The Ethical responsibility to Increase Access to Non-invasive Prenatal Trisomy 21 Testing for Pregnant Women in Low Socio-Economic Groups in South Africa

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Dedication

I dedicate this research to all the women from low socio-economic backgrounds who do their best daily to care for their Trisomy 21 affected babies despite the difficulties they face. I know it is not easy raising a tiny human, let alone one who requires twice the effort and attention from you. To all the mothers that never got the opportunity to better prepare for this phase in their lives, my heart goes out to you, and I can only wish you get all the mental health support needed to equip you with the necessary tools to deal with the stigma from society and family and to seek and find resources to help raise a high functioning human.

May you quieten the noise from the outside and always remember that

“Different is not less”- Dr Temple Grandin

Abstract

Despite the increasing numbers of Trisomy 21 related pregnancies among women below the age of 35, many women from low socio-economic groups in South Africa still do not have access to Trisomy 21 prenatal testing. Research has revealed that low socio-economic conditions play a role in the development of Trisomy 21. This cohort of women could benefit greatly from the government taking the initiative to increase access to screening to afford them the opportunity to better prepare for the affected baby and reinforce their reproductive autonomy. This would also serve as a public health initiative and lower the harms faced by mother and child, thus decreasing the rate of mother-and-infant mortality and morbidity. In turn, the government can lower their long-term expenditure on managing complications from untreated Trisomy 21 related medical conditions. There is, however, an ethical responsibility to increase access to Trisomy 21 prenatal testing for all women in low socio-economic groups in South Africa regardless of their health risks and indication.

Keywords: Trisomy 21, Prenatal testing, Low socio-economic groups

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To my daughter -Thatohatsi Ngaka- I can only hope that you will one day read through this work and be empowered to fiercely pursue the things you are passionate about with the

conviction that we will always be in your corner.

Abbreviations

NIPT - Non-invasive prenatal testing

MII. – Meiosis 2

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CHAPTER 1: Introduction

1.1. Background

Every year many South African households welcome new additions to their families. While this can be a joyous moment for some families, others are faced with the unexpected challenge of their baby being diagnosed with Trisomy 21. This diagnosis often presents difficulties as unprepared family members must assume the responsibility of caring for a baby with complex needs. With most families coming from low socio-economic backgrounds, this new reality can have negative and lasting effects if not anticipated. (Most of the South African population are in low socio-economic groups). I will, therefore, examine the ethical responsibility of increasing access to prenatal testing for Trisomy 21 for all pregnant women in low socio-economic groups. I will define what a 'low socio-economic status' means as it will contextualize the ethical responsibility of increasing access to prenatal testing by the state for Trisomy 21 in this group of women. The term "low socio-economic status" is difficult to define precisely, and I have not found anything definitive in the literature. However, I use a 2019 Research Brief by SA-TIED which describes the socio-economic picture of South Africans as follows: "We divide South Africans into five socio-economic classes: the chronically poor, the transient poor, the vulnerable middle class, the stable middle class, and the elite. We separate the poor from the non-poor using the official Upper Bound Poverty Line of R1,136 per month, below which households are unable to meet their basic needs. We further separate the chronically poor from the transient poor based on their measured propensity to escape from poverty over time. Using these definitions, nearly half of South Africans (48.8%) were chronically poor during the period of study from 2008–17. Another 12% of the population

represented the transient poor, the majority of which remained poor over the period, with only 39.2% escaping poverty during the study. Furthermore, nearly half of the middle class, or 15% of all households, are in the vulnerable middle class and nearly half of these households fell into poverty at least once during the study" (SA-TIED, 2019, pp. 1–2).

Using this scheme, I define those of low socio-economic status as those in the groups described as the chronically poor and the transient poor. Statistics SA puts the latest figure for the Upper Bound Poverty Line (2023 prices) at R1 558 per month. As a rough guide, all whose household income is less than this amount can be identified as being of low socio-economic status. Others, especially in the vulnerable middle class, might also fall within this category when facing particularly difficult challenges.

Based on two reputable sources, (Bugmy Bar Book Comittee, 2020) and (Maloma, 2016) , for the purposes of this report, I rely on markers like education, employment, consumption, income, and wealth to define "low socio-economic groups" as comprising persons with relatively low educational levels and a low income that prevent them from meeting their needs. These groups of people depend on the state for healthcare services as most cannot afford medical insurance and medical aid (Statistics South Africa, 2023, p. 12). The use of these medical services is further impacted by traveling costs and other logistics. My focus in this research report is on the low socio-economic groups in South Africa because these females and their babies have very poor health outcomes in comparison to other social groups and the disparities continue to rise (Ataguba, Akazili and McIntyre, 2011, p. 1,5-7). These women are less likely to know about karyotype abnormalities or know about prenatal testing and when it should be offered. Some have relayed their experiences on raising a child with a congenital abnormality, that their lack of knowledge contributed to the hurt that they felt when they realised that their baby was not normal. Some mothers reported that they did not know what was wrong with their babies until they started getting sick (Mazibuko, Ramukumba and

Ngwenya, 2022, p. 3,4). They also struggle with access to health care facilities due to lack of funds, transportation and that state-owned ambulances cannot reach certain rural areas because of poor infrastructure (Mathebane, 2016a, p. 172). Females in higher socio-economic groups have resources to better prepare for such pregnancies, the education required to make such decisions and have funds to pay for the test should they want to. The issue of access, therefore, does not affect them and the ethical concerns pertaining to an increase in access for these groups differs entirely from the ethical issues raised by an increase in access for the low socio-economic groups.

Trisomy 21 is one of the leading causes of intellectual disabilities in South Africa (de Villiers-van den Eijnde, 2021: 1), with 11.1 % of the children born over a 12-month period in a Rural KwaZulu Natal hospital having Downs Syndrome (Saib et al., 2021, p. 6), and the Western Cape government reporting an increase in Trisomy 21 births to women below the age of 35 (Western Cape Government, 2022). This raised important ethical concerns. The first concern was that of reproductive autonomy. Unfortunately, according to the current national health guidelines, prenatal testing for Trisomy 21 is only encouraged for pregnant women above the age of 35, despite significant increases of women below age 35 being reported with Trisomy 21 pregnancies internationally (Park et al., 2019, p. 9) and locally (Western Cape Government, 2022). Therefore, mothers below 35 years of age do not benefit from prenatal testing and getting to decide whether they want to continue with the Trisomy 21 pregnancy or to terminate. They are only met with the shock at birth. Some parents raising Trisomy 21 babies emphasised that knowing that the expected baby has Trisomy 21 was important to help prepare for the baby (Scott, Futter & Wonkam, 2013).

The second concern is that of harm to the future baby and the mother. Society in low socio-economic backgrounds still consider Trisomy 21 a taboo and may blame the parent and

attribute the condition to spiritual faults that the parents or the family have committed. This might cause social and psychological harms to the unprepared mothers. The mother might also suffer psychological harm if she finds herself without appropriate support structures. Due to infrastructural shortcomings, emergencies may not be able to be handled timeously if both the mother and the health care provider are not prepared for this type of birth. Their birthing facility may be less equipped (a clinic with a midwife instead of a tertiary hospital with access to pediatricians and cardiologists) and result in overburdening already under resourced facilities in South Africa.

Thirdly, the state could benefit financially from increasing access to tests as the costs of managing complications that result from unmanaged Trisomy 21-associated risks could be lowered. The increase in access to prenatal testing would result in an increase in the index of suspicion as a positive test could prompt the attending paediatrician to investigate for heart anomalies and other associated risks, resulting in many conditions not being missed. For example, untreated congenital heart disease could result in frequent respiratory conditions, cardiac failure and pulmonary hypertension, with resulting higher expenditure that could have been avoided (Lawrenson et al., 2006, p. 918).Exact figures of the medical expenditure in South Africa are not available, but can be quantified using countries like Korea where the medical expenditure of Trisomy 21 patients was tenfold that of non-Trisomy 21 patients, and out-of-pocket money spent was double the amount of the non-Trisomy 21 patients (Park et al., 2019,p. 10).

Lastly, this analysis could add to the discussion on the guidelines and policy making. There are many unreported cases on Trisomy 21 births to mothers below the age of 35. If my argument is successful, this research report could raise awareness in the medical fraternity and encourage research on the rising cases of Trisomy 21 to mothers below the age of 35. In this research report, I base my arguments on a practice utilitarian approach and argue that the state has a

moral responsibility to ensure that all pregnant women from low socio-economic groups in South Africa should be offered non-invasive prenatal testing in state facilities to rule out Trisomy 21 regardless of their health risks and indications. As there are many other moral theories, the following section aims to clarify why a practice utilitarian perspective is used.

1.2. Why a practice utilitarian approach?

I discuss why a rule utilitarian perspective was the most appropriate moral theory for my argument and show why other moral theories would not be helpful in making the best argument.

1.2.1. Utilitarian - a consequentialist moral theory

The utilitarian moral theory is a consequence-based theory that branches into act and rule utilitarian. The former is a consequence-based moral theory that defines an act to be morally acceptable or right if the consequences of that act result with a greater balance of happiness, good, or welfare than any other chosen act (Michael et al., 2013, p. 221). “The view is consequentialist, in that it holds that acts are right or wrong solely in virtue of the goodness or badness of their actual consequences” (Michael et al., 2013, p. 221). On the other hand, rule utilitarians consider an act good not on the basis that its consequences amount to a greater balance of well-being and less pain but rather that the acts are accepted by the rules that bring about greater utility or the best consequences (Michael et al., 2013, p. 238). Having explained what these moral theories encompass, why use rule utilitarian instead of act?

A rule utilitarian addresses issues in a more consistent way and does not change on a case-by-case basis. Instead, it follows rules that bring about greater utility (Michael et al., 2013, p. 238), unlike an act utilitarian approach that might justify prenatal testing for a specific group of women because of the indication or risk (that is on a case-by-case basis). A rule utilitarian will follow a policy that allows all women access to prenatal testing regardless of their indication because it brings about a greater balance of utility or the best consequences. This is a moral theory that will set a solid foundation of trust in the health system and not lead to the unfair

benefit of some women over the other within the same social group (avoiding a situation where although all women are struggling to make ends meet, some get access to prenatal testing and are able to better prepare while the majority who also cannot afford the test are dealt with the reality of having to care for an unanticipated Trisomy 21 affected baby). Considering the rising numbers of Trisomy 21 babies born to women who are not of advanced maternal age, offering the test to women who only have indicated risks or are of advanced maternal age can result in an increase in mortality and morbidity rate for the excluded group of women and their infants and other unpleasant outcomes for them and their families, and further affect the health system. A rule utilitarian will always support a policy that leaves members of a smaller group badly off and members of a bigger group well off if there is no better alternative policy to override it and provide greater utility (Michael et al., 2013, p. 240).

It is also the best framework, because unlike act utilitarians, whose focus is on the immediate consequences an act might offer, this is a moral theory that will consider the long- term effects of reliable guidelines. While creating a policy that fosters a society where women from low socio-economic groups can have equal access to prenatal testing as their wealthier counterparts, the policy can also work towards bridging the gap by improving the health outcomes of women and infants in low socio-economic groups and result in a good public health tool that meets the World Health Organization's healthcare goals.

Rule utilitarians can show that the cost of increasing access to the test can be justified by the long-term benefits. A cost benefit analysis which aligns more with an act utilitarian framework in that it evaluates case-by-case costs and benefits and considers specific contexts and circumstances, can be used to evaluate whether or not the policy will produce the greatest balance of good for society and determine which rules/policies are morally acceptable. Increasing access to the test for this cohort of women can be evaluated using Bentham's hedonic calculus, meaning assessing the amount of pleasure and or pain produced by the act.

After deciding on whether the act produces pain or pleasure, we can then measure variables like duration of the produced pain or pleasure, its likelihood of occurring, how soon it can occur from the time the action is put in place, the likelihood of it leading to more feelings of pleasure or pain, its likelihood of being accompanied by pain or pleasure, and how many people will be affected by the feeling (Mitchell, 1918, p. 165). Without exact calculations we can predict that if every pregnant woman gets the tests and has prenatal counselling, there will be more positive outcomes than negative, that the benefits are highly possible to occur, and that they are less likely to be coupled with pain. The women and their families will be affected by the pleasure. Some benefits will be immediate, for example, reduced anxiety, increased reproductive autonomy, and families will get time to better prepare. The reduced long-term expenditure, reduced complications and increased access to resources, will be experienced with the passing of time.

Benefits vs harms

Benefits	**Harms**
Improved health outcomes for the affected child and the mother	False positives and negatives
Reduced Prenatal stress and anxiety	Termination of pregnancies
Reproductive autonomy	Eugenics and discrimination
Better preparation for families	Cultural and societal pressures
Reduced long term health care expenditure on complications	
Increased access to resources	

Reduced risk of complications	

Benefits vs harms to consider when doing the hedonic calculus

Given these reasons, one may argue that because the moral theory does not work on a case-by-case basis, it may fail to consider individual circumstances that contribute to individual's decision to not follow the rules or abide by the policy resulting in them feeling pressured to take the test even when they do not want to. That concern is addressed by clarifying that prenatal testing, like any other medical procedure, requires a patient's informed consent and if the test is refused because of personal reasons, they will not be forced to take it. The aim of implementing the policy is for their benefit and not to oppress or force it upon them. Their rational abilities and autonomy will be respected as the policy is deeply rooted in supporting reproductive autonomy, and the decision not to take the test, is another way of putting their autonomy to practice.

1.2.2. Why not deontology?

I will provide an overview on what deontology is and what the moral theory stands for and explain why it was not the best fit to help defend my thesis. Deontology is a moral theory that uses rules to distinguish between right and wrong. Emanuel Kant calls them the categorical aughts. These are a set of rules we follow because we can reason. This is a duty-based normative ethical theory, that differs from the one recently discussed as it does not consider the consequences or outcomes of an action but rather that a set of rules based on reason is followed (Rachels and Rachels, 2019, p. 137). The first formulation of the categorical imperative is expressed as "act only according to the rule by which you can at the same time will that it should become a universal law" (Rachels and Rachels, 2019, p. 137). Kant specified that we should judge the right or wrongfulness of our actions based on whether we would be comfortable with anyone choosing the same action under similar circumstances, and if we are

willing to have everyone do that, then the act is justified. But if we feel uncomfortable with everyone else choosing that act under the same circumstances, we should not choose the act, and it is forbidden. We should essentially avoid things that we would not wish other people do to us or to others.

The second formulation stipulates that we should treat others "always as an end and never as a means only" (Rachels and Rachels, 2019, p. 147). This formulation is rooted in respect for persons, meaning that we should avoid manipulation or coercion to get what we want. Our goal should be to take the well-being of others into account, avoid any action that harms them and if possible, choose actions that further their interests (Rachels and Rachels, 2019, p. 147). Emanuel Kant uses the categorical imperative to help determine what our moral ought or duties are, and each person needs to abide by them regardless of their desires and solely follow them because of reason. They are based on principles that every person with reasoning abilities would easily accept (Rachels and Rachels, 2019, p. 137). Humans are believed to have the capacity to follow these categorical imperatives because of their innate ability to reason, dignity and desires. This rational capacity and intrinsic worth makes them superior to other creatures and attributes them respect (Rachels and Rachels, 2019, pp. 145–147).

One might reason that this moral theory could support the thesis well since it is rooted in respect for persons. This means that increasing access to prenatal testing for Trisomy 21 would give this cohort of women an opportunity to practice their reproductive autonomy, show that their opinions matter, and that they have a say in the kind of life they want for themselves and their children. The decision would be furthering their ends. The act itself would be acceptable as we would be willing to universalize it and have all women from low socio-economic backgrounds receive the test. While this is true, the moral theory would be unable to fully support the thesis as it is not easily adaptable and flexible. Once the rules are set, there is no room for considering the outcomes and the circumstances. The moral theory might require that Trisomy 21 prenatal

testing be done for all women in South Africa instead of focusing on the vulnerable group because the moral ought would require that no humans be discriminated. It might overlook the fact that women from other economic backgrounds have access to the test because they could afford it or that they can easily access health care because they can afford medical aid and transport (Harris et al., 2011, pp. 10–18). Deontologists can be offended by the decision to terminate pregnancies following a positive test as respecting life might be more important than avoiding all the harms these women may experience should they have a baby they did not anticipate. The rule utilitarian perspective was the most relevant because it leaves room for the consideration of consequences and overall circumstances. It considers factors mentioned in chapter 2 that because of their environment, this cohort of women is prone to Trisomy 21 pregnancies (Hunter et al., 2013, p. 704), and that they experience factors that make them vulnerable and put them at a disadvantage, such as a lack of resources, etc. The moral theory is also relevant because it prioritizes overall utility and will always opt for rules that amount to overall utility when weighed against any other rule that could have been put in place. It aligns with the goal of benefitting the greatest number of people as most South Africans come from low socio-economic groups (Ngubane et al., 2023, p. 2). Having a baby with Trisomy 21 will affect the mother and baby, the family dynamics and resource distribution within the families. As seen in the previous section, rule utilitarians will always prioritize the happiness of bigger groups over the sadness or disadvantage of smaller groups (Michael et al., 2013, p. 240). The next section will discuss why care ethics and virtue ethics were not the best frameworks for discussing this topic. I provide an overview of the moral theories, show how they would not be able to help defend the thesis, and then conclusion.

1.2.3. Why not care and virtue Ethics?

Ethics of care is a moral theory closely linked to feminism and places importance on interpersonal connections. With this moral framework there are no requirements to treat

everyone impartially out of duty, instead it considers living well as advancing the needs of those close to you and valuing their trust. It is inspired by close relationships from friends and family and endorses the natural instincts we have of putting them first and wanting to always protect them over strangers (Rachels and Rachels, 2019, pp. 162–264). Virtue ethics on the other hand answers the question "what traits of character make someone a good person?" (Rachels and Rachels, 2019, p. 169). It places importance on the role of virtues when making decisions and considers living well as being a virtuous person. This means that we should have attractive qualities that are manifested in our day-to-day habits that may be good for everyone to have (Rachels and Rachels, 2019, pp. 170–172).

While these two frameworks may allow for valuable discussions on the implications of increasing access on individuals, they might lack the capacity in arguments where the foetus must be terminated and compromise care. There might be conflict when the virtue of compassion for the affected foetus competes with the respect for autonomy when the mother decides to terminate the affected foetus or when the poor and struggling mother chooses to proceed with the pregnancy regardless of its impact on her and the family and thus undermining fairness and her obligation to care for her family and put their best interest first. The moral theories do well in focusing on specific relationships and individual needs but might struggle with policy making and to provide concise arguments for increased access. Care ethics may be able to make an argument for a struggling family that's raising a Trisomy 21 baby but lack the resources to argue for all women from low socio-economic groups to receive access to the test. Virtue ethics on the other hand focuses on creating virtuous humans, but the framework is not able to say why certain healthcare policies should be put in place. We can opt for policies that show we are virtuous humans such as those showing compassion for the struggling women, but more is required to show that the policy will be of moral value. It must be shown that it will empower women and benefit a greater number of people and thoroughly argue why this

cohort of women is more deserving of access than any others, and further discuss what the countries' public health goals are and how resources and costs will be affected.

Having discussed all 4 four moral theories I conclude that a rule utilitarian framework was the most applicable as it enabled the assessment of the possible outcomes that could arise from increased access and weigh them against limited access. The important aspects that needed to be considered and the possible consequences that could be produced by the implementation of the policy, were considered. The framework is sufficiently flexible to allow for readjustments as needed, especially should rules that produce better utility come about with the advancement in science and health care strategies. Furthermore, it is possible to assess the factors that might influence decision making and policy application, such as the health care disparities between women from low socio-economic groups and their counterparts, public health initiatives and how an increase in access will affect them, the resources distribution and possible expenditure vs loss or gain.

In this research report prenatal testing refers to non-invasive prenatal testing (NIPT) which I will elaborate on in the next section. This argument is made assuming that aborting pregnancies in South Africa is legal and allowed; that anyone can terminate a pregnancy due to personal reasons within the first trimester without breaking the law and that it would be ethically permissible to do so. The next section examines reports about the increase in access for prenatal testing, ethical concerns raised by the implementation of the policy, and how countries that have implemented the policy have addressed ethical concerns.

1.3. Overview of literature

Following the discussion on the background and justification for choosing this topic, this section discusses reports about the topic and discusses the ethical issues that were raised in the process of developing their arguments. I will start by explaining what non-invasive prenatal

testing (NIFT) is and its reliability. Non-invasive prenatal testing is a process where maternal blood is drawn for the purpose of identifying abnormalities in the chromosomes of the unborn foetus using next generation genetic sequencing. The tests indicate probabilities and are not diagnostic; further testing would be required to confirm positive results. If the test was positive, one could decide to undergo invasive procedures like chorionic villus sampling or amniocentesis. The main objective for the NIPT was to avoid unnecessarily exposing the mother and baby to the risks that come with invasive procedures. (Jayashankar et al., 2023: 2). The test has recently shown very high rates of sensitivity, specificity (both being 100%) and accuracy in twin and singleton pregnancies compared to other screening tests. The false positive rates are reported to be 0.10%, proving to be much lower than the 5% rate seen with its counterparts like nuchal translucency, ultrasonography, and maternal serum marker screening (Jayashankar et al., 2023: 9). Discussing increasing access to prenatal testing for all pregnant women, a concern raised is that, though the tests would be accessed by pregnant people to decrease mortality and morbidity, the success of the program will be based on the number of terminations of affected foetuses and that might put some pregnant females under pressure to terminate their affected babies. This could result in their autonomic decision to terminate as a "public health instrument" (Zaami et al., 2021, p. 3). Others expressed the view that it opens debates about the inherent worth of human lives and heavily discriminates against those living with special needs as if heir lives are not worth saving and perhaps are a burden (Zaami et al., 2021, p.3). Some have also argued that increasing access will increase the decision to terminate the affected foetuses and, therefore, promote procreative beneficence and inequality as they would, in essence, be eliminating the disabled. The Trisomy 21 community is also concerned that this would result in less support for the affected families and children and that less research will be done to help manage certain conditions and the prevention of conditions that come with Trisomy 21 (Zaami et al., 2021, p. 5). Countries that have put policies

in place for couples to access the test have addressed some of these ethical issues. They have highlighted that the aim is not to prevent babies affected by the condition from being born but rather to promote reproductive awareness and give couples their full autonomy by providing the necessary information (Zaami et al., 2021, p. 3), which resonates with the point that I am emphasizing.

Given that explanation, it has been indicated that couples undergo counselling before and after the test to ensure that they fully understand what this test would entail and that it might provide information on the karyotype and expose certain maternal conditions. Exposing incidental findings has also raised ethical concerns that this may result with a child growing up with anxiety due to the future the mother might be facing from a condition that was found while doing the test. This might rob the child of certain experiences as the parent's decision-making would be centred around the exposed condition and not done in an "unconditioned fashion" (Zaami et al., 2021, p. 4).

As prenatal testing is normalized, many are concerned that it will be used to normalize selective abortion for minor abnormalities, a specific gender or an undesired paternity. Though the aim of the test will be to do karyotyping, it is able to test for more aspects, including gender (De Jong et al., 2010, p. 271,275). Another moral issue raised by De Jong et al. (2010) is that because the test must be done early in pregnancy, a pregnant woman now has the burden of taking a decision that they may otherwise not need to take. She might feel the need to terminate a pregnancy that could have ended up in a miscarriage (De Jong et al., 2010, p. 273). Another ethical concern is that increasing the test or adding it to routine antenatal care may make pregnant women feel pressured to do the test, but they further state that increasing access to the test should not mean that the guidelines on informed consent should be loosened (De Jong

et al., 2010, p. 274).In support of broadening the scope for prenatal testing, the fact that the test is done early in the pregnancy may be appreciated by some women as it gives them time to decide after a positive test. Should they want to terminate, the decision will not be as traumatic in early pregnancy as it would be later (De Jong et al., 2010, p. 274).

Increasing the access of prenatal testing now may present a problem in the future as technology advances and the test is able to also predict late onset diseases and expose unsolicited conditions of the baby and the parent. Should the findings be unclear for the tested condition, it may result in anxiety for the couple or expecting mother. Should they continue with the pregnancy, the anxiety might persist post-partum. Such findings may also infringe on the future child's right not to know (De Jong et al., 2010, p. 275).

The next sections highlight which research question I answer as I develop this research report and provide the rationale, giving reasons why this research report is important. Ways in which it could contribute positively to the healthcare system and empower women from low socio-economic groups and better their chances of avoiding foetal and maternal morbidity and mortality are discussed.

1.4. Research Question

Given the grave socio-economic status of many South Africans, what are the potential consequences of the state assuming the ethical responsibility to increase access to Trisomy 21 prenatal testing for all women from low socio- economic groups in South Africa regardless of their health risks and indications?

1.5. Rationale

The limited access to prenatal testing in state-owned facilities in South Africa for women below the age of 35 in low socio-economic groups raises ethical concerns about inequalities, harm that is generally posed to the children and the mothers, and infringement to the mother's reproductive autonomy. In South Africa, prenatal testing is accessible in state hospitals for advanced maternal aged women, those with previous Trisomy 21 pregnancies and repeated miscarriages. However, the Western Cape government reported that 80% of the Trisomy 21 babies born are to mothers below the age of 35 (Western Cape Government, 2022). From those records we can deduce that other provinces are also experiencing the same outcome. These mothers and babies experience considerable harm due to a lack of information that results in a lack of preparedness-a consequence that could be avoided if prenatal testing were accessible. Hospitals also spend more money long term on managing the complications that result from the untreated conditions that come with Trisomy 21. Furthermore, the female's reproductive autonomy is infringed upon. Given the grave socio-economic status of many South Africans, an important question arises: what are the potential consequences of the state assuming the responsibility to increase access to Trisomy 21 prenatal testing for all women from low socio-economic groups in South Africa regardless of their health risks and indications?

This research is important for several reasons. Firstly, it attempts to bridge the gap caused by inequalities between the low socio-economic groups and other socio-economic groups. Women and babies from low socio-economic groups experience the worst health outcomes in comparison to the other groups, because of issues with access to health care facilities, inadequate health care infrastructure and affordability. Secondly, my research might support advocacy for a policy reform in South Africa that allows all pregnant women from low socio-economic groups access to prenatal testing for Trisomy 21 in state hospitals regardless of their age and health risks. These groups of women are the most vulnerable because they are not

exposed to information as the other groups are, and even if they were to gain access, they could not afford the test in private facilities (Mazibuko, Ramukumba and Ngwenya, 2022, p. 3,4). Therefore, prioritizing them could lead to a greater balance of utility as they also make up the majority. Thirdly, my research draws attention to the fact that women from low socio-economic backgrounds aged below 35 also have a right to decide if they want to give birth to a baby with Trisomy 21 or not. By not offering them prenatal testing, that right is violated, and they are dealt with the traumatizing experience of only finding out at birth that their child is different and has special needs. In such cases the harm outweighs the benefits. Most of these women are from communities that stigmatize disabilities and genetic disorders. A level of preparedness is required to help them navigate raising a child in such communities. The negative psychological impacts that women from low socio-economic groups experience and that they have little to no psychological support are often overlooked. When assessed using the hedonic calculus, the potential risks of not having prenatal testing accessible to these groups far outweighs the benefits . Lastly, if my argument is successful and results in a change in policies the research report would be a good public health initiative. It would have contributed to lowering the state's health care expenditure in the long run while also improving maternal and child health outcomes. Furthermore, Specific guidelines on prenatal testing may need revision. The medical community may need to tighten the reports from other provinces on the prevalence of Trisomy 21 in females below 35 and the effects of this prevalence on most families below the poverty line, in hopes of amending the guidelines and increasing awareness amongst all pregnant women. The next sections highlight the thesis statement and the aim of the research report, followed by the objectives highlighting the component aims that will help reach the aim of this research report. Each of these aims will be developed and discussed in the 4 subsequent chapters. Lastly, I provide information on the research design, method and the ethics approval before moving to the next chapter.

1.6. Thesis

I defend the thesis that the state assuming the moral responsibility to implement a policy that ensures that all pregnant women in low socio-economic groups in South Africa be offered NIPT to rule out Trisomy 21 regardless of their health risks and indications in state facilities, can mitigate adverse effects and promote health equity.

1.7. Research aim

I aim to defend the thesis that the state assuming the moral responsibility to implement a policy that ensures that all pregnant women in low socio-economic groups in South Africa be offered NIPT to rule out Trisomy 21 regardless of their health risks and indications in state facilities, can mitigate adverse effects and promote health equity.

1.8. Research Objectives

I. To defend my choice to only address females from low socio-economic groups in South Africa and not the other socio-economic groups, by discussing factors that make them vulnerable and showing how the decision can give them reproductive autonomy as the lived realities of such women does not raise similar ethical concerns about increasing access to Prenatal testing as their counterparts.

II. To argue that increasing access to prenatal testing for Trisomy 21 to South African females from low socio-economic groups could prevent harm to the women themselves.

III. To argue that increasing access to prenatal testing for Trisomy 21to South African females from low socio-economic groups could prevent physical and psychological harms to the

affected babies at birth and as they grow and that increasing access to prenatal testing can help reduce the increased mortality rate in infancy and early childhood of Trisomy 21 babies. Lastly to show how the limited testing may affect future children and risk them suffering.

IV. To further argue that increasing access to prenatal testing in South African state hospitals can contribute towards lowering the long-term health care expenditure on complications that result from unmanaged Trisomy 21 related health risks.

1.9. Research design

This is a purely normative bioethical project, in which I defend the thesis that the state assuming the moral responsibility to implement a policy that ensures that all pregnant women in low socio-economic groups in South Africa be offered non-invasive prenatal testing to rule out Trisomy 21 regardless of their health risks and indications in state facilities, can mitigate adverse effects and promote health equity. I answer my research question arguing for what ought to be done using an argumentative strategy and defending each premise to support my conclusion using normative theories.

1.10. Research method

In this type one normative project I did not collect any new data nor analyse it. There were no human nor animal participants involved during the development of this research report. I employed Typical research methods and standards applicable to philosophical research. I discussed findings from literature that is ethically analysed. I further interpreted and critically analysed information to answer my research question. I provided definitions and clarity of specific concepts and criticized, certain assumptions where due. I also analysed and evaluated certain theoretical frameworks and communicated the most reasonable interpretations of some

important concepts found in the literature from multiple sources like research articles, books, and government legislation (Steve Biko Centre for bioethics, 2024, p. 10).

1.11. Ethics approval

This was a purely normative project that did not involve human or animal subjects or collection of empirical data. No ethics approval was required. Following the discussion for my reasons for choosing this topic, what others have reported and given an overview of the ethical dilemmas that have been raised and how they were addressed, I highlighted the research question that will be answered by this research report, the aim of the report and the sub-aims that will help achieve my main aim. The next chapter aims to achieve my first objective, which is to defend my choice to only address females from low socio-economic groups in South Africa and not the other socio-economic groups. I defend it by discussing factors that make them vulnerable and showing how the decision can give them reproductive autonomy as the lived realities of women in low socio-economic groups in South

Africa does not raise similar ethical concerns about increasing access to prenatal testing as their counterparts.

CHAPTER 2: Understanding the Lived Realities of Women in Low Socio-economic Groups

Every year many babies with Trisomy 21 are born within low socio-economic groups in South Africa. Given the poor health outcomes that mothers and their infants in low socio-economic groups face as opposed to their counterparts, can an increase in access to prenatal testing for all women in state owned facilities in low socio-economic groups within the country regardless of their health risks and indication be able to move us closer to bridging the gap between these two groups? While it may be possible to bridge the gap by increasing access, many ethical dilemmas may be raised by the act. It may be seen as a discriminatory act to eliminate the Trisomy 21 community or that it justifies selective abortion for Trisomy 21 with a test that may be relatively unreliable. This chapter clarifies why I chose this cohort of women and factors that make them a vulnerable group and seeks to achieve my first objective for this study. I will discuss how an increase in access to prenatal testing can be an empowering act for them and how it may give them reproductive autonomy. Having discussed the kind of reproductive autonomy, I will discuss how that autonomy can raise concerns and try to address the concerns. This defends the thesis that the state assuming the moral responsibility to implement a policy that ensures that all pregnant women in low socioeconomic groups in South Africa be offered NIPT to rule out Trisomy 21 regardless of their health risks and indications in state facilities, can mitigate adverse effects and promote health equity. My arguments do not apply to women who have the means to raise and support a child with Trisomy 21.

2.1. Socio-economic status and health

In this section, I highlight how low socio-economic status contributes poorly to women's health outcomes and their infants, making them vulnerable when compared to everyone else and their higher socio-economic counterparts. One study reported that alongside childbearing, psychological impacts of caring for the children and reproductive events, socio-economic status plays a significant role on well-being. These women are burdened by poverty, single parenting and having to work multiple shifts to make ends meet because their pay is often low. They also face the hard reality of unemployment, and emotional and sexual violence (Moultrie and Kleintjies, 2006, pp. 352–353). Black South African women are the poorest among the population, resulting in their lack of autonomy and access to resources. They are not only poor within the country but also within their family structures (Moultrie and Kleintjies, 2006, p. 353). This study further shows that despite these women experiencing such harsh realities, female mental health is understudied-yet women are more susceptible than men to suffer from mental health conditions such as anxiety and depression (Moultrie and Kleintjies, 2006, p. 348). These females are at a disadvantage because though their mental health is affected by these factors, there are few resources offering them mental health support. Adding the pressure of having to raise an unanticipated Trisomy 21 baby can exacerbate their mental health burdens and affect the development of the baby.

Further studies have shown that low socio-economic status plays a significant role in the birth of babies with Trisomy 21. This study discusses how low socioeconomic status, especially low income, can impact meiosis 2(MII) nondisjunction error which Day and Taylor (1998, p. 2361) describe as "...the failure of homologous chromosomes to segregate properly to opposite poles during meiosis resulting in the production of gametes that have an improper chromosome complement.". The focus was on those whose household income was below $25 000 (Hunter et al., 2013, p. 703). According to this study, low socioeconomic status exposes one to specific

environmental factors that directly affect meiosis. “For MII nondisjunction, the accumulation of environmental toxins over time may interact with the vulnerable pericentromeric recombination pattern to increase the occurrence of a nondisjunction event. This accumulation might be expedited among women with a history of low socio-economic status as compared with women with a higher socio-economic status, thus showing this effect among younger mothers in addition to older mothers” (Hunter et al., 2013, p. 704). In support of this statement, women with low socio-economic status live in areas where many basic needs are not met such as affordable access to clean water and having to rely on collecting water from rivers. The result of this practice is water borne diseases like cholera and the same women carry the brunt of caring for their ill family members (Kehler, 2001, pp. 46–47). Studies have shown that low socio-economic conditions have a great impact on cognitive development after birth. This low cognitive development on children is the result of many factors like “decreased stimulation and book reading in the early years, less responsiveness for language development, less comfort with teachers and home-work routines, decreased monitoring of child activities, and perhaps less value placed on education” (Larson and Larson, 2007, p. 675). Low socio-economic conditions have also led to increased infant mortality and intrauterine growth restrictions “explained by exposure of poor pregnant women to accumulated chronic stressors, including crowded home environments, unemployment, single-parent households, less social support and financial problems” (Larson and Larson, 2007, p. 674)

This section concludes that many, factors contribute to the vulnerability of females living in low socio-economic environments. Factors such as exposure to harmful toxins, that make them ill and increase the likelihood of having Trisomy 21 pregnancies, single parenting, poverty and unemployment, emotional and sexual abuse make them more vulnerable than their counterparts. These factors contribute to chronic stressors and make it difficult to cope. There is little mental health support for women in general let alone, those in disadvantaged areas

(Moultrie and Kleintjies, 2006, pp. 360–361). These women and their infants have the poorest health outcomes. An increase in access to prenatal testing for Trisomy 21 could benefit them more and serves as public health improvement tool as the decisions taken following the test could lessen the possible effects of having to raise a Trisomy 21 baby that they did not anticipate given their circumstances. Chapter 3 and 4 will further discuss the possible outcomes that each woman and their baby may be faced with should they only find out at birth about their condition. The next section provides the daily expenditure of the households that most pregnant women in low socio-economic groups live in, to show how an introduction of a special needs baby that was not anticipated by the family can further deteriorate the socio-economic status of the family. Concerns that may be raised and that have been raised by some against increasing access to prenatal testing are discussed.

2.2. The precarious financial position of SA women in low socio-economic groups

Because of unemployment in South Africa, most households depend on social grants for survival. It is unfortunate that among the household members surviving on these social grants are pregnant women because of various factors (Scorgie et al., 2015, p. 2). Some have had to leave their jobs as the pregnancy progressed due to increasing demands of their physical state while others lack financial and physical support from their partners (Scorgie et al., 2015, p. 9). The next case study will discuss the expenses of each household and show the lived experiences of pregnant women living in social grant supported households. Sekhampu and Grobler (2011) conducted a study in Kwakwatsi township in the Free State province of South Africa that showed the expenditure patterns of households receiving the state's old age pension. Upon collecting data for their study, they noted that the chosen households comprised pensioners (Women in their 60s and older and males 62 and older) with figures showing the prevalence of single parenting. These pensioners were using their old age grant to support their unemployed

children and their grandchildren (Sekhampu and Grobler, 2011, pp. 45–46). South Africa has many unemployed individuals with most of them at the time of the interview actively seeking employment and willing to start immediately. Those above the age of 40 had given up seeking employment as the cost of transport to travel to industrial towns to work was a burden. During this study, females were the predominant group amongst the unemployed and seeking work, with most of the unemployed group being of childbearing age (Sekhampu and Grobler, 2011, p. 46). It is important to note that should these females fall pregnant, they and their babies will still need to reside in the same households, especially considering that most of them end up being single parents and do not get support from their partners (Mlotshwa et al., 2017, p. 1).When interviewed, the household members mentioned that the state's old age grant comprised 68.9%, salaries 10.8 %, and child support grant 10.8 %. The average household income was calculated to be below R2000 per month with most of the household income coming from government grants. Family members seldom send them money to help them survive (Sekhampu and Grobler, 2011, p. 46).

The reports show that 32.3% of their income was spent on food such as 30kgs of Maize meal (which is incorporated in every meal), 2kgs chicken that would sustain them for the week of the payment, and towards the end of the month they would buy meat cuts to sustain them for the entire month and vegetables. Some relied on hampers which were deemed to be cheaper than buying items individually, while others would grow vegetables in their gardens and eat from the garden on difficult weeks. Some families would take supplies on credit from the local convenience stores. 7% of their income was used to pay for furniture on layby, some percentage was used to contribute to funeral covers with hopes of not burdening their family members upon their passing and some was used to buy fuel-coal, paraffin and electricity for lighting (Sekhampu and Grobler, 2011, pp. 46–49). Their meals during the week would include pap

with potatoes or spinach and some would fry the pap to give it a savory taste and make it edible. They only ate meat when finances allowed. 72.7 % of the participants said that the grant was insufficient to meet all their needs and would appreciate an increase. The household expenditure shows how government grants play a vital role in the maintenance of dignity and sustenance of these households (Sekhampu and Grobler, 2011, p. 50). This provides an indication of the lived realities of those from low socio-economic groups (Scorgie et al., 2015, p. 7). To add to the financial difficulties, most females in South Africa become single parents. Upon becoming pregnant, most women are faced with a harsh possibility of having to raise their children without the support of their families and the father of the unborn child. Most women had to attend antenatal visits alone as their partner's masculinity may be in question if they go to these visits together and be perceived by society as weak. Some women even expressed the possibility of their partners cheating (Mlotshwa et al., 2017, pp. 1–7). Most of them have reported great difficulty in getting healthy food and eating regularly to meet the growing baby's needs, while others also mentioned that they resort to walking long distances to seek medical help because they do not have enough money for transport while a few opted not to go at all. Some of these women are unemployed, others have made money through strenuous work such as housekeeping and hairdressing and have noted that the work becomes difficult to complete as the pregnancy fatigue sets in (Scorgie et al., 2015, pp. 5–9). Most women either start ante-natal visits too early and are turned away while others report difficulties with being on long queues at public facilities and inability to afford transport at the time of labour. Nationally over 17% of women give birth without the attendance of a skilled professional at home, making the diagnosis of Trisomy 21 even more difficult (Scorgie et al., 2015, p. 10). Given the circumstances, having to raise a special needs child that demands extra care and medical attention and adequate financial resources to support adequate development, makes living in these conditions extremely hard to manage. Having access to Trisomy 21

prenatal testing early in pregnancy can sensitize the pregnant woman to seek medical attention at the time of birth instead of resorting to a home birth should she decide to proceed with the pregnancy after a positive diagnosis.

Having discussed how these women experience unfair conditions in their daily lives, that they have no control over factors such as being single parents and having poor access to basic needs, it is morally correct to allow them some form of reproductive autonomy, where they can, decide if they are ready to raise a Trisomy 21 baby or not. They should at least have adequate time for preparations by getting more information and support. Prenatal testing for Trisomy 21 can offer them reproductive autonomy. However, the discussion on increasing access to Trisomy 21 prenatal testing is not without challenges. The next section of this chapter will discuss the ethical dilemmas that come with an increase in access to prenatal testing for Trisomy 21 for this cohort of women.

2.3. Reproductive autonomy

As mentioned in the previous section, increasing access to prenatal testing for Trisomy 21 can be an empowering decision for the already vulnerable group of women. It could be a decision that reminds them that they too have reproductive autonomy like their counterparts. For a better understanding, reproductive autonomy is defined as an "individual's ability to be fully empowered agents in their reproductive needs and decisions and to access reproductive health services without interference and coercion" (Senderowicz and Higgins, 2020, p. 147). In their case, reproductive autonomy could result in terminating a Trisomy 21 pregnancy after determining whether they will have the financial and psychological tools to raise the special needs child or deciding to proceed with the pregnancy after thorough research. Upon understanding that a Trisomy 21 baby may require recurrent medical attention due to the nature

of their condition and its risks, some may require early exposure to therapy and special need schools (Antonarakis et al., 2020, pp. 18–23). Some women may decide to terminate the pregnancy following a positive diagnosis after a screening test. When they realistically evaluate their abilities to give this child the best life possible, some may decide that they are unable to do so and opt for termination. One of the major concerns with this decision and increasing access to prenatal testing is whether the non-invasive prenatal test for Trisomy 21 is reliable or not. Will the decision perpetuate the abortion of healthy unaffected babies due to false positives? Though this might have been a concern 10 years ago, developments in science have led to the improvement of this screening tool. Studies have shown that the test is now more than 98% correct in detecting chromosomal abnormalities and has had less than 1% of false positives and negatives (Abdulameer et al., 2024, pp. 51–57). Therefore, should an individual decide not to proceed with the invasive diagnostic tools like chorionic villus sampling and amniocentesis, they will be reassured that the screening tool was highly accurate and not doubt their decision to terminate.

Furthermore, the decision to terminate on its own might raise questions on the moral acceptability of selective abortion for Trisomy 21, especially given the counterarguments on inherent moral worth. Those who have children with the condition and the affected individuals may see this act as discriminatory and as trying to eliminate those of their kind from existing (Zaami et al., 2021, p. 3). To expand on this, Emanuel Kant reasoned that humans occupied a special place in creation because of their intrinsic worth. He referred to them as rational agents, able to make their own decisions, able to set goals and guiding their behaviour through reason. He emphasizes this by urging us through the categorical imperative to avoid treating others as a mere means to an end but as an end in themselves (Rachels and Rachels, 2019, p. 146). This stipulates that we ought to avoid any action that may imply that we do not attribute all humans

as equal and that we think that some humans are better than others due to their physical appearance and their capabilities. A decision to terminate a pregnancy based on the foetus being affected by Trisomy 21 may be deemed as disrespecting its inherent worth and the parents who choose to terminate the pregnancy may also be deemed as lacking respect for life. If we base our reasoning on the categorical imperative, specific acts are wrong regardless of an individual's reason for choosing it. In this argument, those deciding to terminate a Trisomy 21 pregnancy are violating the categorical imperative because killing is wrong, regardless of the motivating circumstances (Rachels and Rachels, 2019, pp. 136–137). In response to this argument, though Kant places importance on respecting humans and their inherent worth, he also advocates for autonomy. The mother's right to choose not to have a Trisomy 21 baby should be respected. Especially when the decision to end or continue with the pregnancy is based on her rationally weighing her options and understanding that her limitations may not allow her to raise the baby adequately. Her rational capabilities should also be respected and not be considered a discriminatory act. Furthermore, the decision to terminate pregnancies following a positive test and assessing one's circumstances and financial limitations is not derived from the belief that those with Trisomy 21 are lesser persons and do not deserve a chance at life but rather on the pregnant individual's inability to care for and raise the special needs baby.

In these low socio-economic settings, raising a child with special needs can put the families that are already not coping under severe financial difficulties and exacerbate poverty from one generation to the other. This can exhaust the people that are assisting the family financially and put the family at a disadvantage. Increasing access to prenatal testing for Trisomy 21 can help this cohort of women make informed reproductive choices and empower them to, take charge of some aspects of their lives beyond the harsh realities that are beyond their control. Lastly,

when some women choose to terminate their pregnancies, State Resources can also be directed to those who choose to continue their pregnancies and prevent physical and psychological harms that may result from not being prepared.

2.4. Conclusion

I have discussed the reasons why I chose this cohort of women in this research report. It has been highlighted that these women are faced with poor conditions that they cannot control. They lack financial support and rely on family members who receive social grants for sustenance, social grants that may not be enough to cover their basic needs, they lack support from their partners and result in raising their children alone. They must face the unfortunate reality that due to their low socio-economic status; they may be exposed to some toxins that raise their probability to carry a Trisomy 21 pregnancy. Given these circumstances, Trisomy 21 prenatal testing can become an empowering tool, that gives them information and reinforces their reproductive autonomy. However, such an increase in access for these women in state facilities raises ethical concerns including, the possibility of terminating healthy pregnancies due to false positives and selective abortion and eugenics by trying to eliminate the Trisomy 21 community. The message of this chapter was to give the reader an understanding of the lives and the dire conditions that this cohort of women are faced with and show how an unanticipated Trisomy 21 baby can lead to unpleasant outcomes. The next chapter will give an overview of those negative outcomes and how prenatal testing can ease their severity or fully protect the women from them.

CHAPTER 3: The Consequences of limited Access to Trisomy 21 Prenatal Testing: Harms Faced by Women in Low Socio-economic Groups

In this chapter I show how a lack of access to prenatal testing for Trisomy 21 can harm South African women from low socio-economic groups, which correlates with my second objective. I do so by discussing the physical and psychological harm that a lack of access to prenatal testing for Trisomy 21 can have on these women and show how an increase in access could minimize that harm and maximize overall utility. I commence by describing a pregnant woman's journey in state owned facilities, from the time they book to the time of delivery, what the midwife examines for at each antenatal visit, highlight how little to no screening is done for Trisomy 21, and how difficult it may be to have an elevated index of suspicion in women who are not of advanced maternal age. I discuss the impact of financial limitations on raising a child with Trisomy 21 and the psychological and physical harms that women in low socio-economic groups face without access to prenatal testing when they do not have indications, and how an increase in access can alleviate those harms and maximize overall utility.

3.1. Antenatal care and it's shortfalls

Antenatal care is mostly provided by midwives in state clinics and district hospitals. On a woman's first booking or clinic visit, a thorough history is taken where the health care worker seeks to determine the gestational age, foetal heart, whether the mother is infected with any sexually transmitted infections, and confirm blood groups, haemoglobin levels, baseline sugars, and blood pressure. This is done to ensure that she is healthy when starting her pregnancy journey and to enable the midwives to notice when there is a shift from baseline (Hoque et al., 2008, p.66a). Ultrasound is only offered at 24 weeks to women who are unsure

of their dates and their fundal height is less than 24 cm, but it is advisable that every woman should have, at a minimum, one basic obstetric scan at 18-20 weeks to confirm if the implantation happened inside the uterus and that the foetus is alive (The National Maternity Guidelines Committee, 2016, p. 129) . Trisomy 21 screening is not offered routinely alongside ultrasounds and other tests (The National Maternity Guidelines Committee, 2016, pp. 32–33). Congenital anomalies are tested for, only in cases where the pregnant woman is of advanced maternal age or if they had a previous Trisomy 21 pregnancy (The National Maternity Guidelines Committee, 2016, p. 130). Subsequent visits are then scheduled for 20 weeks, 26-28 weeks, 32-34 weeks, at 38 weeks, and 41 weeks should she still be pregnant (The National Maternity Guidelines Committee, 2016, p. 33). Having described the above antenatal care protocols, I emphasize the gaps in the system that make it easy to miss a Trisomy 21 diagnosis in early pregnancy till the end of term. A healthy woman is guaranteed at least one obstetrics scan in her pregnancy journey. A policy where ultrasounds are rarely done makes it easy to miss important stages of foetal development such as specific facial features like a short nasal bone length and perinasal thickness. Most of the foetuses with Trisomy 21 tend to have a rounded forehead and midfacial hypoplasia. Without a second trimester ultrasound, it becomes difficult to raise the index of suspicion and order further tests. There are some features that also raise the index of suspicion in the first and third trimester such as foetal growth restriction and cardiac defects (Vos et al., 2015, pp. 168–169).

Another constraint is the lack of specialized professionals in rural areas since midwives conduct antenatal consultations. Some midwives are not well equipped in ultrasound skills and may only know the basics of a pregnancy ultrasound such as checking for a heartbeat, presentation and placental location (Lukhele et al., 2023, p. 2). Noticing a change in facial features, cardiac abnormalities and the other soft markers of Trisomy 21 requires a skilled professional. Considering these factors, the argument on increasing access to prenatal testing for Trisomy 21

for all women in state facilities from low socio-economic groups becomes more compelling because the only requirement of a non-invasive prenatal testing is to draw maternal blood for laboratory testing (which can be done while drawing other routine bloods).This is within their scope of practice and does not require any skills to interpret as everything will be written on the laboratory results. NIPT is only done once and should preferably be undertaken following pretest counselling organized by a health care professional. In cases of negative results, post-test counselling may be provided by the same professional to offer reassurance and reinforce the importance of ongoing antenatal care(National Department of Health, 2019, p. 26). Referral to a genetic counsellor may only be indicated in the event of a positive test(National Department of Health, 2019, p. 26). This process will help avoid harms for the mother and the future baby and contribute to overall utility. Despite midwives under normal circumstances not being able to diagnose trisomy 21 antenatally, the screening test allows them to know and anticipate the affected baby and follow through with diagnostics tests and referrals as needed. In the next section I discuss the physical and psychological harms that women from low socio-economic groups face secondary to a lack of access to prenatal testing for Trisomy 21. I discuss the financial burdens that would be eased by increasing access to prenatal testing for Trisomy 21, followed by easing of emotional and psychological harm and, lastly, the physical health risks during and after pregnancy.

3.2. Financial limitations and economic hardships

Any pregnancy is difficult to navigate, especially with the physical changes caused by the pregnancy hormones, coupled with a mother's constant worry about the well-being of their unborn baby and whether she will be able to protect and take care of the baby adequately. This worry may be exacerbated by financial insecurities related to the ability to afford the basic medical care such as clinic visits and vaccinations. Despite the state offering free medical care,

affording transport to access those medical services is a major concern. One study highlighted that most women miss their ante natal visits because of poor road infrastructure, limiting accessibility to healthcare facilities, particularly in rural areas, inadequate public transportation, exacerbating difficulties in reaching clinics, and the high cost of transport to get to their ante natal visits (Mathebane, 2016a, p. 172). National guidelines determine that, females below the age of 35 do not get routine access to prenatal screening (The National Maternity Guidelines Committee, 2016, p. 130). Consequently, they find out either at birth that their child has Trisomy 21 when the diagnosis is made relying on the baby's facial features or later if their facial features are less distinct (Skotko and Canal Bedia, 2005, p. 197). Every mother expects and wishes for a healthy baby. Finding out at birth that this baby will have special needs and will require extra medical support and attention is shocking news, especially when it arrives when least expected. Given that most households in low socio-economic groups rely on government grants to make ends meet, most families struggle to survive because the grant does not cover all their basic needs (Sekhampu and Grobler, 2011, pp. 45–46). A healthy baby addition to the family results with more people having to share the limited resources. Finding that the child has special needs at birth or later in life is more shocking as it comes with unexpected costs for medical bills and to meet their developmental needs. When referring to most households depending on social grants, I do so under the assumption that the pregnant women reside in households dependent on social grants (Scorgie et al., 2015, p. 2). Some pregnant women rely on their parents for support and this aspect of single parenthood heightens their vulnerabilities. Some are faced with the harsh reality of discontinuing the manual labour that was sustaining their families financially due to limitations imposed by pregnancy (Scorgie et al., 2015, p. 9). As a result, they struggle to keep up with their nutritional needs to maintain a healthy pregnancy.

The arrival of a baby with Trisomy 21 predisposed to recurrent upper respiratory infections, cardiac anomalies, hearing loss, etc, further worsens financial hardship. Increased hospital and clinic visits, transportation, and overall childcare costs exacerbates the economic strain. The affected baby will require special schooling and extra costs for therapy. The impact of socio-economic and health challenges potentially results in emotional distress and can express itself as depression and other psychological conditions. Therefore, it is important to acknowledge the vulnerabilities of pregnant women in low-income households caring for children with special needs and to understand how prenatal testing for Trisomy 21 would give families an opportunity to expect and prepare for the baby's needs. Early diagnosis of Trisomy 21 during pregnancy would not change the poor circumstances of the family (because only extra income could better their financial state). However, pregnant women and their families would be better prepared to make financial decisions that will allow them to distribute resources efficiently and maximize family welfare and avoid moving funds without prior preparation and budgets to care for unanticipated health scares and emergencies. Some women and their families, after having assessed their situation, may continue with the pregnancy and know that they will be able to move funds to meet the baby's needs while taking care of their basic needs, while others could decide to terminate the pregnancy.

One of the primary care givers might need to reduce their hours at work or leave their employment should the child not be in the high functioning spectrum, or their health be too demanding, especially when they cannot afford to get a helper. Research has shown that most women who fall pregnant in low socio-economic settings become single parents, and their partners are not involved in the child's life (Mlotshwa et al., 2017, p. 1). For women who are the primary care giver, the prospect of leaving a job that offers stability to take care of their child can be financially overwhelming and devastating. A prenatal diagnosis of Trisomy 21

gives women a chance to anticipate any financial changes that will need to be made and thus prevent long lasting economic consequences.

In conclusion of this section, increasing prenatal testing access for all women from low socioeconomic groups in South African state facilities will prevent dire economic harms and allow this cohort of women and their families an opportunity to better prepare for the baby with Trisomy 21's needs without compromising family welfare. It will give the women a chance to anticipate any financial adjustments that may be required and prevent long term financial harm caused by unanticipated expenditure. For example, a family of six that usually used R500 a month distributed between rent, transport for work and school, school fees and groceries and electricity, might consider registering one of the children for social grants, cutting electricity costs, or moving the children to a nearby school and thus have money available for emergencies instead of finding themselves in debt through borrowing money whenever the child is sick. Being better prepared will benefit the women and result in overall utility as their families and the future child will benefit as well. In the next section I discuss the emotional and psychological harms that women without access to prenatal testing for Trisomy 21 endure and how an increase in access can lower the emotional and psychological strain.

3.3. Emotional and psychological hardships

Mental health in South Africa is a significant yet neglected issue and females who use the public sector do not receive the quality of care they should ideally receive (Moultrie and Kleintjies, 2006, p. 347). Given that dire situation, a lack of access to prenatal testing for Trisomy 21 further contributes to compromised mental health conditions amongst South African women. In this section I will discuss how prenatal testing can help ease the anxiety that comes with pregnancy and the self-blame that may result after finding out. As mentioned

in the previous section, pregnancy creates anxiety regarding the child's welfare and health. A pregnant mother is always concerned about whether the foetus will make it to term and if it does make it to term, whether it will be born without any abnormalities. If a pregnancy is considered healthy the system does not offer a chance to get routine scans. Most women, if they cannot afford to pay for a scan in the private sector, rely on the nursing staff for reassurance and foetal movements. Prenatal testing for Trisomy 21 can offer pertinent information on its probability and help reduce uncertainty about that abnormality. Discovering only after birth that your child has trisomy 21 can be a very traumatic experience, filled with guilt and self-blame, especially because no adequate counselling will be offered in preparation of raising that child. A mother may feel that they have done something wrong resulting in them having a special needs child. This may be exacerbated by societal stigma, where the condition is attributed to spiritual ills of the family or mother and even witchcraft(Mahomed and Stein, 2021, p. 67). Along with Prenatal testing, counselling is facilitated through the testing facilities and can also be offered by knowledgeable health care professionals giving the women information about the condition and reassurance that they could not have prevented the condition. Access to prenatal testing could have lowered their emotional distress and allowed them to better raise their children without the risk of depression, postpartum depression, and adjustment difficulties in a system that does not cater well for mental illnesses. Knowing the likelihood of Trisomy 21 also allows the women to prepare mentally for the challenges they might face with their families and society.

Early diagnosis of Trisomy 21 by increasing access to prenatal testing can further prevent primary care giver burnout by allowing them enough time to better prepare for raising the child. In households where the primary care giver cannot afford to hire a helper, early diagnosis and proper counselling can equip her with all the necessary information that will better prepare her

to teach those around her and her support system how to better care for the child once they are born. Preparing those around her and ensuring she has support can prevent a situation where she is the only one who is able to take care of the child and allow her to attend to herself and other responsibilities. An increase in access can prevent the primary care giver and her support system from being overwhelmed and result in overall happiness and less suffering. Mothers raising babies with Trisomy 21 expressed that knowing beforehand that the baby had Trisomy 21 was important in helping them to better prepare for the baby (Scott et al., 2013, pp. 90–91). Knowing about the likelihood of Trisomy 21 before the baby is born can result in a greater balance of good and positive psychological outcomes. This knowledge results in the reduction of anxiety around the baby's well-being, alleviate feelings of self-blame and guilt linked to having a child with special needs, and enable better preparation for challenges upon introducing the baby to society and family. Being prepared by (acquiring knowledge and information from the counselling) can enable healthy coping mechanisms and allow the sharing of information between close friends and family. This might allow them to help with caring for the baby when the primary care giver's other responsibilities become overwhelming and contribute to reducing the risk of burnout and depression (Luthar and Ciciolla, 2015, p. 5). This will build a healthy environment that allows the baby to thrive, enables positive cognitive development, adaptive functioning and result in maximum utility as the mother will be protected from depression and thus promote the well-being of the child. (Canadian Paediatric society, 2004, pp. 576–577). In the final section of this chapter, I discuss the physical harms that women carrying a child with genetic conditions face and show how an increase in access to prenatal testing for Trisomy 21 can lower the physical risks and result in a greater balance of utility.

3.4. Physical health risks during pregnancy and birth

In this section I discuss the risks associated with a Trisomy 21 pregnancy and the impact that increasing access to prenatal testing can have on the lives of women from low socio-economic groups within state owned facilities. Carrying a Trisomy 21 pregnancy comes with risks, the most prevalent being miscarriages, preterm deliveries and foetal deaths, resulting in still births (Antonarakis et al., 2020, p. 18). Given the current guidelines as mentioned in early paragraphs, these conditions may go undetected due to infrequent monitoring through ultrasound, leaving the pregnant women with emotional stress and negative psychological impacts. These preterm deliveries, miscarriages and foetal losses contribute to the health disparities created by the gap in healthcare between women in low socio-economic groups and their counterparts and contribute towards poor health outcomes for women and their infants. An increase in prenatal testing for Trisomy 21 for women in low socio-economic groups could help prevent some of these miscarriages, pre-term labours and foetal losses since a positive screening test prompts the women to undergo diagnosis. Should the diagnosis be confirmed, the health care practitioners and mothers have a high index of suspicion, and the pregnancy can be monitored closely. Any complication during the pregnancy can be handled by skilled professionals who can increase the baby and the mother's chance of survival. It gives the obstetrics and paediatric team time to fully prepare for complicated deliveries and possible premature births. The increase in access can further allow health care providers to save more pregnancies and provide the pregnant women with better emotional support by informing them of all the potential negative outcomes that may impact them psychologically.

3.5. Conclusion

Increasing access to prenatal testing for Trisomy 21 in state healthcare facilities for all women in low socio-economic groups in South Africa can prevent long- lasting economic harm for

women and their families and allow them to adjust financially to accommodate the Trisomy 21 affected baby and distribute resources effectively. Early diagnosis can also alleviate feelings of guilt and help women anticipate negative comments and stigma from society and allow them to better prepare their close family and friends to provide a solid support system that will also benefit the child's development. This increase in access can further result in the empowerment of women by ensuring their reproductive autonomy and reminding them that they have a right to choose whether to have a Trisomy 21 affected baby or not. Those who have calculated their risks can freely opt for termination of pregnancy. Lastly, the increase in access can bridge the gap created by health disparities between women in low socio-economic groups and their counterparts by giving health care workers a chance to emotionally support the pregnant woman, helping her anticipate the potential miscarriages, still births and preterm labour without feelings of guilt or self-blame. The increase in access to prenatal testing for all in-state facilities regardless of health risks and indication can improve the health outcomes of mothers and their children and result in more good than harm.

CHAPTER 4: The Consequences of Limited Access to Trisomy 21 Prenatal Testing: Harms Faced by the Affected Babies

I have described the impact of prenatal testing for Trisomy 21 on women in low socio-economic groups and how an increase in access can lighten their financial load, help them prepare their support structures and reduce the psychological burden they might be faced with due to limited access to prenatal testing. This chapter analyses the negative impact that the lack of access to prenatal testing for this cohort of women can have on the affected baby/child from birth and beyond. The chapter aims to show how the increase in access to prenatal testing for Trisomy 21 for all women in state facilities in low socio-economic groups contributes to overall utility and reduces harm for the affected children. I discuss the physical and developmental harms directed to the child posed by delayed intervention and how that contributes to poor health outcomes for infants. I will reiterate the point made in the previous chapter on finances and show how that can have a negative impact on the child. I will discuss the psychological harms that could be prevented by an increase in access and lastly how the limited testing may affect future children and risk them suffering.

4.1. Physical and developmental harms.

According to Antonarakis et al, Trisomy 21 predisposes affected individuals to “congenital heart conditions, obstructive sleep apnoea, thyroid disease, dementia, epilepsy, gastrointestinal disease, hearing and vision problems, intellectual disability and developmental disorders, mental illness, immunological dysfunction, haematological disorders and musculoskeletal issues” (Antonarakis et al., 2020, p. 18). If left unmanaged some of these conditions can be life threatening, while others may result in a poor quality of life. Failure to get information on the likelihood of the foetus having Trisomy 21 may result in the baby being born in a facility that does not cater for complicated births, and where specialists are not readily available (Ximba et al., 2021, p. 2). Furthermore, considering that Trisomy 21 pregnancies are prone to preterm birth and miscarriage (Antonakaris et.al (2020), they would require the monitoring of a skilled professional in a facility with better skilled professionals and adequate resources (Ximba et al., 2021, p. 2). Many factors can influence, delaying the referral and adequate management of the baby at birth, such as transport difficulties, communication hinderances between the referring midwife and the receiving doctor contributing to a further delay at birth, if the Trisomy 21 baby was not anticipated. Prenatal testing for Trisomy 21 in all state facilities will allow parents an opportunity to plan properly for the medical care after birth. Midwives will have the time to refer the patients and the medical team time to prepare for a high -risk birth in an adequate birthing facility where specialists are readily available, such as pediatric cardiologists and surgeons (Ximba et al., 2021, pp. 3–6). The test can help avoid delays in intervention and allow the affected baby to get timely medical care and contribute to improving the health outcomes for infants (Willoughby et al., 2016, p. 628).

Alongside medical interventions, early knowledge of the condition will allow this cohort of women enough time to do their research on support services available in their areas such as speech therapists, occupational and physiotherapist. Trisomy 21 is the leading genetic cause of

intellectual disability, with most of the affected individuals having mild–moderate disability. They often struggle with expressive language, verbal working memory, and episodic memory. However, their cognitive functions differ, and the majority are on the autism spectrum while others have attention deficit–hyperactivity disorder (Antonarakis et al., 2020, p. 21). Early management of these conditions through therapy will give the affected children a better chance at development and make them less dependent on the care giver even through adulthood. Studies have shown that management of some of these cognitive and affective dysfunctions can start during pregnancy to lactation, by giving the mother a choline supplement. This supplement should improve spatial cognition, attention, and emotion regulation in the affected baby (Powers et al., 2021, p. 1). Therefore, an increase in prenatal testing for Trisomy 21 in state facilities could maximize utility and benefit the affected children and prevent harm.

In conclusion of this section, Limited access to prenatal testing for all women in state facilities results in unexpected births of Trisomy 21 infants who are more likely to have severe and lasting cognitive impairments resulting in lifelong dependence on care givers. Getting early access to prenatal testing enables parents and families to seek vital information on therapeutic interventions that promote high functioning and independence. Early knowledge of the likelihood of the baby having Trisomy 21 also enables the family and health care workers to better prepare for the birth in an adequate facility and resources to improve the chances of survival and lower the rates of infant mortality. In the next section I discuss how the lack of prenatal testing can have negative psychological impact on the affected child and cause strained sibling relationships.

4.2. Psychological harms

The birth of a baby can be joyous for the family and difficult to navigate for the parent, especially when the newborn has special needs that they did not anticipate. It may be difficult for a woman living under resource constrained conditions to determine the best way of parenting such as, how to share time and resources between her existing children and the newborn that demands more of her time and attention. It may be difficult to know how to effectively distribute resources when not having time for proper preparations. The families might find themselves overusing resources on the newborn and sacrificing the other siblings without conscious recognition. The affected baby might be getting more time, attention and resources than the others. Some mothers may have to leave their jobs and take care of the child with Trisomy 21 which will further impact the resources available for all the children. These factors may build tension between the affected child and their siblings, associating their incorporation into the family with feelings of neglect.

Increased access to prenatal testing for Trisomy 21 for all women in state facilities regardless of their health risks and indication avoids outcomes similar to where parents do not get time to prepare for the child with Trisomy 21. Early knowledge that the baby might have Trisomy 21 allows families to be equipped with adequate knowledge and gives the women time to sensitize their families to the change in dynamics. By educating the family she could give her existing children time to process the anticipated change, give them significant roles to play to enable them to feel like valuable members of the family, and access therapy to help them navigate the anticipated change. Instead of feeling that their new sibling with special needs deprived them of their previous lives they might learn to love them and to contribute towards making them as comfortable as possible. This will affect the mother positively by reducing her emotional baggage and could create a warm and secure family environment that promotes good cognitive

development and improve the odds for higher functioning for the affected child. Besides strained siblings' relationships or poor family dynamics, another factor that can have negative psychological outcomes is not being accepted by society. Most African cultures are not accepting of genetic disorders, which results in isolation of the affected babies and their family. They attribute their condition to witchcraft or a curse and may not want to be associated with anyone who may be linked to curses or witchcraft (Mathebane, 2016b, p. 170). Some families have hidden their children, fathers have abandoned them and their mothers, while others have killed the affected baby out of fear (Morris et al., 2015, p. 164). As social beings who find their identity through inclusion and belonging, this has negative psychological implications, leaving the child feeling unwanted and unloved. Most black ethnic Africans find their purpose through meaningful family and community life where they get to share their sorrows and problems as per the principle of ubuntu (Mathebane, 2016b, p. 171). Denying the affected children that experience may cause psychological conditions and deprive them of their identity. However, increasing access to prenatal Trisomy 21 testing can diminish the intensity of the stigma. The genetic counselling offered with each prenatal testing will empower the mothers to educate their family and friends and increase the number of knowledgeable individuals in the community. This can further motivate those who know to raise awareness and alleviate the emotional burdens that each family with Trisomy 21 carries, especially the affected children.

This section has shown how the increase in prenatal testing for Trisomy 21 can foster healthy family dynamics, empower society through an increase in knowledge about the condition and avoid harmful outcomes from stigma and strained family dynamics. The new generation is open to learning and do not depend on stereotypes and ancient beliefs. The next section

highlights how the lack of prenatal testing for Trisomy 21 in all state facilities for all women in low socioeconomic groups can negatively affect future children.

4.3. Negative impact on future children

This section discusses the effects of Trisomy 21 on future children and how lack of access to prenatal testing for the condition can have a negative impact on the future children. In the previous chapter, we discussed that mothers carrying Trisomy 21 babies are prone to preterm birth and miscarriages (Antonarakis et al., 2020, p. 18). In the absence of prenatal testing, miscarriages can happen without the knowledge that the foetus had Trisomy 21. A Trisomy 21 pregnancy increases the chances of having another affected pregnancy (Lister and Frota-Pessoa, 1980, p. 203) resulting in the same problems mentioned in the previous chapter and above, such as financial unpreparedness, physical harms such as unknown miscarriages and preterm births. Their child can be marginalized due to social stigma, and experience strained relationships with siblings. They are at risk of poor cognitive development, and their lives could be compromised at birth due to a lack of preparedness by seeking therapy early and preparing for the birth at an adequate facility. Given the resource constrained background, the struggles of mothers who have Trisomy 21 babies would be exacerbated by incorporating another Trisomy 21 child into the family. Without prenatal testing, genetic counselling is not given, resulting in some females not being informed about the possibility of recurrence. The increase in prenatal testing for Trisomy 21 in state facilities for all women in low socio-economic groups could result in reproductive empowerment of women and avoid the repetition of unpleasant situations that result from unpreparedness.

4.4. Conclusion

An increase in access to prenatal testing for Trisomy 21 in state facilities for all women from low socio-economic groups regardless of their indications can prevent harm to the children by allowing the health care workers and the family to better prepare for the birth in an adequate facility where specialists and resources are readily available. Secondly, it can promote healthy family dynamics by affording each family member an opportunity to process the anticipated change and learn more about Trisomy 21 to better support the new member of the family. It can lower stigma by giving those who have been educated through genetic counselling a chance to impart their knowledge and raise awareness within families and communities. Lastly, it can protect the future child from having to go through all the mentioned misfortunes by increasing preparedness or even deciding not to have another child if the conditions do not allow the family to create an ideal environment for the future baby. The next chapter discusses how an increase in access for prenatal Trisomy 21testing in state facilities for all women from low socio-economic statuses can lower the long-term health care expenditure caused by the complications of unmanaged Trisomy 21 related health risks that could have been prevented and also serve as a public health tool.

CHAPTER 5: The Role of Increased Access to Trisomy 21 prenatal testing in Lowering the States Financial Burden

Trisomy 21 predisposes an individual to many health risks, some of which have been discussed in previous chapters, such as congenital heart defects, recurrent respiratory infections, sleep apnoea, epilepsy, intellectual disability among others. (Antonarakis et al., 2020, p. 18). Some of these conditions, if unmanaged, can result in complications and frequent hospitalizations (Ren et al., 2024, p. 149). In this chapter, I argue that an increase in access to prenatal testing for Trisomy 21 can contribute towards lowering the long-term health care expenditure on complications that result from unmanaged Trisomy 21-related health risks. I show how the health care expenditure varies when an individual gets early intervention and when managing complications. I also show how an increase in access can also serve as a public health tool and address the ethical concerns that could be raised by the increase in access and the notion of the test being a public health tool.

I start by showing how a single complication can be costly to the state as opposed to treating it at birth before developing complications. I use congenital heart defects as an example. Some congenital heart defects are missed at birth and the indivudual may develop recurrent chest infections, inability to thrive and a poor quality of life (Masamba et al., 2001, p. 53). South Africa had a positive decline in child mortality rates since infectious diseases were addressed as one of the leading causes of infant mortality. Congenital defects now negatively impact that positive decline (Malherbe et al., 2016, pp. 138–139). Studies have shown that Trisomy 21 is one of the leading causes of congenital heart conditions, and that late or poor identification of the condition leads to complications (Willoughby et al., 2016, pp. 626, 628). With an increase in the index of suspicion through prenatal testing, the affected baby can

receive screening and get early intervention that may cure or reduce the extent of disability. The corrective surgery can be less costly in comparison with the ongoing cost of the management of untreated congenital conditions and their complications (Malherbe et al., 2016, p. 143). Masamba et al (2001) estimated the cost of one surgical procedure to be around US$20000, which is a once- off expenditure for the health care system as opposed to ongoing costs for recurrent admissions and treatments. The South African government spends almost R4000 per patient yearly for the general population, which can fluctuate depending on the number of admissions and the type of care needed (Statistics South Africa, 2017). The costs of health care for Trisomy 21 patients in South Africa are not well documented, therefore I will refer to studies done in other countries such as Australia to contextualise how much the government might be spending. A study done in Australia documented that on average $4209 was spent on each patient annually, with the cost decreasing as the child grows. The main reason for increased expenditure was congenital heart conditions and their corrective surgeries. The costs decreased after the conditions were managed (Geelhoed et al., 2011, pp. 5–6). The costs varied significantly depending on the variety of conditions being managed and their severity (Geelhoed et al., 2011, p. 6). We can, therefore, assume that the cost of care would be higher in South Africa, given that the diagnosis of the condition is difficult to make due to factors such as the difficulty to recognise Trisomy 21 in black neonates, by health care workers, the incidents of home births leading to infants not having direct access to skilled professionals and poor access to adequate genetic counselling (Elshazali and Abdullahi, 2022, pp. 2–3). Congenital heart conditions are not the only conditions that can lead to complications because of missing a Trisomy 21 diagnosis. Hypothyroidism can also lead to irreversible mental and physical disabilities that would be costly for the state to rehabilitate (Willoughby et al., 2016, p. 626). An increase in access to Trisomy 21 prenatal testing for all women in low socio-economic groups in South Africa can help avoid those detrimental consequences. Access to

prenatal testing for this cohort of women can mean that unlike in the past, health care professionals will anticipate the conditions associated with Trisomy 21. They could do screening echocardiograms and rule out congenital heart conditions and arrange a corrective surgery should there be a need (Vis et al., 2010, p. 1480). This increase in access could save the state money by preventing the management of irreversible complications and rehabilitation and function as a public health tool that supports the World Health Organization on attaining Millennium Development Goal 4 in low- and middle-income countries. This goal was centred on improving the survival of children and infants in low- and middle-income countries (Malherbe et al., 2016, p. 138). By increasing access to prenatal testing for Trisomy 21, conditions that result in death and disability can be managed on time. Situations where some children die and the cause of death is attributed to pneumonia, could be identified as recurrent chest infections secondary to untreated congenital heart conditions that resulted from Trisomy 21 (Willoughby et al., 2016, p. 628). The test can assist with giving Trisomy 21 related deaths the attention they need and help allocate resources to ensure that all children affected by Trisomy 21 get early interventions and screening and prevent dire complications. The state would save money and move closer towards fulfilling the millennium goal 4 by the World Health Organization.

Furthermore, some families, after receiving prenatal testing, can choose a different path and terminate the pregnancy. This decision can further lower the state's expenditure as there would be no baby to take care of, no health care services would be needed, and no social grant support would be given to ensure the child is taken care of. This would allow resources to be distributed towards areas of need and towards early intervention for families who decided on continuing with the Trisomy 21 pregnancy. However, the decision does not come without ethical concerns including that, if access to prenatal testing for Trisomy 21 is extended to all women in low

socio-economic groups in South Africa, those who choose not to take the test will be discriminated against should they have an unanticipated Trisomy 21 affected baby. Secondly, because termination results in more utility as it avails resources for those in need, those who decide to continue with the pregnancy may be viewed as inconsiderate and not supportive of the initiatives to lower infant mortality and morbidity.

These ethical concerns can be addressed, firstly by considering that Emanuel Kant deems humans to be important and worthy of respect because they are "...free agents capable of making their own decisions, setting their own goals, and guiding their conduct by reason" (Rachels and Rachels, 2019, p. 146). Therefore, the moral thing to do in this situation is to show these women respect and remember that increasing access to the test is a measure to empower the disadvantaged and remind them that they have reproductive autonomy. It is not meant to remove, their right to refuse any procedure or treatment as part of informed consent (South Africa Parliament, 2004, pp. 20–22). Therefore, the decision to take the screening test or not should be respected remembering that they are free agents who can guide their conduct by reason (Rachels and Rachels, 2019, p. 146).

It is also important to highlight that the genetic counselling accompanying prenatal testing is a system rooted in patient autonomy. It should not undermine the patient's right to make their own decisions by trying to influence their decision making. It is only used as a supportive tool to help the affected woman make informed decisions (Salema et al., 2019, p. 156). It allows them to ask questions and to leave the session understanding how raising a Trisomy 21 baby looks like and what it entails. Prenatal and postnatal testing are not a means to force individuals to terminate their pregnancies or devalue those with Trisomy 21. They should leave the process with an understanding of their responsibilities when raising a child with special and the

knowledge that they have a right to choose not to have a Trisomy 21 affected baby if they do not want to. Those who choose to continue with their pregnancies without undergoing counselling and fail to better prepare for the pregnancies and get necessary information should their babies be affected by Trisomy 21, can be considered morally guilty of compromising utility. This is especially when they understand the implications of raising an unanticipated Trisomy 21 baby, on their family's economic status, the baby's well-being and their own, and the health care system. Their decision to not take test and further neglect their responsibility to seek information about the condition to help them better prepare, can lead to more harm than good and result in suffering. The next section will discuss the costs of increasing access to the prenatal test whether the cost effectiveness of implementing broad access can be weighed against the benefits to quality of life and the decrease in mortality and morbidity.

5.1. The cost of increasing access vs treating complications long term

Though it may contribute to greater good, the test is not readily available in state facilities due to costs and those in private facilities must pay for the test as medical aid does not cover it (Geerts, 2014, p. 37). A test for a singleton pregnancy costs R5500 and R 6000 for twin pregnancies (Inqaba Bioetec, 2024). Given that over the past year 932 138 births were recorded (Statistics South Africa, 2024) , the estimated cost of implementing the test in all state-owned facilities would be roughly R5 billion annually. Considering the accuracy of the test and that it has a high sensitivity and specificity (Abdulameer et al., 2024, p. 52) there might not be a need for additional testing, which could lower secondary testing expenditure.

Given the figures mentioned previously that an estimated 1 to 500 children with Trisomy 21 are born every year (Willoughby et al., 2016, p. 626) and that a total of 932 138 babies are born yearly (Statistics South Africa, 2024), we can make an estimate based on the Australian figures

that the total yearly expenditure for all children could amount to R 101 752 930. This figure may be significantly higher considering the challenges in South Africa that contribute to delayed and missed diagnosis, and the severity of the complications that those with missed diagnoses may present with. If these individuals have a life span of 60 years at most, the state may expect life-long expenses for all patients born in that particular year to amount to R 6 099 178 052. One might argue that an increase in access to Trisomy 21 prenatal testing can cost the state more since they would have to cover costs for the prenatal test and potentially must also manage complications that may arise since not all pregnant women will opt to terminate their affected pregnancies.

The cost utility analysis can be used to address this concern. This is an evaluation tool that is used to assess how cost effective an intervention is by evaluating how much utility it brings about. It assesses the quality-of-life improvements the intervention produces and its life saving potential (Nicholson et al., 1993, p. 859). While the cost of the prenatal test is high, early detection of the condition could lower the long- term effects and the expenditure associated with missed and delayed diagnoses. This is because stakeholders would have an elevated index of suspicion for Trisomy 21 and be able to timely diagnose and manage risk related conditions. It would contribute to high functioning individuals who require less medical attention and can be part of the workforce and positively contribute to the country's economy by doing appropriate jobs for their condition, thus lowering the long-term costs of the state. The Raised index of suspicion can also improve the health outcomes of mother and child and serve as a public health tool. It will further allow families to better prepare for their babies and get support so that mothers can continue with their career development regardless of the father's lack of support as mentioned in chapter 2. More mothers contribute to the economy once they have developed in their careers. The increase in access can also reduce the level of anxiety and stress

that some mothers may have post-partum after realizing they will be raising an unanticipated special needs child. Where some women opt for termination upon a positive diagnosis, the saving by the state will enable resources to be provided for towards other high-risk conditions.

5.2. conclusion

An increase in access to Trisomy 21 prenatal testing can potentially lower the state's health care expenditure and serve as a public health initiative. I used congenital heart conditions as a practical example that can easily be treated through surgery but that can go undiagnosed and result in poor quality of life and recurrent hospitalizations due to chest infections. The chapter explored how much other countries spend on caring for Trisomy 21 babies and how much each surgical procedure can roughly cost. Using those figures, an estimate of the long-term costs was made and weighed against the costs of universalizing prenatal testing. A further cost utility analysis was made and based on those factors we conclude that the increase in access will result in an overall balance of utility since it can lower the long-term costs through sensitizing stake holders and enabling them to timeously detect and diagnose risk related conditions and manage them before complications arise, leading to a better quality of life and less hospitalizations. The increase in access can contribute to informed decision making and result in women and families being better prepared to take care of the affected baby and improve their outcomes. The anxiety of finding out at birth would be lessened and further support the mother allowing her to also thrive. Some women and their families may choose to discontinue the pregnancy after careful evaluation, allowing for better resource allocation for high-risk pregnancies and the caring of the affected babies. The rate of deaths related to Trisomy 21 complications can be reduced and fewer babies will go undiagnosed. This would be a good public health initiative and move South Africa closer to reducing mother and child mortality and morbidity. The next chapter will summarize the work of the research report and provide a conclusion.

CONCLUSION

In this chapter, I revisit the key points. The purpose of this research report was to answer the question of the potential consequences of the state assuming the ethical responsibility to increase access to Trisomy 21 prenatal testing for all women from low socio-economic groups in South Africa regardless of their health risks and indications. I defend the thesis that the state assuming the moral responsibility to implement a policy that ensures that all pregnant women in low socio-economic groups in South Africa be offered non-invasive prenatal testing to rule out Trisomy 21 regardless of their health risks and indications in state facilities, can mitigate multiple adverse effects and promote health equity. I show how women from low socio-economic groups' lived reality differs from their counterparts as they experience conditions that put them at a disadvantage and disempowers them. I discussed the harms that these women and their babies face and how prenatal testing can help address those harms. The previous chapter further discussed how an increase in access to Trisomy 21 prenatal testing can serve as a public health initiative and lower the state's health care expenditure on Trisomy 21-related complications in the long run.

To support the arguments made to defend the thesis a rule utilitarian framework was the most applicable as it made it possible to assess all the possible outcomes that could arise from the increase in access and weigh them against limited access. It enabled consideration of all the important aspects that needed to be considered and the possible consequences of implementing the policy. It is sufficiently flexible to allow for readjustments as needed, should rules that produce better utility come about with the advancement in science and health care strategies. Furthermore, it leaves room to assess the factors that might influence decision making and policy application such as the health care disparities between women from low socio-economic groups and their counterparts, the public health initiatives and how an increase

in access will affect them, and the resources distribution and possible expenditure versus loss or gain.

Using this moral theory in this research report, I have answered the research question: what are the potential consequences of the state assuming the ethical responsibility to increase access to Trisomy 21 prenatal testing for all women from low socio-economic groups in South Africa regardless of their health risks and indications?

In chapter 2, I showed that most of these women depend on social grants for survival and distributing resources once a baby is introduced to the family becomes a challenge, let alone a baby with special needs. Some families if not successful, may suffer irreversible financial harm and continue to struggle to make ends meet. I also discussed how due to the nature of our society and peoples' beliefs and lack of knowledge, some women may face discrimination and social stigma. I discussed how due to the toxins in the environment they live in, some of these women are predisposed to Trisomy 21 pregnancies. Lastly, I showed how there are health disparities between these women and their counterparts. An increase in access to the test for this cohort of women may afford them an opportunity to better prepare for the coming baby or terminate the pregnancy if the resources do not allow them to carry on with the pregnancy. It may further provide them with enough resources to teach and equip those around them to better support them if they proceed with the pregnancy and slowly eliminate untrue beliefs as they get more knowledge. An early test will increase the index of suspicion of health care workers allowing them to manage miscarriages and pre-term pregnancies early and prepare for the birth in an adequate facility where specialists and resources are available to better the chances of survival of the affected baby and mother.

Chapter 3 and 4 answered the question by showing the potential harms to the mother and child and how an increase in access can reduce or address those harms. Financial harm, psychological and potential threats to the unborn baby and the pregnancy were discussed and points from chapter 2 were reiterated. Chapter 4 reiterated that an increase in access would enable families and healthcare workers to increase the baby's chances of survival by being better prepared and preparing for the birth in an adequate facility. Secondly, the increase in access can promote better family dynamics where families can anticipate the big change that the affected baby will bring to the family, decrease the psychological impact of the changes, and give friends and family an opportunity to learn more about supporting the mother and baby. It can further lower the stigma by giving those who have been educated through genetic counselling a chance to impart their knowledge and raise awareness within families and communities. Lastly, it can protect the future child from having to endure these misfortunes by increasing preparedness or deciding on not having another child if the conditions do not allow the family to create an ideal environment for the future baby.

Chapter 5 showed how there could be a long-term decrease in expenditure on the costs of treating the complications that result from missed management of the Trisomy 21 health risks and the increase in access can serve as a public health initiative. A practical example using congenital heart conditions was used to show how much the country could potentially spend on each patient and how early management and diagnosis can significantly change those costs, using figures from countries that have published their expenditure. A cost utility analysis concluded that universalizing the test can result with greater utility especially when stake holders support the initiative, and everyone is committed to early diagnosis and management of the condition leading to the promotion of fewer hospitalizations and a better quality of life. I discussed how with early diagnosis fewer babies can go undiagnosed, the death rate can decrease as more women choose to discontinue their pregnancies, and those who do carry to

full term can get timely care for their conditions without complications as resources will be correctly allocated.

Many ethical concerns were raised and addressed. These include, the possibility of terminating unaffected babies due to false positive results, justifying selective abortion for gender since the test also reveals gender, discrimination against those who choose not to take the test should they have an unanticipated Trisomy 21 affected baby, and because termination results in more utility as it avails resources for those in need that, those who decide to continue with the pregnancy may be viewed as inconsiderate and not supportive of the initiatives to lower infant mortality and morbidity. Other concerns were that the decision to terminate the pregnancy on its own might raise questions on the moral acceptability of selective abortion for Trisomy 21, especially given the counterarguments on inherent moral worth. Those who have children with the condition and the affected individuals may consider this act discriminatory and as trying to eliminate those of their kind from existing. All these concerns were discussed and addressed in the research report. While addressing the ethical concerns and compiling this research report, I found that South Africa has little published data on the changing state of women below the age of 35 bearing Trisomy 21 babies. Insufficient data has been published on the statistics and even less data discussing the health care expenditure on treating Trisomy 21 related complications or the number of Trisomy 21 babies that die yearly and their complications. It would be interesting to see how many affected babies grow into adulthood and their quality of life as seen in other countries. It would also be helpful to hear the opinions of doctors and nurses about their experience with diagnosing and treating Trisomy 21 among this cohort of women and how often they see patients whose quality of life could have been improved by early management. If more families could be informed and stakeholders empowered to speak up or publish more, policies to support the initiative could be implemented and result in greater benefit for all.

In conclusion of this research report I to refer to the words of Mahatma Ghandi when he said "a nation's greatness is measured by how it treats its weakest members" (Wilkinson et al., 2010, p. 149). Women from low socio-economic groups are faced with debilitating conditions, some being out of their control. Showing them compassion through contributing to factors that can improve their health outcomes and those of their babies is the biggest gift we could give them. Supporting means that can empower them through reproductive autonomy will improve their quality of life and the nature of women in our country. While the cost of doing the prenatal screening is high, it is a small price to pay when compared to improving the quality of life of Trisomy 21 affected babies and lowering the harms caused by a lack of preparedness that they and their families face. In conclusion, the state assuming the moral responsibility to implement a policy that ensures that all pregnant women in low socio-economic groups in South Africa be offered non-invasive prenatal testing to rule out Trisomy 21 regardless of their health risks and indications in state facilities, can mitigate multiple adverse effects and promote health equity.

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