

**Report on Trip to Australia and New Zealand July-September 2010  
to study Donor Register and Donor Linking Services**

**Marilyn Crawshaw**

**University of York**

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**DISCLAIMER** – While every attempt has been made to verify the factual aspects of this report, I take full responsibility for any errors. All views expressed in the report are also mine alone.

**My thanks** go to all those who gave so freely of their time and thoughts during my trip and to those who have kindly commented on the draft of this report.

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## Introduction

This trip was funded by the Nuffield Foundation and designed to provide the opportunity to meet with a range of individuals and organisations with an interest in donor register and donor linking services and to explore networking and research opportunities. The schedule was organised by approaching individuals and organisations that I already knew and inviting them to put me in touch with others. These arrangements worked very well and enabled me to visit Western Australia, Victoria, South Australia, New South Wales, North Island and South Island in New Zealand and to meet with:

- Actual and potential users of donor registers and donor linking services including donor conceived adults and children, parents of donor conceived children and adults; donors.
- Service providers including infertility counsellors and other staff from fertility centres, staff from Birth Deaths and Marriages Register services, adoption staff
- Civil servants and regulators
- Academics

As well as having face to face meetings, I was invited to present papers in a variety of settings. Given my additional research interest in cancer-related fertility matters (including the use of donor assisted conception services) I was also invited to present papers on this subject.

In addition, shortly before I left for the trip, a Federal Inquiry into Donor Conception in Australia was announced with the following terms of reference:

The past and present practices of donor conception in Australia, with particular reference to:

- (a) donor conception regulation and legislation across federal and state jurisdictions.
- (b) the conduct of clinics and medical services, including:
  - (i) payments for donors,
  - (ii) management of data relating to donor conception, and
  - (iii) provision of appropriate counselling and support services;
- (c) the number of offspring born from each donor with reference to the risk of consanguine relationships; and
- (d) the rights of donor conceived individuals.

[http://www.aph.gov.au/Senate/committee/legcon\\_ctte/donor\\_conception/tor.htm](http://www.aph.gov.au/Senate/committee/legcon_ctte/donor_conception/tor.htm):

One host put me in touch with the office of the Senator chairing the Inquiry. After a short telephone call with him, I was invited to submit written evidence. My submission was made in October 2010 and is available on the Inquiry website (no 156) at:  
[http://www.aph.gov.au/senate/committee/legcon\\_ctte/donor\\_conception/submissions.htm](http://www.aph.gov.au/senate/committee/legcon_ctte/donor_conception/submissions.htm).

The Inquiry was due to report by the end of the year but had not done so at the time of this report.

## Key Findings

In the report that follows, I have not attempted to produce a definitive document that compares legislative and practice differences between each of the places visited though, where possible, I have asked individuals to check for factual accuracy. What I have aimed for instead is an account of the key aspects of the work that were presented to me in discussions and meetings.

- There was significantly greater reference to the need to understand and take account of **child and family welfare implications** of policies and practices in relation to donor conception than is, in my experience, evident in similar circles in the UK. This held true geographically – i.e. across all the states that I visited in Australia and in New Zealand – and across contexts – i.e. with civil servants, professionals across the disciplines, regulators and those personally affected. There is a shortfall in both countries between ‘supply’ of donated gamete(s) and ‘demand’ but this does not appear to dominate policy and practice discussions to the extent it does in the UK.
- Policies around **‘matching’ donor and recipient(s) and later linking services** are practised with child and family welfare implications in mind; examples included:
  - Paying attention to whether recipients feel some **beginning ‘connection’ to the donor** as part of the ‘selection’ process as an indicator of enhancing likely family wellbeing.
  - Requiring that a **donor’s partner (if they have one) gives consent** to the donation *and* in order to maximise the likelihood that any children they have/may have are informed.
  - Requiring that **donors complete a profile** about themselves both to assist the ‘matching’ work and to be provided to the recipient(s) once the baby is born to assist them with parenting.
  - Requiring that the **recipients provide a profile** for the donor when the child is born; this reflects due regard being paid both to the donor conceived child and family in relation to any future contact but also to the donor and his/her current or future family.
  - Keeping small the **number of families or children that might be formed from a single donor**. Where there was professional involvement in linking families with dependant children who shared a donor (as was the case in quite a number of fertility clinics I visited) or linking a donor and parents of a young child (true for a smaller number of clinics but nevertheless still happening) or helping a young adult find out more about those to whom they are genetically related, this appeared to reinforce the view among professionals and those personally affected that numbers should be kept **low**. This certainly matches my

conclusions from being involved with donor conceived adults being linked in the UK.

- Requiring all parties in a proposed use of a **'known' donor** to be seen separately and together followed by a **'cooling off' period** before treatment could take place.
- There were also debates in several jurisdictions about whether to **pay donors** (or increase allowances/compensation). Here again the primary discourse was in relation to child and family well being and leaned towards not introducing payment or increasing compensation rates and not blurring the distinctions. This also reflected feedback from parents and donor conceived adults.
- There was more **proactive professional activity through fertility clinics** than in the UK in relation to:
  - linking families who shared a donor when the children were still in early or middle childhood (where those affected requested this);
  - routinely providing recipients with donor codes so that they are able to seek contact with other parents if they wish;
  - linking donors and donor offspring (or their parents) when all parties wished for this, including where the child is below the age of any statutory right to identity release;
  - offering 'letter box' services, i.e. where the donor and recipient(s) can exchange non identifying correspondence if they wish;
  - working with young people through to early adulthood who were coming forward to find out more about their donor or genetic siblings;
  - offering ongoing support to families formed through the use of donor conception treatments.

Such work was being done primarily through the Fertility Clinics and by Infertility Counsellors. Many of the latter are either social work trained or otherwise have experience of working with children and/or families.

- The **provision of professional support in linking work with families with dependant children** was, however, **not consistently available** within and across the countries. In addition, while some infertility counsellors were providing very good quality services in this area (especially to families with dependant children), some did not consider themselves sufficiently skilled or experienced to do so and some were actively discouraged from doing so by their employers. Some did not consider it appropriate to provide post- birth individual or family support services from the context of an infertility treatment centre. There was also concern that the service was vulnerable as there is no income scheme attached to it.

- There appeared to be little or no professional involvement with **adults** conceived prior to the existence of current clinics and hence **without paper records**. Professionals also appeared to have little contact with this 'group' of offspring although many expressed concern at the fact that services were non-existent. Some places had had preliminary discussion about developing DNA based services but these remain at a very early stage.
- Where paper records exist but are held, say, by a health facility or individual medical practitioner then in some cases those responsible for the Donor Registers have the **statutory power to require those records to be produced** (including those for cycles completed before any legislation was in place).
- Those considering *any* infertility treatment are offered (and often take up) **at least two sessions with a counsellor**. This reflects ANZICA Guidelines drawn up very early in the development of ART services. Where donated gametes are proposed, those concerned are usually *required* to attend for at least two sessions. This leads to counsellors having a much **greater presence** in clinics (Melbourne IVF has 10 counsellors, for example) and a much **greater influence** on policy and practice. That said, there appeared to be some changes taking place with some counsellors reporting moves to relax the offer of two sessions especially where donor treatment was not involved.
- The **Donor Registers** that are in existence comprise information relating to donor conception only, unlike the UK HFEA Register of Information which has a much broader remit. Their location and the way that they are run in Australia and NZ therefore has **the needs of donor conceived people and donors as its primary focus**.
- Most of the jurisdictions ran a **voluntary register as well as a 'compulsory' one**. Although this was not universally the case, the voluntary register was usually open to those personally affected – including parents of donor offspring and the non-donor conceived children of donors – from birth onwards. In other words, it was seen as a route for those who wished to have contact with genetic relatives from infancy onwards to do so. This was designed to enable parents to determine for themselves how best to raise their children in terms of the level of information and contact they deemed appropriate to their child's wellbeing.
- Where there was legislation in place that specified the age at which those affected had the statutory right to identifiable information, the policy makers/civil servants did not interpret this to exclude those who wished to identify themselves earlier from doing so, including with the help of professionals within the licensed centres. In some cases this included the donor's identity being released to parents.
- None of the Registers were actively promoted, typically because of budgetary constraints (although counsellors in the clinics do routinely advise both recipients and donors involved with donor conception on the roles of registers).
- There is **no standard model for any of the relevant services in Australia** as the legislative framework is a state matter (though there *are* some national guidelines). There are differences, for example, in:

- what the eligibility requirements and (psychological and social) assessment processes are for various services (including surrogacy which has been newly regulated in many states). The use of psychological profiling/assessment is far greater than in the UK (to my knowledge there is no licensed centre in the UK that requires such testing);
  - the age at which donor conceived people have the right to access information
  - whether they have to pay for counselling (or intermediary services) prior to information release and who will provide that (most have so far opted for there to be mandatory counselling);
  - whether any follow up is available;
  - where the Donor Registers 'sit' – i.e. Dept of Health, Births Deaths and Marriages etc and what the appropriate skill mix for running them is considered to be;
  - which state government departments held responsibilities for the services and policy making – Dept of Health, Dept of Justice, Dept for Childrens Services etc.;
  - even though surrogacy regulations are only newly introduced into the Australian states and NZ, there are significant differences between them.
- It is also of note that there are some **differences between Australia and NZ** even though the two countries 'share' professional organisations in FSA and ANZICA. For example embryo donation is 'allowed' in some Australian states without 'external' scrutiny but in NZ all applications have to go through a rigorous process (including all parties being seen separately and together by the counsellor) and the reports then considered by an independent body who makes the final decision.
  - **Regulation and licensing of clinics** is done through a single system across both countries but, unlike the UK, is entirely separate from Donor Registers or policy making bodies. However policy makers and register staff in some jurisdictions retain certain powers (usually more minor) in relation to licensing and inspection including a scrutiny role and the right, in certain circumstances, to unannounced inspections.
  - The licensing and inspection system falls within the remit of the FSA but runs through the RTAC system. **Recent changes to regulation** are similar to those in the UK insofar as it has shifted to a 'lighter touch' system and one that is more tied to QA. More recently it is being run by an outside accreditation body rather than using panels/teams made up of representative of the different disciplines. Some concerns were expressed to me that the new system is less robust.
  - The **concentration of activity at clinic level rather than more centrally** is in marked contrast to the UK in both countries. It is also the case that there are significantly fewer providers than in the UK. In each state in Australia and in NZ there appear to be only two or three main providers (though comprising a main site and a number of satellite centres).

- It is of note that many of the fertility centres are now **privately owned**, including by **private equity firms**; professionals are concerned that a **business model** will follow with services such as donor linking services being squeezed given that they do not have an income stream. The fact that only an estimated 7% of all treatment cycles in Australia involve the use of donor has, in the views of some, an influence on the approach of some commercial service providers.
- In both Australia and NZ, there are **health insurance schemes** in operation that cover assisted conception treatments leaving individuals and couples having to find smaller costs than in the UK.
- The **Federal Inquiry** had provoked a lot of interest as evidenced by the high number of submissions on their website. There appeared to be a lot of support for a national register and for the right to information to be made retrospective.
- There was a lot of concern about the **proposed demise of the HFEA**, including the implications of this for UK DonorLink, the UK voluntary register for adults genetically related through donor conception that uses DNA as its tool for 'linking'.
- There was concern at two **recent changes to Reproduction Bodies** that had some policy making and service provision functions. The South Australia Reproductive Technology Council was abolished at the end of August 2010 and the Infertility Treatment Authority of Victoria had been renamed to the Victoria Assisted Reproduction Authority and some of its responsibilities hived off to other bodies with effect from 1 January 2010. The latter in particular appeared to have resulted in a drop in the standards and range of service but with increased overall costs.
- Finally it was of interest that there were some instances where informants told me of 'facts' and 'statutory requirements' for which I was not always able to find a basis for in law or regulation. There were also occasions where contradictory statements of 'facts' and 'statutory requirements' were provided by others and it was not always possible to establish which was 'correct'. Such findings are a reminder that, whatever the legal or policy accuracy of such statements, they were the ones that were being used to inform professional practice and service delivery.

## Licensing and regulation of all assisted conception clinics

There is no federal or state run system for licensing and regulation (though see below for some state specific variations involving additional requirements) but this is done instead through the **Reproductive Technology Accreditation Committee (RTAC)** of the Fertility Society of Australia.<sup>1</sup> The FSA is also the body that produces the Code of Practice for ART Units (Australia) and Fertility Services handbook (NZ), a function that is deemed statutory in the UK and carried out by the HFEA. Until 2007, inspection teams were drawn from current practitioners from the key disciplines involved in delivering services and face to face inspections were annual (including to satellite units) under a three year accreditation cycle. Recent changes have seen a move towards a lighter touch approach to regulation with less face to face contact time in inspections and a greater emphasis on checking that quality assurance systems are in place, in particular the paperwork. The work is now contracted out to a firm that specialises in accreditation, JAS-ANZ.

RTAC deals with any concerns within a specified time frame but there is also a role in some of the Australian states for involvement by civil servants (these are included within the separate sections below, where known). There is also no single system in place across these states for dealing with complaints from patients.

ART units are also required to work to **National Health and Medical Research Council (NHMRC) Guidelines**.

The FSA recognises that there are areas where there is inconsistency between the RTAC Code of Practice, NHMRC Guidelines and any federal or state legislation and regulations. As a general rule they advise that national legislation overrides state legislation, and that state legislation overrides regulation/guidelines.

In all the places visited, there were some concerns expressed that the moves to lighter touch regulation had resulted in less scrutiny, less opportunity to promote good practice and collaboration and less involvement of both professionals and patients in the process. This was felt to be a retrograde step.

In some jurisdictions, policy makers and Donor Register staff retain certain powers in relation to licensing and inspection (usually more minor) including a scrutiny role and the right, in certain circumstances, to unannounced inspections.

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<sup>1</sup> Note that contrary to its name, this organisation also covers New Zealand.



## Detailed findings for each state/country

### (i) Western Australia

A legislative framework was introduced in WA in April 1993 with the implementation of the Human Technology (HRT) Act 1991 and the associated establishment of the **Reproductive Technology Council (RTC)** and the **Reproductive Technology Register (RTR)** (see <http://www.rtc.org.au/index.html>).

**The Reproductive Technology Council (RTC)** comprises 10 members and 10 deputy members. The latter can attend all meetings if they wish but are not paid a fee if the sitting member is present. All are Ministerial (i.e. 'public') appointments and the composition is laid down in the Act and includes a member of the RCOG and the Dept of Child Protection, religious leaders, consumers and ethicists. It has had the same Chair since its inception. It has 5 committees:

- PGD (Implementation) Technical Advisory Committee
- Embryo storage Committee
- Counselling Committee
- Scientific Advisory Committee
- Licensing and Administration Advisory Committee

In keeping with the rest of Australia and New Zealand, the direct licensing and inspection of clinics in WA is done through RTAC. DH staff/RTC members look at much of the paperwork required by the Council and produced by the clinics, including patient information, consent to treatment forms etc. The RTU and Council must be satisfied that the clinic is complying with submission of data to the Department of Health and that the clinic's practice is consistent with the legislation. Following inspection and review the Council recommends to the Director General of the Department of Health whether a clinic should be licensed.

Between 1993 and 2004 donors were legally entitled to anonymity though they could if they wished opt to be identifiable. Almost none did and it is not clear how well their 'right' to do so was explained to them at that time – in other words the lack of donors opting to be identifiable does not necessarily reflect the numbers that might have done so if they had been aware of this choice.

### **The Donor Registers**

The RTR records information regarding all treatment cycles and details of all donors and births associated with their donation. However, as in the UK, there have been some problems with the reliability of past record keeping and an audit is currently being carried out to try to make them more robust. This should be completed in 2011. Prior to 1993, there was no legal responsibility to retain any records and this has led to many being lost or destroyed and the whereabouts of others remaining unknown. Since 1993, clinics are required to hold patient information/records for a period of 25 years after which they are turned over to the State records department.

From 1<sup>st</sup> December 2004, amendments to the HRT Act enabled donor offspring aged 16 and above to access identifying information about the donor held on the RTR. This applies for all donations made after that date but the (separate) Voluntary Register also allows for donations made prior to that date providing that the donor consents. The amendments also entitled parents of children aged below 16 to request and be provided with identifying information, providing that the donor agrees, the parties are on the Voluntary Register and they have counselling by a counsellor approved by the Council. Such information can also be released to minors without the donor's permission in some circumstances, for example for certain medical reasons and/or where the CEO Health is satisfied that before donation the donor was adequately informed that future legislative changes might enable release of information without consent (though he will always be informed if he is alive). In exceptional circumstances, Register staff can approach a party not on the register to request information or contact, for example when it relates to a serious medical condition; this only applies when the donation was made after April 1993. 'Case law' on this is yet to be built as no such requests have been received.

The **Voluntary Register** (which can be used retrospectively as well as prospectively) was established in 2002 by the Director General of the DH following recommendations from a review of the 1991 Act that donor offspring should be able to obtain information about their origins, including identifying information. Initially the Register was to be run by the Department of Child Protection but the lack of proactive attention to it led to it being transferred to the Reproductive Technology Unit of the DH where it sits today, together with the statutory register. DH staff can draw on legal advice and so on from departmental resources and they have, within the staff group, experience in social work, nursing and medical science.

Although the early days of the registers saw little work being done on them, this has changed more recently. The key post holder now has regular contact with prospective and current registrants. She is an experienced professional with considerable experience in working directly with service users on sensitive and complex matters.

The voluntary register is open to any adult 'affected' – i.e. including non donor conceived genetic relatives, (though this is at the discretion of the Registrar and it is not wholly clear in the promotional leaflets and website which relatives have entitlement), parents of donor conceived children who are still minors as well as adult donor offspring and donors. Genetic relatives are not entitled to as many services from the VR as donor parties are, for example they are not given the option of accessing identifying information.

Neither is the Register restricted to the time at which the birth/donation took place, i.e. parents can register as soon as they have given birth and donors can register straight after donating (and some clinics advise this). This is seen as especially advantageous for the possibility of establishing contact with half siblings, an option that DH staff believe is important for its potential to be helpful for children while they are growing up.

When someone registers with the Voluntary Register, non-identifying information can immediately be released if a 'match' between donor parties is made (i.e. 2 or more donor

parties who are linked by the same donor number registered on the VR). At that stage, each party is then asked if they would like to proceed with exchanging identifying information. If so, they are advised of the counselling requirement. Once both parties have undergone counselling, identifying information is released. At any stage, a registrant can submit a written message that they do not want to release identifying information, in which case they will not be approached.

Searches may, however, reveal that information is missing or incomplete, both for those born prior to or after 1993. In these circumstances the civil servants have the right to approach the clinic involved (if known and/or if still in existence) to check their records and provide any relevant information providing that the registrant signs a 'release' statement their agreement to this. Their experience is that those holding the records are usually willing to comply. However some records simply cannot be traced. Register staff have considered introducing a DNA based service as well but such discussions are at a very early stage. The paper records 'searching service' is free to registrants.

Donor conceived adults (DCAs) can access identifying information at age 16 (the age when minors are considered 'mature') if born after 2004 as a statutory right; non-identifying information is available at any stage to parents and donor conceived children/teenagers, including the donor code. Where both (adult) parties agree and provide written consent, identifying information can be released while the donor offspring is still a minor.

Prior to the release of any identifying information from the voluntary register, each party must give their written consent (this is not required for the statutory register as all donors on that register are required to give written consent prior to donation). Prior to the release of identifying information from either register, the parties must undergo counselling from a list of infertility counsellors (currently 12 in total) approved specifically for the role by the DH (Social Worker, Psychologist, Clinical Psychologist or counsellor who meets the requirements of an 'Approved Counsellor' – see below). This is likely to be required each time that information is to be released, regardless of whether the parties have already undergone counselling prior to any previous information release (the situation has not yet arisen). Where that professional has any concerns about the safety of releasing information (having provided the counselling) then they are expected to report this to the DH and the information may be withheld. Those concerned have to meet the costs of counselling – provisionally \$190 per hour, in line with current professional practice rates – though it is anticipated that some of the fee will be rebated through private medical insurance. For those in financial difficulties or without insurance, it is hoped that this will not prove a barrier and that some financial assistance will be found from elsewhere. Staff were of the view that it is within the Australian culture to expect to pay for professional services.

Anyone to whom identifying information is released will be bound by Section 14:1 of the HRT Act 1991. This says that no-one is allowed to pass this information on to anyone else. However this is clearly unenforceable in the case of registrants affected.

As none of the children of the parents that are registered have yet reached the age of 18, there is no formal policy in place as to whether to allow parents to remain on the register.

In discussion, we explored the implications of this and the sensitivity of ensuring that donor conceived adults (DCAs) assume full control of 'their' information at the age of majority while at the same time ensuring that they do not drop off the register through failure to turn any *intention* to remain into action. Staff are aware that they need to consider how to facilitate young adults to register in their own right at the same time as assuring their privacy – in other words this cannot necessarily be done through parents at this stage. It is likely that staff will contact parents when a child is nearing 18 to advise them that their child needs to register in their own right. If a child does not take up the option, then staff may retain the parent(s)' registration immediately but will instead continue to liaise with the family until such time as they are confident that an informed decision is made by the donor conceived person, acknowledging that lack of action by the young adult does not necessarily reflect their longer term wishes.

On the Voluntary Register at present there are 144 registrants of whom 76 are parents; 55 are donors and 13 are donor conceived adults (DCAs). At the time of my visit (July 2010), there have been 11 matches identified from the Voluntary Register: 5 parents of donor conceived offspring below age 18 matched with other parents of children conceived from the same donor; 5 parents matched with donors; 1 donor conceived adult (DCA) matched with another DCA<sup>2</sup>. Staff are still in the process of working out how to proceed with informing those concerned: earlier difficulties with the operation of the service meant that these matches had not been identified previously and hence the procedures and relevant staffing needs are still being worked out.

It is of note that the staff member that has most direct contact with registrants spoke of her feelings of professional responsibility towards them as individuals, of the need to retain regular contact and of the need for staff in her position to have professional skills in managing potentially complex feelings and relationships and seeing beyond what the immediate presenting issue might be. In other words that Register services should not stop at being an administrative service alone. She is supported in this view by the other staff not at the coal face.

### **Additional features of the WA situation**

Infertility Counsellors in WA are all either Social Workers, Psychologists or Clinical Psychologists who have to meet certain additional criteria in order to become 'approved'. 'Approved counsellors' must be qualified and experienced counsellors, who possess a significant knowledge of the issues associated with fertility and infertility and can demonstrate evidence of keeping up to date with technological developments (for fuller information see: <http://www.rtc.org.au/counsellors/index.html>). Counselling must be face

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<sup>2</sup> Update as at Dec 2010 - 2 matches (4 parents) have now been through the counselling requirement and are due to exchange information and meet up in the coming weeks. Letters have also been sent via registered post to 2 donors and donor offspring matches. To date, one 'matched' pair are proceeding to counselling while responses are awaited from the other pair.

to face (laid down in the Directions) though this can be through video at the discretion of the counsellor.

There are also community-based infertility counsellors and they do not have to meet the same criteria providing that they do not work in a licensed clinic or specialise in third party reproduction. It is a condition of registration (state law) that the clinic must offer at least one free (implications) counselling session to anyone contemplating a treatment cycle that involves egg collection (i.e. including IVF) or donated gamete(s) and a further free session to anyone withdrawing from treatment. Such counselling can be provided by the clinic's counsellor or the individual/couple can opt to see someone elsewhere from the approved infertility counsellor list. The cost of the additional emotional support counselling can be covered through private health insurance schemes. Alternatively for select emotional problems (e.g. anxiety/depression) Medicare can be accessed and requires a specific referral by a GP. Medicare funded therapeutic counselling can be provided by most Approved Infertility Counsellors (dependent upon their qualifications) or by generalist counsellors. Overall there appears to be little take-up of support counselling within the clinic as these sessions are not rebated. though no figures are available. Sometimes the cost of the *medical treatment* exceeds what the private scheme will pay for, in which case the patient(s) has to find the balance themselves.

There is no routine follow up of those who have attended for counselling and no further stage (e.g. review of treatment; failed cycle; ending treatment) at which there is any formal requirement for counselling to be offered again routinely. Within clinics, most infertility counsellors are only seeing people for implications counselling and mainly for single sessions only, especially where own gamete(s) is being used.

Where a known donor is to be used, the counsellor will see all the parties concerned both separately and together – typically over 3 x 1 hour sessions. There is then a statutory 3 or 6 months<sup>3</sup> cooling off period before treatment can start, but only after the parties have been seen again by the counsellor. At most clinics in W.A. offering treatments using known donor(s), the recipient(s) has to pay for all the counselling.

Clinic recruited Donors must be offered free implications counselling AND their partner must also be seen (if they have one). There is no requirement for pen pictures to be collected from donors, though some clinics encourage them to provide one. Several professionals commented that donors find it difficult to put a profile together. The RTC asks for 100 words only to be provided for the register; any additional information is held at the clinic.

There are a small number of infertility counsellors registered to undertake so-called 'telling' work with parents and donor conceived children; this service has to be paid for by the parents. There is no requirement on clinics to be involved in providing services once medical treatment has finished.

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<sup>3</sup> There were differing views as to the required length of the cooling off period

## **Surrogacy in WA**

Following the public coverage of the difficulty faced by a Federal politician, Stephen Conroy, and his wife in being able to form his family through surrogacy, there was a flurry of surrogacy legislation around the country, including WA.

The *Surrogacy Act 2008* and accompanying Regulations and Directions were implemented in 2009. The RTC were influential in the development of this legislation. Stringent requirements are specified in the legislation regarding eligibility and applications to a surrogacy arrangement. While it is extremely difficult to legislate against 'informal' surrogacy arrangements, there is no legal machinery through which to transfer legal parentage from a surrogate to a commissioning couple without having met the requirements for a surrogacy arrangement.

Surrogacy arrangements will only be permissible where there are medical reasons preventing the intended mother from carrying the pregnancy herself. In practice, surrogates are banned from using their own egg so must use a donated egg if the intended mother cannot supply one

All applications have to go through the RTC for a final decision. Commissioning couples and the surrogate mother are required to undergo (i) psychometric testing by a clinical psychologist using an RTC-approved tool (the MMPI) and (ii) implications counselling session(s) with an infertility counsellor. Following initial counselling, the surrogacy arrangement cannot proceed until after a further three months cooling off period. If the arrangements are approved by the RTC Council, the licensee is required to make all reasonable attempts to facilitate joint counselling for the surrogate and commissioning couple 20 weeks into pregnancy, 34 weeks into pregnancy and 14 days after the miscarriage or birth of a child. Providing that all appears OK, the legal order transferring parental authority can go through.

### **(ii) Victoria**

The Infertility Treatment Act 1995, implemented in January 1998, established the Infertility Treatment Authority (ITA) (within the Dept of Health) and brought in very progressive approaches to information release from the 'new' Central Register that it established (run by the ITA). Prior to this, information held on the Central Register, established under the Infertility (Medical Procedures) Act 1984 in 1988 and run by the Health Department, could only be released with the consent of the person to whom it related – though in practice there were no mechanisms developed for people to make applications.

The Assisted Reproductive Treatment Act 2008, implemented on 1 January 2010 (for a summary, see <http://www.varta.org.au/relevant-acts-regulation-victoria/w1/i1003270/>) retained the principle that the welfare of the donor conceived child is paramount but the parliamentary debates were dominated by 'access to treatment' issues, especially for single women and lesbian couples. Part of the pressure for the legislation came from the Attorney

General - a champion of gay marriage and access to treatment for gays. It was drafted under instructions from the Health and Justice Departments and was a conscience vote in Parliament. The Act:

- introduced a limit of 10 women (section 29) i.e. including partners of the donors and counting both women in a lesbian couple in the limit of 10 (the latter were previously classed as 1 family) - previous practice was to cap the uses of donation to 10 families<sup>4</sup>. However there is an issue of interpretation of Section 29 and whether it in fact means 10 families or 10 women and this has not been resolved by a Court;
- removed the requirement for the partners of donors to also consent to their donation (Note: many clinics retain this requirement as it remains within the RTAC Code of Practice);
- made it possible for single women and lesbian couples to be treated - previously this was only possible if they were infertile, leading many to go inter state for treatment;
- brought in the requirement that all prospective parents must be CRB checked and have a child protection check prior to being accepted for treatment.

The screening requirement is administered by the Managers of Counselling Services (a state department). It has proved to be time and resource intensive and is deeply unpopular with patient(s) and professionals. It may also have contributed to the large fall in numbers coming forward for treatment (though this may also result from some changes to Medicare funding). Where any 'problems' are picked up through screening, the 'case' has to go before the newly formed Patient Review Panel (PRP) as specified under Section 83 of the Act (see [www.health.vic.gov.au/prp](http://www.health.vic.gov.au/prp)). Applicants can attend in person. The PRP is headed by a retired Judge and includes a child welfare expert, lawyer, infertility counsellor, psychiatrist, doctor, a donor administrator. It received no separate State funding, is independent of the State, and received no direction or legal advice from the Health Department. It has no separate premises or facilities and no staff as such though a senior officer in the Health department provides support as part of her duties. Members are paid on a sessional basis. The PRP is meeting more frequently than was anticipated but at the time of my visit only one 'case' was thought to have been turned down<sup>5</sup>. Donors are NOT required to go through these checks even some of them may go on to have contact with their donor offspring when they are still quite young.

The Act also introduced a birth registration scheme that formally records donor conception (of which more below) and established the **Victorian Assisted Reproductive Treatment Authority (VARTA)** (within the Dept of Health). VARTA replaced the ITA though with much reduced functions; responsibility for the Registers, for example, was transferred to the Registrar of Births, Deaths and Marriages . VARTA's functions are:

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<sup>4</sup> Interestingly, some of the people I met thought that this was a statutory requirement; it was not

<sup>5</sup> More recent information suggests that approximately 12% have been turned down out of more than 180

1. Public education about treatment procedures including best interests of children born as a result – including:
  - Protection of fertility
  - Provision of information including health information about infertility
  - Information for potential donors, recipients and offspring
  - Information and seminars for parents to assist them to talk to their children about their means of conception (170 people attended the most recent Parents’ seminar).
  - Information for those considering applying to the Registers
2. Import and export of sperm/eggs/embryos.
3. Monitoring
4. Community consultation
5. Administration of the registration system
6. Promotion of research
7. Informing the Health Minister

Previously ITA had a role in regulation of clinics alongside RTAC but this was not transferred to VARTA, leaving regulation wholly with RTAC. VARTA also still requires clinics to report ‘adverse’ incidents to them but have recently been told that this is no longer appropriate. VARTA’s monitoring to date has led to them being able to prompt national monitoring of such incidents, alert others to risks etc – i.e. an important preventive and scrutiny role.

VARTA does not deal with complaints from patients; if a patient complains about any aspect of a clinic’s service, then this is dealt with by the Office of Health Services Commissioners.

The VARTA website contains podcasts and other good quality material to assist disclosure of origins and managing the experience of donor conception. VARTA sees its ‘public education’ remit as aimed primarily at potential and actual parents of donor conceived children and at promoting good practice in fertility-related services.

The abolition of the ITA appeared to result from three Victorian Law Reform Commission reports in 2005 which covered (i) access to treatment (ii) parentage and (iii) surrogacy. They concluded that the inclusion of ‘Infertility’ in the name might inhibit people from registering but did not review the functioning of the ITA donor linking and support services themselves nor those concerned with the Registers’ services.

In fact, by common agreement, donor linking and Register services had not been fully functional for quite some time after the ‘new’ Central Register was established to complement the 1984 Register. However, from the mid 2000s onwards, they had progressed considerably to the stage where they had developed a highly professional donor linking service and service model with increasing numbers of applications, 62 parties having been linked on the Voluntary Register and 57 applications to the Central register since 2007. The service also included a ‘letter box system’ through which parents, if they wished, were able to thank their donor in writing and donors and recipients, if they wished, were able to have periodic contact. Professional support staff were on hand to help both those seeking



information and those whose information was being sought; and to help those moving on to direct contact. They found that although some donor linking work was provided by (one of) the clinics in the early stages of a family's life, this could run the danger of ceasing without the ITA taking it on proactively. The service model was developed by Jenny Blood and Helen Kane, infertility counsellors/social workers (paper available on request).

With the transfer away of the responsibility for the Central Registers (and Voluntary Register – see below), there was no provision for the continuation of this level and type of professional support. A number of infertility counsellors felt that the Register related support services had since deteriorated as the current service provides only generic implications counselling to the applicant and no mediation and facilitation of information exchange/contact with the outreached party. A *State Enquiry* into aspects of donor conception was underway during my visit (though with a very short consultation period) and its interim report was produced in September ([www.parliament.vic.gov.au/lawreform](http://www.parliament.vic.gov.au/lawreform)). Part of its remit was (i) to look at whether legislation could be made retrospective and (ii) to see whether the changes to the donor registers that came in on 1<sup>st</sup> January 2010 were working well.

With the proposed abolition of the HFEA in mind, it was of interest to see what the staffing and financial implications of the new system were:

- ITA had 6 fte staff (not including licensing) – CEO, Policy Officer, Office Manager, Admin Officer, Manager of Donor Services (0.8), Donor Linking Counsellor (0.4) and Donor Registration Officer (0.4)
- VARTA has 3.4 fte: CEO (ft) Policy Officer (ft) Admin Manager (ft) Community Education Officer (0.4 with a £5000 budget)
- A review of what would be needed by VARTA to carry out its key roles and priorities cost in the region of \$50,000 (Aus)
- Some believe that the PRP is costly to run; in any event it represents additional activity to that before the requirement for a PRP was introduced
- Department of Human Services now employ 4 admin staff to deal with CRB and child protection checks
- Births Deaths and Marriages – although they had no additional funds allocated to them to provide the new birth registration service, there is nevertheless a cost attached to it
- Adoption and Family Records – ditto

The estimated costs of the new Act have been put at \$7.1m over 5 years

### **Victorian Registers and the Birth Registration Process**

There are two registers in Victoria both of which were transferred to the Births, Deaths and Marriages (BDM) Service on 1<sup>st</sup> January 2010 from the ITA:

- (i) *Central Register* – established in 1998 and covers all births. It has two parts and also includes the Central Register of 1988. Parents of minors, donor conceived adults and donors can request information (including identifying information) and contact with the other party(ies). When a request is made then the Register staff are required to approach the other party(ies) to see if they consent to information being released. Parents can still request information and contact even when their child has turned 18 though from this age, donors can no longer request information from parents. In practice, some believe the latter to be a retrograde step as it had been found to be useful at times for the donor to apply to contact the parents and encourage them to tell their child if they had not previously done so. This means that some donor conceived adults may now find out their origins as a result from a letter from BDM when they might in times past have found out from their parents, prompted by a donor’s enquiry.
- (ii) *For those born after 1998*, donor conceived adults have the right to identifying information at age 18, regardless of whether the donor(s) agrees. There is provision to seek consent from the senior next of kin if the donor has died by the time that information is sought.
- (iii) *Voluntary Register (Donor Treatment Procedure Information Register)* – set up in 1998 and had its capacity expanded in 2001. The only way to find siblings is through this Register. It is open to donor conceived adults, parents of children of any age (i.e. including parents of adult children) and to descendants of donor conceived people; also to donors and their descendants. Those donors who have registered tend to do so soon after donating rather than requesting information/contact through the Central Register, reflecting their concern not to intrude into the social family while at the same time making it clear that they are willing to be approached. Many parents now also place their name on the Voluntary Register soon after the birth of their baby, reflecting their interest in having contact with other families containing a donor conceived sibling of their child. However, some parents have used the Register to say that they have not told their child of their origins and want no contact if enquiries are made.

The new Act also introduced a new system of birth registration which is thought to be a ‘world first’. Clinics send a manual notification to BDM (will eventually become electronic) and parents register the birth (written form rather than face to face: must be done within 60 days of the birth) indicating that they have used donor. BDM places details on the Central Register and sends a record of the information to the parent(s) who are then required to confirm its accuracy. The parent(s) is given information at the same time about the Voluntary Register and about VARTA. Some parents have failed to provide information in their initial birth registration and this has required careful handling.

With effect from January 2010, anyone who is donor conceived that applies for a copy of their birth certificates from the age of majority onwards will also receive an ‘addendum’ which informs them that additional information is available to them on request. This will set out details of their biological parents. The *actual* format is still to be drawn up.

It is of note that adoption birth certificates in Victoria are not annotated to ensure the person can become aware that they are adopted (if they do not know already) and the same is true for birth certificates of those conceived through donated gamete(s). Hence such groups will only become aware of their status through the BDM services on application for a copy of their birth certificate (adopted people have had the right to access their original birth certificate from the age of 18 since 1984).

It is also of note that, unlike the UK, birth records are closed to the public for 100 years and marriage records for 60 years.

Anyone applying to the registers for identifying information is required to undergo mandatory counselling with a social worker from the Family Information Networks and Discovery Service (FIND)<sup>6</sup> prior to information release. This is usually a single session though there is provision for additional sessions if necessary. The counselling requirement is not referred to on the BDM website, because of concerns that this may inhibit people from applying. There is no charge for the counselling. Applying to the Central Register is \$61.90 and there is no charge to apply to the Voluntary Register.

Two staff from FIND have been allocated to do this work (alongside their existing work in adoption.) and VARTA staff have provided them with some training. Once an application is received, FIND staff aim to respond quickly, usually within one to two weeks. BDM staff are not allowed to advise FIND staff as to the category of the applicant (this was specified in the Act) so the first job of FIND is to identify whether they are a donor, donor conceived adult or recipient parent. The counsellors have preliminary telephone contact with the applicant, sometimes over several calls. Some applicants have also instigated follow up telephone consultations following the formal counselling session.

Sessions are usually face to face at the FIND office but can also be over the phone if the person lives at a distance. Applicants can bring a supporter if they wish. There is provision for the counsellor to assess whether the applicant needs mental health support alongside the release of information and if they do, this will usually be paid for through Medicare. They are also able to halt the release of information if they feel this would be too dangerous/risky (to be defined).

Once the counselling process is complete, communication from the BDM to the applicant is by person to person registered mail (i.e. when the information from the Register or the birth certificate – whichever is requested - is then issued). There are careful security checks undertaken to ensure that the applicant is who they say they are, most of which have been from their experience in the rest of their BDM work.

Both BDM and FIND staff reported the work to date to be relatively straightforward and that their skills from elsewhere had proved transferable. Both services anticipated privacy would be a major issue and that applicants would want to be in control of what information can be

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<sup>6</sup> At the time of my visit, this was called Adoptions and Family Records Services (AFRS)

released. This has proved to be the case and some applicants change their mind about whether or not to release information after counselling – in both directions.

An NGO, VANISH, has agreed to take on any follow up work. VANISH is an adoption support agency which is interested in the field of donor conception but they currently have no professional staff at all and no staff with experience in donor conception work. No-one has yet taken up the offer of follow up from VANISH and it is unclear at the present time whether or not the service will need to be fee-based.

### **Additional features of the Victoria situation**

It continues to be the case that all have to attend *mandatory* counselling sessions prior to the start of fertility treatment (introduced by the 1995 Act) unlike other States where it is offered but not legally mandatory. Counselling is comprehensive and it is not unusual for it to run over several sessions, especially where donated gamete(s) are involved.

Some clinics, such as Monash IVF, require certain categories of patients to attend seminars prior to treatment, for example prospective parents and known donors. Some run support groups following confirmation of pregnancy for certain groups, for example single women, families formed through the use of egg donation.

In all Victorian clinics, prospective parents choose their donor from a donor profile. Staff believe this enables them to start and make a 'connection' with their donor from these early days and contributes to them being able to manage the family's relationship with donor conception more healthily.

Counsellors see donors once or twice prior to donation. Some need help with compiling their profiles but not all; donors typically take this aspect very seriously. Profiles include a childhood profile and their first name. Counsellors do not 'censor' profiles at all – they believe it is important for them to be completed to the donor's satisfaction and for parents to 'choose' from that format. Parents are given a copy of the profile of the donor once the child is born (or possibly at the time of donor selection).

Recipient parents also compile a profile, albeit a shorter one. This is not routinely given to the donor (though is available on request) but a copy is kept on the clinic records.

Rainbow Families produced a very good leaflet for lesbian couples covering issues to consider in relation to using a known donor.

Melbourne counsellors meet as a group every 2-3 months (sometimes with invited speakers) for CPD etc. Melbourne IVF alone has 10 counsellors (clinic provides approximately 4000 treatment cycles a year) who have produced a range of leaflets including 'Taking Charge of your infertility' 'Coping with Work' 'Coping with family and friends'. Given the size of the counselling workforce, they appear to carry greater influence on clinic services than their UK counterparts and have the advantages of having more opportunities to share and develop practice experiences. However concerns were expressed by the Counsellors Group that there is increasing commercialisation in the clinics

since their acquisition by private equity firms. There are already indications that psychosocial services are being squeezed, e.g. leaflets running out and not being reprinted, and concerns that the current level of counselling provision to those seeking treatment may be under threat in the new financial climate in which clinics are increasingly owned by private equity firms, even though this is budgeted for in the Medicare package.

### **Surrogacy in Victoria**

There was previously no legislation regarding surrogacy, although surrogacy has, of course, existed. The new Act has provided legal arrangements to cover host surrogacy, though not commercial or traditional surrogacy. This means that in future, surrogacy arrangements that have legal standing can *only* be made in licensed centres, i.e. there is no legal machinery to transfer legal parentage from the surrogate to the commissioning parents in 'do it yourself'. Surrogates are banned from using their own egg so must use a donated egg if the intended mother cannot supply one. Surrogacy arrangements will only be permissible where there are medical reasons preventing the intended mother from carrying the pregnancy herself. The details of the assessment, monitoring and 'transfer of parentage' arrangements are yet to be determined; the transfer of parentage is dealt with in Section 147 of the Act which amends Subdivision 1 of the Status of Children Act and provides for Substitute Parentage Orders. All applications will have to go through the PRP. There is talk of an amnesty for past cases involving surrogacy, including host surrogacy.

### **(iv) South Australia**

*NB: Definitions of parent-child relationships in South Australia are to be found in the Family Relationships Act 1975; retrospective 'cover' for donors was made through the Reproductive Technology Act 1988.*

There have been some recent legislative and regulatory changes in South Australia (implementation from September 2010 onwards) together with the abolition of the South Australia Council on Reproductive Technology (end of August 2010). The latter was very active in developing standards, policy discussions and so on in its early days but had become weaker in recent years, thought by some to be because many of its functions are now undertaken via FSA/RTAC.

Although there was some pressure for a new Act completely, the compromise was to amend their existing one, the *Reproductive Technology Act 1988*. The amended Act is called the *Assisted Reproductive Treatment Act 1988*. Some concerns were expressed about the process and outcome of amending the Act, including that the State is now left with compromise law. Some of this arose from the idiosyncrasy that can sometimes be a feature of policy making processes whereby powerful individuals with personal views about, for example, whether gay people should be parents can hold sway. It remains the case that single women and lesbian couples can only be treated if they are clinically infertile, thus leaving some (fertile) women to continue to turn to self insemination or to seek treatment

interstate. However, unexpectedly, posthumous use of sperm under strict conditions was brought in.

A move intended to avoid the need for amending legislation and to adapt to changing technology/community standards in the foreseeable future was the inclusion of a clause in the Act that says that the Minister can add conditions of registration 'as he sees fit' precluding the need to go back to Parliament with primary legislation each time.

As well as the changes to the perceived 'culture' of the State (previously seen as the state with 'liberal' social policies but now more conservative), the influence of service provision of fertility treatments across the state was also felt to be reflected in the amended legislation. With only three clinics in South Australia, the controversy surrounding the sale of the largest one, now ReproMed, and a resulting legal case had significant repercussions. These included that some of the records were not transferred to the new clinic as a result, making 'searching' for information in later years more difficult.

The previous law, now amended, specified the age at which non-identifying info should be provided (at age 16 unless released before with the consent of all parties – which in effect meant parents on behalf of their children) but it did *not* state when identifying information should be released, as it was to be confidential unless there was donor consent. Donor Conception Registration Regulations (still being developed) are likely to specify that identifying info should be able to be accessed from age 16 unless earlier with the consent of all parties.

Policy may also specify the number of families that can be formed from one donor. It is likely that this will reduce from 10 to 5, given the likely psycho-social effect on individuals and their families in later contact should the number remain so high.

Although there have been moves to set up a State Donor Register for some time, allowance for this was only finally successful in the amended legislation. No date has yet been fixed for a Donor Conception Register to be established and some consider that it may be at least 5 years away. However the Regulations providing further governance for it to be set up are likely to be out in mid- 2011 (and consultations will take place on drafts beforehand).

In the meanwhile each clinic keeps its own register and runs its own information sharing and linking services.

As elsewhere NHMRC and RTAC have guidelines on what information should be stored and any that are not complying should be identified and dealt with under the licensing and regulation system. Requests for information will usually go to the Donor Coordinator but any donor linking work is done by infertility counsellors. This is almost all with younger children; there is as yet very little work going on with donor conceived adults. Updating of donor information is usually done by the Donor Coordinator or Andrologist.

### **Additional features of the South Australia situation**

Requirements of donor profiles in South Australia (set at clinic level) are especially comprehensive. Donors are required to complete a 12 page proforma devised by the clinics (same for all donors – known or unknown) *in their own handwriting*. Parents complete a 3 page proforma. Parents choose a donor from their profile (it does not include a photo). Staff reported that donors complete them readily and need little help to do so. A donation is not used until the proforma is completed. Once a child is born, these proforma can be exchanged – parents are automatically given that of the donor; donors can receive the parents' profile on request.

Donors are only paid travel expenses and reimbursement of loss of earnings where this is incurred but it is not seen as payment. Donors can place conditions on who can receive their donation and this can be found difficult to manage by the counsellors. For example, one donor recently said that he did not want his donation to go to anyone with fundamentalist religious views but counsellors felt this would be difficult to determine. He then amended his profile to say that he was atheist in the assumption that no fundamentalist would choose him. By specifying conditions, donors can end up being less likely to be selected by prospective parents.

At Repromed, donors are informed once a pregnancy is confirmed at the 8 week scan and again when the baby is born. In one recent case, the parents elected to send a photo of the baby to the donor; he replied by providing a photo too and they are now wanting to meet up. This is being mediated by the donor co-ordinator (a nurse). However some counsellors' reported having relatively little contact with families after treatment, except perhaps when a parent comes back asking if there is any more information about the donor than that already provided.

Repromed charge a higher rate for treatment (\$10,000 extra, not refundable by Medicare) but argue that included in this is provision for later follow up, donor linking and so on without further charges. Some counsellors said that this reflected the fact that Repromed has recognised the importance of longer term follow up. However, other counsellors said that their clinics also included in their various information that follow up counselling and support around such matters as talking with children about donor conception and enquiries about donors etc was available, even though their up front charges were lower. Concerns were expressed all round that such services may be less sustainable if a more competitive market drives charges down and 'profit' margins are squeezed, especially if prospective parents opt for lower charges in the 'here and now' and hope that they and their children will not require later support.

It appeared that there may be less counselling provision to those seeking non-donor fertility treatments than in some (but not all) other states. There certainly appeared to be less provision than in, say, Victoria – the equivalent of one full time counsellor at each clinic. However counselling is clearly evident where donor conception treatments are involved and with donors themselves. This was said to be the only state where the legislation specifies that counselling can be provided by doctors and nurses as well as infertility counsellors – though others said that this had been changed in the amended legislation. This had led to

not all patients being seen by infertility counsellors but this situation may be set to change with the amended requirements. It is considered to be helpful to infertility counsellors that the ANZICA Guidelines are as specific as they are, including their stipulation that there should be at least two counselling sessions.

Face to face support group activity has diminished in recent years and there is at present no professional involvement at group level in activities such as Telling and Talking workshops. One of the clinics has been running professional led support groups with specified parameters, e.g. that attendance ceases once pregnancy reaches 12 weeks. Professionals thought there was increased use of internet sites by patients such as Bub Hub; Essential Baby; Aussie Egg Donors, but this was still somewhat patchy.

Professionals also thought that there has been a downturn in support and resources for donor conceived individuals or families from groups such as Donor Conception Support Group (DCSG) – though the latter remains a very good political force. Staff are more likely instead to turn to (UK) DC Network's website for resources. ACCESS has also little to offer in the way of ongoing peer support.

### **Surrogacy in South Australia**

Recently approved legislation was implemented in Dec 2010. It has been determined that surrogacy treatment can *only* be undertaken by registered ART providers, i.e. 'do it yourself' surrogacy while not illegal is not considered lawful under a recognised agreement as there is no legal machinery to transfer legal parentage from the surrogate to the commissioning parents. Intergenerational surrogacy is also banned.

Recently approved legislation is due to implemented in Dec 2010. It has been determined that surrogacy arrangements can *only* be made in licensed centres, i.e. 'do it yourself' surrogacy will now be illegal or, at the least, there is no legal machinery to transfer legal parentage from the surrogate to the commissioning parents. Intergenerational surrogacy is also banned.

Surrogates will be banned from using their own egg so must use a donated egg if the intended mother cannot supply one. Surrogacy arrangements will only be permissible where there are medical reasons preventing the intended mother from carrying the pregnancy herself. Commissioning couples and the surrogate mother (and her partner if she has one) are required to undergo an assessment by a counsellor and undergo a legal and medical assessment prior to any treatment. Infertility counsellors are required to offer support to all parties and will see all of them together as well as separately. It is not yet clear how long the infertility counsellors will remain involved with either the commissioning parents or the surrogate and her family (not specified in the regulations so down to local practice). Neither is it yet clear how the service will be paid for and 'policed'. Parentage will be transferred once the baby is born through the Youth Court if all legislated requirements are met. Additional professional involvement may be required in relation to that (not yet clear).

There were concerns in some quarters that the surrogacy regulations were being drawn up in the Dept of Justice by lawyers and hence were unlikely to take sufficient account of



psycho-social aspects, including openness. The surrogacy legislation had very limited provision for regulations, which made no allowance for such measures. Drawing on the UK experience, we discussed in particular the situation where a surrogate uses a donated egg (rather than one from the intended mother). There is the risk that the offspring may not get to know of their genetic origins as their original birth certificate will only record the name of surrogate mother (and her husband if she has one) and not the fact that a donor was involved. In the new legal regime in SA, the clinic will notify the Donor Register that a donor has been used and will notify them when the baby is born but the surrogacy regulations need to work out a way for the surrogacy birth certificate to alert the offspring to the use of donor. Otherwise the spirit of openness in relation to donor as intended by the Assisted Reproductive Treatment Act will not be honoured.

#### **(iv) New South Wales**

NSW had no legislation at all prior to the new Assisted Reproductive Technology Act 2007 despite considerable lobbying over many years. Individual clinics had therefore developed their own practices though of course they have to meet RTAC accreditation and NHMRC standards.

Most of the Act came in on 1<sup>st</sup> Jan 2010, followed by some new conditions concerning registration of clinic providers from 1<sup>st</sup> March. The two Registers that it sets up and which are run by DH (see below) are not retrospective. The Act brought in the use of identifiable donors only. There were previously no legal restrictions on who could access fertility treatments; de facto lesbian relationships for example, were treated as akin to de facto 'straight' relationships in law. Although there is no provision for legal civil partnerships, both women in a female partnership can be named on the birth certificate.

Transitional arrangements are in place for those wishing to use the same (anonymous) donor to complete their family. Donor sperm/eggs can be used for the next 3 years for the creation of siblings and frozen embryos that include donated gamete(s) can be used for the next 5 years. However it was not wholly clear as to how this will be 'policed' except that clinics are expected to comply and will incur hefty fines if they do not. DH officials have some powers to inspect clinics in relation to the accuracy with which they are collecting and supplying information to the new registers (i.e. different powers to those held by RTAC).

There are no restrictions in the Act on who can access ARTs.

Donors can place restrictions on who can use their donated gamete(s). Although there was some opposition to this on the grounds that it could be discriminatory, the view that it was in the interests of the child prevailed – i.e. that it would not be healthy for a child to learn that their donor disapproved of their parent(s)' lifestyle/ethnicity etc at any stage, including if they later met face to face.

A limit of 5 has been set for the number of *women* that can conceive from one sperm/egg/embryo donor. This number includes each woman in a lesbian couple if both

carry a child from the same donor (i.e. and the children will be reared in one family) – but not any women with whom the donor has non donor-conceived children. The reasons for settling on a low number were partly to reduce risk of consanguinity and partly as recognition of the later complexity for offspring wishing contact with half siblings in managing large numbers. Apparently the NHMRC had previously suggested a limit of 10 families and then removed the limit but continues to say that numbers should be restricted.

### **The Registers**

The new Act says that identifying and non-identifying information can be released to donor offspring from either the Central or Voluntary Registers at age 18. Parents will not be allowed to access the Registers at all. However clinics will continue to be expected to release non-identifying information to recipient parents when the child is born (or later on request). Clinics can also continue to operate information exchange and linking services if they wish (i.e. prior to 18) but the DH would expect this to be only with full consent of all parties. In other words, they do not interpret the new legislation as needing to restrict clinics in such work.

Both Registers are being looked after by the Private Health Care Branch of the DH as it is that sector of health care where the bulk of fertility treatments are delivered. Application forms are available on the website or in hard copy by request. There has been very little interest so far with only one full application being received for each Register at the time of my visit. However there has also been almost no publicity for either register and none is planned (though some may be made available for the voluntary register shortly).

Two recent amendments to the Act were secured to give powers to the DH to demand that records of those affected are provided to the registers on request. It will be part of the Register staff's remit to take all reasonable steps to find and secure any paper records of a registrant. For clinics with past records, the only 'rules' that apply are those for all medical records in force at that time – and this is different depending on whether it was private or state health care. However the new Act said that all future records must now be secured for 50 years.

Using DNA testing as a basis for facilitating identification of genetic relatives through the registers was considered but ruled out for the time being as too complex, especially given the privacy laws. However DH have said on their website and will say in their 'matching' letters that registrants may wish to seek DNA confirmation as there may be inaccuracies in the early records.

There is no provision at all for counselling or support to be made available at any stage to those approaching the registers and/or being 'matched'. Neither are any details of counselling/support organisations being provided, as this is considered to be inappropriate in case it is seen as promoting one service over another. However registrants will be advised that it could be important to seek counselling. Information from the registers will be supplied as hard copy print outs.

#### *(i) Central Register*

The Fertility Society of Australia (FSA) has been very involved in its development; therefore DH is confident that information about it is being given to all donors and recipient parents from 1 Jan.

Details of children that are born and those of donors are recorded once the DH is notified *by the ART clinic* of the birth. The form includes details of the siblings born to that donor and this will provide another check on the 5 limit. Where sperm is imported and used by a NSW provider, the 5 limits still applies and clinics are expected to take all reasonable steps to ensure that this is the case.

#### *(ii) Voluntary Register*

This register is open to all donors and donor conceived adults (i.e. 18+) and adult children of donors (18+). Information exchange and contact can only go ahead with the consent of both parties only. Staff are anticipating that most contact will be through the web/email rather than face to face or phone; there is only one member of Private Health Care Branch dealing with all enquiries at present.

#### **Additional features of the NSW situation**

Sydney IVF and IVF Australia are the biggest providers by far and each has several satellite units around NSW (about 12 each). There is also the public health programme at Royal Prince Alfred Hospital and 4 smaller freestanding units.

There was varying experience of donor conception treatment provision with some units only providing services which used known donors and hence doing no recruitment themselves. Where known donors are used, the standard counselling appears to be to see each of the 'parties' at least twice then to see all together. Where the donor has a partner, they are involved. Where the donor is unknown, some counsellors/clinics still seem to insist on 2 sessions (as per ANZICA Guidelines) but others are only routinely offering one session and would provide extra if that appeared necessary. For those using unknown donors, the waiting list was typically about 12 months and some individuals/couples have an implications counselling session prior to joining the waiting list and then again when they reach the top of the list. All clinics offered a choice of donors with recipients choosing from the profiles (though photos were not allowed).

#### **Surrogacy in New South Wales**

As elsewhere, there is new legislation surrounding surrogacy arrangements. Commercial surrogacy is banned and surrogacy contracts remain unenforceable. Surrogate mothers are banned from using their own egg so must use a donated egg if the intended mother cannot supply one. Surrogacy arrangements will only be permissible where there are medical reasons preventing the intended mother from carrying the pregnancy herself. This means that surrogacy arrangements can *only* be made in licensed centres, i.e. 'do it yourself' surrogacy will now be illegal or, at the least, there is no legal machinery to transfer legal parentage from the surrogate to the commissioning parents. However there was some confusion among those I spoke to as to the mechanisms and legal processes for transferring

legal parentage, perhaps reflecting that legislation is very new. At least one professional told me that those using surrogacy arrangements would have to adopt in order to get parentage transferred and, as such, go through the adoption assessment and preparation process in the usual way. However the legal section of the Dept of Health said that commissioning parents would not be able to adopt the child as this would be considered private adoption and hence illegal. Hence they can only apply for some parental responsibilities through the Family Court, i.e. not full legal parental rights. However if the surrogate was a family member, then an adoption can be applied for after 5 years. Adoption is dealt with under the Department of Human Services.

## **(v) New Zealand**

Although NZ has been at the forefront of progressive practice in relation to openness following donor conception treatment, it did not have legislation until 2004 – the Human Assisted Reproductive Technology (HART) Act 2004 implemented August 2005. The Act is the responsibility of the Ministry of Justice (even though the Act went through Parliament via the Ministry of Health) to reflect the fact that the legal status of children is seen as something other than a purely medical matter. The underlying principles are set out at the beginning of the Act. There are some aspects of the Act that do not fully ‘fit’ with family law but they are generally seen as compatible. For more detail on the Act and Registers see [http://www.dia.govt.nz/diawebsite.nsf/wpg\\_URL/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-\(HART\)-Register?OpenDocument](http://www.dia.govt.nz/diawebsite.nsf/wpg_URL/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-(HART)-Register?OpenDocument).

Current practice is that up to 10 children are allowed in up to 5 families<sup>7</sup> (not including the donors’ own family(ies)) – although it was not wholly clear to me how this is policed except through the clinics themselves. Each clinic is required to keep its own records and *should* be liaising with other clinics to ensure that the limit is not breached.

Donors can also set their own preferences for the upper limit as can individual clinics (providing that these are at or below national guidelines). With regard to the latter, one clinic has set their limit at 5 families, another at 4 and another has said that it will allow only 2 from sperm donation and 1 from embryo donation. It is a requirement that donors’ partners consent to the donation going ahead.

Donors are allowed to set restrictions on who receives their donation. In the parliamentary debate on this, it was clear that a key consideration was the importance of donors feeling comfortable with recipients’ life style and so on in the event of them having later contact with the child – i.e. a child-centred view.

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<sup>7</sup> This is not specified in the HART Act.

Donors are allowed to have their expenses met but these are capped. No payments are allowed. There is a national shortage of donors (sperm donors go into a national<sup>8</sup> 'pool') with typical waiting lists of 18 months + for sperm donors and 3 years + for egg donors. This has fuelled more efforts by prospective parents to recruit their 'own'.

Although inter-generational and intra-family donations are not banned, all applications have to go through the (National) Ethics Committee on Assisted Reproductive Technology (ECART) (organised by the Ministry of Health). However this does not apply where it involves siblings or first cousins.

Egg sharing is not allowed in NZ though embryo donation is, though with strict guidelines and assessment procedures (including the involvement of ECART as the final decision making body).

### **The Registers**

The Act provides for two registers: while there is no fee for parties to *provide* information to either Register, there is a fee for receiving information. There are no counselling or professional support services provided, though counselling is recommended (costs to be met by the individual). No counselling or support organisations or individuals are named on the website; instead the advice is to contact a GP, local fertility clinic or look under Counselling Services in the Yellow Pages.

(i) Voluntary Register - people who donated sperm, eggs or embryos prior to 22 August 2005, and people who were born as a result of those donations (and their guardians) can choose to provide information about themselves for inclusion on the register. Donor offspring must be over 18 years of age to provide their details, or 16 or 17 with the approval of the Family Court. Guardians can provide the details of donor offspring under 18 years old. Information release can only take place with the consent of those affected. Any non-donor conceived children of the donor cannot register

The register has had little take up and there is no provision within the Act (or elsewhere) to protect legally any records prior to 2005. There is no budget for promotion of the Register. Those seeking information are thought more likely to approach direct the clinic where they were conceived (if they know) rather than the Register – and clinics are expected to supply them with whatever information they have, providing the other part(ies) consents. Even if someone does register on the voluntary register, Registry staff will simply approach the clinic for confirmation of the details and then any donor offspring registrations will be checked against donor records for a match.

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<sup>8</sup> It has not been possible to verify this; although some people said that there was a national pool, others said that the 'pool' was only shared between clinics run by the same company

Clinics are required to provide all information they hold in relation to donor conception prior to August 2005 to Births, Deaths and Marriages after 50 years (or earlier if they go out of business).

(ii) HART Mandatory Register (from August 2005)

BDM are advised of all births occurring in NZ. Fertility centres where donor assisted treatment is provided are required to notify the Registrar-General of the birth of a child born following donor treatment giving sex, date and place and child's name. They also have to supply the name and address of the guardians, and donor details. Some counsellors reported that their contact with parents following the birth (if parents have not yet notified the clinic and they are therefore chasing them) offers a good opportunity to talk with them again about the birth registration process.

Parents are required (as all parents) to register the child's birth. This is done by written form rather than face to face and submitted to the Registrar, usually within two months.

Manual cross checks of these different notifications are undertaken (this will move to an electronic system in the future) and any discrepancies picked up. Where parents have failed to disclose that their child(ren) was conceived using donated gamete(s) then they are contacted and advised to correct the form. Sometimes this appears to result from confusion and sometimes it appears to be deliberate. Where it is a multiple birth, this fact is *not* recorded on the HART register.

Once Registry staff receive the mandatory notification, they can also check the donor's details on the voluntary BDM Register, checking for matches. Similarly if a donor later changes his/her name, for example, then there is provision for a box on the form to be ticked to identify them as a gamete donor and the HART Register can be updated and the provider advised of the changed details.

Donors' profiles are retained by the clinic rather than stored by the Register staff though clinics are required to provide all such information to Births, Deaths and Marriages after 50 years (or earlier if they go out of business). The issue of collection and retention of non provider records is currently being looked at with the intention that the Registrar-General will store the information.

Since 1 January 2006 all birth certificates issued show the NZ citizenship status of a person, however children born in NZ before this date are automatically NZ citizens. Birth certificates are a public document. Under recent changes, same sex parents can be included on a birth registration which shows on the birth certificate as mother and other parent (but same sex adoptions are not yet allowed).

There is nothing on the birth certificate itself to indicate that the child is donor conceived. The same is true for an adoption birth certificate where it is only indicated if the parents request this specifically: a recent Law Commission Report

[http://www.lawcom.govt.nz/sites/default/files/publications/2000/09/Publication\\_72\\_144](http://www.lawcom.govt.nz/sites/default/files/publications/2000/09/Publication_72_144)

[R65.pdf](#)) recommended that adoption birth certificates should include the original birth certificate but this was not taken up.

The HART Act says that counselling should be *offered* to people approaching the Registers and when they are 'matched'. However no advice is given as to how to provide such professional support and there is no budget for it (see above). This is in contrast to NZ citizens who are adopted. The latter can apply for their original birth certificate at the age of 20. If they were adopted prior to 1985, then they have to undergo mandatory counselling before the certificate is released. This is provided by the Department of Child, Youth and Family (under the Ministry of Social Development) and is free and as much 'as needed'. Post 1985, applicants have the choice: they can receive counselling or they can decline the offer. If the latter they have to confirm twice that they do not wish to receive counselling. Where the adoption was prior to 1985, any of the parties affected can restrict the release of information but that is not allowed for those post 1985. However it should be noted that post adoption services per se are little developed in NZ (despite NZ having one of the highest rates of adoption in the Western world) and hence the professional group with any experience of supporting those exchanging information and contact with those genetically related are in fact infertility counsellors. The tradition in fertility clinics is to take a long term view of what is appropriate in terms of follow up support; hence the development of 'donor linking' services within clinics.

There is currently no provision for adults seeking information and contact with genetic relatives but for whom there are no paper records. There are no plans to introduce DNA testing though the Register website suggests that those receiving information from the Registers may wish to arrange their own DNA testing (at their own cost).

Details of what information can be released, when and to whom, can be found at [http://www.dia.govt.nz/diawebsite.nsf/wpg\\_URL/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-\(HART\)-Register?OpenDocument#thirteen](http://www.dia.govt.nz/diawebsite.nsf/wpg_URL/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-(HART)-Register?OpenDocument#thirteen).

Effectively donor offspring can access identifying information about their donor at age 18 as of right and about siblings, providing that they consent. However their parents/guardians can access it earlier and donor offspring can apply to the Family Court for it to be released at 16 or 17. The Registrar has the right to refuse to disclose information at any stage if its release could 'endanger any person'.

### **Additional features of the NZ situation**

Prior to fertility treatment using donated gamete(s), clinics in NZ insist on two mandatory counselling sessions for all parties with the infertility counsellor. Where the proposed donor is known to the recipients, the practice is that there are usually two counsellors involved in the implications counselling work to enable all parties to be seen separately as well as together. Two key factors were identified in this work:

- Clarity around the boundaries of the donation
- The presence of a pre-existing close relationship

In all work involving the use of donor, the minimum of two counselling sessions are provided at least one month apart. Where a known donor is to be used, a joint session is also offered and strongly encouraged; about half take this up. Sometimes such a meeting is also offered where it is an unknown donor. *Very* occasionally a donor sets a meeting with recipients as a requirement of their donation.

Recipients are actively involved in selecting a donor. Donors provide a profile, including a photo if they wish, and this is passed onto parents once their child is born (having been drawn on in the selection process). Many parents are given the first name of their donor and say that they find that helpful in bringing up their child(ren). In embryo donation and, in some cases, in egg donation, the recipients also provide a profile to the donor. This is much less common in sperm donation.

In recent years, there has been an increase in the numbers of recipients who meet the egg donor (i.e. where the egg donor is unknown) and this is felt to be a positive movement. This has, not surprisingly, led sometimes to one of the parties pulling out when the meeting is prior to treatment, meaning that it is important that clinic staff are supportive of this development (it can result in loss of revenue) as well as those directly affected. Meetings with sperm donors are less common though that too is now starting to happen.

Given its small population size, counsellors reported high levels of awareness among those affected by donor conception of consanguinity risks and of the likelihood of having contact with donor conceived siblings (or children of their donor). In similar vein, there is a good level of awareness among donors that they may be identifiable from their profile.

One counsellor has conducted a small scale study looking at what turns intentions of disclosure into action among parents who have used an egg donor and found the following to be important: the relationship with the woman that donated the eggs; having had face to face contact with her; having a pre-agreed strategy for 'telling' including timings. Another reported the value of having group sessions for parents after their child(ren) is born. In the past they have run group sessions on Saturday mornings (three consecutive sessions) to support parents to start the disclosure and this appeared effective – though is no longer running because of lack of resources. One clinic runs an annual meeting for donors, which is well received.

Counsellors are, on the whole, allowed by their clinics to provide later linking services rather than this being provided through other routes. For example one counsellor I met was in the middle of supporting a fifteen year old to meet his donor. Others have had to help young adults deal with their disappointment when approaching the clinic only to learn that no paper records exist to help them learn more of their origins and genetic relatives.

Where requests are for contact with half siblings, then sometimes the counsellors find that the 'other' family may not have been as open and the donor conceived children in that family are not yet aware. This in itself can lead to counsellors being drawn into supporting disclosure work. Similarly when contacting a donor, counsellors find that they are in a new relationship and have not told their new partner (and perhaps any children from this or



previous relationships) that they were a donor. Again support may be required in managing disclosure before any linking work takes place with the donor conceived child.

Counsellors have a range of experiences of the nature of reunion work. On the whole, it goes ahead smoothly. Meetings may be requested to take place in open social spaces such as cafes or in the more private space of the clinic. Where the request is coming from parents, initial meetings are usually between parents and donor followed by a decision being made on both sides as to whether to proceed to a meeting between donor and child. Occasionally there is a mismatch of expectations, especially in the early stages but these are usually managed by the parties themselves. Parents that I met reported that they were able to arrive at levels of contact with their donor (if they knew them already or if they met subsequently) or other families who shared a donor which felt right for them and their child. It seemed helpful to have access to infertility counsellors if they ever needed some professional support with regard to this.

### **Surrogacy in NZ**

Little information was available concerning surrogacy in NZ. My understanding is that commercial surrogacy is banned but host/ traditional and genetic surrogacy are allowed and legal processes are covered in the HART Act; Guidance from ACART is available at [http://www.ecart.health.govt.nz/moh.nsf/pagescm/6799/\\$File/surrogacy-fertility-providers-nov08.doc](http://www.ecart.health.govt.nz/moh.nsf/pagescm/6799/$File/surrogacy-fertility-providers-nov08.doc). Where fertility clinics are involved, then the decision as to whether the arrangement can go ahead is made by ECART. I was not able to establish current practice with regard to professional involvement prior to the application going before ECART, during the pregnancy or at the time of application for transfer of legal parentage.

Overseas surrogacy is currently being looked at by 5 different government departments. The particular focus is the status of the children born through this route as the commissioning parents typically want their child to be a NZ citizen.