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Duty to the Unborn: 
A Response to Smolensky

JAIME KING*

In her article, Creating Children with Disabilities: Parental Tort Liability for Preimplantation Genetic Interventions, Kirsten Smolensky examines the ever-expanding world of assisted reproductive technology (ART) and the recent development of parental demand to use ART to deliberately create children with disabilities. The article explores the potential for parental tort liability arising from both the use of preimplantation genetic screening (indirect intervention), and genetic manipulation (direct intervention). To summarize, Smolensky argues that children are harmed by direct genetic manipulations that limit their future capabilities, and should be able to sue their parents for their losses. However, due to Parfit's Non-Identity Problem, selecting embryos based on the presence of genes associated with limited future capabilities (indirect intervention) should not incur tort liability.

While Smolensky's basic premise that children should be able to sue their parents for harmful preimplantation genetic manipulations is sound, it both understates the potential scope of tort liability related to preimplantation ART, and overstates the harm caused by genetic manipulation to produce a child with a disablimg condition. Part I of my response briefly considers the parental demand for direct preimplantation genetic interventions to produce a child with disabilities.

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3. See Derek Parfit, Reasons and Persons 358-61 (rev. ed. 1987) (explaining that the Non-Identity Problem argues that a child could not claim to be harmed if he or she was born into disadvantageous circumstances or with a genetic disability because if his or her parents gave birth at a more advantageous time or selected an embryo without a disability, the individual child would not have been born); see also Smolensky, supra note 1, at 301–02, 331–36.
Part II examines the potential risks and benefits associated with preimplantation decision making. Smolensky argues that limitations of a child's future capacity constitute both moral and legal harms without fully addressing the broader range of potential risks and benefits that can result from preimplantation interventions. The decision to use ART to have a child with a disabling condition goes beyond the limitations imposed on the child by the condition. It should also include the risks inherent in using ART and the benefits of being born with a condition into a culture that understands and supports it. Assessing the level of harm requires balancing the full range of risks and benefits associated with the choice, and giving strong consideration to the parents' attempt to act in their child's best interests. Following this assessment of harm, Part III considers the scope of parental liability under both intentional and negligence-based tort claims. I argue in favor of Smolensky's proposed "duty to act as a reasonably prudent parent" in reproductive activities that occur outside the body of the mother, and, in turn, broadening the scope of liability to include additional decisions made during assisted reproduction. Finally, Part IV argues that even though parental tort liability is possible, it does not provide the best mechanism for assuring the welfare of children born through ART. Federal oversight offers a more inclusive and widespread method of protecting this population of future children.

I. THE DEMAND FOR CHILDREN WITH DISABILITIES

As Smolensky notes, anecdotal and empirical research is beginning to detect a small, but growing, desire among some parents to use ART to enable them to have a child with a disabling trait. From anecdotal reports, parents have asked to select embryos with a narrow set of conditions: deafness, achondroplasia (dwarfism), Down syndrome, and phenylketonuria (PKU). While these disabilities and conditions may

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4. Smolensky, supra note 1, at 311-14, 344-45.
5. Id. at 323 & n.136.
8. Down syndrome is a chromosomal disorder that results from three copies of the twenty-first chromosome, and is associated with impaired physical growth, reduced cognitive ability, congenital heart defects, and distinctive facial features. Nat'l Inst. of Child Health & Human Dev., Down Syndrome, http://www.nichd.nih.gov/health/topics/Down_Syndrome.cfm (last visited Dec. 15, 2008).
9. PKU is an autosomal recessive disorder that increases levels of phenylalanine in the blood, which at certain levels can cause mental retardation, seizures, behavioral problems, psychiatric disorders, and other serious health problems. Phenylketonuria—Genetics Home Reference, http://ghr.nlm.nih.gov/condition=phenylketonuria (last visited Dec. 15, 2008). PKU can successfully be
limit the capabilities of a child, their symptoms are also controllable to a
level that children with them can still live worthwhile and fruitful lives.10
Further, individuals with these conditions have created vibrant
communities with powerful cultural identities.11

One reason parents want to use ART to create children with
disabilities is to have their children be a part of their own culture or
community.12 From a genetics standpoint, this is relevant to the potential
demand for genetic manipulation or gene therapy to have a child with a
disability. When both parents carry one of the above genetic conditions,
they have at least a 25%, and in some cases higher than 50%13 chance of
passing the disorder on to any given embryo. Therefore, a given cycle of
in vitro fertilization (IVF) required to produce embryos for
preimplantation intervention will most likely produce at least one
embryo that carries the desired condition.14 As a result, the majority of
parents with the above genetic conditions will produce an embryo with
the desired condition, thereby enabling them to engage in indirect
preimplantation genetic intervention, also known as preimplantation
genetic screening (PGS),15 rather than having to manipulate their

treated through a special low-phenylalanine diet. Id.

10. While their lives are restricted, individuals with all of these conditions go to school, hold jobs,
get married, etc.

11. See generally Paul Preston, Mother Father Deaf: Living Between Sound and Silence
visited Dec. 15, 2008); Down Syndrome Community, http://www.downsyndromecommunity.org (last
visited Dec. 15, 2008) (describing the Down syndrome Community in Washington state); Blogging
15, 2008).

12. Sanghavi, supra note 2; Spriggs, supra note 6, at 283.

13. Parents who both have autosomal recessive disorders like PKU and some forms of congenital
deafness have close to a 100% chance of passing the condition on to any given embryo, as both parents
must only have affected alleles. See Univ. of S. Dakota, Sanford Sch. of Med., Mendelian Patterns of
Inheritance, http://www.usd.edu/med/som/genetics/curriculum/iFMENDL4.htm (last visited Dec. 15,
2008). Parents with autosomal dominant disorders such as achondroplasia have a one-in-two chance of
passing the disorder to any given embryo, and because embryos that are homozygous for the condition
are nonviable, any viable embryo is twice as likely to have achondroplasia as it is to be normal. See
Achondroplasia—Genetics Home Reference, supra note 7. As a result, two-thirds of their
preimplantation embryos should carry the disorder. See id. Finally, while men and women with Down
syndrome tend to have reduced fertility levels, an individual with Down’s has a 35% to 50% chance of
passing on the condition, while two parents with the disorder have an even higher chance of passing it

14. See George B. Inge et al., Oocyte Number per Live Birth in IVF: Were Steptoe and Edwards
thirty-eight treated at the Bourn Hall Clinic in 2000, low yield cycles (n=118) produced on average one
to five oocytes, of which 57.6% became embryos, while intermediate cycles (n=440) yielded six to
fifteen oocytes, of which 59.5% became embryos, and high yield cycles (n=121) produced sixteen or
more oocytes, of which 56.1% became embryos).

15. In this Essay, preimplantation genetic diagnosis (PGD) will refer to preimplantation testing
for a specific genetic or chromosomal disease. Preimplantation genetic screening (PGS) will refer to

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embryos’ DNA to produce the condition. When both parents have the genetic condition they desire for their child, the demand for direct genetic manipulation to produce children with disabilities from which parental tort liability could arise under Smolensky’s analysis will be extremely limited.

However, the demand for direct genetic manipulation may arise in other contexts. First, deafness is not always hereditary. Over 75% of deafness results from nongenetic or nonfamilial causes, and approximately 90% of all children born to deaf parents are hearing. Therefore, deaf parents with different etiologies may wish to use direct genetic manipulation to have a deaf child. Secondly, as Smolensky noted in her Down syndrome example, in rare cases, parents who already have a disabled child that resulted from a spontaneous mutation may wish to have another child with the same disability to ease family dynamics. For instance, parents who already have a child with PKU may prefer a second child that also must adhere to the same strict diet, which can simplify eating practices and meals. In cases of noncongenital causes or spontaneous mutations, parents will not be able to use PGS to select a child with the desired genetic condition. Therefore, having a child that has the disorder will require direct genetic manipulation, which raises significantly more ethical and regulatory implications.

Direct genetic manipulation or gene therapy has never been attempted on a human embryo or a fetus. Research involving gene therapy has mostly focused on adults and severely ill children, for whom the risks of their current condition outweigh both the known and unknown risks associated with gene therapy. Embryologists and geneticists still have much to learn about the role of DNA and its interaction with the uterine environment in the development of the fetus and the child. Altering the DNA of a preimplantation embryo at the use of preimplantation testing for all other conditions, as well as references that include both PGD and PGS.

16. Even for parents who both have congenital deafness, the genes associated with their condition may differ, thereby minimizing the ability to pass recessive traits to offspring.


18. PRESTON, supra note 11, at 13.


stem cell level may significantly affect the overall development of that embryo and have numerous unanticipated consequences.\textsuperscript{22} Gene therapy experimentation in humans has resulted in the untimely death of at least two adult research participants due to overactive immune responses, as well as the development of leukemia in others.\textsuperscript{23} While research on gene therapy in animal models is ongoing, the developmental and possible long term health risks of gene therapy use in human preimplantation embryos will most likely negate its use in the near term, until gene therapy in adults has been improved significantly.\textsuperscript{24}

Regulation by the Food and Drug Administration (FDA) will further stifle this market. Unlike PGS, gene therapy research is extensively regulated within the United States.\textsuperscript{25} Gene therapy differs from PGS because it involves the creation of a biologic viral agent to transfer the desired genes into the cell, while PGS only involves the use of a genetic test.\textsuperscript{26} The addition of the biologic agent thrusts gene therapy research into the FDA's regulatory purview.\textsuperscript{27} The FDA's Center for Biologics Evaluation and Research regulates research on all biologics, prior to the sale and marketing of such products.\textsuperscript{28} In order for a gene therapy product to be sold for use in patients, the product would have to be proven safe and effective, following a series of laboratory tests, animal trials, and then human trials.\textsuperscript{29} To start clinical trials in humans, researchers must submit an investigational new drug (IND) application to the FDA detailing the clinical trial protocol, the possible risks of the trial, the measures it will take to protect patients, and the pre-clinical data available to support moving forward to human trials.\textsuperscript{30} In addition, as part of the IND process, researchers must obtain approval from an Institutional Review Board (IRB), which will examine the risks and benefits of the research and the ethical implications.\textsuperscript{31} In particular, the

\textsuperscript{22} Thrasher & Edwards, supra note 20, at 105 (stating that gene somatic cell gene therapy techniques do not “differ greatly from cloning, with its frequent disasters in fetal life”).


\textsuperscript{24} Thrasher & Edwards, supra note 20, at 102–05.


\textsuperscript{26} Id.


\textsuperscript{28} 21 C.F.R. § 601.2.

\textsuperscript{29} Id.; see also id. §§ 610.9–18.

\textsuperscript{30} Id. § 601.2.

\textsuperscript{31} Food & Drug Admin., supra note 25.
FDA regulations require the IRB to ensure that the risks to subjects are minimized, and that they are "reasonable in relation to the anticipated benefits." Given this level of oversight and the cost of clinical trials, the development of a gene therapy agent designed to excise normal DNA and insert a DNA sequence to create a disabling condition seems difficult to justify and unlikely to survive review. Furthermore, if created and approved by the FDA, researchers who wanted to determine its impact on the development of human embryos would also be subject to the restrictions of the Dickey-Wicker Amendment, which limits the use of federal research funds for research that may harm or destroy embryos. Given the absence of federal funds to support such research, the heavily regulated approval process for gene therapy products, and the limited demand for a biological agent to insert DNA associated with a particular disability into an otherwise normal embryo, few biotechnology companies would consider producing such a product.

While the potential market for genetic manipulation to create a disability will be extremely small, the demand for ART services in general is not, and the demand for PGS continues to grow at a rapid pace. Much of the growth in the use of ART has occurred despite risks to the offspring involved. As a result, the potential scope of Smolensky's parental tort liability arising from preimplantation

33. The Dickey-Wicker Amendment currently prevents the use of federal funds for any activity that involves "the creation of a human embryo or embryos for research purposes or research in which human embryo or embryos are discarded, destroyed, or knowingly subjected to a risk of injury or death greater than that allowed for research on fetuses in utero under 45 C.F.R. 208(a)(2) or 42 U.S.C. 289g(b)." Dickey-Wicker Amendment of 1996, Pub. L. No. 104-99, § 128, 110 Stat. 26, 34 (1996) (codified as amended in scattered sections of 42 U.S.C. and 45 C.F.R.).
35. Maryse Bonduelle et al., A Multi-Centre Cohort Study of the Physical Health of 5-year-old Children Conceived After Intracytoplasmic Sperm Injection, In Vitro Fertilization and Natural Conception, 20 HUM. REPROD. 413, 416 (2005) (finding that 4.2% of children born via ICSI have a major congenital malformation, which is 2.77 times the rate of children naturally conceived. This result was partially due to increased defects in the urogenital system (3.7% ICSI, 2.1% IVF, 0.6% natural conception)); Dorte Hvidtjørn et al., Cerebral Palsy Among Children Born After In Vitro Fertilization: The Role of Preterm Delivery—A Population-Based, Cohort Study, 118 PEDIATRICS 475, 478-79 (2006) (finding that IVF procedures that result in preterm deliveries posed an increased risk of cerebral palsy); Reija Klemetti et al., Health of Children Born as a Result of In Vitro Fertilization, 118 PEDIATRICS 1819, 1823 (2006) (finding that singleton IVF babies had higher incidences of perinatal problems, congenital malformations, and problems of the genitourinary system; interestingly, the study also revealed a slight decrease in respiratory disease in children born via IVF compared to naturally conceived controls (odds ratio 0.80)).
interventions could be broader than her article suggests. On the other hand, courts should also consider any potential benefits to the offspring that may result from preimplantation interventions, a consideration that may narrow the scope of tort liability. Only by examining the full range of risks and benefits can juries accurately determine the parents' intent or level of negligence in their preimplantation decision making.

II. THE RISKS AND BENEFITS ASSOCIATED WITH PREIMPLANTATION DECISIONS

Modern ART offers parents significantly more control over their potential offspring than ever before. After deciding to create a child through in vitro fertilization (IVF), parents’ subsequent choices of what to do with their preimplantation embryos pose a variety of risks and benefits to the resultant child.

A. RISKS ASSOCIATED WITH PREIMPLANTATION INTERVENTIONS

Smolensky unnecessarily constrains the scope of parental tort liability that could arise from preimplantation actions by limiting her discussion to genetic interventions and harms that limit a child’s right to an open future. Parental decisions during ART can create numerous harms for which tort liability may be appropriate, even if those harms do not limit the child’s “right to an open future.” Joel Feinberg’s argument that only those risks that threaten the child’s right to an open future should warrant legal protection stems from the challenge of claiming that nonexistence would have been better than being born with the attendant condition. While determining the level of damages appropriate for the harm done by being born with a disability versus nonexistence may be on the verge of “impossible” for courts, determining the level of harm between being born with a disabling condition versus being born without one, or being born premature versus being born full-term, is more feasible for courts. Plaintiffs may struggle to prove causation in some of

36. See generally Smolensky, supra note 1, 318–39.
37. As noted by Smolensky, the Non-Identity Problem would also prohibit an argument by these children that their parents had harmed them by undergoing IVF because the particular embryos they developed from would not have existed otherwise. See Smolensky, supra note 1, at 331–36.
38. The notion of a “child’s right to an open future” was first discussed by Joel Feinberg in The Moral Limits of the Criminal Law. 1 JOEL FEINBERG, THE MORAL LIMITS OF THE CRIMINAL LAW: HARM TO OTHERS 99–102 (1984). The discussion by Buchanan and his coauthors, regarding the child’s right to an open future goes to the notion that parents should not close off their future children’s abilities through genetic choices in order to direct them into a certain life plan. This would not limit a tort claim for physical harms that did not limit their right to an open future. ALLEN BUCHANAN ET AL., FROM CHANCE TO CHOICE: GENETICS AND JUSTICE 170–72 (2000).
39. FEINBERG, supra note 38.
40. Id. at 101 (quoting Williams v. New York, 223 N.E.2d 343, 344–45 (N.Y. 1966) (Keating, J., concurring)).
these cases, but that should not result in a complete bar on liability for preimplantation decisions outside of direct genetic manipulation.

Since Smolensky limited her argument to examination of preimplantation genetic decisions, employing a harm framework based on child’s right to an open future makes sense from an abstract perspective. Her framework leaves ample room for parental expression of privacy rights within preimplantation genetic decision making by placing limits on parental choice only when the preferred choice would “doom” the child’s future interests. This approach aims to minimize the need for challenging value judgments regarding which genetic conditions parents can select for their children without incurring tort liability. However, Feinberg’s list of conditions that would violate a child’s right to an open future includes conditions that no longer seem to fit his description of conditions that would doom the child’s future interests to “total defeat,” such that the child had been wronged by being brought into existence. The categorization of deafness and many of the other conditions Feinberg lists seems entirely inconsistent with the experiences of many people living with disabilities. Therefore, the open future framework may not still include some of the disabilities discussed in this Essay, and continuing to include them will require juries to make value judgments about which disabilities are so severe as to violate the child’s right to an open future.

While limiting parental tort liability to only those harms that violate a child’s right to an open future may make Smolensky’s argument more palatable to some, it eliminates claims for tort liability for some of the most common and avoidable harms associated with preimplantation interventions. For instance, following IVF, prospective parents have the ability to decide how many embryos to transfer to the uterus, whether to engage in an embryo biopsy to test their preimplantation embryos for genetic traits, and perhaps in the future, whether to engage in gene therapy. Each of these decisions carries risks for prospective children born through the procedure, which could also give rise to a tort claim given the right set of circumstances.

1. **Embryo Transfer**

One of the largest risks to offspring born through IVF results from the transfer of multiple embryos in a given IVF or PGS cycle. While ART clinicians often transfer more than one embryo to improve

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41. Smolensky, supra note 1, at 309 (citing Feinberg, supra note 38, at 98).
42. Feinberg, supra note 38, at 98–99.
43. These risks are discussed below. See infra Part II.A.
pregnancy success rates, the practice increases the incidence of multiple births from 3% with natural childbirth to 33% with IVF. A recent study of over 4500 children born through IVF found that children born from an IVF multiple birth were nearly five times more likely to be born very premature (less than thirty-two weeks) (9.6% versus 2%) or premature (less than thirty-seven weeks) (49.2% versus 9.5%) as singleton IVF births. IVF multiple births were also associated with significantly higher rates of low birth weight (less than 2500 grams) (43.7% versus 6.5%) and very low birth weight (less than 1500 grams) (8.2% versus 1.9%) babies, as well as higher rates of respiratory problems (8.4% versus 2.0%), hospitalization over seven days (47.4% versus 10.8%) and perinatal death (2.0% versus 0.9%). In addition to newborn health complications, premature babies are at risk for significant long-term disabilities, such as mental retardation, cerebral palsy, lung and gastrointestinal problems, and vision and hearing loss.

2. Preimplantation Genetic Testing and Embryo Biopsy

Preimplantation genetic testing also may create additional health risks for embryos and prospective children. In order to conduct preimplantation genetic tests for PGS, clinicians must conduct an embryo biopsy to remove one to two cells from the embryo. A number of scientists have suggested that the embryo biopsy can significantly harm the development of embryos, and may negatively affect the long-term health of the resultant child. While clinical evidence suggests that babies...
born via PGS have similar health statistics to those born through IVF, little information exists regarding the long-term impact of the embryo biopsy on the development and health of the resulting offspring, as most of them have not reached puberty. The known and unknown risks of embryo biopsy should be weighed against the benefit of being able to select between embryos. In cases of selecting for an embryo with a disabling trait, establishing a benefit significant enough to outweigh the risk of the procedure will be difficult. Harms derived from the embryo biopsy required to conduct PGS provide an argument for potential liability irrespective of Parfit's Non-Identity Problem, as those embryos existed and could have been transferred without the removal of the cell for genetic testing.

3. Direct Genetic Manipulation or Gene Therapy

While the data available regarding the risks associated with IVF and PGS remain limited, no data on the risks associated with the use of direct genetic manipulation or gene therapy in embryos exists, as the procedure has never been attempted. Gene therapy holds substantial promise for improving health care for millions of people suffering from genetic disorders; however, translating this promise to practice has been challenging. The deaths of Jesse Gelsinger and Jolee Mohr following participation in gene therapy trials, the development of “leukaemia-like illnesses” in patients in the French SCID-XI clinical trial, and other adverse events have hung like a black cloud over gene therapy research. However, researchers have made substantial progress in recent years, leading to a resurgence in gene therapy research.


52. Children born via IVF have significantly worse health outcomes overall when compared with children conceived naturally, and therefore the risks of engaging in IVF at all should be considered when doing it solely for the purpose of producing a child with a specific disability. However, Parfit's Non-Identity Problem would prevent children born through IVF from suing, as they would not otherwise have been born. Klemetti, supra note 35, at 1822 (finding that overall IVF infants were more likely to be born preterm (23.6% versus 5.5%), to have low birth weight (24% versus 4.8%), to require treatment in the newborn intensive care unit (23% versus 8.2%), to require hospitalization for seven days or more (23.8% versus 6.4%), and to die perinatally (1.3% versus 0.6%) compared to naturally conceived controls); see also M. Bonduelle et al, supra note 35; Jane Halliday, Outcomes of IVF Conceptions: Are They Different?, 21 BEST PRAC. & RES. CLINICAL OB GYN 67, 67-68 (2007) (finding that preterm delivery, low birth weight, and some birth defects occurred more frequently in singleton children born through IVF than naturally conceived controls); King, supra note 49, at 122-26 (discussing these risks more in depth).

53. Thrasher & Edwards, supra note 20, at 100-02.

54. Keim, supra note 23; Thrasher & Edwards, supra note 20, at 102; Weiss, supra note 23.

55. The NIH's Gene Modification Clinical Research Information System (GeMCRIS) shows 180 currently active gene therapy trials in the United States, which represents an increase of forty-one new trials from a year ago. Gene Modification Clinical Research Info. Sys., Gene Transfer Protocol Reports, http://www.gemcris.od.nih.gov/Contents/GC_CT_RPT MAKER.asp (last visited Dec. 15, 2008) (select “Active” under the scroll menu for “Status”; run search); cf. Keim, supra note 23 (stating...
initial safety trials on four adults to improve Leber's congenital amaurosis, one form of congenital blindness, proved safe and effective in the short term.  

Researchers are making slow, but steady, progress in areas of medicine where the risks associated with the disease at least arguably outweigh the aggregate risks and uncertainties associated with gene therapy.  

For these conditions, gene therapy offers significant hope for the future. But those are not the conditions Smolensky addresses. She considers the use of gene therapy, which poses substantial risks even to fully developed adults, for use in embryos for the sole purpose of creating a child with a disability, which seems much more difficult to justify given the current risks and benefits. In fact, one gene therapy researcher stated that the risks of gene therapy techniques used in embryos would not "differ greatly from cloning, with its frequent disasters in fetal life." Parents who wish to engage in direct genetic manipulation to produce a child with a disabling trait should have a very hard time finding a physician who would perform the procedure, and proving to a jury that they did not intend to harm their child, or that they acted as reasonably prudent parents. In this instance, Smolensky's argument for parental tort liability is at its strongest.

In examining potential tort liability for parental preimplantation interventions, courts should consider the medical risks of undertaking the procedures necessary to enacting the parents' wishes. Whether their goal is simply to have a child, to select a child who will or will not have a specific disorder, or to alter the child's DNA to have or avoid a specific condition, these risks shed light on parental intent as well as their potential negligence. Including these risks broadens the scope of parental tort liability for preimplantation interventions. However, the decision to accept these risks or to opt to have a child with a disabling condition does not occur in a vacuum. The existence of potential benefits to the children of the procedure should also factor into a court's consideration of intent and negligence.

B. Benefits Associated with Preimplantation Decisions

For parents, preimplantation decisions do not only include the risk to the future child's health or his/her right to an open future, they also

that in August 2007, GeMCRIS reported 139 active trials).


58. Smolensky, supra note 1, at 301.

contain the broader scope of family dynamics, economic realities, and cultural norms. By not fully considering these factors, Smolensky’s argument overstates the harm associated with preimplantation genetic manipulation to produce a child with a disabling condition.60 If researchers eliminate the risks associated with embryonic gene therapy, in some instances, a reasonable parent, considering all of the risks and benefits, could find that her child may have a better life with the disability than without.

The argument for being born into the same cultural experience as one’s parents is strongest and most likely within the context of the Deaf community, and for the sake of brevity, I will focus on it exclusively in this section. In the absence of significant risks associated with gene therapy, reasonable deaf parents could find that their child would have a better life as a member of the Deaf community, than as a hearing child permanently in between cultures.61

Many scholars and members of the Deaf community argue that being deaf is not a disability.62 In fact, only a small percentage of hearing children born to deaf parents, who are intimately familiar with both the Hearing and the Deaf cultures, believe that being unable to hear is intrinsically disabling.63 Being deaf opens the door to membership in a linguistic and cultural minority with a dynamic language, and a rich and diverse population.64 Deaf individuals maintain an extensive array of life options and possible career paths.65 Just as many hearing parents prefer to raise hearing children, many deaf parents may believe that they are better equipped to raise a child within their own cultural bounds.66

In determining whether a harm has occurred, courts should weigh the overall experience of being raised in the Deaf community against the

60. In her discussion of battery, Smolensky does not discuss the potential benefit to the child of being born into his or her parents’ culture or of the improved family dynamics. See Smolensky, supra note 1, at 318–20. However, she briefly raises this issue as a challenge to intentional battery claims in her discussion of negligence. Id. at 321. In her discussion of negligence, she offers a solution in which courts might emphasize that parents have wide discretion in child rearing and that would “protect legitimate parental prerogatives,” but never explicitly discusses the benefits that could result from a parental decision to have a child with a disability and the necessity of balancing those risks and benefits. Id. at 340 (quoting Parent-Child Immunity: A Doctrine in Search of Justification, 50 FORDHAM L. REV. 489, 526 (1982)).

61. I am using the Deaf community in this example because it provides the most likely case for the use of genetic modification to have a child with a disabling trait.

62. Robert A. Crouch, Letting the Deaf Be Deaf: Reconsidering the Use of Cochlear Implants in Prelingually Deaf Children, 27 HASTINGS CENTER REP. 14, 17 (1997) (arguing that the predominant notion that the deaf are “merely and wholly disabled—is wrong and that we should quickly disabuse ourselves of this ill-begotten notion”).

63. PRESTON, supra note 11, at 227.

64. Id.


66. Id. (“Being deaf does not foreclose legal, scientific, academic, acting, [or] music careers, among others.”).
experience of being raised as a hearing child with deaf parents, as this comparison more accurately represents the decision facing deaf parents. More factors contribute to this analysis than just the loss of hearing. For deaf parents, raising a hearing child presents many challenges involving interpretation, cultural identity, education, and socialization. In his book, *Mother Father Deaf*, Paul Preston recounts the experiences of 150 hearing children of deaf parents. While these individuals had a variety of positive and negative experiences, they discussed numerous difficult family dynamics that may explain why some deaf parents prefer to have deaf children. Hearing children born to deaf parents also bear significant responsibilities for navigating the boundary between the Hearing and Deaf cultures from a young age. Often the hearing children of deaf parents are asked to interpret for their parents, and nearly all of them had an "interpreting 'horror story'" in which they had to interpret for their parents in an inappropriate situation, which ranged from a five or six year old interpreting her mother's breast cancer diagnosis to a teenager being asked to interpret for her parents' divorce proceedings, to a child interpreting at her father's funeral. Preston noted that over half of the individuals he interviewed used "popular psychological terms to describe their family obligations: 'premature duties,' 'parentified child,' 'overly responsible,' 'a little adult,' 'a lost childhood.' While a number of Preston's informants said that they were happy to take on additional responsibilities to aid their parents, and that the added responsibilities prepared them well for adulthood, others "felt they had been crushed by their family responsibilities and by a family system that dissipated their childhoods." At the conclusion of his book, Preston describes the hearing children of deaf parents as

> People without culture—straddling the land between the Deaf and the Hearing. Their family experiences include both the normalcy of deafness and the normalcy of hearing, the stigma of deafness and the tyranny of hearing.

... We speak with blended and broken voices. We speak to hearing parents and hearing educators who never fully understood or accepted deafness, to deaf parents who were shut out of a Hearing world and learned to reject and mistrust Hearing ways, and to the vast majority of others who may learn from our struggles at finding out who we are.

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68. *Id.* at 146-47.
69. *Id.* at 151.
70. *Id.* at 155.
71. *Id.* at 236-37.
Courts should consider the role of these sentiments in the difficult choices faced by parents in determining whether a preimplantation battery or negligent act occurred.

Parents opting to undergo IVF and genetic manipulation to have a child with a disabling condition incur significant personal expense and discomfort to make these choices, and presumably they have given extensive thought to their decision. The known requests for preimplantation genetic selection encompass disabilities that enable individuals to have a relatively full life, i.e., the ones for which a reasonable person might successfully argue that the benefits of being a part of a particular community might outweigh the reduction in the child’s open future. No parents have requested children with devastating disorders such as Tay-Sachs or Fanconi anemia. For children with these conditions, life is difficult, painful, and short. In the case of genetic manipulation for a disability such as deafness or achondroplasia, courts should consider the psychological impact on the child of being different from their parents and their parents’ culture, and the parents’ ability to successfully raise a child with such differences. These considerations can significantly impact the scope of parental tort liability for both intentional and negligence-based claims.

III. The Scope of Parental Tort Liability

A. Intentional Torts

While Smolensky is correct that intentional tort claims appear at first to be the most appropriate for preimplantation interventions, challenges associated with intentional tort claims make negligence claims more viable. In single intent jurisdictions, the liability of parents to children born through ART could be endless. Assisted reproduction remains highly technical and fraught with opportunity for harm to the embryo. If intent to contact the embryo will give rise to a battery claim for any harmful or offensive result that occurs, many parents and physicians may become significantly more reluctant to engage in IVF, PGS, or genetic modification. While most courts remain unwilling to entertain wrongful life claims by children suing for harms resulting from the procedure that brought them life, such as IVF, children could still sue for harms that result from genetic modification, transfer of multiple

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embryos, or embryo biopsy. Given the variable risks and benefits involved for parents in making such preimplantation decisions, permitting claims under battery in single intent jurisdictions seems inappropriate to capture the nature of the decision, except in the most egregious cases.

In dual intent jurisdictions, proving that the parents intended both the contact and the harm also presents significant challenges. Such a claim requires proving that the parents believed their actions would be harmful to the future child. Few parents willing to go through the physical rigors and expense of assisted reproduction would do so to knowingly harm their child. In cases of direct genetic modification to produce a disability, Smolensky argues that even though some parents may not believe that the disability harms the child overall, courts should use an objective standard of offense, rather than a subjective one. She argues that:

Under an objective standard of offense, genetic traits such as deafness or achondroplasia are almost certain to be considered offensive to a reasonable sense of personal dignity. This is illustrated by the fact that most people would be offended if they were unconscious and another person removed their sense of hearing.

However, even an objective standard is not immune to specific circumstance and context. Jurors should be asked to consider what a reasonable person would do under similar circumstances. Of course a reasonable hearing individual would object to being deafened without their consent while unconscious, but whether a reasonable person would find that deaf parents had intentionally harmed their child by rendering it deaf before birth is more subtle and open to question. In addition, the overall harm and perceived disability of never hearing is arguably less than living in the hearing world and then losing the ability. Proving intended harm in these cases will be more challenging than proving negligence arising from engaging in a procedure when the risks significantly outweighed the benefits.

B. NEGLIGENCE

With respect to negligence, I support Smolensky's argument in favor of creating a parental duty of care for preimplantation genetic


75. Smolensky, supra note 1, at 319.

76. Id. 319-20.

interventions. However, I would broaden this argument to include all ART choices made prior to embryo transfer, and account for the range of risks and benefits of undergoing the procedure. Individuals should owe a duty to their potential offspring to act as reasonably prudent parents when making choices that do not conflict with the mother's bodily integrity.\textsuperscript{78}

Preimplantation decisions that occur outside the mother's body, and therefore do not compromise the mother’s bodily integrity, often have serious implications for the health of the prospective child. Given the complete level of control possessed by the parents, and the inability for the child to assent, I agree with Smolensky that individuals undergoing ART should have a duty to act as reasonably prudent parents.\textsuperscript{79} This duty should require parents to weigh the risks and benefits of engaging in an ART decision, and only engage in those activities that a reasonable parent in similar circumstances would, given the attendant risks and benefits to the prospective child. Guidelines for on the risks of engaging in certain procedures, like multiple embryo transfer, embryo biopsy, and embryonic genetic manipulation may assist physicians and parents in determining which procedures are appropriate. When prospective parents make ART decisions where the risks to their potential offspring clearly outweigh the benefits and those risks materialize, the parents should be liable in tort to their children. However, the threat of a potential tort suit should not be the only detraction from or guidance on appropriate uses of ART.

IV. THE CASE FOR REGULATION

Although I agree with Smolensky that courts should permit lawsuits by children against their parents for preimplantation decisions in certain limited contexts, I disagree with her that tort liability may offer a better mechanism than regulation for protecting children born through ART. Since I have detailed my argument in favor of oversight for preimplantation genetic screening and ART elsewhere,\textsuperscript{80} I will limit my discussion of regulation here to three small points: discrimination against the disabled, preemptive protection, and consistency.

First, Smolensky's argument against regulation stems from the challenge of addressing the moral and eugenic issues that arise from genetic selection and manipulation.\textsuperscript{81} The disability community has

\textsuperscript{78} Protecting the mother's right to bodily integrity provides an important legal boundary for the scope of parental tort liability for harm to their potential offspring. Smolensky gives a detailed discussion of the role of bodily integrity in preimplantation decisions in her article, which I will not recount here, but that I agree with. \textit{Id.} at 325–28.

\textsuperscript{79} \textit{Id.} at 323 & n.136.

\textsuperscript{80} King, supra note 49.

\textsuperscript{81} Smolensky, supra note 1, at 300.
expressed concern about any form of government regulation of genetic testing for reproductive purposes, for fear that the government might encourage individuals to select against embryos and fetuses with genes associated with disabling traits. 82 Adrienne Asch, a disability rights advocate and scholar, has spoken out against any government regulation proposing to list those conditions appropriate for reproductive genetic testing. 83 However, the creation of a regulatory agency that works with representatives from the disability community to develop regulations for the use of reproductive genetic testing could bring more light to their experiences, values, and concerns than the action of a lay jury deciding how much money to reward a child for being born with a disabling condition. A large jury verdict in favor of a child against his parents for creating him with the same disability they had could significantly increase discrimination against members of the disability community.

While Smolensky presents a strong argument in favor of the lay juror’s ability to navigate the reasonable person standard, the lay person’s perception of the harm associated with a disabling trait may not be representative of the harm actually experienced by the child. For example, the experience of being deaf is more disabling for deaf children of hearing parents than it is for deaf children of deaf parents. 84 Research using data from test scores, teacher-counselor ratings, and family interviews found that deaf children of deaf parents have more positive self-evaluations, including self-esteem, self-confidence, and positive adjustment to deafness, than deaf children of hearing parents. 85 Positive family climate toward deafness also makes a significant difference in the child’s overall self-image, and has a higher impact within families of deaf parents and deaf children. 86 Likewise, research demonstrates that deaf children in hearing families do not experience the same richness or consistency of language input as that provided by hearing parents to hearing children, or deaf parents to deaf children, which directly impacts language comprehension and expression. 87 As a result, hearing individuals’ perception of the level of harm resulting from being deaf may be significantly increased, even if they have a deaf child. While leaving the decision of how harmful certain traits are to the tort system avoids the risk of reverting to state-sponsored eugenics, society remains

85. Id. at 434.
86. Id.
vulnerable to the much greater potential for ART to do through "the collective impact of individual decision-making what governments have imposed in the past in the name of bettering the human condition."

Second, in addition to a regulatory agency offering more of a voice to the disability community, regulation offers ART children more protection from harm. Smolensky argues that parental use of genetic manipulation to create a child with a disabling condition creates both a legal and moral harm.8 The crux of her argument depends on the genetic manipulation limiting the child's "right to an open future."89 Given the passion with which she argues that using genetic manipulation to create a disability constitutes a significant harm, I am surprised that she favors tort liability over regulation. For the small number of children who may find themselves in this situation, tort liability can only provide monetary restitution; it cannot restore their capacity, nor reverse the harm. In addition, restitution requires the child to sue his or her family members, placing a great deal of strain upon intimate familial relationships. A regulatory scheme that addressed all of assisted reproductive technologies could preemptively limit PGS and gene therapy to choices where the benefits outweighed the risks, and therefore go much further toward protecting children from these types of harms.

Finally, a national regulatory scheme designed to govern all assisted reproductive technologies, including PGS and gene therapy, would offer parents and ART clinicians a consistent set of standards from which to make decisions. Guidelines on appropriate care would strengthen physician resolve against parental attempts to "strong-arm" them into agreement." They would also provide parents with a consistent set of expectations of the appropriate uses of various assisted reproduction procedures based on their risks and benefits. Consistency in ART regulation is of the utmost importance, as many patients travel out of state to have the procedures.92 Otherwise, patients could travel across state lines to have procedures that may result in tort liability after the child is born in a different state.

I agree with Smolensky that creating national regulations may encourage "medical tourism" and regulating genetic interventions overseas will be extremely difficult.93 However, what an individual may do overseas has rarely sufficed as a reason not to regulate in the United

89. Smolensky, supra note 1, at 311-14.
90. Id. at 309.
91. Id. at 305.
92. United States v. Wilson, 73 F.3d 675, 681 (7th Cir. 1995) (finding that there is substantial interstate travel involved in reproductive health care).
93. Smolensky, supra note 1, at 306.
States. As a leader in ART, PGS and gene therapy, the standards we set for ourselves will not only provide guidance to U.S. citizens about what uses are safe, medically justifiable, and ethically appropriate, but they will govern the development and use of these new technologies both in the United States and abroad.

CONCLUSION

The rapid expansion of assisted reproductive technologies in the United States will continue to raise challenging questions regarding the boundaries of parental rights and responsibilities to their children. Smolensky’s article contributes to this growing literature by addressing the scope of parental tort liability for preimplantation genetic interventions. I agree with her proposal to create a parental duty to act as reasonably prudent parents in similar preimplantation decision making. Determining whether an individual acted as a reasonably prudent parent should depend on the relative balance of risks and benefits involved in the procedure. In the case of direct genetic manipulation to bring about a disability, the jury should consider the risks of embryonic gene therapy, the loss of function associated with the disability, and any potential benefits for the child of having the disability. Such a duty would promote the dissemination of information to parents on the risks associated with using ART for different purposes and the potential consequences of their decisions.

On the other hand, tort liability cannot adequately solve the legal, ethical, and medical dilemmas associated with advances in assisted reproduction on its own. An independent regulatory body that requests input from a wide variety of citizens, including numerous members of the disability community, will have a better opportunity to adequately address the challenges of ART use as they arise, while still enabling people to capitalize on the benefits of the technology. I am encouraged by the rich debate that is beginning to exist within the legal literature regarding the use and limits of ART, and hope it continues for some time to come.