Submission No 26

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

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The National Support Group

For Solo Mums by Choice in Australia

Submission to the Legislative Assembly Committee of Law and Safety

Managing Information related to Donor Conception

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Document prepared by a working group of SMC Australia members headed by Sharon Hunt - President

INTRODUCTION

Solo Mums by Choice (SMC) Australia is the national support and advocacy group for women who are (thinking about, or have become) sole parents, and their children.

The group was initially founded in 2002, by two women from Queensland, one a solo mum by choice to one donor conceived child, and the other considering becoming a solo mum. In 2004, SMC Australia began communicating online, initially with a membership of around 30 members. In 2013, the group consists of well over 800 members, 500 of whom are active at any given time, from all states and territories within Australia. Support meetings are held in most capital and large cities. Our members are just a small subset of the total number of Solo Mums by Choice nationwide.

SMC Australia is a self funded and managed organisation administered wholly by volunteers. We receive no government or corporate funding of any kind.

MEMBERSHIP BASE

SMC Australia estimates that of their membership 40% are mothers to between one and five children, the majority of whom are donor conceived (children conceived in previous relationships make up a small number of members offspring as do children from adoption and foster care). The remaining members are in the process of thinking about taking a solo path to motherhood, actively trying to achieve a pregnancy or are currently pregnant. Women from NSW would make up approximately a quarter of the membership of SMC Australia.

Of our members with children approximately one quarter (22%) of those children were conceived using truly anonymous donors (that is non id-release donors) and conceived these children prior to 2005. Many of these women have more than one child to that donor and as such a significant number of children born to our members will be affected by any decisions made regarding the retrospective access to, and management of, information related to donor conception.

It is with this in mind that we make this submission.

Question 1: Should donor-conceived adults conceived before 2010 have retrospective access to donors' identifying details?

The majority of members of SMC Australia believe that retrospective access to donor information, including identifying details, is essential for donor conceived adults. The age at which this information should be accessible is a point of discussion however we would suggest between 16 to 18 years.

We would recommend that non – identifying information be available from birth and that this information would retrospectively be given to mothers to be held for their child. This could include medical background information, ancestry details, areas of interest etc. The reason for this is to allow the child access to information in their formative years, provide a greater sense of self and heritage and minimise the potential for future psychological trauma.

The need for donor conceived individuals to have access to donor information should override any past offers of anonymity made to gamete donors. Donor conceived individuals had no say in their terms of conception and as such should not be penalised through the withholding of information.

We believe that the committee should recommend that all donor conceived individuals, regardless of when they were conceived and laws that were in existence at that time, should have access to the same identifying information about their donor.

Question 2: If retrospective access were granted what conditions should apply?

The model developed to meet the needs of adoptees may well suit the provision of retrospective information for donor conceived individuals by providing information craved while still giving the gamete donor some control over the extent of contact they are comfortable with.

The donor should not have any right to identifying information about the recipient of their donation, ie the donor conceived individual. The handing over of any identifying information related to the donor conceived individual should be done solely at their discretion. Gamete donors should however have the right know how many live births there were as a result of their donation.

Question 3: **What other issues would be raised by granting retrospective access? For example, how would the process of applying for information be managed? Would counselling and support services be required?**

The granting of retrospective access to donor information also opens the door to the question of access to donor sibling information. For many donor conceived individuals this is as important, if not more so, than information about their donor. Some clinics throughout Australia are now facilitating this, however, donor conceived individuals of anonymous/past donors seem to be having significantly more trouble getting access to this information. Correct management of donor conception practices will allow for information being readily available and accessible in regards to donor siblings.

This information is likely to also be best handled by any interested parties being able to put a veto on identifying information if they do not wish to be contacted. This would require a large scale public awareness campaign.

We believe that this information should be held by a National body established specifically to hold the information all ART donors and recipients nationwide. Individuals could apply to this body for information within the specific guidelines and policies established by this group. These guidelines may include the need for prior counselling, cooling off periods or educational material prior to receiving information.

Question 4: **Which agency is best placed to manage the donor register? Is the current management of the register adequate**

Question 5: **Should a standalone body be established to manage the register? What other areas could it have responsibility for?**

"Giving one organisation ownership of all aspects of the donor conception information management process may have substantial benefits, both in terms of resource savings and in producing satisfactory outcomes for stakeholders and the community." One reason most members of SMC Australia believe this is the best way to manage donor information is that there is much "muddy water" between states, that is, many donors who may have made their initial donation in one state may have had portions of their donation transferred to other clinics in other states in order to meet demand. Without a central governing body managing the information much of the detail such as this will be lost.

We believe this role is best suited to a stand alone body that can manage all aspects of donor/recipient information management, donor recipient linking/sibling linking, counselling services, donor and recipient advocacy services and community education.

Question 6: **Should counselling and support services be offered to those seeking Donor conception information from the donor register?**

Question 7: **Are there other types of support that could be offered?**

Yes counselling and support services should be offered to both donors and recipients of ART practice. These services could be offered by the agency whose role it is to manage and distribute information. It may be that a certain level of counselling is essential prior to receiving certain levels of information, this may be especially necessary when looking at donors who were previously assured anonymity and are now required to provide additional information to recipients.

The recommendations from the recent Victorian Inquiry would be a good place to start when looking at the type of counselling required and what should be provided. It recommended that counselling be compulsory for a donor conceived person seeking information about their donor, a donor seeking information about their donor conceived offspring, and a donor or donor conceived person who applies to lodge a contact veto."

In addition other services required may include advocacy services for donor conceived individuals unable to obtain information on their donor due to poorly handled/managed information in the past leading to the donor not being able to be located.

Question 8: How would support services be funded? By the government, the individual seeking the service, or by assisted reproductive technology clinics?

The majority of SMC Australia members believe there is a role for all three in the funding of such as service.

While we understand the constant budget constraints of government at both state and federal level and also understand the establishment of such a service will not be a big vote winner there is a role for government to play in the initial set up and establishment of such a service. An ongoing small grant may be required.

There is no question there is a role for clinics providing assisted reproductive services in the funding model of such a service. These are high profit, mostly large businesses who have made a good percentage of their profit from donor conception. An annual 'donation' from each clinic involved in donor conception would be sufficient to maintain the running of such a service without affecting the bottom line of the ART clinics in any significant way.

While we believe individuals should not be prevented from accessing such a service due to financial hardship it would be reasonable to place a small fee on individuals accessing the service (eg \$50 - \$100). This would assist with covering administration costs. There may be a method in which people who are unable to pay could appeal for waiving of fees.

Question 9: How would such support be provided? By referral to the Department of Family and Community Services (as with adoption) or by a standalone body (as has been recommended in Victoria)?

We would recommend support services are provided through the stand alone body that is established to deal with all aspects of donor conception information. (See Victorian recommendations).

Question 10: How long should ART clinics be required to retain records?

Question 11: What should happen to records if a clinic closes?

Question 12: How can we ensure the integrity of records? For example, ensuring that they are not destroyed or tampered with.

We would recommend that all ART clinics be mandated to provide records to a central register on acknowledgement of live birth and that information be maintained on the register thereafter.

We support the NHMRC guidelines that records should be maintained indefinitely or at least until the individual is deceased.

A central register eliminates problems that arise with obtaining information should clinics close.

All ART clinics that provide donor conception services should be mandated to provide to the register any records created, including those created prior to the establishment of the register and those created under the banner of anonymity. Clinics should make every effort to provide accurate/up to date information on all donors recruited by that clinic since its establishment. Penalties should apply for clinics not complying with these procedures.

We would close by saying that members of SMC would be pleased to appear before the committee to provide further information / opinion around the matter of managing information about donor conception.

We can be contact at

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