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Comment

Countdown begins for ending donor anonymity in British Columbia: Lessons for us all?

06 June 2011

By Professor Eric Blyth and Dr Marilyn Crawshaw

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The regulation of assisted human reproduction in Canada has had a long and tortuous history. Twenty-one years after a Royal Commission appointed by the federal government recommended legislation [1], and following several failed attempts to get legislation through the Canadian parliament, the Assisted Human Reproduction Act 2004 came into force [2].

The Act provided for the establishment of a Personal Health Information (PHI) Registry that would create a national database maintained by the federal regulator, Assisted Human Reproduction Canada, to record information relating to donors, patients using donated embryos or gametes and donor-conceived offspring. It would also allow for offspring to learn the identity of the donor where the donor had specifically consented. However, the PHI Registry was never set up and in December 2010, as a result of a constitutional challenge by the provincial government of Québec that specific measures in the Act violate areas of provincial legislative authority, the PHI Registry was one of several provisions declared unconstitutional by the federal Supreme Court [3].

As a result of the Supreme Court's decision that the federal government has no authority to establish a national register, attention therefore focuses on Canada's provincial governments to promote the interests of donor-conceived people. This includes obtaining information about their donor (and any other genetic relatives they may have as a result of the donation). It has fallen to British Columbia (BC) to pioneer this process – a challenge to which it did not step up willingly.

In May, the BC government found itself on the wrong end of a BC Supreme Court ruling which has given it fifteen months to come up with proposals to end donor anonymity in the province [4]. The ruling upheld a claim by Olivia Pratten, a donor-conceived adult, that donor-conceived people in BC were discriminated against compared to adopted persons who, under BC law, were entitled to access information about their birth origins, and that such discrimination violated Section 15 of the Canadian Charter of Rights and Freedoms [5]

Unless it successfully appeals the ruling, BC will now join a growing number of jurisdictions that have ended donor anonymity [7]. It is therefore in a position to learn from the experiences of those that have already gone down this path, together with the messages from research and professional experience, and to promote 'best practice', rather than opt for minimum compliance. We suggest 'best practice' should include:

· the need to review family law to ensure donors are protected from financial responsibility for offspring and that donors cannot assert any parental rights over them;

- · placing limits on the number of offspring per donor;
- the active promotion of disclosure through counselling and preparation for prospective parents, together with later support through the provision of 'Telling and Talking' workshops and literature such as those of the UK's Donor Conception Network [8] and the Victorian Assisted Reproductive Treatment Authority, Australia [9], and ongoing access to psycho-social professionals;
- · the formal recording of the use of donor gametes/embryo(s) in the birth registration process; and
- · access to funded mediation services when the parties wish for later information exchange and/or contact.

One issue for all jurisdictions that have abandoned anonymity is how to deal with past donor procedures, both where records are known to exist (as in the case of BC since the destruction of donor records was subject to a previous court ruling that has now been made permanent [4]) and where they do not. None of these jurisdictions has applied the new rules retrospectively because of the perceived conflict between the rights of offspring to information and the rights of donors who donated on the basis of their anonymity (although establishing a voluntary contact register for past donations that includes a DNA database and appropriate professional support would go some way to address this).

While voluntary retrospective provision brings its own challenges - including the lack of absolute certainty that is a feature of DNA-based rather than records-based 'linking' and the need for support to donors who had never anticipated considering disclosure [10] - a recent federal inquiry into donor conception in Australia did recommended such a register [11]. At present there are at least two such state-funded registers already in existence - the UK DonorLink Register established in 2004 [12] and the Fiom KID Register established in the Netherlands in 2010 [13]. Others will surely follow. Such services require secured funding in the same way as for those provided prospectively. The proposed removal of state funding for UK DonorLink while retaining funding for the post-legislation HFEA Register of information - despite ministerial recognition of its importance - is of great concern.

There is a further challenge that flows from the BC ruling that has resonance for other jurisdictions, namely the implications for those who import gamete(s) for use within the jurisdiction where they normally reside or who seek treatment outside it. It should be a fairly simple matter to require clinics to use only imported donated gametes that comply with domestic laws, as in the UK. We recognise that managing treatment undertaken in other jurisdictions is considerably less amenable to regulation, although a rigorous approach to requiring compliance where this comprises any form of partnership arrangement between clinics in home and destination jurisdictions is something that more regulators, including the UK, would do well to adopt if they were to remain true to the principles on which decisions such as that in BC are based.

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