

The Flaws of the Expressivist Objection

An inadequate argument against prenatal testing and/or disability-selective abortion

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Abstract

The expressivist objection claims that the use of prenatal testing and/or disability-selective abortion results in the expression of negative and/or discriminatory messages to people with disabilities. From this argument, one can deduce a claim that it is morally wrong to use these technologies. These technologies are inextricably linked to both the rights of people with disabilities and the rights of women to reproductive autonomy. This tension is explored, and four flaws of the expressivist objection are examined: 1) its claim that the aforementioned messages expressed are discriminatory; 2) its presumption that prospective parents' motivations for using these technologies concern only the future child's life, and its consequent oversight of prospective parents' concerns regarding their own lives as caregivers of a child with a disability; 3) its reliance upon the 'loss of support' argument; and 4) the fact that the consequences of acting in accordance with the expressivist objection would be absurd and unreasonable. This thesis concludes that the expressivist objection is an inadequate argument against the use of prenatal testing and/or disability-selective abortion, and recommends excellent, comprehensive genetic counselling as a possible compromise that respects both the rights of people with disabilities and women's rights.

General Summary

Prenatal testing and disability-selective abortion have long been controversial, but an argument known as the expressivist objection claims that the use of these technologies expresses negative and/or discriminatory messages to people with disabilities. Four flaws of the expressivist objection are identified and explored: its claim that these messages are discriminatory, its failure to consider prospective parents' concerns about their own lives as caregivers of a child with a disability, its reliance upon the 'loss of support' argument, and the absurdity of the consequences that would result from acting in accordance with the expressivist objection. This thesis concludes that the expressivist objection is an inadequate argument against the use of prenatal testing and/or disability-selective abortion, and recommends excellent, comprehensive genetic counselling as a possible compromise.

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List of Abbreviations

CF	Cystic fibrosis
DS	Down syndrome
DSA	Disability-selective abortion
MSS	Maternal serum screening
NIPT	Non-invasive prenatal testing
PT	Prenatal testing
PWD	People with disabilities

Chapter 1: Introduction

The topic of my thesis is the expressivist objection. The expressivist objection argues that the use of prenatal testing (PT) and disability-selective abortion (DSA) expresses negative and/or discriminatory messages to existing people with disabilities (PWD) [Holm, 2008]. These messages are said to include “We do not want any more like you” and PWD are “‘too flawed’ to exist; [they] are unworthy of being born” (Wendell, 1996, p. 153; Saxton, 2017, p. 85). The expressivist objection claims that using interventions such as PT and/or DSA to prevent or fix genetic anomalies presumes and expresses negative judgments about the value of the lives of PWD, and that this fact renders the use of these interventions morally wrong (Buchanan, 1996).

My thesis will argue that the expressivist objection is an inadequate argument against the use of PT and/or DSA. This claim will be supported by examining the expressivist objection’s multiple flaws. The expressivist objection’s first flaw is its claim that the use of PT and/or DSA expresses negative and/or discriminatory messages. My thesis will review two possible interpretations of this claim (one, a claim of justice (i.e. ‘these messages are discriminatory in a legal sense’), and the other, a claim of reasonableness (i.e. ‘these messages are discriminatory because they involve prejudice/bias’)) and dismiss both. This discussion will make clear that even if PWD are perceiving such messages, the messages lack the key component necessary to be discriminatory (unfairness); it is fair to believe that disability can be disadvantageous. The second flaw of the expressivist objection is its neglect of prospective parents’ concerns about their own lives as caregivers of a child with a disability. My thesis will argue that these concerns are valid, important, and justify the use of PT and/or DSA. The expressivist objection’s third flaw is its claim that the use of PT and/or DSA will result in future loss of support for PWD. My thesis will argue that concerns regarding loss of support are unfounded. The fourth and final flaw

of the expressivist objection lies in the consequences of accepting and acting on its argument. My thesis will detail the ways in which these consequences would be unreasonable and absurd. These consequences include ceasing treatment of a variety of conditions that are currently treated, as well as a blatant and unacceptable endangerment of reproductive rights (namely, coerced pregnancy).

1.1 Outline of the Thesis

Chapter One introduces the expressivist objection and provides examples of the messages that this argument says are expressed through the use of PT and/or DSA. I will proceed to list various forms of the expressivist objection, and emphasize that while there are multiple versions, my thesis' interpretation is a version that appears frequently in the literature and is the version to which I am responding. I will then set parameters for my argument by informing the reader of the assumptions and beliefs under which my thesis is written. Finally, I will conclude this chapter by pre-emptively addressing any incorrect interpretations of my argument.

Chapter Two provides important background information that is highly pertinent to evaluating the expressivist objection. First, several historical instances of discrimination against PWD will be provided. This section by no means comprises a complete overview of the history of discrimination against PWD. Instead, this section explains the need for continuing caution surrounding technologies that affect PWD, and emphasizes that PWD have legitimate reasons to be wary of PT and/or DSA. The next section focuses on the ways in which women's reproductive freedom can clash with the objectives of the disability rights movement. The final section provides an overview of the basics of PT and DSA as technologies, and notes that not all proponents of the expressivist objection outright oppose PT and/or DSA.

Chapter Three explicates the first flaw of the expressivist objection. This flaw lies in its claim that the use of PT and/or DSA expresses negative and/or discriminatory messages to existing PWD. This chapter begins by reviewing literature that addresses whether messages can be sent irrespective of intention. I will conclude that intention is irrelevant, as a message can still be *perceived* irrespective of the sender's intention, but argue that the 'recipient's' perception of this message may be flawed. Chapter Three will focus only on the 'discriminatory claim' (that the use of PT and/or DSA expresses discriminatory messages to PWD), and will explain why the discriminatory claim demands more attention and is more significant than the 'negative claim' (that the use of PT and/or DSA expresses negative messages). After articulating what it means for something to be discriminatory, this chapter will argue that insofar as it is both just and reasonable, it is fair to believe that disability can be disadvantageous. Finally, this chapter will review various perspectives about disabilities held by PWD, thereby demonstrating the nuanced and varied nature of perspectives on disability. These varied perspectives will also help demonstrate that it is reasonable to believe that disability can be disadvantageous. This chapter will ultimately dismiss the expressivist objection's claim that the use of PT and/or DSA expresses discriminatory messages to PWD.

Chapter Four addresses the second flaw of the expressivist objection: that the expressivist objection fails to consider prospective parents' concerns about their own life. In responding to the second flaw, this chapter focuses on prospective parents and their wellbeing. Caregiver burden will be examined as part of this discussion. This chapter will lay out a multitude of practical considerations that prospective parents may have when opting for PT and/or DSA. This discussion will demonstrate that the expressivist objection is flawed in its apparent assumption that prospective parents assess disability only in terms of the future child's life. Prospective

parents may opt for PT and/or DSA due to concerns about their own wellbeing while caring for a child with a disability.

Chapter Five will review the third and fourth flaws of the expressivist objection. The third flaw is that the expressivist objection's proponents' concerns about future loss of support for PWD are unfounded, and the fourth flaw is that the consequences of acting in accordance with the expressivist objection are unreasonable and absurd. While the expressivist objection does not conflict with women's reproductive autonomy in *theory*, discussion of the aforementioned consequences will illustrate its potential conflicts with women's reproductive autonomy in *practice*.

Chapter Six concludes the thesis, first by restating its main argument (that the expressivist objection is an insufficient argument against the use of PT and/or DSA) alongside its supporting claims, each of which consists of a different criticism of the expressivist objection. The need to remain cognizant of the overt discrimination and violence against PWD throughout history will be emphasized, as will the need to uphold women's reproductive rights. Finally, this chapter will suggest that excellent, comprehensive genetic counselling is the best compromise going forward. This would involve medical information about the fetus's would-be disability, information about the non-medical (e.g. social) ways in which the parents' and child's lives may be affected, and experiential information provided by PWD and their families. This wide, unbiased range of perspectives and experiences will better inform prospective parents as they decide whether to opt for PT and/or DSA.

1.2 The Expressivist Objection: A Closer Look

Proponents of the expressivist objection are typically disability rights supporters and/or disability scholars, who take issue with PT and/or DSA's select focus on the disabling trait (Boardman, 2014). Proponents of the expressivist objection disvalue PT insofar as prospective parents may use it to identify a so-called 'undesirable' fetus, and disvalue DSA because they believe prospective parents opt for it on the basis of the singular, disabling trait – as though this represents the entire fetus or future child, and as though all of the fetus' other possible traits are irrelevant (Boardman, 2014). These technologies have also been criticized as incompatible with unconditional love and acceptance of all children, regardless of disabling traits (Boardman, 2014). While those in favour of these technologies often claim that they alleviate suffering caused by genetic conditions, proponents of the expressivist objection claim that these technologies work against progress by fixating on the eugenicist goal of human perfection (Buchanan, 1996).

According to proponents of the expressivist objection, focusing on the disabling trait equates to an expression of disvalue – of both the fetus and of PWD more generally (Boardman, 2014). Under this view, PT and/or DSA are thought to “harm the fundamental interests of [PWD]” (Buchanan, 1996, p. 20). Here is where the legal claim of discrimination arises; the use of PT and/or DSA are said to be unjust, as the harming of the interests of PWD constitutes a violation of their basic rights (Buchanan, 1996). The expressivist objection also puts forth a claim of discrimination that is not necessarily legal, but used to indicate prejudice and/or bias: that using interventions such as PT and/or DSA to prevent or fix genetic anomalies presumes and expresses judgments about the value of the lives of PWD (Buchanan, 1996). These judgements are said to be negative, damaging, and at odds with a fundamental moral standard: “the value of

human life” (Buchanan, 1996, p. 28). The judgments are as follows: “the lives of [PWD] are not worth living...[,] only perfect” people should be born, “and imperfect individuals have no right to exist” (Buchanan, 1996, p. 28).

The use of PT and/or DSA is said to violate the basic right of PWD to be seen and treated as though their lives are equal in worth to the lives of people without disabilities (Buchanan, 1996). Proponents of the expressivist objection claim that this violation has real-life implications for PWD; namely, neglect, abuse, and possible extermination (Buchanan, 1996). They are also concerned that the use of PT and/or DSA will decrease future support (both social and financial); they believe that as more people opt for PT and/or DSA, fewer PWD will be born, and as their population dwindles, so too will public support for the needs of PWD (Buchanan, 1996). My thesis will use Buchanan’s label for this claim – “the ‘loss of support’ argument” – upon returning to it later (1996, p. 21).

1.2.1 The Various Forms of the Expressivist Objection

It is important to understand that there are various forms of the expressivist objection. However, the version criticized in my thesis reflects similar versions that appear frequently in the literature. One version reflected in my thesis is laid out by Buchanan (1996). He states that the expressivist objection’s central claim is that developing and using genetic interventions to fix or avoid disability expresses judgments that are not only negative, but outright damaging (1996). The implication here is that expressing these judgments is not just a moral error in a theoretical sense, rather it is a genuine violation of the right of PWD to have their lives equally valued (Buchanan, 1996). Hofmann advances a similar version of the expressivist objection, one which claims that the messages expressed convey disvalue for the lives of PWD (2017).

In discussing the expressivist objection, Buchanan claims that the judgments expressed by the use of genetic interventions are both “the lives of [PWD] are not worth living [and] only perfect individuals should be brought into the world (and imperfect individuals have no right to exist)” [1996, p. 28]. Let us note how this claim demands that any use of these genetic interventions to fix or avoid disability necessarily involves a judgment about others. In other words, this claim insists that the decision to use these interventions could not possibly stem from an individual preference or set of circumstances; rather this decision must involve normative beliefs about others. Finally, this version of the expressivist objection emphasizes that the use of genetic interventions will likely cause the neglect, abuse, and extermination of PWD (Buchanan, 1996). Overall, because of the negative/discriminatory/disvaluing messages expressed by the use of PT and/or DSA, the expressivist objection generally sees the use of PT and/or DSA as morally objectionable, morally unjustified, or otherwise morally wrong.

Kaposy emphasizes an important fact about different versions of the disability critique, which in turn applies to different versions of the expressivist objection: that some versions may “attribute the moral wrong either to the prospective parents... or to... the medical profession or society at large” (2018, p. 181). He writes about another version of the expressivist objection, one that takes issue with clinical guidelines that some believe equate the devastation of miscarriage with the ‘devastation’ of having a child with a disability (2018). The various versions of the expressivist objection presented by Kaposy (2018) underline the fact that the expressivist objection can centre around general social practices or individual choices. While Kaposy focuses on PT and DSA specific to Down syndrome [DS], his arguments apply to disabilities more generally speaking, and he claims that while he sympathizes with those who

wish to focus on general social practices, his “arguments are focused on prospective parents since it is in their power to bring children with [DS] into the world” (2018, p. 181).

1.3 Narrowing Our Scope

According to Søren Holm, the centre of the expressivist objection is the claim that PT and/or DSA express particular messages towards PWD, whether as general social practices – “in abstraction or as [they] currently [exist]” – or as an individual choice (2008, p. 24). Some may argue about the ethical permissibility of PT and/or DSA as social practices, by discussing relevant legislature that permits, bans, or mandates the use of these technologies, by discussing how these technologies are funded, and by discussing to whom these technologies are available. This thesis will examine the expressivist objection as it relates to individual choice, meaning that the thesis will focus on whether it is ethical for individuals to use PT and/or DSA, instead of evaluating the acceptability of laws regarding (and/or the funding of) these technologies. This analysis will examine whether an individual’s personal choice necessarily speaks to the individual’s opinion of a larger demographic. In focusing on individual choice, this thesis will thoroughly examine why someone may make the decision to use PT and/or DSA.

The previous section made clear the expressivist objection’s assumption that using PT and/or DSA involves negative judgments about the value of the lives of PWD. While some individuals who use PT and/or DSA may make these kinds of judgments, it is not necessarily the case that they are wrong in doing so, and it is not necessarily the case that they are thinking only of the life of their prospective child; they may also be thinking of their own lives, and in particular, of their prospective lives as caregivers (Allik, Larsson, & Smedje, 2006; Smith & Grzywacz, 2014; Bourke-Taylor, Howie, & Law, 2010). They may be asking not only ‘How will

this affect my child?', but also 'How will this affect *me*?' This thesis will address whether it is ethically permissible to engage in PT and/or DSA due to assumptions or beliefs about how one's own life may be affected by raising a child with a disability.

Finally, there is one particularly important assumption under which this thesis is written. The existence and/or degree of a fetus' moral status has long been debated; some argue that a fetus holds the same moral status as a person, and others argue precisely the opposite. It is not the task of this thesis to explore the multiple and complex theories of moral status. While this is a contentious subject, this thesis will proceed under the assumption that a fetus only possesses the moral status afforded to them by the pregnant woman hosting said fetus, and whatever moral status a fetus *does* possess is rendered irrelevant if the woman chooses to exercise her reproductive right to bodily autonomy. Essentially, fetuses do not have the same moral status as people, and are therefore not equivalent to people.

1.4 A Possible Misinterpretation of My Argument

I will conclude this chapter by pre-emptively addressing a possible, incorrect interpretation of my argument. Perhaps the most important point to emphasize is that this thesis merely claims that the expressivist objection is an insufficient argument against the use of PT and/or DSA. In other words, at no point does this thesis argue that people *should* use PT and/or DSA, that people *should* see disability as disadvantageous, or that disability *is necessarily* disadvantageous. Instead, this thesis claims that people should *be able to* exercise their right to use PT and/or DSA if they so desire, that disability *can be* disadvantageous, and that it is *fair* for people to prefer non-disability to disability because it can be disadvantageous. In addition, at no point whatsoever does this thesis claim that PWD should not live, do not deserve to live, or that

their lives are not worth living. It is important to emphasize these points in light of other existing arguments, which could be interpreted in more than one way. For instance, Savulescu's principle of procreative beneficence: this principle does not just say that it is *acceptable* for prospective parents to use reproductive technology to ensure their child has the best life; rather it says that prospective parents *should* use reproductive technology for this purpose (2001). This thesis does not make these kinds of normative statements, and does not speak of prospective parents' supposed 'obligations.'

Chapter 2: Background Information

2.1 Introduction

This chapter provides important background information that must be understood before evaluating the expressivist objection. First, an overview of forced sterilization in the U.S. and Canada, the Nazi euthanasia program, and institutionalization of children with disabilities will be provided, by referring to work from a multitude of sources. Of course, the history of discrimination against PWD is extensive, and several paragraphs cannot do justice to all of the horrors that PWD have faced. Still, review of these aforementioned instances of discrimination and violence against PWD serves the purpose of this section; to explain existing caution surrounding technologies that affect PWD, and to illustrate the need for continued caution going forward. This section aims to emphasize for the reader the fact that disability rights activists and theorists have legitimate reasons to be wary of PT and/or DSA.

The focus of the next section will be women's reproductive rights versus the rights of PWD. Using Beauchamp and Childress (2001), I will briefly review the principle of bodily autonomy. Drawing from Watkins (1998), I will proceed to explain how the principle of bodily autonomy lays at the center of a historical movement towards sexual liberalization. By referring to Caeton's (2011) work, I will then review how this movement is said to diverge from the disability rights movement at the point of reproductive rights, primarily when a woman's right to abortion is seen as discriminatory because her decision is centered around a fetal abnormality. I will also refer to Kaposy (2018) when discussing the tension between these two movements, and the ways in which this tension can produce real-life consequences in the presence of a normative claim.

Chapter Two ends with an overview of the basics of PT and DSA as technologies. It is important to understand what PT and DSA actually entail before examining their ethical permissibility. I will reference Marteau et al. (1989), Birko et al. (2019), Kuppermann et al. (2014), Harvard Health Publishing (2019), Hull et al. (2016), as well as Natoli et al. (2012) to provide such an understanding. I will conclude by noting that not all proponents of the expressivist objection outright oppose PT and/or DSA. Citing Boardman (2014), I will explain that some simply call for presentation of ‘experiential’ information about disability, rather than just medical information; they want prospective parents to receive firsthand knowledge from people with disabilities and their loved ones. At this point, Chapter Two will have reviewed: a) discrimination against PWD, b) the ways in which women’s reproductive freedom can clash with the objectives of the disability rights movement, and c) the basics of PT and DSA. The relevant descriptive elements of my argument will be established at this point, and I will then proceed to examine the argument itself.

2.2 Disability and Discrimination: A Brief Overview¹

Before assessing the expressivist argument, it is important to understand that disability rights activists and theorists have legitimate reasons to be wary of PT and/or DSA. Let us review key moments in the history of eugenics and institutionalization, and the general discrimination experienced by PWD. These brief paragraphs cannot do justice to all of the horrors that PWD

¹ *Note: Disability is central to this thesis, but is inextricably linked with other terms (e.g. disease, illness, disorder, syndrome, condition, etc.). There is no single, agreed-upon definition of ‘disability,’ and a definition will not be offered here. This thesis emphasizes the importance of individual preferences and perspectives, and ultimately concerns prospective parents’ decision to acquire PT and/or DSA – definitions of disability will vary from person to person.*

have faced throughout history, but serve to explain existing caution surrounding technologies that affect PWD, and to illustrate the need for caution going forward.

While eugenics is often associated with the Nazi era, eugenics is not a practice specific to extremist movements. Forced sterilization for eugenic purposes used to be commonplace in the United States, with the 1927 case of *Buck v. Bell* being a well-known example (Noren, 2013). ‘Buck’ refers to Carrie Buck, a woman born in 1906 who was institutionalized by her foster family because of what they referred to as her ‘feeble-mindedness’ (Noren, 2013). Under “the growing theories of eugenics,” officials believed Carrie’s feeble-minded state was inherited; this was officials’ rationale for forcibly sterilizing her (Noren, 2013, p. 14). A Supreme Court Justice wrote in his decision that it is better for the world to prevent the unfit from producing offspring, and that in this case, “three generations of imbeciles are enough” (Noren, 2013, p. 12). Devastatingly, Carrie was only one of many people targeted by forced sterilization; this practice victimized many Americans before her, and approximately 60,000 to 100,000 others afterward (Noren, 2013). “By 1937, 28 states [in America] had adopted Eugenics Sterilization laws” (Saxton, 1988, p. 219).

Meanwhile in Canada, 1937 saw an amendment of its first Sexual Sterilization Act pass (Amy & Rowlands, 2018). The Canadian National Committee for Mental Hygiene had advocated for “sterilisation of those with mental defect or disorder” in 1921, and the first Sexual Sterilization Act was enacted in 1928 in Alberta (Amy & Rowlands, 2018, p. 127). The Act’s 1937 amendment, however, permitted sterilizations to be non-consensual when performed on the so-called ‘mentally defective’ (Amy & Rowlands, 2018). While Canada has long had a reputation for kindness, diversity, and acceptance, this reputation is neither accurate nor earned.

Alongside the United States, Canada was one of the first countries to enact laws permitting forced sterilization (Amy & Rowlands, 2018).

While forced sterilization was intended to prevent a range of people from reproducing (e.g. deviants or the ‘socially undesirable,’ such as criminals, prostitutes, and/or addicts), its initial preoccupation with the ‘mentally defective’ targeted people with intellectual disabilities and mental illness (Amy & Rowlands, 2018). Of course, the characterization of PWD as inherently deficient or defective is discriminatory in and of itself, as is the assumption that PWD are unfit to have and raise children; the blatant violation of their bodily autonomy is where the discrimination becomes outright violent.

The same discrimination and cruelty were, predictably, seen in the Nazi euthanasia program. While this eugenic practice was referred to as euthanasia, it was based on a pseudoscientific, discriminatory ideology, rather than “benevolent concern for an individual’s condition,” and was state-mandated rather than voluntary (Burgess-Whiting, 2016, p. 590). There are few records detailing this program, and even after its official conclusion, involuntary euthanasia continued in secrecy (Burgess-Whiting, 2016). The Nazi euthanasia program is thought to have claimed the lives of over 160,000 people (Burgess-Whiting, 2016). Known as the T-4 program, after Tiergartenstrasse 4 (the Berlin building that housed its offices), this program was born out of initiatives such as the forced sterilization of PWD, or those “deemed likely to produce ‘diseased progeny’” (Burgess-Whiting, 2016, p. 589). Soon after, an adult euthanasia program was established, with the goal of 65,000-70,000 killings each year (Burgess-Whiting, 2016).

Like the euthanasia program, the medical experimentation carried out by the Nazis was “eugenic in nature... [and aimed] to purify the so-called Aryan race through the elimination of

individuals with genetic abnormalities as well as the destruction of ‘inferior’ races” (Woolf, 2016, p. 1100). Nazi Germany was not alone in its ideas that people with genetic abnormalities were inferior, and that these people should not pass on these abnormalities through procreation. History has seen disability ‘managed’ not just in Nazi Germany, and not just through forms of eugenics such as forced sterilization, but also through literally separating PWD from people without disabilities by institutionalizing them.

Institutionalization was another common discriminatory practice, particularly for children with DS. Many pediatricians recommended institutionalization “in the late 1940s and early 1950s” (Antommara, 2006, p. 207). Later in the 1950s, psychoanalytic developments illustrated the deleterious effects of institutionalization on children (Antommara, 2006). The importance of positive, ongoing child-parent relationships in fostering children’s mental health and character development also became clear (Antommara, 2006). People began to advocate for parents to raise children with DS at home, claiming that this was a manageable task that would not seriously disrupt families’ lives (Antommara, 2006). Many grew to understand “the increased potential of children with [DS],” and more began to understand that institutionalizing one’s child could adversely affect the parents as well (Antommara, 2006, p. 219).

While we may think of Nazi eugenics and colonization as historical events that happened long ago, abuse and mistreatment of PWD persists today. For instance, eugenicist beliefs about women with intellectual disabilities continue to violate their bodily autonomy (McConnell & Phelan, 2022). These beliefs concern the women’s supposed deficiencies and incapacity for parenthood, and result in the women themselves being overlooked when important reproductive decisions are made (McConnell & Phelan, 2022). Consequently, their contraceptive care is negatively impacted; women with intellectual disabilities are not only rarely given information

about different contraceptives, they are also pressured to ‘volunteer’ to be sterilized and to obtain an abortion should they become pregnant (McConnell & Phelan, 2022).

Further contemporary information about the experiences of PWD is found in the 2012 National Survey on Abuse of People with Disabilities, which involved over 7,000 American respondents (Spectrum Institute, 2013). Over 70% of respondents reported experience with abuse, with 87.2% reporting verbal-emotional abuse, 50.6% reporting physical abuse, 41.6% reporting sexual abuse, 37.3% reporting neglect, and 31.5% reporting financial abuse (Spectrum Institute, 2013). The general unemployment rate in Canada is approximately 5.8%, but is 35% for those with mild disabilities, and 74% for those with severe disabilities (Raso, 2018). PWD usually find employment in sales, and earn significantly less than their abled coworkers (Raso, 2018). PWD are more likely to find healthcare unaffordable and/or inadequate, be mistreated in the healthcare system, or be denied healthcare altogether (World Health Organization, “10 facts on disability”, 2017).

There are over one billion PWD worldwide; these statistics regarding abuse, mistreatment, and otherwise discriminatory practices toward PWD are unacceptable (World Health Organization, “10 facts on disability”, 2017). Evidently, PWD have faced and continue to face many forms of discrimination. Given that PT identifies fetal abnormalities (would-be disabilities), and DSA is of course specific to disabilities, it is understandable that these technologies may be met with caution by some PWD. However, it is important to remember that identification of fetal abnormalities can be useful for a variety of reasons, and deciding to undergo DSA can be based on multiple factors; neither PT nor DSA are necessarily discriminatory. Before delving into the issue of disability and discrimination, we must

understand the ways in which women's reproductive rights are potentially at odds with the disability movement.

2.3 Women's Reproductive Rights and the Rights of PWD: A Conflict?

The principle of respect for autonomy has been deemed one of the four main bioethical principles, as laid out by Beauchamp and Childress (2001). Autonomy literally means 'self-rule,' but in the context of healthcare, it refers to *bodily* autonomy; that is, the freedom to make decisions about one's body and healthcare without interference from others, and without other limitations that hinder true choice (Beauchamp & Childress, 2001). Autonomy requires two conditions: "(1) liberty (independence from controlling influences) and (2) agency (capacity for intentional action)" (Beauchamp & Childress, 2001, p. 58).

Bodily autonomy was the crux of the reproductive rights movement, which secured the availability of contraceptives and the right to choose (i.e. abortion). These changes were accompanied by a sexual revolution that saw shifts in sexual attitudes and behaviours; increased premarital sex, less conservative attire, and an overall trend towards sexual liberalization (Watkins, 1998). The availability of the birth control pill was a sizeable catalyst in this revolution; it drove society to seriously consider the function, evaluation, and significance of sexuality in day-to-day life (Watkins, 1998). While changes in societal norms were significant, the legalization of concrete practices (i.e. contraceptives and abortion) that helped ensure women's reproductive rights was ground breaking. These practices granted women more control over their bodies, their sex lives, and their family planning.

As the field of women's studies has grown, so too has the field of disability studies. Although both fields study disenfranchised demographics and strive for equality, they can (but

do not always) diverge at the point of reproductive rights (Caeton, 2011). As stated in Chapter 1, there are various forms of the expressivist objection, and not every version claims that women should not be able to access PT and/or DSA. Some authors, such as Kaposy, make arguments concerning the harms of PT and/or DSA while maintaining a pro-choice position (2018). Kaposy neither advocates for restricted access to PT or DSA, nor makes normative claims that mandate forgoing PT or DSA (2018). He writes, “My goal is to show why having a child with [DS] would likely be a rewarding experience for most prospective parents” (2018, p. 5).

He does suggest that prospective parents’ rationale for choosing PT and/or DSA is rooted in misinformation or biases, and claims that if they were more aware of this, they would no longer endorse said rationale (2018). Kaposy proceeds to specify that his pro-choice argument does not imply that reproductive decision making should be immune from criticism or reflection; he maintains his position in favour of having children with DS by engaging thoughtfully and logically with a multitude of arguments about reproductive ethics (2018). Kaposy’s work demonstrates that there *are* arguments against PT and/or DSA that are congruous with both women’s rights and disability rights.

However, as established in Chapter One, the version of the expressivist objection to which this thesis is responding states that the use of PT and/or DSA is morally problematic, wrong, and/or unjust. Some may argue that this position does not tread on women’s rights, as it is merely a theoretical position, but this thesis examines the real-life consequences of this theory put into practice. These consequences indeed include the endangerment of women’s right to access PT and/or DSA. While claiming that PT and/or DSA are morally unjustifiable may still mean that people *can* use these technologies, claiming that people would be immoral to use these technologies directly translates into a normative argument that says people *should not* use these

technologies. This argument has clear practical implications for women's right to reproductive autonomy.

Ultimately, the reproductive rights movement seeks to protect women's freedom to abort their fetus if they so desire, but when their decision centres around a fetal abnormality – or disability – the disability rights movement may not support their right to choose abortion. This point is emphasized by Caeton, who discusses the tensions between these two movements by asking, “How could... an individual woman's right to abortion never be questioned when it would have to be questioned in order to protect fetuses with deformities or other perceivable disabilities from being unfairly terminated?” (2011, p. 1).

This question requires us to consider whether the rights of the individual woman and the rights of PWD can *both* be protected in the context of PT and/or DSA (Caeton, 2011). Disability scholars may claim that undergoing DSA is an instance of discrimination, that it sends and/or perpetuates the notion of disability as undesirable, and that it is simply the elimination of a PWD (or a would-be PWD) – essentially, the expressivist objection in a nutshell (Caeton, 2011). This set of arguments is inextricably linked to choice, agency, and individual perceptions of health and wellbeing (Caeton, 2011). While choice and agency are necessary freedoms for all persons, choice and agency as related to one's body are not freedoms that are granted to all women. We must remain cognizant of women's bodily rights when discussing technologies developed specifically for women's bodies and the fetuses inside them. Let us now review the basics of said technologies.

2.4 PT and DSA: The Basics

PT encompasses both screening and diagnostic tests (Marteau et al., 1989). As the terms suggest, the former can indicate whether the fetus is more likely to have a certain condition, whereas the latter determines with certainty whether a condition is present. These tests allow prospective parents to learn more about the condition in question, which allows prospective parents to understand treatment options, gain information about said condition, and better prepare for any special medical care during or after the birth (Marteau et al., 1989). These conditions include “cystic fibrosis, Tay-Sachs, fragile-X syndrome, and sickle cell anemia”, among others (Crabtree Burton & Luciani, 2012, p. 33). It should be noted that not every prospective parent wants to know if there are any fetal abnormalities; PT is not sought out by all prospective parents. The decision to pursue PT and/or genetic counselling is highly personal.

Some examples of PT are maternal serum screening (MSS), amniocentesis, and non-invasive prenatal testing (NIPT) [Birko et al., 2019]. MSS is a screening test that poses no risk of miscarriage, and involves drawing blood from the mother (Birko et al., 2019). It detects “[DS], trisomy 18, neural tube defects (e.g. spina bifida), and [other] possible pregnancy complications” (Birko et al., 2019, p. 3). Amniocentesis is a diagnostic test that involves extracting amniotic fluid from the uterus by inserting a needle through the abdomen (Birko et al., 2019). It increases the risk of miscarriage by about 0.5%, and detects “[DS], trisomy 13, trisomy 18, other chromosome anomalies, neural tube defects (e.g. spina bifida), [and the] sex of the baby” (Birko et al., 2019, p. 3).

While both MSS and NIPT are screening tests that involve drawing blood from the mother, the former measures hormone levels, and the latter analyzes the fetus’ DNA (Birko et al., 2019). This poses no risk of miscarriage, and detects “[DS], trisomy 13, trisomy 18, [and the]

sex of the baby” (Birko et al., 2019, p. 3). Accuracy of PT varies depending on the kind of test, and the condition for which the fetus is being tested: for instance, MSS detects approximately 77%-88% of DS cases, amniocentesis detects virtually 100% of DS cases, and NIPT is at least 98% accurate in detecting DS cases in high-risk women (Birko et al., 2019).

The aforementioned screening and diagnostic tests are typically seen as routine prenatal care (Kuppermann et al., 2014). However, there is evidence to suggest that when prospective mothers are more knowledgeable about PT and understand that it is voluntary, they may be more likely to make an informed choice – one that encompasses their preferences and values, one that indicates an understanding of the possible risks involved, and one that may result in forgoing PT altogether (Kuppermann et al., 2014). This makes clear the need for genetic counsellors, so that in these emotionally fraught situations, prospective parents can carefully consider their preferences, values, and desire to learn of potentially serious medical information. Possible motivations for seeking out PT – and their ethical permissibility – will be examined at a later point.

Prior to eight weeks gestation, abortion refers to the removal of pregnancy tissue and products of conception (Harvard Health Publishing, “Abortion”, 2019). After eight weeks gestation, abortion refers to the removal of the fetus and placenta (Harvard Health Publishing, “Abortion”, 2019). More controversy surrounds abortion when performed at or after the point of viability. While – in Canada – “the most commonly reported definition of fetal viability appears to be 24 weeks’ gestation,” there is considerable variation, this term is not consistently defined, and this inconsistency contributes to unequal access to safe abortion (Hull et al., 2016, p. 550).

While pregnant women most often seek out abortion due to an unplanned pregnancy, abortion also occurs in the event of an abnormal fetus, or when the health of the prospective

mother is in jeopardy (Harvard Health Publishing, “Abortion”, 2019). Of course, DSA refers to abortion that is carried out due to the discovery of a ‘disability’, or fetal abnormality. One of the most commonly tested-for disabilities is DS. The weighted mean termination rate post-prenatal diagnosis of DS, as deduced from a multitude of population-based studies, is 67% (Natoli et al., 2012). While this is still a significant finding, it is considerably lower than the termination rate of 92% in the 1980s (Natoli et al., 2012).

It is important to note that not all proponents of the expressivist argument call for an end to PT and/or DSA. Some simply call for presentation of ‘experiential’ information about disability, rather than just medical information; they want prospective parents to receive firsthand knowledge from people with disabilities and their loved ones (Boardman, 2014).

Now that we have an overview of: a) discrimination against PWD, b) the ways in which women’s reproductive freedom can clash with the objectives of the disability rights movement, and c) the basics of PT and DSA, the relevant descriptive elements of this thesis’ argument have been established, and we can begin to look at the argument itself.

Chapter 3: When Is a Message Discriminatory?

3.1 Introduction

This chapter will examine the first flaw of the expressivist objection: its claim that the use of PT and/or DSA expresses negative and/or discriminatory messages to existing PWD. Following this introduction, the first section will provide a brief overview of work from Hofmann (2017), Edwards (2004), Buchanan (1996), and Nelson (2000), in order to understand arguments about whether messages can be sent irrespective of intention. Subsequently, this section will argue that whether a message can be *sent* irrespective of intention is irrelevant, as a message can still be *perceived* irrespective of the sender's intention. However, the perception of the 'recipient' can still be flawed. While some PWD may indeed perceive discriminatory messages from others' use of PT and/or DSA, this chapter will argue that their perception of these messages as discriminatory is flawed.

The next section will first discuss why the negative claim (again, that the use of PT and/or DSA expresses negative messages to PWD) is less important than the discriminatory claim (that the use of PT and/or DSA expresses discriminatory messages to PWD). This discussion will explain why a message being discriminatory is much more ethically significant than a message being merely negative, and in doing so, explain why this section only addresses the discriminatory claim. When discussing the 'discriminatory' claim, discrimination will be defined and its key component (unfairness) will be explored. Something can be unfair in a 'justice' sense, or in a 'reasonableness' sense; both of these interpretations will be explored. This discussion pertains to the following question: Is it *unfair* to believe that disabilities can be disadvantageous? If it is fair to hold this belief, then it is incorrect for someone to perceive this

belief as discriminatory when expressed as a message; the message lacks the necessary quality of discrimination (unfairness).

The following section will examine Savulescu's relevant arguments, paying particular attention to what he terms 'procreative beneficence' as well as the notion that disability is not a mere difference, but a detrimental difference. It will be emphasized that the messages expressed by the use of PT and/or DSA are claims about disabilities, rather than claims about the people who have disabilities and/or the lives of the people who have disabilities. This section will culminate in the argument that it is reasonable to believe that disability can be disadvantageous. In turn, insofar as the messages expressed by the use of PT and/or DSA lack the key component of discrimination (unfairness – in both a justice and a reasonableness sense), they are not discriminatory.

The final section of Chapter Three will look at various perspectives on disability, held by PWD. This section will begin by discussing the nature of preferences, and in doing so, specifying the difference between one's theoretical preference for 'x' and what the same person's real-life attitude would be towards 'x'. Bogart's (2014) work will then be used to examine the perspectives of people with congenital disabilities and people with acquired disabilities. Additional perspectives on disability will be reviewed in reference to work by Horky et al. (2017). This discussion will demonstrate that perspectives on disability are nuanced and highly varied amongst PWD as well as people without disabilities. One of the perspectives comprising this variety is that disability can be disadvantageous. This fact supports this thesis' argument regarding the first flaw of the expressivist objection; the expressivist objection is wrong to claim that the messages expressed by the use of PT and/or DSA are discriminatory.

3.2 The Expression of Messages: Does Intention Matter?

Multiple authors have written about whether messages can be sent irrespective of intention, and more specifically, about whether the use of PT and/or DSA sends negative messages to PWD (Hofmann, 2017). Of course, it is important to analyze whether messages can be sent irrespective of intention when evaluating the expressivist objection, as it centers around the expression of messages. Edwards discusses the argument that “it is not plausible to suppose prevention of disability sends a negative message to [PWD]” based on the implausibility of supposing that reducing instances of the flu sends a negative message to people who have the flu (2004, p. 418). While Edwards grants the expressivist objection’s view of disability as identity constituting, and acknowledges that the flu cannot be identity constituting, he still dismisses the expressivist objection (2004). He argues that it does not follow that perceiving negative messages places an obligation on others to avoid expressing said messages, when this obligation would come at the cost of one’s reproductive autonomy (2004). Buchanan argues that intention is necessary for a decision to express a judgment or message, claiming that the ‘sender’ must believe the judgment to be true and be motivated by it (1996).

Nelson agrees with Edwards and Buchanan, in that PT and/or DSA do not send negative messages to PWD, but disagrees with Buchanan’s reasoning (2000). Nelson uses an example to argue that actions can express messages without being motivated by beliefs: even if someone did not hold racist beliefs, if they decided to fly a Confederate flag, it would be entirely reasonable for onlookers to feel offended and perceive a hateful message (2000). Still, Nelson rejects the idea that PT and/or DSA express negative messages because “they do not function as signs in a rule-governed symbol system” (2000, p. 213). That is, these technologies are too vague and do

not possess semantic significance, unlike flags, which are literal denotations of movements, countries, etc., and are universally recognized as clear symbols (Nelson, 2000).

Additionally, Nelson observes that abortions obtained due to the financial cost of childrearing, or due to increased family size, do not send messages to the impoverished or to large families, and that it is ultimately impossible to differentiate DSA from these abortions (2000). Some argue that abortions for these reasons are not comparable to DSA because in DSA, the woman in question changed her mind upon learning of the single, disabling trait, whereas in the other cases, she did not want the fetus to begin with (Nelson, 2000). Nelson's rebuttal claims that a would-be fourth-born child, or a would-be impoverished child are not distinct from a child that would be born with disabilities; "a person is fourth-born only via her relationship to others, as a person is poor only via her relationship to a particular economic system" (2000, p. 218). He also notes that those who argue that disability is distinct from these other qualities because of its alleged fixed nature, irrespective of circumstance, contradict a pillar of the disability rights movement; "that disabilities are... socially constructed" (2000, p. 219). If disabilities are indeed socially constructed, they must be relational in the same way that birth order and poverty are relational; if disabilities are indeed socially constructed, then there can be no distinction between the messages supposedly expressed by abortions based on disability and those expressed by abortions based on other relational qualities.

Nelson also notes that no negative messages are said to stem from prospective mothers taking folic acid during pregnancy, even though this is done in an effort to ensure the child's health and avoid disabilities (2000). Evidently, the expressivist objection is not compatible with the *fact* that it is uncontroversial, accepted, and encouraged for pregnant women to avoid birth defects by taking folic acid (Nelson, 2000).

Perhaps proponents of the expressivist objection would respond to these scholars by arguing that, irrespective of intention, a message can still be *perceived*. However, this argument can be countered; the recipient's perception can be flawed. While PWD may indeed perceive discriminatory messages from others' use of PT and/or DSA, this thesis will argue that they are wrong to perceive these messages as discriminatory. In turn, we can dismiss the expressivist's assertion that the use of PT and/or DSA sends discriminatory messages to PWD. To accomplish this, we must review what it means for something to be discriminatory. First, however, let us explain why this chapter will not address the expressivist objection's claim that the use of PT and/or DSA expresses negative messages to PWD, and will instead focus on the discriminatory messages claim.

3.3 The 'Negative' and 'Discriminatory' Claims

Proponents of the expressivist objection may claim that the messages expressed are negative simply because they are discriminatory, and discrimination is necessarily negative. This possibility will be covered in this section's discussion of the 'discrimination' claim; in this case, dismissing the 'discrimination' claim ipso facto dismisses the 'negative' claim. The alternative possibility is that proponents of the expressivist objection are making a more general claim of negativity that indicates harmfulness and/or hurtfulness. It is important to acknowledge that messages perceived by some PWD are emotionally fraught and should be discussed in a sensitive manner. It is of course hurtful for someone to perceive messages that deem them flawed, imperfect, and/or unwanted. As was made clear in Chapter Two, there is a lengthy history of discrimination and violence against PWD, a history that expressed such messages loudly and

repeatedly. While remaining sensitive to this history, two facts diminish the importance of the negative claim.

The first is that while some PWD may perceive negative messages from the use of PT and/or DSA, it is impossible to claim that every single PWD perceives these messages. This alone does not prove that these messages are not negative, but it does highlight the fact that the expressivist objection is wrong to describe these messages as negative for PWD as a group when in fact not all PWD perceive these messages as negative. This fact also illustrates that these messages are not inherently negative. The second, more significant fact is that making PT and/or DSA unavailable for the sake of not expressing hurtful messages would result in unreasonable, absurd consequences (namely, people's reproductive rights being threatened, simply so that others do not perceive negative messages). These consequences will be discussed further in Chapter Five.

Let us now turn to the claim that the use of PT and/or DSA expresses discriminatory messages. First, we must define discrimination. While 'discriminate' can be synonymous with 'differentiate', and discrimination can be positive (e.g. in instances of affirmative action), the expressivist objection quite clearly uses 'discriminatory' in a negative sense. In other words, the expressivist objection does not refer to the messages expressed as 'discriminatory' to illustrate how effective the messages are at recognizing differences, or to describe the messages as positive for PWD; the expressivist objection evidently uses the term 'discriminatory' to highlight the perceived unfairness of these messages, and this is the version of discrimination to which this thesis will respond.

Discrimination is inconsistently defined, and often discussed in vague terms; Canadian law refers to discrimination as an act involving negative treatment for characteristics such as

disability, sexual orientation, race, etc. (Government of Canada, 2020). These characteristics are referred to as grounds of discrimination (Government of Canada, 2020). The *Ontario Human Rights Code* does not explicitly define discrimination, but does list the typical elements of discrimination: “not individually assessing the unique merits, capacities, and circumstances of a person... making stereotypical assumptions based on [their] presumed traits... [and resulting in the exclusion of] persons, denying benefits, or imposing burdens” (Ontario Human Rights Commission, 2008, para. 1).

The University of Ottawa goes beyond the *Human Rights Code*’s definition of discrimination by specifying that it refers to “*unfair treatment* [emphasis added]” on the basis of the aforementioned grounds of discrimination (n.d., para. 3). The Ontario Human Rights Commission (OHRC) adds that in the context of employment, employers must avoid discriminating against PWD and strive to accommodate them instead, but only to the point of undue hardship (e.g. “significant costs or health and safety factors”) [Ontario Human Rights Commission, n.d., para. 31]. While prospective parents and their fetuses are not analogous to employers and employees, it is interesting to consider the prospective parents’ potential duty to accommodate; arguably, the research about the wellbeing of caregivers of children with disabilities that is laid out in this thesis identifies the potential undue hardship of said caregivers.

The University of Ottawa’s specification of discrimination as unfair aligns with another definition: “discrimination is defined as negative or unfair treatment of individuals based on their membership in a specific marginalized social group” (Godley, 2018, p. 113). Proponents of the expressivist objection claim that the use of PT and/or DSA sends discriminatory messages to the marginalized social group that is comprised of PWD; discrimination against this group is based on the fact that its members have a disability. This definition of discrimination supports the

argument put forth by expressivist objection proponents, in its description of ‘negative or unfair’ treatment (the expressivist objection describes the supposed messages sent as ‘negative and/or discriminatory’).

This thesis considers ‘unfair’ treatment to be the key component of discrimination, and considers ‘negative’ treatment on its own to be an insufficient criterion for discrimination. Again, a message being discriminatory is much more ethically significant than a message being merely negative; a negative message may still be accurate or reasonable, whereas a discriminatory message has neither of those qualities, due to its unfair nature. For discrimination to occur, the treatment must be unfair, and a connection between the treatment and the individual’s membership in a marginalized group must be made.

For instance, let us say that someone with cerebral palsy gets fired from their job. While this is a case of the employer treating the employee negatively, for the treatment to be discriminatory, the employee’s firing would have to arise from the fact that they have a disability; this disability-specific cause of firing is what makes the firing unfair. That is, the employer would have to have made inaccurate assumptions about the employee because of their disability, and/or the employer would have to have failed to accommodate them to the point of undue hardship. It is interesting that the charge of discrimination is waived if the alternative involves undue hardship; perhaps prospective parents’ ‘discriminatory’ use of PT and/or DSA would not be so labelled if their distinct possibility of future undue hardship was considered.

Let us return to the discrimination alleged by proponents of the expressivist objection, and briefly put aside two facts: 1) that fetuses are not persons under the law (or morally speaking, as far as this thesis is concerned), and therefore fetuses cannot be objects of discrimination; and 2) that PWD cannot themselves be objects of discrimination when the object

of PT/DSA is always a fetus. Let us consider the expressivist objection's claim that the messages expressed are discriminatory in a more general sense; that these messages are anti-disability, and the actions expressing these messages are made arbitrarily (i.e. prospective parents opt for PT and/or DSA based on an inaccurate and/or unreasonably negative view of disability). At the heart of this more general claim lies the focus of this chapter and the defining aspect of discrimination: unfairness.

Something can be unfair in a 'justice' sense, or in a 'reasonableness' sense. It is unclear whether proponents of the expressivist objection are making a legal claim that individuals who use PT and/or DSA are committing acts of discrimination against PWD, or if the proponents are using 'discriminatory' as a descriptor to indicate the presence of prejudice and/or bias. In the former case, the issue is one of justice, whereas in the latter case, the issue is one of reasonableness. In addition to the legal fact that fetuses are not equivalent to existing persons, this thesis presumes that fetuses do not have the same moral status as existing persons (*Criminal Code*, 1985, s 223(1)). Therefore, fetuses cannot be discriminated against. The legal claim of discrimination against existing PWD can be dismissed on this ground alone; the expression of these messages is fair in a justice sense. By the end of this chapter, it will be established that the expression of these messages is both reasonable and just, and we can safely claim that expression of these messages is fair; the main criterion for discrimination (unfairness) is not met.

While we can dismiss the possible legal discrimination claim from proponents of the expressivist objection, we must still contend with the other possibility: that proponents of the expressivist objection use 'discriminatory' as a descriptor to indicate the presence of prejudice and/or bias. Again, this claim of unfairness relates to reasonableness (i.e. whether it is reasonable

for someone to think that disability may be disadvantageous for either their child, themselves, or both parties).

Once again, the more general message perceived by proponents of the expressivist objection is that disabilities can be unfavourable, or disadvantageous. In examining whether this is an unreasonable message to send, we can simply examine whether this is an unreasonable sentiment to hold, as one can send a message irrespective of whether one intends to send the message. So, is it *unreasonable* to believe that disabilities can be disadvantageous? If it is reasonable to believe that disabilities can be disadvantageous, then PWD who perceive this message from the use of PT and/or DSA as discriminatory are wrong to do so. In turn, the expressivist objection's claim that PWD perceive discriminatory messages would be misleading, and therefore flawed. The argument that disability can be disadvantageous can be further elucidated by examining Savulescu's work on disability.

3.4 Disability: Difference or Detriment?

Savulescu put forth the principle of 'procreative beneficence,' which dictates that prospective parents should use the information provided by reproductive technology to "select the child, of the possible children they could have, who is expected to have the best life" (2001, p. 413). He gives the example of a choice between two embryos, one of which will have asthma if it develops into a child (2001). He argues that while asthma may be mild, it may not be, and in any case, it still represents a disadvantage that the other embryo will not experience (2001). This thesis does not support Savulescu's argument that prospective parents *should* use available information to select whichever child will likely have the best life, but Savulescu's work remains highly relevant.

Savulescu recognizes that his argument is inextricably linked to the idea of what constitutes the ‘best life,’ which he explores further in a subsequent paper (2001). In this later paper, he makes several points: the ‘better’ or more able embryo may still have a bad life, it is difficult to ‘rank’ lives, and “the value of an individual feature of a life” differs from “the value of a whole life” (2007, p. 284). Nevertheless, he concludes that “we [still] have a reason to prefer an embryo that [will not have a disease or disability]” (2007, p. 284).

Savulescu argues that the ‘badness’ of a disease or disability is what gives prospective parents a reason to select against said embryo; they still know of the condition’s badness even if they do not know the value of the future child’s full life (2007). He makes clear that while some may believe that procreative beneficence requires asking, “What constitutes a good life?” it in fact asks “Should we select an individual that is expected to have better prospects of a better life?” (2007, p. 286). At no point in Savulescu’s discussion of procreative beneficence does he commit himself to a conception of a good life (2007).

In yet another paper – this one coauthored with Kahane – Savulescu responds to the mere difference view, which claims that “disability is merely a difference” (Kahane & Savulescu, 2016, p. 774). This view is well-aligned with the expressivist objection, in that both arguments object to a sole focus on disability as well as the idea that disability necessarily makes life less valuable. The mere difference view argues that disabilities may make a person different, but the disability itself does not reduce a person’s wellbeing (Kahane & Savulescu, 2016). The mere difference view claims that any negative effect is not caused by the disability itself, but by social failures (e.g. ableism, lack of accommodation) [Kahane & Savulescu, 2016].

Kahane & Savulescu point out that rejecting the mere difference view only requires one to argue that most disabilities are likely to reduce one’s wellbeing in their current environment,

and that this would be true irrespective of the presence of prejudice (2016). Rejecting the mere difference view does not require one to label disability as bad; it requires one to argue that disability generally renders one worse off (2016). Kahane & Savulescu call this the detrimental difference view (2016). They argue that lacking fundamental capacities – in our world, as it stands – results in fewer options and opportunities, and makes these opportunities markedly more difficult to pursue (Kahane & Savulescu, 2016). The authors recognize that some of these disadvantages are worsened due to prejudice, but argue that these disadvantages exist irrespective of whether prejudice is a factor (Kahane & Savulescu, 2016).

They proceed to focus on causation and permissibility; namely, whether it would be permissible to cause a nondisabled person to become a PWD (Kahane & Savulescu, 2016). While some proponents of the mere difference view claim that causing an ‘x’ to become ‘y’ is wrong, without suggesting that being a ‘y’ is worse than being an ‘x’, these proponents ultimately rely upon a “principle of noninterference” (Kahane & Savulescu, 2016, p. 779). Kahane and Savulescu emphasize that the symmetrical nature of this principle means that “it should apply in the same way both to causing disability and to removing it”, yet this is not the case (2016, p. 779). If this principle were to apply in this way, we would be left with the unacceptable implication of not being (morally) allowed to perform eye surgery to correct blindness, to take folic acid during pregnancy, or to take other measures that are considered not just uncontroversial, but totally acceptable (Kahane & Savulescu, 2016). The authors maintain that the principle of noninterference is not symmetrical, and that, in line with Savulescu’s claim that disability is a disadvantage, it is “impermissible to cause disability” (Kahane & Savulescu, 2016, p. 774).

Let us return to the question at hand: Is it *unreasonable* to believe that disabilities can be disadvantageous? Savulescu does not commit himself to a conception of what constitutes a good (or worthwhile) life, but he makes a clear and compelling argument that disabilities are unfavourable. Some may take offense to this claim, but it is important to remember that this is not a claim about *people* with disabilities, rather this is a claim about the disabilities themselves. Even if the message sent by the use of PT and/or DSA was discriminatory, it would discriminate against disabilities, not against the people who have them. As Savulescu wrote: “To attempt to prevent accidents which cause paraplegia is not to say that paraplegics are less deserving of respect. It is important to distinguish between disability and persons with disability” (2001, p. 423). So, while PWD should not be discriminated against, or treated without respect, it is still the case that disabilities can be disadvantageous, and so it is reasonable for one to believe that disabilities can be disadvantageous (and subsequently, to wish to avoid them and/or to have this wish for their child).

Further support for the argument that disabilities can be disadvantageous can be found in the overview of discrimination against PWD, provided in Chapter Two. This section reviews a multitude of statistics about the lives of PWD: widespread verbal, emotional, physical, sexual, and financial abuse; neglect; significant unemployment (as well as discrepancies in pay between PWD and their nondisabled coworkers); issues accessing healthcare; and general stigma. Some would argue that these statistics can be attributed to societal failures (and are not born of disabilities themselves), and Savulescu would argue that these statistics would persist even without prejudice. However, even if societal failures are to blame, the world in which we live is rife with these societal failures. It may be tempting to make arguments in a theoretical utopia, but it is important for practicality’s sake that we acknowledge our current reality. The experiences of

PWD are indeed attached to and worsened by our reality's social failures, but we do need to consider the experiences of PWD as they exist in that climate, as it is the climate in which we currently live.

Ultimately, the expressivist objection's claim – that the use of PT and/or DSA sends discriminatory messages to PWD – is incorrect, as these messages expressing a preference for non-disability are not unfair to send, in either a 'justice' or a 'reasonableness' sense. Additionally, if the messages are not intended to be sent, they are fair to hold as sentiments, whether or not others interpret these sentiments as an expressed message. Now, let us examine various perspectives on disability held by PWD. These perspectives can help us identify whether the perspective that disability can be disadvantageous is fair for prospective parents to hold. Examination of these perspectives will demonstrate that it is fair in a reasonableness sense to believe that disability can be disadvantageous (and therefore, it is fair in a reasonableness sense to prefer non-disability over disability).

3.5 Perspectives of PWD

A brief overview of the nature of preferences must be provided before delving further into this section. In defining the term 'preference,' the element of *choice* must be emphasized. In this case, someone expressing a preference for raising a nondisabled child is simply saying, 'If I could *choose* between raising a nondisabled child or a child with a disability, I would *choose* to raise a nondisabled child.' This is not equivalent to saying, 'If my child happened to acquire a disability, I would feel negatively and/or believe that their life had little or no meaning.' Essentially, one's theoretical preference for raising a nondisabled child does not necessarily indicate what their attitude would be towards raising a real-life child with a disability. In other

words, there is a significant difference between expressing that one would choose ‘x’ over ‘y’ if they could, and expressing how one would feel or respond if ‘y’ happened to occur.

Let us now examine the perspectives of those with congenital versus acquired disabilities. Understanding the differences between the perspectives of people with congenital versus acquired disabilities supports the argument that the use of PT and/or DSA is not discriminatory; not everyone with a disability thinks of their disability as advantageous. The PWD who think of their disability as disadvantageous would necessarily agree that disability *can* be disadvantageous. This fact supports the argument that it is reasonable for people to prefer non-disability over disability on the basis that disability can be disadvantageous.

Bogart (2014) examined differences in adaptation to congenital versus acquired disability, which is a consideration lacking in most theories of adaptation to disability. Previous studies have supported the general presumption that people with congenital disabilities are better adapted than those with acquired disabilities (Bogart, 2014). Bogart explored this idea, and ultimately found that “whether a disability is congenital or acquired plays an important role in the development of the disability self-concept... which in turn, affects satisfaction with life” (2014, p. 2). Self-concept is an integral part of one’s identity, and encompasses “self-esteem, group identity, and self-efficacy” (Bogart, 2014, p. 6).

There is substantial research indicating that earlier age of onset of an acquired disability is typically correlated with higher satisfaction with life (Bogart, 2014). This makes sense, considering that identity is integral to a strong self-concept; if one’s disability is congenital, one is more likely to consider it a key part of one’s identity, and not know what one’s life or identity would look like without the disability (Bogart, 2014). Accordingly, “people with acquired disabilities frequently report feeling a profound sense of loss of identity” (Bogart, 2014, p. 10).

Bogart's conclusion ultimately supported their hypothesis, that people with congenital disabilities typically have a better self-concept and satisfaction with life than people whose disabilities were acquired (2014). This could inspire one to think that DSA is therefore problematic, as the child's disability would evidently be congenital, and therefore the child would be more likely to better adjust to their disability. However, DSA also centres around the perspective of the prospective parents, who consider not just how the child might adjust to life with a disability, but also how they themselves might adjust to being caregivers in this scenario. Perhaps, if they decide to have the child, *knowing* that the child will have a disability, they might feel as though they are (in a sense) acquiring a disability.

If prospective parents undergo PT, and obtain information that accurately predicts having a child with a disability, they may elect to avoid this scenario before it arises. This is not equivalent to believing that "the lives of [PWD] are not worth living" or that PWD are imperfect and therefore "have no right to exist" (Buchanan, 1996, p. 28). There are many scenarios that many people would choose to avoid if possible, but they would not think that their life had no value should one of these scenarios arise. This fact is what distinguishes prenatal from postnatal decision making, and the perspectives of people with congenital disabilities from the perspectives of people with acquired disabilities.

What this discussion demonstrates is that perspectives on disability are nuanced, and vary depending on whether one's circumstances are congenital or acquired. Some PWD view disability as an advantageous, key part of their identity, whereas others view disability as a disadvantageous loss. These divergent views persist even further; that is, these views do not differ only between people with congenital versus acquired disabilities. These views also differ between people who have the same disability.

A paper by Horky et al. (2017) explored the perspectives of multiple people with cystic fibrosis [CF], and concluded that younger and/or healthier adolescents with CF are unlikely to fixate on their illness when describing their self-image/-identity. This finding suggests that these adolescents are in acceptance of their illness, and that their identity is not dominated by CF (Horky et al., 2017). However, for those older and/or sicker adolescents, CF represents a significant part of their identities; their illness limited them more and was therefore more prominent in their lives (Horky et al., 2017). The finding most relevant to this thesis is that CF was reported to affect identities in both positive and negative ways, and “participants did not have just one feeling about CF... [and] felt differently at different times” (Horky et al., 2017, p. 101). This key finding substantiates the first claim of this thesis: that it is fair, in a reasonableness sense (as opposed to fair in a justice sense), to believe that disability can be disadvantageous.

This claim is also substantiated by Boardman & Hale (2018), who interviewed a multitude of adults with different genetic conditions. The authors asked the participants about their views on selective reproduction; that is, using PT for detection purposes, with the intention of obtaining a DSA if a condition is detected (2018). There was a wide range of responses: for people with CF, three participants approved selective reproduction, five disapproved, and two were conflicted; for people with spinal muscular atrophy and fragile X syndrome, five approved, five disapproved, and seven were conflicted; and for thalassemia, all eight participants approved (Boardman & Hale, 2018).

Participants who approved of selective reproduction “associated [their condition] with diminished health and (often) poor quality of life,” and felt that PT enabled informed decision making (Boardman & Hale, 2018, p. 947). These participants highlighted their experiences with

“illness, pain, fatigue... suffering,” and stigma as a result of their condition (Boardman & Hale, 2018, p. 952). One participant with thalassemia said that based on her own life experience, she “wouldn’t risk to have a child with any type of disability that will be a burden on their life” (Boardman & Hale, 2018, p. 947). Another participant with thalassemia spoke similarly, describing having a healthy child as “the most responsible thing you can do as a parent” (Boardman & Hale, 2018, p. 947).

The participants’ interviews illustrate the multifaceted nature of their views on disability (Boardman & Hale, 2018). One participant with CF said that DSA devalued the lives of PWD, and DSA should not be seen as acceptable for some conditions and unacceptable for others (Boardman & Hale, 2018). However, he also said he understood wanting to know about a child’s possible genetic condition, and specified DS, which he felt “would be much harder to deal with than CF” (Boardman & Hale, 2018, p. 950). Other participants’ views similarly vacillated between approval and disapproval of selective reproduction, with one saying that “eradicating CF [would be] fantastic, but just not at the expense of abortions” (Boardman & Hale, 2018, p. 950). Those who saw their condition as a part of their identity were more ambivalent or negative towards selective reproduction; one participant said she could not picture her life without spinal muscular atrophy (Boardman & Hale, 2018). She said that it is both who and what she is, that she has a unique outlook as a result, and that she would not feel inclined to take a cure if one became available (Boardman & Hale, 2018).

Evidently, these participants expressed a range of complex attitudes towards selective reproduction and, in turn, disability (Boardman & Hale, 2018). There are of course PWD who view their disability as a key part of who they are, but there are also PWD who view their disability more negatively, and consider their disability to be more of a limitation than a part of

their identity. The expressivist objection claims that pursuing PT and/or DSA is discriminatory because it involves making inaccurate judgments about the quality of the lives of PWD.

However, the fact that some PWD believe their disability to be disadvantageous demonstrates that beliefs such as, 'Having a child with a disability could be disadvantageous for the child and/or for myself as a parent' are not necessarily inaccurate. The expressivist objection seems to assume that one must feel positively about disability in order to have an ethical perspective on disability, but the varied perspectives of PWD outlined in this section tell us that views on disability are not so straightforward, and that it is not 'incorrect' to acknowledge downsides where they may exist; it is reasonable to say that disability can be disadvantageous, and to prefer non-disability over disability on this basis.

Chapter 4: The Prospective Parents

4.1 Introduction

This chapter will address the expressivist objection's second flaw: its failure to consider prospective parents' concerns about their own lives as caregivers of a child with a disability. In addressing this flaw, the focus of this chapter will be prospective parents. The first section of this chapter will analyze prospective parents' wellbeing. This ties into the aforementioned discussion of prospective parents' perspectives on disability, or more specifically, on raising a child with a disability. This section will lay out a multitude of valid considerations that prospective parents may have when undergoing PT and/or DSA (e.g. financial concerns, time constraints, ability to divide attention between this child and their other children, single parenthood, stress, worries about stigma/bullying experienced by the child), by reference to Nelson's (2000) work.

The following section will reference work from multiple authors in order to understand parents' experiences caregiving for children with disabilities, in turn highlighting the issues of caregiver burden and burnout. While there are no absolutes, and many families have different experiences caring for children with disabilities, the purpose of this section is to illustrate possible difficulties. Review of relevant literature will demonstrate that prospective parents may not be making judgments about the quality of the prospective child's life, rather their main focus may be how their status as caregiver of a child with a disability would affect their own life. This discussion will highlight the expressivist objection's second flaw: its apparent assumption that prospective parents assess disability only in terms of the future child's life. The other concerns parents may have in mind are infinite, complex, and highly personal; to describe the choice of prospective parents to opt for PT and/or DSA as merely discriminatory is an oversimplification.

There are numerous practical reasons why someone might make the decision to acquire PT and/or DSA.

4.2 The Prospective Parents' Wellbeing

The expressivist objection's flawed assumption (that prospective parents assess disability only in terms of how it will affect the child's life) can be deduced from the messages perceived by PWD, according to proponents of the expressivist objection. Let us examine the messages, "We do not want any more like you" and PWD are "'too flawed' to exist; [they] are unworthy of being born" (Wendell, 1996, p. 153; Saxton, 2017, p. 85). The subjects of these messages are PWD, based on prospective parents' actions towards the fetus (or would-be PWD) in question. These messages concern only the lives of PWD, not the lives of the prospective parents. In other words, the messages assume that judgments made by the prospective parents are concerned only with the lives of PWD; the messages do not take into consideration the possibility that prospective parents' judgments may stem from concerns about their own lives as caregivers.

There are many ways in which caring for a child with a disability may affect prospective parents and their family as a whole. Perhaps they are a single parent, or have an unstable financial situation, or are unsure of how evenly they could divide their attention between this child and their other children. Perhaps they cannot afford to take time off, or they do not wish to be a full-time caregiver for any longer than they would be for a nondisabled child, or they worry about who would look after their child when they die (in the event that the child is unable to live independently). Maybe they cannot afford prescription drugs, surgeries, physiotherapy, or whatever else might be associated with the disability in question. Maybe they simply have a low threshold for stress, and are too overwhelmed by the thought of raising a child with a disability.

Maybe they just do not want to subject their child to any pain and/or stigma that might be associated with said disability.

Nelson's work corroborates these reasons why people pursue PT and/or DSA (2000). Perhaps they are unsure of their ability to contend with the additional challenges that can be brought about by disability, or perhaps they simply do not want to contend with those challenges in the first place, and had envisioned the future of their family differently (Nelson, 2000). Evidently, there are many reasons why prospective parents may acquire PT and/or DSA; the expressivist objection is wrong to ignore these reasons, and instead describe these technologies (and the prospective parents' choice to use them) as necessarily discriminatory.

Caregiver burden is defined as strain "from caring for a family member and/or loved one over time" (Liu et al., 2020, p. 438). Caregiver burnout is a consequence of this stress, resulting in some combination of "emotional exhaustion... depersonalization/emotional distancing... and lack of personal accomplishment" (Gérain & Zech, 2018, p. 2). While caregiver burnout is applicable to anyone in a caregiving role, parents who care for a child with a disability are at greater risk of developing burnout (Basaran et al., 2013). Caring for a child with a disability often interferes with the parents' quality of life and mental health; this interference places parents at a higher risk of burnout (Basaran et al., 2013). Let us now review research that provides a closer look at parents' real-life experiences in caring for a child with a disability.

While Asperger syndrome and high-functioning autism are not detectable via PT, literature regarding the wellbeing of parents whose children have these disorders can help us understand the ways in which caring for a child with disabilities can adversely affect the caregiver. Allik, Larsson, and Smedje (2006) examined the health-related quality of life in parents of children with Asperger syndrome or high-functioning autism. Asperger syndrome and

high-functioning autism are pervasive developmental disorders, and “caregiving of a child with a [pervasive developmental disorder] may be associated with high levels of distress and burden, which potentially undermine the mental and physical health of the parents of these children” (Allik et al., 2006, p. 2).

Parenting children with pervasive developmental disorders has been linked to increased stress, fatigue, and feelings of worthlessness and blame, as well as decreased mental health and physical functioning (Allik et al., 2006). The authors found, in keeping with the findings of a previous study that examined parents of children with DS, that maternal physical health was worse than paternal physical health (Allik et al., 2006). Their finding that maternal mental health was worse than paternal mental health was also in keeping with previous studies (Allik et al., 2006). This discrepancy between maternal versus paternal physical and maternal health is important. Few people would need confirmation from research to know that childrearing has long been considered a woman’s task, with the bulk of the work involved falling on mothers. Some may consider access to PT and/or DSA to be an issue of women’s bodily autonomy primarily at the time of pregnancy, but we must recognize these technologies’ importance to women’s bodily autonomy in light of their future as (often primary) caregivers.

Another study corroborates the results published by Allik et al. (2006); Fombonne et al. (2001) found that parents of children whose pervasive developmental disorders resulted in behavioral problems “reported high levels of distress and burden” (p. 826). Another study, by Smith and Grzywacz (2014), detailed the additional stressors involved in parenting children with disabilities. The authors put forth multiple causes of increased stress levels, such as “elevated medical expenses, time demands, physical care, and worry about the child’s future”, and

stipulated that these continued stressors threaten the health and wellbeing of the parents (Smith & Grzywacz, 2014, p. 1).

Bourke-Taylor, Howie, & Law (2010) also interviewed mothers caring for children with disabilities, in an effort to understand their perspectives. The authors focused on mothers specifically because mothers are almost exclusively the primary caregivers of children with disabilities (2010). Their research understood these mothers' perspectives by examining the mothers' health statuses as well as the challenges common amongst them (Bourke-Taylor et al., 2010). They asked four mothers various questions about caregiving for their children with disabilities, and four professionals with relevant experience (e.g. paediatricians, occupational therapists) [2010]. These children had cerebral palsy with spastic quadriplegia, and autism; intellectual disability was present in both conditions (Bourke-Taylor et al., 2010).

All participants relayed the multiple daily stressors, mental health challenges, and emotional aspects of caring for a child with a disability (Bourke-Taylor et al., 2010). They described taking care of their children as particularly “‘relentless’ and ‘intense’” (Bourke-Taylor et al., 2010, p. 132). The mothers reported anxiety around the structure and organization they needed to maintain; being unable to find time for themselves, either to work or to socialize; and being unable to separate from the child, to the extent that caregiving effectively consumed their lives (Bourke-Taylor et al., 2010). The mothers also reported issues with absentee or unhelpful partners, as well as concerns about the children's siblings (Bourke-Taylor et al., 2010). These concerns included worry about how the siblings coped, the level of responsibility the siblings had (or assumed) for the child with a disability, feelings of resentment the siblings had towards the child with a disability, and whether the mothers' primary focus being on the child with a disability contributed to the siblings' unhappiness (Bourke-Taylor et al., 2010).

In addition, the mothers reported financial issues stemming from the disability (i.e. cost of equipment, therapy, etc.) and difficulty accessing relevant services (Bourke-Taylor et al., 2010). Services and supplies were often unavailable, inconsistent, or under-/un-funded (Bourke-Taylor et al., 2010). Mothers also detailed the amount of time and resources spent organizing and obtaining these services; they reported exerting constant effort to be the child's advocate (Bourke-Taylor et al., 2020). Finally, the mothers relayed challenges with physical accessibility (e.g. places not being wheelchair accessible), and upsetting social reactions to their children (e.g. others blaming them for their children's disability, others offering advice that was neither asked for nor helpful, and general isolation in the form of being excluded from social events) [Bourke-Taylor et al., 2020].

Cerebral palsy and autism may have intellectual disability in common with conditions such as DS, but they are not identical to DS, and cannot be detected via PT. Let us now review literature about caregivers of children with DS, a condition that can be tested for in utero that, incidentally, "is the most common genetic cause of significant intellectual disability" (Churchill et al., 2012, p. 477). Van Riper and Cohen (2001) observe that some caregivers of children with DS have reported "the experience as positive and growth-producing," whereas others have found the experience negative and trying, making reference to financial and mental struggles (p. 124). Davidson (2008) discusses medical care for children with DS, and emphasizes that caregivers for children with DS must go beyond typical parenting, and be a patient advocate as well.

This role of patient advocate is illustrated further by Bull (2011), who lists a series of care guidelines for children with DS. These guidelines describe various symptoms and susceptibilities, as well as discussions the caregivers should have with both the child and the child's primary care team (Bull, 2011). Some examples include: parents should monitor the child

for symptoms of obstructive sleep apnea, parents should understand that some sports will increase the child's risk of spinal cord injury, parents should understand that the child faces increased risk of sexual exploitation, and parents should discuss issues pertaining to "guardianship and long-term financial planning" with the care team (Bull, 2011, p. 402).

Dabrowska and Pisula (2010) found that caregivers for children with DS experienced greater stress than caregivers for nondisabled children with respect to: "total stress... dependency and management... cognitive impairment... limits on family opportunities... lifespan care... terminal illness stress... physical limitations... [and] personal burden" (p. 272). This finding, alongside the finding that parental stress increases alongside the number of children, suggests that raising a child with DS is increasingly stressful if the child has siblings (Dabrowska & Pisula, 2010). Aktaş, Kot, and Çifci-Tekinarslan support this idea; the authors interviewed siblings of children with DS to better understand their experience (2021). The authors' research has three main themes: problems at home, problems at school, and social problems (2021).

Problems at home included "use of objects... violence... neglect... inability to meet their needs... health problems... jealousy... [and] communication problems" (Aktaş et al., 2021, p. 7). 'Use of objects' concerned siblings with DS controlling nondisabled siblings' devices, whereas 'violence' concerned nondisabled siblings being hit, kicked, etc. by their sibling with DS (Aktaş et al., 2021). 'Neglect' referred to nondisabled siblings feeling neglected, because their parents seemed more interested in their sibling with DS (Aktaş et al., 2021). 'Inability to meet their needs' referred to nondisabled siblings having an unusually high level of responsibility to help their sibling with DS (Aktaş et al., 2021). 'Health problems' was listed by almost every participant, and indicated the nondisabled siblings being negatively affected by the ill health of their sibling with DS (Aktaş et al., 2021). Their families had to: be more careful; monitor

exercise, medications, and weight; and take frequent trips to the doctor or hospital, all of which was upsetting to the nondisabled siblings (Aktaş et al., 2021). Aktaş et al. (2021) did not elaborate further on ‘jealousy’ or ‘communication problems.’

Problems at school included “inability to study... [and] ridicule” (Aktaş et al, 2021, p. 8). ‘Inability to study’ mirrored ‘use of objects’, in that the sibling with DS took the nondisabled sibling’s school supplies, such as notebooks and pencils (Aktaş et al., 2021). This interfered with the nondisabled siblings’ schooling (Aktaş et al., 2021). ‘Ridicule’ was expressed by the two nondisabled siblings that were attending the same school as their siblings with DS; the nondisabled siblings found it very upsetting to witness their sibling with DS being mocked and bullied (Aktaş et al., 2021). Social problems included “game[s]... [and] ridicule” (Aktaş et al., 2021, p. 9). ‘Game[s]’ referred to siblings with DS having issues understanding and obeying game rules, and often being excluded, which is upsetting for the nondisabled siblings. ‘Ridicule’ was this time expressed by all participants, citing the same mocking and bullying expressed when describing problems at school (Aktaş et al., 2021).

Aktaş et al. (2021) conclude with various recommendations for further research, but also suggests that caregivers of both children with DS and nondisabled children obtain more information about the importance of balance in the family; it is important for the nondisabled siblings to receive adequate attention from their parents, and for the parents to avoid assigning the nondisabled siblings any undue responsibilities. Some may argue that problems such as ‘ridicule’ listed by Aktaş et al. (2021) are brought about by negative, biased societal attitudes, and are not inherent to DS. It is true that bullying, mockery, etc. are caused by other people and are not caused by DS itself, but this kind of research evidences that bullying and mockery are an unfortunate reality for many people with DS. While they are not biological symptoms, bullying

and mockery are likely to affect not just children with DS, but also affect their siblings as well as their caregivers.

In addition, there are behaviour problems that seem to occur more frequently in children with DS than in nondisabled children. Jahromi, Gulsrud, and Kasari (2008) conducted a study of children with DS, children with other intellectual disabilities, and nondisabled children, in which they gave each child two unsolvable puzzles, and one solvable puzzle. Their results revealed that children with DS displayed facial and bodily frustration for considerably longer (and to a greater extent) than both children with other intellectual disabilities and nondisabled children (Jahromi et al., 2008). Children with DS also displayed vocal frustration for considerably longer (and to a greater extent) than children with other intellectual disabilities (Jahromi et al., 2008). Due to the established link between poor ability to cope with negativity and poor behavioral control, the authors believed that their findings were “consistent with much of the work suggesting that children with [DS] display greater behavior problems as they get older, including more noncompliance, stubbornness, disobedience, and in inability to delay gratification” (2008, p. 39).

The authors found that children with DS did not exhibit effective coping skills, as nondisabled children engaged in more “cognitive/verbal self-soothing, experimenter-orientation with assistance-seeking, and assistance-seeking with no experimenter orientation” than did children with DS (2008, p. 40). Of these coping strategies, experimenter-orientation with assistance seeking was the only one found to be truly effective, in that it consistently resulted in a decrease in negativity – yet children with DS most often oriented to the experimenter *without* assistance seeking (Jahromi et al, 2008). This study also suggests that, despite their behavior in infancy, children with DS express more negativity as they grow, perhaps due to their “cognitive deceleration in late childhood” (Jahromi et al., 2008, p. 40). This cognitive deceleration may

cause more experiences with failure and negativity, which may be worsened by poor coping strategies (Jahromi et al., 2008). The authors conclude by suggesting responsive caregiving methods to aid emotional development, such as exposing the child to mild frustration and everyday failure to develop coping strategies (2008). While all children express some degree of behavioral problems at some stage, and we cannot assume that every child with DS has the behavioral problems illustrated in this study, we *can* acknowledge that caring for a child with DS seems more likely to involve a unique set of challenges for the caregiver.

This discussion corroborates this thesis' claim that it is reasonable to prefer non-disability over disability because disability can be disadvantageous, but with a specific focus on how the parents are affected, rather than how the parents believe the child may be affected. The expressivist objection fails to take prospective parents' physical and mental wellbeing into account, including the prospective mothers' physical and mental wellbeing, which is especially relevant given the direct link between women's bodily autonomy and their access to PT and/or DSA. While the expressivist objection takes care to emphasize the quality of the prospective child's life (and of the lives of PWD more generally), its failure to take the prospective parents' quality of life into account constitutes a significant oversight, and contributes to a simplistic picture of having a child with a disability. It is important to note that this discussion does not make claims about whether raising children with disabilities is worthwhile, nor does it suggest that their parents do not love them (love for someone is indeed quite separate from struggles in caring for them). Rather, this discussion provides research regarding the wellbeing of parents of children with disabilities, which the expressivist objection fails to consider.

Again, it is not necessarily the case that someone opting for PT and/or DSA is doing so out of the belief that their prospective child's life would be rendered worthless, or at least less

valuable, by their disability. One's preferences in a context where one has a choice do not necessarily reflect their point of view in the same context without a choice. Additionally, the fact that parents may adjust well to having a child with a disability does not suggest that they *should* choose to have this child; again, one's theoretical preference for not having a child with a disability may outweigh the possibility of a positive response to having a child with a disability, as long as the prospective parent actually has a choice between these two possibilities. Finally, this chapter has reviewed a wealth of articles detailing parents' challenging experiences raising children with disabilities. Evidently, there is plenty of research to support prospective parents' preference against having a child with a disability, and this research demonstrates that prospective parents may well be considering their own wellbeing. This underlines the second flaw of the expressivist objection: its assumption that prospective parents are concerned only with the future life of their child with a disability.

Chapter 5: Loss of Support & Consequences

5.1 Introduction

This chapter will address the third and fourth flaws of the expressivist objection. The third flaw is that the loss of support claim is unfounded, and the fourth flaw is that the consequences of acting in accordance with the expressivist objection are unreasonable and absurd. In addressing the third flaw, this chapter will use work by Buchanan (1996), Shakespeare (1995), McConachy (2010), Gavaghan (2006), and Malek (2008). Buchanan (1996) referred to this flaw as the ‘loss of support argument’; a term that will continue to be used in this chapter. The loss of support argument says that as the population of PWD decreases, so too will their various kinds of support (Buchanan, 1996). This argument is primarily concerned with dwindling resources, but this chapter will make clear that there is little evidence to support this idea.

The following section will address the fourth and final flaw by detailing the kinds of consequences that may result from acting in accordance with the expressivist objection. This section will refer further to Buchanan (1996) and Gavaghan (2006), and will also refer to Edwards (2004). The consequences listed are namely a reduction in (or cessation of) treatments or cures for conditions (in the name of zero bias against disabilities), as well as women being unable to acquire an abortion and being left to have children that they do not want to have.

5.2 The Loss of Support Argument

Let us now address the loss of support argument, which is the third flaw of the expressivist objection. A quotation from a paper by Shakespeare (1995) can help us better understand this argument:

“... reducing the number of impaired fetuses born will possibly lessen the likelihood of effective therapy for affected people: as a condition becomes rarer, the impetus to

discover a cure or treatment diminishes... [and] the proportion of congenital impairment may be reduced, but not eliminated... [therefore PWD] will be further isolated, face increasing prejudice, and the pressure to make society accessible to all will be reduced.” (p. 31)

Firstly, Shakespeare’s (1995) concern about a reduction in treatments or cures for disabilities does not appear to make sense; he seems to simultaneously fear a decrease in the population of PWD, and a decrease in the treatments and/or cures for their disabilities. Presumably, if one wanted to maintain or increase the population of PWD, they would not vie for the treatments and/or cures that could eradicate PWD.

More importantly, as McConachy (2010) observes, Shakespeare does not provide any evidence to support his claim. The lack of evidence is one of Buchanan’s main issues with the loss of support argument: it is a broad generalization with virtually no data to back it up (1996). Gavaghan (2006) notes that despite the lack of evidence, the kind of loss of support described by Shakespeare (1995) is still a possibility. However, Gavaghan (2006) also notes a second possibility: that fewer PWD may bring about an increase in access to resources (e.g. dialysis or organ transplantations). This possibility aligns with the data Buchanan found, concerning an instance in Greece in which, as their population decreased, *more* resources were put towards individuals with thalassemia anemia (Buchanan, 1996).

We must also recognize that there are many causes of disability, and that disability is not always genetic (Malek, 2008). People can acquire disabilities during and after birth; “it seems unlikely, therefore, that the numbers of [PWD] would be radically reduced as a result of [utilizing PT and/or DSA]” (Malek, 2008, p. 132).

Another counterargument Buchanan puts forth is that a decrease in support for PWD is made less likely by the prominence and triumphs of disability advocates today (1996). This point is even more relevant today, 25 years after the publication of Buchanan’s paper; disability rights

are a much more prominent issue now. Even the ways in which our language surrounding disability has changed help illustrate this: the increasing use of person-first language ('people *with* disabilities,' as opposed to 'disabled people'), previously commonly used terms becoming widely unacceptable (the 'r word,' for instance), and many people being at least aware of disability-specific terms such as 'invisible disability.' Overall, there has been a general increase in sensitivity about disabilities and the people who have them.

Ultimately, there is not enough evidence to back up the loss of support argument; we can conclude that the loss of support argument, which constitutes the third flaw of the expressivist objection, is unfounded. Additionally, the loss of support argument presumes that loss of support renders further use of PT and/or DSA unethical, and Buchanan observes that this "only considers the interests of those who will have disabilities" once their population decreases, without considering the interests of prospective parents "in *not having* [a child with] disabilities" (Buchanan, 1996, p. 22). Buchanan's final counterargument will elaborate on this point (the lack of consideration for prospective parents' interests) and show us where this thesis' two final criticisms converge.

5.3 'What If?': The Consequences of Abiding by the Expressivist Objection

As the previous section established, the loss of support argument is unfounded. This section will explain why the consequences of acting in accordance with the expressivist objection are unreasonable and absurd. The fourth flaw of the expressivist objection lies in these consequences.

Buchanan's final counterargument states that if the loss of support argument *was* valid, it would prohibit us from reducing any disability, by any means, such as preventing blindness in a

baby due to gonococcus bacteria (Buchanan, 1996). Likewise, avoiding disability via PT and/or DSA does not imply that only nondisabled people should exist anymore than does surgically correcting blindness (Buchanan, 1996). This is where we start to see unreasonable, absurd consequences of acting in accordance with the expressivist objection; where and how can we draw the line between ethically treating a condition, and imposing ableist treatment? Is illness always part of one's identity, and is treating it always a commentary on that individual's worth?

A paper by Edwards (2004) addresses this, also arguing that abiding by the expressivist objection would have absurd consequences (or "lead to a *reductio ad absurdum*" (p. 419)). He discusses the aforementioned argument in which disabilities are likened to illnesses, and preventing disability is no less plausible than preventing illnesses, such as the flu (2004). Edwards (2004) acknowledges a counterargument, which claims that disabilities can be part of one's identity, and illnesses such as the flu cannot. Edwards (2004) accepts this counterargument, but nevertheless concludes that "the expressivist objection is still not morally compelling" for multiple reasons (p. 418).

While this thesis agrees that illnesses such as the flu cannot comprise part of one's identity, conditions such as blindness certainly can, yet it is generally uncontroversial to treat or prevent blindness (I myself wore an eyepatch and had surgery as a child, to preserve the vision in one eye, and am currently monitoring the other eye's optic nerve, in an effort to prevent further vision loss). Conditions such as blindness pose a problem for the expressivist objection, insofar as their current treatment standards are widely accepted, but they can simultaneously constitute part of one's identity; the fact that one could apply an 'identity claim' to blindness does not suggest it would be wrong to prevent blindness.

Another consequence of acting in accordance with the expressivist objection is arguably more pressing, as it would constitute women having their reproductive rights threatened in the name of people whose fetal counterparts do not get born in the future. As noted in Chapter Three, the absurdity of this consequence helps constitute the grounds for dismissing the aforementioned negative claim. The absurdity of this consequence is highlighted by Gavaghan (2006), who wrote, “We might consider that the fear of a loss of support to existing [PWD] could, and should, be met by guarantees of support, not necessarily by requiring reluctant parents to add to their numbers” (p. 22). It does seem very strange that anyone would want a woman to have a child that she outright does not want to have. It is also difficult to imagine who would win in this scenario, between the woman who has a child she did not want, and the unwanted child the woman now has.

It is widely accepted that forced sterilization is a reprehensible, blatant violation of reproductive rights. It is not the case that forced sterilization is reprehensible purely because of its usual goal (to prevent further PWD from being born); it is also innately reprehensible because it is a violation of reproductive rights. Acceptance of the expressivist objection would result in the absurd consequence of normalized coerced pregnancy. In turn, the expressivist objection appears to suggest that either coerced pregnancy does not threaten reproductive rights (which is clearly incorrect, evident from the ‘coerced’ element), or that coerced pregnancy is acceptable in this instance, given its goal (to avoid expressing negative and/or discriminatory messages to PWD).

It is an absurd notion that one individual would not have control over their own body in any case, but it seems especially egregious that they would be expected to sacrifice their reproductive rights for something that a portion of the population contends is a good or worthy

goal, regardless of whether said individual shares their view. Discussions about individual autonomy versus social responsibility may ask that we consider ‘the greater good’, however: a) the consequence we are discussing is not a matter of willingly limiting our own autonomy, and b) the flaws of the expressivist objection, which have been laid out in this thesis, indicate that its overall claim requires some serious adjustments before it could be considered a worthy enough cause.

Again, this chapter addresses the real-life consequences of abiding by the expressivist objection (namely, the endangerment of women’s reproductive rights to obtain PT and/or DSA). Those writing about the expressivist objection typically avoid making clear, normative statements against women being able to use PT and/or DSA. Theoretically speaking, some may argue that the expressivist objection does not state that women *should not* obtain PT or DSA, or that it is absolutely *wrong* to obtain PT or DSA; some may say that the expressivist objection merely states that the use of these technologies expresses negative and/or discriminatory messages, and that this does not carry any normative statements.

To dismiss this characterization of the expressivist objection, we need simply revisit the terms that appear frequently throughout the relevant literature. These terms will elucidate the expressivist objection’s sentiments regarding the use of PT and/or DSA. Gonter uses the term “morally problematic” (2004, p. 1). Edwards uses the terms morally unjust and “morally wrong” (2004, p. 418). Nelson uses the terms “morally disparaging,” “morally troubling,” “morally problematic,” and “morally objectionable” (2000, p. 213; p. 215; p. 225-226; p. 226).

As Buchanan clearly writes when discussing the expressivist objection, its “implication... is that the error is not merely a mistake in moral theory. To express these negative judgments about disabled people is itself an injury to them, a violation of their most fundamental right, the

right to be regarded as persons of equal worth” (1996, p. 28). Another important point is in the name of the argument itself; presumably, the expressivist *objection* is so-called because it *objects* to the use of PT and/or DSA. In their seminal 1999 paper, Parens and Asch use the term expressivist ‘argument’ rather than expressivist objection. Still, the authors put forth the expressivist argument as one of the reasons why the disability critique deems DSA “morally problematic” (1999, p. 2).

Evidently, proponents of the expressivist objection cannot describe the use of PT and/or DSA as ‘morally problematic/wrong/unjust’ while simultaneously declaring that the expressivist objection does not put forth any normative statements (which, if followed, would threaten women’s reproductive rights). To accept this contradiction would lead us into very murky waters, waters in which women ‘should’ be able to acquire a DSA, but in which they would also be immoral to do so. This message is logically inconsistent and renders ‘morally problematic/wrong/unjust’ in this context to be irrelevant terms.

It is unclear why any bioethical argument would deem an act negative, discriminatory, and damaging to an entire group of marginalized people, without concluding that people should not engage in said act. After all, what does it mean to claim that something is morally wrong, if not that we should refrain from doing it? The purpose of this kind of argument is difficult to identify. Furthermore, we cannot adequately examine arguments when they fail to consider their real-life implications, particularly when these implications include the endangerment of women’s reproductive rights. These arguments suffer when they evade difficult, controversial subjects in an effort to appear straightforward. Ultimately, the expressivist objection carries within it a normative statement against PT and/or DSA, and it is valid to examine the consequences of abiding by the expressivist objection as a result.

In summary, this section has established the fourth flaw of the expressivist objection: that the consequence of threatening women's reproductive autonomy, simply to protect others from possibly perceiving negative and/or discriminatory messages, is unreasonable and absurd. That is, PWD may well perceive these messages from others' use of PT and/or DSA, but the extremity of the solution to this problem constitutes far more than perceiving negative and/or discriminatory messages; the solution to this problem constitutes coercing women to forego their reproductive rights and bear children they do not want to bear. This supposed 'solution' would clearly cause far more damage to women than individual use of PT and/or DSA causes PWD. Future papers about the expressivist objection need to acknowledge that this consequence of abiding by the expressivist objection would contribute to the erosion of women's bodily autonomy, and either find some way to argue for that consequence's acceptability, or concede its sheer absurdity.

Chapter 6: Conclusion

This chapter will conclude this thesis first by reviewing its main argument (that the expressivist objection is an insufficient argument against the use of PT and/or DSA) alongside its supporting claims, each of which consists of a different criticism of the expressivist objection. Subsequently, this chapter will emphasize once again the importance of remaining cognizant of the overt discrimination and violence against PWD throughout history, and will call for a balance between this goal and the need to uphold women's reproductive rights. Ultimately, Chapter Six will offer what appears to be a suitable compromise going forward: excellent, comprehensive genetic counselling.

This thesis has demonstrated that the expressivist objection is an insufficient argument against the ethical permissibility of PT and/or DSA. Insofar as it is just and reasonable to believe that disability can be disadvantageous, it is fair to hold this belief. Because the messages supposedly expressed by the use of PT and/or DSA lack the quality of unfairness, the expressivist objection's first flaw lies in its claim that these messages are discriminatory. The expressivist objection's second flaw has also been established: it overlooks the fact that prospective parents may opt for PT and/or DSA because of how having a child with a disability may adversely affect them as caregivers. The expressivist objection seems to assume that this decision is made only on the basis of the life of the future child with a disability. This thesis has laid out a plethora of reasons why prospective parents might make the decision to use PT and/or obtain DSA, making clear how personal and complex this process often is, and negating the false notion that this is a black-and-white ethical issue.

In addition, it has been made clear that there is not sufficient evidence to substantiate the loss of support argument; this argument constitutes the third flaw of the expressivist objection.

On this basis, we can dismiss the loss of support argument. Finally, this thesis has illustrated how, if we were to act in accordance with the expressivist objection, the consequences of this would be unreasonable and absurd. The absurdity of the consequences of abiding by the expressivist objection constitute its fourth and final flaw. The endangerment of women's rights to bodily autonomy is particularly egregious, and cannot be an afterthought when considering the expressivist objection. As McConachy (2010) wrote, "One must bear in mind that there are strong reasons, based on reproductive liberty, to allow the use of [PT and/or DSA]. Thus, one should not be overly cautious when balancing the issues at stake" (p. 24).

While evaluating the expressivist objection involves in-depth deliberation on a number of theoretical matters, it is important to remain cognizant of the very real subject at hand: disability. The many instances of overt discrimination and violence against PWD throughout history, as well as present-day statistics about the many hardships PWD face, make clear the need for respect and understanding when doubts or fears about reproductive technology are voiced. It is critical that we remain mindful of the ways in which this technology has been weaponized in the past, and ensure that this does not happen again.

The historical events laid out in Chapter Two indicate that reproductive technology is generally weaponized by the state, in the form of mandates that remove any element of choice for the state's citizens. When examining the expressivist objection, some assess PT and/or DSA as general social practices. However, this thesis examined the expressivist objection as it relates to individual choice; this thesis focused on whether it is ethical for individuals to use PT and/or DSA. While this focus on individuals does not address state mandates that result in eugenicist violence, it is imperative that we recognize the very real history of this violence, and acknowledge others' fears of it reoccurring. We must also remember that while PWD have long

been victims of state weaponization of reproductive technology, state control of reproductive technology has (and still does) victimize women and their right to reproductive autonomy as well. The need to be cognizant of the history of PWD must be carefully balanced with the need to uphold women's reproductive rights. The struggle to obtain these rights represents yet another difficult, oppressed history that must be remembered.

A viable compromise lies in excellent, comprehensive genetic counselling. This would involve giving prospective parents: the medical information about the fetus's would-be disability; information about the non-medical (e.g. social) ways in which their own lives, and that of their possible future child, may be affected; and a range of experiential information, provided by PWD and their families, so that prospective parents can gain firsthand, real-life knowledge. Reliable social information must be presented alongside medical information for genetic counselling to be delivered in an ethical manner; a manner that is not steered by discriminatory, eugenicist thinking, but is reliant upon and informed by public communication (Turnbull, 2000). If genetic counselling does not uphold this standard, then genetic medicine will continue to have "ownership of [this] discourse" (Turnbull, 2000, p. 854). More comprehensive genetic counselling would not only improve prospective parents' experiences with prenatal decision making; it would also improve the "relationship between genetic counsellors and disability advocates" (Peterson, 2012, p. 16).

All relevant experiential, social, and medical information should be presented in an unbiased manner, and in an environment in which the prospective parents feel free from any pressure, and feel safe to ask questions. Genetic counsellors' interactions with prospective parents may be emotionally fraught; the language used by genetic counsellors must be sensitive, noncoercive, and achieve non-directiveness (Clarke & Wallgren-Pettersson, 2019). Essentially,

PT and/or DSA must be offered, not recommended (Clarke & Wallgren-Pettersson, 2019).

Because there is a wide range of perspectives and personal experiences of both children with disabilities and their parents, it is very important that this variety be presented to prospective parents as part of the genetic counselling necessary for undergoing PT. While prospective parents cannot know with certainty where their perspectives and experiences may fall within this range until after the child is born, their decision will be more informed with each perspective and experience shared with them.

Excellent, comprehensive genetic counselling would be a promising compromise in the expressivist objection debate, as it would neither weaponize PT and/or DSA against PWD, nor threaten the rights of women to reproductive autonomy. At its core, genetic counselling of this nature includes valuing PWD by presenting prospective parents with experiential information gained from parents who have had children with disabilities, as well as presenting them with relevant medical facts. Genetic counselling of this calibre also values the reproductive rights of women by ensuring that prospective mothers have all the information necessary to make a fully informed decision, and by allowing women the opportunity to freely exercise their reproductive rights irrespective of what they decide. Excellent, comprehensive genetic counselling helps ensure that prospective parents do not make false or uninformed assumptions about the future life of their would-be child with a disability, while also respecting that ultimately, women must be able to exercise their incontrovertible reproductive rights, irrespective of the messages this may express.

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