THE EVOLVING ETHICS OF SPERM DONATION

by
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Abstract

Sperm donation has been available as a treatment for infertility for decades, but the nature of sperm donation has changed in important ways. Along with the changes to the fertility industry, there have been changes to data access since the completion of the Human Genome Project. These combined changes are creating new harms for donor-conceived persons who were conceived in an era when anonymity was guaranteed both to donors and to families.

This thesis attempts to explain how the changes to the fertility industry and to the availability of direct-to-consumer genetic testing have combined to create new harms, and recommends systemic changes that can help mitigate the harms that are being experienced by donor-conceived persons to make the system function in a more ethically sound way.

In Bioethics, we speak of four principles: Autonomy, Beneficence, Nonmaleficence, and Justice (Beauchamp & Childress), each of which generates ethical obligations. In healthcare, agents owe obligations to those whom they serve. When it comes to the system of sperm donation, autonomy and nonmaleficence are the two principles that come into play most prominently: an obligation exists on the part of the fertility industry not to cause harm and a correlative obligation exists to promote the autonomy of donor-conceived persons.

Efforts can be made to avoid these harms moving forward and to promote autonomy for donor-conceived persons. I recommend eliminating donor anonymity to ensure that donor-conceived persons have access to accurate medical history, and ensuring that they have the information necessary to make informed medical decisions. I also recommend regulating the fertility industry and direct-to-consumer genetic testing companies to ensure that there is a
limit on the number of donor-conceived siblings who are born from an individual donor and to ensure that therapeutic resources are made available to individuals who may receive the shocking and potentially traumatic news of a non-paternal event later in life. While the goal of any fertility treatment is to allow the parents to have a child, that resulting child should be given the respect and dignity that they deserve.

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My Story –

Since the age of 6, I’ve known that the Dad who raised me was not my biological father. Growing up, I distinguished between my three dads: my “Daddy” who was married to my mom when I was born; my step-father, Jim, who raised me; and my “Medically Unknown Daddy,” a man I believed I would never get to know. I knew he was a medical student when he donated sperm. My parents visited a fertility doctor to have the baby they always wanted despite my dad having had a vasectomy years earlier. I knew the donor had brown hair and blue eyes, described himself as being tall, musical, and funny. He claimed no family history of genetic diseases or ailments, and was of Eastern European and Ashkenazi Jewish descent. Other than that minimal amount of information, I thought I would never have the opportunity to meet him. I grew up with loving parents who always made it clear I was wanted. Yet, I always had a longing for information about the other half of my DNA and wanted to know what my biological father looked like, where my musical talent came from, my straight teeth, and my curiosity about medicine and science.

I occasionally tried to find him: I would look in alumni magazines from his medical school for pictures and I’d carefully examine them to find any resemblance. In 2009 I found a picture of a man who looked like he could be the one. We had similar eyes and smiles. I emailed him and he was caught completely off guard. He wrote back saying that yes, he had been a sperm donor, but he did not think he was mine because he had hazel eyes, not blue, and he gave me the generic advice to raise my children on healthy food, fresh air, and clean water. At the time, there was no way to verify the accuracy of his assumption that he was not the man I was looking for.
Everything changed in the fall of 2019 when I made the decision to submit a sample to 23andme. I figured I would either find little to no useful information or perhaps a small handful of new cousins I had never met. The day before Thanksgiving, I got an email from 23andme that said, “Your reports are ready!” I quickly opened the email and clicked on the link that said, “View DNA Relatives.” To my shock and delight, there were 17 half siblings listed in my “Close DNA Relatives” section. I had never met any of them, yet as I started to look them up one-by-one on social media and compared my own image to theirs, it became clear that DNA tests do not lie. We all have similarly shaped eyes, the same perfectly straight teeth, and similar smiles. I immediately called my closest DNA match on FaceTime, a half-sister who was a year younger than I, and we talked for no less than an hour. She filled me in on all the details, having received her own results over a year earlier. She had connected the dots because our donor’s sister appeared in our 23andme results and was easily found on social media. She easily identified through her profile who our father was. From there I’ve cultivated amazing relationships with several of my siblings and with my Father. Coincidentally, that man I found in 2009 was the man I was looking for.

Every year, a few weeks after Christmas I get an email that says, “you have new DNA relatives!” The folks who received DNA tests as Christmas gifts get their results about a month or so into the new year. Sometimes the information they receive is not a surprise, but I’ve had more than a few difficult conversations with half siblings who received shocking results. “Are you sure?” one brother asked me. “How sure are you?” He was raised by Italian immigrants, went to college in Italy, and grew up very close with his dad. He was an altar boy at his Catholic Church. Yet, his DNA test clearly showed that he’s only about 50% Italian, and the other half
comes from our biological father. He’s come to terms with the information he’s received but since both of his parents have passed, he has a lot of unanswered questions. It’s a lot to process when your reality, your childhood, your personal narrative, and your identity all come into question in your mid-30’s.

The word I’ve always used to describe this journey of self-discovery has been “wild.” It’s wild to grow up as an only child and then at the age of 34 to find out that you are one of dozens of half siblings. It’s wild to meet your biological father for the first time in your mid-30’s and to see your mannerisms in him, to hear your intonation in his voice, to dive deeper into questions of identity, and nature vs. nurture. It was surreal to share a meal with 9 half siblings during which the conversation flowed effortlessly. Meeting each of my siblings, I am struck by how similarly our minds work: we process information in similar ways, jumping from topic to topic without needing to announce the mental leaps we make. Normally, meeting a stranger for the first time would be awkward, with lulls in the conversation and moments of silence. With my siblings there is none of that: we pick up as though we had grown up together, never losing a beat. At a large gathering, two brothers were wearing the same shoes from a little-known brand. One sister and I had the same exact purse. Are these purely coincidental or is there something more to these similarities?

As I got to know my siblings and my father, ethical issues kept rising to the surface related to sperm donation and I committed to learning more about these issues so that I could answer some of my siblings’ burning questions: Why did so many of our parents not tell us we were donor-conceived? Why were better records not kept? Why did we not have access to our
medical records? What if I had married a half-sibling? How could the fertility doctor let 40 half
siblings be born from the same father? How many of us are there? How is any of this ethical?

**Introduction**

While sperm donation has existed for decades, the nature of the procedure has changed
in important and relevant ways that are creating new harms for donor-conceived persons. The
procedure used to be done in a more intimate and private setting with just a few individuals
involved: the fertility doctor, the sperm donor, and the individual patient receiving the sperm,
along with their partner. In the more recent past, the fertility industry has exploded into a
booming business in which children are the commodity being purchased by families for
thousands of dollars. Sperm donation is just one procedure offered for families looking to have
children when they cannot have their own biological children. Sperm donors are expected to
donate regularly, potentially fathering dozens of children in the process. While anonymity once
was guaranteed to families and donors, the sequencing of the human genome and the
development of direct-to-consumer genetic tests have rendered anonymity meaningless.
These changes have created new ethical obligations on the part of the fertility industry that are
not currently being addressed. As a result, donor-conceived persons are suffering harms that
ought to be mitigated moving forward.

Below, I will briefly explain the problem and describe how both sperm donation and
data availability have evolved in the United States. Next, I will explore some of the ethical
issues that have come up within the system of sperm donation. There are too many to cover in
depth in a thesis of this length, but I look forward to addressing more of them in future writing.
This discussion will include both the obligations that the fertility industry has to donor-conceived persons as well as the harms they are currently experiencing. Finally, I will propose solutions to mitigate these harms moving forward.

The Problem

Donor-conceived persons have been treated for years as the end goal of sperm donation: once a fertility doctor helps a person achieve pregnancy and have a baby, their job is done in their eyes. No thought has been given to the experience of those growing up as a donor-conceived person. Anonymity was the norm and parents were left to decide for themselves whether to reveal the truth about their child’s conception to them. While some donor-conceived persons (myself included) grew up with the knowledge that they were donor-conceived, many did not. Instead, some were never told (which is why I may never know how many half siblings I have), some discovered that truth later in life either when told by a friend or family member, or when they received the results of a direct-to-consumer genetic test that revealed that their social father was not their biological father. Many donor-conceived persons will never know that they were donor-conceived because families often chose donors who physically resembled the social father to reduce the likelihood of stigma. Without a reason to question their parentage, they may never make the decision to do a genetic test and may continue on, blissfully unaware of the truth.

Generations of donor-conceived persons have grown up without access to information about their donor, access to medical records, or information about any siblings or other genetic
relatives. Many have been left traumatized by the experience of a non-paternal event later in life, often causing a crisis of identity and harm to their existing familial relationships.

While the system of sperm donation has evolved in many ways, protections have not been put into place at the same pace to ensure that donor-conceived persons are not being harmed in new ways. Some donor-conceived persons finally have access to the information they have always deserved and to which they should have always been entitled, yet this information has been kept from them for years by a system that has not caught up with the technologies available. The availability of this information for donor-conceived persons who were conceived via anonymous donation is dependent upon whether or not any genetic relatives have themselves used any direct-to-consumer genetic tests. In my situation, for example, the key to finding our biological father was the fact that his full genetic sister had done 23andme and appeared as an “Aunt” in our results. After a few minutes of social media sleuthing my half-sister knew with near certainty who our biological father was. Eliminating anonymity, more closely regulating the fertility industry and the direct-to-consumer genetic testing companies, and ensuring that support systems are in place for donor-conceived persons who experience a non-paternity event will help to mitigate these harms moving forward both for existing donor-conceived persons and for those yet to be conceived.

The History and Evolution of Sperm Donation and Data Availability in the United States

The first documented case of artificial insemination was from the 1770’s, when John Hunter, the “founder of scientific surgery,” advised his patient to collect his semen in a warmed syringe and inject it into his wife’s vagina (Ombelet & Van Robays). Initial cases of artificial
insemination used a husband’s sperm to impregnate his wife—often in cases of male factor subfertility. The first documented case of artificial insemination using donated sperm was in 1884—the patient was never even told that another man’s semen was used (Keshavan).

Sperm donation grew in popularity after World War II as a treatment for male factor infertility. The secrecy that surrounded the practice was “both to protect the man from the stigma of infertility and to protect the child from the stigma of illegitimacy” (Fetters). Sperm donation was largely done in a small clinic setting: a fertility doctor in an academic medical institution would recruit a handful of medical students they knew personally to donate sperm. The students were considered to be of “good stock,” (Kleeman) because they were smart, often good looking, and knew a bit about their own medical history. They would gladly donate sperm for $25-100 per vial. They were also a captive audience because they were in school, then in residency, and could be tracked down easily for repeat donations.

As demand for donor sperm grew, so too did the demand for clinics that provided the service. The modern fertility market developed in the 1970’s, with the first baby conceived through in-vitro fertilization, Louise Brown, born in 1978 (Zoeller, Muller & Janiga). By 2019 there were a total of 489 fertility clinics that performed artificial reproductive technology procedures (CDC). While numbers are hard to verify, one recent estimate was that half a million women each year are impregnated in the US using donor sperm (Arocho, Lozano, and Halpern).

California Cryobank, a fertility clinic that describes itself as an “industry leader for almost 40 years,” boasts on its website that they recruit donors from “world-class universities,” and that their donors are “established professionals in various fields including business,
medicine, law, and the entertainment industry” (California Cryobank). Their donor recruitment brochure describes the process donors must go through—after filling out an online application, potential donors have two office visits, a physical examination, additional testing, a genetic evaluation, and then final review and approval before they begin donating sperm. Once they’ve been approved as a donor, they receive ongoing testing (California Cryobank). When accepted into the program as a qualified sperm donor, donors are “expected to donate at least once per week” but are encouraged to donate 2-3 times per week. Once in the program, donors are expected to be “actively participating for 9-12 months” (California Cryobank).

My own father told me at our first meeting that he donated 2-3 times a week for 2-3 years while he was in medical school. Yet, my mother was told by the fertility doctor that, at the time I was conceived, he had only donated a couple of times. I now know I have at least 5 older half-siblings. One of my half-brothers, 7 years younger than me, who was conceived using frozen sperm, told me his parents were told the same thing. So far, he’s the youngest half-sibling we know about: the youngest of almost 40.

Just as sperm donation has grown as an industry, so too has data availability, particularly with the growth of direct-to-consumer genetic tests from companies like 23andme and Ancestry.com. Direct-to-consumer genetic testing first became available in the early 2000s, allowing “consumers to access information on their genetics without the involvement of a physician” (Allyse, Robinson, Ferber, and Sharp). Today, direct-to-consumer genetic testing is readily available, but it falls within an ambiguous regulatory setting—the Clinical Laboratory Improvement Act (CLIA) regulates procedural aspects of laboratories that process medical samples. Under CLIA, the Food and Drug Administration is tasked with ensuring the safety and
efficacy of medical tests and interventions (Allyse, et al.). The Federal Trade Commission also has regulatory oversight to oversee public claims about regulated products (Allyse, et al.), however, they have generally declined to exercise their right to regulate laboratory-developed tests (Allyse, et al.). This exemption has allowed the rapid development and dissemination of physician-ordered carrier tests for diseases such as Cystic Fibrosis and Tay-Sachs disease. While this decision has resulted in public health benefits, it also meant that there have been no clear regulatory mechanisms in place to assess the analytical validity, clinical validity, and clinical utility of direct-to-consumer tests (Allyse, et al.). Consumers are left to their own devices in choosing which tests to purchase, use, and often in figuring out how to interpret their results.

**Ethical Issues**

**Harms -**

As donor-conceived persons discover this information, they are confronted with several types of harms, i.e., setbacks to self-interest, that could easily be addressed with a number of systemic and policy changes. The first set of harms relate to access to accurate information. Lack of access to information is a clear violation of the autonomy of donor-conceived persons. “Personal autonomy is, at minimum, self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice” (Beauchamp and Childress). The autonomy of donor-conceived persons is violated because, when they grow up without the knowledge about their conception or without access to their personal medical history, they are limited in their knowledge and understanding and
are therefore prevented from making meaningful choices about their own medical care and reproductive future.

I recall going to medical appointments with my primary care provider and filling out only half of my medical history form because I simply lacked the knowledge and information. Donor-conceived persons who grow up unaware of their conception might fill out forms with completely inaccurate information, including their social father’s medical history as their own. This could potentially subject them to unnecessary and inappropriate preventive care, tests, or screenings related to conditions to which they do not actually have a genetic predisposition. It could also prevent donor-conceived persons from advocating for the appropriate testing and preventive care associated with genetic conditions to which they do have a predisposition.

Related to autonomy are a set of harms referred to as “Dignitary harms.” These harms are “incurred when individuals are not treated as persons with their own values, preferences, and commitments, but rather as mere means, not deserving of respect”. Such harms occur in failures to respect personhood or in violations of justice. These types of harms might be present, for example, in research studies in which informed consent is not obtained or in genetic research that results in the discrimination against the individual participant” (National Bioethics Advisory Commission). Many donor-conceived persons, upon discovering more information about their conception, feel as though they were robbed of the ability to engage in a meaningful consent process. They did not choose their parents’ path to conception and because of guaranteed anonymity, they have not been permitted to obtain important medical history information. Rather than being treated as persons, deserving of respect within the equation, donor-conceived persons are treated as a commodity. These dignitary harms have
the potential to come into play whether or not donor-conceived persons are aware of their
cconception. They create the potential for harm, in the form of either trauma related to a non-
paternity event, or in the form of a violation of autonomy.

The next set of harms relates to the principle of Nonmaleficence, which requires that
the fertility industry “do no harm.” These are harms that arise from the trauma associated with
a non-paternity event (Resnick). This term, used by geneticists and genealogists, refers to
misattributed parentage resulting from situations such as informal adoption, kidnapping,
undisclosed step-parent adoption, paternity fraud, donor-assisted conception, non-consensual
sex, or an extramarital affair. It refers to any situation in which it’s discovered that an individual
presumed to be the parent of a particular child... is not the genetic parent” (Resnick). A non-
paternity event causes “confusion, pain, and even undue shame. All effects of trauma”
(Resnick). Many of my half siblings struggled with their family relationships after the discovery
of their genetic origins: they had to grapple with the lies they were told for decades, the
confusion about their identity and sense of self. Imagine growing up part of a vibrant Puerto
Rican family and culture, only to find out you are not Puerto Rican, but instead half Jewish. The
Italian brother I mentioned earlier can’t ask his parents, “why didn’t you tell me?” because they
have passed away. Parents felt they were protecting their children by keeping the information
from them. Were their parents doing more harm than good by keeping the information secret?
My personal belief is that parents should share this information with their kids as early as
possible, and in age-appropriate ways throughout their childhood so that they do not
remember a time they did not know. In my experience, accurate knowledge does not
invalidate the meaningful relationship a donor-conceived person can have with their social
father, and may in fact strengthen that bond because the love shared between a social father and donor-conceived child comes from a place of love and commitment rather than from a feeling of obligation due to the shared genetic connection.

The next set of harms are more theoretical in nature but are certainly possible given the lack of regulation of fertility clinics. These relate to both the principle of nonmaleficence and the principle of autonomy. Consider a case like mine: as of this writing I know that I am one of at least 39 half siblings. All of us were conceived and born in the San Francisco Bay Area and most of us were raised in that area through our childhood. While I knew from a young age that I was conceived from donor sperm, the majority of my half siblings did not grow up with that knowledge. A few were told by their parents later in life, but the vast majority found out accidentally: a relative made a back-handed comment, or they decided on a whim to take a DNA test and received surprising results. A few of my siblings went to the same high school: what if they had dated? Married? Had children? When two people of Ashkenazi descent marry, there is already a higher chance of genetic conditions being passed along but those chances increase when those two people are also half siblings.

Half siblings share approximately 25% of their DNA, which places them at higher risk of having a child with an autosomal recessive condition, such as cystic fibrosis, spinal muscular atrophy, or Tay-Sachs Disease (Tan). Without a family history of an autosomal recessive condition, there is an 8% chance of having a child diagnosed with a problem after birth (Tan). With a family history, the degree of risk would be calculated based on who the affected individual was. However, if the two individuals are not aware that they were conceived from donor sperm, they might have no reason to seek genetic counseling or testing prior to
conceiving a child. How much of a risk is acceptable? Considering autonomy, individuals should be armed with the information to make autonomous decisions and calculate the level of risk with which they are comfortable. Donor-conceived persons are prevented from making fully informed decisions about whom to marry, and with whom to procreate. Considering nonmaleficence, this lack of information can cause both physical and psychological harm to future generations if half siblings reproduce. It is in these ways that this set of harms relates both to autonomy and non-maleficence.

**Obligations -**

Unfortunately, regulations have not evolved at the same pace as the fertility industry or the technology available in regards to data availability. Formerly, ethical obligations were purely related to the interpersonal relationships that existed within the small transactions involved in sperm donation. Fertility doctors had obvious ethical obligations to their patients that arose from the doctor-patient relationship. Specifically, “the relationship between a patient and a physician is based on trust, which gives rise to physicians’ ethical responsibility to place patients’ welfare above the physician’s own self-interest or obligations to others, to use sound medical judgment on patients’ behalf, and to advocate for their patients’ welfare.” (AMA). They also had obvious ethical obligations to the donors they recruited. Donors and recipient families had obligations to one another based upon agreements they signed guaranteeing that families would not seek child support and that donors would not be permitted to contact the children conceived as a result of their donations. The children conceived through sperm donation however, were largely left out of the equation. They are
not, strictly speaking, the patient of the fertility doctor so the doctor does not have clear obligations to them. Donors signed away any responsibility to care for them. Parents do have certain ethical obligations that exist within the parent-child relationship, but parents were left to decide for themselves whether to reveal the truth of their child’s conception to them.

I reached out to the fertility doctor my parents saw around the same time I found my donor’s photo in his medical school alumni magazine in 2009. I asked if he could provide me with any additional information about my donor. He explained that my parents and the donor had signed agreements guaranteeing them both anonymity and privacy and told me he had not maintained records about which donor he used for which families. He promised me that all of the donors he engaged with were healthy and had no known genetic conditions at the time of their donations but he apologized that he could not provide me with any additional information. As an aside, in my conversations with my biological father I became aware of the fact that several conditions, including bipolar disorder, do run in the family. In fact, several of my half-siblings have themselves been diagnosed with bipolar disorder. Screening donors for genetic conditions is covered briefly below, but it is a larger issue somewhat beyond the scope of this paper. What screening tests should be required or made optional before a donor is approved to donate? Given the rapid pace of scientific discovery, should donors be required to provide ongoing information about their physical and mental health?

The fertility doctor’s practices in the 1980’s and 1990’s were common and customary. In retrospect it may seem unwise to keep half of a person’s medical history from them. It may seem unwise to advise parents to keep the truth about their child’s conception from them and lead them to believe that their social father is also their biological father, but in bioethics, we
question “whether we can validly apply current moral standards to actions [that] occurred when those standards were either not known or not widely accepted (Buchanan).” This term, known as “Retrospective Moral Judgment” requires us to think about the context in which decisions were being made and to consider those decisions in light of knowledge available at the time. In the 1980’s when I was conceived, there was no conceivable way to find my donor: the human genome had not yet been sequenced. There was still a great deal of stigma that surrounded infertility and parents desired privacy around their reproductive decision-making. With the advances we have seen in the fertility industry and in data availability, ethical obligations have evolved but we cannot judge the actions of fertility doctors from 35 years ago by today’s standards.

Now that the fertility industry has grown and direct-to-consumer genetic testing is readily available, what ethical obligations are owed to donor-conceived persons being conceived today or to those growing up in an age when anonymity can no longer be guaranteed? Who owes these obligations and from where do they arise? At a bare minimum, the fertility industry (and the regulatory bodies that govern fertility clinics) owe donor-conceived persons three basic ethical obligations: they should do what can be done to promote autonomy. They should seek to minimize harms for donor-conceived persons. Lastly, they should treat donor-conceived persons with the dignity they deserve and not as the byproduct of a transaction.
Proposed Solutions

I propose three sets of solutions that will help to mitigate these harms moving forward. The three types of solutions involve regulations of the fertility industry, regulations of direct-to-consumer genetic testing companies, and lastly training and education for mental health professionals who may encounter donor-conceived persons as they process the trauma associated with a non-paternity event.

The moral considerations discussed above, related to both autonomy and nonmaleficence generate obligations on the part of both the fertility industry and direct-to-consumer genetic testing companies since these two sets of agents are the keepers of the information that has historically been kept from donor-conceived persons. Additionally, these two industries are making a profit off a process that wrongs donor conceived persons in a medical context, so at a minimum they are obligated to avoid causing further harm. The systems should be set up in a way that allows these medical interactions to respect the principles of medical ethics discussed above—autonomy and non-maleficence. A number of systemic and policy changes could address and minimize these harms in important ways.

Fertility Industry -

First, at the level of the fertility industry, eliminating donor anonymity and creating a national sperm donor registry would provide donor-conceived persons with the information they need to make more fully informed decisions and would support their autonomy in important ways. Donor registries have been created in other countries, and could be used as a model for the United States. In Australia, the Central Register was created in 2007 with a
mission to “support information about donor-conceived people, donors of gametes, parents and siblings of children who are donor-conceived and those born through surrogacy arrangements, and to give donors and donor offspring greater opportunity to access information about each other” (The Central Register, Australia). There is certain information that must be maintained within the registry about donors and additional information that can be provided voluntarily.

Screening of donors for physical and mental health conditions must be part of any regulatory schema for the fertility industry: what conditions must donors be screened for? Could families potentially request additional screening tests prior to choosing a particular donor? Should donors be required to update information after concluding their time as a donor? These regulations would need to be informed by geneticists who could determine a set of required and optional screening tests for donors. The donor registry would also be used to limit the number of offspring who could be produced from each donor. Different limits have been proposed, and are often based on the size of the geographic region a particular clinic services. How many is too many? The upper limit would need to be informed by geneticists and statisticians.

An additional step that should be taken for all families pursuing sperm donation moving forward is to counsel them about providing their children with truthful and honest information about their conception so as to avoid non-paternity events moving forward. Families seeking donor sperm need to be made aware of the potential trauma that comes from a non-paternity event and given resources about talking to their children about their conception in age-appropriate ways. This step would promote autonomy and help minimize harms.
There are some who argue that eliminating donor anonymity would shrink the pool of willing and available donors. The fertility industry would likely oppose this proposed change as well. However, given the availability of DTC genetic tests, anonymity simply cannot be guaranteed. Nothing prevents a donor’s siblings, parents, or children from completing a test and making their own results publicly available to any donor-conceived children. Just as my own half-sister used my paternal Aunt’s information in combination with a quick internet search, there is nothing to prevent a donor-conceived person from easily discovering his or her donor’s identity.

**Direct-to-Consumer Genetic Testing Companies –**

Second, regulating direct-to-consumer genetic testing companies more closely would help to minimize harms to donor conceived persons upon receiving their results. Ensuring that consumers are informed about the potential to receive shocking information would at a minimum give them a warning that the information contained in their genetic test results might be disconcerting and unearth family secrets.

Results should be released to consumers along with a list of mental health resources, and more information about how to interpret results. Direct-to-consumer genetic testing companies should be required to provide some initial consultation by phone or text to anyone receiving information who has trouble processing or understanding their results. One of my sisters told me that she called 23andme upon receiving her results and their response was, “Talk to your parents.”
Mental Health Professionals –

Finally, providing therapists with additional training and education on supporting donor-conceived persons through the discovery and processing of a non-paternity event would give them the tools and knowledge needed to address these situations as they arise and would minimize harms.

While the experience of a non-paternity event is similar for donor-conceived persons and adoptees, there are unique aspects of this process particular to donor-conceived persons. One important difference is that most adoptions these days are “open” in the sense that adopted children usually have information about their birth parents, are told about their status as an adoptee, or can easily obtain that information from the adoption agency that facilitated their adoption. If they do not have access to this information from birth, they usually have the option to receive it upon reaching the age of majority. The Federal Government encourages families going through adoption to prioritize the maintenance of healthy family relationships with an adoptee’s biological parents (Child Welfare Information Gateway). This is in stark contrast to donor-conceived persons, whose biological origins are often kept from them.

These systemic and policy changes would help mitigate the harms described above and would promote the autonomy of donor-conceived persons in important ways.

Conclusion

While donor conception has existed for over two centuries, the process has changed in important ways. What was once a small transaction between a donor, a fertility doctor and a patient, has turned into a multi-billion dollar industry (Kowitt) in which donors are paid
thousands of dollars each to help families conceive children. Donors and parents alike are promised anonymity in order to protect parents and children from the stigma of infertility. The resulting children have suffered harms—they have been treated as a commodity, not deserving of respect and dignity. Their autonomy has been violated: they have been prevented, for decades, from receiving accurate information about their medical history, about their donors, and about any genetic relatives. And they have experienced harms from the trauma of non-paternity events.

Ethical obligations used to arise within the context of the doctor patient relationship, but now that the sperm donation process has evolved to involve more individuals and two large industries, these obligations now fall upon the large fertility industry and the companies providing direct-to-consumer genetic testing. I have proposed several systemic and policy changes that, if implemented, will help mitigate these harms moving forward both for existing donor-conceived persons and those yet to be conceived.

Donor anonymity must be eliminated and a national donor registry created to provide access to accurate medical records. Families need to be counseled prior to conceiving a child using donor sperm so that they are aware of the trauma that could come from not sharing information with their children. Regulations must be implemented to control fertility clinics and direct-to-consumer genetic testing companies. Lastly, therapists must be provided with resources and training to help donor-conceived persons process the trauma of a non-paternity event.

References


Naomi Cahn and Sonia Suter, “Sperm donation is largely unregulated, but that could soon change as lawsuits multiply,” The Conversation, January 18, 2022.


