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Publication Date

2026-03-14

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Abstract: This paper applies Social Construction of Technology and Standpoint Theory to embryo selection, arguing that the boundary between medical screening and value judgment reflects the perspectives and incentives of stakeholders rather than scientific necessity.

INTRODUCTION

The Spectrum Is Real, the Line Is Not

Preimplantation genetic testing (PGT) allows prospective parents undergoing in vitro fertilization to screen embryos for genetic conditions before implantation. The technology exists on a spectrum. At one end sits Huntington disease: fatal, degenerative, fully penetrant, with no effective treatment. Screening embryos for Huntington variants through PGT-M carries a misdiagnosis rate below one percent and is considered by the American College of Obstetricians and Gynecologists to have "firmly established" clinical utility [4]. No serious person argues against this. At the other end sit traits like eye color or height, where polygenic embryo screening (PGT-P) can predict a gain of roughly 2.5 centimeters of height or 2.5 IQ points from a typical set of ten embryos, and the highest-scoring embryo for height turns out to be the tallest in only twenty-five percent of simulated families [5]. The science does not work. Every major professional society has declared PGT-P unfit for clinical use [6,7,8]. The endpoints of this spectrum, then, are settled. Huntington screening is straightforwardly beneficial. Selecting for height does not deliver what it promises and should not be marketed as though it does.

The problem is the middle. Down syndrome, deafness, and autism-spectrum conditions sit in a zone where the decision to screen is neither obviously medical nor obviously preferential. In Denmark, approximately ninety-eight percent of pregnancies receiving a positive prenatal diagnosis for Down syndrome are terminated [9]. Iceland reports near one hundred percent, with only one to two children born with Down syndrome per year. The United States estimates sixty-seven to seventy-four percent [10]. These figures are typically cited as evidence that informed parents, given a free choice, overwhelmingly prefer not to carry a Down syndrome pregnancy to term. What those figures do not reveal is whether the choice is as free as it appears, or whether the informational environment in which the choice is made has already shaped the outcome before the parent arrives at a decision.

This paper examines that middle zone. The central argument is not that embryo selection is inherently wrong. It is that the line between medical screening and preference-based selection is not drawn by science. It is drawn by people with specific values, incentives, and blind spots, and the communities most affected by where the line falls are largely absent from the process of drawing it. The frameworks applied are Social Construction of Technology (SCOT) and Feminist Standpoint Theory, supplemented by data from disability studies and bioethics. This work is in partial fulfillment of the ENGR184 course using the blueprint curriculum in Ref [1,2] and captured in a collection [3].

METHODS

Frameworks and Analytical Approach

Two critical frameworks guide this analysis. The Social Construction of Technology (SCOT) holds that technologies are not neutral instruments but embed the values, assumptions, and interests of those who design and deploy them [11]. Applied to PGT, SCOT directs attention to the decision points where normative claims are encoded as clinical ones: which conditions appear on a screening list, how test results are framed during genetic counseling, what language is used to describe a positive finding, and who profits from the expansion of screening categories. The analytical move is to trace how value judgments about what constitutes a "disorder" are made to appear as objective medical facts through the design of the technology and its surrounding clinical infrastructure.

Feminist Standpoint Theory holds that individuals occupying marginalized positions within a social structure develop epistemic resources unavailable to those occupying dominant positions, because navigating a system not designed for them requires understanding both the dominant perspective and their own [12]. The janitor in a corporate office understands the institution more completely than the CEO, because the janitor must navigate the CEO's world to survive in it while the CEO never needs to understand the janitor's. Applied to embryo selection, this framework generates a testable prediction: people living with the conditions being screened for possess knowledge about those conditions that the clinicians, engineers, and parents making selection decisions systematically lack. The analysis tests this prediction against the empirical literature on disability self-assessment.

The case study draws on peer-reviewed clinical evidence, professional society guidance documents, regulatory comparisons between the United States and United Kingdom, genetic counseling research, disability self-report studies, and bioethics literature. The analysis proceeds in three stages: first, demonstrating how the PGT pipeline encodes value judgments as medical decisions (SCOT); second, identifying the epistemic gap between decision-makers and the communities being selected against (Standpoint Theory); and third, proposing concrete community engagement strategies to address the gap.

RESULTS AND INTERPRETATION

The Value Judgment Disguised as Medicine

Every stage of the PGT pipeline involves a decision that looks technical but carries normative weight. The first decision is what to screen for. In the United Kingdom, the Human Fertilisation and Embryology Authority (HFEA) maintains an approved list of over 1,900 serious inherited conditions eligible for PGT-M. Each addition to the list requires review. In the United States, there is no federal law restricting what conditions may be selected for, no dedicated regulatory agency governing PGT use, and no approved list [8,13]. The ASRM and SART publish voluntary guidelines with no enforcement mechanisms. The classification of a condition as a "disorder" warranting screening is not a discovery; it is a judgment made by specific people operating within specific institutional and market incentives.

The second decision point is how results are framed. Michie et al. analyzed 131 transcripts of genetic counseling sessions and found an average of 5.8 advice statements per consultation; half of counselees facing a decision reported feeling steered by the counselor [14]. Bartels surveyed 383 members of the National Society of Genetic Counselors and found that ninety-six percent viewed nondirectiveness as central to their professional identity, yet seventy-two percent acknowledged being sometimes directive in practice [15]. The tension is structural, not personal. Genetic counselors are trained to present information neutrally, but the information itself is not neutral: it is organized around clinical risk categories that frame the condition as a problem to be avoided rather than as a life to be understood. Forty-eight percent of genetic counselors report moral distress, with the highest rates in prenatal settings [16]. The profession was founded on nondirectiveness partly to distance itself from its eugenic history, but a 2003 NSGC workshop concluded that strict adherence had become "an impediment to creative theory and clinical practice" [17].

The third decision point is market expansion. The proportion of US IVF cycles using PGT increased from 4.5 percent in 2011 to 44.9 percent in 2018 [18]. PGT-A alone typically costs four to six thousand dollars

per cycle, and industry analysts have noted it generates roughly fifteen hundred to two thousand dollars in profit per biopsy for clinics [19]. Yet the two largest multicenter randomized controlled trials found no improvement in cumulative live birth rate from PGT-A: Yan et al. reported 77.2 percent for PGT-A versus 81.8 percent for conventional IVF [20], and the Cochrane review covering thirteen trials concluded there was "insufficient good-quality evidence of a difference" [21]. The ASRM 2024 committee opinion states that the value of PGT-A "as a routine screening test for all patients undergoing IVF has not been demonstrated" [6]. Multiple class action lawsuits filed in 2024 and 2025 allege that companies marketed PGT-A as ninety-seven to ninety-nine percent accurate while the positive predictive value for aneuploidy is approximately eighty-nine percent, meaning roughly one in nine embryos called aneuploid may have been viable [22,23]. The technology is expanding not because the evidence supports expansion but because the market rewards it.

The Missing Perspective

Standpoint Theory predicts that the people living with screened-for conditions will assess those conditions differently than the people making screening decisions. The data confirms this with striking consistency. Skotko, Levine, and Goldstein surveyed 284 people with Down syndrome aged twelve and older and found that ninety-nine percent indicated they were happy with their lives, ninety-seven percent liked who they are, and ninety-six percent liked how they look [24]. Companion studies found parents overwhelmingly expressed love and pride, and eighty-eight percent of siblings reported being better people for having a sibling with Down syndrome. A 2023 mixed-methods systematic review confirmed that self-reported satisfaction among adults with Down syndrome was generally higher than proxy-reported satisfaction, meaning outside observers consistently underestimate the well-being of people with Down syndrome relative to their own self-assessment.

The pattern extends beyond Down syndrome. Albrecht and Devlieger conducted the landmark disability paradox study, interviewing 153 persons with moderate to serious disabilities and finding that 54.3 percent reported excellent or good quality of life [25]. The "paradox" is only paradoxical if one starts from the assumption that disability inherently reduces well-being. Non-disabled people systematically overestimate the negative impact of disability, a phenomenon psychologists call “affective forecasting error”. Middleton et al. surveyed deaf adults and found fifty-five percent believed genetic testing would do more harm than good; forty-six percent believed it devalued deaf people [26]. The Autistic Self Advocacy Network stated in 2022 that "eliminating a class of people with disabilities from existence by changing the genes that cause their disability, in all future generations, is an explicitly eugenic act" [27]. Byres, Morris, and Austin found forty-nine percent of autistic adults surveyed did not believe genetic testing for autism should be conducted at all [28].

These are not fringe positions. They represent majority or near-majority views within the communities being selected against. Yet the decision-making apparatus of embryo selection, from screening list governance to genetic counseling protocols to clinical result framing, proceeds without systematic incorporation of this evidence. The United Kingdom explicitly prohibits selecting for traits classified as disabilities under Section 14(4) of the Human Fertilisation and Embryology Act 2008, a provision enacted without documented consultation with disability communities [13]. The philosophical literature reflects the same gap. Julian Savulescu argues that parents have a moral obligation to select "the child, of the possible children they could have, who is expected to have the best life" [29]. Adrienne Asch responds that this framework reduces a future person to a single trait: "the trait obliterates the whole" [30]. Asch was herself pro-choice yet opposed disability-selective testing, a position that demonstrates one can hold reproductive autonomy as a value while still questioning whether the informational environment in which reproductive choices are made is epistemically complete.

Norman Daniels proposed "normal species functioning" as the principled boundary between treatment and enhancement, defining disease and disability as departures from species-typical functioning that impair equality of opportunity [31]. The difficulty is that "normal" is precisely what is contested. The continuum from Tay-Sachs to height passes through cystic fibrosis, sickle cell trait, BRCA mutations,

deafness, and autism without clear breakpoints. Dondorp and de Wert proposed "contextualized proportionality" using sub-criteria like monogenic etiology, high penetrance, absence of treatment, early onset, shortened lifespan, and reduced quality of life [32]. But the disability paradox data complicates even this careful framework: if quality of life is measured by the assessment of the people actually living those lives, many conditions that appear to warrant screening under Daniels or Dondorp and de Wert would not meet the threshold. The line between treatment and preference depends on whose assessment of quality of life is treated as authoritative.

CONCLUSIONS

Toward a More Epistemically Complete Process

The argument of this paper is not that embryo selection should be restricted. It is that the current decision-making process is epistemically incomplete in a way that systematically biases outcomes. The technology embeds normative claims as clinical facts (SCOT), and the stakeholders with the most relevant knowledge about the conditions being screened for are excluded from the process (Standpoint Theory). Two concrete community engagement strategies follow from this analysis.

First, genetic counseling protocols for conditions in the grey zone, including Down syndrome, deafness, and autism-spectrum conditions, should be required to present lived-experience data alongside clinical data. The Skotko study, disability paradox research, and community position statements represent rigorous, peer-reviewed evidence directly relevant to the decision parents are making. This evidence is largely absent from standard counseling frameworks. A policy brief directed at the National Society of Genetic Counselors and ACOG proposing the integration of self-report well-being data into counseling guidelines would constitute a concrete, implementable initiative. The goal is not to discourage screening but to ensure the value judgment parents are making is at least an informed one, shaped by the full range of available evidence rather than exclusively by clinical risk framing.

Second, screening list governance, whether formal as in the HFEA model or informal as in US clinical practice, should include structured representation from disability communities. The National Council on Disability, a federal agency, warned in 2019 that expanded genetic testing threatens disability rights and recommended FDA regulation of laboratory-developed tests used for embryo screening [33]. The people whose existence is evaluated by these technologies possess both the moral standing and the epistemic resources to inform the process. Their systematic exclusion is not an oversight. It is a structural feature of a decision-making apparatus that treats the question of which lives are worth creating as already answered.

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