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Insult to Injury: A Disability-Sensitive Response to Smolensky's Call for Parental Tort Liability for Preimplantation Genetic Interventions

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Professor Kirsten Rabe Smolensky's article, *Creating Children with Disabilities: Parental Tort Liability for Preimplantation Genetic Interventions*, adds a new dimension to the ethical and legal debate about the genetic manipulation of embryos. Engaging in a thoughtful analysis, Professor Smolensky argues that children who were subject to preimplantation genetic manipulation should have the ability to sue their parents for damages when the parents "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."¹ The article raises a number of questions. 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? What is the moral and legal status of an embryo that exists outside of the womb? If a child can be harmed by something done to it as an ex-utero embryo, what is the harm? Is the tort system an appropriate vehicle for addressing preventable prenatal genetic injury? If the tort system is appropriate, is it the parents who should be held responsible for damages to the child, or would the responsibility be better placed on the health care providers or lab technicians who altered the genetic codes of the embryo?

In addressing these and other issues, Professor Smolensky singles out as the "key question" identifying "which modified phenotypes constitute legally cognizable harms."² I am writing to address that question and Professor Smolensky's response to it. In particular, this

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1. Kirsten Rabe Smolensky, *Creating Children with Disabilities: Parental Tort Liability for Preimplantation Genetic Interventions*, 60 HASTINGS L.J. 299, 299 (2008).

2. *Id.* at 301.

Essay addresses the implications for persons with disabilities of the argument that the test for compensable harm in genetically modified children is the presence of a disability.³ After considering the argument from a disability rights perspective, and assuming, for sake of argument, that tort damages should be made available to a child who was the product of genetic interventions, I conclude that damages should not be limited to cases in which the intervention caused physical disability. Limiting damages to cases in which a child is born with a disability unnecessarily and inaccurately devalues life with disability, and leaves unprotected children whose DNA is shaped for traits other than disability at the request of their parents. As an alternative, I suggest an approach for delineating cognizable injury that supports much of Professor Smolensky's argument, but is deliberately sensitive to disability issues. This approach treats genetic modifications for disability like other genetic modifications that shape a future child for cultural, aesthetic, or social reasons,⁴ and identifies as unreasonable the harm caused and risks posed by use of direct genetic interventions that provide no therapeutic benefit to the potential child.

I. DISABILITY AS HARM

Professor Smolensky identifies physical disabilities such as deafness and achondroplasia as legally compensable injuries when they are inflicted on children by direct genetic manipulation of their DNA.⁵ Her analysis explicitly adopts from moral philosophy an "open future" approach for defining cognizable injury.⁶ Under the open future approach, a child suffers a moral harm when a third party's actions unreasonably limit the child's life plans.⁷ Cognizable losses occur only when the "doomed interests" are basic, "natural primary goods," such as "hearing, movement, and minimal mental capacity."⁸ Third party actions that cause minimal losses, and or those that increase a child's life options, do not cause cognizable harm because they do not place unreasonable limitations on the child's future opportunities for important life activities like marriage, reproduction, and employment. By contrast, a parent who causes deafness, blindness, or achondroplasia in a child has harmed the child by depriving him or her of natural primary goods "known to be indispensable to a decent life."⁹

3. I also take issue with the notion that it is the parents, and not the medical professionals and facilities, with whom responsibility should lie, but for purposes of argument I will put that point aside.

4. As Professor Smolensky notes, the technology does not yet exist to add or subtract particular traits from a child's genetic code. See Smolensky, *supra* note 1, at 303.

5. *Id.* at 302.

6. *Id.* at 309, 311.

7. *Id.* at 301, 309.

8. *Id.* at 310.

9. *Id.* at 309 (quoting 1 JOEL FEINBERG, THE MORAL LIMITS OF THE CRIMINAL LAW: HARM TO

Smolensky acknowledges that no bright line identifies the point at which a child's right to an open future is unreasonably impaired, but she argues that the line is always crossed by the infliction of traits that limit a child's functioning.¹⁰ The infliction of "genetic traits such as deafness and achondroplasia," she explains, "are almost certain to be considered offensive to a reasonable sense of personal dignity."¹¹ In this way, "genetically modifying an embryo's naturally occurring set of DNA to choose a particular genetic trait, say deafness, is similar to removing a newborn's hearing via surgical procedure."¹² The intervention unreasonably limits life opportunities for the modified child.¹³

Under an open future framework, the presence of disability is always a harm to be avoided. Professor Smolensky argues, however, that only those disabilities caused by direct genetic intervention constitute legally cognizable injuries.¹⁴ Damages are unavailable for children whose embryos were selected for implantation based on the presence of a naturally occurring gene in their DNA, because the only alternative to life with disability for those children was nonexistence (the Parfit Non-Identity Problem).¹⁵ By contrast, children who were subjected as embryos to direct manipulation of their DNA had an alternative to nonexistence or life with disability. They could have been born with the ability or trait that the genetic modification took away. The child now affected with deafness could have had the ability to hear, or the child now affected with dwarfism the ability to grow. The interventions cost them the opportunity of living a better life in which the breadth of available careers and activities are unlimited.

II. THE INSULT PROBLEM

Although I often disagree with the reactionary response of some disability rights activists to perceived slights,¹⁶ I believe it essential to consider the perspective of the disability community whenever discussing law or policy that affects or concerns persons with disabilities. Not only do people with disabilities have the most at stake in the discussions,

OTHERS 99 (1984).

10. *See id.* at 311.

11. *Id.* at 319–20.

12. *Id.* at 334.

13. Dena Davis also argues that inflicting deafness on a child harms the child by limiting his or her right to an open future. *See* Dena S. Davis, *Genetic Dilemmas and the Child's Right to an Open Future*, 28 RUTGERS L.J. 549, 566–67 (1997).

14. Smolensky, *supra* note 1, at 299.

15. *See* DEREK PARFIT, REASONS AND PERSONS 351–79 (rev. ed. 1987); Smolensky, *supra* note 1, at 335–36.

16. *See, e.g.*, Alicia Ouellette, *Disability and the End of Life*, 85 OR. L. REV. 123, 126–28 (2006); Alicia Ouellette, *Growth Attenuation, Parental Choice, and the Rights of Disabled Children: Lessons from the Ashley X Case*, 8 HOUS. J. HEALTH L. & POL'Y (forthcoming Jan. 2009).

disability scholars are experts in identifying and preventing social oppression of people with disabilities. Professor Smolensky's analysis singles out physical disability as "offensive to a reasonable sense of personal dignity."¹⁷ From the disability perspective, this argument is problematic.

Disability studies is a rich and varied field that emphasizes the dignity and value of life with disability, and identifies social oppression of people with disabilities.¹⁸ Its scholars reject the notion that life with disability is inherently tragic, and they urge abolition of societal barriers that prevent people with physical impairments from leading full lives.¹⁹ A central tenet of disability studies is the rejection of the medical model of disability as a foundation for effective understanding of impairment or disability.²⁰ "The medical view of disability . . . treats the individual as deficient and inherently inferior because she falls below an arbitrary physiological standard that delineates social acceptance and that can only be 'normalized' and incorporated into society through a medical cure."²¹ Disability is problematic in the medical model because "impairment[] of normal species functioning reduce[s] the range of opportunity open to the individual . . . [to] construct [a] 'plan of life' or 'conception of the good.'"²² In this way, the medical model "expressly locates the 'problem' in the disabled person."²³

Disability scholars make a strong case that the medical model of disability harms people with disabilities. They persuasively link the medical model of disability to the eugenics movement, lifetime institutionalization, forced sterilization, and research abuses.²⁴ They explain that so long as the cultural perception is that people with disabilities are inferior, and their lives limited by their disabilities, people with disabilities will face continued marginalization and oppression.²⁵

17. Smolensky, *supra* note 1, at 319-20.

18. See Gaeth Williams, *Theorizing Disability*, in HANDBOOK OF DISABILITY STUDIES 123, 124 (Gary L. Albrecht et al. eds., 2001).

19. See, e.g., ANITA SILVERS ET AL., DISABILITY, DIFFERENCE, DISCRIMINATION 94-95 (1998) ("Recognizing how hostile environments, not personal deficits, disable people whose physical, sensory, or cognitive states are different from those of the dominant class is central to having a disability perspective.").

20. *Id.*

21. Jonathan C. Drimmer, *Cripples, Overcomers, and Civil Rights: Tracing the Evolution of Federal Legislation and Social Policy for Persons with Disabilities*, 40 UCLA L. REV. 1341, 1348 (1993); see Adrienne Asch, *Disability, Bioethics, and Human Rights*, in HANDBOOK OF DISABILITY STUDIES, *supra* note 18, at 297, 300.

22. NORMAN DANIELS, JUST HEALTH CARE: STUDIES IN PHILOSOPHY AND HEALTH POLICY 27 (1985).

23. Laura L. Rovner, *Disability, Equality, and Identity*, 55 ALA. L. REV. 1043, 1044 (2004).

24. See, e.g., SILVERS ET AL., *supra* note 19, at 67-74 (describing "medicalizing's horrible history").

25. See, e.g., *id.* at 95, 142 ("[T]he assumption that to be impaired is to suffer" results in a framework that does "not offer an avenue for equalizing people with disabilities," and "false theories positing" the incompetence of persons with disabilities "create[] conditions hostile to the

In place of the medical model, disability scholars urge various social models of disability in which disability is a socially constructed condition.²⁶ In the social model of disability, a person with a physical impairment has the same inherent ability to lead a fulfilling life as does anyone else.²⁷ It is social barriers that disable the person.²⁸ Architectural, attitudinal, sensory, political, and economic barriers prevent people with disabilities from full participation in society.²⁹ Thus, the social model places the problem with disability (and the corresponding obligation for correcting the problem), on societal and political institutions, not the person with the physical impairment.³⁰

The central lesson taught by disabilities studies is that life with disability is not inherently limited or tragic. Empirical research documents the high value attributed to their own lives by people who live with disability.³¹ Narrative accounts of individual lives demonstrate that for many people, a physical impairment adds such richness and texture to life that the trait is considered a gift.³² By debunking the myth of the tragedy of life with disability, these studies support the use of the social model of disability as a tool for understanding how impairments affect people.

Professor Smolensky's argument runs directly against the central tenets of disability studies. It employs a medical model of disability in which a child born with deafness or dwarfism is a damaged good with limited life options. It perpetuates the notion that life with disability is tragic by adopting a framework in which the presence of a disabling trait is viewed as "dooming of [the child's] future interests to total defeat."³³ And it does nothing to account for the fact that some people experience a disabling trait as enriching their lives.

manifestation of competence by people whose bodies or intellects differ from the commonplace, while simultaneously adducing the resulting absence of signs of their competence in its own defense."); see also JAMES I. CHARLTON, *NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT* 69–82 (2000).

26. SILVERS ET AL., *supra* note 19, at 74–76.

27. *Id.*

28. *Id.*

29. *Id.*

30. *Id.*

31. See Asch, *supra* note 21, at 301 (citing eleven such studies); see also NAT'L ORG. ON DISABILITY & LOUIS HARRIS & ASSOCS., INC., N.O.D./HARRIS SURVEY OF DISABLED AMERICANS 91–96 (1994); Saroj Saigal et al., *Self-Perceived Health Status and Health-Related Quality of Life of Extremely Low Birthweight Infants at Adolescence*, 276 J. AM. MED. ASS'N 453, 456 (1996).

32. See HARRIET MCBRYDE JOHNSON, *Preface of TOO LATE TO DIE YOUNG: NEARLY TRUE TALES FROM A LIFE* 1–5 (2005) (providing a wonderful example). See generally ERIC PARENS ET AL., *SURGICALLY SHAPING CHILDREN: TECHNOLOGY, ETHICS, AND THE PURSUIT OF NORMALITY* (2006); SILVERS ET AL., *supra* note 19, at 89 (explaining how "missing one kind of experience can enhance the quality of the remaining kinds"); Deborah Kent, *Somewhere a Mockingbird*, in *PRENATAL TESTING AND DISABILITY RIGHTS* 57–63 (Eric Parens & Adrienne Asch eds., 2000).

33. Smolensky, *supra* note 1, at 309 n.57 (quoting FEINBERG, *supra* note 9, at 98).

That is not to say that Professor Smolensky lacks respect for people with disabilities. To the contrary, I read her article as a laudable effort to provide compensatory relief to children who may well have been damaged by their parents' actions. Indeed, I agree with her that children may be harmed by the manipulation of their DNA for purposes of creating a disability. But the analytic path she takes implicitly reinforces negative societal perceptions about disability. As the disability rights community has long recognized, "'[b]enevolence' and 'good intentions' have often had disastrous consequences for the disability community. Throughout history, 'for their own good' has motivated and justified discrimination against us."³⁴ Consideration of the disability perspective in the context of preimplantation genetic modification may help prevent a repetition of that history.

In any event, the implication that people with disabilities are damaged goods flows directly from the invocation of Joel Feinberg's conception of the right to an open future to define an actionable injury.³⁵ 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."³⁶ He describes such conditions as "so far below a reasonable minimum as to be inescapably degrading and sordid."³⁷ 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."³⁸

Feinberg's characterizations of life with disability are as inaccurate as they are demeaning. Many people with disabilities are able to advance their "ulterior interests" and have successful careers, participate in their communities, and raise families.³⁹ Their physical impairments do not prevent them from participating in important life activities, although social barriers may. The notion that people living with disabilities have been cheated of a quality life is refuted by the evidence gathered by disability scholars showing that people with disabilities place no less

34. Disability Rts. Edu. & Def. Fund, *Modify the System Not the Person*, Jan. 7, 2007, <http://www.dredf.org/news/ashley.shtml>.

35. See Joel Feinberg, *A Child's Right to an Open Future*, in *WHOSE CHILD? CHILDREN'S RIGHTS, PARENTAL AUTHORITY, AND STATE POWER* 124 (William Aiken & Hugh LaFollette eds., 1980). *But see* SILVERS ET AL., *supra* note 19, at 92-94 (criticizing the open future approach from a disability perspective).

36. FEINBERG, *supra* note 9, at 98.

37. *Id.* at 99.

38. *Id.*

39. Disabled World, *Famous People with Disabilities* (May 18, 2006), http://www.disabled-world.com/artman/publish/article_0060.shtml (listing short biographies of famous people with disabilities).

value on the quality of their lives than do people with full physical abilities, that people lacking disabilities grossly underestimate the value of life with disability, and that traits like deafness, blindness, and achondroplasia may enrich people's lives.⁴⁰

Wholesale adoption of Feinberg's open future approach may well have the unintended effect of reinforcing negative societal perceptions about disability in a way that further marginalizes and alienates the disability community. At the very least, its adoption is likely to cause offense.

III. DISABILITIES ARE NOT THE ONLY GENETICALLY INDUCED TRAITS THAT CAN HARM CHILDREN

The insult problem is not the only limitation of a framework that recognizes as harmed only those children born with manufactured disabilities. That framework does not recognize the harms that will be suffered by children inflicted with genetic traits other than disabilities.⁴¹ Consider, for example, a child born after her DNA was modified so that she would have light skin instead of the dark skin that would have manifested had she grown up with unaltered DNA.⁴² Consider another child whose genes were modified to turn him from gay to straight.⁴³ Under Feinberg's open future approach, these children suffered no harm. Black skin color and homosexuality are surely not traits "known to be indispensable to a decent life."⁴⁴ The modifications would not limit the range of activities, careers, and opportunities that the child has open to her. If anything, under Feinberg's test, being made white or straight opens opportunities for the child because white people face less discrimination in the work place than do people of color, and homosexuals face legal barriers to marriage.

Nonetheless, the child whose DNA was modified to produce a certain skin color or sexual orientation has suffered harm. First, there is moral harm. The parent who seeks to add, delete, modify, or substitute a genetic trait in the potential child for their own social, aesthetic, or cultural reasons has treated the potential child as a property to be

40. See Asch, *supra* note 21, at 301 (citing eleven studies on the quality of life of people with disabilities).

41. Just as the technology to implant a disability gene in an ex-utero embryo is not yet available, the ability to make the other genetic modifications I discuss is not and may never be available.

42. There is no reason to believe that such a modification is technically feasible.

43. Again, this example is hypothetical only. That said, there is research being done in sheep to determine the biologic basis of sexual orientation and the possibility it can be manipulated. See K.L. Pinckard et al., *Influence of Castration and Estrogen Replacement on Sexual Behavior of Female-Oriented, Male-Oriented, and Asexual Rams*, 78 J. ANIMAL SCI. 1947, 1947 (2000), available at <http://jas.fass.org/cgi/reprint/78/7/1947?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&searchid=1&FIRSTINDEX=0&volume=78&firstpage=1947&resourcetype=HWCIT>.

44. FEINBERG, *supra* note 9, at 99.

molded, or a tool by which they can advance their own conception of the good life. Treating a child, even a potential child, as a tool causes moral harm.⁴⁵ A lively debate exists about how best to characterize that harm, but the overwhelming consensus is that genetic enhancement causes moral harm.⁴⁶

45. See MICHAEL J. SANDEL, *THE CASE AGAINST PERFECTION: ETHICS IN THE AGE OF GENETIC ENGINEERING* 83 (2007) (identifying harm caused by techniques that require a “persisting negotiation with the given”); Kathy Davis, *The Rhetoric of Cosmetic Surgery: Luxury or Welfare?*, in *ENHANCING HUMAN TRAITS: ETHICAL AND SOCIAL IMPLICATIONS* 124, 124–34 (Erik Parens ed., 1998) [hereinafter *ENHANCING HUMAN TRAITS*]. See generally Carol Freedman, *Aspirin for the Mind: Some Ethical Worries About Psychopharmacology*, in *ENHANCING HUMAN TRAITS*, *supra*, at 135, 135–50; Eric T. Juengst, *What Does Enhancement Mean?*, in *ENHANCING HUMAN TRAITS*, *supra*, at 29, 29–47; Anita Silvers, *A Fatal Attraction to Normalizing: Treating Disabilities as Deviations from “Species-Typical” Functioning*, in *ENHANCING HUMAN TRAITS*, *supra*, at 95, 95–123.

46. See AUDREY R. CHAPMAN, *UNPRECEDENTED CHOICES: RELIGIOUS ETHICS AT THE FRONTIERS OF GENETIC SCIENCE* 53 (1999) (arguing that genetic enhancement risks human self-destruction rather than improvement due to a lack of knowledge surrounding the creation of human life and the consequences of genetic engineering); FRANCIS FUKUYAMA, *OUR POSTHUMAN FUTURE: CONSEQUENCES OF THE BIOTECHNOLOGY REVOLUTION* 217 (2003) (arguing that humanity will be altered beyond recognition, destroying the foundation of liberal democracy based on the belief that human beings are equal by nature); L. KASS, *THE BEGINNING OF WISDOM* 433–34 (2003) (arguing that genetic enhancement is morally repugnant because it violates nature’s moral boundaries and undermines a moral universe at the most basic of foundations); TED PETERS, *PLAYING GOD?* 152–53 (2003) (reasoning that genetic enhancement will alter the portrayal of human beings as equal creatures, causing some to be viewed as superior to others); SANDEL, *supra* note 45, at 86 (arguing that existence is a gift and genetic enhancement jeopardizes “humility, responsibility, and solidarity”); Cynthia B. Cohen & LeRoy Walters, *Gene Transfer for Therapy or Enhancement*, in *A CHRISTIAN RESPONSE TO NEW GENETICS* 53, 68 (David H. Smith & Cynthia B. Cohen eds., 2003) (arguing that genetic enhancement would result in social disparities and prejudices, exacerbating the divide between the wealthy and poor, and will diminish the value of human life); Sarah M. Markwood, Comment, *Creating a Perfect Human Is Not So Perfect: The Case for Restricting Genetic Enhancement Research*, 110 PENN ST. L. REV. 473, 483 (2005) (arguing that genetic enhancement will change the “meaning of human normality” and transform a child into a commodity); Maxwell J. Mehlman, *The Law of the Above Averages: Leveling the New Genetic Enhancement Playing Field*, 85 IOWA L. REV. 517, 533 (2000) (arguing that “wealth-based access to genetic enhancement” will produce a social inequality; enhanced individuals will achieve social success more easily than non-enhanced individuals, eventually creating a political system dominated by “genetic aristocracy or ‘genobility’”); David A. Prentice, *Brave New World of Genetic Engineering*, 17 ISSUES L. & MED. 312, 314 (2002) (arguing that genetic enhancement will create a “genetic caste system,” will treat children as “manufactured commodities,” and will “degrade human dignity and individuality”); Daniel L. Tobey, *What’s Really Wrong with Genetic Enhancement: A Second Look at Our Posthuman Future*, 6 YALE J.L. & TECH. 54, 57 (2003) (arguing that genetic enhancement will undermine “the most basic [and universal] sources of meaning and well-being in human life”); Dan Brock, Professor, Harvard Med. School, Response to “Or What’s a Heaven For?” Bioscience and Alteration of Human Limits (Nov. 8, 2007), available at <http://www.hds.harvard.edu/cswr/resources/lectures/zoloth.html> (expressing a concern that the poor will be increasingly disadvantaged by not having access to the benefits of genetic enhancement); William LaFleur, Professor, Univ. Penn., Response to “Or What’s a Heaven For?” Bioscience and Alteration of Human Limits (Nov. 8, 2007), available at <http://www.hds.harvard.edu/cswr/resources/lectures/zoloth.html> (arguing that genetic enhancement is a slippery slope, eventually leading to a “post-human dystopia”); N. Schichor et al., *Should We Allow Genetic Engineering? A Public Policy Analysis of Germline Enhancement*, <http://8e.devbio.com/article.php?id=172> (last visited Dec. 15, 2008) (arguing that a child’s “individual personhood” would be jeopardized by genetic enhancement). *But see* NICHOLAS AGAR, *LIBERAL EUGENICS: IN DEFENSE OF HUMAN ENHANCEMENT* 2–3 (2004); Joseph

In addition, modification of a child's DNA causes the future child an injury to identity. Untouched, the child with DNA for dark skin would develop a trait that is, for many, integral to identity. The child with the theoretical homosexual gene would grow up as a gay man or lesbian. The change to the DNA injures the future child's identity by costing him the opportunity to live as a person of color, or to live as a gay man or lesbian. The injury to identity carries with it the real risk of psychological harm. Although we have no experience with the impact of genetic modifications to a trait central to a child's identity, the experiences of intersexed children subjected to genital correction surgery serve as a cautionary tale. Surgically assigning a gender to a child born with ambiguous genitals appears to have horrific consequences for some individuals in the long term.⁴⁷ The assault to identity causes deep psychological trauma. It is impossible to know whether genetic modification of physical traits central to identity will cause psychological trauma to a child in the long run. The intricate weave of genetics, environment, and experience that comprise identity is so complex that we can only guess at the results caused by changing the genetic thread. The risk of psychological trauma is real. Children should be protected from that risk, unless it is justified by a weighty therapeutic benefit.

IV. A DISABILITY-SENSITIVE APPROACH

Given the limitations of the open future framework, it is worth considering whether it is possible to identify a cognizable injury suffered by a child as a result of direct manipulation of her DNA without adopting a framework that makes inaccurate and demeaning assumptions about life with disability. I believe it is. This Part proposes an approach that is sensitive to the concerns of the disability community, and more inclusive than an open future approach.

A. DISABILITY-SENSITIVITY IN THE CONTEXT OF GENETIC MANIPULATIONS FOR DISABILITY

Several principles and goals shape an analytic framework that is consciously sensitive to the concerns of the disability community. First, a disability-sensitive approach should not inadvertently or unnecessarily demean people with disabilities by perpetuating the myth that life with disability is tragic. Second, a disability-sensitive approach should respect the inherent dignity, value, autonomy, and individual choices of persons with disabilities. Third, it should recognize that there is no universal

Jackson, *The Amoralty of Preference: A Response to the Enemies of Enhancement*, 19 J. EVOL. & TECH. 42, 42-50 (2008), available at <http://jetpress.org/v19/jackson.htm>.

47. E.g., Hazel Glenn Beh & Milton Diamond, *David Reimer's Legacy: Limiting Parental Discretion*, 12 CARDOZO J.L. & GENDER 5, 21 (2005); Jo Bird, *Outside the Law: Intersex, Medicine and the Discourse of Rights*, 12 CARDOZO J.L. & GENDER 65, 74 (2005).

experience of being disabled, and that individuals experience disability in as many ways as individuals experience race, gender, and other traits fundamental to identity.

As applied to the problem of identifying cognizable harm caused by genetic interventions, disability sensitivity counsels against singling out disability as uniquely or necessarily harmful. As such, a disability-sensitive approach should not distinguish parents who seek genetic modification for disability from parents who seek genetic modifications for other traits. The reality is that parents who seek to create a disabling trait in their future child have determined that life with that trait is in the best interests of the child. These parents have made a considered decision that the future child's life will be enhanced by the intervention. The deaf child will appreciate deaf culture in a way that a hearing child cannot.⁴⁸ A dwarf child will get better care from her parents and fit in better in a home designed for little people. As with a choice to make a genetically black child white, or a homosexual child heterosexual, the benefit is in the eye of the beholder. To be sure, the decision to create the disabling trait in a future child is not one designed to provide therapeutic benefits to the child, but neither is a decision to modify a child's DNA to select for race or sexual orientation. In this way, a decision to choose disability is no different from a decision to use other genetic enhancements to shape a future child for nontherapeutic purposes.

For that reason, a disability-sensitive approach would treat a decision to choose disability the same way it treats the use of other genetic enhancements.⁴⁹ It would locate the injury, if any, common to uses of direct genetic enhancement, and ask if that injury is legally cognizable. Having identified a cognizable injury, a disability-sensitive framework would require an individual assessment of whether and how the manufactured trait has affected the child's life. Any measure of damages would depend on a showing that the genetic modification had negative consequences in the life of the particular child.

48. See generally HARLAN LANE, *Preface of THE MASK OF BENEVOLENCE: DISABLING THE DEAF COMMUNITY*, at xi-xv (1999) (exploring the benefits of being part of Deaf culture).

49. Although the line between an enhancement and a therapy is sometimes blurry, genetic shaping of a child's DNA to add a trait that pleases the parent but does not improve functionality is clearly enhancement.

Not all genetic interventions are enhancements. Many, and for the time being, almost all, are aimed at treating or preventing disease. A genetic intervention is an "enhancement," however, (1) when it is undertaken for the purpose of improving a characteristic or capability that, but for the enhancement, would lie within what is generally accepted as a "normal" range for humans; or (2) when it installs a characteristic or capability that is not normally present in humans.

Mehlman, *supra* note 46, at 522-23 (citation omitted).

A framework that treats genetic modification as an enhancement respects the value and inherent dignity of individuals with disabilities, and rejects the notion that disability is inherently harmful or tragic. It makes no assumptions about life with disability, and recognizes that some people experience disabling traits as enriching their lives. Moreover, a framework that requires individual assessment of consequential damages allows for the possibility that some children will experience the disability as a neutral or even positive trait, while accounting for the reality that some people experience negative consequences from disability.

B. INTERVENTION AS INJURY

The key to identifying cognizable injury without singling out disability as a uniquely tragic trait is to ask whether adding, deleting, or modifying an embryo's DNA to produce the parents' desired genotype is itself a legal wrong, instead of sorting among manufactured phenotypes to determine which constitute legally cognizable harms.⁵⁰ In other words, focus on the intervention, not the result of the intervention. Separate the question of whether there is a harmful touching from the question of whether touching causes resulting harm. If the intervention itself is a legal wrong for which the law provides a remedy, a child so afflicted has suffered cognizable injury and could recover consequential damages for harm that materializes as a result of the injury.

The law recognizes loss of dignity caused by harmful or offensive touching as a cognizable injury for which it provides a remedy.⁵¹ A person is liable to another for battery if "he acts intending to cause a harmful or offensive contact with the person of the other or a third person [and] a harmful contact with the person of the other directly or indirectly results."⁵² Liability attaches without proof of damages or proof that the actor meant to inflict harm.⁵³ A person can commit a battery with the best of intentions. For example, a person trying to help an injured party can commit a battery,⁵⁴ and the injury is cognizable even if the harmful or offensive touching provided the person who was touched measurable benefits.⁵⁵ Even a doctor who saves the life of a patient can commit a battery.⁵⁶ The focus is on the fact of the touching, and its nature. The essence of a claim for battery is "in the offense to the dignity involved in the unpermitted and intentional invasion of the inviolability

50. Smolensky, *supra* note 1, at 301.

51. RESTATEMENT (SECOND) OF TORTS § 18 cmt. c (1965).

52. *Id.* § 13.

53. *Id.* § 13 cmt. c.

54. *Id.*

55. *E.g.*, Clayton v. New Dreamland Roller Skating Rink, Inc., 82 A.2d 458, 459-60 (N.J. Super. Ct. App. Div. 1951).

56. RESTATEMENT (SECOND) OF TORTS § 13 cmt. c.

of his person and not in any physical harm done to his body, it is not necessary that the plaintiff's actual body be disturbed."⁵⁷

In my view, the intentional manipulation of a child's DNA to create a trait chosen by a parent for no therapeutic reason is a harmful or offensive contact. As discussed above, the manipulation causes moral harm, an injury to identity, and lost opportunities for the future child. Those losses are an affront to dignity of the same kind for which the law provides a remedy. It is of no moment that the contact with the child's DNA was intended to enhance the child. Just as a rescuer or surgeon acting with good intentions can commit battery, an intentional manipulation of a child's DNA may be an offensive touching despite the good intentions of the person causing the contact. The contact is offensive because it modifies the genetic structure of the child's body and causes an offense to dignity.

C. THE PROBLEM OF CONSENT

Under a traditional claim for battery, there is no liability if the plaintiff consented to the offensive contact.⁵⁸ Obviously, an ex-utero embryo cannot consent to anything, but its parent can. The question becomes whether the parent's consent to the intervention is valid. Under the general rules applicable to medical decision making for a child, it probably is.⁵⁹ With very few exceptions, a parent is free to consent to medical interventions for a child so long as the interventions are medically appropriate. Absent some consensus among providers that certain genetic interventions are medically inappropriate or a law or regulation that specifically prohibits the use of genetic modification of embryos, parental consent will likely protect a provider from liability for battery.

That said, there is good reason to question the authority of parents to consent to the use of untested and potentially harmful interventions to modify the DNA of a future child based on their own needs or aesthetic preferences. First, parents may not freely consent to similarly risky, invasive, and permanent interventions that provide no therapeutic benefit to the child. For example, a parent cannot enroll a child in nontherapeutic research protocols that involve more than minimal risks.⁶⁰ They often need court approval to sterilize their daughters,⁶¹ and may need court approval to make their children organ donors.⁶² The same

57. *Id.* § 18 cmt. c.

58. *Id.* § 13 cmt. d.

59. For a general overview, see Walter Wadlington, *Medical Decision Making for and by Children: Tensions Between Parent, State, and Child*, 1994 U. ILL. L. REV. 311, 314-18 (1994).

60. 45 C.F.R. §§ 46.401-409 (2007).

61. *See, e.g., In re Hayes*, 608 P.2d 635, 637 (Wash. 1980).

62. For a synthesis of the cases addressing the use of children as organ donors, see Michelle Goodwin, *The Politics of Health Law: My Sister's Keeper? Law, Children, and Compelled Donation*, 29

concerns that justify limitations on parental consent in those cases apply here: the interventions are risky, the risk is not balanced by therapeutic benefit, the parents' ability to serve as the advocate of the child's best interests is suspect, and the interventions could be abused.

Moreover, some decisions are simply not a parent's to make. A parent cannot, for example, force a child to get married. Nor can a parent decide to refuse life-saving treatment for a child.⁶³ The decision about whom to marry and whether or not to refuse treatment necessary to maintain life are held in trust by the parent until the child is able to exercise them as an adult. Decisions regarding marriage and the refusal of life-sustaining treatment are so fundamental to a child's identity and future in life that a parent has no right to make them for the child. The decision to change a child's DNA also has significant implications for a child's identity and future in life. Such decisions should rest with the parent only if a medical or other necessary reason triggers the need for an immediate decision. Absent the need for intervention, when intervention is sought to "improve" a child for cultural or aesthetic reasons, a decision to modify a future child's DNA is not a parent's to make.⁶⁴

CONCLUSION

Incorporating the disability perspective into an analysis of the potential harm to a child done by preimplantation manipulation of embryos requires a shift in focus from that suggested by Professor Smolensky. Rather than sorting among manufactured phenotypes to identify those that constitute harms, a disability-sensitive framework would treat the infliction of a trait for disability no differently from the infliction of other traits manufactured in children to satisfy an aesthetic, cultural, or societal preference of the parent and seek to locate harm common to those procedures. Applying such a framework, I have argued that although parents seek such traits to enhance the future child's life, the act of manipulating the child's DNA is itself harmful and risky, and absent a clear therapeutic purpose, is unjustified and offensive. Tort damages might be available to children subjected to such unjustified and offensive interventions, but no child, including a child with a manufactured disability, should be allowed to recover more than nominal damages without proof that the manufactured trait affected his or her life

W. NEW ENG. L. REV. 357, 365-77 (2007).

63. Wadlington, *supra* note 59, at 318, 320, 325, 331 (discussing cases that allowed court intervention for life-threatening situations).

64. I expand on this argument in Alicia R. Ouelette, *Eyes Wide Open: Surgery to Westernize the Eyes of Asian Child*, 39 HASTINGS CENTER REP. (forthcoming 2009) (manuscript at 15-18, on file with author).

negatively. There should be no assumption that life with disability is inherently tragic.

In the end, no child may ever recover legal damages for the harm caused by the intentional manipulation of his or her genes. The road to recovery is littered with issues ranging from the legal status of the embryo to the application of parental immunity laws to the problem of consent. Any number of issues could block recovery. Nonetheless, the effort to identify when and how children are harmed or put at risk of harm by genetic modifications may help guide regulators, legislators, and courts as they grapple with the issues. My hope is that resulting policy will both protect children, and remain sensitive to the implications for persons with disabilities.