

Building families through donor conception: An international forum on the personal, professional & public policy issues. 22-23 June/02

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This weekend conference held in Toronto was organized and sponsored by Canada's Infertility Network. The conference heard from 36 presenters from Australia, Canada, Ireland, New Zealand, the United Kingdom and the United States, including adults conceived with donor sperm, parents through donor conception, sperm donors, adopted persons, birth parents and adoptive parents, counsellors, ethicists, law professors, social work professors, a member of the Ministry of Health in Canada, and an infertility specialist.

Key themes

- Although families have been built with donor sperm for more than 100 years, almost no research has been done to evaluate the long-term effects for mature offspring. Third-party assisted reproduction has been an uncontrolled and unmonitored social experiment.
- The issues related to infertility, assisted conception, personal identity and family life are complex, subtle, deeply personal, emotionally profound, and often highly controversial. Individuals will have unique experiences and responses to their life situations. Respectful listening to all sides is necessary.
- Mature offspring and their families discussed the personal, familial, medical and social implications of donor conception. Major issues include secrecy within the family, the challenge for adolescents and young adults to form their personal identity when information about their own origins is withheld from them, and feelings of isolation, loss and disconnection. The lack of detailed information about anonymous donors remains a problem even when parents have been open about the involvement of donors in the formation of the family.
- One of the most basic problems is that we lack appropriate terms to describe the members and relationships of donor-conceived families. Those born from donations do not remain 'children' very long, while 'offspring' sounds somewhat clinical. One person conceived by DI refers to himself as a 'DI adoptee', although the term is not widely used. 'Persons conceived via donated gametes' is perhaps most respectful and accurate, but is unwieldy. Whether the gamete donor is called a 'biological father' (or 'genetic mother'), or referred to more distantly as a 'donor' or 'progenitor', is an emotionally loaded matter for all concerned. Greatest consensus was reached regarding the

social parents, who are clearly perceived by all involved to be the 'real' parents of offspring conceived via donors, regardless of genetic relationships.

- Adult offspring of donors dispelled myths that they would want money from the donors, or are seeking to 'replace' the parents who raised them; they simply want to know the individuals (including half-siblings) to whom they are related.
- Anonymity of donors creates medical concerns for offspring and their descendants, whose genetic family medical history has been purposely withheld. There is also the risk of inadvertent consanguinity (full- or half-siblings having children together).
- Ethics requires that the needs and rights of all affected individuals be considered in personal choices and in law or public policy. The interests of offspring are typically ignored or downplayed relative to the interests of infertile persons and reproductive collaborators. Offspring have no say in setting up the conditions of their birth, and children are much more vulnerable than the adults in the situation.
- The majority of presenters (but not all) called for an end to anonymous sperm, ovum and embryo donation, favouring an open system in which donors are encouraged to reflect more carefully on the meaning of their participation in the creation of children, and in which offspring can learn further information about their genetic progenitors.
- Most presenters called for an end to payment for gametes or embryos, limiting reimbursement to actual expenses incurred.
- The number of offspring born from any single donor must be limited, and records must document the numbers and identities of all related offspring.
- Extensive counselling support is needed for prospective donors, patients, parents and offspring as they navigate complicated relationships and life choices. Most clinics do not have such services available.

About donor conception

- The number of existing offspring of donor gametes is unknown, because record keeping has been inconsistent, records have often been destroyed or lost, and few countries collect data on assisted reproduction outcomes.
- Evidence does not support the assumption that identifying donors will end the supply of donor eggs and sperm. Sweden and the Australian state of Victoria have laws requiring the release of identifying information about donors, and New Zealand has an open system without legislation. The Sperm Bank of California has had an open

donor programme for 18 years. Open programmes tend to recruit different donors, who are typically a bit older and often have children of their own. A prospective user of DI expressed the concern that insufficient donors may be available during the transition period to an open system in Canada.

- Some clinics 'retire' donors when 10 pregnancies result from the use of that donor's sperm. However, Canada (like most countries) has no mechanism to keep track of donors at multiple clinics or to enforce such voluntary guidelines.
 - ◆ A sperm donor who is now in regular contact with adolescent twins born from his donation noted that donors would not have the time or the resources to be involved with many families; even 10 births would be too many.
 - ◆ Donor offspring can have an enormous web of half-siblings. An Australian mother of three donor-conceived children reports that her family has links to at least 24 other families.
 - ◆ One Australian donor is known to have given at least 318 donations in various clinics.

Perspectives of mature offspring

- Very little research on outcomes of donor conception for offspring has been conducted involving adolescents or adults. The most extensive study - a survey of 42 individuals - was conducted by an Australian high school student. Geraldine Hewitt, now attending the University of Sydney, presented her research results, which were echoed in the personal stories of several other adolescent and adult offspring from donor conception.
- Donor conception and adoption often have much in common from the offspring's perspective, and significant social and political links have developed between adoption and donor conception support communities.
- Learning about one's origins is much easier to accept as a young child rather than to find out as an older child or adult, as secrecy may have been damaging both during childhood and when the secret was revealed. Many offspring suspected they were unrelated to the social parent(s) long before they were told. Later disclosure may have occurred during a family crisis, such as the death of a parent.
- The formation of peoples' personal identity typically includes questions throughout childhood and adolescence about whom they resemble, their genetic heritage and cultural roots, how they are connected to others within extended family networks, and where they got their talents, preferences or quirks. These questions cannot be answered when donor anonymity is protected, often leaving offspring feeling 'rootless'. Many offspring express the desire to learn about the 'first chapter'

of their own lives, and to share a sense of kinship with their blood relatives, which is taken for granted by most people.

- The pain of secrecy was a strong and frequent theme among persons conceived by DI. Common emotional responses include grief, anger, loss, shame, depression, a sense of not belonging, an inability to trust or bond with others, a sense of an incomplete identity, and feelings of abandonment or rejection.
- Medical concerns arise when one's genetic origins are unknown. At minimum, donors need to update their family medical records over time, for continuing access by the offspring.
 - ◆ An adolescent woman conceived by donor sperm learned from the donor that his mother recently died of breast cancer. The medical history given at the time of the donation could not have predicted this genetic susceptibility for the offspring.
- Just as many adopted people search to make connections with their birth parents, donor offspring express the desire to meet their donor progenitor(s). They do not desire to 'replace' their social parents, but to know the contributor of a part of themselves. It is not bits of information that most seek, but a sense of the person(s) to whom they are related, including half-siblings and extended relations.
- Presenters from donor conception networks in several countries could not identify a single case in which the offspring wanted money from their donor progenitor.

Family dynamics

- Families created through DI have complex family dynamics because one parent is genetically related to the offspring while the other parent only has a social connection. Anonymity of donors further complicates family communication and relationships.
- The grief and pain of infertility may never fully heal for the parents, even after the birth of a child, and may complicate the marital and family relationships. Forming a family by either adoption or assisted conception is usually not a chosen life plan, but an accommodation to circumstances; these losses must be acknowledged and grieved.
- Physicians still often encourage the parents to not tell their children about how they were conceived. However, this secrecy will often have a damaging effect on family relationships by stifling communication, creating barriers to intimacy, and undermining trust.
- Expert counselling support, books written for children, and infertility support group materials have been very helpful for parents to find age-

appropriate ways of sharing information and answering their children's questions. However, these resources are often unavailable when people need them. If parents do not know how to tell their children about the way they were conceived, they will often put it off for so long that they find they cannot tell.

- Telling children about how they were conceived is not a 'one time' event, nor does it occur in the same way for all children or families. Rather, it is a process that gradually unfolds over time as the parent adds details to the story of how the family came to be, according to the unique needs of the individual children and parents involved.
- Donor-conceived offspring must learn about their conception from the parent; if anybody else knows the details of the conception, then the child is likely to find out in a more traumatic manner. Complete secrecy is not only extremely difficult to maintain, it also cuts parents off from needed psychosocial support and prevents offspring from learning important facts about themselves. Parents discussed the numerous roadblocks to gaining information about the donors. Lacking donor information makes it extremely difficult for parents to answer many of their children's questions about their origins.
- Some presenters had multiple offspring related to different donors. It is difficult for the family when one child has information about or contact with the donor while the other children in the same family do not.

Donating gametes

- Motives for donating gametes have been poorly studied. Commonly stated motives include a desire to help people who want to have a child. The ethics of altruism require that altruism be extended to any child born of this arrangement as well.
- Gamete 'donation' does not really exist in most countries; instead, there is a marketplace of gametes as commodities. The prevalence of payment for gametes, and the commonly raised concern that non-payment would result in shortages, indicates that financial gain is also a common motive.
- Truly informed consent for donors does not exist as a routine part of donor programmes. Very little counselling is offered to help prospective donors (who are often in their early 20s) evaluate what it might mean to them later that they participated in creating children.
- Some groups are calling the donation of embryos (rather than ova or sperm) 'embryo adoption'. However, adoption provides a needed home in the best interests of an existing child, while embryo

and gamete donation bring a new child into existence to meet the needs of the prospective parents. The similarity between donor conception and adoption is the interest of the offspring to know of their origins and extended biological family.

- Some questioned the ethical appropriateness of ever creating embryos and/or offspring that one is not prepared to parent. It was more widely perceived that donors have duties to offspring that include sharing personal information, providing medical updates, and perhaps engaging in personal contact with offspring, although protection from custody and financial obligations to offspring may be appropriate.

Legal implications

- A member of Canada's federal ministry of health gave an update on the pending Bill C-56, to establish a regulatory agency and a legal framework for assisted reproduction. The provisions regarding anonymity of donors generated heated discussion, as the current draft of the bill would not require an open system. Some presenters were hopeful that the regulatory agency would move Canada toward a fully open system, but others believe that the bill will be challenged under Sec. 15(1) of the Canadian Charter [equal protection] and international Human Rights agreements if the sections related to anonymity of donors are passed as currently written.
- Protection of donors from financial or custody obligations to offspring from their donations would require amendments to existing family law.
- Original and/or replacement birth certificates could be revised to include accurate information about genetic, birth and social parents. Governments should explore various mechanisms to ensure accuracy of birth and genealogical records while meeting the needs of offspring, their families and donors.

A final thought:

"I have often wondered why the people fighting for a system based on honesty, openness, and trust are the ones having to explain themselves. Why aren't those who want to continue the present system of secrets, lies, and deception called upon to justify themselves?" (Shirley Pratten, a Canadian mother of a 20-year-old daughter conceived by donated sperm).

Authors

Laura Shanner, PhD. Assoc Prof, laura.shanner@ualberta.ca
Rhonda E. Harris, RN, MN. Rsrch Asst, reharris@ualberta.ca
John Dossetor Health Ethics Centre, University of Alberta

The Infertility Network may be contacted via email:
Info@InfertilityNetwork.org

The following video & books are available through the Infertility Network.
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SYMPOSIUM VIDEO

Building Families through Donor Conception: The Personal, Professional & Public Policy Issues

Keynote: Ken Daniels¹, Prof of Social Work (New Zealand) Researcher, author & policy consultant to gov'ts, professional & patient organizations. Editor, *Donor Insemination: International Social Science Perspectives*.

Making the decision to use donor sperm: Jean Haase, Social Worker, *London Health Sciences Centre*

Making the decision to use donor eggs: Jan Silverman, Infertility Support & Edn Pgm, *Women's Health Centre*

Discussion about the BBC documentary, *Test Tube Dads*, which addresses the issue of anonymity & looks at 1 family's experience of meeting the donor, with the Peck family featured in the film: & their donor, David Ross

Information sharing: Leonie Hewitt, National Secretary, *Donor Conception Support Group of Australia*

The identity issues of offspring: Geraldine Hewitt, author of the largest international study to-date.

Implications of an open market & anonymous donation in human sperm/eggs: Molly Shanley, Prof. of Political Science, (USA) Author, *Making Babies, Making Families: What Matters Most in an Age of Reproductive Technologies, Surrogacy, Adoption, & Same-Sex & Unwed Parents' Rights*

What can we learn from adoption?

- Karen Lynn, Canadian Council of Birthmothers
- Catherine Clute, Adoptive Parents Assocn of Nova Scotia
- Wendy Rowney, Adoption, Support & Kinship (ASK)
- Bill Cordray, (USA) Donor Offspring/Advocate

The UK Consultation on Access to Genetic Origins Information: Eric Blyth², Prof of Social Work (UK) Researcher, author & policy consultant to gov'ts, professional & patient organizations. Editor, *Journal of Fertility Counselling*

The Irish experience: Deirdre Madden, *Irish Commission on Assisted Human Reproduction*

The ties that bind: Caroline Lorbach³, National Consumer Advocate, *Donor Conception Support Group of Australia*; Editor, *Let the Offspring Speak*

Parenting after donor conception:

- Irene Ryll, Mother of 3 children via DI
- Olga Cioci, Single mother via DI
- Jane French, Mother via egg donation

Discussion about the documentary, *Offspring*, re one man's search for his genetic family, with filmmaker & donor offspring, Barry Stevens, his sister & niece

Embryo adoption: In the best interests of the embryos? Ellen Glazer⁴, Social worker & adoption consultant (USA) Author, *Choosing Assisted Reproduction; The Long Awaited Stork*

Offspring speak: Olivia Pratten (Canada), Lynne Spencer & Susan Sermoneta (USA)

Egg donors: Who are they & why do they do it? Sherry Dale Franz, Social Worker; *Hamilton Health Sciences Centre, START Clinic* (now *LifeQuest*) & private practice

When it isn't just about me: Ethics, choices & responsibility: Laura Shanner, Professor of Health Ethics, *U of Alberta*

Donor conception in Canada: Past, present & future:

- Phyllis Creighton, Bioethicist; Member, *Health Canada Advisory Committee on Reproductive & Genetic Technologies*
- Dr. Alfonso Del Valle, *ReproMed* sperm bank
- Francine Manseau, *Health Canada*
- Shirley Pratten, New Reproductive Alternatives Society & DI mom
- Barry Stevens, Donor offspring

BOOKS BY SPEAKERS

¹ Building a Family with the Assistance of Donor Insemination

By Ken Daniels. Combines research by the author & others, along with many years of conversations with offspring, donors, single, lesbian & heterosexual parents around the world, into a book that will contribute to the health & well-being of families everywhere. Parents share their stories, thoughts & feelings.

² Truth & the Child 10 Years On: Information Exchange in Donor Assisted Conception

Co-edited by Eric Blyth. Essays by donor offspring, egg donors, a DI mother, a mother through surrogacy, a family through adoption, as well as counsellors, researchers & lawyers.

Third Party Assisted Conception Across Cultures: Social, Legal & Ethical Perspectives

Co-edited by Eric Blyth. Authors from a broad range of professional backgrounds & 13 different countries in North & South America, Africa, Europe, Asia & Australasia address many contemporary social issues including the role of the state in family creation, the changing forms & conceptualizations of a 'family,' & concerns about the potential commodification of body-parts & functions.

³ Experiences of Donor Conception: Parents, Offspring & Donors through the Years

By Caroline Lorbach. Draws on the experiences of married, single & lesbian parents from families using sperm, egg & embryo donation; offspring; & donors. Explores the process from finding out about an infertility problem, deciding on donor conception, choosing a donor, discussing the decision with others, to considering whether and how to tell children about their conception, & how adult offspring feel. Practical suggestions, as well as in-depth consideration of the emotional & ethical issues involved, including access to information about the donor.

⁴ Having Your Baby Through Egg Donation

By Ellen Glazer. Compassionate support & essential information on the medical, ethical & psychological aspects to help married, single or lesbian women & their partners, as well as gay men/couples, decide whether egg donation is right for them, using an anonymous or known donor. A useful addition in patient care for clinics & professionals.