## **CONCEIVING ABNORMALITY**

by

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Conceiving abnormality

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## Abstract

*In vitro* fertilization (IVF) has transformed how we understand, study, and reproduce human life, generating novel biological entities and possibilities. This dissertation takes shape around one such novelty: the abnormal IVF embryo. Over the last decade, the diagnosis of embryonic abnormality has become central to fertility science and practice. Today, over one third of IVF embryos produced in the U.S. are designated abnormal on the basis of their genetic makeup. My project delves into the complex world of these vexed biological entities, examining the apparatuses through which they come into being and through which they are variably stripped of and imbued with value. Drawing on feminist and crip theory, feminist political economy, science and technology studies, and my own multi-site, multi-methods research, I ask: What worlds of knowledge might be read from the abnormal embryo?

The dissertation makes three main arguments. First, it determines that IVF has precipitated a respatialization of reproduction from within to outside the body. Others have examined the subsequent geographical expansion of reproductive networks. But less attention has been paid to the deepening of the capitalist and scientific interest into the biotic space inside embryos – what I term "involution". In the context of fertility treatment, involution has catalyzed the birth of the abnormal embryo that is my interest. The designation of embryos as abnormal on the basis of their genetic makeup reflects deeply held assumptions about the healthy bodies we are supposed (to want) to have and reproduce. This is my second major argument. Understandings of abnormality are steeped in socio-cultural ideals of health, able-bodiedness, neuro-typicality, and sexual dimorphism. The fertility clinic is thus a key – and until now, overlooked – site in the discursive and material reproduction of the normal, healthy body. Finally, I argue that the

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reproduction of the healthy body in this context is also productive for the bioeconomy. In addition to generating profits in the fertility clinic, embryo genetic screening has created a reserve of surplus embryos seen to have no future life potential. Classified as waste in the fertility clinic, these embryos have complex and contested afterlives as valuable technoscientific objects.

## Lay Summary

This dissertation examines the changing relationship between technology and biological reproduction. It takes as its object of study the abnormal embryos detected via preimplantation genetic testing, an assisted reproductive technology used to screen human embryos for genetic or chromosomal abnormalities during infertility treatment. How do these technologies work? What counts as an abnormality, and how is this changing over time? What is the relationship between biological and social understandings of abnormality in the fertility clinic? What happens to abnormal embryos after they have been designated as such? Drawing on feminist and crip theory, science and technology studies, feminist political economy, and my own multi-site, multi-methods research, *Conceiving abnormality* sets out to answer these questions and to explore their implications for how we understand and reproduce life in the biotech era.

## Preface

This dissertation is the original and independent work of the author. The research program was approved by the University of British Columbia (UBC) Behavioural Research Ethics Board under certificate number H16-01573.

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# List of Abbreviations

AD	Alzheimer's disease
AIS	Androgen Insensitivity Syndrome
ART	Assisted Reproductive Technologies
ASRM	American Society for Reproductive Medicine
CDC	Centers for Disease Control
CHR	Center for Human Reproduction
CLIA	Clinical Laboratory Improvement Act
ERO	Eugenics Record Office
FDA	Food and Drug Administration
hESC	Human embryonic stem cell
HGP	Human Genome Project
HHS	Health and Human Services
IVF	In vitro fertilization
KS	Klinefelter syndrome
NIH	National Institutes of Health
PGT	Preimplantation genetic testing
PGT-A	Preimplantation genetic testing for aneuploidies
PGT-M	Preimplantation genetic testing for monogenic conditions
RJ	Reproductive Justice
WARF	Wisconsin Alumni Research Foundation

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For my parents, Francine and Andrew.

## **Chapter 1: Introduction**

In 1977, the viable human embryo was loosed from the spatial constraints of the body. In mid-November of that year, Robert Edwards, Patrick Steptoe, and Jean Purdy watched as a fertilized embryo underwent the first stages of cell division not in a fallopian tube but in a petri dish. Some 38 weeks later, on July 25, 1978, a baby girl was born of that embryo. Her parents named her Louise Joy Brown. Within less than 24 hours of Louise's birth, hundreds of film crews, photographers, and international press descended on the Brown home in Bristol, clambering for access to the new family. The culmination of decades of scientific experimentation, Louise's birth introduced the world to a new method of sexual reproduction: *in vitro* fertilization (IVF) or fertilization "in glass." Newspapers lauded the "world's first test tube baby" (Evening News 1978) as a "SUPERBABE" (*Ibid*) – a ground-breaking scientific accomplishment on par with the moon landing. Followed in quick succession by IVF births in Australia (1980), the United States (1981), and Canada (1982), the events of that night in July heralded a new means of establishing pregnancy and a new role for technology in the reproduction of life itself.

In the forty-two years since Louise's birth, *in vitro* fertilization has delivered more than eight million infants into the world. But this technology has a much longer history and it has born much more than babies. Using tools developed over centuries by scientists and researchers in natural history, modern and experimental embryology, developmental biology, zoology, genetics, and the agricultural sciences, IVF has given rise to a whole host of biological and technological progeny. It is, as Sarah Franklin (2013) argues, not only a means of treating infertility, but a technological platform and a vector of the biotech industry. Onco-mice, Dolly the Sheep, human embryonic stem cells, and a menagerie of other admixed chimeras, clones, and biological tools owe their existence to *ex vivo*, *in vitro* fertilization.

This dissertation takes shape around one such offspring, a new and contentious class of biotechnological entities: extracorporeal embryos. Produced by the millions in a burgeoning, transnational fertility bioeconomy, these embryos have messy social, economic, juridical, medical, and scientific lives. They sit cryopreserved by the millions in liquid nitrogen in fertility clinics, embryo banks, and research labs. They are the centre of debates over stem cell research and germline gene editing. And we encounter them in court cases and legislative bills asserting their status as property or person. They contain within them the history of eugenics; multiple and contested reproductive futures; and battles over reproductive justice and bodily commodification. Stripped from the "cumbersome assemblage of the whole human body" (Parry 2012, 217), they travel between bodies, across borders, and around the world in global surrogacy and biomedical research networks. Exhumed from the opaque depths of the uterus, their cells, chromosomes, and genes are mapped, manipulated, and intervened upon for productive and reproductive purposes.

If this is a story about extracorporeal embryos, it is also an account of the social, scientific, and technological practices that made possible their extracorporealization. Loosely defined as treatments that include the *in vitro* handling of human sex cells or embryos for the purposes of establishing a pregnancy, assisted reproductive technologies (ARTs) belong to a genre of biotechnologies directed at capturing the reproductive potential of cells by causing them to live differently in space and time (Landecker 2005, 2007). For same-sex couples and for the nearly 12 percent of U.S. women aged 15-44 who experience some form of infertility<sup>1</sup> (Centers for Disease Control 2019), assisted reproductive technologies represent the possibility of

<sup>&</sup>lt;sup>1</sup> The Centers for Disease Control (CDC 2019) defines infertility as the inability to get pregnant or to carry a baby to term after one year (or longer) of unprotected sex.

biological parenthood. Use of ARTs has surged in the U.S. since 1978, nearly doubling in the last decade alone – a trend often attributed to an increase in the average age at which U.S. women have their first child (*Ibid*).<sup>2</sup> In 2018, preliminary data collected by the Centers for Disease Control (CDC) (2020) reported 306,174 ART cycles performed at 456 clinics across the country, resulting in 73,818 live births (defined as the live delivery of one or more infants) totalling 81,465 live-born infants and accounting for around 1.9 percent of the annual birthrate. According to a Pew Research Center Study (2018), one third of adults in the U.S. report that they or someone they know has used some type of fertility treatment in order to have a baby. From my own experience, nearly everyone I've spoken with about this project over the last five years has shared a story about their own or their friend or family member's experience with infertility and assisted reproduction, evincing the integration of these technologies into everyday life.

Coupled with emerging biological theories about human reproduction and development, the growing acceptance and use of ARTs signals a change not only in how life is understood, but also how it is taken hold of and governed. Assisted reproductive technologies are granting researchers, fertility specialists, and prospective parents unprecedented – though always incomplete – control over the means, process, timing, experience, and outcome of sexual reproduction. As Franklin (2013, 14) argues, this "increase in control over biological reproduction 'artificially' is one of the major technological advances of the twentieth century, and yet one that has only recently begun to be theorized."

<sup>&</sup>lt;sup>2</sup> Advanced maternal age is considered a leading cause of female-factor infertility. Unlike men, who produce sperm continuously, women are born with all the oocytes they will ever have. As their oocyte reserve diminishes naturally over time and the quality of eggs decreases, the likelihood of full-term pregnancy likewise lessens.

This dissertation responds to Franklin's invitation to further theorize at the intersection of biological reproduction, technoscience, and society, focusing on one type of ARTs in particular: preimplantation genetic tests (PGTs). Used to screen IVF embryos for genetic or chromosomal abnormalities, PGTs are promoted as a means of increasing the likelihood of a healthy, live birth by selecting for transfer<sup>3</sup> only those embryos that are chromosomally and genetically "competent," to use the language of the fertility clinic. Since the first successful application of this technology in humans in 1989, reproductive medicine has been steadfast in the pursuit of more accurate and cost-effective screening methods. And for good reason. The transfer of normal embryos has been associated with decreased time to conception, a decrease in miscarriage rates, and a decrease in the number of IVF cycles required to achieve a pregnancy, as well as higher implantation rates and higher live birth rates, all of which can greatly improve intended parents' experiences with ARTs. For those who have experienced recurrent failed pregnancies, who carry deleterious heritable conditions in their own genes, or who have given birth to a child affected by a severe illness, these tests can significantly increase the chances of a healthy, live birth.

My specific concern in this dissertation is with the counterpart to these much sought-after normal embryos: the *abnormal* embryos remaindered by the PGT process. The increasingly common use of these tests in the fertility clinic has generated a reserve of embryos seen to have no future life potential as a result of the genetic or chromosomal anomalies carried in their cells. While some of these embryos are almost certainly non-viable, testing positive for mutations never before seen in a live-born infant, others are potentially "compatible with life:" those with

<sup>&</sup>lt;sup>3</sup> By transfer, I mean the transfer of *in vitro* embryos into the womb.

three copies of chromosome 21 (Down syndrome), for example, or those with an increased genetic susceptibility to certain types of hereditary cancers. These abnormal, potentially viable embryos are my especial focus. In the chapters that follow, I delve into their complex life-world, examining the matrix of power through which they are produced, qualified, appraised, and hierarchized. Abnormal embryos, I argue, are key sites in the exercise of power over reproduction and life itself: as the averted births that signify a future free of disease and disability, discussed in Chapter 4, and as experimental objects in the development of new biomedical knowledges and cures, examined in Chapter 5. Preimplantation genetic tests are a key element of the apparatus in and through which this control is exercised – a means of parsing the normal from the abnormal. Under the logic of PGT, embryo selection practices emerge as key processes through which the normal/abnormal binary comes into being and is sustained as a socio-biological formation. These practices suggest pressing and challenging questions about how particular expressions of human difference are understood, hierarchized, and (de)valued.

I understand abnormality in this dissertation as one half of a binary categorization that evaluates bodies and lives in relation to their anticipated success or failure in terms of health, productivity, and mental or physical capacity. As Georges Canguilhem argues, the language of abnormality rarely conjures images of statistical divergence and value-neutral variety, but rather of harmful deformities, of "life gone wrong" (1991, 137), of a departure from the healthy, functioning body. This healthy, functioning body, in turn, describes only a minority of people – what Rosemarie Garland Thomson (1997) calls "the normate." "[P]eel away all the marked traits with the social order at this historical moment," writes Thomson, "and what emerges is a very narrowly defined profile" (8). The normal body against which the abnormal is conceptualized is, in other words, not just a body free of illness or pathology, but an idealized body defined in

relation to geographically and temporally specific social, cultural, and political notions of health. The fertility clinic, I argue, is a key and thus far overlooked site in which the normal/abnormal binary is defined and reproduced, the extracorporeal embryo a vital scale at which it materializes. At these sites and scales, scientific, medical, legal, and social concern for variation intermingle, with implications for bodies, biological possibilities, and the bio-social future. Starting from the abnormal extracorporeal embryo, I ask how abnormality is conceived in and through assisted reproduction, and with what implications for how we understand, reproduce, and (de)value human life and human difference in the biotech era.

# **1.1** A human geographer approaches assisted reproduction, or: Reproduction, expanded and involuted

This dissertation brings a geographical imaginary to bear on these questions and on the contentious biotechnological entities that animate them. Extracorporeal embryos are born of a fundamental respatialization of reproduction. Once confined to the body, fertilization and early embryo development now occur readily and with increasingly high success rates *ex vivo*, opening up the biology of fertility to flexible spatial possibilities. Today, for example, a gay couple from Israel might purchase oocytes from a vendor in the Ukraine, implant the fertilized embryo in the womb of a surrogate in Canada, and bring the resulting baby back home to the other side of the world. Feminist and economic geographers have recently become interested in some of these possibilities. Recognizing the innate spatiality of *in vitro* fertilization, they have set themselves to examining the changing topographies of assisted reproduction and the myriad ways that place continues to matter in an increasingly transnational fertility landscape.

Geographical scholarship builds on a growing social scientific literature on ARTs. This work has examined the novel forms of kinship, labour, and bio-objects born of these

technologies. Sarah Franklin (1993, 1995), Laura Mamo (2007) and Charis Thompson (2005), for example, have explored their potential to denaturalize heteronormative and biologically determined understandings of reproduction and kinship by offering infertile and same-sex couples the opportunity to overcome social and biological obstacles to impaired fecundity. Others have queried the emerging forms of bodily, reproductive, and clinical labour intensified by surrogacy and egg donation (Waldby & Cooper 2008, 2010; Cooper & Waldby 2014) and the formation of new bio-objects such as oocytes, stem cell lines, and extracorporeal embryos that circulate in a burgeoning bioeconomy (Waldby & Mitchell 2006; Dickenson 2007; Cooper 2008).

Attentive to their "disrupting novelty" (Vertommen 2015, 533), social scientists have also examined how these technologies are implicated in much older forms of inequality and exploitation. As Thompson (2005) notes, while they add a degree of flexibility to the reproduction of reproduction, so too do ARTs maintain normative, gendered narratives and structures of nuclear family formation. Moreover, as critical race scholars and feminist political economists in particular have argued, access to and experiences of assisted reproduction are deeply stratified along lines of race, class, and geography: in general, those using ARTs are wealthier, urban, heterosexual, married, and white (see, for example, Roberts 1997; Cooper & Waldby 2014; Schurr 2017). The same Pew study cited above found that familiarity and experience with ARTs increases with educational attainment and income: from 20 percent among those with a high school degree (or less) to 56 percent among those with a postgraduate degree, and from 19 percent among those who make less than \$30,000 per year to 48 percent among those who make more than \$75,000.

In part, this stratification reflects the prohibitively high costs of assisted reproduction. According to FertilityIQ, an online resource for intended parents pursuing fertility treatment, in 2019 the average cost of a single IVF cycle in the U.S. was well over \$20,000. This total includes the costs of medical treatment (about \$12,000),<sup>4</sup> medications (about \$5,000), consultation (about \$400), ICSI (about \$2,000),<sup>5</sup> and PGT (about \$5000). It does not include the cost of preconception carrier screening (which can range from a couple hundred to a couple thousand dollars, discussed further in chapters 2 and 3) or those associated with the use of donor eggs (\$15,000-20,000) or a surrogate (\$100,000+). But as Dorothy Roberts (1997, 2009) has noted, the race- and class-based stratification of access to reproductive technologies exceeds the high cost of treatment. It is inseparable from a broader array of population control strategies that seek to circumscribe, prohibit, and even illegalize the unruly procreative capacities of poor and racialized women. As Ann Bell (2009) notes, while Medicaid often covers contraceptive methods but not infertility treatments, the reverse is true for many private insurers; thus, writes Charis Cussins (1998, 73s) there are "those for whom there is contraception, if only they'd use it, and those for whom there are infertility treatments." Access to ARTs is thus structured by powerful economic, political, and legal forces that seek to incite the "right" kind of reproduction - that of healthy, wealthy, white citizens – while suppressing that of poor women, women of colour, immigrant women, disabled women, and other others (Roberts 1997, 2009).

<sup>&</sup>lt;sup>4</sup> Medical treatment includes monitoring, egg retrieval, anaesthesia, lab fees, and transfer.

<sup>&</sup>lt;sup>5</sup> ICSI, or Intracytoplasmic Sperm Injection, is a fertilization technique. In traditional IVF, sperm swim to the oocyte, attached to its outer shell, and then push through to fertilize. ICSI involves injecting the sperm directly into the oocyte. This technique, understood to increase successful fertilization rates, has become increasingly common in fertility practice.

The "geographies of assisted reproduction" (Schurr 2018a) bring important theoretical insights from geography to bear on these interdisciplinary studies of ARTs: insights on the performativity of borders, the spatial and gendered division of labour, the global and the intimate, and the relationality of space and place. Geographers have charted flows of consumers, workers, oocytes, and knowledge across expansive fertility networks, following bodies, biological substances, and technoscience around the globe (Parry 2012; Bergmann 2011; Greenhough, Parry, Brown & Dyck 2015; Payne 2015; Schurr 2018b). They have examined how spatial unevenness in costs of labour and care structure transnational fertility relations, uncovering the novel (if never entirely new) forms of exploitation, work, and politics produced by this unevenness (Parry 2015, Schurr 2017, Lewis 2016, 2017, 2018a, b, 2019a, b). They have explored how postcolonial preferences for whiteness shape the global geographies of oocyte and surrogacy markets, in which educated white women might be paid up to 100 times more for their eggs than vendors in India, Mexico, or the Ukraine (Payne 2015; Schurr 2017, 2018a, 2018b; Schurr & Militz 2018). And they have grappled with the flexible, transitory nature of the fertility market itself, mapping the seemingly perpetual legal and regulatory changes that structure how and where oocyte and surrogacy markets develop and decline over time (Schurr & Perler 2015; Parry 2015; Greenhough, Parry, Brown & Dyck 2015; Schurr 2018a).

With a focus on the transnational expansion of reproductive economies, relations, and politics across space, this work has delineated the profound *extensification* of fertility networks made possible by the respatialization of reproduction. Much less attention has been paid, however, to a second spatial, scalar effect – what, borrowing from Bronwyn Parry (2012), I call *involution*. The term involution has multiple meanings in mathematics, physiology, biology, and philosophy, at once describing the shrinking of an organ; an instance of enfolding or entangling;

a complicated or intricate formation or structure; an inward curvature or penetration; and a turning or folding in upon oneself. I have gleaned from these definitions in order to define the spatial phenomenon under consideration in this dissertation: the inward curvature of the technoscientific gaze into the intricate structure of the extracorporeal embryo, an entangled biosocial "looking-glass through which we see ourselves" (Franklin 2013, 1).

The technoscientific separation of embryos from their corporeal milieu has rendered them progressively more accessible and manipulable at the most intimate scales of resolution. As Susan Squier (1994, 21) writes, "if we tease out the implications of dominant images of babies in bottles, we can see that they all enact the fantasy of the womb as a see-through container for the previously invisible fetus." No longer obscured by the fleshy materiality of *in vivo* reproduction, IVF has exposed embryos to ever-more intensive modes of inquiry, experimentation, and intervention. In a beautiful scalar metaphor, one researcher I spoke with compared assisted reproductive technologies to the Hubble Space Telescope, saying that they allow us to see things never before seen with the human eye. Like the telescope, ARTs make the previously invisible visible, granting science, society, and capitalist interests ingress not to the far reaches of the universe but to a new biotic landscape inside the living embryo. Unlike the telescope, however, these technologies also make possible an unprecedented degree of intervention in and control over the territory they render perceptible. Extracorporeal embryos are taken in hand and biopsied; genetically screened and, as of November 2018, modified;<sup>6</sup> frozen, stored for long

<sup>&</sup>lt;sup>6</sup> In November 2018, Chinese researcher He Jiankui announced to an international audience that he had successfully modified germline genes in two embryos that resulted in the birth of a pair of twins in the same month. He modified a gene associated with susceptibility to HIV. His work was roundly criticized by the scientific community, many of whom have called for a global moratorium on the clinical application of germline gene editing technology.

periods, and thawed again for implantation; experimented with; dissected; immortalized as stem cell lines and disease models; and put to work as test objects in the tissue economy.

This is the spatial phenomenon in which I am interested in the chapters that follow. To geographers' nuanced and empirically rich studies of the increasingly global geographies of assisted reproduction, this dissertation contributes an analysis grounded in the extracorporeal embryo itself. This responds to Carolin Schurr's (2018a) recent call to geographers to extend the boundaries of the discipline to include assisted reproductive technologies within its remit. As Schurr argues, the extensification of reproductive networks wrought by ARTs puts flesh on the bone of themes long of interest to feminist and economic geographers in particular, including the centrality of reproductive labour to the functioning of capitalism; the gendered geographies of (reproductive) labour; and the commodification and circulation of bodies and body parts in the bioeconomy.

The embryo interiors exposed by the process of involution likewise offer a generative site from which to grapple with these and other themes. At once economic and social, public and private, natural and cultural, global and intimate, embryos upend hierarchies of space and scale, challenging binary oppositions that have been so thoroughly criticized by geographers such as Geraldine Pratt and Victoria Rosner (2012), Doreen Massey (2005), and Sallie Marston (with Jones & Woodward 2005). Key sites at which discourses of normality and abnormality, health and pathology, are materialized and internalized, they offer a heuristic with which to examine intersections of health, bodies, and environments – a trefoil at the heart of human geography (Mansfield 2012a, 2012b; Guthman 2011, 2012, 2015; Guthman & Mansfield 2012; Jackson & Neely 2015). Implicated in both procreation and profit accumulation, they provide an empirical and theoretical standpoint from which to grapple with the entanglements of biological

reproduction and capitalist production that have animated work by geographers such as Rachel Colls and Maria Fannin (2013), Bronwyn Parry (2012), and Carolin Schurr (2017, 2018b). Despite these connections, the extracorporeal human embryo has been subject to woefully little critical analysis in geography (Fannin 2018 is a notable exception). This dissertation attempts to address this lacuna – to put this generative entity on the disciplinary map, so to speak, by inciting geographers' curiosity about the spaces and times of the *ex vivo* embryo.

#### **1.2** The socionatural embryo

In the chapters that follow, I work with an understanding of the embryo as a socionatural construction. In making this case, I join scholars from within and beyond geography who are interested in the ways that bodies are profoundly shaped by social processes. This work is theoretically diverse, empirically rich, and far too substantial to detail comprehensively here. Two knotted threads bear brief elucidation, however, for the ways they have oriented me toward my research subject. The first starts from the "social" in socionatural – from the idea that discourses shape and discipline bodies, bodily comportment, self-expression, identify formation, and so on. Work on discourses of pathologization (Foucault 1978), gender (Butler 1990, 1993), intersex (Fausto-Sterling 2000), and obesity (Valentine 1999; Evans & Colls 2009), for example, demonstrate the various ways that bodies are reworked through psychiatric treatment, gendered performances, surgical or chemical intervention, and consumption habits. These bodily reworkings are not arbitrary or incidental but enduring, patterned, organized practices that discipline bodies according to compulsory norms of, to use the same examples, health, heterosexuality, sexual dimorphism, and thinness. Bodies are, in this sense, relational entities inseparable from the technological, physical, social, and economic environments in which they come into being. This work identifies the body as generative site from which to identify,

negotiate, and grapple with these norms and the mechanisms through which they materialize, producing the effect that they name (Butler 1993). Abnormality, I argue in the chapters that follow, is a productive discourse that materializes in the bodies it categorizes, demarcates, differentiates, and governs.

The second thread, inseparable from the first, directs our focus to the "natural" – to bodily morphology and function. Assembled under the banner of a "political ecology of health and the body" (Guthman & Mansfield 2008), this scholarship examines how social, politicaleconomic, and ecological forces get "under the skin" at the molecular scale (Guthman 2011, 2015; Guthman & Mansfield 2012, 2015; Mansfield 2012a; Jackson & Neely 2015; Braun 2008). Investigating how politically produced conditions – from disease prevalence, to toxic exposure, to poverty – are implicated in bodily re-makings that are "more than evolutionary" (Guthman 2015, 2523), this work moves toward a notion of biological difference and human variation "as part of the warp and weave of space and time, both social and natural" (Mansfield & Guthman 2015). At the molecular scale, bodily phenotype and function are open to what happens outside the body, understood as a "geography of circulation and exchange" (Braun 2008, 252) that continuously swaps properties with a dynamic socionatural world. As Julie Guthman (2012, 952) notes, this line of thinking suggests the imperative to open up the black box of the body – to pay attention to its biochemical and "biophysical workings, albeit with a cognizance of how scientific understandings of the body, as well as the environment, are socially filtered." And it reinforces Emily Martin's (1998) early point that the body is not bounded by the skin but is a dense site of biochemical processes – plastic, porous, malleable – that exists in complex interdependencies with its multiple geographies.

My dissertation draws from and contributes to these threads of thinking on the body. I am concerned with how, in reproductive medicine, the structural impulse toward normalization and health is "part of a regulatory practice that produces the bodies it governs" (Butler 1993, 1), remaking future bodies and bio-social futures at the molecular scale. Much as the anatomists-turned-embryologists of the late nineteenth century began cutting open embryos to investigate the origins of human life, asking what worlds of knowledge might be read from within (Chapter 2), I want to open up the black box of the embryo, bring its concealed interior to light, and ask what it tells us about bodies and the world. I pay careful attention to its biophysical, material workings, to its cells, chromosomes and genes, to its specific biology, as well as to how these are socially produced and embedded.

In this I am also influenced by the work of feminists like Elizabeth Wilson (2010), Robyn Longhurst (1994, 2001, 2008), Donna Haraway (1989, 1997), and Elizabeth Grosz (1994), among others, who argue that biology, while often peripheral to feminist scholars' political concerns, bears down on them in significant and potentially perilous ways. Biology, as Wilson (2010) argues, remains a site of political vulnerability for feminist scholarship, much of which has been prone to what Susan Squier (2004, 45) has called a "knee jerk constructivism." I join these scholars in asking what kinds of feminist theory, what kinds of questions, and what kinds of political projects might emerge from a sustained engagement with biological matter – not as sovereign, intransigent, inert stuff but as an already impure object that is always "becoming given" (Ahmed 2010, 247). An orientation toward abnormal embryos underwrites the claim that bodies and reproductive biology are unruly sites for politics. From this vantage, I ask: what is revealed about the politics of bodies, hierarchical difference-making, production, and reproduction – by a geography of embryo interiors?

### 1.3 Methodology

On the morning of October 17, 2016, after a 12-hour drive from San Diego the previous day, I pulled open the heavy doors at the Salt Palace in Salt Lake City and stepped into the American Society for Reproductive Medicine's (ASRM) Scientific Congress and Expo. A huge banner with that year's slogan – "Scaling New Heights in Reproductive Medicine" – hung from the high ceiling. Below, fertility experts, clinicians, endocrinologists, biotech executives, urologists, lawyers, psychologists, embryologists, nurses, and an assembly of other professionals hurried to find a seat at the opening plenary. A multi-disciplinary, non-profit organization, the ASRM promotes the advancement of science and practice in reproductive medicine. Representatives from leading biotechnology firms, fertility practices, university labs and clinics, law firms, and hospitals attend each year to showcase new and newly refined technologies, share findings and developments, promote their practices, sell products, and maintain and establish profitable working relationships.

Earmarked by the ASRM as a "hot topic" in reproductive medicine for 2016, sessions on assisted reproductive technologies figured prominently at the Salt Palace – a focus reflective of the surge in ART use worldwide over recent years. Sessions and panels explored the latest in *in vitro* fertilization, gamete donation, hormone injection, genetic testing, and embryo screening. Plenaries discussed ART law and bioethics, genetic counselling, genetic and sex selection, and the emergence of transnational fertility markets. And in the expo hall, biotech firms peddled ART products with names reminiscent of Margaret Atwood's *Oryx and Crake*: MaterniT Genome, GenePeeks, TruSight One, PreParent, and Oosight were just a few of the goods on offer.

The ASRM conferences constitute the linchpin of my fieldwork for this project. In addition to the meeting in Salt Lake City, I attended the five-day conference and science expo in San Antonio (2017) – "Advancing reproductive medicine to build healthy families" – and Denver (2018) – "Focus on the next generation." Registration granted me access to interactive and academic sessions and plenaries; to massive expo halls full to bursting with biotech firms marketing their wares to practitioners; to informal conversations with biotech executives, clinicians, embryologists, lawyers, and other professionals; and to the lavish parties thrown by the ASRM's massive corporate sponsors – my favourite being CooperGenomics's 2018 "JURASSIC A.R.T," held in a dinosaur museum and featuring the research of a team attempting to biotechnologically re-produce extinct species à la John Hammond and Dr. Wu.

I gained invaluable insight into the field of assisted reproduction from these sessions, conversations, and events. I learned the basics of reproductive biology and its unique terminology; parsed key debates and disputes in scientific research and clinical practice; was apprised of new and emerging assisted reproductive technologies; and gleaned important information about the complex relationship between ART science, practice, and industry. I spent hours in the exhibit halls, where vendors explained to me the various technologies, drugs, and egg-, sperm-, and embryo-supply and storage services on offer. I also gathered together an extensive collection of promotional materials from major reproductive biotech corporations like CooperGenomics, Illumina, Celmatix, and Progyny. These sources make up the bulk of the empirical material in which chapters 3 and 4 grounded.

Attendance at the ASRM also provided insights into how assisted reproduction is governed in the U.S. Federal and state oversight of ART is scarce across the country. At the federal level, ART practice is overseen by the Fertility Success Rate and Certification Act of

1992, which requires that fertility clinics report their success rates annually to the CDC via the National ART Surveillance System. Data is self-reported and collection is limited,<sup>7</sup> especially compared with other ART hubs like the U.K.; many clinics do not report at all, or report in such a way that success rates are significantly inflated (for example by reporting solely on treatments administered to women under the age of 42) (Frith & Blyth 2014). The Food and Drug Administration (FDA) sets standards for the screening and testing of gamete donors, and for the handling, storage, and identification of reproductive tissues. The FDA is primarily concerned with preventing the transmission of communicable diseases. All donors are screened for chronic viral infections, including HIV, hepatitis B and C, human T-cell lymphotropic virus and cytomegalovirus. Only sexually intimate partners are excluded from testing. Finally, laboratory testing is regulated by the Centers for Medicare and Medicaid Services, under the Clinical Laboratory Improvement Act (CLIA). This does not include procedures performed in embryology labs, such as PGT, which are not considered diagnostic and thus do not fall under CLIA's mandate.

The relative dearth of formal regulation makes the United States unique from other global ART centres, many of which have strictly curtailed, or even prohibited, the commercialization of biological reproduction. Many of the practices subject to rigorous laws elsewhere are widely available in U.S. fertility clinics. As one fertility clinician described it: if you can pay, you can access the technology or service. Preimplantation genetic tests are emblematic in this regard.

<sup>&</sup>lt;sup>7</sup> Self-reported data includes patient demographics, patient obstetrical and medical history, infertility diagnosis, clinical parameters of the ART procedure, and information regarding resultant pregnancies and births.

Tightly controlled in Canada, the U.K., and most of Western Europe,<sup>8</sup> in the U.S. these tests have been incorporated into standard fertility practice across the country. As I discuss in more detail in Chapter 3, in some of the clinics I visited in California, the screening rate tops 90 percent, meaning that almost every embryo produced through IVF is subject to PGT.

In place of well-defined, comprehensive, formal regulation, ART practice is governed by a tangled array of private contracts between intended parents and fertility clinics, legal precedents regarding the status of reproductive tissues, and self-regulation through best practice protocols. The ASRM's Ethics and Practice Committees, for example, generate professional guidelines and good practice protocols for fertility clinics and their staff, who in turn create their own practice standards on a clinic-by-clinic basis. These guidelines and protocols, published online in the ASRM's flagship journal, *Fertility and Sterility*, provide an important textual source in this dissertation.

In addition to the ASRM, I attended the 2016 Families Through Surrogacy symposium in London, UK, the 2016 National Society of Genetic Counsellors annual meeting in Seattle, WA and the 2018 Canadian Fertility and Andrology Society meeting in Vancouver, BC. These conferences provided important context for the project, offering further insight into the global dynamics of assisted reproduction and the rapid expansion of fertility networks around the world, the complex legal landscape established to govern these global networks, the increasingly central role of genetics and genetic screening during IVF, and regional and national differences and overlaps in the governance and use of ARTs. Together with attendance at the ASRM, these six

<sup>&</sup>lt;sup>8</sup> In these countries, access to preimplantation genetic testing is predicated on clearly-established guidelines and requirements. In the U.K., for example, access is limited to those who have a demonstrable history of a severe heritable genetic condition in their family.

professional meetings enabled me to trace the circuits of knowledge, corporate influence, and technological practice over space and time, and to grapple with the scientific, clinical, ethical, political, economic, and legal dimensions of assisted reproduction. I witnessed the rapidity with which the field changes, watching, for example, as polygenic testing (see Chapter 3) and gene editing emerged as topics of intense interest and apprehension. I took extensive ethnographic fieldnotes at each of these conferences and meetings, focusing on the content of the various sessions and plenaries I attended, as well as on audience reactions to presentations and the interest that was generated (or not) by new or controversial topics. Because none of these meetings allow audio recording, quotations are taken from these fieldnotes. I have been meticulous in quoting as accurately and precisely as possible, and in the absence of exact phrasing have done my best to preserve the tone and intention of the speaker.

My reliance on conference sessions and materials in this dissertation is in part the product of the many barriers I encountered while trying to interview clinicians involved in the day-to-day work of assisted reproduction. I had initially intended this dissertation as a study of ART in California. When I started work on the project in 2015, California had the largest number of clinics in the U.S. and performed the most ART procedures, resulting in more live births than any other state. During my first research trip to San Diego in October 2016, it became clear that I would have to rethink my approach. It took me nearly a month to secure a meeting with someone at a fertility clinic – an off-the-record conversation with the clinical director at a fertility centre in the area. To call him cautious is an understatement. He wanted both proof of my student status and confirmation that I was not a reporter looking to blow the lid on a story about "designer babies." After I satisfied his requests during our 45-minute conversation, he agreed to set me up with a series of interviews with his staff over the coming weeks. I never heard back again,

despite multiple phone calls to the clinic. This happened twice more – preliminary, off-therecord meetings followed by the promise of further access, followed, in turn, by silence.

As I became more familiar with the language and politics of the field, in large part through attendance at the ASRM in Salt Lake City, my approach to interview requests improved. I learned that clinicians were much more comfortable, during the early stages of the interview, answering technical questions about *how* the technology works rather than questions about *what* it is used for. When asking the "what" questions, I learned to use the language of the clinic, speaking in terms of aneuploidies,<sup>9</sup> genetic abnormalities, and viability rather than using a language of disability, human difference, and life. Finally, I learned that I was much more successful in approaching smaller, independent clinics, as well as those associated with universities. During visits to San Diego (October-December 2016), the Bay Area (March-April 2017) and Sacramento (April-May 2017), I conducted formal or semi-formal interviews with twelve practitioners currently working across nine fertility clinics, including clinical directors, lab directors, physicians, and embryologists. Many of these interviews were incredibly in-depth, lasting between 1.5 and 2 hours, sometimes included a tour of the clinic, and often covered both the practice and politics of assisted reproduction in the United States.

As Elizabeth Dauphinée (2016, 77) says in an interview with Richa Nagar, "surprise has theoretical and empirical value" and "the journey itself is epistemologically relevant." The difficulties I experienced in attempting to interview fertility practitioners prompted me to look further afield – to explore new points of access and means of answering some of my many lingering questions. Some of the most compelling interview material derives from conversations

<sup>&</sup>lt;sup>9</sup> Chromosomal abnormalities

with those less directly involved in fertility practice. While in San Diego, I spoke at length with two of California state's only lawyers with experience in trying wrongful birth and wrongful life lawsuits, interviews that have been essential to my understanding of prohibitive transfer policies for abnormal embryos, detailed in Chapter 4. While in the Bay Area, I interviewed three life scientists working at the forefront of stem cell research in university labs, conversations that impelled my interest in the use of abnormal embryos as experimental objects and disease-in-adish models in the research context, and providing the material for Chapter 5. I interviewed two bioethicists and spoke with three social scientists interested in assisted reproduction at Berkeley, the University of California-San Francisco, the University of California-Davis, and the University of San Diego, whose insights provided both practical advice on research methods and theoretical context for my own work. I also interviewed two California BioBank employees, a high-risk OB/GYN, and an organizer and policy critic involved in social justice issues around reproductive biotechnologies.

Together, formal and semi-formal interviews with professionals variously involved in the embryo bioeconomy, textual analysis of promotional materials and ASRM committee opinions, and observations at the ASRM and other professional conferences make up a mixed-method approach that incorporates clinical, socio-cultural, political-economic, material, and academic sources. This approach aims to uncover and trace the circuits of power and knowledge through which abnormal embryos come into being, and through which they are variably stripped of and imbued with different kinds of value. My aim is not to expose evidence of bad science or bad practice. It is not to understand or critique the motivations of those who promote the use of preimplantation genetic testing during fertility treatment or those who decide to use them in their efforts to become pregnant. And it is not to diminish the important role of these tests in clinical

practice or the difficulties parents face in making decisions about which embryos to implant and which to discard. Rather, I want to shed light on the specific regimes of biomedical, legal, and institutional power and authority that hierarchize variation as normal or abnormal; to interrogate the ways that politics are deeply entangled with scientific paradigms; and to begin exhuming the structures – social, biomedical, legal, technological, economic, and otherwise – that produce and reproduce some forms of life, some specific forms of difference, as undesirable, even non-viable. The designation of some embryos, some lives and bodies, as abnormal is a social and political process imbricated with relations of power. Those relations, their assumptions, and their effects are contested and contestable, open to dissent and debate. In this dissertation I begin unpacking these power relations and assumptions, contributing to ongoing debate at the intersection of social difference, reproductive technologies, and reproductive politics. I take as my subject not the individual clinicians, scientists, patients, corporate executives, and others whose lives are intimately entwined with assisted reproduction, but the broader biomedical, scientific, political, social, and economic formations within which they live, work, and (re)produce.

My encounters with abnormal embryos in this project required me to bone up on the basics of reproductive biology, genetics, and the science of inheritance. I spent hours on YouTube, reading introductory textbooks (one of the most helpful of which was generously proffered by a stem cell scientist I interviewed), perusing scientific journals, and studying the informational booklets provided to potential clients by biotech companies (many of which were surprisingly in-depth). As I mention above, interviews put me in conversation with embryologists, obstetricians, clinicians, and stem cell scientists, all of whom were patient and generous in explaining to me the scientific terminology, processes, and practices with which they work every day.

In the context of this work, I understand my dissertation as an act of translation. In the pages that follow, I have attempted to provide a scientifically robust, politically grounded, and keenly critical translation of this learning and these conversations. I have tried to steer clear of overly scientific explanations for the technologies and phenomena under consideration, while also avoiding ethical or moral polemic. Assisted reproductive technologies are, to borrow from Franklin (2013), "ambivalent": both potentially liberatory and potentially oppressive; both new and locked in a process of co-evolution with existing and unequal sexual, gender, race, and class formations. I have tried to keep this ambivalence at the fore in the chapters that follow, to attend to the nuances, subtleties, and convolutions that saturate and structure preimplantation genetic testing: technologies that avert future suffering, prioritize some lives over others, make profits, generate cures, and justify loss. I do not set out to oppose the use of PGTs to prevent illness, impairment, and suffering on behalf of future children or their parents. I do not contest the practice of discarding IVF embryos, normal or abnormal. And I am not against the use of these embryos in biomedical research. However, I do think it is imperative that we continue to wrestle with terms like "illness," "impairment," and "suffering," attending to the slippage around these terms associated with the routinization of PGT; that we query the formations – biomedical, legal, and otherwise – that structure embryo selection decisions along the normal/abnormal binary; and that we be concerned with how embryos are procured for research purposes, and from whom.

#### **1.4** A note on reproductive politics

Debates over the moral status of the embryo stalk the insights, observations, and interviews in which this dissertation is grounded. When I started fieldwork for this project in 2016, I was surprised by how often conversations and conference sessions about IVF turned to reproductive politics. I shouldn't have been. My first trip to the U.S. coincided with the final months of
Donald Trump's presidential run, culminating a few weeks after his election; the second time I drove down to California, Trump was three months into his first term as president. In a country already mired in debate over the moral status of the embryo, the Trump Administration stood poised to embolden a well-organized religious right long determined to overthrow the Supreme Court's decision in *Roe v. Wade*, which guarantees a woman's right to choose an abortion. Since the *Roe* decision was handed down in 1973, it has faced over three hundred constitutional challenges, the first coming within a week of the judgement. "Neither the United States nor any State shall deprive any human being, from the moment of conception, of life without due process of law; nor deny any human being, from the moment of conception … equal protection of the laws" read the first of what would come to be known as personhood amendments (HJ.Res.261 1973). In the four decades since, waves of these amendments have ebbed and flowed at state and federal levels. Despite repeated failure, the personhood movement has persisted. Invigorated by a Trump presidency, an influx of personhood amendments has swept the country since 2017.

*In vitro* fertilization has not, historically, been a primary target of these constitutional challenges – especially as compared with abortion, embryo research, and stem cell science, as I discuss further in Chapter 5. The relative ease with which embryos are created and discarded in the ART sector affirms a perspective that privileges their reproductive (rather that productive or regenerative) potential. As Judith Daar (2017) notes, the construction of IVF as a family-formation technology in scientific writing and popular media has shielded it, to a certain degree, from the actions of well-organized, pro-life groups that have targeted activities like stem cell research and abortion. Unlike these latter activities, ART gives the possibility to the struggle *for* parenthood, affirming traditional values around motherhood in particular (Katherine Watson, plenary address, 2018 ASRM). The performance and reproduction of conventional gender roles

and familial models in the ART industry and by users have been important means of domesticating and naturalizing the social and technical novelty of reproductive technologies, integrating them into the social fabric as family formation technologies (Thompson 2005). Thus, while 48 percent of U.S. Americans identify themselves as anti-choice (Gallup 2019), only 12 percent believe that IVF is morally wrong (Pew Research Center 2013).

The political terrain has shifted somewhat, however, in the wake of Trump's election. Heartened by the Trump Administration's critical stance on abortion, those who believe that embryos are the juridical and moral analogue of born human beings have recently begun targeting the discard, indefinite cryopreservation, or donation to science of supernumerary IVF embryos - embryos created but no longer desired for reproductive purposes. A speaker at the 2018 ASRM meeting recounted having weekly protestors outside his fertility clinic, fulminating against immoral embryo disposition practices. Speaking to this shifting political terrain, ASRM President Dr. Richard Paulson said in his 2017 address: "For the first time, we have an administration that is, frankly, hostile [to assisted reproduction]. If the government does decide that life begins at the moment the egg and sperm are fertilized, this could put a damper on in vitro fertilization." For many of the practitioners I interviewed, this was a very real possibility. "It could happen. It's not that farfetched," a fertility clinician told me. "And it would drastically change our practice. We obviously do not want to be cavalier with creating, sorting, discarding these embryos, because there is a lot – again, that's my moral stand. But I'm also completely against the idea of calling it a person from when it's created."

In Louisiana, where extracorporeal embryos have been granted personhood status, viable *in vitro* embryos cannot be intentionally destroyed.<sup>10</sup> Surplus IVF embryos must be thawed for implantation, made available to another married couple for adoptive implantation, or kept frozen (Louisiana Revised Statutes 2017). Italy's Law 40 likewise restricts disposition options, limiting the number of embryos that can be created from each round of IVF and banning their discard, donation to science, or indefinite cryopreservation. As Greer Gaddie (2018) notes, proposals by right-to-life organizations in the United States to legally protect embryos as juridical persons could succeed in persuading state or federal governments to pass similar laws, drastically compromising the effectiveness of IVF and in turn increasing the number of IVF cycles (and thus the costs) required to achieve a live birth. "We're likely to see the Supreme Court ban a lot of the techniques we rely on," said a speaker at the 2018 ASRM, echoing Gaddie's view.

In the years since my time in the U.S., evidence for my interlocutors' concerns has mounted. In 2018, the U.S. Department of Health and Human Services (HHS) updated its fiveyear strategic plan, highlighting as a core component of their mission a commitment to "serving and protecting all Americans at every stage of life, from conception" (Human Health Services 2018). Later that year, Trump nominated Brett Kavanagh to the Supreme Court seat vacated by Anthony Kennedy, tipping the court to a 5-4 conservative majority. (In my fieldnotes from the 2018 ASRM, I wrote, "it's impossible to escape Kavanagh's face. He's everywhere!"). 2019 saw a flurry of states enact restrictive anti-abortion laws, many facing constitutional challenges that may eventually land them a hearing before this same conservative-learning Supreme Court

<sup>&</sup>lt;sup>10</sup> LA-RS 9 §129 states that a "viable *in vitro* fertilized human ovum is a juridical person which shall not be destroyed by any natural or other juridical person or through the actions of any such person."

(hence the ASRM members' interest in Kavanagh). Also in 2019, the Trump Administration restricted research using fetal tissue collected from elective abortions. In their statement on the decision, the HHS said that "promoting the dignity of human life from conception to natural death is one of the very top priorities of President Trump's administration" (quoted in Reardon 2019). Early in 2020, Trump became the first sitting president to speak in person at the anti-abortion March for Life Rally in Washington, DC. Accusing his democratic rivals of infanticide, Trump announced to the crowd of religious-school groups and anti-abortion activists that "unborn children have never had a stronger defender in the White House."

Using abnormal embryos as a foil with which to infer the differential value of human life in this context poses political and methodological challenges. As Alison Kafer (2013) details in Feminist, Queer, Crip, right-to-life organizations have a long and disreputable history of coopting disability rights language in defense of the rights of the unborn. A 2012 Feminists for Life campaign, for example, used posters featuring photos of people with various disabilities with the slogan: "Would you say that to my face?" In smaller text underneath, the poster read: "Would you tell me that I should never have been born? This is the message sent out when people talk about aborting 'gross fetal anomalies'. People who overcome adversity inspire, challenge, and enrich our world. It's time to question abortion" [italics original]. In these fraught conditions, those studying reproductive and disability politics have had to be very clear in their allegiances (Kafer 2013). Given the topic, context, and history of my research, I feel likewise compelled to be direct about my political stance: I unequivocally support the right to safe and legal abortion as one part of a reproductive justice framework that guarantees access to free, universal reproductive health care and an end to disciplinary practices aimed at curbing, prohibiting, and illegalizing the reproductive autonomy of marginalized women.

But I also recognize that this impulse to clarify my position speaks to the ways that the pro-life/pro-choice binary has circumscribed reproductive politics. Within the structure of this binary, critiquing the ableist and oppressive forces that distribute reproductive futurity along the normal/abnormal binary risks being misinterpreted as – or appropriated by – a pro-life stance. In the following chapters, I aim to chart a different path through reproductive politics. At the heart of this dissertation are long-standing and complicated questions about who gets to reproduce whom, and under what conditions; an attentiveness to how these questions percolate through contemporary practices of assisted reproduction; and a concern for how they articulate with reproductive politics in the U.S. more broadly. As I argue most explicitly in the conclusion, the right to reproduce and the right to terminate are two sides of the same coin, and neither is about the embryo or the fetus as a life.

## **1.5** Organization of the dissertation

This dissertation proceeds from here in four substantive chapters, each organized around one facet of the extracorporeal abnormal embryos that are my interest. It offers, in a sense, a life cycle of these vexed biological entities, charting their separation from the whole human body during the early years of modern human embryology (Chapter 2), their detection and diagnosis via preimplantation genetic testing (Chapter 3), the severing of their ties to "biographical biology" (Waldby & Squier 2003) (Chapter 4), and their "uncanny afterlives" (Gidwani & Reddy 2011, 1626) as scientific research objects (Chapter 5).

While often conceived as new, the reproductive techniques and technologies under consideration in this dissertation are in historically dynamic and cumulative relation with much older methods of technoscientific practice, knowledge production, and reproductive discipline. I begin with an examination of some of these methods and practices. In Chapter 2, *A brief history* 

of involution, I delve into the work in and through which human embryos were separated from the spatial constraints of the body and enfolded within regimes of scientific and technological investigation and experimentation. Although widely accepted as the origins of human life today, the "embryological view of life" (Hopwood 2000, 32) is a relatively recent accomplishment, one initiated by the anatomists-turned-embryologists of the late nineteenth century. Chapter 2 traces the "genealogy of technique" (Franklin 2013, 111) in and through which this accomplishment was realized, following the embryo's crossing from its origin in living bodies to life and growth in a petri dish. Buried in the womb, embryos remained shrouded in mystery; once separated from the body, they could be collected, dissected, anatomized, cultured, and immortalized. This process of involution transformed embryos into objects of scientific knowledge and technical production, providing an empirical method for studying embryogenesis, the internal mechanisms of development, cellular organization, and perhaps most importantly to the chapters that follow, the causal dynamics of heredity. As the nineteenth century rolled into the twentieth, this knowledge both impelled social and political interest in sex and its fertility and furnished myriad means through which they might be disciplined. In part two, I examine how involution is implicated in the state's desire to govern and discipline the timing, means, and frequency of conception, and especially its prevention. The appropriation of embryos by science and the access it granted to embryo interiors, I argue, facilitated a specific apparatus of social and political control that put sexual reproduction in a position of biological responsibility with respect to the individual, the race, and the species.

Preimplantation genetic tests and the class of abnormal embryos to which they have given rise are preconditioned by the knowledge and techniques generated through the work processes of late-nineteenth and early-twentieth century embryologists: by the respatialization of

reproduction and the involution it made possible. Chapter 3 examines PGTs as a technological recapitulation and intensification of the fantasies of biological control and discipline inaugurated during the early years of embryology. Their routinization in the fertility clinic, I argue, reveals a persistent genetic determinism that mobilizes the gene as a master molecule on the basis of which life can be anticipated, measured, and (de)valued. Used to scour embryonic cells for evidence of abnormal genetic and chromosomal rearrangements, PGTs cultivate the notion that embryos can be classified as normal or abnormal, viable or non-viable, on the basis of their genes. This affirms an understanding of abnormality as a natural property of the embryo, a quality grounded in the genetic substrate of life itself. Concealed in such an understanding is the constellation of institutions, legal structures, power-differentiated human labours, technical practices, and social norms in and through which human variation and difference are assigned social value.

Chapter 4 brings this constellation to the fore, elucidating the complex set of relations in and through which abnormal embryos as devalued as reproductive entities. Most fertility clinics have formal policies in place prohibiting the transfer of abnormal embryos for reproductive purposes. These transfer policies effectively sever abnormal embryos' ties to what Catherine Waldby and Susan Squier (2003) term "biographical biology" – a developmental narrative in which human life is imagined to unfold ineluctably from the embryological process. Designated as a non-viable remainder to the IVF process, they are cast out of the reproductive stream as a threat to the biosocial future. Working from the subset of abnormal embryos carrying variations that are "potentially compatible with life," I argue that abnormal embryos are not surplus but actively *surplussed*, rendered surfeit to the reproductive project by a tangle of technoscientific, legal, biomedical, and social practices. Against the classification of abnormality as a natural fact,

then, this chapter offers an exploration of abnormal embryos as social and political entities enmeshed in power relations. Debate over the reproductive potential of embryos is inseparable from broader questions about the value of human difference – from a process of hierarchical difference-making in which some bodies are rendered desirable while others are controlled, eliminated, or averted on the basis of their biology. As in many other chapters in the history of control over biological reproduction, idioms of improvement and optimization – of merging nature with progress in service of a particular future – are central to the logic of preimplantation genetic testing. Decisions about which embryos to implant and which to discard both reflect and reproduce deeply held assumptions about the healthy bodies we are supposed (to want) to have and reproduce. The fertility clinic is thus a key site in which value distinctions between normal and abnormal variations are made, maintained, and remade, the extracorporeal embryo a scale at which they materialize. At these sites and scales, scientific, medical, legal, and social concern for difference intermingle, with implications for bodies and biological possibilities.

*In vitro* fertilization produces many more embryos than will be used for reproductive purposes. An estimated 600,000 to one million supernumerary embryos sit frozen in fertility clinics and embryo banks in the U.S. alone. Whereas some of these will be transferred back into the uterus to produce a new human life, others are reconfigured in the lab, diverted toward more biotechnological ends. Reproductive potential has, in this sense, been bifurcated by assisted reproductive technologies, diverted into biomedical domains unconcerned with the reproduction of children (Waldby & Cooper 2008). The fifth and final substantive chapter follows abnormal embryos out of the fertility clinic and into the research lab, where they have scientifically and commercially valuable afterlives as a new species of investigative apparatus: living tools in the study of disability and disease. The abnormal embryo, I argue, is playing an increasingly central

role in reengineering the facts of life, breeding new, increasingly intense and productive efforts to optimize and enhance the body by technoscientific means. This role for the abnormal embryo places it in a profitable position with respect to capitalism. Abnormality, I argue, enables a form of "accumulation by difference-making" (Collard & Dempsey 2018, 1349), generating new economic opportunities and potential by devaluing those who do not (or will not) conform to idealized norms of health and capacity. While specific in its function and its effects, like other axes of social difference the designation of some bodies and lives as abnormal creates an uneven social topography that capitalist interests instrumentalize. Surplussed out of reproductive futurity by the genetic and chromosomal mutations carried in their cells, abnormal embryos are a starting point for new rounds of investment and speculative development in the tissue economy: as disease-in-a-dish models used to study pathological development and as test objects in the development of new pharmaceutical products.

Interrogating the hierarchization of human variation from embryo selection practices puts me on uncomfortable terrain. At a time of proliferating personhood laws and a right-to-life community emboldened by the Trump Administration, it is absolutely essential to resist any reification of embryos as future life. And yet, embryos are scientifically valuable for the same reason that they are objects of intense social and moral scrutiny: because they have the potential to produce human life. In addition to examining the relationship between abnormality and capitalism from the vantage of the abnormal embryo, Chapter 5 grapples with the tensions between the biographical and economic potential of embryos. I examine how this tension is resolved, to a certain extent, by the designation of embryos *as* abnormal, a process that calls into question their very status as the beginning of human life.

By way of conclusion, I bring this reproductive politics to the fore. Drawing on the reproductive justice framework developed by feminist of colour scholars and activists and bringing back into the fold a focus on the various ways that women's reproduction is disciplined in service of the population and the future, I put abnormal embryos to work one final time in order to elucidate how the normal/abnormal binary charted in this dissertation articulates with reproductive politics in the U.S.

## **Chapter 2: A brief history of involution**

As Lynn Morgan (2009) writes in her chronicle of European and American embryo collecting, the construction of human embryos as objects/subjects of social, medical, and scientific interest is a relatively recent accomplishment. As late as the early-twentieth century, few physicians could have conjured the image of an embryo as it is known today. Women did not interpret the contents of their wombs in embryological terms. Most mainstream doctors and scientists described embryonic development as a mixture of spiritual, emotional, and biological processes, citing quickening<sup>11</sup> as evidence of ensoulment. And obstetricians were more likely to encourage pregnant women to think pleasant thoughts than to offer them detailed descriptions of embryonic stages.<sup>12</sup>

Embryos as we understand them today cannot be separated from the intellectual, experimental, social, and political conditions that transformed them into the developmental origins of human life. Nor, in the words of a speaker at the 2017 American Society for Reproductive Medicine (ASRM), can we "envision the world of today without the results of embryo research. ... We wouldn't even know that chromosomes are the means of inheritance." This chapter provides an account of this co-constitution – of, on the one hand, the work through which the embryo was figured, decontextualized, homogenized, and purified as an object of scientific inquiry and, on the other, the effect of this work for late-nineteenth and early-twentieth century understandings of the world, and of biological reproduction and heredity in particular.

<sup>&</sup>lt;sup>11</sup> The moment that a woman first feels fetal movement

<sup>&</sup>lt;sup>12</sup> The theory of "maternal imagination" attributed to the mother the capacity to influence the contents of her womb through her thoughts. As Rosi Braidotti (1999) writes, a special warning was issued against reading, an activity seen as likely to influence and inflame women's imaginations, with unpredictable and potentially catastrophic consequences for the outcome of pregnancy. The theory held sway during the seventeenth and eighteenth centuries and lingered into the early decades of the nineteenth.

Separated materially and discursively from the whole human body, *ex vivo* embryos supplied a physical space within which scientists could study the structures and dynamic relationships that govern the development of the individual, the family line, and the species, placing embryos at the centre of the story of organismic development. This "embryological worldview" (Morgan 2009) in turn constituted the embryo as a key space-time in the governance of the human species and its sociobiological future.

Today, embryos are firmly established as the starting point of human life and thoroughly naturalized as the property of science and medicine; as I discuss further in the chapters that follow, they are readily manipulated for reproductive purposes using assisted reproductive technologies that are widely accepted in the United States. Embryos' status as developmental objects that can be "taken in hand" by clinicians and scientists in the twenty-first century is preconditioned by the histories of embryology and reproductive discipline traced in this chapter: by the respatialization of reproduction from within to outside the body; by the attendant integration of embryos into regimes of scientific knowledge production; and by their ensuing constitution as objects of intense social interest.

In section 2.1, I examine how the embryo, once firmly seated inside the body, becomes available as a "tooled-up experimental vivarium" *ex vivo* (Franklin 2013, 116). The respatialization of reproduction, I argue, is at once a respatialization and territorialization of the embryo itself – part of a process of recasting embryos as technoscientific objects with an interior biological terrain that can be mapped, measured, quantified, represented in atlases, preserved on slides, and kept alive indefinitely in solutions of lymph fluid. The collection and systematic anatomization of human embryos by modern embryologists and the culturing of the embryos of viviparous species by experimental embryologists transformed embryos into objects of scientific

knowledge and technical production. These practices in turn generated new conceptions of bodies and living process, bringing to light their hidden interiority. As embryos made their journey from *in* to *ex* vivo, researchers were granted access to a new biotic landscape, allowing them to observe, experiment with, map, and manipulate the once imperceptible forces of heredity, conception, and development within. I term this inward burrowing of scientific interest *involution*.

Others have examined the role of evolutionary biology (McWhorter 2009; Subramaniam 2014), genetics (Mukherjee 2016; Kevles 1998), and the agricultural sciences (Franklin 2007) in shaping the confluence of social and scientific interest in human reproduction and heredity, with especial focus on the implications of this work for the American eugenics movement. As Clarke (1998) writes, the offices and memberships of U.S. eugenics organizations read like a manifest of American life scientists, whose intellectual and political commitments found purchase in eugenics' rigorous and empirical approach. Less attention has been given, in this context, to the embryo and the scientific field established to study it (Cooke 1998, 2002 are exceptions). I address this gap in section 2.2. Here, I consider the relatively under-examined role of embryo science in shaping eugenic debates, trajectories, policies, and projects, asking how involution trucks with attempts to govern biological reproduction. The knowledge generated through embryo research, I argue, had direct bearing on debate over how best to manage procreative capacity and heredity in the public sphere- debate that was ongoing at the height of the eugenics movement. Involution, I argue, is thus embroiled in centuries of reproductive and hereditary management by a variety of actors, perhaps most notably the state – what Adele Clarke (1998) calls "the disciplining of reproduction."

Given the geographical setting for the chapters that follow, I orient myself in particular to the convergence of political and scientific concern for heredity and degeneration in the American eugenics projects of the early- to mid-twentieth century. While I acknowledge the global dimensions of the eugenics movement and the ties – economic and otherwise – between countries like the U.S. and Germany,<sup>13</sup> I focus on the U.S. in order to more clearly delineate continuities and ruptures between this history and the presents and futures I trace in the rest of this dissertation. This also contributes to efforts to "extract eugenics from the shadow of Nazism" (Stern 2015, 2). While familiarity with German racial hygiene is without a doubt essential to grasping the geographical and philosophical conditions within which the eugenics movement flourished, it also important to carefully analyze specific expressions of eugenic practice, policy, and law in particular places – to decentre the vantage from which the story of eugenics is so often told.

I rely on the work of historians of science and technology in order to excavate the history of the dual spatial phenomena that are my interest in this chapter; their archival research provides much of the empirical detail. Wherever possible, I have also used original archival materials, including articles and book-length publications by notable scientists and eugenicists, often onein-the-same, many of which are available online.

# 2.1 Reproduction, respatialized

While technological evolution is never purely technical, there is, as Sarah Franklin (2013, 111) writes, a "genealogy of technique" that can be followed in the form of a legacy of skill and

<sup>&</sup>lt;sup>13</sup> As Stern (2015) and others have noted, German race biology was funded by charitable organizations established by well-known Americans such as Charles Davenport; many American scientists corresponded regularly with their German counterparts; and U.S. eugenic laws and policies became a blueprint for those in Nazi Germany, France, Belgium, Sweden, and England.

knowledge. In this section, I examine the genealogy of technique through which the human embryo was territorialized – observed, mapped, measured, represented – as a site and scale of scientific analysis. At its heart, this is a spatial story – a story of the human embryo's crossing from its origin in living bodies to life and growth in vitro. It is an account that traverses geographical, biological, species, and disciplinary boundaries. It is also an account that spans centuries, the detailed tracing of which could fill an entire volume. I have chosen to delimit the history retold here to the period of about 1880-1950, a chapter of intense embryological investigation and rapid scientific progress (see Appendix A). While more recent innovations in the respatialization of mammalian, and specifically human, oocytes and embryos from within to outside the body may seem the closest relatives of contemporary assisted reproductive technologies, they are not so much my interest here, and I touch on them only briefly at the end of this section. Rather, I am interested in the techniques and technologies that came before – those that normalized and naturalized the *ex vivo* embryo as a valuable and manipulable scientific research object. The 1880s mark the beginning of efforts to both systematically collect and dissect human embryos as biological specimens (see Morgan 2009) and to cultivate life itself outside the body (see Landecker 2007). These dual scientific endeavours, I suggest, make up the early work of respatialization and involution. In and through the systematic collection, dissection, and culturing practices of early embryologists, human embryo interiors emerged as a key scale of observation, experimentation, and intervention - as useful sites in the study and manipulation of biological life. Contemporary reproductive technologies, include preimplantation genetic tests, are founded on this work.

The history of *in vitro* reproduction is meandering and circular, and human clinical IVF has a "very mixed, or hybrid, technical parentage" (Franklin 2013, 132). Into the early decades

of the twentieth century, the study of embryos was materially, methodologically, and epistemologically tied to zoology, genetics, cytology, evolutionary biology, and agriculture, as well as to a broader natural history born in the mid-seventeenth century that set out to identify, analyze, classify, map, and transcribe living beings according to their visible characters (Foucault 1989). The processes of respatialization and involution that are my interest exist in complex interdependency with a staggering array of experimental and epistemological trajectories – developmental biology, endocrinology, and genetics, to name just a few – that I do not address in detail here. In the late-eighteenth and early-nineteenth centuries, boundaries between these specialities were almost invisible (Clarke 1998), and scientists and researchers moved regularly between fields during their professional lifetimes (as they do to a lesser extent today). These connections make it difficult to trace a distinct genealogy of embryo research. As such, I use disciplinary categories and labels ambivalently – as a matter of emphasis, not as a strict partitioning – knowing that they represent tangled fields of scientific knowledge and practice.

I have also selected the historical material that best allow me to tell the story of respatialization and involution. I read widely in preparing to write this chapter; in the version that follows I have cut away dozens of noteworthy embryo scientists and their experiments. My aim in this chapter is not to provide a comprehensive overview of embryology, but rather to situate the embryo as a key source of scientific and technical knowledge and a key site of social and political interest. While many of the figures who appear in the pages that follow, including those like Theodor Boveri and August Wesimann, are not only – or best – known as embryologists, their work with embryological specimens was integral both to the establishment of the embryo as a scientific object and to the production of knowledge about reproduction and heredity.

## 2.1.1 Modern human embryology

Much was already known about the origins of life by the close of the nineteenth century. Each individual life was understood to begin with an egg provided by a female and sperm provided by a male. These cells joined together during fertilization to initiate cell division. Cell division resulted in an embryo. And the embryo developed over time into a living being.<sup>14</sup> Very little was known, however, about this genesis story's central figure – the embryo – or the forces that compelled its development. Buried in women's whole, fleshy wombs, embryos remained shrouded in mystery, unattainable objects imagined to contain within them all the secrets of biological life. As German zoologist and Darwinian Ernst Haeckel wrote in 1874, "Human embryos hold within them a greater treasure of the most important truths and form a deeper source of knowledge than most sciences and so-called 'revelations' put together" (quoted in Hopwood 2000, 35). It was to uncovering these secrets that a host of life scientists turned in the waning decades of the nineteenth century.<sup>15</sup> If scientific truths could be read from the whole human body, these scientists reasoned, what worlds of knowledge might the human embryo reveal?

Populated for the most part by patrician university researchers and physicians trained in gross anatomy and dissection, the discipline was founded on careful empirical observation and analysis, work that required access to biological specimens (Morgan 2009). This presented a

<sup>&</sup>lt;sup>14</sup>This knowledge was generated over more than two centuries by physicians and scientists experimenting with eggs and sperm from a variety of animals: first those of oviparious species like frogs and starfish in the eighteenth and early nineteenth centuries, and then those of vivaparious species like rabbits and dogs in the mid- late-nineteenth century (Clarke 2006). Much of this learning stemmed from the discovery of human sperm by Antonj van Leewenhoek in 1679.

<sup>&</sup>lt;sup>15</sup> Nick Hopwood (2000) traces the first signs of the embryological view of life to the work of German anatomist Samuel Thomas von Sömmering in the late 1700s. But, he points out, Sömmering's ideas were slow to catch on, and the modern embryological view of life did not take hold until nearly a century later with the work of Swiss anatomist Wilhelm His.

dilemma for the anatomist-turned-embryologist. While the corpses of executed criminals and others excluded from the social contract had been relatively accessible since the sixteenth century (Foucault 1994; Waldby 2000), human embryos were almost impossible to lay hands on. How could anatomists proceed with their dissections in the absence of biological specimens? Collect them, of course! The scarcity of research embryos spurred an enormous collection project resulting in the amassing of thousands of human embryos in the U.S. and Europe between the 1890s and 1960s.<sup>16</sup> These anatomical collections – preserved in glass slides and housed in universities, hospitals, research institutes, and private physicians' offices – would provide the empirical basis on which to answer pressing questions about human health, race, evolution, and the development of the human species, in addition to providing data for medical experimentation and research. They would also affirm the extracorporeal human embryo as a knowable, measurable scientific object that could be wrested from the human body and taken in hand.

Collectors primarily gathered their specimens from early abortions and miscarriages, and less often during post-mortems of pregnant women.<sup>17</sup> Because most collectors lacked access to the women whose bodies concealed the embryos they sought, they had to depend on their clinical colleagues. Initially, this required that they teach doctors how to look for the chorionic sac – just a few millimeters in diameter in the first month of pregnancy – in the blood clots and tissues that

<sup>&</sup>lt;sup>16</sup> Embryo collection projects were not limited to the U.S. and Europe, especially by the mid-twentieth century. In her chapter the Kyoto Collection, established in 1961 at the Kyoto University in Japan, Maria Fannin (2018) examines how embryo collections are embedded in and reflective of specific social, spatial, and historical contexts. I focus predominantly on U.S. collections and collection practices in this chapter because the U.S. provides the geographical setting for the chapters that follow.
<sup>17</sup> Human embryologists also collected and studied animal embryos as a means of filling holes in their data. They

<sup>&</sup>lt;sup>17</sup> Human embryologists also collected and studied animal embryos as a means of filling holes in their data. They scoured the woodlands and seashores for amphibian eggs and pregnant females; set up breeding colonies for rats, mice, and guinea pigs; opportunistically collected the embryos of northern hemisphere farm animals; and travelled long distances to kill monkeys and look for pregnant uteruses in their remains (Morgan 2009).

passed from women's wombs. Whenever a woman came in with vaginal bleeding, whenever a uterus was scraped, removed through surgery, or examined during autopsy, surgeons and pathologists were alert to signs of this chorionic sac and the coveted fresh embryo inside (Morgan 2009).

Wilhelm His, often recognized as the founder of modern human embryology (Hopwood 2000), developed a unique strategy to encourage physicians and gynaecologists to give him the embryos they found. Referring to them as "treasures" and "precious objects" (quoted in Hopwood 2000, 38-39), he suggested to his clinical colleagues it would be wasteful to discard human embryos, and that they had a medical and scientific duty to donate the materials to him. We will encounter His's discarded-embryos-as-waste argument again in Chapter 5, where it operates productively at the nexus of fertility treatment, laboratory practice, and biotech research and development as a means of securing surplussed IVF embryos for biomedical and technoscientific projects. In the late nineteenth century, His's work convinced a generation of researchers that the tissues resulting from abortion, pregnancy loss, and autopsy rightly belonged to the fields of science and medicine. His persuasive tactics yielded him an impressive collection of seventy-nine specimens – the largest known at the time (Morgan 2009). As I discuss in more detail below, over the next four decades, His and his colleagues would begin to systematically destroy these and other embryonic specimens amassed in public and private collections, slicing them apart to learn more about early human development and in so doing ushering in the modern embryological era.

Collection efforts intensified throughout Western Europe and the United States over the following decades, driven in large part by a desire for generic information about humans as a species – information that required hundreds or even thousands of high-quality, well-preserved

specimens. By the 1920s, embryo collection was a common practice, due in no small part to the efforts of Wilhelm His and his collaborators and students. Trained to identify specimens and convinced to donate them to their colleagues in research, clinical medical staff adopted the habit of saving virtually all embryos and fetal remains that came into their possession. An embryo pipeline was established, consisting of physicians linked to embryo collectors through personal relationships, professional courtesies, and ties of reciprocity (Morgan 2009). The separation of human embryos from women's bodies and their transfer from the physician's office to the research lab was thoroughly normalized during this period, and, as we will see in Chapter 5, continues to generate significant scientific and commercial value in today's tissue economy. By the 1940s, many universities, hospitals, and even individual physicians had their own embryo collections – preserved, sectioned, and mounted on glass, as I discuss further below – to use for reference, teaching, and research. In and through the embryo collection projects of the early 1900s, modern embryology was firmly established as an independent anatomical speciality dedicated to the study of early human development (Maienschein 2003; Morgan 2009).

Access to specimens secured, His and his contemporaries could now put their anatomical training to work, plunging their scalpels not into whole human bodies but into their microscopic antecedents. Much like human dissections, the process of preparing and processing the specimens was painstaking and involved significant training and skill. Embryologists' labour required excellent eyesight, dexterity, practice, patience, and tenacity (Franklin 2013). First, the embryological specimen was fixed in a precise chemical solution. Next, it was opened up, its opaque outer coat was removed and its translucent inner membrane dissected away. This allowed the embryologist to ascertain the embryo's stage of development and its degree of normality, and to take certain biometric measurements (length, for example). Given the complex and often

unexpected paths by which variations in morphological form developed, only meticulous investigation at this stage could rule out the possibility that an embryo was pathological. This was a very important step. As in the anatomical sciences more broadly (see Waldby 1996, 2000), early modern embryologists were dogged by the problem of representativeness. The purpose of study and anatomization was to prepare a typical, standardized class of embryonic objects which could claim a general representativeness, with the goal of illustrating a normative model of development upon which scientists could learn to judge both individual normality and the normality of entire species. Embryologists took extreme care in the selection and standardization of typical specimens that existed within the range of normal variation (Hopwood 2000, 2007) – single specimens that could stand in for a whole class of objects.

As Waldby (1996) argues in the context of anatomy, and as I discuss further in Chapter 4, this process of standardization and representation was not and is not neutral – natural variation cannot be condensed into a single image, or series of images. Rather, "condensation always involves judgements about what counts as normal, judgements which precede the process of condensation itself" (*Ibid*, 34). Early embryologists were profoundly implicated in this process of condensation, in part through practices of discarding any embryo found to be abnormal. According to Hopwood (2000), His summarily rejected more than 22% of his embryological specimens based on perceived abnormalities. Debate raged among embryologists over how best to measure specimen normality, over which embryos should be included and which should be discarded on the basis of their morphological features. These practices and debates began a centuries-long project of normalizing embryonic objects and developmental pathways, depicting distinctions between the normal embryo and pathological variations.

Embryos found to be normal were embedded in paraffin blocks to render them solid, preserving them indefinitely for scientific study. Using a microtome – a cutting apparatus developed by His, "similar to a delicatessen meat slicer" (Morgan 2009, 43) – each fixed embryo was cut into very thin sections, stained,<sup>18</sup> and arranged on slides. In combination with large-scale modelling techniques, the systematic dissection and preservation of embryos allowed scientists to observe even their smallest morphological details. For the first time, embryologists had gained ingress into the biological interior of the human embryo.

In the first decades of the twentieth century, research using these specimens focused almost exclusively on defining and describing the early stages of embryo development, known as embryogenesis. Converted into thin slices and preserved on slides, specimens were sequentially ordered to produce "developmental series": visual representations of standard embryos organized into successive stages to convey a normal pathway of development. Each slide represented a temporal point in the embryogenic process; each gained meaning in relation to the slides that preceded and followed it. Developmental series became human embryologists' stock in trade, a means of ordering and illustrating human development as a set of predictable, normalized phases beginning with conception and passing progressively through a sequential series of pre-partum stages. As I discuss further in Chapter 4, abnormal embryos are seen to diverge from this set developmental pathway – mutations, deviations, and anomalies understood as evidence of development gone awry. For His and his colleagues, these series allowed them to track normal human development back and forth through time, across a set of discrete specimens, beginning from the very moment of conception.

<sup>&</sup>lt;sup>18</sup> Selective staining practices allowed embryologists to observe different cell types.

Although a routine part of the pregnancy experience in the Western world today – we need think no further than the developmental series reprinted ad nauseam in pregnancy books for expectant parents – the embryological origin story has a relatively recent history. As historian of science Nick Hopwood (2000) argues in his analysis of Wilhelm His's work, embryological development was less studied than produced by embryologists. The selection, preparation, and ordering of standard embryos – and the exclusion of those deemed abnormal and those that "could not be made to fit" (*Ibid* 48) – formed the material, biological basis for illustrations and understandings of normal human development, rendering religious and spiritual interpretations outmoded. This labour, Hopwood writes, "can account for the triumph of the embryological view of life and show how our own embryo-laden world was made" (*Ibid*, 32).<sup>19</sup>

Developmental series and the collection projects on which they relied produced human embryos as valuable technoscientific objects. Separated materially and discursively from women's bodies and translated into data points in the embryological origin story, human embryos were enfolded in the rational, highly controlled, authoritative regime of science. Stripped of their social and corporeal context and the messy, fleshy conditions of re-production – Wilhelm His, for example, diligently named the embryos he collected not for the women who donated them but for the physicians who claimed them as research specimens – they became what Haraway calls "things-in-themselves" (1997, 141). Embryo collection efforts and the knowledge production they catalyzed thus mark an important moment in the processes of respatialization and involution under consideration in this chapter. The anatomists-turned-

<sup>&</sup>lt;sup>19</sup> His's work would form the foundation for the Carnegie Stages of Development, a standardized system of 23 stages developed over the 1920s, '30s, and '40s, and finally published in 1987, using embryos from the Carnegie Institute. The Carnegie stages provide a unified developmental chronology of the vertebrate embryo, still in use today.

embryologists of the late-nineteenth century were the first to wrest human embryos from the whole human body, open them up, and take them "in hand," affirming them as a knowable, manipulable, and valuable biological resource that could be harvested at little or no cost from the otherwise wasted by-products of failed pregnancies.

Despite significant progress in describing and ordering human life during the late nineteenth and early twentieth centuries, the study of human embryos faced major constraints. Maybe most crucially, the techniques required to peer inside human embryos utterly destroyed them. For each developmental stage, a new individual organism was fixed, preserved, stained, and sliced, a process that ultimately "killed" the embryo. Embryologists were thus limited, as I discuss above, to working with and illustrating embryogenesis as a spatial and temporal composite of a sequence of moments embodied in a series of distinct embryos. Their understanding of human development was based on description and classification of inert biological materials – on a series of snapshots that, when sequentially ordered, composed a linear view of normal embryo development. From their inception, then, developmental series both embodied and produced embryogenesis as a predetermined pathway of development, marked by discrete stages, in which each phase, each slide, each slice gave rise to the next.

## 2.1.2 Experimental embryology

In the first decades of the twentieth century, another branch of embryology was emerging to study the space and time between these snapshots, slices, and slides. This was the field of experimental embryology. Fascinated with developmental mechanics, with problems of physiology and function, experimental embryologists wanted to watch life unfold in real time. Like that of human embryologists, this work required a large number of specimens. Unlike His and his associates, however, experimental embryologists needed their specimens alive. In the late

1880s, they began collecting the living embryos of worms, frogs, salamanders, and sea urchins, among those of other egg-layers. These oviparous critters made ideal subjects for embryological research. They were widely available and freely collected from local ponds and seashores. They reproduced often throughout the year. They were easy to maintain and breed in the laboratory. And, perhaps most importantly, they had large embryos that developed outside the female's body in simple liquid solutions of pond or sea water. In a "mad rush to experimentation" (Maienschein 1985, 33), these living embryos were dissected, disassembled, reassembled, ablated, bifurcated, explanted, implanted, transplanted, shaken, lanced, electrocuted, and poisoned. Such experimental methods allowed embryologists to access the embryos' internal mechanisms of development and to test various hypotheses regarding the effects of interference on cellular organization, regeneration, growth and morphology.

Although my interest is in human embryos, scientific work with other species, including the oviparious creatures so valuable to experimental embryologists, bears examination. As Sarah Franklin (2007, 2013) has shown, the movement of techniques across species is a primary means of technological development in reproductive medicine and the life sciences more broadly. We can observe in the history of reproductive technologies a pattern of technology and knowledge transfer that circulates through diverse animal models before being translated into human application. Although experimental embryologists only began using mammalian embryos in the 1930s, and human embryos decades after that, the techniques and knowledges generated during the early years of experimental embryology have been vital both to the scientific territorialization of human embryo interiors and to the disciplining of human reproduction. Of particular importance to this chapter, this interventionist branch of embryology provided an empirical

method for studying the causal dynamics of heredity (Maienschein 2003; Franklin 2013; Mukherjee 2016).

By the 1880s, scientists had established that fertilization occurs when an egg and sperm cell fuse, suggesting that embryos inherit biological material – variously labelled "germs," "gemmules," "physiological units," or "granules," among other names – from both parents. As yet unknown, however, was how this fusion of materials influenced embryo development and morphology, or whether it did so at all. How or why does "like beget like"? How does an organism emerge from an embryo? Was development the result of interactions between cells and their environments? Or was it guided by the unfolding of unchangeable heredity material? These questions were a matter of significant debate at the time (as they are today, if in slightly different form). In the 1890s, German scientist Theodor Boveri set out to answer them once and for all. Building on work by Gregor Mendel and August Weismann, detailed below, Boveri's experiments work would ultimately affirm the chromosome as a unit of heredity, as the locus of what, in 1909, Wilhelm Johanssen would christen "the gene." As I discuss in section 2.2.1, the results of Boveri's experiments influenced debates over how best to manage the nation's biological stock during the eugenic period.

Boveri worked with the embryos of *Ascaris megalocephala*, a small, parasitic roundworm. *Ascaris* embryos made excellent specimens for his experiments. Their large, clear cells have only two pairs of chromosomes each (for a total of four), making it easy for Boveri to trace their movements with great precision. Moreover, *Ascaris* embryos develop two distinct cellular types during the first few cleavage divisions:<sup>20</sup> those that will become sperm and eggs,

<sup>&</sup>lt;sup>20</sup> The cell divisions immediately following fertilization.

called germ cells, and those that form all other bodily tissue, called somatic cells. Boveri noted that during cellular division, somatic cells retained the full complement of chromosomes. Germ cells, on the other hand, divided in such a way that the "daughter cells" retained only one half of each pair of chromosomes. The full set was restored during fertilization, when egg and sperm cells fused, and so on across each subsequent generation.

Boveri's experiments built on the theoretical ruminations of German embryologist, cytologist, and evolutionary biologist August Weismann. Weismann was a reluctant theorist, having abandoned the empirical study of microscopic phenomena, including the development of germ cells in jellyfish embryos, following the deterioration of his eyesight (Zou 2014). He remained inspired by his embryological work, however, and it formed the basis for what would come to be known as the Weismann germplasm theory. Weismann postulated that organisms are made up of two entirely distinct types of cells: germ cells and somatic cells. Counter to Darwin's hypothesis that all cells in the body produce heritable "gemmules," Weismann proposed that parents transmit to their offspring only the germplasm present in germ cells and not the somatoplasm present in somatic cells. The germplasm was the unique locus of what Weismann called "ids" – units of hereditary information. Ids were, in turn, carried on "idants" – theoretical units that corresponded to chromosomes. Weisman predicted the halving and recombination of idants that Boveri would observe in the chromosomes of *Ascaris* embryos almost a decade later.

Weismann's germplasm theory refuted Jean-Baptiste Lamarck's theory of evolution,<sup>21</sup> which argued that characteristics acquired during the lifetime of an organism – changes to its

<sup>&</sup>lt;sup>21</sup> Epigenetics, the theory that traumatic experiences and stress can be expressed in our genes, and thus become heritable, is sometimes described neo-Lamarckian. I discuss epigenetics further in Chapter 3.

somatic cells – could be transmitted to an organism's offspring: the oft-cited, if oversimplified, example being that giraffes acquired long necks by straining for leaves on high branches. A version of Lamarckism could be found in embryological study as well. Epigenesists, as they were sometimes known, believed that the environment, both within and outside the cell, played a significant role in shaping physical (and in humans, mental and moral) characteristics. Famed American embryologist Edwin G. Conklin was among those who believed that the manipulation of environmental factors at the early stages of embryonic development could lead to permanent changes in the adult (eg. Conklin 1913, 1915). He hypothesized that changes to the somatoplasm, which could be influenced by external factors, could affect the health of the adult in ways that were transmissible across generations. Conklin theorized that the movement of somatoplasm about the cell during early embryo development – visible in the embryos of his experimental species of choice, the *Styela partita*, or sea squirt – was a powerful factor in cell differentiation. Changes to the somatoplasm, he reasoned, would produce changes in cell differentiation, and in turn variations in morphological form.

In contradiction to these studies, Weismann argued that only changes to the germplasm would be inherited: no matter how diligently a giraffe's ancestor stretched its neck, the biological information – the ids – coding for long necks would not enter into its hereditary material. He tested his hypothesis by removing the tails from five generations of mice. In each generation of tailed mice, Weismann found evidence to support the germplasm theory. Evolution, he reasoned, occurred not as a result of environmental factors or changes to the somatoplasm, but through spontaneous alterations to the germplasm – basically, through mutation. In the absence of mutation, hereditary material was passed on, without change, down the genealogical line. As I discuss further below, Weismann's theoretical and experimental findings would profoundly

influence the development of eugenic policy and practice in the U.S. as evidence for "strict hereditarianism."

Boveri was the first to observe Weismann's germplasm theory in action. Unlike Weismann, however, Boveri had the prodigious advantage of working with living embryos. This allowed him to add a key piece to the inheritance puzzle: he was able to identify, or at least posit, chromosomes as the carriers of hereditary information. Recall that the *Ascaris* embryos preferred by Boveri had two sets of large chromosomes, easily visible inside their translucent cellular vessels. Boveri was able to watch as the chromosomes inside sperm and egg cells combined during fertilization, halved during germ cell development, and combined again to create the next generation in a process that neatly recapitulated the pattern of germplasm transmission proposed by Weismann. In 1902, Walter Sutton corroborated the halving of chromosome pairs in germ cells while experimenting with grasshopper embryos.

Boveri and Sutton's confirmation of chromosomal inheritance coincided propitiously with the rediscovery of the work of Austrian monk Gregor Mendel. Siddhartha Mukherjee (2016) thoroughly details Mendel's work in his book *The gene: An intimate history*. Working with pea plants in a monastery in Brno, Mukherjee recounts, Mendel observed and documented the transmission of visible variants – such as flower colour, seed texture, and height – across generations. Like Boveri and Sutton, Mendel was interested in heredity, a concept he set out to investigate through the cultivation of pea plant hybrids. Over the next four years, Mendel dedicated himself to cross-fertilizing white flowering plants with purple flowering ones, plants with smooth peas with those with wrinkled ones, tall plants with short ones. By 1857, he was crossing hybrids with hybrids, meticulously recording the results. In the second generation of plants, he noted, the variants did not blend as he had expected. Rather, plants always resembled

one of the parental forms: tall plants crossed with shorts ones produced only tall plants, the cross-fertilization of purple- and white-flowering plants produced only plants with purple flowers. All visible variants followed this pattern, with one variant proving dominant and the other recessive. Heredity, Mendel's plant experiments showed, could only be explained by the passage of discrete units of information from parents to offspring. The female brought one copy, the male another. The dominant copy asserted itself, while the other seemed to disappear. But where had the recessive trait gone? Mendel extended his understanding with a second set of experiments, cross-fertilizing hybrids with one another. This third generation of plants revealed surprising results. In some crosses, traits that had disappeared in the second generation reappeared in the third. Purple hybrids produced white flowering plants and tall hybrids short ones, suggesting that recessive traits did not disappear, but remained, intact and discrete, within the organism. A hybrid was, in fact, a composite of both traits with a visible, dominant variant and an invisible, latent one. Despite the remarkable nature of Mendel's discoveries, he and his pea plants virtually disappeared from the scientific literature for nearly five decades.

This brief excursion into the nineteenth century garden of an Austrian monk is not without purpose. The rediscovery of Mendellian inheritance by Boveri and Sutton (among others) in the early 1900s transformed scientific understandings of inheritance. Intuitively, many evolutionary biologists guessed that the best place to look for hereditary units was inside the embryo. Boveri and Sutton put Mendel's meticulous records and Weismann's germplasm theory to work interpreting what they observed in their oviparous specimens. Chromosomes, they hypothesized, were the physical material of germplasm, containing within them, or on them, Mendel's discrete units of hereditary information. In today's terms, Boveri and Sutton had

placed genes on chromosomes inside the cells that make up embryos, and in so doing affirmed the role of sexual reproduction in the transmission of traits.

In 1910, Thomas Hunt Morgan confirmed the link between genes and chromosomes in his now-famous Fly Lab, adding another important piece to the puzzle in the process. Like Mendel, Morgan began by identifying heritable traits, this time in fruit flies, that he could track across generations. Unlike those in pea plants, however, Morgan's fruit fly traits did not behave independently. A sable coloured fly, for example, almost always had short wings. And whiteeyed flies were disproportionately male.<sup>22</sup> For Morgan, this linkage could only mean one thing: traits had to be physically linked to each other like beads on a string, or, in this case, genes strung along a chromosome (Mukherjee 2016). The extrapolation to humans from plants, worms, grasshoppers, and fruit flies of this link between genes, reproduction, and morphological variation would prove vital to the American eugenics movement of the early- to mid-twentieth century, as I discuss in more detail in the next section.

Before turning to this discussion, a second major innovation in the study of embryo interiors bears consideration. If modern human embryology was primarily about disembodiment, about removing embryos from the womb so that they could be dissected and observed, experimentalists were much more concerned with continuity – with the ability to establish life itself *ex vivo* (Landecker 2007). Theirs was a project that sought to exceed observation and description. They wanted to delve into the living substance of life itself and reshape it to particular ends. In 1907, American experimental embryologist Ross Granville Harrison made a discovery that would mark the beginning of a period of rapid innovation in this vein: he

<sup>&</sup>lt;sup>22</sup> For a clear and detailed overview of Morgan's Fly Lab studies, see Miko 2008.

persuaded embryonic frog cells to live and regenerate outside the body in a solution of adult frog lymph: the fluid that flows through the lymphatic system. Harrison had devised the first tissue culture.

Tissue culture techniques are essential to contemporary assisted reproduction and to the preimplantation genetic testing technologies that are the subject of the next chapter. In the 1900s, Harrison's experiments had the profound effect of proving that internal biological events could be observed and manipulated ex vivo, in ways that defied taken-for-granted spatial and temporal limits (Maienschein 2003; Landecker 2007). To be sure, Harrison's experiments were not the first to show that parts of the body could survive for periods of time after the death of the whole, nor were they the first to experiment with living embryos (Boveri and others were doing so decades earlier). The difference was that the embryonic nerve cells under his care did more than survive temporarily. The fragments continued to develop as they would have done had they remained part of the embryo. Undifferentiated tissues cut from a specific region of the embryo changed shape to become nerve cells with characteristic branched filaments – not inside a body but in an artificial, controlled solution of clotted lymph created by Harrison. Innovations in tissue culture technique radically altered assumptions about the interiority and hiddenness of certain bodily processes. As Hannah Landecker (2007, 32) writes, the live nerve cell growing in a seethrough chamber in Harrison's lab was "an entirely new form of life – life *in vitro*." This life could be examined, manipulated, and experimented with in new and imaginative ways.

Experimental embryologists progressed in the years that followed to culture the cells of higher order oviparous vertebrates. Building on Harrison's experiments, in 1912 Alexis Carrel coaxed the embryonic heart cells of a chicken to reproduce in a petri dish surrounded by a culture medium of chicken blood plasma and water. By manipulating this growth medium,

Carrel and his associates were able to keep the heart cells alive and dividing for decades. Their cellular specimens garnered the moniker "the immortal chicken heart." In 1951, George and Margaret Gey would use frog and chicken embryo culture techniques to successfully cultivate the first "immortal" human cell line, produced from cancerous cells scraped from the cervix of Henrietta Lacks.<sup>23</sup>

Perhaps more than any other biotechnological innovation of its era, developments in tissue culture transformed mammalian – and human – embryological research. During the latenineteenth and early-twentieth centuries, experimental embryologists were limited to the use of oviparous species, those whose embryos live and grow outside of the body in easily replicable salt and pond water solutions. Mammals, the vast majority of which are viviparous, posed a much more difficult challenge. Fertilization and early embryo development relied on a complex interplay between the gametes and the fallopian environment – one that had proved impossible to simulate into the early decades of the 1900s. With the advent of tissue culture, scientists had a means of substituting an *in vitro* growth environment for the *in vivo* one. The culture acted as a transparent body – indeed, it was often made up of bodily biological tissues like blood plasma or lymph – within which life itself could be observed as it divided and grew. The years following Harrison and Carrel's work saw an explosion in experimentation with mammalian embryos.

<sup>&</sup>lt;sup>23</sup> In 1951, an African American woman named Henrietta Lacks was admitted to Johns Hopkins University Hospital in Baltimore, seeking treatment for intermenstrual bleeding. She was diagnosed with cervical cancer. As part of her diagnosis, her physician took a biopsy of her cervical cells, without her knowledge or consent. This sample was transferred to the lab of tissue culture expert George Gey. Gey had been enlisted in efforts to propagate cervical cells outside the body such that they might be more closely studied. To his surprise, Gey found that Lacks's cells, when placed in an appropriate medium, did what no other normal cells could: they continued to grow and divide, unperturbed, in their artificial environment. Lacks's cells became the first immortal human cell line. The HeLa line, as it came to be known, became ubiquitous in labs in countries around the world, and has, since its creation, been subject to over 11,000 separate patent claims (Parry 2012). For a detailed account of Henriette Lacks and the HeLa cell line, see Landecker 2000; Skloot 2010; Parry 2012.

Fertilized eggs and early embryos were routinely excised from the fallopian tubes and uteruses of experimental animals and placed in diverse culture media. By the 1930s, embryologists were culturing the embryos of mice, rats, rabbits, hamsters, and guinea pigs, exploring their interior biological terrain, many of them looking for evidence of the hereditary mechanisms and pathways identified by early experimentalists. It would be nearly thirty years until scientists would successfully replicate and observe the entire process of mammalian fertilization *in vitro* in 1959, another ten until Barry Bavister would successfully fertilize a human egg in a cell culture developed for hamsters,<sup>24</sup> and nine more before the technique was successfully translated into clinical practice by Edwards and Steptoe in 1978.

By this time, on the basis of accumulated experimental and technological knowledge and practice, the live, *ex vivo* mammalian embryo had made its journey from within to outside the body. Over the course of this journey, the embryo's place at the centre of developmental and reproductive biology was secured. Embryos were affirmed as the purview of the medical and biological sciences, their interiors naturalized and normalized as sites of observation and experimentation.

The naturalization and normalization of embryos as objects of scientific inquiry was coconstitutive with the disciplining of embryology as an independent scholarly field (Clarke 1998). Embryologists' attempts to access embryo interiors catalyzed the development of new experimental approaches, techniques, and technologies, like the microtome, which in turn secured the embryo as an experimental object. Practical methods for acquiring, cataloguing,

<sup>&</sup>lt;sup>24</sup> This required the development of a set of techniques and technologies that allowed scientists to harvest human eggs without killing the host.

studying, and manipulating embryos were routinized. And scientific journals were established as the primary means of disseminating research results and engaging in key debates in embryo research (Maienschein 1991; Morgan 2009). Core life sciences projects of the twenty-first century owe much to the accomplishments of these early life scientists. Chapter 5 will provide an account of some of these contemporary projects, one that will immerse us in present embryo research and in the legal and political morass that continues to surround the moral status of the *ex vivo* human embryo. In the first decades of the twentieth century, access to embryo interiors generated extraordinary insights into the functioning of human conception, heredity, and development, and yielded new and powerful techniques for intervening in and administering life (Clarke 1998). It is to the social and political application of these knowledges and techniques that I now turn.

## 2.2 Reproduction, disciplined

Efforts to take embryos in hand were emblematic of a broader shift in early-twentieth century biology away from observation and description and toward the manipulation and control of biological life (Clarke 1998; Franklin 2013). Longstanding concerns with evolution and taxonomy acquired an interventionist bent as anxiety around bad heredity and degeneration grew. So too, in the early decades of the twentieth century, was social and political interest in the utility of science and technology in the management of society swelling (Allen 2001; Stern 2015). Since the late 1800s, processes of industrialization, urbanization, immigration, and imperialism had been transforming national, cultural, and economic landscapes in the United States (as elsewhere). It was a period of terrific technological and scientific innovation and advancement, accompanied by a proliferation of perceived social ills. As alarm grew over

sprawling urban tenements, disease, class conflict, racial strife, immigration, and race suicide<sup>25</sup> in the early 1900s, social, political, and economic elites turned to the explanatory power of science to make sense of, and re-make, a world in flux (Stern 2015). These were the social and political conditions in which the U.S. American eugenics movement flourished. Alongside hygiene projects aimed at maximizing the health and productive powers of populations in the present, efforts to improve the national stock by eliminating risks to its wellbeing in the future proliferated, most notably through the targeting and regulation of reproductive bodies and sexual reproduction. As I explore further in Chapter 3, interest in the reproductive future and its management persists today, alive and well in embryo selection practices.

The construction of late-nineteenth and early-twentieth century eugenic thinking was not a steady, frictionless process, but rather an unsettled and complex contest between competing eugenics frameworks. The study of embryos had a direct bearing on debate over how best to manage procreative capacity and heredity in service of the future. The scientific knowledge generated through *ex vivo* embryo research was a basis for theories about the nature of variation and its inheritance. Along with the techniques perfected by embryologists, this knowledge both impelled social and political interest in the management of sex and its fertility – most notably in "good" and "bad" heredity – and furnished myriad means through which they might be disciplined. Debates over the role of inheritance versus the environment in the production of morphological variation were particularly influential, as I discuss in more detail below. In short, embryo science was (and continues to be) a key site in which scientific questions about

 $<sup>^{25}</sup>$  Sociologist Edward Ross coined the term "race suicide" in 1901, referring to a combination of the overbreeding of the unfit with the underbreeding of the fit, resulting in the "death" of the white – wealthy, heterosexual, Anglo-Saxon – race.
development and variation intersected with social and political questions about the meaning, value, and management of diversity and difference.

While not itself explicitly eugenic, embryological research fell within the domain of the scientific concerns of eugenicists. The bibliography in the eugenic exposition Applied Eugenics reads like a Who's Who of embryo researchers, with references to Boveri, Morgan, and Weismann, among dozens of others. Understandings of development and heredity were essential to controlling the reproduction of individuals and the species, and embryos were essential to understanding heredity and development. If, as Foucault (1978) writes, eugenics is a technology of sex, a method of governing human beings, then what I suggest here is that it is one both driven and facilitated by, among other forces, the dual phenomena of respatialization and involution through which embryos emerged as vital sites in the production of biological knowledges and techniques. As British polymath and eugenics pioneer Sir Francis Galton<sup>26</sup> wrote, heredity "is the sum-total of the germs, gemmules, or whatever they may be called, which are to be found, according to every theory of organic units, in the newly fertilized ovum ... a space not exceeding the size of a pin" (1876, 330). From the point of conception, Galton went on, embryos receive "nothing further from its parents, not even from its mother, than mere nutriment." The collection and anatomization of human embryos and the culturing of living cells in vitro made possible a specific apparatus of social and political control (eugenics) at the individual and population level, facilitating the state's efforts to manage, govern, and redirect the sexual energy of the population. Sexual and reproductive health interventions, including policies to increase or decrease the birth

<sup>&</sup>lt;sup>26</sup> Galton is variously labeled as an evolutionary theory, a statistician, a psychologist, a psychometrician, a sociologist, an anthropologist, a geographer, a meteorologist, an explorer, and an inventor.

rates of (un)desirable traits, were informed by the results of embryo research, which posited the activities happening inside embryos as vital to understanding how to control reproduction. Embryo experiments, in other words, put sexual reproduction in a position of biological responsibility with regard to the individual, the race, and the species.

My interest in the place of embryos and embryo science in eugenicists' project of biological control and the idiom of improvement that animated it is important to the chapters that follow. The question of whether or not preimplantation genetic testing patterns eugenic selection is central to popular and academic debate on the topic (see for example Franklin & Roberts 2006; Squier 1994; Landecker 2005). This thread runs through my dissertation as well. I am attentive to the ongoing role of extracorporeal embryos in projects of socio-biological enhancement and optimization – as sites where the line between the normal and the abnormal is negotiated and materialized (Chapter 3), as targets of reproductive discipline (Chapter 4), and as sources of new biomedical knowledges and cures (Chapter 5) – and to the ways that these projects are molded (or not) by the spectre of eugenics. In what follows, I examine some of the discursive and material connections between early embryo research and eugenics. These connections continue to structure popular, political, and scientific debate and practices in assisted reproduction today – not least in the ongoing elaboration of the embryo as a key site in the management and disciplining of life itself.

## 2.2.1 Embryo science and the American eugenics movement

At the same time that Boveri was gathering *Ascaris* embryos to study the mechanisms of heredity during embryogenesis in the 1890s, Galton was engaged in a collection project of a different sort. Fascinated with the black box of hereditarianism and its potential actionability in the human species, in the 1880s Galton began collecting the biographies of eminent men in a bid

to prove that musical, intellectual, and other traits were not learned but innate and inherited. His data revealed 102 family connections among notable men living between 1453 and 1843. If an accomplished man had a son, Galton estimated that this son had a one in twelve chance of also being eminent; only one in three thousand randomly selected men would achieve such distinction (Mukherjee 2016).<sup>27</sup> Emboldened by his findings, Galton began to espouse the principles of what, in 1883, he would term "eugenics:"<sup>28</sup> "the science which deals with all influences that improve the *inborn* qualities of a race [and] with those that develop them to the utmost advantage" (Galton 1909, np, emphasis mine). The purpose of eugenics was, simply put, to improve the human race through better breeding. Every trait in a human, Galton argued, from height and weight to beauty and intelligence, is the product of ancestral inheritance. By measuring these traits and encouraging the reproduction of those with superior alleles, he suggested that humanity could accelerate the evolution of species. "What nature does blindly, slowly, and ruthlessly," he wrote, "man may do providently, quickly, and kindly. As it lies within his power, so it becomes his duty to work in that direction. The improvement of our stock seems to me one of the highest objects that we can reasonably attempt" (1904, np).

Galton was one of many social and life scientists – so-called "strict hereditarians" – who subscribed to the notion that hereditary material was transmitted generation upon generation, with absolutely no modification, at the moment of fertilization.<sup>29</sup> Embryos, strict hereditarians reasoned, carry within them the innate, essential characteristics that they will hold as fully-grown

<sup>&</sup>lt;sup>27</sup> Mukherjee writes that Galton did consider the possibility that eminent men produced eminent sons as a result of their relative privilege and opportunity. So deep were Galton's anxieties about his own class and status, however, that he "barricaded the most fragile of his convictions – that purely hereditary influences could explain such patterns of accomplishment – from any scientific challenge" (2016, 67).

<sup>&</sup>lt;sup>28</sup> Galton had earlier considered the term *viriculture*, literally the "cultivation of men."

<sup>&</sup>lt;sup>29</sup> Other (in)famous strict hereditarians include Charles Davenport, Paul Popenoe, and Harry Laughlin.

individuals, which were understood as "an unfolding of embryonic forms of themselves" (Meloni 2016, 20). Heredity was a continuous line of descent, "sprung immediately from embryos whence our parents were developed, and these from the embryos of their parents, and so on forever" (Galton 1865, 322). As a result, individuals were not, for strict hereditarians, susceptible to design. Only through the increase in good stock and the elimination of bad stock – by inciting the procreative capacities of the "fit" and curbing those of the "unfit" – could the future of society be redirected, managed, and optimized.

This doctrine found scientific legitimacy in embryo science: in Weismann's theory of germplasm, which demonstrated the separation of germplasm from somatoplasm and proved that embryos only inherit the former during fertilization; in Boveri and Sutton's embryological experiments, which placed genes on chromosomes inside the nuclei of embryos' germ cells; and in the developmental series produced by twentieth century embryologists, which produced an embryological view of life that "encourages us to see in every embryo a tiny, telescoped image of our present selves" (Morgan 2009, 11). From this work, strict hereditarians constructed a theory of development as a predetermined and predictable process of unfolding governed by internal stimuli. Heredity became congenital, "something inside us and beyond us" (Meloni 2016, 58).

As I discuss further below, strict hereditarianism would eventually come to dominate American eugenic policy and practice. But at the turn of the twentieth century, its ascendancy was not a foregone conclusion (Briggs 2012; Cooke 1998). Alongside strict hereditarianism ran a second thread of eugenic discourse, one that likewise grounded its legitimacy in the revelations of embryo science. Emphasizing the role of the environment in embryonic and human development, so-called moderate or progressive eugenicists drew on the work of Conklin,

himself a prominent American eugenicist, and other quasi-Larmarkists interested in the interplay of inherited material and environmental influence in order to lobby for expanded education, health care, and social welfare. Conceding the role of heredity in the development of species – as Conklin wrote, "men differ from horses or turnips because of their inheritance" (1913, 47) – moderate eugenicists nonetheless insisted on the importance of "training, habits, physiological states, upbringing, and education" (*Ibid*, 50). The response of organisms to these and other external stimuli, they argued, is one of the most important factors in development, both of the body and the mind, and must be considered in the creation of policies and practices aimed at the improvement of the species. To do otherwise would simply be bad science, not in accordance with the evidence (*Ibid*; see also Conklin 1915).<sup>30</sup>

Debates about embryological development and knowledge generated from embryological experiments thus had direct bearing on the early eugenics movement. If heredity was not destiny, if the environment could influence development, then the translation of hereditary material from embryo to adult and on to subsequent generations could be affected by, for example, social welfare and education programs, to the benefit of society as a whole. For many moderate eugenicists, this led to the promotion of health care for the sick; expanded education and welfare for the poor; and efforts to curb pollution, protect natural environments, and limit the exposure of women of reproductive age to harmful work environments, among other legislation. If, on the other hand, development was strictly determined by material from the germ cell, guided by predetermined internal stimuli and not easily mutable, then progressive legislation, including

<sup>&</sup>lt;sup>30</sup> Conklin went as far as to label strict hereditarians senile. He writes in *Heredity and responsibility*: "This debilitating philosophy in which everything is predetermined, in which there is no possibility of change or control, in which there is hypertrophy of intellect and atrophy of will, is a symptom of senility, whether in men or nations" (1913, 54).

social betterment campaigns, were economically wasteful and socially ineffective. Anatomical, physiological, and psychological difference were rooted in biology, fixed from the moment of fertilization; poverty, "feeble-mindedness," and criminality reflected poor germplasm. Efforts to help the poor thus hindered evolutionary improvement by natural selection by facilitating the reproduction of those non-white, licentious, colonized, working-class, disabled, abnormal others whose germplasm threatened the bio-social future.

By the 1910's, strict hereditarianism had taken root in U.S. America (Briggs 2012; Stern 2015). Evidence for Mendel's "units of heredity" had mounted rapidly between 1900 and 1910, bolstered in no small part by the theoretical and experimental contributions of Weismann, Boveri, Sutton, and Morgan, whose work affirmed chromosomes as the physical locus of these units – Wilhelm Johanssen's *genes*.

While much of the writing and thinking on eugenics has rightly focused on racism and the targeting of non-white bodies, eugenic practices and projects were much broader, molding severe national and local logics of class, caste, origin, geography, indigeneity, morality, and hierarchies of physical and cognitive ability with theories of degeneracy (McWhorter 2009; Subramaniam 2014). Criminals, the "mentally deficient," homosexuals, prostitutes, immigrants, the physically disabled, as well as members of all "lower races," were united under a banner of abnormality, each bearing the stigma of biological deficiency, each posing a threat to the evolutionary future. And while the nature of the individual may be fixed, the biological future of the population was malleable, plastic, subject to redirection through the disciplining of reproduction. Resting on differential claims of life worth based on biological variation, eugenic methods grounded in strict hereditarianism sought to manage the future by inciting or curbing the heredity of desirable and undesirable traits.

Political and economic interest in sexual reproduction intensified, encompassing a series of tactics that married the disciplining of the body with the regulation of the population. Selective methods ranged from voluntary birth control and coerced or forced sterilization to incarceration, segregation, euthanasia, and mass murder. Characterized by rigid sex and gender ideologies and enforced through top-down control over biologically reproductive bodies, women were the especial targets of such selective projects (Subramaniam 2014; Stern 2015). Compulsory sterilization and other negative eugenics campaigns - campaigns to prohibit the reproduction of those deemed unfit – could be the only means of halting the spread of defective germplasm. "It would be hard," write influential strict hereditarians Paul Popenoe and Roswell Johnson in their treatise Applied Eugenics, "to find a eugenicist to-day who would propose, with Plato, that the infants with bad heredity should be put to death, but their right to grow up to the fullest enjoyment of life does not necessarily include the right to pass on their defective heredity to a long line of descendants" (1918, 161). While many scientists, including embryologists like Morgan and Conklin, remained focused on determining the hereditary pathways of specific traits, popular eugenics often glossed over the finer points of hereditary science in its designation of who was fit or unfit to reproduce. There was much confusion and contention, both scientific and popular, about what kinds of traits could be inherited (Clarke 1998). As the following chapters will show, this debate continues today in scientific and social realms.

In the early-twentieth century, family pedigree studies abounded as scientists and social scientists alike sought to delineate the multi-generational transmission of bad genes in particular – those that might cause poverty, immorality, criminality, feeble-mindedness, and sexual perversion, among other defects. Describing three generations of "Family L." who were plagued by alcoholism, "imbecility," and epilepsy and were frequent recipients of public relief, Popenoe

and Johnson write (1918, 168-170), "it is abundantly demonstrated that much, if not most, of their trouble is the outcome of bad heredity. ... From an ethical standpoint, so few people would now contend that two feeble-minded or epileptic person have any 'right' to marry and perpetuate their kind that it is hardly worthwhile to argue the point." Charles Davenport's<sup>31</sup> laboratory, the Eugenics Record Office (ERO), housed a massive, centralized collection of data on such traits in the *Trait Book*, a complete listing of the qualities that might be found in families, collected by ERO caseworkers and recorded on 3" X 5" cards (over 1 million were collected between 1910 and 1939). Davenport was particularly concerned with "feeblemindedness," a hereditary condition to which a large number of abnormalities detrimental to the state could be ascribed (Crampton 2016). Described as objective and scientific by the ERO, data collected by caseworkers was most often based on subjective impressions and community reactions, "euphemisms for common gossip" (Allen 1986, 243).

Thus did embryological research shape the politics of eugenics, guiding projects along lines of strict hereditarianism. But so too was scientific knowledge profoundly influenced by social and political questions about variation, diversity, and difference. The focus on bad genes responded to growing anxiety over degeneration – the regression of the nation toward a more primitive state due to the rampant propagation of the unfit, the flagging propagation of the fit, and the dilution of the good stock through race-mixing and intermarriage (Stern 2015; McWhorter 2009). By the early twentieth century, the concept of degeneration was already well established – applied to individuals or series of individuals that diverged from their specific

<sup>&</sup>lt;sup>31</sup> Davenport was a leading eugenicist in the U.S. and has been described as "the chief American advocate of eugenics" (Allen 1986, 225).

types; to bodily tissues that ossified or became fatty or cancerous; to the slow decline of biological function associated with disease and death; and broadly to the negative, the a-typical, the counter-natural (Foucault 1994). Under the rubric of eugenics, the term became suffused with social meaning – a modern way of discussing social problems and promoting social policy under the guise of the objective and apolitical language of science and the laws of nature (Subramaniam 2014).

Politicians and elites in particular worried about the infection of the white Nordic germplasm by the socio-biology of racialized, sexualized, and classed others, purportedly prone as they were to licentiousness, idiocy, criminality, intemperance, and disease. These concerns found fertile ground among the middle and upper classes, who bristled at the thought of their tax dollars supporting masses of supposedly defective people and saw institutional cost savings in preventing more defective births (Allen 2001; Stern 2015). Figures detailing these costs circulated widely; in *Applied Eugenics* (1918), Popenoe and Johnson included sums, furnished in 1917 from the U.S. National Committee for Mental Hygiene, specifying the annual cost of "maintaining a feeble-minded ward of the state" (172), organized by commonwealth: \$136.50 in Illinois, \$222.99 in Maine, \$170.16 in Kansas, and so on. These types of calculations exhorted massive funding for eugenics projects from wealthy corporate tycoons and philanthropists (including the likes of John D. Rockefeller and Mary Harriman), and millions of federal, state, and local tax dollars for programs that targeted for prevention the transmission of negative hereditary materials through sexual reproduction (McWhorter 2009; Kevles 1998).

Such practices and policies are a manifestation of what Foucault (2003a) has called state racism – the application of a series of techniques for identifying and ordering groups as "good" or "inferior" for the health of the population. Racism, Foucault writes, "is born at the point when the theme of racial purity replaces that of race struggle, and when counter-history begins to be converted into a biological racism" (81) – a historical shift from a struggle between races to a struggle to maintain the purity of the race. In this articulation, racism is not just the abhorrence of difference, but also the imposition of a break along the biological continuum, among as well as within populations, between the fit and the unfit. Abnormality, deviance, "feeblemindedness," criminality, and "moral imbecility" were understood to threaten the purity of the race, which must be protected from pollution by unworthy stock (Crampton 2016; McWhorter 2009). The U.S. government, writes Ladelle McWhorter (2009, 203), became "a creature of Anglo-Saxon germplasm," curtailing immigration from Asia and southern and eastern Europe, upholding state and local segregation laws, restricting and licensing marriage, putting so-called inferior people in sex-segregated custodial institutions for the duration of their reproductive lives, and forcibly sterilizing tens of thousands of its own citizens (Kevles 1998; McWhorter 2009; Stern 2015).<sup>32</sup> Fear of degeneration, as Sara Ahmed (2004) notes, became associated with the bodies that embodied the failure of the white, heterosexual, abled, neuro-typical norm.

As discussed above, the theory that traits were hereditary – that preventing people with defects from procreating would prevent the transmission of these defects to future generations – played a great role in public and scientific support for these projects, and for this particular form of state racism. If tight immigration laws would protect the nation from without, surgical operations and interracial marriage bans could do the same from within. Writes zoologist, famed

<sup>&</sup>lt;sup>32</sup> Women in particular were the targets of forced sterilization, believed to present a greater threat to public health than men: while a defective male was unlikely to attract sexual interest from a normal female, a defective female may well partner with a normal male. Women were thus more likely to spread disease and to produce generations of offspring more degenerate than themselves, corrupting the germline of normal males in the process (McWhorter 2009).

conservationist, and close Roosevelt associate Madison Grant, sterilization "is a practical, merciful, and inevitable solution of the whole problem [of degeneration] and can be applied to an ever widening circle of social discards, beginning always with the criminal, the diseased and the insane and extending gradually to types which may be called weaklings rather than defectives and perhaps ultimately to worthless race types" (1932, 51). Following the Supreme Court's ruling on *Buck v. Bell*<sup>33</sup> in 1927, thirty-two states passed sterilization laws; over 60,000 involuntary sterilizations were performed over a period lasting into the 1960s. With the implementation of these and other eugenic policies, the United States government sought to fulfill its role as manager of the American germplasm.

Anxiety over human heredity in the twentieth century was not, of course, new. Efforts to protect the boundaries of the human race embodied in its highest form – white, Western European, heterosexual, able-bodied, wealthy, healthy, productive, and appropriately fecund – have a history that long predates the birth of eugenics as a state project in the early twentieth century. As a political practice, eugenics is in many ways continuous with practices of slavery and colonialism. Anti-miscegenation laws in the territory that is now the United States, for example, date back to the 1600s and were explicitly organized around the protection of white purity (McWhorter 2009). But as a science, eugenics is impossible to apprehend in the absence of the study of evolution, psychiatry, medicine and, I argue here, embryology. The goal of

<sup>&</sup>lt;sup>33</sup> On September 10, 1934, Dr. Albert Priddy, superintendent of the Virginia State Colony for Epileptics and Feebleminded, filed a petition to his Board of Directors to sterilize Carrie Buck, an 18-year old patient. Buck's mother, Priddy claimed, had a history of prostitution, immorality, and promiscuity. Carrie's own child was assumed to be feebleminded. On this evidence, Priddy claimed that Buck represented a genetic threat to society and should thus be sterilized. In an 8-1 decision, the Supreme Court ruled that a state statute permitting compulsory sterilization of the unfit, including the intellectually disabled, for the protection and health of the state did not violate the Fourteenth Amendment. See Paul Lombardo (2008) and Adam Cohen (2016) for detailed accounts of the case.

improving the human race through "better breeding" (Davenport 1911, 1) existed well before 1900. But the eugenics movement, informed by the results of embryo science, mobilized this sentiment as a scientific solution to perceived social ills, especially among influential scientists and intellectuals for whom eugenics offered a program "compatible with the world view of the naturalistic mind" (Ludmerer 1972, 14).

The hold of strict hereditarianism in the U.S. weakened in the post-WWII period, largely in response to the brutal extremes of the Nazis' racial hygiene and extermination campaigns, which culminated with horrifying consequence in the Final Solution. As before the war, embryo research remained paramount and continued to play a central role at the nexus of society and science after it. Just as the eugenics projects espoused by strict hereditarians were founded in the science of their times, so too was the shift away from such campaigns. Further investigations into genetic and hereditary mechanisms revealed that the transition from embryo to adult was far more complex than initially believed, and that the environment did indeed play a vital role in development. Many eugenicists had recognized this complexity in the early twentieth century. Even ardent strict hereditarians like Popenoe and Johnson were alert to the uncertainty surrounding the precise manner and mechanisms of heredity. For them, though, the hypotheses posited by the "meticulous researchers of environmental breeders do work" (Popenoe & Johnson 1918, 99 [italics original]) – that is, their agricultural and animal experiments proved that the species, as an aggregate, could be improved through auspicious breeding. The absence of detailed understanding as to why they worked was an insufficient excuse for inaction in the face of looming social and economic collapse.

In the wake of the Final Solution, however, public and political support for eugenics largely evaporated, and eugenicists were forced to rethink – or perhaps more accurately,

repackage (Stern 2015) – their scientific narrative.<sup>34</sup> Eager to sever any association with state coercion, eugenicists in the postwar period shifted their scope in two primary directions: population control and the pursuit of family planning and birth control abroad; and medical genetics, which emphasized individual choice and private decision making, at home. Under the umbrella of the latter, genetic counselling<sup>35</sup> services were launched at a number of heredity clinics and university genetics departments in the 1940s. As they do today, genetic counsellors encouraged couples to make genetically informed and rational decisions about reproduction, using family pedigree charts and nascent knowledge of genetic diseases to advise them on the probability that their offspring would carry deleterious or lethal traits. As I show in chapters 3 and 4, these practices continue to operate today in the fertility clinic. Embryos, "the sum-total of the germs, gemmules, or whatever they may be called" (Galton 1876, 330) figure ever-more prominently: as the targets of selection practices (chapters 2 and 3) and as living tools and technologies in technoscientific attempts to eradicate genetic diseases and disorders (Chapter 5). Whereas Galton had proposed using physical and mental traits to select the best specimens for breeding, medical geneticists and genetic counsellors encouraged parents to think not in terms of the selection of features, but of genes - to make genetically informed decisions about reproduction (Stern 2015). Height, weight, beauty, intelligence, even health, were merely an expression of what lay much deeper: of those tiny bits of microscopic information strung along

<sup>&</sup>lt;sup>34</sup> Only in the early 2000s did the governors of some states begin to apologize for the eugenics policies and practices of the twentieth century. As Stern (2015) notes, these apologies have tended to assert a stark division between the "enlightened" present and the past atrocities linked to Nazi pseudoscience. Revelations about ongoing forced sterilizations – for example, the 144 unauthorized sterilizations performed on female inmates in California prisons between 2006 and 2010 – suggest otherwise.

<sup>&</sup>lt;sup>35</sup> See Rapp 1988 for an early history of genetic counseling.

chromosomes, contained within nuclei, surrounded by cytoplasm, carried inside the cells that make up the embryo.

It is to contemporary practices of identifying, reading, and mobilizing these tiny bits of microscopic information that I now turn. In the 21<sup>st</sup> century, human embryos – separated from the materiality of the body – continue to be subject to novel forms of regulation, management, and involution. These practices are at once and inextricably productive and reproductive. In the next two chapters, I examine them at work in the increasingly routinized use of preimplantation genetic testing technologies in the fertility clinic, focusing in particular on their reproductive effects – on their implications for how we make and remake human life in the biotech age. The use of these technologies is preconditioned by the techniques and knowledges required to sustain living embryos outside the body and by their discursive naturalization as sites and scales of scientific experimentation, manipulation, and investment charted above.

# **Chapter 3: Abnormality as natural fact**

On June 26, 2000, Craig Venter of Celera Genomics, Francis Collins of the National Human Genome Research Institute, U.S. President Bill Clinton, and U.K. Prime Minister Tony Blair gathered in the East Room at the White House to announce the completion of the first map of the human genome. Clinton spoke first, comparing the map to one that had been laid out by Thomas Jefferson in the same room nearly two centuries earlier. "[Lewis and Clark's] map defined the contours and forever expanded the frontiers of our continent and our imagination," Clinton said. "Today, the world is joining us here in the East Room to behold a map of even greater significance. We are here to celebrate the completion of the first survey of the entire human genome. Without a doubt, this is the most important, most wondrous map ever produced by humankind" (2000). One year later, a draft of the human genome was published simultaneously in *Nature* and *Science*, the former by the International Human Genome Consortium, the latter by Craig Venter and his team of privately funded researchers at Celera Genomics.<sup>36</sup>

The publicly funded Human Genome Project (HGP) was formally launched in 1990 by an international research initiative led by the National Institutes of Health and the U.S. Department of Energy. An involutionary project *par excellence* from its inception, its goals were threefold: to analyze the structure of human DNA, to map the locations of genes on all major sections of each human chromosome, and to create linkage maps to connect these genes to specific human traits and diseases. At the time of publication, Collins compared the work to a book with many uses: "It's a history book – a narrative journey of our species through time. It's

<sup>&</sup>lt;sup>36</sup> Craig Venter founded Celera Genomics in 1998 in response to what he perceived as the Human Genome Project's unacceptably slow process. Funded by the private sector, Celera Genomics planned to profit from their work by creating genomic data to which users could subscribe for a fee.

a shop manual, with an incredibly detailed blueprint for building every human cell. And it's a transformative textbook of medicine, with insights that will give health care providers immense new powers to treat, prevent and cure disease" (National Human Genome Research Institute 2018, np). For Collins and many others, the publication of the human genome map would clarify history, biology, and the future of medicine, providing unprecedented insights into health, illness, risk, and self. On the basis of this map, scientists and clinicians would be able to conceive a clear distinction between normal and abnormal genetics, parsing the specific sequences necessary to produce healthy function. "Perhaps the most important area of DNA diagnostics will be the identification of genes that predispose individuals to disease," U.S. biologist Leroy Hood wrote in 1993. "Human genetic mapping will permit the identification of specific predisposing genes and DNA diagnostics will facilitate their analysis" (155).

Few anticipated the surprising biological revelations and developments that ensued. Instead of the expected 100,000+ genes, the HGP found that human beings are made up of approximately 20,687 genes – only 1,796 more than worms, 12,000 fewer than corn, and 25,000 fewer than rice or wheat (Mukherjee 2016). In the wake of these findings, the perceived complexity of human life could no longer be accounted for by the number of genes alone. Rather, scientists reasoned, it must be the sophistication of genetic interactions, gene networks, and environmental factors that made human life so elaborate. For many, these revelations signalled a break from the genetic determinism that had predominated in basic and life sciences research since the 1900s, launching a new, postgenomic era. Deterministic and atomistic understandings of the relationship between genes and human characteristics gave way to dynamic and non-dualistic theories about the complex and indeterminate relationship between environments, genes, bodies, and health (Tremain 2017; Stevens & Richardson 2015a; Mansfield

& Guthman 2015; Guthman & Mansfield 2012, 2015; Mansfield 2012a). Biology was not so much fixed by our genes – not locatable and originary – but rather mutable, constantly changing in ways that are more than evolutionary. Neo-Mendelism was giving way to neo-Lamarkism.

Epigenetics, the study of heritable phenotype changes that do not involve genetic alterations, is emblematic of this shift. Inverting the traditional causal relationship between biological and social inequality, epigenetic research has begun to investigate how the social and economic order becomes embedded in the body at the molecular scale in ways that actually produce biological differences in individuals (Guthman & Mansfield 2012, 2015; Mansfield 2012a; Gravalee 2009; Kuzawa & Sweet 2009; Delpierre et al. 2018). Unequal exposure to environmental toxins, trauma, and poverty, among myriad other influences, this work has found, are written into the body such that they get, quite literally, under the skin (Mansfield & Guthman 2015; Mansfield 2012a; Gravalee 2009). This growing focus on plasticity and mutability has trained researchers' attention on the various environments and environmental influences that affect biological elements and processes in the human body.

Theories of epigenetics and biological plasticity are potentially liberatory in their application, drawing attention to the ways that structural inequality is implicated in the reproduction of poor health outcomes (Mansfield 2012a). In practice, however, they have tended to escalate, proliferate, and further individualize maternal responsibility. Age-old anxieties about how pregnant and pre-pregnant people comport themselves has gained a new intensity. Lifestyle decisions and consumptions habits, long recognized as forces that condition fetal development, are now understood to shape the ovarian and uterine environment in ways that materially alter the epigenome of oocytes, embryos, and fetuses down the genealogical line. "Fetal programming," as one stem cell scientist put it during our interview, "not only informs childhood

and adult pathologies, but also the next generation's development." Affirmed as a "key spacetime of epigenetic becoming" (Mansfield & Guthman 2015, 6), under the theory of epigenetics the womb must be controlled in service of reproducing not only the right kind of fetus but also, in turn, the right kind of socio-biological future. Claims about the powerful role of environmental, social, and economic forces are converted into the rigid regulation of prepregnant and pregnant people, who become responsible for managing the plasticity and mutability of biological life (Subramaniam 2014; Mansfield 2012a).

As Becky Mansfield and Julie Guthman (2015) observe, this kind of thinking has taken hold in scientific and public spheres over the last five to ten years, influencing policy, press coverage, and activists in a range of places and pursuits. Epigenetic stories recounting the various ways that trauma, inequality, and other social, political, and economic factors influence our very bodily natures have captured public and scientific attention, renegotiating the relationship between body and world in material and discursive ways. When I first started my dissertation research, one of my aims was to better understand how this thinking was influencing clinical fertility practice in the context of rapidly rising rates of genetic testing of embryos, intended parents, and gamete donors. How, I wondered, have clinicians navigated growing patient demand for genetic screening technologies with emerging theories about biological plasticity?

As it turns out, they haven't. Not really. As quickly became clear during my fieldwork, the fertility sector remains a hotbed of genocentric thinking and action, on display in conspicuous form in the burgeoning use of preimplantation and preconception genetic testing. Given the penetrance of epigenetic thinking into reproductive medicine and its well-stated implications for biological reproduction, sessions on epigenetics were thin on the ground at the

American Society for Reproductive Medicine (ASRM) annual meetings that I attended. According to one practitioner I talked to at a Sacramento area clinic,

Physicians never talk with their patients about epigenetics. You don't want to freak them out by telling them things you have no solution for. Or be like, 'well, you know there is this thing, but it has zero relevance for your treatment right now because we literally can't fix anything, or alter anything, to change your embryo's development'.

Said a perinatal researcher and stem cell scientist involved in reproductive genetics during our interview: "I think it's because it's actually not an easy thing to get a handle on, that there isn't so much clinical attention being paid [to epigenetics]." In fertility practice, it would seem, Collin's concept of the human genome as a shop manual and medical textbook persists. As I discuss further below, reproductive genetics firms continue to embark on massive gene hunting expeditions, hoping to discover and map the genes and genetic combinations associated with a host of physiological and psychological conditions. And embryos remain the subjects of their genetic codes.

This chapter examines the persistence of genocentric thinking in the U.S. fertility sector through an examination of one of assisted reproduction's flagship technologies: preimplantation genetic tests (PGTs). In what follows, I offer both an empirical explication of how these technologies work and a caveat to the growing body of social scientific work on postgenomics. Even when characterized as a critical stance in relation to genetics rather than a specific time period, the "post" in postgenomics is, at root, a temporal prefix. It refers to a period beginning after the completion of the human genome project – to a time when the genetic epistemology of contemporary science has moved beyond the gene-centred view of the earlier genomic era and toward "an emergent understanding that human form and function is not simply derived from the genome but is part of a complex web of cellular and environmental interactions" (Guthman

2015, 2533). Postgenomic and epigenetic theory have become productive domains for geographers and other social scientists, offering a potentially powerful analytic for rethinking concepts of race, social difference, environmental and reproductive justice, health, and humanenvironment interactions. This work has been invaluable to my thinking and research in this project. Here, however, I want to account for the ongoing presents and presence of genetic determinism – for the ways that human form and function continue to be reduced to their genetic makeup. The gene and genetic theories of inheritance and development, I argue, bear down on reproductive politics and reproductive futures in specific and distinct ways. The following chapter accounts for some of these specificities and distinctions. Taking my cue from the fertility practitioners with whom I spoke, I orient myself toward assisted reproduction as a field that is, as one ASRM speaker put it, "becoming more and more genetic."

The genetic knowledges and practices that animate preimplantation genetic testing are tied up with the Human Genome Project and with the much longer histories of involution detailed in Chapter 2. They are preconditioned by the ability to take embryos in hand, to excise their cells, to peer inside their nuclei. And they rely on detailed biological maps that plot the location of disease-causing mutations and chromosomal rearrangements in the embryo's internal geography. Through the dual processes of gene mapping and PGT, the embryo is structured, organized, and categorized: as healthy or unhealthy, normal or abnormal, male or female. On the basis of this information, they are selected or de-selected for transfer in a process of future-oriented reproductive control that, as I discuss in Chapter 4, is at once about the distribution of power and life itself. Akin to the logic that animated strict hereditarianism in the early- to mid-twentieth century, while the individual embryo is seen as genetically determined – not susceptible to design – reproduction at the aggregate scale is seen as malleable, plastic, open to

intervention and manipulation through, among other avenues, the identification and aversion of abnormal embryos and the genetic mutations they carry (Chapter 4). Together, PGT and the gene maps on which they rely thus constitute a form of governance born of involution – of the inward curvature of the technoscientific gaze into the deepest recesses of the body and the spatialization of the territory within.

For Haraway (1997), gene maps reify the gene, transmuting "material, contingent, human and nonhuman liveliness into maps of life itself and then mistak[ing] the map and its reified entities for the bumptious, nonliteral world" (135). This particular kind of spatialization, she argues, produces the gene – a "deeply contingent, physical, semiotic, tropic, historical, located" (142) entity – as a thing-in-itself, a master molecule on the basis of which life can be anticipated, measured, and (de)valued. Haraway terms this "gene fetishism" - a process in which the realm of social, natural, and technical production that brings the gene into being is obscured, even denied. Designated as abnormal on the basis of this fetish-gene, I suggest in section 3.2 that abnormal embryos are likewise fetishized in and through preimplantation genetic tests and gene maps on which they rely. The understanding of abnormality as natural fact propagated by preimplantation genetic tests mistakes normal and abnormal embryos for concrete entities that are the source of their own (reproductive) value. In Chapter 4, I shed light on the array of social, legal, and biomedical forces in and through abnormal embryos are stripped of their reproductive potential, and thus their value in the fertility setting. Here, I examine how abnormal embryos come into being as things-in-themselves in the first instance.

This account entails careful empirical engagement with preimplantation genetic testing. Used to screen IVF embryos for genetic and chromosomal abnormalities before they are implanted in the womb, these tests are preconditioned by the dual processes of respatialization

and involution chronicled in Chapter 2. They recapitulate the forms and fantasies of control and discipline over biological reproduction precipitated by twentieth century embryo science, furthering the penetration of the medical gaze into the embryo and reproducing it, in turn, as the purview of biomedicine. The increasingly common use of PGTs in the fertility sector is deepening scientific, social, and economic interest in embryo interiors, while at the same time granting clinicians, scientists, and intended parents' access to the concrete space of the embryo itself and to the genetic and chromosomal information that resides there.

## **3.1** Preimplantation genetic tests

Since the first clinical application of PGT in humans in 1989,<sup>37</sup> reproductive medicine has been committed to developing more accurate and cost-effective genetic screening methods. This is for good reason. As I mention in Chapter 1, the transfer of "normal" embryos has been linked with decreased time to conception, a decrease in miscarriage rates, higher implantation rates, and higher live birth rates, all of which can greatly affect intended parents' encounter with ART. In part because of these results, and in keeping with trends toward the medicalization of pregnancy and the universalization of reproductive imaging and screening technologies like ultrasound and amniocentesis (Duden 1993; Rapp 2000; Tremain 2006, 2017), while initially intended for use only in high risk populations, PGT has been integrated into routine clinical practice over the last 30 years. In California, the average screening rate across clinics is around 60 percent; in some clinics, over 90 percent of all embryos are comprehensively genetically screened. The goal: to increase the live birth rate by selecting only the "healthiest" embryos for transfer.

<sup>&</sup>lt;sup>37</sup> The first successful use of PGT in a clinical context was by Alan Handyside, Elena Kontogianni, and Robert Winston at Hammersmith Hospital in London.

Again, my interest in this chapter and in the chapters that follow is in the counterpart to these much sought after "healthy" embryos: the abnormal embryos remaindered by the PGT process. While categorized as such on the basis of putatively objective genetic and chromosomal norms, abnormal embryos are as much social as biological entities, the product of an assemblage of technoscientific, biomedical, legal, and political practices. As I show in more detail in chapters 4 and 5, abnormality operates as a form of hierarchical difference-making – a means of delineating, organizing, and disciplining bodies and lives according to their biology. Abnormal embryos, I argue, are thus key biopolitical sites, both as the "averted births" (Murphy 2017) that signify a future free of disability and disease (Chapter 4) and as experimental objects in the development of new biomedical knowledges, products, and profits (Chapter 5). This section considers the technology that has given rise to this class of abnormal embryos: PGTs. This technology, I argue, produces and reproduces abnormality as a natural, fixed property of biological life by situating it firmly within the genes and chromosomes of preimplantation embryos, concealing its social, political, and legal dimensions. At a time when scientific and social scientific communities are captivated by the protean, mutable quality of biological life, reproductive genetic technologies like PGTs remain the bastion of a calculative logic that mobilizes the gene as a master molecule on the basis of which life can be anticipated, measured, and (de)valued. While in many cases, as I mention above, the abnormal embryos averted by the PGT process are non-viable, in what follows I am particularly concerned with those embryos carrying viable abnormalities in their genes and which, like their non-viable counterparts, are consequently surplussed out of reproductive futurity.

Preimplantation genetic tests are a relatively new addition to the suite of assisted reproductive technologies currently in use in the fertility clinic.<sup>38</sup> They are used to screen IVF embryos for genetic or chromosomal abnormalities, information that helps doctors and patients select embryos for transfer. "Our aim is to put in one normal embryo for each patient ... and we're focusing on the embryo that then has the highest chance of getting us a healthy baby," a clinician explained to me during our interview at his San Mateo, CA clinic. "PGT is a tool that helps us prioritize which embryos to choose first – this embryo has the best chance because of its physical attributes and its genetics, and this would be the second, the third, the fourth, the fifth..."

In a quintessential act of involution, the test uses a small laser to biopsy a sample of 5-10 cells from the embryo at the blastocyst stage, somewhere between five and seven days after fertilization. The cells are removed from the trophectoderm, the outer ring of cells that becomes the placenta. The inner cell mass, the cells that will become the fetus, remains intact (figure 3.1).



#### Figure 3.1 Blastocyst biology

At the blastocyst stage, human embryos are made up of two types of cells: a ring of around 200 trophectoderm cells, which will develop into the placenta, and a bundle of cells called the "inner cell mass," which will develop into the fetus. Preimplantation genetic tests biopsy the trophectoderm, removing 5-10 cells for screening.

<sup>&</sup>lt;sup>38</sup> The test was first used in humans in 1989.

The process relies on a peculiarity of human embryology: the embryo's capacity, for a brief moment in time, to regenerate itself, much like a salamander or a starfish. Where the cells are removed, the remaining cells divide to fill the gap. The IVF embryo can thus be biopsied at an early stage without destroying its developmental potential. Following biopsy, the embryo is cryopreserved.

The biopsied cells become a proxy for the whole embryo from which they were excised – a practice that, as I discuss further below, raises questions about the accuracy of preimplantation genetic testing. With the exception of rare cases in which a fertility clinic has an in-house lab, the cell sample is sent away to an independent lab for testing. Different labs use different screening platforms developed by different biotech companies, each of which may target a slightly different set of genetic and chromosomal abnormalities. Illumina, Igenomix, and CooperGenomics offer three of the most widely used. These platforms scour the biopsied cells for chromosomal and genetic abnormalities. On the basis of these results, embryos are selected or de-selected for reproductive use.

There are two broad categories of PGTs, each with its own clinical indications and objectives: preimplantation genetic testing for aneuploidies (chromosomal abnormalities), commonly referred to as PGT-A, and preimplantation genetic testing for monogenic (single gene) conditions, called PGT-M.<sup>39</sup>

<sup>&</sup>lt;sup>39</sup> This nomenclature is the result of a recent name change in clinical practice. Previously, PGT-M was called preimplantation genetic diagnosis, and PGT-A was called preimplantation genetic screening.

## **3.1.1** Preimplantation genetic testing for aneuploidy

Most humans have 23 pairs of chromosomes, for a total of 46. When one copy of a pair is missing, the condition is referred to as a "monosomy." An example is Turner Syndrome, which occurs when someone has only a single X chromosome (as opposed to XX or XY). Turner Syndrome is the only known viable monosomy in humans. "Trisomy" describes conditions that result from an extra chromosomal copy. Down Syndrome, for example, occurs when there are three copies of chromosome 21; it is among the most common trisomies. If an embryo is found to be monosomic or trisomic, it is referred to as aneuploid. Aneuploidy is the cause of an estimated 70 percent of miscarriages, both during *in vivo* and *in vitro* conception. PGT-A is used in this context as a means of decreasing the chance of a miscarriage, increasing the likelihood of a normal live birth, and decreasing the time to conception by eliminating the "chromosomally incompetent" embryos that are unlikely to result in a pregnancy. As I discuss in more detail in Chapter 4, in the fertility clinic, aneuploid embryos are generally understood to be non-viable, and are rarely selected for implantation.

These technologies have all but replaced traditional methods of grading embryos on the basis of morphology (based on how they look). As one ASRM speaker explained, even the most beautiful<sup>40</sup> embryos can carry fatal chromosomal errors in their cells. Embryos of the highest morphological score might be aneuploid, while euploid embryos may appear to be of significantly inferior quality (see also Alfarawati et al. 2011). PGT-A addresses this disjuncture, using "chromosomal health" (Armenti et al. 2016, 47) rather than morphology as the basis for

<sup>&</sup>lt;sup>40</sup> During an ASRM session a clinician recalled getting a call from a patient asking about that "beautiful" embryo in the photo he had sent them. "It wasn't so beautiful after all," he told the audience. "It actually had Down Syndrome or Turner Syndrome."

selecting the best embryo for transfer. Almost everyone I interviewed about PGT-A described the technology to me in this way – as a means of identifying embryos that will "not only increase the probability of having a child, but a healthy one as well" (clinician, San Francisco Bay Area). As the lab director at San Mateo area fertility clinic put it: "Medicine and society have challenged us to provide a normal, single,<sup>41</sup> healthy child. We're not throwing away abnormal embryos so much as prioritizing normal ones."

The use PGT-A relies on genetic and biological information compiled in a reference genome. This genome is made up of multiple human genomes – the latest one from 13 anonymous individuals from Buffalo, New York – which together create a genomic norm. The current reference genome, GRCh38, is the twentieth version released by the Genome Reference Consortium since the completion of the Human Genome Project in 2003. Each new version adds additional information, plotting new genetic sequences and clarifying old ones. The first reference genome had roughly 150,000 known gaps. GRC38 has about 150. Very basically, during PGT-A the genetic information contained in the biopsied cells is aligned and compared with the reference human genome, allowing practitioners to identify areas where the two differ. These differences can indicate additional or missing chromosomal material: trisomies or monosomies. As the resolution of these tests increases, it has become possible to detect other forms of chromosomal rearrangements in addition to whole gains or deletions: chromosomal inversions, for example, in which a small segment of a chromosome is flipped and reinserted upside down, changing the order of the DNA base-pairs that make up that segment. Describing

<sup>&</sup>lt;sup>41</sup> As IVF success rates increase, there has been a recent push toward transferring single, rather than multiple, embryos.

the process of involution at the centre of this dissertation, a speaker at the 2017 ASRM said: "We are looking deeper and deeper into chromosomes. Right now, what we're looking at is aneuploidy: the gain or loss of a chromosome or part of a chromosome or an arm of a chromosome. We'll be able to see more and more as we go deeper into the genome. Sequencing gives us this ability."

In the use of a reference genome as a basis for determining embryo ploidy status, we can begin to see how definitions of biological normality are technologically produced and mediated. Because it is derived from so few individuals – indeed, 70 percent of the original referent was obtained from a single sample, an individual at high risk for diabetes - the reference genome is by no means representative of a statistically average individual or population. Rather, it is made up of DNA from the first twenty volunteers to respond to a recruitment ad in the Buffalo News in 1997, most of whom were of European descent (Begley 2019). Thus, while the referent offers a well-defined and increasingly "complete" type specimen, it is no closer to a given sample than any other arbitrarily chosen genome would be (Ballouz, Dobin & Gillis 2019). The normal reference genome, in other words – the genome against which PGT samples are compared – is not a statistical average, but a composite of a small number of individuals from the United States. As one group of scientists recently found, this can pose significant problems if you are working with a sample from an individual that is of a significantly different genetic background: in their study, individuals of African descent (Sherman et al. 2018). In this case, the reference genome omitted nearly 300 million DNA base pairs found in their population sample. There are a number of ways of compensating the lack of diversity in the reference genome, and efforts to improve the referent have recently turned to providing a more robust representation of the human

population. As it stands, however, the reference genome remains a composite of DNA sourced from a small number of individuals and representing only a fraction of human genetic variations.

Because it provides a reading of each embryo's chromosomal makeup, PGT-A can also be used for sex selection, or "family balancing" as it is more euphemistically called in the fertility sector. In their use as sex selection technologies, preimplantation genetic tests perform and reproduce an understanding of sex as a biological characteristic inherent in the very building blocks of life. As I explore further in Chapter 4, this understanding of sex-as-biology is imbricated with notions of sexual dimorphism that designate as abnormal any chromosomal variants that diverge from the expected XX or XY arrangement. Much like the hormone injections and sex reassignment surgeries detailed by Anne Fausto-Sterling (2000) in her work on intersex, PGTs are part of a regulatory practice that produces sexual dimorphism in the bodies it governs – assigning sex not at birth but *in vitro*, at the very moment of conception, and casting out of reproductive futurity any embryos that do not chromosomally conform to the male/female binary (Chapter 4). In this instance of (de)selection, sexual dimorphism becomes visible as a cultural norm that governs the materialization of bodies and biological futures, which take shape as an effect of power (Butler 1993).

Almost all of the clinics and websites I visited offer sex selection (always called "gender selection") within the remit of their fertility services. While about half of the practitioners I interviewed at fertility clinics in California reported an even split between requests for male and female embryos, others said that an overwhelming number of their patients were selecting male

embryos.<sup>42</sup> "It's very common to see people selecting for boys. There's occasional selection for girls. It's silly to say this but we're all like, 'yay! Someone chose a girl!', especially when you're mostly, you know, boy, boy, boy, boy" (embryologist, Palo Alto). Another clinician in the Sacramento area told me,

In Northern California it seems to be a very big thing. ... The overwhelming majority of patients who do IVF for gender selection are doing it for a boy. It's disheartening. ... You'd be surprised how prevalent the desire for a male child is.

Reflecting on her own upbringing in India, she spoke at length about sex selection, raising concerns about its broader social implications.

It just sort of perpetuates this idea that one gender is superior to the other, because the people who are choosing – lots of these, maybe not 100% but a majority of people who are choosing male embryos or female embryos are going to bring up ...their boys to believe that they're superior and their girls to believe that they're inferior. And it just sort of perpetuates that society.

Preimplantation genetic testing has its roots in sex selection. During the early years of

PGT, the technology could only be used to screen for X-linked recessive conditions: genetic mutations that are carried on the X chromosome. By selecting only XX ("female") embryos for transfer, Alan Handyside and Robert Winston – the first to attempt, and succeed in, using PGT in humans in the clinical context – were able to significantly decrease the chances that the resulting embryo would carry the disease.<sup>43</sup> Today, the test has far exceeded this remit, emerging as the most accurate means of sex-selection technology currently available on the market. In multiple

<sup>&</sup>lt;sup>42</sup> Early on in my fieldnotes, I wrote, "when it's come up so far, two women have said there's a preference for boys, two men said that it's equally divided in the U.S., while also recognizing that in *other* places, specifically India and China, sex selection has posed a significant demographic problem."

<sup>&</sup>lt;sup>43</sup> In XY embryos, a single copy of the mutated gene is sufficient to cause the condition. In XX embryos, the mutation must be present on both chromosomes. This means that males are much more likely to be affected by X-linked recessive disorders.

interviews and conversations, practitioners reported an increasing number of fertile patients accessing IVF solely for sex selection. "We get a lot of patients where the only reason they're doing IVF is to do gender selection," a clinician told me. "These are people with no fertility problems," another said, "and they expect that they just have to order a gender." Hers was one of three clinics I visited that had recently limited their sex selection services to infertile or sub-fertile patients, reporting that fertile patients often have much lower success rates<sup>44</sup> either because they do not follow the medication regime or because they prioritize the embryo's sex over morphological or genetic fitness.

As the ASRM Ethics Committee recently mused, "the uncertainties of life find no refuge at its beginning" (2017, 1132). Preimplantation genetic testing for aneuploidies can and does produce results that are indeterminate, inaccurate or both at multiple scales of scientific practice. When one of the labs I visited in 2017 was considering switching to a different lab for their PGT analysis, they decided to conduct a small experiment first. Splitting a single biopsy into two samples, they sent one to their current lab and one to a new lab. The two samples produced completely different results; only the sex was consistent. Similar results were found in another small study designed to assess the accuracy of PGT-A (Gleicher et al. 2016). Of the 11 aneuploid embryos submitted for reassessment, only two were identically assessed at two different PGT labs. Four were found to be chromosomally normal on repeat analysis. Five were found to have a completely different set of reported aneuploidies. And two were found to be mosaic, meaning they contained both normal and abnormal cell lines, a phenomenon I discuss further below.

<sup>&</sup>lt;sup>44</sup> Success rates are important for clinics who report to the National ART Surveillance System. Patients will often look at this data when choosing a fertility clinic.

Technological uncertainty can also arise in the process of interpreting differences between the reference genome and the cell sample. Embryologists and clinicians talk about "noisy" diagrams – visual readouts of chromosomal counts that show variation from the reference genome, but to a degree that is inconclusive.

Incongruences and uncertainties exist at the scale of the embryo, too. At one of the clinics I visited in California – the only one with its own in-house lab and research program – researchers were using surplussed aneuploid embryos to examine the concordance between the ploidy status of the trophectoderm (recall: the ring of cells that forms around the outside of the embryo that will become the placenta, from which the PGT biopsy is drawn) and the inner cell mass (the bundle of cells that will become the fetus). Their preliminary results suggested that the trophectoderm biopsy is not always representative of the ICM. This could occur for a number of reasons. First, the cells in the trophectoderm and those in the inner cell mass may be chromosomally unique; in a sample of about 50 embryos, they found significant discordance in about seven percent of them. Second, the biopsy process itself may affect the sample, producing false negatives and false positives. "Everybody's always thought about the embryo, worried about the effects of biopsy on the embryo, but we're worried about the sample," the lab director explained. "What kinds of artifacts does the biopsy cause on the sample? Because obviously the decision based on that analysis decides whether or not that embryo is used."

Finally, the embryo may be mosaic. From their position deep inside the embryo's cells, reproductive biologists have recently discovered a "new class of embryos" (speaker, ASRM 2017). Described by a researcher at the 2017 ASRM as "a biological phenomenon that we're finally able to see," mosaicism has, in recent years, moved to the center of debates over reproductive genetics and embryo transfer practices. Neither wholly normal nor wholly

abnormal, these embryos, called mosaics, contain both euploid and aneuploid cells (figure 3.2). The presence of mosaicism has significant implications for preimplantation genetic testing. A trophectoderm biopsy usually includes only about 5-6 cells, while the whole trophectoderm contains a hundred at the blastocyst stage. This means that, depending on the section of cells



### Figure 3.2 Embryo mosaicism

Mosaic embryos contain both euploid and aneuploid cell lines. As a result, depending which cells are biopsied during PGT, the results may show that the embryo is euploid, aneuploid, or mosaic.

removed, biopsy results taken from a single embryo could come back as normal, abnormal, or mosaic. Furthermore, because of the discordance between trophectoderm and ICM mentioned above, a mosaic test result does not necessarily mean a mosaic ICM, raising new and difficult questions about whether, when, and how to transfer mosaic embryos.<sup>45</sup>

In part as a result of this technological uncertainty and because of practitioner concerns over potential or perceived mis-uses of the technology, in some clinics the application of PGT-A has been restricted to patients who meet predetermined clinical indications for the test: those who have experienced unexplained recurrent pregnancy loss, those who have had repeated

<sup>&</sup>lt;sup>45</sup> Mosaic results likewise raise questions about the viability and genetic status of fetuses during prenatal testing. Unlike during PGT, in prenatal testing it is possible to determine whether the mosaicism is confined to the placenta or whether the fetus itself is mosaic, for example through chorionic villus sampling, opening up a range of different treatment and intervention options.

implantation failure over the course of multiple IVF cycles, and women with "age-related" risk factors. As others have documented in relation to screening technologies like ultrasound and amniocentesis (see for example Duden 1993; Rapp 2000; Tremain 2017), advanced maternal age is understood as a significant risk factor and powerful predictor of aneuploidy. "When we're at age 20, one fifth of our eggs are chromosomally abnormal. And as we get older, we see that our egg abnormality or aneuploidy rates are nearly 100 percent in our forties. Nothing in life is zero or 100 percent, but our eggs have a shelf life," one clinician explained.<sup>46</sup> Results of randomized control trials measuring the effectiveness of PGT-A for women over the age of 35 are unclear – some show significantly improved implantation and live birth rate while others do not. According to interviews conducted with clinicians in California, observations at the ASRM, and the promotional materials provided by biotech firms like CooperGenomics, despite these uncertainties PGT-A is promoted as best practice for older women experiencing difficulty conceiving. For women aged 38-40, a CooperGenomics informational booklet cited an ongoing pregnancy rate almost three times higher with the use of PGT (2017).

In contrast to the clinics that have restricted the use of PGT-A, many have introduced the tests as standard practice. Given the relatively high rate of embryo aneuploidy – "again, nothing is ever zero percent or 100 percent, but virtually every single batch is going to have an abnormal embryo in it," the same clinician told me – many clinics now perform the test routinely alongside IVF for all patients. Biotech firm pamphlets and materials – circulated around the ASRM and available in the waiting rooms of many of the fertility clinics I visited in California – promote the

<sup>&</sup>lt;sup>46</sup> I was often asked my own age during interviews with fertility doctors or embryologists. Twenty-nine at the time, I was advised (usually in a tone both explanatory and tongue-in-cheek) that my fertility had already declined significantly over the last decade.

test as a standard component of fertility treatment when using IVF. "Is PGS [PGT-A] right for me?" asks a CooperGenomics brochure. The answer: a resounding yes. "All couples are at risk of producing chromosomally abnormal (aneuploid) embryos ... PGS [PGT-A] is appropriate for the vast majority of IVF patients" (2017). As concerns over the implications of embryo biopsy on embryo quality wane, and as the technology itself becomes more "widely available, easier to access, and more cost effective, people are developing a comfort with it," a clinician explained to me during our interview at her Sacramento area clinic. "It seems pretty unregulated," I replied, "Like, as long as you can pay you can get access." "Yeah, yep. That's another reason," she responded. "The whole free market thing. ... People are more affluent around these parts [of California]." In California, the average screening rate across clinics is around 60 percent and rising rapidly; in some clinics, this number skyrockets to more than 90 percent – nearly every single embryo is tested using PGT-A.

## **3.1.2** Preimplantation genetic testing for monogenic conditions

In addition to the array of potential complications caused by chromosomal errors, embryos may also carry specific genetic mutations in their cells. Preimplantation genetic tests for monogenic conditions are used to screen embryos for precisely such mutations. "For those with a genetic disease in the family," a CooperGenomics (2018) brochure reads, "the decision to have a baby can come with added concerns about the health of your future child. ... PGT-M is an option that allows you to take action before pregnancy to give you the confidence that a healthy child is on the way." The test has three primary applications. Most commonly, it is used when one or both of the intended parents is at an increased risk of passing on a specific genetic condition such as cystic fibrosis or Huntington's disease. Parents' risk of transmission is established in four primary ways: through a multi-generation family medical history; through expanded carrier

screening, a form of personalized genetic testing used to detect heritable conditions prior to conception, discussed further below; genetic testing on products of conception<sup>47</sup> following a spontaneous abortion, miscarriage, or still-birth; or as the result of the live birth of a healthaffected child. Less frequently, PGT-M is used to select an embryo with a particular blood or bone marrow type to create a future donor, or "saviour sibling," for an existing affected child. Recent cases in Canada (Ghebreslassie 2017), the United Kingdom (Walsh 2010) and the U.S. (Shapiro 2018) have stirred public controversy over the practice, which is at once celebrated as a life-saving medical breakthrough and decried as an example of runaway science and lagging regulation (on the saviour sibling debate, see Franklin & Roberts 2006). Finally, PGT-M can be used for what practitioners call "intentional diminishment": the intentional selection of an embryo with a genetic mutation, usually one the parents carry, often related to sensory or mobility conditions such as deafness (see Gray 2008) or dwarfism (see Sanghavi 2006). Although cases of intentional diminishment are extremely rare, they were a frequent topic of discussion at the ASRM, where many expressed concern that the practice represents the misuse of a technology intended to eradicate, not reproduce, illness and disability. As I discuss in more detail in Chapter 4, many clinics have strict policies in place to prohibit the transfer of embryos diagnosed as abnormal via PGT, regardless of parental wishes, reproducing the presumption that intervention is permissible – even preferable – in cases of genetic and chromosomal abnormality and the construction of PGTs as technologies of termination.

<sup>&</sup>lt;sup>47</sup> Products of conception refers to the tissues produced during pregnancy, such as embryonic, fetal, and placental tissue.
Like PGT-A, the efficacy of PGT-M relies on genetic maps – in this case, maps that plot the absolute locations of disease-causing mutations on the 23 pairs of chromosomes that sit within the nucleus of each biopsied cell. As geographer Edward Hall (2003, 152) argues, these biological maps "are central to the construction of knowledge about the (mal)function of genes and their relation to bodily (mal)function," providing the only means by which the genes associated with specific conditions can be identified. "We have to know the exact mutation, and its exact locus, to have a diagnosis established," a clinician explained to me during our interview at his clinic in the San Francisco Bay Area. If the location of a disease-causing mutation is not known, the test cannot be directed to the appropriate stretch of DNA on the right chromosome. If it is known, the test can be targeted. So, for example, if an intended parent or couple present with a family history of Tay-Sachs disease the test will examine the long arm of chromosome 15 at position 24.1, the locus of the HEXA mutation that causes the disease. If someone with Huntington's disease wants to screen their embryo for the condition, the test will look for a mutated HTT gene on the short arm of chromosome 4 at position 16.3. Conditions are added to the list as their associated genes are located within the genomic landscape. "Any disease that comes along, if we can sequence the gene, we can test the embryo," a lab director told me. Reproductive genetics company CooperGenomics advertises PGT-M for more than 6,000 single gene conditions, including BRCA 1 and 2,<sup>48</sup> Cystic Fibrosis, Huntington's disease, Sickle-Cell Disease, and Spinal Muscular Atrophy (2017). Advances in deciphering the genome since the conclusion of the HGP have driven rapid growth in the number of detectable genetic conditions

<sup>&</sup>lt;sup>48</sup> BRCA is a cancer susceptibility gene that puts carriers at increased risk of breast and ovarian cancer. The gene received significant media attention in 2013 following Angelina Jolie's opinion piece in the New York Times, "My Medical Choice." In it, Jolie chronicled her preventative double mastectomy, intended to reduce her likelihood of developing breast cancer as a carrier of the BRCA gene.

and, in turn, in the clinical applications for PGT-M. Mutations associated with familial Alzheimer's disease, hereditary cancer predisposition, and Familial Hypercholesterolemia LDLR-Related,<sup>49</sup> for example, have recently been added to the list.

The use of PGT-M remains relatively uncommon during fertility treatment. During our interview at her clinic in Sacramento, one clinician told me she had performed less than ten in as many years. Another described PGT-M cycles as a "very, very small" proportion of the hundreds of PGT-A cycles they might perform in a year. Usage rates are increasing steadily in the United States, however, where there are no regulations governing the use of these tests (Bayefsky 2016). One study presented at the 2017 ASRM found an increase in the PGT-M caseload of almost 30 percent between 2014 and 2016. At the 2018 meeting, a clinic shared their data on screening for cancer predisposition, showing an increase in the number of PGT-M cycles from less than five in 1999 to more than 100 in 2017. Much of this growth is attributed to the inclusion of expanded carrier screening as a routine part of fertility treatment. Carrier screening is a form of personalized genetic testing in which intended parents or gamete donors are tested as potential carriers of recessive or X-linked conditions that could cause a genetic disorder in their offspring. If both partners are carriers of a recessive condition, their child has a 25 percent chance of inheriting the disease. If the female partner is a carrier of an X-linked condition, her male child has a 50 percent chance of having that condition. Under the logic of PGT-M, non-symptomatic carriers of heritable genetic conditions are sub-fertile, given that they are incapable of reliably reproducing a genetically normal child. And increasingly within fertility practice, everyone is

<sup>&</sup>lt;sup>49</sup> Familial Hypercholesterolemia LDLR-Related is an inherited disorder associated with high cholesterol levels in the body and a 20-fold increase in risk of early coronary artery disease and heart attack.

considered to be at risk of carrying a heritable genetic condition. "Every person has an average of six recessive mutations that could cause genetic disease in future generations," a GenePeeks brochure informs its readers. The more conditions you screen for, the greater the chance of a positive result. Promotional materials for CooperGenomics's CarrierMap<sup>TM</sup> test, which screens for over 300 conditions, report that 45 percent of individuals are identified as carriers of at least one condition, and almost four percent are at risk of transmitting that condition to their offspring (2017).

In response to this sense of heightened genetic risk, some clinics have made personalized genetic screening a condition of fertility treatment. The director at a Bay Area clinic explained to me that they screen everyone with a 24-gene panel that includes common mutations associated with conditions like thalassemia, cystic fibrosis, spinal muscular atrophy, and Fragile X:

It's a prerequisite for acceptance into the program. ... It's mandatory. We do the 24-panel as well as looking at a four-generation pedigree<sup>50</sup> to see if there's anything we missed. We've picked up on all sorts of things. A 38-year-old woman who didn't realize that four of her extended family had colon issues. And she turned out to have colon cancer which was found on the colonoscopy that the genetic risk assessor said should be done.

The goal of these screening practices: to reduce live births with genetic diseases for couples or individuals who were *previously unaware of those risks*.<sup>51</sup> According to a speaker at the 2017 ASRM, in about 80 percent of cases with a single gene disorder there is no known family history prior to the birth of an affected child, meaning the parents did not know they were carriers. Providing (and in some cases, requiring) the option of carrier screening helps to ensure that

<sup>&</sup>lt;sup>50</sup> Family history

<sup>&</sup>lt;sup>51</sup> As opposed to those who already know their risk, for example because of the birth of an existing affected child.

couples and individuals are aware of their carrier status prior to attempting to conceive, "empowering ... patients in their decision to build a healthy family" (speaker, ASRM 2017).

Carrier screening is increasingly being promoted as an essential item on the "pregnancy checklist" for anyone planning to conceive – fertile or infertile.<sup>52</sup> "Healthy babies start here" reads the slogan for one company's expanded carrier screening program. "As we get more genetic information about people, we're doing more carrier screening for gene mutations, and we're doing more PGD [PGT-M] for individuals" a clinician told me. "We're reaching a point where patients will come in and they'll have a test for 300 recessive gene mutations, so with that their partner will be tested and there's a probability that they will both be positive." The tests offer, in effect, an individualized, future-oriented risk management strategy intended to reduce the likelihood of an abnormal birth by combing through intended parents' genes for evidence of mutation. Such individualized understandings of genetic risk are an integral part of the apparatus through which the abnormal embryo comes into being. As the PGT-M caseload increases, driven by increasing rates of personalized genetic testing, so too does the number of embryos designated as abnormal on the basis of their test results.

### 3.2 Situating abnormality

As the eighteenth century slipped into the nineteenth, Foucault writes in *The Birth of the Clinic* (1994), the body acquired a new place in the study and classification of disease. Once visible only in the flat, two-dimensional space of the nosological table, illness and disease began to find their place in their bodily seat: articulated upon the thick, dense volume of the organism,

<sup>&</sup>lt;sup>52</sup> Acknowledging that preconception carrier screening is not always possible, especially in middle- and low-income countries, the March of Dimes Birth Defects Foundation (2006, 55) recommends it as "a tool of primary prevention" that should be offered to everyone before conception.

embodied within a system of bones, organs, blood vessels, fatty deposits, and tissues. Foucault calls the emergence of the body as a key site in the observation, study, and classification of disease "the secondary spatialization of the pathological" (*Ibid*, 10).<sup>53</sup> During this period, attention shifted from the classification of diseases in their taxonomic family tree to discerning and isolating corporeal forms, structures, variations and anomalies. The clinical gaze, Foucault writes, "plunges into the space that it has given itself the task of traversing. ... The medical eye must see the illness spread before it, horizontally and vertically in graded depth, as it penetrates into the body, as it advances into its bulk, as it circumvents or lifts its masses, as it descends into its depths" (136). In the nineteenth century, in other words, the body became the object to which medical observation addressed itself in its quest to discover the sites from which pathological development radiates and unfolds. Just as the navigators of the time were mapping the new world, anatomists and physicians were surveying, exploring and charting the topography of the body in an endeavour to diagnose disease and forestall death (Sawday 1995; Waldby 2000). In the wake of the secondary spatialization, "the whole dark underside of disease came to light, at the same time illuminating and eliminating itself like night, in the deep, visible, solid, enclosed, but accessible space of the human body" (Foucault 1994, 195).

Foucault acknowledges that the solid geography of blood, bones, and organs is only one – and in all likelihood, neither the first nor the most fundamental – way in which we might spatialize disease. "There have been, and will be, other distributions of illness," he writes (1994, 3). Gene mapping represents one such method of distribution. The Human Genome Project and

<sup>&</sup>lt;sup>53</sup> Foucault (1994) identifies three spatializations: the primary spatialization, which refers to the organization of diseases into nosological tables, where the proximity of one disease to another indicated its degree of kinship; the secondary spatialization, in which illness comes to be interpreted in relation to the concrete materiality of the body; and the tertiary spatialization, in which disease and ill-health become the purview of the medical clinic.

the "wondrous" maps it produced impelled the involution of the medical gaze deeper into the body still, placing "abnormality" in genes, on chromosomes, within nuclei, inside the cells that make up the whole tissues and organs that were the focus of nineteenth century anatomists and physicians. As Hall (2003, 154) writes, "the map of the human genome encapsulates a progressive and deepening spatialization of the genes and the body." Physical maps plot the absolute location of genes on chromosomes: BRCA 1 on the long arm of chromosome 17 at position 21.31, Hemophilia A on the long arm of the X chromosome at position 28. Expression maps connect these genes to particular traits, linking them in precise ways to the morphological terrain of the body: to breast cancer and bleeding disorders. Under the rubric of gene mapping human traits find their seat in molecular space, becoming visible in a spatial system of genes and chromosomes.

As Doreen Massey (1999a, b) has argued, the process of making something spatial allows it to be known, interpreted, and ultimately controlled and manipulated. Although different in format from cartographic representations of land and water, gene maps likewise imply the possibility of mastery over nature, sharing an "explorer analogy" (Squier 1994, 61) that seeks to render our internal biology as visible, legible, ordered terrain (Hall 2003; Wald 2000; Zward 2009). Deeply embedded in the production of these maps is the assumption of a physical territory that can (and will) be read and plotted in its totality. "The scientist," – or in this case, the geneticist – "becomes the European explorer, mapping the dark continent, achieving control over all its little denizens" (Squier 2004, 61). As Steven Hsu (2018), co-founder of reproductive genetics corporation Genomic Prediction, said in a recent lecture on gene mapping: "[Our

skeptics] say to us 'You'll never be able to do<sup>54</sup> cognitive ability. Cognitive ability is too hard.' Just watch the skeptics get crushed as progress continues." Like their more traditional cartographic counterparts, gene maps offer a way of enclosing a territory – in this case, corporeal territory – through accurate, technical, spatial depictions of real elements (genes) such that they can be known in precise and specific ways (Haraway 1997). As more and more genes and genetic interactions are mapped, a multitude of physiological and psychological conditions become visible in geography of our genes; genes themselves are condensed and consolidated as master molecules, as fetishized things-in-themselves, as, to borrow again from Collins, a detailed blueprint for human living-being.

As I discuss further in Chapter 5, this process of enclosure via map-making readies molecularized life for further exploration, management, commercialization, contract, speculation, even sale. In the fertility clinic, this cartographic knowledge, read by preimplantation genetic tests, becomes a technology of government. By making it possible to identify embryos carrying deleterious traits in the geography of their genes, the spatialization of abnormality along chromosomes, inside nuclei, inside embryos facilitates its management, drawing a boundary between the normal and the abnormal and, in turn, furnishing a mechanism of control over the outcome of biological reproduction and the reproductive future.

Enthusiasm for gene mapping is greater than ever in the postgenomic era (Stevens & Richardson 2014a, b). In part, this is because the cost of whole genome sequencing has fallen dramatically. What took the HGP 15 years and almost \$3 billion dollars to accomplish now costs

<sup>&</sup>lt;sup>54</sup> By "do," Hsu means "map" – skeptics believe that scientists like Hsu will never be able to map the complex genetic sequences and interactions that allow them to predict IQ.

about \$1000 and takes less than 24 hours. This means it is now possible to sequence the whole genomes of hundreds of thousands of people, at relatively low cost, in the hunt for genes associated with particular human traits. As Bronwyn Parry (2013; see also Parry & Greenhough 2018) notes, this newfound ability to extract individual, genome-wide genetic information from cohorts of tens, even hundreds, of thousands of people is producing an unprecedented volume of bioinformation, including information on the role of specific genes in human physiology and behaviour.

In 2015, the 1000 Genomes Project published an integrated genetic map of structural variation in 2,504 human genomes donated by individuals belong to 26 discrete populations.<sup>55</sup> Structural variations have been implicated in phenotypes ranging from cognitive disabilities to cancer predisposition. The primary goal of the project was to complete a detailed catalogue of human genetic variations, which can in turn be used for association studies linking genetic variation to disease. The 1000 Genomes Project is just one of the many large sequencing projects recently completed or currently underway. In 2014, researchers using data from the Psychiatric Genomics Consortium – an international consortium of scientists conducting meta- and mega-analyses of genome-wide genetic data – pooled samples from more than 150,000 people, of whom 36,989 had been diagnosed with schizophrenia. Their research uncovered 108 loci where the DNA sequence in people with schizophrenia tends to differ from those without the disease (Ripke et al. 2014). In September 2019, the UK Biobank announced that it would be partnering

<sup>&</sup>lt;sup>55</sup> The data was collected from anonymous, volunteer donors over the age of 18, each of whom declared themselves to be healthy at the time of collection. Participants consented to a blood draw, to have a cell line made from that draw, to have all of their genetic information included in a scientific database available on the internet, and to the use of these samples by scientists. They were variably compensated for time, travel, and inconvenience. The informed consent process included a section specifying that donors will not receive any of the profits resulting from any commercially products resulting from the use of their sample.

with four pharmaceutical companies and the Wellcome Sanger Institute to fully sequence the genetic codes of the 500,000 participants whose DNA is stored in the bank.<sup>56</sup> At an estimated cost of \$247 million, the project aims to generate new knowledge that could "unlock the causes of some of the most terrible diseases and how we can best tackle them" (Leadsom, quoted in Wired Magazine 2019), ushering in what Patrick Vallance, President of R&D and GlaxoSmithKline called "a new era of drug discovery." GlaxoSmithKline also signed a \$300 million agreement with direct-to-consumer genetic testing company 23andMe, granting the pharmaceutical giant access to the saliva – and thus the genetic information – of 23andMe's five million customers for use in drug discovery and development. Samples contained in the UK Biobank have also been used to find the genetic loci associated with loneliness (Day et al.), risk-taking behaviour (Strawbridge et al. 2018; Linnér et al. 2019), and cognitive function (Davies et al. 2016), among other traits.

The projects evince the genocentric thinking that continues to dog biomedicine in the postgenomic era. As Haraway (1997) has argued, the gene that animates this thinking is deeply fetishized: a contingent, semiotic, historical, social, and located entity that is mistaken for a fixed, seemingly objective thing. In making this argument, Haraway borrows from Karl Marx's concept of commodity fetishism – the idea that the social relations of labour that produce objects for market are concealed in capitalist exchange, made to appear as relations between material objects. Contemporary genetic technologies are deeply implicated in the production of genes and embryos as sources of value in capitalist market relations. Direct-to-consumer genetic tests and

<sup>&</sup>lt;sup>56</sup> Participants aged 40-69 years old were recruited by UK Biobank between 2006-2009. They provided blood, urine, saliva samples, and detailed personal information for future analysis, and have agreed to have their health followed. 100,000 participants wore a 24-hr activity monitor for a week, and the UK Biobank has recently embarked on a study to scan 100,000 participants (brain, heart, abdomen, bones & carotid artery). Participants are not compensated.

tailored pharmaceuticals and therapies promise large profits to private corporations like Glaxo-Smith-Kline and 23 & Me, who pay relatively nominal fees for access to what Parry and Greenhough (2018, 4) describe as an "exceptionally valuable" new resource: bioinformation.

But for Haraway, gene fetishism is not reducible to capitalization or commodification. Genes are "thing-like" even if they are not commodified, and the relations belied by the process of fetishization are not just social labour relations. The fetishized gene is not only a source of economic value, but also of social value – a "code of codes" (Haraway 1997, 147) understood to convey an essential truth about the body, including information about individual health and wellbeing (see also Nelkin & Lindee 2004). As James Watson, co-discoverer of DNA, said in 1989: "We used to think our fate was in our stars. Now we know, in large measure, our fate is in our genes" (quoted in Jaroff 2001). We see this fetishization at work, for example, in stories announcing that a genetic firm is spending millions of dollars to sequence the genomes of star athletes, looking for the genetic basis for athleticism (Kayayerli 2017); that our DNA can predict our chances of financial success (Ward 2018); that a "motivator gene" may determine a horse's willingness to race (O'Sullivan 2019); or that University of Connecticut geneticists are studying the DNA of Sandy Hook shooter Adam Lanza for evidence of abnormalities or mutations associated with an increased risk of violent or aggressive behaviour (Walshe 2012). These and other stories populate the pages of newspapers, magazines, academic journals and books, films, and novels.

And we see it, too, in the routinization of "genetic testing for every step in the family planning journey" (CooperGenomics 2017). The results of gene mapping projects wind their way into assisted reproduction via the proprietary preconception, preimplantation, and prenatal screening platforms developed by biotech companies like CooperGenomics, Illumina, and

Genomic Prediction and peddled to fertility clinics at conferences like the ASRM. Some of these companies have even begun their own mapping projects. Genomic Prediction, for example, has sequenced the genomes of hundreds of thousands of tissue donors – whose samples are accessed through, among other sources, the UK Biobank – looking for the combination of genes that will predict height (Hsu 2018) and IQ (Regalado 2017). On a platform of what they call Expanded Preimplantation Genomic Testing, or E-PGT, Genomic Prediction plans to begin offering intended parents risk assessment reports for polygenic disorders – those involving variants in multiple genes. These reports identify IVF embryos whose genetic scores place them at the wrong end of the statistical curve for conditions like type 1 and 2 diabetes, coronary artery disease, heart attack risk, intellectual disability, and idiopathic short stature. Under the logic of PGT, these and other genes become the threshold for implantation decisions, operationalized as a tool for partitioning and controlling reproduction on the basis of anticipated health outcomes.

In these mapping endeavours we can see evidence of what Charis Thompson, borrowing from military terminology, calls "mission creep" (personal communication 2017): the extension of preimplantation genetic testing beyond disease-specific applications and into the realm of embodied enhancement by technoscientific means. These projects reflect a new and intensifying focus on health, broadly conceived, in addition to the more traditional focus on illness, disease, and injury – part of what Adele Clarke and her collaborators call "biomedicalization" (2000, 2003, 2009, 2010). As I discuss further in Chapter 4, they reproduce an assumed-to-be-shared assumptions about what constitutes a healthy human body and life, and a concomitant pathologization of that which does not meet this healthy form.

In much the same way that the gene is fetishized, so too might we consider the extracorporeal embryo a contingent, semiotic, historical, socio-technical and located entity that is

mistaken for a fixed, seemingly-objective, developmental thing-in-itself. Concealed in the work processes of PGTs are all the institutions, narratives, legal structures, power-differentiated human labours, technical practices, affective desires, social norms (and much more) in and through which the abnormal embryo comes into being. By cultivating the notion that embryos can be classified as normal or abnormal, reproductive or non-viable, on the basis of their genes, PGTs consolidate abnormality as a natural property of biological life, an objective quality that inheres in its very building blocks. In the fertility clinic, the presence or absence of these abnormalities is used to categorize whole embryos as normal or abnormal; these classifications in turn imply risks of material conditions, defined as illness, disease or disability, conveying a seemingly self-evident measure reproductive value (or lack thereof).

Used to scour embryonic cells for evidence of abnormal genetic and chromosomal arrangements – read as a set of "displaced, destroyed, or modified elements bound together in a sequence according to a geography that can be followed step by step" (Foucault 1994, 136) – PGTs affirm that our fate is, indeed, in our genes. Biological abnormality is mistaken as a fixed, pre-existing, transhistorical, and transcultural property of biological life. In the process of fetishization, categories of illness, "defect," deviance, and disability are naturalized as biological markers of inferiority, as innate characteristics that are fundamentally damaging to the biological fabric of the population. The social, biomedical, legal, and political structures that hierarchize biological variation as normal or abnormal, healthy or pathological, viable or non-viable remain invisible. As Rosalind Petchesky (1984) has argued, this kind of biological reductionism fuels an obsessive focus on embryos (and fetuses), affirming them as key sites in the management and disciplining of life itself (see also Rose 2007). Understood as the result of the union of two individuals' genetic material – a genesis story written and produced by modern human

embryologists over a century ago – embryos constitute a crucial space-time in the governance of the human species and its socio-biological future.

# Chapter 4: Abnormality as bio-social hierarchy

In November 2001, parents Sharon Duchesneau and Candace McCullough welcomed into the world their second child, a baby boy they named Gauvin. Like his older sister Jehanne, Gauvin was conceived through assisted insemination. Also like his sister, he was born deaf. For their parents, Gauvin and Jehanne's congenital condition was a welcome, if not entirely unexpected, surprise. Both deaf themselves, Duchesneau and McCullough had sought out the sperm of a congenitally deaf donor prior to conceiving each of their children. After being turned away from a number of local Maryland sperm banks – congenital deafness, these banks informed them, is precisely the sort of condition that disqualifies would-be donors – they turned to a friend with five generations of deafness in his family. Said McCullough: "I would say that we wanted to increase our chances of having a baby who is deaf" (Mundy 2002). "A hearing baby would be a blessing. A deaf baby would be a special blessing," Duchesneau added (*Ibid*). Together with the four generations of deafness on Duchesneau's side, the couple's genetic counsellor gave them a 50-50 chance that their child would be born deaf. With Gavin's birth, they were two for two.

In 2002, Duchesneau and McCullough's story was published in the *Washington Post Magazine* in an article written by journalist Liza Mundy (2002). Mundy's essay provided a detailed account of these women's reproductive choices, taking care to explain the women's understanding of deaf identity and to situate them within a nuanced understanding of deaf culture and community. The story was quickly picked up by newspaper and wire services across the United States and England, which promptly abandoned Mundy's balanced approach. While Mundy's account was, for the most part, sympathetic, subsequent publications roundly criticized the couple for their reproductive choices. The Family Research Council, a Washington-based organization that "champions marriage and family as the foundation of civilization" issued a press release with comments from Ken Connor, the group's then president. Describing Duchesneau and McCullough as "incredibly selfish," Connor reproached them for imposing on their children the burden of disability. "One can only hope," Connor wrote, "that this practice of intentionally manufacturing disabled children in order to fit the lifestyle of the parents will not progress any further" (quoted in Kafer 2013, 77). Said bioethicist Arthur Kaplan in an interview with the Lancet, while the use of these technologies for "disease avoidance is clearly ethically defensible," this couple's decision took away the child's choice, imposing on him "functional limits" (McLellan 2002).

Although McCullough and Duchesneau did not use PGT-M to select their embryo, their story stirred, and continues to stir, controversy over "intentional diminishment," the practice of expressly conceiving a child with a genetic mutation, usually one the parents themselves carry; the most common examples are deafness and achondroplasia (drawfism). In one out of dozens of admonitory and accusatory letters to the *Washington Post* following Liza Mundy's 2002 article on the couple, one reader wrote: "That three people (I include the sperm donor) could deliberately deprive another person of a natural faculty is monstrous and cruel ... There are laws that give access to medical care for children of parents who would deny it on religious grounds. There should be similar protections for children subject to the abuse of being *genetically programmed to replicate the disabilities of misguided parents*" (*Washington Post* 2002) [emphasis added].

Emblematic of the criticism faced by Duchesneau and McCullough in the wake of their reproductive decision, this letter writer's words reflect much broader ideas about the nondesirability of particular forms of genetic variation and difference. In Chapter 3, I examined how preimplantation genetic tests and the gene maps on which they rely cultivate notions of normality and abnormality as natural forms of biological difference engrained in the very substrate of life. Here, I am interested in how, together with deeply held social and cultural assumptions about the healthy, normal bodies we are supposed (to want) to have and reproduce, this particular form of difference operates to surplus abnormal embryos out of reproductive futurity. Anxiety surrounding the birth of abnormal babies has bred a pervasive reluctance among fertility care providers to transfer abnormal embryos, which are cast as a non-viable remainder to the IVF process. My aim is to bring into view the complex set of relations in and through which abnormal embryos are devalued as reproductive entities – only to be revalued, as I explore in Chapter 5, as productive scientific objects in the study of disability and disease. The biological norms examined in Chapter 3, I argue, cannot be separated from social understandings of health and pathology. Distinctions between the biomedical norms of the body and the disciplinary norms of society cannot be maintained (Rose 2009). Like science and biomedicine themselves, vital norms of longevity, procreative capacity, sexual dimorphism, weight, disease, pathology, ability, and cognitive capacity – in short, of prevailing notions of health – are socially and politically produced, filtered, and embedded.

As I discuss in Chapter 3, advances in genetic science, biotechnological innovation, and massive gene hunting projects have combined in the fertility sector to proliferate the number of genetic and chromosomal conditions for which embryos are routinely screened. In concert with increasing rates of PGT and a widespread reluctance to transfer abnormal embryos, these changes have produced a growing reserve of embryos seen to have no future life potential. Many of these are very likely non-viable, carrying multiple, complex mutations and genetic variations never observed in a live-born human. My interest in this chapter is in the small subset of abnormal embryos carrying variations that are "potentially compatible with life," to use the

language of the fertility clinic. These include embryos with viable aneuploidies identified during PGT-A (e.g. trisomy 21, or Down syndrome) and those carrying specific genetic mutations discovered during PGT-M (e.g. embryos with cancer predisposition genes). These embryos, I argue, are not surplus but *surplussed*, rendered surfeit by a constellation of technoscientific, biomedical, legal, and social practices and power relations. Debate over the reproductive value of these embryos is thus inseparable from a broader politics of social difference – from a process of hierarchical difference-making in which some bodies are rendered desirable, some lives worth living, while others are controlled, eliminated, or averted on the basis of their biology. Against the classification of abnormality as a natural fact, then, this chapter offers an exploration of abnormal embryos as social and political entities embroiled in power relations.

In conceptualizing abnormal embryos as social and political, I am not contesting the material existence of biological variation or its corporeal effects. Rather, I follow Banu Subramaniam (2014) in insisting that the questions of variation that lie at the heart of the biological sciences – and, I would add, at the heart of twenty-first century fertility medicine – are also thoroughly implicated in social and political questions about the value and purpose of human difference; how we understand and (de)value variation is, as Subramaniam writes, "fundamentally about power – the politics of life and death" (7). At the genomic level, none of us is "normal." We all harbour, in the 20,687 genes that make up our 23 pairs of chromosomes, variations of both known and unknown significance. There is, in many ways, no normal human genome; variations thus involve questions about the social value of particular kinds of difference; they can never be disentangled from a culturally and historically specific normativity (Waldby 1996). In the fertility clinic, genetic and chromosomal "abnormalities" remain a means

of classifying, ordering, hierarchizing, and (de)valuing variants in ways that both reflect and reproduce idealized definitions and categories of health, which are vacated of their historically specific social, economic, and political meaning. And so too does the translation of social norms around health into everyday clinical practice reinforce and change the various expressions of these norms beyond the clinic, placing restrictions on and contributing to the fashioning of the embryo, human life, and the future.

#### 4.1 Surplussing abnormal embryos

Each time a preimplantation genetic test is run two related determinations are made: whether the embryo is normal or abnormal; and whether it will be made available for implantation or not. Because there is no specific law in the United States governing the transfer of genetically and chromosomally abnormal embryos,<sup>57</sup> transfer policies are typically negotiated on a clinic-by-clinic basis. In an opinion recently published in *Fertility and Sterility* (2017), the Ethics Committee of the American Society for Reproductive Medicine (ASRM) strongly encouraged fertility clinics to draft written policies regarding their program's position on the transfer of embryos with known genetic or chromosomal anomalies. "Whether intentional or incidental," the committee writes, "the discovery and request for the transfer of embryos likely to result in the birth of offspring with health-affecting conditions pose ethical dilemmas for physicians and their staff, patients, and society" (1131).

<sup>&</sup>lt;sup>57</sup> In contrast the U.S., the U.K. explicitly prohibits the selection of an embryo for treatment if it is known to 1) have a gene, chromosome, or mitochondrial abnormality involving a significant risk that the person with the abnormality will develop a serious physical or mental disability, a serious illness, or a serious medical condition; or 2) be of a sex that carries a particular risk that any resulting child will have or develop a gender-related serious physical or mental disability, serious illness, or serious medical condition. In cases where there is no other embryo suitable for transfer, an embryo with these characteristics may be transferred (Human Fertilization and Embryology Authority 2019). The U.K.'s regulations on anomalous transfers are in keeping with much tighter ART restrictions more broadly, including limits on who can access PGTs during fertility treatment. These restrictions do not exist in the U.S.

Many clinics have responded with transfer policies that prohibit the use of abnormal embryos for reproductive purposes. This position is supported by the committee.

Transferring an embryo that is highly likely to result in the birth of a child with a serious disease or disability can be interpreted as the physician causing harm by facilitating the birth of an unhealthy person. ... Physician assistance in the transfer of embryos in this category is ethically problematic and therefore highly discouraged. This conclusion is consonant with prior Committee analysis that physicians may be morally obligated to withhold services when significant harm to future children is likely (1134-5).

Provider refusal to transfer embryos in which a child is highly likely to be born with a condition that is treatable or effectively manageable through medical intervention likewise falls within "appropriate ethical boundaries" (*Ibid*, 1135). As I recorded in my fieldnotes from an interactive session at the ASRM, 59 percent of audience members responded that they would never transfer abnormal embryos under any circumstances. Thirty-six percent said that they would consider transferring such an embryo only under certain conditions, for example if it is a patient's only opportunity for biological parenthood. Only three percent responded that they would transfer abnormal embryos for reasons of patient autonomy.

In what Charis Thompson described to me as a "collapse of the abnormal with the nonviable" (personal communication 2017), embryos that screen positive for non-fatal abnormalities are subject to the same prohibitive transfer policies. Indeed, abnormal embryos or embryos with a high degree of mosaicism that are "potentially compatible with life" are often the last choice for transfer, behind those carrying lethal mutations. This is because the risk of an affected birth is lower in the latter case. If the PGT test results are incorrect or if the mosaic embryo selfcorrects,<sup>58</sup> the non-viable embryo could result in a healthy, live birth. However, if the results are correct or the embryo does not self-correct, the viable embryo could result in the birth of a health-affected child, whereas the non-viable embryo could only result in a loss. Many clinics' transfer policies reflect this logic. "It is ethical to consider the transfer of embryos ... reported as aneuploid as long as reported aneuploidies are known to be lethal," writes the Center for Human Reproduction (CHR) in their transfer policy, published online in 2014. "Non-lethal' chromosomal abnormalities can lead to genetic disorders like Down syndrome and Turner syndrome (and others) if delivered. ... Potentially non-lethal aneuploidies should never be transferred." The CHR's position was echoed by all but one of the clinicians and embryologists I interviewed in California, with Down syndrome (three copies of chromosome 21) and Turner syndrome (a single copy of sex chromosome X, with no Y chromosome) frequently cited as specific examples by clinicians unwilling to transfer abnormal embryos.<sup>59</sup> "It's very uncommon for [fertility] practices to transfer a chromosomally abnormal embryo that would be compatible with life, like a Down syndrome type of embryo," a clinician told me during our interview at her San Diego area clinic. "It would be very infrequent." An embryologist at a small clinic in Palo Alto explained: "We will not take that risk of implanting these [potentially viable, abnormal] embryos and then somebody coming back to us and saying, you know, 'this baby isn't normal'. We just don't take any risk with it."

Transfer policies that prohibit the use of abnormal embryos for reproductive purposes are grounded in two primary justifications: one legal, the other medical. Legally, wrongful birth and

<sup>&</sup>lt;sup>58</sup> There is some evidence that mosaic embryos sometimes self-correct: euploid cell line takes over while the aneuploid line dies off, resulting in a normal live birth.

<sup>&</sup>lt;sup>59</sup> Down syndrome and Turner syndrome are among the highest live-born aneuploidies.

wrongful life suits, detailed in section 4.1.1, expose practitioners to legal action in the event that a child is born with a health-affecting genetic or chromosomal condition. Medically, clinicians are bound by the precepts of procreative beneficence and reproductive non-maleficence. In both cases, abnormality and abnormal births are constituted as an injury or threat: to intended parents, the child itself, or society as a whole.

### 4.1.1 Wrongful birth and wrongful life

The risk mentioned by the embryologist quoted above and by many other clinicians I interviewed is closely tied to the two types of legal action just mentioned: wrongful birth and wrongful life. Wrongful birth is a malpractice claim brought by the parent(s) of a child born with a birth defect against a physician or health-care provider whose alleged negligence deprived the parents of the opportunity to make an informed decision about avoiding or terminating the pregnancy. A lawyer I interviewed in California offered an example, a case he tried in which new parents sued their hospital following the birth of a child with no arms. "The ultrasound reports had said, you know, 'extremities present. Arms and legs normal'," he recounted. "But when the baby was born it came out without any arms. Not even shoulders!" In relation to PGT, these suits can arise if parents feel inadequately informed about the risks and costs associated with conceiving, giving birth to, and raising a child born with disabilities or other severe health conditions. "It's a very contentious ethical area because you just - is there truly ever a way to have informed consent about what it will be like to have a child with Down syndrome?" a clinician said during our interview at her Palo Alto clinic. "You have the potential that the parents could sue and say, 'we weren't truly informed or well educated about what that actually means to us'." Lab mix-ups (as

in the case of *Cramblett v. Midwest Sperm Bank*, <sup>60</sup> inaccurate or mis-read PGT results and insufficient genetic counselling resulting in the birth of a health-compromised child could also precipitate a suit.

Wrongful birth cases hinge on two criteria: first, parents must confirm that, had they been fully informed about the health status of their embryo or fetus, they would not have proceeded with the pregnancy. Second, the health-affecting condition must require "extraordinary expenses." It is these expenses that parents can recover if successful in their wrongful birth claim: the medical costs associated with caring for a child with a disability; the costs of tuition and special education; and, in some states, those associated with the emotional distress caused by learning of or living with a health-compromised child<sup>61</sup> – costs they would not have incurred had they terminated the pregnancy. While most U.S. states allow wrongful birth claims, they are rare and notoriously difficult to win. At the time of writing, 12 states<sup>62</sup> have statutorily banned these suits on the basis that doctors under threat of legal action may feel obliged to share information that could result in a termination even if they consider abortion

<sup>&</sup>lt;sup>60</sup> A recent case is emblematic of these cases as a whole. In *Cramblett v. Midwest Sperm Bank, LLC* Jennifer Cramblett filed a wrongful birth complaint against her sperm bank, alleging that it had mistakenly provided her with sperm from an African-American donor instead of that of the white donor she had pre-selected. She asked the court to recognize a claim to compensate her for the emotional distress of having to care for a child who is racially different than the child she and her partner desired. The complaint argues that the child's existence has caused "personal injuries, medical expenses, pain, suffering, emotional distress, and other economic and non-economic losses." The judge dismissed the lawsuit, agreeing with the defendant that a claim of wrongful birth "could not be legally sustained in a case where a healthy child was born" (Illinois Circuit Court 2014; see also Lenon & Peers 2017 for further discussion of the case and of others related to sperm donation and wrongful birth lawsuits).
<sup>61</sup> Other states prohibit compensation for emotional damages on the basis that parents "may yet experience a love that even an abnormality cannot fully dampen" (Court of Appeals of the State of New York 1978).
<sup>62</sup> These states are Texas, Arizona, Idaho, Indiana, Michigan, Minnesota, Missouri, North Carolina, North Dakota,

Pennsylvania, South Dakota, and Utah, Iowa was included on this list until June 2017, when the Iowa Supreme Court recognized a wrongful birth claim for the first time.

unethical. In these states, physicians are not required to share the health status of the embryo or fetus with the parents if they feel it may precipitate a termination.

The second type of legal action is wrongful life, also a malpractice claim. In wrongful life cases, legal suit is brought by or on behalf of a child affected by a genetic or congenital abnormality as a result of negligent advice or treatment from a health-care provider.<sup>63</sup> In the U.S., the first such case was heard in 1967 in the New Jersey Supreme Court. Brought in conjunction with a wrongful birth suit, the plaintiffs in *Gleitman v. Cosgrove* sued Mrs. Gleitman's doctor for failing to inform her that the rubella she contracted in the early stages of her pregnancy would likely lead to fetal impairment. The mother sued for the emotional distress caused by her son's birth defects; the father sued for the costs incurred in caring for their child; and the child sued for his birth defects. This last action constitutes the wrongful life suit.

The court's reasoning in agreeing to hear the suit was based on the presupposition that every child has a right to be born a whole, functioning human being – a right denied because of the alleged actions of the doctor. The court argued on the basis of this reasoning that, since this right had been infringed and the plaintiff subsequently born impaired (and thus not a whole, functioning human being), the harm was the impaired life itself. From the legal archive for the case:

> The plaintiff is therefore required to say not that he should have been born without defects but that he should not have been born at all. ... But for the negligence of the defendants, he would not have been born to suffer with an impaired body. In other words, he claims that the conduct of the defendants preventing his mother from obtaining an abortion which would have terminated his existence, and that his very life is wrongful (New Jersey Supreme Court 1967, 692).

<sup>&</sup>lt;sup>63</sup> Wrongful life claims are most often brought by the parents or legal guardians on behalf of their healthcompromised child.

The judge ultimately rejected the wrongful life claim in *Gleitman*, ruling that the sanctity of life prevailed over non-life, and that in any case monetary damages would be too difficult to calculate given that such a calculation would require the courts to measure a "life with defects against the utter void of non-existence" (New Jersey Supreme Court 1967, 692). But the precedent had been set for the admission of wrongful life suits before the courts and the construction of some forms of human life as "wrongful" in their essence.

The California case of *Curlender v. Bioscience Laboratories* (California Court of Appeal 1980) provides an early example of support for a wrongful life claim by the courts. The plaintiff in this case was born with Tay-Sachs disease, a heritable genetic disorder that progressively destroys neurons in the brain and spinal cord. The Curlenders had consulted Bioscience Laboratories to determine if they carried the gene for Tay-Sachs. The ensuing report suggested that they did not. In 1978 their daughter was diagnosed with the disease. In 1980, the parents sued on her behalf, arguing that the lab had incorrectly processed their genetic test results and were therefore responsible for bringing her into the world in an impaired state. The court in this case recognized that her "painful existence is a direct and proximate result of negligence by others," (826) and thus constituted an injury recognizable at law. The reality, the judges stated in their ruling, is that the "plaintiff both exists and suffers due to the negligence of others" (829).

From these two cases we see that the injury incurred in a wrongful life case is not the birth of a disabled or health-compromised child to unexpecting parents, but rather the impaired life itself. The geography of wrongful life claims is highly circumscribed by this allocation of injury. Most states have been extremely hesitant to weigh non-existence against life in an impaired state and to affix a monetary value to the difference. Life, these courts have ruled,

cannot be considered an injury; it is, in any and all conditions, preferable to non-existence. Today in the U.S., only Supreme Courts in California, Washington state, New Jersey, and North Carolina have ever allowed for wrongful life actions to proceed.<sup>64</sup> In these states, a child could recover damages for the duration of their lifetime, but only for costs directly associated with their medical care. As a lawyer explained to me during our interview at his San Diego-area firm, as in wrongful birth case, "one of the prerequisites for winning the case is testimony from the parents that they would have terminated had they known." This means that "you can't recover for loss of earnings and emotional harm, loss of enjoyment of life, because if the pregnancy had been terminated, you never would have had those things." In a legal catch-22, parents *must* testify that they would have terminated the pregnancy, but once this testimony is given the child can only recover damages associated with the costs of their care.

Despite these limits, the damage awards that can arise following the birth of a child affected by a genetic or congenital condition are steep. Recent wrongful birth cases in Oregon (Duerson 2012) and Florida (Yakren 2018) awarded parents \$2.9 million (for the birth of a child with Down syndrome) and \$4.5 million (for the birth of a child with no arms and one leg), respectively. These awards are much higher than those that might result from a fertility clinic's refusal to transfer an abnormal embryo, which are limited to dignitary harms, the costs associated with embryo procurement (e.g. reimbursement for IVF and PGT costs), and claims for the intentional infliction of emotional distress (Daar 2018).<sup>65</sup> We can begin to see, here, how the juridico-economic threat posed by the transfer of abnormal embryos and the birth of health-

<sup>&</sup>lt;sup>64</sup> North Carolina has not allowed a wrongful life suit to proceed since 1985.

<sup>&</sup>lt;sup>65</sup> No one I spoke with had ever been sued for refusal to transfer; if determined to use the embryo, patients will generally move to a clinic willing to proceed with the implantation of an abnormal embryo.

compromised children – characterized, quite literally, as *wrongful* – shapes embryo selection policies and practices. The law is incorporated into the fertility apparatus in a way that actively incentivizes restrictive transfer policies that prohibit the use of abnormal embryos for reproductive purposes, effectively rendering them surplus to the reproductive project.

Wrongful birth and wrongful life cases are rare and difficult for plaintiffs to win. Only a small handful of cases directly related to technologically assisted conception have been tried in the U.S., many of these involving sperm donation;<sup>66</sup> only a very small number have involved preimplantation genetic testing.<sup>67</sup> Thus far, all have been dismissed by courts or been resolved in favour of the physician defendants. Even so, the fertility practitioners I spoke with repeatedly cited these causes of action as justification for their unwillingness to transfer abnormal embryos following PGT. This was especially obvious during the interviews I conducted in California, a state that is, one lawyer explained, at the forefront of both wrongful birth and wrongful life litigation. But my observations at the ASRM suggest that it is true in other states as well. As Sarah Lochlann Jain (2006, 3) writes in her anthropology of U.S. injury law, tort law holds a vital place both in the judicial system and in American culture more broadly, "undoubtedly as a result of the lack of universal health care coverage, the dearth of regulatory bodies, and the particular qualities of money." Consequently, and combined with the shifty and unsettled nature of the law, the non-liability outcomes in many wrongful life and wrongful birth cases provide

<sup>&</sup>lt;sup>66</sup> See footnote 60 above.

<sup>&</sup>lt;sup>67</sup> In *Bergero v. University of Southern California Keck School of Medicine*, for example, parents of a boy born with Babry's, an X-linked recessive genetic disease, sued the physicians who performed IVF and PGT on the embryo resulting in their son's birth. The mother had previously been diagnosed as an asymptomatic carrier of the disease. Since the father was not a carrier, the couple sought PGT-M to determine which embryos were affected by the genetic mutation, and to rule out transferring any impacted male (XY) embryos. The couple moved forward with the transfer of what they were told were unaffected female (XX) embryos, but an affected male was mistakenly transferred. The jury found in favour of the physicians; the verdict was upheld on appeal.

little solace to clinicians; rather, the multi-year legal battles associated with the transfer of abnormal embryos and births operate as a cautionary tale to those who work with PGT in clinics in the litigious United States.

Injury is allocated slightly differently in wrongful birth and wrongful life cases: in the first, it is the birth of disabled child, in the second it is that child's life itself. But both constitute abnormality as a damage. These actions are, as Fiona Kumari Campbell (2009, 157) writes, "substantially claims about the 'wrongful formation' of the human person." Although the right to determine the form of a child has not been established in the courts, this right is often implied in instances where abnormality, *qua* disability, impairment, or disease, are created. That is, courts have supported the argument that parents should be availed of their embryo or fetus's health status, giving them the right to terminate should they so choose. Conversely, as is clear in the story with which I opened and as I discuss further below, the right to choice of form is rarely implied (or even countenanced) in cases of "intentional diminishment." Implicit in both the right to informed choice and the circumscribed right to select for a particular genetic condition is the construction of abnormality as a burden or affliction, a form of life that is inherently negative and should therefore be avoided (Campbell 2009).

### 4.1.2 **Procreative beneficence and reproductive non-maleficence**

The two core medical principles of *beneficence*, the moral imperative to "do good" whenever possible, and *non-maleficence*, the doctrine that physicians should, above all, do no harm, take on specific meaning in the context of reproductive medicine and assisted reproduction. Promulgated perhaps most infamously by philosopher and bioecthicist Julian Savulescu (2001,

2008),<sup>68</sup> the concept of procreative beneficence argues that "couples (or single reproducers) should select the child ... who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information" (Savulescu 2001, 415). Preimplantation genetic testing, Savulescu argues, is not an option but a moral imperative. Parents have an obligation to ensure the best future for their child by selecting those embryos free from the burden of genetic disease. "One of the prime dictates of parenting," said Dr. Robert Stillman, a Washington, DC area physician who has denied patient requests to use PGT-M to select for certain genetic conditions, "is to make a better world for our children. Dwarfism and deafness are not the norm" (Sanghavi 2006).

The application of the theory of procreative beneficence is perhaps most evident in the widespread condemnation of the use of PGT for the purposes of "intentional diminishment." Although cases are rare, they were a frequent topic of discussion at the ASRM, especially during sessions on PGT and the ethical dilemmas posed by the transfer of abnormal embryos. For many providers, "intentional diminishment" represents the misuse of a technology intended to prevent by de-selection, not reproduce by selection, illness and disability, the latter understood as a foreclosure of what philosopher Joel Feinberg (1980) calls "the child's right to an open future." "If we make a diagnostic tool, the purpose is to *avoid* disease," a Chicago-area ART clinician told the New York Times (Sanghavi 2006). Arguing that "to deprive a baby of a natural faculty is unethical behaviour," Peter Garrett, research director for LIFE, described the story with which I opened this chapter as yet "another example of reproductive technology running riot" (BBC

<sup>&</sup>lt;sup>68</sup> Savulescu is well known in the field of bioecthics. He completed his PhD at Monash University under philosopher Peter Singer, and is now Uehiro Professor of Practical Ethics at the University of Oxford and head of the Melbourne-Oxford Stem Cell Collaboration, which is devoted to examining the ethical implications of cloning and embryonic stem cell research.

2002). In a 2008 study of U.S. fertility clinics by researchers at the Genetics and Public Policy Centre, only three percent reported that they would perform PGT to intentionally "select for a disability"<sup>69</sup> (Baruch, Kaufman & Hudson 2008).

The practice of procreative beneficence is facilitated by increasing rates of preconception and preimplantation genetic screening. As discussed in Chapter 3, multiple forms of genetic testing are now not only routine but often mandatory in many fertility clinics. The involution they make possible allows parents and clinicians to access detailed information about the health status of each embryo, and thus (the logic goes) their future child's health status. This facilitates the selection of the healthiest embryo for transfer. The principle of procreative beneficence dictates that when genetic testing reveals an embryo that has a genetic anomaly, both parents and physicians have a moral obligation not to transfer that embryo. As I was asked (rhetorically) multiple times during interviews: Why go through with testing if you're not going to choose to implant the "best" – meaning the genetically and chromosomally "normal" – embryo?

A companion to the tenet of procreative beneficence, the precept of reproductive nonmaleficence describes a clinician's obligation not to inflict harm in the course of delivering reproductive health care. From the perspective of some of the clinicians I spoke with, facilitating the birth of a health-compromised child by transferring an abnormal embryo comes dangerously close to violating this precept. Assisting in the transfer of an abnormal embryo, in other words, violates the duty to prevent or avoid harm. Expressing frustration over a patient who wanted to transfer an embryo positive for the BRCA gene, a speaker at the 2018 ASRM asked his audience: "Shouldn't the children we help to bring into this world not be encumbered by

<sup>&</sup>lt;sup>69</sup> The term "disability" was not defined by the stud

potential illness and disability when they're born? ... This patient had BRCA. She didn't even want to be tested. I convinced her" – knowing chuckles from the audience – "but, well, it's very upsetting. She wants to transfer it [the BRCA positive embryo] anyway." In reference to another BRCA case, a physician asked: "Is transferring this embryo doing harm? ... If we implant that embryo, then the child grows up. And when she is of reproductive age, she has to worry about passing it on again to the next generation." Hinting at their capacity to secure a disease-free legacy into the future through the use of PGT, this speaker was encouraging his audience not only to consider the implications of transfer decisions for patients and their offspring, but also their multi-generational consequences.

Much as wrongful birth and wrongful life causes of action reproduce abnormality as injury, procreative beneficence and reproductive non-maleficence impel the development of transfer policies that prohibit the use of abnormal embryos for reproductive purposes by constituting particular genotypic and phenotypic variants as harm. These medical precepts are deeply implicated in the construction of abnormal embryos as a non-reproductive remainder in the IVF process – as a form of biological life with, as I discuss below, no "biographical" future.

### 4.2 Biographical biology, interrupted

As I describe in Chapter 2, nineteenth- and twentieth-century modern human embryologists ushered in a new theory of human development: embryogenesis. The earliest traces of this theory appear in the late-eighteenth century, but as historian of science Nick Hopwood (2000) demonstrates, the idea did not take hold until almost one hundred years later, solidified in the work of anatomist-turned-embryologist Wilhelm His. His was, recall from Chapter 2, a renowned embryo collector and by many accounts the founder of modern embryology, responsible for standardizing the techniques used to gather, study, and order human embryos into

developmental series. These series were instrumental in producing a biological genesis story in which each human life begins, in organismic terms, at conception and passes progressively through a sequence of pre-partum stages, ultimately resulting in the birth of a human life. Catherine Waldby and Susan Squier (2003, 36) term this developmental narrative "biographical biology" – a normalized ontogenetic<sup>70</sup> model in which the human subject is imagined to emerge ineluctably from the embryological process in a series of predictable stages. These stages, they observe, convey a stable formula of progressive development in which each phase, each form, gives rise to the next; the generation of human life can be tracked back and forth across these stages and forms, the embryo retrospectively constituted as the originary moment of life.

Generated in and through the work processes of modern human embryologists, developmental series produced biographical biology as a normative model from its very inception. Recall again from Chapter 2 that His and his contemporaries went to great lengths to exclude pathological and abnormal embryos from their developmental series. "For human embryos recovered from abortions," writes Hopwood (2007, 4), "the main concern was to avoid abnormalities." This is because their goal was to produce a normative model of embryogenesis comprising representative embryos in terms of which scientists could learn to judge not only specimen normality and the stage of development of new individuals, but also the entire species. Only embryos representative of normal human development could be used.

The pathological and abnormal embryos discarded by His and his colleagues formed the empirical material for a subset of embryology called teratology. From the Greek *teratos*, or

<sup>&</sup>lt;sup>70</sup> Ontogenesis refers to the development of an individual organism or anatomical or behavioural feature from the earliest stage through to maturity.

monster, teratology emerged alongside modern human embryology as the study of abnormal – monstrous – development. These monsters were theorized as developmental anomalies, specimens whose development had deviated from the normal pathway. Borrowing from their experimentalist counterparts, teratologists proceeded by exposing the embryos of oviparous and, eventually, viviparous animals to a host of chemical and physical assaults. Unlike experimentalists, however, they were not so much interested in discerning the mechanisms of normal development, but rather the causes of abnormal development. Their objective was to discover the etiology of what would come to be known in the mid-twentieth century as "birth defects."

As social scientists and humanities scholars studying teratology have demonstrated, the deviant monsters of interest to teratologists were not limited to those with an "excess, lack or displacement of organs" – to the cyclops and six-fingered men of early-twentieth century circus side shows and freakshow imaginaries. The category of monster included those whose bodies did not conform to the white, heterosexual, sexually-dimorphic, abled, neuro-typical norm – to what Rosemarie Garland Thomson (1997) terms "the normate" (on teratology and hierarchies of social difference, see McWhorter 2009; Shildrick 2002; Braidotti 1999; Lykke & Braidotti 1996). The normate, Thomson (1997, 11) writes, "names a figure outlined by the array of deviant others whose marked bodies shore up the normate's boundaries, … a figure through which people can represent themselves as definitely human." For those studying congenital abnormalities and abnormal formations under the rubric of teratology, the non-normate were not so much ill as deformed, regressive. "Idiots," non-whites, homosexuals, the disabled, and other "degenerates" were born of a natural process of maturation halted or gone awry, distinguished from the proper human life by degree and pathway of development. Their births served an important function,

confirming by negation a central tenet of biographical biology: that the normative developmental process results in the birth of a normate child. The relationship between biographical biology and its normate subject is, in this sense, congenital, inborn from conception.

As I show in the previous chapter, despite advances in the field of epigenetics and the study of biological plasticity, preimplantation genetic tests and the physicians who use them continue to privilege genetics as the driving force behind embryonic and fetal development. The genetic information contained within the embryo is understood as a "code of codes," to borrow again from Haraway (1997, 147), that directs the developmental process, determining whether the embryo will be, for example, male or female, tall or short, abled or disabled, healthy or unhealthy. This identity will unfold gradually and steadily from one developmental stage to the next, according to the blueprint carried inside each embryonic cell. Genetic and chromosomal abnormalities are understood to skew this blueprint, to corrupt the code of codes, sending the developmental process off course. The product of an abnormal developmental pathway, the resulting embryo, fetus, child, adult may be ambiguously sexed, suffer from pathological short stature, carry a genetic mutation predisposing it to certain forms of cancer or other adult onset illnesses, or an extra X chromosome that causes lower than normal testosterone production, resulting in non-dimorphic sex/gender characteristics. In short, it will be non-normate.

Over the course of my fieldwork, I observed many ways that IVF embryos are imbued with a biography in the fertility clinic: photographed under the microscope as one might photograph a fetus during ultrasound; described as "beautiful" or "healthy" by intended parents and practitioners; assigned a sex *in vitro*. In these and other ways, embryos come to embody the future lives they represent. This form of representation is crucial in the fertility clinic. *In vitro* fertilization has a constitutively promissory core; embryos are produced with the expectation that

they might become babies. Patients and practitioners trade in the hope attached to this expectation, intended parents predicating reproductive desire and resource expenditure on future imaginings of the infant they might soon bring home. As Charis Thompson (2005) notes in her ethnography of U.S. fertility clinics, although fertility treatment is more about intentional reproduction than protonatalism – as I described in the introduction, fertility clinicians eschew a pro-life politics – the anticipatory socialization that accompanies this hope, once pregnancy is established, is often expressed as an ascribed "quasi-personhood" (24). In moments like those described above, embryos are, if only temporarily, treated as protopersons, subjects of affective personhood with biographic futures.

Abnormality is taken by clinicians to sever these ties, to interrupt biographical biology. As one clinician put it bluntly: "abnormal embryos just don't make babies." Or, to quote James Watson:<sup>71</sup> "We already accept that most couples don't want a Down child. You would have to be crazy to say you wanted one, because *that child has no future*" [emphasis mine]. As crip feminist scholar Alison Kafer (2013) argues, the hoped-for children that animates procreative desire embodies the compulsory able-bodiedness and able-mindedness at work in reproductive futurity – they are always already assumed to be healthy, abled, neuro-typical, long-living, sexually dimorphic. Genetic abnormality signals not only the loss of health, ability, and capacity, but also the loss of that future child, whose birth must be avoided at all costs. Transfer policies that prohibit the use of these embryos for reproductive purposes both recapitulate and shore up the congenital relationship between biographical biology and its normate subject, reaffirming the nonviability of embryos that, as a result of their genes, will not follow a normalized

<sup>&</sup>lt;sup>71</sup> James Watson was involved in the discovery of DNA and the development of the Human Genome Project.

developmental pathway. Never transplanted, they will never develop. In the fertility clinic, the abnormal embryo – designated as legal injury, as medical harm, as intentional diminishment – has no biographical future; it cannot (be let to) develop into a full human life.

## 4.3 Securing the biosocial future

Cast out of reproductive futurity, we might think of these embryos as what Michelle Murphy has called "averted births": "a figure of the better-not-born, a naming and counting of a better-to-have-never-lived" (2017, 48). These undead-never-alive figures, Murphy writes, were not singular, but represented "a dense presence of aggregate devalued life" (*Ibid*) populated by those whose existence cost more than it contributed: the poor, racialized, disabled, unproductive but highly fecund others whose existence, both abroad and at home within the borders of the nation-state, was negative in its value. In the twenty-first century U.S. fertility clinic, the economic rationale behind averted births is more implicit and indirect, more individualized, the reproduction of abnormality discussed less as a threat to the nation's economy than to the finances of the individual family unit. This individualization of responsibility was initiated, as I discuss briefly in Chapter 2, in the wake of public shock over the Final Solution and a collateral withdrawal of state and public support for eugenics projects in the U.S. Today, PGT and expanded carrier screening ostensibly put intended parents in charge of their reproductive futures, enrolling infertile and subfertile patients in often-mandatory preconception and preimplantation testing regimes that aim to secure the birth of a genetically and chromosomally normal infant by alerting them to the potential risks contained within their genes or the genes of their embryos. As one clinician mentioned offhand, somewhat surreptitiously: in states with more robust government-subsidized health care programs, such as that in California, these screening regimes in turn save on public health expenditure, preventing the births of those who

may cost the system more than they contribute (see also Konrad 2005; Reuter 2007). But for the most part, individualization is reflected in the discourses of familial economic burden that prevail in wrongful birth and wrongful life lawsuits which, in a climate of austerity and cuts to social welfare supports, are one of the only ways to pay for life-enabling medical costs and support (Campbell 2009; Rinaldi 2009). These legal suits are emblematic of a broader devolution of financial responsibility for medical care into the hands of individuals and their families, something I do not discuss in this dissertation but has been well-documented elsewhere (see for example Campbell 2009; Briggs 2017; Reuter 2007; Konrad 2005).

While the worth of abnormal embryos averted in and through regimes of preconception and preimplantation genetic testing may not be explicitly calculated in relation to the macrological figure of the economy, they are value producing. In the next chapter I examine how, surplussed out of reproductive futurity, abnormal embryos are transformed into a starting point for new regimes of capital accumulation. Here, I am interested in how these averted embryos contribute to dominant narratives of progress, and what these narratives reflect about how we value and hierarchize bodies according to their biology. As Kafer (2013) argues, dominant narratives of progress often assume a curative bent, in which the future is defined through the eradication of disability and pathology. Biological reproduction and reproductive bodies figure prominently in this narrative. Since the emergence of specular examination and the subsequent inversion of internal corporeal space from opacity to quasi-transparency in the midnineteenth century, the womb has materialized as a point of articulation for society, a social and biophysical space that is both the result and site of performative practice (Stormer 2000). Nineteenth- and twentieth-century discourses of race suicide (see Chapter 2), for example, linked women's reproductive lives not only with the lives of her kin, but also to the vitality and health
of the nation, conjoining the anatomo-politics of the body and the biopolitics of the population (Foucault 1978). During the years of the U.S. eugenics movement, this link served to justify, even necessitate, the state's active interest in prenatal and natal space – an interest enacted, in part, in and through the medicalization of pregnancy and birth.

Today, we see this medicalization at work in the growing range of technological interventions associated with pregnancy, among them the preimplantation and preconception genetic screening options under discussion in this dissertation. Preimplantation genetic tests share a kinship with other, older futures-oriented, anticipatory screening technologies like ultrasound, chorionic villus sampling, and amniocentesis; they are an extension backward in biological time of a futures-oriented logic that determines fitness on the basis of biological characteristics. As Vincanne Adams, Michell Murphy, and Adele Clarke (2009, 249) argue, "Anticipation is not just betting on the future; it is a moral economy in which the future sets the conditions of possibility for action in the present, in which the future is inhabited in the present." Seen to wield the power to propagate life and death – to individual children, to the race, to the future - women's procreative capacity must be surveilled and disciplined now in order to reproduce the right kind of bodies, the right kind of life, the right kind of future. Individual women's conduct in the present is, in other words, yoked to the vitality of the population in the future (Patchin 2019). Carrying the oocytes, embryos, fetuses, children and adults of the next generation in their ovaries and bellies, pre-pregnant and pregnant people are understood as a temporal threshold – a futures-generating machine that must be appropriately managed in anticipation of a better future (Mansfield 2012a, 2012b; Kafer 2013; Adams, Murphy & Clarke 2009).

Preimplantation genetic testing intensifies these regimes of reproductive anticipation, further deepening what Jade Sasser (2018) describes as "sexual stewardship." Women's childbearing decisions, she writes, are never individual, never free from the weight of the wellbeing of the population, and thus never free from the duty to reproduce responsibly. Sasser is writing in the context of population control measures in the era of climate change and efforts to recruit women in the management of pending ecological crises by inducing them to make appropriate family choices – choices that include the proper management of their fertility. But her concept of sexual stewardship applies to the disciplinary logic at work in the fertility clinic as well, where infertile and subfertile women are constructed as stewards of a plastic, malleable sociobiological future that can be redirected through appropriate embryo selection practices. Discourses of maternal responsibility – which circulate both within and well beyond the fertility clinic – normalize and routinize painful, anxiety-inducing, and expensive preconception, preimplantation, and pre-natal tests in service of the early detection of impaired embryos and a "better" future (Kukla 2005; Duden 1993; Oakley 1984; Tremain 2006, 2017).

As I demonstrate in Chapter 3, expanded carrier screening has been introduced in many fertility clinics as a means of availing intended parents of the potential genetic risks carried in their genes – risks that may prevent them from reliably reproducing a healthy child. Refusal of such technological intervention is condemned as backward and dystopic (Kafer 2013) – "very upsetting," in the words of the ASRM speaker cited above, whose BRCA-positive patient initially declined preimplantation genetic testing. Pregnant and pre-pregnant people carrying genetic defects and those with embryos or fetuses that have tested positive for various conditions are understood as a threat to the future, having "failed to guarantee a better future by bringing the right kind of child into the present" (Kafer 2013, 29). Abnormal embryos embody this threat as

an obstacle to the curative future described by Kafer, a mark of the failure to control, discipline, and normalize bodily natures by eradicating abnormality and pathology, understood to damage the social fabric and pollute the genetic legacy. The threat of abnormality applies not only to the individual or to the family unit, but to the well-being of the next generation. As a result, as Judith Daar (2017) notes, for individuals disabled by genetics, disease, traumatic or other processes who desire to have a family and require medical assistance to do so, accessing treatment can present significant challenges, including widespread provider unwillingness (see also Kafer 2013).

In the face of significant legal and medical momentum toward the de-selection of embryos considered genetically and chromosomally abnormal, technological attempts to eliminate burdensome biological differences – increasingly integrated into the experience of pregnancy within and beyond the fertility clinic – are celebrated as integral to a future in which disability and disease have no place, an expression of technological control over our biology. Once averted from the reproductive stream, abnormal embryos play a starring role in this narrative. Accurately identified and marked for discard, they become proof of progress, technological and social development, and the triumph of technoscience over mind, body, and the future.

The exclusion of abnormal embryos from the reproductive stream is explicitly understood as a means of eliminating from the future the abnormalities contained within their cells. As a clinician I interviewed at his clinic in northern California put it, "families may have BRCA in the family. Or cystic fibrosis. Or Huntington's disease. They access assisted reproduction to *take that out of the family line*" [emphasis mine]. Understood in this way, embryo selection practices become a means of redirecting the biosocial future along the normal/abnormal binary. Much as

the averted births under consideration in Murphy's work counted toward a macroeconomic future in which poverty would no longer exist, the abnormal embryos averted in and through regimes of preimplantation genetic testing signify a social future free of biological variations considered negative in their value – of "abnormalities". Targeted for elimination, they represent a dense presence of devalued life – life that does not conform to norms of health, productivity, and mental or physical capacity.

#### 4.4 (Re)producing the (ab)normal body

The averted births contained within discarded embryos reflect well-established assumptions about the healthy bodies we are supposed (to want) to have and reproduce: abled, neuro-typical, sexually dimorphic, long-living. As Kafer (2013) argues, while these "healthy" bodies appear to be self-evidently desirable and pre-given, they must be understood within the context of a normalizing impulse coloured by histories of ableism and disability oppression – as part of a pattern in which particular forms of variation and difference are figured as a threat to reproductive futurity. They are, in other words, deeply political. The increasingly routinized use of genetic screening technologies and other forms of preconception and prenatal diagnostics cultivates the notion that embryos can be classified on the basis of the genes, using biology as a means of parsing the normal from the abnormal. This effaces their political dimensions, belying the processes through which humans demonstrating particular variations in form, function, or capacity have been – and continued to be – categorized, medically objectified, problematized, hierarchized, and socially marginalized. As Rebecca Tremain (2006, 2017) argues, the seemingly objective language of impairment, disability, and disease obfuscates contentious debate over, for example, whether deafness is a medical condition or a culturally-defining quality (Kafer 2013), whether cognitive variations constitute a form of disability or a value-neutral neuro-divergence

(McWade, Milton & Beresford 2015), or whether Klinefelter syndrome (KS), androgen insensitivity syndrome,<sup>72</sup> and other sex chromosome rearrangements causing non-dimorphic sexual development are medical disorders or simply among many possible intersex variants (Fausto-Sterling 2000; Herlihy & Gillam 2011). Under the logic of PGT, health is, in other words, vacated of its historically specific social, economic, and political meaning.

Klinefelter provides an illustrative example. Also known to as XXY for it characteristic chromosomal rearrangement, KS is caused by at least one extra X chromosome in "male" (XY) embryos, resulting in lower than normal testosterone production. Symptoms can include a taller, less muscular body, broader hips and longer legs and arms, larger breasts, a smaller penis, weaker bones, lower energy levels, delayed or incomplete puberty, and less facial or body hair following puberty – all defined in relation to the expected, phenotypically normal male body. According to KidsHealth.org (2017),<sup>73</sup> boys with KS "tend to have quiet personalities. They rarely cause trouble and are often more helpful and thoughtful than other boys. They're often shy and sensitive, and many are less self-confident and less active than other boys their age." As Amy Herlihy and Lynn Gillam (2011) note, many of the symptoms most commonly associated with KS would not be unexpected features in females – some of whom may also carry the XXY karyotype but are significantly less likely to be diagnosed. This line of thinking, they argue, can

<sup>&</sup>lt;sup>72</sup> Androgen insensitivity syndrome (AIS) is an X-linked recessive condition caused by mutation in the AR gene that prevents androgen receptors from working properly, making them less responsive to "male" sex hormones or prevents cells from using these hormones at all. Depending on the level of androgen insensitivity, an affected person's biological sex characteristics can vary from mostly female to mostly male. As with KS, treatment can include hormone therapy and surgery.

<sup>&</sup>lt;sup>73</sup> KidsHealth.org is run by Nemours, a non-profit children's health system that provides resources and tools to children with health-compromising conditions and their parents. Their resources are produced and reviewed by certified medical doctors.

be extended to those who do not identify with typical notions of gender, sexual identity, or masculinity, who may not frame the variations characteristic of KS as medical symptoms at all.

The diagnosis of KS in males and the clinical interventions it precipitates (most notably, testosterone replacement therapy beginning at an early age) illustrates a normalizing drive toward sexual and gender dimorphism, in which norms of gendered and sexual behaviour – proper masculinity and femininity – are based on normalized bodies and comportments. Those who do not conform to expected gender and sex norms are considered abnormal, medically objectified, and designated as in need of intervention or cure. In the case of KS, this normalizing drive is grounded in seemingly natural, self-evident proof offered by the divergent karyotype (XXY), one shored up, as I described in Chapter 3, by the use of preimplantation genetic testing as a sex-selection technology that grounds both sex and gender in chromosomal makeup. Denied in this medical diagnosis are the spectrum of possible human variations in both sex chromosomal arrangements and sex and gender expression, with material implications for those whose chromosomal makeup may not describe their gendered or sexed identity.

Although the ASRM Ethics Committee recommendations discussed above offer guidelines to clinicians regarding the transfer of abnormal embryos, there is no policy in the United States, at any level, regarding which abnormalities should be targeted for elimination. State-sponsored laws or rules used to determine which lives are worth living, characteristic of early- and mid-twentieth century eugenics, are now ostensibly left to individual choice and decision-making. In practice, however, as University of California, Berkeley bioethicist Osagie Obasogie said during our interview, the notion of individual choice at work in contemporary practices of genetic selection is "illusory at best." Obscured is the array of powerful social, legal, and biomedical forces that shape and circumscribe reproductive autonomy – for example,

clinical policies and legal suits that structure embryo selection practices along the normal/abnormal binary. I discuss this further in the conclusion to this dissertation.

While there is near-consensus, among fertility care providers, over the non-desirability and non-viability of particular genetic and chromosomal variants such as Turner syndrome or Down syndrome – itself an accomplishment realized over time – there is significantly less agreement over conditions more recently included within the remit of preimplantation genetic testing. Clinicians debate, for example, whether or not parents should be supported in transferring embryos carrying the gene for hereditary deafness, genetic risk factors associated with autism, or those with an XXY karyotype. With the identification of cancer and Alzheimer's predisposition genes, they are forced to grapple with transfer decisions for embryos that test positive for adult onset conditions and conditions with incomplete penetrance.<sup>74</sup> In an interactive session at the 2018 ASRM, for example, 46 percent of respondents said they would not offer PGT-M testing for a couple in which one partner is found to be a carrier of familial Mediterranean fever, a recessive disorder of incomplete penetrance, on the basis that results would not predict affected offspring. Fifty percent responded that they would offer PGT-M, citing the ethical principles of informed choice.

Polygenic testing platforms like that offered by Genomic Prediction (see Chapter 3) has likewise precipitated significant dispute over how to characterize and categorize conditions like intellectual disability and type-1 diabetes. Audience members at the 2018 ASRM balked at the notion of polygenic testing for type-1 diabetes, denouncing the presenter – a member of

<sup>&</sup>lt;sup>74</sup> Penetrance refers to the likelihood that a clinical condition will occur when a particular genotype is present. A condition is said to show incomplete penetrance when some individuals carrying the pathogenic variation express the associated trait while others do not.

Genomic Prediction's research team – for stretching the boundaries of "serious disease or disability" to the breaking point and for opening to the door to testing for conditions not reasonably considered life threatening, severe, or even clinically relevant. The very real possibility of germline gene editing via CRISPR Cas-9 has impelled heated discussion over the range of possible mutations that might be targeted for correction. As gene maps are refined, preimplantation genetic tests become more sensitive, and the range of detectable genetic and chromosomal variations grows, clinicians will continue to be confronted with difficult decisions about how to define abnormality and whether, when, and how to transfer abnormal embryos.

This debate suggests that the boundary between the normal and the abnormal is unstable, shifting in response to technological and scientific developments, social expectations, and reproductive politics. This puts flesh on the bone of one of Kafer's (2013) central arguments: that, despite the seemingly self-evident nature of pathology, the parameters of terms like "disability," "defect," and "abnormality" are unsettled and open to contestation. Again, the distinction between the vital biomedical norms of the body and the disciplinary norms of society cannot be maintained. Disability is not a category inherent in certain minds and bodies but is more akin to what Joan W. Scott calls (1989) a "collective affinity" - "identifications that have been attributed to individuals by their societies, and that have served to exclude or subordinate them" (quoted in Kafer 2013, 11). Conceptualizing disability in this way, Kafer argues, eschews fixed, discrete definitions of "abled" and "disabled," recognizing that these categories are porous, flexible, and tenuous. Disability thus becomes contested and contestable terrain - a concept that is temporally and geographically specific, produced and reproduced over space and time. Borrowing from Kafer and Scott, I suggest that abnormality likewise forms a collective affinity comprising those whose genetic and chromosomal makeup places them at the wrong end

of a bio-social hierarchy that (de)values bodies according to variants defined as incompatible with full life – as life gone wrong in a *biographically biological* sense. The regimes of valuation and devaluation at work, here, are both culturally and temporally specific and impermanent, defined not only according to the poles of health and illness or to the presence or absence of disease, but to understandings of "optimal" biological states and "best" possible futures. The U.S. fertility clinic is a key site in which these states and futures are disputed, negotiated, constituted, reinforced, and made material.

Despite the uncertainty and debate over the reproductive potential of some forms of biological variation, the increasingly routine – even mandatory – use of preimplantation genetic tests in the fertility clinic sends a strong message about the proper and expected approach to variations defined as abnormal. At work in the proliferation of these tests is the assumption that all positive diagnoses will be addressed through the de-selection of genetic variants considered negative in their phenotypic effects. As we saw in section 4.1, both medical and legal precepts have largely conflated the use of preconception, preimplantation, and prenatal tests with technologies of termination, collapsing reproductive self-determination with ableist imperatives to avert the genetically or chromosomally anomalous embryo or fetus (Tremain 2006, 2017; Kafer 2013). As the California Court of Appeals (1980, np) writes in the Curlender decision: "the wrongful life cause of action ... is based upon negligently caused failure by someone under a duty of care to do so to inform the prospective parents of the facts needed by them to make a conscious decision not to become parents" [emphasis added]. These practices coalesce in what Kafer (2013), borrowing from Robert McRuer (2006), calls a compulsory reproduction of ablebodiedness and able-mindedness. Medically and legally construed as injury, harm, or diminishment, abnormal births are categorized as births to be averted. They do not constitute a

whole, functioning human being. As I discuss further in the conclusion, reproductive choice is thus constrained at the same moment that it is legally and medically upheld.

The normal and the abnormal are inherently political concepts, elements on the basis of which power is exercised, founded, and legitimated (Foucault 2003b). The construction of a category of abnormal embryos in the fertility clinic evinces such an exercise of power. Medical and legal forces impel a drive toward normalization, narrowing possible and appropriate responses to pregnancy and reproduction in the process. In the fertility clinic, these forces give rise to embryo selection practices in which particular forms of biological difference, hierarchized as abnormalities, are eradicated from the future. This erasure is not mere metaphor. As Rolls-Hansen (2010) and Subramaniam (2014) observe, individual choices by parents can and do create population-level changes. According to a promotional brochure, CooperGenomics alone has provided PGT-M for almost 8,000 families with heritable single-gene conditions (2018). Theirs is one of numerous screening platforms on offer to fertility clinics and their patients. Through regimes of preconception and preimplantation genetic screening, through the government of their own bodies, intended parents are enrolled in the normalization of the embryo, the fetus, the child, responsibilized for reproducing a genetic legacy and genetic future free of ill-health, disability, and disease. The designation of embryos as abnormal severs their ties to biographical biology, casting them out of reproductive futurity. Cast out, too, are all those chromosomal and genetic variants considered undesirable, non-valuable. Embryo selection practices are thus implicated in aggregate bodily reworkings that are, to quote Guthman once again, "more than evolutionary" (2015, 2523). As some traits are selected and others averted, social and cultural norms around health, capacity, and ability become embedded in our sociobiological future at the molecular scale, raising crucial questions about who gets to reproduce

whom, under what conditions, and with what effects. Embryo selection practices, and abnormal embryos in particular, are thus key sites in the exercise of power over reproduction and life, both signifying and materializing a future free of some forms of biological difference.

## **Chapter 5: Abnormality as accumulation strategy**

A long tradition of feminist, critical race, and post-colonial scholarship has examined the immanence of social difference to the accumulation of profits and power (these critiques are too numerous to recount here, but for foundational texts see Mies 1998; Federici 2004; more recently, Pulido 2016a). The rise of capitalism, this scholarship argues, was coeval with the construction of social hierarchies that classified and ranked bodies and whole populations according to perceived differences, often delineated according to biological discourses of variation and deviance (McWhorter 2009; Subramaniam 2014). Like the geographical unevenness described by literature on the "spatial fix" (Harvey 2001), the production of social difference is essential to the unfolding of capitalism, comprising a powerful means of demarcating those who are inferior and thus more exploitable as labourers or commodities. As Sylvia Federici (2004, 16) writes, "capitalism, as a socio-economic system, is necessarily committed to racism and sexism. For capitalism must mystify the contradictions built into its social relations ... by denigrating the 'nature' of those it exploits: women, colonial subjects, the descendants of African slaves, the immigrants displaced by globalization."

Pushing our thinking beyond the labour and commodity form, geographers like Laura Pulido (2016a, 2016b), Vinay Gidwani (2008; Gidwani & Reddy 2011), Ruth Gilmore (2007), Julie Guthman (2011, 2015) and Rosemary-Claire Collard and Jessica Dempsey (2017, 2018) have drawn our attention to the multiple and varied ways that hierarchized bodies and lives become entangled in capital accumulation. In order to better understand how bodies and lives are enmeshed in capitalism, this work argues, we must attend to the myriad ways that this enmeshing takes place, beyond their integration as what Collard and Dempsey call "officially valued" (2017, 79). Like the people, places and natures under consideration in this work, embryos are multiply oriented in relation to capitalism as both productive and reproductive entities.

Understood as the beginnings of human life, they are highly contested economic objects, holding a unique position within the phalanx of tissues circulating in a burgeoning bioeconomy. In the United States, where biological reproduction services like IVF, egg donation, and surrogacy have been thoroughly commercialized, extracorporeal embryos remain outside the pale of "officially valued." They cannot be bought and sold; they cannot be created for research purposes. And yet, these embryos are caught up in circuits of capital accumulation as a scientific resource integral to the development of new (and promissory) biomedical knowledges, products, and profits.

In this chapter, I add abnormality to Federici's list of denigrated natures. I do so by examining the relationship between abnormality and capitalism from the vantage of the abnormal IVF embryo. Like race, gender, and other axes of social difference, abnormality enables a form of "accumulation by difference-making" (Collard & Dempsey 2018, 1349), generating new opportunities for capital accumulation by devaluing those who do not (or, in a tense more appropriate to a discussion of embryos, *will* not) conform to idealized norms of health and capacity. While particular in its function and its effects, like other forms of social difference the designation of some bodies as abnormal creates an uneven social topography that capitalist interests instrumentalize to generate new economic opportunities. In this chapter, I focus in particular on the value derived from what, borrowing from Gidwani and Reddy (2011, 1621), I call the "uncanny afterlives" of abnormal embryos in biomedical research. Surplussed out of reproductive futurity by the genetic and chromosomal mutations carried in their cells, abnormal embryos are a starting point for new rounds of investment and speculation in the tissue economy.

Academic work in the social sciences and humanities has examined the integration of female reproductive biology, including extracorporeal embryos, into circuits of commercial

transaction and capital accumulation as a valuable source of patentable stem cells for use in regenerative medicine (Waldby 2002; Waldby & Squier 2003; Squier 2004; Thompson 2005; Franklin 2006a, b; Waldby & Mitchell 2006; Cooper 2008; Svendsen and Koch 2008; Gottweis, Salter & Waldby 2009; Waldby & Cooper 2008, 2010; Cooper & Waldby 2014; Colls & Fannin 2013; Yoshizawa & Hird 2019). Beyond the scientific literature, however, scant attention has been paid to the particular role of abnormality in the process of biotechnological reformulation that transmutes life itself into what Catherine Waldby (2000, 2002) terms "biovalue": the yield of surplus life capacity – reproductive, regenerative, autopoietic – derived from marginal tissues that can be put to work to improve human health. By severing embryos' ties to biographical life, I argue, preimplantation genetic tests transform embryos into a form of waste, thus smoothing their entry into the tissue economy. Once there, they become uniquely productive as models in the study of debility and pathology, reconfigured as biotechnologies aimed at eradicating abnormalities from the future.

I find biovalue a particularly useful term in a context in which the production and circulation of living tissues are not only geared toward the generation of profits. The ART industry is characterized by a complex landscape of legal relations (see section 5.1 below) in which the outright commodification of certain tissues (e.g. oocytes and sperm) coexists with highly restricted forms of commercialization (as in the case of embryos), along with other commercial constructs such as tissue donation and hybrid forms of property rights (Cooper 2008). As Bronwyn Parry (2012) observes, the ontological status of these bodily parts, tissues, and derivatives is constantly in flux. Take the case of human oocytes: at one point embedded in living ovaries and viewed as completely inalienable, they may later be proffered as a donation or gift (itself a practice imbued with meaning and obligation, as I discuss further below), bartered

for objects or services of equivalent value (for example, discounted oocyte banking), or sold by individual women to egg banks for thousands of dollars per cycle. In the context of embryo research, it is common for human embryonic stem cell (hESC) lines to travel between between labs for little or no cost. The National Institutes of Health (NIH) Stem Cell Registry was developed to facilitate this kind of sharing, providing samples of patented lines for minimal licensing fees. While not necessarily (or only) oriented toward the generation of profits, the sourcing, storage, exchange, and circulation of hESCs is about intensifying and multiplying the vital productivity of living tissues along lines that make them useful for human projects and in ways that are often amenable to commercial enterprise. As Charis Thompson (2005) argues, this "biomedical mode of reproduction" has a constitutively promissory core, depending on the capacity of tissues to lead to new and unexpected forms of economic value - for example, marketable pharmaceutical products. In both productive and reproductive senses, the extracorporeal embryo at the heart of this dissertation is, in fact, constitutively promissory: in the fertility clinic and, as we will see below, the biomedical research lab, its value stems from its lively potential.

Again, I understand abnormality here in its bio-social guise: as one half of a binary categorization that evaluates bodies in relation to their success or failure in terms of health, productivity, and mental or physical capacity. In a time of intense biomedicalization – during which health has become a moral imperative and the body is understood as open to intervention and optimization at the molecular scale – failure is increasingly the norm (Clarke et al. 2010). As the early medicalization literature notes, the expansion of medical jurisdiction and authority into new realms in the post-WWII period transformed moral, legal, and social problems into medical conditions. Over the ensuing decades, categories of disease, disability and pathology swelled at

the same time that definitions of health contracted, establishing health as an increasingly unattainable ideal (Zola 1972; Conrad 1975, 1992; Lupton 1995). There is, as Jasbir Puar writes, "no such thing as an 'adequately abled' body anymore" (2013, 182).

The concomitant, but not coincidental, rise of a rapidly growing life sciences industry over the last five decades has made for big business, especially in the wealthy countries of the global north. In the new "biopolitical economy of medicine, health, illness, living, and dying ... biomedical knowledges, technologies, services, and capital are ever more co-constituted," breeding new, increasingly intense and productive efforts to optimize and enhance the body by technoscientific means (Clarke et al. 2010, 1). The expansion and capitalization of medical categories described by the biomedicalization literature is on full display in the fertility clinic. As I argue in chapters 3 and 4, while ostensibly about innate biological differences inscribed in the embryo's genetic code, decisions about which embryos to implant and which to discard are steeped in socio-cultural ideas of able-bodiedness, health, sexual dimorphism, neuro-typicality and longevity: in short, of normality and abnormality. These ideas are not trans-historically given, but rather constitute a flexible description of health that takes hold in particular times and places, gathering force as it is reproduced. The fertility clinic is one such site of reproduction – a time and place in which biomedical understandings of health and normality condense, materializing in, among other practices, embryo selection and disposition decisions.

Querying biological abnormality as a value-producing social hierarchy by running it through embryo selection practices is a risky maneuver. Helmed by a stridently pro-life administration, the United States, as I describe in Chapter 1, is in a time of proliferating personhood laws that would see embryos afforded the same legal status as the full human beings they are imagined to embody. As legal scholars have noted, extracorporeal embryos represent a

potentially fruitful avenue for those looking to secure such protections (Gaddie 2018; Rao 2008). Because *Roe v. Wade*<sup>75</sup> deals almost exclusively with a pregnant person's right to bodily integrity, and in fact explicitly declines to pass judgement on the question of when life begins,<sup>76</sup> extracorporeal embryos could, in theory, be granted personhood status without contravening the 1973 Supreme Court decision in *Roe*, opening the door to further constitutional challenges. As bioethicist Alta Charo told attendees at the 2005 ASRM, "It's entirely possible that the first real challenge to *Roe* will be looking at the embryo in isolation. The question about discard is very, very important. This will be where they start their litigation strategy, to chip away at *Roe*" (quoted in Mundy 2008).

Inferring the differential valuation of human life from embryo selection practices in this context runs the risk of reifying extracorporeal embryos as future persons. It is absolutely essential to resist any such reification. I do not contest the practice of discarding embryos, whether normal or abnormal. Rather, I am interested in the formations – biomedical, legal, and otherwise – that structure embryo selection decisions along lines of normality and abnormality and in the calculative and disciplinary logic that averts some embryo from the reproductive stream more readily than others on the basis of their biology. In what follows, I examine the particular value of these averted embryos in the tissue economy, and I ask what we might learn from these embryos about abnormality as a value-producing social hierarchy.

The use of embryos as sites of investment and accumulation in the tissue economy is in keeping with a much broader biotech revolution made possible by a series of regulatory

<sup>&</sup>lt;sup>75</sup> *Roe v. Wade* is the U.S Supreme Court decision that protects a pregnant person's right to abortion. <sup>76</sup> The majority opinion states: "When those trained in ... medicine, law, philosophy, and theology are unable to arrive at any consensus, the judiciary, at this point in the development of man's knowledge, is not in a position to speculate as to the answer" (Supreme Court of the United States 1973).

measures designed to generate profits from our "bodily natures" (Castree 2000, 287) - our blood, bones, organs, cells, and DNA. I begin section 5.1 with a recent history of this period, situating extracorporeal embryos within the assembly of body parts commercialized in its wake. As Kaushik Sunder Rajan (2006) notes, the roll out of these regulations has not gone uncontested. "The corporatization of the life sciences," Rajan writes, "has simultaneously been rapid and hegemonic on the one hand, and contingent and contested on the other" (4). Embryo research typifies this "frictioned terrain" (Ibid). Despite the extension of property rights over the molecular elements of life set in motion during the 1980s, embryos, as I discuss in section 5.2, remain particularly difficult to commodify, an accomplishment realized in no small part by rightto-life organizations (and sympathetic government officials) that insist on embryos' personhood status. Others have looked at donation as a way of facilitating embryos' entry into regimes of capital accumulation in this fraught social and political context (see especially Waldby & Mitchell 2006). In section 5.3, I examine the designation of embryos as abnormal as a productive, and thus far overlooked, means of disentangling embryos from the dense web of affect, kinship, and embodiment within which they are embedded. Understood to be non-viable in the fertility clinic, abnormal embryos are rendered as a form of reproductive waste that must be recuperated so that its value to others is not squandered. Research is understood as one such means of recuperation. In the lab, the cause of abnormal embryo's devaluation in the clinic because the source of its biovalue. Section 5.4 explores how researchers put these embryos to work to study disease and to test new interventions and cures, generating scientific knowledge and the promise of economic profits. In the final section, I ask what these embryos reflect more broadly about abnormality as a form of accumulation by difference-making.

### 5.1 Biological reproduction and the biotech revolution

In 1973, just a few years prior to Louise Brown's birth, a different techno-scientific breakthrough was making waves in the life sciences community. This was the invention of recombinant DNA technology (RDT) by Herbert Boyer and Stanley Cohen. Known colloquially as genetic engineering, RDT is a set of techniques that allows scientists to cut up and join together DNA molecules in the lab. By transposing these molecules into other organisms (usually bacteria or viruses) called vectors, scientists could study the functionality of genes and DNA sequences. Vectors could also be used as production factories for more DNA or for the protein coded by that DNA. The discovery of RDT is often credited with catalyzing the rise of the contemporary biotech industry (Rajan 2006). In part, this is because the technology revolutionized understandings of biological life and its perceived limits, allowing scientists to produce cellular or molecular matter – some of which could have valuable therapeutic effects – in an industrial mode. But at least as important as the invention itself were the regulatory and legal apparatuses established to commercialized it. The successful patenting of the Cohen-Boyer process by Stanford in 1980 (via a claim filed in 1974) resulted in one of the first and most lucrative technologies ever to be licensed from university research; it was a major step in a series of regulatory changes that would lubricate the commercialization of biotechnological innovation (Rajan 2006; Prudham 2007).

The 1980s was a decade of transformation in life sciences R & D, investment, and patent regulations in the U.S. In December of 1980, Congress adopted the Bayh-Dole Act, also known as the Trademark Law Amendments Act, virtually obliging publicly-funded institutions like universities to patent federally funded research results. Patent holders could then issue exclusive licenses on their inventions to large private companies. This set the scene for what bioethicist

Lisa Ikemoto calls "the university-biotech industry complex" (2009, 763). Public-private alliances and biotech start-ups exploded in the years following Bayh-Dole, all seeking to commercialize the results of public research. In the post-1980 period, universities' propensity to patent rose rapidly, with particularly notable increases in drug and medical patents (Henderson, Jaffe & Trajtenberg 1998). Over the same decade, the passage of new legislation made it possible for large institutional investors like pension funds to invest in high risk venture capital funds, the standard business model in the biotech industry (Cooper 2008). There was a concomitant increase in federal dollars allocated to the life sciences sector.

The 1980s also witnessed landmark U.S. Supreme Court rulings that facilitated the extension of property rights over the molecular elements of life, the infamous *Diamond v*. *Chakrabarty* court ruling providing a case in point.<sup>77</sup> The patent invention in Chakrabarty was a genetically engineered *Pseudomonas aeruginosa* bacterium that could break down crude oil spills. In a 5-4 decision, the Supreme Court concluded that the bacterium was patent-eligible because it was a modified version of the bacterium found in nature. Their decision was the first to extend to living organisms the sentiment enshrined in the U.S. Patent Act of 1952, which set forth that patentable subject matter would include "anything under the sun made by man" (Office of Technology Assessment 1989, 5). (Thus, as I discuss further below, while the whole embryo cannot be patented, the hESC line – disaggregated from the embryo through regimes of scientific labour and expertise – can, alongside any potential products and profits derived from it.) The significance to the commercial life sciences sector of the legal power to enclose nature, so long

<sup>&</sup>lt;sup>77</sup> In this case, the supreme court awarded patent rights on a genetically engineered microorganism that could break down crude oil spills to Chakrabarty, an employee of General Electric.

as it is mixed with human labour, cannot be overstated. As Cooper (2008) argues, the biotech revolution could not have proceeded without the extension of property rights to the processes of biological regeneration. Developments in patent law fundamentally overhauled the legal status of life itself in relation to commercial enterprise, opening up new opportunities for investment and speculation. As a series of new biotechnologies reached fruition, a new lineup of living products awaited commercialization, promising huge profits to those willing to invest. This is what Hannah Landecker calls "the biotechnological touch" (2005, 2) – a phrase meant to evoke the Midas touch, but one that is also about "much more than gold. It is about the touch itself, which transmutes something into another condition – fragments buzzing, swarming, virtually untouched forms of life into molecules, proteins, enzymes, glow in the dark proteins, peptides, and toxins and reconstitutes them into products, tools, machines, therapies, subjects, and objects of research and knowledge and profit." Enclosed in property relations, bodies, bodily functions, and biologies flow through circuits of capitalism in ways that go well beyond the process of producing and consuming commodities.

The confluence of this period of rapid biotechnological and regulatory shift with the U.S. fiscal crisis of the 1970s and 1980s is not coincidental (Rajan 2006; Prudham 2007; Cooper 2008). The legislative and institutional decisions described above were part of a concerted and deliberate effort by the federal government to foster the nation's nascent biotech industry at a time of flagging economic growth. The biotech revolution was "the result of a whole series of legislative and regulatory measures designed to relocate economic production at the genetic, microbial, and cellular level, so that life becomes, literally, annexed within capitalist processes of accumulation" (Cooper 2008, 19). Confronted by the depletion of non-renewable resources, notions of ecological limits, new federal environmental regulations, decreasing competitiveness

in international markets, and declining profits, the life sciences industries intensified the process of involution described in previous chapters, regrouping "to plumb an everyday more intensive nature" (Katz 1998, 46): bodies. Enclosed within new property regimes, corporeality became the basis for generative forms of capital and a whole host of commercial products – from genetically engineered organisms to genetic sequences to cell lines. As Donna Haraway put it in her debate with David Harvey, the living body became "an accumulation strategy in the deepest sense" (Harvey & Haraway 1995, 510), far beyond its role as labourer and consumer. Between 1980 and 2000, combined revenues from the five largest US biotech corporations<sup>78</sup> rose from \$9 million USD to over \$8 billion (Parry 2006). In 2019 this number topped \$67 billion, according to publicly-available company reports.<sup>79</sup>

Biological reproduction has been central to the economic change and development born of the biotech revolution. Women's reproductive tissues are a primary site of the annexation of life by capital described by Cooper, their bodies garnering particular economic and biomedical interest in the context of marketized biological vitality. As middle-class white women entered the work force *en masse* in the 1970s and 1980s, so too did the process of biological reproduction migrate out of the private space of the home and more fully into the formal economy, part of a growing service sector in affective, sexual, and care labour (Cooper & Waldby 2014; Briggs 2017; Vora 2014).

<sup>&</sup>lt;sup>78</sup> The five largest biotech firms at the time were Genentech (co-founded by Herbert Boyer of RDT fame), Amgen, Biogen, Chiron, and Genzyme.

<sup>&</sup>lt;sup>79</sup> It's difficult to parse pharmaceutical corporations like Johnson & Johnson (who posted over \$82 billion in 2019 revenues) from more strictly defined biotech corporations. The total listed above includes the combined revenues from Amgen, Inc., Gilead Sciences, Celgene Corporation, Biogen Inc., and Vertex, listed as the five largest biotech companies by market value on ExploreBiotech.com.

To be sure, the integration of human reproduction within modes of capitalist production is not new. It is tied geographically and temporally to tangled histories of racial, colonial, and patriarchal capitalism (Golden 2006; Roberts 1997; Beckles 1989; Federici 2004). As Dorothy Roberts (1997) argues in Killing the black body: Race, reproduction, and the meaning of liberty, the interlocking logics of reproduction and property – on display in conspicuous and brutal form during chattel slavery - organized capitalism in the first place and continue to sustain it as a system. The extraction of profits from reproductive bodies and tissues is ineluctably and inescapably shaped by histories of race- class- and gender-based exploitation. In the slipstream of the biotech revolution, however, these processes of extraction have acquired a new valence. Technologies designed to harvest multiple mature oocytes from the body (ovarian stimulation), fertilize those oocytes with sperm in a petri dish (IVF), keep the resulting embryos alive ex vivo (tissue culture), freeze and thaw those embryos without destroying them (cryopreservation), and immortalize them in vitro (as human embryonic stem cell lines) have medicalized, technologized, and standardized reproduction and reproductive labour, rendering it pliant and available for commercial investment in previously impossible ways. The dual processes of respatialization and involution wrought by IVF, in other words, have enrolled reproductive biology in novel forms of labour and productivity, what Waldby and Cooper (2008, 59) have called a "new microbiopolitics of reproduction."

These technologies have brought reproductive biology to market in two primary ways. The first is through the commercialization of fertility services. In 2018, the U.S. ART market was work an estimated \$5.8 billion, and growing rapidly (Marketdata LLC 2019). Second, and at the heart of my argument in this chapter, a whole array of reproductive tissues derived from the "maternal-embryonic nexus" (Waldby & Cooper 2010, 4) and donated or sold to scientific

research has been integrated into global circuits of scientific and economic innovation, where, as I discuss in more detail in the next section, they form a source of unpriced but useful biological inputs. As Cooper and Waldby (2014) note, women constitute the primary tissue donors in the new stem cell industries, which require high volumes of human embryos, oocytes, placental and fetal tissue, and umbilical cord blood. Although there has been some debate, recently, about the potential of induced pluripotent stem cells derived from, for example, from adult skin cells, to replace stem cells from these sources, embryos in particular remain the gold-standard in regenerative medicine – a source of cleanly cultivated lines free from the degree of epigenetic effects that affect tissues derived later in life.<sup>80</sup>

Apart from oocytes, which can be bought and sold in the U.S., these tissues are mostly made up of "surplus" reproductive materials donated in the wake of successful or failed pregnancies. Cooper and Waldby (2014) term the labour that produces these materials "clinical labour" – a form in which the *in vivo* biology of human subjects is enrolled in the labour process itself, either through the production of experimental data (as in clinical trials) or through the transfer of tissues (as in embryo donation). The form of clinical labour of interest to me here is akin to what Collard and Dempsey (2017) call "the underground": labours or inputs that are integral to capitalist production but are unwaged or unpriced. Similar to social reproduction, the flagship example of the underground, unpaid clinical labour produces an invaluable resource that is located outside the realm of that which is "officially valued" as commodity of labour: a natural resource produced for free, the cost of which would otherwise have to be covered by capitalists

<sup>&</sup>lt;sup>80</sup> As a stem cell researcher explained, only some epigenetic effects are heritable. This means that embryos are less affected by epigenetic changes than induced pluripotent stem cells derived from adult tissues or those derived from a fetus or umbilical cord blood (which are influenced by the uterine environment).

(Mies 1998). While essential to capitalization in the biotech sector – clinical labour and the stem cells it produces make possible the dream of regenerative medicine – as I discuss further in the next section this form of feminized economic (re)productivity goes largely unrecognized, its products seen as the freely available, otherwise wasted by-product of the natural process of biological reproduction. As I discuss in Chapter 2, the construction of reproductive tissues as the natural property of biomedicine was nascent during the early years of modern human embryology, in which embryological specimens were named not for the women who donated them, but for the physicians who claimed them for science (Hopwood 2000). In the twenty-first century, the appropriation of embryos by science continues, and, as I discuss in the next section, remains essential to the derivation of value from them.

### 5.2 Embryos, enterprised up

Embryos are unique in many ways among the tissues obtained for biomedical use from the maternal-embryonic nexus. Like placental tissue, umbilical cord blood, fetal remains, and oocytes, embryos are a source of significant biovalue. But unlike these other cell types, they have the potential to produce a human being. This potential is productive in the tissue economy. As I mentioned above, human embryos are an unparalleled source of pluripotent stem cells for use in regenerative medicine. And, as I discuss further in the next section, they constitute invaluable disease-in-a-dish models in the study of developmental disorders and their treatments. But their reproductive potential also renders them particularly intractable at the intersection of science and capitalism. Embryos are objects of social and political contestation for the very reason that they are sites of scientific investment: because they are biologically reproductive. As one clinician put it, "Embryos, I feel, deserve special respect because they are capable of making a life. They are not a life. But they are capable of becoming a human life."

In contrast to the assisted reproduction market, which is thoroughly commercialized and largely unregulated in the U.S., especially as compared with other global ART centres around the world (Frith & Blyth 2014), embryo research is highly – if unevenly – regulated at both the federal and state level. The annually-renewed Dicky-Wicker Amendment, passed in 1995, prohibits the use of federal funds for research in which human embryos are "directly created, destroyed, or knowingly subject to risk of injury or death" (National Institutes of Health 2019). In 2001, president George W. Bush extended this ban to prohibit the use of federal funding for any and all research using human embryonic stem cell lines, including those derived using private funds. In a public address announcing his decision, Bush appealed explicitly to debates over the moral status of the embryo. "Human life is a sacred gift from our creator. I worry about a culture that devalues life. … And while we're all hopeful about the potential of this research, no one can be certain that the science will live up to the hope it has created" (2001). Federal funds remained available for research on hESC lines created before August 2001 – embryos for which "the life-and-death decision has already been made" (*Ibid*).

In 2009, Obama reversed Bush's 2001 decision but continued to renew the Dickey-Wicker Amendment.<sup>81</sup> This means that while NIH funds can be used to conduct research on hESC lines created using private or state-level funds, the restriction on the use of federal funds to create new lines – to destroy embryos for research purposes – remains in place. In addition, federal funds can only be used for research on lines that have been approved for inclusion in the NIH's hESC registry, which requires that they meet rigorous – and, per the California stem cell

<sup>&</sup>lt;sup>81</sup> At the time of writing, Trump had yet to make any changes to the governance of human embryo research in the country, although revisions to the NIH's human embryonic stem cell guidelines were under consideration.

researchers I spoke with, highly restrictive – ethical derivation guidelines.<sup>82</sup> This regulatory landscape has created a host of complications for those working with human embryos in the lab. One researcher I interviewed lamented the difficulty of having hESC lines approved by the NIH, and the barriers this creates to collaborative research. "Even if you generate a line using private funds, you can't put it on the registry if it doesn't strictly follow the definition [of an hESC line], and therefore other scientists cannot use federal funds to study that line." Another researcher explained further,

> Anybody who has NIH money can't bring [unapproved lines] into their lab. The whole thing gets very Draconian and weird. ... Let's say we're in this building and we need to use a microscope in another building [funded by NIH], you could not take that slide over there, put it under there, and look at it. That would violate the rules.

Both interviewees absolved, to a certain degree, "the people who are actually in the NIH," blaming instead the fact that embryo research is "so highly politicized in the U.S."

Many states have responded to this unstable regulatory landscape by crafting their own legislation to govern human embryo research. California has long been at the forefront of such action, both in terms of its regulatory framework and the amount of state funding dedicated to research. In 2004, in response to the Bush administration's cutbacks, California voters elected to support embryo science in the state to the amount of \$3 billion under the Stem Cell Research and Cures Act (popularly known as Prop. 71), creating a new state agency, the California Institute for Regenerative Medicine, in the process. Some states followed suit, modeling their propositions on California's, which had successfully withstood legal challenge from various right-to-life organizations. Others took a different tack, enacting regulations further restricting embryo

<sup>&</sup>lt;sup>82</sup> The guidelines are available at https://stemcells.nih.gov/policy/2009-guidelines.htm

research or prohibiting it entirely. In each of these latter states, legal justification for these regulations centres on the embryo's status as a human life and the harm done to that life by the scientific practices associated with embryo research. Chapter 3 of Louisiana's Health Law, for example, goes so far as to protect extracorporeal embryos as juridical persons, the use of which is "solely for the support and contribution of the complete development of human in utero implantation" (Louisiana Revised Statutes 2017).<sup>83</sup> Because the law affords personhood status *only* to extracorporeal embryos, recognizing them as juridical persons that cannot be purposefully deprived of life, that can sue and be sued,<sup>84</sup> the statute avoids contravening the *Roe* decision. As a result, it has not yet faced constitutional challenge.

The administration of human embryo science illustrates the fictioned terrain of embryo research. Intact extracorporeal embryos are, like the organs described by Michel Callon (1998) in his influential work on the embeddedness of markets, deeply "entangled" entities, produced through onerous forms of bodily and emotional labour and signifying a much hoped-for child. Hedged around with complex forms of regulation, they remain largely sequestered from the market until the point of donation (Waldby & Mitchell 2006). They cannot be created, bought, or sold for research. As explicitly stated in the Dicky-Wicker amendment, these protections and prohibitions are informed by ongoing debate over the moral status of the embryo. Their profound ontological significance as the beginnings of human life (or, for some, as full human life) has thus insulated them, to a certain degree, from a post-1970s economic landscape designed to

<sup>&</sup>lt;sup>83</sup> Currently, Louisiana is the only state with a bill protecting extracorporeal embryos as juridical persons.
<sup>84</sup> In a widely publicized case in 2016, actress Sophia Vergara was sued by her own frozen embryos in a suit brought by her former fiancé, Nick Loeb, who was seeking custody of them. The Louisiana judge dismissed the case on the basis that Vergara, Loeb, and their embryos were residents of California, not Louisiana, despite Loeb's attempts to establish residency status by purchasing and furnishing a home in the state.

facilitate the expansion of markets in bodies and body parts, protecting them in their intact form, for example, from outright commodification in the life sciences industry. Per NIH guidelines, only lines derived from surplus IVF embryos originally created for reproductive purposes and freely donated by intended parents are eligible for inclusion in the registry.

Donation is a means of "disentangling the embryonic gift" (Waldby & Mitchell 2006, 156), freeing it to circulate in more complex and flexible ways in the tissue economy. The donation process requires official relationships between those who have possession and control of the embryos in the fertility setting – the intended parents, who are considered the legal proprietors of their embryo(s) – and those who would receive the embryos for research, in and of itself a complex and often costly arrangement. Many of the clinics I visited have longstanding relationships with a particular research lab, to which they will send, for free, any available donated embryos. "Usually yearly or so [clinics] will send out something to their patients saying 'do you want us to continue to preserve your embryos? Do you want us to discard them? Do you want us to donate them?' [These clinics] have that kind of process, and so they've been referring patients to us … we get maybe 50 embryos per year," a researcher told me. Her lab had relationships with three major fertility clinics across southern California.

A standard donation form includes a brief description of the research project to which embryos are being gifted, with emphasis on the fact that embryos will be manipulated, destroyed, and/or immortalized as stem cell lines in the process – this text is often in bold; questions regarding donors' willingness to be contacted in the future for additional health information or to be apprised of the research results; a confidentiality statement; a discussion of donors' rights to withdraw from the study up until the moment that their embryos are released to the lab; and the

risks and benefits of donation. One final section appeared on every consent form I looked at – some variation of the following

Any materials you have donated to research, or results of research including new products, tests, or discoveries, may be patentable or have commercial value. In some instances, research results may be developed and owned by the Investigators, and/or others. Under California law and rules, if you consent to donate materials, you will have no legal or financial interest in any commercial development.

As this statement evinces, the legal forms of custodial and property rights formalized by the donation process are a means of both disentangling embryos from their corporeal, affective and social ties and re-entangling them in regimes of scientific and economic productivity. In the fertility clinic, embryos represent what, in the context of their work on colonial India, Gidwani and Reddy call "a horizon of property relations" (2011, 1621) – a potential resource awaiting transformation by dint of, in this case, scientific labour and stewardship.

The donation process realizes embryos' enclosure as property. As many commentators have noted (see for example Waldby & Mitchell 2006; Waldby & Cooper 2008; Cooper & Waldby 2014), the U.S. tissue economy has institutionalized a Lockean notion of property wherein the cognitive and technical labour of the scientist preconditions the establishment of intellectual property in living matter. The scientist's inventive step in isolating a particular genetic sequence or creating an immortal stem cell line is understood as that which generates both property rights and commercial value from what is otherwise a naturally occurring biological resource. The bodily contribution of tissue providers – their clinical labour – goes unaccounted for. This definition of property is used to justify the denial of donors' rights to the

(potential) economic benefits derived from their tissues.<sup>85</sup> Thus, although intended parents own the embryos they pay to create for reproductive purposes, they cannot sell or exchange these embryos for economic gain; once donated to scientific research, the lab holds an exclusive claim to any patentable or commercial potential deriving from them.

In seeming contradiction to federal laws on embryo research, the United States has some of the most liberal human embryonic stem cell patent laws in world, allowing patents even on unmodified lines. Since the first hESC patent was issued to the Madison-based Wisconsin Alumni Research Foundation (WARF) in 2001, over 1,000 patents have been issued on human hESC lines in the U.S. (Fendrick & Zuhn 2015). The value of this market is difficult to approximate, but stem cell patents are understood to facilitate significant (if also highly speculative) investment and accumulation in the U.S. tissue economy. And while the promise of stem cell science has largely failed to deliver actual products and services, the patenting of hESC lines has nonetheless spurred capitalization. National Institute of Health funding for human embryonic stem cell research topped 306 million in 2019, estimated to increase by another 15 million in 2020. In December 2019, the top three stem cell companies traded on the NASDAQ had a combined market capital of 2.22 billion (Aspa 2019). Patents covering human embryonic

<sup>&</sup>lt;sup>85</sup> This concept of property rights was enshrined in the Supreme Court of California's decision in *Moore v. Regents of the University of California.* In 1976, John Moore's physician, Dr. Golde surgically removed Moore's spleen, part of a course of treatment for hairy-cell leukemia. Moore later discovered that Dr. Golde had made his recommendation with the knowledge that Moore's cells produced unusually large numbers of lymphokines, proteins of significant interest to researchers that are notoriously difficult to produce in large amounts. In 1979, Golde used material from Moore's excised spleen to create the "Mo" line, and in 1981 established a patent on that line. Production and use of the line was licensed to the Genetics Institute, Inc. in exchange for stocks and cash. In 1984, Moore filed suit against his former physician and Dr. Golde's employer, the Regents of the University of California, claiming that they had effectively stolen his cells and transformed them into a commercially profitable product. In their final (split) decision, the Supreme Court of California concluded that Moore had abandoned his diseased cells to the "safe hands" of the UCLA hospital system when he consented to their surgical removal. These tissues could thus be lawfully recuperated by medical staff, who had no obligation to compensate Moore.

stem cell lines, as well as methods and techniques for isolating, growing, manipulating, and manufacturing them, represent assets that can be used to produce value and, at the same time, have value as property (Birch 2017).

The effect of strict embryo research laws and loose patent laws is a dichotomous research environment in which the market-oriented private sector carries out research prohibited in the public sector, which in turn facilitates that research: what, in the run-up to the Bush-era restrictions, bioethicist Jeffrey Kahn referred to as a situation of "private supplier, public buyer" (2000, np). Of course, non-federally funded does not necessarily mean privately funded. As discussed above, many individual states, including California, have invested public money into the derivation of new stem cell lines. However, most lines available through the NIH are held under patent by private research organizations and foundations or by private-public partnerships.

This is the case with WARF, mentioned briefly above. The non-profit patent and licensing arm of the University of Wisconsin – a partnership made possible following the passage of the Bayh-Dole Act, discussed in section 5.1 – the institute was founded to capitalize on the pioneering work of scientist James Thomson. With \$1 million in funding from private biotech giant Geron Corporation – offered in exchange for a variety of exclusive and non-exclusive rights under patents that might result – in the late 1990s Thomson headed up the research team that derived the first hESC line. Patents on five such lines were subsequently registered by WARF in the early 2000s and licensed through their subsidiary, WiCell. Through WiCell, commercial actors and university researchers could get access to these lines for a licensing fee of \$100,000 and \$5,000, respectively. Because these lines were derived prior to 2001, WARF held patents on the majority of viable stem cell lines when Bush made the decision to prohibit the creation of new hESC lines, effectively guaranteeing a captive market for their

supply. Amidst complaints over the limitations to research created by high licensing fees, in 2005 the NIH selected WiCell to host the National Stem Cell Bank. WiCell became the main distribution centre for hESCs in the U.S. for the duration of the Bush Administration. In return for an NIH subsidy, WARF decreased its licensing for academic research to \$500; commercial fees increased to \$125,000, with yearly maintenance fees of \$40,000 and a commitment to royalty payments in the event of commercialization. The Stem Cell Bank gave way to the NIH's Stem Cell Registry in 2010, following Obama's reversal of Bush's 2001 restrictions. Today, the NIH is the primary source of licensed stem cell lines in the U.S. Lines registered through the NIH tend to dominate non-NIH listed competitors, largely because research using these lines is more fundable (McCormick, Owen-Smith & Thomas 2009; Beltrame 2018).

Restrictive embryo research measures and liberal patent laws, while seemingly contradictory, thus operate together in the tissue economy to facilitate the speculative value of the U.S. biotech sector. As Cooper (2006, np) writes, while tight regulations on publicly funded research appear to affirm life as "an inalienable gift, one that must be protected at all costs from the laws the market, ... the patented embryonic stem cell line seems to function like an endlessly renewable gift – a self-regenerative life which is also a self-valorizing capital." Debate over the moral status of the embryo prohibits their outright commodification in the life sciences industry, keeping free the reproductive labour of those who produce and donate them. This, in turn, keeps embryos cheap, outside the realm of "officially valued," facilitating their integration into regimes of patentable invention as disaggregated stem cell lines derived by the private corporations and public-private research institutes that make up Ikemoto's "university-biotech industry complex." Once disaggregated, they are licensed out via the NIH to circulate as experimental objects in the tissue economy.

## 5.3 Disentangling the abnormal embryo

The designation of embryos as abnormal facilitates this sequence of surplus to cell line to experimental object. My many conversations with clinicians and stem cell scientists suggest that, while they are subject to the same rigorous donation procedures, abnormal embryos are much more easily entered into the tissue economy than their normal counterparts. As I explore at length in Chapter 4, abnormal embryos are typically deemed not suitable for implantation. Understood to be non-viable, they are more easily disentangle from the web of social and political relations that can make embryo research so fraught. They are, in effect, a standing reserve of surplussed biological vitality – a form of waste that should be given so that its value to others can be realized. This narrative of discarded-embryos-as-waste is reminiscent of that used by Wilhelm His in the late 1800s in his attempts to encourage physicians and gynaecologists to give him the embryos they scraped from the uteruses of their patients. As in His's day, donation to biomedical research is framed as a means of repurposing reproductive failure as a valuable tool for scientific enterprise. Today, in the case of abnormal embryos, this is especially true in relation to the study of disease. "Couples now have the opportunity to make a valuable contribution to our understanding of the disorder present in their families by donating these otherwise discarded embryos to human embryonic stem cell research," the University of Michigan Stem Cell Research Program (2013) writes in their public appeal for abnormal embryos.

Although none of the clinics I visited keep records on embryo disposition decisions according to PGT results, many of the practitioners I interviewed told me anecdotally that intended parents are much more likely to donate their abnormal embryos to research than they are to donate their normal ones. One clinician estimated that his patients donate their

"abnormals" 70-80 percent of the time. "Patients want to *do* something *useful* with them. They want to give them to research," a stem cell scientist told me. Sarah Franklin and her collaborators noted a similar narrative at work in the U.K. Their study at a PGT-M centre found that 67 percent of patients were willing to donate embryos to research, of whom more than 80 percent expressed a desire to "give something back" (2005; see also Franklin 2013).

Genetic and chromosomal abnormalities ease embryos' entry into the tissue economy in a second sense. Although subject to the same prohibitions under the Dicky-Wicker Amendment, abnormal embryos are frequently described by researchers as a source of biological material free from the ethical constraints typically associated with embryo research. This is largely "due to the fact that they are derived from an abundant source of discarded embryos ... diagnosed by preimplantation genetic testing" (Huang et al. 2015, 507; see also Stephenson et al. 2013; Wainwright et al., 2006). In their research on stem cell science in the U.K., Wainwright et al. (2006) found that some scientists would work *only* with abnormal embryos, which do not come with the same "ethical baggage" (737) as those that could, in the future, be used for reproductive purposes. The scientists I spoke with often emphasized that the abnormal embryos used in stem cell research were embryos with "no future" - material pre-emptively assumed to be discarded as waste, regardless of their viability status. In their experiments with germline gene editing using CRISPR-Cas9, a team of Chinese researchers led by Junjiu Huang used abnormal embryos obtained from a local fertility clinic – an attempt to forestall public and scientific concern over the implications of their work and quell fears over the potential development of their experimental objects into full human life (Le Page 2017). For all of these researchers, abnormal embryos offer a source of scientific materials "one step closer" to normal embryos than, for example, animal models (Cyranoski & Reardon 2015) – an object closely related to, but not the

same as, human life. As a speaker at the 2018 ASRM asked their audience: "Are aneuploid embryos actually embryos? Do they count *as* embryos? There is no consensus."

In the fertility clinic, abnormality operates to sever embryos' ties to full human life. They fall on the wrong side of the bio-social binary that hierarchizes life in relation to idealized norms of health, ability, and productivity and as such are rendered wholly and enduringly superfluous to the reproductive process; they are, in short, a form of waste that is of no use to patients on their "reproductive journey." Scientific research is framed as a means of rehabilitating this waste – of redeeming abnormality as a surplus value of vitality and instrumental knowledge that can be placed at the disposal of human populations – what Waldby (2000, 2002) calls biovalue. In the research lab, the genetic and chromosomal mutations carried within abnormal embryos are leveraged as tools that can be put to work to lessen debility, improve capacity, produce health, and forestall death – as, in Waldby's words, a form of "life accumulated against death" (2000, 141). It is to this process of scientific redemption that I now turn.

# 5.4 The "uncanny afterlives" of abnormal embryos

Vinay Gidwani and Rajyashree Reddy (2011, 1625) write that "the things, places, people, and lives cast outside the pale of value at particular moments as superfluity, remnant, excess, or detritus ... return at times in unexpected ways." Like the forms of waste under consideration in their work, the abnormal embryos remaindered by the PGT process have "uncanny afterlives" (*Ibid*, 1626) in different times and places – in this case, in the biomedical research lab. Here, they constitute an unpriced but highly valuable resource donated by intended parents to public and commercial research ventures. The donation of abnormal embryos to biomedical research is a means of rehabilitating what would otherwise be needless waste, transforming it into an active, flexible, and valuable supply of biological material.
Biovalue, as Waldby (2000, 19) writes, "is produced through the setting up of certain kinds of hierarchies in which marginal forms of vitality – the foetal, the cadaverous and extracted tissues, as well as the bodies and body parts of the *socially* marginal – are transformed into technologies to aid in the intensification of vitality in other living things." Designated as useless or even dangerous biological material marginal to the reproductive process in the fertility clinic on the basis of their genetic makeup, embryos with specific mutations are converted into powerful tools for studying the space-times of pathology and mapping the terrain of disease at the micrological scale.

The biovalue specific to these embryos in the research lab derives from the source of their devaluation in the clinic: abnormality. As a stem cell researcher explained, most single gene diseases are developmental, meaning that pathogenesis begins at the very earliest stages of development, inside the embryo, inside the womb. For decades, researchers had to rely on animal models and living patients to study this crucial but inaccessible stage of the disease process. The dual phenomena of respatialization and involution described above, however, have opened the door to human model studies of disease progression, in petri dishes instead of human patients. As the researcher put it: "You can take an early embryo, put it under the microscope, pluck out one cell, and just study it." Involution, indeed.

As Rosi Braidotti (1999) notes, "monstrous" bodies have served as valuable material for experimentation in biomedical practices for centuries, comprising the foundation for the scientific field of teratology, discussed briefly in Chapter 4. Much as late-eighteenth and earlynineteenth century pathologists directed their gaze to the body in their quest to discover the sites from which pathological development radiates and unfolds, today's researchers have directed their gaze to the embryo. Much as human corpses were (and continue to be) used to learn about

the embodied actions of diseases, allowing doctors and their pupils to examine illness as a set of forms and deformations distributed horizontally and vertically in the graded depth of the body (Foucault 1994; see also Waldby 2000), hESC lines with specific mutations are used to model disease *in vitro* – to create a living tool for studying the spatial and temporal starting point of pathology and its dispersion through corporeal space over time. "In the previously hidden world of early human development," University of Michigan stem cell researchers write, "the ground-breaking answers to genetic disease will be found. … This is a revolution in developmental biology" (2013). Abnormal embryos, in other words, offer pathologists and others an opportunity to explore and map the terrain of disease in the most minute detail.

Like most embryos that are donated to science, many abnormal embryos are not left intact but are disaggregated and immortalized as hESC lines (on cell culture and immortalization, see Landecker 2007). As discussed above, these lines represent a biological form more amenable to scientific and commercial enterprise. While the human organism – and by extension, its intact embryonic precursor – is expressly excluded from the realm of patentable material under U.S. law, the surplus value of autopoietic, self-regenerative capacity represented by the immortalized hESC line can be freely entered into circuits of patentable invention. With the introduction of PGTs into clinical practice, the number of disease-specific (or "mutant") human embryonic stem cell lines has skyrocketed. At the time of writing, there were 148 such lines registered with the NIH (of 404 total lines) embodying more than 60 unique mutations including Klinefelter syndrome, Turner syndrome, BRCA, Huntington's disease, and various muscular dystrophies. Twenty-eight of the 52 lines registered with the NIH since 2016 are disease specific. These numbers do not include mutant lines derived with private funds that, for various reasons, have not been registered with the NIH.

Because it is technically challenging to induce controlled mutations in normal human embryonic cells, the natural mutations in hESCs derived from abnormal embryos render them indispensable for modeling human genetic disorders. In the lab, mutant hESC lines can be coaxed to differentiate into virtually any cell type: muscle, fat, skin, nerve, bone, brain, blood... whatever type carries the disease under investigation. In a study on the development of Alzheimer's disease (AD), for example, researchers cultured embryos carrying the mutation for Down syndrome, which is associated with a very high risk of early-onset AD (Shi et al. 2012).<sup>86</sup> They induced the hESCs into cortical neurons; in a matter of weeks, these induced neuronal stem cells developed the characteristic pathological hallmarks of AD. These lines could then be used to study the molecular mechanism by which mutation affects brain development at the cellular level, shedding light on the factors that drive pathogenesis.

The use of abnormal embryos as disease models evinces Georges Canguilhem (1991) argument that, in medicine, abnormal states hold the key to normal ones; the usual value-polarity between the abnormal and the normal (or the pathological and physiological, in Canguilhem's words) is reversed. Abnormal embryos are, a stem cell researcher I interviewed in California told me, actually "much more valuable, in many ways, than normal embryos." Just as the monstrous subjects of teratological investigations provided a basis for the definition of the normate, abnormal embryos – exemplary manifestations of disease – provide a foundation for new understandings about the progress and pathway of pathological development.

<sup>&</sup>lt;sup>86</sup> Early onset familial Alzheimer's disease is associated with the APP gene located on chromosome 21. This gene is associated with the production of beta-amyloid, a prime suspect in Alzheimer's-related brain changes. Recall that people (and embryos) with Down syndrome have an extra copy of chromosome 21, meaning that they produce more beta-amyloid, triggering a chain of events that eventually leads to AD.

In addition to generating valuable biomedical knowledge about the developmental nature of human diseases, abnormal hESC colonies have been instrumentalized as test sites for new disease-oriented pharmaceutical products. Lines carrying clinically relevant mutations are being used to screen new drug compounds and examine their beneficial and adverse effect on cellular and embryo development. In the biopharmaceutical sector, these lines promise vast improvements to the drug discovery phase, which is generally accepted as time consuming and inefficient, requiring high levels of financial investment without any guarantee of a financially viable outcome. Abnormal embryos are put to work in this context as less expensive surrogates for the animal (and eventually human) test subjects on which new pharmaceutical products are routinely tested.

In these examples we see the transformation of embryos into new experimental sites, into means of generating new bodily knowledges and conceptions of living processes. As Rajan (2006), Cooper (2008), Parry and Greenhough (2018) and others have shown, these bodily knowledges and living processes have become increasingly embroiled with capitalism, part of the process of involution that has relocated economic production to the cellular, genetic, and microbial scale. Abnormality offers one such means of knitting together living-being with formations of capital. Harvestesd from the otherwise wasted by-products of failed fertility treatment and enclosed as property via biological patents, abnormal embryos detected via PGT are rendered as use value in the study of disease and the development of new and potentially profitable cures for an ever-increasing array of medical conditions. These embryos thus constitute freely given, constituent elements in a bioeconomy geared toward the optimization and enhancement of bodily capacity. By donating their abnormal embryos to research, intended parents fulfill a duty to contribute their reproductive substance to the body politic as a whole,

giving to an imagined future community that will be made healthy by the knowledge and products generated from their embryos.

Commercial enterprise, in turn, looks to profit from these knowledges and products. Patents conferred on disease-specific cell lines extend into the future to apply to any commercial products developed from them. While they cannot guarantee that anticipated commercial gains will be realized – it is very difficult to pin down the profits generated to date – these patents ensure that, if actualized, profits will accumulate in the hands of patent holders. In this sense, mutant hESC research epitomizes the logic of speculative accumulation that organizes the contemporary life sciences industry, which, though biological patents and the venture capital business model, has "formalized the prospective value of a promise" (Cooper 2008, 28; see also Thompson 2005). The wasted reproductive potential embodied by abnormal embryos, transformed into a surplus value of vitality, breeds the promise of new products and profits in the tissue economy.

## 5.5 Accumulation by difference-making

Biological discourses of variation and deviance have long been used to define and stabilize the borders of who counts as fully human. The hierarchy of being that places white, male, abled, Western bodies at the apex and cedes lesser human status to those whose bodies do not conform to this norm has its roots in biological theories that expounded the inherent inferiority of women, people of colour, and colonial others. The twentieth century eugenic policies I discuss in Chapter 2 are emblematic of this logic, geared toward protecting white germplasm (and white male supremacy) from the biological threat posed by myriad vectors of degeneracy and defect: "morons," the descendants of slaves, migrants, and poor women primary among them. At work in these policies, and in other methods of conferring innate biological inferiority, is a process of

biologization that naturalizes perceived social differences as pathologies. Racialized, colonized, and sexualized others, women, the neuro-diverse, and disabled people – each of these categories represents a group subject to exploitation, degradation, disposability, and violence on the basis of social differences re-produced as biologically inferior.

Feminist political economists, among other critical social theorists, have examined how these forms of difference are implicated in regimes of capital accumulation. Sexual hierarchies service the domination that underpins women's exploitation, naturalizing their relegation to the realm of social reproduction and securing a pool of unremunerated workers essential to the functioning of capitalism (see for example Mies 1998; Federici 2004; Dalla Costa & James 1973; Fraser 2013). Appeals to innate racial inferiority likewise buttressed the commodification of human beings as slaves, potentiating massive wealth accumulation through the dispossession of freedom and life itself (Williams 1994; Pulido 2016a). The biomedical sciences, too, have "colluded with a more general sacrificial order which designates certain categories of people as more or less valuable than others, according to their closeness to nature and distance from the fully human" (Waldby 2000, 52). In these and other instances, capital accumulation is facilitated by the division and enclosure of social groups into categories defined by recourse to discourses of biological variation. Designated as less-than-fully human – as lower on the hierarchy of being than the white, Western, heterosexual male that sits at its pinnacle – the bodies and lives of the socially marginal have been rendered disposable in the pursuit of profits. These division "are thus not just epiphenomenal to the reproduction of the capitalist system, but absolutely central to it" (Mitchell, Marston & Katz 2003, 427).

Preimplantation genetic tests are a means of discerning difference at the most minute scales of resolution. As I have argued in the preceding chapters, their use in the fertility clinic

categorizes and divides embryos according to a normal/abnormal binary that casts some forms of biological difference as less desirable than others in relation to highly sedimented definitions of health, productivity, and capacity. Embryos that are seen to fail in relation to these measures become surplus to the fertility process – a non-reproductive remainder with no value in the clinic. While some of these embryos are discarded, others have economically and scientifically productive afterlives in the study of pathology and its cures. I have charted some of these afterlives in this chapter. The bio-social hierarchy that deems some forms of biological difference as more or less desirable than others, I have argued, drives scientific and commercial investment in technologies geared toward the differential reproduction of healthy (read: able-bodied, neuro-typical, healthy, long-living, sexually dimorphic) bodies and lives.

I am not proposing, here, that embryo (after)lives represent an analog for the human lives and bodies maimed, poisoned, tortured, and killed by colonial, racial, and patriarchal capitalism. The abnormal embryos under consideration in this dissertation do not constitute full human life. No embryo does – a point on which both I and the clinicians and scientists I interviewed emphatically insist. As one California clinician put it: "Embryos have the *potential* to be a life. *They are not human life*" [emphasis hers]. And yet, during assisted reproduction, the health of the potential life and the health of the future life are collapsed; transfer decisions are routinely based on the predicted health status of the child anticipated to unfold from the embryo. This collapse is illustrative of a regime of biomedicine that measures the value of (future) life on the basis of perceived biological differences, ranked according to idealized health norms. The designation of embryos as abnormal in relation to these norms renders them as waste, facilitating their entry into the tissue economy. As Braidotti (1999, 291) writes, "disposable bodies are useful to science." In this way, the role of abnormality can be understood as structurally related

to the role of other social hierarchies as a form of accumulation by difference-making. Abnormal embryos represent a generative vantage point from which to consider some of the ways that normative understandings of health and bodily capacity are operationalized in service of capital accumulation -- how "difference" is both produced by and productive for capitalist interests. Abnormality is yet another means of placing procreation and biological reproduction at the service of capital accumulation. Following abnormal embryos out of the fertility clinic and into the research lab thus offers an opening through which to grapple with the relationship between reproduction, social difference, and capitalism – an opportunity to parse the mechanisms of accumulation through difference-making and the varied and multiple ways that life itself becomes enmeshed in the capitalist system.

## **Chapter 6: Conclusion**

This dissertation set out to critically examine the normal/abnormal binary – to exhume its history, its investments, and the complex of practices, assumptions, and knowledges that bring it into being and sustain it as a system – from the vantage of the abnormal embryo. In the preceding chapters, I followed the biotechnological gaze inside the abnormal extracorporeal embryo in order to explore its social, political, and economic dimensions, asking what these embryos reveal about how we understand the body, social hierarchies of difference, and the relationship between production and reproduction in the slipstream of the biotech revolution. This analysis drew our attention to biomedicine and fertility as key sites in which social differences are biologized and capitalized; and it oriented us toward questions of biology and biological difference and the various ways that these continue to bear down on our political concerns.

Chapter 2 began with a brief history of embryo science, which followed the embryo from its *in vivo* origins to life and growth *in vitro*. The dual processes of respatialization and involution born of early embryology, I argued, transformed embryos into scientific objects of intense social interest. This transformation and the knowledge and techniques it generated precondition the preimplantation genetic tests (PGTs) that were my interest in Chapter 3. Here, I used abnormal embryos as a site from which to query the persistent genetic determinism that mobilizes the gene as a "code of codes" (Haraway 1997, 147) on the basis of which life can be anticipated, measured, and (de)valued. Used to detect variations in genetic sequences and chromosomal arrangements, PGTs construct abnormality as a natural property of the embryo – something "there" to be found in the very substrate of life itself. Obscured by this understanding of "abnormality as natural fact" is the constellation of technoscientific, medical, legal, and social 176

relations that hierarchize variation and difference as normal or abnormal. Chapter 4 shed light on this constellation, forwarding an understanding of abnormal embryos as social and political entities shot through with power relations and highlighting the fertility clinic as a key site in which value distinctions between the normal and the pathological are born and made. Abnormal embryos, I argued, are less surplus than *surplussed* – rendered surfeit to the reproductive course by a process of hierarchical difference-making in which some lives are considered more or less valuable than others on the basis of their biology. In Chapter 5, I examined how this process of hierarchical difference-making orients embryos to capitalism as an unvalued but invaluable biological resource integral to the production of new biomedical knowledges, products, and profits.

The question of reproductive politics has lingered at the margins of each of these chapters. In this final installment, I explore the imbrication of assisted reproduction and reproductive politics in more depth. Beginning with a brief recapitulation of the relationship between IVF and the legal right to abortion introduced in Chapter 1, I turn my attention in the remaining pages to the tensions and questions evoked by abnormal embryos in particular. These embryos and the forces that restrict their use for reproductive purposes, I argue, demand a more capacious understanding of reproductive politics, one that exceeds the right to termination. Drawing into the fold the work of feminist of colour activists and scholars who insist on a "reproductive justice" framework, I put abnormal embryos to work one final time in order to examine how the normal/abnormal binary under consideration in this dissertation works in tandem with racism and sexism to differentially (de)value and bound reproductive capacity along well-worn lines of social difference.

As I discuss in Chapter 1, disputes over the moral status of the embryo percolate through the field of assisted reproduction, which entails the production and discard of a large volume of supernumerary embryos. These embryos have recently garnered increased attention from rightto-life organizations in the U.S, which, emboldened by a Trump Administration, have renewed their efforts to pass personhood legislation at multiple levels of government. As legal scholars have noted (Gaddie 2018; Rao 2008), and as I examine briefly in Chapter 5, these embryos represent a potential loophole for those working to overturn the Supreme Court's decision in *Roe v. Wade*. Because *Roe* centres a pregnant person's right to bodily integrity and avoids passing verdict on the question of when life begins, IVF embryos could ostensibly be granted personhood status without contravening the 1973 decision, opening the door to further constitutional challenges. Any success on this front has the potential to seriously hamper assisted reproduction, restricting clinics' ability to dispose of what could be considered the legal equivalent of a born human being.

In this fraught political atmosphere, those involved in the fertility bioeconomy – including the clinicians, lab directors, embryologists, and scientists I spoke with – continue to stress the relationship between access to fertility treatment and the legal right to access abortion and contraception (see also Gaddie 2018; Feinberg 2017; Boggs 2012 for further discussion of this relationship). At the 2018 meeting of the American Society for Reproductive Medicine (ASRM), Ethics Committee chair Judith Daar implored fertility specialists to align themselves against regressive abortion laws alongside groups like Planned Parenthood, whose director, Cecile Richards, had given the ASRM President's Address to a packed auditorium the previous year. Said ASRM president Dr. Richard Paulson in his 2017 remarks introducing Richards: "We think it's important to make sure people understand this is not just about banning abortions. They

are, in fact, banning access to fertility care." In 2019, in response to Alabama's new laws restricting access to many reproductive medical services, including abortion, the ASRM announced that it would be moving its headquarters from that state, where it had been located for 75 years, to Washington, DC.

At the crux of Daar's, Paulson's and others' appeals is a call to protect the individual right to private reproductive decision-making. This right has long animated the mainstream reproductive movement in the U.S., which is defined by federal and state laws that preserve individual reproductive freedoms, with an especial focus on the right to access legal and safe abortion (Sasser 2018). The study of abnormal embryos presented in the preceding pages orients us somewhat differently at the intersection of reproductive politics and assisted reproduction. Here, the normalizing drive that casts these embryos out of reproductive futurity raises the spectre of a eugenic logic that seeks to curtail and prohibit the reproductive capacities of those whose genes are considered a threat to the bio-social future, in turn raising pressing questions about who gets to reproduce whom and under what conditions – or, in Hannah Arendt's terms, "who should and should not inhabit the world" (1977, 279). These questions complicate liberal notions of reproductive freedom, directing our attention away from a single-issue focus on the right to limit fertility, for example, through access to abortion, and toward imposed means of coercive fertility regulation, through, for example, prohibitions against the transfer of abnormal embryos.

Founded by activists in the wake of the 1994 International Conference on Population and Development in Cairo, the Reproductive Justice (RJ) movement emerged to so complicate reproductive rights in the U.S. Their primary aim was to redress the systematic exclusion of women of colour from mainstream reproductive rights. "The supreme court has elevated

reproductive liberty to the level of a fundamental right against government interference deserving of the highest judicial scrutiny," writes Dorothy Roberts (1997, 247). "But black women's reproductive choices seem to fall outside this sphere of protection." The movement organized itself around a critique of the dominant reproductive rights discourse espoused by organizations like Planned Parenthood and, today, the ASRM. Based on a rhetoric of "choice" grounded in social and racial privilege, RJ activists argue, this discourse ignores the forces that compel, coerce, and restrict the reproductive decision-making of poor women and women of colour (Nelson 2003; Roberts 1997, 2004, 2017; Silliman et al. 2004). As Jade Sasser (2018) writes, it is abundantly clear in the history of population control that this discourse is far more complex than it appears in that "choice" is not, nor has it ever been, available to all women. While middle-class white women fight for the right to limit their fertility, poor and racialized women, stereotypically defined as hyperfertile, fight forced sterilization and punitive child custody laws, among myriad other mechanisms aimed controlling their fertility by rendering it problematic and even criminal. Given the histories and presents of these extant mechanisms, RJ activists argue, a robust reproductive justice framework must include "not only the right not to have a child, but also the right to have children and raise them in safe, healthy, and supportive environments" (Roberts 2017, xix).

Preimplantation genetic testing traffics in the fantasy of unconstrained choice critiqued by the RJ movement. For its proponents, preconception and preimplantation genetic screening increase the scope of reproductive choices available to prospective parents by providing them with more information about and control over the genetic makeup of their children. As PGTs become more technologically sophisticated and knowledge of the human genome increases, so too will the choices available to intended parents multiply. Already, parents have the option, as I

discuss in chapters 3 and 4, to select for sex; to eliminate from the "family line" heritable conditions like Down syndrome, cystic fibrosis, Tay-Sachs disease, and Huntington's disease, among hundreds of other single gene disorders; to discard embryos carrying predisposition genes linked to adult- and late-onset conditions like Alzheimer's disease, breast cancer, and colon cancer; to de-select embryos with sex chromosome rearrangements linked to intersex conditions like Klinefelter syndrome; and, on the horizon, to screen for genetic combinations associated with height, IQ, and other polygenic characteristics and risk factors. Alongside preconception carrier screening and with the help of their treatment teams, these options "empower ... patients in their decision to build a healthy family" (speaker, ASRM 2017).

Working within a reproductive justice framework orients us to the structuring forces concealed by the construction of preimplantation genetic testing as a form of empowered and expanded reproductive choice: in this case, to the powerful impetus toward normalization outlined in this dissertation. Preimplantation genetic tests do not offer the choice of embryo selection but the choice to build a "healthy family," not the option to select embryos with "undesirable" traits but the option to avert them. Grounded in taken-for-granted assumptions about the non-desirability of particular forms of biological difference, the social, legal, and medical prohibitions against transferring abnormal embryos detailed in Chapter 4 narrow the field of possible conduct in response to pregnancy, disciplining reproductive capacity along the normal/abnormal binary. The goal of empowering families by increasing reproductive autonomy thus sits in tension with the restriction of reproductive options in the face of embryonic abnormality. Reproductive choice is constrained at the same moment that it is legally and medically upheld.

Much as the experiences of poor and racialized women encapsulated by the RJ movement challenge and exceed the notion of "free choice" promulgated by the mainstream reproductive rights movement, so too does the language of choice fail to account for the ableist structures that shape intended parents' decisions about preconception and preimplantation screening and embryo selection. Intensified preconception surveillance via expanded carrier screening assures that abnormal embryos will be properly screened and identified; prohibitive transfer policies ensure that the freedom to choose a healthy embryo is properly exercised; and follow-up prenatal regulation via non-invasive prenatal testing,<sup>87</sup> chorionic villus sampling, and amniocentesis securitize that choice. Together, these technologies ensure that parents make the "right" reproductive choices. Onus for the genetic fitness of their children shifts to individual women, who become the site of governance through the self-regulation of genetic risk. PGTs thus intensify a gendered biopolitics that empowers pregnant and prepregnant women to protect the health of their future children, and the health of the population, through what Becky Mansfield has called "free-yet-disciplined individual choice" (2012b, 594). Enrolled in increasingly mandatory preconception, preimplantation, and prenatal genetic screening regimes, intended parents, and women in particular, are responsibilized to reproduce a genetic legacy, a genetic future, free of ill-health, disability, and disease.

Understood this way, preimplantation genetic testing is part of a long history, in reproductive politics, of controlling women's procreative capacity for the sake of future populations. This history and its presents are haunted by the ghost of eugenics: by the explicit,

<sup>&</sup>lt;sup>87</sup> Non-invasive prenatal testing analyzes small fragments of DNA circulating in a pregnant person's blood in order to determine whether a fetus will be born with certain genetic abnormalities.

state-sanctioned eugenics that operated across the U.S. in the early- to mid-twentieth century, overviewed in Chapter 2, and by a lingering, anticipatory logic that mobilizes and hierarchizes biology as a measure of difference and value, examined in Chapter 4. To suggest a continuous history between these pasts and presents is not to suggest that nothing has changed. Preimplantation genetic testing and reproductive genetics more broadly are emblematic of a shift, post WWII, from formalized, state-based eugenic policies to a market-driven model that operates under the auspices of individual choice – part of an effort to sever its ties to the scientific racism realized by eugenics. Incorporating a seemingly benign form of selection, PGTs ostensibly rely on individuals to make appropriate decisions about their own reproduction.

But the abnormal embryos averted by these tests also direct our attention to the illusory nature of "choice" – to the ways that eugenic fantasies linger, highlighting ongoing efforts to redirect the socio-biological future by managing the reproductive present. The law remains deeply implicated in these efforts, a mechanism of control (enacted through, for example, wrongful life and wrongful birth claims) that shapes embryo selection practices in material ways. These efforts place fertility, and women's fertility in particular, in a position of responsibility with respect to the future, constructing women, to borrow again from Sasser (2018) as "sexual stewards." Seen to wield the power to mete out life and death – not just of individual children, but also the population, the race, the nation state – women's procreative capacities are administered and disciplined in both explicit and surreptitious ways, directed toward the right kind of life, the right kind of bodies, the right kind of future. While the fertility of some – especially white, middle-class, heterosexual, able-bodied, and neurotypical – women is incited in service of this future, that of others – queer, disabled, immigrant, indigenous, racialized, and poor women – is curbed, constrained, and prohibited.

We can observe these prohibitions at work in the ongoing non-consensual sterilization of Indigenous women in Canada (Rao 2019), in the practice of offering reduced jail sentences to inmates who "volunteer" for long-term birth control in the U.S. (BBC 2017), and, I argue, in policies that prohibit the selection of viable, abnormal embryos for reproductive purposes. While different in scope, scale, effect, and experience, these cases are tied together by the structural, systematic expulsion from the future of those deemed "unfit" for inclusion – Indigenous people, criminals, and those who do not conform to idealized health norms. This process of expulsion fits with a much longer "crusade against deviance" (McWhorter 2009, 13) – against the racialized, criminal, poor, and pathological other whose genes are imagined as a threat to the biosocial future.

Michelle Murphy (2017) writes that the lives averted through mechanisms of family planning, population control, fertility management, and, I add here, reproductive genetics, do not just devalue the averted life itself. So too do they cast a shadow over the living people who were also better-not-born, better-to-have-never-lived (Murphy 2017). The abnormal embryos expelled from reproductive futurity demand our attention not because they constitute the moral or social equivalent to the human lives anticipated to unfold from them, but because of what they reveal about the ongoing elaboration of biology as a means of devaluing and hierarchizing human difference and about the forces that continue to structure reproductive capacity along the normal/abnormal binary. Preimplantation genetic tests work together with other population control measures to maintain a reproductive hierarchy that delineates and (de)values populations according to biological discourses of variation and deviance. This is not to say that racism, classism, and ableism are the same thing, or even that they articulate with reproductive politics in exactly the same way. Rather, it is to illuminate how discourses of biological variation and deviance continue to bear down on reproductive politics and capacities. And it is a call to continue working toward a reproductive politics that fights for safe and legal access to abortion as just one part of the fight against disciplinary practices that aim to curb, prohibit, and illegalize women's procreative autonomy.

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## Appendix: A timeline for embryo sciences

