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Dutch Act on Data of Donors in Artificial Insemination (WDKB)

Reflections on findings Second Evaluation



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Program

- Impressions from the second WDKB-evaluation
 - aims and results of empirical and legal analyses
- Children's rights context
 - 'substantial interests of the donor'
 - legitimacy of WDKB's content on donor anonymity





WDKB (2004) in short



Aim: to protect right of the child, that knows/suspects to originate from donor semen, -eggs or -embryo's, to know his/her donor.

- DKB-Foundation has key position, for:
 - responsible to preserve (80 y), store & provide data on donors & women who had donor insemination in fertility clinics.

- WDKB states: donor child
 - as of age 12 can request non-identifying donor information from DKB-F
=> *physical marks, education, profession, social background, some personal features.*
 - as of age 16, can request donor-identifying information from DKB-F
=> *family name, first name, date of birth, SoSec-nr., place of residence*

Info provided unless 'substantial interests of the donor'; DKB-F Board decides



Second WDKB-evaluation (2019)

■ Objects of research:

- Application of WDKB by DKB-F and clinics in view of preserving, managing and providing donor information.
- Bottlenecks in view of societal evolutions and debates.
- Overall issue: is WDKB future-proof or are adaptations needed in light of WDKB-aims and developments in implementation practice?

Evaluation included empirical and legal review of:

- performance DKB-F => donor register management; counsel, support and informing donor child, donor and parents
- right of (donor) child to know his/her genetic origin and other matters of child and family law.
- effects of ending donor anonymity, also with regard to position of donor.



Some empirical findings



- increased number of IVF-clinics since 2012: 12 => 16,
 - Egg banks: 2 => 3; Sperm banks: 8 => 6
- 6 other clinics report data to DKB-F
- clinics report broad practice of home insemination;
- 8 IVF-clinics and 2 hospitals collaborate with sperm banks from abroad;
- increased number of donations by sperm banks from abroad;
- 5 IVF-clinics do not operate with own or foreign sperm bank, but merely use own donors.

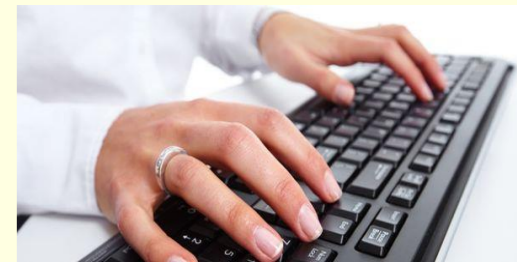
- number of donors registered during WDKB-evaluation.
 - mid 2011 = 1038
 - mid 2018 = 4292



DKB-F's performance I

Second evaluation shows:

- Improvements in comparison to 2012 => more registrations, clinics more aware of registration duties ('own donor')
- Nevertheless, current donor registration remains incomplete !
 - no data on home insemination, nor on treatments abroad (fertility tourism);
 - KIDS-system was operational not before 2006;
 - SoSec-nr. and data on Danish donors documented not before 2014
 - DKB-F does not check incoming data !!
- DKB-F has restricted interpretation of managing and storage duties
 - available data are not checked prior to request to provide donor information;
 - clinics register offspring per donor, but DKB-F does not link/monitor these data; so, it remains possible to exceed norm of max. 25 children per donor;
 - medical data / blood type of donor are insufficiently registered.





DKB-F's performance II

- DKB-F approach of its role and tasks not really changed, although first WDKB-evaluation (2012) showed cause for re-evaluation already. In 2019, still need for alterations.
- DKB-F operates reactive although, in view of 2021, pro-active approach is required.
- Composition of DKB-F's Board and background of board members should be reconsidered; DKB-F's secretary is firmly overworked, due to limited personnel capacity.
- DKB-F counts per Jan '14 as on-departmental public body (NDPB), but (still) has no objection & appeal proceedings.





Providing information by DKB-F



Two bottlenecks:

- Declaration of confidentiality (art. 12 par. 2 WDKB)
 - DKB-F registered no *identifying information* of donors using such declaration, although this is required under WDBK.
 - DKB-F should archive such declarations, but passed this on to clinics.
 - WDKB limits use of declaration 'til June '04, but it still occurs in clinical practice, with knowledge of Dutch Minister of Health Care (letter of 19/12/2018) !

- Switch from B-donor to A donor:
 - Some clinics allowed donors who donated before June '04 and were registered as B-donor, to switch to being A-donor after June '04.

Such a switch violates WDKB's transitional provisions; switching for A-donors only!



Legal analysis



Main focus on:

- role legislator in stimulating parents to be clear towards their donor child about its genetic origin
- should statutory age limits in requesting donor information be reconsidered?
- are positions of donor children, donors and parents adequately regulated, or are changes in WDKB or practice necessary?
- general legal developments and alignments with related legislation (i.e. on embryo protection, human tissue, patient's rights, etc.)



Additionally, ..as a formal check

- Review of WDKB-effects against *issues of children's rights and family law* as a service to examine whether WDKB is future proof.

Of particular interest: to what extent can WDBK realize main aim, which is:

to protect, as far as possible, the child right to know his or her parents, as in Article 7 par 1. CRC?





Some findings



Analysis showed that:

- Art. 8 par. 3 DKB-F Protocol (still) not in conformity with art. 3 par 2 WDKB
 - no ‘*balancing of interests*’, but to establish ‘substantial interests of the donor’
- No rationale for age limits in WDKB
 - recomm: allow supported access to donor information as of age 12
 - further research to be initiated
- Lack of surveillance – several years no DKB-F annual reports
 - Health & Youth Care Inspectorate and Ministry of Health Care did not really bother...



Main issue: is WDKB art. 7 CRC-Proof?

WDKB prioritises child's right to access to information on genetic origin over donor's interest in anonymity, unless 'substantial interest of the donor' requires otherwise.

Yet, procedure to assess 'substantial interests' has (still) not been adopted!

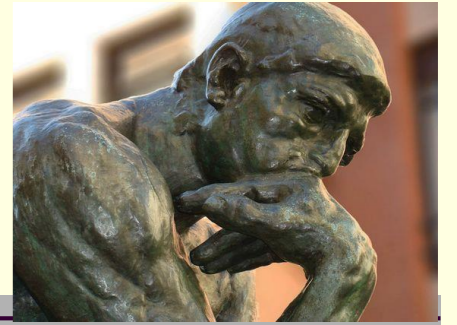
- not clear which steps in judgment and which measures must be applied.
- Government announced to establish advisory committee to support new DKB-F Board (= College). Yet, WDKB-amendment had not yet been submitted to Parliament !

⇒ WDKB's aim still not realized, even though Netherlands is bound by treaty obligations under Article 7 CRC as of March 1995.





Donor anonymity safeguard



How does child's right to information on decent relate to donor's privacy interest, especially when guaranteed anonymity was basic condition for donation?

- to find and respect 'substantial interest' means to prioritize adult's interest over child's interest !
- adoption research shows: to withhold information on biologic origin may lead to serious damage (i.e. 'distorted self-esteem') to child.

Statutory guaranteed anonymity before June '04 is problematic!

- ⇒ NL is bound by art. 7 CRC as of March '95 => donor anonymity cannot be agreed to limitless; at most '*as far as possible*'.
- ⇒ NL failed to implement this CRC-condition in Dutch donation practice, which affects donor child 'conceived' between March 1995 – June 2004 !



Besides: donor anonymity & civil law

- Is anonymity agreement between donor and clinic lawful, if it impairs donor child's legitimate interest in information on decent?
- Donor child is third party, so no party to this agreement, yet affected by it..

Article 6:248 par 2 CC: “*A rule that applies between parties as a result of an agreement does not apply, insofar as this would be unacceptable in the given circumstances according to standards of reasonableness and fairness.*”

(i.e. Article 3:12 CC)

Considering clause wordings, clause history, parties' awareness of its nature / effects..

- ⇒ Can child, seeking donor information, invoke ‘wrongful act’ (Article 6:162 CC) while claiming illegitimacy of WDKB's transitional provisions with reference to Article 6:248 par. 2 CC jo. Article 7 CRC, against clinic (or DKB-F) that upholds donor anonymity?





Currently 2 court cases



■ Arnhem case – Mother & donor child vs. hospital

- Hospital told mother in 1997 she was inseminated with B-donor's semen, so child could later learn about donor's identity
- After 2004, hospital allows donor to switch to A-donor (= unlawful !) => hospital cannot live up to earlier promise, as donor persists to honor his present wife's wishes..
- Mother & donor child claim information on donor (K34) but hospital cannot comply, as donor holds on to declaration of confidentiality.
- Court sympathizes with claim (= supported by findings of 2nd WDKB-evaluation), but must decline. It cannot weigh interests of donor, who is no known party in this case. Court urges legislator to act!

■ The Hague Case

- 5 donor children + 4 mothers jointly claim information on donor (nr. 605), but clinic cannot comply, as donor switched from B- to A-donor; plaintiffs were not informed..
- Point of interest: claim also directed to DKB-F; yet, nr. 605 no known party in this case. => Ruling expected June 2nd 2021 !





Conclusion



- Second WDKB-evaluation revealed ongoing shortcomings in the Act's implementation practice.
- Findings in children's rights analysis are no less than fundamental !
 - these must be faced, also because of persisting shift in societal views on WDKB-issues.
 - final rulings in current court cases will outline legislator's legislative responsibility !

