is that conserving currently normal distributions of disease requires genetic interventions to offset increasing rates of gene-based disease that will inevitably occur in current medical and public health environments. This is the Evolutionary Catch 22: Genetic conservation requires genetic intervention. Unwittingly, therefore, Garland-Thomson has offered novel reasons to engage in systematic germline genetic intervention.

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REFERENCES

Bostrom, N., and T. Ord. 2006. The reversal test: Eliminating status quo bias in applied ethics. *Ethics* 116(4): 656–679.

Brandon, R. N., and D. McShea. 2011. *Biology's first law: The tendency for diversity and complexity to increase in evolutionary systems*. Chicago, IL: University of Chicago Press.

Garland-Thomson, R. 2012. The case for conserving disability. *Journal of Bioethical Inquiry* 9(3): 339–355.

Powell, R. In press. In genes we trust: Genetic engineering, eugenics and the future of the human genome, *Journal of Medicine and Philosophy*.

Powell, R. 2012. The evolutionary biological implications of human genetic engineering. *Journal of Medicine and Philosophy* 37(3): 204–226.

Sandel, M. (2007). *The case against perfection: Ethics in the age of genetic engineering*. Cambridge, MA: Harvard University Press.

Sparrow, R. 2015. Imposing genetic diversity. *American Journal of Bioethics* 15(6): 2–10.

Genetic Technology to Prevent Disabilities: How Popular Culture Informs Our Understanding of the Use of Genetics to Define and Prevent Undesirable Traits

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While the demand that we protect genetic diversity at the risk of allowing for the birth of disabled children is arguably abhorrent, there are some disabled communities that take offense at efforts to eliminate their disabilities through genetic selection; typically, the deaf community comes to mind. More recently, the measles outbreak, associated with unvaccinated children due to concerns of autism, has resulted in the non-neurotypical community, particularly high-functioning autistic individuals, also coming out in defense of their disability and their quality of life. As a result, in assessing what ought to be the metes and bounds of selection in the course of assisted reproduction, we look to one area of law to best accommodate the moving target of parental intentions in employing that selection. To this end, we aim to provide a framework for preventing the misuse of the technology.

With current technologies, putative parents have an unprecedented opportunity to select against a whole host

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of genetic diseases, conditions, and predispositions for their next generation.

One such technology, preimplantation genetic diagnosis (PGD), can identify genetic defects in embryos at the preimplantation stage of in vitro fertilization (IVF). Currently, PGD is primarily used by couples who have a family history of a genetic defect, with the desire to conceive a healthy child. Using technologies like PGD requires that we determine where, if any, the parameters are in limiting this technology. Sex selection is one provocative example: Many abhor the idea, seeing it as gender discrimination in its purest form. Sparrow raises, and then argues against another concern with technologies like PGD, that of the limiting of genetic diversity in society by eliminating particular diseases or harmful conditions.

As we continue to tease out the genetic and/or epigenetic basis of more diseases, conditions, and traits, there will be even more ethically and morally questionable PGD options to select against and/or select for particular traits that could potentially lead to the elimination of a greater number of diseases from humanity.

And according to cultural references such as the films *Gattaca* and *The Perfect 46*, when we do try to remove genetic diseases from humanity, we are guaranteed to quickly slide down that slippery slope toward genetic discrimination and eugenics where an ever-increasing set of heretofore relatively benign or even neutral traits will be selected against.

Part of the problem is the inherently moving target: Whenever we select against a trait through assisted reproductive technologies, what ought to be the litmus test deciding which genetic disorders are "bad enough" to select against and what genetic conditions ought to be positively selected for? Is an objective set of criteria even possible?

As an illustration, the recent outbreak of measles, likely the result of an antivaccine trend wherein the fear of raising an autistic child, the conjectured but medically unlikely potential outcome of the measles mumps and rubella vaccine (MMR), is balanced against the likelihood that the unvaccinated child will contract a dangerous, and in some instances, fatal case of measles. As a result of this fear, some in the autistic community have argued that as high-functioning, albeit, non-neurotypical individuals, they feel delegitimized by this choice the antivaccine parents are making (Kurchak 2015).

Similar to segments of the deaf community that see deafness as an important and even positive aspect of their culture, or of individuals with achondroplasia who might like similarly affected offspring, individuals along the autistic spectrum may see their autism in a positive light and particularly not a condition that ought to be removed from the gene pool.

With these examples in mind, we can appreciate the possibility that parents might, for whatever reason, select for what most of society considers an arguably negative trait (Baruch et al. 2008), a possibility already outright banned in at least one jurisdiction (Human Fertilization and Embryology Act 2008), but likely still legal, in most others (Appel 2011). Thus, while even the selection against a medically benign trait without a clear therapeutic purpose is fraught with ethical and social concerns (Robertson 2003), a greater concern may be this selection for an outright negative trait.

Currently, a child born from such a situation has little legal recourse. Reproductive autonomy is a basic human right (*Eisenstadt v. Baird* 1972), enshrined (somewhere) in the U.S. Constitution (Jellinek 1999). Under this right, parents have the long-standing ability to select for disputably detrimental traits within their children, either actively through assisted reproduction techniques, or more commonly by having a child with another individual wherein a statistically likely result of that union will be a child with some detrimental trait.

However, parental rights vis-à-vis their children are not absolute (Vermette 2014). In light of the growing power to select for or against genetic traits, children need to be protected from the possibly misguided and potentially even capricious whims of their parents.

To some degree, the very limited (in scope and in jurisdiction) wrongful life cause of action provides a deterrent for parents and their physicians from making very poor reproductive choices; however, the philosophical, rational, and legal contortions necessary for this cause of action to be effective limit its usefulness. In particular, courts are loath to suggest that the disabled child is better off never having been born, rather than born with its disability.

In its stead, we argue for a "wrongful selection resulting in child abuse" cause of action. This cause of action would be useful for children whose parents egregiously, maliciously, or perhaps even negligently selected for a trait that has a detrimental outcome for the child. While many jurisdictions do not have an affirmative duty of care and/or retain immunity for family members in the case of private causes of action in the area of child abuse (Johnson and Hargrove 2006), one could conceivably be created for this special case.

This cause of action would be limited to the recovery for damages from the expected lifelong burden on the child, as a result of having been born with a disability. While the but-for proximate cause of the child's negative traits is the selection by the parents of a particular embryo for its known traits, in introducing the legal fiction that the alternative to being selected with a particular disability is not the standard "no life at all," the courts can avoid religious and philosophical issues relating to identity of one embryo as distinct from other sibling embryos. The confounding issue of the alternative possibility of never having been born is not relevant in typical cases of parental child abuse, and should not be relevant here.

The courts would have to develop a workable distinction between a disabled child as the natural product of a union of two affected individuals where practicing their right to procreate results in a child that happens to have the disability, and an active selection by one or more parents for a disability for their child; this active selection,

rather than passive procreation, would necessarily seem to create a greater degree of culpability.

Additionally, this cause of action would carry a high burden of proof, necessitating that the affected child show a high degree of likelihood that his or her parents were knowingly acting improperly when they selected a particular embryo with a negative trait, protecting most parents from the fear that any selection they make could potentially lead to this type of suit later in life.

The metes and bounds of recoverable damages would have to be crafted such that the courts do not create value judgments on the general lives of the disabled and/or sanctioning eugenics. For example, damages could be limited to the actual damages associated with the cost of care, but not emotional damages that might necessitate that the court makes a value judgment that a particular disability always necessarily results in a damaged life (Stein 2010).

Moreover, clinical personal at PGD clinics would be incentivized to maintain accurate records and provide necessary counseling, either for or against an action, as they could be included within this cause of action.

Returning to *Gattaca*, in the film, parents were faulted for failing to use PGD. However, even as we argue for regulation to protect children from the potential negative implications of PGD, we have to recognize current limitations of science and the technologies. Courts need to make sure that we don't get ahead of ourselves, and in the course of working to put constraints on the use of PGD, that we don't inadvertently create a positive duty on parents to use assisted reproduction to prevent disease. As *Gattaca* and *The Perfect 46* suggest, we will quickly reach an undesired dystopian future if we put too much reliance on these technologies too soon. ■

REFERENCES

Appel, J. M. 2011. Genetic screenings and child abuse: Can PGS rise to the level of criminality. *UMKC Law Review* 80: 373.

Baruch, S., D. Kaufman, and K. L. Hudson. 2008.Genetic testing of embryos: Practices and perspectives of US in vitro fertilization clinics. *Fertility and Sterility* 89(5): 1053–1058. http://dx.doi.org/10.1016/j.fertnstert.2007.05.048

Eisenstadt v. Baird. 1972. 405 U.S. 438.

Human Fertilization and Embryology Act. 2008. §14(4). Available at: http://www.legislation.gov.uk/ukpga/2008/22/contents

Jellinek, M. A. 1999. Disease prevention and the genetic revolution: Defining a parental right to protect the bodily integrity of future children. *Hastings Constitutional Law Quarterly* 27: 369.

Johnson, V. R., and C. G. Hargrove. 2006. Tort duty of parents to protect minor children, the. *Village Law Review* 51: 311.

Kurchak, S. 2015. I'm m autistic, and believe me, it's a lot better than measles. Available at: https://medium.com/the-archipelago/im-autistic-and-believe-me-its-a-lot-better-than-measles-78cb039f4bea

Robertson, J. A. 2003. Extending preimplantation genetic diagnosis: Medical and non-medical uses. *Journal of Medical Ethics* 29(4): 213–216. http://dx.doi.org/10.1136/jme.29.4.213

Sparrow, R. 2015. Imposing genetic diversity. *American Journal of Bioethics* 15(6): 2–10.

Stein, J. T. 2010. Backdoor eugenics: The troubling implications of certain damages awards in wrongful birth and wrongful life claims. *Seton Hall Law Review* 40: 1117.

Vermette, R. 2014. A case for an exception in the domain of parental autonomy with testing for Huntington disease. *Michigan State Journal of Medicine & Law* 18: 29–161.

The Diversity of Genetic Perfection

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In response to both disability advocates and advocates of so-called "new eugenics," Rob Sparrow (2015) argues that it is difficult to maintain that (genetic) diversity is a valuable good that ought to be preserved. His argument is largely based on the idea that imposing such diversity would always be at the expense of those people who—in this spectrum of diversity—are worst off. Even if diversity would increase overall or average happiness or well-being, it is unjust that genetic scapegoats would be sacrificed to obtain this social good. We agree with Sparrow's conclusion that neither the claim that genetic diversity would be inherently valuable nor the claim that it would be instrumentally valuable is convincing enough to plead for the deliberate conservation of disabilities. However, we disagree with the conclusion that the new eugenic logic would ultimately lead to "a world of striking uniformity."

A large part of Sparrow's reasoning is based on the possibility of determining which genome is "the" best genome. There are a number of problems with this account. First of all, it is scientifically unrealistic. A number of publications have demonstrated that even for severe Mendelian diseases, we currently lack the knowledge to predict which

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