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# Article

## DISABILITY AND DESIGNER BABIES

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*If deaf parents purposely use new genetic technologies to give their child the genes for deafness, have the parents harmed the child? This and similar questions regarding parents who make genetic choices in favor of disability have preoccupied much of the scholarship regarding new artificial reproductive technologies. Some have argued that we should determine whether a child has been harmed by pondering whether the child's "right to an open future" has been violated by the parents' genetic intervention. If that right is violated, some say, the parents should be subject to tort liability for inflicting a harm upon the child.*

*This Article considers the consequences of attempting to hold parents liable in tort for making genetic decisions in favor of socially disfavored physical attributes, such as disabilities. A legal scheme that asks judges and juries to separate "good" physical attributes from "bad" ones is problematic, especially when dealing with disabilities. Parents who have personal experience with the physical traits in question are better equipped to decide what is best for their offspring than jurors who have less experience and less at stake. Using the "open future" framework to second-guess parental decisions about socially disfavored physical traits only disrupts the parent-child relationship and suggests that discriminatory attitudes are natural and acceptable.*

*Moreover, the concern over genetic interventions in favor of disability is largely misplaced. Disabled parents who want disabled children are few in number and diverse in purpose. The recent focus on these parents in the debate over genetic intervention improperly assumes that such parents are incapable of making good choices and that the physical traits they prefer are inherently damning.*

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*All that is not given is lost.*<sup>1</sup>

## I. INTRODUCTION

Two years ago, a fertility clinic in New York made headlines by claiming to offer parents the opportunity to choose the eye color, race, and hair color of their future children.<sup>2</sup> The clinic said it could use genetic testing known as preimplantation genetic diagnosis (“PGD”) to determine which embryos have genetic markers of the parents’ preferred attributes.<sup>3</sup> The embryos with the preferred genetic markers would then be implanted.<sup>4</sup> Some responded with delight to the clinic’s promise to create so-called “designer babies,” while others condemned the practice.<sup>5</sup>

There is some doubt whether current technology gives physicians the ability to do what this clinic advertised – i.e., specifically test for the genetic markers for attributes like eye color and race in embryos prior to implantation.<sup>6</sup> There is little doubt, however, that such technology will soon be available.<sup>7</sup> Moreover, some predict that before long, scientists will be able not only to *test* embryos for specific genetic attributes, but also they will actually be able to *change* the genetic structure of the embryo to match the attributes preferred by the parents.<sup>8</sup> The prospect of genetic manipulation of embryos, often called “genetic intervention,” raises a number of questions about identity, diversity, and the proper

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<sup>1</sup> Indian proverb. See Rumer Godden, *Luck That Seems Like Torture*, N.Y. TIMES, Nov. 3, 1985 (reviewing DOMINIQUE LAPIERRE, *THE CITY OF JOY* (Kathryn Spink trans., 1985)).

<sup>2</sup> Gautam Naik, *A Baby, Please. Blond, Freckles – Hold the Colic*, WALL ST. J., Feb. 12, 2009, at A10; Hattie Kauffman, “*Designer Babies*” *Ethical?*, CBS NEWS: THE EARLY SHOW (Mar. 3, 2009, 7:24 AM), <http://www.cbsnews.com/stories/2009/03/03/earlyshow/health/main4840346.shtml>; Gina Salamone, *Custom-Made Babies Delivered: Fertility Clinic Doctor’s Design-A-Kid Offer Creates Uproar*, N.Y. DAILY NEWS (Mar. 4, 2009), [http://www.nydailynews.com/news/2009/03/02/2009-03-02\\_custommade\\_babies\\_delivered\\_fertility\\_cl.html#ixzz0dHZmEE4M](http://www.nydailynews.com/news/2009/03/02/2009-03-02_custommade_babies_delivered_fertility_cl.html#ixzz0dHZmEE4M).

<sup>3</sup> See services cited *supra* note 2 (explaining that reproductive technologies are allowing parents to choose the attributes of their children).

<sup>4</sup> See services cited *supra* note 2 (noting that lab-created embryos with the preferred traits are used).

<sup>5</sup> Salamone, *supra* note 2; see also Kauffman, *supra* note 2. The owner of the clinic responded to critics as follows: “Genetic health is the wave of the future . . . It’s already happening and it’s not going to go away. It’s going to expand. So if they’ve got major problems with it, they need to sit down and really examine their own consciences because there’s nothing that’s going to stop it.” Salamone, *supra* note 2.

<sup>6</sup> See services cited *supra* note 2 (noting that some doctors question the ability to give parents their pick of traits).

<sup>7</sup> See services cited *supra* note 2 (suggesting that technology will likely be available in a couple years).

<sup>8</sup> DENA S. DAVIS, *GENETIC DILEMMAS* 35 (2d ed. 2010); Nancy Pham, *Choice v. Chance: The Constitutional Case for Regulating Human Germline Genetic Modification*, 34 HASTINGS CONST. L.Q. 133, 134 & n.10 (2006) (citing advancing research).

role of technology in conception. Should genetic intervention be permitted? If so, should there be limits on which genetic traits may be chosen? And if we do impose limits, who is best qualified to decide and enforce those limits?

Presumably, parents who attempt genetic intervention would do so in the hope of benefitting their child. Recently, however, a number of commentators have expressed concern that—despite good intentions—some parents may use genetic intervention to impose upon their offspring attributes that are actually *harmful* to the child.<sup>9</sup> Two examples of purportedly harmful genetic interventions are repeated in the literature, both of which center around parents with disabilities who want to have a child that shares their same disability. First, deaf parents might use genetic intervention to have a deaf child.<sup>10</sup> Second, parents of short stature<sup>11</sup> might use genetic intervention to have a child with achondroplasia.<sup>12</sup> Worried that deafness and short stature might be harmful to children, some commentators have called for legal remedies to prevent parents from using genetic intervention to produce a child with physical attributes commonly associated with disability.<sup>13</sup>

Thus, the debate over parental liability for genetic decisions seems to call for determinations about the consequences of particular disabilities<sup>14</sup> and, impliedly, the competence of disabled parents to make beneficial

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<sup>9</sup> DAVIS, *supra* note 8, at 61–90; Owen D. Jones, *Reproductive Autonomy and Evolutionary Biology: A Regulatory Framework for Trait-Selection Technologies*, 19 AM. J.L. & MED. 187, 220–21 (1993); Kirsten Rabe Smolensky, *Creating Children with Disabilities: Parental Tort Liability for Preimplantation Genetic Interventions*, 60 HASTINGS L.J. 299, 299–301 (2008) [hereinafter Smolensky, *Genetic Interventions*].

<sup>10</sup> I have attempted to follow the convention of capitalizing the word “deaf” when referring to the culture and community and not capitalizing the word when referring to the physical condition. See Edward Dolnick, *Deafness as Culture*, ATLANTIC MONTHLY, Sept. 1993, at 38. In many cases, it is difficult to distinguish the cultural aspects of deafness from the physical aspects because they overlap.

<sup>11</sup> I use the terms “persons of short stature” and “persons with dwarfism” as interchange. I also make reference to persons with achondroplasia, which is the most common genetic condition causing dwarfism. See *Frequently Asked Questions*, LITTLE PEOPLE AM., <http://www.lpaonline.org/mc/page.do?sitePagelD=84634&orgId=lpa> (last visited Mar. 14, 2011) (providing answers to numerous questions relevant to dwarfism).

<sup>12</sup> DAVIS, *supra* note 8, at 61–90; Jones, *supra* note 9, at 223; Smolensky, *Genetic Interventions*, *supra* note 9, at 300, 308.

<sup>13</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 299.

<sup>14</sup> I use the term “disability” in this Article to refer to physical traits that are generally associated with disability. Such physical traits might physically limit a person, or the limitations might derive, in whole or in part, from environmental factors, such as physical barriers and social attitudes. This definition purposely treats disability as vague and protean—because so too are the attitudes and environmental factors that can make a physical trait disabling. To emphasize this point, I use “disability” interchangeably with “socially disfavored physical traits.”

genetic decisions for their children.<sup>15</sup> In a recent symposium,<sup>16</sup> Professor Kirsten Rabe Smolensky argued that parents who choose genetic intervention in order to have a child who has a disability should be subject to tort liability if the parents' genetic choice is later found to have violated the child's "right to an open future."<sup>17</sup> Not wanting to prohibit all genetic interventions but rather only those that are harmful to children, Smolensky would leave it to judges and juries to decide when a parent's genetic intervention in favor of disability is sufficiently harmful to warrant liability.<sup>18</sup>

This Article considers the consequences of attempting to hold parents liable in tort for making genetic decisions in favor of socially disfavored physical attributes, such as disabilities. A legal scheme that asks judges and juries to separate "good" physical attributes from "bad" ones is problematic, especially when the physical attributes in question are commonly viewed as disabilities. When judges and juries are forced to speculate about the future consequences of physical conditions that most of them have never experienced, they are likely to rely upon long-established social stereotypes that disability is inherently tragic. This can lead to wrong results and, equally disturbing, reinforcement of negative views about disability and the competence of parents with disabilities.

But there is also a more subtle problem with the debate over genetic intervention when it comes to disability. Commentators tend to use terms such as "diminishment," "untherapeutic," and "defect" without explaining how a decision maker like a judge or jury could realistically and objectively determine which physical attributes fall into these categories. The result of this ambiguity is that the debate forever hangs in the air, awaiting the moment when a decision maker will tell us what kinds of genetic interventions are harmful and which ones are neutral or beneficial. No one points to a particular disability as being uniformly harmful. Yet the debate continues to rely on the assumption that there remains some terrible, albeit unidentified, threat of parents harming children by favoring attributes associated with disability. Indeed, given how few parents with disabilities actively seek to have children who share their disability, this threat, if there is any, is hardly worthy of alarm. Deconstructing the role of disability in this debate provides insights into the unspoken cultural and moral assumptions embedded in

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<sup>15</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 317, 330.

<sup>16</sup> *See id.* at 299. This Article primarily responds to the arguments made in that symposium and expands upon the issues that have received less attention.

<sup>17</sup> *Id.* at 310-12.

<sup>18</sup> *Id.* at 339-41.

arguments about the intersection between genetic intervention, physical difference, and parenthood.

Part II of this Article gives a general background of the current and emerging technologies for choosing the genetic makeup of a child, the parties who control and influence genetic decisions, and the existing legal doctrines that might be evoked if a child sought to hold her parents liable in tort for genetic intervention. Part II.B through Part II.C then summarizes Smolensky's proposal to expand tort liability and identifies some of the questions left open by Smolensky and her commentators. Part III reexamines the policy reasons that have been suggested in support of parental tort liability for genetic interventions. Although there may be good reason to prohibit genetic intervention generally, there is no solid basis for prohibiting genetic intervention only when parents are seeking to give their child socially disfavored attributes. Moreover, it appears that there is no great threat of parents using genetic intervention to choose attributes that are ultimately harmful to children. Part IV provides a critique of Smolensky's proposal. Judges and juries are unlikely to be able to properly determine the consequences of genetic decisions in favor of disability. Indeed, holding parents liable for negative social views about disability only serves to legitimate those views. The final section offers some thoughts on why disability has been a focal point in the debate over genetic intervention, ultimately concluding that parents who show an appreciation for genetic diversity should not be threatened with tort liability but rather should be given the benefit of the doubt.

## II. BACKGROUND

### A. *The Technologies and the Gate-Keepers*

There are two general types of artificial reproductive technology at issue in this debate—one that currently exists in some forms and one that scientists expect to develop in the coming years. The first technology, genetic testing, is widely used to determine the genetic propensities of an embryo or fetus.<sup>19</sup> Often, parents who are not using in vitro fertilization ("IVF") and who are predisposed to an unwanted genetic trait use genetic testing to determine whether to continue a pregnancy.<sup>20</sup> Wide use of genetic testing has already changed the make-up of society: today, fewer children are born with Down syndrome, a result believed to

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<sup>19</sup> Angela M. Hannemann, *A New Routine: Assisting Patients in Responding to Prenatal Diagnosis*, 90 MARQ. L. REV. 337, 337–38 (2006); Lois Shepherd, *Protecting Parents' Freedom to Have Children With Genetic Differences*, 1995 U. ILL. L. REV. 761, 775–76.

<sup>20</sup> Hannemann, *supra* note 19, at 337–38; Shepherd, *supra* note 19, at 775–76.

be caused by a growing number of parents aborting fetuses that have tested positive for the genotypes associated with Down syndrome.<sup>21</sup>

Parents who are using IVF to become pregnant may use PGD to help them decide which embryos to implant and which ones to discard.<sup>22</sup> Currently, PGD can be used to test for genotypes of a number of genetic conditions, including Down syndrome and susceptibility to some cancers.<sup>23</sup> In the United States, parents are free to screen embryos using PGD and select embryos that have the parents' desired characteristics.<sup>24</sup> Indeed, fertility clinics routinely use PGD to help parents select embryos with the parents' preferred genetic attributes.<sup>25</sup>

In the vast majority of cases, parents use genetic testing to avoid having a child who has attributes associated with disability.<sup>26</sup> As Lois Shepherd notes, the practice of genetic testing itself suggests to parents that they should take some action based on the results—and usually that means not bringing a child with genetic differences to term.<sup>27</sup> A number of scholars have also shown that doctors and genetic counselors, whom parents rely upon to describe the consequences of genetic conditions, tend to emphasize the negative effects of genetic differences and thereby encourage parents to avoid bringing a child with such characteristics to term.<sup>28</sup> This general bias among healthcare providers, when combined with social pressure to have a “normal” child, makes parents hesitant to have a child who has socially disfavored genetic traits.<sup>29</sup>

Physicians not only serve as would-be experts on the consequences of genetic conditions, they also act as discretionary gatekeepers to Assisted Reproductive Technology (“ART”). Fertility clinics routinely screen patients and may refuse fertility services when they believe that the parents are unfit or that such services are not in the best interests of

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<sup>21</sup> Hannemann, *supra* note 19, at 338–39 (“[C]urrently about 80% of fetuses diagnosed with Down Syndrome through prenatal tests are aborted.”).

<sup>22</sup> DAVIS, *supra* note 8, at 40–41; Pham, *supra* note 8, at 134 & nn.11–14.

<sup>23</sup> Dov Fox, *Silver Spoons and Golden Genes: Genetic Engineering and the Egalitarian Ethos*, 33 AM. J.L. & MED. 567, 567 n.2 (2007).

<sup>24</sup> In the UK, by contrast, parents are prohibited from implanting an embryo known to have genes for “a serious condition,” including genetic deafness. DAVIS, *supra* note 8, at 86–87.

<sup>25</sup> Susannah Baruch et al., *Genetic Testing of Embryos: Practices and Perspectives of U.S. In Vitro Fertilization Clinics*, 89 FERTILITY & STERILITY, May 2008, at 1055–57, available at <http://www.dnapolicy.org/resources/GeneticTestingofEmbryos.pdf>.

<sup>26</sup> Shepherd, *supra* note 19, at 777–79.

<sup>27</sup> *Id.*

<sup>28</sup> *Id.*; see also Cara Dunne & Catherine Warren, *Lethal Autonomy: The Malfunction of the Informed Consent Mechanism Within the Context of Prenatal Diagnosis of Genetic Variants*, 14 ISSUES L. & MED. 165, 191–93 (1998).

<sup>29</sup> Shepherd, *supra* note 19, at 777–79.



the future child.<sup>30</sup> In the United States, “patient screening is conducted in a haphazard manner, based on criteria fashioned by individual providers that may or may not conform to the voluntary codes of professional organizations.”<sup>31</sup> A number of ART physicians have stated openly that they would refuse to use PGD to help parents select a child with genetic deafness or achondroplasia.<sup>32</sup> Parents seeking to use PGD to select for an embryo with the genotypes for attributes associated with disability are likely to find that they must forum-shop to find a fertility clinic that will work with them.

Despite these barriers to using PGD to select an embryo with socially disfavored physical traits, there is a small number of reported cases of parents using PGD to ensure that their child has traits associated with disability. In 1995, one couple used PGD to select for a child with achondroplasia.<sup>33</sup> In a 2006 survey of 186 fertility clinics, three percent of clinics reported that they had used PGD to help parents select an embryo that had attributes associated with disability.<sup>34</sup> The survey, however, did not define “disability,”<sup>35</sup> and some have questioned whether the reported results are accurate.<sup>36</sup> In any case, there appears to be an interest among a small group of parents in having children with physical features associated with disability, in particular, features associated with short stature and genetic deafness.<sup>37</sup>

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<sup>30</sup> Kimberly M. Mutcherson, *Disabling Dreams of Parenthood: The Fertility Industry, Anti-Discrimination, and Parents With Disabilities*, 27 LAW. & INEQ. 311, 311–12 (2009).

<sup>31</sup> *Id.* at 319.

<sup>32</sup> Lindsey Tanner, *Some Ponder “Designer” Babies With Mom or Dad’s Defective Genes*, USA TODAY (Dec. 21, 2006, 3:09 PM ET), [http://www.usatoday.com/tech/science/genetics/2006-12-21-designer-disability\\_x.htm](http://www.usatoday.com/tech/science/genetics/2006-12-21-designer-disability_x.htm); Sarah-Kate Templeton, *Deaf Demand Right to Designer Deaf Children*, SUNDAY TIMES (Dec. 23, 2007), <http://www.timesonline.co.uk/tol/news/uk/health/article3087367.ece>. The extent to which physicians may refuse treatment based on their personal values, as opposed to based on the welfare of the patient or child, is subject to considerable debate. See, e.g., Robin Fretwell Wilson, *The Limits of Conscience: Moral Clashes Over Deeply Divisive Healthcare Issues*, 34 AM. J.L. & MED. 41, 42–43 (2008) (discussing the controversy over conscience-based refusals by healthcare professionals asked to provide emergency contraceptives).

<sup>33</sup> Faye Flam, *Designing the Family Tree a Road to Eugenics?*, BUFFALO NEWS, June 25, 1995, at F7. Furthermore, a deaf couple has also utilized artificial insemination to have a deaf child by choosing a sperm donor who had a family history of deafness. Merle Spriggs, *Lesbian Couple Create a Child Who Is Deaf Like Them*, 28 J. MED. ETHICS 283 (2002).

<sup>34</sup> Baruch et al., *supra* note 25, at 1054.

<sup>35</sup> See Johns Hopkins Univ. Genetics & Pub. Policy Ctr., *Preimplantation Genetic Diagnosis: Practices and Attitudes of Assisted Reproductive Technology Clinics*, GENETICS & PUB. POL’Y CTR. (April 2006), [http://www.dnapolicy.org/resources/PGD\\_Survey\\_Questionnaire.pdf](http://www.dnapolicy.org/resources/PGD_Survey_Questionnaire.pdf).

<sup>36</sup> See Tanner, *supra* note 32.

<sup>37</sup> See *supra* notes 25, 32–33 and accompanying text (noting that some parents seek to have children with genetic deafness or achondroplasia).

The second technology at issue—genetic intervention—is not yet available. Genetic intervention involves manipulating the genetic makeup of a fetus or embryo. Rather than simply testing an embryo for genetic traits, genetic intervention would involve changing the DNA of the embryo in an effort to produce the parents' preferred characteristics.<sup>38</sup> Geneticists predict that genetic intervention is more likely to work on gametes or embryos rather than children or adults.<sup>39</sup> Some predict that genetic intervention will, at least in the early stages, only be possible using an embryo prior to implantation.<sup>40</sup>

Currently in the United States, there are no laws directly addressing whether parents may use genetic intervention to have a child with particular characteristics.<sup>41</sup> Thus, if no regulations are put in place, once the technology becomes available, parents will be free to custom-design their perfect baby. That baby might grow up to disagree with her parents' genetic choices. If a child had her DNA modified through genetic intervention while she was still an embryo and later attempted to sue her parents for changing her genetic makeup, courts would need to cobble together common law and constitutional doctrines to decide whether to permit the lawsuit to go forward. The next section considers how courts might apply existing law to determine whether to permit a child to bring a tort action against her parents based on the parents' use of genetic intervention.

### B. Existing Law on Parental Liability for Prenatal Decisions<sup>42</sup>

A century ago, in *Dietrich v. Inhabitants of Northampton*, Oliver Wendell Holmes asserted the general common law rule that a fetus is not a separate legal person from its mother.<sup>43</sup> For seventy-five years, courts

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<sup>38</sup> Dov Fox explains the following: "Genes do not by themselves determine human physiology or psychology. Genes influence a person's genotype, the instructions for development and functioning in human beings. Genotype often diverges from phenotype, a person's manifested characteristics, as when genetically identical twins exhibit striking disparities among a wide range of phenotypic traits." Fox, *supra* note 23, at 568 n.3 (parenthetical omitted).

<sup>39</sup> *Id.* at 573–74.

<sup>40</sup> *Id.* at 567 n.2.

<sup>41</sup> DAVIS, *supra* note 8, at 86–87. Outside of the U.S., regulation of PGD varies. *Id.*

<sup>42</sup> Genetic intervention would probably not be a "prenatal" decision because it would take place prior to implantation. However, courts would likely look for guidance in tort cases involving prenatal injuries. In addition, courts may look to cases where claims of intentional or negligent infliction of emotional distress were brought based on mishandling of embryos. See, e.g., Ingrid H. Heide, *Negligence in the Creation of Healthy Babies: Negligent Infliction of Emotional Distress in Cases of Alternative Reproductive Technology Malpractice Without Physical Injury*, 9 MICH. ST. J. MED. & LAW 55, 58–59 nn.4–6 (2005).

<sup>43</sup> 138 Mass. 14, 17 (1884).

followed the rule laid out in *Dietrich*, holding that a child could not bring a tort action against another for injuries the child suffered in utero.<sup>44</sup> Beginning with *Bonbrest v. Kotz* in 1946, however, courts began to move away from the traditional rule.<sup>45</sup> Noting that a developed fetus can survive independent of its mother, the *Bonbrest* court held that a viable fetus is indeed a separate legal person who may bring a cause of action for prenatal injuries.<sup>46</sup> Following *Bonbrest*, courts in most jurisdictions have held that a viable fetus—i.e., one capable of surviving outside the womb—is a separate legal person from its mother.<sup>47</sup> In addition, some jurisdictions permit tort claims to be brought on behalf of non-viable fetuses.<sup>48</sup>

Still, it is uncertain whether courts would treat an embryo as a separate legal entity capable of suffering harms that could form the basis of a tort action against a third party.<sup>49</sup> Even if courts do give this kind of legal status to pre-implantation embryos, it is unclear whether courts would permit children to bring tort claims against their parents based on genetic intervention that occurred when the child was an embryo. The viability of a claim based on genetic intervention depends greatly on how courts categorize genetic intervention. If genetic intervention is treated as a form of negligent prenatal care or as an intentional tort to the person, courts in some jurisdictions may permit the child to bring a tort action against her parents. If, however, genetic intervention is treated as a medical or reproductive decision, courts are very unlikely to allow recovery.

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<sup>44</sup> Linda C. Fentiman, *The New "Fetal Protection": The Wrong Answer to the Crisis of Inadequate Health Care for Women and Children*, 84 DENV. U. L. REV. 537, 576 (2006) [hereinafter Fentiman, *The New Fetal Protection*].

<sup>45</sup> 65 F. Supp. 138 (D.D.C. 1946).

<sup>46</sup> *Id.* at 140.

<sup>47</sup> Linda C. Fentiman, *Pursuing the Perfect Mother: Why America's Criminalization of Maternal Substance Abuse Is Not the Answer—A Comparative Legal Analysis*, 15 MICH. J. GENDER & L. 389, 412 (2009) [hereinafter Fentiman, *Pursuing the Perfect Mother*].

<sup>48</sup> *Id.*

<sup>49</sup> Professor Ouellette effectively frames the question as follows: "Can a parent or healthcare provider inflict a legally cognizable harm on an embryo before it is implanted, when the same parent or provider could dispose of the embryo without penalty?" Alicia R. Ouellette, *Insult to Injury: A Disability-Sensitive Response to Smolensky's Call for Parental Tort Liability for Preimplantation Genetic Interventions*, 60 HASTINGS L.J. 397, 397 (2008) [hereinafter Ouellette, *Insult to Injury*]; see also *Davis v. Davis*, 842 S.W.2d 588, 597 (Tenn. 1992) ("[P]reembryos are not, strictly speaking, either 'persons' or 'property,' but occupy an interim category that entitles them to special respect because of their potential for human life.").

### 1. Parental Tort Immunity and the Right to Make Medical and Reproductive Decisions

The doctrine of parental tort immunity has had an unsettled life in most jurisdictions.<sup>50</sup> This doctrine, which gave parents absolute immunity from civil actions brought by their minor children, was developed in three cases commonly referred to as “the great trilogy.”<sup>51</sup> These foundational decisions gave various justifications for giving parents immunity from claims by their children, including the state’s interest in preserving family harmony and the need to protect parental discretion and authority.<sup>52</sup>

Some states adopted the parental immunity doctrine wholesale while others adopted parental immunity only in limited situations.<sup>53</sup> A handful of jurisdictions never adopted the doctrine.<sup>54</sup> In 1963, the Wisconsin Supreme Court reversed its earlier adoption of parental immunity and abrogated the doctrine except in limited circumstances.<sup>55</sup> *Goller v. White* began a “long-overdue landslide” of court decisions restricting the scope of parental immunity.<sup>56</sup>

Today, parental tort immunity survives only in qualified forms in those jurisdictions that have adopted the doctrine.<sup>57</sup> Some jurisdictions maintain parental immunity except in cases “of abuse or intentional, wanton acts” by parents.<sup>58</sup> Other jurisdictions have excepted from parental immunity injuries resulting from certain acts like driving or business activities.<sup>59</sup> A third group of jurisdictions follow the approach taken by Wisconsin in *Goller*. Under the *Goller* test, parental tort immunity is retained only in matters involving ordinary parental discretion and authority. Parental tort immunity may be invoked only in the following situations: “(1) where the alleged negligent act involves an exercise of parental authority over the child; and (2) where the alleged

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<sup>50</sup> Irene Hansen Saba, *Parental Immunity from Liability in Tort: Evolution of a Doctrine in Tennessee*, 36 U. MEM. L. REV. 829, 835–36 (2006).

<sup>51</sup> *Id.* at 835; Martin J. Rooney & Colleen M. Rooney, *Parental Tort Immunity: Spare the Liability, Spoil the Parent*, 25 NEW ENG. L. REV. 1161, 1163 (1991); Benjamin Shmueli, *Love and the Law, Children Against Mothers and Fathers: Or, What’s Love Got to Do With It?*, 17 DUKE J. GENDER L. & POL’Y 131 (2010).

<sup>52</sup> Rooney & Rooney, *supra* note 51, at 1163; Saba, *supra* note 50, at 837–38.

<sup>53</sup> Saba, *supra* note 50, at 839–40.

<sup>54</sup> *Id.* at 836–37; Rooney & Rooney, *supra* note 51, at 1162 n.12.

<sup>55</sup> *Goller v. White*, 122 N.W.2d 193, 198 (Wis. 1963).

<sup>56</sup> Saba, *supra* note 50, at 843 (quoting W. PAGE KEETON ET AL., PROSSER & KEETON ON TORTS § 122 (5th ed. 1984) [hereinafter PROSSER & KEETON ON TORTS]).

<sup>57</sup> Only two states, Ohio and North Carolina, have abolished parental immunity completely without replacing it with some form of parental privilege. *Id.* at 848.

<sup>58</sup> *Id.* at 849 & n.95.

<sup>59</sup> *Id.* at 849 & nn.96–97.

negligent act involves an exercise of ordinary parental discretion with respect to the provision of food, clothing, housing, medical and dental services, and other care.”<sup>60</sup>

In negligence actions brought by children against their parents in California, parental tort immunity has been replaced by the “ordinarily reasonable and prudent parent” standard.<sup>61</sup> A parent’s acts or omissions will not result in liability if those acts conform to this standard.<sup>62</sup> A minority of states have followed California’s approach by adopting the ordinarily reasonable and prudent parent standard in place of parental immunity.<sup>63</sup>

Finally, some courts follow the Restatement’s approach to child-parent liability.<sup>64</sup> The Restatement abolishes parental immunity but provides that some activities are privileged because of the parent-child relationship.<sup>65</sup> The Restatement recognizes a privilege for parental discipline and “[t]he intimacies of family life,” and suggests that liability is warranted only when the parent’s conduct is “palpably unreasonable.”<sup>66</sup>

Although courts have developed different tests for assessing the limits of parental liability, there is at least some consensus that there is a “continued need for parental authority, discipline, and discretion in matters uniquely related to the home and family.”<sup>67</sup> Indeed, courts applying the different tests for parental liability have recognized that, except in extreme cases, judges and juries should not second-guess the social, cultural, economic, and philosophical factors that shape parental

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<sup>60</sup> *Goller*, 122 N.W.2d at 198.

<sup>61</sup> *Gibson v. Gibson*, 479 P.2d 648, 653 (Cal. 1971) (en banc) (emphasis omitted).

<sup>62</sup> *Saba*, *supra* note 50, at 849. It is unclear how, if at all, the reasonable parent standard differs from the reasonable person standard. See *Zellmer v. Zellmer*, 188 P.3d 497, 503 (Wash. 2008) (“[I]t should be noted that substituting ‘parent’ for ‘person’ is of little consequence, as a judge or jury always is required to consider the status of the actor in applying the reasonable person standard in a negligence case. Thus, the ‘reasonable parent’ standard is, in fact, the ordinary negligence standard.”); *Rooney & Rooney*, *supra* note 51, at 1174 (“[T]he difference between the two standards is purely semantic. The question of what the reasonable and prudent person would do in similar circumstances is equivalent to asking what the reasonable and prudent parent would do in similar circumstances. The substitution of the word ‘parent’ for ‘person’ adds nothing new to the question.”); *Shmueli*, *supra* note 51, at 153 (“This standard . . . label[ed] ‘the California approach,’ test[s] whether the parent had acted the way an ‘ordinary and careful’ parent would reasonably have acted towards his children in similar circumstances.”).

<sup>63</sup> *Zellmer*, 188 P.3d at 502 (collecting cases).

<sup>64</sup> *Saba*, *supra* note 50, at 850.

<sup>65</sup> RESTATEMENT (SECOND) OF TORTS § 895G(2) (1979) (“Repudiation of general tort immunity does not establish liability for an act or omission that, because of the parent-child relationship, is otherwise privileged or is not tortious.”).

<sup>66</sup> *Id.* at cmt. k.

<sup>67</sup> *Saba*, *supra* note 50, at 854.

discretion and authority.<sup>68</sup> As one court notes, if there were no privilege for parental discretion, “juries would feel free to express their disapproval of what they consider to be unusual or inappropriate child rearing practices by awarding damages to children whose parents’ conduct was only unconventional.”<sup>69</sup>

To the extent parental immunity survives, in some respects it runs parallel to the constitutional right of parents to exercise discretion in raising their children without state interference.<sup>70</sup> “[T]he interest of parents in the care, custody, and control of their children . . . is perhaps the oldest of the fundamental liberty interests recognized by [the Supreme] Court.”<sup>71</sup> So long as parents are capable of providing for their children, the state will not question the parents’ ability to make the best choices for their children.<sup>72</sup> Thus, “courts are generally unwilling to consider the child’s best interests when the desired intervention has the support of even one licensed medical provider.”<sup>73</sup>

Parental discretion over medical decisions is, however, not absolutely protected from state intervention. The state may intervene where “it appears that parental decisions will jeopardize the health or safety of [a] child.”<sup>74</sup> Thus, parents may not refuse their child life-saving treatment.<sup>75</sup> Drawing a proper line between parental discretion and

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<sup>68</sup> See, e.g., *Broadbent v. Broadbent*, 907 P.2d 43, 49 (Ariz. 1995) (acknowledging the need “to protect the right of parents to raise their children by their own methods and in accordance with their own attitudes and beliefs”); *Paige v. Bing Constr. Co.*, 233 N.W.2d 46, 49 (Mich. Ct. App. 1975) (displaying a court’s reluctance to “enable others, ignorant of a case’s peculiar familial distinctions and bereft of any standards, to second-guess a parent’s management of family affairs”); *Foldi v. Jeffries*, 440 A.2d 58, 62 (N.J. Super. Ct. App. Div. 1981) (“[D]iscretionary judgments involving the adequacy of child care and supervision can rarely be separated from the parents’ philosophical dispositions as to how the physical, moral, emotional and intellectual growth of their children can best be promoted.”); *Zellmer*, 188 P.3d at 503 (“Subjecting parents to liability for negligent supervision inevitably allows judges and juries to supplant their own views for the parent’s individual child-rearing philosophy.”); see also *Rooney & Rooney*, *supra* note 51, at 1169–70 (“A jury’s substitution of its decision concerning the exercise of authority or the provision of necessities in place of the parents’ decision would be based on only a brief view of the family situation and could only be judged against, at best, loosely defined standards.”).

<sup>69</sup> *Broadwell v. Holmes*, 871 S.W.2d 471, 476 (Tenn. 1994).

<sup>70</sup> *Saba*, *supra* note 50, at 879 (“Parental immunity under the *Broadwell* standard extends no further than the constitutional rights of the parent.”).

<sup>71</sup> *Troxel v. Granville*, 530 U.S. 57, 65 (2000).

<sup>72</sup> *Id.* at 68–69; see also *Parham v. J.R.*, 442 U.S. 584, 602 (1979) (asserting a “presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life’s difficult decisions”).

<sup>73</sup> Alicia Ouellette, *Shaping Parental Authority Over Children’s Bodies*, 85 IND. L.J. 955, 969 (2010) [hereinafter Ouellette, *Shaping Parental Authority*].

<sup>74</sup> *Commonwealth v. Robinson*, 910 NE.2d 911, 918 (Mass. App. Ct. 2009) (quoting *Custody of a Minor*, 379 N.E.2d 1053 (Mass. 1978)).

<sup>75</sup> *Custody of a Minor*, 379 N.E.2d at 1063.

appropriate state intervention is particularly difficult when the child is yet a fetus. Some courts have compelled pregnant women to undergo a Caesarean section when the health of the fetus was deemed at risk.<sup>76</sup> And in some states, a pregnant woman who engages in substance abuse may be civilly committed to protect the health of the fetus.<sup>77</sup> These developments in the "fetal protection" movement have been criticized by many as impinging upon the mother's rights to privacy and self-determination.<sup>78</sup>

Related to parents' discretion in raising their children is the right of parents to make reproductive decisions free from unwarranted state intrusion. The Supreme Court has asserted that parents have a fundamental right to decide whether to reproduce.<sup>79</sup> It is not clear, however, how far this procreative liberty extends.<sup>80</sup> Some have argued that parents' reproductive rights include the right to make genetic decisions about what kind of child to conceive.<sup>81</sup>

Courts have not asserted that these constitutional parental rights directly limit the scope of private lawsuits between children and parents. Courts have, however, recognized that tort law must take into consideration parents' privacy rights and discretionary authority.<sup>82</sup> Thus, the boundaries of private tort law are influenced, if not directly constrained, by constitutional limits on interference in family affairs. The policies underlying parental decision-making authority, in combination with the surviving aspects of parental tort immunity,

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<sup>76</sup> See *Pemberton v. Tallahassee Mem'l Reg'l Med. Ctr., Inc.*, 66 F. Supp. 2d 1247 (N.D. Fla. 1999); *Jefferson v. Griffin Spaulding Cnty. Hosp.*, 274 S.E.2d 457 (Ga. 1981); see also *Fentiman, The New Fetal Protection*, *supra* note 44, at 568; Nancy K. Rhoden, *The Judge in the Delivery Room: The Emergence of Court-Ordered Cesareans*, 74 CALIF. L. REV. 1951 (1986); cf. *In re A.C.*, 573 A.2d 1235, 1252 (D.C. 1990) (holding that a mother's wish to avoid a Cesarean section should be followed in "virtually all" cases).

<sup>77</sup> *Fentiman, The New Fetal Protection*, *supra* note 44, at 566-67 & nn.37-38 (collecting statutes).

<sup>78</sup> *E.g., id.* at 564-70.

<sup>79</sup> Lori B. Andrews & Nanette Elster, *Regulating Reproductive Technologies*, 21 J. LEGAL MED. 35, 45 (2000).

<sup>80</sup> *Id.*

<sup>81</sup> See *id.* (indicating that some commentators believe that the right of procreative liberty is broad and most objections to the ARTs do not justify a ban or burden on their use); Fox, *supra* note 23, at 569-70 (summarizing authorities arguing for a right to make genetic decisions).

<sup>82</sup> See, e.g., *Stallman v. Youngquist*, 531 N.E.2d 355, 361 (Ill. 1988) (detailing a mother's privacy and autonomy); *Chenault v. Huie*, 989 S.W.2d 474, 477 (Tex. Ct. App. 1999) (explaining that not all mothers are the same, as many have differing beliefs and resources); see also sources cited *supra* note 68 (discussing cases favorable to the protection of parents' rights).

suggest a policy for giving some deference to the varying social and cultural dynamics within families.

## 2. Tort Liability of Parents for Prenatal Injuries

Since Holmes's pronouncement in *Dietrich*, courts have struggled to determine when a civil action may be brought based on prenatal injuries. Today, every state permits a tort action against a third party for prenatal injuries if the child is born alive.<sup>83</sup> Most states allow a wrongful death action on behalf of a viable fetus that dies prior to birth due to prenatal injuries.<sup>84</sup> A minority of states also permit a wrongful death action on behalf of a non-viable fetus.<sup>85</sup>

Although there is some agreement that a child may bring a claim for prenatal injuries against a third party, it is not clear that the same action may be brought against the child's mother.<sup>86</sup> Cases in which the alleged tortfeasor is the mother of the plaintiff are considerably rarer—and more difficult. There are only six reported decisions addressing whether a child may bring an action for negligence against its mother for prenatal injuries suffered by the child.<sup>87</sup> Three of these courts permitted such an action<sup>88</sup> and three refused to recognize the cause of action.<sup>89</sup> There appears to be no case law addressing whether a child may sue her mother for intentionally inflicted prenatal injuries.<sup>90</sup>

The courts that have permitted negligence claims against a mother for prenatal injuries have focused primarily on the abrogation of the doctrine of parental tort immunity. In *Grodin v. Grodin*,<sup>91</sup> the plaintiff alleged that his mother negligently took tetracycline during her

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<sup>83</sup> Fentiman, *Pursuing The Perfect Mother*, *supra* note 47, at 411–12.

<sup>84</sup> *Id.*

<sup>85</sup> *Id.*

<sup>86</sup> Presumably an action for prenatal injuries inflicted by the father would be treated the same as injuries inflicted by a third party because fathers do not have the unique symbiotic relationship with a fetus that mothers do during pregnancy. See, e.g., *Chenault*, 989 S.W.2d at 475–76 (refusing to find a duty of a mother to her fetus because of “[t]he unique symbiotic relationship between a mother and her unborn child” and noting that “[i]n no other relationship is one so completely dependent upon another for life itself”).

<sup>87</sup> See sources cited *infra* notes 88–89 (listing three cases permitting a cause of action for prenatal injuries and three cases denying a cause of action for prenatal injuries).

<sup>88</sup> See *Nat'l Cas. Co. v. N. Trust Bank*, 807 So. 2d 86 (Fla. Dist. Ct. App. 2001); *Grodin v. Grodin*, 301 N.W.2d 869 (Mich. Ct. App. 1980); *Bonte v. Bonte*, 616 A.2d 464 (N.H. 1992).

<sup>89</sup> See *Stallman v. Youngquist*, 531 N.E.2d 355 (Ill. 1988); *Remy v. MacDonald*, 801 N.E.2d 260 (Mass. 2004); *Chenault*, 989 S.W.2d at 478.

<sup>90</sup> Clearly, a child can sue her parent for intentional torts inflicted after birth. To the extent courts permit claims based on prenatal negligence, they would most likely also permit claims based on intentionally tortious prenatal conduct.

<sup>91</sup> 301 N.W.2d 869.



pregnancy, causing plaintiff to develop discolored teeth. The Michigan Court of Appeals held that the lawsuit could proceed so that the jury could determine whether Mrs. Grodin's actions fell within one of the exceptions to Michigan's abrogation of prenatal tort immunity.<sup>92</sup> If taking tetracycline was not a "reasonable exercise of parental discretion," Mrs. Grodin could be held liable for her son's darkened teeth.<sup>93</sup>

Similarly in *Bonte v. Bonte*, a father brought an action against the mother as a next friend of a child who suffered prenatal injuries in a car accident.<sup>94</sup> He alleged negligence for failing to use reasonable care in crossing a street and failing to use the designated crosswalk.<sup>95</sup> The Supreme Court of New Hampshire permitted the action to go forward. Although recognizing "the unique relationship of the pregnant woman to her fetus," the court held that it was not "logical . . . to disallow [a] child's claim against the mother for negligent conduct that caused injury to the child months, days, or mere hours before the child's birth."<sup>96</sup> This principle was followed in *National Casualty Co. v. Northern Trust Bank*, where the Florida Court of Appeals also held that the abrogation of parental immunity allows for a child to bring a claim for prenatal negligence against her mother.<sup>97</sup>

The courts that have rejected claims for prenatal injury by a child against her mother have done so based in part on the problems inherent in attempting to develop a fair standard for judging a mother's prenatal decisions. In *Stallman v. Youngquist*, the Illinois Supreme Court held that a child who suffered prenatal injuries in a car accident could not sue her mother for negligently driving.<sup>98</sup> The court criticized the *Grodin* court's failure to recognize the unique relationship between a mother and fetus, which is "unlike the relationship between any other plaintiff and defendant."<sup>99</sup> Virtually every action of a pregnant mother as well as some actions taken prior to conception, the court said, may affect the

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<sup>92</sup> *Id.* at 870.

<sup>93</sup> *Id.* Michigan law provides an exception to the abrogation of parental immunity where "the alleged negligent act involves an exercise of reasonable parental authority over the child." *Id.* The *Grodin* court read this exception to require a jury determination of whether the parent acted "reasonably" in exercising parental authority. *Id.* at 871. This approach, however, seems to render the exception meaningless. If a parent's act is "reasonable" then there is no basis for a claim of negligence in the first place, and thus no need to inquire into whether parental immunity applies to the situation. *Id.*

<sup>94</sup> 616 A.2d 464 (N.H. 1992).

<sup>95</sup> *Id.*

<sup>96</sup> *Id.* at 466.

<sup>97</sup> 807 So. 2d 86, 87-88 (Fla. Dist. Ct. App. 2001).

<sup>98</sup> 531 N.E.2d 355, 361 (Ill. 1988).

<sup>99</sup> *Id.* at 360.

health of a fetus.<sup>100</sup> The court declined to recognize a duty that would make mothers the guarantors of the health of their unborn children: "Judicial scrutiny into the day-to-day lives of pregnant women would involve an unprecedented intrusion into the privacy and autonomy of the citizens of this State."<sup>101</sup>

In *Chenault v. Huie*, the Texas Court of Appeals followed *Stallman* and refused to permit a cause of action by a child injured by her mother's negligent alcohol and drug abuse during pregnancy.<sup>102</sup> The court further elaborated on the problems that arise from attempting to define a duty of a mother to her unborn child: "[R]eligious beliefs, social and economic status, age, maturity, and educational level differ significantly among women. Each of these factors may affect a woman's decisions with respect to prenatal care."<sup>103</sup> The court refused plaintiff's proposal that the court adopt a modified "reasonable person" standard in assessing prenatal conduct: "The 'reasonable person' standard . . . is simply not designed to apply to matters involving intimate, private, and personal decisions."<sup>104</sup> Because prenatal decisions "involve applying inherently subjective values," jurors would inevitably "apply their own personal views to the facts presented resulting in verdicts that would be varied and, in all probability, inconsistent and unpredictable."<sup>105</sup> The court condemned maternal alcohol and drug use during pregnancy, but expressed doubt that tort liability was the appropriate way to discourage such conduct.<sup>106</sup>

In the most recent case involving a claim against a mother for prenatal injuries, the Massachusetts Supreme Judicial Court in *Remy v. McDonald* held that a child could not bring a claim against her mother for prenatal negligence.<sup>107</sup> The court criticized the *Grodin*, *Bonte*, and *National Casualty* courts for "fail[ing] to address the collateral social and other impacts of the imposition of a legal (as opposed to a moral) obligation that would hold a pregnant woman to a standard of care towards her unborn child."<sup>108</sup> The court thus declined to find a legal duty of a mother to her unborn child, noting that permitting such claim

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<sup>100</sup> *Id.* at 359.

<sup>101</sup> *Id.* at 361.

<sup>102</sup> 989 S.W.2d 474 (Tex. App. 1999).

<sup>103</sup> *Id.* at 477.

<sup>104</sup> *Id.* For other criticism of the reasonably prudent parent standard, see *supra* note 62.

<sup>105</sup> *Chenault*, 989 S.W.2d at 478.

<sup>106</sup> *Id.*

<sup>107</sup> 801 N.E.2d 260, 262 (Mass. 2004).

<sup>108</sup> *Id.* at 265.

"could have profound social implications and far reaching unforeseen legal consequences."<sup>109</sup>

### 3. Where Does Genetic Intervention Fit in?

The prenatal negligence cases raise some of the same issues that would be raised by a case in which a child sued her parents for using genetic intervention to give the child particular traits. Both kinds of cases seek to prevent acts that could result in injury to the later-born child, and courts would need to find some appropriate objective measure by which to judge parental acts.<sup>110</sup> This is a difficult task given the diversity of viewpoints and circumstances surrounding conception and prenatal care.

Despite these common issues, however, negligence law is an uncomfortable fit for claims based on genetic intervention. Unless genetic engineering becomes so common and routine that it occurs by default, genetic intervention will most certainly be considered an intentional act. Parents would not fall into genetic intervention through carelessness; rather, parents would intentionally engage in genetic intervention with specific objectives. If the decision to engage in genetic intervention is irresponsible or foolish, the harm that comes from intervention is the result of a bad calculation of what will help the child—rather than a failure to take some precaution.<sup>111</sup> A parent's decision to use genetic intervention is much more deliberate than, for example, a pregnant mother's failure to anticipate the consequences of taking a medication (as in *Grodin*)<sup>112</sup> or a mother's failure to use the designated crosswalk (as in *Stallman*).<sup>113</sup> Mrs. Grodin did not ingest tetracycline for the purpose of giving her son discolored teeth any more

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<sup>109</sup> *Id.* at 264.

<sup>110</sup> On the other hand, some of the prenatal negligence cases are strongly influenced by the unique symbiotic relationship between a mother and her fetus. See, e.g., *Chenault*, 989 S.W.2d at 475-76. Parents who engage in genetic intervention outside the womb do not have such a relationship with an embryo at the time of the intervention. Arguably, in this respect genetic intervention cases are easier to resolve because they do not raise questions about the mother's right to privacy and self-determination. See Smolensky, *Genetic Interventions*, *supra* note 9, at 323 (arguing that the rationales that led courts to find no duty in prenatal negligence cases do not support the same rule in cases of genetic intervention).

<sup>111</sup> Cf. *United States v. Carroll Towing Co.*, 159 F.2d 169 (2d Cir. 1947) (characterizing negligence as a failure to take adequate precautions in light of probable risks); RESTATEMENT (THIRD) OF TORTS: LIAB. FOR PHYSICAL HARM § 3 (Tentative Draft No. 1, 2001) (stating that a determination of negligence includes considering "the burden that would be borne by the person and others if the person takes precautions that eliminate or reduce the possibility of harm").

<sup>112</sup> See *Grodin v. Grodin*, 301 N.W.2d 869 (Mich. Ct. App. 1988).

<sup>113</sup> See *Stallman v. Youngquist*, 531 N.E.2d 355 (Ill. 1988).

than the mother in *Stallman* crossed the street carelessly in order to harm her fetus. Thus, even courts that do find parents owe a duty to their unborn child are unlikely to characterize the intentional act of genetic intervention as a form of negligence.

Battery law supplies a slightly better fit for a claim based on genetic intervention. As an intentional tort, battery corresponds with the intentional nature of genetic intervention. Battery is generally defined as an intentional, harmful or offensive contact with the person of another.<sup>114</sup> Smolensky explains that genetic intervention would require multiple intentional contacts with the embryo: "In the preimplantation context, there is intent to make contact with the embryo when it is formed in the petri dish, when it is manipulated or has cells removed, and when it is implanted in the womb."<sup>115</sup> In most jurisdictions, an intentional contact is a battery, even if the tortfeasor intended no harm or offense, so long as the tortfeasor intended to make contact with another's "person."<sup>116</sup> Under this rule, parents who engage in genetic intervention may be found to have the necessary intent for battery despite the fact they did not intend the intervention to harm or offend the child.

Determining whether a genetic intervention is "harmful or offensive" would require a leap of imagination. An embryo has no physical abilities to lose; it only has certain tendencies and potentials. Likewise, an embryo is incapable of being offended or expressing consent. Lacking direct evidence, courts could leave it to juries to determine, based on the juror's experience with the physical attributes chosen by the parents, whether the particular genetic intervention was harmful or offensive.

Given that this inquiry requires speculation about future abilities of children as well as value-laden decisions about what kinds of things are beneficial in life, courts may choose to defer to parental discretion. In some jurisdictions, parents could invoke parental tort immunity by claiming that genetic intervention falls within discretionary provision of medical services. Even outside the doctrine of parental immunity, courts may defer to parents' decisions to use genetic intervention based on the general rule that a minor is presumed to consent to most medical procedures authorized by the parents.

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<sup>114</sup> RESTATEMENT (SECOND) OF TORTS §§ 13, 18 (1979).

<sup>115</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 319.

<sup>116</sup> See RESTATEMENT (SECOND) OF TORTS § 13; Kenneth W. Simons, *A Restatement (Third) of Intentional Torts?*, 48 ARIZ. L. REV. 1061, 1066 (2006). There may be some arguments that an embryo is not a "person" prior to implantation because at that point embryos may legally be discarded. See *supra* note 49.

In order to justify court interference with parental rights, courts would need a means for determining when genetic intervention constitutes a significant, legally cognizable harm to the child. The next section describes Smolensky's proposal for expanding tort liability by measuring harm by the anticipated future consequences of the genetic traits imposed upon the child.

### C. Arguments for Expanding Tort Liability

#### 1. The "Open Future" Test for Harm

In her article, *Creating Children with Disabilities*, Smolensky argues that parents "should be liable to their children in tort where they directly intervene in the child's DNA, and consequently cause that child to suffer a disability that limits the child's right to an open future."<sup>117</sup> Citing anecdotal evidence that some parents with certain disabilities have sought to have children who share the parents' disability, Smolensky concludes that there is a real threat that parents may attempt to use intervention to harm their future children.<sup>118</sup>

Smolensky starts from the position that parents should be permitted to use technological advances in artificial reproductive technologies to make procreative decisions except when those decisions are likely to cause harm to the later-born child.<sup>119</sup> "The key question then becomes," Smolensky asserts, "which modified phenotypes constitute legally cognizable harms?"<sup>120</sup> In the context of genetic intervention, Smolensky argues, harm should be assumed when parents choose to give their child a trait that "unreasonably limit[s] the life plans available to their child."<sup>121</sup> First, Smolensky appears to advocate a shift in the burden of proof when a parent has used genetic intervention to conceive a child with a disability.<sup>122</sup> Adopting the approach of John Robertson, Smolensky argues that

if parents purposefully produce a child with fewer capabilities, or less health, when they could produce a more healthful or capable child, there [should be] a presumption of harm unless it can be shown by a

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<sup>117</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 299.

<sup>118</sup> *Id.* at 304 ("[D]espite the general expectation that parents will make beneficial genetic choices for their future children, this may not always be the case. In fact, some evidence suggests that parental preferences for arguably harmful interventions are real.").

<sup>119</sup> *Id.* at 307-08 (adopting the modern traditionalist view of procreative liberty).

<sup>120</sup> *Id.* at 301.

<sup>121</sup> *Id.*

<sup>122</sup> *Id.* at 308-09.

preponderance of the evidence that such children are at least as well-off as their more healthful or capable alternate selves.<sup>123</sup>

Second, Smolensky argues for adoption of the moral rights approach of Joel Feinberg to provide a test for harm.<sup>124</sup> Under this approach, courts would assume a legally cognizable harm has been inflicted if the parents' choice infringes upon the child's "right to an open future."<sup>125</sup> Under the open future test, Smolensky believes that "most, if not all, traits defined as disabilities under the Americans with Disabilities Act ("ADA") should be considered legally cognizable injuries."<sup>126</sup>

Therefore, Smolensky argues in favor of liability under both intentional and negligence tort theories.<sup>127</sup> She asserts that genetic intervention could be treated as a battery because the process of intervention involves multiple contacts with the body of the embryo. Because genetic intervention is done without the consent of the future child, Smolensky argues that courts should use an objective standard to determine whether the particular intervention is harmful or offensive.<sup>128</sup> She concludes that

[u]nder an objective standard of offense the creation of 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

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<sup>123</sup> *Id.* at 309 (citing JOHN A. ROBERTSON, *CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES* 22 (1994)).

<sup>124</sup> *Id.* at 309-10 (citing Joel Feinberg, *The Child's Right to an Open Future*, in *WHOSE CHILD? CHILDREN'S RIGHTS, PARENTAL AUTHORITY, AND STATE POWER* 124, 126 (William Aiken & Hugh LaFollette eds., 1980)).

<sup>125</sup> *Id.*

<sup>126</sup> Kirstin Rabe Smolensky, *Parental Tort Liability for Direct Preimplantation Genetic Interventions: Technological Harms, the Social Model of Disability, and Questions of Identity*, 60 *HASTINGS L.J.* 411, 418 (2008) [hereinafter Smolensky, *Technological Harms*].

<sup>127</sup> Despite her assertion that disability prevents children from having an open future, Smolensky supports tort liability only when the parents have physically intervened in their child's genetic makeup. Smolensky, *Genetic Interventions*, *supra* note 9, at 301. Parents who use PGD to determine which embryo to implant would not be liable, however, because the child cannot be said to have suffered harm because the child would not have existed if the parents had chosen a different embryo. *Id.* at 331-32 (applying Derek Parfit's Non-Identity Problem); see also DEREK PARFIT, *REASONS AND PERSONS* 351-79 (1987).

<sup>128</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 319-21.

unconscious and another person removed their sense of hearing.<sup>129</sup>

Smolensky argues that courts could reach this same conclusion under the open future approach.<sup>130</sup>

With respect to negligence, Smolensky argues that parents have “a duty to act as . . . reasonably prudent parent[s] when making preimplantation genetic choices.”<sup>131</sup> Juries would decide whether parents have violated this duty based upon the circumstances surrounding the parents’ decision to use genetic intervention.<sup>132</sup> Presumably, this duty is breached when parents choose to give their child traits that violate the child’s right to an open future.<sup>133</sup>

Smolensky argues that neither parental tort immunity nor constitutional parental rights should insulate parents from liability for selecting attributes that violate a child’s right to an open future.<sup>134</sup> This is so, she says, because parental rights do not extend to actions that are harmful or not in the best interests of the child.<sup>135</sup> Parental tort immunity

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<sup>129</sup> *Id.* at 319–20. In her response, Smolensky clarifies that it is not the mere experience of these disabilities that is “offensive to a reasonable sense of personal dignity,” but rather *the creation of these genetic traits that she believes is objectively offensive*. Smolensky, *Technological Harms*, *supra* note 126, at 421–22. It is not clear, how, if it all, this distinction matters. After all, if choosing a particular trait is offensive, it must be so because the trait is in some way offensive or harmful. Otherwise, choosing any trait would be offensive—a position Smolensky clearly disputes.

Smolensky’s illustration makes two dangerous assumptions. First, it assumes that what is “reasonable” is whatever seems normal to “most people.” Unusual and unreasonable are entirely different inquiries. Second, it assumes that the offense experienced has something to do with the new physical attribute (deafness) rather than the change in physical traits imposed without consent. Many persons with dark skin would be offended if someone bleached their skin while they were unconscious, but that is not because light skin offends a reasonable sense of personal dignity. Indeed, we cannot assume that light skin offends a reasonable sense of personal dignity even if “most people” have dark skin and “most people” would be offended by having their skin bleached without consent. The confusion with respect to consent arguments is discussed in Part III.B.

<sup>130</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 319–20.

<sup>131</sup> *Id.* at 323; *see also supra* note 62 and text accompanying note 104 (providing a criticism of the reasonably prudent parent standard).

<sup>132</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 323 n.137.

<sup>133</sup> *Id.* at 344–45.

<sup>134</sup> *Id.* at 314–17, 328–30.

<sup>135</sup> *Id.* at 328–30. This argument, of course, assumes that courts are able to effectively and accurately determine whether the child has suffered cognizable harm without unwarranted intrusion into family affairs. But how could courts make such a determination if not by reference to general stereotypes and social assumptions? The very purpose of parental tort immunity and constitutional protection of parental decisions is to prevent the state from interfering with family affairs except when clearly necessary to protect a child. If these

should not apply because “genetic interventions that select for a disability would result in reduced health and capabilities.”<sup>136</sup> Smolensky also concludes that “[w]here children might be harmed by their parents’ constitutionally protected decision making, the State should limit the parents’ rights.”<sup>137</sup>

Although Smolensky raises important ethical and legal issues, her proposal leaves a number of questions unanswered. Smolensky asserts that there is a real threat of parents harming their children by engineering characteristics associated with disability. But she also admits that the two kinds of disability she discusses—deafness and achondroplasia—are not necessarily harmful to children.<sup>138</sup> Smolensky would leave it to judges and juries to decide which characteristics associated with disability are indeed harmful.<sup>139</sup> Yet Smolensky never addresses the question of whether judges and juries are *better* at evaluating the effects of genetic intervention than parents. Nor does she consider how her proposal would affect genetic diversity and public perceptions of disability.

## 2. Responses to Smolensky

Three scholars have responded directly to Smolensky’s call for imposing liability on parents who use genetic intervention to have a child with physical traits associated with disability. Smolensky has responded to these comments by clarifying some of her theories and backing away from others. Next, this Article introduces the way two of these responses recast the problem Smolensky posed.

### a. *The Dangers of Genetic Intervention*

Professor Jamie King writes in favor of Smolensky’s basic premise that “children should be able to sue their parents for harmful

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doctrines are only considered *after* the court has evaluated the parents’ decisions according to the court’s standards, then these doctrines serve no purpose.

<sup>136</sup> *Id.* at 317.

<sup>137</sup> *Id.* at 329.

<sup>138</sup> Smolensky’s position on this is not entirely clear. On one hand, she states that all traits that qualify as disabilities under the ADA should be found to be cognizable harms. Smolensky, *Technological Harms*, *supra* note 126, at 418. On the other hand, she advocates a case-by-case evaluation of the effects of the chosen attributes on the child. Smolensky, *Genetic Interventions*, *supra* note 9, at 340–41.

<sup>139</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 300 (“Given the specter of eugenics, it may be best to have the tort system, rather than the government, determine which traits are harmful.” (footnote omitted)).



preimplantation genetic manipulations."<sup>140</sup> However, King argues that a federal regulatory scheme would be more effective than tort liability.<sup>141</sup> King finds the open future test for harm appropriate in the context of genetic interventions, but she notes that at least some of the disabilities that Feinberg assumes violate a child's right to an open future are no longer considered as damning as they once were.<sup>142</sup> Given the changing status of various disabilities, determining whether a child has suffered harm "will require juries to make value judgments about which disabilities are so severe as to violate the child's right to an open future."<sup>143</sup>

Ultimately, King supports Smolensky's assertion that parents should be treated as owing a duty to their offspring to act as reasonably prudent parents.<sup>144</sup> King asserts, however, that this duty should not just apply to decisions to produce a child with a disability but to "all ART choices made prior to embryo transfer."<sup>145</sup> Thus, King promotes a balancing test, in which the benefits of genetic intervention would be weighed against the risks and harms.<sup>146</sup> She argues that this balancing should not just consider the merits of the genetic trait chosen by the parent, but also the risks inherent in the process of genetic intervention and the potential benefits to the child of sharing the same physical traits as the child's parents.<sup>147</sup>

Notably, King recognizes that in some situations a child might be better off growing up with a disability than without one.<sup>148</sup> In King's view, however, it will be a long time before those benefits outweigh the inherent risks of genetic intervention.<sup>149</sup> Nonetheless, King states, "[i]f researchers eliminate the risks associated with embryonic gene therapy, in some instances, a reasonable parent, considering all of the risks and

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<sup>140</sup> Jaime King, *Duty to the Unborn: A Response to Smolensky*, 60 HASTINGS L.J. 377, 377 (2008).

<sup>141</sup> *Id.* at 392.

<sup>142</sup> *Id.* at 387-88.

<sup>143</sup> *Id.* at 384.

<sup>144</sup> *Id.* at 392.

<sup>145</sup> *Id.*

<sup>146</sup> *Id.* at 388-89.

<sup>147</sup> *Id.* at 387.

<sup>148</sup> *Id.* at 389.

<sup>149</sup> *Id.* at 387. King states the following:

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.

*Id.*

benefits, could find that her child may have a better life with the disability than without.”<sup>150</sup>

*b. A Disability Rights Perspective*

In response to Smolensky’s article, Professor Alicia R. Ouellette explains what she calls a “disability rights perspective” of Smolensky’s proposal.<sup>151</sup> Although noting that she “often disagree[s] with the reactionary response of some disability rights activists to perceived slights,”<sup>152</sup> Ouellette expresses concern that the open future approach might offend persons with disabilities because it relies upon stigmatizing assumptions about disability.<sup>153</sup>

Ouellette explains that the open future approach Smolensky adopts from Feinberg assumes that disability is inherently harmful:

In his work, Feinberg unabashedly accepts as true the myth of the tragedy of life with disability. He asserts that a newborn child born with blindness, deafness, or permanent paralysis has “[i]mpaired faculties that are essential to the existence and advancement of any ulterior interests.” He describes such conditions as “so far below a reasonable minimum as to be inescapably degrading and sordid.” He suggests that being born with a disability “is not merely to have ‘bad luck.’ It is to be dealt a card from a stacked deck in a transaction that is not a ‘game’ so much as a swindle.”<sup>154</sup>

The view that disability is inherently tragic and limiting derives from the traditional definition of disability by medical professionals as a physiological flaw to be treated, cured, or condemned.<sup>155</sup> This “medical model” of disability has been repeatedly deconstructed and debunked

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<sup>150</sup> *Id.* at 388.

<sup>151</sup> Ouellette, *Insult to Injury*, *supra* note 49, at 398. Ouellette does not indicate whether she agrees with this perspective; instead, she argues that this perspective must be considered because “[n]ot only do people with disabilities have the most at stake in the discussions, disability scholars are experts in identifying and preventing social oppression of people with disabilities.” *Id.* at 399–400.

<sup>152</sup> *Id.* at 399.

<sup>153</sup> *Id.* at 402.

<sup>154</sup> *Id.* (alteration in original) (footnotes omitted) (quoting 1 JOEL FEINBERG, *THE MORAL LIMITS OF THE CRIMINAL LAW: HARM TO OTHERS* 98–99 (1984)).

<sup>155</sup> *Id.* at 400; *see also infra* notes 178–81 and accompanying text (discussing the traditional medical model of disability).

by disability scholars.<sup>156</sup> In place of the medical model of disability, disability scholars have advanced a “social model” of disability that corresponds with other minority perspectives.<sup>157</sup> The social model of disability recognizes that many (and sometimes all) of the limitations that are associated with disability derive not from physical impairment but from “[a]rchitectural, attitudinal, sensory, political, and economic barriers.”<sup>158</sup>

Ouellette argues that Feinberg’s characterizations of disability “are as inaccurate as they are demeaning.”<sup>159</sup> She notes that empirical and anecdotal evidence suggests that persons who have not experienced disability “grossly underestimate the value of life with disability.”<sup>160</sup> As a result, Ouellette advocates a “disability-sensitive” approach that would treat genetic intervention in favor of disability no differently than genetic interventions that attempt to impose any kind of enhancement upon an embryo.<sup>161</sup> “[A] decision to choose disability is no different from a decision to use other genetic enhancements to shape a future child for nontherapeutic purposes.”<sup>162</sup> Rather than “sorting among manufactured phenotypes to determine which constitute legally cognizable harms,” Ouellette argues that the law should “ask whether adding, deleting, or modifying an embryo’s DNA to produce the parents’ desired genotype is itself a legal wrong.”<sup>163</sup> This approach, Ouellette asserts, avoids offending the sensibilities of persons with disabilities and provides redress for any child whose identity has been unnecessarily manipulated through genetic intervention.<sup>164</sup>

By connecting the language of the open future approach to the outdated medical model of disability, Ouellette makes significant headway toward reorienting the discussion of disability.<sup>165</sup> But Ouellette’s focus on the possibility of offending persons with disabilities does not, by itself, provide a persuasive argument against Smolensky’s

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<sup>156</sup> Ouellette, *Insult to Injury*, *supra* note 49, at 400; *see also infra* note 178–86 and accompanying text (explaining the shift from the traditional medical model of disability to a social model of disability).

<sup>157</sup> Ouellette, *Insult to Injury*, *supra* note 49, at 401; *see also infra* note 184–87 and accompanying text (discussing the adoption of a social model of disability).

<sup>158</sup> Ouellette, *Insult to Injury*, *supra* note 49, at 401.

<sup>159</sup> *Id.* at 402.

<sup>160</sup> *Id.* at 403.

<sup>161</sup> *Id.* at 406.

<sup>162</sup> *Id.*

<sup>163</sup> *Id.* at 407.

<sup>164</sup> *Id.* at 409.

<sup>165</sup> Indeed, I agree with Ouellette’s ultimate conclusion that genetic intervention in favor of disability be treated the same as any other attempt at genetic enhancement.

proposal.<sup>166</sup> To be sure, it is good to avoid using legal doctrines that offend or belittle a portion of the population. This concern, however, weighs lightly when the life of a child is at stake. Few would argue that we should permit parents to harm their children simply because the basis for liability does not acknowledge the perspective of one group.

Focusing on Ouellette's critique of the medical model of disability, Smolensky responds by arguing that even if disability is not *inherently* limiting, the continuing existence of social and environmental barriers for persons with disabilities warrants treating disability as a cognizable injury.<sup>167</sup> Smolensky willingly disclaims Feinberg's "offensive" characterization of life with a disability, but maintains that the open future test remains a viable tool for measuring cognizable harm.<sup>168</sup>

What we are left with, then, are a number of line-drawing questions that seem to depend upon how disability is characterized. Is there a real threat of children being harmed by parents using genetic intervention in favor of disability? Or should genetic intervention be treated as a harm in itself? If we do attempt to identify when genetic intervention is harmful, should we define the consequences of disability normatively or descriptively? And who is best qualified to make determinations about the advantages and disadvantages of socially disfavored physical traits?

### III. TAKING A STEP BACK: POLICY ARGUMENTS

#### A. A Neglected Question

A compelling question underlies much of the debate over whether parents should be held liable in tort for making genetic choices in favor of disability: Why would a parent *choose* to give her child a disability? Very little has been written in an attempt to answer this question.<sup>169</sup>

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<sup>166</sup> Ouellette also recognizes that the open future framework could "have the unintended effect of reinforcing negative societal perceptions about disability in a way that further marginalizes and alienates the disability community." Ouellette, *Insult to Injury*, *supra* note 49, at 403.

<sup>167</sup> Smolensky, *Technological Harms*, *supra* note 126, at 418–21.

<sup>168</sup> *Id.*

<sup>169</sup> There are likely two reasons for the dearth of information about why some parents might seek to give their child physical traits associated with disability. First, there are very few parents who actively seek to have a child with disfavored physical characteristics. See *infra* note 173 (showing statistics that only a relatively small portion of parents would prefer to have a deaf child). Second, parents who are likely to select in favor of disability do not speak openly because of the stigma associated with having a child with a disability. See, e.g., Carina Dennis, *Deaf by Design*, 431 NATURE 894 (Oct. 2004), available at <http://www.geneticsandsociety.org/article.php?id=1516> (quoting Carol Padden as saying, "[d]eaf people know that it's a very risky thing to say in public that you would consider genetic testing to have a deaf child"). One exception to the general tendency to give short

Although some commentators acknowledge that there may be circumstances where disability is not a detriment, this perspective is usually offered only to qualify the more general assumption that disability is itself a kind of injury.<sup>170</sup> As a result, parents who are willing to take active measures to conceive a child with a disability are often characterized as selfish, unreasonable, or politically radical.<sup>171</sup>

Two points must be emphasized at the outset. First, not all persons with a particular disability would like to have a child with the same disability, and even those who do might not be willing to use genetic intervention to that end. Headlines like, “Deaf Demand Right to Designer Deaf Children” suggest that all deaf persons would seek to have a deaf child.<sup>172</sup> Within the Deaf and disabled communities, however, there are a variety of viewpoints on this issue, and apparently only a small number of deaf or disabled parents say they would consider using genetic testing to make sure their child is deaf.<sup>173</sup>

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shrift to the psychological and cultural motives of parents with disabilities who seek to have a disabled child is the analysis in Davis’s book. See DAVIS, *supra* note 8, at 61–90. Although I disagree with Davis’s ultimate conclusion that fertility professionals should refuse to assist Deaf parents in having a deaf child, she does attempt to analyze the diverse motives of parents who want to have a deaf child. *Id.* at 82.

<sup>170</sup> See, e.g., N. Levy, *Deafness, Culture, and Choice*, 28 J. MED. ETHICS, 284–85 (2002) (discussing the current controversy on the parental choice of creating a deaf child); Smolensky, *Technological Harms*, *supra* note 126, at 418–20 (suggesting that most, if not all, traits defined as disabilities under the ADA should be considered legally cognizable injuries). Even Ouellette seems to fall into this presumption in titling her article “Insult to Injury.” Ouellette, *Insult to Injury*, *supra* note 49. If the “insult” is the stigmatizing language of the open future framework, the “injury,” it appears, is disability.

<sup>171</sup> See, e.g., K.W. Anstey, *Are Attempts to Have Impaired Children Justifiable?*, 28 J. MED. ETHICS 286, 286–88 (2002) (suggesting that parents seek to have a deaf child for political reasons, a practice which takes them outside the “moral community”); Fox, *supra* note 23, at 582 (suggesting parents who avoid socially disfavored physical traits “prefer not to sacrifice their children on the altar of moral principle, or in support of a political cause, even a very worthy one”); Levy, *supra* note 170, at 285 (arguing deaf parents seek to have deaf children because of apparent misplaced fears caused by the parents’ own difficult childhood); Karen E. Schiavone, Comment, *Playing The Odds Or Playing God? Limiting Parental Ability To Create Disabled Children Through Preimplantation Genetic Diagnosis*, 73 ALB. L. REV. 283, 298 (2009) (“[P]arents who desire to have children with disabilities, and do so intentionally, are doing so to satisfy their own autonomy and their own needs, without respect to the future autonomy of the child in question.”).

<sup>172</sup> Templeton, *supra* note 32.

<sup>173</sup> DAVIS, *supra* note 8, at 79; Elizabeth A. Chen & Judith F. Schiffman, *Attitudes Toward Genetic Counseling and Prenatal Diagnosis Among a Group of Individuals with Physical Disabilities*, 9 J. GENETIC COUNSELING 137, 137 (2000); Anna Middleton et al., *Prenatal Diagnosis for Inherited Deafness—What is the Potential Demand?*, 10 J. GENETIC COUNSELING 121, 121 (2001) [hereinafter Middleton et al., *What is the Potential Demand?*] (providing survey showing that only two percent of deaf persons surveyed would prefer to have a deaf child and would consider terminating a pregnancy if prenatal testing showed they were going to have a child with hearing impairments); Anna Middleton et al., *Attitudes of*

Second, although discussions about genetic intervention refer broadly to “disabilities” and “genetic defects,” there are really two kinds of disability that we know parents with disabilities have expressed an interest in selecting through genetic intervention—deafness and achondroplasia.<sup>174</sup> Although there may be other forms of disability that are so connected with identity that parents would seek to engineer those characteristics, there is no reason to assume that, if permitted, parents would pay thousands of dollars to engineer children with all sorts of disabilities and diseases. Hypothesizing about parents purposely engineering the genes for breast cancer may be philosophically interesting, but it provides little insight into the reality of why parents might choose to use genetic intervention.<sup>175</sup>

There is nothing new about parents wanting to have children who share the parents’ physical attributes. Adopting parents, for example, often state a preference for children who share the parents’ racial background.<sup>176</sup> To the extent that parents with disabilities view their disabilities as a part of their identities, it is not surprising that some might want to have children who can share that identity. Most nondisabled fertile couples can assume that their children will share their physical attributes without any need for genetic intervention. Because deafness is less common, and because parents with achondroplasia face risks of having a child born with a fatal condition, these parents cannot count on biology to pass these traits on to their children.<sup>177</sup>

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*Deaf Adults Toward Genetic Testing for Hereditary Deafness*, 63 AM. J. HUM. GENETICS 1175, 1175 (1998) [hereinafter Middleton et al., *Attitudes of Deaf Adults*] (finding 16% of deaf persons studied would consider using prenatal diagnosis and that of these, only 29% would prefer to have a deaf child); cf. Jeanne Weir Brunger et al., *Parental Attitudes Toward Genetic Testing for Pediatric Deafness*, 67 AM. J. HUM. GENETICS 1621, 1621 (2000) (presenting study of parents who are not deaf but have deaf children that found that 96% of such parents were in favor of genetic testing for deafness; however, none of these parents said they would terminate a pregnancy upon learning that their child is going to be deaf).

<sup>174</sup> There is, however, one report of non-disabled parents seeking to use PGD to have a child with Down syndrome. Melissa Healy, *Fertility’s New Frontier*, L.A. TIMES, July 21, 2003, <http://articles.latimes.com/2003/jul/21/health/he-pgd21>.

<sup>175</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 320 (discussing consequences of parents selecting genes associated with breast cancer).

<sup>176</sup> See Twila L. Perry, *Transracial Adoption and Gentrification: An Essay on Race, Power, Family and Community*, 26 B.C. THIRD WORLD L.J. 25, 30–34 (2006) (indicating that most commonly, black children adopted from foster care are adopted by black women, not by whites).

<sup>177</sup> If both parents have achondroplasia, there is a 50% chance the child will be born with achondroplasia and a 25% chance the child will be born with double-dominant syndrome, which usually leads to death of the child at birth or shortly afterward. See *Frequently Asked Questions*, *supra* note 11.

There is a growing academic and cultural movement toward questioning traditional assumptions about disability and identity. As discussed above, over the past thirty years, disability scholars have challenged the traditional portrayal of disability as a medical flaw. The traditional medical model of disability<sup>178</sup> assumed that disability is a problem existing within the bodies of persons who are physically different.<sup>179</sup> Disability was treated as a physiological phenomenon that must be cured or corrected,<sup>180</sup> or in the language of genetics and products liability, a “defect” to be avoided or ameliorated.<sup>181</sup> Laboring under the assumptions of the medical model, persons with disabilities were expected to prove their moral and emotional validity by “overcoming” their physical states and trying to approximate the lives of nondisabled persons.<sup>182</sup> Under the medical model, access and employment rights were viewed as special treatment charitably bestowed upon persons with inherently broken bodies.<sup>183</sup>

Following on the heels of the civil rights movement, the disability rights movement rejected the medical model and adopted a minority-group model of disability.<sup>184</sup> This social model of disability recognizes that, for most people with disabilities, discrimination is a much greater obstacle than any physical impairment.<sup>185</sup> The social model of disability thus calls for social and environmental changes to give persons with

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<sup>178</sup> I refer to the medical model in the past tense here because it is no longer the dominant model for discussing disability. Unfortunately, however, the assumptions underlying the medical model persist. See generally Bradley A. Areheart, *When Disability Isn't “Just Right”: The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma*, 83 IND. L.J. 181 (2008) (portraying the medical model of disability as a “Goldilocks” dilemma: people with disabilities are either too disabled or not disabled enough).

<sup>179</sup> Paul K. Longmore, *The Second Phase: From Disability Rights to Disability Culture*, in *WHY I BURNED MY BOOK AND OTHER ESSAYS ON DISABILITY* 217 (2003); see also Wendy F. Hensel, *The Disabling Impact of Wrongful Birth and Wrongful Life Actions*, 40 HARV. C.R.-C.L. L. REV. 141, 146–47 (2005).

<sup>180</sup> Hensel, *supra* note 179, at 146–47; Longmore, *supra* note 179, at 217.

<sup>181</sup> See Shepherd *supra* note 19, at 764.

<sup>182</sup> See, e.g., Longmore, *supra* note 179, at 232.

<sup>183</sup> *Id.* at 219.

<sup>184</sup> *Id.* at 218; Hensel, *supra* note 179, at 147; Michael E. Waterstone & Michael Ashley Stein, *Disabling Prejudice*, 102 NW. U. L. REV. 1351, 1356–57 (2008).

<sup>185</sup> Hensel, *supra* note 179, at 147; Longmore, *supra* note 179, at 218. There are differing conceptions of this social model. Some suggest that the obstacles associated with disability are purely social and environmental, while others argue that these obstacles are partially the result of the physical condition and partially the result of discrimination. Adam M. Samaha, *What Good is the Social Model of Disability?*, 74 U. CHI. L. REV. 1251, 1255 (2007). Proponents of the social model generally agree, however, that the key to combating discrimination and oppression is to demand social and environmental changes. *Id.* at 1267–68.

disabilities equal access to social and economic activities.<sup>186</sup> The social model of disability provided the basis for disability rights legislation, like the Americans with Disabilities Act of 1990, which introduced a definition of disability that, in part, recognized the social construction of disability.<sup>187</sup>

Rejection of the medical model did not just provide justification for equal opportunities. It also allowed for persons with disabilities to take control of their own identities. Unfettered by the stigmatizing assumptions of the medical model, persons with disabilities could reevaluate majority values about physical difference.<sup>188</sup> Drawing from their own experience, some persons with disabilities have expressed values quite different from nondisabled norms.<sup>189</sup> As Professor Paul Longmore explains, "They declare that they prize not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community."<sup>190</sup> Longmore argues that these sublime values are desperately needed in American society:

American culture is in the throes of an alarming and dangerous moral and social crisis, a crisis of values. The disability movement can advance a much-needed perspective on this situation. It can offer a critique of the hyperindividualistic majority norms institutionalized in the medical model and at the heart of the contemporary American crisis. That analysis needs to be made, not just because majority values are impossible for people with disabilities to match up to, but, as important, because they have proved destructive for everyone, disabled and nondisabled alike.<sup>191</sup>

This analysis suggests that those parents who select in favor of disability may do so not to press a political agenda or strengthen a shrinking population, but in an effort to perpetuate their own positive values and

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<sup>186</sup> Longmore, *supra* note 179, at 218; Waterstone & Stein, *supra* note 184, at 1357.

<sup>187</sup> Wendy E. Parmet, *Plain Meaning and Mitigating Measures: Judicial Interpretations of the Meaning of Disability*, 21 BERKELEY J. EMP. & LAB. L. 53, 59 (2000). The ADA's expansive definition of disability has been called "transformative" because it seeks to displace social norms regarding what it means to be disabled. Linda Hamilton Krieger, *Afterword: Socio-Legal Backlash*, 21 BERKELEY J. EMP. & LAB. L. 476, 479-80 (2000). *But see* Samaha, *supra* note 185, at 1280 (claiming the social model of disability has no policy implications).

<sup>188</sup> Longmore, *supra* note 179, at 221-22.

<sup>189</sup> *Id.* at 222.

<sup>190</sup> *Id.*

<sup>191</sup> *Id.*



culture. Sharon Duchesneau and Candace McCullough, a Deaf couple who actively pursued having a deaf child, explain their perspective:

Our view . . . is that being deaf is a positive thing, with many wonderful aspects. We don't view being deaf along the same lines as being blind or mentally retarded; we see it as paralleling being Jewish or black. We don't see members of those minority groups wanting to eliminate themselves.<sup>192</sup>

Parents often attempt to control their children's options in an effort to instill values and develop cultural understanding. Wealthy parents sometimes deny their child access to family funds because they want the child to develop a strong work ethic and know the joy of accomplishment. Parents intentionally limit with whom their child interacts, where the child goes to school, and what activities the child pursues. These restrictions may significantly limit the child's opportunities in life, but, as the parents recognize, they also create opportunities to develop character and values.

Admittedly, limiting a child's access to funds or activities is a far cry from intentional manipulation of a child's DNA.<sup>193</sup> But all of these limiting measures recognize the same principle: that one's values and identity are strongly influenced by one's circumstances. Parents who wish to use genetic intervention to change their child's physical characteristics are attempting to shape the child's circumstances in life, and thereby affect the child's culture and character.

There are, of course, additional, sometimes related reasons why parents with certain socially disfavored physical traits might want their child to share those traits. Deaf parents might be concerned that they will have difficulty maintaining a close relationship with their child if the child does not share their culture and primary language.<sup>194</sup> They may

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<sup>192</sup> Dominic Lawson, *Of Course a Deaf Couple Want a Deaf Child*, INDEP. (London), Mar. 11, 2008, at 40; see also Dolnick, *supra* note 10, at 38 ("So strong is the feeling of cultural solidarity that many deaf parents cheer on discovering that their baby is deaf.").

<sup>193</sup> One distinction between these social measures and genetic intervention is cost. DAVIS, *supra* note 8, at 36-39. Davis argues that the costs of directed procreation, whether by genetic intervention or otherwise, is so high that it gives parents a sense of entitlement to a child that meets the parents' preconceived notions about what the child should do in life. *Id.* This concern, however, cautions against permitting genetic intervention generally; it does not suggest that parents should be prohibited from choosing only certain, socially disfavored characteristics.

<sup>194</sup> *Id.* at 77-78. Some have argued that preference should be given in adoption to parents who share the same race and culture as the child. See 25 U.S.C. § 1915(a) (2006) (establishing preference for adoption of Indian children by Indian parents); Perry, *supra*

also be concerned that, as hearing parents increasingly use genetic testing to avoid having a deaf child, the Deaf community will shrink, and so too will understanding and appreciation of Deaf perspectives.<sup>195</sup>

To the extent that genetic intervention appears to be the wrong way of perpetuating one's values and identity, we must ask why this is so. But if we claim that genetic intervention is wrongful only when used to favor certain physical traits, we must ask what, if anything, makes those kinds of genetic interventions different from genetic interventions in favor of other physical traits. To start this inquiry, we must look to the policies underlying arguments in favor of imposing tort liability on parents who use genetic intervention to have a child with a disability.

### *B. Policies Underlying Arguments for Parental Tort Liability*

The policies that are invoked in favor of parental tort liability fall generally into two camps. First, some policies, if credited, support prohibiting genetic intervention altogether or with limited exceptions. These policies treat genetic intervention as wrongful in itself, regardless of which physical attributes are the object of the intervention. There is no need for a decision maker to define which physical attributes are harmful and which are not. The very act of intervention is harmful.

The second camp consists of policies that may be invoked to support prohibiting a certain kind of genetic intervention, that is, the use of genetic intervention to give a child physical attributes that are believed by some to be harmful, such as disabilities. Although these policies may be appealing on their face, they provide no workable means of determining when liability is appropriate. Moreover, it is doubtful that there is a serious need to prohibit parents from using genetic intervention to choose traits that are generally assumed to be harmful.

#### 1. Genetic Intervention as a Moral Wrong

Some oppose genetic interventions that result in disability based on a general conviction that genetic intervention is wrong. This position may derive from a belief that humans should not further tinker with the natural course of conception and identity, that genetic engineering will ultimately dilute positive social values, that intervention is fundamentally unfair to the unborn child, or some other moral

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note 176, at 30 (describing positions on transracial adoption). A similar concern expressed by some Deaf persons is that hearing parents cannot properly raise a deaf child because hearing parents are outsiders to Deaf culture. Dolnick, *supra* note 10, at 51; *see also* DAVIS, *supra* note 8, at 76.

<sup>195</sup> DAVIS, *supra* note 8, at 66-69.

framework.<sup>196</sup> Virtually every advancement in artificial reproductive technology has been—at least initially—met with moral opposition.<sup>197</sup> Over time, opposition has waned to each new technology.<sup>198</sup> This does not mean, of course, that we must assume that genetic intervention is morally acceptable. It simply means that, for better or worse, views on the subject are likely to change over time.

In any case, if genetic intervention is wrong in itself, it is wrong no matter what traits are being chosen in the process. This remains true even if we find a basis for minor exceptions to a general policy opposing genetic intervention. The kind and scope of those exceptions vary depending on the ethical framework motivating categorical opposition to intervention. Thus, for example, if one opposes intervention because it effects a change in the child without the child's consent, then one will likely hold that intervention is not tortious if the intervention is one we assume any child would certainly consent to, such as an intervention necessary to save the life of the child.<sup>199</sup> If, however, one opposes intervention because it alters a child's identity, one will likely oppose interventions that are deemed significant enough to affect identity, but permit interventions that are deemed less substantial.<sup>200</sup>

Recognizing these kinds of exceptions is different—theoretically and practically—from saying that parents should be held liable when they choose certain physical traits (such as deafness or short stature) but not others (such as blue eyes or fair skin). In the first situation, the intervention is itself wrongful, but we are willing to excuse the wrong for what we assume to be a greater good. Because this scenario starts from the assumption that intervention is wrongful, the intervention will not be permitted unless found to offer significant benefits to the child or society. Under this framework, the decision maker must determine when the danger of refraining from intervention is significant enough to warrant departure from the moral grounds calling for prohibition of such techniques.

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<sup>196</sup> See, e.g., Fox, *supra* note 23, at 572–74.

<sup>197</sup> Andrews & Elster, *supra* note 79, at 35–38. Smolensky makes it a point to note that “disability advocates” have always opposed new fertility technologies. Smolensky, *Genetic Interventions*, *supra* note 9, at 301. Although this may be true to some degree, disability advocates are certainly not the only ones who approach new fertility technologies with a degree of suspicion.

<sup>198</sup> Andrews & Elster, *supra* note 79, at 35–38.

<sup>199</sup> This approach arguably follows tort cases where consent is implied by operation of law for medical assistance in emergencies. See PROSSER & KEETON ON TORTS, *supra* note 56, at 117.

<sup>200</sup> See I. Glenn Cohen, *Intentional Diminishment, the Non-Identity Problem, and Legal Liability*, 60 HASTINGS L.J. 347, 350–59 (2008); Fox, *supra* note 23, at 594–95.

In the second scenario, intervention is not considered wrongful in itself, so any intervention is permissible so long as it does not do legally cognizable harm.<sup>201</sup> Under this framework, the decision maker is not determining whether to avoid some catastrophe but rather guessing at the consequences different physical traits might have on future children. As discussed below, this is a much more complicated and difficult decision because it requires sorting through the multifarious advantages and disadvantages that each physical trait might have on a child who is not yet born.

There is confusion in this area because some of the rationales given to support categorical opposition to genetic intervention do not quite fit. For example, some suggest that intervention is wrongful, in part, because it is done without the consent of the child.<sup>202</sup> The problem, however, is that no child ever has a say in choosing her genetic makeup regardless of whether genetic intervention is used.<sup>203</sup> Alternatively, even if we assume that there is some form of consent lacking in genetic intervention, a child would be hard-pressed to prove that, had she been given a choice at some metaphysical moment before her genes were chosen, she would have rejected the physical traits the parents preferred. The most a child could do is point to evidence that people generally disfavor the physical attribute chosen by the parent and argue, by extension, that she would have rejected the physical trait, as well.

Thus, in the context of genetic intervention, consent arguments have less to do with the autonomy of the child and more to do with denying the will of nature or the generalized assumptions of society. This is an important distinction. It is one thing to say a person should have an opportunity to express or deny consent to medical procedures. It is quite another to say that unborn children have the right to be born with certain attributes that are socially favored. The latter argument is not about consent but rather an assertion that some physical traits are intrinsically better than others.<sup>204</sup>

Consent aside, it is possible that there are very good policy reasons to oppose genetic intervention categorically. As King points out, genetic intervention could have unanticipated negative physical

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<sup>201</sup> This framework is referred to as the modern traditionalist approach. See Smolensky, *Genetic Interventions*, *supra* note 9, at 308 (indicating that modern traditionalists view reproductive choice as a basic freedom that exists so long as it aids in successful reproduction and does not cause direct harm to society or others).

<sup>202</sup> *E.g.*, *id.* at 319.

<sup>203</sup> For example, I never had the opportunity to choose blue eyes and a muscular build, and this has nothing to do with whether my parents engaged in genetic intervention.

<sup>204</sup> See *supra* Part III.A (discussing problems with this assertion).

consequences.<sup>205</sup> Additionally, Dov Fox argues that, if left unregulated, genetic engineering of children would “undermine civic compassion by entrenching perceptions of human control over individual identity and social advantage.”<sup>206</sup> These rationales do not call for sorting through the advantages and disadvantages of different physical traits or for presuming disfavored physical traits constitute cognizable harms. If anything, these policies call for a general prohibition with exceptions for unusual situations.

## 2. Concern that Children May Be Harmed

There are some parents who knowingly or recklessly place their children in danger. Some mothers use illegal drugs during pregnancy. Some parents neglect their children. Other parents engage in abuse. It appears, however, there is little cause for concern that parents will use genetic intervention to give their child traits that parents know to be detrimental to the child. Parents who go to the expense of using genetic intervention to choose a trait for their child will likely do so believing that the trait will benefit the child.<sup>207</sup>

Good intentions, however, do not always lead to good results. Thus, a third potential reason for holding parents who choose disfavored physical traits through genetic intervention liable is that children might suffer harm as a result of the chosen physical trait. Tort law generally seeks to recompense persons who suffer harms unnecessarily; thus, if disability is a harm, then it might make sense to hold parents who impose such a trait on their child liable.<sup>208</sup> Implicit in this policy justification is an assumption that parents will sometimes make bad decisions when choosing physical traits and the expense of those decisions should be borne by the parents.

But determining what will be harmful or beneficial for a child, or even what will limit or expand life opportunities for a child, is no simple task. As King notes, a child born deaf might face challenges in communicating with those who are not deaf, but the child may also benefit from being a part of the Deaf community, or if the parents are

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<sup>205</sup> King, *supra* note 140, at 381.

<sup>206</sup> Fox, *supra* note 23, at 619.

<sup>207</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 319. There certainly may be exceptions, such as parents who try to serve their own interests in reckless disregard for the child. The possibility of this sort of recklessness, however, does not call for questioning all parental decisions in favor of disability. Rather, it calls for enforcing existing criminal and civil laws against persons who intentionally or recklessly cause emotional distress. See Ann M. Haralambie, *Children's Domestic Tort Claims*, 45 WASHBURN L.J. 525 (2006).

<sup>208</sup> See DAVIS, *supra* note 8, at 53–56 (discussing the role of tort law in reproductive technology).

themselves deaf, from sharing the physical and cultural attributes of her parents.<sup>209</sup> Whether one finds greater value in communication opportunities or in familial and cultural bonding depends on one's culture and experiences, and it would be difficult to say that one set of values is right while the other wrong. Indeed, the comparison of harms and benefits is more likely to reflect social preferences than any inherent quality of the physical trait.<sup>210</sup>

The difficulty of balancing harms and benefits persists regardless of whether the physical traits in question are ones commonly viewed as disabilities. Giving a child six fingers on each hand might be seen as an enhancement to parents who dream of their child being a pianist;<sup>211</sup> but to others, this may seem a cruel disfigurement that will severely limit social opportunities. So too, parents might attempt to bless their child with the physical prowess of Michael Jordan but then damn the child with severe pressure to succeed as an athlete. A child engineered with exceptional intelligence may suffer socially in her youth. And there are myriad non-genetic interventions, such as circumcision and inoculations, that are just as permanent as genetic decisions and could be found to harm or benefit the child depending on the social situation, cultural mores, and later developments. Some of these parental decisions may be harmful in some respect, but few people would find judicial intervention and parental liability are necessary to test all of these early parental decisions.<sup>212</sup>

This is not to say that the question of harm is always too speculative to reach. The point is, rather, that the decision about whether a physical trait is a harm or a benefit should not be made based upon overgeneralizations that having more physical ability is always better than having less, that some physical traits are inherently damaging, or that everyone is better off looking like the majority of folks we see on television. There is value in the broad swath of human possibilities, even if some of those are misunderstood by many. When the physical trait chosen by the parents is not one that most people have experienced or

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<sup>209</sup> See King, *supra* note 140, at 389 (providing examples of the potential benefits of being born deaf). There may very well be myriad other benefits of being deaf.

<sup>210</sup> See *infra* Part IV.C (explaining that the social benefit of a trait should not be the primary measure of its value).

<sup>211</sup> See GATTACA (Columbia Pictures Co. 1997).

<sup>212</sup> Smolensky admits that parents can harm their children in many ways, aside from genetic intervention, and still avoid civil or criminal liability. Smolensky, *Genetic Intervention*, *supra* note 9, at 341–42. She argues that parental liability for genetic interventions is appropriate, however, because genetic changes are permanent and parental misconduct can be proven more readily than other more subtle parental choices. See *id.* at 342.

can reasonably understand, we must be careful that the decision about harm is not based upon social stereotypes and cultural assumptions. If people do not accurately perceive the nature of the challenges and opportunities faced by a person with a particular physical trait, it would be a mistake to give juries the final word on whether that trait is a harm or a benefit.

### 3. The Costs of Disability on Society

A third policy that has been asserted in support of parental tort liability is that persons with disabilities impose costs on the society in which they live. If parents who use genetic intervention in favor of disability were subject to tort liability, perhaps fewer parents would use genetic intervention for that purpose. This might decrease the number of children with disabilities and free up funds that would otherwise be needed to support such children.

This rationale assumes that children with disabilities are more expensive than others.<sup>213</sup> Although this may be true with regard to some disabilities, the two disabilities that have been potential candidates for genetic intervention—deafness and short stature—are not particularly costly. Persons who are deaf or of short stature (or both) generally live independently and without high medical costs.<sup>214</sup> Their limitations derive more from prejudices and environmental barriers than any physical limitations.<sup>215</sup> Although it is possible that parents might use genetic intervention to have children with other kinds of socially disfavored physical characteristics, it is unlikely parents would use genetic intervention to choose particularly expensive traits because the parents will be initially responsible for the costs.

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<sup>213</sup> This policy also relies upon the implied assumption that society generally would be better off with fewer persons with disabilities and more resources. It is a mistake, however, to assume that persons with disabilities cost more than they are worth. Indeed, what little research there is on the subject—focusing on the utility of providing reasonable accommodations to employ persons with disabilities—suggests that the benefits of having such persons in the workplace far outweigh the costs. Waterstone & Stein, *supra* note 184, at 1376.

<sup>214</sup> See DAVIS, *supra* note 8, at 47 (explaining that deaf people live independently and also refuting the social costs argument); *Frequently Asked Questions*, *supra* note 11 (explaining that persons of short stature generally have average life spans and live independently).

<sup>215</sup> See *supra* notes 185–86 and accompanying text (describing the social model of disability).

*C. The Scope of the "Problem"*

Two observations place the policies supporting parental liability in context. First, neither Smolensky nor her commentators appear to claim that giving a child physical attributes such as deafness or short stature *always* harms the child.<sup>216</sup> It may very well be that children whose parents give them these physical traits do not suffer a cognizable harm, even under the open future test.

Second, as Smolensky admits, there is not likely to be a great number of parents who are interested in giving their child a trait that is associated with disability.<sup>217</sup> This should come as no surprise. The costs of genetic engineering will be high, especially in the early years. Moreover, the social pressure to have a "normal" baby, that is, one who has attributes that are socially favored, is likely to continue to be immense.<sup>218</sup> The size of the problem Smolensky is attempting to solve shrinks with each condition: (1) only a small number of parents will want to give their child socially disfavored physical traits and will resort to genetic intervention to do so; (2) only some of these parents will be able to afford genetic intervention; (3) only some of these parents will follow through despite opposition from physicians and friends; and (4) only rarely, if ever, will the chosen trait actually do more harm to the child than good.

The apparent small scope of the problem raises questions about whether there is a need to adopt a new standard for liability just for parents who choose to give their child socially disfavored traits. Perhaps there is a moral basis to prevent genetic intervention generally; but if that is the case, there is no need to focus the inquiry on whether socially disfavored traits like disabilities are inherently disadvantageous. As discussed in the next section, putting parental decisions in favor of disability on trial is likely to lead to inaccurate results and further entrench discrimination against those who are physically different.

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<sup>216</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 340–41.

<sup>217</sup> *Id.* at 300.

<sup>218</sup> See Shepherd, *supra* note 19, at 779 ("Societal pressures . . . to bring only 'non-defective' children into the world, can obtain such widespread currency that they become assumptions of medical, legal, spiritual, and community institutions, to the point of obviating entirely the need for government action in this area."); see also Longmore, *supra* note 179, at 221 (discussing the relationship between conceptions of wholeness and of being valid Americans).



IV. THE RIGHT TO AN OPEN FUTURE IN A WORLD WHERE IRRATIONAL  
DISCRIMINATION PERSISTS

Smolensky suggests that in the context of genetic intervention we should alter the standard in tort law used to determine when a genetic change results in a cognizable injury.<sup>219</sup> Under her approach, judges and juries would ask whether the genetic intervention violated the child's right to an open future.<sup>220</sup> Using the open future analysis, Smolensky argues that courts should decide whether parents who select in favor of disability are reasonable in doing so.<sup>221</sup>

Scholars have proposed a variety of different models for evaluating the legal obligations between parents and children.<sup>222</sup> Rather than attempting to compare and critique these various models, this Part focuses on the practical problems that derive from using the open future test to assess the consequences of disability. This focus points to more general problems with the way in which scholars, judges, and the media have approached the intersection between genetics and disability. The open future test proposed by Smolensky fails to address the incompetence of juries to evaluate the consequences of disability or the social problems with categorizing certain socially disfavored physical features as harmful.

A. *Of "Sound" Bodies and "Open" Futures*

Smolensky finds some support for the open future approach in a series of cases that make reference to a child's "right to begin life with a sound mind and body."<sup>223</sup> These cases, she argues, manifest a judicial movement toward recognizing that children have a moral right to be born free from impediments.<sup>224</sup>

Even if these cases did describe a legitimate moral right, the "right to a sound body" provides an impossible and arbitrary standard for evaluating damages. The problems with using the right to a sound body to determine harm are very much the same as the problems with using the open future framework to assess harm. Both approaches purport to use an objective standard to measure harm, when in fact they rely upon

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<sup>219</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 337.

<sup>220</sup> *Id.* at 311. Davis also supports the "open future" approach; however, she does not call for new laws to enforce it. DAVIS, *supra* note 8, at 26, 30.

<sup>221</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 340.

<sup>222</sup> See Ouellette, *Shaping Parental Authority*, *supra* note 73, at 30-33.

<sup>223</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 302. For the sake of brevity, I refer to the "right to begin life with a sound mind and body" simply as the "right to a sound body."

<sup>224</sup> *Id.* at 312.

artificial, subjective notions about what makes a person complete. Ultimately, both approaches fail to measure whether the plaintiff has actually suffered harm and instead presume harm whenever the plaintiff has a different body type or experience than most people expect in life.

In *Smith v. Brennan*, the New Jersey Supreme Court made the following comment when attempting to explain why a child should be permitted to recover against a third party for prenatal injuries:

[J]ustice requires that the principle be recognized that a child has a legal right to begin life with a sound mind and body. If the wrongful conduct of another interferes with that right, and it can be established by competent proof that there is a causal connection between the wrongful interference and the harm suffered by the child when born, damages for such harm should be recoverable by the child.<sup>225</sup>

Aside from the conclusory assertion that “justice requires” the “legal right to begin life with a sound mind and body,” the *Brennan* court made no attempt to explain the basis or scope of this newly invented right. Nonetheless, a number of courts have quoted this language to support liability for prenatal injuries, but with little analysis of their own.<sup>226</sup>

The problem is that this “right” is artificial and vague. Even when there has been no tortious conduct, children are born with a variety of different characteristics and abilities, some of which might be considered “sound” and others that might be called “unsound.” Simply because society tends to identify a certain set of characteristics as “normal” or “sound,” does not mean that a child has been harmed if born without these characteristics. Indeed, the characteristics we associate with a “sound” body might not even be those that are particularly common. Medical studies suggest that one third of the adults in the United States are obese, but most people would probably not say that children have

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<sup>225</sup> 157 A.2d 497, 503 (N.J. 1960).

<sup>226</sup> See, e.g., *Womack v. Buchhorn*, 187 N.W.2d 218, 222 (Mich. 1971); *Grodin v. Grodin*, 301 N.W.2d 869, 870 (Mich. Ct. App. 1980); *Gleitman v. Cosgrove*, 227 A.2d 689, 692 (N.J. 1967); *Draper v. Jasionowski*, 858 A.2d 1141, 1144 (N.J. Super. Ct. App. Div. 2004); *Sylvia v. Gobeille*, 220 A.2d 222, 224 (R.I. 1966); see also *Jarvis v. Providence Hosp.*, 444 N.W.2d 236, 239 (Mich. Ct. App. 1989); *Hoener v. Bertinato*, 171 A.2d 140, 144 (N.J. Bergen County Ct. 1961) (referring to right to sound mind and body to support taking custody of child to provide blood transfusion against parents' wishes); *Evans v. Olson*, 550 P.2d 924, 927 (Okla. 1976); *Leal v. C. C. Pitts Sand & Gravel, Inc.*, 413 S.W.2d 825, 830 (Tex. App. 1967) (Cadena, J, dissenting), *rev'd* 419 S.W.2d 820 (Tex. 1967).

the right to be born with a tendency toward obesity.<sup>227</sup> A “sound” body is really a body that has the characteristics those making the decisions prefer.

The subjective and protean nature of the “sound body” standard invites decisions based upon stereotypes. Thus, in *Stallman*, the Illinois Supreme Court expressly rejected the “right to a sound mind and body” language because it suggests a duty of the mother to guarantee her child has socially favored characteristics.<sup>228</sup> The court asked:

By what objective standard could a jury be guided in determining whether a pregnant woman did all that was necessary in order not to breach a legal duty to not interfere with her fetus’ separate and independent right to be born whole? In what way would prejudicial and stereotypical beliefs about the reproductive abilities of women be kept from interfering with a jury’s determination of whether a particular woman was negligent at any point during her pregnancy?<sup>229</sup>

By cloaking cultural conceptions in the seemingly objective measure of “soundness,” the right to a sound body permits juries to express their prejudices as though they were objective moral imperatives.

It is true that the environment we live in appears to be more suited to some physical body-types than others. A person who uses a wheelchair cannot always access buildings and events as easily as those who walk. Persons who are exceptionally tall must duck to get into most cars. And people who are perceived as not being “good-looking” face challenges in both their jobs and social lives.<sup>230</sup> Although we might assume that judges and juries find bodies “unsound” when those bodies are incompatible with our social and physical environment, this is not necessarily true. In fact, as discussed below, decision makers tend to misjudge the consequences of socially disfavored physical characteristics.<sup>231</sup> Moreover, by calling certain bodies “unsound,” the right to a sound body jurisprudence relocates environmental and social

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<sup>227</sup> See Katherine M. Flegal et al., *Prevalence and Trends in Obesity Among US Adults, 1999–2008*, 303 J. AM. MED. ASS’N 235, 235 (2010), available at <http://jama.ama-assn.org/cgi/content/full/303/3/235?ijkey=ijKHq6YbJn3Oo&keytype=ref&siteid=amajnl>.

<sup>228</sup> *Stallman v. Youngquist*, N.E.2d 355, 359 (Ill. 1988).

<sup>229</sup> *Id.* at 360. Shepherd makes a similar point: “When values, risk tolerance, faith, love, fear, and biological impulse naturally and necessarily factor into a decision, it is impossible to say whether the decision is reasonable or unreasonable.” Shepherd, *supra* note 19, at 805.

<sup>230</sup> See Jeff E. Biddle & Daniel S. Hamermesh, *Beauty, Productivity, and Discrimination: Lawyers’ Looks and Lucre*, 16 J. LAB. ECON. 172 (1998).

<sup>231</sup> See *infra* Part IV.B (discussing the misperception of disabilities).

problems—like discrimination and lack of access—to the physical body of the person being subjected to prejudice. This displacement of fault onto the plaintiff discourages necessary changes to the social and environmental status quo.

Thus far, none of the courts referencing the right to a sound body have evoked the right as a means for determining whether the plaintiff suffered actual harm. The language of the “sound body” jurisprudence, however, seems to suggest that there is no need to consider whether the plaintiff is actually worse off because of defendant’s actions. Instead, it would appear that the court may simply look to whether the defendant caused the plaintiff to have characteristics that are different from the court’s conception of a sound body. Rather than evaluating whether the plaintiff’s physical state has had an overall harmful effect on the plaintiff, courts can assume harm based purely on the fact that the plaintiff is physically different. This approach unfairly suggests that simply because a plaintiff has unusual attributes, the plaintiff must have been harmed. Shepherd explains:

Rather than signifying merely the limits of others’ tortious behavior, the language of the “right to a sound mind and body” exhibits an independence from others’ noxious conduct and connotes an affirmative obligation on the part of other people to eliminate any obstacles, natural or otherwise, to achieve this societal concept of a sound mind and body.<sup>232</sup>

The “right to an open future” similarly invites courts to conflate damages with difference. Like the right to a sound body jurisprudence, the open future test implies the existence of a right that does not normally exist. People are born into a wide variety of circumstances with a variety of physical abilities. Those who are born into poverty do not have the same opportunities as those born with wealth. Those who are born blind do not have the same opportunities as those born sighted. Certainly, all persons are not born with an equal array of opportunities, regardless of whether their parents use genetic intervention.<sup>233</sup>

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<sup>232</sup> Shepherd, *supra* note 19, at 770. A similar problem arises in wrongful life cases. See Hensel, *supra* note 179, at 144 (“Rather than focusing on a defendant’s conduct, as in a traditional tort action, both wrongful birth and wrongful life suits ultimately focus on the plaintiff’s disability, a status that is at least partially a societal construction.”).

<sup>233</sup> Davis concedes that her reference to a “right” to an open future is more “metaphorical” than literal. DAVIS, *supra* note 8, at 46. She asserts, however, that having a child who happens to be born into poverty or is otherwise limited in opportunities is different from deliberately giving a child attributes that limit the child’s options. *Id.* at 84.

Asking the question of whether a child's right to an open future has been violated implies that any departure from what is commonly accepted as a normal future violates the child's inalienable right. Just as the right to a sound body prefers certain physical attributes, the right to an open future gives preference to a certain array of opportunities in life. A person born with hearing is limited in her ability to enter Deaf culture. But we are apt to treat deafness as a restriction on one's future opportunities because our society tends to value hearing culture above Deaf culture.<sup>234</sup> Commentators automatically assume that it is better to be born hearing than deaf—not because people who cannot hear have less appealing opportunities in life by some objective standard, but because *most people think* that the opportunities afforded the hearing are better than those given the Deaf.<sup>235</sup> The "open future" language is code for those generally accepted activities that most people think they want to experience in life. Simply because an experience is common or valued highly by a dominant group does not mean that the experience is superior to other activities or that a child has suffered harm if she does not have the opportunity for those experiences. There may well be

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This distinction suggests that what Davis calls a "right to an open future" is really a right to not have one's genetic identity manipulated in ways that might constrain one's opportunities in life. But every genetic manipulation, if effective, changes the child's genetic identity and thereby changes the child's opportunities in life. For example, if my parents give me great intelligence, I might never be able to enjoy low-brow movies; if they give me low intelligence, I may never appreciate high-brow ones. Davis would likely argue that the right to an open future is violated only if the parents' choice prevents the child from having a "wide variety" of opportunities. *Id.* My concern is that what constitutes a "wide variety" will be decided based on overgeneralizations about what opportunities are valuable. This problem is exacerbated by the implication that children have an independent right to activities the dominant culture deems superior.

<sup>234</sup> Davis argues that choosing deafness for a child violates the child's right to an open future because the Deaf community is relatively small and those who are deaf often have difficulty with written language. These consequences, she argues, unreasonably narrow a deaf child's social and vocational opportunities. However, even if Davis is correct about the scope of opportunities available to a deaf child, her conclusion that these opportunities are inferior to those permitted a hearing child relies upon value judgments about what makes for a complete life. Is it better to be part of a large, impersonal community than to be part of small, intimate one? See Dennis, *supra* note 169 (some assert that there is greater intimacy among members of the Deaf community). Is it better to have more job and marriage prospects than less? Some might say that it is better to have a few meaningful opportunities than to have myriad unfulfilling ones. Simply because the dominant culture thinks more is better than less and bigger is better than smaller does not mean that those values are correct or applicable to every situation.

<sup>235</sup> See Jones, *supra* note 9, at 223 (stating genetic intervention should not be permitted when used for "things that virtually anyone would agree are harmful," such as to create a deaf child); Smolensky, *Genetic Interventions*, *supra* note 9, at 319–20 ("Under an objective standard of offense the creation of genetic traits such as deafness or achondroplasia are almost certain to be considered offensive to a reasonable sense of personal dignity.").

uncommon and unpopular experiences in life that are more valuable than the ones that most people seek. Some may, as Longmore suggests, “prize not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community.”<sup>236</sup>

The problems with the open future framework reflect a more fundamental ambiguity in the discourse regarding genetic intervention. Commentators frequently distinguish between “therapeutic” and “nontherapeutic” interventions, or between “enhancements” and “diminishments.”<sup>237</sup> But these terms have meaning only by reference to some subjective standard for what makes a person whole.<sup>238</sup> Some would consider it therapeutic to modify the DNA of an embryo that has the phenotype for deafness so that it has the phenotype for hearing. Others would consider this modification diminishing.<sup>239</sup> In either case, the embryo will have a different identity and experience than it would have had without intervention. As discussed in the next section, judges and juries cannot accurately measure the degree to which such a change will be an advantage or disadvantage for the child.

#### B. *Pervasive Misperception of Disability*

As discussed above, courts have repeatedly recognized that judges and juries are ill-equipped to assess accurately the subtleties of intra-family relationships.<sup>240</sup> This assessment becomes all the more problematic when the jury attempts to determine the consequences of physical attributes that most of them have never experienced.<sup>241</sup> In the usual tort action, jurors draw from their own experiences to do what juries do best—decide whether conduct violates community values. The open future test asks juries to do something much more speculative and

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<sup>236</sup> Longmore, *supra* note 179, at 222. In his critique of scholarship advancing the social model of disability, Adam Samaha recognizes an important, though underdeveloped, implication of the social model of disability: “[The social model’s insights might] suggest a class of decisionmakers different from the group that other perspectives suggest.” Samaha, *supra* note 185, at 1254. In the context of genetic interventions in favor of disability, the social model points to the problems with relying on outsiders to decide what it is like to have physical traits associated with disability.

<sup>237</sup> Ouellette, *Shaping Parental Authority*, *supra* note 73, at 960, 985; see also Cohen, *supra* note 200, at 349.

<sup>238</sup> To some extent, Cohen recognizes this problem in responding to Smolensky. See Cohen, *supra* note 200, at 349–50.

<sup>239</sup> See DAVIS, *supra* note 8, at 67–69; Longmore, *supra* note 179, at 221–22.

<sup>240</sup> See *supra* note 68 and accompanying text (suggesting that social, cultural, economic, and philosophical factors that shape parental discretion and authority should not be second-guessed).

<sup>241</sup> A similar objection applies to wrongful life cases. See Hensel, *supra* note 179, at 185.

subject to bias—determine the future consequences of having a particular physical trait.<sup>242</sup> This inquiry adopts wholesale the assumption of the medical model that physical features carry inherent limitations that can be scientifically explained and assessed.<sup>243</sup> Juries, guided by purportedly “expert” testimony from physicians who are steeped in the medical model, are likely to base their decisions on deep-seated biases and negative stereotypes about disability.<sup>244</sup> Generally, juries tend to “emphasize evidence consistent with [their] own views and attitudes while . . . discount[ing] or ignor[ing] evidence inconsistent with [their] attitudes.”<sup>245</sup>

The artificial, subjective nature of the open future test is particularly problematic in the context of disability because people tend to overestimate the harms associated with disability and underestimate the extent to which those harms are socially created. Carol J. Gill summarizes the counterintuitive results of research on quality of life and disability:

A remarkably consistent finding across studies using widely varying samples and methods is that life satisfaction does not diminish with increasing degree of physical impairment. In fact, several studies indicate that persons with “severe” physical disabilities, such as spinal cord quadriplegia and neuromuscular disabilities requiring mechanical ventilation, express greater life satisfaction than do those with less disabling conditions.<sup>246</sup>

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<sup>242</sup> The reference to a “right” to an open future gives the appearance that juries are contemplating a moral question, when in fact they are speculating about the future based on general assumptions.

<sup>243</sup> See Hensel, *supra* note 179, at 183 (discussing similar problematic assumptions in wrongful life cases).

<sup>244</sup> *Id.* at 185.

<sup>245</sup> M. Neil Browne et al., *The Shared Assumptions of the Jury System and the Market System*, 50 ST. LOUIS U. L.J. 425, 454 (2006); see also Monica K. Miller, Alayna Jehle & Alicia Summers, *From Kobe Bryant to Saddam Hussein: A Descriptive Examination and Psychological Analysis of How Religion Likely Affected Twenty-Five Recent High-Profile Trials*, 9 FLA. COASTAL L. REV. 1, 1 (2007) (noting that “jurors tend to be more lenient toward defendants who follow society’s norms”).

<sup>246</sup> Carol J. Gill, *Health Professionals, Disability, and Assisted Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia*, 6 PSYCHOL. PUB. POL’Y & L. 526, 529 (2000) (citations omitted); see also Waterstone & Stein, *supra* note 184, at 1359–61 (discussing prevalence of unconscious discrimination “even amongst people who profess strong egalitarian beliefs”).

This research suggests a serious flaw in the common assumption that having more capabilities is better than having less. In addition, surprising to some, research suggests that healthcare professionals—the gate-keepers of ART and the most likely expert witnesses in genetic intervention litigation—significantly underestimate the quality of life of persons with disabilities.<sup>247</sup> Gill concludes that “the gap between health professionals and people with disabilities in evaluating life with disability is consistent and stunning.”<sup>248</sup>

The urge to prevent parents from using genetic intervention to select in favor of disability arguably does not come from direct hostility toward persons with disabilities. It is, instead, a case of misguided benevolence—an impulse based upon the presumption that disability is inherently tragic. Equating disability with suffering embraces the medical model’s central tenet that physical difference is a misfortune to be avoided or overcome, but not embraced. Shepherd explains why this attempt at benevolence is problematic:

The creation of rights in response to someone’s or some group’s suffering assumes that we as a society can identify when suffering is taking place. But suffering is individual and personal, and not always obvious. Many well-meaning people who do not live with disabilities will assume that a fetus with disabilities will suffer if brought to term. Yet people living with disabilities and persons working and living with disabled people often say otherwise.<sup>249</sup>

Although the medical model of disability has been challenged repeatedly, commentators discussing genetics still tend to assume disability is synonymous with detriment. Commentators conclude, with little or no analysis, that: (1) having a disability means having fewer capabilities; and (2) “reasonable” people would rather have more abilities rather than less.<sup>250</sup> This analysis, of course, fails to recognize that abilities and opportunities are not uniformly valued or mathematically measured; that capabilities are not inherent and permanent but are affected by environmental and social factors; that

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<sup>247</sup> Gill, *supra* note 246, at 530.

<sup>248</sup> *Id.*

<sup>249</sup> Shepherd, *supra* note 19, at 782; *see also* Dunne & Warren, *supra* note 28, at 168 (“Though a noble goal worth pursuing, reducing affliction must not be accomplished by targeting individuals having, or perceived as having conditions considered undesirable.”).

<sup>250</sup> *See, e.g.*, Jones, *supra* note 9, at 223; Smolensky, *Genetic Interventions*, *supra* note 9, at 319–20.



having more physical functions does not necessarily mean having greater opportunities and happiness; and that reasonable people may place different values on common experiences and norms. If even persons somewhat educated about disability and genetics tend to presume harm, it is unlikely that juries will be able to see beyond the old stereotype that disability is inherently tragic.

C. *The Problems with Treating Prospective Discrimination as Harm*

As discussed above, parents would face significant obstacles in attempting to convince a jury that a disability like deafness or short stature is not inevitably tragic. This, however, is only the first great hurdle for parents attempting to avoid liability. Under Smolensky's approach, a genetic intervention could be considered harmful if, although not inherently limiting, the intervention gives the child attributes that subject the child to discrimination. Returning to the example of parents who use genetic intervention to have a deaf child, Smolensky argues genetic deafness may violate the child's right to an open future because "environmental factors are not changing rapidly enough to alleviate harm caused by a disabling trait."<sup>251</sup>

Smolensky is correct that persons with disabilities face significant social and environmental obstacles, such as prejudice and inaccessible areas, that arguably limit the life opportunities of persons with disabilities in some cases.<sup>252</sup> She may also be correct that negative assumptions about disability will likely persist even in the future when the technology for genetic intervention is available. But even if we assume that the negative social consequences of a particular disability will at times outweigh the benefits of the physical trait—and that it is possible to evaluate the benefits and burdens with any degree of accuracy—this does not justify holding the parents liable for choosing a disfavored physical trait.

There is something sadly ironic about using the existence of discrimination as a reason to prevent the creation of the traits that subject a person to discrimination. In effect, we are saying that even if society's views are wrong, those views should constrain parents' ability to make choices about their children. As discussed below, this "social harm approach" is unfair to parents and would serve to further entrench discrimination. In the context of genetic testing and intervention, the

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<sup>251</sup> Smolensky, *Technological Harms*, *supra* note 126, at 418.

<sup>252</sup> See Areheart, *supra* note 178, at 188 (asserting that many of the challenges persons with disabilities face are socially construed barriers that limit participation in mainstream society).

law should take a normative rather than a descriptive approach to evaluating the consequences of disability.

1. Over-Deterrence and the “New Eugenics”<sup>253</sup>

The first problem with the social harm approach is that it rests precariously on the edge of a slippery slope. If we presume a child has suffered legally cognizable harm whenever parents choose to give the child a trait that will subject the child to discrimination, then parents could be found liable for choosing any among a wide variety of socially disfavored physical traits.<sup>254</sup> It is not difficult to imagine children claiming that they will suffer discrimination because of the skin color, gender, or other physical characteristic chosen by the parents. Parents may have legitimate reasons for wanting their child to be of a particular race or gender or to have certain traits, such as deafness, that correspond with the parents’ identity and culture. These attributes could benefit the child as well as the social group the child joins. Under the social harm approach, however, parents risk liability if they fail to choose the attributes that a jury will recognize as socially beneficial.

Because social values change over time, parents will be unable to know in advance which traits will subject the parents to liability years later when the child has reached majority and decides to sue her parents. This is especially hard with disabilities because it is difficult to predict how changes in the law will affect environmental obstacles and social attitudes toward disability.<sup>255</sup> Moreover, given the small number of parents who want to offer their child an unpopular physical trait, many years will pass before there is any clear precedent establishing which physical traits are found to violate a child’s right to an open future and which ones are fair game. Parents who know their actions will be judged after the fact based on future social conditions will be hesitant to choose any trait that could possibly subject them to litigation. In this way, the social harm approach would prevent parents from choosing a wide array of physical traits, many of which may not actually be harmful to the child.

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<sup>253</sup> Fox, *supra* note 23, at 569.

<sup>254</sup> *But see* Burnette v. Wahl, 588 P.2d 1105, 1111–12 (Or. 1978) (noting that while in other situations it may be appropriate to award damages based solely on emotional harm, this rationale does not apply to parent-child relationships).

<sup>255</sup> See Alex B. Long, *Introducing the New and Improved Americans with Disabilities Act: Assessing the ADA Amendments Act of 2008*, 103 NW. U. L. REV. COLLOQUY 217, 217 (2008) (discussing how the expected social and environmental impacts of the Americans with Disabilities Act of 1990 failed to materialize).

The problem of over-deterrence has broad implications. Some scholars have warned that if genetic intervention is legal and readily available, we will see physical diversity shrink as parents feel pressured to use genetic intervention to give their children the most prestigious physical traits. Some predict a *Gattaca*-esque world where those who are naturally born with traits that are viewed as imperfections become part of a lower caste, a minority rejected and demoralized for their inborn failings.<sup>256</sup> Fox refers to the *laissez-faire* approach to genetic intervention as a “new eugenics”<sup>257</sup>—because he believes it could lead to further marginalization and eradication of members of disfavored groups.<sup>258</sup>

If widely available genetic intervention threatens physical and cultural diversity, then this threat can only be made worse by a legal scheme that punishes parents who seek to give their children unpopular physical traits. Under the social harm approach, parents could freely choose to give their child any of the attributes commonly favored in society, but they could not consider other physical traits without risking liability. The social harm approach is not truly “eugenic” inasmuch as it is not a state-sponsored attempt to cleanse the population of characteristics presumed inferior.<sup>259</sup> But the social harm approach threatens a eugenic consequence: through civil tort liability, the state would implicitly condemn and punish the creation of socially disfavored physical attributes while permitting the creation of physical attributes that society deems beneficial.

## 2. Parents with Disabilities

A second problem with the social harm approach is that it limits parental discretion to conform with dominant social views. Smolensky admits that parents who might use genetic intervention in favor of disability would do so with good intentions.<sup>260</sup> Nonetheless, she argues that there is a danger of parents imprudently selecting attributes that will be bad for the child.<sup>261</sup>

It must be noted that in Smolensky’s analysis the misguided parents who cannot be trusted to choose the best traits for their child are usually parents with disabilities. Arguing that the threat of harm to children is

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<sup>256</sup> Fox, *supra* note 23, at 572 (summarizing arguments regarding polarization and critiquing them).

<sup>257</sup> *Id.* at 569.

<sup>258</sup> *Id.* at 607–12.

<sup>259</sup> See generally Paul A. Lombardo, *Disability, Eugenics, and the Culture Wars*, 2 ST. LOUIS U. J. HEALTH L. & POL’Y 57 (2008).

<sup>260</sup> Smolensky, *Genetic Interventions*, *supra* note 9, at 308–09.

<sup>261</sup> *Id.* at 305, 317.

real, Smolensky tells of an “[o]ff-the-record” story about parents of short stature strong-arming their physician to implant an embryo that has the genotype for achondroplasia:

According to one account, parents with achondroplasia told their physician that if he refused to help them select a child with achondroplasia, they would go to another IVF clinic, refuse PGD testing, get pregnant, have the fetus tested via amniocentesis for achondroplasia, and abort any child not carrying the gene. . . . Not wanting to be the cause of an unnecessary abortion and recognizing that the end result would be the same with or without his assistance (a child with achondroplasia), the physician agreed to help the parents utilize PGD to select for a child with achondroplasia.<sup>262</sup>

Those who find the actions of the parents in this story reprehensible would probably find the behavior just as bad, or perhaps worse, if the parents had been threatening to abort any child that did not test with the genotype for blue eyes. Because this story focuses on disabled parents, it might be misread as implying that disabled parents are irrational or amoral.<sup>263</sup>

Smolensky likely focuses on parents with disabilities because she assumes that disabled parents are more likely than others to choose traits that are associated with disabilities.<sup>264</sup> If this assumption is correct, however, then the legal scheme Smolensky proposes would fall harder on parents with disabilities than others.<sup>265</sup> Parents who are not disabled could choose to select a child with their own physical attributes while parents with disabilities could not make such a choice without risking liability.

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<sup>262</sup> *Id.* at 305 (footnotes omitted).

<sup>263</sup> I do not think Smolensky intends this story to suggest such a sweeping and politically incorrect statement. I point out the implied meaning, however, because historically Western culture has often punctuated the moral depravity of characters by giving them unusual physical traits.

<sup>264</sup> There is a reason for this. Parents with disabilities might want to have children who have socially disfavored traits. See *supra* Part III.A (discussing why parents may choose to give their child a disability).

<sup>265</sup> See Templeton, *supra* note 32: “If choice of embryos for implantation is to be given to citizens in general, and if hearing and other people are allowed to choose embryos that will be ‘like them’, sharing the same characteristics, language and culture, then we believe that deaf people should have the same right.” (quoting Francis Murphy, chairman of the British Deaf Association)).

Parental autonomy takes on new meaning when the parents are themselves disabled. Historically, courts and legislators have underestimated the ability of parents with disabilities to make responsible reproductive decisions and care for their children. Carl H. Coleman explains:

In the early part of the twentieth century, many states passed laws requiring the sterilization of certain categories of persons, a primary goal of which was to prevent people with disabilities from having children. The constitutionality of these laws was upheld in *Buck v. Bell*, in which Justice Holmes, upholding the involuntary sterilization of an allegedly "feeble minded white woman," famously declared that "three generations of imbeciles are enough." While *Buck v. Bell* has been criticized extensively, the U.S. Supreme Court has never expressly overruled it.

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While coercive eugenics laws fell out of favor after World War II, the perception that individuals with disabilities cannot be good parents has remained widespread. In many states, laws governing the termination of parental rights specify a parent's disability as a factor to consider in terminating the parent's rights. Courts sometimes interpret these statutes as creating a presumption that individuals with disabilities are unable to parent: "[D]eaf parents are thought to be incapable of effectively stimulating language skills; blind parents cannot provide adequate attention or discipline; and parents with spinal cord injuries cannot adequately supervise their children." These beliefs, as Dave Shade notes, reflect the "all-too-familiar picture of the parent with a disability: unable to provide care, unable to provide love, unable to be a parent."<sup>266</sup>

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<sup>266</sup> Carl H. Coleman, *Conceiving Harm: Disability Discrimination in Assisted Reproductive Technologies*, 50 UCLA L. REV. 17, 24-26 (2002) (alteration in original) (footnotes omitted). See also generally Dave Shade, *Empowerment for the Pursuit of Happiness: Parents with Disabilities and the Americans with Disabilities Act*, 16 LAW & INEQ. 153, 159 (1998); Michael

Given the persistence of discrimination against disabled parents, Coleman argues, "there is a real danger that disability-related denials of ARTs will be based on ignorance or bias against people with disabilities."<sup>267</sup>

This unsightly history of discrimination against parents with disabilities does not suggest that disabled parents will always make the right genetic decisions for their children. It does, however, give reason to suspect that judges and juries will fail to give such parents the full deference they deserve. We should be wary of any approach that attempts to second-guess parental decisions, especially when those decisions are being made by parents who are inappropriately assumed to be inadequate.

### 3. Legitimizing Discrimination

A final problem with the social harm approach, and with the open future structure generally, is the message it sends about the consequences of disability. The negative message sent by the open future approach to disability has both public and private effects.

There is some similarity between the implied message of wrongful life actions and that of lawsuits based on genetic intervention in favor of disability. Both communicate a similar, disempowering message: "as a matter of law, your impairment, standing alone, is a sufficient basis upon which to evaluate the quality of your life."<sup>268</sup> This negative message becomes personal, and is more likely to be internalized, when the disability becomes the subject of litigation. Children would be compelled to offer testimony of how the traits their parents chose for them have made it so they cannot enjoy a complete life. And jury verdicts in the child's favor would suggest state approval of the view that persons with socially disfavored physical traits are destined for a life of woe and misery.

Also problematic, the open future approach promotes unnecessary conflict between the interests of the parents and what we assume to be the interests of the child. When this conflict interferes with the parent-child relationship, it may do more harm than a miscalculation by the parents about which physical traits are best for their child. Discussing parents who choose not to terminate pregnancy when they discover they are having a child with a genetic anomaly, Shepherd writes:

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Ashley Stein, *Mommy Has a Blue Wheelchair: Recognizing the Parental Rights of Individuals with Disabilities*, 60 BROOK. L. REV. 1069, 1083 (1994).

<sup>267</sup> Coleman, *supra* note 266, at 20.

<sup>268</sup> Hensel, *supra* note 179, at 174 (discussing the message sent by wrongful birth and wrongful life actions).

[I]t is not that parents make the best decisions for their children, but that it is generally best for children, or children-to-be, for parents to make these decisions. By deferring to the parents in this regard, we recognize value in the bond that exists between parent and child, a bond that first develops, in the usual instance, between mother and fetus.<sup>269</sup>

Although Shepherd does not address either the right to an open future or genetic intervention, she criticizes courts and commentators who attempt to balance the child's right to bodily integrity against the mother's right to bodily integrity.<sup>270</sup> Instead of focusing on presumed competing rights of the mother and fetus, Shepherd argues, we should recognize a common right that benefits mother and fetus, "a right to attachment":

[T]his conception of the right recognizes that the interests of these two "beings" are generally aligned. It arises from the needs of the child, developing now as a fetus, because children need to belong, to be a welcomed member of their family. Their need to belong is threatened when we evaluate parental decisions made concerning their welfare within a rights analysis that depends on conflict.<sup>271</sup>

This right to attachment recognizes that assessments about quality of life are primarily subjective and that failing to respect the parent-fetal relationship weakens the ties between parent and child.<sup>272</sup>

The problem with the open future framework is not simply that some persons with disabilities might be offended by its implied messages. The problem is that in the course of litigation those messages create conflicts where they may not already exist and would also fortify unproductive stereotypes about the value of persons who have socially disfavored physical traits.

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<sup>269</sup> Shepherd, *supra* note 19, at 799.

<sup>270</sup> *Id.* at 793-94, 796-97.

<sup>271</sup> *Id.* at 798.

<sup>272</sup> *Id.* at 805 ("The right to attachment protects decisions that most members of society would regard as unreasonable as well as those it would think reasonable. When values, risk tolerance, faith, love, fear, and biological impulse naturally and necessarily factor into a decision, it is impossible to say whether the decision is reasonable or unreasonable.").

V. THE MOTHER OF INVENTION<sup>273</sup>

Why has so much of the debate over genetic intervention focused on whether parents ought to be able to genetically engineer their child to have traits associated with disability? Certainly, it is not because there is a large population of parents longing to create children with disabilities.

There would be little controversy in asking why parents might want to give their child blue eyes. Asking why parents might choose to give their child a disability is much more provocative because it draws into conflict two perspectives: on the one hand, the traditional presumption that disability is inherently tragic, and on the other hand, the modern call for politically correct discussion of disability.<sup>274</sup>

When considering genetic intervention in favor of disability, we must reach beyond both of these limited perspectives. Policies in this area should not rely, overtly or impliedly, upon the old stereotype that disability is inherently tragic. Nor should policies be set merely to satisfy ephemeral notions of political correctness. The problem with asking juries to decide whether a particular physical trait is harmful or beneficial is that the question itself implies that physical traits are inherently helpful or harmful and that public perceptions of disability are legitimate. The consequences of having physical traits associated with disability are not objectively discernable or uniform in nature; they derive from protean social attitudes and environments. Parents, who have personal experience with the physical traits in question, are better equipped to decide what is best for their offspring than jurors who have less experience and less at stake. Second-guessing parental decisions about socially disfavored physical traits only disrupts the parent-child relationship and suggests that discriminatory attitudes and practices are natural and acceptable.

Of course, there are other options. Rather than imposing tort liability on parents, we could pass legislation that prohibits the use of genetic intervention to choose certain traits or requires physicians to

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<sup>273</sup> The proverb, "necessity is the mother of invention," first appears in English print in 1545: "Necessitie, the inuenter of all goodnesse (as all authours in a maner, doo saye) . . . inuented a shaft heed." OXFORD DICTIONARY OF PROVERBS 214 (Jennifer Speake, ed. 2003) (quoting ROGER ASCHAM, TOXOPHILUS II. 18<sup>v</sup> (1545)). A slightly earlier proverb takes the point a step further: "Necessity knows no law." *Id.*

<sup>274</sup> The dramatic force of this question is used to capture readers' attention. Thus, for example, Davis opens her book on ethical issues in reproductive technologies with a fictional story of Celia, a woman of short stature who wanted a child with similar traits. DAVIS, *supra* note 8, at 1-5. Smolensky adds an air of mystique to the controversy, introducing her article as developing out of "back-of-the-room conversations" and relying upon "[o]ff-the-record" conversations. Smolensky, *Genetic Interventions*, *supra* note 9, at 299, 305.



evaluate the appropriateness of genetic interventions on a case-by-case basis. Both of these approaches carry problems of their own. Physicians are notoriously biased in favor of existing social norms.<sup>275</sup> And legislatures may not be much better than juries at evaluating the benefits and drawbacks of physical traits, especially given that social and environmental factors are constantly in flux.

The debate over genetic intervention has veered down an unnecessary path. Disabled parents who want disabled children are too few in number and diverse in purpose to serve as the poster children for the debate over genetic intervention. If, contrary to the evidence, there is some threat of parents with disabilities intentionally or recklessly using genetic intervention to inflict pain and distress on their child, then we already have civil and criminal remedies to address such behavior. We need not expand tort law to meet these remote possibilities. The potential problems with genetic intervention have little to do with disability and even less to do with the competence of parents with disabilities. Common fears about physical difference should not be used to support asking juries to pass judgment on the cultural and philosophical values that guide parental decisions.

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<sup>275</sup> Gill, *supra* note 246, at 530; Longmore, *supra* note 179, at 178–80.