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# Reimagining disability: the screening of donor gametes and embryos in IVF

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## ABSTRACT

In this article, we examine how disability is figured in the imaginaries that are given shape by the reproductive projects and parental desires facilitated by the bio-medical techniques and practices of assisted reproductive technologies (ARTs) that involve selection and screening for disability. We investigate how some users of ARTs understand and deploy these imaginaries in ways that are both concordant with and resistant to the understanding of disability embedded within the broader sociotechnical and social imaginaries. It is through users' deliberations, choices, responses, and expectations that we come to understand how these imaginaries are perpetuated and resisted, and how maintaining them is also dependent upon the individual actions and actors who have internalized them. Our examination is grounded in a close analysis of a small selection of interviews drawn from data gathered during a 4-year project funded by the Australian Research Council exploring the Australian experience of cross border reproductive treatment, looking particularly at surrogacy, and gamete and embryo donation. Our interviewees were individuals or couples who used gamete or embryo donation, coupled at times with surrogacy in attempting to have a child. Participants discussed their views on testing, screening, and future disability.

**KEYWORDS:** assisted reproductive technology (ART), disability, genetic screening, genetic testing, imaginaries, law

## I. INTRODUCTION

In this article, we examine how disability is figured in the imaginaries that are given shape by the reproductive projects and parental desires facilitated by the bio-medical techniques and practices of assisted reproductive technology (ART) that involve selection and screening for disability. This study is part of a special issue that examines

the way that imaginaries underpin the engagement of law with biomedical technologies and science. This special issue provides a space for the development of diverse understandings of imaginaries and their role in law and regulation, in science and technology studies, and in the field of biomedical technoscience. We investigate how some users of ARTs understand and deploy these imaginaries in ways that are both concordant with and resistant to the understanding of disability embedded within the broader sociotechnical and social imaginaries. It is through users' deliberations, choices, responses, meaning making, and expectations that we come to understand how these imaginaries are perpetuated and resisted and how maintaining them is also dependent upon the individual actions and actors who have internalized them. Our examination is grounded in a close analysis of a small selection of interviews drawn from data gathered during a 4-year project funded by the Australian Research Council exploring the Australian experience of cross border reproductive treatment, looking particularly at surrogacy, and gamete and embryo donation.<sup>1</sup>

Within the social imaginary, understandings of disability are shaped by contemporary and historical discriminatory practices of social exclusion. A social imaginary is a governing set of images, symbols, values, and emotions that fashions how something is understood or felt and within which people both construct their social existence and come to know it. Therefore, when exclusionary practices are framed as a common sense feature of the social imaginary, as they tend to be in the context of disability, they limit our vision of a desirable future. This, as we shall show, is particularly evident in the field of ART where biotechnologies are routinely deployed to screen disability out. Importantly however, there is both conformity and resistance to these framings among users of ART. Users of reproductive technology have, over time, created sites of resistance where the social imaginary is expanded beyond conventional understandings of family formation. While the evidence of such expansion or resistance is less obvious in the area of disability, an analysis of ART users' attitudes to disability offers an opening to examine the possible contours of a 'disability imaginary' in the ART context where the ambit of its claims is made actionable—where people with disabilities are included in policies and laws which shape opportunities and futures.

'Sociotechnical' imaginaries have become a dominant conceptual apparatus used in the field of Science, Technology, and Society Studies to understand the development and use of new biomedical technologies in the social imaginary. Jasanoff posits that sociotechnical imaginaries are 'collectively held, institutionally stabilized, and publicly performed visions of desirable futures, animated by shared understandings of forms of social life and social order attainable through, and supportive of, advances in science and technology'.<sup>2</sup> In this article, we extend this conceptual apparatus to aid our understanding and critique of the regulation and use of ART aimed at limiting or excluding disability.

While imaginaries shape individual understandings, they do not reside in the minds of individuals. They are shared visions that incorporate emotions and symbols that

1 ARC DP 15010157 Regulating Relations: Forming Families Inside and Outside Laws Reach.

2 Sheila Jasanoff, *Future Imperfect: Science, Technology, and the Imaginations of Modernity*, in DREAMSCAPES OF MODERNITY: SOCIOTECHNICAL IMAGINARIES AND THE FABRICATION OF POWER (Sheila Jasanoff and Sang Hyun Kim eds., 2015), at 4.

contribute to the creation of collective identities, institutions, and policies. Despite their conceptual status, they have 'material outcomes' that create social practices and shape how the community views the world while also inscribing regulatory norms.<sup>3</sup> It is imperative, therefore, to examine (and critique) how the logics, values, and understandings that animate sociotechnical imaginaries envision disability. Indeed, an understanding of their networks, and their power to create practices, systems, institutions, and policies, can assist us to comprehend why, out of the range of possibilities, social and biotechnological orderings that centre disability avoidance rather than disability acceptance, materialize while others do not.

It is our contention that both regulators and biomedical professionals rely on communally endorsed social and sociotechnical imaginaries to justify the investments made in developing reproductive technologies and to shore up the moral purpose of that technology. Scientists and developers of ART draw on these imaginaries to guide and inform the work they undertake while also contributing to the shape of those imaginaries. Similarly, policy makers and regulators use these imaginaries to support their claims to responsible and responsive regulation.<sup>4</sup> This is especially the case where the technology involves selective disability avoidance technologies. The centrality of preconception and preimplantation genetic screening and testing of gamete and embryo donors, and the screening and choice of surrogates in ART, is evidence that disability avoidance is one significant pivot around which the sociotechnical imaginary for ART users is framed.

From June 2015 to June 2018, 66 semi-structured interviews were conducted. These included parents and intending parents through domestic or international third party reproduction including: surrogacy, donor gametes, and/or donor embryos.<sup>5</sup> For the purposes of this article, we narrowed our focus to 41 interviews where gamete or embryo donors were used because these interviewees typically spent some time considering genetic screening and testing of their donors. These patient interviews were entered into an NVivo database and a search was undertaken to identify those transcripts where participants discussed their views on testing, screening, and future disability. The cohort used in this article is a small selection (22) of those 41 interviews where specific consideration was given to the possibility of disability in one's future child. We also included data from four interviews with doctors who work in IVF clinics. Two of those interviews are referred to in this article.

3 Sheila Jasanoff and Sang-Hyun Kim, *Containing the Atom: Sociotechnical Imaginaries and Nuclear Power in the United States and South Korea*, 47 MINERVA 119 (2009).

4 In making this claim, we have applied Jasanoff's understanding of the sociotechnical imaginary, *supra* note 2. She further notes that 'legal practices are equally important to the construction of sociotechnical imaginaries in countries where power is differently allocated among the major branches of government' at 39.

5 The study utilized a multi-method recruitment process, using both clinical avenues and broader advertising to the public and draws responses from patients who have engaged in surrogacy or are donor egg or donor embryo recipients. Social media was also used including a facebook page and community websites such as Buhhub, as well as advertising for interviewees at surrogacy conferences. Volunteers were invited to participate through either engaging in face-to-face or phone interviews and were also asked to complete an optional demographic survey either online or by hand. The sole inclusion criterion of the broader study was that participants currently or previously engaged in surrogacy, egg or embryo donation or are service providers assisting in the latter ARTs. Many of the participants engaged in more than one form of third party reproduction. Ethics approval to conduct this research was obtained through the UTS Human Research Ethics Committee ref. 2015000094. Pseudonyms are used for all interviewees.

## II. THE SOCIOTECHNICAL IMAGINARY, LAW AND THE BIOTECHNOLOGIES OF ART

For over three decades, individuals and couples<sup>6</sup> have been accessing a number of forms of assisted reproduction with the goal of having a baby. These reproductive projects and parental desires are facilitated by a range of increasingly specialized biomedical procedures and techniques as well as an assemblage of professionals including ART doctors, counsellors, geneticists, lawyers, donor gamete recruitment agents, surrogacy agencies, and, in some states and overseas jurisdictions, regulatory bodies. Alongside, these exist a range of informal participants including online peer support groups formed through social media platforms, such as Facebook, and more structured private social groups, such as BubHub.<sup>7</sup> All of these actors, together with the intending parents, sperm donors, egg donors, and surrogates, carry out their activities against a backdrop of legislative prohibitions and regulatory frameworks that shape, and at times, thwart, the assisted reproductive choices available to an individual or couple in a particular jurisdiction. Throughout the assisted reproductive process, bio-social technologies also provide (and restrict) opportunities for intended parent(s) to 'choose' the characteristics of the intended child. Selecting a sperm or egg donor on the basis of physical characteristics or genetic screening tests, providing a detailed medical history of a donor, selecting embryos on the basis of preimplantation testing for a range of genetic conditions, or scrutinizing its shape or screening its chromosomes at the blastocyst stage are all materializations of sociotechnical imaginaries regarding the place of persons with disabilities in present and future communities. So too are the legal limits on how donor gametes may be obtained and who may access them,<sup>8</sup> the guidelines and rules regarding what kind of testing may be undertaken, discussed below, and the use of complex contractual arrangements to ensure, for example, a surrogate's participation in a range of prenatal testing and screening procedures.

### II.A. The law

Sociotechnical imaginaries are given legitimacy by the state through policy and law,<sup>9</sup> while at the same time drawing their rationale or justification from what is purported to be the expression of communal desires and values. They are understood to be inclusive of regulatory regimes and serve to justify an exercise of state power as an expression of the collective vision of the proper and desirable future. In fact, as we see in the data we present below, there is variability in what is understood to be a proper and desirable

6 While the focus of our research project was Australian users of ART, the research traces their decisions to cross state and national borders to obtain treatment. Interviewees undertook treatment in South Africa, Thailand, India, Australia, USA, Canada, and Mexico. Therefore, much of what we are arguing may also be relevant for those destination jurisdictions especially those that have similar regulatory systems such as the UK, Canada, and, to a lesser extent, the USA.

7 Anita Stuhmcke, Jenni Millbank and Isabel Karpin, *Assisted Reproductive Technologies, the Internet and Information Seeking: a case study of Australian women using peer online forums to seek donor eggs across borders*, 24(2) GENDER, TECH. AND DEV. 155 (2020).

8 See Isabel Karpin and Jenni Millbank, *Regulation of Assisted Reproductive Technology and Surrogacy in Australia*, in ROUTLEDGE HANDBOOK OF FAMILY LAW AND POLICY 201 (John Eekelaar and Rob George eds., 2014) for a discussion of the laws around access to and importation of gametes.

9 Jasanoff, *supra* note 2, at 39.

future, significantly contingent on reproductive possibility and opportunity.<sup>10</sup> What is sanctioned by the state, however, tends to be a more narrow view of what is valued, and is presumptively exclusive of persons with disability. In Australia, ART clinics must comply with the Australian Reproductive Technology Accreditation Committee Code of Practice,<sup>11</sup> the National Health and Medical Research Council guidelines on Assisted Reproduction,<sup>12</sup> and state based legislation.<sup>13</sup> Apart from standard disease transmission controls, and some limits placed on the use of preimplantation genetic testing,<sup>14</sup> there are few specific limitations on the use of other forms of genetic testing such as prenatal testing or preconception screening. The absence of limiting legislation, it might be argued, is an unspoken endorsement of the use of genetic screening and testing. Instead, decisions around their use are left to the disciplines of medicine and ethics and the practices of self-surveillance. Robertson emphasizes that: '[N]eo-liberal notions of individual autonomy, the free market and limited government are related, in a mutually producing and sustaining way, to the imperatives of 'self-care' - in the form of self-surveillance and self-regulation.'<sup>15</sup> In the neo-liberal context, using biotechnologies to facilitate individual responsibility for limiting risk in the context of reproduction enables biomedical conceptions of normalcy to pervade decision-making around future children. Therefore, the state largely governs from a distance in the area of regulating reproductive genetic screening and testing, rather than directly by enacting legislation or formal regulations.

In Australia, the use of preimplantation genetic testing (PGT) is, however, subjected to some semi-legal limitations in that the NHMRC ART Guidelines prohibit its use other than to 'select against genetic conditions, diseases or abnormalities that would severely limit the quality of life of the person who would be born'<sup>16</sup>, to select an embryo with compatible tissue for subsequent stem cell therapy intended for a parent, sibling, or other relative, or to increase the likelihood of a live birth. While there is no specific requirement in the guidelines that embryos that test positive for genetic conditions be discarded, in fact the guidelines do limit the right of a clinic or a couple to implant an embryo that has tested positive for a condition where there is an embryo that has not tested positive that could be transferred instead. In para. 8.15.2, the guidelines

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- 10 See Roxanne Mykitiuk and Isabel Karpin, *Fit or Fitting in: Deciding against Normal When Reproducing the Future*, 31 CONTINUUM 341 (2017), which undertakes a case study of four interviews from the same research project and examines the role of contingency in selection decisions.
  - 11 REPRODUCTIVE TECHNOLOGY ACCREDITATION COMMITTEE (RTAC), CODE OF PRACTICE FOR ASSISTED REPRODUCTIVE TECHNOLOGY UNITS (2015).
  - 12 NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL (NHMRC), ETHICAL GUIDELINES ON THE USE OF ASSISTED REPRODUCTIVE TECHNOLOGY IN CLINICAL PRACTICE AND RESEARCH (ART guidelines) (2017).
  - 13 E.g. Assisted Reproductive Treatment Act 2008 (Vic).
  - 14 See NHMRC, Ethical Guidelines, *supra* note 12. See also: *infra* note 16.
  - 15 Ann Robertson, *Risk, Biotechnology and Political Rationality: Lessons from Women's Accounts of Breast Cancer Risks*, in THE GENDER OF GENETIC FUTURES: THE CANADIAN BIOTECHNOLOGY STRATEGY, WOMEN AND HEALTH: NNEWH WORKING PAPER SERIES 64 (Fiona Miller et al. eds., 2000).
  - 16 NHMRC, Ethical Guidelines, *supra* note 12, at 73. The Research Involving Human Embryos Act 2002 (Cth) specifically limits the use and development of embryos in the course of a woman's reproductive treatment to ART units that have been accredited by RTAC (s 8, 11). Consequently, all clinics that create, develop, or store embryos must comply with the RTAC Code of Practice (*supra* note 11). The RTAC Code of Practice, in turn, requires compliance with the Ethical Guidelines, unless a registered ethics body affiliated to the clinic has directed alternate policies (*supra* note 11, at 8).



specifically prohibit the use of PGT to ‘preferentially select in favour of a genetic condition, disease, or abnormality that would severely limit the quality of life of the person who would be born’. While this provision has not yet been legally tested, it is speculated that where it is possible to choose an embryo without such a condition one must do so. It is only in circumstances where all embryos have a condition that would ‘severely limit the quality of life’,<sup>17</sup> that choosing to transfer an ‘affected’ embryo would be permissible. This reasoning follows because such action would not amount to the exercise of a ‘preference’ for disability. These limits then drive a state supported view that selection against disability is an appropriate goal whereas acceptance of disability is not.

These biotechnologies are offered to prospective parents as a way of providing information to support choices: to select a particular gamete for fertilization or embryo for implantation, or to make decisions about whether to reproduce using one’s own gametes or donor gametes. They are also used to guide decisions about whether to abort an affected fetus once pregnancy has been achieved or to take other measures such as surgery—if viable—in utero to reduce the ‘negative’ effects on a future child. Genetic screening and testing may also be used simply to provide information to facilitate preparation for the birth of a child with a disability or a genetic disease. However, in a social context where ableism is pervasive, where full inclusion for people with disabilities is non-existent, and where individuals have internalized the imperative of self-governance, exercising a meaningful choice becomes almost no choice at all. Given the absence in Australia of overt legislative limits or permissions, apart from the context of preimplantation testing, it is necessary to examine the underpinning assumptions regarding disability that are contained within the sociotechnical imaginary and expose them to social and political debate that may ultimately invite legislative limits. Because imaginaries play a role in influencing action and material ‘outcomes’, they are instrumental and futuristic. However, to date, they have not adequately addressed alternative understandings of disability that show how assumptions about future disablement are informed by the distorting lens of existing inequalities and injustices. As Marcus has suggested scientists and technologists are ‘constantly trying to understand the present by borrowing from a cautiously imagined emergent future, filled with volatility, and uncertainty, but in which faith in practices of technoscience become even more complexly and interestingly constructed’.<sup>18</sup> So too are lawyers, and our project provides an opportunity to examine individual decision-making and actions, and the material expression of the collective imaginings of a desired future in order to consider whether regulation that enfranchises alternate imaginaries is necessary to remedy existing dehumanizing and exclusionary practises. To this end, we examine, through the interview data with a select group of users of ARTs, how disability imaginaries have been navigated, taken up, negotiated, and resisted at an individual level.

17 It is important to note here that there is no consensus around what constitutes a condition that severely limits the quality of life and the NHMRC ART Guidelines go on in para. 8.16.1 to say ‘It is not possible to list the genetic conditions, diseases or abnormalities for which the use of PGT is ethically acceptable, as context is important and the assessment may change over time.’

18 GEORGE E MARCUS, *TECHNOSCIENTIFIC IMAGINARIES: CONVERSATIONS, PROFILES AND MEMOIRS* (1995), at 4.

## II.B. Biotechnological possibilities

Biotechnological developments have given rise to two pivotal moments in the ART process when participants are generally asked to contemplate and reject a possible future with disability prior to achieving pregnancy: preconception and preimplantation.<sup>19</sup> Preconception carrier screening is typically offered to intending parents for themselves or their potential gamete donors to check for known and common genetic conditions. PGT may also be offered to intending parents who wish to have their *in vitro* created embryos tested for a known genetic condition or for chromosomal abnormalities prior to transfer to the uterus. The technologies for both forms of testing are advancing rapidly and creating an environment where the choices around testing track to an idea of normalcy that is contracting as the scope of what is testable expands.

### II.B.i. Preconception screening

Most clinics have extensive screening and testing regimes that are made available to intending parents and are also used to screen gamete donors. Testing and screening protocols aim to ensure that donor gametes used for reproduction are unaffected by genetic anomalies or other heritable conditions. Protocols reflect a conception of what, in the clinical context, is considered to be 'normal' and permissible as opposed to abnormal and requiring exclusion. Importantly, however, there is no clear consensus even among clinicians about what is 'normal', and so without strict regulatory limits, screening and testing practices vary quite markedly across clinics.

Until recently, genetic screening has been limited to specific conditions that are a known risk based on familial history or ethnicity. However, expanded carrier screening creates the potential of testing a single gamete provider (whether donor or intended parent) for a multitude of possible conditions with one test. Expanded carrier screening tests saliva samples for genetic markers indicating the presence of a genetic susceptibility to a list of 'disorders' that may include as many as 250 autosomal recessive or x linked conditions.<sup>20</sup> The availability of expanded carrier screening inevitably raises the question: of all the possible genetic mutations for which expanded carrier screening can test, which of them are definitively excluded from the sociotechnical imaginary of reproductive futures? Moreover, on what basis is it determined that the mutation for a specific condition should be included in a screening panel, what constitutes a disability, and when is it appropriate to offer such screening? Bajaj and Gross note that '[e]xpanded panels have received criticism because some of the disorders selected may

19 Once pregnant, a woman will usually be subject to an array of prenatal tests, ultrasounds, and other technological checks. Women who use, and women who do not use, ART are offered prenatal testing. While our aim in this article is to interrogate the contours of a disability imaginary in the ART context there is necessarily some overlap with non-ART users and some of our discussion and interview excerpts below reflect this. Women who become pregnant during the course of ART undergo a high degree of technological surveillance particularly if they do so while acting as a surrogate. Prenatal testing technology is, therefore, relevant to decisions made in the context of surrogacy and forms part of the larger disability imaginary that arises in the context of reproductive futures.

20 Stephanie A. Kraft et al., *The Evolving Landscape of Expanded Carrier Screening: Challenges and Opportunities*, 21 GENET. MED. 790 (2019).



not be clinically significant, have an overall low frequency or a variable onset and clinical course.<sup>21</sup>

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) has, to date, maintained a position that recommends offering referral for information on screening and testing where there is a risk of a genetic disorder based on family history or ethnic background.<sup>22</sup> They recommend that all pregnant women be offered basic screening for thalassaemia carrier status and that all women planning a pregnancy, or in the early stages of pregnancy, be offered information on carrier screening for the more common genetic conditions (i.e. cystic fibrosis, thalassaemia, spinal muscular atrophy, and fragile X syndrome).<sup>23</sup> They note that genetic carrier screening for low-probability couples is not currently funded by the public health system in Australia, and call for the ‘development of funding models that provide for equitable access to screening’ as an urgent health policy priority.<sup>24</sup> Notably, in the US the American College of Obstetricians and Gynaecologists (ACOG), the American College of Medical Genetics, and the US National Institutes of Health recommend that all individuals who are planning a pregnancy or are in the early stages of pregnancy should be offered carrier screening for cystic fibrosis.<sup>25</sup> In contrast, population carrier screening for cystic fibrosis is not currently recommended in the UK<sup>26</sup> and Canada.<sup>27</sup>

In the IVF context however, some clinics offer the narrower form of genetic screening for the ‘common’ conditions, while others offer expanded carrier screening especially where donor gametes are being utilized. Australian clinics have both a domestic and imported supply of donor gametes for reproductive use, and this means that testing and screening protocols can be different depending on the clinic (overseas or domestic) supplying the gametes. One clinic may choose to have all gamete providers, including donors, undergo expanded carrier testing, and may also require psychological testing, while another may test for only a select few conditions viewed as common. What is

- 21 Komal Bajaj and Susan Gross, *Carrier Screening: Past, Present and Future*, 3 J. CLIN. MED. 1033 (2014), at 1039. This is supported by a statement by RANZCOG, *infra* note 43, at 8. The statement notes that expanded carrier screening is rapidly evolving, but that ‘clinicians should be aware that expanded carrier panels may vary substantially in their content, mutation coverage, and reporting strategies, depending on the provider’. For couples with no family history of a genetic disorder, it recommends that expanded carrier screening only be offered ‘in the context of well-defined clinical pathways for . . . genetic counselling’ as nearly a quarter of adults will be found to be a carrier of at least one disorder.
- 22 Genomics Advisory Working Group and Women’s Health Committee, *Statement: Genetic carrier screening, Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)* (March 2019), [https://ranzco.edu.au/RANZCOG\\_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical-Obstetrics/Genetic-carrier-screening\(C-Obs-63\)New-March-2019\\_1.pdf?ext=.pdf](https://ranzco.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical-Obstetrics/Genetic-carrier-screening(C-Obs-63)New-March-2019_1.pdf?ext=.pdf) (accessed Jan. 20, 2020), at 7–8.
- 23 *Id.* at 8.
- 24 *Id.* at 11.
- 25 American College of Obstetricians and Gynecologists (ACOG) Committee on Genetics, *Committee Opinion No. 690: Carrier Screening in the Age of Genomic Medicine*, 129 OBSTET. GYNECOL. e35 (2017); ACOG Committee on Genetics, *ACOG Committee Opinion No. 486: Update on Carrier Screening for Cystic Fibrosis*, 117 OBSTET. GYNECOL. 1028 (2011).
- 26 UK National Screening Committee, *NSC RECOMMENDATION ON CYSTIC FIBROSIS SCREENING IN PREGNANCY*, UK NATIONAL SCREENING COMMITTEE (last reviewed August 2019), <https://legacyscreening.phe.org.uk/cysticfibrosis-pregnancy> (accessed Jan. 20, 2020).
- 27 R. Douglas Wilson et al., *Joint SOGC-CCMG Opinion for Reproductive Genetic Carrier Screening: An Update for All Canadian Providers of Maternity and Reproductive Healthcare in the Era of Direct-to-Consumer Testing*, 28 J. OBSTET. GYNAECOL. CAN. 742 (2016).

interesting to see in our data is that some IVF participants assumed that the testing undertaken by the clinic was a standard testing protocol and did not question what conditions were either included or excluded. For example, Millie stated:

‘So they test for genetic - common genetic disorders. Yeah. I think there’s only three or four that they test for while they’re doing all the medical - they check them out medically. I know cystic fibrosis is one, but there’s also a few others that they actually check, not just predominance, but if they’ve got the recessive gene as well.’

Millie, at 49

Similarly, when asked whether any genetic tests were performed on her egg donor, Rosalind stated:

‘Yeah, she had - like her Cystic Fibrosis tests - they get two of the HIV tests and stuff but other than that, I don’t think there’s much more testing done on them. There could be. I don’t know . . .

I know that they had - obviously the donors all had it done.’

Rosalind, at 32

While these interviewees clearly assumed that the clinician made the appropriate decision about what testing to undertake and which conditions to test, the clinicians we interviewed did not share a consensus about what should be tested.

In our interviews with clinicians, we asked what screening they routinely asked their patients to undergo and whether they also required gamete donors to undergo preconception screening. One clinician cited the Victorian Clinical Genetic Service Panel—Prepair—as their standard. Prepair is a test that offers carrier screening for cystic fibrosis, spinal muscular atrophy, and fragile X. The clinician justified the choice to test for the three conditions as follows:

‘Obviously cystic fibrosis is the - not only it shortens life expectancy but also has a high burden of disease in the patient, in the affected person. Spinal muscular atrophy is associated with a very short life expectancy where babies usually die before their fifth birthday and fragile X is the most common form of inherited mental disability, particularly in boys.’

Ramona, at 7–8

On the other hand, another clinician, who did use expanded carrier screening for donor gametes, advised that in his view:

‘[T]here are things that are more common than CF but we don’t test for them.’

Peter, at 9

He went on to note that while expanded carrier screening was twice the price of the CF test, it screened for 100 conditions not just three (Peter, at 11).

### *II.B.ii. Preimplantation genetic testing or diagnosis*

The second form of testing that is made possible by ART is PGT, also referred to as preimplantation genetic diagnosis (PGD). This is used to test embryo blastocysts at the

5-day stage for known genetic anomalies for the purpose of determining which embryo to transfer. A variation of PGT—preimplantation genetic screening or PGS—is used to test embryos for ‘unspecified and multiple genetic or chromosomal abnormalities where the gamete providers are not known to have any genetic condition, disease or abnormality, or who do not carry a known causative abnormality’ to ‘improve live birth rates (by improving pregnancy rates from embryo transfer and reducing incidence of miscarriage) and may be suitable in cases of advanced maternal age and repeated implantation failure.’<sup>28</sup> The same concern arises with PGT and PGS as in the context of preconception carrier screening, namely that what constitutes a disease or disability is in part determined by what conditions it is possible to test for.<sup>29</sup>

As stated earlier, sociotechnical imaginaries of reproductive futures cannot operate separately from the biotechnical. The fact that such tests are possible has created the conditions through which a particular imaginary of disability avoidance is enabled. As the cost of expanded carrier screening decreases and it becomes less expensive to screen for a vastly increased range of conditions assumed to be associated with a genetic marker, it is expected that an increasing number of individuals will avail themselves of this technology. While PGT is not currently publically funded in Australia and is still unaffordable for many individuals, clinics and hospitals are working hard to overcome these limits by lobbying the government and providing some PGT at a more affordable price for certain conditions such as Huntingtons. If more people access these technologies, we will find that what becomes known as a disability, and concomitantly an undesirable future, expands depending on what technology is able to screen for.

In that case, there may be concerns raised about the potential for litigation where a particular condition is not tested despite the technology being available to do so. Clinician, Peter, for example, raised a concern that he expressed to his lawyer about using a donor who had tested positive. He said:

‘There is another side to this testing as well. That was my call to [lawyer] is if we have a potential donor who is a carrier and her opinion was we shouldn’t be using them. Which means we start losing a hell of a lot of donors. They just aren’t a readily available resource.’

Peter, at 15

Significantly, in a couple of instances, where our interviewees did receive results that their donors were carriers they chose to continue with the donor once it was clear that the other gamete provider was not also a carrier.

For example, Yuri and Noah said:

‘For Malia, we knew that she had a predisposition where she was a carrier for cystic fibrosis, so that was obviously a worry for us, so before we even had gone through egg collections, me and Yuri actually had genetic testing done as well to see if we had that gene, which we didn’t, so our children couldn’t develop cystic fibrosis.’

Yuri and Noah, at 17

28 NHMRC, *Ethical Guidelines*, *supra* note 12, at 8.

29 Genea, GeneSure, PGS and PGD, GENE (n.d.), <https://www.genea.com.au/assisted-conception/genetic-testing/pgd-genetic-test> (accessed Jan. 20, 2020).

In our 2017 paper published in *Continuum*, we described the decision-making of Dian whose relationship with her egg donor trumped the issue of her carrier status for Tay Sachs. Dian had ‘fallen in love’ with that donor, and therefore, once it was clear that her husband was not a carrier, they decided to go ahead with the donor. Dian said:

‘Yeah, William was tested. We just thought, well, we don’t fall in love with people based on them being perfect, so I guess it – from that point of view. As a result, here she is [the baby].’

Dian, at 32

In these examples, genetic testing and donor screening construct the mere identification of chromosomal or genetic variation as worrying. The eradication of that risk becomes a paramount concern for the interviewees and for the clinician an overriding one. The conflation of risk and disability is another component of the technoscientific imaginary that forecloses a disability imaginary.

When pressed on the question of whether screening for more was therefore better, Peter stated:

‘It depends if you are looking at it from a cost effective point of view. Or whether you are looking at it from a personal point of view. So . . . we had a [couple who had a] child . . . with an abnormality which could not have been detected with this. Because of that I had the[m] tested. Her and her husband were picked up with a short-chain fatty acid dehydrogenase deficiency. Both of them. They occur one in I think 25,000. But they were both carriers. Which means that we had a one in four chance of a child affected. Whilst it won’t kill the child it will seriously affect the child’s wellbeing and health. So from that point of view, . . . it was a very good move.

You may say that from an economic and public health point of view while you would only have picked up one child in, I don’t know, 100,000 that’s not what we can spend our dollar on. But the bottom-line is it depends who is spending it. . . . So what we did was we did PGD... We found for any children to be born, PGD was done and any embryos that carried the short-chain were taken out.’

Peter, at 17

There is no consensus about what constitutes an abnormal or unhealthy trait or condition, and no agreed upon list of conditions to test for, notwithstanding that clinicians and patients often use language that suggests there is. If the default position among clinicians is to increasingly screen or test for more traits and conditions not less, and if our laws and regulations are silent about setting limits on those traits and conditions, the disability imaginary warns of a closed future not an open one.

### III. ALTERNATIVE DISABILITY FUTURES AND THE SOCIOTECHNICAL IMAGINARY

#### III.A. Resisting insider imaginaries

If sociotechnical imaginaries are animated by shared understandings of values, interests, and forms of social life that can be achieved through scientific and technological developments, we need to attend to the place, if any, for outsider imaginings. Because sociotechnical imaginaries seem to be such large, structural edifices with the persuasive

power of creating and supporting socially endorsed institutions, policies, laws, and practices, it is important to investigate whose imaginaries come into being and are shared—become powerful—and whose do not. In what follows, and through the data we have obtained in our interviews with participants in ART, we explore how individuals understand the place of disability inside those sociotechnical imaginaries and their consciousness of disability avoidance and ableism. We see how the imaginary is constructed and reformed, contested, resisted, and understood. We have the benefit of the contemporary materialization of the imaginary futures that were envisioned by the decision-makers in ART 30, 20, and even 10 years ago. Over those three decades that imaginary has radically changed from a technology reinforcing heteronormative reproduction with genetically related children to one facilitating reproduction within same sex relationships, among single parents, and with progeny that are sometimes the product of genetically unrelated donors and gestated in genetically unrelated surrogates.<sup>30</sup>

One thing that has remained remarkably consistent, however, has been the approach to disability. The use of ART to assist couples with hereditary conditions to access donor gametes and, as the technology has developed, to utilize preconception, preimplantation, and prenatal genetic testing facilitates a sociotechnical imaginary that prioritizes the possibility of a future without disability. However, it is clear from our interviews that people are tentative and ambivalent about that aim and do not conceive of the future in such a limited way. Instead, factors such as the length of time it has taken to become pregnant, to find a donor or indeed the stage in the process or the age of the intended parent, all make the decision to eschew disability far less certain. For example, one of our interviewees—Katinka—stated:

‘Nobody wants a child that’s disabled - that is going to have more challenges in life than they need to . . . But . . . because of my age I had had to think thoroughly through the whole concept of things such as Down syndrome and other age-related disabilities that - well that increase the chances when you’re - once you’re 40 - or it’s less than 40. So I’d already started to think through those processes. At the end of the day if I’d had a child that had mild disability that’s fine . . . That’s the child that you have, and you have a different sort of life than what you would have had if you had a child without disability. If . . . I’d been in the pregnancy and a major disability had been discovered then that might have been - you might have stopped and thought, well is this a terminating issue or do you look for [growth] with the pregnancy? So I suppose from my point of view is I look overall.’

Katinka, at 21–22

It is necessary, therefore, to consider how the sociotechnical imaginary is adopted at an individual level, what is excluded, and what else is capable of being imagined about (our) possible futures. The imaginaries that operate in and around assisted reproduction and their concomitant practices, policies, and regulatory frameworks about disability have the material effect of (potentially) eliminating a part of the population who might put forth a competing or alternative imaginary to the very one at work. In this way, we see that these are the imaginaries through which disability is allowed to

30 SEE SARA FRANKLIN AND CELIA ROBERTS, *BORN AND MADE: AN ETHNOGRAPHY OF PREIMPLANTATION GENETIC DIAGNOSIS* (2006); Adiva Sifris, *Dismantling Discriminatory Barriers: Access to Assisted Reproductive Services for Single Women and Lesbian Couples*, 30 MON. U. L REV. 229 (2004).

(or not allowed to) come into being. In order to understand this process properly, we need to investigate the relationship between the power and expression of this collective imaginary, the rules and laws that give it shape, and the material choices and decisions of individual actors. We need to know what space exists for disability and for the tentative voices of people like Katinka and for different conceptualizations of disability. What happens when the norms or ‘understandings of forms of social life and social order attainable through, and supportive of, advances in science and technology’<sup>31</sup> are not shared by the community but are contested. We have to pay attention to resistant imaginaries.

### III.B. Outsider imaginaries—imaginaries of resistance

The lives and preferences of future persons are consistently imagined in the construction of sociotechnological imaginaries. However, these imaginaries borrow descriptively and prescriptively from the past and present in imagining the kind of future to bring into being as well as who is imagined in that future. Through a variety of techniques, procreation has now become fragmented from sex, facilitating relational, geographical, and temporal shifts within the procreative context. Relational shifts result from the inclusion of multiple (not just two) parties in the creation of a child. Geographical shifts occur where individuals travel to achieve their reproductive goals, either to avoid regulatory prohibitions or to access those parts of the reproductive process (eggs, surrogates, and sperm) that are in short supply in their home land. Finally, temporal shifts occur, for example, when a person spends 3, 5, or even 10 years trying to produce a baby, when gametes and embryos are frozen and stored for later use, and when genetic siblings who were created as embryos at the same time are gestated years apart. Additionally, the use of genetic and other prenatal screening and testing technologies have enabled specific characteristics (often associated with disability) of the embryo and future person to be predicted so that decisions about implantation or termination can be made. This represents another form of temporal shift—acting now to avoid predicted futures. Such normative visions clearly implicate the interests of future persons, but of course, future persons and communities cannot express their interests and experiences directly. Weiss argues that:

‘[i]t would be difficult, if not impossible, to predict [the preferences of future generations], either because their values, and hence their preferences, will change over time, or because technological developments may change the options available to them upon which they will base their preferences.’<sup>32</sup>

The social and material circumstances of future lives and communities call for responses grounded in an understanding of human persons and communities as embodied, diverse, and constituted by their social, historical, and material circumstances.

To this end, we suggest that it is essential to critically engage with dominant perspectives on what constitutes desirable futures in the sociotechnological imaginaries.

31 Jasanoff, *supra* note 2, at 4.

32 EDITH BROWN WEISS, IN FAIRNESS TO FUTURE GENERATIONS: INTERNATIONAL LAW, COMMON PATRIMONY, AND INTERGENERATIONAL EQUITY (1989), at 39.



Instead of treating future communities and the persons who inhabit them as singular and impenetrable, we need to consider diverse, situated perspectives that illustrate the values and priorities that are omitted from imaginaries shaped from majoritarian communal projections and in particular the inequalities and injustices that underpin them. For example, among our interviewees, was a woman who at the very beginning of the interview stated that she had not been diagnosed, but thought ‘that I probably do have either Asperger’s or autism and it takes me a while to process stuff’ (Cybil, at 2). Furthermore, after revealing that her egg donor had indicated she had a history of autism in her family, she said:

‘Yeah, it was not unlikely and it was a risk we took, so okay, well he could have a chance of having anything.’

Cybil, at 28

On the other hand, Cybil went on to describe her concerns around Down Syndrome which she viewed as a condition she could not imagine in her future child. She said:

‘Probably the thing that I was most apprehensive about was if it had a genetic disorder . . . such as Down Syndrome or anything else.’

Cybil, at 28

These contrasting views suggest that there is more work to be done around the question of why some conditions are viewed as self-evidently problematic while others are not. We suggest that we cannot make sense of these decisions outside of the socio-cultural or medical practices and familial and governance relationships that give them meaning. Indeed it is possible to speculate from Cybil’s response that she was more accepting of a disability with which she was familiar than one with which she was not. However, here, it is also worth considering the way in which particular conditions such as Down Syndrome figure in the social imaginary.

Thomas has written, for instance, about the reutilization of Down screening, and how studies exploring the decision-making processes of parents-to-be around screening for Down syndrome variously show that although screening can occur as a result of ‘rational decision-making processes’, it can also be ‘an instance of conformity rather than an expression of choice.’<sup>33</sup> Thomas describes the normalization of Down screening where ‘mundane, familiar, and taken-for-granted “micro” practices, routines, rhythms, and rituals of everyday clinical life . . . reproduce order and values.’<sup>34</sup> This is born out by the interviewees in our study some of whom, when asked about their decision to

33 GARETH THOMAS, *DOWN’S SYNDROME SCREENING AND REPRODUCTIVE POLITICS: CARE, CHOICE AND DISABILITY IN THE PRENATAL CLINIC* (2017), at 3. Thomas cites numerous studies to support this claim including: H.H. Chiang et al., *Informed Choice of Pregnant Women in Prenatal Screening Tests for Down’s Syndrome*, 32 J. MED. ETHICS 273 (2006); H. Gottfredsdóttir et al., ‘This Is Just What You Do When You Are Pregnant’: A Qualitative Study of Prospective Parents in Iceland Who Accept Nuchal Translucency Screening, 25 MIDWIFERY 711 (2009); S. Markens et al., ‘Because of the Risks’: How US Pregnant Women Account for Refusing Prenatal Screening, 49 SOC. SCI. MED. 359 (1999); N. Press and C.H. Browner, *Why Women Say Yes to Prenatal Diagnosis*, 45 SOC. SCI. MED. 979 (1997); P. Santalahti et al., *Women’s Decision Making in Prenatal Screening*, 46 SOC. SCI. MED. 1067 (1998); R.D. Sooben, *Antenatal Testing and the Subsequent Birth of a Child with Down Syndrome: A Phenomenological Study of Parents’ Experiences*, 14 J. INTELLECT. DISABIL. 79 (2010).

34 Thomas, *id.* at 6.

access genetic testing, assumed we were referring to testing for Down syndrome and talked knowledgeably about the reduced risk they encountered by using donor eggs from young women.

For instance, Oliver responding to a general question about genetic testing stated:

'It was something we discussed and it was something that - the clinic in Thailand sent through and sidestepped me a thing about the 12-week scan and said, do you want the normal one, or do you want the blood test, which was \$300, I think. I was confident in the fact that we had a 19-year-old egg donor that Downs was not really going to [unclear] affect us hopefully. It always could.'

Oliver, at 34

Similarly, Millie stated:

'The IVF thing was more important than the donor egg. But even when you do all the testing, you do your testing, which is a blood test and an ultrasound to see if they're Down syndrome. That, of course, is very important for someone over 40. But because I had a donor egg, it was actually a very low risk, we were in the lowest category for Down syndrome because we had a 23 year old's egg. So having a young donor is actually medically better for your pregnancy than if we had have used our own eggs anyway. So we had lower risk for everything, for Down syndrome, for heaps of other chromosomal problems.'

Millie, at 51

It is clear then that in any consideration of the way in which disability futures are imagined, account must be taken of the 'micro practices' as Thomas puts it, which fashion the shape and understanding of particular conditions as unwelcome or routinely to be excluded. This consideration ought to inform our construction of resistant imaginaries.

### III.C. Disability imaginaries

Critical disability studies literature argues for an orientation regarding futurity that fosters social/technological/legal norms that are welcoming of difference and this is necessary, we suggest, in order to envision disability imaginaries.<sup>35</sup> Disability is dynamic and relational: residing in the environments that differently embodied individuals inhabit. Disability is not having an anomalous body or mind that needs to be prevented, rehabilitated, treated, cured, or eliminated, but occurs when environments of all kinds are unable to welcome a diverse array of bodies and minds. This approach acknowledges the corporeality of experiences of disability but contextualizes these 'experiences' within the changing institutional relationships that give them meaning (socio-cultural, medical practices, familial, and governance relationships).<sup>36</sup> Disability is an experience relative to one's normative structural surroundings. In this way, it is not an ontological pathology, in the sense that it exists outside or independently of socio-material contexts. Rather, disability is conditional upon those contexts. Disability is a

35 Robyn Lee and Roxanne Mykitiuk, *Surviving Difference: Endocrine-Disrupting Chemicals, Intergenerational Justice and the Future of Human Reproduction*, 19 FEM. THEORY 205 (2018).

36 DAN GOODLEY, *DIS/ABILITY STUDIES: THEORISING DISABLISM AND ABLEISM* (2014), at 64.

form of disadvantage or oppression socially superimposed upon an anomalous body or mind.<sup>37</sup>

It is important to consider the sometimes complex relationship between disability and illness. Disability is not illness, but some disabled people are ill. Additionally, while the somatic dimension of disability can involve bodily suffering,<sup>38</sup> ART discourses (those technoscientific discourses posited by IVF clinicians and professionals about genetic testing and donor screening for disability) appeal to a conception of disability, which characterizes the eradication of chromosomal or genetic variation, and the risk of future impairment, as a means to achieve more than the avoidance of suffering in future persons. It is about creating 'normal' or 'healthy' children. Indeed, ART discourses propounded by the clinicians rely on a conception of the 'normal' or the 'healthy' that is unwelcoming to disability. For example, one of the doctors we interviewed stated:

'Basically, there's guiding principles in the . . . derivation . . . of our policies. How can we do the most good with doing the least harm? So, when we are involved in the creation of a baby, of a new life, we try and create a healthy baby.'

Ramona, at 7

Critical disability studies, on the other hand, demand a framework for openness, imploring an understanding of disability that recognizes the significant role of inequality in constructing difference as 'unhealthy' and turning it into disability. Indeed, critical disability studies 'recognizes a responsibility to protect difference across and within generations.'<sup>39</sup> Eisen, Mykitiuk, and Scott have argued elsewhere that:

'Institutional and policy approaches must acknowledge that deep uncertainties about the future must be moderated by the knowledge that contemporary inequalities will be infused, one way or another, into future persons and communities—into their physical environments, their social worlds, and in their very flesh.'<sup>40</sup>

Thinking about how disability is configured in sociotechnical imaginaries, and alternative understandings of disability offered by disability studies points to the need for resistant and alternate disability imaginaries informed by the inequalities and injustices of the present.

37 Shelley Lynn Tremain, *Foucault, Governmentality, and Critical Disability Theory: An Introduction*, in *FOUCAULT AND THE GOVERNMENT OF DISABILITY* 9 (Shelley Lynn Tremain ed., 2005).

38 See, for example, ELI CLARE, *BRILLIANT IMPERFECTION: GRAPPLING WITH CURE* (2017), at 60–61. Clare writes about experiences of cancer, chronic painful and fatiguing illnesses and breathing difficulties as examples of conditions that those who embrace bodily difference would nonetheless choose to cure or treat; CAROL THOMAS, *SOCIOLOGIES OF DISABILITY AND ILLNESS: CONTESTED IDEAS IN DISABILITY STUDIES AND MEDICAL SOCIOLOGY* (2007); Roxanne Mykitiuk and Jeff Nisker, *The Social Determinants of 'Health' of Embryos: Practices, Purposes, and Implications*, in *THE "HEALTHY" EMBRYO: SOCIAL, BIOMEDICAL, LEGAL AND PHILOSOPHICAL PERSPECTIVES* 116 (Jeff Nisker et al. eds., 2010); Susan Wendell, *Unhealthy Disabled: Treating Chronic Illnesses as Disabilities*, 16(4) *HYPATIA* 17 (2001).

39 Lee and Mykitiuk, *supra* note 35, at 216.

40 Jessica Eisen, Roxanne Mykitiuk and Dayna Nadine Scott, *Constituting Bodies into the Future: Toward a Relational Theory of Intergenerational Justice*, 51 *UBC L. REV.* 1 (2018), at 53.

### III.D. Disability imaginaries in ART

The imaginaries that inform(s) the decisions that users of reproductive technology (users of donated gametes, embryos, and surrogacy arrangements and various combinations thereof) make in relation to the possible disability of their future child have so far been under researched. What is the imaginary of disability that emerges from or animates 21st century, western, late capitalist, ART procreation and individual decision-making about one's possible future child?

In our data, we find that collectively held imaginaries regarding reproductive futures are both coercive and contested. Users of ART with donor sperm, eggs, embryos, and/or surrogates partake in a sociotechnical imaginary of 'desirable reproductive/-familial/parental futures' which import normative ideals of filiation and where what constitutes normative well-being is malleable, contingent, and subject to change over time. For example, after waiting a considerable period of time for donor sperm, one interviewee acknowledges that she had limited choice in choosing the characteristics of her donor. Carole's desire for a child meant that she would need to choose among possible donors with a history of a psychological disability. Carole opines for instance:

'So we waited nine months to have some sperm available and we were given three choices to choose from at that point in time. The challenging part of that was that most of the choices were not, to me, ideal. So they were people who were suffering from depression and anxiety or were taking medication for ADHD. Or things that I would not have necessarily wanted to use for donor sperm, so that's what I mean by the choices were slim. If you went out choosing or shopping for your ideal genetic donor, they were a long way from that. So, yeah, I found that hard.'

Carole, at 8

However, interviewee's descriptions of the process itself is highly inflected with the clinical language of medical practitioners suggesting that a narrow conception of disability is informing decision-making at this stage. For instance, Gerry describes the process of selecting embryos for implantation in the following way:

'Yeah and then after they did, ICSI, intracytoplasmic sperm injection on those eggs, we actually went down to 20 eggs growing. Then I think the next thing was with the - with the blasts we had six and we had four more growing that were a little bit slower and then we went down to - we had eight blasts and then we did - we had a PGD, PGS done on eight of those blasts, four of them turned out to be - have some kind of genetic imbalance, but they have a word for when there's a perfect balance of the chromosomes, the perfect reflection, I think it's called a [unclear] cytoplasm, we had four of those, one male and three females. Those are the ones, those are frozen now.'

Gerry, at 36

We see in these examples, how a sociotechnical imaginary configured around genetic screening and testing technologies in a reproductive context, directed at identifying that which is normal and healthy and eliminating the abnormal or unhealthy—even at the level of the gamete or the embryo—creates a future where life with a disability is disappeared. There is no space in this clinical setting to encounter a conception

of disability that holds out the promise of an open future. Our interview with Olivia illustrates this. In narrating her experience of selecting embryos for implantation, she stated:

'They - it depends on the embryos - they were 10 cell embryos on day five and there were only 12 that were ready to be tested on day 12, sorry day five. Day five there were 12 ready, only eight of them were viable embryos, were healthy normal embryos. The others had genetic issues and they do the full array, they call it, full array genetic testing, so it's quite detailed. They give you the information. Only one of those 12 was a female and it was an abnormal embryo, in fact it was identified as having Down syndrome . . .'

Olivia, at 19

There is no future for an 'abnormal' embryo identified as having Down syndrome, and according to this logic, there is no future for the future child that embryo might have become with Down syndrome. Indeed, there is no place in this imaginary for disability to be configured as a relationship between environments and embodiment rather than as pathology, nor systemically as a site of oppression. By locating disability within the individual, disability itself becomes a matter of individual choice.

Importantly, though, interviewees' decisions about using PGD to screen for disability were weighed by some individuals against the risk of losing a pregnancy or the chance of becoming pregnant. According to Celeste:

'Then also with PGD you can destroy healthy embryos because they don't survive the test. We ruled that out.'

Celeste, at 19

Dederick too, in relation to the use of PGD said:

'So, in our case, we didn't have the tests performed . . . because we thought it was too risky . . . Most - we could have if we wanted to, but there's a risk that the - damages the embryo and then the embryo won't take. My understanding is that it's trying to find - [unclear] looking for genetic defects that could be picked up in the early stages, that might get missed if you do the later test. We looked at the risk of it all and we thought, look, if we did that test - we were actually advised not to do the test. We said they could do it, but our IVF doctor really advised us not to because it then makes the whole process riskier. Because it may damage the - there was a reasonable chance that the embryo would be damaged and then not take and then . . .'

Dederick, at 31–32

Avoidance of disability futures in these instances is not inevitable, but rather, highly contingent on the competing desire to avoid a childless future.

Ethan and Ava, for example, having gone through 10 unsuccessful cycles of IVE, numerous medical procedures, egg donation with two different donors and miscarriage, and finally having a successful pregnancy when they entered into a surrogacy arrangement using an egg donor, viewed the issue of potential disability as secondary. When asked whether they discussed disability or its potential with their surrogate, they said:

'Yeah. I mean it came up again once we knew we were having multiples obviously. Yeah. We talked about that and, you know . . .  
We ended up sort of saying we've going to stick with this, come what may right. Yeah. We just said well if I was carrying them we would continue to do whatever parents would do. The one caveat to it was if her life was at risk or the child's life was at risk or that ultimately the child was never - it was never going to progress and the doctor's recommendation was to terminate then we would . . .'

Ethan and Ava, at 54–55

In response to a question about what they would do in the context of a surrogacy arrangement if the child was 'born' with a disability, there seemed to be general agreement among our interviewees about accepting a child with a disability. As Jody declared: 'if it was born with a disability that wasn't picked up, I mean we would - I mean it's our baby, we would just deal with it' (Jody, at 21).

Similarly, Oliver stated, 'we would've brought the child home and loved and cared for it' (Oliver, at 36). Interestingly, Maria mirrors the language of Jody when she states, in response to the same question:

'Well, it's our baby, so we'll just deal with it sort of thing . . . I suppose it's just a given really. It's our baby, [unclear] if it did have disabilities or something wrong with it, then it's still our child and we would just need to do whatever we need to do to get them better and help them.'

Maria, at 46

In these circumstances, the choice of the parties is clearly constrained; however, faced with the reality of disability, these individuals actively embraced the normative responsibilities of parenthood to provide for and take care of a child one has actively and willingly chosen to bring into being.

The data that we have been drawing on suggest that the sociotechnical imaginaries of reproductive futures cannot operate separately from biotechnical limits, and the social context and relational desires of the individuals who inhabit them. They flow from that which the bio-medical technologies enable and are co-produced by those technologies and practices, normative expectations, and legal framings and orderings.

Sociotechnical imaginaries that devalue disability or create a normative frame that excludes difference and anomaly are prevalent in the field of assisted reproduction where assumptions are made about the necessity for prenatal, preconception, and preimplantation genetic testing, and the appropriate response to certain test results.

Biomedicine in the 21st century, in the global North, is frequently characterized by the promise and expectation that 'increasingly sophisticated and complex biotechnologies will finally alleviate age-old fears of disease and ill health'.<sup>41</sup> Health, then, according to this view, is an objective status residing in the body of an individual while 'disease and ill health may constitute an estrangement from what is perceived to be the proper form of one's own body'. The sociotechnical imaginary encompasses the view that it is the job of biomedicine, along with the tools and information generated by biotechnology,

41 Margrit Shildrick and Debrah Lynn Steinberg, *Estranged Bodies: Shifting Paradigms and the Biomedical Imaginary*, 21 *Body Soc.* 3 (2015), at 4.



‘to restore normative structure and function.’<sup>42</sup> While few, if any of us, have normative bodies, we internalize the notion that a normative embodiment to which we should conform exists and that the ideal state of health is under threat unless we participate in active management and surveillance.

For intending parents using ARTs in circumstances where they are not accessing ARTs to deliberately prevent having a child with a disability, there is nevertheless, a sense that a ‘healthy baby’<sup>43</sup> is a base line expectation, both on the part of the intending parents and the clinicians. What is in fact meant by ‘healthy’ or ‘normal’ varies markedly among interviewees. Consider for instance, the language of Gerry who says:

‘you only really want to transfer embryos that you know are healthy enough to form a child. I mean you’ve really - it kind of defeats the objective, after having gone to all those lengths to transfer an embryo that is really - that you going to result in a miscarriage.’

Gerry, at 38

Celeste conflates the microscopic analysis of her embryos with the child that is ultimately born when she states:

‘Ricky was yeah, actually it’s really funny. He’s a really big boy. So at two years old our GPs predicted he’s going to be about six foot three. He’s really tall and as five-day embryo he had more cells. So he actually looked like he was a six-day embryo, he had so many cells that at five days he was ahead of the lot. He was grade Triple A, or Double A. He was a really top [the professor] said look this is the one you’d choose. I said alright, we’ll chose you. He’s a very headstrong boy. He’s a very dominant boy. He’s very strong. So we were like yeah [unclear]. He was just the one.’

Celeste, at 18

The application of biotechnology has generated the idea that a ‘healthy embryo’ is made synonymous with a ‘healthy’ child. ARTs (using IVF) have created a practice in which embryos are graded<sup>44</sup> *in vitro* and the most ‘healthy’ looking ones are selected for implantation. While the NHMRC in Australia created what it terms ‘objective’ criteria for determining the suitability of an embryo for implantation, by looking at factors such as fragmentation and cell division rates,<sup>45</sup> these visual assessments are controversial as results differ between individual embryologists.<sup>46</sup> Nevertheless, this practice is routine in clinics. Perhaps most interesting is that interview subjects often made the assumption that not only should abnormal looking embryos not be implanted because either the implantation would not be successful or the resulting child would be ‘abnormal’, but also the implantation of what had been determined to be a healthy looking embryo would lead to the birth of a healthy child. The logic that healthy embryos will produce healthy children is embraced enthusiastically.

42 *Id.* at 6.

43 Mykitiuk and Nisker, *supra* note 38.

44 *Id.*

45 NHMRC, *Objective Criteria for Determining Embryos that Are Unsuitable for Implantation* (2007), <https://www.nhmrc.gov.au/about-us/publications/objective-criteria-determining-embryos-are-unsuitable-implantation> (accessed Jan. 23, 2020).

46 Pegah Khosravi et al., *Deep Learning Enables Robust Assessment and Selection of Human Blastocysts after In Vitro Fertilization*, 2 DIGIT. MED. 21 (2019).

However, the expectation of a relationship between the ‘health’, ‘normalcy’ or rating of an embryo, and the birth of a (healthy) child was thwarted for a number of our participants. For example, Helen opined that she had ‘perfect embryos and they still didn’t work’ (Helen, at 21).

Cybil, in the context of using PGD stated:

‘We did that on all of them from day one and we didn’t get many normal embryos. One cycle we got two normals and we put them both in and . . . I got pregnant but I lost it, so any time we got anything normal to put back I miscarried. But mostly we didn’t get anything normal to put back, so it was quite gruelling and really expensive.’

Cybil, at 7

The imperative to eliminate disability ‘defects’ and to conform to a normative form of embodiment that biomedicine can help bring into being is pervasive, and extends to forms of embodiment that might otherwise be characterized as merely different or anomalous when engaged at the early preconception and preimplantation stage. How we think about or conceptualize disability in the present determines how we envision disability in the future. The common normative view is that ‘it is the very *absence* of disability that signals [the] better future’<sup>47</sup> for us and for our progeny. Disability is viewed as the sign of no future or no good future. A variation on this perspective is expressed by Dederick who stated:

‘We took the view that if it was going to be deformed - my view was, if it was a physical deformity I could live with that, if it was an intellectual deformity I probably couldn’t. I know it sounds a bit cruel but, I look at some people who are severely intellectually disabled and I think, what’s the point of their life? I know that sounds really cruel and nasty but I just didn’t see the point, it’s not the type of child I wanted in my life.’

Dederick, at 38

Deploying biotechnologies to engage in practices of health risk management and self-monitoring and to shore up bio-medical conceptions of normalcy are pervasive in the current conditions of neo-liberalism. These practices operate to justify a decrease in government activity in economic terms and signify an ideological commitment to recognize and reward individual choice and personal decision-making. The neo-liberal citizen is individually responsible for the risks to their well-being and to the well-being of their family members including those that are not yet born. Integral is the notion that the best forms of governance create the conditions that facilitate autonomous self-regulation; the individual is rendered an active entrepreneur of his or her self and his or her family (intimate relations).<sup>48</sup> ARTs are one means through which the neo-liberal citizen governs themselves and is materially produced.

Press and Browner suggest that the success of preconception screening, preimplantation testing and prenatal diagnosis, rests upon the willingness of individual women

47 ALISON KAUFER, *FEMINIST, QUEER, CRIP* (2013), at 2.

48 A. Petersen, *Public Health, the New Genetics and Subjectivity*, in *POSTSTRUCTURALISM, CITIZENSHIP AND SOCIAL POLICY* 114–153 (A. Petersen. et al. eds., 1999).

to take personal responsibility for deciding whether to have a disabled child.<sup>49</sup> These practices are promoted and offered as services or technologies with the means of reassuring a pregnant woman that her future child is healthy. 'Women view pregnancy as supremely risky because society imposes nearly total responsibility on them as prospective mothers for assuring a favourable birth.'<sup>50</sup> In order to reduce this risk, women are often willing to refer to medical or scientific knowledge (which carries a certain amount of cultural authority as truthful and real), to reassure themselves. This practice of turning to one's physician to guide decision-making about one's future child was evident in our interviewees. Abbie, for example, in response to a question about whether disability and termination were subjects of discussion during prenatal counseling, stated:

'We had decided that if - well, we hadn't really talked any further than say Downs or anything like that, so I guess we were waiting to see that it was - just get the advice from the doctor after that, but Downs we had made a decision of what we'd do for that.'

Abbie, at 20

Ethan and Ava also stated, in the context of a surrogacy arrangement, that:

'if [the surrogate's] life was at risk or the child's life was at risk or that ultimately the child was never - it was never going to progress and the doctor's recommendation was to terminate then we would . . .'

Ethan and Ava, at 54–55

Rowan too had a similar approach:

'In terms of when we would consider termination. Again I think we were very comfortable being guided by doctors. If we had of received advice that okay this child appears to be growing and developing in a way where they've got a condition that's not going to be compatible with life. Certainly we'd terminate in that instance. I think we would, something like Down's syndrome I think we were very happy to go ahead. Then certainly more minor things we'd be very happy to go ahead.'

Rowan, at 13

People using ART technologies and their health care providers are made responsible for deciding what kind of life is worth creating. Thus, the impetus behind selecting the qualities or traits of offspring, through the use of genetic and reproductive technologies, must be contextualized within the prevailing neo-liberal ideology and political order within which risk consciousness and freedom of choice prevail.

#### IV. CONCLUSION

We have argued that the sociotechnical imaginary in which ART takes place is informed by both neo-liberal rationality and biomedical conceptions of normalcy that are based

49 Carole H. Browner and Nancy Ann Press, *The Normalization of Prenatal Diagnostic Screening*, in *CONCEIVING THE NEW WORLD ORDER: THE GLOBAL POLITICS OF REPRODUCTION* 308 (Faye D. Ginseberg and Rayna Rapp, eds., 1995).

50 *Id.* at 309.

on values and practices about who is marginalised in the present. Within this rationality, individuals are expected to govern themselves through processes of self-examination and self-improvement to exclude not just disability, but the risk of disability. The individual who chooses to know about and behave prudently concerning health risk is a self-reliant citizen who governs herself to avoid becoming a burden on society and to maximize her or his potential. This individual makes informed decisions, and reproductive choices—which in the neo-liberal context—are shaped by the desire to produce children who conform with neo-liberal rationality and biomedical normalcy.

This is perhaps best exemplified by our interviewee Charlotte, who expresses tremendous ambivalence about her decision to avoid disability through reproductive technology, as someone who lives with a disability, teaches in the field of disability studies, and has experienced social stigma. She says:

‘So there’s a medical severity, but there’s also a social stigma that you were worried about your child having. I know what it’s been for me, but it’s kind of me feeling a little bit uncomfortable, I guess, at times with my appearance. I had been - my Father had it too and he was probably more disfigured than me - but I think that it was that whole thing I was not sure that I wanted to put a child through. Yet I was President of the Association for this for over 10 years and I’d met plenty of children and they’re lovely kids, so I had that kind of [unclear] ambivalence between oh, they’re lovely kids, it’s going to be okay. But then again, if I don’t have to put another generation through it - because one of my chief areas of research and teaching was on disability studies. For me, it’s like I’m saying everything I tell my students not to do.’

Charlotte, at 6

Even for Charlotte, the routine availability of genetic testing and screening creates a dilemma where the creation of individuals with certain diseases and traits should be avoided. While acknowledging that ‘social stigma’ is the ‘harm’ to be avoided, Charlotte still contemplates using ART to eliminate a future child with a disability. This impetus suggests just how powerful the sociotechnical imaginary through which ARTs have been developed and regulated is in excluding a future for disability. Moreover, it illustrates why sociotechnical imaginaries need to consider the value of those who are marginalized in the present and how their degraded conditions may be unjustly mirrored in the future that is contemplated by the imaginary.

Thus, while pursuant to the dominant sociotechnical imaginary, scientific and research resources are allocated to the elimination or prevention of physiological and morphological mutations that result in disability in current and future generations, from a disability justice perspective, it is social environments that are in fact harmful to present and future generations of persons with disabilities. These environments are related to discrimination, lack of accommodation, and socioeconomic disadvantage for persons with disabilities and are reinforced in the world of emerging and increasingly promoted preconception and preimplantation screening practices that encourage prevention of the conception, gestation, and birth of persons with disabilities. To combat this, in our view, space for resistance and opposition should be built into the sociotechnical imaginary, including through the use of law and regulation.

Notwithstanding, as demonstrated in this article, at various stages in their encounter with ARTs, users confronted with decisions about the possibility of disability in their

future children make complex and personal choices. These choices emanate from, but also challenge (reshape), the sociotechnical imaginary that operates in the context of ART. While sociotechnical imaginaries are conceptualized as communally shared values, we have seen that these values are not necessarily shared and that there are sites of resistance, or at least ambivalence, that operate within them. In the sociotechnical imaginary through which ART is offered and regulated, individuals and couples are constrained by a biomedical conception of disability to exercise individual choice about whether to contemplate disability in their future child. Despite the limits of this sociotechnical imaginary, we have seen that some have found a way of keeping the door open to welcome a future with disability in.

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