

## **Response to the Review of Assisted Reproductive Treatment in South Australia**

**From:** Marilyn Crawshaw, PhD (York), MA (Bradford), CQSW (Sheffield), DipApplsSocStud (Sheffield), BSc(Soc)(London) – [REDACTED]

**Involvement in assisted reproduction matters:** I have been involved in this field since the 1980s variously as a social work practitioner running a fertility counselling service for several years and as an academic. I have conducted research into donor conception, surrogacy, cancer-related fertility and adoption. I have been a Social and Ethical Inspector and External Adviser to the Human Fertilisation and Embryology Authority, most recently working with them on developing a pilot support and intermediary service for people approaching their Register for information release. A founder member of the British Infertility Counselling Association, I edit their Practice Guide series. I am Chair of the multi-agency UK Project Group on Assisted Reproduction (PROGAR) which is administered by the British Association of Social Workers and draws on a number of national bodies concerned with child and family welfare. From 2003 to 2013, I was national adviser to UK DonorLink, the government funded DNA-based voluntary register for adults genetically related through donor conception. I am also actively involved with Donor Conception Network, the peer support organisation for families formed through donor conception and I contribute a seminar to their Preparation for Parenthood workshops. In 2010, I spent five weeks in Australia and New Zealand, funded by the Nuffield Foundation, to learn more about the ways in which your services and policies are run and developed; this included a visit to South Australia. I am currently Honorary Fellow (formerly Senior Lecturer) in the Department of Social Policy and Social Work, University of York.

PLEASE NOTE: I am not in a position to comment on the application of the law in South Australia; my comments come from my practice and research experience primarily here in the UK but also internationally, together with the guiding principles to which I adhere.

### ***Fact Sheet 2 - Welfare of the child***

I am firmly of the belief that the needs of those born as a result of ART should be treated as paramount and these should be considered within a lifespan perspective rather than restricting them to childhood alone. Of course the definition of 'needs' is a matter open to interpretation, especially when one considers the range of identified needs such as 'felt' 'absolute' or 'relative' and so on. I prefer to use the term 'human rights' which better enables consideration against universally accepted definitions in UN Conventions etc. of what human beings should be afforded and hence gives access to commonly accepted standards. It also moves debate away from seeing the matter as a 'welfare' issue alone with a focus exclusively on whether or not certain professional or parental practices are harmful. Of course there is still room for interpretation if ones uses 'human rights' as a measure but arguably less. Where there is considered to be a conflict of rights – such as donors' rights to privacy versus donor conceived people's right to information about their identity – this allows the paramountcy of the rights of those born as a result of ART treatment to come into play.

The key reason for such paramountcy in my view is that these individuals had no say (and hence could not exercise autonomy) in the decision to bring them into existence but they are the ones living their lives with the consequences (whatever they are – good, bad, neutral etc) throughout the whole of their lifetime.

It seems clear to me that what follows from this are the following:

- The right to regulated medical and scientific practices at the time of their conception that is well informed by current research together with longitudinal follow up studies on the development and wellbeing of offspring
- The right to screening of prospective parents in such a way that meets the threshold of avoidance of potential 'significant harm' that is used in child protection services. Of course one cannot ensure that prospective parents will not harm their offspring and any checks need to be proportionate but it is not acceptable to do nothing, given the involvement of a third party, ie medical treatment services. In other words, a straight parallel with those conceiving without medical assistance cannot be drawn.
- The right to full *identifying and biographical* information about genetic parent(s) and, in the case of gestational surrogacy, such information about the surrogate. This means that donors and surrogates should be required to provide such information about themselves and to do so to an agreed standard. There is room for discussion as to the age at which identifying information should be made available though I am increasingly of the view that this should be from birth
- The right to a birth registration process that:
  - Provides clarity about their legal parenthood and nationality
  - Enables them to be aware of their origins and whether or not the parents raising them are also their genetic parents, including whether the woman who gave birth to them is also their genetic mother

In keeping with this, I am also of the view that:

- Anyone considering surrogacy should be made aware of the additional potential complexity for the offspring where gestational surrogacy is used with an egg donor. The offspring will need to work out how to accommodate the meaning that each of these women hold for them over their lifespan. In addition, it may be more difficult for them to become aware of their origins depending on the availability of information being stored and released to them about both their genetic parent (the donor) and the woman who carried them through pregnancy and gave birth to them. There is some emerging evidence that prospective parents are not always fully informed about these implications when 'choosing' which type of surrogacy arrangement to use.
- Anyone considering donor-assisted treatment should be provided with preparation for parenthood sessions that enable them to receive professional assistance to prepare for parenting and family life where there is genetic difference; this is in addition to being offered counselling if they wish it (the two are not the same).
- Parents of donor-conceived offspring should be provided with ongoing support, if they wish it, with talking with their children about their origins and associated matters.
- donor-conceived offspring should be facilitated to have contact with their donor(s) if they wish.
- Those born as a result of donor-assisted treatment and non donor-conceived offspring of donors should be facilitated to have contact with each other if they wish (so-called 'sibling' contact) – In other words this should include children of the donor who are not donor conceived.

### ***Fact Sheet 3 - Registration scheme for ART clinics***

I am not sufficiently familiar with the current registration processes to comment here beyond saying that it is important that such processes take account of the human rights of the offspring over their lifetime rather than focussing exclusively on medical and scientific matters.

### ***Fact Sheet 4 - Dissolution of SACRT and the Code of Ethical Clinical Practice***

I am not sufficiently familiar with these matters to comment here beyond saying that it is important that discussion should take account of the human rights of the offspring and the unique context of ART and its lifelong impact rather than focussing exclusively on medical and scientific matters.

### ***Fact Sheet 5 - Access to ART***

I am not sufficiently familiar with these matters to comment here beyond saying that it is important that discussion should take account of the human rights of the offspring and the unique context of ART and its lifelong impact rather than focussing exclusively on medical and scientific matters.

Please also see my answers in relation to 'welfare of the child'.

I note that under point 4, you refer to 'the above-mentioned counselling provisions' but there is no reference to counselling in points 1 to 3. If you instead mean reference to the screening provisions at point 3, this is not counselling! It strikes me that it would be extremely difficult to know whether the removal of screening provisions and counselling provisions would have any impact unless there were large scale longitudinal studies being undertaken. As far as I am aware there are not. Here in the UK, for example, we do not have such studies and we are unable to say whether, for example, children born through ART in general or donor-assisted ART in particular are any more or less likely to come to the attention of child protection, mental health or court services than other groups or even whether their parents (if a couple) are any more or less likely to remain together. If such information is also absent in the South Australia context, it would be difficult to consider this question at anything other than an anecdotal level.

### ***Fact Sheet 6 - Donor conception register***

I am hugely disappointed to learn that South Australia has still not set up a DC Register as this was being actively debated when I visited in 2010. It is lagging behind many parts of the world and indeed other parts of Australia. While it was disappointing that the decision at national level was to not set up a National Register (which I would have favoured) the establishment of one for SA is surely now long overdue. There is now plenty of research, lay and practice evidence that those directly affected by donor conception want the *choice* about when and how to access information relating to them, including identifying and biographical information about their donor(s) and see this as their *right*.

As I said in my response under 'welfare of the child' above, Register provisions should, in my view, take account of:

- The right to full *identifying and biographical* information about genetic parent(s) and, in the case of gestational surrogacy, such information about the surrogate. This means that donors and surrogates should be **required** to provide such information about themselves and to do

so to an agreed standard. There is room for discussion as to the age at which identifying information should be made available though I am increasingly of the view that this should be from birth (and thus for their legal parents by proxy while they are a minor).

- The right to a birth registration process that:
  - Provides clarity about their legal parenthood and nationality
  - Enables them to be aware of their origins and whether or not the parents raising them are also their genetic parents, including whether the woman who gave birth to them is also their genetic mother. This does not mean that those who are donor conceived or born through surrogacy arrangements should have a birth certificate that identifies this for all to see. It does mean, in my view, that birth certificates for all people should include a section that says that it is a certificate of legal parentage but not necessarily genetic parentage and directs people to those places where information about genetic parentage might be held.

The relationship between the birth registration process and the Register needs to be considered carefully for those conceived using donor(s) and/or surrogates, including the unique needs associated with gestational surrogacy as identified above.

I am also of the view that the associated duty of care means that those seeking information should be provided with professional support (and counselling if they require it but these are different services with different skill sets) when seeking information, having information released and making contact with those genetically related to them be they – ‘siblings’ or donor(s). There is an excellent model for this at VARTA. Such a service should also be available to non donor-conceived offspring of donors.

*If there is no age restriction on the release of information*, then I suggest that there should be only one Register that records details of all donors, recipients and donor-conceived offspring and also allows non donor-conceived offspring of donors and other genetic relatives to register **if they wish**. Recipients should only be allowed access while their child is below the age of legal majority unless they have the written agreement of their child to access it later. Professional support services should be available at all stages.

*If there is an age restriction on the release of information*, then I would support the provision of a Voluntary Register (i.e. in addition to a statutory Register) that allows those who wish (donor-conceived offspring, donors, non donor-conceived offspring of donors, recipients and other genetic relatives) to register. All but recipients should be allowed to receive information and/or make contact if they wish at any stage/age; recipients should only be allowed access while their child is below the age of legal majority unless they have the written agreement of their child to access it later. Professional support services should be available at all stages.

Finally I was encouraged to hear of the recent decision of the State of Victoria to allow retrospective release of information, with safeguards in place. Of course its operation is yet to be tested but I suggest it is crucial that SA adopts a similar model so that it does not exclude the thousands of people affected by the delay to the establishment of a Register or other means of obtaining the information they need. In keeping with this, SA could *require* treatment centres and gamete donor

banks to provide it with information about past treatments or at least include a free DNA database service similar to UK DonorLink (now Donor Conceived Register) in its provision to those disadvantaged by the lack of a Register to date.

***Fact Sheet 7 - Record-keeping and confidentiality provisions***

I am not sufficiently familiar with the current record-keeping systems in place in SA to comment on them. However the principles are clear, in my view:

- There should be statutory requirements with regard to record keeping to ensure standardisation and transparency across services
- There should be long term research into the outcomes of ART, including aspects specific to donor-assisted treatment and surrogacy. This should not focus exclusively on medical, scientific and developmental psychological matters but should instead include attention to impact on family and social processes and those areas I identified under 'Access to ART' such as whether children born through ART in general or donor-assisted ART or surrogacy in particular are any more or less likely to come to the attention of child protection, mental health or court services than other groups or even whether their parents (if a couple) are any more or less likely to remain together. Given the low base of funding for such research when compared to that for medical/scientific/developmental psychology, there should be consideration given to state-funded research in this field.
- Record keeping requires close attention to confidentiality. However we have a situation in the UK whereby treatment centres cannot release information to family practitioners or other medical colleagues without the written permission of prospective parents. In the view of many, this requirement was instigated primarily to 'protect' prospective parents from stigma and is outdated insofar as it may paradoxically sustain stigma and could anyway adversely affect the right of people born through ART (whose rights should prevail).

Thank you for the opportunity to comment on this important area. I have not provided References in this submission but could do so if this would be helpful.

*M.A. Crawshaw*

Marilyn Crawshaw

8<sup>th</sup> April 2016