210, p 7.

<sup>214</sup> The American Society of Reproductive Medicine is a professional society that has developed a voluntary accreditation program that requires clinics to adhere to the program’s guidelines and practice standards. Adhering to such guidance is therefore voluntary, and is not underpinned by any legislative requirements. The Report was published in 2009, and updated in 2013.

<sup>215</sup> Ethics Committee of the American Society for Reproductive Medicine American Society for Reproductive Medicine, ‘Child-rearing ability and the provision of fertility services: a committee opinion’, *Fertil Steril* 2009;92:864–7; updated *Fertil Steril* 2013;100:50–3.

- Fertility programs may withhold services from prospective patients on the basis of well-substantiated judgments that those patients will be unable to provide minimally adequate or safe care for offspring.
- Fertility programs should develop written policies and procedures for making determinations to withhold services on the basis of concerns about the child-rearing capacities of prospective patients.
- A program's assessment of a patient's inability to care for a child or potential to cause harm to a child should be made jointly among members of the program. A home study is not required.
- Persons with disabilities should not be denied fertility services solely on the basis of disability.

The ASRM Ethic Committee's view however, is that professional autonomy should not be hindered. They note that in their view professional autonomy has two aspects: it entitles physicians to 'choose not to treat persons whom they think will be inadequate childrearsers (as long as they comply with anti-discrimination laws). It also generally entitles them to treat such patients if they choose'.<sup>216</sup>

As such, in the United States, it is up to health professional discretion to decide whether to provide A.R.T., whether or not they think the person applying for A.R.T. would be an 'inadequate childrearsers' or posed a risk of harm to any child that would result. Two studies conducted some years ago of clinicians in the United States regarding screening practices showed substantial variation in assessment practices, and incidents of inappropriate (or discriminatory) denial of treatment in some clinics.<sup>217</sup>

### Summary

Other jurisdictions to South Australia take differing approaches to screening, ranging from legislated screening criteria and presumptions against treatment (Victoria), to comprehensive

---

<sup>216</sup> The Ethics Committee of the American Society for Reproductive Medicine, 'Child Rearing Ability and the Provision of Fertility Services' (2009) 92(3) *Fertility and Sterility* 863, 863-4.

<sup>217</sup> J. Stern, C. Cramer, A. Garrod, R. Green 'Access to services at assisted reproductive technology clinics: a survey of policies and practices' (2001) 184 *Am J Obstet Gynecol* 591-597; A. Gurmankin, A. Caplan, and A. Braverman, 'Screening practices and beliefs of assisted reproductive technology programs' (2005) 83 *Fertil Steril* 61-67.

guidelines that must be adhered to under legislation (United Kingdom); to guidelines promulgated by an ethics committee that ultimately defer to clinical discretion (United States); to opting to not have any legislation or guidelines on the matter at all (NSW).

Analysis of the different regimes suggests there is a risk that the absence of legislation or guidelines may result in clinicians and/or counsellors exercising idiosyncratic judgments in screening applicants for A.R.T. that may lead to discrimination and/or inconsistency in practice. When there are genuine concerns, policy, guidelines, or legislation may assist clinicians and/or counsellors in being able to ‘put treatment on hold’, to ‘impose a cooling off period’ in which further assessment or therapeutic counselling may take place, or to refuse treatment.<sup>218</sup> On the other hand, creating overly burdensome bureaucratic processes that do little to protect children are unpopular and highly criticised.

### **3.6.7. Discussion**

In evaluating the operation and effectiveness of the current *Assisted Reproductive Treatment Act 1988* (SA) in South Australia, it is apparent that removal of explicit screening requirements has led to an inconsistent approach amongst clinics in South Australia. Of three clinics that spoke to this issue, one continued to use the statutory declaration required before the 2010 amendments to the Act; one left such judgments to the clinician’s discretion and consultation with an internal committee; and one said it was not their role to screen patients at all.

In the majority of submissions that addressed the paramountcy of the welfare of the child principle there was a clear preference for some kind of screening to occur to protect children from risk of harm. While the pre- 2010 statutory declaration was seen a burdensome by some in South Australia, others lamented its removal and the loss of being able to refer difficult cases to the SACRT. Overall, there was a call for clearer guidance regarding criteria and process to be followed to uphold the paramountcy of the welfare of the child principle.

In comparison, one submission from a medical indemnity insurer cautioned it would be ‘difficult, if not impossible, to develop any appropriate ‘screening’ which would not create real and significant risks of different determinations based on the same criteria’.<sup>219</sup> However,

---

<sup>218</sup> E. Lee, J. Macvarish, S. Sheldon. ‘Assessing child welfare under the human Fertilisation and embryology Act 2008: a case study in medicalization’ (2014) 36 *Social HealthIlln* 500-515; Sheryl L. de Lacey, Karen Peterson, and John McMillan, ‘Child interests in assisted reproductive technology: how is the welfare principle applied in practice?’ (2015) *Hum. Reprod.* First published online January 6, 2015 doi:10.1093/humrep/deu343.

<sup>219</sup> Confidential, submission 64.

in giving consideration to this, it is necessary to recognise that the law in South Australia currently provides there is no obligation to provide A.R.T. services and enables health professionals to refuse treatment in cases in which there is concern about risk to any child that may be born as a result. It was evident that the removal of a uniform system requiring a basic level of screening has detracted from the upholding the welfare of the child principle as clinics in South Australia are in fact currently screening applicants in an inconsistent way. A uniform system that espouses acceptable criteria and processes surrounding the conditions in which delay or refusal of treatment may occur, is preferable to no system or guidance at all. Nevertheless, criteria do need to be clear and evidence based. Discussion of criteria that is often debated, follows.

### Marital Status and Sexual Orientation

The review received a number of submissions that raised the issue that the paramountcy of the welfare of the child principle is not supported by denying recognition of same-sex and single parents.<sup>220</sup> Anna Petts added that it 'is outdated to believe that two women, or two men, or a man and woman who are committed in a de facto relationship are not able to provide a loving, secure home.'<sup>221</sup> It was also submitted that '[s]ingle parenting does not mean less capable parenting, nor does it mean the welfare of the child is necessarily impacted'.<sup>222</sup> Fertility SA noted that denying access to single and same-sex couples in fact had negative implications for the best interests of children.<sup>223</sup>

In contrast, Family Voice submitted that the *Assisted Reproductive Treatment Act 1988* (SA) must protect the right of children to be conceived and raised by their biological parents. They said, 'in situations where A.R.T. services would compromise this relationship, by discriminating against the fundamental right of the child to be raised by both biological parents, the rights of the child should trump the desires of adults seeking A.R.T. services'.<sup>224</sup> Such a view implies limiting A.R.T. to heterosexual couples, and stopping donor conception.

---

<sup>220</sup> Rosalie Dow Schmidt, submission 6; Anna Petts, submission 17; Confidential, submission 20; Confidential, submission 22; Damien Riggs, submission 23; Fertility SA, submission 49.

<sup>221</sup> Anna Petts, submission 17.

<sup>222</sup> Confidential, submission 20.

<sup>223</sup> Fertility SA, submission 49.

<sup>224</sup> Family Voice, submission 59.

I found no evidence that children reared in same-sex families, or by single people, are at an *increased* risk of harm when compared to children reared by heterosexual couples such that their conception should have been prevented in the first place. In fact, in a review of research and literature on the matter more than a decade ago, Short et al found that ‘...it is family processes (such as the quality of parenting and relationships within the family) that contribute to children’s wellbeing and ‘outcomes’, rather than family structures, per se.’<sup>225</sup> Such research indicates that parenting practices, and children’s outcomes in families parented by lesbian and gay parents, are likely to be at least as favourable as those in families of heterosexual parents.<sup>226</sup>

Marital status or sexual orientation is an unacceptable criterion upon which to deny access to A.R.T. when considering the welfare of the child to be born as a result.

#### Physical Disability and/or Illness

Domestic anti-discrimination laws generally prevent blanket discrimination against providing services to people with a disability. Moreover, disability and/or illness, in and of itself, may not compromise the welfare of a child, and must be considered in light of a person’s commitment to the health, well-being, and development of the child. Great care must be taken not to make discriminatory or unfounded judgements about the life a disabled child or person will lead, nor the capacity of a person who has a disability to parent. In the absence of any reasonable cause for concern that a child may be born as a result of A.R.T. might be at risk of significant harm or neglect, disability alone is not a reason to preclude treatment.

#### Psychiatric Disability or Mental Health Issues

While many psychiatric illnesses respond to medications and therapy, there are some that are recalcitrant to medical treatment. Professor Emeritus Bernard Dickens, a renowned health law academic, has said that ‘mental disorder of a severe nature, although not requiring

---

<sup>225</sup> E. Short et al, *Lesbian, Gay, Bisexual and Transgender (LGBT) Parented Families: A Literature Review* Prepared for the Australian Psychological Society (2007) (Australian Psychological Society).

<sup>226</sup> Ibid. See also Henny M.W. Bos, Justin Knox, Loes van Rijn-van Gelderen, Nanette Gartrellm, ‘Same-Sex and Different-Sex Parent Households and Child Health Outcomes: Findings from the National Survey of Children’s Health’ (2016) 37(3) *Journal of Developmental & Behavioral Pediatrics* p 179–187; Simon Robert Crouch, Ruth McNair, and Elizabeth Waters, ‘Impact of family structure and socio-demographic characteristics on child health and wellbeing in same-sex parent families: A cross-sectional survey’ (2016) 52(5) *Journal of Paediatrics and Child Health*, pp 499–505.

institutionalisation, may justify ineligibility for a childrearing role, whether children result from natural or medically assisted procreation'.<sup>227</sup> Similarly, Professor Bonnie Steinbock, a bioethicist, states that mental illness may be an example of a situation where physicians may be warranted in refusing treatment when there is a well-substantiated concern about a person's mental health.<sup>228</sup>

Where mental health issues are severe in a parent, significant negative impacts are known to occur for young children growing up in the home. Tough *et. al*, for example, found that poor maternal mental health put young children at significantly increased risk of developmental delay.<sup>229</sup> However, again caution must be had. The presence of a mental disability or mental health issues, does not alone justify preventing a person from accessing A.R.T.

Many mental disorders are transient, of different levels of severity, and amenable to treatment.<sup>230</sup> While concerns may be raised about the impact that an existing mental condition will have on the welfare of a child to be born, with proper care and treatment the concern may be allayed. In addition, research has found that children who have parents with mental health issues may cope adequately, provided they are given the appropriate care, explanations and support systems both in and out of home.<sup>231</sup>

Thus, while living with a parent with mental illness may pose challenges for a child/children, 'equity requires that particular applicants for A.R.T. be clinically assessed on their *individual merits*, and not be denied rights of access on grounds of impersonal, collective stigmatisation and discrimination'.<sup>232</sup> In such cases, assessment of the applicant by an independent mental health worker and/or consultation with a disability advocate may be warranted, to assess short and long term actions and suitability for treatment.

---

<sup>227</sup> B. M. Dickens, 'Ethical issues arising from the use of assisted reproductive technologies. In Current Practices and Controversies' in Vayena, E. Rome, P. J. and Griffin P. D. (eds) *Assisted Reproduction* (2001), 320-333. (Geneva, Switzerland: World Health Organization).

<sup>228</sup> B. Steinbock, 'Do Variations in Assisted Reproductive Technology Programs' Screening Practices Indicate a Need for National Guidelines? Another Perspective' (2005) 84(5) *Fertility and Sterility*, 1551-1552.

<sup>229</sup> S. C. Tough, J. E. Siever, S. Leew, D. W. Johnston, K. Benzies, and D. Clark, 'Maternal Mental Health Predicts Risk of Developmental Problems at 3 Years of Age: Follow Up of a Community Based Trial' (2008) 8 *BMC Pregnancy and Childbirth* 16.

<sup>230</sup> Dickens, above n 227.

<sup>231</sup> Vicky Cowling, *Children of Parents with Mental Illness 2: Personal and Clinical Perspectives* (2004) (ACER Press, Victoria).

<sup>232</sup> *Ibid.*

### A History of Violent or Sexual Offences

Exposure to crime and violence can have a severe and long lasting impact on a child's subsequent development, influencing their physical, social and psychological functioning.<sup>233</sup> The review received both oral and written submissions that screening for a history of violent or sexual offences should be required in order to assess whether there is a need to proceed with caution, if not preclude access to A.R.T., and to uphold the paramountcy of the welfare of the child principle.

The Australian Bureau of Statistics reports that in most cases of assault and sexual assault, the offender is known in some way to the victim. This is especially true for children as the reliance they have on others to meet their primary needs makes them particularly vulnerable to victimization from people known or related to them.<sup>234</sup> Given that abuse commonly occurs within families there is a role for A.R.T. providers and the State in managing that risk where possible to preserve the welfare provision. However how this should be managed is a difficult issue.

Examination of data concerning violent or sexual crimes reveals that relying upon criminal record checks of applicants and their partners (if any) for such offences may identify people with prior convictions but would not *guarantee* identification of a person who may be violent or sexually abusive toward a child. For example, the screening of a woman's male partner, while allowing for the detection of his prior convictions (if any), may not protect the child from abuse from known non-family members, male relatives, acquaintances, or neighbours, who are more frequently the perpetrators of such crimes.<sup>235</sup> Note also that in many cases offenders may not have prior convictions for sexual offending as the majority of

---

<sup>233</sup> Australian Institute of Criminology, Australian Crime Facts and Figures 2011, Chapter 8: Spotlight on Child Victims – crime and child maltreatment, [http://www.aic.gov.au/publications/current%20series/facts/1-20/2011/8\\_spotlight.html](http://www.aic.gov.au/publications/current%20series/facts/1-20/2011/8_spotlight.html) accessed 8 January 2017.

<sup>234</sup> Australian Institute of Criminology, above n 233.

<sup>235</sup> Ibid. In 2010 (the most current data available to the review) it was reported in relation to the crime of assault that the most common relationship between child victims (aged 0-14) and their offenders was of known, non-family members (43%). Thirty-four percent (34%) were victimised by a family member, while only 19 percent (19%) were reportedly victimised by a stranger.<sup>235</sup> In relation to child victims (aged 0-14) of sexual assault, the offender was reported as a known, non-family member for 45 percent (45%), with a further 40 percent victimised by a family member (40%). Eleven percent (11%) were reported to have been perpetuated by a stranger. Consideration of the younger age group of 0-9, reveals children who were assaulted were primarily victimised by family members (61%), as were those who were sexually assaulted (52%).

sexual offences against both adults and children are never reported to police.<sup>236</sup> In addition, given sexual offenders against children are far more likely to be men<sup>237</sup> than women, imposing blanket criminal record checks of women who wish to access A.R.T. for violent and sexual offences may prove to be a bureaucratic burden that does little to detect risk.

This does not mean that *reasonable* checks regarding a history of violence or sex offences should not be conducted. A system that

- a) sets out a procedure for discussion of history and present circumstances,
  - b) allows for further checks *in individual cases in which there is a concern* (for example, via police record, ANCOR, child protection order checks, or other follow up with authorities), and
  - c) provides for a procedure to be followed if treatment is to be delayed or refused,
- would enable consistent action and uniform processes for when there is a concern. Of course, as any screening process may not identify all people who go on to harm children, it also remains incumbent upon the State to have strong laws in place to safeguard children whose rights have been compromised.

### Child Protection Issues

Child protection notifications are often raised when there is concern that a child has been, is being, or is likely to be, abused, neglected, or otherwise harmed. Such issues may include family situations involving domestic violence, mental health issues, substance abuse, neglect, and maltreatment. In most cases, child protection matters are dealt with by statutory child protection services in each state or territory,<sup>238</sup> and the majority of cases are managed through health and other therapeutic interventions. Less than 10 percent of all child protection matters in Australia involve the prosecution of an offender through the criminal justice system. This in itself explains the call for separate discussion and/or checks of whether child

---

<sup>236</sup> Dr Karen Gelb, *Recidivism of Sex Offenders* (2007) (Sentencing Advisory Council).

<sup>237</sup> The Australian Bureau of Statistics reports in relation to sexual assault and related offences that ‘the majority of offenders in this category are male, accounting for 93 per cent, or 6,677 offenders’: Australian Bureau of Statistics, Media Release: Offender statistics show sexual assault and related offences on the rise, 25 February 2015, [http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4519.0~2013-14~Media%20Release~Offender%20statistics%20show%20Sexual%20assault%20and%20related%20offences%20on%20the%20rise%20\(Media%20Release\)~34](http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4519.0~2013-14~Media%20Release~Offender%20statistics%20show%20Sexual%20assault%20and%20related%20offences%20on%20the%20rise%20(Media%20Release)~34) accessed 8 January 2017.

<sup>238</sup> Australian Institute of Criminology, *Australian Crime: Facts & Figures 2011: Chapter 8 Spotlight on Child Victims – Crime and Child Maltreatment*, Canberra: Australian Institute of Criminology, March 2012.

protection orders have been made, as criminal record checks would not identify the majority of such cases.<sup>239</sup>

When the issues that have warranted child protection intervention and/or orders are ongoing, or likely to present continued risks to children, it may not be appropriate to immediately provide A.R.T. This is especially so as only 10% of cases lead to such orders, thus representing the most serious of matters. Such circumstances might instead warrant referring the applicant to appropriate other services, such as mental health, drug and alcohol, or family violence services; and/or liaising with Families SA to determine an appropriate course of action. Both Fertility SA and Repromed reported having done this when faced with concern about applicants to their respective clinics.<sup>240</sup> Formalising a process to enable consistency of approach when child protection concerns are raised, which starts with discussion and enables further checks if required, as well as referral to appropriate services, would again be desirable.

### Conclusion

The *Assisted Reproductive Treatment Act 1988* (SA) provides that refusal of treatment is lawful, but there is no guidance provided as to the circumstances in which such refusals may occur. The review heard from a number of people who lamented the 2010 changes to the Act in this regard, and called for requirements for screening of applicants to A.R.T. to be reinstated. Some called for a return to the statutory declaration-SACRT model. One clinic maintained their use despite them not being required any longer by law. Some staff at IVF clinics also called for a system that enabled them to call on an external body or relevant organisation, to get more information, to do an assessment, or follow up on concerns. A few people made submissions to the review that said that they did not wish for a return to the statutory declaration system, or did not desire any screening at all.

On balance, given that screening is occurring in an inconsistent way across clinics in South Australia, and that there is a need to give operational effect to the paramountcy of the welfare of the child principle, I recommend that a clear and consistent approach is needed. What such an approach should look like may be informed by consideration of evidence regarding risks to children, as well as examination of alternate models and approaches to such

---

<sup>239</sup> Ibid.

<sup>240</sup> Repromed, face-to-face consultation, 19 April 2016; Flinders SA, face-to-face consultation, 20 April 2016.

screening, and the submissions to the review. Reference to the prior Memorandum 6 of the SACRT regarding the pre- 2010 requirement for counselling of all clients on the paramount importance of the welfare of the child is also useful.<sup>241</sup>

Having considered all such things in detail, I recommend that a system similar to that found in the United Kingdom be implemented in South Australia. I recommend that the Minister should develop a directive that must be adhered to as a condition of registration, which stipulates criteria that must be discussed in relation to the welfare of the child, and sets out the process to follow when having the discussion. However, in addition, I recommend that there be explicit options and processes included for clinicians and/or counsellors to seek support and advice from experts, agencies or authorities (such as Families SA), as well as the ability to obtain further information via criminal record, child protection, ANCOR, or other checks if needed in individual cases. Like the UK. there should also be a form that all providers of treatment must use on which the outcomes of the assessment must be recorded, and that may be audited from time to time. This approach would create a consistent baseline for all A.R.T. clinics to engage in open dialogue with applicant(s) about areas of known risk to children, and enable decisions to be made to delay or refuse treatment if a significant risk is identified. The directive should also require referral of the applicant to appropriate support services if needed (for example drug, alcohol, family violence, mental health services, or otherwise).

I note that prior to the 2010 changes to the legislation in South Australia, there was an 'Eligibility Review Panel' (ERP),<sup>242</sup> established by SACRT which served as an avenue for appeal by those prevented from accessing A.R.T. due to prior conviction(s) for a crime involving violence (but not prior sexual offences against a child for which refusal of treatment was 'ineligible' for appeal). Consideration of the last five years of SACRT annual reports

---

<sup>241</sup> The memorandum was issued in July 1998 and revised in 2002. It included recommendations regarding clause 11 part 4(a) of the Code of Ethical Clinical Practice, which provided that infertility treatment must not be provided unless a couple had received adequate counselling from a medical practitioner or counsellor regarding the paramount importance of the welfare of any child that may be born in consequence of that treatment.

<sup>242</sup> The Eligibility Review Panel consisted of a legal practitioner, who was the Presiding Member; a member of the SACRT; a social worker, nurse or clinical psychologist with experience in child welfare; a person experienced in the rehabilitation of persons who have committed offences involving violence; and a consumer representative.

revealed that the ERP reviewed eight cases over that period.<sup>243</sup> I do not here recommend reinstating that panel, or a panel such as the PRP in Victoria, as the recommended process here does not prescribe blanket presumptions against treatment, but rather sets a framework for criteria to be discussed in relation to the welfare of the child, decision making processes regarding delay or refusal of treatment, and referral to other agencies, experts, authorities and/or support services when needed. The recommended process should be one in which *treatment decisions are arrived at between the applicant(s) and the clinician/counsellor with support from appropriate agencies, experts and/or authorities as necessary or required.*

The focus of the process should always be upon the welfare of any child to be born as a result of A.R.T. and decisions should not be premised upon a social or moral judgement of the applicants. It should be an offence for applicant(s) to provide false information during the assessment. If a person is unfairly discriminated against, judicial review is open to them. All applicants for A.R.T. should be made aware of this. (Likewise, if a person alleges a government department has made an unjust decision, avenues of administrative review are open to them.) It is recommended that the Minister monitor the adherence of clinics to the directives, and any issues concerning discrimination that arise via the recommended auditing process and A.R.T. Advisory Panel, and act responsively if needed.

It will also be important that clinics—who are in a co-regulatory partnership with government—support systems implemented by the Minister that provide for consistency and transparency, and that operationalise the paramountcy of the welfare of the child principle in a meaningful way.

#### **FINDING 18**

The paramountcy of the welfare of the child principle, and the involvement of third parties such as the state and health professionals in the provision of A.R.T., supports the requirement for a level of assessment of people wishing to access A.R.T. regarding any risks of physical and/or psychological harm that may exist for a child born as a result of providing treatment.

<sup>243</sup> The ERP reviewed two cases in 2004, one of which was finalised in 2005 (with no further cases that year), two cases in 2006, one case in 2007, two cases in 2008, and one case in its final year, 2009. In 2009 another two cases did not proceed, the first due to ineligibility, and the second because the couple became pregnant naturally after altering their lifestyle on the advice of a clinician.

**FINDING 19**

The removal of prior uniform requirements for screening applicants for A.R.T. for risk pursuant to the welfare principle, and the lack of guidance under the current *Assisted Reproductive Treatment Act 1988* (SA) and regulations, has led to inconsistent practices amongst clinics in South Australia. Inconsistency and some such practices do not serve to uphold the paramountcy of the welfare of the child principle.

**RECOMMENDATION 11**

The Minister should develop a directive that provides for a clear and consistent risk assessment framework and process to be used by clinicians/health professionals when assessing applicants and their partners (if any) in relation to any to risk they may pose to a child born as a result of providing A.R.T. Such a directive should

- 1) include criteria to be considered,
- 2) outline the process to be followed,
- 3) provide for referral to, and consultation with, external experts, authorities, agencies, and/or support services,
- 4) make it an offence for applicants to provide false information in relation to the assessment,
- 5) allow for criminal record, ANCOR and/or child protection order checks in individual cases that raise significant concern, and
- 6) require information to be given to applicants regarding avenues available to them for judicial review (as appropriate).

A form should also be developed that all providers of treatment must use on which the outcomes of the assessment must be recorded, that may be audited by the Minister from time to time.

### 3.7 Screening of Donors for Prior Criminal Convictions

The review also received two submissions regarding screening of *donors* for prior criminal convictions. Kylie Dempsey submitted that there is a need to provide recipients with details

about prior criminal convictions of donor(s), so that they could decide whether or not they wished to proceed using his/her sperm, egg(s), embryo(s). In addition, she suggested record keeping regarding reasons for clinics rejecting a donor. She said:

*just like medical information is provided to potential parents, criminal convictions should also be provided to [them] so they can make a fully informed decision. There should be an independent appeals process for declined donors to ensure natural justice and an independent centralised record of declined donors that includes reasons for decline to support consistency of application of the provision across clinics (i.e. allow clinics to identify declined donors before undertaking all tests and requesting reports).<sup>244</sup>*

Mr. John Mayger, a sperm donor, also stated that children have a right to know their donor's medical and criminal history.<sup>245</sup>

I am unable to make recommendation regarding the call for such checks, as further research is needed regarding whether disclosure of a donor's criminal history should occur; and if so, in what circumstances. Further research is also needed regarding the scope, and limits, of the current welfare provisions and whether they extend to screening of donors for prior criminal records. Such research may also be relevant when early contact with donors is to take place. I did not have the opportunity or resources to conduct such research as part of this review, but suggest that this is a matter that the recommended A.R.T. Advisory Council should consider and advise the Minister upon (see Chapter Two).

**FINDING 20**

The review received two submissions that called for release of information about the criminal history of donors to parents and children. A recommendation could not be made on this matter, as further research into whether there is a call for such checks, and the scope, and limits, of the paramountcy of the welfare of the child provision, is needed.

<sup>244</sup> Kylie Dempsey, submission 69.

<sup>245</sup> John Mayger, submission 31.

**RECOMMENDATION 12**

The A.R.T. Advisory Council should consider whether donors of gametes and embryos should be screened in relation to prior criminal history; and the scope, and limits, of the paramountcy of the welfare of the child principle.

**3. 8 Research on the Short and Long Term Outcomes of A.R.T.**

A number of written submissions also discussed a need for more research and follow-up of children born as a result of A.R.T. and donor conception, as part of maintaining the paramountcy of the welfare of the child provision.<sup>246</sup>

Professor Marilyn Crawshaw submitted that such research should not just be focused exclusively upon medical, scientific, and developmental psychological matters but should also include attention to impact on family and social processes, and whether children born through A.R.T. in general, donor-assisted A.R.T., or surrogacy, are any more or less likely to come to the attention of child protection, mental health or court services than other groups, or even whether their parents (if a couple) are any more or less likely to remain together.<sup>247</sup>

Another submission noted concerns about poor perinatal and longer term outcomes for children born as a result of A.R.T., and that the U.S. National Institutes for Health recognised a lack of knowledge about this in 2014. The submitter emphasised:

*Until recently, data have[sic] not been available on a scale large enough to separate “parent” and “treatment” contributions to suboptimal health of children at birth or subsequently. After three decades, and with one in 25 children born in South Australia now conceived with medical assistance, this situation has changed.*

<sup>246</sup> Damian Adams, submission 34; Kim Buck, submission 41; Professors DeLacey & Tremellen, submission 45; Professor Marilyn Crawshaw, submission 51; Professor Eric Blyth, submission 52; Professor Olga Van den Akker, submission 57; Sofie Gregory, submission 70; Confidential, submission 71; International Social Service, submission 72; the Robinson Research Institute, submission 74; Reece Trevellin, submission 79.

<sup>247</sup> Marilyn Crawshaw, submission 51.

*South Australia has in place infrastructure to facilitate this research, including the perinatal registry and the birth registry.*<sup>248</sup>

Specific calls were also made in relation to the need for research and follow-up with donor-conceived children and adults.<sup>249</sup> Kim Buck emphasised that such research would help in a multitude of ways stating:

*Rigorous empirical research will be beneficial in further upholding the welfare principle of the Act, but will also inform public education campaigns, people who are contemplating using donor gametes to build their family, professionals who work with donor-conceived people and policy makers who seek to develop law changes and regulations and report on the efficacy of existing laws. This research gap must be addressed to protect future generations of children born through assisted reproductive technologies.*<sup>250</sup>

In the face-to-face consultations unanimous support by clinics, donor-conceived people, donors, and consumers of A.R.T. for short and long term research and follow up, was again shown.<sup>251</sup>

Submissions also called for a requirement that present and future knowledge stemming from research about outcomes for children born as a result of A.R.T. inform regulation of A.R.T. This included a desire for responsive regulation in which the Minister may, for example, issue relevant directives to set acceptable bounds for practice in response to research outcomes. For example, obstetrician and gynaecologist, Dr. James Harvey, called for ‘stronger guidelines for clinicians with respect to multiple embryo transfers, not just what is an “acceptable” twinning rate at a unit ...’ given there ‘is no doubt’ that the welfare of the child principle is served by single embryo transfer, with it now known that the risks related to double embryo transfer are significant.<sup>252</sup>

---

<sup>248</sup> Confidential, submission 71.

<sup>249</sup> Damian Adams, submission 34; Kim Buck, submission 41; Professors DeLacey & Tremellen, submission 45; Professor Marilyn Crawshaw, submission 51; Professor Eric Blyth, submission 52; Reece Trevellin, submission 79.

<sup>250</sup> Kim Buck, submission 41.

<sup>251</sup> Donor Conceived Forum, 18 April 2016; ReproMed/MyIVF, 19 April 2016; City Fertility, 19 April 2016; Fertility SA, 20 April 2016; Donor Consultation, 21 April 2016; Consumer Consultation, 21 April 2016.

<sup>252</sup> Dr James Harvey, submission 38.

In relation to the operation and effectiveness of the current *Assisted Reproductive Treatment Act 1988* (SA), the role the current regulatory regime plays in regard to research was therefore considered and compared to the pre- 2010 regime. The now defunct SACRT had a number of functions related to research including that they were to

- carry out research into the social consequences of reproductive technology;
- promote research into the causes of human infertility;
- keep under review research involving human embryos; and
- promote informed public debate on the ethical, legal and social issues raised by A.R.T.<sup>253</sup>

In examining the last five years of the SACRT reports it was apparent that such functions were operationalised in a number of ways, including that members of SACRT all engaged in research in their respective fields of expertise, and reported on such research in the annual reports; research was also promoted by the SACRT via reporting of research occurring in South Australia related to A.R.T. at clinics, independent institutes and centres, and academic environments, as well as research beyond South Australia; exchange of information with other similar bodies also occurred. The SACRT also reported each year on statistics from the previous year regarding people accepting infertility treatment; embryo transfer cycles (fresh and frozen); donors of reproductive materials; freezing, thawing and storage of embryos; take home baby rates for all A.R.T. procedures; take home baby rates for donor insemination; and multiple pregnancy rates for all A.R.T. procedures. All such information was provided to the Minister in the annual reports, tabled in Parliament, and publically available.

Of concern is that nothing has replaced the above SACRT functions, leaving a void where information, reporting, and relevant action once existed. The concern is that while research may continue in the field via normal academic and/or commercial processes, the changes to the legislation in 2010 have meant that an avenue to promote research, to report on what is being done, to exchange information, and to directly inform the Minister and public about the outcomes of such research and A.R.T. has been lost. There nevertheless continues to exist a need to understand the short and longer term impacts upon children born as a result of the use of A.R.T. in relation to their health and well-being.<sup>254</sup> The risks are significant in an

---

<sup>253</sup> *Reproductive Technology (Clinical Practice) Act 1988*, s 10 (c) (d) (da) (f). (Repealed)

<sup>254</sup> I note the need for research related to infertility for men and women, impact of treatment, and long term outcomes for recipients of A.R.T. and/or donors is also necessary, but that the discussion here is focused upon the welfare of the child.

industry that is increasingly commercialised and sometimes lacking in evidence based practice.

A 2015 Sax Institute Evidence Check review on maternal, pregnancy and neonatal outcomes following IVF pregnancies also confirms that high quality research on the topic is currently limited. The Sax Institute said:

*Studies that use national A.R.T. registry data offer the advantage of large sample sizes; however they are retrospective and limited in the number of variables (potential confounders) they include, since they usually have not been designed for research purposes. Well-designed prospective, longitudinal studies which are focused on the most important clinical questions (such as hypertensive disorders of pregnancy, preterm birth, perinatal morbidity and mortality, as well as short and long term health outcomes for children after A.R.T.) are warranted in order to produce high quality data regarding specific research questions.<sup>255</sup>*

Quality research should thus be supported and/or promoted to the extent possible by the Minister for Health, who is responsible for the oversight of A.R.T. practice in South Australia. At the very least, the Minister should be informed of research results so as to be able to respond in a regulatory fashion when needed, noting the Minister has power under the legislation to make regulations and or to enact conditions in relation to the provision of A.R.T. services in South Australia.<sup>256</sup> Greater exercise of that power is warranted.

Further, establishing reporting requirements by clinics may serve to necessitate follow-up and/or provide data on A.R.T. practices and outcomes that would likely benefit knowledge and may make possible future research. In addition, encouraging the industry to engage with long term follow up and research may improve outcomes for all.

Finally, the Minister may consider the government's role or ability to fund or support independent research to contribute to ensuring the health, welfare and safety of children

---

<sup>255</sup> CA Venetis, GM Chambers, Maternal, pregnancy and neonatal outcomes following IVF pregnancies: an Evidence Check review brokered by the Sax Institute ([www.saxinstitute.org.au](http://www.saxinstitute.org.au)) for NSW Kids and Families, June 2015, 23-24.

<sup>256</sup> *Assisted Reproductive Treatment Act 1988* (SA), ss 9 and 20.

who are born as a result of A.R.T. into the future.

**FINDING 21**

A failure to implement a reporting system following changes to the Act in 2010 have meant that an avenue to promote research, to report on what is being done, to exchange information, and to directly inform the Minister and public about the outcomes of such research is now lacking

**FINDING 22**

There continues to exist a need to understand the short and longer term impacts upon children born as a result of the use of A.R.T. in relation to their health and well-being. The risks are significant in an industry that is increasingly commercialised and sometimes lacking in evidence based practice, and in which the result of their practices are children. Doing nothing fails to uphold the paramountcy of the welfare of the child principle.

**RECOMMENDATION 13**

The Minister should re-establish the promotion of research, and reporting on research and the outcomes of A.R.T. practices, as a required function of the recommended A.R.T. Advisory Council under the *Assisted Reproductive Treatment Act 1988 (SA)*.

**RECOMMENDATION 14**

The Minister should, pursuant to sections 9 and 20 of the *Assisted Reproductive Treatment Act 1988 (SA)*, issue regulations, conditions of registration, or directives from time-to-time, informed by research on the short and long term outcomes for people born as a result of A.R.T., that may set the bounds of A.R.T. practice necessary to uphold the principle of the paramountcy of the welfare of the child.

**RECOMMENDATION 15**

The Minister should consider and act upon the government's ability (if any) to fund and/or support independent research that may contribute to ensuring the health, welfare and safety of children who are born as a result of A.R.T. and donor conception.

### 3.9 Inclusion of the Word ‘Health’ in the Paramountcy Provision

The paramountcy provision refers to the ‘welfare’ of the child to be born as a result of A.R.T. The current statement of principle does not explicitly include reference to health outcomes for the child. It was submitted to the review by the Robinson Research Institute, that:

*the absence of a reference to health may now be regarded as an omission... the statement of principle should include wording that both the “...health and welfare...” of the child is paramount.*<sup>257</sup>

In light of the considerations above, including a call for research into the long term health outcomes for children born as a result of A.R.T. (amongst other things) as relevant to the paramountcy principle, there is merit to this suggestion. On the other hand, one may consider that the ‘welfare’ of the child encompasses all aspects of its welfare, which would include its emotional, social, physical, psychological health and well-being. By comparison, the Victorian legislation, which also includes a paramountcy provision, includes reference to the ‘health and well-being’ of the child. On balance, and for clarity, it would be prudent to add ‘health’ to the current paramountcy provision within the Act.

#### RECOMMENDATION 16

The Minister should amend the statement of principle concerning the paramountcy of the welfare of the child within the *Assisted Reproductive Treatment Act 1988* (SA) to include the wording that both the *health* and welfare of the child born as a result of A.R.T. is paramount.

### 3.10 Donor Conception and the Welfare Principle

A major focus of the review was upon issues arising in relation to donor conception, including access to information by donor-conceived people about their donors, siblings, and genetic

<sup>257</sup> Robinson Research Institute, submission 74.

heritage, and the establishment of a donor conception register in South Australia. The issues raised by donor-conception, and how they are, or are not, currently being addressed in South Australia, speak loudly to the operation and effectiveness of the Act in relation to the paramountcy of the welfare of the child principle. Donor conception, however, warrants an in-depth discussion and is considered in the next two chapters.

### 3.11 Conclusion

The welfare of the child provision was maintained and strengthened in the 2010 changes to the *Assisted Reproductive Treatment Act 1988 (SA)*, by requiring that such welfare was not only paramount in the provision of A.R.T. services but also a fundamental principle in respect of the operation of the Act.

While there was unanimous support for the paramountcy of the welfare of the child principle to be maintained, there was also a strong call for further guidance concerning what falls within the bounds of the provision, and how it should be operationalised. A number of participants in the review expressed concern that due to the removal of previous systems and guidelines, the absence of consistent and independent review, and lack of regulation on certain matters, there were no assurances that the principle was being upheld in a uniform manner, and that its effectiveness was compromised.<sup>258</sup>

Despite efforts being made in South Australia to uphold the welfare principle, it was clear that more was needed to ensure the operation and effectiveness of the Act.

Particular matters submitted to the review as relevant to the welfare principle included

- screening applicants, embryos, and donors for heritable disease, disorder, or illness;
- screening applicants in relation to whether they may pose a risk of physical or psychological harm to children born as a result of A.R.T.;
- screening donors for criminal history (in addition to health screening);

---

<sup>258</sup> See for example, Kim Pace, submission 19; Caroline Lorbach, submission 27; Confidential, submission 32; Damian Adams, submission 34; Kim Buck, submission 41; Fertility SA, submission 49; Myfanwy Cummerford, submission 56; Kylie Dempsey, submission 69; Sofie Gregory, submission 70; International Social Services, submission 72; ANZICA, submission 82.

- a call for long term research and follow-up on the outcomes of children born as a result of A.R.T.;
- extending the welfare principle to explicitly include reference to the ‘health’ and welfare of the child born as a result of A.R.T.; and
- matters relating to donor conception, and access to information.

The associated findings and recommendations made in relation to such matters within this and following Chapters, are all made with the intent of improving the operation and effectiveness of Act in relation to the paramountcy of the welfare of the child principle.



# Chapter Four

## Establishment of a Donor conception register

# Chapter Four: Establishment of a Donor Conception Register

## 4.1 Introduction

The donation of gametes (sperm or eggs) and embryos, has meant that people who may not have otherwise had children, have been able to do so. However, historical moral, religious, social, cultural views, and legal concerns, regarding such things as whether the practice amounted to adultery; the use of instrumental insemination; the illegitimacy, and/or the legal parentage of the child born as a result; whether the child could inherit from his/her non-biological parent and/or donor; the legitimacy of donor-conception as a ‘medical treatment’ or ‘cure’ for infertility; and the stigma and shame associated with infertility, also led to a culture of secrecy that underpinned its practice for many years.<sup>259</sup> In many cases donors of gametes were told they must remain anonymous, and the recipients of such gametes were sworn to secrecy. The involvement of third parties such as the medical practitioner served to keep recipients and donors apart, and unknown to each other.

Little regard it seems was had for the interests and/or needs that some donor-conceived people might have in knowing about the method of their conception, and/or their genetic heritage, although research reveals that such issues were being discussed at least as early as the 1950s. Nor was consideration given to the fact that many recipients and donors did not wish to be sworn to secrecy or condemned to anonymity. In fact, while it may have been thought that it was in the best interests of all parties to keep the method of conception a secret, time has shown this has not been the case.

Secrecy was hard to maintain or something that people rejected. Some parents were open with their children, compelled to tell them the truth surrounding their conception and wanting to be open. Sometimes children found out in other ways—in the context of divorce, illness, death, family conflict, and in more modern times via popular genetic testing related

---

<sup>259</sup> For more in depth discussion of the history of donor conception please see Sonia Allan, *Donor Conception and the Search for Information: From Secrecy and Anonymity to Openness* (2017) Routledge, Oxford UK.

to ancestry tracing. Donors wondered about the children they had helped to create. It became apparent that some children born as a result of the use of donated gametes or embryos, may desire further information about the donor and/or genetic relatives, including but not limited to siblings. However, whether access to information about the donor(s) was possible, depended upon when and where a donation was made and/or the child conceived, as laws differed over time and place. The impact upon some donor-conceived people has been significant. The psycho-social and medical consequences reflect a range of issues including matters related to identity, a need to access medical information, concern about risks of forming consanguineous relationships, and a desire for openness, honesty, and equality and non-discrimination. Each of these factors is considered further below at 4.3.

In some jurisdictions from the early 1980s into the modern day, laws were enacted to provide access to information. This now includes legislation in the Australian states of New South Wales,<sup>260</sup> Victoria,<sup>261</sup> Western Australia;<sup>262</sup> and the countries of Austria;<sup>263</sup> Argentina<sup>264</sup> Croatia;<sup>265</sup> Finland;<sup>266</sup> Ireland;<sup>267</sup> the Netherlands;<sup>268</sup> New Zealand;<sup>269</sup> Norway;<sup>270</sup> Sweden;<sup>271</sup> Switzerland;<sup>272</sup> the United Kingdom,<sup>273</sup> and Uruguay.<sup>274</sup> In these jurisdictions the donor-conceived person who knows of their status and wishes to obtain information about their donor(s) may turn to a special register,<sup>275</sup> to the clinic<sup>276</sup> or hospital<sup>277</sup> that assisted in their

---

<sup>260</sup> *Assisted Reproductive Technology Act 2007* (NSW).

<sup>261</sup> *Infertility (Medical Procedures) Act 1984* (Vic) (Repealed); *Infertility Treatment Act 1995* (Vic) (Repealed); *Infertility Treatment Regulations 1997* (Repealed); *Assisted Reproductive Treatment Act 2008* (Vic).

<sup>262</sup> *Human Reproductive Technology Act 1991* (WA).

<sup>263</sup> Fortpflanzungsmedizingesetz. 275 Bundesgesetz, 1992.

<sup>264</sup> Código civil y comercial de la nación (Civil and Commercial Code of the Nation), Title V, Ch2, approved by Law 26,994.

<sup>265</sup> ZAKON O MEDICINSKI POMOGNUTOJ OPLODNJI (Law on Medically Assisted Reproduction, 12 July 2012) (Croatia), No: 71-05-03 / 1-12-2, Article 15(2).

<sup>266</sup> Act on Assisted Fertility Treatments (1237/2006).

<sup>267</sup> *Children and Family Relationships Act 2015* Act No. 9 of 2015, s 25(1).

<sup>268</sup> Wet donorgegevens kunstmatige bevruchting, 2002.

<sup>269</sup> *Human Assisted Reproductive Technology (HART) Act 2004* (NZ).

<sup>270</sup> Act on Biotechnology 2003.

<sup>271</sup> Lag om insemination (Law on Insemination) 1984 (replaced by Genetic Integrity Act 2006).

<sup>272</sup> Federal Act on Medically Assisted Procreation of 18 December 1998 – FF 1996 III, 197 (LPMA).

<sup>273</sup> *Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004* (UK).

<sup>274</sup> Law Regulating Human Assisted Reproductive Techniques (22/11/2013 No 19.167)

<sup>275</sup> Australian states of New South Wales, Victoria, Western Australia; countries of Croatia; Finland; Ireland; The Netherlands; New Zealand; Switzerland; United Kingdom.

<sup>276</sup> Austria; Switzerland (pre-2001).

<sup>277</sup> Sweden.

conception, or apply for judicial approval<sup>278</sup> to access information about their donor(s), and possibly siblings. Donors and recipient parents in some jurisdictions may also be able to obtain some information under these laws.

Four jurisdictions—Victoria, Ireland, Croatia and Argentina—also moved to require entry of information about the method of conception on the birth register to ensure that a donor-conceived person knows they are donor-conceived and then may seek further information if desired. Victoria and Ireland explicitly state that such information will be provided to the donor-conceived person on application for their birth certificate at age 18. Croatia mandates disclosure by parents to the child regarding its donor-conceived status no later than age 18. Argentina lists information on the birth record, but it is unclear as to how this information will be conveyed.

Other nations, including the United States, Canada and Denmark, have seen a greater move to offering open identity gamete donation, albeit those nations still also offer anonymous donors.<sup>279</sup>

In most of the jurisdictions above-mentioned, the right to access information is prospective, meaning it has been given only to those conceived with gametes donated after the enactment of the law. Access to past donations may only occur if the donor consents. However, there has been ongoing debate about whether people conceived in the past, when donor anonymity was required and/or “guaranteed” by clinicians, should all be given access to identifying information.<sup>280</sup> Switzerland, provided for retrospective access to information in 2001. There, a register of donor information for children born post 2001 was established, but the law also provides that those born before 2001 can apply to clinics for information, who are obliged to release it. In Germany, Supreme Court recognition has been given to donor-conceived people’s constitutional and human rights to access identifying information about their donor, at any age.<sup>281</sup> Victoria, most recently adopted laws recognising the right of all

---

<sup>278</sup> Argentina, Uruguay

<sup>279</sup> For detailed discussion of all of the above jurisdictions and their laws, Allan (2017), above n 259.

<sup>280</sup> G. Pennings, (2012). How to kill gamete donation: Retrospective legislation and donor anonymity. *Human Reproduction*, 27(10), 2881–2885. doi:10.1093/humrep/des218; Sonia Allan, Donor identification kills gamete donation: A response. *Human Reproduction*, 20, 1–5.

<sup>281</sup> Supreme Court of Germany decision XII ZR 201/13, summary, available at <https://www.crin.org/en/library/legal-database/supreme-court-germany-decision-xii-zr-201/13>, accessed 28 February 2016

donor-conceived people to equal access to information, regardless of when they were born, subject to a contact veto/preference system.<sup>282</sup>

The passing of such laws, and the establishment of donor conception registers, continues to mark the tides of change as access to information by donor-conceived people about their donors is increasingly recognised as a fundamental human right, and/or as a means to uphold the paramountcy of the welfare and best interests of a child born as a result of donor conception. The history and changes over time form the backdrop to the following discussion of the operation and effectiveness of the current *Assisted Reproductive Treatment Act 1988* (SA) and my recommendations to the Minister.

## 4.2 Why is Access to Information Important?

The review revealed that in South Australia there is a significant call for access to information by donor-conceived people, recipient parents, and donors. To understand the call and to in turn reflect upon the current operation and effectiveness of the *Assisted Reproductive Treatment Act 1988* (SA), I considered why people seek information, and possibly contact. These reasons are discussed below.

### 4.2.1 Self-Identity

Self-identity involves the “who am I?” questions that many people ask at various stages of their life. In childhood they may include questions such as “where do I come from”. In adolescence they may be asked as one develops a sense of individual self. In adulthood, as relationships are formed, marriage occurs and children and grandchildren are born, the questions become relevant in an inter-generational sense, giving a broader picture of who a persons and their identity within and across generations.<sup>283</sup> For donor-conceived people such questions are in this sense similar to those asked by those in the general population. However, such questions are made more complex as donor-conceived people have parent(s) who rear them but are also the genetic offspring of sperm and/or egg donor(s). Further compounding

---

<sup>282</sup> For detailed discussion of the Victorian laws see Sonia Allan, ‘Donor Identification: Victoria gives Rights to all Donor-Conceived People’ 98 *Family Matters*, November 2016.

<sup>283</sup> Allan (2017), above n 259.

such complexity is that for some donor-conceived people there may be a stronger sense of lost identity when they are denied access to information. A number of written submissions to the review described such feelings.<sup>284</sup> For example, Belinda Leibel said:

*I believe this is important information for my well-being and sense of identity, and not having it has impacted my life and affected my choices whether to have children myself.*<sup>285</sup>

There is also evidence that some donor-conceived people who have been told of their conception later in life may experience confusion about their identity, and feel significantly deceived about who they are.<sup>286</sup> In the consultation forum with donor-conceived people one attendee described how she felt that she had lost half her identity and had gained nothing but questions in return.

Kim Buck stated in her submission:

*I learnt of my donor conceived status at age 15. My reasonably well-formed identity was subsequently thrown into disarray upon learning such unexpected information.*<sup>287</sup>

It is noted however that not all donor-conceived people describe feeling a sense of lost or fractured identity, some seek further information for other reasons, and some do not seek information at all. Perhaps most clear is that while the small amount of existing research points to varied feelings regarding donor conception and outcomes for families,<sup>288</sup> when

---

<sup>284</sup> Kim Buck, submission 41; Belinda Leibel, submission 48; Family Voice, submission 59; Relationships Australia, submission 66; Sofie Gregory, submission 70; Reece Trevenen, submission 79; Kimberley Turner, submission 81. See also A. Turner, & A. Coyle (2000). What does it mean to be donor offspring? The identity experience of adults conceived by donor insemination and the implications for counselling and therapy. *Hum Reprod*, 15(9), 2041.

<sup>285</sup> Belinda Leibel, submission 48.

<sup>286</sup> M. Dennison, (2008). Revealing your sources: The case for non-anonymous gamete donation. *Journal of Law and Health*, 21(1), 1–27 at 13; V. Ravitsky, (2010). Knowing where you come from: The rights of donor-conceived individuals and the meaning of genetic relatedness *Minnesota Journal of Law, Science & Technology*, 11(2), 655–684 at 670, referring to Warnock, M. (1987) The good of the child. *Bioethics*, 1, 141 at 151.

<sup>287</sup> Kim Buck, submission 41.

<sup>288</sup> R. McNair, (2004). *Outcomes for children born of A.R.T. in a diverse range of families*. Melbourne: Victorian Law Reform Commission; S. Golombok, J. Readings, L. Blake, P. Casey, L. Mellish, A. Marks, & V. Jadv, (2011). Children conceived by gamete donation: Psychological adjustment and mother-child relationships at age

people do decide to search for information, their reasons almost always include the desire to know and understand more about the donor, and about oneself. This often also extends to a desire to know and understand more about other genetic relatives, including most frequently, siblings.

### **4.2.2 Medical history**

Knowing about familial medical history of heart disease, diabetes, cancer, mental health issues and/or other heritable diseases may enable early intervention, and/or prevention of disease.<sup>289</sup> Chapter Two of this report reflected upon how screening for certain heritable diseases, disorder, and or illness, was seen as an integral part of upholding the paramountcy of the welfare of the children, and is practiced widely in the context of A.R.T. It also discussed how upholding the welfare principle includes being able to identify and communicate medical issues that pose a risk to another person’s life, health, or safety.

Donor-conceived people who are denied access to familial medical histories may be placed at increased risk as a result of not having access to information. This becomes very significant as people age. Despite some receiving medical information about the donor gathered at the time of donation, there are many conditions which develop later in life. A donor may discover a heritable disease many years after donation. Similarly, a donor-conceived person may become aware of a heritable condition, but in an anonymous regime has no way to notify their donor(s) or donor-siblings. This may have ramifications for the person unaware of such information and generations to come.

The call for access to medical information in submissions to the review was strong.<sup>290</sup> A number of submissions<sup>291</sup> noted the story of Narelle Grech, a Victorian donor-conceived girl who died of bowel-cancer in 2013 at the age of 30. She had searched for her donor for fifteen

---

7. *Journal of Family Psychology*, 25(2), 230–239; S. Wise, & G. Kovacs, (2014) Secrecy, family relationships and the welfare of children born with the assistance of donor sperm: Developments in research, law and practice. In A. Hayes & D. Higgins (Eds.), *Families, policy and the law: Selected essays on contemporary issues for Australia* (pp. 81–88). Melbourne: Australian Institute of Family Studies.

<sup>289</sup> Centers for Disease Control and Prevention (CDC). (2004). Awareness of family health history as a risk factor for disease. *Morb Mortal Wkly Rep*, 53(44) 1044.

<sup>290</sup> Kim Pace, submission 19; Damian Adams, submission 34; Chloe Allworthy, submission 35; Ms Hayley Smith, submission 39; Danica Little, submission 40; Kim Buck, submission 41; Belinda Leibel, submission 48; Dr Kelly Ann, submission 55; Sandra Bevan, submission 67; Kylie Dempsey, submission 69; Western Australia, Reproductive Technology Council, submission 78; Reece Trevenen, submission 79.

<sup>291</sup> Reece Trevenen, submission 79; Kimberley Turner, submission 81;

years. Her submission to the Victorian Law Reform Committee in 2011 illustrated the kinds of questions that plagued her:

*I was diagnosed with Stage 4 bowel cancer following an emergency surgery...The first thing the doctors and surgeons asked me was: is there any family history of cancer in your family? ...I am sure there was no family history of illness at the time that [the donor] donated but who is to say he simply didn't know...What if he or someone else has developed cancer since? What if he died from cancer himself? ...What if my eight half-siblings are at risk of cancer? What if there are children whose aunty has bowel cancer? It's really quite important that they should know this if they are at risk. It's believed that in most cases where a person is diagnosed with bowel cancer under the age of 30 there is a genetic link.<sup>292</sup>*

The Victorian Law Reform Committee noted that as time passes, the number of donor-conceived people who may benefit from medical information will only increase as medical knowledge of the influence of genes on disease develops. They also noted the extreme detriment that may potentially be avoided by sharing information provided a strong case for access to information to be possible.<sup>293</sup>

### **4.2.3 Consanguineous relationships**

Another significant driver in the search for information for some donor-conceived people is the fear or risk of unknowingly forming relationships with siblings or possibly their donor. Again, the review received numerous submissions in this regard.<sup>294</sup> For example, Sofie Gregory submitted:

---

<sup>292</sup> Narelle Grech, *Transcript of evidence*, Melbourne, 12 September 2011, reported in Victorian Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information about Donors* (March 2012), p55.

<sup>293</sup> *Ibid*, Victorian Law Reform Committee, p 55.

<sup>294</sup> Damian Adams, submission 34; Belinda Leibelt, submission 48; Family Voice, submission 59; Ross Hunter, submission 60; Confidential, submission 68; Sofie Gregory, submission 70; Confidential, submission 71; Western Australia, Reproductive Technology Council, submission 78; See also Victorian Law Reform Committee. (2012). *Access by donor-conceived people to information about their donors*. Melbourne: Victorian Law Reform Committee. Retrieved from [www.parliament.vic.gov.au/57th-parliament/lawreform/article/1468](http://www.parliament.vic.gov.au/57th-parliament/lawreform/article/1468), accessed 8 January 2017 ; Senate Legal and Constitutional Affairs References Committee, Donor Conception Practices in Australia, 11 February 2011. Commonwealth of Australia.

*Secrecy must end. How do adopted and DC children know if they are about to begin a relationship with a relation? We do not know our brothers and sisters. But we do know there is genetic attraction for people who have lived with genetic bewilderment.*<sup>295</sup>

Family Voice submitted that

*More than half say that when they see someone who resembles them they wonder if they are related. Almost as many say they have feared being attracted to or having sexual relations with someone to whom they are unknowingly related.*<sup>296</sup>

Another submission noted,

*It is possible for a donor to provide gametes to more than one registered organisation provider on more than one occasion. [Our] view is that the possibility of having multiple children should not be underestimated and the risks of consanguinity are magnified by the potential number of children.*<sup>297</sup>

The risk may be significant within smaller populations, or where there are no or high limits upon the number of families for which the same donor’s gametes may be used. The risk and fears associated with forming consanguineous relationships has long been recognised in Australia.<sup>298</sup>

While one way to avoid half-siblings forming relationships is to restrict a donor to one donation or to one recipient family, this is not, and has not been, the approach to donor conception in most jurisdictions,<sup>299</sup> including South Australia. In fact, in South Australia, there are no legislated limits on how many families may use the same donor. It is known that most

---

<sup>295</sup> Sofie Gregory, submission 70.

<sup>296</sup> Family Voice, submission 59.

<sup>297</sup> Confidential, submission 68.

<sup>298</sup> New South Wales Law Reform Commission. (1984). *Artificial conception: Human artificial insemination*, (Discussion Paper 11). Sydney: New South Wales Law Reform Commission.

<sup>299</sup> Some jurisdictions limit the number of families to which a donor may donate. For example, in Victoria, the maximum number of families is ten: *Assisted Reproductive Treatment Act 2008* (Vic.), s 29). In New South Wales, the number is five: *Assisted Reproductive Technology Act 2007* (NSW), s 27(1). In Western Australia, the number is five: *Human Reproductive Technology Act 1991* (WA) (see “*Human Reproductive Technology Directions* (WA)”, *Western Australian Government Gazette* (30 November 2004) p. 5434 at [8.1]).

often donors are likely to have donated multiple times. Some may also have donated at multiple clinics, and privately. Others may have been used by specific clinics to assist families in a particular area at a particular time. There is evidence in areas of Australia that multiple half-siblings were born within a small time frame to a variety of families all living in the same vicinity, and stories have emerged in which donor-conceived people have found they went to school with their half-siblings.<sup>300</sup>

NHMRC Ethical Guidelines, to which registered A.R.T. practitioners are required to adhere, do not provide for a numerical limit, but rather state:

*Persons conceived using donor gametes, and the donors of gametes, need to be protected from the consequences of having many genetic siblings and offspring, respectively. Clinics must take all reasonable steps to reduce the numbers of genetic relatives created through donor gamete programs. ... Gametes from one donor should be used in a limited number of families. In deciding the number of families, clinicians should take account of*

- *the number of genetic relatives that the persons conceived using the donation will have;*
- *the risk of a person conceived with donor gametes inadvertently having a sexual relationship with a close genetic relative (with particular reference to the population and ethnic group in which the donation will be used);*
- *the consent of the donor for the number of families to be created; and*
- *whether the donor has already donated gametes at another clinic.<sup>301</sup>*

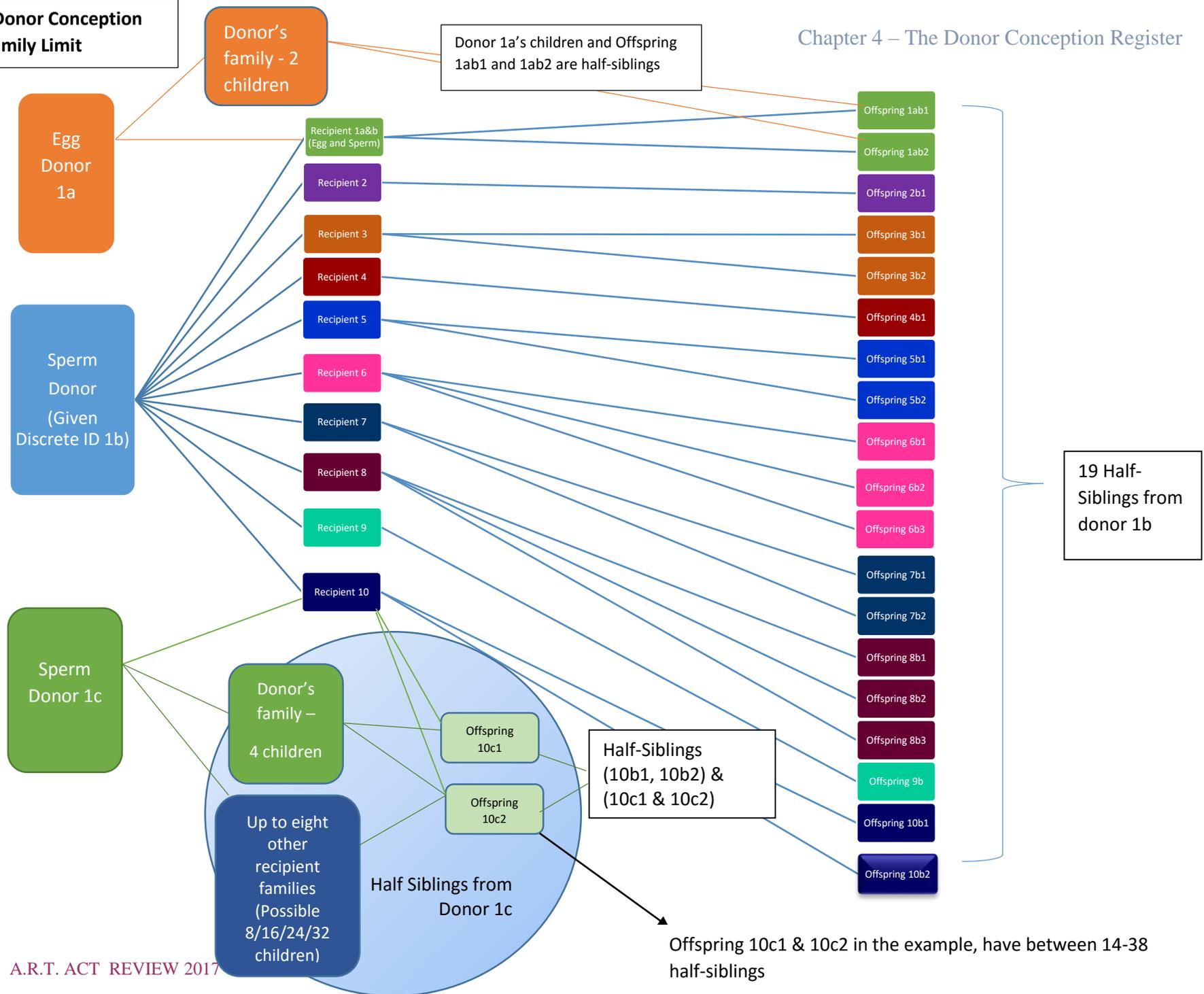
The current practice in South Australia is reported to be ten families.<sup>302</sup> One may consider Figure 3 on the next page for a depiction of how many genetic siblings may result when a ten family limit is practiced. (An explanation follows the figure to illustrate the complexities and possible risks).

<sup>300</sup> See, for example, the story of Bridgette Reynolds, reported in James Purtill, “A Daughter’s Search for her Anonymous Sperm Donor”, RMR1084, *JJJ Hack*, [www.abc.net.au/triplej/programs/hack/a-daughter-s-search-for-her-anonymous-sperm-donor-father/7201012](http://www.abc.net.au/triplej/programs/hack/a-daughter-s-search-for-her-anonymous-sperm-donor-father/7201012) accessed 8 January 2017).

<sup>301</sup> NHMRC Ethical Guidelines [6.3].

<sup>302</sup> This accords with advice given in RTAC Technical Bulletin 3, issued in April 2011, <http://www.fertilitysociety.com.au/wp-content/uploads/20110506-technical-bulletin-number-3.pdf>.

**Figure 3 - Example Donor Conception Relationships: 10 Family Limit**



*Explanation of Figure 3*

Figure 3 depicts a hypothetical scenario for families formed under the ten family limit using a variety of one, two, three, or four children to illustrate how many siblings may result.

It shows an egg Donor(1a) who has two children of her own, and donates eggs to Recipient (1ab) who also uses a sperm Donor (1b). Recipient (1ab) had two resulting children.

The sperm of Donor (1b) is used to create 10 families, resulting in 19 children being born in total. Children within families in which children are conceived using the same sperm donor and mother's/donor eggs are full siblings. Children across families conceived with Donor 1b's sperm share the same genetic father and are half siblings.

Recipient 1a's two children are full siblings, they are half-siblings with Egg Donor 1a's two children, as well as the 17 other children born as a result of the use of Donor 1b's sperm.

However, to illustrate further the complexities of donor conception, Recipient 10 is shown to have used two different sperm donors (1b) and (1c). Two of her children are full siblings with her and Donor (1b) as genetic parents, these two children are also half-siblings of the other 17 offspring born as a result of the use donor 1b's sperm. The two children are also half siblings with the two children born to their mother using the sperm of donor (1c)—as they share the same mother. The children born to Recipient 10 as a result of the use of sperm donated by Donor 1c, are also half-siblings of 1c's own four children, and any children born as a result of the use of 1c's sperm in up to eight more families. The diagram suggests there may be eight, sixteen, twenty-four, or thirty-two other children based upon a calculation of an average of 2-4 children per recipient family. This would leave the children of Recipient 10 and Donor 1c with between 14 to 38 half-siblings (two of which they live with).

One might further consider that it is possible that the sperm may have been used over a short period of years, with all children thus being aged quite closely. The children may live in close proximity to each other, and perhaps some of them will even attend the same school. Some children may know they have half-siblings, but not know who they are. Others may not know they are donor-conceived at all. Families may not be informed that other families who have used the same donor live in close proximity.

Further complexities may arise when the sperm donor has donated at more than one clinic, or interstate and not revealed prior donations—as there currently is no way to track his donations.

Entering consanguineous relationships may have negative legal ramifications.<sup>303</sup> There is also the chance that such relationships would bear children, leading to the risk of genetic or chromosomal abnormalities.<sup>304</sup> The fear of this occurring can cause great distress for some donor-conceived people.<sup>305</sup> The threat of consanguinity may thus also affect the emotional and social wellbeing of some donor-conceived people, and clearly does not uphold the paramountcy of the welfare of the child principle.

The reality in South Australia that such things could occur was confirmed by a nurse working at a clinic during face-to-face consultations. She said that it was their practice to tell recipient parents the number and gender of offspring, but not year of birth. She reported that they had recently had people living close by to each other who had used the same donor, but said that they do not alert them about this. The risk of forming consanguineous relationships would be greatly reduced if donor-conceived people were able to obtain information about the identity of their donors and donor siblings. Early disclosure to recipient parents regarding donor siblings who may live in close proximity is also called for.

#### **4.2.4 Openness, honesty, and equality**

There are other reasons beyond those above that drive some donor-conceived people to search for information. Many donor-conceived people wish to know a name for their donor; others wish to say thank you; while others want to know whether they have any half-siblings. Cutting across all of these reasons is a desire for openness, honesty and an end to secrecy and lies that donor-conceived people feel have formed the foundation of their life.<sup>306</sup> During the review, donor-conceived people called for an end to secrecy and anonymity, and an opportunity to choose for themselves whether to pursue access to information about their

---

<sup>303</sup> For example, the Australian *Marriages Act 1961* (Cth), s 23(1)(b), makes marriages involving “prohibited relationships” void. Section 23(2)(a)–(b) states that “marriages between an individual and their parent and an individual and their sibling, including half siblings” are “prohibited relationships”. State criminal law also makes incest between individuals and their parents and half-siblings a punishable offence: e.g. see *Crimes Act 1958* (Vic.), s 44(2), (4).

<sup>304</sup> R.L. Bennett, A.G. Motulsky, A. Bittles, L. Hudgins, S. Uhrich, D.L Doyle, (2002). Genetic counseling and screening of consanguineous couples and their offspring: Recommendations of the National Society of Genetic Counselors. *Journal of Genetic Counselling*, 11(2), 97–119.

<sup>305</sup> Commonwealth, Senate Committee, *Hansard* (3 November 2010), oral evidence of donor-conceived individuals.

<sup>306</sup> Damian Riggs, submission 23; Laura Easthope, submission 32; Kim Buck, submission 41; Ross Hunter, submission 60; Relationships Australia, submission 66; Sofie Gregory, submission 70;.

donor and/or further contact. The maintenance of secrecy and anonymity was shown to cause a number of people distress, and the call for the government to act was noted. For example, Kim Buck submitted:

*I find it unacceptable that such fundamental information is deliberately withheld from donor-conceived children, and believe the government has a responsibility to act to shift the current culture of secrecy and deception towards one of openness and honesty.<sup>307</sup>*

Ross Hunter said in his written submission:

*Reform of [the] Act has the potential to finally remove that shameful stigma, promote openness and equality and allow us to get on with our lives.<sup>308</sup>*

A number of submissions saw this as fundamental to upholding the paramountcy of the welfare of the child.<sup>309</sup>

#### **4.2.5 Recipients and donors wish to share information**

There have also been many recipient parents and donors who have called for release of information and an end to secrecy. The review received a number of written and oral submissions from recipients who reported upon the toll secrecy had taken upon them, and regarding their desire to be open and honest with their children. All recipients that participated in the review reported that they wished to end the secrecy, which a number felt they had been forced to maintain. One recipient described her experience as follows:

*When my pregnancies were confirmed ...I was told to forget all about the donor...to go home and enjoy my babies and not to bother telling them of their genetic origins because information would not be retained... [but] I have wondered nearly every day*

---

<sup>307</sup> Kim Buck, submission 41.

<sup>308</sup> Ross Hunter, submission 60.

<sup>309</sup> Caroline Lorbach, submission 27; Confidential 32; Damian Adams, submission 34; Kim Buck, submission 41; Kylie Dempsey, submission 69; Sofie Gregory, submission 70; Reece Trevenen, submission 79;

*since my pregnancies so long ago just who the wonderful person was who helped us start a family and go on to have these two amazing people in my life. I kept my secret until March 2015 (even my partner of 17 years had no idea), remembering the clinic nurse's words never to tell the truth because it would be futile ...<sup>310</sup>*

She further reported that when she told her children 'it brought us closer.' She said her son immediately contacted the clinic for information about his donor, but they felt 'terrified'.

Another recipient emphasised during the 'consumer forum' held in South Australia that she saw it as fundamental to sharing values of openness and honesty with her son that she be able to discuss information about his method of conception and his donor with him. She described how it was important to her family to have information and contact with donor siblings too, but felt thwarted in her efforts to do so.

Donors also reported wondering about the offspring they have helped to create, and some have actively engaged in searching for information about numbers of offspring, sex of offspring, and/or have attempted to let the donor-conceived person know that they are open to sharing information and further contact.<sup>311</sup> I heard from a number of donors who had done this primarily by way of communicating their questions and openness to clinics and who reported mixed levels of support in doing so. One donor described to me how he keeps a diary in which he has recorded the number, year born and sex of each child born as a result of his donations—sharing that information with his own family and relatives.

Another donor described how he 'cried his eyes out' when he found out that there had been children born as a result of his donation. He said he was so happy to have been able to help another family, and that the recipients and children were always welcome to contact him for information. He currently receives Christmas cards from one family, and letters from a father with 'little bits of information updating me on what has happened in their family'.

Another donor described how he would never have donated if he wasn't completely open to sharing information and having contact in the future.

---

<sup>310</sup> Confidential 32.

<sup>311</sup> Peter Liston, submission 9; Confidential, submission 30; Ian Smith, submission 73; Nathan O'Callaghan, oral submission 21 April 2016; Jarrod Whitbread, oral submission 21 April 2016; Corey, oral submission 21 April 2016.

Donor views have also been demonstrated in past inquiries and evidenced in other states, illustrating it is not necessarily the case that past donors wish to remain anonymous.<sup>312</sup> For example, the Donor Conception Support Group quoted in their submission to the Senate Committee Inquiry into Donor Practices in 2010 a former sperm donor who stated:

*I was a sperm donor during 1997-1998. [M]y donations were during the period when [d]onors had to sign away any future contact. This was a condition of participation and I only wanted to help people – but at the back of my mind was the hope that the rules would change to allow the resultant children to trace their donor fathers, if they wished to do so.*<sup>313</sup>

Similarly, the Victorian Assisted Reproductive Treatment Authority (VARTA) has long recognised that the belief that secrecy was paramount to protect all parties to the arrangement was based on myths. They have said such myths included the view that donors would not want to be contacted, that parents would not want to know more about their donor, and that donor-conceived individuals would not want information about their donor if they really loved their parents.<sup>314</sup> VARTA reports further that *donors do not forget they have donated and often wonder about the people they helped to create. Who are they? Are they healthy? Are they happy? Are they loved?*<sup>315</sup>

**FINDING 23**

Reasons that donor-conceived people, recipient parents, and donors wish to exchange information range from issues concerning identity, medical information, fear and risks of forming consanguineous relationships, concern for each other's well-being, and a desire for openness, honesty and equality. In many circumstances the reasons given highlight the devastating impact that not having access to information has on some people. Allowing people to suffer in this way does not accord with upholding the paramountcy of the welfare of the child principle.

<sup>312</sup> Senate Legal and Constitutional Affairs References Committee, Submission 73 (Rainbow Families Council) p 2 and Submission 122 (Donor Conception Support Group) p 139.

<sup>313</sup> Senate Legal and Constitutional Affairs References Committee, Submission 122 (Donor Conception Support Group) p 74.

<sup>314</sup> Victorian Assisted Reproductive Treatment Authority, *Time to Consent? Information Pamphlet* (2008).

<sup>315</sup> *Ibid.*

### 4.3 South Australia: Calls for Information

For more than thirty years, there have been calls for access to identifying information in South Australia by donor-conceived people, recipients and donors. The calls increasingly drew public attention as donor-conceived people aged and shared their experiences. As Victoria established donor-registers in the 1980s, and Western Australia began holding information centrally from 1991, calls for a donor conception register in South Australia increased.

At least from the early 2000s the SACRT was also calling for the establishment of a donor conception register. In 2003 the SACRT ‘Donor Conception Working Party’ communicated its concerns about the delay in establishing such a register to the then Minister for Health. By 2004 nothing had occurred, and the working party reported that they would reconvene when they received indication that the register would be established.<sup>316</sup>

In 2005, the South Australian Parliament’s Social Development Committee (SDC) and the SACRT again raised concerns about the lack of access to identifying information about gamete or embryo donors in South Australia, and recommended that donor registration be addressed. The then Minister for Health, Lea Stevens MP, responded that ‘competing health priorities did not allow for the establishment of a donor conception register to be further progressed at [that] time, but that a proposal had been drafted and that she hoped to be able to progress the initiative as soon as funding became available.’<sup>317</sup> The SACRT Donor Conception Register Working Party moved to work with clinics to build on information collection and management procedures to allow voluntary registers to be established in the interim. SACRT also said it would seek funding from the Department of Health (as it then was) for a publicity and education campaign to encourage donors to register with clinics.<sup>318</sup>

In 2006, the SACRT reiterated to the Minister its preference for legislative amendments to remove donor anonymity and for both mandatory and voluntary registers to be established within a government agency.<sup>319</sup>

<sup>316</sup> South Australian Council on Reproductive Technology, *Annual Report for 2004*, p 16.

<sup>317</sup> South Australian Council on Reproductive Technology, *Annual Report for 2005*, p18.

<sup>318</sup> Ibid.

<sup>319</sup> South Australian Council on Reproductive Technology, *Annual Report for 2006*, p18. There were no further reports included from the donor conception register Working Party in SACRT’s annual reports from 2007-2009.

In 2007, the SDC again recommended that the legislation be amended to ensure that people conceived through donor conception have access to information about their genetic parentage should they request it.

## 4.4 What has Happened Since?

Changes to the *Assisted Reproductive Treatment Act 1988* (SA) were introduced to parliament in 2008 and came into force in 2010, providing that the Minister may keep a register of donors, and removing any impediments to transferring information onto the register.<sup>320</sup> The new laws also provided for the Minister to pass regulations which would establish the information to be kept on the register, who would have access to such information, and how access to information held on the register would occur. Parliament noted that such regulations would be determined based upon consultation with relevant stakeholders, to ensure that consideration be given to the model of register to be adopted. (Such consultation has formed part of this review). The provisions in the legislation are as set out in Table 3.

**Table 3: Donor conception register: *Assisted Reproductive Treatment Act 1988* section 15**

- (1) The Minister may keep a register of donors of human reproductive material used in, or in relation to, assisted reproductive treatment provided in accordance with this Act and resulting in the birth of a child (the donor conception register).
- (2) If the Minister does keep the donor conception register, the register must contain, in relation to each donor on the register:
- (a) the donor’s full name and nominated contact address; and
  - (b) the full name and nominated contact address of the person to whom assisted reproductive treatment using the donor’s human reproductive material was provided; and
  - (c) the full name of any child born as a consequence of such assisted reproductive treatment (if known); and
  - (d) any other information required by the regulations, and may include any other information that the Minister thinks fit.
- (3) The Minister must correct an entry in the donor conception register that is not correct.

<sup>320</sup> Section 18aa was introduced into the *Assisted Reproductive Treatment Act 1988* (SA) which permits the disclosure of the identity of human reproductive treatment ‘as required or authorised by or under this or any other Act’.

- (4) The donor conception register may only be inspected in accordance with the regulations.
- (5) A certificate stating that a donor was, or was not, registered on the donor conception register in relation to the birth of a specified child, and purporting to be signed by the Minister will, in the absence of proof to the contrary, be accepted in legal proceedings as proof of the registration, or of the fact that the person was not so registered.
- (6) The Minister may, by notice in writing, for the purpose of preparing and maintaining the donor conception register, require a person to provide the Minister with such information as the Minister may require.
- (7) A person must not, without reasonable excuse, refuse or fail to comply with a requirement under subsection (6). Maximum penalty: \$10,000

In 2011 a Federal inquiry into donor conception practice that had been led by the Senate Constitutional Affairs Committee resulted in recommendations for a national donor conception register to be established.<sup>321</sup> However, the Commonwealth government responded that it did not have the power to establish such a register, and referred the matter back to the states and territories noting that issues concerning access to information by donor-conceived people should be addressed as a '*matter of priority*'.

In South Australia, in 2013-2014 draft regulations for the state-based register were put out for public consultation. However results of that consultation were never publically forthcoming. Hopes that the register would be established, were not met. In 2017, a central donor conception register still does not exist.

**FINDING 24**

Despite decades of discussion and calls for the establishment of a donor conception register in South Australia, including consistent recommendations being made to respective Government Ministers by their own advisory bodies; and despite the enactment of the current A.R.T. legislation in 2010 making such a register possible, a donor-conception register has not been established.

---

<sup>321</sup>Senate Legal and Constitutional Affairs, Committee Inquiry into Donor Conception in Australia [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Legal\\_and\\_Constitutional\\_Affairs/Completed\\_inquiries/2010-13/donorconception/index](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Completed_inquiries/2010-13/donorconception/index) accessed 8 January 2017.

## 4.5 Current Practices by Clinics in South Australia

Under South Australia’s current legislative framework, a person must not disclose the identity of a donor of human reproductive material except as required or authorised under the Act (or any other Act); in the administration of the Act; in order to provide A.R.T.; or with the consent of the donor of the material.<sup>322</sup> There is a maximum penalty of \$10,000 or imprisonment for 6 months for breach of these requirements.<sup>323</sup>

At present, this means people in South Australia only have access to identifying information if the donor has consented. Such consent must have been given pursuant to NHMRC Ethical Guidelines since 2004.<sup>324</sup> The NHMRC Ethical Guidelines also stipulate that records relating to donor conception are to be kept indefinitely (or at least for the expected lifetime of any person born).<sup>325</sup> Pursuant to the NHMRC Ethical Guidelines to which clinics must adhere,<sup>326</sup> when the information exists and the fertility clinics have access to it, donor-conceived people, once 18 or of “sufficient maturity”, may access identifying information about their donor with the donor’s consent. Those born as a result of the use of gametes donated after 2004 should be able to assume consent.

Those conceived with gametes donated prior to the 2004 Guidelines are presently only able to access identifying information if the donor consented at the time of donation, or afterwards, to release of identifying information. The NHMRC Ethical Guidelines further stipulate that for donations that took place prior to the guidelines being introduced fertility clinics are obliged to make an appropriate effort, consistent with the original consent document of the donor and their privacy rights, to encourage the donors and donor-conceived people to consent to being contacted by their genetic children, or genetic siblings and half-siblings, respectively.<sup>327</sup>

Beyond identifying information, all donor-conceived people may also be given non-identifying information about their donor, including medical and family history information;

<sup>322</sup> *Assisted Reproductive Treatment Act 1988 (SA)*, s 18.

<sup>323</sup> *Ibid.*

<sup>324</sup> NHMRC Ethical Guidelines, 6.1.4 (with an exception in cases in which a sibling is to be created using gametes donated prior to the introduction of the provision – 6.1.5).

<sup>325</sup> NHMRC Ethical Guidelines, 10.1.

<sup>326</sup> *Assisted Reproductive Treatment Regulations 1988 (SA)*, Reg 8.

<sup>327</sup> NHMRC Ethical Guidelines, 6.1.3.

and information about the number and sex of persons conceived using donated material from the same donor, the number of families involved, and any identifying information that a sibling has consented to being released.<sup>328</sup>

The NHMRC Ethical Guidelines also provide for access to certain information by recipients and donors. Recipient parents may access identifying information about the donor with the donor's consent; non-identifying information about their donor, including medical and family history information; and information about the number and sex of persons conceived using donated material from the same donor.<sup>329</sup>

A donor may request non-identifying information about the recipients of their donor material, including the number and sex of persons born.<sup>330</sup>

In conducting the review I found that all clinics currently collect information and maintain records regarding donor conception and adhere in principle to the NHMRC Ethical Guidelines. However, there were differing interpretations of what the guidelines require. For example, there were reported differences in the type and amount of information collected. One clinic described extensive data (up to nine pages of information) now being held including personal characteristics, education, whether the donor was a parent and if so, how many children, motivations for donating, hobbies and interests, three-generational medical background, and any other information they wished to provide. Another clinic described focus on familial medical history and basic personal data such as name, address, and occupation.

Meetings with an array of people who worked at the various clinics in South Australia also revealed different practices and views regarding providing access to information under the current system. Such differences existed across clinics, and within clinics. Nevertheless each person I met with, was strongly supportive of the establishment of a donor conception register, and of regulations governing access to information.

The observed lack of consistency regarding current practices and interpretation of NHMRC Ethical Guidelines accorded with reported experiences of donors, recipients, and donor-conceived people who had attempted to access information. The review heard from a variety of people who said they had experienced opposition or resistance to information

---

<sup>328</sup> NHMRC Ethical Guidelines, 6.1.3 and 6.1.11.

<sup>329</sup> NHMRC Ethical Guidelines, 6.1.10.

<sup>330</sup> NHMRC Ethical Guidelines, 6.1.12.

disclosure by some clinicians and counsellors, and or an unwillingness to encourage donors to come forward. Others reported more positive experiences regarding sharing information; donor-linking (i.e. via letter exchange and/or contact); and support of donors, recipients, and donor-conceived people.<sup>331</sup> Some such experiences differed according to when donations and/or conceptions occurred. Differences were also dependent upon which clinic was being approached. Some reported it also depended upon who they spoke to at a particular clinic at any given time as to what information or help was provided.<sup>332</sup>

There were also concerns expressed to the reviewer about proposed changes to NHMRC Ethical Guidelines, a draft of which had been circulated in late 2015.<sup>333</sup> Such concern centered upon potential changes that may remove recognition of the child's interests as paramount, placed emphasis upon 'privacy' and adult 'autonomy' over a child's 'right' to know information about their conception and genetic heritage, and proposed a softening of requirements upon clinics to actively engage in encouraging and supporting information release. A number of people expressed distress about a potential loss of the emphasis upon the paramountcy of the welfare of the donor-conceived person, which was seen as a major factor supporting the 'right' to information. Representative of such concern was a comment by Caroline Lorbach, a recipient parent, and head of the Donor Conception Support Group. She said:

*...the NHMRC Ethical Guidelines...have just had a new version released in draft form, while much of them is unchanged one of the main ethical principles has undergone a dangerous alteration. No longer is the welfare of the donor-conceived person listed as paramount now respect for the people involved is called for with donor-conceived people coming last on the list behind recipients and donors. While some may say that the listing order makes no difference our question would be then why change it? How is it being used, and to what effect?*<sup>334</sup>

---

<sup>331</sup> Confidential, submission 1; Gerard, live consultations.

<sup>332</sup> These concerns were raised in person with the reviewer during the donor-conceived forum, consumer forum, and in some of the donor consultations.

<sup>333</sup> Ibid. See also Caroline Lorbach, submission 27; Damian Adams, submission 34; Premier's Council for Women, submission 62; Confidential, submission 80.

<sup>334</sup> Caroline Lorbach, submission 27.

**FINDING 25**

Dissatisfaction exists amongst donor-conceived people, recipients, and donors, as well as some providers of A.R.T. that the NHMRC Ethical Guidelines are inconsistently interpreted and are subject to change that may impact them negatively. This provides further reasons for their call for the establishment of a central donor conception register.

**FINDING 26**

Use of the NHMRC Ethical Guidelines as the mechanism to establish the right for donor-conceived people to access their donor information is problematic. While compliance with the Guidelines is mandatory under the Act, they are written in ethical terms and are open to different interpretations. This undermines the operation and effectiveness of the Act. Reliance upon ethical guidelines is not as desirable as having an explicit provision in relevant legislation requiring information recording and release.

**FINDING 27**

All people who made submissions to the review showed overwhelming support for the establishment of a donor conception register, and of regulations governing access to information by donor-conceived people, donors, and recipient parent(s). The Minister should Act to establish the donor conception register as a matter of priority.

**RECOMMENDATION 17**

The Minister should exercise his powers under section 15 of the *Assisted Reproductive Treatment Act 1988 (SA)* to establish the donor conception register as a matter of priority.

**RECOMMENDATION 18**

The Minister should amend section 15 of the *Assisted Reproductive Treatment Act 1988 (SA)* to state that the Minister must establish the donor conception register – to ensure that the register is maintained into the future.

## 4.6 Past Records

Issues regarding past records related to donor conception in South Australia were also considered relevant to the review, particularly as the changes to the Act in 2010 were intended to maintain and strengthen the paramountcy of the welfare of the child principle. In addition, it was relevant to consider what should be done in relation to such records given the Act provides that the Minister may establish a donor conception register, and in doing so can determine what information the register should contain, how the register should operate, and the conditions upon which the register may be inspected.

In the following sections of this report I examine, and make recommendations to the Minister concerning past donor conception records associated with Repromed and its predecessors, and Flinders Fertility, the only registered clinics that existed prior to 2010. I also examine whether in establishing a donor conception register and developing associated regulations, the Minister should provide for access to identifying information by *all* donor-conceived people about their donors in South Australia, regardless of when they were born or when the gametes with which they were conceived were donated.

### 4.6.1 Past Records (*Repromed and its predecessors*)

The current legislation and provisions in the NHMRC Ethical Guidelines do not protect the rights of some donor-conceived people, recipients or donors to access information because it is not the clinics that hold this information. This is particularly relevant to those people conceived at Repromed or one of its predecessors prior to 2006.

Repromed has provided fertility services in South Australia over many years, however due to the business changing ownership and place of business during this time a situation has arisen in which A.R.T. and donor-conception records are held in various locations in Adelaide (including places which do not fall under the remit of the *Assisted Reproductive Treatment Act 1988* (SA) nor are governed by NHMRC Ethical Guidelines). Repromed was originally operated by a group of individual doctors/researchers from the Reproductive Medicine Unit at The Queen Elizabeth Hospital (public hospital/private providers). In 1987, it was incorporated into a company Repromed Pty Ltd which (at least in later years) was owned by a subsidiary company of the University of Adelaide. In 2006, the Repromed business was sold

to a private company, Adelaide Fertility Centre (A.F.C.) which continues to trade as Repromed. The former Repromed Pty Ltd continues to exist as a shell company, ACN, for which the University of Adelaide has been the sole shareholder since 2016. Currently:

1. the Queen Elizabeth Hospital holds some records from the mid-1960s to 1996;
2. the University of Adelaide holds some records from 1980 to 2006, including some birth outcome records; counselling records; and donor codes;
3. A.F.C. (trading as Repromed) holds records of their current clients and some older records, including an electronic database that allows for the identification of some genetic siblings and donor/patient cross referencing, but this is primarily for patients from 2006 onwards.

Those people conceived, or who donated or received treatment at the Queen Elizabeth Hospital or Repromed seeking information may need to contact all three of these organisations to request any information that may be held about their donor conception. The difficulties they have experienced in having to do so were conveyed to me during the donor conception forum held in South Australia in April 2016. They are exemplified by the experiences of Damian and Tiffany, which are summarised in Case Studies 1 and 2 below.

#### **Case Study 1: Damian**

Damian was conceived in 1973 at the Queen Elizabeth Hospital. He has always known he was donor-conceived (against the clinician's advice). He described his Dad as a 'lovely man who I lost at 10 years old'. At such a young age, and in such circumstances he felt he could not talk about being donor conceived for fear of hurting his mother, but in 1988 when he was 15 years old his mother requested non-identifying information from the Queen Elizabeth Hospital. She was told the records were lost.

At 19 years old Damian had a health problem and his treating immunologist suggested he try to find more information about his medical history. He contacted the Queen Elizabeth again, and that time was told the records had been destroyed. He later spoke to Repromed, who referred him for counselling, but no information was gained.

He said that the next time the desire for information really struck him was when he had children of his own. He described how holding his newborn daughter made him think about how much he loved her and how much it would devastate him if she didn't know who he was. He said that although everyone would recognise that he is her father, they didn't recognise his need to know about his biological father. His mother then made a Freedom of

Information application for her treatment records, which she was given. The records had a donor-code and said Damian had been born from frozen sperm.

Damian has since spoken to Adelaide University, the Queen Elizabeth Hospital, Repromed and State Records but still only has a donor code. He describes feeling like he and his mother were lied to. He also described wanting to know how many siblings he has, and having spent around \$2000 trying to find information via doing DNA testing.

He appealed during the donor conception forum, *'It has been nearly thirty years that I have been treading this path. Somebody has to help'*.

### **Case Study 2: Tiffany**

Tiffany travelled down from Queensland, where she now lives, to participate in the donor-conceived forum. She was conceived in 1990 and born in 1991. She found out when she was seventeen (in 2008) that she was donor-conceived when she overheard someone in her family saying they would tell her she was donor-conceived unless her parents gave them money. She said *'yes, it was blackmail'*. Tiffany struggled with knowing, felt she wanted to know more, but was conflicted. She felt at times that her feelings weren't valid because her parents had *'spent lots of money to get [her]'*. She described feeling angry and hurt about being lied to. However she said that she could *'never have imagined how many more secrets were to come'*.

Tiffany was conceived at Repromed and so approached them in around 2009 to seek information. She was told that the records were not held by them, and that she had to contact Adelaide University. She did so, but reported that nobody got back to her for nine months. She was not able to gain any information when they did so. She described going back again later, and said it was *'all very hard'*.

In 2011 she went back again, and asked about whether she had any siblings whereby she was told there was a female sibling a month younger than her. She was also told her donor code was 28R. Over time Tiffany became concerned the code she had been given was not like other South Australia codes, and that it might be from Monash IVF, in Melbourne. She asked Adelaide University about that in 2015, and was told that they don't usually give that information. She then went to Monash. She said she was *'constantly having another crack as they too kept changing their response.'* She tried twice with Monash, before hearing that Victoria had changed their laws to permit third party contact with the donor to seek consent for release of information. However, Monash initially refused to do so because she is from

Adelaide. Tiffany described feeling completely frustrated that they didn't just ask him. She said she didn't want to have to put her story on the front page of a newspaper, but felt that that seemed to be how people managed to get donors to come forward. She added, *'I had a lump in my breast, not knowing my medical history meant I was classified in a lower risk bracket, which delayed treatment. Look at what they've done.'*

Tiffany contacted me after the forum to say that she had found a half-sibling through Monash; and had discovered the donor-code given to her sibling was slightly different to the one she had been told.

Both Damian and Tiffany emphasised to me that the current situation of records being 'all over the place', and their experience in relation to this, has caused them much angst and despair. Both expressed that they feel they cannot trust what they are told, as they have been told many different things over time. They said that they would be comforted if all records that do exist are gathered and entered into a register in one location. They would know the records could then not be lost or destroyed, and there would be hope that some people may gain access to information. Damian further submitted that for those for whom there are no records, *'at least we would know that things were done properly, and maybe at last we could trust what we are being told'*.

Tiffany's case raises a further issue that there are donations that were shared between Melbourne and South Australia, and that information may also be spread across states. The Victorian Assisted Reproductive Treatment Authority confirmed to me that this is the case. From March 2017 information about donors that donated in Victoria and about children conceived in Victoria, will be available to all donor-conceived people. This means that some donor-conceived people in South Australia may be able to access information in Victoria, but not in South Australia. This creates further inequities in South Australia regarding access to information by some, but not all donor-conceived people.

#### *Further Information regarding current records and practices*

During the consultation period and afterwards I met with people who were responsible for the records at Queen Elizabeth Hospital; people who worked in A.R.T. at the time some such records were being made; as well as received a written submission, engaged in a telephone conversation, and received follow up information from Adelaide Uni/ACN. I

endeavoured to find out as much as I could about the records and current practices so that I could inform the Minister of what should be done to address the current situation—which is causing distress to donor-conceived people, recipients and donors, and has done for years. In the interest of transparency and openness, all of the details I obtained concerning records/information that are held by the Queen Elizabeth Hospital are given in Appendix 7 of this report, and by Adelaide University/ACN in Appendix 8. All information that I received was via oral or written responses to my questions, and I did not view or inspect any of the records myself in the interests of maintaining privacy of such records. I have accepted and impart the information I was given in good faith.

The information gathered confirmed that the records are spread across three locations (state records—where the Queen Elizabeth records are stored, ACN, and some at Repromed). Those held by the Queen Elizabeth Hospital are unsorted, and it remains unclear how much information might be contained within some of them. Where records have been sorted (for example, by ACN), it is apparent that some information is available, while other information is incomplete. Understanding what exactly is or is not available would require further sorting of records and collation of relevant data by an expert in records and data management.

My discussions with the Queen Elizabeth Hospital freedom of information officers and ACN representative revealed regular enquiries by donor-conceived people, donors, and recipients for information related to past donations. The Queen Elizabeth officers said such enquiries increased following media coverage to ‘about one enquiry every week’. The Legal Counsel at Adelaide University reported having received 63 enquiries by 60 people to ACN since 2009 (See Appendix 8). The Queen Elizabeth officers also noted that a few donors have asked to have their information kept in case a donor-conceived child asks to access it, but which is kept in a file kept by the officers. ACN also maintains a small list of names of people who consent to release of information if a relative approaches ACN seeking information.

The Queen Elizabeth freedom of information officers observed and acknowledged that people are very frustrated that the information is piecemeal, and that information cannot easily be accessed. This is made worse by the fact that information is held and may need to be linked across three different sites. The officers were concerned that it appeared they were withholding information, when it was actually extremely difficult for them to understand or know what was there given the present state of storage of records which comprises 400 boxes

of unsorted A.R.T. patient records and 30 large boxes containing individual sheets of paper, only some of which relate to donor conception and are coded in a manner they did not understand. They called for information to be transferred to a central register, sorted, and properly entered into a database. They also stressed that state records guidelines changed recently so that information will only be kept for up to 99 years, and that without laws to preserve the A.R.T. records they may be lost.

Regarding records held at ACN, the General Counsel of Adelaide University noted that as a shell company ACN has no employees, and does not have the resources or expertise to offer support to those seeking information. She has over the past years worked to sort donor conception records, clarify all that they have, to record the number of inquiries they get, as well as maintain the above-mentioned ‘voluntary register’ (list of those who consent to their information being released) (see Appendix 8). If not for her efforts there may not be anyone there to maintain the records. She noted in her written submission to the review:

*The University / ACN strongly supports the establishment of a central donor conception register. Such a register should be established not only to store all information mandated from the date of establishment but also with a view to capturing historical donor conception records, insofar as they exist. In addition to requests from donor-conceived children or donor-recipients about their donor, ACN also receive requests from former gamete donors seeking information about children resulting from their donations. The current dispersion of historical records across ACN, AFC and QEH makes it confusing and difficult for persons seeking access to information. A central donor conception register will enable records to be centralised in one location. Persons will need only lodge an access request with one entity, access requests will be responded to in a consistent manner and the register will be subject to the controls prescribed under the Act.<sup>335</sup>*

In the course of conducting the review I found that there was no malice or lack of effort by the people who currently hold such records. Rather there exists a significant problem

---

<sup>335</sup> Geraldine Yam, submission 50.

that the current people responding to enquiries for information regarding donor conception are not adequately placed to do so, and the current state of the records as unsorted, and difficult at times to decipher. There is also a lack of resourcing and ability to offer adequate support—noting again that at Queen Elizabeth Hospital the people responding to enquiries are freedom of information officers, and at ACN, there are in fact no employees.

Actions and attitudes of devolving responsibility due to a change of company name, and location that have led to significantly detrimental impacts upon donor-conceived people, recipients and donors are also of great shame. Despite arguments that there is no ‘legal’ responsibility for prior records, many of the same people who created and were once responsible for such records still work in the same industry. In addition, as noted above, I found that some donor-conceived people, recipients, and donors have been appealing to respective governments and/or clinics for more than *thirty years* for support. For at least *sixteen years* there has also been a call from various government advisors such as SACRT, the Social Development Committee, and members of parliament, for a donor register to be established. The government has known about the issues for an extended period of time, and rectification of the current situation is well overdue.

The issues faced by those seeking information could begin to be addressed if the Minister required that *all* records regardless of when treatment took place be moved to the central donor conception register for sorting and entry of relevant material onto the register. Such action is also warranted as otherwise the records are at risk of being lost or destroyed.

Note 1: Amendment to the legislation will be required in order for the transfer of such records to the donor conception register. Section 15(8) of the *Assisted Reproductive Treatment Act 1988* (SA) currently limits the provisions within section 15 (which allow for the Minister to establish the donor conception register), to apply only to assisted reproductive treatment that occurred after the commencement of that section in 2010. The Minister would therefore need to amend Section 15(8) to allow for *all* A.R.T. records to be placed on the register *regardless of when A.R.T. treatment occurred*. Following such amendment the Minister should then exercise his power under section 15(6) to issue a notice in writing to require all A.R.T. and donor conception records, wherever they are held, to be transferred to the central donor conception register. This would serve to preserve such records in perpetuity, and to ensure that any further decisions regarding release of information to the donor-conceived people, recipients, and/or donors are not in vain.

Note 2: amendment of s15(8) would simply allow for transfer of such records, pursuant to a notice issued in writing under s15(6)) – it would not in itself lead to access to information. Further action regarding whether such records could be inspected, by whom, and the criteria that would be required to do so, would need to be stipulated in regulations promulgated under section 15(4), which provides ‘the donor conception register may only be inspected in accordance with the regulations’. For discussion of what approach is recommended in this regard see below at 3.6.3.)

**FINDING 28**

Historical A.R.T records held at the University of Adelaide/ACN and the Queen Elizabeth Hospital are not captured by the current A.R.T regulatory framework. Donor-conceived people, donors and recipients seeking to access information in those historical records may not be accorded the rights and processes provided to people who may access information held by registered A.R.T providers. This situation has caused, and continues to cause people distress, and is unacceptable. Rectification of the situation is well overdue.

**FINDING 29**

There is a need to centralise and to sort all past A.R.T. records held by the University of Adelaide/ACN, the Queen Elizabeth Hospital, and Repromed to enter all relevant information on the donor conception register (when established). This will preserve records that otherwise are at risk of loss. It will also make clear what information is, and is not available regarding past donor conception.

### **4.6.2 Past Records: Flinders Fertility**

Issues were also raised during the review in relation to past records of Flinders Fertility (also referred to as Flinders Medical Center)<sup>336</sup>—which also has a long history of providing A.R.T. in South Australia.

As there is no central donor register in South Australia, individuals conceived at, donors who donated at, and recipients who obtained reproductive material through, Flinders

---

<sup>336</sup> Flinders Fertility is sometimes referred to by donor-conceived people/recipients/donors as Flinders Medical Center because that is a location where Flinders Fertility is housed.

Fertility currently need to request information directly from Flinders Fertility. Flinders Fertility is a registered clinic and must observe their obligations under the NHMRC Ethical Guidelines. However, the experiences of some people trying to obtain information about their donors or siblings from this clinic, particularly in relation to donations that occurred prior to the NHMRC Ethical Guidelines, or prior to current South Australian legislation, were described to the review as causing distress and trauma. For example, Kim Buck submitted.

*I learned the truth of my conception during a painful family breakdown when I was 15 years old. The trauma of this discovery was compounded when I contacted Flinders Medical Centre shortly after and was told that all records containing information on the identity of my biological father had been destroyed. There was no offer of support or counselling from the clinic staff, and certainly no acknowledgement of the gravity of this information.<sup>337</sup>*

Ms. Buck's distress was compounded by the subsequent discovery that she and her brother had been conceived using different donors. She explained:

*My brother was also conceived via donor sperm at Flinders in 1989... Records containing information about my brother's sperm donor had in fact been preserved - because he was a different donor altogether. My brother has since met his biological father, some of his extended paternal relatives and several of his additional 17 half-siblings. I have witnessed the beneficial impact of these experiences; learning the truth of his identity, medical history and familial background has provided my brother with a sense of personal stability and wholeness that he had been lacking since learning our dad was not our biological father.<sup>338</sup>*

Another submission by a recipient parent (of a different family), reiterated a similar experience. She said:

---

<sup>337</sup> Kim Buck, submission 41.

<sup>338</sup> Ibid.

*Due to the destruction of donor records, I have been unable to access any information about [my daughter]’s biological father. FMC were able to provide the donor code for [my son] with non-identifying information. I have learned that FMC have provided other recipient parents of donor sperm records from their patient files. However I have not been so fortunate and now have to consider preparing a request to the clinic under the Freedom of Information Act.*<sup>339</sup>

Leonie Waite, submitted to the review on the public YourSAy site:

*I am 33 and donor-conceived, through Flinders Medical Centre, however my donor initially visited a private South Australian clinic that destroyed my records. Because of this, there is no identifying OR non-identifying information available to me. Flinders Medical Centre have given me the only information they have - a donor code (SVM) and the information that I have a half-sister that has not approached them. It is likely that she is unaware of her DC status, and may never find out. I myself have only been aware of being donor-conceived for twelve months. While I have been fairly accepting of this information, it came as a shock to me that my brother was conceived using a different donor... Fortunately for him, information has been recorded and FMC are aware of who his donor is. The problem with this, is that there is no urgency on their part to find [the donor] and request consent to release any information. My brother has eight siblings through this donor and is no closer to finding them.*

*My experience with being donor-conceived is that seeking information has been pointless. The fact that there is no legislation to support our searches, means that we are not entitled to even the small amount of information that FMC do hold. While I do genuinely believe they think they are doing the right thing by protecting donors' privacy, there needs to be recognition of our rights as donor-conceived people. ... I feel that I have lost half of my identity, and have*

---

<sup>339</sup> Confidential, Submission 32.

*gained nothing but questions in return; questions that will remain unanswered without a change to the current Act.*

Leonie was born in 1983-donor code SVM, and her brother in 1985, donor code-D5.

Another family described distress about their experience with Flinders Fertility in which the 10 year old donor-conceived son, conceived in 2004 with sperm donated in 2002, had initially been given the identity of his donor. The donor had subsequently withdrawn his consent to contact or further information release after marrying. The clinic has interpreted the current regime as enabling him to do so because he donated prior to the current NHMRC Ethical Guideline requirements for consent. The family is aware that there are 14 other children, and report having asked Flinders Fertility to contact them, however said that Flinders Fertility had refused.<sup>340</sup>

During the consultations, I asked the donor-coordinator and counsellor to describe the practices of Flinders Fertility regarding past donor information. The donor-coordinator informed the review that in some instances they have accessed the electoral roll to locate past donors, and they have sometimes contacted past donors to ask whether they will consent to release of identifying or non-identifying information. She said that older records were ‘more difficult’ as while technically there may be ways to trace records the ‘tricky part’ is to link the donor-code to the name of the donor as this information was kept separate.

The donor-coordinator said regarding pre-1988 records that they ‘didn’t keep the records of donors’ and that such records had been ‘actively destroyed’. She emphasised there was no legal requirement for them to keep past records from that time. However, she also said there may be some records from 1986-1989 still around. Notably the example of Leonie and her brother above pre-dates both 1988 and 1986, but they have been given their respective donor codes, and it appears further information is available regarding the brother. Such inconsistencies in information create uncertainty for people about whether they are being told the truth, and add to their angst about not being able to access information.

The counsellor, who had worked at the clinic for many years, conveyed that there were limits to what they could do, despite wanting to do more. The donor-coordinator

---

<sup>340</sup> Note both the boy and his mother attended the consumer forum, and the boy described his story and desire to meet his siblings to the forum.

indicated that they could not contact some past donors or siblings directly, as under the current regime, they did not have the authority to do so.

The situation in relation to past records related to donors, recipients, and donor-conceived people associated with Flinders Fertility was found to be confusing and distressing for those people who had made submissions to the review. That some records have been said to have been destroyed has also been traumatic for those seeking information. I found again that there are calls and support for requiring all A.R.T. and donor conception records to be preserved, and to centralise all donor-conception records on a central donor conception register. The staff at Flinders Fertility were supportive of a donor conception register.

**FINDING 30**

The situation in relation to *past* records related to donors, recipients, and donor-conceived people associated with Flinders Fertility is confusing and distressing for some donor-conceived people, recipients, and potentially also donors. There would be benefit in centralising all A.R.T. and donor conception records for their preservation and to enable a system to be established that includes a sensitive and consistent way of addressing enquiries.

**RECOMMENDATION 19**

The Minister should amend section 15(8) of the *Assisted Reproductive Treatment Act 1988* to apply to A.R.T. provided both before and after the commencement of section 15 of the Act.<sup>341</sup>

**RECOMMENDATION 20**

The Minister should, subsequent to amending section 15(8), act pursuant to section 15(6) of the *Assisted Reproductive Treatment Act 1988* to provide notice in writing requiring all record(s) held by any person, establishment, organisation, A.R.T. clinic or otherwise, that relate to A.R.T. and/or donor-conception in South Australia, including (but not limited to) Queen Elizabeth Hospital and Adelaide University/ACN, Repromed, and Flinders Fertility to be transferred to the donor conception register as a matter of priority.

<sup>341</sup> Such amendment would also allow for any such transfer to accord with s18(1)(aa) of the *Assisted Reproductive Treatment Act 1988* (SA) which provides an exception to the confidentiality provisions if disclosure of information is 'required or authorised by the Act'. Here the disclosure would be the transfer by the holders of records to the register.

**RECOMMENDATION 21**

The Minister should pass legislation prohibiting the destruction of any record that relates to donor conception, and the donation of gametes and/or embryos, as a matter of priority.

**4.6.3 Access to Information Concerning Past Donor-Conception**

The above discussion at 4.6.1 and 4.6.2 demonstrates that in South Australia there are donor-conceived people, recipients, and donors, about whom records may exist who wish to access information, but that are currently are unable to do so. Many of these people have publically and privately revealed the effect that being unable to access such information has. This includes the impact secrecy and anonymity has upon their sense of self and or identity, a lack of adequate medical knowledge, and fear and risks of forming consanguineous relationships. All have a desire for openness and honesty, and some have suffered for decades in the face of uncertainty and ‘closed doors’. All call for equality. They see it as unjust that some people may be given access to information, while others may not. This was heightened in families in which one sibling may have access to information and the other may not.

The current situation was described to me as a ‘lottery’ that is decided upon by the time and place of the gamete donation or A.R.T. donor conception. It appeared perverse to some that third-parties could see the information they sought, but were then able to withhold such information from them.

All participants in the review supported the release of information to donor-conceived people regardless of when the donation of gametes or embryo took place, and that such information should be managed by the donor conception register. However there were differences in views as to whether or not consent should be required from the donor or donor-conceived person prior to release of *identifying* information. This is further discussed below.

**SUPPORT FOR ACCESS TO INFORMATION CONCERNING PAST DONOR CONCEPTION**

Strong support by donors, donor-conceived people, recipient parents, support services, academics, and some health service providers working in the field, was shown during the review for the release of identifying information to all donor-conceived people about their

donors regardless of when they were born (or when gametes were donated)—if such information is available.<sup>342</sup> For example, Kimberley Turner, a donor-conceived woman, said in her submission to the review:

*I am writing to you to express my explicit support for all donor-conceived people to have access to know who their genetics parents are, regardless of arbitrary factors such as: year of birth, method of conception and location of conception... These changes will provide equality to people who are currently denied integral medical, ancestral and identity information. As a 31 year old donor conceived adult, lack of this vital information has had a daily impact on myself and my family... and [implications for] my physical and mental health.*

Kim Pace wrote:

*ALL donor-conceived people should be able to request information. As a donor-conceived person I can't tell you how frustrating it is to know that the person I am on the phone to can see my donors name, know everything about him, yet I am not 'allowed' to know this.<sup>343</sup>*

Hayley Smith said:

*Decisions made by consenting adults that result in the creation of a child ...who cannot consent to being conceived using artificial reproductive technology must consider above all else the welfare of that child and the flow on effects to that individual and their own future children. It is not fair or just to expect*

---

<sup>342</sup> Confidential, submission 2; Confidential, submission 5; Peter Liston, submission 9; Kim Pace, submission 19; Caroline Lorbach, submission 27; John Mayger, submission 31; Confidential, submission 32; Lauren Burns, submission 33; Damian Adams, submission 34; Chloe Alworthy, submission 35; Hayley Smith, submission 39; Kim Buck, submission 41; Confidential, submission 47; Marilyn Crawshaw, submission 51; Myfanwy Cummerford, submission 56; VANISH, submission 58; Ross Hunter, submission 60; International Social Services, submission 72; Ian Smith, submission 73; Reece Trevenen, submission 79; Confidential, submission 80; Kimberley Turner, Submission 81. Donor Conception Forum, 18 April 2016; Consumer Forum, 21 April 2016; Donor Consultations, 21 April 2016 –Nathan; Jarrod; Corey; and Gerard; Jane Kennelly, YourSAy comment, 8 February 2016; Peter Kennelly, YourSAy Comment, 10 February 2016.

<sup>343</sup> Kim Pace, submission 19.

*donor-conceived people to forgo medical history and information about who they are genetically related (information which is vital to their long term wellbeing) simply because a donor or recipient parent decided that anonymity was an acceptable scenario. Donors willingly entered an arrangement in which they full well knew that children would be created. Removing anonymity will not place the burden of parenthood onto donors, but it would remove the burden of genetic bewilderment from humans who had no say in a contract that was signed relating to their identity.*<sup>344</sup>

Peter Kennelly, a father of a donor-conceived person, wrote:

*I support donor conceived people in having access to information regardless of when they were conceived. I feel basic human rights are being violated and no donor conceived person can feel complete not knowing who they truly are and where they come from.*<sup>345</sup>

The Australian and New Zealand Infertility Counsellor's Association (ANZICA) submitted:

*ANZICA believe that at present within SA the rights of donor-conceived individuals to access information regarding their biological and genetic heritage is largely dependent upon where and when their parent had treatment. It is our strong belief that this inequality of access once again contravenes the principle of paramountcy of the welfare of the child.*<sup>346</sup>

The Office for women submitted:

*It is ...important to ensure that adults born by ART are able to access information about the process of their inception including information about*

---

<sup>344</sup> Hayley Smith, submission 39.

<sup>345</sup> Peter Kennelly, YourSAy comment, 10 February 2016.

<sup>346</sup> ANZICA, submission 82.

*donors. The paramountcy principle must extend beyond the inception of the child into their adult lives with regard to information about the ART process.*<sup>347</sup>

The International Social Services said:

*ISS Australia advocates for the right of the donor-conceived person to have access to this information, and that this right to information should be retrospective. If the welfare of any child to be born as a consequence of the provision of A.R.T. is to be treated as being of paramount...the need for people to have access to their records and information held about their biological history, should be regarded as a necessity.*

Donors were also supportive of ‘retrospective release’ of information that in the past was considered ‘anonymous’. Some supported the release of identifying information regardless of past ‘guarantees’ of anonymity or confidentiality. For example, one donor told me that he was ‘fully supportive of retrospective release regardless of consent’. He said ‘we have to deal with our choices and follow through, it was a mistake in the past to make people anonymous, we can’t stick our heads in the sand, we need to fix those mistakes’.<sup>348</sup>

Another donor said that he was very comfortable with all information being released, including that of past donations that were meant to be anonymous. He qualified this however by saying he was keen to know there would be no financial obligations placed upon him, and that everyone should be helped to understand why this is important.<sup>349</sup>

Another donor said that ‘it is tricky if a person donated in the past. I believe that the donor-conceived person has a right to all information regardless of whatever was promised before, they deserve to know, but donors need support if this is going to happen too.’<sup>350</sup>

Other submissions, while supportive of release of information to all donor-conceived people, said that retrospective release of *identifying* information should only occur with the

---

<sup>347</sup> Office of Women, submission 54.

<sup>348</sup> Meetings with donors held April 2016.

<sup>349</sup> Ibid.

<sup>350</sup> Ibid.

consent of the donor.<sup>351</sup> These latter views were generally underpinned by concern about donors who may have donated under the belief that their identity would never be revealed, and a view that their privacy should be protected. For example, Kylie Dempsey submitted:

*Whilst I believe it was wrong to provide anonymity for donors, I do not believe this should be corrected by releasing an anonymous donor's information without their consent. Instead, I think the information should be included in the registry, if available, [and where] there are anonymous donors that can be identified and contacted, they should be advised of the register and asked to make their information available for the benefit of the child.*<sup>352</sup>

Dr. Kelly Anne, wrote:

*I think all information other than the name is safer for the donor, and that the name is only released if the donor consents to that change in anonymity. All medical records and the personality profile without the patient/donors name should definitely be accessible to the DC person.*<sup>353</sup>

The Council for the Care of Children was of the view that:

*The right to access information from a donor conception register should apply from a point in time, not retrospectively, except with the specific and informed consent of a donor (who donated prior to the introduction of the NHMRC guidelines on the basis that it was done on a confidential basis).*<sup>354</sup>

Mark Dodd in his written submission and face-to-face meeting with me emphasised:

---

<sup>351</sup> Mark Dodd, submission 26 and personal consultation meeting; Fertility SA, submission 49; Council of the Care of Children, submission 65; Kylie Dempsey, submission 69; Confidential, submission 68.

<sup>352</sup> Kylie Dempsey, submission 69.

<sup>353</sup> Dr. Kelly Anne, submission 55.

<sup>354</sup> Council of the Care of Children, submission 65.

*It is important that the privacy of individuals be respected, and that previous agreements be respected. Although donor-conceived people may wish to find out information from a time when the laws were different, there should not be retrospective changes to the laws. As a sperm donor, I chose to provide more information to the IVF clinic than they requested, since I believe in the importance of donor conceived children and their parents having access to information. In fact, the IVF clinic did not usually seek photos of their donors, but I requested that mine be provided to potential parents. In the best interests of all parties involved I would want to share any appropriate information. However, I would certainly not appreciate a law retrospectively changing the arrangement that I had entered into.<sup>355</sup>*

#### **BALANCING ‘COMPETING INTERESTS’ CONCERNING ‘RIGHTS TO ACCESS INFORMATION’ AND ‘RIGHTS TO PRIVACY’**

While the direct juxtaposition of donor versus donor-conceived people’s interest is often not correct, as it fails to take into account that many donors also call for information release and an end to anonymity, it is nevertheless very important to consider how to balance respective interests of parties when interests do compete in relation to accessing identifying information and maintaining privacy. Two further questions thus arose. First, whether changes to the law that relate to past practices providing for ‘retrospective release of information’ are possible, and second, how to ensure any such changes are fair, just and reasonable. This section therefore gives further consideration to these questions.<sup>356</sup>

---

<sup>355</sup> Mark Dodd, submission 26.

<sup>356</sup> In the interests of openness and transparency I note again that I have spent much of the past decade researching and writing about such issues, and have drawn on such work for the purposes of this report. See for example, S. Allan, ‘Psychosocial, Ethical and Legal Arguments for and Against the Retrospective Release of Information about Donors to Donor Conceived Individuals in Australia’ (2011) 19(1) *Journal of Law and Medicine* 354; S. Allan, ‘Donor conception, Secrecy, and the Search for Information’ (2012) 19(4) *Journal of Law and Medicine* 631; S. Allan, ‘Donor Identification: Victoria gives Rights to all Donor-Conceived People’ 98 *Family Matters*, November 2016S; Allan (2017), above n 259. I have also referred to other literature that has considered relevant issues, including but not limited to D. Adams and C. Lorbach, ‘Accessing Donor conception Information in Australia: A Call for Retrospective Access’ (2012) in 19(4) *Journal of Law and Medicine* 704; Naomi Cahn, ‘Legal parent versus biological parent: The impact of disclosure’ (2012) 19(4) *Journal of Law and Medicine* 790; R. Chisholm ‘Information rights and donor conception: Lessons from adoption?’ (2012) 19(4) *JLM* 722; The Victorian Law Reform Committee Report, *Access by Donor-conceived people to Information about their Donors* (2012) (available at <http://www.parliament.vic.gov.au/57th-parliament/lawreform/article/1468>); Victorian Government, *The Right to Know Your Identity: Giving Donor-*

Changes to the law that relate to past as well as present practices

In general, laws in all jurisdictions operate from the day they were enacted onwards, that is, prospectively. This is seen as particularly important in criminal law contexts as it would be unjust to expose people to criminal sanctions and penalties for behavior already committed that was legal at the time.<sup>357</sup> In addition, a retrospective law that interferes with judicial functioning by altering the laws of evidence or removing judicial discretion regarding sentencing of certain offenders, may be unconstitutional.<sup>358</sup> Occasionally however, laws are acceptably passed that relate to actions undertaken in the past. In Australia, there has been judicial recognition of the power to pass ‘retrospective’ legislation<sup>359</sup> that applies to situations where no law existed at the time, or the prior law is seen to give rise to an injustice that needs to be corrected.<sup>360</sup> This is so, even if such laws ‘might be considered to work some injustice to one party, but are clearly required to rectify a manifest injustice to others’.<sup>361</sup>

In South Australia, an example of a change to the law that had retrospective effect in the context of A.R.T. includes rules relating to legal parentage of children born as a result of a fertilisation procedure. Laws were enacted over time to recognise the husband, or person

---

*Conceived People the Right to Access Information Identifying their Donor* (Discussion Paper, Victorian Government, 29 June 2015). In addition I refer the Minister to the Victorian parliamentary consideration of laws that from 17 March 2017 will implement a contact preference system in that state. See Parliamentary Debates (Hansard) Legislative Assembly Fifty-Eighth Parliament First Session Book 2 23, 24 And 25 February 2016, available at [http://www.parliament.vic.gov.au/images/stories/daily-hansard/Assembly\\_2016/Assembly\\_Weekly\\_Feb-Jun\\_2016\\_Book\\_2.pdf](http://www.parliament.vic.gov.au/images/stories/daily-hansard/Assembly_2016/Assembly_Weekly_Feb-Jun_2016_Book_2.pdf).

<sup>357</sup> *Director of Public Prosecutions (Cth) v Keating* (2013) 248 CLR 459, 479 [48] (French CJ, Hayne, Crennan, Kiefel, Bell, Keane JJ). Many jurisdictions therefore have express provisions in their Constitutions or law that prohibit ‘ex post facto’ criminal laws or penalties: See for example, Brazilian Constitution, Art 5 Sect XL; Canadian Charter of Rights and Freedoms, s11(g); French Penal Code, Art 112-1; Constitution of Ireland, Art. 15.5.1; *Wetboek van Strafrecht (Criminal Law)* (Netherlands), Art 1; Portuguese Constitution, Art 29. In Australia the general presumption against ex post facto criminal laws is found at common law.

<sup>358</sup> *Liyanage v The Queen* [1967] AC 259; approved in *Australian Building Construction Employees’ and Builders Labourers’ Federation v Commonwealth* (1986) 161 CLR 88, 96

<sup>359</sup> See *R v Kidman* (1915) 20 CLR 425 per Isaacs, Higgins, Gavan Duffy, Powers and Rich JJ (Griffith CJ dissenting); *Millner v Raith* (1942) 66 CLR 1; *Polyukhovich v Commonwealth* (1991) 172 CLR 501; and *Tuitupou v Minister for Immigration and Multicultural Affairs* (2000) 60 ALD 361. Noting that where such laws deprive someone of a property right they must do so ‘on just terms’. See *Georgiadis v Australian and Overseas Telecommunications Corp* (1994) 179 CLR 297; Australian Constitution Act 1901 (Cth), s 51(xxxi).

<sup>360</sup> Pearce DC and Geddes RS, *Statutory Interpretation in Australia* (6th ed, Butterworths, Sydney 2006) p 314.

<sup>361</sup> *Doro v Victorian Railways Commissioners* [1960] VR 84, Adam J at 86. In the United Kingdom a number of retrospective Acts have been passed on the basis of Parliamentary sovereignty: See for example, *Statutory Instruments (Production and Sale) Act 1996*; *Caravans (Standard Community Charge and Rating) Act 1991*; *Domestic Rates Etc (Scotland) Act 1987*; *The Scotland Act 2012*; *The Wireless Telegraphy (Validation of Charges) Act 1954*. For discussion see Oonagh Gay, *Retrospective legislation Standard Note: SN/PC/06454* Last updated: 14 June 2013 (Section Parliament and Constitution Centre).

with whom a woman is in a domestic relationship with, as a legal parent of any child born as a result of a fertilisation procedure,<sup>362</sup> with provision that they apply (a) in respect of a fertilisation procedure carried out, and of a child born, before or after the commencement of the *Reproductive Technology (Clinical Practices) (Miscellaneous) Amendment Act 2009* either within or outside the State.<sup>363</sup>

The passing of law regarding donor conception that occurred before or after the commencement of section 15 of the *Assisted Reproductive Treatment Act 1988* is thus possible. In regard to the release of identifying information, the argument in favour of doing so is that it would rectify the injustice that exists in denying access to such information to people based upon time and place of previous gamete donation and their conception. Any such action would however need to consider how to balance the competing interests of those gamete donors who donated under the belief they would remain anonymous, and when laws and/or practices required that such information only be released with their consent. In considering how this might be done, it is useful to consider the analogous situation of the opening of adoption records to allow access to identifying information.

#### *The Analogous Situation of Adoption*

Throughout much of the 20th century, many Western countries had legislation intended to prevent adoptees and adoptive families from knowing the identities of birth parents and vice versa.<sup>364</sup> Then after a decline in the social stigma surrounding adoption and increased understanding of the impacts denial of information was having upon adoptees, a number of jurisdictions changed laws with retrospective effect to allow for the release of formerly ‘sealed’ birth records. The changes to the laws were however subject to some limitations in some jurisdictions, such as contact or information vetoes or preference forms which were intended to balance the interests of parties involved.<sup>365</sup> Information vetoes allowed people to ‘veto’ the release of identifying information, while the contact veto/preference system operated to protect people from unwanted contact by another person, while still allowing the release of identifying information. Such systems were

---

<sup>362</sup> See Part 2A of the *Family Relationships Act 1975* (SA).

<sup>363</sup> *Ibid*, section 10B.

<sup>364</sup> Allan, above n 259.

<sup>365</sup> *Ibid*.

implemented in some states of Australia, the United Kingdom, and some states in the United States over the past thirty years.

Notably, over time the veto system, which allowed relinquishing parents or adopted children to ‘opt out’ of the retrospective system, has slowly been removed across jurisdictions. For example, in 2010 Queensland enacted the *Adoption Act 2009* (Qld), which retrospectively removed the option of placing an information veto on identifying information that related to adoptions that occurred prior to 1991. The then acting Child Safety Minister, Karen Struthers said at the time:

*No longer will we have the most restrictive adoption laws in the country...Under the new Act, which will come into force on February 1, 2010, adopted people and birth parents will have the right to identifying information regardless of when the adoption took place. The new laws balance people's right to information about their birth parents or son or daughter who was adopted, with the right of others to maintain their privacy. Currently more than 3000 Queenslanders affected by an adoption that occurred before 1991 are prevented from obtaining identifying information about their birth parents or son or daughter who was adopted. The new Act will give these people the right to access information about their own identity or that of a son or daughter for the first time. The new laws will make it possible for people to access identifying information about themselves and their birth parents but still requires them to respect another person's privacy if they do not wish to be contacted.<sup>366</sup>*

The explanatory memorandum of the Queensland bill details that peoples’ privacy would be protected via enabling contact vetoes, and placing fines for breach of such vetoes. It states that ‘retrospective removal of their rights must be balanced with the benefits that arise by allowing other parties to those adoptions access to information about their identity, family and heritage. The change in the law also ensures that parties to adoptions are treated equally,

---

<sup>366</sup> Queensland Government, Department of Child Safety statement reported at <http://www.mysunshinecoast.com.au/articles/article-display/new-adoption-laws-for-queensland,16035> accessed 8 January 2017.

regardless of when the adoption occurred, as there is no longer any entitlement to object to the release of identifying information.<sup>367</sup>

Similarly, Western Australia previously allowed for both contact and information vetoes, however information vetoes were subsequently removed. There, a person seeking access to information where a contact veto is in place, is required to be interviewed by an approved counsellor and to sign an undertaking not to contact the person who has placed the contact veto. Breach of the undertaking imposes penalties of \$10,000 and 12 months in prison. The purpose of counselling in these instances is to ensure that the rights of all involved parties are fully understood and that people are made aware of some of the issues which may arise in the search and reunion process.<sup>368</sup>

In 1992 the NSW Law Reform Commission detailed the reasoning for retrospective release of information about adoptees in that state, reiterating there is no legal principle preventing legislation from having retrospective operation.<sup>369</sup> They recognised that the law relating to information about adoption needed to deal fairly with many different people and situations, and that adoptions had taken place over a long period of time (from the 1920s-1970s) during which there were major changes to adoption law and practice. They noted:

*The degree of secrecy that prevailed at the time of the adoption, the amount of information supplied to the parties, and the information available from existing records, all vary considerably according to the period in which the adoption took place, the agency which arranged the adoption, and other factors. It is a difficult task to design a law that will deal appropriately with all the people and situations involved in this complex picture.<sup>370</sup>*

In recommending retrospective laws in NSW that allowed identifying information release to adoptees the NSW Law Reform Commission concluded:

---

<sup>367</sup> Adoption Bill 2009 (Qld), Explanatory Memorandum, pp 19-20.

<http://www.legislation.qld.gov.au/Bills/53PDF/2009/AdoptionB09Exp.pdf> accessed 8 January 2017.

<sup>368</sup> The Australian Institute of Health and Welfare, *Adoptions Australia 2006-2007*, (2008).

<sup>369</sup> New South Wales Law Reform Commission, *Review of the Adoption Information Act 1990*, Issues Paper 7 (1992), Chapter 3, [3.14].

<sup>370</sup> *Ibid*, Chapter 3.

*[T]he view that prevailed was that the law should enable adopted persons and birth parents to have the right to information, even though this did mean a change from the position as it was when the adoption order was made. The interests of those who felt threatened by the new law were acknowledged by a number of measures, notably the contact veto system.<sup>371</sup>*

In South Australia at the time of writing this report the option to place an information veto in relation to past adoptions remained. However, in a review of the South Australian *Adoption Act 1988* conducted in 2014-2015, it was found (amongst other things) that adoption information vetoes should be abolished and phased out over 5 years. The review further recommended that contact vetoes not be introduced.<sup>372</sup> In September 2016, the South Australian Government introduced into Parliament the Adoption (Review) Amendment Bill 2016, which if passed will enshrine the recommendations into law. A person whose veto expires after the 5 year transition period may make a ‘Statement of Wishes’ about contact with the other party. This statement will be held into the future by Families SA and by the Registrar of Births, Deaths and Marriages.

The Victorian Adoption Network for Information and Self Help Inc. (VANISH) note that despite the initial anxiety surrounding retrospective release of identifying information to adoptees it is now well accepted that it is normal for adopted people to want information about their birth parents, and information release has proceeded well.<sup>373</sup> Consideration of what has occurred in other jurisdictions also highlights this point.

### *United Kingdom*

Since 1930 in Scotland, adopted persons aged seventeen and older have had the right to access to their adoption records and original birth records.<sup>374</sup> In England and Wales, laws have been adopted and changed over more than 40 years regarding disclosure and contact.<sup>375</sup>

---

<sup>371</sup> Ibid.

<sup>372</sup> Lorna Hallahan, *Adoption Act 1988 (SA) Review* (2015), pp 46-49 available at [http://assets.yoursay.sa.gov.au/production/2016/03/04/03/44/12/ac7e1986-1021-4c3f-913f-a029586f8bff/Adoption\\_Act\\_Review\\_Report\\_.pdf](http://assets.yoursay.sa.gov.au/production/2016/03/04/03/44/12/ac7e1986-1021-4c3f-913f-a029586f8bff/Adoption_Act_Review_Report_.pdf) accessed 8 January 2017.

<sup>373</sup> Commonwealth, Senate Committee Hansard, 3 November 2010, 65-70, Mr. Cole (from VANISH).

<sup>374</sup> *The Scottish Adoption Act 1930* (UK).

<sup>375</sup> See for example, *Children Act 1989* (UK); *Adoption and Children Act 2002* (UK)

Debates followed the same course as has been seen in Australia, including that there was support for access to past records, but opponents worried that opening records would violate promises to birth mothers that children would not be able to trace them, and lead to unwanted contact or people full of resentment ‘landing’ on the mother’s doorstep. Compulsory counselling prior to being able to access birth records was thus required.<sup>376</sup>

Approximately 225,000 people (55 percent of 550,000 people adopted in the UK) have now sought genealogical information and/or established contact with a birth relative. Carp notes, *‘no cases have been reported of blackmail or vindictiveness being displayed on the part of adopted people... Studies have demonstrated that searches for birth family members by adopted adults have been highly successful’*. He notes further that *ninety-seven percent of the searchers state that meeting their birth relatives made no difference in their feelings for their adoptive parents.*<sup>377</sup>

#### *United States*

In early 1980s in the United States voluntary mutual consent adoption registries and intermediary services were established in a number of states to assist adoptees searching for information and/or contact. However complaints that such registries and intermediaries were ‘cumbersome, expensive, and ineffective’ led to calls that adoptees deserved equal rights to information.

In response, in 1998 Oregon, passed laws that enabled access to information, subject to a contact preference form.<sup>378</sup> Over the next five years 8,190 adopted adults accessed their original birth certificates, during which time only 503 birth parents filed contact preference forms. By 2006, 9,129 birth certificates had been issued, with the number of birth parents attaching requests for ‘no contact’ being eighty-three.<sup>379</sup> By May 2016 there had been 11,733 records issued and 691 contact preference forms submitted by birth parents: 568 asked for contact with the adoptee, 37 asked for contact through an intermediary, and 86 asked for no

---

<sup>376</sup> E. Wayne Carp, ‘Does Opening Adoption Records Have an Adverse Social Impact? Some Lessons from the U.S., Great Britain, and Australia, 1953–2007’ (2007) 10(3-4) *Adoption Quarterly*, 29-52.

<sup>377</sup> *Ibid*, p. 43.

<sup>378</sup> Carp, above n 376.

<sup>379</sup> *Ibid*, p 38.

contact.<sup>380</sup> There have been no reported adverse events or harm reported to have occurred to any party, including birth parents.<sup>381</sup>

Many other states also have laws that allow access to identifying information, with or without contact vetoes. A number have seen progressive removal of such vetoes. A summary of various state practices follows:

- Alabama, uses contact preference forms;
- Alaska provides the original birth certificate (OBC), no contact vetos/preferences;
- Colorado, access to records and birth certificates has been available for some time but different rules applied dependent on when the adoption took place. Amendments to the law in 2014 eliminated different standards of access. The law also removed prior ability to place a contact preference as it was no longer seen as necessary;
- Kansas, adoption records were never sealed, and adoptees could always access information once they turned 18.
- Maine, access legislation was enacted on January 1, 2009, allowing adults, age 18 and older, to get their OBC, with more than 1,280 OBCs having now been released. Of the limited number of birth parents completing Contact Preference Forms, only eight have requested no contact;
- New Hampshire, since June 2005, OBC have been available to adoptees age 18 and older. As of January 2012, over 1,572 OBCs were released. Only 12 birth parents have indicated they do not want contact. No harm has been reported.
- Rhode Island, since 1 July, 2011 adult adoptees 25 years of age or older may obtain a non-certified copy of their original birth certificate. Since July 2, 2012, 759 adoptees have received their OBC with 10 birth mothers indicating preference for no contact.<sup>382</sup>

I could find no official reports in the above jurisdictions of birth mothers' lives having been destroyed, as had been repeatedly predicted by those who opposed the release of identifying information. In the years that have followed such release there have been no reports of

---

<sup>380</sup> Oregon Health Authority, Measure 58 History, <http://public.health.oregon.gov/BirthDeathCertificates/GetVitalRecords/Pages/58update.aspx#05312010> accessed 8 January 2017.

<sup>381</sup> American Adoption Congress, State Legislation Website, <http://www.americanadoptioncongress.org/state.php#OR> accessed 16 March 2016.

<sup>382</sup> S. Allan (2017) above n 259.

privacy violations, nor the break-up of families as a consequence of unwanted contact. Very few people placed ‘no contact’ preferences on their form.<sup>383</sup>

*Applying the analogy to donor conception*

The analogy between adoptees and donor-conceived people can be drawn in relation to their search for information about their biological heritage.<sup>384</sup> In particular it has been shown that donor conceived and adopted people may share common feelings concerning being denied information about their status, being denied access to information about their biological parent(s) and or siblings, and about the secrecy that has shrouded such practices.<sup>385</sup>

Like adoptees, an increased call for identifying and non-identifying information has occurred globally as donor-conceived people have grown. Many have called for similar treatment as that accorded adoptees, in which records have been opened with or without an option for a contact veto/preference to ‘balance rights’. In the Senate Committee Inquiry into donor conception practices in 2010, Mr. Egan of Family Voice Australia commented:

*if legislation establishing a national register was retrospective, contact vetoes could be put in place the way they are in adoption cases. No-one wants to force themselves on someone else, but they do have a right to know where they come from, who they are, who their relatives are and so on. That should include the ability to track donor siblings so you know who your brothers and sisters are. That seems to me a fundamental human right.*<sup>386</sup>

I have also reached the conclusion, and advocated, that contact vetoes or preference forms are a way to *balance competing interests* when they exist, while allowing for release of information to all donor-conceived people who seek it.<sup>387</sup> The donor’s privacy is protected by

---

<sup>383</sup> Ibid.

<sup>384</sup> R. Chisholm, ‘Information rights and donor conception: Lessons from adoption?’ (2012) 19(4) JLM 722.

<sup>385</sup> A. Turner and A. Coyle ‘What does it mean to be Donor Offspring? The Identity Experience of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy’ (2000) 15(9) Human Reproduction, 2041.

<sup>386</sup> Commonwealth, Senate Committee Hansard, 29 October 2010, pp 19-20, Mr. Egan (Family Voice Australia).

<sup>387</sup> See for example, S. Allan (2011) above n 356.

allowing him/her to control the intimate sphere of their daily lives from intrusion.<sup>388</sup> Simultaneously, the donor-conceived person's privacy<sup>389</sup> is respected by allowing access to information necessary to uncover the truth about an important aspect of her or his personal identity. However, there is also a compromise. If the donor refuses contact via a contact veto/preference statement, then the donor-conceived person's 'rights' do not go so far as to be able to act to establish a relationship with the donor.<sup>390</sup>

Although in the adoption context such veto systems have been removed over time, donor conception differs to adoption due to the potential for high numbers of offspring and the number of families. For some people who donated gametes in the past the thought of contact with all such people may be overwhelming. The right to control whether, and if so to what extent, such contact occurs may serve to ensure a person feels in control and that they are supported in light of changes to the law. This is reason to differ from the South Australian adoption review in its recommendation against implementing a contact veto system in that context. Over time, it may be found that such contact vetoes/preference statements are also not necessary in the donor-conception space, but they may in the first instance serve well.

Here it is useful to consider approaches that have been taken in other jurisdictions.

### Victoria

In 2012, the Victorian Law Reform Committee inquiry into access to information by donor-conceived people in Australia, recommended release of information to all donor-conceived people pursuant to the contact veto system. The Chair, Mr. Clem Newton Brown said:

*While the release of identifying information to donor-conceived people may potentially cause discomfort and distress to donors (although this will not always be the case), it is certain that donor-conceived people are actually*

---

<sup>388</sup> As noted by Lord Mustell in *R v Broadcasting Standards Commission; Ex parte British Broadcasting Corp* [2001] QB 885 at [48].

<sup>389</sup> In the context of 'rights' in the UK, a donor-conceived person's right to privacy has been recognised as a 'right to obtain information about a biological parent who will inevitably have contributed to the identity of his child' (*Rose v Secretary of State for Health and Human Fertilisation and Embryology Authority* [2002] EWHC 1593 (Admin)).

<sup>390</sup> In European Court of Human Rights this was recognised in the early decision of *X v Iceland (Application 6825/74)* (1976) 5 DR 86 at 87 to be part of the concept of 'respect for private life' now protected by Art 8 of the *European Convention on Human Rights*.

*suffering from their lack of knowledge about donors. Although debates about the consequences of releasing identifying information often focus on the suffering that donors may experience, the fact is that many donor-conceived people are already suffering, in some cases quite profoundly, from not having access to this information.*<sup>391</sup>

An interim measure was adopted in Victoria on 29 June 2015 to extend the law that allowed those conceived with gametes donated in the state before 31 December 1997 (the date after which consent to release was compulsory in Victoria) to those conceived prior to 1988. This enabled all such donor-conceived people to access identifying information *if the donor gave consent*.<sup>392</sup>

The two-tiered system, however, retained differential treatment based upon whether a person was conceived with sperm donated pre- or post-1998. A Bill to rectify this was introduced into the Legislative Assembly in late November 2015,<sup>393</sup> where it was passed with a free vote of 56 to 27. It moved to the Legislative Council on 23 February 2016, and again was shown bipartisan support. Emphasis in the passage of the bill was given to honouring the guiding principles of the Victorian ART Act, that *“the welfare and interests of persons born or to be born as a result of treatment procedures are paramount”* and that *“children born as the result of the use of donated gametes have a right to information about their genetic parents.”*<sup>394</sup> The Victorian contact veto/preference system will provide access to information by all donor-conceived people about their donors regardless of when donation of gametes took place.<sup>395</sup> The Victorian laws commence in March 2017. Breach of a contact preference will result in a significant fine (of approximately \$7000).

#### Other jurisdictions that recognise a right to access information by all donor-conceived people

Other jurisdictions that have recognised a right to access identifying information by all donor-conceived people include Switzerland, which was the first in the world to enact laws

<sup>391</sup> Victorian Law Reform Committee, *Inquiry into Access by Donor-conceived people to Information about the Donors* (March 2012) p 73 (emphasis added).

<sup>392</sup> *Assisted Reproductive Treatment Act 2008* (Vic) s 59.

<sup>393</sup> *Assisted Reproductive Treatment Amendment Bill 2015* (Vic.)

<sup>394</sup> *Assisted Reproductive Treatment Act 2008* (Vic) s 5

<sup>395</sup> It also makes provision for recipients, siblings, and donors.

that enabled this; and Germany. Neither has a donor conception register, and neither implements a ‘contact veto/preference’ system. Brief consideration of the models follow.

### *Switzerland*

In 1992, Switzerland incorporated into its constitution a guarantee to access to data concerning lineage for children born as a result of donor conception. The *Swiss Federal Act on Medically Assisted Procreation 1998*, which came into effect in 2001, further provides for access to information by all donor-conceived people at age eighteen, or earlier where there is a legitimate purpose in obtaining it. The access is provided for those conceived with sperm donated both before<sup>396</sup> and after<sup>397</sup> the Act – with the source of information being based at clinics in the former case, and on a government-established register in the latter. The system implemented in Switzerland supports retrospective release for those conceived prior to the date of the law’s enactment. However, in practice, access to information related to past donations proves difficult. Some years ago the Swiss authority reported to me that:

*treatments before 1.1.2001 cannot be traced as documents were destroyed after 10 years. Attempts from individuals, which have been conceived before the new law came into force (FMedG 2001), to get information have ended negatively. It seems to be impossible to find the donors before that time.*<sup>398</sup>

### *Germany*

In Germany a right to know about genetic heritage is supported constitutionally. A number of judgments have supported this right. For example, in February 2013, the Higher Regional Court in Hamm, Germany, granted a 21-year-old donor-conceived woman the right to access the identity of her donor.<sup>399</sup> The Court ruled her interest in ascertaining her

---

<sup>396</sup> *Federal Act on Medically Assisted Procreation 1998* (Switzerland), Art. 41 provides that if sperm cells were donated before, but used after, the commencement of the Act, the information release provisions still apply. In addition, in all other cases, if a donor-conceived person makes a direct inquiry to the clinic physicians who used assisted reproductive techniques using donated reproductive cells must provide information, with the provisions of the Act applying mutatis mutandis regardless of when such cells were donated.

<sup>397</sup> *Federal Act on Medically Assisted Procreation 1998* (Switzerland), Art. 27.

<sup>398</sup> Personal communication to Sonia Allan via email, 2013.

<sup>399</sup> Oberlandesgericht Hamm, I-14 U 7/12. Available at [http://www.justiz.nrw.de/nrwe/olgs/hamm/j2013/I\\_14\\_U\\_7\\_12\\_Urteil\\_20130206.html](http://www.justiz.nrw.de/nrwe/olgs/hamm/j2013/I_14_U_7_12_Urteil_20130206.html) accessed 16 March 2016.

parentage was higher than the interests regarding nondisclosure of donor information; and that an agreement between a clinic and rearing parents to maintain donor anonymity was an illegal contract as it was to the detriment of the offspring. The decision was described as improving the legal position of children of sperm donors, but also of doctors, as it meant they could not be held liable for breaking doctor-patient confidentiality. Flowing from this decision, it was considered that children over the age of 16 could access identifying information.

In January 2015, the German Supreme Court (Bundesgerichtshof) confirmed that all donor-conceived children have a right of access to information, regardless of age, and that the right trumps any right the donor has to privacy.<sup>400</sup> In that case, two sisters, aged 12 and 17, had been refused access by a clinic to the donor's identity on the basis that the girls' legal parents had initially waived the sisters' right to know who the donor was.<sup>401</sup> The Court held that the right of the sperm donor to informational self-determination,<sup>402</sup> was outweighed by the right of the child to know his/her heritage, noting the donor had willingly participated in the procreation of the child and had to accept a certain social and ethical responsibility towards it.<sup>403</sup> The right of the child to know his or her heritage was seen to also surpass the right of the doctor not to disclose information about patients as part of his/her professional freedom.<sup>404</sup> The Court found no basis to support an age requirement, finding that a child would have a desire to know his/ her parents independent of age, and that naturally such a desire does not only emerge when a child turns 16.<sup>405</sup>

The Supreme Court judgment was applied again in October 2016 in Hanover in a case in which a clinic again argued it must uphold the donor's right to privacy as the donor had agreed his name would remain undisclosed. The Hanover Court ruled that a child's right to know about where they come from weighed more significantly than a sperm donor's right to determine how their personal information is shared.

---

<sup>400</sup> BGH, Urteil vom 28. Januar 2015 - XII ZR 201/13.

<sup>401</sup>The Claim was seen to exist pursuant to Arts. 1(1) and 2(1) of the German Constitution, and arose as a civil claim between two private individuals under the German Civil Code § 242 existed. Child rights international network, Supreme Court of Germany decision XII ZR 201/13, summary, available at <https://www.crin.org/en/library/legal-database/supreme-court-germany-decision-xii-zr-201/13>, accessed 8 January 2017.

<sup>402</sup> Also contained in 1(1) and 2(1) of the German Constitution.

<sup>403</sup> Ibid.

<sup>404</sup> Derived from Article 12(1) of the German Constitution.

<sup>405</sup> Ibid.

In practice however, those who seek information in Germany have a very difficult time. Information is held at clinics, and they often do not wish to provide access to such information. While the German judgments uphold the right of donor-conceived people to information there are calls for legislative reform for a central register that holds all data about donor insemination, and for a comprehensive legal framework, to ensure the rights of donor-conceived people.<sup>406</sup> This would avoid them having to go to Court to seek orders to enforce their rights.

Submissions to the review

A number of the submissions that supported the release of identifying information to all donor-conceived people regardless of when the sperm with which they were conceived was donated, also explicitly supported that a donor/donor-conceived person be able to lodge a contact veto/preference statement.<sup>407</sup> These are illustrated by the submissions of Caroline Lorbach who said:

*While donor-conceived people should have the right to access identifying information about their donor a veto system akin to that used in adoption should be available to prevent unwanted contact between parties;*<sup>408</sup>

and Ross Hunter, who submitted:

*My hope is that [South Australia] will adopt the recent reforms made in Victoria in granting [donor-conceived] people access to identifying information about their donors, with contact preferences in place to protect both parties. Anything less than this suggests that DC people, as well as sperm donation in general, is a secret that needs to be kept. This is damaging and demeaning to both parties.*<sup>409</sup>

---

<sup>406</sup> Ibid.

<sup>407</sup> Lauren Burns, submission 33; Damian Adams, submission 34; Chloe Allworthy, submission 35; Kim Buck, submission 41; VANISH, submission 58; Ross Hunter, submission 60; International Social Services, submission 72; Reece Trevenen, submission 79; Kimberley Turner, submission 81;

<sup>408</sup> Caroline Lorbach, submission 27.

<sup>409</sup> Ross Hunter, submission 60.

**FINDING 31**

The contact veto/preference system, if implemented properly, with sensitivity to each person's needs, rights and interests, would enable release of information to donor-conceived people about their donors, while allowing for a donor to lodge a contact veto/preference that stipulates the level of contact he/she is willing to have (be it none; via email, letter, meeting, or otherwise). It is a lawful, and respectful way of allowing the release of identifying information concerning past donor conceptions, that requires a compromise by each party when rights to information and rights to privacy compete. In this regard, the approach is intended to *balance* competing interests when they exist, by allowing both parties some level of recognition and respect for their rights while not completely favouring either.

**THE 'CONSENT FIRST' APPROACH**

The alternative approach would be to allow for release of *identifying* information only with the consent of the donor. As discussed above, the review also received a number of submissions that supported the consent first approach.<sup>410</sup>

Assuming records are centralised upon the donor conception register, one option would be to only allow release of *identifying* information if the donor comes forward to register consent to such release on the donor conception register. This basically mirrors the current situation in South Australia which allows access to identifying information by all donor-conceived people provided there is consent by the donor. The only difference would be that records would be centralised, and preserved upon the donor conception register. It would require no other action than moving past records to the donor conception register.

Another option would be to transfer records to the register, and then to *actively contact* donors to ask them whether they consent to the release of identifying information. This approach was adopted as an interim measure in Victoria in which donors were able to be contacted by a third party to seek such consent when a request for information was made. As noted above, that approach was subsequently changed to allow for release of all information regardless of whether consent had been obtained. The active approach was also adopted in the Netherlands for pre-2004 donors (anonymity being abolished post 2004).

---

<sup>410</sup> Mark Dodd, submission 26 and personal consultation meeting; Fertility SA, submission 49; Council of the Care of Children, submission 65; Kylie Dempsey, submission 69; Confidential, submission 68.

There, clinics were required to contact *all* past donors and ask them for their consent, regardless of whether an inquiry had been made. All details of the donors were transferred to the register, but identifying information can only be released if consent was forthcoming. My prior research revealed some opposition by clinicians in the Netherlands, and it is unknown whether all donors had been contacted.<sup>411</sup>

The argument in favour of the ‘consent first’ approach is that waiting for, or actively seeking via a third-party, the donor’s consent would not interfere with the donor’s right to privacy or previous assumptions about anonymity albeit active consent approaches still require contacting them to ask for their consent.

However, the ‘consent first’ system is akin to having an information veto, as whether identifying information is released depends solely upon what the donor decides. If the donor says ‘No’ there is no information release. The consent first approach therefore weighs in favour of a donor who decides he/she does not wish for such information to be released, rather than the donor-conceived person’s interests in having such information. This does not accord with the paramountcy of the welfare of the child principle. Such an approach was also seen as maintaining and perpetuating significant inequity by the Victorian government prior to their latest changes to their laws, as some donor-conceived people would be entitled to information while others would not.

**FINDING 32**

The contact veto/preference system adopted in Victoria is more effective in *balancing* the rights and interest of donor-conceived people with those of donors who wish to protect their privacy than ‘consent first’ systems. The latter systems weigh in favour of donors’ interests/rights and may effectively amount to an information veto, which does not accord with the paramountcy of the welfare of the child principle.

Ensuring a sensitive and supportive system

The above discussion, and related ‘Finding 32’ however does not mean that identifying information about a person should be released without sensitivity and support. A system that

---

<sup>411</sup> Sonia Allan, A Cross-Jurisdictional Study of Regulatory Requirements and Practice Regarding the Recording of Donor Information and its Release to Donor-conceived people 2012 Report prepared for the Winston Churchill Memorial Trust.

allows the release of identifying information should be respectful to the person(s) about whom such information relates. It should require a reasonable attempt to contact them *prior* to any such release. In contacting them, the process of information release should be explained, and they should be offered support services. The person would also be given the opportunity to lodge a contact veto/preference statement, and to access intermediary services if wanted, if they are open to contact. Release of such information should not occur until the donor has been contacted, or after a reasonable period of time during which a donor cannot be located (or if the donor is deceased).

If a contact veto/preference is lodged, a donor-conceived person should have to meet with the appropriate support services and undertake not to breach the veto/preference prior to being able to access information. Breach of any contact veto/preference statement should be subject to an appropriate penalty. Process and operational matters for the donor conception register are further discussed in Chapter Five.

#### **RECOMMENDATION 22**

Access to identifying information by donor-conceived people about donors who donated prior to the requirements for consent to release of such information in South Australia, should be permitted pursuant to regulations (promulgated under section 15(4) of the *Assisted Reproductive Treatment Act 1988 (SA)*) that establish a contact veto/preference system. Such a system should include a careful process that is supportive and respectful of all parties.

## **4.7 Conclusion**

The operation and effectiveness of the *Assisted Reproductive Treatment Act 1988 (SA)* has been compromised by the delay in establishing a central donor conception register to record and release information about donor-conception. There was unanimous support, by all those consulted during the review, for the establishment of the donor conception register.

It was found that in South Australia people have been calling for access to information for more than thirty years, and that government advisory bodies and committees had openly supported the establishment of a donor conception register for at least the past sixteen years. The significant delay in acting upon such calls is causing continued distress and frustration for

donor-conceived people, recipients and donors alike. Such delay does not accord with upholding or strengthening the paramountcy of the welfare of the child principle within the South Australian legislation.

The Minister for Health is therefore called upon to establish the donor conception register as a matter of priority.

In establishing the donor conception register the Minister also has the opportunity to address the issues faced by donor-conceived people who are already in existence, who seek information about donor(s) who donated prior to a regime that required their consent to release of identifying information. It was seen that records are currently held in different locations across South Australia, are difficult to access, and that attempts to do so have caused significant distress. There is confusion and a lack of trust regarding what records exist, and inequality regarding whether access is provided. This sometimes occurs within the same families in which one sibling has access and the other does not.

I have therefore also concluded that the Minister for Health should so act on the basis of equity and compassion for those recipients, donors, and donor-conceived people affected by practices of the past. This would serve as a significant restorative measure to address injustices caused by the past “closed” culture that perpetuated donor anonymity. To this end there are two steps involved. The first is to centralise all records on the donor conception register, ensuring their preservation and enabling full knowledge regarding records that exist and those that do not. The second step is to determine what (and how) information may be accessed. I have in this Chapter recommended that access to identifying information should be permitted, while balancing of interests would occur via introducing a contact veto/preference system that relates to any release of such identifying information.

The following Chapter moves to further consider operational matters related to donor conception and access to information.



# Chapter Five

## Further Matters Regarding Donor Conception and Access to Information

# Chapter Five: Further Matters Regarding Donor Conception and Access to Information

## 5.1 Introduction

Chapter Four recommended that a donor conception register be established as a matter of priority. It was also recommended that past records held in various locations be transferred to a central location for sorting, and relevant information entered onto the register. It was further recommended that a system be established to allow those people conceived with gametes donated prior to 2004 access to information subject to a contact-veto/preference system, as has been implemented in Victoria, noting all those born with gametes donated after that time fall under NHMRC Ethical Guidelines that required consent to the release of such information when the child turned 18 or reached ‘sufficient maturity’.

This chapter continues examination of matters related to donor conception that were raised with me during the review. In particular, it focuses upon matters related to:

1. the operation of the donor conception register, including where such a register should be located, and the provision of intermediary and support services;
2. donor access to information;
3. access to information by siblings;
4. voluntary registration;
5. information to be held on the donor conception register;
6. notification of donor-conceived status; and
7. cost considerations regarding transferring records to the register and provision of intermediary and support services.

These matters go to the operation and effectiveness of the current Act as it provides for the establishment of a donor conception register. How such a register operates will, in turn, speak

to upholding the paramountcy of the welfare of the child principle, as well as respecting the interests of donors and recipients of A.R.T.

## 5.2 Operation of the Donor Conception Register

### 5.2.1 *Where should the Donor Conception Register be Held?*

Chapter Four recommended that the Minister exercise his power to establish a central donor conception register as a matter of priority. This is preferable to clinic based access or access via other locations at which past records are currently held, as it will provide for access in one central location, consistency of practice, and security of data.<sup>412</sup> Three options of where the register should be held were presented to me during the review:

- 1) internally at the Department for Health and Ageing;
- 2) by a stand-alone authority, which would have to be established; or
- 3) at Births, Deaths and Marriages.

In examining which would be most suitable, I considered factors such as the size of the population in South Australia, the number of donor-conceptions per year, the number of operational clinics (being four), the need to preserve the records in perpetuity, the level of expertise and focus of work in various government departments, preferences expressed by the South Australian donor-conception community, and the system of co-regulation that has been adopted in South Australia (which led to the recommendations in Chapter Two regarding oversight functions).

Discussion with the four operational clinics in South Australia indicated that 60 to 100 donor-conceived people are being born per year. As per the discussion in Chapter Four there are several hundred files pertaining to historical donations being held in various locations across Adelaide that need to be collated. The ACN, the primary location that has (partial) information about past donor codes, said they hold a birth outcomes spreadsheet that estimated approximately 1000 births from 1980 to 2003. They have had sixty-three enquiries for information, by sixty people from 2009; and hold a small list of people (a ‘voluntary register’) of people who have said they may be contacted if someone makes an enquiry that

---

<sup>412</sup> For example by protecting it against being lost if a clinic closes down, or changes business owners or structure such as has occurred in the past.

relates to them, being 6 sperm donors; 2 egg donors; 1 embryo donor; and 3 donor-conceived people. Queen Elizabeth Hospital holds records related to recipients dating back to the 1960s, and also received enquiries, often they need to gain some information from their records and then send the person to ACN and Repromed to follow up on donor code.

The number of past records held by Flinders Fertility is unknown, with them reporting to me that some had been destroyed and some still existed.

For comparison's sake it is noted there are 7706 registered births on the Victorian central donor register, which has operated since 1984. There were 565 donor births registered in Victoria in the 2015-16 financial year. There were 102 applications to the donor register in that year. There have been a total of 613 applicants to the voluntary register.<sup>413</sup>

South Australia is significantly smaller in population size (1.7million) when compared to most other states in Australia (NSW (7.7million), Victoria (6.05million), Queensland (4.8million), and Western Australia (2.6million)).<sup>414</sup>

With increased use of donor-conception by single women and same-sex couples it is likely that donor conception will increase. What kind of system children born as a result of donor-conception will be subject to into the future is also an important consideration.

In considering various models, I held meetings during the consultation period with the government departments that look after adoption and the associated support services (Relationships Australia South Australia (RASA)); Births, Deaths and Marriages (BDM); and representatives from the Epidemiology Unit, which houses the Perinatal Outcomes Unit and Cancer Register among other things. Visits were also made to NSW Ministry of Health, and the Victorian Assisted Reproductive Treatment Authority (VARTA). A submission was received from Western Australia Reproductive Technology Council, and follow up phone conversations were had.

### ***Births, Deaths, and Marriages (with external provider of support services)***

I found that in South Australia the processes conducted between adoption services, RASA, and BDM, were most akin to the information recording and release processes seen in other states regarding donor conception. My understanding of that system was supported via

---

<sup>413</sup> VARTA, *Annual Report 2016*.

<sup>414</sup> Australian Bureau of Statistics, *Australian Demographic Statistics*, June 2016, <http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0> accessed 8 January 2017.

a meeting with a representative from the Department of Education and Child Development, and Nikki Hartmann from RASA on 20 April 2016, who worked closely in relation to the information release system regarding adoptions in South Australia. Nikki Hartmann emphasised that *'children should never remember a time they didn't know [their genetic heritage] – that is the lesson from adoption.'*<sup>415</sup>

I also met, corresponded with, and spoke with representatives from BDM on a number of occasions. BDM collects and manages data relevant to birth and parentage. They maintain the birth register, and issue birth certificates. BDM also noted that they have the capability for external operators to upload information and that hospitals and funeral services currently do this. Such capabilities would support direct entry of records from clinics to BDM. BDM also said they can engage in linking records and do so in relation to births and deaths.

Regarding cases of information related to adoption in which people search for information regarding their biological parentage, BDM holds the data, while RASA provides support services. The process for obtaining information then involves accessing the records, and determining how such information shall be released (for example, if there are difficult circumstances a suggestion that the person come in to discuss the information may be made, however ultimately how information is received is left to the person to decide). There is also no requirement for mandatory counselling, it being noted by Ms. Hartman that mandatory counselling has been found to be of little to no benefit for people if they are only there because they have to be.

In South Australia, RASA is a 'trusted partner agency' (hereafter 'trusted agency') of the BDM and so therefore can access records directly to facilitate family tracing and linking services. RASA also works with SA Link Up, Salvation Army Family Tracing, and Nunkuwarrin Yunti (Aboriginal Health service that assists the stolen generation) for assistance in family linking. Such access and processes would serve well in the donor-conception context. (Note: this may be compared to Victoria, whose movement of their donor register to BDM was frustrated by similar services not being able to access necessary information for linking. The South Australian system is more akin to what will now happen in Victoria as VARTA takes over the management of the donor register-noting the difference is VARTA is a stand-alone

---

<sup>415</sup> Face-to-face meetings held in April 2016.

authority with other regulatory functions, whereas RASA is an independent provider of family support services.)

I followed up with BDM after our meeting giving them more details about the types of information that would need to be recorded and asking them to assess their capacity to run the register. They responded that subject to start up and ongoing costs, BDM may provide a suitable location for the establishment and ongoing operation of the Register; with a third-party such as RASA or another body that would engage in the face-to-face client liaison when providing services permitting donors and children to meet or forge relationships (that is, ‘donor-linking’, which operates much like the adoption services currently provided in South Australia).<sup>416</sup>

I also noted that changes to the *Family Relationship Act 1988 (SA)* in June 2016 have given BDM responsibility for recording and release of information about donor conception on birth registration statements and second birth certificates, supporting the argument that all information should be held in the one location.

In a follow up conversation with a donor-conceived person who lives in state, I was told that his preference would be to go to Births, Deaths, and Marriages and have any support provided by an independent counselling service such as happens with adoption.<sup>417</sup>

In considering locating the donor conception register at BDM I was mindful that the recording and release of donor information is for the benefit of the donor-conceived person. The parents’ infertility should not prevail upon the child throughout his or her life,<sup>418</sup> whether such ‘infertility’ is a medical condition or due to social reasons, relationship status, or any other factor. Centralising all information about a child’s birth at BDM may help to normalise donor conception (as another way in which families are formed) and recognise that donor-conceived people desire information about their genetic parentage in the same way as others born to families created in other ways.

---

<sup>416</sup> It was noted by BDM that while the Minister for Health is responsible for the Register (including the voluntary Register) under s15 of the *Assisted Reproductive Treatment Act 1988 (SA)*, that BDM would need to control setting up the policy and operational framework for the Register itself e.g. how to collect data from clinics, policies to ensure the integrity of the data etc.

<sup>417</sup> Follow up conversation with donor-conceived person, September 2016.

<sup>418</sup> Victorian Law Reform Commission, *Assisted Reproductive Technology & Adoption: Final Report (2007)*, p 52.

***Internal to Department of Health***

Options for where the donor conception register would be held internal to the Department of Health and Ageing were presented to me by the staff providing executive support to the review as including 1) by the Epidemiology Unit (which houses the Pregnancy Outcomes Unit), or 2) within another unit within the Department such as that where staff supporting the review were located.

However, in considering establishing the donor conception register within one of these units, neither unit was observed to work in a manner that is akin to services needed for a donor conception register. The Pregnancy Outcomes Unit (POU) collects population based information regarding birth outcomes and complications, but does not provide individual data release services. On meeting with the POU representative I was informed that they have very strict privacy provisions, that their focus is quite different to what is required for a donor register, and that currently they can share the information they collect with only two specified bodies – ‘AIHW datalinkage’ and ‘SANT datalinkage’ – for research purposes.

The internal unit that was responsible for supporting the current review focused on policy issues regarding numerous areas of health. I observed that a small number of personnel staffed the unit. There was no current expertise within the unit regarding establishing or running a donor conception register that would hold information about biological parentage or that could provide support services that would enable family linking.

It was also not apparent how people searching for information would proceed, or experience having to go to the Department of Health and Ageing to access some information about their donor-conception and to BDM to access other information relevant to their birth, (for example, their birth certificate).

In order to house the register in either unit it would be necessary to establish the infrastructure (including appropriate IT and data protection systems), to hire staff with relevant data management expertise, and most likely to outsource community liaison services, as well as intermediary and support services. This may not only delay the establishment of the donor register further, but also may not result in the same level of expertise in comparison to BDM, which is experienced in handling public enquiries about information release relevant to genetic heritage and birth, and working with other agencies to assist access to such information and family linking.

I also considered both Western Australia and New South Wales, where the donor conception registers are held within their respective health departments to inform deliberations as to whether establishing the register within the Department of Health and Ageing would be desirable.

The Western Australian regulatory system differs significantly from the co-regulatory system that has been introduced in South Australia. As explained in Chapter Two, they have an established Reproductive Technology Unit (RTU) within their health department, as well as a Reproductive Technology Council (RTC), and have significant licensing and oversight functions, as well as other functions. The RTU is responsible for the donor conception register, provision for which has been contained within the legislation since 2004. In its submission to the review however, the RTC said ‘current experience of donor linking and release of information is through the small number of people who have joined the Voluntary Register’.<sup>419</sup> The central donor conception register is not fully operational, and the RTU is currently seeking another staff person to assist.

There has been expressed frustration by some donor-conceived people concerning an inability to access information in Western Australia from the voluntary register, and issues associated with having to pay for counseling before being able to do so.<sup>420</sup> I observed that those operating the register, are also sometimes frustrated, as they convey doing their best in a situation in which access to pertinent information and staffing was sometimes lacking. The WA RTC noted in its submission to the review

*Council is aware that mandatory and voluntary Donor Registers are just one aspect of a package of interventions, resources, and policy decisions that are required to appropriately manage donor information. The management of Donor Registers is operationally complex because it is inextricably linked with sharing of sensitive and personal information, which must sit within a legal framework that requires translation into policy, operational procedures, service delivery and the role of statutory authorities.<sup>421</sup>*

---

<sup>419</sup> WA RTC, submission 78.

<sup>420</sup> James Purtill, ‘A daughter's search for anonymous sperm donor RMRI084’ *ABC* <http://www.abc.net.au/triplej/programs/hack/a-daughter-s-search-for-her-anonymous-sperm-donor-father/7201012> 8 January 2017.

<sup>421</sup> WA RTC, submission 78.

The comments of the RTC were important to highlight the need to consider where expertise, resources, and capacity for service delivery sits in relation to birth information in South Australia.

In comparison to Western Australia, New South Wales has a light touch regulatory system in which the primary focus of their legislation is the donor conception register. As noted above registration of clinics occurs on a paper basis via the compliance unit. The NSW Ministry of Health did not make a submission to the current review. However, on a visit to meet with people at the NSW Ministry of Health in 2016, I observed that there was no designated person operating their register at the time, although it was indicated that staffing might change as donor-conceived people on the register, which has operated since 2010, get older and more wish to access information.

I also attended a donor-conception support group in NSW as an invitee to discuss their experiences with the register and/or Ministry, and was informed of some people's extreme frustration with trying to gain help in relation to donor conception matters. A number of donor-conceived people said that they were now inclined to try to find information via DNA ancestry websites rather than have to keep fighting the system for no outcome.<sup>422</sup>

The situation in NSW demonstrated to me that establishing a donor conception register within a government health department may not be the best place for such a register if adequate resourcing and support services are not available.

An understanding of issues related to A.R.T. and the psycho-social impacts of being denied access to information is also important when dealing with people who seek information about their biological heritage.

Although each of the jurisdictions visited have acted to establish donor conception registers, neither illustrated an approach that was suitable for South Australia.

Establishing the donor conception register at the Department of Health and Ageing was the least preferred option by those that I discussed this with in South Australia.

---

<sup>422</sup> There have been issues in NSW regarding the removal of donor codes from past records held at a hospital in Sydney, where the donor codes have been torn out of the records. The NSW Register does not operate in relation to such records, but there is ongoing debate in that state regarding what should occur in relation to past records. A prohibition on destruction of past records was introduced in 2016, and the legislation is due for further consideration by parliament in 2017.

### **Stand-alone authority**

The United Kingdom Human Fertilisation and Embryology Authority (HFEA) and the Victorian Assisted Reproductive Treatment Authority (VARTA) operate stand-alone regulatory authorities related to A.R.T., which both also operate donor registers as part of their functions. There are no other jurisdictions in the world that adopt this model. The regulatory authorities that operate in the United Kingdom and in Victoria differ in their functions and the degree to which they engage in direct oversight of clinics (with VARTA being lighter touch than the HFEA). They also differ in the size of the populations they serve, both compared to each other, and compared to South Australia.

In the UK, the HFEA has comprehensive regulatory functions, including but not limited to the licensing and monitoring of all A.R.T. clinics in the UK, plus oversight of embryo research, provision of information and advice, and the operation of a donor register. Donor-conceived people seeking information about their donor may be able to obtain information about donor(s) via the HFEA register if they were conceived post 1991 (non-identifying information) and after 2005 (identifying information).<sup>423</sup> Donor-conceived people may also seek information from the HFEA about any siblings that have consented to share information via ‘Donor Sibling Link’. There is also an independent not-for-profit voluntary register known as the UK Donor-Conceived Register for people conceived with gametes donated prior to 1991. The HFEA receives government funding of £5.5 million per annum, with additional fees and levies placed upon clinics for IVF treatments, to support its functions.<sup>424</sup> There are more than 100 clinics across the UK.

In Victoria, VARTA is also an authority funded by government, whose functions were noted in Chapter Two. As of 2017 VARTA will manage the donor registers (central and voluntary), which over time have moved from the former Infertility Treatment Authority (ITA), where the register(s) were established in 1984; to Births, Deaths and Marriages in 2010; and to VARTA (which replaced the ITA) in 2017. The move to VARTA follows the most recent changes to the law which have given the right of access to information by all donor-conceived people in that state, subject to the contact-veto/preference system discussed in Chapter Four. VARTA will now function as a ‘one-stop-shop’ for clinic registration and oversight, as well as support services (counselling and intermediary services), administering the donor registers,

---

<sup>423</sup> After which anonymous donation was prohibited

<sup>424</sup> See HFEA, Licence Fees, <http://www.hfea.gov.uk/5785.html> accessed 8 January 2017.

and undertaking its other functions. Employees at VARTA include counselling staff who have worked in adoption information, search and find services, as well as staff that have worked in infertility services.

VARTA is impressive in terms of its functions and resources. In relation to South Australia however, the Victorian model of a stand-alone-authority did not appear to be the best fit. For example, there are considerations regarding the regulatory system that has been adopted in South Australia, for which I have not recommended a ‘stand-alone regulatory authority’ or ‘reproductive technology unit’ be established. The size of the state and population that will be served by the donor conception register, and the fact that relevant services already exist in state, are important. In addition, while some people praised the Victorian model, and suggested that South Australia adopt the same, others expressed that they would not like to see some aspects of the Victorian approach to information release introduced in South Australia. This included that the Victorian model was seen to impose too many requirements upon people seeking information, such as requirements for mandatory ‘information sessions’ and for adults to provide written statements about why they seek information. (See further discussion below at 5.2.2 regarding intermediary and support services). Nevertheless, if the recommendations that I have made in this report are not implemented, a VARTA like body was the preferred alternative when compared to an internal Department for Health and Ageing unit (albeit without the mandatory counselling or some of the other stipulated requirements for access to information).

**FINDING 33**

The South Australian offices of Births, Deaths, and Marriages (BDM) are the most suitable location for the donor conception register in South Australia. Locating the register at BDM would enable information about donor conception to be collected, administered, and disseminated alongside other birth information, where records are also securely stored in perpetuity. Access to information concerning a person’s birth, biological and legal parentage, would occur in one location. Such a measure would minimise donor-conceived people being treated differently to all other people in South Australia who seek information about their legal and/or biological parents. It would also enable utilisation of existing expertise, resources, practice and process within South Australia.

**RECOMMENDATION 23**

The Minister should develop laws and undertake any other measures necessary to enable the donor conception register to be held at the South Australian Attorney General’s Department, Births, Deaths, and Marriages (BDM) allowing for recording of all data alongside all other records held on the birth register and access to information concerning a person’s birth, biological and legal parentage, to occur in one location.

**5.2.2 Intermediary and Support Services**

Pursuant to the recommended model in which the donor conception register is operated by the South Australian office of Births, Deaths and Marriages, it is recommended that information services be supported by an intermediary and support services agency that is experienced in delivering services to people who are searching for genetic relatives and supporting familial relationships.<sup>425</sup> *Intermediary services* are those provided by a third party who acts as a ‘go-between’ between two other parties. They may for example, undertake search and find, contact the relevant parties, and implement the contact veto/preference system, particularly in relation to donor conceptions that occurred under anonymity regimes, or when there are children under the age of 18 involved. *Support services* are those provided where counselling is necessary. For example, these may be necessary when information is not available such as when past records have been destroyed; or following donor conception, or donation of gametes.

The provider of such services should have ‘trusted agency’ status as per that which happens with the current provider of such services in the adoption context in South Australia. This would enable it to operate in an effective manner in terms of conducting search and find and family linking services. It is noted that this is a proven method in South Australia for engaging in intermediary and support services needed.

The availability of such support services would be particularly relevant to any pre-2004 donor conceptions (or 2010 given this date marks requirements for adherence to the NHMRC Ethical Guidelines under South Australian law), where donations took place under a

---

<sup>425</sup> Examples of other jurisdictions that provide external intermediary and/or support services directly related to donor-conception are found in the Netherlands, the United Kingdom, and Western Australia. This model also replicates the model applied to accessing adoption records in South Australia.

regime of anonymity, and there has not been prior agreement to consent to release of identifying information nor an expectation of contact; and to any further services offered in relation to linking siblings or families with children under the age of 18.

*Should Intermediary and Support Services be Mandatory?*

During the conduct of the review, I found some difference in views regarding whether such services should be provided at all, should be mandatory, or should be provided on an ‘as needed’ basis. For example, Wendy Kramer, who runs the largest voluntary register in the world situated in the United States<sup>426</sup> said:

*With almost 13,000 people connected on the [Donor Sibling Registry] we are certain that a counselor doesn't need to be present at these initial meetings. We don't have a counselor present when a child meet's their visiting cousins, right? I think some look at donor families as different than "normal" families. We're not though, we meet new relatives just like anyone else.*<sup>427</sup>

The Western Australian Reproductive Technology Council submitted:

*‘donor-linking’ is an emerging area of practice. Counselling and support services should be made available. However, individuals ought to be able to choose the services they wish to access.*<sup>428</sup>

Similarly, as noted above, Ms. Hartman from RASA noted in the context of adoption information services, that mandatory counselling has been found to be of little to no benefit for people if they are only there because they have to be. Nevertheless, RASA also said:

---

<sup>426</sup> The Donor Sibling Registry, is a voluntary register operated in the United States, which was established by Wendy Kramer and her son, Ryan who is donor-conceived. See <https://www.donorsiblingregistry.com/> accessed 8 January 2017.

<sup>427</sup> Wendy Kramer, email to me dated 30 January 2016. Wendy noted that many Australian families use U.S. sperm donors, and are parts of very large groups of half siblings due to there being no regulation in the U.S. on family limits (or otherwise). She noted of their 48000 members (from all over the world), they have more than 800 Australian families on the register, and have helped to connect more than 320 people in Australia.

<sup>428</sup> WA RTC, submission 78.

*specialist [intermediary] services can ...assist donor-conceived people, donors and families in searching, making contact with and facilitating positive relationships between the parties. Our experience highlights the importance of people obtaining support in preparing to search, possible outcomes of the search including when the other party declines to have contact. While ideally there will exist information in files regarding parties thoughts about contact, it needs to be recognised these can change over time. This service can also assist in the relationship building and supporting the parties to engage in a way that they are all comfortable with.*<sup>429</sup>

The Australian New Zealand Infertility Counselling Association (ANZICA), supported mandatory counselling.<sup>430</sup>

In considering what other jurisdictions require, a variety of approaches was again found. Some jurisdictions provide for registers, but do not mandate support services. These jurisdictions include Switzerland, New South Wales, Finland and Croatia. In New Zealand, counselling is not required, but is recommended. The view in these nations is that while information should be made available, it is up to the person accessing such information, who in most cases will be an adult, to decide whether he or she needs support services.<sup>431</sup>

Other jurisdictions provide for registers and mandate intermediary and/or support services. These include the Netherlands, the Australian states of Victoria and Western Australia. In Victoria and Western Australia counselling prior to access to information is required. In Victoria and the Netherlands an intermediary service is also provided to support people if they wish to make contact.<sup>432</sup> In Western Australia people are required to pay for the mandated counselling, which may act as a barrier to accessing information if the person cannot afford to pay. In Victoria and the Netherlands, services are funded by the state.

In Argentina and Uruguay, approval by a judicial authority is required before information will be released, and it does not appear any further counselling or intermediary services will be required.<sup>433</sup>

---

<sup>429</sup> RASA, submission 66.

<sup>430</sup> ANZICA, submission 82.

<sup>431</sup> Allan, above n 259.

<sup>432</sup> Ibid.

<sup>433</sup> Ibid.

In considering other models, and the submissions put to me during the review, I recommend that there is a need for intermediary services particularly in cases that involve a significant change from the old anonymity regime, or when recipient families are applying for access to information prior to a child reaching the age of 18 or ‘sufficient maturity’. Intermediary services would act for example, to inform a person that an inquiry has been made, provide information about the information release process, and discuss the contact veto/preference system (if one is put into place). They may also support people in making contact if required. Here it will be important that the government and clinics support the costs of such services (see further below) as making donor-conceived people pay has been a barrier to their accessing such services in other jurisdictions.

However, while I find the need for intermediary services in such circumstances, I find that mandating *counselling* support services should not occur. Such support services should be available to donor-conceived people, recipients, and donors *as required and desired by them* but should not be imposed upon them.<sup>434</sup>

To illustrate how the recommended system would work and to clarify the above discussion, I provide an indicative process that would be followed below. This may inform the Minister when enacting regulations required under section 15(4) of the *Assisted Reproductive Treatment Act 1988 (SA)* that govern the *release* of information.<sup>435</sup>

### *Inquiries for Information by Donor-Conceived People/Recipients*

#### **A: Release of Information about Donor Regarding Post 2004 Donations**

1. *Inquiry about donor by offspring aged 18 or of ‘sufficient maturity’:*
  - a. Information released (both identifying and non-identifying)
  - b. Prior to information release donor-conceived person is informed of the existence of support services and told they can choose to access such services if required.

---

<sup>434</sup> See further Premier’s Women’s Council, submission 62; Kim Buck, submission 41. A call for follow-up support was also made by donors during the donor consultation, 21 April 2016.

<sup>435</sup> Section 15(4) of the *Assisted Reproductive Treatment Act 1988 (SA)* provides that the donor conception register may only be inspected in accordance with the Regulations. Note - detailed decisions about processes entail would need to be made by the register and intermediary support services.

2. *Inquiry about donor by recipient family of offspring— offspring under age 18 however conceived with gametes/embryos donated post 2004:*

- a. Non-identifying information released;
- b. Referred to intermediary services regarding identifying information;
- c. Intermediary services contact donor and seek consent to identifying information release prior to age 18 (identifying information only released with consent; further contact negotiated if wanted by all parties).

**B. Release of Information Regarding Past Donations (pre- 2004)**

*Inquiry by donor-conceived person (aged 18 or of ‘sufficient maturity’) about donor conception with donation made pre-2004 – which means donor may have donated confidentially:*

- a. Non-identifying information released;
- b. Donor-conceived person referred to intermediary and support services regarding access to identifying information about their donor;
- c. Intermediary service provider liaises with donor conception register (BDM), clinic in which person was conceived, and other services (as necessary) to locate and contact donor:
  1. Where information does not exist (for example, records destroyed; donor cannot be identified), support and counselling services offered to person making the enquiry, and provided if wanted by that person.
  2. If donor is located, intermediary services discuss with donor identifying information being released and contact veto/preference system, with the following outcomes:

Full release of identifying information within a designated time period after contact by the intermediary services provider with donor – with

    - a. Donor lodging contact veto/preference form;
    - b. No contact veto/preference form lodged.

Donor and offspring offered ongoing intermediary and support services (if required).
  3. If donor cannot be located or contacted by intermediary services within a period of two months—identifying information released after period expires.

**FINDING 34**

Donor conception register information services should be supplemented by intermediary and support services. Such services should be provided on a needs basis, and should not be mandated except as required in relation to intermediary services concerning retrospective access to information; contact vetoes/preferences; and information exchange concerning people under 18 years of age.

**RECOMMENDATION 24**

As part of the establishment of the donor conception register at BDM, the Minister should engage an agency to provide intermediary and support services, and take whatever measures necessary (in law or otherwise) to ensure the agency be given ‘trusted agency’ status in relation to all donor conception records.

**RECOMMENDATION 25**

The Minister should pass regulations that provide that intermediary and support services should be provided on a needs basis, and should not be mandated except as required in relation to intermediary services concerning retrospective access to identifying information; contact vetoes/preferences; and information exchange between recipients and donors concerning people under 18 years of age.

**5.2.3 Access to information by donors about donor-conceived people**

The issue of whether donors should have access to information about the children born as a result of their donations was also raised during the review. Consideration of current practices revealed that the conveying of non-identifying information to donors was inconsistent across clinics, with some clinics taking the initiative to let donors know when children were born as a result of their donations and others not doing so unless a donor requested information.

I recommend that *active* notification of donors regarding non-identifying information about the children born as a result of their donation(s) should be required. This would allow a donor to keep informed of the number and age of children that have been born, who may one day wish to have information about, and contact with, the donor. It may also encourage donors to update the register if heritable medical conditions are discovered, as they will be

aware of living people who may be at risk. I also heard from donors who felt that active notification would demonstrate appreciation for their part in helping conception to occur, and help them in not feeling dismissed or forgotten once the donation had been received.<sup>436</sup>

It is also recommended that a donor should, at any point in the future, be able to request from the donor conception register non-identifying information regarding age, number, and sex of children born; and the number of recipient families that have resulted. It was however made clear to me by donors, as well as other people who made submissions, that the preferred approach in South Australia was that access to *identifying* information about a donor-conceived person under the age of 18 by the donor should only occur if the recipient parent(s) consent, or a child of sufficient maturity consents; and after a donor-conceived person is 18, to situations in which that donor-conceived person consents.<sup>437</sup>

The process recommended regarding donor requests of the register for information concerning the donor-conceived child(ren) born as a result of his/her donation(s) is thus:

*Inquiry by donor – offspring below age 18:*

- a. Non-identifying information released (age, number, and sex of children; and number of recipient families);
- b. Identifying information released only if recipient family has registered consent on the register to such release, or child of sufficient maturity has done so.
- c. Donor is informed about intermediary and support services (not compulsory);
- d. Intermediary service may contact recipient family(ies) and let them know donor has made an enquiry and/or facilitate any other information exchange relevant to the case (for example they may facilitate updates and exchange of photos.)

*Inquiry by donor – offspring over age 18*

- a. Non-identifying information released (age, number, and sex of children; and number of recipient families released);
- b. Identifying information released only if donor-conceived person has registered their consent to such release on the register.

---

<sup>436</sup> Donor consultations, 21 April 2016.

<sup>437</sup> See for example Damien Riggs, submission 23. Also communicated to me during the donor consultations.

- c. Donor told about intermediary and support services if wanted (not compulsory);
- d. Intermediary and support services may or may not contact donor-conceived person and let them know donor has made an enquiry, depending on circumstances.<sup>438</sup>

**FINDING 35**

Clinics should have an obligation to actively notify a donor of gametes or embryo(s) of the birth of a child(ren) resulting from such donation, the number and sex of children born; and the number of recipient families that have resulted.

**RECOMMENDATION 26**

The Minister should issue a directive that clinics must *actively* notify a donor of gametes or embryos of the birth of a child(ren) that have resulted from the donation, including the number, age and sex of children born; and the number of recipient families that have been formed as a result of the use of the donor’s gametes or embryo(s).

**FINDING 36**

Donors should be able to contact the donor conception register to ask for non-identifying information about number, age and sex of children born as a result of their donation, and the number of recipient families.

**FINDING 37**

Recipients of donated gametes/embryos with children under the age of 18, and donor-conceived people over the age of 18 or of sufficient maturity, should be able to register their consent on the donor conception register to the release of identifying information to donors.

---

<sup>438</sup> Whether a person would be contacted in such a situation may be left to the discretion of the support services, or may require a voluntarily registered consent by a family or donor-conceived person to such contact at BDM. I recommend that advice from experts in relevant support services regarding such contact should be sought when finalising the regulations.

**FINDING 38**

Any request for identifying information about a person born as a result of a donor conception should not occur without the above registered consent. In all cases the donor should be referred to the intermediary and support services provider where he/she/they may discuss further their request and engage with support services as required.

**RECOMMENDATION 27**

The Minister should provide in the regulations regarding inspection of the donor conception register that

1. donors are able to contact the donor conception register to access non-identifying information about number, age, and sex of children born as a result of their donation, and the number of recipient families;
2. recipients of donated gametes/embryos with children under the age of 18, and donor-conceived people over the age of 18 or of sufficient maturity, should be able to register their consent on the donor conception register to the release of identifying information.
3. that when a donor requests *identifying* information about donor-conceived offspring that release of such information can occur only with the registered consent of recipient parents (when the child is under 18) or the donor-conceived person if over 18 or of sufficient maturity.
4. when consent has not been given a donor should be referred to the agency providing intermediary and support services, who may provide support services as required.

**5.2.4 Access to Information about Siblings**

The question of whether people should be able to access information about their donor-siblings was also considered. For many donor-conceived people this is especially important to avoid risks or fears concerning forming consanguineous relationships (see discussion in Chapter Four). There is also a desire for openness, honesty; as well as a call for information sharing that recognises and shows acceptance of their family formation and extended kinship.

It was submitted to the review during face to face consultations that any identifying information should only be shared with the consent of the siblings involved. Consent may be registered on the donor conception register by recipient parents if person is under 18, or the donor-conceived person if of sufficient maturity or over the age of 18. If consent has not been registered, then referral should also occur to intermediary services who together with the person(s) making the enquiry will determine whether it would be appropriate to seek such consent via contacting the recipient parents or donor-sibling. The required process that should follow should then be facilitated by BDM and the intermediary services, who are experts in the area of information handling and family linking respectively. The process would proceed, for example, as follows:

*1. Inquiry by donor-conceived person about siblings who are over the age of 18*

- a. Non-identifying information released (age, number, and sex of children; and number of recipient families released);
- b. Release of identifying information subject to consent being registered on the donor conception register, informed of support services
- c. If no registered consent, referral to intermediary services if request for identifying information to determine whether contacting sibling to seek consent is appropriate;
- d. All parties made aware of existing support services.

*2. Inquiry by donor offspring/recipient family about siblings who are under the age of 18*

- a. Non-identifying information released (age, number, and sex of children; and number of recipient families);
- b. Identifying information released only when consent has been registered on the donor conception register;
- c. Person making the inquiry is referred to intermediary and support services who may consider contacting recipient parents and/or will offer support as appropriate and required.

**FINDING 39**

Recipient families of donor-conceived people under the age of 18, and donor-conceived people over the age of 18 or of ‘sufficient maturity’ should be able to access from the register non-identifying information about number, age and sex of children born as a result of a shared donor/s, and the number of recipient families (including the donor’s family). They should also be able to place consent on the register to the release of identifying information to siblings.

**FINDING 40**

Release of identifying information about a sibling should not occur without registered consent by the sibling’s parent(s) if the sibling is under 18, or by the sibling if of sufficient maturity or over the age of 18. When consent has not been registered referral of the person making the request to intermediary services should occur, where further consideration of whether is appropriate to contact the parent(s) or sibling to seek such consent may be had.

**RECOMMENDATION 28**

The Minister should provide in the regulations regarding inspection of the donor conception register that:

1. Recipient families of donor-conceived children under the age of 18, and donor-conceived people of age 18 or sufficient maturity are able to:

- a) contact the donor conception register to access non-identifying information about number, age, and sex of children born to a common donor, and the number of recipient families (including the donor’s own family if any);
- b) register their consent on the donor conception register to the release of identifying information to donor-siblings.

2. when a recipient family of a child under 18, or donor-conceived person over the age of 18 or sufficient maturity requests *identifying* information about donor-conceived siblings that release of such information can occur only with the registered consent regarding a sibling who is under the age of 18.

3. when consent has not been registered, the requesting party should be referred to the agency providing intermediary and support services, who will determine whether it would be appropriate to contact the parent(s) or sibling(s) to seek such consent.
4. All cases should be made aware of the presence of support services available to them if required.

### 5.3 Voluntary Registration on Donor Conception Register

I have above recommended that all past records be transferred to the donor conception register. In some situations, there will be no records about who the donor was. When this is the case, there needs to be an option for past donors to be able to check the register and to register upon it if there are no records about them being a donor.

If the contact veto/preference system I have recommended is not adopted, provided all records are still transferred to the register, a ‘consent first’ approach would allow past donors to both check the register to ensure their donor status is recorded, and to register their *consent* to release of his/her identifying information. (I.e. like in the UK or Netherlands).

When the donor conception register is established, people who donated prior to 2004 should be encouraged to come forward to check their details are on the register, and if not to register their details.

Donor-conceived people who know of their status, or their recipient parent(s), should also be able to check with the donor conception register that such status is recorded upon the register, and submit any donor-code known to them to the register to increase the chances of possible matches to donors and siblings. As discussed above, all such parties should also be able to register their consent to release of identifying information directly on the donor conception register. It will be important in such instances that the operation of the register and the linked intermediary and support services as ‘trusted agency’, will then be able to put in place the requisite processes to assist with release of information and family linking, as required.

It is not recommended that the donor conception register be able to hold gifts as this raises numerous issues concerning ownership, storage, and deceased estates, and moves beyond the administration and facilitation of information exchange and possible contact

between donors, recipients, and donor-conceived people. The intermediary services however may wish to facilitate the exchange of letters, photos, gifts or other things, once parties are engaged with family linking. Where a person wishes to leave something for an unknown genetic relative, it may be more prudent to express such a wish in their own will. The intermediary and support services may also keep a record of people who are unable to place their name upon the donor conception register (*e.g.* due to an inability to prove donor status), but who are seeking information or open to contact.

**FINDING 41**

Voluntary registration by past donors of gametes/embryos and donor-conceived people onto the donor conception register should be possible, subject to any requirements of BDM for confirmation of status.

**RECOMMENDATION 29**

The Minister in drafting regulations regarding inspection of the register, should provide that voluntary registration by past donors of gametes/embryos and donor-conceived people onto the donor conception register should be possible, subject to any requirements of BDM for confirmation of status.

## 5.4 Information to be held on the Donor Conception Register

Section 15(4) of the *Assisted Reproductive Treatment Act 1988* (SA) provides the register *must contain, in relation to each donor on the register (a) the donor's full name and nominated contact address; and (b) the full name and nominated contact address of the person to whom assisted reproductive treatment using the donor's human reproductive material was provided; and (c) the full name of any child born as a consequence of such assisted reproductive treatment (if known); and (d) any other information required by the regulations, and may include any other information that the Minister thinks fit.*

In speaking with donors, donor-conceived people, recipient parents, and numerous people who worked in registered A.R.T. clinics in South Australia, I found that such minimal information as a name and address, and the name of any children born as a result of donations, was not seen as adequate. As noted above, I found that some clinics already collect much more extensive information than this, although there was inconsistency in practice across South Australia. Overall, there was support for a more comprehensive list of information than the basic information currently provided for in the *Assisted Reproductive Treatment Act 1988 (SA)*. Where information is available, this should include in relation to the donor(s) of gametes or embryo(s):

Identifying information:

First name, last name, address, *and* date of birth.

Non-identifying information:

Medical details (including familial medical history)
Blood type
Genetic information
Height
Weight
Colour of hair
Colour of eyes

Age at time of donation
Highest education
Occupation
Marital status
With whom the donor lives
How many children the donor has, their sex and age

Such details are important because as seen in Chapter Four the search for information is often undertaken to have a better understanding of a multitude of things relevant to genetic heritage, kinship, and family formation. Depending on the register’s capacity, and how it operates, it may be considered as to whether further information—such as a statement as to reasons for donating, a more comprehensive statement of hobbies and interests, and a photo—should also be included as required or optional. In the alternative such things may be held by the intermediary and support service provider.

**RECOMMENDATION 30**

The Minister should pass regulations pursuant to section 15(2)(d) of the Act to require the recording of comprehensive identifying and non-identifying information regarding the donor on the donor conception register. This is especially important to ensure consistency across clinics, and to ensure the recording of meaningful information about a person’s genetic heritage.

## 5.5 Notification of Donor Conceived Status, Birth Registration, and Birth Certificates

### 5.5.1 Parental Disclosure of Donor-Conceived Status

Consideration was given during the review to whether a person, or couple, who wishes to use donated gametes or embryos should be required to undertake to tell the resulting child about its donor conception prior to receiving treatment. On this matter, Professors DeLacey and Tremellen submitted:

*there is a view that if parents openly refuse to acknowledge the child’s interests when discussing disclosure in counselling for donor conception that they should be denied treatment. This denies the human capacity for maturation of perspective and there is no evidence available about how this view might alter with parenthood. There is also a view that treatment should be delayed until such time as parents acknowledge the child’s interest appropriately. There is evidence that such practices occur and constitute nudging.... Nudging is a contentious practice that can generate both benefits and harms ...and may result in people providing the answer that is expected rather than the intended behavior...<sup>439</sup>*

The view generally expressed about parental disclosure in South Australia, was that rather than requiring an undertaking by potential recipients prior to treatment, or placing a legal obligation upon them to do so after birth, it was of utmost importance that persons

<sup>439</sup> Sheryl de Lacey and Kelton Tremellon, submission 45.

considering the use of donor-conception should be counselled to understand the implications of using a donor(s) to build their family, the importance of disclosure to children that may result, and the right of such children to access information. This practice is operationalised under the Act, via the current NHMRC Ethical Guidelines, to which all registered A.R.T. providers are required to comply.<sup>440</sup> The NHMRC Ethical Guidelines provide:

*Clinics should help prospective recipients to understand the significant biological connection that their children have with the gamete donor. Recipients should be advised that their children are entitled to knowledge of their genetic parents and siblings; they should therefore be encouraged to tell their children about their origins.*<sup>441</sup>

The RTAC Code of Practice also provides that clinics must adhere to NHMRC Ethical Guidelines, and that ‘*counselling by a suitably qualified counsellor with training and experience in assisted reproductive technology is mandatory for all donors, recipients and surrogates.*’<sup>442</sup> Accreditation by RTAC is required by law in South Australia for any person authorised to provide A.R.T.,<sup>443</sup> and/or for the purposes of registration.<sup>444</sup> To this end, the operation and effectiveness of the Act appears sound in upholding the interests of the child by encouraging parents and donors to understand the importance that information about donor-conceived status and genetic relations may carry for any resulting child.

However, it was submitted to the review that more could be done regarding the provision of *ongoing* information and support to recipient parents about how to tell their children of their status and discuss donor-conception with them as they grow.<sup>445</sup> For example,

<sup>440</sup> Assisted Reproductive Treatment Act 1988 (SA), s 9(1)(e); Assisted Reproductive Treatment Regulations 2010, reg 8(2)(a).

<sup>441</sup> NHMRC Ethical Guidelines, [6.1.2]. It is noted that a similar obligation exists for clinics in relation to donors: see NHMRC Ethical Guidelines [6.1.1].

<sup>442</sup> Fertility Society of Australia and the Reproductive Technology Accreditation Committee, *Code of Practice for Assisted Reproductive Technology Units* (Revised 2015), p13. (Critical Criteria, Section 12. See further discussion of oversight requirements in Chapter 2)

<sup>443</sup> *Assisted Reproductive Treatment Act 1988 (SA)*, s 5(1); *Assisted Reproductive Treatment Regulations 2010 (SA)* reg 5.

<sup>444</sup> *Assisted Reproductive Treatment Act 1988 (SA)*, s 6(b); *Assisted Reproductive Treatment Regulations 2010 (SA)* reg 6.

<sup>445</sup> See for example, Marilyn Crawshaw, submission 51; International Social Services, submission 71; WA RTC, submission 78; ANZICA, submission 82.

Marilyn Crawshaw emphasised that *'parents of donor-conceived offspring should be provided with ongoing support, if they wish it, with talking with their children about their origins and associated matters.'*<sup>446</sup> Both Western Australia and Victoria have recognised the importance of such an approach.

In 2002, the Western Australia RTC produced a pamphlet on 'Talking to children about donor conception', which was circulated to relevant organisations and groups during the year, with the aim of providing practical assistance to parents of donor offspring in telling their child about the method of his/her conception. The Western Australia RTC also conducts workshops during which people involved in the donor conception process may explore some of the 'telling' issues, such as: 'With whom should they share their experiences with?'; 'Should the children be told?'; 'At what age is it best to tell?'; and 'Where is help and support available?'.

In Victoria, the 'Time to Tell Campaign', which is run by VARTA and has been operating since the previous ITA was in its place, is aimed at encouraging and supporting parents to share information about the method of conception and the donor with their children.<sup>447</sup> Workshops are held for those considering donor-conception, and those that are at different stages following its use. They include talks by other families, donors, and donor-conceived people, and educate people about the issues that they may face. Such events are well attended and are extremely successful. VARTA also maintains an excellent website with information about disclosure (among other things).

It is noted that currently Croatia is the only jurisdiction in the world that places a *legal obligation* upon the parents of a donor-conceived person to inform them about the nature of their conception no later than the age of 18.<sup>448</sup> How such a requirement will (or could) be enforced is unknown. Active encouragement and support in telling may be more effective than imposing a legal obligation that would be difficult to enforce.

---

<sup>446</sup> Marilyn Crawshaw, submission 51.

<sup>447</sup> Johnson, Louise, Kate Bourne and Karin Hammarberg, 'Donor conception legislation in Victoria, Australia: the "Time to Tell" campaign, donor-linking and implications for clinical practice' (2012) 19(4) *Journal of Law and Medicine* p 803-819. The Time to Tell Campaign has been said to have been modelled on, or to mirror, the very successful workshops run by the United Kingdom Donor Conception Network: 'Telling children about being donor conceived'.

<sup>448</sup> ZAKON O MEDICINSKI POMOGNUTOJ OPLODNJI (*Law on Medically Assisted Reproduction*, 12 July 2012) (Croatia), No: 71-05-03 / 1-12-2, Article 15(2).

**FINDING 42**

More could be done to operationalise and make effective the *Assisted Reproductive Treatment Act 1988* (SA), by the Minister and A.R.T. providers to ensure ongoing information and support is given to recipient parents of donated gametes or embryos about access to information, the significance of biological connection to genetic parents and siblings, and how to discuss donor-conception with their children, all of which are required pursuant to NHMRC Ethical Guidelines, and so therefore under the law.

**RECOMMENDATION 31**

To ensure recipient parents of donated gametes or embryos are given information and support regarding the significance of biological connection to genetic parents and siblings, and how to discuss donor-conception with their children, within the context of the recommendations made in this report:

1. BDM and the support services should publicise the donor conception register and how it works;
2. the A.R.T. Advisory Council should exercise its functions to promote and engage in public education and forums via producing information brochures and/or running a yearly 'Time to Tell' seminar;
3. auditing of clinics from time-to-time should include consideration of what clinics have done to uphold their obligations under the NHMRC Ethical Guidelines<sup>449</sup> and the Act.

It is also important to examine further the recording and notification of a person's donor-conceived status.

**5.5.2 Recording and Notification of Donor-Conceived Status**

For a variety of intra and interpersonal, social and family life cycle factors, many children born as a result of the use of donor conception are not informed that they are donor-conceived.<sup>450</sup>

<sup>449</sup> NHMRC Ethical Guidelines, 6.1.2.

<sup>450</sup> A. Indekeu, K. Dierickx, P. Schotsmans, K.R. Daniels, P. Rober, and T. D'Hooghe, 'Factors contributing to parental decision-making in disclosing donor conception: a systematic review' 19 (6) *Hum. Reprod. Update* (November/December 2013), 714-733 first published online June 27, 2013 doi:10.1093/humupd/dmt018

This is despite it being considered to be in the best interests of children to know.<sup>451</sup> With increased moves toward openness, there has also been a call for mechanisms to be put in place to not only record donor-conceived status, but to ensure there are mechanisms to notify a person of such status. This is especially so as access to information cannot occur without knowing one is donor-conceived. During the conduct of the review such a view was shown by recipient parents, donors, donor-conceived people, clinics and associated health professionals and staff.<sup>452</sup>

As noted in Chapter Four, a number of jurisdictions that allow for information release have moved to legislate to require that donor-conceived people be informed of their status via addendums to birth certificates, recording of status on birth records, or a legal requirement of parents to inform the person of their status.<sup>453</sup>

Since 2010, Victoria has required an addendum to the birth certificate of a donor-conceived person.<sup>454</sup> On applying for a birth certificate at or after age 18, a donor-conceived person in Victoria will be told there is more information about them held on the register.

In Argentina, information regarding the person born by the use of assisted human reproduction with gametes of a third party must be included in the corresponding base file to birth registration. It appears that donor-conceived people will be made aware of their status when they obtain this document, if their parent(s) have not told them previously.<sup>455</sup>

Ireland has implemented a system in which a note is added to the entry in the register of births that the child is donor conceived and that additional information is available from the National Donor-Conceived Register.<sup>456</sup> When a person reaches 18 years of age and applies

---

<sup>451</sup> A. Barron and R. Pannor *Lethal Secrets: The Psychology of donor insemination problems and solutions* (2008). Las Vegas, NV: Triadoption Publications.

<sup>452</sup> Kim Pace, submission 19; Caroline Lorbach, submission 27; Lauren Burns, submission 33; Kim Buck, submission 41; Marilyn Crawshaw, submission 51; Eric Blyth, submission 52; Dr. Kelly Ann, submission 55; Natalie Parker, submission 61; Sofie Gregory, submission 70; Western Australia, RTC, submission 78; Reece Trevenen, submission 79; Donor Conception Forum, 18 April 2016; Consumer Forum, 21 April 2016; Donor Consultations, 21 April 2016 – with express support for addendum and or information on birth-certificate by Nathan O’Callaghan; Jarrod Whitbread; Corey; and Gerard Killick; Consultations with Clinics: ReproMed/My IVF, 19 April 2016; City Fertility, 19 April 2016; Fertility SA, 20 April 2016; and Flinders Fertility, 22 April 2016.

<sup>453</sup> Sonia Allan (2017) above n 259.

<sup>454</sup> *Assisted Reproductive Treatment Act 2008* (Vic), s 153; *Births, Deaths and Marriages Registration Act 1996* (Vic), s 17B(2).

<sup>455</sup> Código civil y comercial de la nación, Article 563.

<sup>456</sup> *Children and Family Relationships Act 2015* Act No. 9 of 2015 (Ireland), s 39.

for a copy of his or her birth certificate the Registrar General shall inform the person that further information relating to him or her is available.<sup>457</sup>

In Croatia the law requires parents to inform their donor conceived child about the nature of their conception no later than the age of 18.<sup>458</sup>

### **Recent Changes in South Australia Regarding Recording of Donor Information**

Changes to the *Births, Deaths and Marriages Registration Act 1996* (SA), in September 2016:<sup>459</sup>

1. require the recording of particulars about the biological parent(s) (if known) on the **birth registration statement**. 'Biological parents' are defined as the person who provided semen resulting in the birth; and the person who provided the ovum resulting in the birth;<sup>460</sup> and
2. allow for the inclusion of a biological parent on the **birth certificate** of the donor-conceived person if they consent, or their legal parent(s) or guardian(s) consent to such inclusion and the donor-conceived person is under the age of 18.<sup>461</sup>

The amendments provide an interim measure until the donor conception register is established, as they include a provision that they will expire on that day.<sup>462</sup>

In this regard, the Honourable T. Kenyon M.P., who introduced the amendments, noted it had in fact been a donor-conceived adult searching for information and the difficulties she faced that had turned his mind to such things, and that he expected that '*the register that is contained but not yet in operation in the Assisted Reproductive Technologies [sic] Act will take care of most of those.*' Such anticipation and expectations were also expressed by other members of Parliament during the second reading and committee stage of the bill. The amendments passed thirty-one to ten votes in the House of Assembly.

The discussion in Parliament made clear that the intention was to emphasise the rights

---

<sup>457</sup> Ibid.

<sup>458</sup> Ibid, Article 15(2).

<sup>459</sup> The *Family Relationships (Parentage Presumption) Amendment Act* (2016) was introduced to amend the *Family Relationships Act 1975* (SA) to remove a three-year co-habitation requirement for the recognition of the domestic partner of a person who has used donor-conception to have a child, as a legal-parent of that child. Amendments to the *Births, Deaths, and Marriages Act 1996* were included in a Schedule to that Act. The Act was assented to on 23 June 2016 and came into effect three months after that date.

<sup>460</sup> *Family Relationships (Parentage Presumption) Amendment Act 2016* (SA), Schedule 1(1), amending section 14 of the *Births, Deaths, and Marriages Act 1996* (SA).

<sup>461</sup> Ibid, Schedule 1(2), amending section 46 of the *Births, Deaths, and Marriages Act 1996* (SA).

<sup>462</sup> Ibid, Schedule 1(1) and 1(2).

of donor-conceived people to have information about their biological heritage. The Hon T. Kenyon M.P. noted during the debate on the second reading that they were intended to *'...ensure that there is an accurate record of someone's personal history so that, at a later point in life, they can come back and fully understand that history.'*<sup>463</sup> During committee stage he further clarified to members of Parliament that such amendments were to apply to all person's in all circumstances whose biological parent(s) were known stating that *'[d]espite the circumstances of the conception, it may still be genetically relevant at some point in the future, and the child has a right to know.'*<sup>464</sup>

The changes to the law have been operationalised by including a space on the birth registration statement to include a known donor's details (noting a donor must also sign the registration statement to acknowledge they were a donor);<sup>465</sup> and by implementing a system whereby there is a standard birth certificate which shows details of legal parents, and a second birth certificate which can be issued to include details of donor(s).<sup>466</sup> People will be notified of a second birth certificate existing when they apply for their birth certificate.

Because birth registration statements are generally filled out by the parent(s) of a child, the provisions mean that parent(s) who have used a 'known' donor (i.e. known to them), have somewhere to record who that person was, and also—if they choose—to include that person's name on the child's second birth certificate. This would apply whether or not the child was conceived in a clinic.

At present clinics also record the names of donors to recipients when the donor is not known to the recipient, but is known to the clinic—as a child born as a result has the right to access identifying information about their donor when they reach the age of 18 or 'sufficient maturity' under the NHMRC Ethical Guidelines.

The provisions in effect mean that:

1. The system now includes 'known' donations whether or not they occurred in a clinic;
2. All recipients have the option of entering on the birth registration statement that a child was donor-conceived but only some will have a donor known to them – meaning only some will in fact be able to do so;

---

<sup>463</sup> Hansard, House of Assembly, Wednesday 10 February 2016, The Hon T Kenyon, page 4214.

<sup>464</sup> Ibid, p 4222.

<sup>465</sup> See Appendix 9 for a copy of the form.

<sup>466</sup> Communicated to me by the Registrar of Births, Death and Marriages on 4 January 2017.

3. Only some recipients will choose to include the donor's name on the second birth certificate before the child turns 18, noting further that only those who know the donor's name will be able to make that choice;
4. If the parents don't put the name of the donor on the second birth certificate, a donor-conceived person may after turning 18, but would have to know they are donor-conceived, in order to do so. They could then check either the birth registration document or at the donor register (or clinic) if they didn't know the donor's name.

Although intended to expire when the donor conception register is established, the provisions will have been operational for some time before then. A number of issues arise. First, while operative they will give rise to different results for people born as a result of donor conception depending on whether a known donor is used, and upon subsequent choices made by the parent(s). Thus, while well intended, in practice they may result in inequity in that some people will have information recorded, some won't. It will be important to ensure that any subsequent laws enacted ensure all people have the same rights.

Second, given the intended effect is to ensure donor-conceived people have access to information, the changes to the law support the argument that donor-conceived people should be notified of their status.

Third, now that a 'right' has been given to donor-conceived people to place the name of their donor on their (second) birth certificate when they turn 18, if they so choose, it would seem unjust to take such a right away. Similarly, now that a right has been conferred to include information about 'known' donors on birth registration and certificates, it should not be taken away.

Notification of status, inclusion of details on the birth certificate, and inclusion of known donors, are discussed in turn below.

**FINDING 43**

Interim changes to the *Births, Deaths, and Marriages Act* provide for recording of known donor details on the birth registration statement and for the option of including such details on a second birth certificate. The intention of Parliament in making such changes was to ensure donor-conceived people have a way of knowing their genetic heritage. The changes will expire on the establishment of the donor register.

**FINDING 44**

The current law that allows for registration of a known donor on the birth registration statement and the option of including donor details on a second birth certificate, confer rights that should not be lessened by the implementation of the donor conception register.

Notification of Status

The interim amendments to the *Births, Deaths and Marriages Registration Act 1996* (SA), provide for some notification of donor-conceived status to some donor-conceived people.

The review heard from a number of people who supported that notification of donor-conceived status occur. Reece Trevenen submitted that ‘the lack of mandated notification to DC people is a direct breach of the welfare of child principle’.<sup>467</sup> All donors but one who were consulted supported that a child be notified of their donor-conceived status. One donor emphasised to me that he thought the addendum to the birth certificate is a ‘must’ as ‘kids have a right to know their make-up’.

It is recommended that in order to achieve equal treatment of donor-conceived people, as well as to ensure restorative practices to address past injustices caused by the previous “closed” culture, that once information is held upon the donor conception register, an addendum should be added to their birth certificate stating that further information is held on the register about them.

This would be consistent with approaches taken in other jurisdictions such as Victoria and Ireland, although it would apply to all donor-conceived people for whom further information is available. It would also ensure that true recognition of a donor-conceived person’s right to information, starting with their right to know their status. They may then choose whether they wish to access further information about their genetic heritage. As discussed above, parents of donor-conceived people should be informed, supported, and educated, about the importance of such notification and disclosure via brochures and workshops.

---

<sup>467</sup> Reece Trevenen, submission 79.

**FINDING 45**

While providing information for some the current law will not ensure all donor-conceived people can choose to access such information, as some will not know that they are donor-conceived. This should be addressed by ensuring notification of status once a donor-conceived person turns 18 via an addendum to their birth certificate.

**RECOMMENDATION 32**

The Minister should amend the law to require an addendum to a donor-conceived person's birth certificate that will notify them at age 18 when they apply for their birth certificate of more information being held on the donor conception register about them.

Option of Placing Donor on Birth certificate

In addition, the *option* of placing upon a second birth certificate information about both legal and biological parentage should be maintained – with clear provision that in the case of donors, such inclusion does not constitute an acknowledgement of parentage for the purposes of the *Family Relationships Act 1975* or any other law; and does not otherwise operate to make that person the mother or father of the child for the purposes of any other law.<sup>468</sup> The maintenance of such an option would provide a right that donor-conceived people have long fought for, and would ensure that right that has now been given is not taken away.

Notably, the changes to the *Births, Deaths and Marriages Act* also confer this right to people before they are 18 if the recipient parents so request. Such provision should also continue, as an *option*, noting the above discussion concerning not imposing *legal* obligations upon parents to tell; and that if the parents do not do so, provided the notification system via addendum to the birth certificate is implemented, the donor-conceived person will be able to choose for themselves once 18. The review heard from people who believed that the birth certificate should be a source of truth, and that this was very important to the donor-conceived people who already are in existence. The option to have the biological parent(s) named on a second birth certificate should also be given to them. This would serve the restorative process of addressing the impact of secrecy and anonymity upon them.

---

<sup>468</sup> This was explicitly included in the section 14 amendments to the *Births, Deaths and Marriages Act*.

**FINDING 46**

The possibility for inclusion of any biological parent(s) on a second birth certificate should be maintained. The option for issuance of a second birth certificate should be available to all donor-conceived people once they turn 18 whether a ‘known’ donor or clinic based donor was used.

**RECOMMENDATION 33**

Provision should be made to maintain recent amendments to section 46 of the *Births, Deaths and Marriages Registration Act 1996* (SA), for voluntary inclusion of the name of any biological parent(s) on a second birth certificate of a donor-conceived person at their request, or the request of their legal parent(s) if the donor-conceived person is under the age of 18. The provision should be strengthened to apply to births that occurred before and after the commencement of the section. The option for issuance of a second birth certificate should be available to all donor-conceived people once they turn 18 whether a ‘known’ donor or clinic based donor was used.

Known Donors from Private Arrangements

The 2016 section 14 *Births, Deaths and Marriages Registration Act 1996* (SA) amendments allow for information about ‘known’ donors to be recorded on birth registration statements, and upon second birth certificates, but such provisions cease upon establishment of the donor conception register. As a right was created via the section 14 amendments, it would be unacceptable to take it away. The ability to record information on the birth registration statement, and to request a second birth certificate, should remain following the establishment of the donor conception register.

There was also support shown during the consultation for inclusion of known donor details on the donor conception register.<sup>469</sup> This is a complicated matter as confirmation of donor status may be difficult to establish in some circumstances. Nevertheless, provided evidence of donor status and relationship between the ‘donor’ and ‘recipient’ is provided, recording the donor upon the register would be consistent with upholding a child’s right to information. At present, the BDM require the donor to sign the birth registration statement

---

<sup>469</sup> For example, Confidential, submission 68; Donor, oral submission 25 February 2016.

acknowledging that he/she is a donor (See Appendix 9). BDM should determine what proof is required for inclusion of a known donor on the donor conception register. There may also be a presumption against a person claiming to be a donor in relation to a particular child, if there has been a previous relationship with that child's other biological parent that resulted in other children being born for whom both parties are the legal parents. This would protect the child from being placed in a situation in which their parent has legal rights and responsibilities for other children in the same family, but not for the latter born child due to claiming donor status.

**FINDING 47**

The option to include 'known' donor details on birth registration statements should remain, with further option for a 'known' donor to register his/her details upon the donor conception register subject to any verification requirements of BDM.

**RECOMMENDATION 34**

Section 14 amendments to the *Births Deaths and Marriages Act 1996 (SA)* that require recording of information on the birth registration statement about 'known' donors, should remain.

**RECOMMENDATION 35**

The Minister should include in any changes to the law and/or regulations provision to allow known donors from arrangements outside of clinics to be recorded on the donor conception register, for the addendum to be placed on the resulting child's birth certificate, and for the option of the known donor's name to be placed on a second birth certificate, as per all donor conception arrangements, subject to meeting any BDM requirements.

**RECOMMENDATION 36**

The Minister should provide (via law/regulations/directive as necessary) for a presumption of legal parentage when an alleged 'known' donor and recipient have been in a prior relationship with each other that resulted in them having a child/ren together for whom the alleged 'donor' is considered the legal parent.

## 5.6 Responsibility for Costs related to the Register

In relation to all records held by persons, establishments, organisations, A.R.T. clinics, or otherwise, consideration was given to how to resource the transfer of records to, and ongoing operation of, the donor conception register and support services. It was noted that the existence of the donor conception register would not, and should not, negate current operating clinics' responsibility for the collection and recording of information pertaining to donors, recipients, and any child(ren) born as a result of the use of donor gametes or embryos. By enabling the transfer of information onto the donor conception register, the Government would be providing a service to the clinics by way of maintaining a register upon which information and records relating to donor-conception would be stored in perpetuity. It would also be assisting the clinics in their responsibilities toward donors, recipients, and donor-conceived people to provide for, and to facilitate, information exchange, noting intermediary and support services in relation to release of information would also predominantly be taken over by the Government by way of engaging a third-party provider of such services.

It is recommended that an annual fee should be levied upon registered A.R.T. clinics to support the establishment and maintenance of the register and intermediary and support services. This could be somewhat akin to the charging of fees to clinics in the United Kingdom by the HFEA, however the fee would need to be determined in relation to the cost of the register and associated support services, the number of clinics in South Australia, and what would be appropriate in the circumstances. I defer to the Minister and relevant parties to determine such things, but stress that in order for the changes that are needed to occur there needs to be a commitment by government and others—including clinics—to ensure proper funding and resourcing for the effective operation of all matters related to the Act.

In relation to past records, the administrative burden of receiving enquiries, searching for, and releasing information, as well as making quasi-registers and recording information upon them, would be relieved. It is therefore recommended that the current holders of records contribute to the cost of transferring such records to the donor conception register. In relation to past records held by ACN at Adelaide University, and those held by the Queen Elizabeth Hospital, transfer of records to the register should involve a one-off negotiated fee.

Again, what this fee will be should be determined by the government and holders of such information; contribution from Repromed should also be sought. Similarly, for past records held by Flinders Fertility, a fee to support their entry onto the register should be levied.

Ideally, other people holding records (for example, General Practitioners; retired A.R.T. providers, or otherwise), should also be *required* to come forward and provide to the donor register any information they have on past donors, recipients, and donor-conceived offspring. A fee may be levied in such instances to transfer any records they hold to the register, or the Minister may consider waiving the fee in special circumstances to encourage people to come forward and provide whatever records they have. For example, when a family of a former provider have inherited information/records that they wish to pass to the register.

**RECOMMENDATION 37**

An ongoing levy or yearly fee paid by registered clinics and A.R.T. providers should be established to support the ongoing maintenance and operation of the donor conception register, and provision of intermediary and support services. The Minister should pass any laws or regulations and/or take any other actions necessary to make this possible.

**RECOMMENDATION 38**

Responsibility for the costs related to the transfer of past records to the donor conception register should be borne by any person, establishment, organisation, A.R.T. clinic or otherwise, that currently holds records that relate to donor-conception in South Australia, unless special dispensation or agreement as to costs is granted by the Minister.

## 5.7 Clinics and the Recording and Reporting of Information

The importance of clinics following-up on all pregnancies and births resulting from donor-conception to ensure they are recorded on the donor conception register (once established) was also emphasised to the review.<sup>470</sup>

---

<sup>470</sup> Natalie Parker, submission 61.

A stark example of how a system of recognising donor-conceived people's rights to information can 'fall down', if proper follow-up does not occur, was provided to the review by Ms. Natalie Parker. Ms. Parker had undergone A.R.T. treatment with her husband, and had subsequently decided to donate their remaining embryos to another person. The donors and recipient all underwent counselling together, and the recipient undertook to ensure the resulting child would know its genetic heritage. However, it appears that once pregnant, the recipient informed the clinic she had lost the baby in order to avoid having the details placed on the NSW donor-conception register. She ceased all contact with the donor family, who discovered the apparent deception by chance via photos of a child that bore resemblance to their own on the recipient's Facebook page. The child appeared to be of an age that matched the approximate timing of embryo transfer, and Ms. Parker was convinced the child was the result of the use of her donated embryo.<sup>471</sup> Due to the recipient's actions, information about the child's heritage may never have made it onto the NSW donor register.

Ms. Parker's experience may not be a solitary incident. It highlights the importance of recording *and following up* on donor-conception to confirm whether there has been a live-birth. It also supports a requirement to record and report information at the time of donation (on the donor's record), treatment, including whether a pregnancy has occurred and expected date of delivery (on the donor's and recipient's records), and birth (on the donor's, recipient's, and donor-conceived person's record). This approach is taken in Ireland,<sup>472</sup> the most recent jurisdiction to pass legislation on matters related to donor conception. A similar system prevails in the Netherlands, in which it is also assumed there has been a birth unless proven otherwise.<sup>473</sup> Western Australia also requires such record keeping and reporting, and informed the review that it would be possible to trace and link information regarding a birth outcome with treatment, should the situation arise in that state.

RTAC has also since issued a technical bulletin<sup>474</sup> drawing licensed A.R.T. clinics' attention to NHMRC and RTAC requirements for counselling of donors, recipients, and

---

<sup>471</sup> Ibid.

<sup>472</sup> *Children and Family Relationships Act 2015* Act No. 9 of 2015 (Ireland), s 25.

<sup>473</sup> See further Allan (2017), above n 259; Sonia Allan, *A Cross-Jurisdictional Study of Regulatory Requirements and Practice Regarding the Recording of Donor Information and its Release to Donor-conceived people 2012 Report* prepared for the Winston Churchill Memorial Trust.

<sup>474</sup> The FSA notes that from time to time RTAC will become aware of issues, questions or comments where it may consider assisting units enhance the quality of their service to patients. A Technical Bulletin is an educational communication to all units, and Bodies certifying units to the RTAC Code of Practice, offering advice and guidance. It is not enforceable.

surrogate mothers regarding donor conception. The technical bulletin further recommends the following as measures to ‘minimise the risk of adverse outcomes’:

- 1. Detailed counselling notes should be kept to document the areas covered in relation to potential issues in regards to recipient compliance with their agreed undertakings with the donor(s).*
- 2. Explicit written agreement [should be sought] from the recipient patient to return to the clinic (or mutually agreed pathology lab) to have a pregnancy test performed following the completion of donor (egg, sperm or embryo) treatment.*
- 3. Report[ing of] the recipient patient's failure to attend to the Medical Director who will submit a report to the State Donor Registry (where applicable). This process will be outlined in the written agreement together with a reasoned argument why the patient's attendance is so important.*
- 4. Compl[iance] with any State or Commonwealth regulation in relation to egg/sperm/embryo donation.<sup>475</sup>*

**FINDING 48**

Consultation with the registered clinics in South Australia revealed that each clinic had a system in place for following up with recipients of donor gametes/embryos regarding birth outcomes. However, many relied upon phoning or writing to recipients and obstetricians, and an ability to cross-check recorded birth outcomes was not apparent. The current system could be strengthened by implementing a number of measures. This includes that the Minister should *require*

1. specific record keeping concerning donation, treatment, pregnancy, and birth.
2. follow-up on birth outcomes following donor conception,
3. adherence to the RTAC technical bulletin 8, and
4. reporting on matters related to the use of donor-conception.

---

<sup>475</sup> Reproductive Technology Accreditation Committee (RTAC) Technical Bulletin 8: Donation of Gametes and Embryos (May 2016).

**RECOMMENDATION 39**

The Minister should pass regulations that require clinics to record information at the time of 1) donation (on the donor’s record), 2) treatment, including whether a pregnancy has occurred and expected date of delivery (on the donor’s and recipient’s records), and 3) birth (on the donor’s, recipients, and donor-conceived person’s record). Such information should be regularly reported to the Minister, as well as relevant information being entered into the donor conception register.

**RECOMMENDATION 40**

The Minister should require, and monitor, adherence to the RTAC technical bulletin 8 concerning counselling, agreement, and reporting on matters related to the use of donor sperm, eggs, or embryos.

## 5.8 Conclusion

In being tasked with reviewing the operation and effectiveness of the Act, I have considered how best to give effect to the provisions and requirements within it. This Chapter has considered numerous operational issues relevant to the recommended donor conception register and associated matters that further the upholding of the paramountcy of the welfare of the child principle that were raised with me during the course of the review.

After extensive inquiry, reflection upon submissions, consultation with people in South Australia that work in various agencies, visits and discussions with people across other states, and consideration of various models and systems across the world, I have made recommendations that:

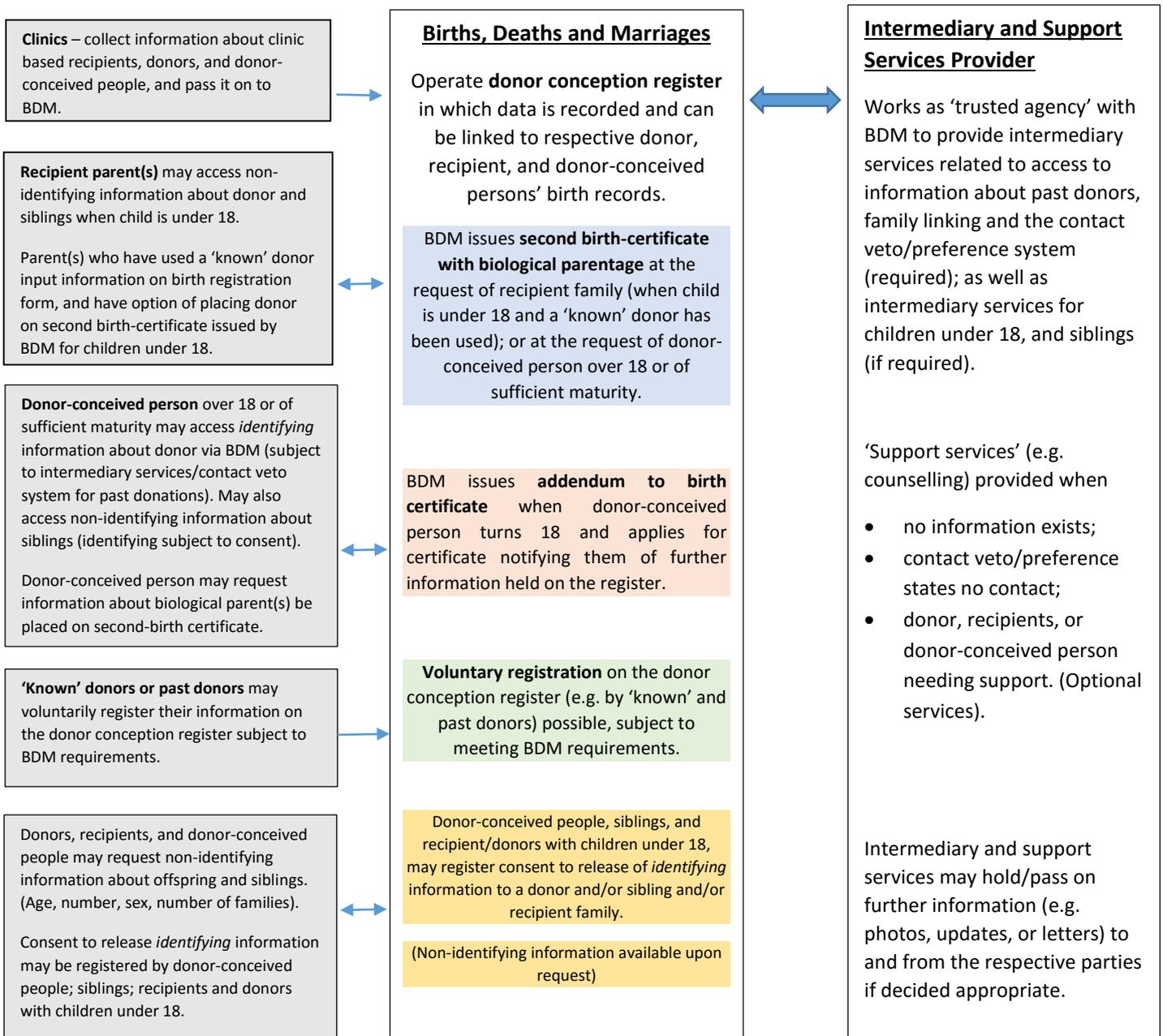
- the donor conception register should be held at Births, Deaths and Marriages;
- the provision of intermediary and support services be provided by a ‘trusted agency’ that has expertise in supporting people seeking information about their biological heritage and family linking;
- voluntary registration upon the donor conception register by donors (for example past donors, and ‘known’ donors) should be possible, subject to any requirements of BDM;

and regarding:

- associated operational issues related to
  - the collection of information and its entry onto the register,
  - access to information on the register to information by donor-conceived people, recipient parents; donors; and siblings,
  - registration of consent to release of identifying information upon the donor conception register by the respective parties, and
  - the provision of intermediary and support services;
- information to be held on the donor conception register;
- notification of donor-conceived status via an addendum to the birth certificate;
- recording of donor information on birth registration forms, and upon second birth-certificates; and
- cost considerations regarding transferring records to the register, and the ongoing operation of the donor conception register and associated services.

Figure 4 on the following page illustrates the recommendations I have made in this regard.

**Figure 4: Recommendations for Donor Conception Register and Access to Information in South Australia**



INFORMATION ← EXPERTISE → SUPPORT

System operational now, but also ready for a future in which  
 \* all donor information has been consented to be released;  
 \* requirement for support services declines (donor-conception families are accepted as "normal families" who are curious about, and meet relatives, like everyone else).

- System will continue to be able to provide a place to consent to release of information and make links between siblings that may otherwise not be known.
- System may also provide a way of tracking that the ten family limit is not exceeded by linking data about donor to his/her birth record.



# Chapter Six

## Access to A.R.T.

# Chapter Six:

## Access to Assisted Reproduction

### 6.1 Introduction

The *Assisted Reproductive Treatment Act 1988 (SA)* and *Assisted Reproductive Treatment Regulations 2010* provide for when a person may access assisted reproductive treatment (A.R.T) in South Australia. The law does this by setting ‘conditions’ for registration for clinics providing A.R.T that determine to whom, and under what circumstances, clinics may provide such treatment.<sup>476</sup>

Under the current law a person (or couple) can access A.R.T at a registered clinic if they satisfy one of the following criteria:

- the woman or her partner are, or appear to be, infertile;
- there is a risk that a serious genetic defect, disease or illness would be transmitted to a child if A.R.T. was not used;
- the woman’s deceased genuine domestic partner/spouse has left written instructions (prior to his death) that his sperm could be used by his widow to conceive a child (posthumously);
- the treatment is for the purposes of a recognised surrogacy agreement; or
- the woman or her genuine domestic partner/spouse may become infertile in the future due to a serious medical condition or disease, or its treatment (for example, cancer, or chemotherapy).

A document provided as part of the conditions of registration by the Minister for Health to registered providers also stipulates that the woman must be under the average age of menopause.<sup>477</sup> As noted above, providers must also adhere to NHMRC Ethical Guidelines to

<sup>476</sup> *Assisted Reproductive Treatment Act 1988 (SA)*, s 9; *Assisted Reproductive Treatment Regulations 2010 (SA)*, reg 8; and Conditions of Registration to Provide Assisted Reproductive Treatment in South Australia signed by Minister for Health and given to registrants.

<sup>477</sup> Conditions of Registration to Provide Assisted Reproductive Treatment in South Australia signed by Minister for Health and given to registrants.

the extent that they are consistent with the legislation and regulations of South Australia.<sup>478</sup> There is a maximum penalty of \$120,000 for a clinic that provides A.R.T. services outside of the conditions for registration requirements.<sup>479</sup>

A registered provider is not obliged to provide A.R.T. to any person, whether or not A.R.T. may be provided in accordance with the Act or its regulations.<sup>480</sup>

## 6.2 Changes to previous legislation and regulations

The subject of this review is to evaluate the operation and effectiveness of the current law in light of changes introduced in 2010. It is therefore important to note what is different (and what is the same) regarding access to A.R.T. in the current act to that which existed before. Some of the previous requirements regarding who could access A.R.T. and in what circumstances were maintained including, requirements of infertility for more invasive treatments, and risk of a child being born with a serious genetic defect. The changes to the Act and regulations also introduced more instances in which A.R.T. could be used including:

- when there appears to be a risk that a ‘serious disease or serious illness would be transmitted to a child conceived naturally’;<sup>481</sup> (that is, as additional factors other than ‘serious genetic defect’);
- if a woman or man living with a woman on a genuine domestic basis had an illness which may in the future result in infertility;<sup>482</sup> and
- for the posthumous use of sperm the woman’s deceased genuine domestic partner/spouse has left written instructions (prior to his death) that his sperm could be used by his widow to conceive a child posthumously.<sup>483</sup>

In addition the amendments included the deletion of the marital requirement for access to A.R.T, enshrining in legislation the judgment in *Pearce v South Australian Health Commission* (1996) 66 SASR 486, which held it was inconsistent with Commonwealth anti-

<sup>478</sup> *Assisted Reproductive Treatment Regulations 2010* (SA), reg 8(2)(b) and reg 8(3).

<sup>479</sup> *Assisted Reproductive Treatment Act 1988* (SA), s 9(3).

<sup>480</sup> *Assisted Reproductive Treatment Regulations 2010* (SA), reg 4.

<sup>481</sup> *Assisted Reproductive Treatment Act 1988* (SA), s 9(1)(iii).

<sup>482</sup> *Assisted Reproductive Treatment Regulations 2010* (SA), reg 8(1).

<sup>483</sup> *Assisted Reproductive Treatment Act 1988* (SA), s 9(1)(iv).

discrimination laws prohibiting discrimination on the grounds of marital status in the provision of services.

Other eligibility requirements removed from the law included that:

1. the woman who was to undergo treatment and her partner if any had to sign a statutory declaration stating neither was subject to a term of imprisonment or outstanding charges for an offence for which imprisonment may be imposed on conviction; neither had been found guilty of a sexual offence involving a child; whether either had been found guilty of an offence involving violence; and/or whether either had had a child permanently removed from his or her guardianship other than by adoption. If any such things applied, infertility treatment was not to be provided;
2. infertility treatment should cease if the above signed declaration was found to be false, or if one of the conditions relevant to the declaration became true;
3. infertility treatment should cease if a licensee was of the opinion that either spouse had become ill or had a disease or disability that would interfere with the ability and capacity of the couple to care for a child throughout childhood; and
4. applicants had to undergo counselling about the psychological and physical outcomes of A.R.T. for children born as a consequence; and when donor gametes or embryos were to be used, current opinion on the disclosure to children born in consequence of the use of donor reproductive material, and about access to donor information.

The removal of these requirements were considered in Chapter Three regarding the paramountcy of the welfare of the child principle, and recommendations made there. They are not discussed further in this Chapter. The focus of the following discussion is therefore upon the operation and effectiveness of the other provisions regarding when access to A.R.T. may occur in South Australia.

## **6.3 Operation and Effectiveness of the Act in relation to Access Provisions amended in 2010**

### **6.3.1 Access to A.R.T. – Infertility Requirement**

Access to A.R.T. is presently limited under the Act, as a condition of registration of A.R.T. providers, to situations in which a woman—regardless of her marital status—is or appears to

be infertile;<sup>484</sup> or a man who is living with her on a genuine domestic basis as her husband is or appears to be infertile.<sup>485</sup> ‘Assisted reproductive treatment’ is defined by the Act as meaning ‘any medical procedure directed at fertilization of a human ovum by artificial means and includes an in vitro fertilization procedure’.<sup>486</sup> This encompasses ‘assisted insemination’, which is defined as assisted reproductive treatment (not being an in vitro fertilization procedure or a surgical procedure), in which human sperm are introduced, by artificial means, into the human female reproductive system.<sup>487</sup>

The review received numerous submissions that viewed the ‘infertility’ requirement as discriminatory or placing women at risk.<sup>488</sup> Many also drew attention to the recent South Australian Law Reform Institute (SALRI) audit of South Australian’s laws to identify any legislative or regulatory discrimination against individuals and families on the grounds of sexual orientation, gender, gender identity, or intersex status. Illustrative of such submissions was that made by ANZICA that said:

*... the requirement of women to have a diagnosis of medical infertility in order to seek A.R.T. particularly discriminates against same-sex couples and single women. It is our belief that these current regulations:*

- *encourage such women to seek help outside of South Australia;*
- *increase the likelihood of women using unsafe and unregulated treatment options in their desire to have a child; and*
- *potentially force women in a same-sex couple to choose the gestational mother based not upon her desire to carry a child, but rather upon her medical status.*

<sup>484</sup> Assisted Reproductive Treatment Act 1988 (SA), s 9(c)(i).

<sup>485</sup> Ibid, s 9(c)(ii).

<sup>486</sup> Assisted Reproductive Treatment Act 1988 (SA), s 3.

<sup>487</sup> Noting both the definitions of A.R.T. and artificial insemination refer to procedures occurring by ‘artificial means’.

<sup>488</sup> Confidential, submission 2; Confidential, submission 3; Ms Dow-Schmidt, submission 6; Confidential, submission 7; Peter Liston, submission 9; Confidential, submission 12, Ms Aimee, submission 15; Anna Petts, submission 17; Ms Kay, submission 18; Confidential, submission 20; Confidential, submission 22; Damian Riggs, submission 23; Confidential, submission 25; Mark Dodd, submission 26; Confidential, submission 28; Danica Little, submission 40; Confidential, submission 42; Professors De Lacey & Tremellen, submissions 45; Rebecca Mackay, submission 46; Belinda Liebelt, submission 48; Fertility SA, submission 49; Confidential, submission 53; Office for Women, submission 54; Dr Kelly Ann, submission 55; Premier’s Council for Women, submission 62; City Fertility, submission 63; Confidential, submission 68; Confidential, submission 71; Robinson Research Institute, submission 74; Repromed, submission 75; South Australian Law Society, submission 77; ANZICA, submission 82.

*The above can result in serious and burdensome consequences for both parties involved.*<sup>489</sup>

Family Voice, in comparison, submitted that ‘South Australia’s laws are based upon infertility and not sexuality, and that should remain the case’.<sup>490</sup>

The recommendation of SALRI following its review of all South Australian laws in relation to the *Assisted Reproductive Treatment Act 1988 (SA)* was:

**Recommendation 13: Access to assisted reproductive treatment**

*...SALRI recommends that s9 of the Assisted Reproductive Treatment Act 1988 (SA) be amended to: clarify that a person can access ART if, in the person’s circumstances, they are unlikely to become pregnant other than by an assisted reproductive treatment procedure; and include the guiding principle that people seeking to undergo ART procedures must not be discriminated against on the basis of their sexual orientation, marital status or religion.*<sup>491</sup>

Such a recommendation is consistent with practice and laws in other jurisdictions of Australia. Given the extensive review, consultation with community, and expertise on these matters by SALRI, I defer to their recommendations on these matters and recommend that the Minister amend section 9 of the *Assisted Reproductive Treatment Act 1988 (SA)* accordingly.

**FINDING 49**

The Minister should amend section 9 of the *Assisted Reproductive Treatment Act 1988 (SA)* in accordance with the recommendations of the South Australian Law Reform Institute following their audit of South Australian laws to identify any legislative or regulatory discrimination against individuals and families on the grounds of sexual orientation, gender, gender identity, or intersex status.

<sup>489</sup> ANZICA, submission 82.

<sup>490</sup> Family Voice, submission 59.

<sup>491</sup> South Australian Law Reform Institute, *Rainbow Families: Equal Recognition of Relationships and Access to Existing Laws Relating to Parentage, Assisted Reproductive Treatment and Surrogacy* May 2016.

**RECOMMENDATION 41**

The Minister should amend section 9 of the *Assisted Reproductive Treatment Act 1988 (SA)* to provide that a person can access A.R.T. if, in the person's circumstances, they are unlikely to become pregnant other than by an A.R.T. procedure; and include the guiding principle that people seeking to undergo such procedures must not be discriminated against on the basis of their sexual orientation, marital status or religion.

**6.3.2 Access to A.R.T. - Risk of Serious Disease or Serious Illness**

The 2010 addition of permitting access to A.R.T. when there a risk that a 'serious disease or serious illness would be transmitted to a child conceived naturally'<sup>492</sup> as additional factors other than 'serious genetic defect', did not raise any concern. Permitting access in such circumstances was also seen to accord with the paramountcy of the welfare of the child principle as discussed in Chapter Two.

**6.3.3 Access to A.R.T. – Future Risk of Infertility**

The 2010 addition of the provision permitting access to A.R.T. if a woman or man living with a woman on a genuine domestic basis had an illness which may in the future result in infertility,<sup>493</sup> did not raise any concern.

**6.3.4 Access to A.R.T. – Posthumous Use of Sperm**

Changes to the Act in 2010 allowed for the posthumous use of sperm of a woman's deceased genuine domestic partner/spouse if he had left written instructions prior to his death that his sperm could be used by his widow to conceive a child posthumously, provided the sperm had been collected, or used to fertilise an ovum or an embryo, before he died.<sup>494</sup>

The review received two submissions on this matter. Family Voice expressed dissent to the provision stating:

<sup>492</sup> *Assisted Reproductive Treatment Act 1988 (SA)*, s 9(1)(iii).

<sup>493</sup> *Assisted Reproductive Treatment Regulations 2010 (SA)*, reg 8(1).

<sup>494</sup> *Assisted Reproductive Treatment Act 1988 (SA)*, s 9(1)(iv).

*The practice of allowing a surviving widow to conceive a child using her deceased husband's sperm does not align with the best interests of the child as it involves bringing a child into existence with no living father. This is to be distinguished from those circumstances in which the child comes into existence before the death of the father, including when a human embryo has already been conceived by assisted reproductive technology and is in frozen storage, or when a child is naturally conceived by a married couple who are aware the father is terminally ill. The essential difference is that in the case of posthumous use of sperm a child is being brought into existence using sperm from a man who is already dead. It is unjust to impose on a child in his or her very origin the burden of having been conceived by a dead man. This applies even if the man has consented to posthumous use of his sperm.<sup>495</sup>*

In addition to the above requirement in the *Assisted Reproductive Treatment Act 1988* (SA), the *Assisted Reproductive Treatment Regulations 2010* (SA) contain requirements for registration that include adherence to NHMRC Ethical Guidelines and RTAC accreditation. The NHMRC Ethical Guidelines stipulate that clinics must not facilitate use of gametes posthumously to achieve pregnancy, unless all of the following conditions are met:

- a deceased person has left clearly expressed and witnessed directions consenting to the use of his or her gametes; or
- a person in a post coma unresponsive state ('vegetative state') prepared clearly expressed and witnessed directions, before he or she entered the coma, consenting to the use of his or her gametes; or
- a dying person prepares clearly expressed and witnessed directions consenting to the use, after death, of his or her gametes; and
- the prospective parent received counselling about the consequences of such use; and
- the use does not diminish the fulfilment of the right of any child who may be born to knowledge of his or her biological parents.

The NHMRC further advise that as these situations arise infrequently and involve serious

---

<sup>495</sup> Family Voice, submission 59.

ethical issues, clinics should ensure that those involved seek advice and guidance from a clinical ethics committee on the ethical issues raised, and, if necessary, seek advice regarding the application of relevant laws. In addition, they note ‘the loss of a spouse or partner will be followed by a period of grief. Clinics must allow adequate time for this grieving process and ensure that counselling is available to the surviving spouse or partner before assisting in conception attempts using gametes collected from persons described’. [Paragraph 6.16]

The law, and the requirements of the NHMRC Ethical Guidelines, require that certain conditions be met and that proper ethical consideration is given to the posthumous use of gametes on a case-by-case basis. It does not seem warranted that the provision regarding the posthumous use of sperm in limited circumstances be repealed. However, I do acknowledge that posthumous use of gametes is a contentious and emotionally fraught area, and highlight that these are the kinds of issues that the recommended A.R.T. Advisory Council would ‘keep watch’ on and advise the Minister further if there was a perceived need for change.

The other submission on the matter of posthumous use of gametes drew to the attention of the review that there is a ‘get around’ to the South Australian legal requirement for *written* consent regarding posthumous use of sperm, due to being able to transport sperm out of South Australia for use in another jurisdiction that does not have such requirements.<sup>496</sup> Such action was permitted following the South Australian Supreme Court judgment in *re H, AE* (no3) [2013] SASC 196. Professors De Lacey and Tremellen from Flinders University stated in their submission that in that case the sperm was transported to the ACT which only has NHMRC Ethical Guidelines, which they said are not enforced. They said –

*these NHMRC guidelines are merely guidelines for good clinical practice, with no penalty for non-compliance without the restrictions of a local statute prohibiting use.*<sup>497</sup>

An article in the popular press, which reports on the matter, further highlights issues raised by the case. It included quotes from Professor Tremellen:

---

<sup>496</sup> Professors De Lacey and Tremellen, submission 45.

<sup>497</sup> *Ibid.*

*"[I was initially ambivalent about being involved]. One reason was that I thought it was going to be a waste of time, and the other was I didn't know if it was the right thing to do" [Dr. Tremellen] said "But this lady had asked many of the doctors in Adelaide to do it and they had all declined. "In the end I decided I would do it because I felt it wasn't a battle she should have to fight at that point when she had just lost her husband... and the evidence suggests that the majority of widows don't go on to use the sperm they collect". He said many people would probably think that it was "Frankenstein medicine" to take sperm from a dead man. When the Supreme Court victory was reported in South Australia, some... groups said it was unethical.*<sup>498</sup>

Professor Tremellen was reported in that article to now support the removal of sperm posthumously without written consent.<sup>499</sup>

This raises two issues, first a need to clarify South Australia's position on collecting sperm *without written consent*, including for transport to another jurisdiction. The Minister should act to clarify the law regarding the collection, use and/or transport of gametes to another state when there has not been written consent.

Second, that such a case may be illustrative of the issues raised in Chapter Two concerning the NHMRC Ethical Guidelines and the level to which they are respected, and given differing interpretation both within South Australia, and in other states. On this issue, the matter again highlights, the need for the government to have an active role in administering the *Assisted Reproductive Treatment Act*, providing some level of oversight, and taking a responsive regulatory role. I refer the Minister to discussion in Chapter Two and recommendations therein regarding the A.R.T. Advisory Council, independent auditing of clinics, and the issuance of directives as needed to govern A.R.T. practice in South Australia.

---

<sup>498</sup> Amy Corderoy, 'Healthy baby from sperm taken 48 hours after a man died', *SMH* 11 April 2015, <http://www.smh.com.au/national/health/healthy-baby-from-sperm-taken-48-hours-after-a-man-died-20150410-1miaci.html> accessed 8 January 2017.

<sup>499</sup> *Ibid.*

**FINDING 50**

The operation and effectiveness of the *Assisted Reproductive Act 1988* (SA) would be enhanced by the Minister clarifying matters related to the posthumous use of gametes. Issues raised in relation to such use highlight the need for a mechanism that enables ongoing consideration and recommendations concerning any regulatory steps needed to ensure clarity regarding what is or is not intended by the law.

**RECOMMENDATION 42**

The Minister should act to clarify the law regarding the posthumous collection, use and/or transport of gametes to another state when there has not been written consent by the person from whom such gametes are to be or have been collected.

## 6.4 Other Matters Raised in Relation to Access

The review also received submissions on a number of other areas for which some wanted to see a broadening of access provisions, while others called for prohibitions or narrowing of access. Each of the areas raised are mentioned in turn below.

### 6.4.1 Access restrictions based on factors such as BMI and smoking

The review received two submissions from medical practitioners regarding limiting access to assisted reproductive services based on matters such as body mass index, smoking, and two parent families. Dr. Jane Andrews submitted:

*My main comment is that we need to ensure that publicly funded access to ART is limited to people with good health who are likely to have children with good health. This means limiting access by BMI (well documented risks to mother, pregnancy, infant and resulting child/adolescent from obese parent), smoking status (likewise this is based on data, not simply discrimination) and whether*

*parent is in a stable union (again data support best outcomes for children in 2 "parent" household).<sup>500</sup>*

In considering Dr. Andrew's submission, I reiterate that a person's relationship status is not reason in itself to deny access to treatment. As discussed above, marital status should not be used as a criterion to exclude people from treatment in relation to upholding the paramountcy of the welfare of the child principle (see 3.6.7), and exclusion on the basis of marital status is discriminatory (see 6.3.1, and Recommendation 41).

BMI is an example of a recipient health factor that may impact fertility, pregnancy and birth outcomes, as well as maternal risks. In relation to BMI and obesity, Dr. Harvey, explained:

*Obesity, unfortunately it is a growing problem in our society and is quite frequently an issue at infertility clinics. We have evidence of obesity affecting the quality of oocytes, the quality of embryos (especially animal studies), adversely affecting the success of embryo transfer and leading on to higher miscarriage rates, fetal abnormality rates, stillbirth and neonatal death rates. This is not to mention the maternal risks which are increased particularly anaesthetic and airway issues, obstetric haemorrhage, pre-eclampsia, gestational diabetes and Caesarean section (52% for BMI>40, Australian publication).<sup>501</sup>*

He noted that the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) guidelines recommend ART should not be carried out in women with a BMI>35; and that in New Zealand IVF is not available if BMI is >32, and called for direction to be given to fertility units regarding the importance of weight reduction before IVF, with attention drawn to RANZCOG guidelines. He suggested that it

*would be good if units had a structure in place to direct obese women and their partners, if the partners are also obese, to weight reduction strategies -*

<sup>500</sup> Dr. Jane Andrews, submission 11.

<sup>501</sup> James Harvey, submission 38. (Obstetrician, gynaecologist, A.R.T. practitioner).

*dietician, exercise plan +/- consideration of bariatric surgery where appropriate. The reasons for these steps need to be explained, with some real sensitivity to the patients. Again an information sheet for patients including all steps to be taken to optimise pregnancy outcome could help. If all fertility clinics could be uniform it would help stopping patients shopping around to get the unit which will give them the treatment they want immediately.*<sup>502</sup>

On an ABC Four Corners program that aired during the course of the review, Professor Robert Norman, a fertility specialist based in South Australia, noted that exercise and weight loss programs, among other things, may lead many people to getting pregnant without IVF. He said:

*My estimate is: probably 40-50 per cent of people [who attend clinics could] get pregnant without IVF. And that is by understanding their... fertility window; by...tracking their cycle properly; by losing weight and exercise; or having ovulation induction.*<sup>503</sup>

#### **FINDING 51**

The review received submissions that BMI can impact A.R.T. and birth outcomes, as well as increase maternal risks. A call was made for directives to ensure uniform standards of practice and defining when treatment is acceptable. In addition a call was made for patients who have a high BMI to be provided information on how to optimise pregnancy outcomes and to be directed to appropriate weight loss programs/support services. It would accord with the functions of the recommended A.R.T. Advisory Council (Recommendation 4) to consider these matters further and to provide advice to the Minister about any action that should be taken.

I did not receive any further submissions regarding the impacts of smoking on maternal and child outcomes during the review. Nevertheless, smoking as a risk factor may similarly be an

<sup>502</sup> Ibid.

<sup>503</sup> Ibid.

issue that the recommended A.R.T. Advisory Council could consider and provide advice to the Minister about. For example, there may be a need to provide further information, education, and support to applicants regarding the impact of smoking upon fertility, pregnancy and birth outcomes, and maternal risks, and measures that may be taken to improve such things.

#### **FINDING 52**

The review also received a submission that made mention of smoking as a risk factor for children, and possible consideration regarding access to A.R.T. Similarly, in relation to smoking and its impact on A.R.T. the A.R.T. Advisory Council would be well placed to evaluate medical evidence, and to make recommendations to the Minister.

#### **RECOMMENDATION 43**

The Minister should seek further evidence and advice from the A.R.T. Advisory Council concerning health factors that may compromise A.R.T., pregnancy and birth outcomes, and increase maternal risk, including but not limited to factors related to Body Mass Index, as well as smoking. Based on such advice the Minister should issue directives, if deemed necessary, so that consistency of practice regarding access to treatment and information in such circumstances occurs in South Australia. The A.R.T. Advisory Council may also assist to encourage public discussion and information regarding effects of such things upon fertility, maternal risks, and pregnancy and birth outcomes.

#### **6.4.2 Age restrictions (for and against)<sup>504</sup>**

The review also received a number of submissions that mentioned the age requirement for access to A.R.T. which is currently set in the conditions of registration as ‘the average age of menopause’.

One submission noted arguments given for and against setting a limit upon A.R.T. when a person is of advanced age:

*Arguments in favour of IVF and egg donation to patients of advanced age are based upon, for example:*

<sup>504</sup> Ms. Aimee, submission 15; Professors DeLacey and Tremellen, submission 45; Sandra Bevan, submission 62; Confidential, submission 68; Sofie Gregory, submission 70;

1. *Reproductive right. Society recognises individuals' rights to make reproductive choices regardless of their life expectancy or age;*
2. *Age discrimination. The Equal Opportunity Act 1984 (SA) makes it unlawful when providing services to discriminate against a person because of age, although there are some exemptions.*

*The major arguments against include:*

1. *That there is a natural' limit to reproductive capacity that is intrinsic to being human, and to go beyond this limit is unnatural;*
2. *Pregnancy in postmenopausal women pose a greater risk of obstetrical and neonatal complications to both mother and child;*
3. *Parenting poses significant emotional and physical demands that some people of advanced age may not be able to handle;*
4. *Welfare of the child;*
5. *Potentially diminishing financial and social support systems.*<sup>505</sup>

The submitters called for evidence based professional standards aligned to the legislation or regulations, which would 'strengthen the ability of health professionals to reach decisions with patients that truly serve their interests and the welfare of the child.'<sup>506</sup>

Another submission questioned what the 'average age of menopause' actually is. Sandra Bevin, a woman who had accessed A.R.T. at age 45, said:

*A further concern I have is that the new Act says that you cannot go through IVF in SA if you are the average menopausal age (what is this and would all doctors agree on what the average age is). Bearing in mind I was told I was menopausal at 45 years with the particular IVF agency I went through and yet at another IVF agency it may have been considered that 45 years wasn't the average age. Whilst I agree that there has to be some cut-off as after a certain age a person's uterus (because of menopause) may reject an embryo and a miscarriage may occur, I think each case should be looked at.*

---

<sup>505</sup> Confidential, submission 68.

<sup>506</sup> Ibid.

Ongoing public discussion and concern regarding clinics providing treatment to women of an advanced age where ‘success’ rates—that is delivering a live baby—are extremely low was also noted.<sup>507</sup> For example, on the ABC Four Corners program mentioned above, it was reported that while the number of women receiving IVF over the age of forty has tripled:

*based on figures provided by the industry, a 43-year-old Australian woman, using her own 43-year-old eggs to conceive, has less than a three per cent chance of going home with a live baby. Put another way: she has a more than 97 per cent chance of failure every time.*<sup>508</sup>

While the success rates with donor eggs or embryos are higher, other issues were also raised concerning the age at which a person becomes a parent, and why people are not being encouraged to have babies in their twenties or early thirties when their fertility is still high.

The review also received two other submissions that raised other age related concerns. Ms. Aimee wrote that she wondered whether there was an age limit for donors of sperm, or whether the age limit was just being applied to women.

Sophie Gregory raised a concern about providing treatment to people who had shorter life expectancy, as may now happen in the UK. for mitochondrial disease using mitochondrial transfer techniques (commonly referred to as ‘three-parent IVF’). She said ‘[a] child who is being created with mixtures of heritage different from their commissioning parents deserves to be placed in a family with normal life expectancy’.<sup>509</sup>

In relation to assessing the operation and effectiveness of the Act, I found that more clarity was needed surrounding the age requirement, as there is ambiguity surrounding how ‘the average age of menopause’ cut off should be interpreted. There again is further need to continue to discuss and educate people about their fertility, and optimal ages for successful pregnancy and birth outcomes, and lower maternal risks; as well as consideration of the issues raised in relation other age related matters.

---

<sup>507</sup> Four Corners, The Baby Business, 13 May 2016, <http://www.abc.net.au/4corners/stories/2016/05/30/4469652.htm> 8 January 2017.

<sup>508</sup> Ibid.

<sup>509</sup> Sophie Gregory, submission 70.

**FINDING 53**

Age plays a significant factor in the success of A.R.T. in terms of pregnancy and birth outcomes. The continued treatment of women beyond a certain age may be unacceptable for these, and other reasons. There is a call for clearer directions regarding the South Australian requirement within the conditions for registration under the Act that presently limits access to treatment based upon ‘age of menopause’. The operation and effectiveness of the Act is compromised if there is ambiguity surrounding how its requirements should be interpreted.

**RECOMMENDATION 44**

The Minister should clarify the age limit requirement currently contained in the conditions for registration for the *Assisted Reproductive Treatment Act 1988 (SA)*.

**6.4.3 Social egg freezing**

Egg freezing for medical reasons has been used since the 1990s for fertility preservation for young women with cancer who are at risk of infertility as a result of their cancer or its treatment. It may also be used for women who are at risk of early menopause or endometriosis that affects their ovaries. In South Australia it is available to a woman pursuant to section 9 of the *Assisted Reproductive Treatment Act 1988 (SA)* who is suffering infertility,<sup>510</sup> or from an illness or other medical condition that may result in infertility at a future time.<sup>511</sup>

‘Social egg freezing’ (egg freezing for non-medical reasons), is typically offered to women in their early to mid-thirties who want to preserve the option of becoming a genetic parent for a later time; reduce the risk of having children with chromosomal abnormalities associated with ovarian aneuploidy (which is more likely in older age); or to provide an alternative to embryo freezing about which a woman may have moral concerns.

In South Australia, due to the restrictions on access to A.R.T. requiring infertility, social egg freezing is currently not available. However, the implementation of recommendation 41 (above at 6.3.1) will remove the infertility requirement for access to A.R.T. on the basis that it is discriminatory to women who are single or in same-sex couples. A follow on consequence of the removal of the infertility requirement will be that women will be able to access A.R.T.

<sup>510</sup> *Assisted Reproductive Treatment Act 1988 (SA)*, s9(c)(i).

<sup>511</sup> *Ibid*, s 9(f).

services for the purposes of freezing her eggs for non-medical reasons ('social egg freezing') unless the practice is otherwise prohibited.

A number of submissions to the review supported making available 'social egg freezing' in South Australia.<sup>512</sup> For example, one submission said:

*It is unfair that a single woman is not eligible for ART unless she has a medical condition. I have personally tried to access treatment to have eggs frozen until I am able to find a partner. I was required to undergo extensive testing to determine if I had a medical condition that would inhibit conception. As this is not the case I was denied treatment and referred interstate, away from my family and support networks. For this reason I chose not to go ahead with the treatment at all.*<sup>513</sup>

Rebecca MacKay submitted:

*Females without an infertility indication should be allowed to store their gametes/eggs (...often referred to as 'social egg freezing'). Currently males are able to freeze their sperm for future use however females without an infertility indication are not able to access the same service. This law is inconsistent state to state. Women should have the same rights to make these reproductive choices no matter where they live. The egg freezing procedure does not need to be government funded however women who are prepared to outlay the considerable cost should be allowed to access the service if they choose.*<sup>514</sup>

Repromed submitted:

*single female patients who would like to cryopreserve their eggs (commonly referred to as social egg freezing) must travel interstate for this treatment as*

---

<sup>512</sup> Confidential, submission 16; Professors DeLacey and Tremellen, submission 45; Rebecca Mackay, submission 46; Confidential, submission 68; Robinson Research Institute, submission 74; Repromed, submission 75; ANZICA, submission 82; Fertility SA, submission 49.

<sup>513</sup> Confidential, submission 16.

<sup>514</sup> Rebecca Mackay, submission 46 (A.R.T. Practitioner).

*they do not meet any of the eligibility criteria [in South Australia]. The Act does not currently inhibit single males from cryopreserving their sperm for future use. Thus we believe the status quo is gender discriminatory with respect to the freezing of gametes. There are a number of patients who would like to access ART treatment to freeze their eggs (knowing that they would not be able to claim any Medicare benefit).<sup>515</sup>*

Fertility SA said:

*With respect to access to fertility preservation, the current legislation discriminates against women because, unlike other states, South Australian women do not have access to an ART procedure to preserve their eggs. This results in a classic Catch 22 scenario - women can only bank their eggs when their fertility is already compromised, thus reducing chance of a positive outcome. Men are able to bank sperm and preserve fertility without legal restraint. This is clearly inequitable. In 2012, the American Society for Reproductive Medicine [ASRM] announced that egg freezing should no longer be considered experimental and it is now a first line fertility treatment. Given that technology for successfully freezing eggs has been developed, this discrimination should be removed.<sup>516</sup>*

I note that subsequent to their 2012 endorsement of egg freezing as no longer to be considered experimental, the ASRM and the Society for Assisted Reproductive Technology (SART) released a joint practice guideline in 2013 that specifically cautioned against the use of egg freezing as a guard against age-related fertility decline, owing to limited data about the safety, efficacy, cost-effectiveness and emotional risks of egg freezing for healthy women of reproductive age.<sup>517</sup> The American College of Obstetricians and Gynecologists endorsed the

---

<sup>515</sup> Repromed, submission 75.

<sup>516</sup> Fertility SA, submission 49.

<sup>517</sup> Practice Committees of American Society for Reproductive Medicine, Society for Assisted Reproductive Technology, 'Mature oocyte cryopreservation: a guideline' (2013) 99 *Fertil Steril* 2013, p 42.

ASRM–SART guideline in 2014. However, notwithstanding these cautions, the use of social egg freezing has increased in the United States.

In Australia, social egg freezing may be accessed in Queensland, New South Wales, Victoria, the ACT, and Tasmania. Western Australian restrictions for access to IVF based upon infertility mean that social egg freezing is not available in that state.

In SALRI’s report, it acknowledged that the proposed changes to the *Assisted Reproductive Technology Act 1988 (SA)* to remove the infertility requirement in South Australia, would

*have implications for the type of fertility services being provided in South Australia and potentially for the demand on those services. This is particularly the case if SALRI’s recommendations are implemented so as to permit what is known as ‘social egg freezing’ — that is services accessed by potentially fertile but single women to preserve their future fertility options.*<sup>518</sup>

The retrieval of eggs for egg freezing carries with it a number of risks. These include medical risks associated with ovarian stimulation and egg retrieval, which can result in ovarian hyper stimulation syndrome.<sup>519</sup> There may also be a risk of an increase in breast, uterine and other cancers, although the evidence of this is limited and conflicting. Women who later use their eggs will need to undergo IVF which also carries risks, alongside the risks of pregnancy at an advanced age. That said, provided legal consent is obtained—which involves explaining all material risks to the person and making sure they understand them before they consent—there is no reason why an adult woman cannot decide whether or not she wishes to proceed.

Other issues should however be kept in mind, such as the need to consider (and counter) the largely unmet need of educating girls early about their fertility, and matters that will lead to better pregnancy and birth outcomes; pressures upon young women to remain in the workforce and to delay child-bearing, including by giving them the option of social egg

---

<sup>518</sup> SALRI, above n 491.

<sup>519</sup> Mild-to-moderate ovarian hyperstimulation syndrome can lead to fatigue, nausea, headaches, abdominal pain, breast tenderness and irritability; 0.1%–2% of patients may experience severe ovarian hyperstimulation syndrome, abdominal pain, resulting in blood clots, dehydration shortness of breath, and vomiting which necessitates admission to hospital; and in rare instances ovarian hyperstimulation can lead to death.

freezing;<sup>520</sup> the marketing and provision of social egg freezing to women as a ‘fallback’ plan, at high financial<sup>521</sup> and possibly emotional costs; the possibility that the eggs may never be used; and/or risks that when such eggs are used, a baby may not result. One clinic (not in South Australia) advertises their social egg freezing services as follows:

*This treatment is best considered by women in their early 30s. For the best outcome we aim to freeze at least 12 eggs before the age of 36 to give you a more than a 50% chance of a live birth when you come back to use your eggs.*<sup>522</sup>

Such figures indicate a woman may be asked to undergo more than one round of egg retrieval, and that the future use of such eggs does not guarantee a live birth. However, again, such issues need not be addressed by preventing access to social egg freezing. Women may choose how to proceed, provided they are openly given data in order to make an informed choice. In addition there are laws against misleading or false advertising;<sup>523</sup> laws regarding failure to warn people of material risks (such as the law of negligence in which a person could claim compensation in such circumstances if they suffer loss or harm);<sup>524</sup> and other laws and standards by which health practitioners must abide.

Of course, as called for in relation to all IVF, there is a need for long term follow-up research to confirm the risks and outcomes for women and children born of IVF, amongst which it will need to be determined whether there are risks specifically associated with births from frozen eggs that should be considered. While clinics have moved swiftly to want to offer egg freezing to everyone, and not only those who have a medical need, the practice of social egg freezing is in its early days. Again, there is a role for the recommended A.R.T. Advisory Council to keep an eye on the evidence, and to respond with advice to the Minister about any further action needed, if and when required.

---

<sup>520</sup> Such as Facebook and Apple did in 2014.

<sup>521</sup> Clinics usually charge for the management of the stimulation, the drugs used to stimulate the ovaries, the egg collection procedure, and the freezing and storage of the eggs.

<sup>522</sup> TasIVF, Egg Freezing, <https://www.tasivf.com.au/fertility-services/fertility-preservation/egg-freezing> accessed 8 January 2017.

<sup>523</sup> *Competition and Consumer Act 2010* (Cth), Schedule 2.

<sup>524</sup> *Civil Liability Act 1936* (SA), Part 5.

**FINDING 54**

Recommended changes to the *Assisted Reproductive Treatment Act 1988* (SA) to remove the infertility requirement for access to A.R.T. (see Recommendation 41) will have the additional effect of allowing social egg freezing to occur in South Australia unless such practice is specifically prohibited. Although the use of social egg freezing may highlight certain social and structural issues faced by women in societies in which social egg freezing is being used (which ideally society should address), prohibiting an adult woman from deciding for herself whether she wishes to pursue egg freezing is not necessary. Women considering social egg freezing must be fully informed of the risks involved in engaging in such procedures, and the potential outcomes. Laws exist to prohibit misleading and deceptive conduct or advertising; require informed consent; and establish professional standards of care and practice for all health practitioners. There is again a role for the recommended A.R.T. Advisory Council to encourage public discussion and education concerning women’s fertility, and to monitor evidence and respond with advice to the Minister, if and when required.

**6.4.4 Sex selection for social reasons**

The review received two submissions concerning sex selection for social (non-medical) reasons.<sup>525</sup> Sex selection was discussed in Chapter Three in relation to the paramountcy of the welfare of the child provision. It was found that it would be unacceptable to provide access to sex selection for social (non-medical) reasons noting that arguments against sex selection prioritise the child, whereas arguments in favour of sex selection prioritise the recipients.

**6.4.5 First line of inquiry before IVF**

The review received a submission that noted differences in clinical practice that may lead to more expensive and invasive treatments being administered unnecessarily, without conducting simple tests first. For example, Karley Foord said,

*I have a high level of Natural Killer Cells in my uterus which prevents conception in my case but in many cases also causes repeated miscarriage and "unexplained infertility". It basically means I have a great immune system that*

<sup>525</sup> Fertility SA, submission 49; Family Voice, submission 59.

*kills invading cells including sperm/embyros. I went to [my treating clinic] with an article I'd read about this condition suspecting I had it. I was tested ... (endometrial biopsy) and once it was confirmed I was able to conceive naturally by taking prednisoline to lower my immune system. This condition is not usually tested for until 3 failed ivf attempts. I know of several others who've also had this condition. I would like to see it tested for as part of "initial" testing by fertility clinics as it could save \$\$\$\$\$ on ivf.<sup>526</sup>*

I was not in the position to make further inquiry into the processes of clinics surrounding such testing, or the order in which testing and treatment is conducted, however acknowledge that this again may be something that the recommended A.R.T. Advisory Council would consider, and advise the Minister upon whether there is a need to for example, ensure standard processes and order regarding less invasive testing and treatments prior to more invasive, and costly, treatments. The Minister could then respond accordingly.

#### **FINDING 55**

Less invasive testing and treatment should precede more invasive testing and treatment when clinically reasonable to do so. Consideration of the order in which A.R.T. patients are subjected to certain inquiry and/or treatments should be had by the recommended A.R.T. Advisory Council, and advice as to whether there should be any directives on the matter should be provided to the Minister.

#### **RECOMMENDATION 45**

Consideration of the order in which patients are subjected to certain inquiry and/or treatments should be had by the recommended A.R.T. Advisory Council, and advice as to whether there should be any directives on the matter is required.

<sup>526</sup> Karley Foord, submission 36.

## 6.5 Conclusion

Changes to the *Assisted Reproductive Treatment Act 1988 (SA)* and *Assisted Reproductive Treatment Regulations 2010 (SA)* regarding access to A.R.T. in South Australia led to a broadening of access possibilities. Such expansion has been welcomed by many and is operating in an effective manner in South Australia. Few issues were raised in this regard during the review. However, matters relating to the removal of some eligibility requirements when the Code of Ethical Practice was repealed in 2010, may have negatively impacted the paramountcy of the welfare of the child principle being upheld. These matters were discussed in Chapter Three, such discussion not being repeated in this Chapter.

It was also found that changes regarding posthumous use of gametes, while broadening access provisions, needed further clarification regarding when such gametes may be used, and whether they may be transported out of the state without written consent.

The review also received submission from a number of people concerning what is perceived to be discriminatory and possibly risky exclusion of women who do not meet the infertility requirement under the Act. Extensive inquiry into discrimination across all laws of South Australia has recently been conducted by the South Australian Law Reform Institute (SALRI) on matters related to discrimination, and its recommendations included reference to the *Assisted Reproductive Treatment Act*. The review defers to that inquiry in relation to its findings on removing the infertility requirement to allow single women and same-sex couples to access A.R.T., and recommends that the Minister act in this regard.

Other issues raised in relation to access to A.R.T. were also considered. These included factors that may affect fertility, pregnancy and birth outcomes and maternal risk (body mass index, smoking, and age), social egg freezing, social sex selection, and what the first line of inquiry should be prior to IVF. Such matters highlight that new issues continually arise in the field of A.R.T., as technology and medical evidence evolves. In turn, they again illustrate the need for the government to put into place mechanisms that provide for more effective regulatory oversight, consultation on ethical and policy issues, and responsive regulation. While I have made recommendations in regard to social egg freezing and sex selection for social reasons in this report, I noted that some other matters would benefit from further consideration by the recommended A.R.T. Advisory Council and advice to the Minister.



# Chapter Seven

## Record Keeping

# Chapter Seven: Record Keeping

## 7.1 Introduction

Record keeping in relation to A.R.T. is very important. Records may provide information about the types of treatment applied, and the treatment outcomes, which are important for research on short and long term health outcomes for children born as a result of A.R.T. and for recipients and donors. (See Chapter 3). In Chapters Four and Five the report discussed how important records about donor-conception are for recipients, donors, and donor-conceived people, and generations to come. In addition records regarding A.R.T. treatment and outcomes may enable consideration of how much personal and public<sup>527</sup> expenditure is involved. Such information may assist in deciding how much funding in the future should be directed toward A.R.T. Information about outcomes may also assist people who wish to access A.R.T. services decide whether, and where, to proceed with such treatment.

This Chapter provides brief information on the pre- 2010 South Australian legislative provisions regarding record keeping<sup>528</sup> and the operation and effectiveness of the *Assisted Reproductive Treatment Act 1988* (SA) following the changes to the act.

## 7.2 Record Keeping – Previous Regulations

Prior to the 2010 changes the South Australian Council on Reproductive Technology (SACRT)'s Code of Ethical Clinical Practice set out strong record keeping requirements relating to recipients of assisted reproductive treatment; donors of reproductive material; clinical standards and procedures. These were removed by the 2010 changes as the Code was repealed.

<sup>527</sup> E.g. At a Federal level via Medicare, at a state level via public health expenditure.

<sup>528</sup> Matters concerning confidentiality raised in the initial consultation Fact Sheet 7 'Record Keeping and Confidentiality', were discussed and addressed in Chapter Four noting the changes to confidentiality provisions in 2010 were intended to facilitate transfer of records to the donor conception register.

## 7.3 Record Keeping – Current Regulations

The current law allows for record keeping conditions to be required of registered providers of A.R.T. Section 16 of the *Assisted Reproductive Treatment Act 1988* (SA) now provides that a person who is registered under the Act to provide A.R.T., or a health professional approved under the Act to provide assisted insemination, must make such records, and keep such documents, as may be required by the regulations in relation to the provision of A.R.T. or assisted insemination. A person who is required to make a record or keep a document under section 16 must retain the record or document in accordance with any requirement set out in the regulations. There is a maximum penalty of \$50,000 for not doing so.

However, there are currently no regulations regarding the making of records or keeping of documents.

The current RTAC Code of Practice provides some minimum requirements concerning data monitoring and reporting, and require adherence to the NHMRC Ethical Guidelines. The Code of Practice also requires that clinics have in place a policy for the future disposition of records and cryopreserved material should they cease to operate.

The NHMRC Ethical Guidelines, to which registered clinics must also adhere, require A.R.T. providers to ‘keep detailed records’ stating that

*Good record keeping is an essential component of clinical practice and vital for ART because of the long term consequences of procedures involving ART on the health and psychosocial wellbeing of the persons who are born and are the participants in ART procedures themselves (and their spouses and partners, if any). Clinics must keep accurate records of all gametes and embryos in their care in accordance with Section 10.<sup>529</sup>*

Section 10 of the NHMRC Ethical Guidelines provide further requirements concerning:

1. Maintaining integrity and privacy of personal information;
2. Observing, recording, monitoring, and evaluating procedures and outcomes;

<sup>529</sup> NHMRC Ethical Guidelines, section 5.7.

3. Recording information about donation, use and storage of gametes and embryos;
4. Monitoring the number of embryos created and stored; and
5. Ensuring public accountability for all activities and procedures.

Clinics also provide comprehensive data to the Australian & New Zealand Assisted Reproduction Database (ANZARD), which was implemented in 2004 as an initiative of the Fertility Society of Australia (FSA) to provide a joint data collection for both the National Perinatal Epidemiology and Statistics Unit and RTAC. The purpose of the ANZARD collection is stated as being to monitor the perinatal outcomes of assisted reproduction and to assess the effectiveness of A.R.T. treatments.<sup>530</sup> ANZARD includes information about

- Patient demographics, age, parity, cause of infertility;
- the A.R.T. treatment procedures of in-vitro fertilisation, intracytoplasmic sperm injection, gamete intra-fallopian transfer, pre-implantation genetic diagnosis, and intrauterine insemination using donated sperm (IUI-donor) (ANZARD does not contain information about IUI if the woman's partner's sperm was used);
- A.R.T. treatment using thawed embryos;
- treatment involving donated gametes or embryos;
- the use of techniques such as assisted hatching, pre-implantation genetic diagnosis and blastocyst culture; and
- pregnancy and birth outcomes, including the method of birth, birth status, sex, birthweight, gestational age, plurality, perinatal mortality and selected information on maternal morbidity.

## 7.4 Operation and Effectiveness of the Act: Record Keeping

I found that there are areas that may be improved in relation to record keeping and reporting relevant to A.R.T. to enhance the operation and effectiveness of the Act. These have been discussed throughout the report in context, and recommendations made accordingly. For example, discussion in Chapter Two concerned the need for auditing of record keeping and

---

<sup>530</sup> See further <https://npesu.unsw.edu.au/data-collection/australian-new-zealand-assisted-reproduction-database-anzard>,

reporting to better be able to establish compliance with the Act and to monitor the processes, practices, and outcomes of A.R.T. to inform future regulation, policy and practice of A.R.T. in South Australia. Throughout the report there was further pointed discussion regarding the need to collect information about clinical practices related to screening of applicants to A.R.T.; for data to be gathered about the short and long term outcomes of A.R.T. for women and children; and of the recording and release of information concerning donor-conception.

In addition it is suggested that clinics provide all data recorded and reported to ANZARD, to the recommended A.R.T. Advisory Council, who would include relevant data in an annual report (much like the former SACRT did). This would enable further monitoring of records and data; inform decisions concerning the regulation of clinical practice; and provide evidence regarding outcomes for policy development. It would also provide a point of reference for people seeking information about such things noting no easy access to such information is currently possible.

I also note that RTAC submitted to the review that ‘it seems reasonable’ that the Government also define in the reviewed Act:

1. The length of required preservation of patient, donor and surrogate records and those of any children born as a result of A.R.T. procedures;
2. Should a clinic close, its obligations for the disposition of those records and cryopreserved material and who should assume its on-going obligations for any patient, donor or progeny counselling;
3. Should a clinic change its ownership, the obligation of the new owner to assume responsibility for the maintenance of past patient records and cryopreserved material and the provision of any required on-going patient, donor or progeny counselling that arises from past treatments at the clinic.<sup>531</sup>

#### **FINDING 56**

The review revealed gaps in past and present record keeping practices as highlighted throughout the report on a number of important matters related to A.R.T. and donor conception practices in South Australia. There is also an absence of regulations providing guidance concerning record keeping.

<sup>531</sup> RTAC, submission 44.

**RECOMMENDATION 46**

The Minister should issue regulations pursuant to section 16 of the *Assisted Reproductive Treatment Act 1988* (SA) concerning requirements for record keeping and documents in relation to the provision of A.R.T. and donor-conception, the length of required preservation of records, ongoing obligations concerning records should a clinic close, and responsibilities concerning records when a clinic changes hands.

**FINDING 57**

A system of auditing and required reporting concerning data and records required to be kept by A.R.T. clinics and health professionals should be established by the Minister. This should include reporting of data and records supplied to ANZARD and/or other bodies.

**FINDING 58**

The Minister should reflect upon the auditing/reporting of records and data relevant to the safety and quality of A.R.T. treatment; clinical practice of A.R.T.; and outcomes to inform regulatory responses and policy development concerning the practice of A.R.T. in South Australia.

**RECOMMENDATION 47**

Further to recommendations 4 and 6, the Minister should establish a system of auditing and required reporting that includes (but is not limited to) reporting of data supplied to ANZARD, which may inform reflection upon clinical practice of A.R.T. and its outcomes, and regulatory responses and policy development.

## 7.5 Conclusion

The operation and effectiveness of the *Assisted Reproductive Treatment Act 1988* (SA) will be enhanced by the Minister addressing current issues regarding record keeping and reporting requirements as discussed in this and throughout this report. Having clear record keeping and reporting requirements will in turn enable effective oversight and monitoring of A.R.T. practice and outcomes, to inform the regulation of A.R.T.



# Chapter Eight

## Conclusion

# Chapter Eight: Conclusion

## 8.1 Introduction

The review of the operation and effectiveness of the *Assisted Reproductive Technology Act 1988* (SA) has provided the opportunity to assess changes to the Act that were made in 2010 and the regulation of assisted reproduction in South Australia. In the years since the changes, there has been time for all associated with A.R.T. and donor conception to experience their impact, and to now have spoken in relation to what is working, what more needs to be done, and what changes need to be made. I have listened to them in the conduct of this review, and have made findings and recommendations concerning the operation and effectiveness of the Act.

The following summarises the main areas that the review addressed being the regulatory structure and oversight under the Act, the paramountcy of the welfare of the child principle, establishment of a donor conception register, access to A.R.T., and record keeping.

I end the report looking to the future, noting the need for a commitment by government and others to ensure the effective operation of all matters related to the Act.

## 8.2 Regulatory system and oversight

The changes in 2010 moved from a licensing system, to a co-regulatory system which requires registration of clinics, adherence to NHMRC Ethical Guidelines, and RTAC Accreditation. They were meant to reduce what was seen as duplication in terms of regulatory oversight and ethical guidance, regulatory costs and burden, and to improve the regulation of A.R.T. practices in South Australia. They have succeeded in removing what were seen as anti-competitive restrictions on the number of A.R.T. clinics in South Australia. But, they have also left gaps, in terms of some of the functions that the South Australian Council on Reproductive

Technology (SACRT) used to perform, and the participation of the government in the co-regulatory system.

In Chapter Two it was found that while there are areas upon which people would like advice, seek clarification on points of ethics and law, or that need regulatory responses in terms of what is or is not permitted, and what changes may need to be made, there was no point of contact for that to occur. It was noted that an effective co-regulatory system requires the government and those subject to the regulation to act in a manner that mutually reinforce one another and the sharing of responsibilities between public and private partners. Yet, monitoring of compliance, and enforcement of the Act is not being adequately operationalised by the Government. Lack of reporting to, and auditing by, the Minister regarding the self-regulatory aspects of the regime also compromises the accountability and openness required for an effective a co-regulatory regime.

I recommend that the answer to such gaps is not to introduce a statutory authority or a dedicated A.R.T. regulatory unit within the Department for Health and Ageing, as this would serve to put in place what the changes were intended to avoid. Rather, I have recommended that the Minister should establish an A.R.T. Advisory Council whose role it is to

- a) advise the Minister regarding medical, social, scientific, ethical, legal, and moral issues arising from A.R.T., and upon any necessary directives that need to be issued to clarify acceptable practice in South Australia;
- b) monitor compliance with the Act, via receiving annual reports from clinics that include details of the RTAC audit and any recommendations for improvement, and any further reports necessary to inform the Council of action that has been taken in response;
- c) consider the results of any inspection or audit undertaken by a suitably qualified person appointed by the Minister, and make recommendations (when necessary) concerning appropriate action to be taken by the Minister;
- d) promote and engage in public education and forums concerning A.R.T.
- e) promote research, and provide the Minister with information regarding any research that may inform regulation and governance of A.R.T.
- f) report annually on the above, as well as upon outcomes of A.R.T. in South Australia, and any other matters decided by the Minister.

The Council should include at least one A.R.T. health professional, consumer representatives (for example a donor of gametes, and a recipient of A.R.T.), religious leader representatives,

a person born as a result of A.R.T., a person born as the result of donor-conception, a person with legal expertise in A.R.T. and health law, a person with expertise in ethics, a person with relevant expertise in counselling, and a scientific expert(s). The Minister should ensure that the A.R.T. Advisory Council is supported in its functions by an appropriate Department for Health and Ageing staff member (or members as required) who in addition undertake functions relevant to the implementation, oversight, monitoring, and enforcement of the Act. Coupled with the appointment of a suitably qualified person to audit and/or inspect providers of A.R.T. from time to time, for the purposes of ensuring compliance with the requirements under the Act, the government would ensure the operation and effectiveness of the regulatory system established under the Act.

The model I have recommended is explained graphically in Figure 2 on page 50.

### 8.3 Paramourncy of the Welfare of the Child Principle

The changes in 2010 to the *Assisted Reproductive Treatment Act 1988* (SA) maintained and strengthened what is known as ‘the paramourncy of the welfare of the child principle’ under the Act. Discussion in Chapter Three illustrated that parliament had said that the interests of children born as a result of A.R.T. must be placed above all other parties.

In considering the welfare of the child provision in the context of the operation and effectiveness of the Act, I found unanimous support for the paramourncy of the child principle and it being strengthened as part of the 2010 changes.

I examined how the provision was being used, and to what effect; what sorts of considerations were being made and/or systems put in place to uphold the provision; what guidance was needed, if any, as to the sorts of considerations that should/should not be made; whether the paramourncy of the welfare of the child principle was being upheld in practice; and whether more needs to be done to ensure the paramourncy of the welfare of the child principle is met, and if so, what.

Consultation concerning the above revealed uncertainty about how to operationalise the principal, and differences in interpretation and practice were found across clinics. I made a number of recommendations in this regard intended to enable effective operationalisation of the principle and monitoring by the Minister as to compliance with the Act. The

recommendations are premised on the implementation of the system suggested in Chapter Two that would involve the A.R.T. Advisory Council, auditing of clinics from time to time by a person appointed by the Minister, the issuance of directives clarifying current requirements and addressing areas of need to uphold the paramountcy of the welfare of the child; and amending the legislation, regulations, conditions of registration, or otherwise, in a responsive manner when required.

Specific recommendations in this regard included that the Minister should:

1. conduct audits of clinics from time to time which include examination of such things as
  - a. the circumstances in which pre-implantation genetic diagnosis (PGD) has been used;
  - b. adherence to the law, conditions of registration, and relevant guidelines that speak to the paramountcy of the welfare of the child principle;
2. issue conditions of registration/directives regarding requirements for:
  - a. screening for heritable conditions, including and when PGD may be used, including the prohibition of use of sex selection for social reasons;
  - b. screening of donors of gametes/embryos for heritable conditions and for disclosure to genetic relatives when such a disease, disorder, or illness is discovered by a donor/donor-conceived person that may pose a threat to the life, health, or safety of a related person;
  - c. a clear and consistent risk assessment framework in relation to screening applicants for A.R.T. for whether they may pose a serious risk of harm to any child born as a result of providing them with treatment;
  - d. any other matters reported or found to be in need of such directives based on advice from the A.R.T. Advisory Council;
3. take advice from the A.R.T. Advisory Council regarding:
  - a. whether donors of gametes and embryos should be screened for criminal history, and if such history should be released to recipients and/or donor-conceived people,
  - b. research on the outcomes of A.R.T. practices for children born as a result (as well as upon recipients and donors of gametes/embryos);

4. promote (via the A.R.T. Advisory Council) and support to the extent possible, research into the short and long term outcomes of A.R.T. for the health and welfare of people born as a result; and
5. amend the statement of principle concerning the paramountcy of the welfare of the child within the *Assisted Reproductive Treatment Act 1988* (SA) to include the wording that both the health and welfare of the child born as a result of A.R.T. is paramount.

Such action would serve to uphold the paramountcy of the welfare of the child principle by better enabling it to be consistently operationalised across clinics, and for attention to matters which support the paramountcy principle to be had.

## 8.4 The Donor Conception Register

Also of great relevance to upholding the paramountcy of the welfare of the child born as a result of A.R.T. using donor conception, is that children are told about their status as donor-conceived, and may choose to access information about their donors and siblings if they decide to do so. This issue formed a major focus of the review, especially given that the changes to the Act in 2010 provided for the donor register to be established, but the Minister has not exercised his power to do so. Chapters Four and Five are thus dedicated to examination of whether the register should be established and the many associated issues this raised in order to uphold the paramountcy of the welfare of the child principle.

Chapter Four focused on issues surrounding the establishment of the donor conception register. The review revealed the call for information by recipients, donor-conceived people, and donors, has existed for more than thirty years. From at least the year 2000 the government's own representatives and advisors (including SACRT and the Social Development Committee) have been calling for the donor conception register to be established. I found the delay to be unacceptable given the impact it has had, and continues to have on those born as a result of A.R.T., as well as their families, and donors and their families. It is contrary to the paramountcy of the welfare of the child principle. My recommendation is thus that the Minister establish the donor conception register *as a matter of priority*.

I was also informed of issues regarding past records related to donor conception, and the difficulties surrounding access to information by donor-conceived people, recipient parents, and donors. Some past records are currently held in places that do not fall under the auspices of the Act, and donor-conceived people that they relate to are not afforded the same protections as others. A devolving of responsibility by the clinic who had created such records (and the children to whom they relate) due to changes in company ownership and place of business existed. The experiences people had when trying to access such records had caused them, and continues to cause, great distress and angst.

Attempts to access past records at another clinic had also caused some people distress.

In relation to all past records held in South Australia, recipients, donor-conceived people, and donors reported having been met by different staff who told them different things at different times about whether or not records had been destroyed; or if told they did exist, whether or not access to information could be had. In some families children had been conceived using sperm from different donors, which had increased distress and had also resulted in differential access to information about respective donors by siblings within the same family.

I found confusion and lack of support about past records and practices, and the current situation to be unacceptable. My recommendations in this regard are to first ensure all past records are transferred to the donor conception register. This would require having an expert in data management sort them, and determine what is there, but would ensure that remaining records are preserved. This would serve as a significant restorative measure to address injustices caused by the past “closed” culture that perpetuated donor anonymity, it being expressed to me that at least then donor-conceived people could trust what they are being told. I also recommend as a matter of priority that the Minister make it an offence to destroy past records relating to donor conception.

My inquiry then led to examination of whether to provide access to information by all donor-conceived people including those born under the past systems of secrecy and anonymity, and if so, how to balance their interests with those who donated under a previous regime. I found that while there was unanimous support for the register to be established by everyone that participated in the review, there were differences in opinion about whether consent should be required prior to the release of *identifying* information from past records.

Careful consideration of how to balance the interests of those who wish to access information, with those about whom the information relates was given, and a strong analogy drawn with the release of information about past adoption records, which had also once been subject to a culture of secrecy. My final recommendation in this regard was to implement a system in which identifying information could be accessed by donor-conceived people subject to a contact veto/preference statement being able to be lodged by past donors.

Chapter Five then moved to discuss further operational and other issues related to the donor register and access to information, raised during the review. Recommendations in relation to where the register should be held, how intermediary services would work to compliment it, access to information by donor-conceived people, recipients, donors and siblings, notification of donor-conceived status, information to be held on the register, voluntary registration, and record keeping followed.

Although presented with different views and options regarding where the donor conception register should be held, I was influenced by the view that although needing support to access information in certain instances, families formed using donor conception should not forever be treated differently to families formed in other ways. I also found that practices and expertise already existed at the BDM working in partnership with a trusted agency in relation to past adoption records. I found that this system was preferable to others that were considered. In addition, I noted that Births, Deaths, and Marriages, had already developed some systems in relation to the recording and release of information related to donor conception on birth registration forms and second birth certificates due to changes in the law in June 2016.

My final recommendations were for the donor conception register to be held at Births, Deaths and Marriages supported by a 'trusted agency' that supplies intermediary and support services. My recommendations also provide for notification of donor-conceived status, options regarding the issuing of a second-birth certificate showing biological heritage; and voluntary registration on the register by 'known' and past donors subject to BDM requirements, and the registration of consent to release of identifying information by donor-conceived people, recipients, and/or siblings. The system is one that would function well for what needs to happen now, but also into the future as all donor-conceived people are born as a result of gametes/embryos to which consent to release of information has already been provided. (See Figure 4 on page 204).

Chapter Five concluded by examining record keeping practices and follow-up by clinics in relation to donor conception. It was found that the current system could be strengthened by implementing a number of measures. This includes that the Minister should *require*

1. specific record keeping concerning donation, treatment, pregnancy, and birth,
2. follow-up on birth outcomes following donor conception;
3. adherence to the RTAC technical bulletin 8 issued which related to the matter; and
4. reporting on matters related to the use of donor-conception to recommended A.R.T.

Advisory Council or via the auditing process.

Adoption of the recommendations in Chapters Four and Five would ensure better access to information by donor-conceived people, recipients, and donors, and better practices and processes surrounding the recording and release of such information, into the future.

## 8.5 Access to A.R.T.

Chapter Six moved to discuss the issues raised during the review, and my findings and recommendations regarding the operation and effectiveness of the *Assisted Reproductive Treatment Act 1988* (SA) in relation to access to A.R.T. in South Australia. How the current law operates via the setting of ‘conditions’ for registration was noted, and compared to the previous regime by which an extensive Code of Ethical Practice determined access requirements. It was noted that some previous requirements regarding who could access A.R.T had been maintained, and in addition further instances had been introduced with the changes in 2010.

I found, in accordance with the recommendations of the South Australian Law Reform Institute concerning discrimination on the grounds of sexual orientation, gender, gender identity, or intersex status, that the Act should be amended to allow people to access A.R.T. if they are due to their circumstance unable to become pregnant, thus removing the infertility requirement.

I also recommended that the Minister clarify matters related to the provision within the Act that enables posthumous use of gametes, particularly in relation to whether it is acceptable to transport gametes out of the state without the *written* consent of the person from whom the gametes have been taken.

Other issues raised in submissions relevant to access to A.R.T. were also considered. Recommendations in relation to such things as body mass index, smoking, age related considerations, social egg freezing, social sex selection, and process issues, were made. While some issues called for the Minister to issue directives or clarify the law immediately (social sex selection, age limits being set at ‘menopause’ but lacking clarity), or for changes to the Act (social egg freezing), others lent themselves to further consideration.

It was noted that the operation and effectiveness of the Act is compromised if there is ambiguity surrounding how its requirements should be interpreted, or a lack of responsiveness by government when new issues arise. The role the recommended A.R.T. Advisory Council would play was again emphasised, noting it would have the ability to advise the Minister on such issues, which would in turn enable the Minister to act in a responsive regulatory manner if required.

## 8.6 Record Keeping

Chapter Seven provided brief information on the pre- 2010 South Australian legislative provisions regarding record keeping, and the changes to the Act in 2010. In that chapter it was noted that there are areas that may be improved in relation to record keeping and reporting relevant to A.R.T. that would enhance the operation and effectiveness of the Act. In this regard, throughout the report issues relevant to record keeping have been discussed and recommendations made in context—including in relation to the effective functioning of the co-regulatory system, the paramountcy of the welfare of the child, the establishment of a donor conception register, and matters that may inform policy and practice in relation to access to A.R.T.

In addition, I made two further recommendations in Chapter Seven. First, I recommend that the Minister should exercise his power to issue regulations under the Act, to stipulate the requirements concerning record keeping and documents in relation to the provision of A.R.T. and donor-conception, the length of required preservation of records, ongoing obligations concerning records should a clinic close, and responsibilities concerning records when a clinic changes hands.

Second, the Minister should establish a system of auditing and required reporting that includes (but is not limited to) reporting of data supplied to ANZARD to the A.R.T. Advisory Council. This would inform reflection upon clinical practice and outcomes of A.R.T., and in turn regulatory responses and policy development by the Minister. It should also be included in an annual report which would make such information accessible to the public.

Again, the recommendations throughout the report in relation to record keeping and reporting would support the better functioning of the co-regulatory system, promote better practice by requiring consistency across clinics, and enhance the operation and effectiveness of the Act.

## 8.7 The Future

The review of the operation and effectiveness of the *Assisted Reproductive Treatment Act 1988* (SA) proved extensive. Many issues were raised, new laws passed while I was conducting the review which required significant consideration, and I conducted an extensive inquiry into experiences, practices, existing expertise, resources, and regulation in South Australia relevant to A.R.T.

The recommendations I have made are intended to enhance the operation and effectiveness of the Act in relation to current issues, and to enable responsive regulation within the South Australian co-regulatory regime into the future. This will require follow up regarding the short and long term outcomes of A.R.T., examination of new technologies as they arise, and continuing public discussion of the ethical, legal and social issues raised by A.R.T., and responses to them over time.

In addition to the current issues discussed in this report, there were some matters that I did not address in this review but that may be considered as relevant to current practice. For example, whether the embryo cryopreservation limit of 10 years; and also whether the increased commercialism of the IVF industry calls for practitioners to have to disclose any vested interests they have in the clinics or treatments they provide. These again are matters that may be considered by the recommended A.R.T. Advisory Council if deemed necessary by the Minister.

There are also new issues on the horizon that most likely will need to be considered before the next review. For example mitochondrial donation (aka ‘three-person IVF’) has of late attracted much ethical debate and controversy. Proponents argue that mitochondrial donation offers women with mitochondrial disease an opportunity to have healthy, genetically related children. However, concerns have been raised about potential impacts concerning information about the donor<sup>532</sup>; about the impact mitochondrial DNA may have on a range of traits and functions such as fertility, cognitive ability, ageing, and personality;<sup>533</sup> and regarding the lack of understanding and knowledge of the long term impacts of the technique. The United Kingdom is currently the only nation that has passed regulations allowing the technique to proceed. In the United States a distinction has been drawn between “mitochondrial replacement techniques” (MRT) and the heritable genetic modification of nuclear DNA, a committee concluding that it would be ethically permissible to conduct clinical investigations of MRT provided they were subject to strict conditions. While currently prohibited in Australia,<sup>534</sup> no doubt there will be future debate concerning whether mitochondrial donation as a method to avoid mitochondrial disease should be permitted.

Secondly, in May 2015 Chinese scientists reported having used the new gene editing technique CRISPR-Cas9 to edit genes in *non-viable* human embryos.<sup>535</sup> This was followed in February 2016, by approval from the UK HFEA of a request by the Francis Crick Institute in London to modify the genes of *viable* human embryos using the technique for research provided the embryos were not permitted to grow beyond seven days. The aim of the UK research is to study early embryo development, however the broader potential for using the technique to modify disease-causing genes has been much discussed. When used on reproductive (germline) cells, it may lead to heritable changes. Proponents of human germline editing argue this is a positive thing, as it could decrease or eliminate many serious genetic diseases. Opponents however have expressed ‘grave concerns regarding the ethical and safety implications of ...research [that applies gene editing techniques to sperm, eggs, or

---

<sup>532</sup> F Baylis, ‘The ethics of creating children with three genetic parents’ (2013) 26 *Reprod Biomed Online* 531–4.

<sup>533</sup> Ted Morrow, ‘Three person IVF: Science shows ethical questions remain unanswered’ (2015) *The Conversation* <https://theconversation.com/three-person-ivf-science-shows-ethical-questions-remain-unanswered-36992>

<sup>534</sup> Prohibition of Human Cloning for Reproduction Act 2002 (Cth), s 23.

<sup>535</sup> P. Liang, Y. Xu, X. Zhang *et al.* ‘CRISPR/Cas9-mediated gene editing in human tripronuclear zygotes’ *Protein Cell* (2015) 6: 363. doi:10.1007/s13238-015-0153-5.

embryos]’.<sup>536</sup> At present numerous countries have laws against altering the human genome, including Australia.<sup>537</sup> But, the discussion continues. While at the time of writing there appeared to be no support for the clinical application of germline gene editing, and there does not appear to be any demonstrable high unmet medical need for its use, there is clearly some support for basic research to continue. Where this will lead in terms of A.R.T. is as yet unknown, but again is clearly something that will be debated into the future, and most likely will demand further regulatory response.

Consideration of such issues requires much more than regulatory expertise and oversight, it requires scientific, medical, ethical, and community expertise and input. The model I have recommended via the A.R.T. Advisory Council would serve this well.

My recommendations, if implemented, will also enable access to information by donor-conceived people, their families, and donors, via Births Deaths and Marriages, in a way that may serve them now and into the future. It is hoped that such a future will be one which increasingly recognises that secrecy and shame surrounding families formed using donor conception is not necessary, and can be very harmful. To this end, I have also suggested a role for the A.R.T. Advisory Council in engaging in community education and discourse, as well as a requirement for clinics to uphold their obligations under the NHMRC Ethical Guidelines to inform recipients and donors about the importance that children know about their biological heritage and to provide them support. The recommended model will also serve well as society moves to understand and accept that seeking information about biological and legal parentage is something all people should be able to do.

The future of A.R.T. is likely to be one just like its past, one that promises hope and may assist family building, but also one that raises ethical, legal and social issues that challenge us as a society. Having a system that operates effectively to enable family building; ensure quality and safety of practice; achieve the best outcomes possible for children born as a result of A.R.T., recipients and donors; and that enables responsive regulation when required, will support South Australia in being a leader in the field.

On the basis of having now completed my review of the *Assisted Reproductive Treatment Act 1988* (SA) I provide details of my deliberations, my findings and recommendations, in this report. I note, in conclusion, Recommendation 7, that the Minister

---

<sup>536</sup> Edward Lanphier, *et al.* ‘Don’t edit the human germline’ *Nature Comment* 12 March 2015.

<sup>537</sup> *Prohibition of Human Cloning for Reproduction Act 2002* (Cth), s 15.

should ensure provision in the Act for review of its operation and effectiveness five years after the date of this report being tabled in Parliament. This will enable assessment of whether the recommendations in this report have been implemented, or what has been put in their place, and how such things are working. It will again support the role of government to maintain active participation in the co-regulatory regime, and to respond to any matters required.

# Appendices

# APPENDIX 1:

## Consultation letters inviting contribution

Individual letters were sent to the following providing them with Fact Sheets containing information about the review, and inviting them to participate:

- all fertility clinics in South Australia;
- the Australian New Zealand Association of Infertility Counsellors (ANZICA);
- the Victorian Assisted Reproductive Authority (VARTA);
- the Reproductive Technology Council (RTC) of Western Australia;
- the New South Wales Central Register (Department of Health);
- the Fertility Society of Australia (FSA);
- the Reproductive Technology Accreditation Committee (RTAC);
- leading Australian and international academics who had researched and/or published in the area of assisted reproductive technologies;
- religious representatives of the Islamic, Muslim, Jewish, Catholic, Christian, Greek Orthodox, Sikh, and Hindu faiths;
- the Donor Conception Support Group Australia;
- the Australian Donor Conception Network;
- individuals who had previously contacted South Australia Health in relation to the regulation and outcomes of assisted reproduction (including recipients, donors, and donor-conceived people) and/or who had engaged in prior consultations on matters related to assisted reproduction;
- the Fay Gale Centre for Research on Gender;
- Healthy Development Adelaide;
- the Hawke Research Institute;
- the Victorian Adoption Network for Self Help (VANISH);
- ACCESS Australia;
- Shine SA;
- the Council for the Care of Children;
- MADMen (a support group for donors of sperm);

- the Australian Human Rights Commission;
- the South Australian Office for Women;
- the South Australian Premier's Council for Women;
- Relationships Australia;
- the Law Society of South Australia;
- a number of doctors at the Women's and Children's Hospital in South Australia;
- Paediatrics SA, Memorial Medical Centre;
- Fertility Nurses SA;
- Scientists in Reproductive Technology;
- Heads of Schools at South Australian Universities in which research on assisted reproductive treatment had occurred (requesting dissemination of information about the review); and
- Solo Mum's by Choice.
- Fertility Nurses Australia (FNA)
- Scientists in Reproductive Technology (SIRT)
- Health and Community Services Complaints Commissioner
- General Practice SA
- Health Consumers Alliance of SA Inc.

## APPENDIX 2: Consultation Poster

**Review of the  
*Assisted Reproductive  
Treatment Act 1988 (SA)***

Have you worked in A.R.T?  
Have you accessed or tried to access A.R.T?  
Have you been or are thinking of becoming a donor?  
Have you been born as a result of A.R.T, including through donor conception?  
Have you had any other experience of A.R.T?

**WE WANT TO HEAR YOUR STORIES.**

A legislated independent review is being conducted by Associate Professor Sonia Allan in relation to the operation and effectiveness of the *Assisted Reproductive Treatment Act 1988 (SA)*, following significant changes made to the Act in 2010.

Written submissions are invited from interested parties on matters relevant to these changes with particular focus on the welfare of the child, provision for a donor register, oversight of clinics, certain conditions for access to A.R.T., and record keeping.

Join the discussion, make an online submission and find further information about the review at <http://yoursay.sa.gov.au/art-act-review>

**Please provide your submission by 15 April 2016**

Submissions may also be emailed to A/Prof Sonia Allan at [HealthPolicyLegislation@sa.gov.au](mailto:HealthPolicyLegislation@sa.gov.au) (subject heading "ART Act Review")

Or mailed to:  
A/Prof Sonia Allan  
ART Act Review  
c/- Policy and Intergovernment Relations Unit  
SA Health, PO Box 287, Rundle Mall, ADELAIDE SA 5000

FIG: 16004.8 January 2016



## APPENDIX 3:

# Meetings and Live Consultations

18/04/2016:

1. Meeting with a lawyer, previously a member of the former South Australian Council on Reproductive Technology (SACRT), interested in the regulation of assisted reproduction, and practising in the area;
2. Meeting with representatives from the South Australian Health Epidemiology Unit from the pregnancy outcomes unit; and cancer research unit;
3. Meeting with representatives from the South Australian Attorney General's Department, Births, Deaths and Marriages (including the Manager/Registrar and Senior Policy Officer);
4. Meeting with the Freedom of Information Officers (x2) from the Queen Elizabeth's Hospital Assisted Reproductive Treatment Records Unit;
5. Donor-conceived consultation forum, attended by donor-conceived people

19/04/2016:

6. Meeting with Repromed/My IVF including individual meetings with:
  - a. Hamish Hamilton (General Manager),
  - b. Richard Henshaw (Medical Director)- clinician since 1995
  - c. Karen Rivers – Day Surgery Manager, Quality Manager and Infection Control and Josie – Administrative Manager
  - d. Carole Tilbrook – Nurse Manager
  - e. Emma Angel - Counsellor and head of donor program
  - f. Deidre Zander-Fox -- Scientific Director of Monash, Repromed, Labs in Qld, MyIVF, Kuala Lumpur

19/04/2016:

7. Meeting with City Fertility including meeting with:
  - a. Adnan Catakovic – CEO and Scientific Director

- b. Tania Centofanti – Senior nurse and donor-co-ordinator
- c. Helena Jericho – Program manager – Vic and SA.

20/04/2016:

- 8. Meeting with Fertility SA including meeting with:
  - a. Prof Robert Norman – Medical Director
  - b. Dr Sally Reid – Clinician
  - c. Lee Battye – General Manager
  - d. Michael Barry – Scientific Director
  - e. Paula Scanlon – Nurse Manager
- 9. Meeting with a representative of the South Australian Government’s Adoption Policy Unit;
- 10. Meeting with a representative counsellor from the South Australian branch of Relationships Australia;

21/04/2016:

- 11. Donor consultation: In person and phone consultations with four sperm donors;
- 12. Phone consultation with donor-conceived person;
- 13. Meeting with representatives from the South Australian Attorney General’s Department, Births, Deaths and Marriages (including the Manager/Registrar and Legal Policy Officer);
- 14. Consumers of A.R.T. forum, held at the Health Consumers Alliance (meeting included people who had accessed A.R.T. with and without use of donor, a researcher from the Robinson Institute, a donor conceived youth (under 18, accompanied by parent), a religious leader from the Greek Orthodox faith)

22/04/2016:

- 15. Meeting with Flinders Fertility including meeting with:
  - a. Stefan Moro, CEO
  - b. Herman Fernandez, Scientific Director

## May 2016

16. Further phone consultations were conducted in May, after the above consultation period, with the following people (who could not make the April meetings):
  - a) Geraldine Yam, Company Secretary ACN 008123466 Pty Ltd, The University of Adelaide (about historical records held by the University of Adelaide):
  - b) Flinders Fertility:
    - a. Angela Harding, Donor Conception Coordinator
    - b. Julie Potts, Counsellor.

## May 2016 to January 2017

17. Follow up phone calls and emails received and responded to from donor-conceived people, recipients, and donors;
18. Visits to:
  - a. New South Wales Ministry of Health
  - b. Victorian Assisted Reproductive Treatment Authority
19. Follow up phone discussions with Western Australia, Reproductive Technology Unit
20. Follow up discussions with Registrar of Births, Deaths and Marriages, South Australia

## APPENDIX 4: Written Submissions

Submission Number	Date Received	Name	Interest
1	18-Jan	CONFIDENTIAL	Donor
2	19-Jan	CONFIDENTIAL	ART Parent and Consumer
3	20-Jan	CONFIDENTIAL	General Public
4	20-Jan	CONFIDENTIAL	ART Consumer
5	18-Apr	CONFIDENTIAL	Donor-conceived person
AC	21-Jan	Name Withheld	General Public
6	21-Jan	Mrs. Rosalie DOW-SCHMIDT	ART Consumer
7	21-Jan	CONFIDENTIAL	Donor-conceived person
8	21-Jan	CONFIDENTIAL	General Public - Interested in becoming a donor
9	21-Jan	Peter LISTON	Donor
10	21-Jan	CONFIDENTIAL	General Public - Medical Practitioner
11	21-Jan	Professor Jane ANDREWS	General Public - Medical Practitioner
12	22-Jan	CONFIDENTIAL	General Public
13	22-Jan	CONFIDENTIAL	ART Consumer
14	22-Jan	CONFIDENTIAL	ART Parent
15	25-Jan	Mrs. Aimee	General Public
16	26-Jan	CONFIDENTIAL	General Public
17	27-Jan	Dr. Anna PETTS	General Public
18	27-Jan	Kay	ART Parent
19	19-Jan	Miss Kim PACE	Donor-conceived person
20	29-Jan	CONFIDENTIAL	ART Consumer
21	29-Jan	Mrs. Amanda FISCHER	ART Consumer
22	03-Feb	CONFIDENTIAL	General Public
23	04-Feb	Dr. Damien W. RIGGS	Academic

24	04-Feb	Mrs. Amanda ALDERSON	ART Parent
25	08-Feb	CONFIDENTIAL	ART Parent
26	12-Feb	Dr. Mark DODD	ART Parent and Donor
27	14-Feb	Mrs. Caroline LORBACH	ART Parent
28	19-Feb	CONFIDENTIAL	ART Consumer
29	22-Feb	Health & Community Services Complaints Commissioner - Steve Tully	Other
30	22-Feb	CONFIDENTIAL	Donor
31	25-Feb	Mr. John MAYGER	Donor
32	26-Feb	CONFIDENTIAL	ART Parent
33	28-Feb	Lauren BURNS	Donor-conceived person
34	28-Feb	Damian ADAMS	Donor-conceived person
35	28-Feb	Miss Chloe ALLWORTHY	Donor-conceived person
36	29-Feb	Karley FOORD	ART Consumer
37	04-Mar	Lyndall KAY	General Public
38	06-Mar	James HARVEY	ART Practitioner
39	10-Mar	Miss Hayley SMITH	Donor-conceived person
40	11-Mar	Mrs. Danica LITTLE	Donor-conceived person
41	17-Mar	Kim BUCK	Donor-conceived person
42	20-Mar	CONFIDENTIAL	ART Consumer
43	21-Mar	CONFIDENTIAL	ART Consumer
44	22-Mar	RTAC	Other
45	24-Mar	Professor Sheryl DE LACEY & Kelton TREMELLON	Academic
46	24-Mar	Miss Rebecca MACKAY	ART Practitioner
47	29-Mar	Wendy KRAMER	Other
48	05-Apr	Belinda LIEBELT	Donor-conceived person
49	08-Apr	Fertility SA	ART Clinic
50	08-Apr	Adelaide University - Geraldine Yam	Other
51	11-Apr	Marilyn Crawshaw	Academic

52	11-Apr	Eric Blyth	Academic
53	11-Apr	CONFIDENTIAL	ART Consumer
54	22-Apr	Office for Women	Other
AA	11-Apr	VARTA	Other
55	11-Apr	Dr. Kelly Ann	Donor
56	12-Apr	Myfanwy Cummerford	Donor-conceived person
57	12-Apr	Professor Olga van den Akker	Academic
58	12-Apr	Vanish	Other
59	12-Apr	Family Voice	Other
60	12-Apr	Ross Hunter	Donor-conceived person
61	12-Apr	Natalie Parker	Donor
62	14-Apr	Premier's Council for Women	Other
63	14-Apr	City Fertility	ART Clinic
64	14-Apr	CONFIDENTIAL	Other
65	15-Apr	Council for the Care of Children	Other
66	15-Apr	Relationships Australia	Other
67	15-Apr	Sandra Bevan	ART Parent
68	15-Apr	CONFIDENTIAL	ART Clinic
69	14-Apr	Kylie Dempsey	Donor-conceived person
70	14-Apr	Sofie Gregory	Other
71	14-Apr	CONFIDENTIAL	Other
72	14-Apr	International Social Service Australia	Other
73	15-Apr	Ian Smith	Donor
74	15-Apr	Robinson Research Institute	Other
75	15-Apr	Repromed	ART Clinic
76	18-Apr	CONFIDENTIAL	ART Parent
77	18-Apr	Law Society	Other
78	22-Apr	WA RTC	Other
79	22-Apr	Reece TREVENEN	Donor-conceived person
80	26-Apr	CONFIDENTIAL	Other

81	26-April	Kimberley Turner	Donor-conceived person
82	27-Apr	ANZICA	Other
83	29-April	CONFIDENTIAL	Other

## APPENDIX 5: Comments on YourSAy

Leonie Waite, 1 April 2016

Rebecca MacKay, 24 March 2016

Rosalie Grace, 17 March 2016

Laura Easthope, 07 March 2016

John Mayger, 25 February 2016

Kim Buck, 17 February 2016

Peter Kennelly, 10 February 2016

Jane Kennelly, 08 February 2016

Talia DC, 29 January 2016

Karen Abraham, 22 January 2016

# APPENDIX 6: HFEA Welfare of the Child Guidance

(See <http://www.hfea.gov.uk/5473.html>)



## Mandatory requirements

### Human Fertilisation and Embryology (HFE) Act 1990 (as amended)

Section 13 (5): A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for supportive parenting), and of any other child who may be affected by the birth.

Section 2 (1) ... "treatment services" means medical, surgical or obstetric services provided to the public or a section of the public for the purpose of assisting women to carry children.

### Licence conditions

T56 A woman must not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for supportive parenting), and of any other child who may be affected by the birth.

[Back to top](#)

Cont.....



### Scope of the welfare of the child provision



#### Interpretation of mandatory requirements

8A

No treatment services regulated by the HFEA (including intrauterine insemination - IUI) may be provided unless account has been taken of the welfare of any child who may be born as a result (including the need of that child for supportive parenting) and of any other child who may be affected by the birth.

- 8.1 This guidance note applies to all fertility treatments regulated by the HFEA, including IUI. Centres providing treatments that are not regulated by the HFEA but that fall within the definition of 'treatment services' (see above) may also find this guidance note helpful.

### The welfare of the child assessment process

- 8.2 The centre should have documented procedures to ensure that proper account is taken of the welfare of any child who may be born as a result of treatment services, and any other child who may be affected by the birth.
- 8.3 The centre should assess each patient and their partner (if they have one) before providing any treatment, and should use this assessment to decide whether there is a risk of significant harm or neglect to any child referred to in 8.2.
- 8.4 If the child is not to be raised by the carrying mother (ie, in a surrogacy arrangement), the centre should assess both those commissioning the surrogacy arrangement and the surrogate (and the surrogate's partner, if she has one) in case there is a breakdown in the surrogacy arrangement.

**See also:**  
[14 - Surrogacy](#)

- 8.5 Assessments do not need to be done on gamete or embryo donors (including mitochondrial donors), or in cases where gametes are being stored for later use.
- 8.6 The centre should repeat the assessment if:
- the centre has been out of contact with the patient for two years or more
  - the patient has a new partner
  - a child has been born to the patient since the previous assessment, or
  - the centre has reason to believe that the patient's medical or social circumstances have changed significantly.

- 8.7 Those seeking treatment are entitled to a fair assessment. The centre is expected to consider the wishes of all those involved, and the assessment must be done in a non-discriminatory way. In particular, patients should not be discriminated against on grounds of gender, race, disability, sexual orientation, religious belief or age.

**See also:**

**29 - Treating people fairly**

- 8.8 If patients have referred themselves for treatment, the centre should take all reasonable steps to verify the identity of those seeking treatment with appropriate evidence (eg, passport or photocard driving licence).
- 8.9 The centre should take a medical and social history from each patient and their partner (if they have one). Where appropriate, the patient and their partner may be interviewed separately. The information gathered should relate to the factors in paragraphs 8.10–8.12 below.

**Factors to take into account during the assessment process**

- 8.10 The centre should consider factors that are likely to cause a risk of significant harm or neglect to any child who may be born or to any existing child of the family. These factors include any aspects of the patient's or (if they have one) their partner's:
- a) past or current circumstances that may lead to any child mentioned above experiencing serious physical or psychological harm or neglect, for example:
    - i) previous convictions relating to harming children
    - ii) child protection measures taken regarding existing children, or
    - iii) violence or serious discord in the family environment
  - b) past or current circumstances that are likely to lead to an inability to care throughout childhood for any child who may be born, or that are already seriously impairing the care of any existing child of the family, for example:
    - i) mental or physical conditions
    - ii) drug or alcohol abuse
    - iii) medical history, where the medical history indicates that any child who may be born is likely to suffer from a serious medical condition, or
    - iv) circumstances that the centre considers likely to cause serious harm to any child mentioned above.
- 8.11 When considering a child's need for supportive parenting, centres should consider the following definition:
- 'Supportive parenting is a commitment to the health, well being and development of the child. It is presumed that all prospective parents will be supportive parents, in the absence of any reasonable cause for concern that any child who may be born, or any other child, may be at risk of significant harm or neglect. Where centres have concern as to whether this commitment exists, they may wish to take account of wider family and social networks within which the child will be raised.'
- 8.12 If the child will not be raised by the carrying mother, the centre should take into account the possibility of

a breakdown in the surrogacy arrangement and whether this is likely to cause a risk of significant harm or neglect to any child who may be born or any existing children in the surrogate's family.

### Obtaining further information during the assessment process

**8.13** The centre should obtain consent from the prospective patient (and their partner if they have one) to approach any individuals, agencies or authorities for any factual information required for further investigation if:

- a) information provided by the patient (and their partner if they have one) suggests a risk of significant harm or neglect to any child
- b) the patient (and their partner if they have one) has failed to provide any of the information requested
- c) the information the patient (and their partner if they have one) has provided is inconsistent, or
- d) there is evidence of deception.

A refusal to provide consent to disclosure of information should not, in itself, be grounds for denying treatment but the centre should take this into account in deciding whether to provide treatment. The centre should discuss with the patient (and their partner if they have one) the reason for refusing to provide consent.

**8.14** If information has been provided in confidence to a member of staff, the staff member should seek consent from the information provider to discuss it with other staff. If such consent is refused and the member of staff considers the matter to be crucial to a decision, they should use their discretion, based on good professional practice, in deciding whether to break that confidence. In line with professional guidance, patients should normally be informed of the decision to break confidence and the reasons for it, before the information is shared with other members of staff.

### Refusing treatment

**8.15** The centre should refuse treatment if it:

- a) concludes that any child who may be born or any existing child of the family is likely to be at risk of significant harm or neglect,
- or
- b) cannot obtain enough information to conclude that there is no significant risk.

**8.16** In deciding whether to refuse treatment, the centre should:

- a) take into account the views of all staff who have been involved with caring for the patient (and their partner if they have one),
- and
- b) give the patient (and their partner if they have one) the opportunity to respond to the reason or reasons for refusal before the centre makes a final decision.

**8.17** If treatment is refused, the centre should explain, in writing, to the patient (and their partner if they have one):

- a) why treatment has been refused
- b) any circumstances that may enable the centre to reconsider its decision
- c) any remaining options, and
- d) opportunities for obtaining appropriate counselling.

## Record keeping

- 8.18** In all cases, the centre should record in the patient's medical records the information it has considered during the assessment. If further information has been sought or discussion has taken place, the record should reflect the views of those consulted in reaching the decision and the views of the patient (and their partner if they have one).

---

## APPENDIX 7:

### Information Regarding Past Records Concerning A.R.T. and Donor Conception Held at Queen Elizabeth Hospital

During the review I was able to ascertain that information that the Queen Elizabeth Hospital Freedom of Information (FOI) officers manage related to A.R.T. involves 400 archive boxes of female A.R.T. patient records. Some, but not all such records, relate to donor-conception.

The 400 archive boxes are stored at State records.

At present to obtain access to a record people need to put in a Freedom of Information request. For donor-conceived people and/or recipients wanting information, this generally means that the mother (recipient of donor-conception) needs to agree to her record being accessed. The record is then given to her, and she needs to take it to Adelaide University to see if they can provide any further information regarding the donor. Note, in relation to these files, information is only accessed upon request. There has not been any sorting of the records to determine which ones relate to donor-conception, nor of information contained within them.

#### Further discovery

In addition to the above 400 boxes of records, I was informed during the consultation period that recently the Queen Elizabeth Hospital FOI officers also recently discovered 30 larger boxes of random unsorted A.R.T. records. Some such records also relate to donor-conception. The boxes had not been 'sentenced' (which means they had not been identified or classified according to retention or disposal authority), and thus were sitting in storage undiscovered for some time.

The 30 boxes are full of different unsorted coloured sheets of paper which the records officers were not able to understand or decipher.

## Appendix 7 cont....

Persons who worked in A.R.T. at the time such records were created were able to provide some further information. However such information indicates extensive sorting would be necessary to establish exactly what data is there. For the purposes of being transparent and open, I note I was informed the sheets include (but are not limited) to the following:

- Forms of the colours Yellow/Blue/Green that are IVF cycle sheets. They may be marked with an R if the woman is a recipient of donor material (e.g. 99-001R). If the woman is a donor, they may be marked with a D, but not necessarily;
- Embryo Freezing Worksheets – these sheets contain no indication of outcomes (pregnancy or birth) but may include information about being a recipient or donor.
- Pink Embryo Thaw and Transfer Worksheets, which may have donor embryo marked on it. When there has been a pregnancy the sheet is marked with a P.
- White patient registration documents which identify whether a patient was involved in donor program. Such sheets could pertain to an anonymous oocyte donor; anonymous ovum donor, or a donor embryo recipient. Such sheets may contain Medicare number, name and address and date of birth, medical history, and physical characteristics.

Note, although the records contained in the 30 boxes may aid in identifying links between some recipients and donors, and also identifying some donors, what is there is unclear. Information would need to be sorted and data linked. In order to undertake such a task, appropriate privacy protections need to be implemented, including access only by an authorised person.

## APPENDIX 8:

### Information Regarding Past Records Concerning Donor Conception Held at Adelaide University/ACN

ACN is not a registered clinic nor do they provide A.R.T. services. They are therefore not bound by any A.R.T. legislative requirement or NHMRC Ethical Guidelines. Nevertheless, they continue to store some records, and to receive and process requests for information by donors, donor-conceived people, and recipients.

Via consultation with the person who currently oversees the information held at ACN, I was able to establish that the following information is held by them.

#### **1. Birth outcomes spreadsheet – donor sperm**

The ACN holds an Excel spreadsheet on birth outcomes using donor sperm that was generated from patient data extracted from pre-2006 Repromed's electronic records database. A copy of the original database remains in storage (with offsite 3<sup>rd</sup> party hosting service). There are **895 entries** in the birth outcomes spreadsheet sorted by patient, with the following columns for each patient: Patient RMU number (unique identifier / patient number); Surname; Given name; Patient DOB; Donor code used; Delivery date; Gestation period; No of babies delivered; Baby's sex; Whether baby was born alive / stillborn / died <1 year.

Some patients have multiple entries if they had multiple treatments; some patients had multiple births. The estimated number of births in the spreadsheet equals approximately 1000. The delivery dates range from **1980 – 2003**. It is unclear why pre- 1987 birth outcomes are recorded given that Repromed Pty Ltd was only established in 1987. There are no entries from 2003 onwards – it is believed this is due to a change in Repromed's electronic records system at the time. It is possible that post-2003 birth outcome records may still be held by the current Repromed.

There were **156 different donor codes** used in the entries recorded in the spreadsheet. From the data contained in this spreadsheet, it is possible to ascertain the sperm donor code used for an individual patient; and to filter by donor code to obtain the number

of births by that sperm donor code. It is not possible to link an individual sperm donor to a patient in the spreadsheet as there are no names associated with the donor codes. The identity of the donor can only be ascertained if the donor code is in the records outlined in item (4) below.

## **2. Birth outcomes spreadsheet – donor embryos / eggs**

The ACN holds an Excel spreadsheet on birth outcomes using donor embryos or eggs that was generated from patient data extracted from pre-2006 Repromed's electronic records database. A copy of the original database remains in storage (with offsite 3<sup>rd</sup> party hosting service). There are **92** entries of egg recipients that resulted in **97** births; and **9** entries of embryo recipients that resulted in **10** births. For each entry, the following data is contained in the spreadsheet: Recipient RMU number; Recipient surname; Recipient given name; Recipient DOB; Whether egg / embryo used; Donor RMU number; Donor given name; Donor DOB; No of babies delivered; Delivery date; Baby's sex; Whether baby was born alive.

From this spreadsheet, it is possible to match each recipient with the egg/embryo donor. The delivery dates range from **1988 – 2003**. There are no entries from 2003 onwards – it is believed this is due to change in Repromed's electronic records system at the time. It is possible that post-2003 birth outcome records may still be held by the current Repromed.

## **3. Hardcopy patient / counselling files in ACN's possession**

The ACN holds the following hardcopy patient/counselling files:

<b>Category</b>	<b>Number of persons</b>
Donor sperm recipients	312
Donor egg / embryo recipients	67
Egg / embryo donors	46
Possible sperm donors (counselling notes only)	67*

The 67\* possible sperm donor files are counselling files under male names. As patient files are under the female patient's name, it is assumed that such files relate to persons who were interviewed as possible sperm donors, but this would need to be verified.

All of the abovementioned files have been isolated from the rest of the patient files in ACN's possession. The ACN notes that it is understood that many patient files were retained by the Queen Elizabeth Hospital where the patients received their treatment.

#### **4. Sperm donor codes and names**

The only documents in ACN's possession that match a sperm donor code to a name are:

- a) Photocopied pages from a diary (referred to as "the black book") in which there is a handwritten list of names against codes. There are 169 entries not including entries that have been crossed out.
- b) A PDF table which has 23 donor names, donor code and contact details. This table is believed to be a list used to contact donors to seek transfer consents leading up to the business sale in 2006.

The ACN noted that the above documents are not a complete list of donor codes used. There have been instances where it has not been possible to match a donor code (obtained from the birth outcomes spreadsheet) to a name.

Also in ACN's possession is an Excel spreadsheet of donor names and contact details extracted from a CD that was in one of the boxes of records left with ACN. This does not contain any donor codes. Most of the contact details are now out of date, however this information may be useful in comparing against search results from the electoral roll.

#### **5. Voluntary register**

A Word document was established by ACN in 2011 to record the contact details of inquirers who consent to being contacted by their donor parent, child/ren or sibling/s (as the case may be). At present it holds the details of **6 sperm donors; 2 egg donors; 1 embryo donor; and 3 donor-conceived people.**

Recordkeeping on donor-related inquiries has only been kept in easily accessible form since 2009. The number of enquiries since then are as follows: 2009 (x6); 2010 (x5); 2011 (x6); 2012 (x4); 2013 (x11); 2014 (x10); 2015 (x16); 2016(to May) (5), totaling sixty-three enquiries (made by sixty people as some enquirers returned at a later date with further inquiry and were recorded as a separate enquiry). Enquiries came from donor-conceived children (or parents on their behalf) (thirty-five from donor sperm; two from donor egg; two from donor embryo); donors (eight from sperm donors; two from egg donors; three from embryo donors); or former patients treated with donor material (eight)

# APPENDIX 9: Birth Registration Form (BDM)

## d) Father/co-parent's details (as at the birth of this child)

Father/co-parent's details must be provided and he/she must sign this form. If father/co-parent will not sign see item j).

I am the father co-parent

Surname

Surname at birth (or adoption)

Given name/s

Father/co-parent's date of birth

Father/co-parent's place of birth

suburb/town

state/country

Usual occupation (e.g teacher, mechanic, home duties, unemployed)

Street address (as at time of birth of child)

postcode

Is the father/co-parent of Aboriginal or Torres Strait Islander origin\*

No

Yes, Aboriginal

Yes, Torres Strait Islander

\* For persons of both Aboriginal or Torres Strait Islander origin, mark both "Yes" boxes.

This information is collected for statistical and community planning purposes only and will not appear on the birth certificate.

## e) Marriage details (if legally married)

Date of marriage of mother to father

Place of marriage

suburb/town

state/country

## f) Previous children of this relationship

- If no previous children of this relationship write 'None' in first column
- Enter children in order of birth
- If legally adopted enter 'A' in X column
- If deceased enter 'D' in X column
- If not born alive enter 'SB' in X column

Given name/s	Sex	Date of birth	X
		/ /	
		/ /	
		/ /	

## g) Other children of the birth mother\*

(but not of this relationship)

- Enter children in order of birth
- If legally adopted enter 'A' in X column
- If deceased enter 'D' in X column
- If not born alive enter 'SB' in X column

Given name/s	Sex	Date of birth	X
		/ /	
		/ /	
		/ /	

## h) Children conceived via a fertilisation procedure

1. Was the child conceived via a fertilisation procedure?
 

Yes	No	(if no go to section j)
-----	----	-------------------------
2. Did the father/co-parent consent to the fertilisation procedure that led to the birth of this child?
 

Yes	No	N/A
-----	----	-----
3. If not legally married at the time of conception of the child, were you living together as a couple in a marriage-like\* relationship as domestic partners<sup>1</sup> for 3 years total or 3 out of 4 years?
 

Yes	No	N/A
-----	----	-----
4. If you do not meet the requirements of Q3, were you living together with your partner in a marriage-like relationship?
 

Yes	No	N/A
-----	----	-----
5. If yes, a Section 10c declaration<sup>2</sup> must be made and signed by each party to the declaration. For more information refer to FAQs on back page.
 

Do you know who the donor was?

Yes	No
-----	----

If you answered yes, you are required under S14(2) of the BDM Act to include the donor's details. Please have the donor sign the statement acknowledging they were the donor and that the information provided is correct. Please go to section i).

\*for definition of these terms, please see back page.

## i) Donor's details (as at the birth of this child)

The donor must complete and sign this section. If you do not wish to contact him/her yourself, please provide contact details and Births, Deaths and Marriages will contact him/her on your behalf. If there is more than one donor, please attach a statement with the other donor's details, their signature and contact details.

Surname

Given name/s

Donor's date of birth

Donor's place of birth

suburb/town

state/country

Donor's Sex

Male Female

I (donor's name)

of (current postal address and postcode)

postcode

Telephone: Mobile (preferred) Home

Email

certify that I have read this form thoroughly and that the information provided in this section, to the best of my knowledge and belief, correct for the purpose of insertion in the Register.

I understand that donor information will be available to the child when they reach 18 years.

Donor's signature

Date

/ /

## j) Parents' signatures

Both parents must complete and sign this form, whether they are legally married or not, and whether they are in a continuing relationship or not. Signing the form acknowledges parenthood of the child. Refusal to sign because of an unresolved dispute may result in a parent losing the opportunity to have a say in the naming of the child at the time of registration. If the parents are in dispute over the name of the child, both are still required to sign the statement and attach explanatory information. If only one parent has signed this statement, he or she must **attach a statement** explaining why the other parent has not signed.

[ ] Tick here if you **DO NOT** want to receive information from the State/Commonwealth Government on how to **improve your child's development and wellbeing**.

I (birth mother's name)

of (current postal address and postcode)

postcode

Telephone: Mobile (preferred) Home

Email

certify that I have read this form thoroughly and that the information provided is, to the best of my knowledge and belief, correct for the purpose of insertion in the Register.

Birth mother's signature

Date

/ /

I (father/co-parent's name)

of (current postal address and postcode)

postcode

Telephone: Mobile (preferred) Home

Email

certify that I have read this form thoroughly and that the information provided is, to the best of my knowledge and belief, correct for the purpose of insertion in the Register.

Father/co-parent's signature

Date

/ /



# Index

## A

- ACCC (Australian Competition and Consumer Commission), 36, 38
- ACT (Australian Capital Territory), 43-44, 231
- access
- age limit, 33, 220-22
  - A.R.T., to 4, 6, 8, 33, 74, 82, 86, 88, 207-08, 211, 218, 221, 226, 228
  - body mass index (BMI), 215-18, 228, 244
  - infertility requirement, 208-9, 221, 224, 226, 228, 243
  - information, to 6, 23, 54, 56, 100, 105-10, 115, 118, 120-121, 123, 125, 129, 133, 135, 138, 140, 146-7, 151-55, 159, 162, 169-72, 174-75, 177, 180, 189-190, 191, 193, 203-204
  - adoption, 149, 151-55
  - donors, by 177
  - notification of status, 26, 67-68, 162, 186, 189-90, 193-94, 203, 242
  - known donors, about 191, 196-197
  - siblings, about 180
  - See also addendum to birth certificate; birth certificate; birth registration
  - marital status, 77, 85-86, 208, 210-211, 216
  - non-medical reasons, 60-61, 221-22
  - posthumous use of sperm, 4, 207, 211-13
  - provisions, 208, 215, 228
  - smoking, 215, 217-18, 228, 244
  - social egg freezing, 221-22, 224-26, 228, 244
- accreditation, 3, 19, 26, 28, 30-31, 36, 187
- addendum, to birth certificate, 190, 194-95, 197, 203
- Adelaide Fertility Centre. *See* AFC
- administrative review, 92
- adoptees, 145, 147-51
- adoption, 8, 76, 143, 145-48, 150-52, 156, 164-66, 208, 243
- information services, 172, 173
  - records, 145, 148, 150
  - services, 164, 166
  - US, 149-50
- AFC (Adelaide Fertility Centre), 20, 127, 131, 274
- age, 106, 108-10, 150, 154-55, 172-73, 175-82, 185, 188, 190-92, 195-96, 200, 204, 219-21, 225, 228
- advanced, 218-20, 224
- American Society of Reproductive Medicine. *See* ASRM
- ANCOR (Australian National Child Offender Register), 78, 89, 91, 93
- annual reports, 26-27, 43, 45, 47-48, 91, 97, 119, 164, 233, 237, 245
- anonymity, 104, 115-16, 119, 138, 140-43, 155, 157-58, 160, 172-73, 175, 195, 241
- ANZARD (Australia and New Zealand Assisted Reproduction Database), 28, 232-34, 245
- APPs (Australian Privacy Principles), 66-67
- Argentina, 105-6, 174, 190
- A.R.T. Advisory Council, 24, 44-48, 94-95, 99, 189, 213, 217-18, 225-28, 233, 237-40, 243-45, 247
- ASRM (American Society of Reproductive Medicine), 82-83, 223-24
- assault, sexual, 88-89
- audit, 28, 45-48, 209, 237-38
- auditing, 22, 31, 38-39, 42, 45-46, 48, 77, 189, 232, 234, 237, 239, 245
- Australia and New Zealand Assisted Reproduction Database. *See* ANZARD
- Australian Competition and Consumer Commission (ACCC). *See* ACCC
- Australian Health Ethics Committee, 32
- Australian Institute of Health and Welfare, 147
- Australian National Child Offender Register. *See* ANCOR
- Australian Privacy Principles. *See* APPs
- Austria, 8, 62, 105

## B

- BDM (Births, Deaths, and Marriages), 164-67, 171-72, 176-77, 179, 181,

184, 189, 191, 193, 196–97, 202, 204, 242, 271

best interests, of children, 22, 34, 42, 52, 54, 61, 75, 85, 107, 190, 212

biological,  
 parents, 85, 143, 171, 191–92, 212  
 heritage, 151–52, 169, 192, 202, 242, 247

birth certificate, 106, 149–50, 167, 186, 190–95, 203–4

child’s, 197

original, 149–50

second, 166, 192–97, 204, 242

birth,  
 live, 58, 225  
 mothers, 149–50  
 notification system, 24  
 outcomes, 200–201, 216–18, 220–21, 224, 232, 243, 268–69  
 outcome records, 127, 268–69  
 records, 106, 149, 190, 204  
 registration, 186, 190, 193  
 registration forms, 203–4, 242, 271  
 registration statement, 191–94, 196–97

Births, Deaths, and Marriages. *See* BDM

BMI (body mass index), 215–18, 228, 244, 274

body mass index. *See* BMI

## C

cancer, 33, 109–10, 206, 221, 224  
 bowel, 66, 110

case study, 82, 84, 127–28

cases, difficult, 81, 84

Certification Body (CB), 29, 31

child  
 abuse, 69, 71, 73, 76, 88  
 health, 86, 98, 100, 230  
 interests, 78, 84  
 maltreatment, 88–89  
 protection, 89  
 protection orders, 69, 74, 76–77, 89–90, 93  
 outcomes, 96, 108  
 risk of harm to, 70, 72, 79

welfare and safety of, 98–99

childrearers, inadequate, 83

child-rearing ability, 82

clinicians, 8, 27, 30, 54, 57, 74–75, 78, 83–84, 91–92, 96, 106, 112, 124, 158, 253–54

compliance, 45–46, 48, 238  
 monitoring, 45, 47, 50, 237

conception, 64, 66, 73, 104, 106, 108, 124, 135, 140, 146, 190–91, 193–94, 199, 224, 228

condition  
 genetic, 58, 65, 67  
 medical, 58, 65, 67, 80, 166, 206, 221–22

conditions of registration, 5, 12, 18, 21, 23, 33, 35, 45–46, 48, 50, 91, 99, 206, 208, 239

confidentiality, 3, 5–6, 12, 137, 141, 230

connection, biological, 187, 189

consent, 5, 66, 122, 130–31, 136, 138–39, 141–42, 153, 157–60, 176, 178–83, 191, 203–4, 241–42

donor, 122–23, 158

informed, 28, 142, 226

written, 213–15, 228, 243

consent first systems, 158

contact, 8, 12, 15, 116–18, 124, 127, 136–37, 145, 147–52, 156, 158–59, 172–77, 179–80, 182–84, 200  
 address, nominated, 120, 184  
 preference forms, 149–50

contact veto/preference system, 107, 145, 146, 148, 150–1, 154, 157–60, 172, 175–76, 183, 204

conviction, prior, 74, 88, 91

co-regulation, 37–38, 163, 280  
 active participation, 39, 44, 46, 50, 280  
 effective, 38–39, 49–50, 237  
 partnership, 16, 92

co-regulatory system, 16, 18, 37, 44, 46, 48, 50, 168, 236–37, 244–45

costs, 37, 40, 42–43, 82, 175, 198–99, 222, 225

counselling, 28, 32, 43, 47, 65, 68, 72, 91, 170, 172, 174, 186–87, 200, 202, 204  
 mandated, 72, 149, 165, 171, 173–74

therapeutic, 84  
services, 166, 176  
See also support services  
counsellors, 18, 54, 74–75, 78, 81, 84, 91,  
124, 136, 253, 255  
couple, 56, 60, 62, 69, 75, 77–78, 81, 91–  
92, 95, 186, 206, 208, 212  
infertile, 62  
married, 212  
same-sex, 85–86, 164, 209, 221, 228  
criminal record, 70, 74, 76–78, 81, 88, 90–  
91, 93  
Croatia, 62, 105–6, 174, 188, 191  
Cystic Fibrosis, 65

## D

directives, 46, 48, 50, 92, 99, 217, 227,  
239  
disability, 58, 83, 86–87, 208  
disclosure, 66–68, 94, 105–6, 120, 137,  
143, 186–88, 194, 208, 239  
parental, 186  
discretion, clinical, 84  
discrimination, 6, 61, 77, 84, 87, 92, 208,  
215, 223, 228, 243  
disease, 56–59, 65–66, 68, 109–10, 206–8,  
211, 239  
Danish sperm donor (7042), 66  
genetic, 4, 56–57, 246  
heart, 109  
hereditary, 65  
mitochondrial, 220, 246  
disorder, 56–58, 63, 65–66, 68, 101, 109,  
239, 275  
mental, 86–87  
sex-linked, 59, 63  
distress, 115–16, 130, 133–34, 136, 152,  
159–60, 241  
documents, birth registration, 193  
domestic violence, 75, 77  
donated gametes, 4, 105, 112, 152–53,  
186, 189  
donation, mitochondrial, 246  
donor  
anonymity, 106, 119, 155  
code, 128–29, 136, 183

codes, 268–70  
conception, 6–10, 13, 37, 40, 99–102,  
104, 107, 120–22, 126–27, 138, 143,  
151–52, 154, 160–204, 240–43  
egg, 54, 107, 113–14, 164, 220, 269–  
70  
embryo, 119, 164, 269–70  
gametes, 42, 65, 96, 112, 198, 208  
identification, 106–7, 143, 192, 270  
information about, 105–6, 125, 155,  
158, 166, 168, 191, 200, 203–4, 208  
See also access, information  
insemination, 97, 108, 151, 156  
known, 192–94, 196–97, 202, 204  
linking, 124, 166, 173, 188  
past, 118, 136–37, 158, 183–84, 199,  
202, 204, 242  
registers, 40, 43, 45, 132, 165, 167–68,  
170, 193, 240, 242, 276  
siblings, 8, 68, 109, 180–82  
sperm, 109, 114, 134, 268, 270  
status, 183, 196  
donor-conceived,  
children, 5, 96, 116, 131, 155, 156,  
158, 182, 270  
person, 66–68, 105–6, 124, 138–41,  
152, 154, 156, 158, 166, 175–76,  
178–82, 188, 190–91, 193–96, 199–  
200, 204, 256–59  
siblings, 66, 182  
status, 106, 162, 186–87, 189–90, 194,  
203, 242, 279  
donor conception  
records, 131–32, 137, 177  
register, 125, 131, 137, 159, 163  
Donor Conception Support Group, 118,  
124, 276  
Donor Sibling Link (UK), 170, 276  
Donor Sibling Registry, 173, 276  
donor siblings, 115, 117

## E

education, public, 42, 45, 47, 237  
egg.  
donation, 34, 73, 218  
retrieval, 224–25

freezing, *See* access, social egg  
freezing  
EHAC (Ethics Health Advisory Council), 4,  
27, 44, 276  
electronic records system, 268–69  
embryo  
  cryopreservation limit, 245  
  development, early, 246  
  donated, 32, 200  
  early, 56  
  screening, 57  
  thawed, 232  
  transfer, 75, 96–97, 200, 216  
enforcement, 38–39, 41, 47, 237–38  
equality, 58, 105, 115–16, 118, 138–39  
ethical issues, 26, 32–33, 87, 213  
ethical practice, 2, 25–26, 33, 228, 243  
Ethics Committee, 82–84, 276  
  clinical, 64, 213  
Ethics Health Advisory Council. *See* EHAC  
evidence, 6, 21, 85–86, 90, 98–99, 108,  
110, 112, 186, 196, 214, 216, 218–19,  
224–25, 233

## F

family  
  family history, 109–10, 122–23  
  limit, 112–14, 204  
  linking, 165, 167, 181, 183–84, 202,  
  204  
  structures, 86  
  support services, 166  
  violence, 69–70, 91  
  violence services, 90  
father, 117, 127, 140, 195, 212  
  biological, 127, 134–35  
fertility, 20, 33, 53, 55, 60, 83, 85, 87, 90,  
218, 220, 222–24, 226, 254  
  clinics, 14, 66, 122, 217, 227, 250  
  Nurses, 251  
  preservation, 221, 223  
  procedures, 82  
  services, 82–83, 126, 224  
  specialist, 217  
Fertility Society of Australia. *See* FSA  
Finland, 8, 62, 105, 174

Flinders Fertility, 20, 90, 126, 133–37, 164,  
190, 199, 254–55  
FOI. *See* Freedom of Information  
forums, 12–13, 45, 47, 108, 129, 136, 189,  
237, 254  
  consumer, 34, 117, 124, 136, 139, 190  
  donor-conceived, 124, 128, 139, 190  
Freedom of Information (FOI), 130, 132,  
135, 253, 266, 276  
FSA (Fertility Society of Australia), 3, 18,  
26, 28–29, 187, 232, 250, 276

## G

Gametes 8–9, 32, 46–47, 65–66, 104,  
111–12, 122, 138–39, 153, 162, 176,  
184, 179, 212–15, 228, 231–32, 239,  
242, 243  
  cryopreserved, 29  
  donation, 26, 106, 108, 138  
  open identity, 275  
gender balancing for families, 60  
genetic  
  counselling, 115  
  defect, 57, 206–7, 276  
  heritage, 56, 104, 124, 140, 154, 165,  
  167, 185, 193–94, 200  
  information, 67, 185  
  materials, 64–66  
  parents, 114, 139, 153, 187, 189, 221,  
  246  
  relatives, 66–68, 105, 109, 112, 172,  
  239  
  siblings, 112, 122, 127  
Germany, 62, 106, 154, 156  
governance, 9–10, 23, 27, 31, 37–38, 44–  
49, 237  
government inquiries, 6, 8  
guidelines, 19, 27, 32–35, 41, 57–58, 64,  
67, 84, 96, 101, 122–23, 125, 213,  
216, 223

## H

harm, 39, 56, 64, 69–70, 72–74, 77, 79–  
80, 82–84, 86, 150, 186, 225, 239,  
277

psychological, 69–70, 72, 80, 92, 101  
 health, 5–8, 10–13, 18–19, 24, 30–33, 36–41, 45–47, 67–69, 76–77, 79–80, 97–100, 119, 166–69, 206, 237–40  
 information, updating, 68  
 outcomes, 98, 100, 230  
 professionals, approved, 22–23  
 public, 7, 32, 41, 43, 67  
 risks, 24  
 health professionals, 3, 21–23, 30, 36, 43, 72, 85, 92, 219, 234  
 approved, 22–23  
 Health and Community Services  
   Complaints Commissioner (HCSCC), 36, 251  
 heritable conditions, 57, 66–68, 109, 239,  
 heritable diseases, 46, 65–66, 101, 109  
 heritage, 146, 155, 186, 220  
 HFEA (Human Fertilisation and Embryology Authority), 57, 80, 105, 152, 170, 198,  
 HFEA Guidance Note, welfare of the child 80  
 HLA typing, 63–64, 279  
 human cloning, 10, 36, 246–47  
 Human Fertilisation and Embryology Authority. *See* HFEA  
 human leukocyte antigen (HLA), 63–64  
 human rights, 54, 61, 76–77, 106, 152  
 human rights discourse, 54

## I

identity, 14, 105, 107–8, 115, 118, 120, 122, 134–36, 138, 140, 142–43, 145–46, 152, 154, 269  
 gender, 61, 209–10, 243, 276  
 personal, 152  
 illness, 4, 46, 56–59, 63, 65–66, 68, 86, 101, 104, 109–10, 206–7, 211, 221, 239  
 inconsistencies, 34–35, 84, 93, 136, 185  
 infectious diseases, 56, 65, 277  
 transmitting, 24  
 infertility  
   male, 25  
   medical, 209  
   prevention of, 42  
   requirement, 208–9, 221, 224, 226, 228, 243, 274  
   risk of, 211, 221  
   treatment, 91, 97, 208  
   unexplained, 226  
 Infertility Treatment Authority (ITA), Victoria (ITA), 170  
 information,  
   exchange of, 97, 99  
   identifying, 106, 119, 122–23, 141, 143, 145–46, 148, 150, 153, 155–60, 176, 178, 180–83, 185, 204  
   recording and release of, 40, 166, 233, 242  
   registration of consent to release of, 203, 242  
   release of, 122, 138, 141, 145, 147, 150, 152, 154, 156–57, 159, 176, 179–80, 182, 241;  
     consent first, 158, 183  
     retrospective release, 141, 143, 147, 154  
   veto, 145–48, 158  
 injustice, 144–45, 277  
 insemination, 21–23, 105, 231, 276–77  
   artificial, 22–23, 209  
 interests, 52, 54–55, 63–64, 130, 143, 145, 148, 153–55, 157–58, 160, 185, 187, 241–42  
   best, 22, 34, 52, 61, 75, 104, 107, 143, 212  
   child, 72, 78, 84, 124, 186  
   donor-conceived person, 158  
   donor, 155  
   commercial, I, 34  
   competing, 143, 145, 151, 157  
   respective, 143  
   vested, 245  
 intermediary, 149, 162, 172, 174, 180, 185, 202–3  
 intermediary and support services, 45, 149, 159, 167, 170, 172–84, 198, 204, 242  
   provision of, 162, 199, 202–3  
 Ireland, 105–6, 144, 190, 194, 200

ITA. *See* Infertility Treatment Authority (ITA), Victoria  
IVF, 21, 36, 58, 62, 75, 170, 216–20, 224–28  
Clinics, 36–37, 78, 90, 143  
three-person, 246

## J

judgement, clinical, 74–75  
judicial review, 92–93  
jurisdictions, 7, 9, 75, 105–6, 144–46, 148, 150, 152–53, 169–70, 172, 174–75, 188, 190, 210, 213–14  
comparisons with other, *See*  
ACT (Australian Capital Territory),  
Argentina,  
Austria,  
Croatia,  
Finland,  
Germany,  
Ireland,  
Netherlands,  
New South Wales,  
New Zealand,  
Northern Territory,  
Queensland,  
Sweden,  
Switzerland,  
Tasmania,  
United Kingdom,  
United States,  
Uruguay,  
Victoria,  
Western Australia

## K

known donor, 192–193, 196–97, 202, 204  
name, 197  
recording of details, 193

## L

Lab reports, 60  
laws  
anti-discrimination, 36, 74, 79, 83, 208

contract, 36  
corporations, 36  
criminal, 36, 144  
ex post facto criminal, 144  
medical, 25, 64  
negligence, 36, 225  
restrictive adoption, 146  
retrospective, 144, 147  
legal issues, 6–7  
legal parentage, 8, 41, 104, 144, 171–72, 197, 247  
legal parents, *See* parents, legal  
letters, 11–12, 117, 157, 184, 204  
LGBT (Lesbian, Gay, Bisexual and Transgender), 86  
licence, 5, 19, 28–29, 31  
life expectancy, 219–220

## M

material risks, 224–25  
maternal risks, 216–18  
lower, 220  
medical history, 65, 80, 109, 123, 127, 129, 134, 140, 185, 267  
mental health, 69, 86–87, 89, 109  
maternal, 87  
services, 91  
worker, independent, 87  
mental illness, 69, 81, 87  
untreated, 70  
mother, 114, 127–28, 136, 195, 215, 219, 266

## N

Narelle Grech, 66, 109–10  
National Health and Medical Research Council. *See* NHMRC  
National Perinatal Epidemiology and Statistics Unit. *See* NPESU  
neglect, 69, 76–77, 80, 86, 89  
Netherlands, 8, 38, 62, 105, 144, 157–58, 172, 174, 183, 200  
New South Wales, 7, 15, 40, 42, 44, 79, 84, 105, 111, 147, 164, 168–69, 174, 224

New South Wales Ministry of Health, 255  
New Zealand, 18, 28, 62, 105, 174  
NHMRC (National Health and Medical  
Research Council), 3, 5, 18, 31–32, 34,  
58, 61, 67, 212  
NHMRC Ethical Guidelines, 3–4, 18, 20,  
25–28, 31–36, 39–40, 58–60, 62–64,  
112, 122–26, 134, 187, 189, 212–14,  
231  
non-compliance, 213  
Norway, 62, 105  
notification, of donor-conceived status,  
See access to information,  
notification  
NPESU (National Perinatal Epidemiology  
and Statistics Unit), 28, 232  
Northern Territory, 43

## O

obesity, 216, 228  
obligations, 69, 72, 85, 134, 179, 187, 189,  
233, 247  
financial, 141  
legal, 69, 186, 188, 195  
ongoing, 234, 244  
offences, 88–89, 92–93, 208, 241  
offenders, 88–89, 144  
OHHS, *See* Ovarian hyper stimulation  
syndrome  
openness, 7–9, 38–39, 104–5, 115–18,  
130, 138, 143, 180, 190, 237  
operational matters, 159–160  
outcomes, 45, 47, 91, 93, 96–99, 102, 108,  
174, 176, 230–31, 233–34, 237, 239,  
inter-generational, 37  
long term, 95  
neonatal, 98  
optimise pregnancy, 217  
perinatal, 28, 232  
physical, 208  
pregnancy and birth, 216, 218, 220–21,  
224, 232  
Ovarian hyper stimulation syndrome,  
(OHHS) 28, 224  
over-regulation, 37  
oversight functions, 163, 168

## P

paramountcy, 22, 51–55, 57, 59, 63–65,  
67–68, 72, 84–85, 88, 90, 92–95, 99–  
102, 115–16, 158, 238–40  
parentage, 120, 165–66, 195, 210  
parentage presumption, 191  
parental disclosure, donor conceived  
status, 186  
parenting, 10, 85–86, 219  
supportive, 80  
parents  
biological, 85, 143, 151–52, 171, 191–  
92, 195–97, 204, 212  
commissioning, 220  
genetic, *See* genetic, parents  
heterosexual, 86  
legal, 143, 145, 155, 191–92, 196–97  
non-biological, 104 (*See also* genetic,  
parents)  
recipient, *See* recipient, parents  
relinquishing, 146  
same-sex, 86  
single, 85  
supporting, 188  
parliament, 2, 4–5, 13, 15, 18, 35, 39, 48,  
52, 77, 97, 120, 191–93, 238, 248  
Parliamentary briefings, 15  
past donations, 106, 130, 141, 154, 204  
patient records, 131, 266  
Patient Review Panel. *See* PRP  
perinatal registry, 96  
personal information, 66, 155, 168, 231  
PGD, *See* pre-implantation genetic  
diagnosis  
postmenopausal women, 219  
POU. *See* Pregnancy Outcomes Unit  
pregnancy, 36, 58, 65, 81, 98, 116–17,  
199–202, 212, 215, 224, 243, 267  
multiple, 28  
Pregnancy Outcomes Unit (POU), 26, 167,  
253  
pregnancy test, 201  
pre-implantation genetic diagnosis (PGD),  
46, 57–64, 239

preimplantation genetic screening (PGS),  
57, 60  
presumption, 76, 78, 83, 197  
    legal parentage, of 197  
principle, fundamental, 6, 9, 52, 54–55,  
65, 101  
privacy, 124, 135, 142–43, 146, 155, 158,  
231  
    rights to, 143, 152, 155, 157–58  
procreation, 87, 105, 154–55  
prospective parents, 23, 54, 72–74, 80,  
212  
prospective patients, 74, 81, 83  
providers  
    commercial, 36  
    independent, 166  
    public hospital/private, 126  
    registered, 12, 20, 69, 206–7, 231  
    third-party, 198  
proximity, close, 114–15  
PRP (Patient Review Panel), 42–43, 60, 62,  
76–78, 92  
psychiatric illnesses, 77, 86

## Q

Queensland, 43–44, 146–47, 253  
quasi-judicial review system, 76, 279  
Queen Elizabeth Hospital, 126–30, 132–  
33, 137, 164, 198, 266, 269

## R

RANZCOG (Royal Australian and New  
Zealand College of Obstetricians and  
Gynaecologists), 216  
recipient  
    families, 111, 113–14, 175–76, 178–  
82, 189, 204  
    parents, 106–7, 115–16, 118, 123–25,  
134–35, 138, 140, 178, 181, 183, 185,  
187, 190, 195, 203–4  
    registered consent of, 180  
recipients, 4–5, 14–16, 70–71, 104, 113–  
14, 116–17, 123–26, 132–33, 137–38,  
192–93, 196–202, 204, 230, 239–43,  
266–69

    care, 22  
    seeking information, 266  
    supporting, 23  
recording of donor information, 158, 200,  
203  
record keeping, 229–34, 244  
records  
    adoption, 145, 148, 150, 172, 242  
    auditing, 234  
    birth, 106, 145, 148–149, 190, 204  
    birth outcome, 127, 268–269  
    counselling, 127  
    donor-conception, 126, 131–2, 137,  
177  
    donor, 135  
    electronic, 268–269  
    historical, 13, 131, 133, 255  
    in ACN's possession, 129, 137, 268–70  
    linking, 165  
    medical, 142  
    past records, 126, 128, 233, 241, 266,  
268  
    patient, 131, 266  
    preservation, 234, 244  
    recipient, 200, 202  
    State 131  
    transfer of, 157, 198–199, 230  
    treatment, 46, 128  
    Queen Elizabeth, 130, 253, 266, 270  
register, 5, 19–20, 119–21, 125–26, 131–  
32, 157–58, 162–63, 166–71, 173–75,  
177–80, 182–84, 190–91, 196–99,  
203–4, 240–42  
    birth, 106, 165, 172  
    donor conception, 125, 131, 137, 159,  
163  
    voluntary, 119, 131, 163–64, 166, 168,  
170, 173, 270  
registered clinics, 14, 22, 39–40, 43–44,  
50, 69, 126, 134, 199, 201, 206, 231,  
268  
registration, 3, 5, 10, 12, 19–23, 25, 30,  
33, 35, 40, 42, 45–46, 48, 206, 239  
    cancel, 19–20  
    conditions on, 20, 42  
    requirements, 20–21, 23, 207  
    scheme, current, 20

- regulation
    - responsive, 46, 49–50, 96, 228, 245, 247
    - top down, 37
  - regulatory functions, 39, 166, 170
  - regulatory system, 39, 42–44, 46, 168–69, 171, 236, 238
    - See also co-regulation; co-regulatory system; self regulation
  - relationships
    - consanguineous, 105, 110–11, 115, 118, 138, 180
    - prohibited, 115
  - religion, 77, 210–11
  - representatives, religious leader, 46–47, 237
  - Reproductive Technology Accreditation Committee. *See* RTAC
  - Reproductive Technology Council (RTC)
    - Western Australia, 40–42, 109–10, 168–69, 190, 250
  - reproductive technology in clinical practice and research, 3, 18, 32, 58, 61
  - Reproductive Technology Unit (RTU), Western Australia 15, 28, 42, 168, 171, 187, 255
  - Repromed, 20, 90, 126–28, 130, 133, 137, 164, 199, 209, 222–23, 253, 268–69
  - Research, 32. 96. 98. 99, 247
    - Sax Institute Evidence Check, 98
  - rights, 52, 54, 85, 87, 89, 124, 126, 133, 135, 143–44, 146–47, 152, 156–58, 193–94
  - rights of donor-conceived individuals, 108, 140
  - risks, 4, 37, 56–57, 66–70, 74–77, 79–81, 84–93, 96–97, 109–12, 115, 132–33, 206–7, 211, 221, 224–26
    - harm, of 69–70, 72, 74, 77, 83–84, 239
    - increased, 65, 86–87, 109
    - screening for, 65, 70
  - Robinson Research Institute, 54, 95, 100, 222
  - Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), 216
  - RTAC, (Reproductive Technology Accreditation Committee), 3, 18, 26, 28–32, 38, 40, 44, 187, 200–202, 232–33, 243, 250
    - accreditation, 30, 40, 42, 50, 212, 236
      - critical criteria, 28–29, 187
    - audit, 45, 47–48, 50, 237
    - Code, 28–30, 35, 44, 187, 200
    - licences, 30
    - system, 30
      - technical bulletin, 200–202, 243
  - RTC. *See* Reproductive Technology Council
  - RTU. *See* Reproductive Technology Unit
- S**
- SACRT (South Australian Council on Reproductive Technology), 2–5, 18, 25–27, 35, 75, 84, 91, 97, 119, 230, 233, 237, 240, 253
    - dissolution of, 26–27
    - Eligibility Review Panel (SACRT), 91
  - SALRI (South Australian Law Reform Institute), 209–10, 224, 228, 243
  - SART (Society for Assisted Reproductive Technology) (US), 223
  - saviour siblings, 63–64
  - screening, 4, 46, 56–59, 65–67, 69–70, 72–76, 78–79, 82–85, 88, 90, 109, 115, 233, 239
    - applicants, 56, 69, 84–85, 101, 239
    - donors, of 23, 65, 66. 68, 93, 94, 101, 239
    - embryos, 56–57
    - genetic, 57
    - medical, 63–64
    - non-family members, 88
    - practices, 65, 83
    - process, 69, 89
    - provisions, 69–70
    - requirements, 70–71, 74, 84
  - SDC (Social Development Committee), 119–20, 132, 240
  - secrecy, 104, 109, 115–16, 118, 143, 147, 151, 195, 241–42, 247
  - secrecy and anonymity, 104, 115–16, 195, 241

- self-regulation, 37, 38
  - self regulatory, 3, 18, 28, 31-32, 36, 38-39, 44, 49, 237
  - services, 36, 38, 40, 72, 75, 83, 85-86, 91, 165-67, 171-77, 198, 200, 207-8, 222, 224
    - community, 36
    - mental health, 91
    - social, 81
    - support, *See* support services
    - withhold, 82-83
  - sex of children, 5, 178-82
  - sex selection, 6, 32, 34, 56, 59-63, 226, 228, 239
    - for social purposes, 6, 57, 61, 63, 228, 244
  - siblings, 5-6, 63-64, 105-6, 109-10, 114-15, 122-23, 128-29, 134-38, 151, 153, 180-83, 189, 203-4, 240-42
    - contact, 181
    - donor, 8, 66, 68, 109, 115, 117
    - genetic, 112, 122, 127
    - half, 113-15, 151, 173
    - linking, 173
    - savior, 63-64
  - smoking, *See* access, smoking
  - Social Development Committee. *See* SDC
  - social egg freezing, *See* access, social egg freezing
  - social issues, 2, 7-8, 26, 37, 50, 97, 245, 247
  - social media, 11
  - South Australian Council on Reproductive Technology. *See* SACRT
  - South Australian Law Reform Institute. *See* SALRI
  - sperm, 64-65, 104, 107, 113-14, 153-54, 156, 201-2, 206-7, 211-14, 220, 222-23, 241, 246, 250
    - posthumous use of, 4, 207, 211-13
    - See also*, donors
  - status, 5, 33, 58, 66-67, 105, 151, 183-84, 187, 190, 193-95, 240
    - donor-conceived, 106, 162, 186-7, 194, 203, 242
    - donor, 183, 196
    - notification, of *See* access to information, notification
    - marital, 77, 86, 185, 208, 210-11, 216
    - medical, 209
    - requirements of proof, BDM, 184
    - trusted agency, 172, 177
  - statutory child protection services, 89
  - statutory declaration, 69, 74, 84, 208
  - statutory declaration system, 76, 90
  - storage, 26, 32, 97, 130, 183, 225, 232, 266, 268-69
  - success rates, 6, 36, 38, 220
  - support services, 8, 45, 70, 92-93, 159, 162, 164-65, 167, 169-81, 183-84, 189, 198-99, 202-4
    - See also*, intermediary and support services
  - surrogacy, 8, 10, 32, 41, 54, 73, 95, 210
  - Sweden, 8, 62, 105
  - Switzerland, 8, 62, 87, 105-6, 153-54, 174
  - system,
    - co-regulatory, *See* co-regulatory system
    - immune, 226-27
    - self-regulatory, *See* self regulatory system
- T**
- Tasmania, 43-44, 224, 278, 282
  - thalassaemia, 65
  - therapeutic goods, 36, 282
  - time to tell campaign, 188
  - transparency, 7-9, 27, 31, 35, 49, 92, 130, 143
  - trauma, 134, 137
  - treatment, 3-4, 71, 75-79, 81, 83-87, 91-92, 186, 200-202, 206, 216-18, 220-22, 227, 230, 232
    - accessing, 57, 70
    - refusal of, 74, 76, 79-80, 85, 90-92
- U**
- UK, *See* United Kingdom
  - UK Donor-Conceived Register, 170

United Kingdom (UK), 8, 62, 79, 80–81, 84, 91, 105, 144, 146, 148–9, 152, 170, 172, 183, 198, 220–246  
United Kingdom Donor Conception Network, 188  
United Nations Children’s Fund, 61  
United Nations Conventions, 52, 54  
United States, 8, 82–84, 106, 149, 173, 224, 246  
Uruguay, 105–6, 174

## V

VANISH (Victorian Adoption Network for Self Help), 139, 148, 156, 250  
VARTA (Victorian Assisted Reproductive Authority), 42–43, 77, 118, 164–65, 170–71, 188, 250  
VCAT (Victorian Civil and Administrative Tribunal), 60, 62, 76–77  
Victoria, 38–39, 42–43, 74, 76, 105–7, 128–29, 152–53, 156–58, 162, 164–65, 170, 174, 188, 190  
Victorian Adoption Network for Self Help. *See* VANISH  
Victorian Assisted Reproductive Authority. *See* VARTA  
Victorian Civil and Administrative Tribunal. *See* VCAT  
Victorian Government, 143–44, 158  
Victorian Law Reform Committee, 7, 66, 110, 153  
violence, 69, 71, 73–74, 80, 88–89  
voluntary register, *See* register, voluntary  
voluntary registration, 162, 183–184, 202, 204, 242

## W

welfare, 3–4, 6, 9, 22–23, 33–34, 51–102, 107, 109, 115–16, 124, 139–41, 158, 219, 238–40  
principle, 9, 78, 84, 93, 96, 100–102, 109  
Western Australia, 40–42, 105, 109–11, 119, 164, 168–69, 172, 174, 188, 190, 200, 250, 255

Reproductive Technology Council, (RTC), 23–24, 41, 44, 168, 173, 187  
Reproductive Technology Unit (RTU), 15, 28, 42, 168, 171, 187  
WHO (World Health Organization), 61, 87, widow, 206–7, 211, 214  
World Health Organization. *See* WHO

## Y

YourSAy website, 11–14, 139–40, 260

