




The 1985 Swedish legislation on identity-release donation – follow-up 30 years later


Claudia Lampic
Associate professor
Karolinska Institutet, Stockholm, Sweden




Sweden - first country in the world to abolish anonymous gamete donation

1985 legislation: offspring right to identifying information about the donor

- Parents responsible for sharing information about the donor conception with their offspring
- No information about donor conception in official documents, e.g. birth records
- Donor information stored at fertility clinic




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Identity-release donation – RECIPIENT COUPLES

- Must accept sharing information about the donor conception with offspring
- Instructed to start sharing information from early age
- Have no information about the donor

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Identity-release donation – OFFSPRING

Two-step process

- Disclosure of donor conception (by parents)
- Obtaining identifying information about donor
 - Mature age (≈18 years)
 - Contact with clinic
 - Meeting with counselor


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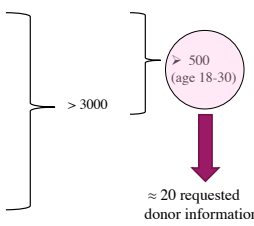
Identity-release donation – DONORS

- Must accept that identity will be released to offspring
- Have no information on recipient couples or offspring + no rights/responsibilities with regard to offspring
- Must be prepared to be contacted by offspring
 - Some clinics alert donor when offspring request information


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The Swedish situation – donation offspring

Legislation	Offspring
1985 Identity-release	
1995	
2003 Oocyte donation	
2005 SD - lesbian couples	
2016 SD - single women	≈ 20 requested donor information

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Why have only 20 of >500 offspring (4%) requested information about their donor?

Possible explanations

- They **don't want** any information about the donor (- yet?)
- They **don't know**
 - about their conception by donor sperm
 - that they can obtain information about the donor

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Do these (now adult) offspring know about their donor conception?

Parents of a subset of the >500 now adult offspring.
148 families after treatment 1985-1997 with children aged 1-15 years (Gottlieb et al 2000):


Half of parents had/intended to disclose

- 11% had started
- 41% planned
- 21% did **not** intend to disclose
- 27% unsure



Follow-up of 19 couples indicates increase of disclosure (61%) (Lalos et al., 2007)

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Experience from the USA


First cohort of adult offspring following identity-release donation at the Sperm Bank of California (1983-1993)

- 256 families with adult offspring
- 35%** (n=85) of offspring requested donor information in the first 10 years of releases
- Most made their request around age 18 (range 18-27).
- Main motivation: curiosity and to learn about oneself.

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The Swedish Study on Gamete Donation



C Lampic, Karolinska Institutet
G Sydsjö, Linköping University
A Skoog Svanberg, Uppsala University

- Multicenter cohort study
- Recruitment 2005-2008, regular follow-up
- 300 donors of oocytes/sperm
- 307 recipients of donor oocytes
- 587 recipients (heterosex/lesbian) of donor sperm
- 302 recipients of standard IVF (comparison group)
- 20 publications, 2 PhD theses

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Disclosure attitudes and behaviour of heterosexual couples treated 2005-2008

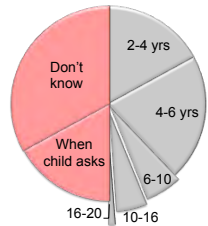
<p>2 months post-treatment 179 couples (OD/SD)</p> <p>90% positive disclosure Open towards others</p>	➔	<p>Offspring age 1-4 111 couples (OD/SD)</p> <p>6% negative or unsure 16% started disclosure 78% planned disclosure - when?</p>
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(Isaksson et al, 2012)

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Among the 78% who planned for later disclosure: when did they plan to start?




(Isaksson et al, 2012)

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Parents' concerns

- Unsure **when** and **how** to share information about donor conception with offspring
- Concern about offspring's potential **contact with donor**
 - In the best interest of the child?
 - Threat to the child or family?
- **Need for support** (counselling, information material etc)



(Isaksson et al, 2012)

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Follow-up of heterosexual couples' disclosure intentions at child age 7

First cohort of OD/SD parents (n=109) with disclosure intentions/ practice reported at offspring age 1-4 and 7

Based on intentions when offspring were toddlers – how many of parents had started disclosing at age 7:

- Intention to disclose
 - at offspring age 2-6 (n=31) 77%
 - "when child ask questions" (n=11) 91%
 - "when child understands" (n=25) 36%
 - at offspring age 6-20 (n=13) 0%

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Follow-up of heterosexual couples' disclosure intentions at child age 7 (cont.)


Among 109 parents with donor-conceived offspring age 7:

- 63% had started the disclosure process
- 23% planned to disclose in the future
- 4% were unsure or unwilling

No indication of selection bias (i.e. similar disclosure intentions at first follow-up among responders and non-responders to second follow-up). No sign. differences between parents after OD/SD

Increasing compliance with the intentions of the Swedish legislation. Couples may benefit from opportunities to discuss appropriate ages for start of disclosure process.

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Donors' perspectives

210 oocyte and sperm donors (5-8 years post-donation)

- **Positive (67%) or neutral (16%) towards being contacted**
- **Focus on offspring's** needs and wishes
- 1/4 wanted **counselling** on future contact with offspring
- **Preferences** for notification when offspring request donor identity: 57% positive - 29% negative

(Isaksson et al, 2014)


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Selected ongoing/planned research studies

- Within the 'Swedish Study on Gamete Donation'
 - Follow-up of all recipients 8-10 years after treatment, incl. parents of offspring age 7
- Multicenter study on adult offspring requesting information about their donor
 - Interview/FGD with offspring, donors, family members
- Multicenter cohort study of single women using SD
- Development of webbased psycho-educational programme

Claudia Lampic

 Karolinska Institutet

Thank you for your attention!

claudia.lampic@ki.se