Comment

The birth of donor offspring rights in the USA?

27 June 2011

By Professor Naomi Cahn and Wendy Kramer

Wendy Kramer is Director and co-founder of the Donor Sibling Registry and Naomi Cahn is the John Theodore Fey Research Professor of Law at The George Washington University Law School

Appeared in BioNews 613

The fertility industry in the US state of Washington will be transformed in late July 2011, when a new law to recognise rights of donor-conceived people comes into effect. Under the changes, anyone who provides gametes to a fertility clinic in the state must also provide identifying information about themselves and their medical history (1).

While most fertility clinics already collect this information, and make medical information available to the people who use it, the law will allow donor-conceived children, once they reach 18 years old, to contact the clinic that provided the gametes to request identifying information about their donor and their donor’s medical history. The law states, however, that the donor can veto disclosure to prevent the clinic from revealing his or her identifying information - but the donor offspring will still be entitled to their anonymised medical history.

Washington is the first US state to take such a step. Elsewhere in the US, not only can fertility clinics destroy records before the child turns 18, but also donor-conceived people are not entitled to any information held about their donor. Medical information is also rarely updated and shared among donors and recipients' families.

Other countries have adopted similar measures. Sweden enacted legislation in 1984 that allows donor offspring the right to receive identifying information about their donor. Austria, New
Zealand, the Netherlands, Norway, Switzerland, the UK, and some states in Australia have also removed donor anonymity and have established systems to help people find out their donor’s identity. In May, shortly after Governor Christine Gregoire signed the Washington state legislation, the British Columbia Supreme Court in Canada declared donor-conceived people must be treated in the same way as people who had been adopted with respect to accessing information about their biological origins.

The new law in Washington is an important US milestone. It is, however, flawed because it allows for a disclosure veto, allowing donors' alleged interests in privacy to trump the interests of donor-conceived people in learning the donor’s identity.

For many donor-conceived people, learning about their biological parent(s) is much more than just learning about their donor’s medical history. The issues and concerns of donor offspring are often complex and multi-dimensional. As in adoption, many donor-conceived people feel that until they know about their ancestral and genetic heritage, they will not have a full sense of self-identity. After many decades of silence, and fueled by the movement towards full disclosure within families, the voices of donor conceived people are being heard world-wide, demanding what they see as their basic human right to know about and connect with their genetic families.

Dr Vasanti Jadva, at the Centre for Family Research at the University of Cambridge, collaborated with Wendy Kramer, and several others, in a study looking at the experiences of donor-conceived people in searching for, and contacting, their donor siblings and donor. They recruited 165 participants through the Donor Sibling Registry and found 77 percent were actively searching for their donors. In this group, the top reasons for searching were listed as 'Curiosity about characteristics of your donor'; 'Wanting to meet your donor'; 'Medical reasons'; and 'To have a better understanding of why I am, who I am' (2).

More recently, in a large-scale study of donor-conceived people (751 in total) - with about half of the respondents coming from the general public - 82 percent of respondents indicated a desire to be in contact someday with their donor (3). Top reasons for searching were 'To see what he looks like'; 'To learn more about my ancestry' and 'To learn more about myself'.

Several explain: 'It makes me angry that I am denied the basic right of knowing who my father was and what ethnicity I am'; and: 'Angry and frustrated that I can’t get information about my heritage, genetics, looks, and medical history'.

Some argue that lifting anonymity might cause a donor shortage, but experiences in other countries show otherwise. For example, although a reported shortage of sperm in the UK has been blamed on the removal of anonymity, journalist Liza Mundy documented last year that 'there has not been a decline in registered sperm donors following the 2005 change, and it's arguable that there is not a shortage of donor sperm now' (4). She said: 'The number of sperm donors has risen in the UK since the identity-disclosure rule took effect'.

There are also fears that banning anonymity is part of a slippery slope towards regulating not just what gametes are available but who has access to those gametes. This is unjustified. In fact, the UK has extended equality of treatment to same-sex couples after abolishing donor anonymity (5).
The new Washington state law is a first step towards what we hope will be a new attitude of openness throughout the USA.

SOURCES & REFERENCES

1) Engrossed Second Substitute House Bill 1267 - Uniform Parentage Act

2) Jadva, V; Freeman, T; Kramer, W; Golombok, S. 'Experiences of offspring searching for and contacting their donor siblings and donor' Reproductive Bio Medicine online, (2010) March 2010 | 03 February 2010


4) Shortage? What shortage? How the sperm donor debate missed its mark The Guardian | 19 September 2010

5) Same-sex couples given equal IVF rights Nursing Times | 06 April 2009

RELATED ARTICLES FROM THE BIONEWS ARCHIVE

Donor information - time for a debate 27 February 2012 - by Dr Marilyn Crawshaw and Walter Merricks

It is now eight years since the HFEA first issued guidance to UK licensed treatment centres to respond as fully as possible to patients' requests for non-identifying donor information... [Read More]

Lesbian couple have sperm donor removed from birth certificate 22 August 2011 - by Oliver Timmis

An Australian court has ruled that a lesbian couple can have the name of the sperm donor removed from their child's birth certificate.... [Read More]

What the kids really want 08 August 2011 - by Professor Naomi Cahn and Wendy Kramer

The largest study to date of donor-conceived people has just been published in Human Reproduction. Its findings show the need to address two different effects of anonymous donating: first, when should children find out that their parents used donor sperm or eggs; and second, should children ever find out the identity of their donors?... [Read More]

Countdown begins for ending donor anonymity in British Columbia: Lessons for us all? 06 June 2011 - by Professor Eric Blyth and Dr Marilyn Crawshaw
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)...

Canadian woman wins legal case to end donor anonymity in British Columbia
23 May 2011 - by Sarah Guy
Anonymous egg and sperm donation will no longer be permitted in British Columbia (BC), Canada, after a donor-conceived woman, Olivia Pratten, took the provincial government to court to argue that its adoption laws discriminated against individuals such as herself....

My daddy's name is adoption
16 May 2011 - by Vince Londini
On November 2, 2010, Elizabeth Marquardt testified before the Australian Senate. Her remarks included this statement: 'But I also want to make clear that - even with openness - the problems [allegations that donor-conceived children are more prone to social and legal trouble] do not completely go away. There seems to be something else about knowing that the person who raised you also deliberately denied you your other parent before you were even born'...

Australian donor conception report published
14 March 2011 - by Ben Jones
An Australian Senate Standing Committee has published a report calling for widespread updates to the law governing donor conception, including greater monitoring of compliance among clinics and practitioners and the development of new forms of oversight to support the current regulatory framework....

Donor anonymity to bite the dust in South Australia
06 December 2010 - by Professor Eric Blyth
Australia has been a noted pacemaker in the field of assisted reproduction. It was the first nation to report embryo relinquishment for family-building, and a pregnancy and live birth from a previously cryopreserved human embryo. The Australian state of Victoria was among the world's first jurisdictions to remove the rights of gamete and embryo donors to remain anonymous...

Published by the Progress Educational Trust