Harvard Journal of Law & Technology
Volume 38, Number 2 Symposium 2024

SELECTING FOR DISABILITY: HOW AN ANECDOTE CAN INSPIRE REGULATION OF GENETIC REPRODUCTIVE TECHNOLOGIES

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ABSTRACT

Research on rapid developments in genetic reproductive technologies traditionally deals with the ethics of offspring selection. The scholarly debate mostly explores the "new eugenics" implications of selecting against embryos genetically found to have a disability. However, some have raised concerns about prospective parents with disabilities selecting for an embryo with the same disability. This Article is the first to examine the phenomenon of selecting for disability and demonstrates that there is lack of evidence that such selection is occurring. This Article traces discussions on this matter to one single story published in the media in 2002 which reported on an American Deaf couple who chose a deaf sperm donor to have Deaf children. The story inspired a moral panic leading to the enactment of legislation in the United Kingdom that bans prospective parents from selecting embryos with disabilities over embryos that do not. Despite the sensationalism of the story, the couple and their children live a happy and full life as part of Washington, D.C.'s large Deaf community. By foregrounding the U.K. legislation and its origin, this Article argues that regulation of genetic reproductive technologies should be based on evidence of an existing problem and not on a moral panic based on speculations. This Article also highlights how the regulation of prospective parents selecting for disability expresses problematic ableist messages about life with a disability. This discussion is a cautionary tale at a time when state legislators and courts are poised to intervene on the issue of reproductive rights.

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For fruitful engagement with this work and for their helpful advice I wish to thank Rabia Belt, Michal Buchhandler-Raphael, I. Glenn Cohen, Leah Fowler, Dov Fox, Clare Huntington, Asaf Kletter, Trudo Lemmens, Sarah Lorr, Katherine Macfarlane, Solangel Maldonado, Kimberly Mutcherson, Roxanne Mykitiuk, Jennifer Oliva, Natalie Ram, Jessica Roberts, Neoshia Roemer, Shelly Simana, Ed Stein, Sonia Suter, the participants of the New York Area Family Law Scholars Workshop, the participants of the Health Law, Policy & Ethics Seminar at the University of Toronto Faculty of Law, and the participants of the Harvard Journal of Law & Technology Symposium on Medical and Legal Uncertainty in Emerging Genetic Technologies. I am incredibly grateful to Maura Quinn for excellent research assistance. This work was supported in part by the National Institute of Mental Health and the National Human Genome Research Institute of the National Institutes of Health, grant R01MH128676.

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I. INTRODUCTION

In March 2002, the Washington Post published the story of Sharon Duchesneau and Candace (Candy) McCullough, a lesbian couple from the Washington, D.C. metropolitan area who had two kids using a sperm donor.[1] Duchesneau and McCullough are both proudly Deaf and run a mental health practice for the large Deaf community in D.C.,[2] one of the world's most Deaf-friendly cities.[3] The couple felt that they would be able to connect more strongly with — and be better parents to — a deaf child, so they chose a deaf sperm donor with a genetic history of hearing loss.[4] Though the couple argued that they were not trying to make a political statement about Deaf culture, but rather sharing a glimpse into their life and personal decisions about growing their

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[1] Liza Mundy, *A World of Their Own*, WASHINGTON POST (Mar. 31, 2002, 12:00 AM EST), https://www.washingtonpost.com/archive/lifestyle/magazine/2002/03/31/a-world-of-their-own/abba2bbf-af01-4b55-912c-85aa46e98c6b/ [https://perma.cc/88VU-VDPZ].

[2] Some members of the Deaf-pride community utilize the term "Deaf" with a capital D to signify a cultural-linguistic community as a contrast to a lower-case deafness that identifies hearing loss. Members of this community often reject the label of disability altogether. *See* BRENDA JO BRUEGGEMANN, DEAF SUBJECTS: BETWEEN IDENTITIES AND PLACES 9–15 (2009); Harlan Lane, *Constructions of Deafness*, 10 DISABILITY & SOC'Y 171, 173 (2010); John Lawson, *Disability as a Cultural Identity*, 11 INT'L. STUD. SOC. EDUC. 203, 215–16 (2001).

[3] *Life at Gallaudet, Washington D.C.*, GALLAUDET UNIV., https://gallaudet.edu/life/washington-dc/ [https://perma.cc/J33Z-ZDHT] ("Washington, D.C. is home to a large deaf community. As a result, it's become one of the world's most deaf-friendly cities.").

[4] Mundy, *supra* note 1.

family, their story became known worldwide. It has been shared by countless news sources and has inspired philosophical debates among bioethics scholars for over twenty years.[5] However, perhaps even more surprising, the Duchesneau-McCullough story inspired a legislative amendment in the United Kingdom.[6] The amendment, which was enacted in 2008, bans prospective parents who are engaged in In-Vitro Fertilization ("IVF") from selecting for disability, meaning they may not choose an embryo with a "serious physical or mental disability, illness, or medical condition" over an embryo that is "not known to have such an abnormality."[7] This U.K. ban on selecting for disability is overbroad,[8] lacks a definition of a "serious physical or mental disability," and was enacted despite protests from the Deaf community.

Considering there is very little evidence that prospective parents are actually selecting for disability through IVF,[9] it seems this regulation was driven by a moral panic and not an actual social problem.[10] While there is some literature showing that people with disabilities may want to have a child "like them," such desires seem to only exist within specific disability communities centered around specific impairments.[11] Only three percent of American fertility clinics in a large study had ever encountered such a request — diminishing implications for the general population.[12] In addition, research has shown that such desires do not easily come to fruition.[13] Furthermore, such a ban is specifically unwarranted when considering the context of the Duchesneau-McCullough story.

The United States currently does not regulate, at the federal level, line-drawing decisions by prospective parents with respect to selecting certain embryos and the rights to procreate using technology.[14]

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[5] *See infra* Section V.A.

[6] *See infra* notes 85–86 and accompanying text.

[7] *See infra* Section V.B.

[8] For the purpose of this Article, selecting for disability means selecting an IVF-created embryo that is known to have a disability for implantation. Some may argue that choosing not to abort an embryo with a diagnosed disability should also be considered under this category. While I am sympathetic to this argument, *see infra* notes 46–48 and accompanying text, it is beyond the scope of this Article.

[9] Prospective parents may inadvertently select to have a child with disability by choosing a partner with genetic inclinations. A ban on such a relationship would be unconstitutional and is beyond the scope of this Article.

[10] Moral panic is a term coined by sociologist Stanley Cohen to describe a situation where a "condition, episode, person or group of people emerges to become defined as a threat to societal values and interests." Cohen emphasized the important role the media plays in enforcing moral panics. *See* STANLEY COHEN, FOLK DEVILS AND MORAL PANICS 9 (1972).

[11] *See infra* notes 50–54 and accompanying text.

[12] *See infra* note 53 and accompanying text.

[13] *See infra* note 44 and accompanying text.

[14] I. Glenn Cohen, *The Right(s) to Procreate and Assisted Reproductive Technologies in the United States*, *in* THE OXFORD HANDBOOK OF COMPARATIVE HEALTH LAW 1009, 1016 (Tamara K. Hervey & David Orentlicher eds., 2020) ("[I]t is remarkable how much of the regulation of reproductive technologies is left to individual US states.").

Nevertheless, we are in an era where the future of reproductive rights is fraught. Dobbs v. Jackson Women's Health Organization[15] and the 2024 Alabama Supreme Court decision LePage v. Center for Reproductive Medicine,[16] which assigned fetal personhood to IVF-created embryos, may give state legislators and courts the green light to regulate different clinical aspects of IVF.[17] This Article exposes how moral panics supported by very little evidence can inspire bad law. The issue of selecting for disability should thus serve as a cautionary tale for the future of genetic regulation by state legislators and courts.

This Article proceeds in five parts. Part II briefly explores concerns raised by the use of genetic reproductive technologies, specifically ones involved in "new eugenics" and the creation of "designer babies." In Part III, this Article explains the rationale behind the desire to choose to have a child with a disability using the concepts of horizontal and vertical differences between children and their parents. Part IV showcases the lack of evidence that the phenomenon of selecting for disability actually exists. Part V delves into the Duchesneau-McCullough story and explores how it inspired the U.K. ban on selecting for disability. Finally, in Part VI, this Article examines the lessons from the U.K. ban, arguing that the United States should not regulate prospective parents' selection for disability.

II. PRE-IMPLANTATION GENETIC TESTING AND DESIGNER BABIES

Legal scholars and bioethicists have long debated the benefits and ethical issues surrounding pre-implantation genetic testing ("PGT", formally known in the literature as "PGD"), an umbrella term for investigations into the genomic makeup of in-vitro embryos during Assistive Reproductive Technology ("ART") procedures.[18]

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[15] Dobbs v. Jackson Women's Health Org., 597 U.S. 215 (2022).

[16] LePage v. Center for Reproductive Medicine, No. SC-2022-0515, 2024 WL 656591 (Ala. Feb. 16, 2024).

[17] I. Glenn Cohen, Judith Daar & Eli Y. Adashi, *What Overturning* Roe v Wade *May Mean for Assisted Reproductive Technologies in the US*, 328 JAMA 15, 15 (2022) ("[n]ew state legislation that seeks to restrict in vitro fertilization (IVF) is easy to imagine [following the Dobbs decision]"); Courtney G. Joslin, Katherine L. Kraschel & Douglas NeJaime, *The High Stakes of Gamete Regulation in a Post-*Dobbs *World*, SPERM|HEALTH|POLITICS (forthcoming 2024) (manuscript at 3) ("Some of the new and proposed laws aimed at sperm and egg provision impose retroactive penalties — civil, criminal, and/or professional discipline — on parties who engaged in forms of 'misconduct' during the fertility treatment process.").

[18] *See, e.g.*, Julianna S. Swann, *Preimplantation Genetic Testing: A Fundamental Right*, 28 WM. & MARY J. RACE GENDER & SOC. JUST. 815, 829 (2021) (noting that after the possible overturning of *Roe* and *Casey*, which occurred after the publishing of this paper, preimplantation genetic screening can act as an alternative to abortion and "has the potential to give some peace of mind in knowing that genetic conditions can be screened out"); Dov Fox,

PGT is the procedure of testing embryos prior to implantation into the womb to determine various genetic characteristics, including the possibility of being born a certain biological sex or having certain diseases or disabilities.[19] Some scholars argue that access to ART and PGT is included in the fundamental right to procreative liberty under the Fourteenth Amendment,[20] meaning a person's right to procreate if they desire without having the state interfere or prevent one from doing so.[21] Yet even those scholars acknowledge that the use of such technology is subject to criticism for having negative ethical and societal implications.

The main ethical criticism of PGT is that parents can use these procedures to create "designer babies."[22] Scholars argue that unregulated use of reproductive technologies could marginalize minority populations — including women, people with disabilities, and people of color.[23] Gene editing, PGT, and mitochondrial editing could allow underlying eugenic ideas to resurface, even if unintentionally, in pursuit

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Selective Procreation in Public and Private Law, UCLA L. REV. DISCOURSE 294, 309 (2016) (noting justifications for selective procreation, including reproductive autonomy and parental well-being); Seema Mohapatra, *Global Legal Responses to Prenatal Gender Identification and Sex Selection*, 13 NEV. L.J. 690, 699 (2013); Seema Mohapatra, *Politically Correct Eugenics*, 12 FIU L. REV. 51, 52 (2016) (explaining how the use of reproductive technologies without regulation "may affect and further disadvantage women of color and families of color").

[19] There are two types of PGT: PGT-M is genetic testing for monogenic conditions which are caused by inheriting a single gene mutation; PGT-P is genetic testing for polygenic conditions caused by multiple genetic factors. For an overview of the science of PGT, see Naomi Cahn & Sonia M. Suter, *The Art of Regulating ART*, 96 CHI.-KENT L. REV. 29, 30–33 (2021); *see also* Kimberly Mutcherson, *Making Mommies: Law, Pre-Implantation Genetic Diagnosis, and the Complications of Pre-Motherhood*, 18 COLUM. J. GENDER & L. 313, 313–14 (2008).

[20] Kimberly Mutcherson, *Procreative Pluralism*, 30 BERKLEY J. GENDER L. & JUST. 22, 24 (2015); JUDITH DAAR, THE NEW EUGENICS: SELECTIVE BREEDING IN AN ERA OF REPRODUCTIVE TECHNOLOGIES 29–30, 153–68 (2017) (arguing that "the true eugenic impact of modern-day reproductive technologies is not in their use but in their deprivation" and describing the various harms of depriving people access to ARTs); Cohen, *supra* note 14, at 1012.

[21] *See, e.g.*, Santosky v. Kramer, 455 U.S. 745, 753 (1982); Quilloin v. Walcott, 434 U.S. 246, 255 (1978); Moore v. City of E. Cleveland, 431 U.S. 494, 499 (1977). In *Eisenstadt v. Baird*, the Supreme Court drew a right to procreate from the right to privacy when stating that if "the right of privacy means anything it is the right of the individual, married or not, to be free from government intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child." 405 U.S. 438, 453 (1972); ROLAND DWORKIN, FREEDOM'S LAW: THE MORAL READING OF THE AMERICAN CONSTITUTION 101–02 (1996).

[22] Sonia M. Suter, *A Brave New World of Designer Babies?*, 22 BERKELEY TECH. L.J. 897, 929–30 (2007); Swann, *supra* note 18, at 820–21; *see also* Benjamin B. Williams, *Screening for Children: Choice and Chance in the Wild West of Reproductive Medicine*, 79 GEO. WASH. L. REV. 1305, 1318 (2011).

[23] Swann, *supra* note 18, at 834–35; Mohapatra, *Politically Correct Eugenics*, *supra* note 18, at 52, 78–79; Suter, *supra* note 22, at 916–18; HENRY T. GREELY, THE END OF SEX AND THE FUTURE OF HUMAN REPRODUCTION 246–47 (2016).

of healthy babies.[24] As Professor Judith Daar eloquently states: "[T]his branch of ART has prompted some to cast those who embrace these technologies as modern-day eugenicists, manipulating the birth and non-birth of offspring in some normative version of human value."[25]

Based on this "new eugenics" critique, some scholars argue for heavier regulation of these technologies.[26] Others note the difficulties in establishing the contours of such regulation: what genetic characteristics could be selected against using PGT, and how can we ensure that such regulation is immune to biases?[27] Professor Dov Fox convincingly argues that regulation of offspring selection through PGT should consider inherent tensions between acceptance of certain characteristics as legitimate and control over parental choices, "leaving space to disapprove certain instantiations."[28] Yet, as of today, American policymakers, unlike their counterparts in other countries, have generally refrained from making decisions that involve line-drawing and philosophical questions on the rights to procreate through ART.[29]

While most of the scholarly debate surrounding genetic testing concerns selecting *against* certain characteristics largely deemed undesirable, some attention has been devoted to selecting *for* characteristics deemed desirable in the eyes of certain prospective parents.[30] Specifically, some have raised concerns about the possibility of parents with certain disabilities choosing to transfer an embryo that has been genetically shown to have the same disability as the parents'.[31]

What I aim to show is that the discussions over this possibility have been focused almost exclusively on one single U.S. story from 2002 —

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[24] DAAR, *supra* note 20, at 29–30; *see also* Mohapatra, *Politically Correct Eugenics*, *supra* note 18, at 52, 71–72.

[25] DAAR, *supra* note 20, at xiii.

[26] Williams, *supra* note 22, at 1308; *see also* Swann, *supra* note 18, at 822 ("[T]here are currently no requirements for IVF clinics to report data relating to PGD according to the CDC.").

[27] *See* Mutcherson, *supra* note 19, at 280–81 ("It is suspect at best to suggest that there is an unbiased way for a state to determine some limited set of circumstances in which PGD is legally acceptable."); *see also* Fox, *supra* note 18, at 301–02 (arguing that while public law permits selective procreation, private law condones it); *id.* at 303–05 (showing support to regulatory schemes which "reflect social understandings about the [conflicts surrounding the usage of PGT]").

[28] *Id.* at 318.

[29] Kimberly M. Mutcherson, *Welcome to the Wild West: Protecting Access to Cross Border Fertility Care in the United States*, 22 CORNELL J.L. & POL'Y 349, 362–63 (2012); Camille Gear Rich, *Contracting Our Way to Inequality: Race, Reproductive Freedom, and the Quest for the Perfect Child*, 104 MINN. L. REV. 2375, 2386–87 (2020); Cahn & Suter, *supra* note 19, at 30; Cohen, *supra* note 14, at 1019–20.

[30] An outlier is the exploration by Professor Judith Daar of physicians' conscience dilemmas around facilitating prospective parents' requests to transfer health-affected embryos. *See, e.g.*, Judith Daar, *A Clash at the Petri Dish: Transferring Embryos with Known Genetic Anomalies*, 5 J.L. & BIOSCIENCES 219 (2018).

[31] *See, e.g.*, DOV FOX, BIRTH RIGHTS AND WRONGS: HOW MEDICINE AND TECHNOLOGY ARE REMAKING REPRODUCTION AND THE LAW 144 (2019); Daar, *supra* note 30, at 224; *see also infra* note 94.

that did not even involve PGT — concerning a Deaf couple who successfully had deaf children by choice.[32] Discussions of this story traveled abroad and inspired regulatory intervention in the United Kingdom.[33] This single case, with unique circumstances, seemingly created a moral panic. In reality, the story did not indicate a trend or a common phenomenon, certainly not one that required legislative intervention, regardless of theoretical discussions on the normativity of such a choice.

In the next part, this Article briefly discuss the theoretical explanation for why prospective parents would choose to have a disabled child.

III. WHY SELECT FOR DISABILITY: TURNING HORIZONTAL DIFFERENCE VERTICAL

The American scholarly tradition has been focused on applying social constructive theories when analyzing social difference, inequality, and the participation of minoritized individuals in social and economic markets.[34] Social constructionism is the complex process where society develops a set of (mostly negative) meanings around a characteristic (a person's sex, race, sexual orientation, or impairment) to deem it deviant,[35] thus creating a hierarchical order between those who have power and those whom power is exercised against.[36]

In his exploration of difference in the parent-child relationship, Andrew Solomon distinguished between vertical and horizontal differences.[37] Vertical identities are transferred from parents to their children and are shared identities.[38] Racial and ethnic identities are prime

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[32] *See infra* Section V.A.

[33] *See infra* Section V.B.

[34] Helen Meekosha, *Drifting Down the Gulf Stream: Navigating the Cultures of Disability Studies*, 19 DISABILITY & SOC'Y 721, 726 (2004).

[35] For feminist studies and disability studies, see SUSAN WENDELL, THE REJECTED BODY: FEMINIST PHILOSOPHICAL REFLECTIONS ON DISABILITY 5 (1996) ("The more I learned about other people's experiences of disability and reflected upon my own, the more connections I saw between feminist analyses of gender as socially constructed from biological differences between females and males, and my emerging understanding of disability as socially constructed from biological differences between the disabled and the non-disabled."); within critical race theory, see Ian F. Haney-López, *The Social Construction of Race: Some Observations on Illusion, Fabrication, and Choice*, 29 HARV. C.R.-C.L. L. REV. 1, 19 (1994) (arguing that "races exist as powerful social phenomena . . . a social conception of race need not rest on bad biology"); within queer theory and disability studies, see Mark Sherry, *Overlaps and Contradictions Between Queer Theory and Disability Studies*, 19 DISABILITY & SOC'Y 769, 776 (2004) ("The feminist deconstruction of the public/private divide, the distinction between sex and gender, and the development of the analytical category of the 'Other' were groundbreaking analytical tools upon which both Queer Theory and Disability Studies would later develop . . . .").

[36] Kimberlé Crenshaw, *Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color*, 43 STAN. L. REV. 1241, 1296–97 (1991).

[37] ANDREW SOLOMON, FAR FROM THE TREE: PARENTS, CHILDREN, AND THE SEARCH FOR IDENTITY 2 (2012).

[38] *Id.*

examples of vertical difference, and religious identity is considered "moderately vertical."[39] Horizontal identities consist of a trait not inherited or one that is acquired later in life that makes a child different from their parents. Being LGBTQ+ is a prime example of a horizontal identity, as most gay children are born to straight parents. Certain disabilities are also good examples of horizontal identities.[40] Solomon observes that while vertical identities are mostly respected by society, horizontal identities are oftentimes seen as flaws, with many parents experiencing their child's horizontal identity as an affront.[41]

According to Solomon, the experience of being perceived as different unites people with horizontal identities,[42] such as LGBTQ+ and disabled individuals,[43] and affects their relationship with society as a whole and with their parents in particular.[44] The child who is different from their parents often suffers because of it and feels misunderstood, rejected, and even experiences self-loathing because of their difference.[45]

Solomon's illuminating exploration explains why some parents would like to have a child "like them" and would attempt to ensure it by using PGT. More specifically, it explains why disabled parents might want to have a child with the same disability and, by doing so, transform horizontal difference into vertical difference. As this Article shows in the next part, while such an explanation seems plausible, there is little evidence that such choices occur in real life.

IV. THE DEARTH OF EXISTING EVIDENCE ON SELECTING FOR DISABILITY

The use of PGT has been traditionally criticized by members of disability communities due to prospective parents' ability to choose against difference — meaning not to transfer an IVF-created embryo that possesses certain impairments they see as undesirable.[46] When it comes to prenatal testing and selective abortion, many disability studies scholars emphasize the expressive value, meaning the problematic messages conveyed when parents are advised by healthcare professionals

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[39] *Id.*

[40] *Id.*

[41] *Id.* at 4.

[42] *Id.* at 4, 11.

[43] *Id.* at 31 ("Being blind and being gay are different, but having a selfhood that others perceive as undesirable is identical.").

[44] *Id.* at 4.

[45] *Id.* at 10, 19.

[46] Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing Reflections and Recommendations*, 29 HASTINGS CTR. REP. 1, 2–3 (1999); GREELY, *supra* note 23, at 173; Ruth Hubbard, *Abortion & Disability: Who Should and Should Not Inhabit the World*, *in* THE DISABILITY STUDIES READER 107, 114–15 (4th ed. Lennard Davis ed. 2010).

to "select against disability."[47] These messages include ideas that the lives of disabled people are not worth living, that families and society are better off not having disabled members who are thought of as burdens, or that parental love is dependent on the child's health status and abilities.[48] Indeed, these messages came loud and clear in the infamous Supreme Court decision Buck v. Bell[49] that upheld Virginia law permitting eugenical sterilization of people with mental disabilities; specifically, one can simply look at Justice Oliver Wendell Holmes, Jr.'s statement: "Three generations of imbeciles is enough."[50]

Selecting *for* disability is a radical move that disrupts such ableist narratives.[51] Yet how many prospective parents using ART choose to have a disabled child? It is incredibly hard to answer this question accurately. This is because selecting an embryo for implementation is a private decision that prospective parents do not usually go public about. Nevertheless, a review of the literature shows that such decisions are rare.

The only scientific study I could find on this issue is a 2006 survey of 186 fertility clinics in the United States,[52] which found that only three percent of the clinics reported the use of PGT to select an embryo that carried a genetic disease caused by a mutation on the X chromosome.[53] Nevertheless, the study did not indicate whether those embryos

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[47] Stephen M. Campbell & Joseph A. Stramondo, *Expressed Ableism*, 9 ERGO 1627, 1628 (2022).

[48] *Id.* at 1631; *see also* Sagit Mor, *The Dialectics of Wrongful Life and Wrongful Birth Claims in Israel: A Disability Critique*, 63 STUD. L., POL. & SOC'Y 113, 120 (2014).

[49] 274 U.S. 200 (1927).

[50] *Id.* at 207. For insightful discussions of the decision and its historical context, see generally PAUL A. LOMBARDO, THREE GENERATIONS, NO IMBECILES: EUGENICS, THE SUPREME COURT, AND BUCK V. BELL (2008); Robyn M. Powell, *From Carrie Buck to Britney Spears: Strategies for Disrupting the Ongoing Reproductive Oppression of Disabled People*, 107 VA. L. REV. ONLINE 246 (2021).

[51] Disability scholars offered multiple definitions of ableism over the years. Yet most scholars see ableism as encompassing deeply held negative beliefs about productivity, attractiveness, and the value of human life based on the rating of nondisabled people. *See* SIMI LINTON, CLAIMING DISABILITY: KNOWLEDGE AND TRUTH 9 (1998); TOBIN SIEBERS, DISABILITY THEORY 7–9 (2008); DAN GOODLEY, DIS/ABILITY STUDIES: THEORIZING DISABLEISM AND ABLEISM 21 (2014); Gregor Wolbring, *The Politics of Ableism*, 51 DEVELOPMENT 252–53 (2008); Fiona Kumari Campbell, *Ability*, *in* KEYWORDS IN DISABILITY STUDIES 13, 13 (Rachel Adams, Benjamin Reiss & David Serlin, eds., 2015); Talila A. Lewis, *Working Definition of Ableism* (2022).

[52] This is quite a large sample as the CDC estimates that there are about 500 fertility clinics in the United States. *National ART Surveillance*, CDC (June 7, 2023), https://www.cdc.gov/art/nass/index.html [https://perma.cc/D54X-MLRQ].

[53] Susannah Baruch, David Kaufman & Kathy L. Hudson, *Genetic Testing of Embryos: Practices and Perspectives of US In Vitro Fertilization Clinics*, 89 FERTILITY & STERILITY 1053, 1055 (2006) ("Preimplantation genetic diagnosis can be used to select the sex of an embryo, either to avoid a genetic disease caused by a mutation on the X chromosome (X-linked disease) or simply to satisfy the preferences of the future parents. Fifty-eight percent of IVF–PGD clinics had provided PGD to avoid X-linked diseases, with 3% of PGD cycles provided for this indication."); *see also* Silvia Camporesi, *Choosing Deafness with*

were implanted. Some anecdotal stories about selecting for disability appear in the popular press from time to time,[54] but these stories are not backed by evidence that would indicate their truthfulness. Importantly, most news stories revolve around inherited forms of deafness and achondroplasia (dwarfism).[55]

Different impairments produce myriad experiences and call for different degrees of support and care. Therefore, it seems more appropriate in recent years to speak of disability communities, multiple subcultures organized around a specific impairment, rather than one disability community.[56] The biggest and most significant sub-culture within the disability community is the Deaf community. Members view themselves as a linguistic minority and their hearing impairment as "Deaf gain."[57] People with dwarfism, or little people, also have their own community and distinct culture that has been documented for decades, including through important work by medical anthropologist Joan Ablon[58] and through Little People of America, a nonprofit organization that meets yearly and provides community support.[59] Another community is the neurodiversity community, which is composed mostly of people on the autism spectrum.[60] Members of this movement reject the medicalization of autism and see it as a product of longstanding neurological differences, not deficits or diseases, that should be respected rather than cured or eliminated.[61]

Preimplantation Genetic Diagnosis: An Ethical Way to Carry on a Cultural Bloodline?, 19 CAMBRIDGE Q. HEALTHCARE ETHICS. 86, 86 (2010).

[54] Daar, *supra* note 30, at 233.

[55] *Id.*

[56] Rabia Belt & Doron Dorfman, *Disability, Law, and the Humanities: The Rise of Disability Legal Studies*, *in* THE OXFORD HANDBOOK OF LAW AND HUMANITIES 145, 150 (Simon Stern, Maksymilian Del Mar & Bernadette Meyler eds., 2019).

[57] BRUEGGEMANN, *supra* note 2, at 12; CAROL PADDEN & TOM HUMPHRIES, INSIDE DEAF CULTURE 8–9 (2005).

[58] Joan Ablon, *The Parents' Auxiliary of Little People of America: A Self-Help Model of Social Support for Families of Short-Statured Children*, 1 PREVENTION HUM. SERVS. 31, 35 (1982). *See generally* JOAN ABLON, LITTLE PEOPLE IN AMERICA: THE SOCIAL DIMENSION OF DWARFISM (1984); JOAN ABLON, LIVING WITH DIFFERENCE: FAMILIES WITH DWARF CHILDREN (1988); JOAN ABLON, BRITTLE BONES, STOUT HEARTS AND MINDS: ADULTS WITH OSTEOGENESIS IMPERFECTA (2008).

[59] Ablon, *supra* note 58, at 34–35; *Welcome to Little People of America*, LITTLE PEOPLE OF AMERICA, https://www.lpaonline.org/ [https://perma.cc/PTD7-55SE]; SOLOMON, *supra* note 37, at 115–16.

[60] But may also refer to people with bipolar disorder or traumatic brain injury.

[61] ANNE MCGUIRE, WAR ON AUTISM: ON THE CULTURAL LOGIC OF NORMATIVE VIOLENCE 20 (2016); STEVE SILBERMAN, NEUROTRIBES: THE LEGACY OF AUTISM AND THE FUTURE OF NEURODIVERSITY 16–17 (2015); ERIC GARCIA, WE'RE NOT BROKEN: CHANGING THE AUTISM CONVERSATION 47–48 (2021); CATHERINE TAN, SPACES ON THE SPECTRUM: HOW AUTISM MOVEMENTS RESIST EXPERTS AND CREATE KNOWLEDGE 6–7 (2024); Susan D. Carle, *Analyzing Social Impairments Under Title I of the Americans with Disabilities Act*, 50 U.C. DAVIS L. REV. 1109, 1114 (2017); Amy Harmon, *Neurodiversity Forever, The Disability Movement Turns to Brains*, N.Y. TIMES (May 9, 2004), http://www.ny

Some research shows that members of these disability communities express interest in potentially selecting for disability. In 1998, a U.K. study documented some Deaf parents expressing interest in using genetic testing to choose for deafness.[62] In 2006, the New York Times reported that prospective parents with dwarfism approached fertility specialists asking to have a baby who is a little person.[63] Professor Dov Fox notes in his 2019 book, *Birth Rights and Wrongs*, that couples who both have the most common kind of dwarfism, achondroplasia, often create embryos using IVF to eliminate a one in four chance of the prospective child dying soon after birth.[64] They could, therefore, potentially select an embryo "who is like them."[65] Professor Fox also notes that some clinics would reject such requests,[66] referring to a report by a Chicago-based geneticist who "once flatly refused a couple who asked him to identify an embryo with Down syndrome, so they could give their Down-affected child a similar sibling."[67] In a 2024 qualitative study conducted with non-autistic parents of autistic children who have a genetic disposition for autism, one parent shared how his autistic daughter expressed interest in having autistic children.[68]

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times.com/2004/05/09/weekinreview/neurodiversity-forever-the-disability-movement-turns-to-brains.html [https://perma.cc/UB48-RNUG]; Katherine Reynolds Lewis, *Autism Is an Identity, Not a Disease: Inside the Neurodiversity Movement*, MEDIUM (July 1, 2020), https://elemental.medium.com/autism-is-an-identity-not-a-disease-inside-the-neurodiversity-movement-998ecc0584cd [https://perma.cc/KRY7-QE7Z].

[62] Anna Middleton, Jenny Hewison & R. F. Mueller, *Attitudes of Deaf Adults Toward Genetic Testing for Hereditary Deafness*, 63 AM. J. HUM. GENETICS 1175, 1178 (1998) ("13 (15%) of the 87 individuals in the entire sample, and 4 (29%) of the 14 who were interested in PND for deafness, said that they would prefer to have deaf children. These results are supported by the work of Kalla et al. (1996), who showed that 14 (19%) of a sample of 74 deaf and hard-of-hearing college students also had a preference for having deaf children. It is understandable that culturally Deaf persons may want to have deaf children, since this would allow them to pass on their language, identity, and history to the next generation, thereby keeping the Deaf culture alive.").

[63] Darshak Sanghavi, *Wanting Babies Like Themselves, Some Parents Choose Genetic Defects*, N.Y. TIMES (Dec. 5, 2006), http://www.nytimes.com/2006/12/05/health/05essa.html [https://perma.cc/ZEV7-LJMM].

[64] FOX, *supra* note 31, at 144.

[65] *Id.*

[66] *Id.* Professor Judith Daar explored similar conflicts between prospective patients and providers. *See* Daar, *supra* note 30, at 224, 227.

[67] Melissa Healy, *Fertility's New Frontier*, L.A. TIMES (July 21, 2003, 12:00 AM PT), https://www.latimes.com/archives/la-xpm-2003-jul-21-he-pgd21-story.html [https://perma.cc/S2ZR-A6ZQ]; *see also* FOX, *supra* note 31, at 143. For an interesting review on the effects of using PGT on the dwindling number of people with Down syndrome in Iceland, see generally Kalena R. Kettering, *"Is Down Always Out?": The Right of Icelandic Parents to Use Preimplementation Genetic Diagnosis to Select for Disability*, 51 GEO. WASH. INT'L L. REV. 1534 (2019).

[68] Robert Klitzman, Ekaterina Bezborodko, Wendy K. Chung & Paul S. Appelbaum, *Receiving De Novo Genetic Diagnoses for Autism with Intellectual Disability: Parents' Views of Impacts on Families' Reproductive Decisions*, 15 J. CMTY. GENETICS 85, 92 (2024):

It is important to recall that these are all reports about interest, not about actually implementing an embryo with a disability. Having a child, specifically using ART, is a complex decision. It is a long process where people's ideas and preferences are likely to change throughout the multiple stages of the procedure, from creating embryos until implementation. Expressing interest in selecting for disability before starting a process, or even in the initial stages, as documented in the previously mentioned studies, tells us little about whether prospective parents actually go through with that preference. As mentioned, cooperation on the side of the fertility clinic is also not a given and could stand in the way. It is safe to assume that, in most cases, very few will choose — or be permitted — to have a child with a disability.

Nevertheless, one story from over twenty years ago seems to have created a fascination with the topic in academic circles, but even more interestingly, it inspired intervention by policymakers. This Article turns to this story and its consequences in the next part.

V. THE STORY OF THE D.C. DEAF COUPLE AND ITS RIPPLE EFFECTS

In the first section of Part V, I will discuss the story of the Duchesneau-McCullough family, which is cited extensively and serves as the basis for the discussion on selecting for disability in the literature. In the second part, I will discuss a U.K. law enacted in 2008 that bans selecting for difference based (at least in part) on the Duchesneau-McCullough story.

A. The Duchesneau-McCullough Story

In 2002, news outlets around the world reported on the story of Sharon Duchesneau and Candace (Candy) McCullough, a Deaf lesbian couple from the Washington, D.C. metropolitan area who went to great

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> 'When my daughter initially received her autism diagnosis, one of her questions was, 'Will my children be autistic?' That was her first question to the geneticist: 'What about my kids?' . . . I misinterpreted why she wanted to know that. I assumed that she wanted to know that because she was worried that her children would be autistic and that she would have to contend with that. But when she found out, she told us she was 'relieved.' She was actually hoping to have an autistic child like herself: 'There are not a lot of people like me, and I just think it would be nice to have more people around who understand why I do what I do, because they feel the same way.'

A few other parents in this study expressed grave concerns about their child having children. One parent admitted that the genetic test resulted in a decision to have his severely autistic daughter undergo tubal ligation.

lengths to have two deaf babies, a girl and a boy, five years apart.[69] The babies were conceived through artificial insemination and not IVF. The couple first contacted a sperm bank requesting a deaf donor, but they were refused as congenital deafness disqualifies donors.[70] They, therefore, turned to a male friend who came from five generations of deafness, and he donated the sperm twice.[71]

Because reproductive technologies did not play a part in conceiving the babies, the couple had to wait until the children were around two months old to discover whether they were actually deaf. In an interview conducted before receiving the hearing test results of their younger son, the parents made sure to refute any assumption that they would not love a hearing baby, stating that "[a] hearing baby would be a blessing. A deaf baby would be a special blessing."[72]

Duchesneau and McCullough wholeheartedly believed that they would be better parents to a deaf child as they could better guide the child's emotional development, understand the deaf child's emotions, and communicate with them more easily. The fact that the family resides in the D.C. area, home of Gallaudet University, a higher education institution for deaf persons, and one of the largest Deaf communities in the United States, also contributes to the social constructionist ideal of raising a multi-generational Deaf family.[73] Indeed, the couple's daughter, Jehanne McCullough, studied at Gallaudet and later graduated from the University of Virginia Law School.[74] Duchesneau and McCullough continue to run a mental health practice for the Deaf community, which they founded in 2001.[75]

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[69] Mundy, *supra* note 1; Faith McLellan, *Controversy Over Deliberate Conception of Deaf Child*, 359 LANCET 1315 (2002); David Teather, *Lesbian Couple Have Deaf Baby by Choice*, GUARDIAN (April 7, 2002, 9:22 PM EDT), https://www.theguardian.com/world/2002/apr/08/davidteather [https://perma.cc/V8F4-6FPE]; *Hear No Evil*, SYDNEY MORNING HERALD (April 13, 2002, 10:00 AM), https://www.smh.com.au/world/hear-no-evil-20020413-gdf6zt.html [https://perma.cc/M7JG-MTZP].

[70] As scholars point out: "Most clinics have extensive screening and testing regimes that are made available to intending parents and are also used to screen gamete donors. Testing and screening protocols aim to ensure that donor gametes used for reproduction are unaffected by genetic anomalies or other heritable conditions. Protocols reflect a conception of what, in the clinical context, is considered to be 'normal' and permissible as opposed to abnormal and requiring exclusion." Isabel Karpin & Roxanne Mykitiuk, *Reimagining Disability: The Screening of Donor Gametes and Embryos in IVF*, 8 J.L. & BIOSCIENCES 1, 7–8 (2020).

[71] Mundy, *supra* note 1.

[72] *Id.* The journey of parents accepting their children's difference stands at the heart of Solomon's incredible work, *see* SOLOMON, *supra* note 37, at 5–6, 26–27.

[73] Mundy, *supra* note 1.

[74] Mike Fox, *Student Led Voter Outreach Effort Before Law School*, UNIV. VA. SCH. L. (Apr. 3, 2020), https://www.law.virginia.edu/news/202004/student-led-voter-outreach-effort-law-school [https://perma.cc/BC3C-56MV].

[75] Rachel Pomerance Berl, *Why Deaf People Need Psychotherapy More Than Ever (and How Two North Bethesda Women Are Helping Them)*, MOCO360 (Aug. 8, 2022, 12:23 PM), https://moco360.media/2022/08/08/why-deaf-people-need-psychotherapy-more-than-ever-and-how-two-north-bethesda-women-are-helping-them/ [https://perma.cc/G42E-QGHR].

Duchesneau and McCullough also made specific reference to the idea of them wanting to turn horizontal difference into vertical difference when analogizing the choice of having a Deaf baby to having a Black baby:

> 'Some people look at it like, 'Oh my gosh, you shouldn't have a child who has a disability,' . . . . But, you know, [B]lack people have harder lives. Why shouldn't parents be able to go ahead and pick a [B]lack donor if that's what they want? They should have that option. They can feel related to that culture, bonded with that culture.'[76]

The journalist who reported the original story continued in the same line of thinking, stating that "Sharon and Candy are a little like immigrant parents who, with a huge and dominant and somewhat alien culture just outside their door, want to ensure that their children will share their heritage, their culture, their life experience."[77]

Importantly, Duchesneau and McCullough acknowledge that their decision "was a personal one, not an attempt to make a political statement about deaf [sic] culture."[78] Nevertheless, what was a personal decision became a sensation, inspiring not only philosophical discussions on the issue but also a legislative intervention across the pond in the United Kingdom.

B. The U.K. Ban on Selecting for Disability

The Human Fertilization and Embryology Act ("HFEA"), first passed in the United Kingdom in 1990, regulates reproductive technologies, including PGT.[79] U.K. Clinics can only offer fertility services that are licensed by the HFEA.[80]

In 2008, the U.K. parliament amended HFEA to ensure the law kept up with twenty-first-century technological and societal

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[76] Mundy, *supra* note 1; *see also* Camporesi, *supra* note 53, at 89.

[77] Mundy, *supra* note 1. Nevertheless, it is important to note that race and the law scholars have criticized the ART industry's practices with regard to racially marked gametes in a way that normalizes the idea that a monoracial family should be desired and commodifies race. *See* DOROTHY R. ROBERTS, KILLING THE BLACK BODY: RACE, REPRODUCTION AND THE MEANING OF LIBERTY 267–70 (1997); Dorothy E. Roberts, *Race, Gender, and Genetic Technologies: A New Reproductive Dystopia?*, 34 SIGNS 783, 798 (2009); Rich, *supra* note 29, at 2391–92, 2405–06.

[78] McLellan, *supra* note 69, at 1315.

[79] *See* Edward M. Taylor, *Procreative Liberty, and Selecting for Disability: Section 14(4) Human Fertilization and Embryology Act 2008*, 2 KING'S STUDENT L. REV. 71, 73 (2010).

[80] *Id.*

developments.[81] Among the amendments, a new prohibition was added concerning the implantation of embryos.[82] While the older HFEA rule afforded U.K. medical professionals and fertility clinics full discretion "when deciding whether to license PGD for new uses," the 2008 Amendment specifically singled out and prohibited the possibility of selecting for disability. Section 14(4) of HFEA now reads:

> Persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop —
>
> (a) a serious physical or mental disability,
>
> (b) a serious illness, or
>
> (c) any other serious medical condition,
>
> must not be preferred to those that are not known to have such an abnormality.[83]

Interestingly, the HFEA amendment does not include a definition of what is considered "a serious physical or mental disability."[84]

The story of Duchesneau and McCullough choosing to have children who, like them, were deaf was a catalyst for this ban.[85] The explanatory note to the HFEA amendment included a clear reference to the Duchesneau-McCullough story, stating that "outside the UK, the positive selection of deaf donors in order deliberately to result in a deaf child has been reported. This provision would prevent selection for a similar purpose."[86]

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[81] Human Fertilization and Embryology Act 2008, c. 22; Lynn Eaton, *Controversial Embryo Bill Receives its Second Reading in Lords*, 35 BMJ 1063, 1069 (2007).

[82] Human Fertilization and Embryology Act 2008, c. 22, § 14(4)(9); Gerard Porter & Malcolm K. Smith, *Preventing the Selection of "Deaf Embryos" Under the Human Fertilization and Embryology Act 2008: Problematizing Disability?*, 32 NEW GENETICS & SOC'Y 171, 171 (2019).

[83] Human Fertilization and Embryology Act 2008, c. 22, § 14(4)(9); Taylor, *supra* note 79, at 73. Additionally, the amended Act made it "a criminal offence to perform PGD without a licen[s]e, outside the terms of a licen[s]e, or use to it to select an embryo on the basis of its sex for non-medical reasons." Sara Fovargue & Rebecca Bennett, *What Role Should Public Opinion Play in Ethico-Legal Decision Making: The Example of Selecting Sex for Non-Medical Reasons Using Preimplantation Genetic Diagnosis*, 24 MED. L. REV. 34, 35 (2016).

[84] Porter & Smith, *supra* note 82, at 171.

[85] *Id.* at 172 ("The reference to the positive selection of deaf donors in the original version of the Explanatory Notes [of the 2008 HFEA] is most likely a reference to the decision of a lesbian couple in the USA who had succeeded in their desire to have a 'disabled child.'"); Taylor, *supra* note 79, at 72.

[86] Porter & Smith, *supra* note 82, at 172.

The fact that the ban on selecting for disability in Section 14(4) of the HFEA implicitly considers deafness as a "serious physical or mental disability" did not go unnoticed. It yielded an extensive intentional campaign initiated by British Deaf activists,[87] reports of which also traced the controversy to the Duchesneau-McCullough story.[88] The exploratory note to the HFEA, which originally included a reference to deafness, was changed following the campaign, yet there is still no definition under the law for what is considered "a serious physical or mental disability," leaving the question of whether deafness is included open for interpretation.[89]

VI. WHY THE UNITED STATES SHOULDN'T REGULATE SELECTION FOR DISABILITY

PGT was originally designed to detect and select against genetic mutations that lead to serious diseases such as Tay-Sachs, thalassemia, cystic fibrosis, sickle cell anemia, Gaucher disease, and hemophilia. Yet the technology has developed so much that it can now detect far less serious health conditions, like colorblindness.[90] These technological developments, therefore, bring up difficult philosophical line-drawing questions: what conditions could be viewed as minor or at least allow a life worth living (closer to the colorblindness end of the spectrum), and which ones are life-threatening or can be considered so severe that life is not worth living (closer to the Tay-Sachs end of the spectrum)?[91] Those questions arise when discussing selecting against or selecting for disability. It is the disabilities that are somewhere along the spectrum between minor to extremely serious, between colorblindness and Tay-Sachs, that are up for debate. It is unlikely that prospective parents would choose to have a child with cystic fibrosis or hemophilia, which have grave implications to a person's health and are not associated with a subculture. Yet, when discussing deafness,

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[87] For details on the campaign, see Steven D. Emery, Anna Middleton & Graham H. Turner, *Whose Deaf Genes Are They Anyway?: The Deaf Community's Challenge to Legislation on Embryo Selection*, 10 SIGN LANGUAGE STUD. 155, 159–62 (2010).

[88] Richard Gray, *Couples Could Win Right to Select Deaf Baby in Embryo Bill Change*, DAILY TELEGRAPH (Apr. 13, 2008, 12:01 AM), https://www.telegraph.co.uk/news/uknews/1584948/Couples-could-win-right-to-select-deaf-baby.html [https://perma.cc/Z6PF-B2D8] ("The issue first came under the spotlight six years ago in America, when it emerged that a deaf couple had sought out a sperm donor with a family history of deafness.").

[89] Emery et al., *supra* note 87, at 165.

[90] Daar, *supra* note 30, at 228.

[91] For a helpful typology of fetal anomalies into (1) fatal conditions, meaning certain childhood death, (2) life-threatening conditions, meaning substantial chance of death and significant disability in survivors, and (3) survival with disability, in the abortion ban debate, *see* Greer Donely, *Parental Autonomy over Prenatal End-of-Life Decisions*, 105 MINN. L. REV. 175, 182 (2020).

dwarfism, autism/neurodiversity, or even Down syndrome, things are more complex.[92] Other than the line-drawing questions arising from the type of disability found through PGT, legal scholars identify three implications that must be taken into account when considering selecting against or for disability: the interests of the parents,[93] the child, [94] and

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[92] Disability philosopher Joel Reynolds has discussed how "across the history of philosophy, conceptions of what we today call 'disability' are shaped by the ableist conflation: the assumption that disability is a harmful lack and coincident with pain and suffering." JOEL MICHAEL REYNOLDS, THE LIFE WORTH LIVING: DISABILITY, PAIN, AND MORALITY 115 (2022). Other scholars have also observed a tension between how society perceives disability (i.e., an outside view) and the way people living with disabilities and their close ones view it (i.e., an inside view). *See* Elizabeth F. Emens, *Framing Disability*, 2012 U. ILL. L. REV. 1383, 1389 (2012). While the outside view observes disability to be an "unhappy place," the inside view simply sees it as "a mundane feature of a no-less-happy life, rendered inconvenient or disabling largely by interactions with the surrounding environment, which legal accommodations alter in ways that sometimes provide benefits to many," *id.* at 1386; *see also* PAUL K. LONGMORE, TELETHONS: SPECTACLE, DISABILITY, AND THE BUSINESS OF CHARITY 98–101 (2015); DANA S. DUNN, THE SOCIAL PSYCHOLOGY OF DISABILITY 20–22 (2014).

[93] For example, some scholars recognized a limit to procreative liberty: a parent should not inflict intentional harm to a born child. JOHN A. ROBERTSON, CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES 16 (1994); Judith F. Daar, *Accessing Reproductive Technologies: Invisible Barriers, Indelible Harms*, 23 BERKELEY J. GENDER L. & JUST. 18, 49 (2008).

[94] *See, e.g.*, Julian Savulescu, *Procreative Beneficence: Why We Should Select the Best Children*, 15 BIOETHICS 413, 419 (2001) ("[L]egislation in Australia and the United Kingdom related to reproduction gives great weight to consideration of the best interests of the child."). In 2008, a scholarly debate among law professors ensued around the topic of tort liability for parents who chose to have a disabled child in a wrongful life lawsuit of the child. A wrongful life claim is one in which the child that results from a reproductive choice brings suit claiming that the harm is their life themselves (as opposed to a wrongful birth claim which is brought by parents usually against medical professionals, for medical and financial harms in raising the child). Professor Kristen Rabe Smolensky argued that while parents should not be liable in a wrongful life claim if they select for an embryo through PGT but that liability would attach if parents were to genetically manipulate an embryo to create an impairment (referred to as "direct genetic interventions"). Kirsten Rabe Smolensky*, Creating Children with Disabilities: Parental Tort Liability for Preimplantation Genetic Interventions*, 60 HASTINGS L.J. 299, 332 (2008). In response, Professor Alicia Ouellette agreed that a direct genetic intervention creates a moral harm to the child and therefore that tort liability should attach to the parents. To not signal out disability and enforce the myth of a life with disabilities as a tragedy, Ouellette suggested such liability should be attached to other identities that have been genetically manipulated (such as lighter skin or sexual orientation). *See* 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, 401, 403–04, 406–07 (2008). Professor I. Glenn Cohen on the other hand, complexly rejected the idea of tort liability for parents choosing for difference (whether through selection or manipulation). Cohen's underlying argument is that we should not be transferring the best interest of the child principle from family law (situations that involve an existing child) to the regulation of reproduction (that discusses bringing a child into existence). I. Glenn Cohen, *Intentional Diminishment, the Non-Identity Problem, and Legal Liability*, 60 HASTINGS L.J. 347, 348, 360 (2008) [hereinafter Cohen, *Intentional Diminishment*]; I. Glenn Cohen, *Regulating Reproduction: The Problem of Best Interest*, 96 MINN. L. REV. 423, 435, 437, 443 (2011) [hereinafter Cohen, *Regulating Reproduction*]. Professor Dov Fox agrees with Cohen stating that a child who was selected to have some genetic disability generally speaking is "nowhere near bad enough that it might be better for him never to have lived at all." FOX, *supra* note 31, at 145.

society at large.[95] Those interests, and specifically the "future welfare of the child," were considered while enacting the 2008 HFEA amendment,[96] yet the interest analysis has been criticized in the context of U.K. HFEA as well as by American legal scholars when discussing the doctrine of wrongful life.[97]

The goal of this Article, however, is not to delve into these important philosophical discussions. My goal is to point out how one American story that did not even include PGT has inspired a ban on selecting for disability in the UK. This is even more remarkable considering how unlikely the possibility that prospective parents would select for disability. As I have discussed, there is barely any evidence other than some indication that disabled people theoretically would like a child who is "like them."[98] Only three percent of 186 American fertility clinics surveyed reported on such requests,[99] which is far from having implications on public health.[100] Even when these requests occur, they usually do so under conditions that are not debilitating and are not viewed by parents as disabling, like deafness or dwarfism.[101]

It seems that the sensationalism and moral panic of both disability issues and genetic technologies played a large part in the enactment of the U.K. ban. In previous work on "fear of the disability con," I showed how a moral panic around people faking disabilities to exploit and abuse the law led to changes in legislation and policy to the detriment of disabled individuals.[102] Professor Myrisha Lewis has also explored a present-day moral panic surrounding "reproductive genetic innovation."[103] While discussing other types of technologies, like germline

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[95] FOX, *supra* note 31, at 145 ("Having the next generation arrive with more "normal" abilities or "healthy" functioning might be thought to help produce a productive citizenry, or one that costs less for the government to educate, accommodate, or care for."); Dov Fox, *Reproductive Negligence*, 117 COLUM. L. REV. 149, 236 (2017).

[96] Member of the House of Lords of the United Kingdom Earle Howe "stated that 'the idea [of selecting for disability] is repellent because it ignores one of the issues central to any IVF procedure, namely, the future welfare of the child.'" Porter & Smith, *supra* note 82, at 175–76.

[97] *See supra* note 94.

[98] *See supra* notes 62–68 and accompanying text.

[99] Baruch et al., *supra* note 53, at 1055.

[100] FOX, *supra* note 31, at 145.

[101] *Id.*

[102] Doron Dorfman, *Fear of the Disability Con: Perceptions of Fraud and Special Rights Discourse*, 53 L. & SOC'Y REV. 1051, 1085–86 (2019) (documenting changes in Social Security procedures to obtain disability benefits due to suspicions of fraud); Doron Dorfman, *[Un]Usual Suspects: Deservingness, Scarcity, and Disability Rights*, 10 U.C. IRVINE L. REV. 557, 577, 603–04 (2020) (discussing changes to disabled parking regulation and to disability accommodations policies at Disney theme parks due to the fear of the disability con); Doron Dorfman, *Suspicious Species*, 2021 U. ILL. L. REV. 1363, 1382–83 (2021) (discussing defensive policies with regard to the use of service dogs).

[103] Myrisha S. Lewis, *How Analogizing Socio-Legal Responses to Organ Transplantation Can Further the Legalization of Reproductive Genetic Innovation*, 74 SMU L. REV. 665, 668 (2021).

genome editing, Lewis identifies the broader concern for future generations as one that feeds the moral panic regarding the use of techniques involving genetic innovation in reproduction.[104] She also explores how moral panic and sensationalism affected the regulation of reproductive technologies through state law.[105] She concludes that, "[w]hile there are certainly reasoned concerns that accompany reproductive genetic innovation, such as those related to efficacy, equality, and eugenics, these issues should be approached through a lens of medical analysis as opposed to sensationalism."[106]

Concerns that carry a eugenic-ableist tone appear to be behind the 2008 HFEA amendment. It relied on one unique story of a Deaf couple's choice to create deaf children, where the consequences of the selection were far from problematic or harmful. Although the phenomenon of selecting for disability through PGT is incredibly rare, it was deemed pressing enough to legislate a ban against it. Banning the possibility of selecting for disability, at the very least, carries a concerning message about the value of living with disabilities,[107] specifically ones that are considered by many as a distinct cultural identity and a legitimate human difference.

Unlike the United Kingdom and other countries, the United States does not currently have explicit federal regulations for PGT. The safety and efficacy of the technology are regulated by the Food and Drug Administration ("FDA"), and its use is subject to the treating physician's discretion.[108] Nevertheless, the current legal landscape regarding reproductive rights is fraught, with federal and state courts engaging in regulation through case law.

Following the 2022 Supreme Court decision in *Dobbs v. Jackson Women's Health Organization* that gives states discretion in regulating abortion[109] and the 2024 Alabama Supreme Court decision in *LePage v. Center for Reproductive Medicine*, where the court assigned legal personhood to embryos created through IVF,[110] there is concern state

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[104] *Id.* at 683.

[105] *Id.* at 716.

[106] *Id.* at 717.

[107] *See supra* notes 46–50 and accompanying text.

[108] Kate Nakasato, Beverley Anne Yamamato & Kazuto Kato, *Evaluating Standards for 'Serious' Disease for Preimplantation Genetic Testing: A Multi-Case Study on Regulatory Frameworks in Japan, the UK, and Western Australia*, 16 HUM. GENOMICS 1, 2 n.2 (2022).

[109] Dobbs v. Jackson Women's Health Org., 597 U.S. 215, 302 (2022).

[110] LePage v. Ctr. Reprod. Med., No. SC-2022-0515, 2024 WL 656591, at *7 (Ala. Feb. 16, 2024). The case concerned three couples who underwent IVF at a clinic in Mobile, Alabama who had surplus embryos stored at the clinic. *Id.* at *1. After an unrelated patient of the clinic allegedly broke into the clinic and destroyed the embryos, the couples sued the clinic under Alabama's Wrongful Death of a Minor Act. *Id.* at *2. The trial court declared the embryos not to be "persons" or "children" within the meaning of the state statute and thus dismissed the wrongful death claims. *Id.* The Alabama Supreme Court however reversed

legislators and courts will soon make significant interventions in issues related to genetic reproductive technologies.[111] One could imagine, for example, that the fetal personhood argument could give rise to the best interest of the child standard as it relates to embryos. However, several scholars object to the application of such standards in situations when parents have selected for disability.[112] As scholars have noted following *Dobbs*, "[c]linical aspects of IVF make it vulnerable to restrictions in the name of embryo protection . . . . It is possible that some states have not yet restricted IVF or other forms of assisted reproductive technologies because of a belief that the Constitution restricts them from doing so. If so, the *Dobbs* decision will reassure them that they may go forward."[113]

It is therefore important to uncover the incredibly lean evidentiary record about the possibility of selecting for disability and to show that such legal intervention is unwarranted. The regulation of genetic reproductive technologies should be based on evidence of an existing problem, specifically as it has the potential to lead to more devaluation of life with disability through ableist messaging.[114]

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concluding that the couples may recover punitive damages for the death of their "extrauterine children" and "unborn children." *Id.* at *8. Justice Mitchell who delivered the opinion found the reading of the statute unambiguous yet suggested that even if ambiguity exists, the recognition of legal personhood of the embryos is compelled by a 2022 amendment to the Alabama Constitution titled "Sanctity of unborn life." *Id.* at *6.

[111] Rebecca S. Feinberg, Michael S. Sinha & I. Glenn Cohen, *The Alabama Embryo Decision — The Politics and Reality of Recognizing "Extrauterine Children*,*"* 331 JAMA 1083, 1084 (2024). In this case, however, the state worked to protect IVF clinics. In March 2024, the Alabama legislature promptly passed a new bill granting criminal and civil immunity to IVF clinics in the state. The law states: "no action, suit, or criminal prosecution for the damage to or death of an embryo shall be brought or maintained against any individual or entity when providing or receiving services related to in vitro fertilization." This new law is "intended to apply retroactively" to stop litigation against IVF clinics based on past conduct. ALA. CODE § 6-5-810 (2024). The law also provides criminal immunity and some protections against civil liability to manufacturers of products used in the IVF process, limiting remedies "to compensatory damages calculated as the price paid for the impacted in vitro cycle." ALA. CODE § 6-5-811 (2024). Nevertheless, the IVF clinics who are parties to this case formally stated that since the law does not deal with the question of "when life begins" and the issue fetal personhood, "[a]t this time, we believe the law falls short of addressing the fertilized eggs currently stored across the state and leaves challenges for physicians and fertility clinics trying to help deserving families have children of their own." Alander Rocha, *University of Alabama Birmingham Pauses IVF Treatments After Court Ruling*, ALA. REFLECTOR (Feb. 21, 2014, 5:57 PM), https://alabamareflector.com/2024/02/21/university-of-alabama-birmingham-pauses-ivf-treatments-after-court-ruling/ [https://perma.cc/AW3Z-4LG2].

[112] *See* Cohen, *Regulating Reproduction*, *supra* note 94, at 435, 437, 443; Cohen, *Intentional Diminishment, supra* note 94, at 360; FOX, *supra* note 31, at 145.

[113] This even while considering that the topic of regulating IVF has been garnering less interest among political groups than the topic of regulating abortion. *See* Cohen et al., *supra* note 17, at 15–16.

[114] *See supra* notes 47–50 and accompanying text.

VII. CONCLUSION

Section 14(4) of the British Human Fertilization and Embryology Act, enacted in 2008, bans prospective parents from selecting an IVF-created embryo that is prone to develop a "serious physical or mental disability." This law, I argue, serves as a cautionary tale for the post-*Dobbs* United States, where states have much more leeway to regulate reproduction. The U.K. law was at least partially based on one story of an American Deaf couple who chose to have deaf children through the selection of a sperm donor and not through IVF. The Deaf family, which promotes Deaf culture and disability pride, has succeeded in raising their children in a supportive and nurturing environment. Their story is far from an imagined dystopian world where prospective parents will choose to bring into the world a child with conditions like Tay-Sachs. There is no actual evidence that prospective parents would choose a disability that would make their child's life not worth living or endanger public health. Therefore, I conclude that to ensure procreative pluralism and the fundamental right to procreate,[115] states should not regulate the ability to select for disability. Indeed, as Professor Kimberly Mutcherson argued, procreative pluralism means "[i]magining a world that celebrates the pluralism of procreation [and] mirrors efforts to imagine and protect pluralism in families. That work includes demands for the law and society to take account of and value a range of families."[116]

Refraining from regulating this issue would also secure the equilibrium between respecting disability as part of human diversity and policy considerations regarding the multiple interests at stake in situations of genetic reproductive technologies.

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[115] Mutcherson, *supra* note 20, at 25.

[116] *Id.* at 27–28.