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The Case for a Parental Duty to Use Preimplantation Genetic Diagnosis for Medical Benefit

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Preimplantation genetic diagnosis (PGD) is a reproductive genetic technology that enables potential parents to learn the genetic makeup of their early embryos and thereby avoid having a child affected by a particular disease or disorder. Embryos are created using in vitro fertilization (IVF) and each is then tested for certain genetic mutations or chromosomal abnormalities that are known to be associated with the disease in question. In a typical PGD cycle, only those embryos that do not carry the disease-causing mutation or abnormality are selected to be transferred into a woman’s uterus and given the opportunity to develop. As genetic research progresses, the number of genetic conditions that can be prevented through the use of PGD is increasing, making this technology an ever-more powerful tool to improve the health of future generations.

This article explores the possibility that there is a parental duty to use PGD for the medical benefit of future children. We find that such a duty can be supported on ethical and legal grounds. Using one genetic disorder as a paradigmatic example, we develop a multifaceted case to support the claim that such a duty does, in fact, exist under some circumstances. The duty is strongest when prospective parents make an independent decision to reproduce using IVF and know they are at significant risk for birthing a child with a serious genetic disorder. We recognize that PGD can detect a range of anomalies and traits, many of which pose little or no risk to life or health. It is not our goal herein to weigh the merits of extending the duty to use PGD to those clinical scenarios, but rather to support recognition of the duty under the limited circumstances delineated in this article.

A PARADIGM CASE

Autosomal recessive polycystic kidney disease (ARPKD) is caused by mutations in the PKHD1 gene, located on chromosome 6, that cause the development of cysts in the kidney and liver. The disease follows recessive inheritance patterns, meaning that if each parent carries an unexpressed mutated gene, any offspring the couple may conceive has a 25% chance of being affected by the disease, a 50% chance of being an unaffected carrier, and a 25% chance of being neither. Because the genes that cause ARPKD are relatively rare (Zerres et al. 1998), individuals most often discover that they are carriers when they have a child with the disease. The disease takes somewhat different forms depending on the mutations present in the PKHD1 gene and there is a range of the severity of its symptoms (Gunay-Aygun 2010). Many infants born with ARPKD die within 1 year as a result of problems with their respiratory development (recent estimates range from 13 to 50%). In those cases, the fetus’ impaired renal function produces low levels of amniotic fluid, negatively impacting lung development (Bergmann 2005; Capisonda 2003; Roy 1997). Those who survive the first year of life are likely to experience enlarged kidneys, compromised renal function, hypertension, urinary-tract infections, growth failure, and end-stage renal disease (Guyen-Woodford and Desmond 2003). Individuals with ARPKD also have chronic hepatic fibrosis (CHF), which interferes with liver function. The severity of CHF-related symptoms varies significantly among patients. There is no cure for ARPKD, but its symptoms can often be managed with medication, dialysis, surgical intervention, kidney transplant, or liver transplant.
Advances in medical technology have improved outcomes for patients with ARPKD. One study found a 10-year survival rate of 82% for affected individuals who survived the neonatal period (Bergmann 2005). Children with ARPKD are often on antihypertensive medication and may require dialysis to compensate for renal insufficiency. Most have end-stage renal disease requiring transplant by the time they are adolescents. Those with milder forms of the disease can survive into early adulthood, but CHF-related symptoms are likely to become severe in this population, requiring shunt placement and eventually liver transplant (Capisonda 2003; Roy 1997).

Gigarel and colleagues have reported using preimplantation genetic diagnosis (PGD) to identify embryos with two copies of the mutated PKHD1 gene for couples who have a child affected by ARPKD. Embryos were created using in vitro fertilization and genetic testing was performed to determine each embryo’s ARPKD status. Only those embryos without two copies of the mutated gene were made available for transfer (Gigarel et al. 2008). It is therefore possible for couples who know that they are at risk of having another child affected by ARPKD to dramatically decrease their odds of birthing a similarly affected child.

There are certain key characteristics of ARPKD that make it an appropriate paradigm case. First, ARPKD is a serious medical condition that causes significant morbidity and mortality. Second, the probability that a future child will be affected by the disease is not trivial. There is a 25% chance that any future child conceived by two ARPKD carriers will be affected by the disease. Finally, couples who have had a child with the disease are likely to know about the risk of passing the disease-causing genes on to their future children. The analyses offered in this article are applicable to other diseases with similar features. It is also worth noting that an even stronger case for a parental duty to use PGD can be made for genetic diseases that are more serious, more likely to be transmitted, and more foreseeable than ARPKD. We acknowledge that there is vagueness inherent in descriptors such as “serious” and “likely to be transmitted” but hope that the reader will find the use of a paradigm case helpful in understanding our intent.

THE ETHICAL CASE

There is a substantial body of literature on the ethics of the use of PGD. Many authors take a morally neutral stance on the use of this technology for the medical benefit of a future child, holding that the use of PGD to prevent disability is ethically acceptable but not required. Such authors emphasize parental autonomy in their moral analyses (e.g., Harris 1998; Robertson 1994; 2005). Other scholars, grounded in a disability rights perspective, have argued against the use of PGD to prevent disabling conditions because of the negative impact that such choices may have on those who live with disability (e.g., Asch 2000; Parens and Asch 2000). Still others have claimed that such choices reflect a lack of humility with respect to our ability to control the world around us and a failure to appreciate the giftedness of life (Sandel 2007). These arguments against the use of PGD for medical benefit have kept the ethical debate about this technology alive and well.

With a few notable exceptions, authors have refrained from taking a strong positive stand on the use of PGD to prevent disability. That is, while many scholars hold that the use of PGD is morally permissible, most have not gone so far as to claim that it can be morally required. In contrast, Julian Savulescu and Guy Kahane have argued for a principle of procreative beneficence, holding that potential parents “have a significant moral reason to select the child, of the possible children they could have, whose life can be expected . . . to go best or at least not worse than any of the others” (2009, 274). As its name suggests, this principle focuses on the well-being of future children and takes a consequentialist perspective on reproductive choices. John Harris has also taken a strong positive position on the use of genetic technologies to “create healthier, longer-lived, and altogether ‘better’ individuals” (2007, 9). His argument is grounded on the premise that genetic technologies are no different than other methods used to promote people’s interests, and so, like Savulescu and Kahane’s, builds on an ultimately consequentialist foundation. Our ethical arguments explore the positive position more comprehensively, considering whether there are sound arguments from fairness and autonomy as well as from outcomes to support the idea that some parents have a duty to use PGD when conceiving children.

It is worth emphasizing that our goal is not to prove that objections to the use of PGD for medical benefit are unfounded or that the parental duty to use this technology outweighs all other ethical considerations in any reproductive situation. Instead, we aim to lay out the best case possible in favor of this position so that it can be accurately balanced against ethical concerns that are well articulated in the existing literature.

There are at least three distinct ethical arguments that can be made in support of the claim that potential parents have an ethical duty to use PGD to prevent genetic conditions such as ARPKD. First, using PGD for this purpose can promote the well-being of the future child. Second, the use of this technology can broaden the array of possibilities open to the future child. Third, preventing disability through PGD can prevent the future child from experiencing unfair disadvantages. These three arguments are explored in detail in the following paragraphs. The ethical case for a parental duty to use PGD to prevent a serious, likely, and known genetic disease can apply to most cases of intended conception and, as explained next, is strongest in situations in which parents have already made the decision to use in vitro fertilization (IVF).

Increasing Well-Being

As noted in the previous section, an individual who has ARPKD shoulders burdens that an individual without this disease does not have to carry. While an individual may
experience some positive outcomes as a result of having ARPKD, these are unlikely to outweigh the suffering and limitation associated with the disease. It would be tangential to delve into the long debate (Griffin 1986) over what constitutes “well-being” here, but under any plausible definition of this concept, a life without a disabling genetic condition is likely to be lived at a higher level of “well-being” than one with such a condition. That is, it seems reasonable to hold that, all other things being equal, well-being is increased when PGD is used to prevent genetic diseases such as ARPKD.

One could object to this conclusion on the grounds that “all other things” are not, in fact, equal in such cases. An individual’s level of well-being is determined by so many different aspects of her or his life, one could argue, that having ARPKD is just one small factor that contributes to how that individual’s life goes overall. And judging one life to be better than another simply based on this one factor reduces the value of the individual to that single characteristic in a morally problematic way (Asch 2000). While this argument is persuasive in many contexts, it is less so in the context of preimplantation decision making. In the case of PGD, all else is, epistemically, equal (Malek 2010). Nothing is known about the characteristics or qualities of the possible future children represented by the available embryos other than the fact that they do or do not carry the genes for ARPKD. The “all things being equal” judgment that it is better to live a life without a debilitating genetic condition is therefore a reasonable one to make in this context.

Nonetheless, philosophers have debated at length the question of whether reproductive choices can make a future child better off. Derek Parfit (1984) has argued that most reproductive choices cannot benefit a future child because the choice itself changes the genetic identity of the child brought into existence. As a result, a decision that changes the timing or method of conception cannot benefit a child who would be born affected by a genetic condition because that child (as defined by his or her genetic makeup) no longer is brought into being; a different child comes into being instead. As a result, these scholars have argued, it is not coherent to say that a particular choice about when and how to bring a child into the world (e.g., to use PGD to prevent ARPKD) can improve that child’s well-being. The resulting philosophical puzzle is known as the “non-identity problem.”

While this challenge must be noted, it does not pose insurmountable problems for our purpose here. Parfit’s argument purportedly demonstrates that standard person-affecting principles cannot support a duty to use PGD in such cases. This argument relies on the assumption that a future child’s identity is determined by his or her genetic makeup. In reproductive contexts, however, it may be more appropriate to take a relational view of the identity of the future child. That is, for the purposes of reproductive decision making, the morally relevant characteristics of a future child are not genetic but are instead related to the role that that future child will play in the world (Malek forthcoming). In describing parental duties, it is appropriate to use a relational understanding of the future child and to focus the ethical analysis on duties of the potential parent. This approach provides a continuity of identity among possible future children, making it possible to say that a potential parent can, in fact, increase the well-being of her or his future child (in a standard person-affecting way) by using PGD to prevent ARPKD.

Even if the reader is not convinced that, contra Parfit, standard person-affecting principles can be used to support a duty to use PGD in some cases, a case for such a duty can be built using other ethical approaches. One could take a “wide person-affecting” view and hold that parents have a duty to bring into being whichever child would benefit most from the decision (Parfit 1984; Savulescu and Kahane 2009). Under this view, a potential parent who uses PGD to bring a child without ARPKD into the world may increase well-being because that child is better off than one who would have had ARPKD. This perspective is person-affecting because it uses the well-being of a future child as its point of reference, but is not a standard person-affecting view because it compares the well-being of two possible children. Alternatively, impersonal moral principles can be used to show that well-being is increased if the child without the disabling genetic condition is brought into being (Brock 1995; Savulescu and Kahane 2009). Under this approach, no individual child is made better off as a result of the parents’ decision because the use of PGD changes the identity of the child brought into being. However, that decision increases the level of well-being for the class of children brought into being and potential parents should therefore use PGD to prevent the suffering associated with ARPKD to reduce suffering overall.

Whether a parent is making a child better off or making a better-off child is an interesting conceptual question but is a distinction without a difference for our purposes here. Under all of the approaches just described, a potential parent is likely to increase well-being by using PGD to prevent a child from experiencing the suffering and burdens associated with ARPKD. These consequentialist reasons form one pillar of the ethical case for PGD.

It is worth noting that if the use of PGD technology holds its own risks, those risks must be considered. The limited available evidence suggests that PGD does not put future children at increased risk of congenital malformations (Desmytere 2009; Liebaers et al. 2010), delayed mental or psychomotor development (Nekkebroeck 2008a), or socioemotional or language development difficulties (Nekkebroeck 2008b). However, at least one meta-analysis suggests that IVF (which must be used to perform PGD) has been associated with an increased risk of birth defects (Hansen 2005). This potential risk must be taken into account when evaluating a case for a parental duty to use PGD to prevent ARPKD on the basis of the well-being of the future child, but is likely to be offset by the value of avoiding this debilitating condition. In cases in which parents are already undergoing IVF for infertility purposes, however, the child is not put at any increased risk as result of the use of IVF. As a result, the balance of risks and
benefits in such cases more strongly favors the use of PGD. Parents who have already made the decision to use IVF, therefore, have a greater moral duty to use PGD based on the consideration of the well-being of the child.

Expanding Self-Determination

A second argument in favor of the use of PGD for medical benefit can be built on the future child’s interest in self-determination. There is general agreement that it is valuable for individuals to make their own life choices and that promoting conditions that expand an individual’s opportunity to make such choices is morally good. Joel Feinberg has called this idea a child’s “right to an open future” (Feinberg 1980), holding that parents should preserve the future possibilities that may be available to their child. Expanding this conclusion to conception decision making, Dena Davis has argued that parents should not use genetic technologies in a way that is likely to significantly narrow the range of choices that will be available to their future children (e.g., by increasing the likelihood that the child will be deaf) (1997; 2001, 66).

This same argument supports a positive duty for using PGD to prevent diseases such as ARPKD. ARPKD does not limit an individual’s capacity to self-determine the course of one’s life. It can, however, create a barrier to such self-determination because it puts limits on the options that the child can realistically choose. And the capacity to make such choices is less meaningful if the range of options actually available is severely limited. An individual who lives with ARPKD may be unable to pursue certain careers, hobbies, and even relationships as a result of his or her condition. Preventing this disease through PGD can therefore prevent such limitations for a future child. If, as Feinberg and Davis have argued, avoiding such limitations is ethically required, an appeal to the self-determination of the future child creates an argument in favor of using PGD for medical benefit.

This is not to say that individuals must be afforded every opportunity that could possibly be available to them or that parents have a moral imperative to maximize the possibilities available to the future child at all costs. All moral goods must be placed in balance with their associated costs and burdens. A more accurate formulation would be to hold that when a parent can, at reasonable cost, make a decision that prevents significant limitations to the array of opportunities that will be available to his or her future child, the parent has a duty to do so. It is worth noting that this conclusion can be drawn based on standard person-affecting, wide person-affecting, or impersonal principles using reasoning analogous to that laid out in the previous section on well-being, thereby avoiding the non-identity problem.

Reducing Inequalities

The goal of equality of opportunity derives from the fundamental principle of justice and so is a commonly accepted ethical good. However, what, exactly, it means to promote equality of opportunity is less obvious (Buchanan et al. 2000). Some have argued that the demands of justice require only that a society’s structures are designed to allow any of society’s members the same opportunity to succeed or fail while navigating them (Rawls 1971). Others have taken the stronger view that true equality of opportunity requires that any factor that is out of an individual’s control must be taken into account in determining just arrangements (Dworkin 2000). This latter view has the consequence that the outcomes of the natural lottery are the concern of justice and therefore that there is some moral requirement to adjust for these outcomes.

If this latter view can be defended, it has clear implications for a case in favor of a duty to use PGD for medical benefit. As discussed earlier, disabling genetic conditions limit the ability of the individuals who live with them to succeed at certain pursuits. Individuals with ARPKD do not have the same opportunities that similar healthy people are afforded. These limitations are not the result of anything these individuals have done or of any choice they have made. Therefore, if there is an obligation, supported by requirements of justice, to create equality of opportunity by taking into account the natural lottery, then there is a moral reason for using this technology because its use can prevent such inequalities. Taking action to prevent an individual from having unequal opportunities in life, even if that choice occurs before that child is brought into being, is squarely in line with the requirements of this version of justice.

It is worth noting that the primary objections against this version of equality of opportunity relate to the challenges of trying to make up for the disadvantages of the natural lottery (i.e., that a small number of people would require so many resources that the system would not produce good outcomes) and that this approach embraces a concept of the good that fails to take into account the plurality of values that exist in society. However, these objections do not apply clearly in the context of using PGD for medical benefit because this technology would be used to prevent inequalities and barriers to opportunity, rather than try to make up for them retrospectively. Certainly, it is not possible or desirable to truly equalize all genetic assets. However, it is possible to use this technology to make it less likely that a future child does not have some of the basic goods compromised by a disabling condition like ARPKD.

Parental Duties

The arguments given thus far have established that well-being, self-determination, and equal opportunity are moral goods that can be promoted through the use of PGD to prevent genetic disease. They therefore provide reason to believe that there is at least some duty to use PGD for medical benefit. There is, however, an additional factor that makes this duty significantly stronger than suggested already. Any individual has some duty to promote the well-being, self-determination, and equality of opportunity of any other individual, simply because that is a morally good thing to do. However, that duty is much stronger when there is
a relationship between those two individuals, particularly
during their relationship. Parents have many special
responsibilities associated with the relationship they have
with their future children. A precise definition of those
duties is beyond the scope of this article. But it should not be
controversial to claim that parents must promote their chil-
dren’s well-being, encourage their self-determination, and
give them equal opportunities. The case in favor of using
PGD for medical benefit is therefore strengthened by the
fact that it is grounded in the set of obligations that parents
have to their future children.

A Reason Without Moral Weight
There is at least one other ethical consideration that could
support the idea that a potential parent has a duty to use
PGD to prevent a genetic condition like ARPKD in his or
her future child: that the use of these technologies would
reduce a burden on society. There may be a valid argument
based on true premises to back up this position. However,
this consideration should not be considered in the moral
calculus or should be heavily discounted for at least two
reasons: First, such ethical considerations are historically
problematic. Because of past abuses, appeals to social bur-
den are layered with social meanings and associated with
values we never reject. As a result, a case that relied on the
support of this problematic argument would be controver-
sial and subject to critique. Second, people living with a
disabling genetic condition such as ARPKD may benefit so-
ciety in a way that outweighs the burdens on that society.
Their existence may make society as a whole more inclusive,
accommodating, open-minded, and thoughtful. Such ben-
efits are incommensurable with the burdens created and
so it would be difficult to conclude with confidence that
preventing such disabilities would create a net benefit for
society.

THE LEGAL CASE
The case at law for mandating parental use of PGD to avoid
birthing offspring with certain genetic anomalies can be con-
structed using existing precedents that are reconfigured to
apply to the clinical scenario at issue. Specifically, prospec-
tive parents who make an independent decision to repro-
duce using IVF and who know or reasonably should know
they are at substantial risk for transmitting a serious genetic
anomaly to their offspring may be subject to legal liability
for failing to utilize PGD to avoid birthing a child who
suffers grave harm from the heritable condition. This claim
is strongest as applied to parents who voluntarily chose to
undergo IVF to achieve parenthood, because PGD becomes
a minimal added step in the context of its harm-preventing
benefit. The legal arguments that follow are based on the
premise that once parents initiate the reproductive process,
they have a duty to execute that process in a manner that
produces the least harm to a resulting child. The extension
of this duty to a broader parental population is less cer-
tain in law, as the stand-alone duty to undertake assisted
reproductive technology (ART), even under the paradigm
case, does not flow comfortably from existing legal
parameters.

The framework for a legally cognizable claim relies ini-
tially upon the existing jurisprudence governing parental
duties, including duties owed to existing children, fetuses
in utero, and embryos developing in vitro. Enacted and
common law make clear that parents have duties both to act
(e.g., by providing necessary food and shelter) and to refrain
from acting (by not intentionally placing a child in harm’s
way) throughout the child’s life cycle. As the law surround-
ing assisted reproductive technologies comes into focus, it
appears these same caretaking duties are being increasingly
vested in third parties who assist in the development of IVF
embryos through reproductive technologies. Inevitably, we
argue, these same active duties of care will conflate with
parental obligations, imposing a duty on IVF-reproducing
parents to maximize the well-being of their future offspring
by all reasonable means.

Parental Duties Across the Life Cycle
Legally enforceable parental duties arise in all major sources
of law, including constitutional interpretation (Prince v. Mas-
sachusetts 1944), statutory enactments (e.g., Cal. Penal Code
§270 2012), and case law (Walker v. Superior Court 1988).
Though capable of dissection in myriad ways, for purposes
of asserting a duty to use PGD to avoid birthing offspring
with devastating genetic anomalies, the law of parental duty
is most logically viewed through a life-cycle lens. That is,
unpacking what law requires and prohibits of parents as
their children pass from mind’s eye to emancipation pro-
vides context and support for what we consider to be the
emerging duty to use PGD in certain circumstances. Though
no such duty has yet been formally recognized at law, and
some commentators argue against such a duty (Smolensky
2008), we believe current legal trends portend the duty’s
eventual appearance on the legal landscape.

Duties to Existing Children
In American culture, the parent–child relationship enjoys
significant legal protection and status, often resulting in the
elevation of parental autonomy over other competing val-
tues. That said, parental autonomy—the right to act or fail
to act in a self-directed manner toward one’s children—is
not absolute and can be diminished or overridden in
certain circumstances to protect the best interests of the
child (Zimmerman 2009). Legal restrictions on parental
autonomy are perhaps most highly scrutinized in the con-
text of parental decisions to refuse or withdraw medical
treatment in a manner that causes harm to a child. Over-
whelmingly, though not unanimously, courts rule against
parental autonomy in these cases, finding that the child’s
welfare supersedes personal freedoms (State v. Perricone
1962; Zimmerman 2009). This body of law, Zimmerman
opines, reflects a utilitarian ethic in which society’s desire
to protect the well-being of its children, and hence its
own future, outweighs its concern for individual agency.
“Parents,” the U.S. Supreme Court admonished decades ago, “may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves” (Prince v. Massachusetts 1944).

Legal outcomes in which parents are ordered to yield to a court order mandating medical treatment on behalf of their child follow a typical pattern. Generally, the request for treatment is made by a third party, often a state actor invoking the legal doctrine of parens patriae (authorizing the state to intervene against a negligent parent or guardian, and to act as the parent of a child who is in need of protection). Courts then balance the interests of the respective parties, invoking a three-part analysis to determine the merits of contravening a parent’s express wish. The court will balance (1) the proposed treatment’s likelihood of success, (2) the risks the treatment poses, and (3) the potential outcome if no treatment is provided (Custody of a Minor 1978). Application of this tripartite analysis is fairly straightforward when the order to treat (or the approval to not treat) is directed at the parents of an existing child. But is this balancing test useful in the clinical scenario at issue—that is, can the trilogy of benefits, risks, and consequences support a duty to use PGD when IVF is undertaken and risks of heritability are known? One strand of parental duty law may prove useful in making the case for such a duty.

Since our argument is for an “add on” legal duty to use PGD—and not for the duty of all parents, even those who know they are at risk for transmitting a serious genetic anomaly through natural conception—we are drawn to the law that addresses whether parents who are already acting on behalf of their child’s welfare have a duty to introduce the most beneficial modality, judged according to modern medical standards. Cases in which religious parents use prayer in lieu of medicines or surgery are instructive. In these cases, parents typically assert both religious freedom and parental autonomy arguments to support their course of action. Importantly, the legal challenge in these tragic cases is not that the parents are doing wrong by not acting, but rather that the action they are taking is inadequate to serve the best interests of the child. Those advocating for treatment do not dismiss the value of prayer and other spiritual aid, but argue it should be augmented with therapies that are proven to have beneficial, even lifesaving, effects.

One could liken parents who utilize IVF in their quest for parenthood to parents who use spiritual means to heal their ailing children to the extent that both are relying on means they believe will produce a desired result—the birth or continued life of a child. In those cases in which courts order conventional treatment over parental objection, the three-part balancing test weighs heavily toward the first and third factors—great likelihood of success coupled with a dire outcome from nontreatment (Dwyer 1994). In our case, the use of PGD to select against lethal or seriously debilitating genetic anomalies is highly effective, the risks of adding the screening technique in an IVF cycle are relatively low, and the avoidance of dire medical outcomes for the offspring resulting from that particular IVF cycle ranges from modest to substantial depending upon the recessive or dominant nature of the particular anomaly (Desmyterre 2009; Liebaers et al. 2010). In the case of ARPKD, the use of PGD has virtually eliminated disease transmission (Gigarei et al. 2007).

Admittedly, applying the parental duty tripartite analysis in the PGD scenario suffers a certain lack of equivalency; decisions about medical treatment involve existing children who may be harmed but for the mandated action, while decisions about PGD involve two populations of potential children—those who may be benefited if they are later born alive and those who will be harmed by the deselection process. The duty we envision would vest in the population of persons who are benefitted by being born, but who suffer harm from a debilitating genetic disorder. American law is overwhelmingly unfriendly to damage claims brought by these individuals, rejecting these “wrongful life” cases in virtually every state. Shunning inquiry into philosophical matters, courts profess an inability to “weigh the value of life with impairment against the nonexistence of life itself” (Gleitman v. Cosgrove 1967). This legal version of the non-identity problem—a child born with a disability has not been harmed if the alternative was to never have been born (Parfit 1984)—has engendered thoughtful critique, with one scholar urging a broader view of legal duties surrounding the intentional or negligent birth of a disabled child (Cohen 2008).

We acknowledge the wrongful life/non-identity problems as barriers but not necessarily bars to a parental duty. Cohen suggests a “welfarist” approach, positing that “global welfare is maximized . . . when the undiminished child comes into existence; and any intervention ought to be keyed to creating a situation where the undiminished child comes into existence” (Cohen 2008). Viewing the duty from the perspective not of those upon whom the acts are committed but of those who commit the acts (or fail to act, in our case), a certain equivalency with existing parental duty jurisprudence emerges. Once parents undertake an action on behalf of their existing/potential children, they have a duty to perform that duty with a high degree of care and in the best interest of the resulting child. That duty, as the cases mandating unwanted medical treatment demonstrate, often provokes parental anguish, which is subordinated to the anticipated beneficial outcome bestowed upon the child. Imposing on IVF-using prospective parents a duty to maximize the well-being of the child they are acting to create by using enhanced genetic technologies fits within existing notions of parental duties.

**Duties to Fetuses**

The legal relationship between prospective parents and their fetuses, though less jurisprudentially evolved than that between parents and existing offspring, offers some insight into the question at issue. Whether the law would support a clinically-specific parental duty to utilize PGD depends...
in part on the extent of care owed pre-born children. Legal duties to fetuses typically revolve around three essential questions—whether the fetus was viable at the time of injury? Whether the fetus was later born alive? Whether the duty-bearer’s actions were intentional or merely negligent? For purposes of our hypothetical case, we can assume that the IVF embryo was not a viable fetus at the time of the injury, that the child was later born alive, and that parents who know or should know they are at significant risk of passing a deleterious genetic anomaly to their child act in an intentional manner by refusing the offered PGD. How would the law respond?

The legal relevance of fetal viability first gained constitutional moment in Roe v. Wade (1973), the 1973 U.S. Supreme Court decision in which Justice Blackman, writing for the majority, formulated the so-called “trimester analysis” for determining the legality of state abortion laws. During the first trimester, the woman was at liberty to determine the course of her pregnancy, including a decision to seek an abortion. During the second trimester, the state could regulate the abortion procedure to advance maternal health; after fetal viability in the third trimester, a state could prohibit abortion in most instances.

The Supreme Court’s subsequent decision in Planned Parenthood of Southeastern Pennsylvania v. Casey (1992) abandons the Roe trimester analysis, but retains an allegiance to fetal viability as a significant demarcation under the law. According to Casey, a state may not “place a substantial obstacle in the path of a woman seeking an abortion before the fetus attains viability.” This right to avoid proscription, it is argued, enjoys a constitutionally protected companion right to engage in procreation free of state-imposed obstacles (Robertson 1994). In the context of reproductive technologies, including PGD, the procreative liberty jurisprudence protects a parent’s right to shape her future child’s genetic make-up by prohibiting state interference with access to pre-viability genetic technologies (Dworkin 1994; Robertson 2004).

At first blush, this rights-based interpretation of procreative liberty seems to directly conflict with the duty-based argument we make herein. How can a right to access PGD coexist with a duty to utilize the technology to deselect certain embryos? If the law is least intrusive when future children are least viable, how can the refusal to use embryo screening technology be legally actionable? The answer comes in probing the second and third questions posed when courts confront assertions of parental duties to their pre-born children. When an IVF-conceived child of parents at known risk for transmitting a serious genetic anomaly is born alive (with the anomaly) after the parents refused the opportunity to add PGD to their reproductive regimen, the child may have a claim for this prenatal harm based on strands of tort and statutory law. These laws rest on the same premise: Once a person demonstrates an intent to proceed with reproduction (by forgoing abortion, or accessing IVF), that individual has a duty to act as a reasonably prudent parent when taking all subsequent reproduction-related actions. This includes the duty to maximize the well-being of any potential future child by avoiding known hazards.

Notably, the case law in regard to parental duty to avoid prenatal harm is both sparse and mixed. A handful of cases discuss the obligation of a later born child to sue a parent—typically a mother—for prenatal injury, and the results are in equipoise (Smolensky 2008). In those cases denying liability, courts focus on the doctrine of parental immunity and a woman’s rights to bodily integrity and procreative liberty. Jurists worry that imposing liability for negligent conduct during pregnancy wrongfully disrupts a pregnant woman’s right to exercise physical autonomy (Stallman v. Youngquist 1988). In the case of in vitro embryos, a woman’s bodily integrity is not implicated by requiring the use of PGD, rendering this line of cases less persuasive. Cases in which courts find liability emphasize the child’s “legal right to begin life with a sound mind and body.” Third parties, even parents, whose wrongful conduct causally interferes with that right can be subject to legal liability (Womack v. Buchhorn 1971). Certain statutory law addressing parental duties is also-friendly to liability for prenatal wrongs, declaring a child conceived but not yet born to be under the jurisdiction of the child-protective act (Cal. Penal §270 2012).

The equivalency problem discussed in connection with applying the law of parental duties to existing children to the use of PGD likewise plagues application of paternal-fetal jurisprudence to our clinical case. The latter law addresses acts and omissions with respect to a particular child who is harmed as a result. In our case, we are not so much focused on the harm to the existing child but on the harm caused by the failure to investigate and select the healthiest embryos from among the group presented. Our lifeboat ethics approach views each embryo in an IVF batch as a unique opportunity to exercise parental beneficence on behalf of the future family (Daar 1992). In any IVF cycle in which more than one or two viable embryos are produced, a process of selection and deselection ensues, typically based on the size and shape of the developing cells. Swapping genetic health for morphology as a basis for selection seems at the very least a neutral trade-off from an ethical and legal perspective. On balance, we believe the law would favor the relatively minimal bump up in parental waiting time and expense attendant to accessing and utilizing information that could substantially improve the future child’s health profile.

**Duties to Embryos**

The law’s reluctance to recognize formal parental duties of care to unborn children, or to require that parents make optimal choices on behalf of their existing offspring, is understandable in light of the deference parental autonomy enjoys in American life. On the matter of parental duties to in vitro embryos, the law is still unformed, but by extension of existing precedent it is logical to surmise that courts would be reluctant to elevate the rights of extracorporeal would-be persons over those of the extant progenitors.
In the bilateral relationship between parents and potential children, parental autonomy may trump, but when third parties enter the relationship, their rights are further subordinated to those of the parents and would-be child. The susceptibility of third parties to legal liability in the context of ART is on the rise, and may ultimately serve as a foray into parental liability for failure to exercise reasonable care in using reproductive technologies.

When cryopreserved embryos are negligently lost or destroyed, courts often permit plaintiff parents to recover against doctors and clinics for economic loss equal to the value of the irreplaceable property and for breach of fiduciary duty (Jeter v. Mayo Clinic 2005). While careful to clarify that frozen embryos are not persons for purposes of wrongful death or other tort laws, courts have acknowledged that those who take responsibility for handling embryos owe them “special respect” and a high duty of care. At least one court has suggested that such a duty exists. In Paretta v. Medical Offices for Human Reproduction (2003), the parents of an egg donor-conceived child born with cystic fibrosis (CF) sued the ART clinic for failing to use PGD to “ascertain whether the embryo had genetic diseases.” The court permitted the Paretas to proceed to trial on this matter, calling the physicians’ conduct “grossly negligent—possibly even fraudulent” because they were aware of the egg donor’s CF carrier status and failed to determine whether the embryos were affected.

If ART practitioners have a duty to use PGD when they know or should know that embryos they helped create are at risk of inheriting a deleterious genetic anomaly, is extension of such a duty to similarly situated parents an untenable breach of existing norms and laws? We think not. Parents who voluntarily seek medical assistance to reproduce are reasonably suited to absorb the minimal burden caused by adding PGD to an IVF regimen. Tweaking the conduct of ART-using adults to maximize the well-being of their future children should not be viewed as an affront to parental autonomy, but rather as a salute to modern science for alleviating human suffering, one ART birth at a time.

CONCLUSION

The emergence of PGD as a method to prevent the birth of children with devastating genetic disorders raises questions about the legal and ethical viability of an affirmative duty to use the technology in certain clinical scenarios. We argue that parents who undergo IVF and know or reasonably should know they pose a significant risk of passing a lethal or serious genetic anomaly to their offspring have a legal duty to use PGD to avoid birthing an affected child. Well-worn ethical principles that promote individual well-being, self-determination, and avoidance of inequity support the duty to use PGD as a prenatal parental action to prevent lifelong suffering. While existing law remains dedicated to protecting parental immunity and reproductive autonomy, a growing body of critique agitates for parental tort liability in the context of ART (Goodwin 2010).

We are not unmindful of the cost and access barriers associated with PGD, making it unavailable to some to whom we would ascribe a duty of use. Ideally, recognition of a duty to use PGD would be accompanied by a mandate to provide coverage on the part of payers who would ultimately be responsible for supporting the health care of an affected offspring. Shifting benefit outlays for significant post-birth health care to a far less costly preconception procedure strikes us as a worthy public policy trade-off.

REFERENCES


California Penal Code Sec. 270. 2012. [requiring parents “furnish necessary clothing, food, shelter, or medical attendance, or other remedial care for his or her child”]. Available at: http://law.onecle.com/california/penal/270.pdf


Gleitman v. Cosgrove. 1967. 49 N.J. 22, 227 A.2d 698 (1967) [rejecting wrongful life claim by child born with birth defects after doctors failed to warn mother of dangers from German measles].


Prince v. Massachusetts. 1944. 321 U.S. 158, 170 (1944) [upholding child labor law over mother’s religious objection].


State v. Perricone. 1962. 37 N.J. 463 (1962) [ordering blood transfusion of infant over objection of Jehovah’s Witness parents, reasoning society’s interest is paramount to personal freedoms].

