

Disclosure and Anonymity: The Impact of Genealogy and Testing On Adoption and ART: 21st Century Realities

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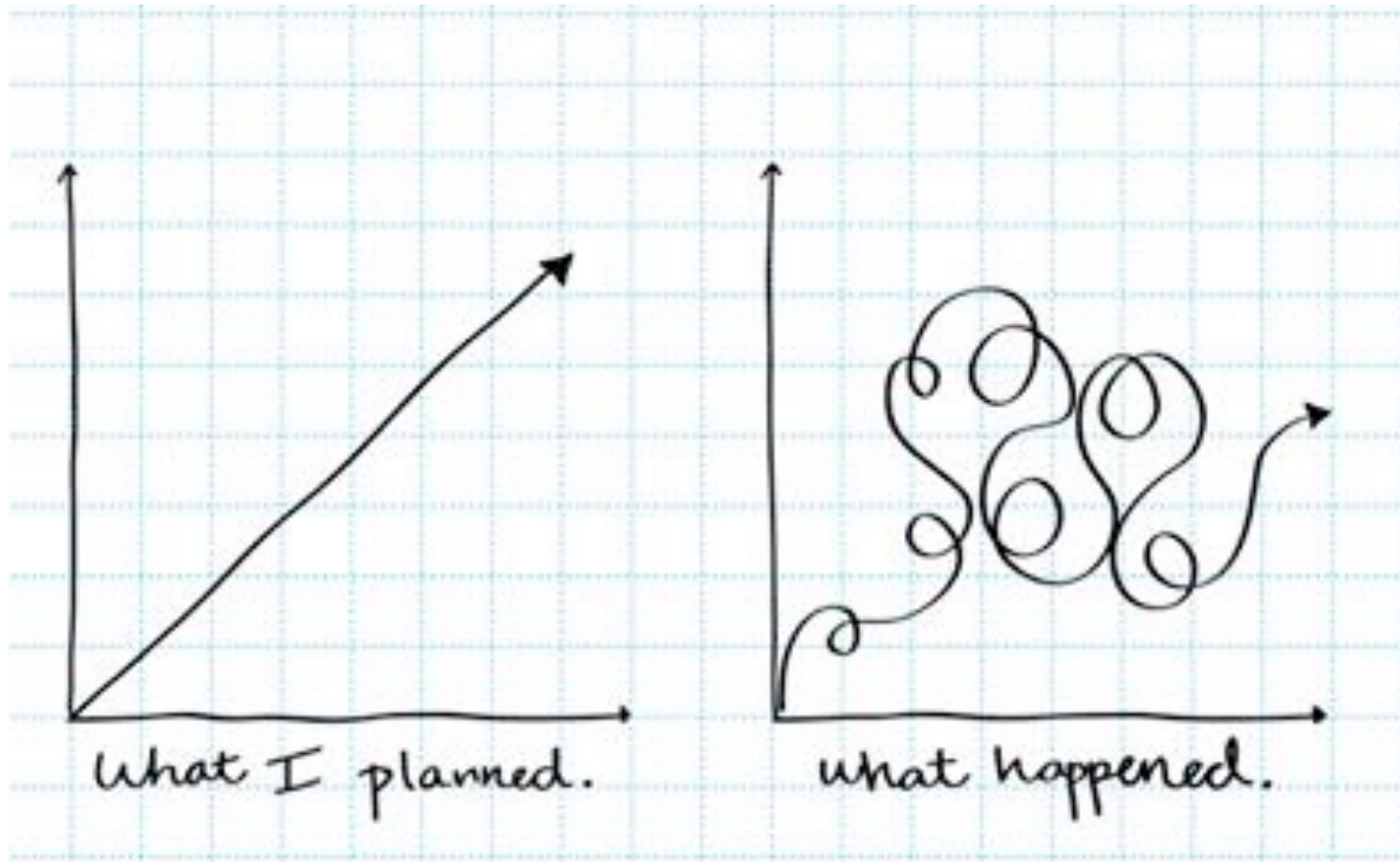
DISCLOSURE

Dr. Grill is a co-owner of FertiCalm LLC, FertiStrong LLC, and Aliz Health Apps, LLC and is on MERCK's speaker's bureau

Learning Objectives

1. Identify how donor linking can occur through DNA banks and websites
2. Examine the dilemmas posed by donor linked contact
3. Discuss the implications of donor linking for professionals in the ART field

Donor Anonymity



To Disclose or Not to Disclose?



Secrecy and Anonymity are No Longer Viable Assumptions

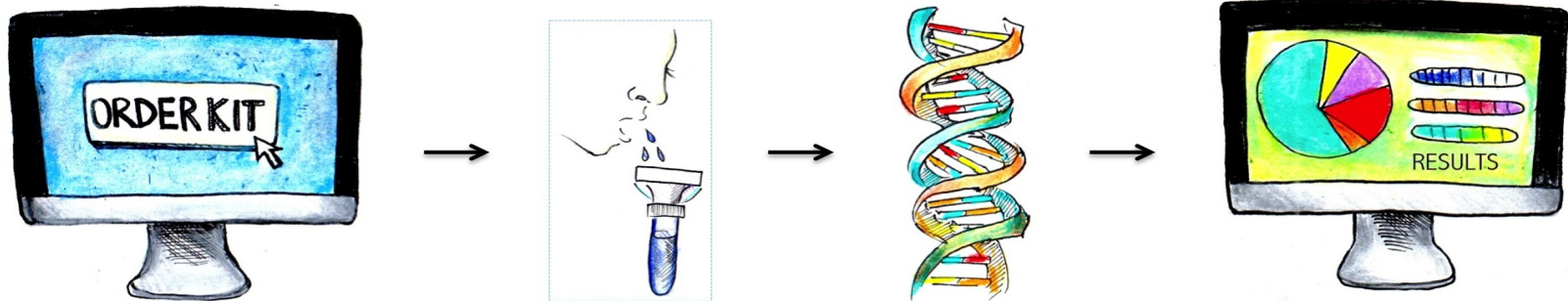
- Assumption #1: It is the parent's decision whether to disclose
- New Reality #1: Parents can still decide whether to disclose BUT it is no longer their choice whether their child will find out!
- Assumption #2: The donor will remain anonymous
- New Reality #2: Donor Anonymity is Anachronistic
- Assumption #3: There will be no contact among the parties.
- New Reality 3: Contact and connection is happening and may become the norm.

Pasch LA. New realities for the practice of egg donation: a family-building perspective. *Fertility & Sterility*. 2018; 110:1194-202.

What Happened to Anonymity?

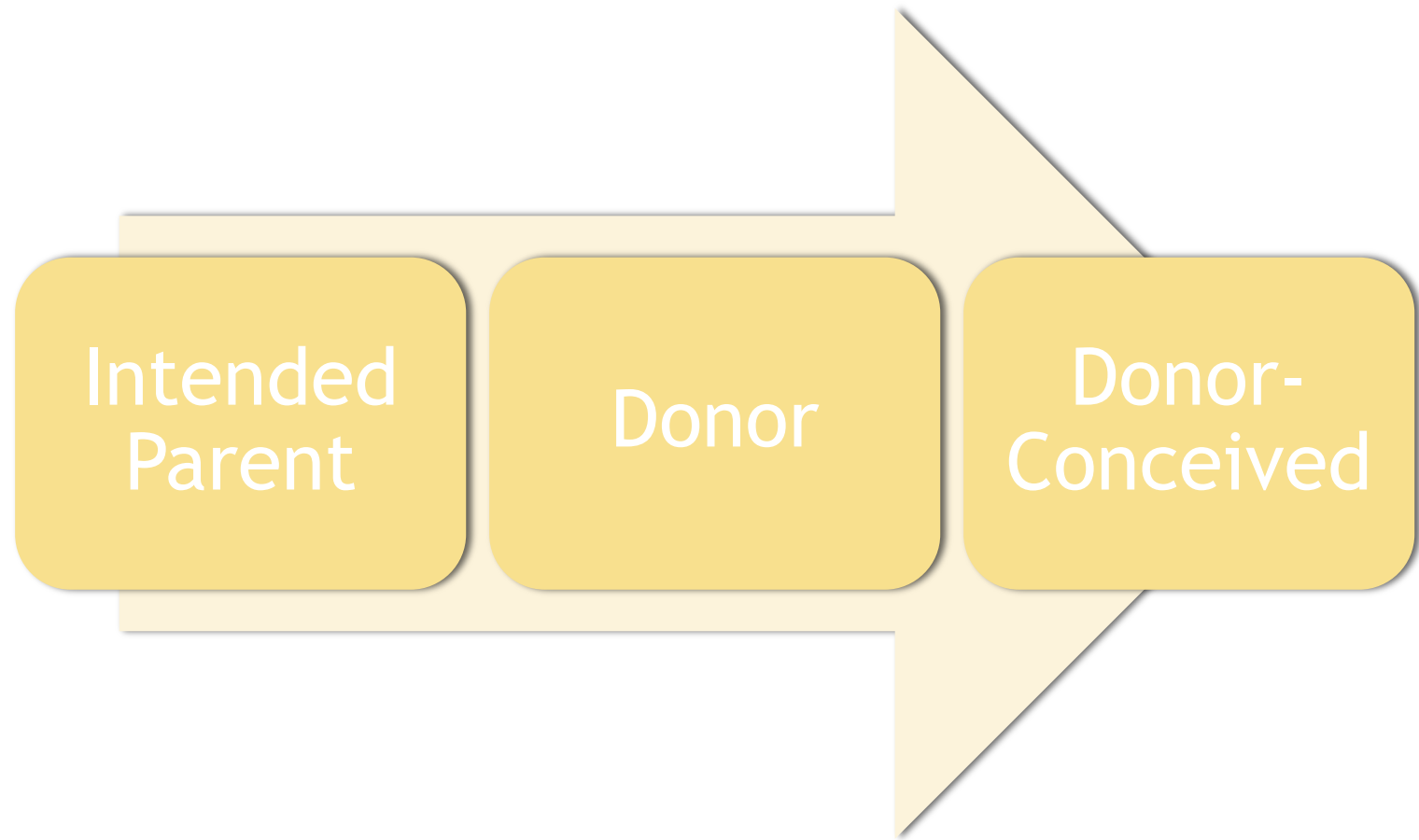
“Thus, in one quick stroke, technical advances and the availability of genetic information, facial recognition software, and social media have crushed the illusion of donor and recipient privacy like a paper-mache castle.”

Peter G. McGovern, M.D. and William D. Schlaff, M.D., 2018, p. 231



Braverman, Andrea Mechanick. "How the Internet is reshaping assisted reproduction: from donor offspring registries to direct-to-consumer genetic testing." *Minn. JL Sci. & Tech.* 11 (2010): 477.; McGovern, Peter G., and William D. Schlaff. "Sperm donor anonymity: a concept rendered obsolete by modern technology." (2018).; Pasch LA. New realities for the practice of egg donation: a family-building perspective. *Fertility and sterility.* 2018 Dec 1;110(7):1194-1202.

Our Focus of Attention/Concerns Has Evolved



Relationships Among and Between Stakeholders

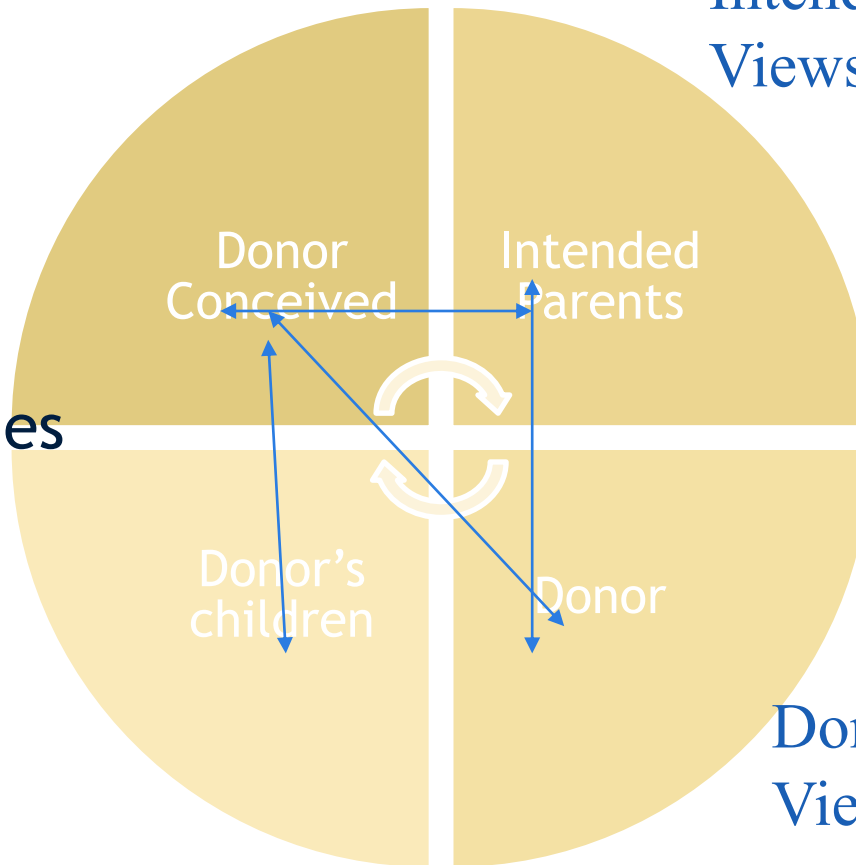
Intended Parents Family
Views and Influences

ART facilities
Recruiters

Gamete Banks

Professional Societies

???



Donor's Family
Views and Influences

Connections

- Most DCP's express modest expectations about contact with their donor
- Most DCP's view contact as neutral or positive
- Most DCP's are not seeking an ongoing parent-child type of connection
- Some DCP's view the donor and others born from the same donor, as their extended family
- Some donors desire to learn the outcome of their donations and want to connect with offspring

Scheib JE et al., Who requests their sperm donor's identity? The first ten years of information releases to adults with open-identity donors. Fertil Steril 2017;107:483-93; Jadva V, et al., Sperm and oocyte donors' experiences of anonymous donation and subsequent contact with their donor offspring. Hum Reprod 2011;26:638-45; Hertz R, et al., Donor sibling networks as a vehicle for expanding kinship: a replication and extension. J Fam Issues 2017;38: 248-84. ; Lampic C, et al., Attitudes toward disclosure and relationship to donor offspring among a national cohort of identity- release oocyte and sperm donors. Hum Reprod 2014;29:1978-86.

One Person's Yuck Is Another Person's Yum



THE
DONOR SIBLING REGISTRY
EDUCATING, CONNECTING AND SUPPORTING DONOR FAMILIES

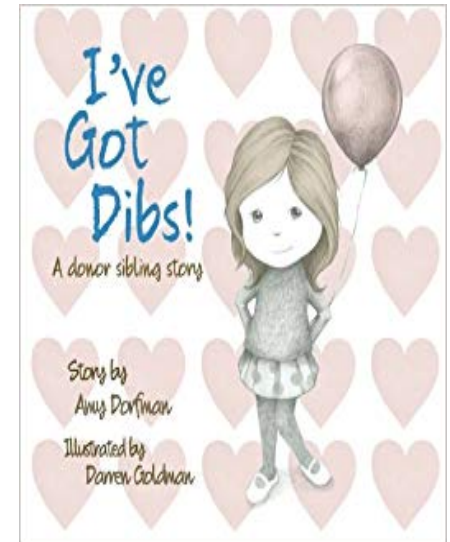
- DCP's sometimes see themselves as the voiceless party in third-party reproduction
- DCP's resent that their interests were not considered at the time of conception by:
 - Parents
 - Medical providers
 - Society at large



What is Kinship?

- Sperm donor half-sibling groups have been large in number (one group approaching 200). Source: Donor Sibling Registry

# of Groups	# of half-siblings per donor
376	5-9
82	10-15
19	16-20
18	21 or more



Sawyer N, Blyth E, Kramer W, Frith L. A survey of 1700 women who formed their families using donor spermatozoa. Reproductive Biomedicine Online (2013)

What is kinship?

FASHION

Nobody asked for 'sperm donor' jewelry, but here it is anyway

By Bree Bonagofsky

November 2, 2017 | 2:59pm



Courtesy of Parent On A Chain



Jefferson

Philadelphia University +
Thomas Jefferson University

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Genetics Are Not Neutral

“Genetic heritage is an important influence in temperament, appearance, abilities and other personal traits. These biologically based experiences of the self are important components of an individual’s identity”

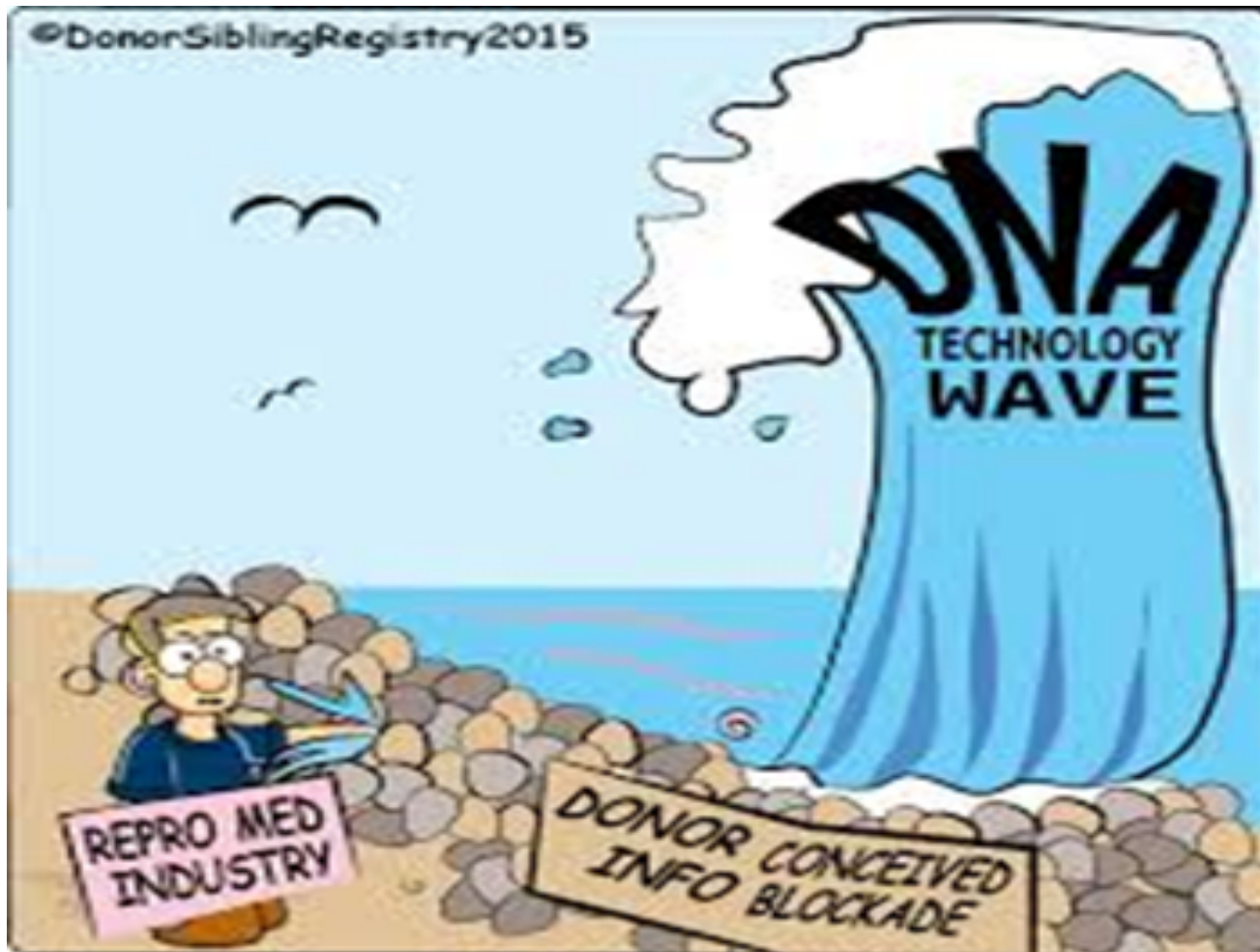
Benward J, Braverman A, Galen B. Maximizing autonomy and the changing view of donor conception: the creation of a national donor registry. DePaul J of Health Care Law 2009: 12:225-240.

What Information Do DCP's Search For?

- Simple curiosity appears to be the driving factor
- Genetic heritage
- Health history for themselves and their children
- Commonalities due to genetics (“Am I like him?”)
- Information to help them better understand themselves and their identity

Freeman T. Gamete donation, information sharing and the best interests of the child: an overview of the psychosocial evidence. Monash Bioeth Rev 2015;33:45-63; Blyth E, Crawshaw M, Frith L, Jones C. Donor-conceived people's views and experiences of their genetic origins: a critical analysis of the research evidence. J Law Med 2012;19:769-89.

These Are New Concepts For Gamete Donation Professionals



Disclosure

- 1) Children react to donor conception with curiosity or indifference rather than distress
- 2) Parents who disclose usually view the overall impact as neutral or positive
- 3) Offspring who are told as children are more comfortable with donor conception than those who learned as adults
- 4) Those who learn as adults can have significant distress about being misled by their parents throughout childhood

Ilioi E, Blake L, Jadvā V, Roman G, Golombok S. The role of age of disclosure of biological origins in the psychological wellbeing of adolescents conceived by reproductive donation: a longitudinal study from age 1 to age 14. J Child Psychol Psychiatry 2017;58:315-24.; Imrie S, Golombok S. Long-term outcomes of children conceived through egg donation and their parents: a review of the literature. Fertil Steril 2018; 110:1187-93.

Age Matters

Piaget's Periods of Cognitive Development			
Birth to 2 years	Sensori-motor	Uses senses and motor skills, items known by use	Object permanence learned
2-6 yrs	Pre-operational	Symbolic thinking, language used; egocentric thinking	Imagination/ experience grow, child de-centers
7-11 yrs	Concrete operational	Logic applied, has objective/rational interpretations	Conservation, numbers, ideas, classifications
12 yrs to adulthood	Formal operational	Thinks abstractly, hypothetical ideas (broader issues)	Ethics, politics, social/moral issues explored

Moral Development

Kolberg's Theory

Level/Stage	Age Range	Description
I: Obedience/Punishment	Infancy	No difference between doing the right thing and avoiding punishment
I: Self-Interest	Pre-school	Interest shifts to rewards rather than punishment -- effort is made to secure greatest benefit for oneself
II: Conformity and Interpersonal Accord	School-age	The "good boy/girl" level. Effort is made to secure approval and maintain friendly relations with others
III: Authority and Social Order	School-age	Orientation toward fixed rules. The purpose of morality is maintaining the social order. Interpersonal accord is expanded to include the entire society
III: Social Contract	Teens	Mutual benefit, reciprocity. Morally right and legally right are not always the same. Utilitarian rules that make life better for everyone
III: Universal Principles	Adulthood	Morality is based on principles that transcend mutual benefit

The Psychology Notes Headquarter - <http://www.PsychologyNotesHQ.com>

Gilligan's Stages of the Ethic of Care Levels and Characteristics (*)

Level 1: Orientation to Individual Survival

*individual survival

First Transition: Selfishness to Responsibility

*connection and responsibility to others

Level 2: Goodness as Self-Sacrifice

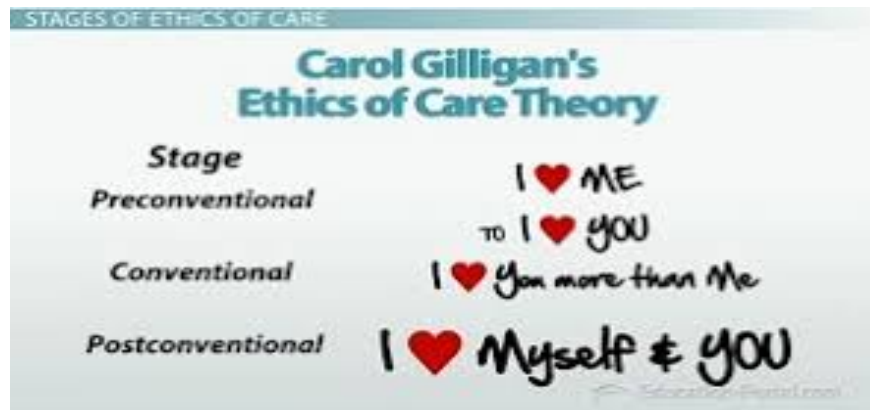
*reliance on others, social acceptance

Second Transition: Goodness to Truth

*questioning comparative value of self vs. others

Level 3: Morality of Nonviolence

*heightened understanding of choice between own needs and care for others; do not harm others or self



Just Because Parents Can... Doesn't Mean They Should...

- Parents/DCPs can make contact with donors at any time.
 - Risky because it violates the “social” contract with donor and can have opposite intention
- Parents have a choice of what type of contact they select.
- Parents also have a responsibility both to their child and other parties to sustain their decision over time.
- Parents' perceptions of their child's needs doesn't automatically supersede the interests of the donor and his/her family.

Braverman AM, Schlaff WD. The end of anonymity: stepping into the dawn of communication and a new paradigm in gamete donor counseling. Fertility & Sterility, 2019: 111:102-1104.

Age and Stage

- Unexpected contact can have many different responses

The New York Times

Sperm Bank Threatens to Sue.

The results of a consumer genetic test identified the mother of the man whose donated sperm was used to conceive Danielle Teuscher's daughter. Legal warnings soon followed.

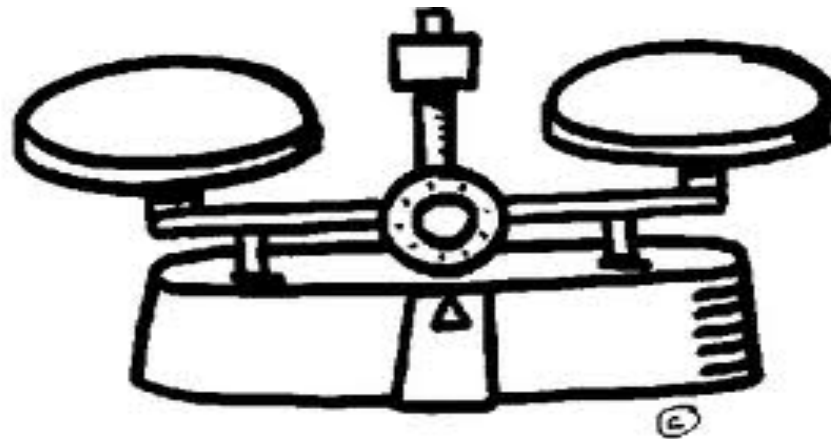


Balancing Needs

In this complex mix of interests, whose should be paramount, and what boundaries of privacy should be unequivocally respected?

Donor Conceived

Donors



Laws Govern Actions But Not Feelings

- Contracts may fail to regulate behavior, and they certainly do not regulate feelings and emotions
 - You cannot “unring” the anonymity bell after contact is made so the remedy may be financial damages but are likely to be inadequate or unsatisfactory under the circumstances
- The contract will inform the roles that stakeholders can anticipate for themselves or their respective families



Braverman AM, Schlaff WD. The end of anonymity: stepping into the dawn of communication and a new paradigm in gamete donor counseling. *Fertility & Sterility*, 2019; 111:102-1104.

Feelings Are Not Necessarily Rights (Or Wrongs)

- Competing “rights” talk is not helpful in the highly emotional boiling pot of competing interests
- Invoking a “right” as a rationale for a behavior can be a dangerous decision= the action directly pits one person’s needs against those of another and fundamentally claims preeminence
 - donor versus donor-conceived
 - parents versus children
 - donor versus family of origin
- You can force contact. You cannot force a relationship.
- You cannot legislate feelings or behaviors

Braverman AM, Schlaff WD. The end of anonymity: stepping into the dawn of communication and a



Jefferson University
Thomas Jefferson University

new paradigm in gamete donor counseling. Fertility & Sterility, 2019: 111:102-1104.

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Perspectives Can Differ



Andrea Mechanick Braverman, PhD Thomas Jefferson University June 8, 2018

You Can't Stick Your Head In The Sand And Hope This Will All Go Away

- The new reality of non-anonymity needs to be clearly explained to stakeholders and by all parties going forward
- Better informed stakeholders ensures the best relationships going forward



Braverman AM, Schlaff WD. The end of anonymity: stepping into the dawn of communication and a new paradigm in gamete donor counseling. *Fertility & Sterility*, 2019: 111:102-1104.

If You Can't Find A Decent Remedy, Maybe You Need Another Perspective

- Working through a gamete bank rather than direct-to-consumer testing = better chance of getting the information they want.
- Donor banks and programs can align expectations prior to donation = create a more successful context for future success.
- Implementing procedures and policies that will last through new staff, management, and even ownership of IVF clinics will require administrative, legal, and technical expertise.

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Shifting The Narrative To A Family-building Perspective

- Ultimate goal is not just the establishment of a pregnancy but positive family functioning.
- 1) DCP's will eventually learn they are not genetically related to both parents and information sharing is important for optimal family functioning.
- 2) The focus is not on disclosure versus nondisclosure but is an ongoing process of information sharing across time, people, and circumstances starting when the child is younger.
- 3) Any of the parties may desire future contact, connection, and even relationship, and that these interests may or may not coincide.



Psychosocial Challenges

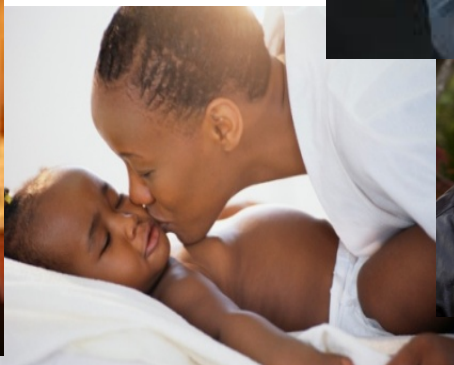
- Should parents/programs share identifying information from the beginning, or only in response to offspring request?
- What happens when requests are made for contact but there are no records?
- What do you do when desire for contact is not mutual?
- Reactions to contact with donors and others conceived via the same donor
- One size does not fit all!

Pasch LA. New realities for the practice of egg donation: a family-building perspective. *Fertility & Sterility*. 2018; 110:1194-202.



"FROM LEFT TO RIGHT: MY POST-MENOPAUSAL BIRTH MOTHER, THE FATHER OF MY SPERM, THE MOTHER OF MY EGG, AN ATTORNEY TO KEEP THEM ALL STRAIGHT. AND A PSYCHIATRIST TO HELP ME MAKE SENSE OF IT ALL."

We Have An Obligation To The Future – And All The Stakeholders



THANK YOU!



Center for Reproductive Medicine
Weill Cornell Medical College, New York, NY