

INQUIRY INTO INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS

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Legislative Assembly Committee on Law and Safety: Inquiry into inclusion of donor details on the register of births

NSW Government Submission

Inquiry and District Court Judgement

On 17 October 2011 the NSW Legislative Assembly Standing Committee on Law and Safety announced an 'inquiry into inclusion of donor details on the register of births.' The terms of reference for the inquiry are:

'That the Committee inquire into and report on whether there should be provision for the inclusion of donor details on the register of births maintained by the Registrar of Births, Deaths and Marriages.'

The inquiry into whether to include donor details on the register of NSW Births, Deaths and Marriages (BDM) was self-referred by the Standing Committee in response to a District Court decision on 17 August 2011. In the case, *AA v Registrar of Births, Deaths and Marriages and BB [2011]*, the former same-sex de-facto partner of the birth mother ('AA') wished to be listed as a parent on the BDM register, which required the removal of the sperm donor ('BB') from the list, as only two individuals may be listed as parents on the Register at any one time. BB donated his sperm under a private arrangement.

BB felt that the removal of his name from the BDM register was unfair, as he had played a significant role in the child's upbringing, including long-term financial contributions and an ongoing relationship, with Family Court orders providing for regular contact between the two. However, the District Court ruled that, as BB had not been the husband or de-facto partner of the birth mother, but AA had, BB was not entitled to be listed as a parent on the BDM birth register.

In his judgement the judge stated that '...a provision for registration of a third parent for a situation such as this one might be a neat answer to the problem this case presents.'

This case was in effect a dispute between the rights of the donor as opposed to the rights of the partner of the birth mother. In addressing the issues raised by the case, the Government believes the Standing Committee should not frame their inquiries in the above terms, but rather should look at the policy outcomes of their recommendations, including whether there should be provision for registration of a third parent in terms of the best interests of the child. The provision for registration of donor information on the BDM register also inevitably has implications in determining what information about the circumstances of the birth and the donor should be available to a donor conceived child, and the manner in which that information should be made available.

Current arrangements for recording the information of donor-conceived children

Until recently, there was no system in NSW for recording and disclosing information about a person who assists in the conception of a child through the donation of sperm, eggs, or embryos (gametes). This has meant that many of the donor offspring were unable to identify a biological parent or obtain information about their genetic heritage and background. It has also meant that there has been no means for officially recognising donors.

The ART Central Register

In order to assist the collection and exchange of information on donor conceived births, the NSW Parliament enacted the *NSW Assisted Reproductive Technology Act 2007* (ART Act). This Act created the ART Central Register under the control of the Ministry of Health, to maintain information about donors and children born as a result of ART treatment being:

any medical treatment or procedure that procures or attempts to procure pregnancy in a woman by means other than sexual intercourse, and includes artificial insemination, in-vitro fertilisation, gamete intrafallopian transfer and any related treatment or procedure that is prescribed by the regulations.

For all ART conceptions before 1 January 2010, information was collected on a voluntary basis. However, with the commencement of the *Assisted Reproductive Technology Regulation 2009* (ART Regulation) on 1 January 2010, it became mandatory for information about births resulting from donor conception occurring on or after 1 January 2010 to be recorded on the ART Central Register. In the first full year of operation, from September 2010 to September 2011, the ART Central Register recorded 194 notifications. Clause 12 of the ART Regulation establishes what information must be collected by the ART provider and provided to the ART Central Register:

- (1) For the purposes of section 30 (1) of the Act, an ART provider, who obtains a gamete (other than a donated gamete) from a gamete provider, must obtain the gamete provider's full name, date of birth and residential address.
- (2) For the purposes of section 30 (1) of the Act, an ART provider, who obtains a donated gamete from a donor, must obtain the following:
 - (a) the full name of the donor,
 - (b) the residential address of the donor,
 - (c) the date and place of birth of the donor,
 - (d) the ethnicity and physical characteristics of the donor,
 - (e) any medical history or genetic test results of the donor or the donor's family that are relevant to the future health of:
 - (i) a person undergoing ART treatment involving the use of the donated gamete, or
 - (ii) any offspring born as a result of that treatment, or
 - (iii) any descendent of any such offspring,
 - (f) the name of each ART provider who has previously obtained a donated gamete from the donor and the date on which the gamete was obtained,
 - (g) the sex and year of birth of each offspring of the donor.

A donor-conceived child can have access to all mandatory details on the register at 18 years, whilst parents can obtain non-identifying donor information at any time. In the case of a medical emergency or life threatening situation, parents may also apply to the Director General of Health for identifying donor information. Donors may apply for non-identifying information relating to their donor-conceived offspring, and donor-conceived offspring can be sorted by donor for cases where a donor has conceived a number of children. Offspring of the donor who are not donor-conceived may also voluntarily register their details and the level of access they wish other parties to obtain when applying for information.

The ART Central Register does not operate retrospectively. For donors who donated gametes prior to 1 January 2010, a voluntary donor register exists for those who choose to provide information and who consent to having that information accessed by parents and

donor conceived children. Both voluntary and mandatory information can be updated by a donor, parent or offspring on a voluntary basis.

The ART Central Register only holds information on donors and their offspring who were conceived using an ART provider's services. Section 4 of the ART Act sets out that an ART service is considered to have taken place when one or more of the following services, treatments or procedures were provided for fee or reward, or provided in the course of a business (whether or not for profit):

- (a) an ART treatment,
- (b) the storage of gametes and embryos for use in ART treatment,
- (c) the obtaining of a gamete from a gamete provider for use in ART treatment or for research in connection with ART treatment.

Conceptions using so-called non-medical donations or private arrangements are not covered by this definition, and, as such, information on private donors and their offspring are not recorded by the ART Central Register. This means that, under the current system, for donors such as BB, there is no possibility of being formally recognised as the donor of the child, or for children born as a result of private donor arrangements to formally get access to information about their donor parent.

The Births, Deaths and Marriages Register

The NSW Registry of Births, Deaths and Marriages (BDM) records all births in NSW. Section 15 of the *Births, Death and Marriages Registration Act 1995* stipulates that both parents are required to make a joint application for the inclusion of information about the identity of the child on the register. However, there is significant scope in the legislation for variation on this rule. For instance, the legislation allows for a parent to make the application unilaterally if it is not practicable to obtain the signatures of both parents on the birth registration statement. Some of the information that is recorded on the register is included on a birth certificate. A birth certificate helps to provide proof of identity for the individual listed on the certificate, and is used to secure other Australian identification documents such as a passport, driver's license and Medicare Card. The birth certificate also establishes the identity of the individual's legal parents (in cases involving adoption, surrogacy or donor conceived births, this may differ from the biological parents). Legal parents have rights and responsibilities in relation to the child that others (such as a sperm donor, or biological father) do not.

Under Clause 5 of the *Births, Deaths and Marriages Registration Regulation 2011*, the register of births must contain the following information in relation to births:

- (a) the sex and date and place of birth of the child,
- (b) the weight of the child at birth,
- (c) whether or not the birth was a multiple birth,
- (d) the full name (including, if applicable, the original surname), date of birth (or age), place of birth, occupation and usual place of residence (at the time of delivery) of each parent of the child,
- (e) the date and place of marriage of the parents of the child (if applicable),
- (f) the full name, sex and date of birth of any other children (including any deceased children) of either of the parents of the child,
- (g) whether or not either of the parents of the child is of Aboriginal or Torres Strait Islander origin,
- (h) if either parent of the child was born outside Australia, the period of residence in Australia of that parent.

The Victorian model

After the commencement of the *Assisted Reproductive Treatment Act 2008*, the Victorian Registry of Births, Deaths and Marriages became responsible for the two registers relating to donor conception in Victoria, the Central Register and Voluntary Register, which record information about people involved in donor conception.

For conception using an ART service, the ART provider lodges information with the Victorian BDM's Central Register about the parents, the donor and the offspring. When registering a birth, the parent confirms on the birth registration statement that donor conception occurred.

The Voluntary Register allows people who have been involved in donor conception using an ART service in Victoria at any time, including prior to the introduction of the ART Act 2008, to voluntarily record information about themselves and their wishes to exchange information with other persons on the Voluntary Register, which can then be accessed according to the level of consent, by donors, donor-conceived children and relations.

Private Arrangements

The current NSW ART Central Register does not provide for donors in private arrangements and any children conceived from those arrangements to have their details recorded. Whilst it would be impractical to require such information to be recorded, making it available on a voluntary basis would provide equal access to information for all donor children conceived through private arrangements, or before 1 January 2010 through ART treatment. The existing voluntary register could be expanded to provide for information relating to private arrangements. This would allow for the collection and disclosure of information relating to all donors and their offspring to be consistently managed under existing mechanisms contained in the voluntary register. While the provision of such information on a voluntary basis entails some risk of misinformation, this risk is considered minimal.

Alternatively, information in relation to donor-conceived births resulting from private arrangements could be included on the BDM Register on the basis of a birth registration statement from the parents and a notification from the relevant medical authority at the time of birth, in line with existing birth registration practices. It is an offence to make a false representation in a notice to the Registry under section 57 of the *Births, Deaths, and Marriages Registration Act 1995*. Therefore, if donor information in private arrangements were to be included on the BDM Register, it would be reasonable to require that such information be similarly verified in a formal notice to BDM by the parents and the donor, and be subject to the same obligations.

Should donor information be included on the BDM register of births?

A client-centred approach and, in particular, the best interests of the child must be central in determining where donor information should be held, in order to provide a simple, easy to use and effective register for people to access their information and the information of those relevant to them. Maintaining disparate or overlapping repositories of information around donor conceived births would not provide a positive outcome in terms of the administrative costs for government nor in terms of the ease of use for individuals.

Registering donor information on the BDM register of births would represent a significant change from the current mechanism for recording such information, namely the ART Central Register.

By creating a sole repository of information regarding genetic as well as social history, a BDM-held donor register would provide a one-stop-shop for individuals to access information regarding their origins and identity. BDM records key information relating to the birth of a child. By including donor details with BDM's existing records, it would provide recognition for the important role (genetic and sometimes familial) of the donor.

If the BDM register were to hold donor information, this could be provided in a number of ways. The NSW Ministry of Health could maintain the existing ART Central Register and the voluntary register, and transfer the required information to BDM. However this may create an unnecessary duplication of information and administrative work. The alternative would be to close the current ART Central Register and voluntary register and transfer all data currently held on those registers (including medical and other non-identifying information not required by the register of births) to the BDM register, or a new BDM managed register. This donor information should be held by BDM only if a birth (or stillbirth) actually occurs. Should the registers be moved to BDM, the responsibility for other aspects of ART, such as regulation of ART providers, would remain with NSW Health.

In that case, new relationships would have to be developed between BDM and the ART providers who collect information for the existing ART Central Register (although it should be noted that there are only 13 such providers), and there would potentially be the need for new regulatory instruments to reflect the change. There would also be costs associated with closing the existing registers, transferring the information, setting up a new register or providing for the additional information within the existing BDM register, as well as ongoing administrative and potentially staffing requirements. That said, there would also be cost savings from the closure of the ART Central Register.

There is also the issue of whether the cost-recovery model of BDM, which relies on fees charged to customers to fund its services, would create a disincentive for donors who may otherwise wish to place their information on the voluntary register. It is noted that, under the current NSW Health system, the \$50 administration fee is waived. In placing the registers under the control of BDM, it would be important to ensure that BDM's cost structures do not become an impediment to donors providing information on a voluntary basis.

Donor details on the Birth Certificate

If it were decided that donor details were to be included on the BDM register, then consideration would need to be given as to whether, and how, such information should be presented on a birth certificate. It is noted that the register of births already contains more information than that which appears on the birth certificate. BDM is currently reviewing the information that will be included on a birth certificate and will be seeking feedback from stakeholders and members of the community in the near future. It is suggested that the issue of whether donor details should be presented on the birth certificate could be addressed through this review. Again, these decisions should be made in the framework of what is in the best interests of the child. Options for including donor information on the birth certificate would need to take into account issues of privacy, to ensure that donor-conceived children

are not stigmatised by being treated differently to others' children. One such option would be to provide an endorsement (a note on the birth certificate indicating that further information is available), or a hidden addendum to the birth certificate that is then made available to the donor-conceived child when he or she turns 18.