

## FROM THE PAGE TO THE PILL: WOMEN'S REPRODUCTIVE RIGHTS AND THE LAW\*

*Panel 2—Reproductive Healthcare  
Legislation: Where We've Been  
and Where We're Going*

### REMARKS OF JUDITH DAAR\*\*

I'm going to be talking about an area of law and medicine that I've had a real privilege to speak about and teach about for decades. In the decades that I've been teaching about reproductive technologies and bio-ethics in general, I've developed a bit of a mantra - the more we learn, the less we understand. Certainly that is true in the area of reproductive technologies and the law. Over the last twenty to thirty years, we've learned a great deal about human embryonic development. We can manipulate eggs and sperm in a way that would have been unheard of many years ago. We can watch the human as it develops from those commutic portions to where we stand today. But I would suggest to you that we still don't understand human nature. We have deciphered the human genome, but we still don't understand women. And that really is the way that this

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\* On October 11, 2012, the Albany Law Journal of Science and Technology presented a symposium on women's reproductive rights and the law. These remarks have been annotated and edited by the Journal staff. The webcast of the event is available at <http://www.totalwebcasting.com/view/?id=albanylaw>.

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field goes. I can talk to you about the science, but I'd like to hear from you about the way the science integrates into the way that we live our lives and how we think about life in general.

Even though this area is quite modern, and the technology is quite advanced, the legal story surrounding reproductive technology actually begins at the height of World War II with a case that students who have taken constitutional law are very familiar with, the case of *Skinner v. Oklahoma*.<sup>1</sup> Just like so many Supreme Court cases, the acts that led up to the case were seemingly insignificant in and of themselves but they've led to a significant piece of jurisprudence in my field. This case revolved around a man, Mr. Skinner, who had some trouble during the depression and was twice convicted of committing theft. The third time that he committed armed robbery and was arrested, he was prosecuted under a law known as the Oklahoma Habitual Sterilization Act. Under this law, the punishment for this armed robbery was a vasectomy, which was actually an improvement over the previous punishment of castration. To give you some context, this Oklahoma law was part of what is now referred to as the American Eugenics movement, a period that began in the early 1900's and lasted until this case was decided in which a combination of law and policy came together to orchestrate a way in which people reproduce, to encourage the right people to reproduce and to discourage the wrong people from doing so. This of course was supported by a very nascent but growing interest in genetics, and the genetic connection between crime, for example, and heredity. The thinking in Oklahoma was somebody who committed crimes of moral turpitude more than two times was better off not reproducing because they would only produce their own kind - criminals. Therefore, forced sterilization was considered to be the best way to stop criminal activity in the future.

The interesting part about *Skinner* is that it remains today the only time the United States Supreme Court has ever talked about the affirmative right to reproduce. Yes, the Court has talked extensively about the right to avoid procreation through the use of contraception, but in *Skinner* the Court commented on the affirmative right to reproduce. What you see from Justice Douglas is that the right to reproduce is what he calls one of the

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<sup>1</sup> 316 U.S. 535 (1942).

basic civil rights of man, he calls it a basic liberty.<sup>2</sup> The word liberty for us is very important today, it tweaks certain interest that we know exist under our constitutional jurisprudence. For me, studying this area of the law, I try to put together a constitutional analysis with emerging technologies. I have to contextualize *Skinner v. Oklahoma*, because Justice Douglas had only one world view about the way reproduction occurred - it was one man, one woman, and so on. So for scholars today, that question is how would Justice Douglas feel about the right to reproduce in a given scenario?

Then we have my friend Nadya Suleman. Who you might know as the Octomom. An out-of-work single mother of six who visited her reproductive endocrinologist in Beverly Hills, and insisted that he implant twelve embryos that she had produced from an in vitro fertilization cycle. She gave birth to the octuplets and is now the mother of 14. We might say, does she have the right to do that? Should the law step in to say that that's an unreasonable thing to do? The miracle of Octomom is that the kids are generally healthy. The morbidity and mortality associated with multiple births, even triplets and certainly high-order multiples like octuplets, is extraordinary.

What about a woman, talking to her doctor asking, are you sure it's mine? These days, the answer is that you can't be sure. You can be a gestational carrier who accepts \$25,000 to gestate an embryo from a donor egg and donor sperm. In that case, the gestational carrier is going to give birth to a child and turn it over without any legal rights whatsoever. In many states, that child is not the carrier's and they are not the mother. How would Justice Douglas feel about that? What about laws that might prohibit individuals from engaging in these kinds of commercial transactions?

What about Thomas Beatie, a transgender legal male in the state of Oregon? He and his wife, actually now ex-wife, have three children. At the time, when he appeared on Oprah - that was a mistake, let me tell you - there were quite a lot of questions about whether the father, the intended father, could be the biologic mother. Is this too confusing for the child? Is this in the best interest of the child? Should the law prevent the Thomas Beaties of the world from reproducing in this way, possibly because of harm that it might do to their children?

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<sup>2</sup> *Id.* at 541.

What about the right to select the sex of your child? We have technologies that permit that in a very robust way. We can detect the sex of a child at seven weeks gestation. The pink or blue or the other tests aren't quite as accurate as some of the blood tests and the genetic tests that we have. We can even detect the sex of the child before the embryo is implanted.

Moving on in time a little to 1978, I now want to talk about Louise Brown, the first human being to have been conceived and born using in vitro fertilization. The way that in vitro fertilization works is that the gametes, the egg and the sperm, are retrieved from either the intended parents or donors, and they are placed together in the so-called test tube. It's not really a test tube, it is a laboratory specimen in which the culture medium promotes the fertilization and growth of the embryo, but the word test tube baby has certainly emerged. On day one, we have the pre-fertilization when the sperm first approaches the egg. On day two, the cells begin to divide. On day three, there is a between four and eight cell embryo. During the in vitro cycle, once these embryos are formed, typically the embryos are transferred back to the woman's uterus, either the gestational carrier or the intended mother. That's the basic procedure of in vitro fertilization.

Based on Center for Disease Control (CDC) data from 2010, there were over 61,000 babies born in the United States using in vitro fertilization.<sup>3</sup> The number for artificial insemination by donor is much less precise, but we think based on more anecdotal and some statistical evidence that roughly the same number of children are born through sperm donation, whether the donation is from a known donor or any anonymous donor through a commercial sperm bank. You add those numbers together and assisted conception accounts for about 2.7% of all births in the U.S. That means roughly three of every 100 children born today meet their earliest moments with medical assistance. That's an extraordinary number, far surpassing the number of kids that are adopted at the neonatal stage. Clearly, this has become part of our culture.

Now to discuss the particular technology that we're talking about. When IVF was first introduced in the late 1970's, in this country in 1981, it was not very successful and most of the cycles

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<sup>3</sup> Center for Disease Control, Data and Statistics, [http://www.cdc.gov/reproductivehealth/data\\_stats/](http://www.cdc.gov/reproductivehealth/data_stats/) (last updated Apr. 11, 2013).

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failed. The success rates were about in the teens, and we really didn't know why. The doctors tried to base the selection of embryos back to the uterus was based mostly on morphology, or the way in which the embryos appeared. Did the cells appear to be even, the embryologist would look at the edges, and so on. That again didn't prove to be very effective, but then there was a breakthrough in the early 1990's with a technology known as pre-implantation genetic diagnosis or PGD. The goal behind PGD was to be able to understand the genetic makeup of the embryo, not just the morphologic makeup, and to make decisions about whether embryos should be transferred or should be discarded based on that information. Like IVF, PGD was developed in the UK because of some of the laws that we have in this country that didn't promote research on embryos. The way that the technique works is that they take a biopsy of three-day-old embryo, meaning that they take out one of the cells and look at its genetic makeup. The reason this is helpful is because at this point in embryonic development, cells are what is known as totipotent or all-potential. They all are exactly the same, they all have the potential to become a fully-formed human being. We don't start to differentiate until about day five. So if you take out one of an eight-cell embryo, you're taking out essentially the genome of the whole person.

So what can we do with this information? We could use PGD for medical selection, meaning if we detect that an embryo has a medical anomaly that would cause great pain or disability, parents can decide not to transfer that embryo back to the uterus and to discard it. We can use PGD for sex selection. A little more futuristic though much discussed in the academic literature is trait selection. This is the ability to know whether an embryo is going to have blue eyes, blonde hair, athletic, musicality and so on.

What about selecting embryos for medical reasons? There are several reasons why people who use PGD in order to select embryos for medical purposes. One is just for the sake of the embryos' health, to promote the health and safety of the embryo and ultimately the child that is formed from that embryo. PGD can detect a number of genetic anomalies, including Down's Syndrome, Tay-Sachs, cystic fibrosis, sickle cell, and so on. Many of these are lethal anomalies that would cause the child to suffer great pain and have a very short lifespan. Some of them are not lethal and in fact the child can live pretty much a normal

lifespan. These are just examples of some of the genetic anomalies that PGD can detect.

The interesting ethical debates focus not just on lethal anomalies, or anomalies that present at birth, but so-called susceptibility features. For example, we know from our heredity that we can be susceptible to certain cancers. The ethical question is whether it's appropriate to discard an embryo because it might someday develop breast cancer in the fourth or fifth decade of life. Another ethical issue is about using PGD to create what's known as a 'savior sibling'. There are some childhood cancers that can only be treated by compatible stem cell therapy. So, parents will use PGD to create an embryo and give birth to a child that can be a stem cell donor for their other ailing child. This of course tests the so-called content and means categorical parentive – that it's never appropriate to use a human being as the means to an end. I know that parents who have used PGD in a savior sibling scenario abjectly reject application of that parentive. For example, Lisa and Jack Nash were the first American couple to use PGD for their daughter Molly. They created their son Adam to be a donor because Molly was dying of Fanconi's anemia. Today Molly is 17 years old and doing fine, and Lisa and Jack talk very passionately about how much they love Adam and they would have had a second child anyway, and how meaningful his contribution to their family has been. If Molly had died, would they feel differently about their son? It's hard to know. A final example of an ethical dilemma that is faced, rarely but nevertheless it happens, is where parents that have certain genetic anomalies want to birth children with similar anomalies. This has been seen in two medical scenarios, one of which is achondroplasia, or dwarfism. Another is deafness, because certain forms of deafness are hereditary and can be detected through PGD. Is it appropriate for parents to select what normally we would consider a disability? Is it appropriate for physicians to instruct patients on how this could be done and of course to assist them? Many topics abound in this area, including inherent medical law to disability, particularly in the case of deafness, with what the deaf community expresses as a social model, where deafness is a culture, not a disability.

There are many reasons when some individuals might object to the use of PGD for medical selection. One argument is that it is morally wrong to create embryos knowing that they're going to be destroyed. This argument is made because during PGD selection

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happens concomitant with deselection. Therefore every intended parent who goes through a PGD cycle, I think implicitly understands that the purpose is for selecting and deselection based on the preference of the parents have expressed. There are also some more nuanced arguments about orphaning certain diseases. For example, if we were to use PGD to eliminate Down's Syndrome, then it's going to be the case that not everyone can access PGD because it is expensive and not covered by insurance. So you are going to have this sort of binary approach where people who are wealthier and can afford PGD will not have kids with these disabilities but people who cannot afford PGD are going to have children who do have these genetic anomalies. There is also the whole eugenics concern that flows from making selections based on what some would consider benign traits.

Another interesting part of PGD is the idea of selection based on sex. There are non-medical reasons for sex selection such as gender balance. Parents might have two girls and they want a boy and so on. Some might want a girl first or a boy first. There are also some culturally preferred genders. You see that a lot in Asian and Middle Eastern populations. Even if the United States they use PGD disproportionately to select males. Another reason for sex selection is to produce an anticipated rearing experience. For example, you think you have the girl, it's going to go a certain way. What are the concerns about the use of PGD for sex selection? Data gathered internationally shows that natural selection produces more males than females. However if you then look at some countries in regions that I have mentioned, there is a disparity between the number of males and females born. For example some of the villages in China have ratios of almost 130 males to 100 females, not through PGD but through selective abortion and infanticide. So the concern is that with the access to PGD technology in the U.S., this disparity will could begin to expand outside of these select regions. Again, the data so far suggests that overall in the U.S. the use of PGD is fairly gender-neutral, but when you start to delve into the sub-populations, southeast Asia, the middle east, they do tend to have preferences for males. You might ask, what's wrong with sex selection? Why should we be concerned? One argument is that sex selection is itself sex discrimination. As law students know, selecting on the basis of a preferred sex is per se discrimination. There are arguments that sex selection can be harmful to offspring. The

psychological literature is concerned that if you birth a child because you want a particular gender, then you are going to impart psychological burden on your children of fulfilling that expectation. So if parents have a boy and then their lifestyle turn isn't so manly and he doesn't have the typical male patterns, are the parents going to say to him, I paid for you to be a boy, now be a boy. Is the idea of spending money going to impact parenting that the kids can expect?

To bring this discussion back to the law, there is no law on PGD. In general, an analysis of a law regarding reproduction depends on your perspective. If the law is about reproductive autonomy, you might have a certain Constitutional calculus. If the law is about parental autonomy, you might have an entirely different calculus. If it's about access to experimental treatment, again, you may look at it another way.

And finally, a common critique of PGD is that it is a way for parents to be diabolical narcissists, and to make up for their own imperfections in their lives. And I say so what? If you think about parenting in that way, is that really any different than the way people parent without the technology? We still want the best and to maximize the well-being of our children. If we do it in this matter, is it really any different than the way we do it during their lives? I'll just end by saying that I spend a lot of my professional time talking about assisted conception and technology, and I don't pay enough attention or give enough credit to the old-fashioned method. So, in a tribute, my husband and I tried 70 times to get pregnant, and that was one hell of a weekend.