

Opening the Register: The Parents' View

HFEA Annual Conference

13th October 2008

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Conception Network

This information has meaning

- What do the statistics mean for families?
- These figures are not from a factory production line
- The figures represent people's hopes and dreams of starting a family
- When donated eggs or sperm have been used the result is a creation of a ***different*** sort of family

My Family



Which parents will be affected?

- All parents of donor conceived children
- Most positive for
 - Single women and lesbian families
 - Heterosexual couples who accept DC as a second choice that is not second best
- Less positive for
 - Those who still have a sense of failure or stigma
- Least positive for
 - Families where children have not been told

Least positive group

- If children have not been told, parents may see information in the register as frightening, even threatening the very foundations of family life
- May be a trigger to tell but many will sit tight
- Most profound implications for family if a young person discovers for the first time from the register that they are donor conceived
- All parents will have some apprehension

Prospective Partners

- Parents who have not told are likely to worry when their children start having serious relationships and then having children of their own
- Could be another trigger point for telling
- A DC individual who is planning to marry can, with their partner, use the Register to find out if they're genetically related

Services, what services?

- Prior to UK DonorLink no professional service for DC families
- DC Network can only offer peer support but many complex family situations come our way
- Sharon Pettle gives guidance to DC Network and is sometimes able to see families
- Nothing like pre and post adoption services available for DC families

What this means for HFEEA

- All parents may require empathy and support as children seek information
- Ripples of disturbance may go back through generations for non-telling families
- Need for a service that can be flexible for requirements of all family members not just donor conceived people

What might the demand be

- Hard to anticipate demand
- Those conceived in early years following HFE Act less likely to have been 'told'
- Less information to give from this era
- Possibly small number of applicants but more complex situations to start with
- As openness has spread, possibly more applicants but fewer complex ones

What about the future?

Attention to family well-being
now may mean less complex
services needed in the future

Conditions for Well-being

- Conditions for DC family well-being are
 - Parents who are able to grieve and talk about infertility and need for DC
 - Parents able to make informed decisions that include understanding of responsibility to be open
 - Parents who feel confident and comfortable – able to put children's needs first because they have dealt with most of their own issues.
- Some will manage without help, many others require guidance and support.

What this means for clinics

- Need for change in culture as old attitudes still haunt some clinics
- Clinic staff hugely influential
- Not only a need to understand that donated gametes not just another fertility treatment, but it is part of the duty of care to patients that staff keep in mind the future well-being of the family – not just the achievement of a pregnancy.

The spirit as well as the letter of the Act

- “Clinics should encourage and prepare patients to be open with their children from an early age about the circumstances of their conception” *Part 5 current Code of Practice*
- New HFE Act will strengthen the requirement on clinics to prepare would-be parents for openness and new CoP will reflect this.
- Family well-being promoted by entering into the spirit rather than just following the letter.

Counselling *and* Preparation vital

- Counselling will remain important for couples and individuals
- Preparation for Parenthood workshops run by DCN and funded by DH now available in London, Birmingham and Manchester
- Parents who attend these workshops will be well-prepared for treatment and the future of their family.

Preparation for DC Parenthood workshops

- For further information and booking forms go to our web site

www.dcnetwork.org



Donor Conception Network
Charity Number: 1041207

Preparation for Parenthood Workshops

Are you thinking about creating a family using donated eggs, sperm or embryos or currently going through treatment?

Using donated gametes brings some differences to having a child using your own eggs or sperm. Although it may never be a first choice, with the right preparation the long-term prospects for a happy family life are the same as for any other family.

DC Network's pilot Preparation for Parenthood workshops will provide information about the law, reproductive medicine and psychological research relating to family building by donor conception. There will also be opportunities to talk in small groups with others facing the same questions and to meet with parents of donor conceived children.

The workshops are appropriate for **heterosexual or lesbian couples**, who are invited to attend together, for **single women**, and for **those having treatment in the UK or abroad**

Three major centres have been chosen to pilot these workshops:

LONDON	Weekend of 15th/16th November 2008 to include an overnight stay
BIRMINGHAM	1 day Saturday 24th January 2009 plus half a day on Saturday 7th February 2009
MANCHESTER	1 day Saturday 28th March 2009
LONDON	Monday 20th April 2009 6-10pm and Monday 27th April 2009 6-10pm

There will be a small charge for each workshop with concessions available.

If you are interested in taking part in one of these workshops
please complete the form below and send to:

DCN, Preparation for Parenthood Workshops, 32 Cholmeley Crescent, London N6 5HA



NAME(s)

WORKSHOP OF CHOICE

ADDRESS

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TELEPHONE EMAIL