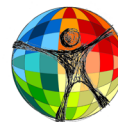


Bridging the Gap: Reconciling Feminist and Disability Perspectives on Prenatal Screening

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ABSTRACT

This paper recognizes that in the human rights landscape, there will inevitably be conflicting rights that may never be able to be fully reconciled, or satisfactorily respected in all instances, and considers the ever-expanding body of human rights that are envisioned to be absolute. The case of prenatal genetic screening is used to illustrate this challenge of conflicting rights, and as a case where we can work on finding common ground and bridging the gap between the feminist and disability groups who are sitting in opposing camps on this issue. While we accept that rights cannot always be absolute, this paper seeks to find the common concerns and interests of these groups to work towards a practical solution that reduces the threat of rights infringements for both groups.

Prenatal screening and selective abortion are viewed by feminist scholars as essential tools to facilitate free and informed reproductive choice. The disability community, however, views these technologies as a threat to their very existence, by failing to embrace the social model of disability, and a tool that serves a problematic underlying social purpose of eliminating persons with disabilities. This has fueled concerns that these technologies will reinforce existing social prejudices and stereotypes that paint persons with disability as “undesirable” and will contribute to a reduction in already limited social services and programs. This paper looks to harness the desire of the feminist community to promote free, independent and informed reproductive decision making among pregnant women to find common ground with the disability rights perspective. The disability community frequently criticizes the clinical testing and medical environment for being coercive and failing to accurately represent the lives and contributions of persons with disabilities to parents deciding whether to continue or terminate a pregnancy. This paper advocates for a non-coercive, non-directive approach by physicians and healthcare providers, that provides a full and balanced account of the conditions, possibilities, and social services available to persons with disabilities. Additionally, this paper envisions the active participation of persons currently living with disabilities in the creation of this policy, and as serving as an essential resource to families and mothers faced with these decisions.

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Introduction

As technology has evolved, and access to more information during pregnancy through prenatal screening has become widespread standard practice, this paper seeks to examine the human rights implications for two communities heavily invested in the outcomes of these technologies. The feminist community is heavily focused on these technologies that have implications for reproductive choice, while the disability community views these technologies as a threat to their very existence. Because of these competing interests, the feminist and disability activist communities take strong and opposing stances on these technologies. This paper will seek to use this example of competing rights and competing interests to demonstrate the challenges faced by the human rights community in treating rights as “absolute”. While this paper will acknowledge the challenge and occasional impossibility of meeting both groups’ rights-based demands it will seek to find a common ground between the two groups. The majority of this discussion will be framed in the context of Western medicine and nations with advanced and established biomedical policies with highly accessible prenatal care.

To begin, this paper will discuss and challenge the theory of absolute rights, in addition to discussing the concept of hierarchy of rights and the challenges of implementing these concepts when the rights in question are seen as fundamental to both groups in question. This analysis will be followed by a presentation of the technologies being challenged in this debate, and an overview of the essential arguments and critiques being presented by both sides. Using this understanding of both sides of the debate, this paper will return to the theory of absolute rights, acknowledging that we cannot satisfy both groups in this case, and that we must seek to find some common ground, or interest that may be shared by these groups. To conclude, while not attempting to solve the problem, this paper will suggest a shift in practice, rather than in principle. This shift will focus on the role of free and informed consent, and a less coercive process for mothers undergoing testing. The section will include a discussion of how doctors can impact the way women perceive disability, and the meaning of a truly “informed choice”. This will lead into conclusions about the potential for compromise in these cases, and a conclusion that while absolute rights may not always be achievable, there is always a possibility to take the concerns of a

variety of groups seriously and implement their suggestions in a meaningful way.

Disclaimer

Arguments about genetics, or about genetic testing are frequently accompanied by a slippery slope argument that any kind of genetic testing will inevitably lead to a society of preferential sex selection, and a superhuman race of designer babies. Even when the argument is only about selective abortion in the case of disability, there is frequently an argument made that the kinds of conditions that will justify terminating a pregnancy will become increasingly less severe. As a tolerance for selective abortion increases, there is an argument that we will likely be able to find justifications for selecting out a wider range of people and conditions.¹ This paper, however, will try to avoid the slippery slope arguments to the degree possible, and will attempt to focus on immediate concerns and the current state of affairs. This is, in part, due to the degree of scientific uncertainty that surrounds what these technologies will even be able to screen for, or identify in the future, and a hesitance to dive into discussions of hypotheticals, particularly given the number of real challenges presented by the technologies as they stand in their current state.

Theories of absolute rights

Philosophers and legal scholars have long debated the idea that any one of us have “absolute” rights. It is a widely held position among philosophers that we do not have any “absolute” rights or obligations. Even the most basic or fundamental rights, like the right to life, or the obligation not to kill are not absolute, and can be compromised in situations that we deem morally permissible². These situations are extreme, however, and many in the human rights community have argued that barring these specific circumstances one can make the case that some rights are (or are envisioned to be), absolute. This concept requires us to

¹ Michael J Selgelid "Eugenic abortion, moral uncertainty, and social consequences." (2001) 20:2 Monash Bioethics Review 26-42 at 37.

² Alan Gewirth "Are There Any Absolute Rights?" (1981) 31:122 The Philosophical Quarterly 1-16.

define an absolute right. This paper will use Allen Gewirth's definition. He claims that, "A right is absolute when it cannot be overridden in any circumstances, so that it can never be justifiably infringed, and it must be fulfilled without any exceptions."³

This definition posits the idea that there will never be a sufficient justification for infringing or violating certain rights that we consider to be absolute. In the human rights context, there are frequently conflicts of rights, or conflicts of norms- situations in which a right is threatened regardless of the outcome. These conflicts of rights have become more prevalent and more challenging as the number of internationally recognized rights has skyrocketed to include the first generation, second generation, and third generation rights. Together these internationally recognized and supposedly inviolable rights total into the hundreds. Hundreds of rights that must all be respected. As these conflicts become more inevitable and more common, we must question whether there can truly be any absolute rights at all⁴. In an attempt to reconcile the challenge of protecting all of these rights simultaneously, international courts and scholars have discussed a "hierarchy of rights". This idea was seemingly embraced by the International Court of Justice who stated that "basic rights of the human person create obligations and rights that are *erga omnes*".⁵

This seems to suggest that there are certain rights that are unlike others, or more "fundamental". This has led to claims that there is a hierarchy of rights, where certain rights are more "fundamental" than others.⁶ This hierarchy is a challenging tool to use, as an internationally agreed upon hierarchy of rights has not been established. The importance of each right, and its corresponding place in a hierarchical structure is heavily shaped by cultural, social, and economic factors, and this lack of general agreement makes it difficult to select the rights that we deem to be

³ *Ibid.*

⁴ Natasa Mavronicola, "What Is an Absolute Right: Deciphering Absoluteness in the Context of Article 3 of the European Convention on Human Rights" (2012) 12:4 Human Rights L Rev 723 at 734.

⁵ Theodor Meron, "On a Hierarchy of International Human Rights" (1986) 80:1 American J of Intl L 1.

⁶ *Ibid.*

fundamental or absolute.⁷ While it may be possible to identify an irreducible core of several rights, including the right to life, prohibitions on slavery, torture and retroactive penal measures⁸, it is challenging to rank and classify rights that exist outside of this small core.

Despite the discussion of a hierarchy of rights by courts and scholars, the application of this tool and a clear definition of the hierarchy has yet to be clearly defined by the international community.⁹ This presents us with the challenge of reconciling conflicting rights, particularly in the context of rights that are strongly defined and influenced by the communities advocating for them. This challenge becomes especially evident when examining new and existing technologies that screen pregnant mothers before birth, or even more recently, screen embryos before implantation. These screening processes can reveal certain types of disabilities, or risk factors indicating a high likelihood that the child may be born with certain conditions. These new technologies have provoked a heated debate between the feminist community and members of the disability movement.¹⁰ This framework of understanding rights will be used to frame both the debate outlined below, and to inform a discussion of compromise, finding middle ground, and moving towards bridging the gap between these groups.

Before addressing both sides of this debate, it is important to acknowledge that the disability community is not a homogenous group. According to United Nations statistics, upwards of 500 million people are living with a disability around the world.¹¹ The conditions causing disability vary broadly, and the perspectives of members of this vast community will naturally vary equally. Throughout this paper, when making reference to the perspective of the “disability community”, this is a reference only to the specific body of disability scholarship, activism, and literature used in this paper. Likewise, when referring to the “feminist

⁷ *Supra* note 5.

⁸ *Supra* note 5.

⁹ *Supra* note 4 at 734.

¹⁰ Marsha Saxton, “Disability rights and selective abortion.” (2006) 4 *The Disability Studies Reader* 87.

¹¹ World Programme of Action Concerning Disabled Persons, UNGA, 37th Sess, Sup No 51, UN Doc A/37/51 (3 December 1982).

perspective”, there will of course be a wide range of perspectives offered, however for the purposes of this paper this will be used in reference to the particular body of feminist literature and activism explored by this paper.

Existing mechanisms of genetic testing and selection

To understand the perspectives of the feminist movement and the disability community on these technologies, and the ethical dilemmas they pose, it is worthwhile to briefly explain what these technologies accomplish and the individual dilemmas they present.

Prenatal genetic testing

Prenatal genetic testing is an umbrella term that includes a number of tests performed on a fetus at varying stages of its development. Prenatal testing can be done in the first or second trimester of pregnancy. It can be completed in the form of screening, that can tell expecting parents the chances that the fetus may have certain disorders or chromosomal anomalies. Prenatal testing can also be done to diagnose whether the fetus actually has a certain disease or *aneuploidy*.¹² This testing is voluntary, and couples may choose whether to undergo some testing, all testing, or none at all. The ethical dilemmas of this testing often present themselves when couples who undergo testing decide what impact, if any, the results will have on their desire to carry the fetus to term.

The increasing frequency and accessibility of genetic testing, and the ability of parents to terminate pregnancies upon finding out that a fetus either has or is likely to have a disease or disability has serious ethical implications, as well as serious implications for the disability community. Although this can give parents more knowledge, it also presents parents with difficult choices. The first challenging choice is whether or not to undergo

¹²“Prenatal Genetic Screening Tests” (July 2017), online: The American College of Obstetricians and Gynecologists
<https://www.acog.org/Patients/FAQs/Prenatal-Genetic-Screening-Tests?fbclid=IwAR3xTyQxN0jP-CH19xWwn_x3LdHvY9WCKH_17oz7y5UgyxdzUheXqZeKqHA>.

testing in the first place. There are many prospective parents who would either rather not know the results of this testing, or who know that whatever the results of the tests may show will not impact their desire to have the child. The second choice, as discussed above, concerns what parents decide to do with the information that the fetus has some kind of disability or disease.

Pre-implantation genetic diagnosis (PGD)

PGD is a relatively new technology, first emerging in the 1990s¹³. Pre-implantation genetic diagnosis involves the biopsy of one or two cells extracted from In Vitro embryos before they are implanted. These cells are then analyzed to detect certain genetic disorders. This procedure is often used to determine which embryos will be implanted into the womb of the mother. As IVF usually requires the fertilization of more embryos than will be implanted, this procedure is used to select the embryos with the best chance of producing a successful pregnancy that can be carried to term. Due to the scientific link between certain genetic abnormalities or mutations and miscarriage, PGD allows embryos that are at higher risk of miscarrying to be selected out.

Two types of pre-implantation testing are commonly used. The first is a DNA examination that can identify dominant or recessive genes leading to disease-causing mutations. This technology has been marked as a major breakthrough in reproductive therapies for couples who may be carriers of inherited diseases. The second kind of testing commonly performed on embryos before implantation reveals chromosomal abnormalities and can also reveal the sex of the embryo¹⁴. These tests have been able to reveal the presence of several chromosomal abnormalities such as trisomy 21 (Down syndrome), as well as Turner's syndrome, sickle cell anemia, and cystic fibrosis.

Although this technology has a number of promising medical applications, it also has a number of applications that create more cause for concern. There is widespread concern that

¹³ Bartha M. Knoppers, Sylvie Bordet, and Rosario M. Isasi "Preimplantation genetic diagnosis: an overview of socio-ethical and legal considerations." (2006) 7, *Annu. Rev. Genomics Hum. Genet.* 201-221 at 202.

¹⁴ *Ibid.*

this technology will not always be used to select for health and medical traits, but could also be used to select for sex, physical traits, or character traits.¹⁵ PGD can easily identify for sex, which has medical benefits for hereditary illnesses that are only carried by one sex, but also creates concern that sex selection for non-medical reasons could become widely used and negatively impact women.¹⁶ While this technology is not the focus of this paper, it is likely to become an essential part of an evolving debate in the coming years, as the prevalence of assisted reproduction and IVF increases.

Discarding embryos that show abnormalities

PGD involves the selection of embryos to be implanted. Those showing no signs of abnormality are frequently selected for implantation, however the question of what to do with those embryos that are not selected remains. In cases where none of the embryos are considered viable, or all show some signs of abnormalities, they will all be discarded. The question of what to do with these embryos has plagued nations and couples since the creation of IVF. The moral and legal status of the embryo, however, falls outside of the scope of the paper and therefore will not be discussed in detail, however this evolving dimension of the debate is worthwhile to recognize and keep in mind.

What are the principal concerns of the disability community about these new technologies?

Much of the fundamental critiques and misgivings about these technologies from disability rights activists appear to stem from one fundamental principle. Throughout recent years, the preferred approach to disability rights and disability issues is by approaching them using a social model of disability. The previously used medical and rehabilitative models of disability focused on disability as an individual issue, and as a clinical or medical "problem" that needed to be solved or rehabilitated.¹⁷

¹⁵ John A. Robertson "Extending preimplantation genetic diagnosis: medical and non-medical uses." (2003) 29:4 Journal of Medical Ethics 213-216 at 214.

¹⁶ *Supra* note 15.

¹⁷ Deborah Marks "Models of disability." (1997) 19:3 Disability and Rehabilitation 85-91.

This approach does not take into consideration the social factors that discriminate against disabled members, of all disabilities, in our societies. These models of approaching disability have been shown to be harmful and ineffective, and many organizations advocated for a transition towards a social model of disability. This model was foundational to the creation of the UN Convention on the Rights of Persons with Disabilities and was embraced by most groups who participated in the creation of the convention.

Social model of disability

Modern disability studies, as well as the International Convention of the Rights of Persons with Disability have embraced a “social model” of disability. A social model of disability presents disability as a societal issue, one that is caused by our society’s failure to be inclusive to the whole spectrum manifestations of the human condition. This model of approaching disability dictates that not only should those with disabilities be included within society, but they should also be recognized for the unique contributions, and the richness that they bring to our societies.¹⁸ The social model of disability advocates for the removal of barriers, both structural and attitudinal, that prevent people with disabilities from participating fully in our societies. The social model of disability opposes the idea that disability is an individual issue or that it is defined by the condition of an individual. Prenatal testing and selective abortion that may result from certain prenatal diagnoses may stem from benign intentions. These intentions, however benign they may seem, are still problematic, as they seek to limit disability by limiting the number of persons born with conditions, instead of seeking to limit or eliminate disabling factors, structures and attitudes from our societies¹⁹. It is important to note, however, that despite the social model being widely accepted in disability activism and scholarship, there are those who still believe that while the inability of society to recognize contributes to further “disabling” those who require adaptation,

¹⁸ Javier Romañach Cabrero, and Agustina Palacios Rizzo. "El modelo de la diversidad: una nueva visión de la bioética desde la perspectiva de las personas con diversidad funcional (discapacidad)." (2008) 2.2. Intersticios. Revista sociológica de pensamiento crítico.

¹⁹ Dov Fox "Prenatal screening policy in international perspective: Lessons from Israel, Cyprus, Taiwan, China, and Singapore." (2009) 9 Yale J. Health Pol’y L. & Ethics 471 at 482.

there is a medical component as well. While this disabling can be increased by social factors, there are medical conditions that can have a disabling effect on their own. A purely social model may fail to take this into account, which may prevent the kind of compromise and bridging of the gaps between these two communities that this paper advocates for.

The fundamental critique from the disability community is that these technologies do not fit within this model. There are three main reasons for this critique, the first being that these technologies serve a social purpose of trying to reduce the number of births of children with disabilities. The second critique is that the underlying premise of these technologies is that the disabled are incapable of having a quality of life that makes their existence worthwhile, and that these technologies can have the effect of framing the lives of the disabled as not worth living. The final critique is that negative perceptions of the disabled community are reinforced by these technologies, and that this can negatively affect the lives of people currently living with disabilities.

Critique one

The first critique, that the underlying premise of these technologies is based on an attempt to limit the number of persons coming into the world with disabilities, is effectively articulated by the activist Deborah Kaplan. She noted that “if persons with disabilities are perceived as individuals who encounter insurmountable difficulties in life and who place a burden on society, prenatal screening may be regarded as a logical response. However, if persons with disabilities are regarded as a definable social group who have faced great oppression and stigmatization, then prenatal screening may be regarded as yet another form of social abuse.”²⁰ Activists have challenged the underlying premise of this testing, and the idea that reducing the incidence of disability is a desirable outcome. Part of the critique is against the seemingly unquestioning approach the medical profession and of our society more broadly takes towards these issues, and the assumption that the outcome of increased testing, and possibly decreasing instances of certain disabilities is

²⁰ *Supra* note 10 at 148.

beneficial²¹.

The history of eugenics and eugenic abortion policies that limit the number of births of people with disabilities also come to mind when we begin to examine this critique in detail. The word eugenics stems from Greek words *eugenes*, which means "good in stock."²² While the most common images that come to mind when we think of eugenics are likely images of Nazi eugenic programs during the Holocaust, eugenic policies have actually existed around the world in ways that are much more subtle and easily disguised as social policies designed to better society.

If we look towards China and Japan, we can see that eugenic policies relating to persons with disabilities manifest in a number of different ways, however the common thread underlying these policies is generally that they are viewed as "undesirable". "Negative eugenics", enthusiastically advocated by Nagai Hisomu, involves the prevention of sexual reproduction, through induced abortion or sterilization, among people deemed unfit. "Unfit" was an ambiguous term that included alcoholics, "lepers," the mentally ill, the criminal, the physically disabled, and the sexually alternative among other categories of people."²³

In China, there were also a number of eugenic policies that were widely condemned by the disability community. The Maternal and Infant Health Care Law in particular attracted widespread attention and has been called the "most overt eugenic policy the world had seen for three decades". This legislation acts under the guise of attempting to "guarantee the health of mothers and infants and to improve the quality of births". Improving the quality of birth is clearly intended to reduce the number of births of children with any kind of abnormality or condition. While the goal of improving infant and maternal health is undoubtedly laudable, this goal has helped to create policies that have led to the sterilization of hundreds of thousands of people with disabilities. These programs, while technically still voluntary, placed the decisions of who could procreate in the hands of the government, and those with any kind of disease or disability that

²¹ *Ibid.*

²² *Supra* note 19 at 471.

²³ Jennifer Robertson "Blood talks: Eugenic modernity and the creation of new Japanese." (2002) 13:3 *History and Anthropology* 191-216 at 196.

could be passed along hereditarily were prohibited from having children. In addition, "a 'medical opinion on terminating the pregnancy' is to be given in the event of foetal contraction of 'serious hereditary diseases', 'serious deformity', or risk to the life of the mother."²⁴ This approach took a purely medical approach to disability and was clearly guided and influenced by social prejudice that painted persons with a disability as undesirable. The underlying premise that reducing the prevalence of disabilities is a positive societal outcome has led to policies like those outlined above, which has caused irreparable harm and suffering to communities of persons with disabilities around the world. The aversion of people with disabilities to prenatal testing stems in part from a concern that these technologies will lead to similarly problematic policies.

Critique two

The second critique is that the desire to eliminate the prevalence of disability is based on the idea that in addition to being considered a burden on societies, the disabled are incapable of having a quality of life that makes their existence worthwhile. This attitude underpins much of the medical discourse that often takes the approach of "eliminating harm and suffering". This kind of discourse manifests itself in the approach to genetic screening that makes persons with disability feel as if they are "viewed as unfit to be alive, as second-class humans, at best, or as unnecessary persons who would not have been born if only someone had gotten to them in time."²⁵ The challenge with this approach lies in the way it ignores and attempts to erase the contributions that the disabled can make to our societies and is often centered around the things that people with disabilities cannot do, as opposed to the many things that they can. It also asks parents and medical professionals to make a determination of what an appropriate or "acceptable" quality of life would look like. This assessment of what an acceptable quality of life would look like, or what would justify selective termination can be based upon several factors, all centered around the "best interest of the child". These factors may include assessments of life expectancy,

²⁴Emma Stone "A law to protect, a law to prevent: contextualizing disability legislation in China." (1996) 11:4 Disability & Society 469-484 at 473.

²⁵ *Supra* note 19 at 478.

pain, suffering, the possibility of extensive hospital stays, mobility, and cognitive ability.²⁶ These factors are most often compared against the quality of life of a non-disabled child. This framing of prenatal screening can also be challenging, and problematic, as prenatal testing and selective termination of pregnancies can send the message that a quality of life that is different than the “normal” is so tragic and burdensome that it would be preferable for children with disabilities not to be born. Much of this critique centers around the dialogue happening surrounding disability, and the framing a disability as a tragedy such that the child would be better off not being born than being disabled.²⁷

Critique three

This critique centers around the idea that prenatal testing and selective abortion will increase discrimination against those people currently living with disabilities.²⁸ This critique stems from several concerns in particular. The first concern comes from the message that prenatal screening and selective termination can send to those living with disabilities, and to our societies at large. Studies have shown that modern Chinese communities show greater support for eugenic policies and have a generally more negative view of persons with disabilities than their American or European counterparts, which has been attributed in part to the country’s history of eugenic policies.²⁹ The second concern centers around secondary effects that may stem from this kind of messaging, including the more tangible concerns like loss of funding, or increased violence or oppression against the disability community. The messages outlined in critiques one and two, that the disabled would have been better off not being born or are undesirable for some reason, can send the message to those currently living with disabilities that they are viewed by society as undesirable because of their conditions. It may also reinforce or

²⁶ Lynn Gillam "Prenatal diagnosis and discrimination against the disabled." (1999) 25:2 Journal of Medical Ethics 163-171 at 168.

²⁷ *Ibid* at 167.

²⁸ Convention on the Rights of Persons with Disabilities, UNGA, 61st Sess, Sup no 49, UN Doc A/61/106 (24 January 2007) 2.

²⁹ WonPat-Borja, Ahtoy J., et al. "Eugenics, genetics, and mental illness stigma in Chinese Americans." (2012) 47:1 Social psychiatry and psychiatric epidemiology 145-156.

increase prejudices among the non-disabled population.

A fear of increased discrimination against the disabled is exacerbated by the worry that a reduction in the number of people with disabilities will be caused by prenatal screening. This fear is particularly common for those suffering from congenital or hereditary illnesses such as Down Syndrome (Trisomy 21), who express concern that their community will be completely wiped out as these technologies become increasingly more commonplace. Statistics on selective abortion after prenatal screening suggest that the vast majority of couples who discover that the fetus the mother is carrying will have down syndrome choose to abort.³⁰ While there are those who argue that these statistics show massive declines in the population of people with down syndrome, there is an argument to be made that these statistics only show part of the story. Prenatal testing is completely voluntary, and many couples choose not to have any testing. This means that the statistics about selective abortion only encompass the data of those who choose to undergo testing in the first place. Additionally, in the case of trisomy 21, these statistics fail to encompass the rising prevalence of this chromosomal abnormality due to increased risk factors. The likelihood of a fetus having trisomy 21 rises exponentially based on the age of the mother at the time of her pregnancy. In most of the Global North, women are having fewer children, and waiting until much later in their lives to start families than they were several decades ago, placing their babies at higher risk. This counterargument still only applies in a limited number of cases, and with very specific situations, however it is important to acknowledge that these statistics cited by the disability community should not simply be taken at face value.

While the negative messaging, decreasing visibility, and the possibility that it may hurt those living with disabilities because of the implication that they are less valued or welcome in society. There are those, however, who argue that prenatal screening could also constitute a more tangible form of discrimination. Many of the rights that were won for the disability community through

³⁰ Darrin P Dixon, "Informed Consent or Institutionalized Eugenics - How the Medical Profession Encourages Abortion of Fetuses with Down Syndrome" (2008) 24:1 Issues in L & Medicine 3 at 7.

the creation of the CRPD, and its subsequent adoption by nations around the world are viewed as rights that are won temporarily, but there is always fear that those rights will be taken away. For some, the possibility of a reduction in the number of children being born with disabilities indicates that disability policies will be rolled back or cut. A reduction in the number of people with disabilities is feared to prompt governments to reconsider their investments into projects and policies for the disability community. This concern has been reinforced by the medical community and by those developing these technologies who, by nature of their background and training tend to take a medical or clinical approach to disability, which fails to take into account factors outside of the medical condition³¹. Peter Singer, a prominent bioethicist, has been widely criticized for taking a utilitarian approach to disability in arguing that "it does not seem quite wise to increase any further draining of limited resources by increasing the number of children with impairments."³² These kinds of commentaries add fuel to the fear that increased prenatal testing and selective abortion will be seen as a way to reduce expenditure by eliminating types of functional diversity that require accommodation.³³ This fear is unfortunately supported by statistics, and as noted by Klein, "research has illustrated that financial outlays for administering screening programs and performing abortions when a fetus is found to be affected are less than the amount which would be spent caring for affected children."³⁴ These kinds of economic and clinical approaches give credence to the concerns of the disability community that prenatal screening and selective abortion do not conform to the social model of disability, and could thus increase discrimination against persons living with disabilities.

In addition to the critiques outlined above, there is a frustration among disability activists that much of the preoccupation of those trying to prevent disability is directed towards preventing the births of children with genetic conditions or hereditary disabilities. They argue that many people who are

³¹ *Supra* note 18.

³² *Ibid.*

³³ *Ibid*

³⁴ Stacy Klein, "Prenatal Genetic Testing and Its Impact on Incidence of Abortion: A Comparative Analysis of China and Ireland" (1999) 7:1 *Cardozo J Intl & Comp L* 73 at 75.

born healthy are injured or become disabled every day through carelessness, workplace accidents, and economic and healthcare mismanagement.³⁵

What are the primary concerns of the feminist community?

Abortion and access to meaningful reproductive choices have long been seen as fundamental to women's emancipation. The "feminist" perspective of prenatal genetic testing and the resulting decision is that women, and expecting mothers have a right to make informed decisions about their bodies, their pregnancies, and their lives as mothers once the baby has been born. This perspective takes a right to make free and informed reproductive choices as a fundamental pillar of women's emancipation that should not be interfered with. The right to choose, and access to abortion should be unencumbered and permitted for whatever reason the woman sees fit.

This position, seemingly in opposition to much of the disability perspective outlined above, is perhaps best articulated by the Italian gynecologist B. Brambati, who argued that:

An expectant mother has the right to base decisions as to her pregnancy on protecting or attaining her own well-being. In the case of foetal anomaly, she should be given as complete, objective and updated information as possible on the implications the anomaly holds for the life of the future individual in its own right and with reference to society. To set up criteria for distinguishing pathology from normality, serious from less serious, acceptable from unacceptable, and claim thereby to guide the mother/couple's decisions as to going ahead with the pregnancy or not, is an act of arrogance, ideological violation towards the mother and an infringement of her privacy and individual freedom.³⁶

There have been deep chasms of disagreement that have formed between the pro-choice feminist movement, and disability

³⁵ *Supra* note 10 at 101.

³⁶ C Viafora "Towards Responsible Management of Prenatal Diagnosis: Arguments for and against." (2006) 19:1 *Rivista di Neuroradiologia* 5-12 at 6.

activists on this issue. The feminist movement has attempted to redefine what it means to be a woman in our world, and views reproductive choice as an essential part of this redefinition. Any suggestion that women should be forced or encouraged to carry a fetus to term that she does not want to, deeply offends the core of this movement. The criticism that has been fired at this movement is that women are perpetuating pro-eugenic and anti-disability biases through prenatal testing, and selective abortion.³⁷ The feminist movement has responded defensively to these criticisms, and claimed that these disability activists are working alongside the far right wing anti-abortion activists, and claiming that "the right wing wants to force us to have defective babies."³⁸ This is naturally an extreme stance, but represents the anger and frustration felt by many activists who feel as though the responsibility to prevent discrimination against people with disabilities should not fall on the shoulders of women by obligating them to carry fetuses to term and undermining their reproductive rights and autonomy.

While the social model posits disability as a societal problem that is the responsibility of all, it is widely acknowledged that there are often not enough resources available to support those who with disabilities and their families. For women especially, the vast majority emotional labor, and uncompensated work with children and around the home falls on their shoulders.³⁹ While many women feel they would be able to love a child with a disability as they would love any other child, some women simply feel the burden is too great given the relatively small amount of aid available to them. Many women also feel that the added burden financially and emotionally could have the effect of detracting from the quality of life and the amount of attention given to other children in their families. It has been argued that for these reasons, "the births of children with disabilities all too often lead to the further oppression of women."⁴⁰

Many feminists would argue that in a truly just society a mother would not have to sacrifice herself to care for such a child,

³⁷ *Supra* note 10 at 107.

³⁸ *Supra* note 10 at 108.

³⁹ Victoria Seavilleklein "Challenging the rhetoric of choice in prenatal screening." (2009) 1 *Bioethics* 68-77.

⁴⁰ *Supra* note 30 at 56.

because the entire society would assume this care. The responsibility of caring for a child with a disability often does not end after childhood, and truly constitutes a lifetime commitment, as social services for adults with disabilities are limited and often inadequate. It has been noted that periods of transition into adolescence and adulthood can be particularly challenging for parents and families⁴¹, especially as they themselves age. According to this argument, a woman should not have to choose between her own oppression and the elimination of a fetus that belongs to another oppressed group, those with disabilities.⁴² These arguments are often framed as a pressure on women to assume the burden of caring for a child themselves, despite the fact that the utopian dream of whole societies collectively assuming the burden of caring and providing for this child has yet to come to fruition.⁴³

Many women struggle with the criticisms of the disability community, who can be seen as treating abortion as an “easy way out” for women who choose not to carry a pregnancy to term. This could not be further from the truth, as many women suffer immensely from choosing to abort.⁴⁴ Studies on the psychological impact of abortion have shown that, “even years later, remembering the fact and the circumstances is like an open wound, with all the trappings of repression, shame and guilt, remorse for the unborn child and intense feelings of self-punishment. Even when the woman wittingly declares that in the same circumstances, she would do the same thing, the suffering is still felt.”⁴⁵

Regardless of the choice a woman makes, there is a fundamental argument that the woman in question is truly the only person who is able to make that decision, as she will be coping with the ramifications of that decision for the rest of her life. The

⁴¹Patricia Minnes, Lynn Woodford & Jennifer Passey, “Mediators of Well-being in Ageing Family Carers of Adults with Intellectual Disabilities” (2007) 20:6 J of Applied Research in Intellectual Disabilities at 539.

⁴²Dorothy C. Wertz, and John C. Fletcher. “A critique of some feminist challenges to prenatal diagnosis.” (1993) 2:2 Journal of women's health 173-188.

⁴³ *Ibid.*

⁴⁴ *Supra* note 36 at 8.

⁴⁵ *Ibid.*

argument that selective abortion is based on negative perceptions of persons with disabilities, or what it is like to have a child with a disability, may fail to take into consideration the numerous reasons why women make the choices they do when faced with an extremely challenging decision. It is important to note that even women who choose not to have prenatal screening during their pregnancies or have the testing and choose to continue and carry the pregnancy to term, are glad to have the choice and to have the technology available to them.

These perspectives appear to be diametrically opposed on a number of fronts and present the clear challenge of how we can simultaneously satisfy and protect the rights of both groups of people. If we return to the definition of an absolute right that was introduced at the very beginning of this paper, we see how the conflicts of rights in the human rights field can quickly become complicated and challenging. The right of women to make their own informed choices about their own bodies, reproductive autonomy, and their futures and families has been clearly defined above by feminist activists as a non-negotiable part of female emancipation and liberation.⁴⁶ They have argued that this right must include the option of having all of the information they can about their bodies and pregnancies (should they want it), to make informed choices. The disability community has taken the position that allowing and encouraging widespread use of prenatal testing is designed to promote selective abortion, and that its social purpose is to eradicate or "select out" the disabled and may increase discrimination during the process.

Returning to the theory of absolute rights

If we accept the premise that the rights of both of these groups should be absolute, then we have clearly arrived at a seemingly insurmountable problem. This is emblematic of the challenges of an ever-expanding series of rights, and the occasional impossibility of protecting or guaranteeing all rights for all groups. Here, we have an example of the rights of two

⁴⁶ Carole J. Petersen "Reproductive justice, public policy, and abortion on the basis of fetal impairment: Lessons from international human rights law and the potential impact of the convention on the rights of persons with disabilities." (2015) 28 JL & Health 121 at 130.

oppressed groups coming in seemingly irreconcilable conflict with one another. If we accept that the fundamental basis of these rights, and the underlying concerns of both sides cannot be reconciled, we are faced with a choice about what to do, and which interests to prioritize and protect. While this paper does not purport to present the solution to this problem, or propose to be able to answer these questions, it can be argued that there is always a potential to find a common ground, or a feature of the conflict to bring these opposing sides closer together.

Finding common ground

The feminist and disability perspectives diverge on a number of questions and issues involving prenatal screening. Based on the literature, and the critiques and concessions made by both sides of the debate, the common ground between the two sides appears to exist virtually exclusively concerning the question of coercion, and free and informed choice in prenatal screening.⁴⁷ Autonomy and independent decision making are important values to both camps. The disability community views the choice to abort as coerced, or heavily influenced by social stigma. The feminist community advocates for these technologies as an expression of free and informed reproductive choice. There has, however, been relatively widespread criticism of the approach to disclosing information to women either before undergoing screening, or upon receiving the results of their testing. Current best practice protocols require doctors to disclose, "details about the conditions being screened, the likelihood of detection, the method of screening, the meaning of a screen-positive result and a screen-negative result, the choices following a screen-positive result (amniotic fluid alpha fetoprotein, acetylcholinesterase and fetal karyotype, detailed ultrasound for fetal anomaly), the choices following a positive diagnosis (abortion or continuation of the pregnancy) and details as to how further information can be obtained."⁴⁸ Naturally, this is a huge and overwhelming amount

⁴⁷ *Supra* note 39 at 69.

⁴⁸ Francois Audibert, et al. "No. 348-joint SOGC-CCMG guideline: update on prenatal screening for fetal aneuploidy, fetal anomalies, and adverse pregnancy outcomes." (2017) 39:9 *Journal of Obstetrics and Gynaecology Canada* 805-817.

of information to attempt to process in a short appointment.⁴⁹ There has been criticism that many physicians are spending on average less than five minutes with their female patients to discuss the matters listed above. Surveys of women who undergo prenatal testing show a widespread lack of basic understanding of the testing.⁵⁰ This general lack of understanding challenges the idea that women are making autonomous, informed, and independent choices about their pregnancies. There is fear among both camps that women may be coerced not only into having testing, but also into opting to terminate their pregnancies upon the discovery of a positive testing result.

The way in which this testing is framed by physicians can have the effect of implying that expecting mothers are somehow irresponsible should they choose to refuse it. Because physicians are under pressure to offer this testing, in order to avoid liability in so-called “wrongful birth” suits, there has been criticism that the language of identifying “risks”, “problems” or “defects”, has the effect of making women feel inherently responsible for being tested and safeguarding the health of their families.⁵¹ Medical professionals often employ language like this to encourage women to undergo testing, as “the idea that one would not want information is so counter to the medical profession’s world view.”⁵²

In addition to the fear of women being coerced into undergoing testing in the first place through a rhetoric of risk, and a lack of sufficient information, there is a concern that women are being coerced or pressured into terminating their pregnancies if a disability is detected. This coercion can begin at the moment when the results of tests are delivered to expecting parents through the use of language by medical professionals. When the discussion of test results begins with “I’m sorry”, or “we have bad news”, this indisputably shapes the conversation about next steps, or about the choices available to the couple.⁵³ This kind of language is demonstrative not only of general societal prejudice against the disabled, but also exposes the complicated relationship between

⁴⁹ *Supra* note 39 at 69.

⁵⁰ *Supra* note 39 at 70.

⁵¹ *Supra* note 39 at 74.

⁵² *Supra* note 30 at 25.

⁵³ *Supra* note 30 at 4.

the medical community and the disability community. Medical professionals, by nature of their training, exposure to liability, and Hippocratic oath are often at odds with disability activists. The role of physician liability should not be downplayed either, as the increasing number of suits being filed against doctors in relation to genetic conditions has caused doctors to practice a more "defensive" medicine.⁵⁴ This kind of practice can lead to less emphasis on informed consent, and more pressure for doctors to take steps that shield them from liability.

One of the primary issues is that doctors are often ill-equipped to discuss the possibilities with parents, as test results that may be able to identify genetic abnormalities are unable to predict how that genetic condition will manifest itself. In the case of down syndrome, for example, there is a spectrum of symptoms that may or may not affect people with this condition. This uncertainty, along with a general lack of training in genetics in medical schools can mean that parents are often not counselled or informed on the wide range of possible outcomes for the child. This tends to shape a one-dimensional narrative that fails to adequately inform parents of the possibilities for their children, as well as the community support systems that may be available to them.⁵⁵ Concern about this one-dimensional perspective, and incomplete information is cause for concern in both feminist and disability circles. This concern is exacerbated by statistics that suggest that women in more vulnerable situations, such as immigrant women who may have less command of the language are less likely to make informed decisions.⁵⁶ As with any technology, equitable access and application are essential to responsible management of technology and its results.

While their concerns may differ, both sides of the argument about prenatal screening for disabilities can agree that women should feel empowered to make choices based on accurate and complete information, even if they may disagree on the outcome of those choices. Many in the disability community

⁵⁴ *Supra* note 30 at 53.

⁵⁵ *Supra* note 30 at 4.

⁵⁶ Mirjam P. Fransen, et al. "Ethnic differences in informed decision-making about prenatal screening for Down's syndrome." (2010) 64:3 *Journal of Epidemiology & Community Health* 262-268 at 266.

argue that they are the only ones who can give accurate information about what it is like to live with a disability, and therefore the highly medicalized perspective offered to expecting mothers by physicians barely scratches the surface. Here, this paper will argue for a non-coercive and fully informed policy for mothers both considering prenatal screening, and those confronted with the choice of whether or not to continue with their pregnancy.

Developing a non-coercive policy

For mothers to receive complete and accurate information about disability causing genetic conditions, there is an important role for the disability community to play. Any policy for both prenatal screening, and post-screening decision making that is effective in being non-coercive, non-directive, and truly informative must be inclusive of the disability community and recognize the important role this community can play.

In addition to providing another perspective to the debate theoretically, it is essential that parents deciding whether or not to continue with a pregnancy have access to speak to other parents who have raised children with disabilities, or to people with disabilities themselves. This will allow parents to have a better understanding of the conditions themselves, but also the quality of life that people with these conditions may be able to have. This is the only way that parents can gather accurate information from families who have been confronted with the same challenges, but also the joys that many families have identified in raising a child with disabilities. While the journey is undoubtedly different, many families describe the joy that their differently-abled children have brought to their lives and to the lives of their other children. This resource is essential for expecting parents, but also for healthcare providers who rarely interact with the disability community outside of the boundaries of the healthcare setting. Many of these professionals could benefit from having their preconceptions about disability challenged by exposure to the disabled community outside of a hospital setting and by experiencing their capacity to lead meaningful and productive lives.

While some disability scholars attempt to argue for a non-coercive approach to prenatal screening and selective abortion by healthcare practitioners, often the non-coercive approach manifests itself as preventing women from being coerced into

deciding to abort. This non-coercive approach envisioned by many disability activists seems to seek to prevent women from being coerced into aborting.⁵⁷ While preventing this kind of coercion is important, it is equally important that women feel empowered to exercise their right to choose to terminate a pregnancy, should that be the path they choose. Abortion is already accompanied by deep feelings of guilt and shame, and any process that may inadvertently or otherwise seek to influence women to make one choice or another is problematic. Dixon argues from the disability perspective, stating that “the reality is no matter how many steps the medical profession takes toward improving the prenatal genetic process there will always be those who find it convenient to abort a fetus with a genetic anomaly. With choice comes free will and free will sometimes results in poor decisions.”⁵⁸ These kinds of statements imply that there is a wrong choice here, and that abortion of a fetus with a disability-causing condition is the wrong decision. Any policy that begins from the perspective that there is a “wrong” choice that expecting mothers can make will almost certainly fail to be non-coercive in a way that could satisfy both movements interested in these technologies.

Any policy that seeks to truly be impartial, informative, and non-manipulative to women must emphasize presenting both sides of the story, by presenting women with the opportunity to discover the social and community services that would be available to them, as well as connecting them with families who have had similar experiences. It is important that conversations with physicians realistically present the potential medical challenges these families may face, but that the discussion of disability does not simply end with the discussion of the condition or the limitations it may cause. Most importantly, perhaps, this kind of policy should emphasize that the only “right” choice, is the choice that feels right for the woman in question and her family. As noted above, even women who respond positively to the idea of having a child with a disability may have reasons for aborting that are not at all tied to their own prejudices but are based on other factors. This is a reminder that regardless of the choice a woman arrives at, there will be serious implications for both her and her family. A non-coercive and non-directional policy for

⁵⁷ *Supra* note 30 at 59.

⁵⁸ *Supra* note 30 at 59.

healthcare providers giving these services must be mindful of these challenges, while remaining sensitive to their responsibility to give families a full and accurate spectrum of information and the full range of perspectives from those best informed to offer it.

Conclusion

This paper has sought to acknowledge one of the challenges facing the human rights field in an era of ever-expanding rights and obligations. The reality that there may be conflicting rights has become an inevitability, as demonstrated by the ethical and moral predicaments presented by prenatal testing and selective abortion. This example has demonstrated that both camps have legitimate and serious concerns about these technologies, and that these concerns place them almost completely at odds. While the theory of absolute rights presents rights as completely inviolable, and never able to be justifiably infringed upon, this paper recognizes that there will be conflicting rights that may never be able to be fully reconciled, or satisfactorily respected in all instances. This paper has sought to demonstrate that while there may be wide chasms of disagreement between feminist and disability groups on the underlying issues and principles of these screening technologies, there are always opportunities to attempt to meet in the middle. These solutions, while imperfect may serve to put both parties more at ease, and to facilitate protocols and practices for using these technologies that are more sensitive to the needs of different groups. This paper seeks to provide an example that may serve as a reminder that those issues that may appear so polarizing as to be irreconcilable on the surface should be explored more deeply to truly understand the interests and concerns of the parties that may be impacted. By diving deeper, and truly working to understand these perspectives, it is very possible that we may find a common ground that brings us one step closer to bridging the gap.

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