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# Law, Policy & Evidence about Children's Interest in Genetic Relatives in the Era of Open Disclosure

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# Nuffield Council on Bioethics (2013)

## ‘Stewardship model’ of regulation

‘to facilitate what are seen as beneficial behaviours: to provide conditions, whether physical or social, that help and enable people in making their choices, while avoiding active intrusion in those choices unless there is very strong evidence to justify such intrusion for the benefit of others.’

[5.67]

# The Move to Open Disclosure

- 1988 Victoria consent release identity register
- 1998 Victoria identity register replaces it
- 2004 West Australian register begins
- 2004/5 NHMRC requires identity release donors only – clinics left to manage the information exchange in non-legislated states
- NHMRC guidelines also promote parental disclosure and efforts towards consent based retrospective identity release
- 2010 NSW register begins
- 2009 SA legislation enabling register, but no register yet

# The Central Registers

When 18 year old offspring will be able to apply for identifying information on donor as of right:

- 2016 in Victoria
  - 2020 in Western Australia
  - 2023 in the UK
  - 2028 in NSW
- 
- Consent based access in Victoria from 2006
  - Access to clinic held information as adults 2023, consent based release earlier.

# Rationales for Family Limits

Previously in era of anonymity:

- **Chance of Consanguinity**

ie unintentional sexual contact between genetically related adults

Now in era of open disclosure

- **‘Manageable number of genetic links’**

ie intentional social contact between offspring & donor (and also between offspring)

# Rationale and Evidence for Limits: Pre-disclosure

## Consanguinity

- No empirical basis for number based on objective risk
- Numbers set by reference to other jurisdictions or to cultural factors
- Subjective experience of risk often overlooked
- Both objective and subjective risk ameliorated by open disclosure and access to information

# Family Limits & Identity Disclosure

- WA and NSW *lowered* limit at the same time as introducing identity disclosure
- Victoria, the UK and the Netherlands did not change limit when introducing identity disclosure
- Internationally, limits tend to be *higher* in identity disclosure regimes
- UK reconsidered limit (up or down) in 2011 in the context of concern about gamete shortages and cross border reproductive travel, but left it at 10 families

# Family Limits per Donor

2002

- RTAC: not more than **10 families** in a particular geographic area
- ITA Vic licensing condition limit of **10 families**

2004

- NHMRC Guidelines: 'reasonable steps to reduce numbers of genetic relatives'
- WA legislation: **5 families**

2010

- NSW legislation: **5 women**
- Vic legislation: **10 women**

2011

- Senate Report recommended 4 families but 'preference' for 1 family per donor

2013/4 NSW reconsidering 5/10 and women/families

# Rationale for Limits: Open Disclosure

Manageable number of genetic links

- Numbers set by reference to 'today's kin'
- Ability to develop and maintain 'Meaningful relationships'

Embedded assumptions about:

- Number of families & number of offspring
- Proportion seeking information
- Proportion going from information to contact
- What contact entails
- What kind of kinship this is

## Sawyer (2010)

*The quality of the future relationships between donors, their DI offspring and their respective families will be directly affected by the number of DI offspring each donor fathers ... the number of potential familial contacts needs to be contained, as soon as possible, to give donors and their offspring the **best possible chance of having positive, sustainable and manageable relationships with their extended DI family members in the future.*** (Emphasis added)

# How many is 'too many'?

- What is a 'manageable' number of genetic links?

Will depend on actual numbers of offspring, on what links are made, and what they mean to the people who make them.

What do we know?

What do we NOT know?

# What do we know?

## Family Numbers:

- US and UK press reports of 'horror stories': the 'sperminator', doctors who substituted their own sperm, 'hundreds' of offspring
- US very high limits in self regulation guidance, UK cases where limits breached by fraud or negligence, or from much earlier era when no limits applied
- Very little data on actual numbers (some from UK HFEA review)
- Almost nothing on parents, donors and offspring views and experiences of numbers in open disclosure era

## Contact:

- Almost all research drawn from large scale survey studies in the USA involving one voluntary register in context of anonymous donation and no legislated family limit
- Most studies about intentions rather than experience of contact; none specifically on family numbers
- Offspring express interest in information and believe it is their right to access it
- More interest in other offspring than in donor?
- Single mothers and, to a lesser extent, lesbian-led families more likely to have interest in early contact and in contact with other offspring families
- Most contact is reported as positive
- Most contact is **not** face to face

# What do we know about Australia?

- Much, much less.

## Family numbers:

- Data on offspring numbers only from Victorian central register
- Data on family size from FSA
- Change from 'families' to 'women' in NSW & Vic had adverse impact on lesbian-led families who place value on genetic links between their children

## Contact:

- Reports to inquiries from DCA from era of anonymity on anger and pain at being denied information
- Limited data from central and voluntary registers about numbers of applications and who is applying for information
- No qualitative studies on the experience of using formal registers for information seeking or of any resulting contact

# Family Numbers

Widespread assumption that a family limit of 10 means 3-4 children per family and so equates to 30-40 offspring in total.

FSA data: families using donor gametes average 1.25-1.8 children per family, ie less than national average

Victorian central register: overall averages since 1988

- 4.3 children per sperm donor
- 1.2 children per egg donor

From 1988-1998 ie when there was NO family limit at all:

- 6.8 children per sperm donor
- 1.13 children per egg donor

UK centralised data from HFEA from 1991 shows even smaller number of children.

# Some offspring views on genetic links

I was born in 1984, therefore have basically no knowledge of my genealogical heritage on my Father's side. For 21 years I was given a false sense of my biological origins; part of my identity. When finally I did learn the truth, I was then faced with the shattering news that I had no rights to access information about my own family in order to re piece my identity.

I cannot fathom going through life never knowing where I have come from; my ancestry and my identity. Every day I look at the faces of people around me and wonder "Could you be my Father, my half sister, my half brother, my Grandparent?" I search for similarities in their faces, but will I ever know for sure? I know I have more family out there somewhere, and I mourn the loss of them every day.

Kimberly Springfield, Victorian Inquiry (August 2010)

# Other offspring views on genetic links

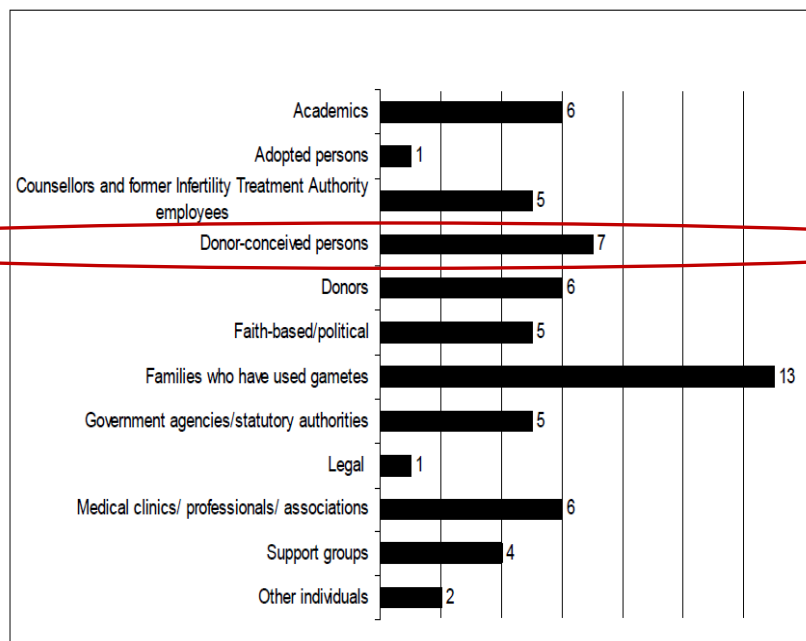
I have never met my donor “father”, and I have no desire to do so. I do not see this lack of contact with my biological father as something missing in my life, and I have no hurt at the fact of my creation. What does cause me hurt, however, is the idea, constantly repeated by small numbers of donor-conceived children, and in popular media representations of the issue, that there must be something wrong with your life if you do not know your biological father. ...

What a tragic and fruitless search is being pushed onto donor-conceived children by the idea that the only place they can find such personal and cultural meaning is through a biological connection rather than cultural and personal connections.

Amy Corderoy, Victorian Inquiry(October 2011).

a breakdown of the types of organisations and persons who made submissions to the Inquiry.

**Figure 1: Unique submissions to the Inquiry by type**



The Committee convened six public hearings between September and December 2011. Details of the hearings are set out in Appendix Two. The Committee heard evidence from a total of 51 witnesses: 20 individuals, and 31 witnesses representing 14 organisations. Witnesses included donors, donor-conceived people, parents of donor-conceived people, and academics, as well as representatives from government agencies, fertility clinics, medical associations and support groups.

# The impact of anonymity on views about family limits

The views of adult donor conceived people drawn from the era of anonymity are deeply impacted by:

- o the inability to access donor identity
- o the inability to access information on offspring numbers
- o common experience of deception and/or late disclosure.

HFEA Review focus groups with 20 DCA. Found a sharp distinction between **the views of donor conceived adults who had 'always known' about their conception and those who 'found out as adults'**. All those who found out as adults argued in the HFEA Review for a lower number, while those who had always known were unconcerned with limits and more laissez faire generally.

# Enhancing Reproductive Opportunity Study

- o Qualitative interviews from 2010-2012 as part of a broader study
- o 21 parents from 19 families who utilised donor sperm in licenced treatment in Australia
- o 7 single women, 5 members of heterosexual couples, 9 members of lesbian couples
- o 18 had conceived in open disclosure era
- o All had disclosed, or intended to disclosure, fact of donor conception and were very mindful of children's possible interest in donor
- o Most suggested a preference for 5 or 10 reflecting the No in their own jurisdiction, 1 opted for 3 (the number of families in existence for her donor)
- o Only 1 did not support any family limit
- o 3 did not know what the limit was
- o Several did not know how many families had been created by their donor

# Some parents views on a limit from open disclosure era

*I think that's when it starts to get a little bit creepy and when it starts to get really bad publicity and things get a little bit, perhaps, scarier for the offspring; the thought that their donor donated just openly to hundreds of families or what have you and that their genetic family is so huge... I get images of – what's the right word? You know, like wacko priest type prophet cult sort of numbers. You know, like that one bloke can create 100 children. ... I would hate for my daughter to find 100 siblings. But then, that said, she may not hate that. That's only my thoughts. She may – you know, if that happened to her she may be really excited by the fact that there was so many of her around. I don't know.*

Rose (single mother)

# Other parents views on a limit

*If there's 10 or 5 or we're the only ones it's not really an issue to me ... But we quite like that [the donor] is from overseas so the chances of seeing him on the street or anything are just that bit more removed ... We were really comfortable with that.*

Olivia (heterosexual couple)

*Being in a lesbian community, it's a pretty small community, and we know four other couples that have used the same clinic as we do, and we don't even live in that state. So it really does worry me that one day we'll have a child and actually [the children of those other couples] will be genetically related to my child.*

Jess (lesbian couple)

# A limit exceeded

*When I got onto that donor sibling registry I was really shocked. I was actually ashamed that I had done this to my first son back then. I thought, oh my God, I've just put him into a big family, like an extended family and I did feel ashamed. Then I connected with the other families and I just – I see their children, they've got their photos of their children up and you can sort of see the similarities between the kids.*

*We're all sort of really attached to each other now and they actually – because most of the families are over in America or Canada – and they actually met ... So it actually feels like an extended family now ... We've got a Yahoo group so we do talk about it together. It's more about what it's going to mean to our children than what it means to us. I just think it's really lovely that we're all connected. It does feel like this extended family ... It sort of feels like they're cousins in a way.*

Anne (single mother)

# How many is “too many”

- Geographical spread
- Cultural concentration
- Intentions about future contact
- Knowledge of the actual limit (and assumptions about what it means)
- Knowledge of existing offspring numbers and other non-identifying information
- Understanding of, and access to, information sharing regimes
- Views about the **meaning of genetic links** (siblings or cousins? Family, extended family, family friends? Acquaintances or an information resource?)
- How few is too few?

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