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Birth Rights & Wrongs: How Medicine & Technology Are Remaking Reproduction & the Law

Dr. Pickard:

Medical and legal literature, newspapers and social media are constantly calling society's attention to reproductive negligence. These errors occur in three major areas: Deprived pregnancy or parenthood, imposed pregnancy, and in confounded efforts, which are failed attempts to prevent a disease in a progeny, again due to negligence. We are only just beginning to deal with these controversies. I'm your host, Dr. Maurice Pickard, and you're listening to Book Club on Reach MD, and with me today is Dov Fox, Professor of Law at the University of San Diego School of Law, where he directs the Center for Health Law Policy and Bioethics. He is also the recent author of "Birth Rights and Wrongs: How Medicine and Technology are Remaking Reproduction and the Law." Thank you, Dr. Fox, for joining us today.

Dr. Fox:

Thanks for having me.

Dr. Pickard:

To begin with, what drew you to this area of law and medicine?

Dr. Fox:

I came of age in revolutionary era of reproductive advances. You know, headlines – I remember long-lasting, reversible birth control growing up. More recently, screening for a range of disorders early in pregnancy. Nothing more than a simple blood test. I remember finding out when I was a bit older that I had actually been born just a couple days before Elizabeth Carr, who was the first American baby conceived by in vitro fertilization, and I was just fascinated by the new questions that these advances posed for the meaning of family and life itself.

Dr. Pickard:

In my introduction, I mentioned three areas which you go into great detail. For our listeners, could you please frame what procreation deprived means?

Dr. Fox:

Sure. When people want to have children but need assistance to do so, wrongdoing by professionals can keep them from either getting pregnant or becoming parents in the way that they sought out. Whether it frustrates their reproductive capacities or the reproductive materials that they have created or stored for the purpose of reproduction. Courts have a really hard time dealing with these cases, whether embryos are implanted into somebody else, or cases of mass destruction when a freezer that is storing people's sperm or egg malfunctions and leaves them beyond rescue or repair. You know, courts say that these patients were never promised a baby to take home, and that however devastating their loss, they can't point to the kinds of physical or economic harm that the law typically requires to close off the floodgate of litigation. And judges also say that victims can still adopt. And it's not like the error left them any more childless than they were before, given the infertility that they already had. For people who wanted to reproduce and go to great lengths to do so, being denied that chance is a very real and substantial injury, one that I argue courts ought to remedy.

Dr. Pickard:

You know that in your book it's interesting that as a physician I've always been touched by the tremendous emotions that patients experience, especially the stress of not being able to have a child. But really, in your book, there's really no market value for loss, and in your book you mention the only time that emotional stress or free-standing emotional stress is recognized by the court is a misdiagnosis, and you're told that you have a fatal disease and you don't have one, informing a family that a relative has died and the

relative hasn't, and the mishandling of corpses. So, those three are the only exceptions and yet, when you discard an embryo by mistake or you discard frozen sperm by mistake, there is no market value for this. Why hasn't the court begun to recognize this?

Dr. Fox:

There are two reasons why courts are slow to remedy purely emotional or other forms of intangible loss. One is an evidentiary reason having to do with the proof required to show that the harm is real rather than exaggerated or falsified. A monetary harm, you can show receipts or prove damages in that way. Physical harm, you can provide an x-ray or a doctor's note that speaks to the bleeding or the broken bone, but dignitary or emotional or other forms of intangible harm to the very important and serious life plans you may have made or relationships you've formed are harder to prove in that sense, which isn't to say they are less real or less meaningful. In fact, many times they are far more so in their repercussions for people's lives, but the proof is trickier. The second reason is the floodgate of litigation that courts worry would be opened were nontangible forms of harm more readily remedied, and that's connected to the questions of proof. The concern goes, well if anyone can just say that they have been harmed in these ways without putting forms – without having the stronger forms of evidence, then the courts will be inundated. They will not be able to distinguish worthy or meritorious from unworthy or less worthy cases, and they will be unable to perform their core function of righting wrongs and society providing redress to those in need and deterring misconduct from perspective wrongdoers. I think there is a lingering reason in the background, which is neither of those two principle justifications, which is just an outdated notion that emotional injuries are not real or are not to be taken as seriously. That individuals ought to just steel themselves against these consequences. Buck up, as it were, and that they are not worthy of the same kind of redress, and that, I think, is the product of a bygone era, certainly a way of thinking worth correcting in the law.

Dr. Pickard:

Surveys of Americans rate not having a child on the same level as a divorce or a diagnosis of a terminal illness. But moving on, what is procreation imposed? And why is wrongful birth such a poor label?

Dr. Fox:

Procreation imposed is when people had set out precisely not to have a child – used birth control or voluntary sterilization, had their tubes tied or a vasectomy, used long-term contraception or other measures in order to avoid having a child for the reason that they were not in a position to do so. They didn't have a reproductive partner or the kinds of financial or social support necessary, or their current life plan would not leave them in a position to support a child at that time or maybe ever, and a negligence on the part of those who helped them in that effort – provide birth control or sterilization. When that fails, a child or a pregnancy can be imposed. Wrongful birth is a poor label which is the, often times, characterization by courts of these cases when people are left in a position to bring suit because the parents are not suing for a wrongful birth, exactly, and the term itself is pejorative. It suggests that the child or the child's birth was, itself, wrong, when the fact is that the parents now have a child who they deeply love and have come to value and cherish in the course of their lives. These courts sometimes condition the ability of victims to pursue a remedy on their willingness to – they would have aborted the child or should have put the child up for adoption and prove that they would have. But that prerequisite only exacerbates the reproductive injury they have suffered when they were denied the chance to avoid having a child. Other courts express a deeper concern that even if parents didn't plan on having a baby, well, once he or she is born, you hold him in your arms and hear him coo, how could you not appreciate him as a gift that's a blessing? One that makes their life only better and not worse. This objection purports the sound and the sweet register of parental love, but if you listen closer, you'll hear just mother shaming. Standing up for your own reproductive interest in these cases of procreation imposed, doesn't mean that you love your child any less. It doesn't mean that you regard his birth as wrongful. And loving your child unconditionally doesn't mean that you weren't injured in a real and potentially substantial way when procreation was imposed.

Dr. Pickard:

I understand. Thank you. And then the last – procreation confounded. These are parents who do want a child and do many things to avoid that child having a disease, and yet the child is born with a disease. Could you explain this and how the court reacts to this?

Dr. Fox:

Judges fear sending an intolerable message if they were to provide a remedy to parents who got a different sort of child than the one that they had set out to select – one who is not free of a disease they screened against because they were at higher risk of passing it along or one who was not genetically related to them in the way they had wanted. Judges worry that they will send a message that parents wish their own child had never been born in the first place, or that people with the condition that they – the parents – had targeted are too defective in their very DNA to justify their existence. Now, after all why, courts say, parents had sought to have a child not like that in the first place, and accordingly, courts conclude that they simply will not say that life will – could ever amount to a legal injury. And they forbid these claims as no less than eugenic. But these parents, they're not trying to eliminate people with disabilities. They are making heart-rending decisions in a society that's often inhospitable to vulnerability and difference about whether their family

has the wherewithal to care for a child with particular needs. Courts that are willing even to entertain these grievances, as you mentioned, usually under the pejorative of wrongful birth, usually insist the damages would, at any rate, be too speculative to award. That it's impossible to predict how this baby's life will turn out as compared with a baby with different characteristics, or how his arrival would end up impacting his parents. That's true enough, but just because we can't calculate the harm of confounded procreation with precision, it doesn't make it any less real or harmful, and in many other areas of the law with other sorts of intangible or unpredictable injuries, courts are in regular practice of ballparking awards based on best available estimates or, indeed, speculation. They say better to provide what guesswork you can to right a serious wrong than to throw up your hands, leave that wrong unredressed, and provide no remedy at all.

Dr. Pickard:

This whole area of reproductive technology doesn't seem to have the same regulations that other areas in medicine have as far as the FDA or other regulatory bodies. It appears to be a free market where most of the funds are outside the provinces or taxes. Does this have something to do why it's not well regulated, why we're seeing these kinds of things, and also, why we don't have a reliable way to track negligence?

Dr. Fox:

Absolutely. The provision of federal money in the course of medical research is what authorizes agencies like the National Institutes of Health and the US Department of Health and Human Services to enforce clinical safety measures and require the reporting of errors and accidents. But, in this subspecialty of assisted reproduction, anxiety about complicity in the destruction of human embryos led Congress in the 80s and 90s to call off administrative watchdogs. And, as a result, fertility medicine grew into a private, consumer-driven, multibillion dollar practice that is oriented more around the market than it is medical research notwithstanding the terrific medical expertise required to practice in this area, and medical and scientific equipment and training that it draws on. And so, it has developed relatively unimpeded by government oversight and the private seer of for-profit clinics that function surprisingly more like trade businesses than medical practices, and this multibillion dollar industry, in turn, sustains powerful lobbying forces that have, from time to time, blocked what efforts there were to reign in its operations by requiring things that other countries do in this area, and we do not, like strict licensure to operate fertility clinics and labs, or tougher inspection of them, or robust record keeping standards, including of egg and sperm donation, let alone the tracking and reporting you mentioned of adverse events or catastrophes like the fertility freezer failures to large medical centers last year that destroyed thousands of eggs and embryos and, with it, the hopes and dreams of many, many individuals and couples that they had for biological parenthood.

Dr. Pickard:

Hearing all of these conflicts and the heartaches that it's causing, what can the courts and the medical profession do to confront, with compassion, these controversies that you and I have been discussing?

Dr. Fox:

It's been over 100 years since the courts named a new cause of action to remedy wrongs that our legal system was not adequately addressing. That was back when we had no right to privacy against invasions, incursions, personal space, and a private sphere of intimacy beyond the scope of prying cameras or infiltrating listeners, and the time has come to recognize new actions for procreation deprived, procreation imposed, and procreation confounded. These aren't harmless errors; they are wrongs in need of rights, and where our lawmakers do not regulate in a way that prevents these mistakes from happening in the first place and our courts have no legal resources available to them to remedy them after they happen, then we need new tools. And courts have that power, that common law power to create new rights, like the right to privacy. They should do that today to remedy these problems of reproductive negligence.

Dr. Pickard:

Well, thank you very much for joining us today. I appreciate it and I encourage our listeners to get the book, *Birth Rights and Wrongs*, by Professor Dov Fox. Thank you very much.

Dr. Fox:

Wonderful to speak with you, Dr. Pickard. Thank you so much.

Dr. Pickard:

This is Dr. Maurice Pickard, and if you've missed any of this discussion, please visit reachmd.com/bookclub to download this podcast and many others in this series. Thank you for listening.