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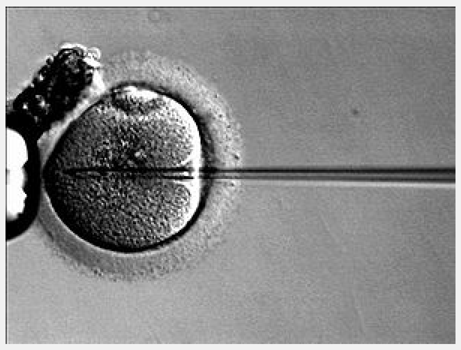
Balancing the Rights of Donor Offspring With Those of Donors: But What About Parents?



Intracytoplasmic sperm injection

Technologies, including assisted reproductive technologies, continue to race ahead—way ahead—of society's ability to develop meaningful social practices that allow us to adapt and comfortably use the new options provided. We just don't yet know how to be with all the new tools we're creating, and given how fast we're developing new options we just may have to get used to living in an ever growing adaptive gap.

Nevertheless, as of July, Washington State will be implementing a new law designed to balance the needs and rights of gamete donors (i.e., sperm and egg donors) with those of the offspring conceived with the aid of those donations. And when only donors and donor conceived offspring are considered the new law does a pretty good job.

But does this law care for all those who have an emotional stake in technology-assisted reproduction? Are the complexities of technologically-assisted families respected? Are important players and processes getting ignored?

BioNews— published by the London based Progress Educational Trust with a mission to provide "accurate, balanced and timely news and comment on genetics, assisted conception, embryo/stem cell research and related areas"—has an article in the June 27th 2011 issue by two leading advocates for "donor offspring rights." The article tries to celebrate the new law as a "first step towards what we hope will be a new attitude of openness." However, closer inspection shows the law failing to serve the actual needs and rights of all those involved:

> “ The fertility industry in the US state of Washington will be transformed in late July 2011, when a new law to recognise rights of donor-conceived people comes into effect. Under the changes, anyone who provides gametes to a fertility clinic in the state must also provide

> identifying information about themselves and their medical history .
>
> While most fertility clinics already collect this information, and make medical information available to the people who use it, the law will allow donor-conceived children, once they reach 18 years old, to contact the clinic that provided the gametes to request identifying information about their donor and their donor's medical history. The law states, however, that the donor can veto disclosure to prevent the clinic from revealing his or her identifying information – but the donor offspring will still be entitled to their anonymised medical history.
>
> Washington is the first US state to take such a step. Elsewhere in the US, not only can fertility clinics destroy records before the child turns 18, but also donor-conceived people are not entitled to any information held about their donor

via BioNews – The birth of donor offspring rights in the USA?.

So, who are the missing players whose needs are being ignored? Parents. The actual men and women who built their families using donor gametes and then their spend their lives raising their children have been taken out of the equation.

On the one side, donors who donate have a right to move on with their lives. On the other, donor-conceived offspring have a right for access to medical and perhaps personal information about those donors. But legally requiring fertility clinics to disclose to donors at age 18, at minimum, anonymized medical information and actual identifying information unless the donor opts-out ignores both how fertility treatments are provided in the US and the fact that parents are routinely given all that information during the donor selection process. The child's parents—the actual parents who actually raised the child—typically have the anonymized medical information, along with additional information about the donor such as likes and dislikes, reasons for donating, education history and other information included in a prospective donor profile.

Currently, fertility treatment practices in the U.S. are largely self-regulated. This law is an early salvo in an activist effort to change that by enshrining evolving guidelines into hard-to-change law. As things currently work, The American Society for Reproductive Medicine (ASRM) provides guidelines. Disclosing information about the medical history and identity of a donor has two parts. The first is disclosing to a child ***that*** he/she has been conceived with donor gametes (recognizing, of course, that there are lots of different kinds of families—heterosexual, and of different ages; single-sex; single parent—and each is a different context for disclosure) and the second is information about the donor.

Here are the current ASRM guidelines from *FERTILITY AND STERILITY* VOL. 81, NO. 3, MARCH 2004:

> “ 1. While ultimately the choice of recipient parents, disclosure to offspring of the use of donor gametes is encouraged.
> 2. Parties should agree in advance on how and when ART programs and sperm banks will release donor information to the recipients
> 3. Programs and sperm banks should gather and store medical and genetic information concerning donors.
> 4. Counseling and informed consent about disclosure are essential for the donor and recipients.
> 5. Programs and sperm banks should expect inquiries from donor offspring and consider developing a written policy to respond to these inquiries.
>
> via http://www.asrm.org/uploadedFiles/ASRM_Content/News_and_Publications/Ethics_Committee_Reports_and_Statements/informing_offspring_donation.pdf

What Washington State has enshrined into law is a very questionable analogy to open adoption: just as adopted children are increasingly granted the right to access information about their birth parent or parents so too should donor offspring have the right to identifying information about the donor. However, granting gamete donors the same status as birth parents in an adoption just because there is a comparable contribution of genetic material raises many questions. The authors of the BioNews article reveal this analogy in many ways but no where near as clearly as when they refer to donors as biological parents: "(f)or many donor-conceived people, learning about their biological parent(s)." Many people are unwilling to make the leap from gamete donation to status as biological parent.

I contacted Dr. Allison Rosen, a clinical psychologist specializing in reproductive medicine (with affiliations at New York Medical College, Institute for Fertility Preservation , New Hope Fertility Center, and the William Alanson White Institute). She was very clear stating her opinion about the questionable analogy: "A sperm donor is not a biological parent; the analogy to adoption is incorrect and fuzzy. A person masturbating into a vial is not a parent, nor is a young woman who donates her eggs to help pay for her college tuition."

Furthermore, she stated, "The limiting factor for donor conceived children is not due to the medical establishment keeping vital information from children. Rather, their parents do. Parents of donor conceived children need to be informed how to tell their children about their origins and given resources to help them."

Finally, when I asked her how a law like this might change her practice if it were to be enacted in NY or NJ where she practices, she said,

> The ASRM guidelines suggest a pretreatment counseling session to help individuals make informed choices about when and how to discuss donor origins with their child/ren. The law would make no difference in my practice since I'm already helping couples discuss these issues with their children. I help them overcome their fears that their children will not love them as much or their concerns that their children will feel a loss or feel stigmatized if they know that one parent is not genetically related. I help them find the right time for them to talk to their children and discuss the implications of children's cognitive understanding at different developmental ages. Parents want to do what they believe is in the best interest of their child. Donors' needs and the needs of their children must also be protected. Only they can know what is best for them.

In other words, if a family has already disclosed the fact of gamete donation then the parents can also choose to disclose the content of the donor profile when it is in the best interests of their child to do so. This eventuality would make this new law unnecessary. And if the parents, for whatever reason, have not disclosed the fact of gamete donation, then this new law will have no effect since the now grown child will not have any reason to seek out the information. The only time this law will have any effect are those rare instances when a grown child knows he/she has been born via gamete donation and is unable to access the donor profile information originally given to his/her parents. This is hardly transformative legislation, although it is, in my opinion, another example of legislation trying to dictate how and when families make intimate decisions.

The bottom line is that disclosure should remain a family choice and not become a government-mandated regulation. The professional community should work to make sure families have the information and support they need to make the best decisions they can make. But law is a blunt instrument for solving problems of having more technology than social practices guiding its use.

This article is available online at:
http://www.forbes.com/sites/toddessig/2011/06/30/balancing-the-rights-of-donor-offspring-with-those-of-donors-but-what-about-parents/