

Submission to Federal Inquiry into Donor Conception in Australia

Marilyn Crawshaw PhD, MA, BSc(Soc), CQSW

I am a recently retired Senior Lecturer in Social Work at the University of York, UK. I retain links with the university and am continuing to work as an independent researcher and consultant. I have long standing professional and research interests in the field of infertility, in particular donor conception; for many years I delivered an infertility counselling service. I am the Co Chair of PROGAR, (Project Group on Assisted Reproduction), a UK coalition of professional and user groups with key interests in child and family welfare that is serviced by the British Association of Social Workers. PROGAR played a significant role in the campaign to lift donor anonymity in the UK and continues to work on associated activities. I am the Chair of the Advisory Group of, and national adviser to, UK DonorLink, the UK Department of Health funded voluntary information exchange and contact register for adults genetically related through donor conception; this is the only register in the world that uses DNA testing to identify potential genetic relationships in the absence of paper records. I am also a past Human Fertilisation and Embryology Authority (HFEA) Social and Ethical Inspector and External Adviser. Finally I have long standing involvement with DC Network, the UK support group for families formed through donor conception treatment, and currently contribute to their Dept of Health funded initiative, Preparation for Parenthood.

This summer, I received a Nuffield Foundation grant to visit Australia and New Zealand over six weeks to study the ways in which donor registers and donor linking services were run and to explore networking and research opportunities. In Western Australia, Victoria, South Australia, New South Wales, North Island and South Island in New Zealand, I met 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

This submission represents my personal and professional views rather than being on behalf of any of the organisations with whom I am associated.

Key observations from my study tour of Australia and my research and practice experience considered against the Inquiry's Terms of Reference

Please note that my comments relate to non-medical aspects of donor conception alone. I have not referenced this submission but can provide references on request.

1. A country's legislative and policy approach to donor conception related services needs to be informed by what it considers to be its '**duty of care**' to those affected as well as broader principles, research evidence, practice experience and feedback from service users. The same is true for the practice approaches of service providers. The most obvious complication in determining such 'duty of care' is that there are a key group of stakeholders who are either yet to be born or, if already born, who are unaware of their origins or otherwise 'hard to reach' – i.e. donor conceived people. In my view, their interests should be paramount but there has been a long standing tendency that remains today to conflate their interests with those of prospective or recipient parents in all matters.

In similar vein, there is the danger that the needs of the family unit as a whole can become obscured, including its unfolding needs over its lifetime.

Given that donor conceived people can only come into being with professional intervention (except through the informal use of self insemination which falls outside the legal remit), the onus is especially great to ensure that consideration of their emotional and social wellbeing and that of any family unit of which they are a part throughout their lifetime is at the centre of the 'duty of care'.

Neither do the lives of donors stand still. They too continue to negotiate the impact of their involvement in donor conception treatments and they too may do so from within the context of a family(ies).

'Duty of care' in this setting must therefore extend beyond what is deemed medically or scientifically safe and must encompass longer term individual and family wellbeing (this is returned to later).

2. The **limited research base** to guide policy making in psycho-social matters arises from (i) that fact that certain types of data can only be gathered over the **long term** and is methodologically complex, such as the impact of the number of families used from one donor and the impact on donor offsprings' well-being of payments to donors – but it is not ethical or safe to (only) wait for the long term evidence (ii) inadequate **funding** of existing psycho-social research; levels are shockingly low when compared to those for medical and scientific research and (iii) the relatively narrow range of psycho-social research with a dominance of psychologically informed research. Policy making must therefore draw too on **key principles** of child and family welfare, research evidence from the **broader field of child and family welfare** and the so-called '**grey**' literature reflecting the experiences of those

personally affected as well as that specific to the assisted conception context. For these reasons, it is not acceptable in my view to conclude that practices/policies should be introduced or be allowed to continue *on the basis that there is no research evidence to say that they do harm*. Indeed where any proposed change to a policy or practice is designed to address the needs of the adults concerned, i.e. the prospective parents (typically to improve supply of donors for example), then there is a strong case to be made for saying that the **onus should be to demonstrate that any change will NOT do harm to those thus conceived**.

3. The need for improved **standardisation and harmonisation** across Australian states is clear and, arguably, increasingly so with the increased involvement of commercial interests. While there will always be some 'local' interpretation of policy in any national framework, the key advantage of having a national regulatory and legislative framework is that the **broad parameters are fixed and minimum standards are in place and enforceable**. Australian citizens could thereby be assured that they would not feel/be discriminated against by dint of receiving services in a state that has less progressive policies, for example. With relatively small populations in each state, there are also advantages of having country wide policies both in terms of pooled resources and in terms of exposure to wider influences. The majority of the professionals and those personally affected that I met found the current patchwork to be unsatisfactory and difficult to manage. In particular, the following areas (not in order of priority and not exhaustive) should, in my view, be standard:

- Exclusion/eligibility criteria and minimum (psycho social) assessment requirements for services where gamete donation is involved (including surrogacy and known donation).
- Minimum standards for the provision of counselling and psycho-social preparation for parenthood to those considering and undertaking donor conception treatment, including any additional factors according to whether the donor is known or unknown to the recipients.
- Minimum standards for counselling and support and any financial recompense (i.e. reimbursing expenses) to both unknown and known donors (and partners/children if they have them). Payments to donors should not be allowable in keeping with the principle that 'selling' of children (and hence of gametes for use in creating children) is considered to be immoral.
- Minimum standards for availability of counselling and support – including the need for staff with non medical 'counselling' qualifications such as social work and clinical psychology - to all those affected prior to entering treatment, registering on state registers (where voluntary registers exist) and prior to release of information from any of the donor registers.

- The age at which donor conceived people have the right to access identifying and non-identifying information.
 - The number of offspring that is allowed from a single donor. (I return to this later)
 - Provision with the birth registration system for recording details of the donor-conceived person's genetic parents (see later for more detail).
 - Minimum standards for the provision of intermediary services to those seeking contact with others to whom they are genetically related through donor conception. In my experience, those affected have far greater need for such services than for therapeutic counselling though the latter may be required as a second line service. (I return to this later)
 - The requirement on service providers to supply Donor Registers with information about the conception and birth, and to collect and supply specified information about the donor(s).
 - The rights of those responsible for keeping Donor registers to acquire, where indicated, medical records from past providers in relation to anyone entering the Register (including those for cycles completed before any legislation was in place).
4. I do not believe that it is appropriate for the *offer* of **counselling and support** services to be considered sufficient; it is the **actual provision that is important**. There is anecdotal evidence to suggest that prospective parents and donors are inhibited from taking up counselling and support services when they are not presented as routine and when they have to pay for them themselves. Financial barriers cannot be underestimated, making it crucial that the funding stream for such services is found other than from potential users' own pockets. Similarly the provision of such services needs to be routine, making them more likely to be seen as non stigmatising and designed to build strengths rather than deal with problems.
5. The outcome of having a national framework should be to encourage '**best practice**' rather than drive it to the lowest common denominator – the danger of introducing minimum standards is that the latter will result. Regulators, policy makers and the professional bodies need to be alert to this. In other words, national frameworks should not be used to stifle bottom up creative developments. For example the bottom up developments in donor linking services coming out of some clinics that I visited that were responding to user-centred needs and wishes (i.e. voluntary) were very exciting. Moreover they were not being held back by the fact that *statutory* rights to information sharing and contact were only available when the children were older. This is commendable and I return later to some examples of this.

6. As in the UK, there have been moves in Australia in recent years towards 'lighter touch' **regulation** of clinics and greater interpretation of regulation as being a quality assurance activity. What appears to be lost is the role of regulation in driving up standards by sharing 'best practice', understanding the actual delivery of services rather than determining whether written procedures are in place and disseminating lessons learnt from adverse incidents. It is especially difficult, in my view, to marry successfully the need to attend to ethical and psycho-social as well as medical and scientific aspects of services once the regulatory process is approached within a broadly bureaucratic framework through such as (only) checking ISO paperwork/procedures.

Given the current split between regulation (through RTAC and, recently, sub contracted to an independent body) and policy making, it is also crucial that there remains a clearly defined role in regulation for the latter *and* for those responsible for running donor registers and associated services. The latter bodies need effective 'teeth' if they find that service providers are not paying due attention to matters that carry long term implications such as adequate and appropriate collection of donor information for later release to donor conceived people and recipient parents.

7. The need for a **national Donor Register** has been well made in a number of quarters. This too reduces the likelihood of state-associated discrimination and reflects the fact that Australian citizens can and do move between states (including for medical treatment). Having a national Donor Register on which those conceived from donor assisted conception know that details of their genetic and biographical origins are stored and can be made available to them is imperative. The case is now very strongly evidenced that those personally affected can suffer adverse emotional, medical and social consequences if they wish for information and contact about those to whom they are genetically related through donor conception and this is not forthcoming. This in turn has led me to the view that **the right to access such information should be applied retrospectively as well as prospectively**. This will not be easy for some donors but this should be addressed through the provision to them of good quality professional support rather than by allowing the denial of access to information to continue for another generation.
8. **Provision of a voluntary register as well as a 'statutory' one** in some Australian states is worthy of strong consideration in relation to national registers. Voluntary Registers have the potential to facilitate information exchange and contact much earlier than through statutory entitlement – including from infancy onwards for donor conceived people - and hence be more responsive to individual need as it arises and more geared to enabling 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. They also enable those without statutory rights at all – i.e. those born outside of a legislative framework – to have a vehicle for seeking information and contact.

9. The **appropriate location for either the national or state registers** is an important matter for debate and I do not hold a clear view on this. There are advantages to locating them with Births, Deaths and Marriages services - or at the least ensuring that there is a strong organisational link between BDM services and those running Donor Registers – given BDM services’ experiences in running registers containing personal information (including adoption records) and having direct contact with the public. They may also be seen as a neutral organisation in the eyes of potential users, especially donor conceived adults who in the UK at least have expressed concern about Donor Registers residing with bodies whose primary remit is fertility treatments.

From my trip, I am aware of a **recent change to service provision arrangements in Victoria** which some believe may prove regressive. The Infertility Treatment Authority of Victoria was renamed the Victoria Assisted Reproduction Authority and some of its responsibilities hived off to other bodies with effect from 1 January 2010. This appeared to have resulted in a drop in the provision and range of professionally led services (which were well regarded) but with increased overall costs. Fuller analysis of the effectiveness of the old and new models might provide very valuable evidence for informing the way forward.

Perhaps the most crucial consideration is to do with how well **resourced** the register services are; whether they have the **appropriate range of skill and experience** in their workforce to meet the range of need in this complex area; whether their remit allows them to offer **intermediary services as well as only retrieving and providing information**; and **how proactively accessible** the services are to enquirers/registrants. In other words whether they avoid the danger of providing a service that is dominated by bureaucratic operation. The need for **public education, promotion of the Register and mechanisms for feeding in to policy and practice in present day provision of donor conception services** is also important.

10. Mention of BDM services also raises the important matter of the **birth registration process following donor conception**. There is evidence to suggest that although the numbers of parents of donor conceived children that inform their children of their origins in infancy is increasing, there are still some that do not disclose at all or in a planned, child-centred way. Donor conceived adults have argued, and I support their view, that it is discriminatory for the birth registration system not to record the fact of their donor conception in such a way as to maintain their privacy but nevertheless enable them to be aware of their origins without this being dependant on disclosure by their parents.
11. In the Inquiry’s Terms of Reference, comment on the **number of offspring from one donor** is requested but only with reference to consanguinity. This is of concern as consanguinity is far from the only consideration. Policy makers and professionals need to remember that those being conceived using donated gamete(s) today have

to manage that fact throughout their lifetime and it throws up a number of challenges. For those who later have information about or contact with those to whom they are genetically related through donor conception, they have to be able to integrate this knowledge and its implications at many levels into their own sense of identity, their life planning and, sometimes, their medical decision making. It is not only individual genetic relatives of whom they have to take account. Family and friendship networks of these relatives can be extensive as well as those of the person themselves, increasing the complexity and risks involved in integrating this knowledge into one's own sense of being let alone the challenge of managing *actual* relationships should direct contact result (see also below).

Consanguinity risks also feature. Statisticians may be able to estimate such risks and others may challenge the mathematical formulae used. However, working from statistical risk alone is limited in understanding the medical, social and emotional risks and meaning to an individual donor conceived person or child of a donor: one cannot control for the movement of specific genetically related individuals throughout their lifetime! In my experience, it is the *threat* arising from consanguinity risks that poses the greater risk to emotional and social well being - where individuals fear entering intimate relationships, when they question whether their attraction to someone may be 'genetic sexual attraction', when the otherwise innocent statement of 'you look just like so-and-so' carries a very different significance to those personally affected by donor conception. Not all donor conceived people experience such distress and those who do, do not necessarily experience it at all the time but policy makers and professionals needs to be aware that the living experience with regard to consanguinity does not necessarily reflect the statistical risk.

12. In a number of services/sectors in each of the states that I visited, there was evidence of a careful and commendable approach to child and family well being and regular reference to the need to understand and take account of **child and family welfare implications** of policies and practices in relation to donor conception. It is, in my view, crucial to maintain and build on this. Some **good practice examples** included:

- The importance of paying attention to whether prospective parents are able to feel some **beginning 'connection' to the donor** when trying to 'match' parties as an indicator of enhancing likely family wellbeing.
- Requiring that a **donor's partner (if they have one) gives consent** to the donation in order for them as a couple to be committed to the implications of 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** (and see earlier) 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.
- Not **paying donors** (or taking an approach to expenses or compensation that encourages blurring); again reflecting feedback from parents and donor conceived adults.
- routinely **providing recipients with donor codes** so that they are able to seek contact with other parents if they wish
- **linking families who shared a donor** when the children were still in early or middle childhood (where those affected requested this);
- offering '**letter box**' services, i.e. where the donor and recipient(s) can exchange non identifying correspondence if they wish and **linking donors and donor offspring** (or their parents) when all parties wished for this
- working with **young people through to early adulthood** who were coming forward to find out more about their donor or genetic siblings

13. However, the **provision of professional support** as described above is not consistently available within and across Australian states. 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 is the need for a national debate, in my view, about the appropriate skill mix and experience in linking/intermediary services for the range of individuals and families that might require such a service. At the least, it requires professionals experienced in **family work and intermediary work** (such as that with post adoption experience) but with awareness of the unique aspects arising from donor conception to provide such a service, working from an **infrastructure** that provides the necessary flexibility attached to the likely 'stop-start' or 'little and often' nature of contact. For this reason, the use of independent counsellors working to a traditional counselling model is not appropriate.

There is also likely to be a secondary service requirement for **therapeutic counselling** provision for some of those seeking information exchange/contact.

Consideration should also be given as to how to provide any **professional support that may be required from time to time** to individuals, couples or families resulting from any **difficulties** they experience arising from donor conception outside of any need to search for genetic relatives.

The debate will also need to encompass **funding** aspects. Donor conceived individuals and the non-donor conceived children of donors have said elsewhere that they should not be required to pay for a service that comes out of a decision made by their parent(s). Donors too may feel disinclined to come forward unless (free) support is available to them, especially when the long term implications of donating were not made clear to them at the time.

14. Finally and very importantly, it is of great concern that there appeared to be little professional activity in Australia with **donor conceived adults** conceived prior to the existence of current clinics and hence **without paper records**. None of the current donor registers make provision for the use of **DNA testing** as the basis for assisting 'linking'. While such a service brings its own challenges, the experience of UK DonorLink is that it is highly valued. **In my view, it is not defensible to stop short of such a development; not providing a service to one group of donor-conceived individuals and donors simply because there are no paper records when an alternative exists is discriminatory.**

I am very willing to be approached to expand on any part of my submission. Thank you for giving me the opportunity to comment on this very important subject.

Marilyn Crawshaw

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