Non-Invasive Prenatal Testing on Down Syndrome: Choice or Control?

A Study on the Notion of Reproductive Autonomy and Informed Choice in the Routinization of the NIPT in The Netherlands

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Preface

For the past twelve years, I have worked as a medical pedagogical care provider in the hospital to support children with various physical health problems. During these years I have provided almost daily counseling to children with Down Syndrome, who need extra guidance to make medical interventions as least stressful for them as possible. My affinity for the special needs of children with Down Syndrome has remained, which is partly the motivation for making Down Syndrome the focus of this thesis.

Another motivation for the subject of this thesis is related to my personal stage of life. Friends around me are concerned with procreation, and I notice that this is inextricably linked to prenatal testing and the need for clarity about having a healthy child. The question is not whether people have performed prenatal testing, but whether test results are negative, i.e., if the future child is healthy. So, it seems very common to want to know preventively if a baby has possible health problems.

More and more I wonder if people still think about the idea of prenatal testing, why we want it, and why we take prenatal testing on Down Syndrome for granted. I started questioning if we still think consciously about the choices we make during pregnancy and becoming parents. Or maybe we became too conscious of risks and abnormalities?

I cannot quite reconcile the feeling I get working with children with Down Syndrome, with the need to want to know during pregnancy whether a child has Down Syndrome, yes or no. Does the possibility of testing for an abnormality outweigh the not-knowing? Did we lose having an open-minded pregnancy in which we can especially enjoy the hopes and dreams of a future with a child, regardless of if it is a child with a disability or not?

These questions and my personal interests became the starting point of research on the Dutch Non-Invasive Prenatal Test and the notion of reproductive autonomy, informed choice, and Down Syndrome.

Contents

1 Introduction

"The threshold for the Non-Invasive Prenatal Test (NIPT) goes down further: Down Syndrome screening to become free of charge," see figure 1, right side, (Herderscheê, 2022); *"The NIPT will be free of charge. What does that mean? 'The choice for abortion is made (too) quickly', "* figure 1, left side, (Tetelepta, 2022). A small sample of the many newspaper headlines in the Netherlands over the past year. The Netherlands' standard prenatal screening program will include the NIPT permanently as of April 2023, making the test free of charge for all expectant women. Previously, women could only have the test performed if they participated in a scientific study, which involved a co-payment of 175 euros. This change has triggered an ethical debate about NIPT, with questions being raised from various perspectives about the reproductive autonomy of expectant parents.

De NIPT wordt gratis. Wat betekent dat? 'De keuze voor abortus wordt (te) snel gemaakt'

ACHTERGROND Ieder jaar worden er minder mensen met het downsyndroom geboren. Uit wetenschappelijk onderzoek blijkt dat er een link is met het steeds eenvoudigere en goedkopere aanbod van diverse testen tijdens de zwangerschap. Nu de NIPT gratis wordt, vanaf volgend jaar, bestaat bij Stichting Down Syndroom (SDS) de angst dat vrouwen zonder al te goed nadenken de test ondergaan.

Berendien Tetelepta
vrijdag 13 mei 2022 om 11:23 aangepast 11:38

Drempel voor Nipt-test gaat verder omlaag: onderzoek naar downsyndroom wordt gratis

De zwangerschapstest op het Down-syndroom wordt volgend jaar gratis aangeboden aan alle zwangere vrouwen. Nu moeten zij daar nog 175 euro voor betalen Dat heeft minister Ernst Kuipers (D66) van Volksgezondheid laten weten aan de Tweede Kamer.

Gijs Herderscheê 19 april 2022, 14:16

Figure 1: Dutch media outlets about the NIPT, related to the change to free offering the test, as of April 2023. Copyright 2022 by Tetelepta, Nederlands Dagblad; copyright 2022 by Herderscheê, De Volkskrant.

In Dutch liberal health ethics, autonomy is a core value. In the field of reproduction, reproductive autonomy is also referred to as reproductive autonomy: the freedom of the individual to decide for himself or herself whether you want children and if so, how, when, how many, with whom, and under what circumstances (de Jong, 2013). The Gezondheidsraad (2013) (Health Council), writes the year before the first official implementation of NIPT in the Netherlands, that NIPT aims to increase women's reproductive autonomy by providing meaningful reproductive choices. In other words, providing women with the option of choosing between carrying a pregnancy to term or terminating it (Gezondheidsraad, 2013). NIPT also provides many advantages to expectant mothers. The primary benefits include quick results availability, non-invasiveness, reduced risk to the fetus, and higher accuracy compared to earlier screening technologies Rijksinstituut voor Volksgezondheid en Milieu (National Institute of Public Health and the Environment) (RIVM, n.d.-b). According to Foster, Royal, and Sharp (2006), the test is now routinely provided to all pregnant women in the Netherlands because of this favorable combination of factors. Foster et al. (2006) describe this process toward routinization of genetic information as normalizing a unique and extraordinary medical examination, into an everyday and ordinary aspect of health care.

However, there are several issues with the NIPT's routine that have been brought up. The routine offering of the test may influence the degree of informed decision-making, increase (social and moral) pressure on women to undergo testing, and/or raise the possibility of stigmatization and discrimination against people who have a particular condition, such as Down Syndrome (van der Meij et al., 2022). To detangle these issues that have emerged, I study the historical and current Dutch situation regarding the NIPT. Additionally, I conduct a literature review on the notion of reproductive autonomy and informed choice from different perspectives. The dominant bioethical understanding of reproductive autonomy emphasizes the individual's right to self-determination.

Nonetheless, from a feminist perspective, the promise that NIPT would increase women's reproductive autonomy has been questioned. From a feminist formulation of autonomy, an individual makes choices based on his or her relational and societal affiliation and thus also depends on the circumstances in which they or find themselves (Sherwin, 1998). Additionally, discriminatory messages about people and groups who have diseases are believed to be inextricably linked to prenatal screening for chromosomal abnormalities (Dondorp et al., 2015). Prenatal screening programs' social accessibility, as well as individual women's preferences, are both considered in this perspective, which is also referred to as the disability rights critique of prenatal screening (Dondorp et al., 2015; Gezondheidsraad, 2013).

In summary: In our society which is built on the liberal ethos of autonomy, we must ensure that people make free and fully informed decisions about their future children and family. This requires health professionals who are supportive and provide balanced and accurate information. It also means that we need to know more about the rich and varied lives of people with disabilities and not just about genetic ”errors”.

With this thesis I aim to critically think about the potential dangers of the NIPT on reproductive autonomy, wishing that expectant parents remain autonomous in what they desire in their step toward parenthood. Therefore, I investigate the pros and cons of the routinization of the Dutch NIPT that will be offered free and routinely as of April 2023. Although the NIPT technology is claimed to increase women's ability to make their own decisions and reproductive choices, there are arguments that raise new questions about autonomy, informed choice, and the potential social implications of testing for Down Syndrome. How can we deal with the routinization of the NIPT ethically and socially? How does the routine offering of the NIPT affect the reproductive autonomy of expectant parents? What impact does this potentially have on the choice to carry a pregnancy with Down Syndrome to term, or to terminate it? And what are the implications of this on Down Syndrome? To delve deeper into these questions, the main research question of this thesis is as follows:

> How can we understand the routinization of the NIPT test in The Netherlands, in relation to the notions of reproductive autonomy and informed choice?

By examining different meanings and values that are involved in understanding reproductive autonomy and informed choice, I take a critical view on the assumption that the current routine offering of the NIPT entails solely benefits for women's reproductive autonomy. In doing so, I highlight the importance of continuing critical research on NIPT, which is so embedded in Dutch society, from the various moral concerns that have been raised about the constitution of reproductive autonomy.

To answer the research question, I have conducted literature research on the concepts of reproductive autonomy and informed choice, to understand the different meanings and values involved in these concepts. In doing so, I critique the assumption that the current routine provision of NIPT only benefits women's reproductive autonomy. To enable a close reading of these concepts, my literature review is conducted on three different perspectives on reproductive autonomy, which are addressed by each important author in separate chapters in this thesis. As a result, the thesis is structured as follows.

To gain insight into the origins and development of the current NIPT program, the literature review starts with studying Dutch policy documents on NIPT in Chapter 2. This involves several agencies, including the National Institute for Public Health and the Environment with its department of pre- and neonatal screening, and the Health Council of the Netherlands. In addition, a brief sociocultural biography of Down Syndrome is outlined, for which the work "*Downs: The history of a disability (Biographies of Disease)*" (Wright, 2011), forms the basis. This literature provides insight into the social status of people with the syndrome and the origins of prenatal testing for Down Syndrome.

Furthermore, the literature review delves into the concept of reproductive autonomy as understood from three different perspectives. Chapter 3 deals with the bioethical liberal perspective. Dr. and author Catherine Mills examined reproductive autonomy from the perspective of individual choice as it relates to reproduction and pregnancy. Her work "*Futures of Reproduction*" (Mills, 2011) discusses thoughts on the freedom of being able to make reproductive choices.

A third perspective discussed in Chapter 4 is grounded in disability rights criticism, in which Parens and Asch (1999) provide an expressivist critique of the social-societal implications of reproductive and informed choices on Down Syndrome. In addition, my literature review is also partly based on Dutch representatives concerned with the position of Down Syndrome in Dutch society and specifically within NIPT, such as Stichting Downsyndroom, 2021 (Down Syndrome Foundation), which originates from parent initiatives.

Finally, because reproductive autonomy relates closely to the female body, my literature review in Chapter 5 draws on the views of Prof. and philosopher Susan Sherwin. In her work "*The politics of women's health: exploring agency and autonomy*" (Sherwin, 1998), Sherwin emphasizes the importance of social conditions, as a counterpoint to the prevailing liberal method of contemporary health care. Sherwin explores the concept of relational autonomy, in which social norms influence decisions about who will or will not be born. The literature review is followed by the discussion in Chapter 6, which combines the insights from the different perspectives to critically analyze the moral concerns that have been raised about the constitution of reproductive autonomy within the current NIPT. The final Chapter 7 of the thesis is the conclusion, in which I bring together all the findings until a concluding final word is given on the moral pros and cons of routinizing NIPT on the concept of reproductive autonomy and informed choice.

2 The Non-Invasive Prenatal Test

In this chapter, I take a closer look at the non-invasive prenatal test (NIPT). In the first part of this chapter, I provide a brief historical sketch of NIPT and prenatal screening in general, with which reproductive autonomy is closely related. In the next section, I explain more about Down Syndrome, the main chromosomal abnormality detected by prenatal screening. In the final sections, I explain the current situation of the NIPT in the Netherlands and the ethical concerns raised about the test, that underlie this study.

2.1 Background of NIPT

In the next paragraphs, research by Lo et al. (1997) and de Jong (2013) forms the basis for the historical sketch of prenatal screening and NIPT. Also, policy documents from the Rijksinstituut voor Volksgezondheid en Milieu (RIVM, National Institute for Health and Environment) and the Gezondheidsraad (Dutch Health Council), provide important insights into the background and purpose of NIPT in the Netherlands.

2.1.1 History of prenatal screening

In her ethical reflection on the scope of testing for fetal anomalies “Prenatal screening à la carte? Ethical reflection on the scope of testing for foetal anomalies” (de Jong, 2013), Antina de Jong describes the history of prenatal screening. Soon after the first report in 1961 on the possibility of screening the fetus in utero for abnormalities by amniocentesis, prenatal testing found its way into clinical practice. Amniocenteses are invasive tests that allow the detection of fetal disorders during pregnancy, using a needle to aspirate amniotic fluid through the abdominal wall to test the fluid for chromosomal abnormalities in the fetus. From that point on, prenatal screening as offered today in most Western countries gradually developed. Initially, screening was used as a public health tool to reduce morbidity and mortality by preventing the birth of children with (severe) genetic disorders, including Down Syndrome (trisomy 21), Edward Syndrome (trisomy 18), and Patau Syndrome (trisomy 13). Amniocentesis was offered only to pregnant women of advanced maternal age (first ≥38 years, later ≥36 years in most countries), because they have an increased risk of having a child with a chromosomal abnormality (de Jong, 2013).

Beginning the mid-1980s, this offering expanded to include the chorionic villus test.

Using ultrasound, a needle through the abdomen is used to extract villous tissue from the placenta for testing of genetic abnormalities in the fetus. This conventional prenatal screening has long been the gold standard for prenatal diagnosis. Both invasive methods, however, carry a miscarriage risk. Because of this risk and given the relatively high cost of the invasive techniques, offerings were limited to pregnant women with advanced gestational age (de Jong, 2013).

Subsequent screenings increasingly offered a fetal ultrasound to all pregnant women to detect congenital anomalies. A wider range of possible abnormalities was screened for, including sex chromosome abnormalities, or neural tube defects such as spina bifida (spina bifida) and anencephaly (open skull). These testing techniques remained constant for decades, with the screening strategy consisting of a limited set of standard test offerings that pregnant women could accept, or refuse (de Jong, 2013).

The availability of new techniques has led to the possibility of faster and cheaper diagnostic tests, including the non-invasive prenatal test (NIPT), which also targets the most common chromosomal abnormalities (trisomy 21, 18, and 13) and drastically reduces the number of invasive procedures as the test is done by a blood test of the pregnant woman. As a result, NIPT has over time replaced the invasive diagnostics of amniocentesis and chorionic villus testing (de Jong, 2013, p. 12).

2.1.2 History of NIPT

In 1997, Yuk-Ming Dennis Lo, director of the Li Ka Shing Institute of Health Sciences at the Chinese University of Hong Kong and a foreign member of the National Academy of Sciences, found a way to examine fetal health without the dangers associated with invasive procedures such as amniocentesis or chorionic villus testing (Lo et al., 1997). In fact, blood from the placenta, see figure 2, is a rich source of knowledge about fetal health and possible chromosomal abnormalities, thanks to fetal DNA fragments circulating in the pregnant woman's blood (Lo et al., 1997). From this discovery emerged the non-invasive prenatal test. To check for the most common chromosomal abnormalities, such as Down Syndrome, Edward Syndrome, and Patau Syndrome, NIPT is performed on the pregnant woman's blood, which can be drawn from gestational week 10.

However, the result is not conclusive and does not guarantee a diagnosis: If the result is abnormal, the expectant mother is still offered the option of chorionic villus testing or amniocentesis (RIVM, 2021). The NIPT is especially praised because the test does not initially involve any invasive procedures in the uterus and thus the pregnant person is not at risk of miscarriage because of the test. Partly because of this, NIPT has become the leading method of prenatal testing. More than 60 countries around the world began offering non-invasive prenatal testing in 2011 (Ravitsky et al., 2021). And since April 1st, 2017, Nederland's Bevolkingsonderzoek (Dutch population screening program) has offered NIPT as a prenatal screening method (Gezondheidsraad, 2016).

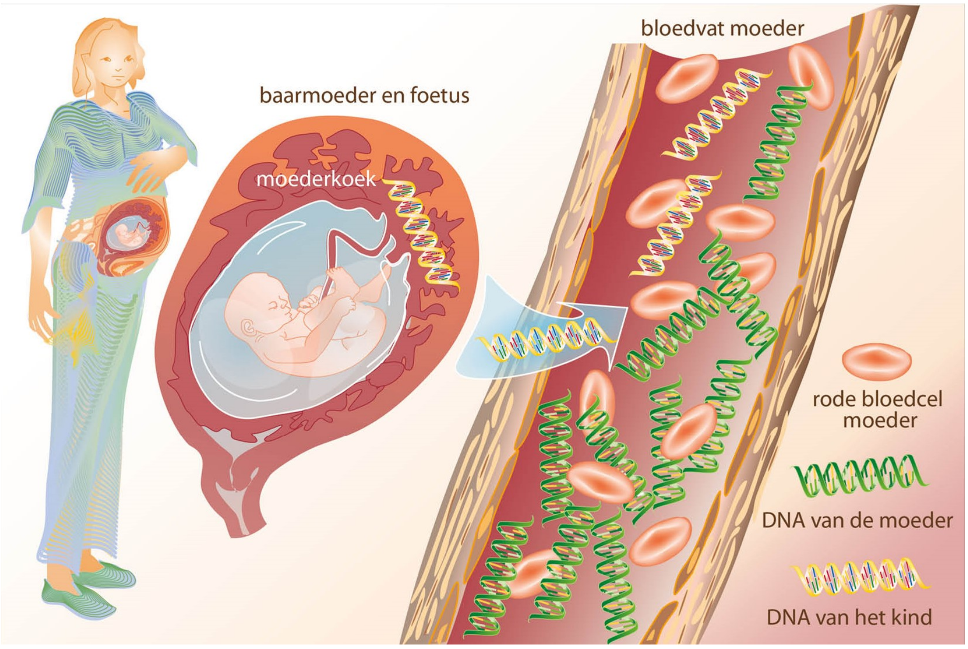

Figure 2: The non-invasive prenatale test. DNA fragments from the placenta are released into the pregnant woman's blood. Non-invasive prenatal testing is based on the analysis of placental and maternal DNA fragments in the pregnant woman's blood. The NIPT technique makes it possible to look for trisomies in the fetus. Copyright 2019 by Janssen, Multimedia department UMCU.

2.1.3 Aim of prenatal screening

Prenatal screening is recognized by Nederland's Bevolkingsonderzoek as population screening. Population screening involves the medical examination of people who have no health problems. People are invited by the government to participate in these medical examinations that look for disease, an inherited predisposition to disease, or conditions that increase the risk of disease. The idea behind population screening is, that through early diagnosis disease or its onset can be detected earlier, allowing treatment to begin sooner, and resulting in less invasive treatment options (RIVM, n.d.-a).

According to the Gezondheidsraad, prenatal screening adds a special aspect to the general features of population screening because prenatal screening aims to detect chromosomal abnormalities, for which there are often no or limited treatment options (Gezondheidsraad, 2016). As a result, prenatal screening serves two distinct purposes. First, screening for chromosomal risk factors serves the overall goal of population screening, which is to improve the health of the pregnant woman and her unborn child. In addition, prenatal screening focuses on detecting chromosomal abnormalities for which there are often no or few treatment options, and because prenatal screening involves detecting chromosomal abnormalities for which there are often no or few treatment options, the second goal is to provide meaningful choices and promote reproductive autonomy (control over one's reproduction) to the pregnant woman and her partner (Gezondheidsraad, 2016). In this way, prenatal screening allows parents to make meaningful reproductive choices, for example, to prepare for the birth of a child or to consider terminating the pregnancy if the screening reveals that the unborn child has a chromosomal abnormality (RIVM, 2021).

From the beginning of the prenatal screening program in the Netherlands, the policy regarding prenatal screening has been questioned, as the purpose of offering testing for fetal abnormalities has been questioned. While other population screening programs offer options for primary prevention or treatment, treatment in the prenatal context is rarely an option because there are often no or few treatment possibilities. Moreover, "the only preventive measure in this context would be selective abortion" (de Jong, 2013, p. 12). Describing selective abortion as a preventive measure is ethically problematic because this may send the message that women should have an abortion if they are pregnant with a fetus in which an abnormality has been found and that people with certain conditions are not welcome in society (Parens & Asch, 1999). The preventive goal of prenatal screening was therefore increasingly criticized and replaced by an autonomy view, emphasizing individual reproductive decision-making (de Jong, 2013). Since then, the goal of offering prenatal screening has no longer been formulated in terms of prevention or health benefit, but as providing valuable options by providing prospective parents with health-related information about the fetus and offering the possibility of reproductive choice. To summarize this goal: To facilitate autonomous reproductive choice. Thus, with prenatal screening, the focus is not so much on improving health at the population level as in population screening, but on promoting reproductive autonomy (Gezondheidsraad, 2016).

2.1.4 Reproductive autonomy and informed choice

The non-invasive prenatal test offers pregnant women reproductive choices in screening for the possible presence of Down Syndrome in the fetus (Gezondheidsraad, 2016). In practice this means first, offering the opportunity to participate in prenatal screening and second, being able to make a choice depending on the screening results to terminate or carry the pregnancy to term in preparation for the possible death of the fetus in utero of the arrival of a child with Down Syndrome. In this process of making choices, it is critical that the information provided is accurate, about possible ethical and psychosocial consequences (Gezondheidsraad, 2023). This is also known as an informed choice. Informed, voluntary choice by the participant is necessary for screening within a population-based study (Gezondheidsraad, 2016). The Gezondheidsraad argues that if informed choice cannot take place, the goal of prenatal screening - to provide reproductive autonomous action options - will not be achieved. As a result, the provision of prenatal screening, including NIPT, would lose its "moral justification" (Gezondheidsraad, 2016, p. 35).

In summary, the concept of informed choice seems closely related to the goal of prenatal screening (and therefore NIPT) to promote reproductive autonomy. But in this view, if informed choice cannot be met, it can be argued that in practice this may undermine rather than promote autonomy. Because of the complexity of - and interaction between - these concepts, these concepts are discussed in detail later, which forms the heart of this study.

2.2 NIPT & Down Syndrome

For a long time, the NIPT has carried the name the Down Syndrome test and still today, the main chromosomal abnormality detected by prenatal screening is indeed Down Syndrome. In this chapter, I elaborate on what Down Syndrome is, and how this syndrome has grown into the most discussed condition in the field of prenatal screening. Therein, it is also important to outline how Down Syndrome is viewed in society today.

2.2.1 What is Down Syndrome?

It has been more than 150 years since John Langdon Down, an English physician, first described a group of people with a condition now known as Down Syndrome, sharing similar external symptoms: short limbs, reduced muscle tone, limited physical growth, a flat facial profile, and a large protruding tongue (Thomas, 2017). Down Syndrome is known as one of the most common chromosomal disorders in the world, and in most cases (96%) is caused by an error during cell division before or after fertilization (Gezondheidsraad, 2023). If there is a whole chromosome too few or too many, we speak of a numerical chromosomal abnormality or aneuploidy (Gezondheidsraad, 2016).

Down Syndrome is caused by trisomy 21, which means three copies of chromosome 21 occur with the disorder and therefore also bears this name, see figure 3. The Dutch dictionary Van Dale used the terms idiocy and moron up until 2010 to refer to Down Syndrome. The text in the books was changed to 'mental weakness' and 'a mongoloid appearance' in response to an email from a mother of a girl with Down Syndrome. According to the dictionary, Down Syndrome is a mental impairment characterized by a round face and a small nose. Since the 1960s, the term 'mongoloid' has not been used to describe a person with Down Syndrome.

When someone with Down Syndrome was referred to as a Mongol, the People's Republic of Mongolia complained to the World Health Organization (WHO) in 1965. In 1965, the WHO formally ordered the removal of this designation from all official documents (Lindeman, Danijs, & Slager, 2016, p. 17). In the Prenatal Screening Script (RIVM, 2021), Down Syndrome is explained as follows: People with Down Syndrome have intellectual disabilities, which can range from mild to very severe. They develop slower and more limited than people without Down Syndrome; it is not possible to predict developmental progress; this varies from child to child. That is why, according to the RIVM, it is important for people to interact with others so they can learn (speech) skills that are important for everyday life. Adolescents with Down Syndrome are often shy and withdrawn. Attention problems and behavioral problems are twice as common in these adolescents as in other adolescents. How severe the behavioral problems are is directly related to the severity of the intellectual disability. Up to about 30 years of age, half of the adults with Down Syndrome live at home. Others live in small living arrangements or their own home with supervision. Throughout life, people with Down Syndrome require

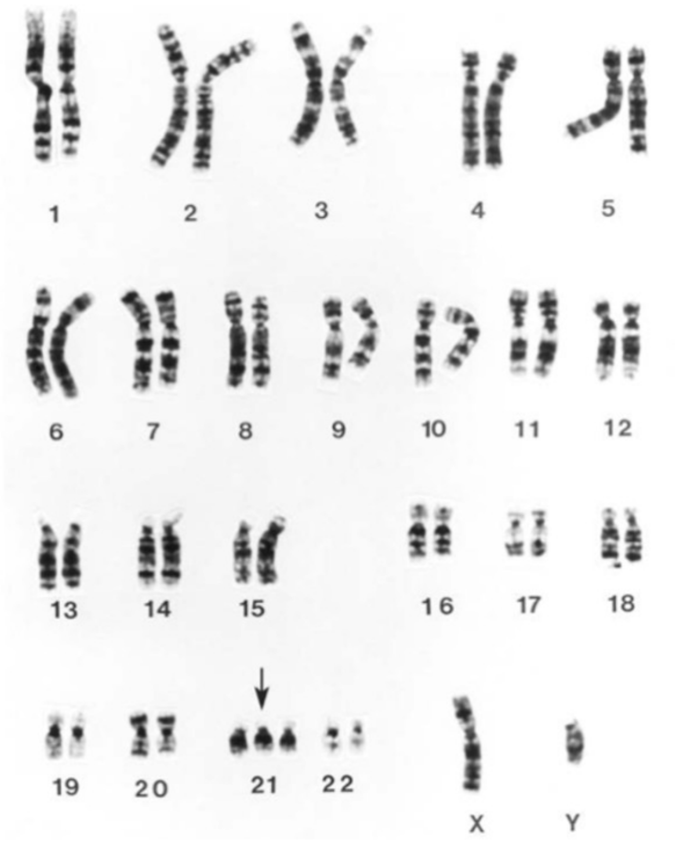

Figure 3: Illustration of the chromosomes of newborns with trisomy 21 (three copies of chromosome 21). Copyright 2013 by Williatt, East Anglian Regional Genetics Service/ Scientific Photo Library.

guidance and support (RIVM, 2021, p. 13-14).

People with Down Syndrome also have an increased risk of various physical defects and health problems. About half of the people with Down Syndrome are born with a heart defect. If necessary, this defect can be treated surgically. This almost always yields a good result. It is also possible for a child with Down Syndrome to be born with a gastrointestinal defect; in that case, too, surgery is necessary and possible shortly after birth. In addition, people with Down Syndrome are more likely to have problems with the respiratory system, hearing, eyes, and defenses against infection. Adults with Down Syndrome develop Alzheimer's disease more often and at a younger age than average. How severe the health problems are, varies from person to person. People born with Down Syndrome currently have a life expectancy of 60 years (RIVM, 2021, p. 13-14).

2.2.2 Down Syndrome and prenatal screening

In *Down's Syndrome Screening and Reproductive Politics: Care, Choice, and Disability in the Prenatal Clinic (1st ed.)* (Thomas, 2017), Thomas provides useful insights into the history of Down Syndrome and prenatal screening, in which he illustrates how the routinization of prenatal screening frames Down Syndrome as a negative pregnancy outcome. Beginning in 1968, Down Syndrome could be detected thanks to amniocentesis. Soon amniocentesis became the most popular prenatal test for chromosomal abnormalities. At the time of the rise of amniocentesis, medical opinions warned expectant parents of the consequences of giving birth to a child with Down Syndrome and their ability to properly raise their other children. In discussions of prenatal screening, Down Syndrome was "framed" as a daunting and stressful experience, a genetic disease that was to be avoided and could be avoided by prenatal technology. Society had come to see Down Syndrome as a burden; people had expectations of a perfect baby. At the time, the main purpose of prenatal testing seemed to be to inform expectant parents sufficiently so that they could choose abortion, rather than to prepare them psychologically for the burden of having a child with Down Syndrome (Thomas, 2017).

However, in the late 1970s, Down Syndrome was viewed somewhat more favorably. The burden of having a child with Down Syndrome was no longer so emphatically described. In "*Downs: The history of a disability (Biographies of Disease)*" Wright (2011), Wright looks at this profound change in the attitude toward Down Syndrome over the past decennia when society began to take more account of people's abilities. More and more people with Down Syndrome were receiving therapy and children attended regular schools, so their communication and reading skills generally improved. People with Down Syndrome became much more likely to work and got more influence over their own lives, many of them were also granted the right to vote. There was not only concern about the severity of the disorder and the genetic cause, but also about the quality of life of people with Down Syndrome and the psychological counseling of families with children with Down Syndrome. People with Down Syndrome were acknowledged for typically making positive contributions to their families, community, and peer groups. Small groups of Down Syndrome parents came together to form a social movement to advance the conversation in society about Down Syndrome and disability (Wright, 2011).

Despite these changing societal attitudes, prenatal screening for Down Syndrome became the subject of debate. Indeed, reciprocally, the loosening of legal restrictions on the selective termination of fetuses led to an increase in the prevalence of prenatal testing and in the number of pregnancies ending with fetuses with Down Syndrome. Conversely, prenatal screening raised the question of whether people with Down Syndrome should be born now that the technologies were there to end the condition through abortion (Stichting Downsyndroom, 2022). In summary, Down Syndrome evolved into the stereotypical condition used to argue for prenatal screening. In doing so, prenatal screening has significantly changed the way families and communities view individuals with Down Syndrome (Stichting Downsyndroom, 2022).

2.3 The current Dutch situation

Prenatal screening is currently in the spotlight in the Netherlands. This is mainly due to recent developments in the offering of the NIPT program. In the following paragraphs, I look at the current Dutch situation of the NIPT, to understand the concerns that have been raised about the test and that underlie this study.

2.3.1 Latest advice

From April 1st, 2017, pregnant women in the Netherlands can choose NIPT as a first-tier test for prenatal screening (RIVM, 2021). Until April 1st, 2023, this offering of the NIPT was still part of a scientific study (TRIDENT-2), in which participants made a personal contribution of 175 euros. As of April 2023, the Minister of Health, Welfare, and Sport wanted to include NIPT in the national prenatal screening program, offering the test free of charge to all pregnant women in the Netherlands, which the Gezondheidsraad has translated into its latest advisory report on February 20, 2023: Wet Bevolkingsonderzoek: de niet-invasieve prenatale test (NIPT) als bevolkingsonderzoek (Population Research Law: the non-invasive prenatal test (NIPT) as a population-based study). Briefly, that opinion reads as follows:

> "The committee advises the Minister of Health, Welfare, and Sport to grant Regional Prenatal Screening Centers the license to include NIPT in the national prenatal screening program, under the conditions of implementing 'accessible and understandable information and counseling' for an informed decision" (Gezondheidsraad, 2023, p. 5).

The committee also recommends that screening henceforth be called screening for severe chromosomal abnormalities (Gezondheidsraad, 2023, p. 5). Both recommendations address risks associated with changes in NIPT offerings beginning April 2023, which the Gezondheidsraad recognizes as routinization and discrimination.

2.3.2 Set up of the NIPT program

A brief outline of the NIPT program shows how pregnant women will face NIPT starting April 1st, 2023. In fact, pregnant women will be offered NIPT, as well as a 13-week ultrasound, as standard within prenatal screening. In practice, the offer of NIPT looks as follows.

During the first consultation, the midwife asks all pregnant women if she wants to be informed about the possibility of prenatal screening for chromosomal abnormalities (the so-called touch-up). If the pregnant woman indicates that she does not wish to be informed about this, the information about this screening offer stops. This is noted in the pregnant woman's file. No counseling session follows. When the pregnant woman indicates that she wishes to be informed about prenatal screening, a counseling session takes place with a qualified counselor, usually the midwife. During the counseling interview, the counselor provides the pregnant woman with the information and support needed to make an informed decision about participating in prenatal screening with NIPT. The pregnant woman can have blood drawn for NIPT at a blood collection location nearby and will receive the NIPT result within ten working days.

If this result indicates an abnormality, such as Down Syndrome, the counselor calls the pregnant woman. If she wishes, the counselor refers the pregnant woman to a Center for Prenatal Diagnostics where she is informed about the options for follow-up testing. That follow-up testing, which takes place at the Prenatal Diagnostic Center, usually consists of invasive diagnostics with chorionic villus testing or amniocentesis and/or ultrasound.

If the follow-up testing reveals that secondary Down Syndrome is present, the pregnant woman has two options: continue or terminate the pregnancy. In both parts of the program, pregnant women (who wish to do so) are informed promptly of the possible presence of Down Syndrome in the fetus. In this way, they are offered a reproductive course of action. This means they are given the opportunity to make an informed choice to terminate or carry the pregnancy to term and prepare for the possible death of the fetus in utero or the arrival of a child with Down Syndrome (Gezondheidsraad, 2023, p. 23).

2.3.3 Risks

The Gezondheidsraad advice describes two risk factors that relate to the recommendations in this opinion. These risk factors relate to the standardization of NIPT and prenatal screening and the relationship to Down Syndrome. As described in the advisory report, the routinization of NIPT means that the offering is presented as an ordinary part of pregnancy care, so participation is taken as self-evident. Concerns about routinization have arisen in part because of the good testing properties and safety of NIPT and the simplicity of the test. As a result, pregnant women may not sufficiently realize that NIPT may involve potentially radical and difficult follow-up decisions. The Gezondheidsraad mentions that due to routinization, pregnant women may experience pressure from the environment or from the obstetric healthcare professional, to participate in screening. And that, for making an informed choice, “good counseling is important” (Gezondheidsraad, 2023, p. 32).

Also, there are concerns from society on the discriminatory effect of NIPT, which through routinization would express that people with a (severe) congenital anomaly such as Down Syndrome, are not or are less welcome in society. The Gezondheidsraad indicates that the way in which the screening is offered must make clear that the purpose of the screening is to offer pregnant women reproductive options for action. This may be evident, for example, in how the screening is presented as a choice to be considered and not as a routine test. It must also be evident that the efforts made enable participants to make their own informed choice; the latter assumes, for example, that proper care for those with congenital anomalies and intellectual disabilities is guaranteed. As has been described, the opinion, therefore, advocates referring to “screening for chromosomal abnormalities” to better cover the purpose of NIPT. The use of the term Down Syndrome in the title and purpose of the screening may inadvertently give the impression that children with these conditions are less welcome.

Through routinization of NIPT poses a risk that NIPT will be presented as an ordinary part of antenatal care, with participation taken as self-evident. But precisely to ensure informed choice, according to the Gezondheidsraad (2023), it is essential that NIPT not be presented as a routine test but as a choice to be considered. Thus, routinization poses a threat to the informed choice, and thus the reproductive autonomy, of the pregnant woman. Also, NIPT could have a discriminatory effect on Down Syndrome in society.

2.4 Conclusion

In this chapter, I explained that NIPT is applauded for several reasons and why the test has become the most common prenatal screening method in the Netherlands. Yet, there are also concerns about the new offering of the NIPT program per April 1st, 2023, which is currently in the spotlight, because of the potential effects of routinizing the test on the concept of informed choice. This chapter also explained how Down Syndrome has become the focus of prenatal screening and how this has a potential discriminatory social impact.

Because of the complexity of - and the interaction between – the concepts of informed choice, reproductive autonomy, routinization, and discrimination, in the following chapter, I first explore the concept of reproductive autonomy in more detail before examining how this concept enacts within the routinization of NIPT. Secondly, to truly understand the effect of the routinization of NIPT in the Netherlands in relation to the notions of reproductive autonomy and informed choice, I explore the concept of reproductive autonomy because this concept expresses the intent of prenatal screening, which is an essential aspect of NIPT. What exactly does reproductive autonomy entail, in the context of the routinization of prenatal screening? I examine these concepts from different perspectives, all of which are involved in the field of prenatal screening and/or Down Syndrome.

3 The liberal understanding of reproductive autonomy

In this chapter, I dive deeper into the concept of reproductive autonomy, by first elaborating on the importance of reproductive autonomy. In the following paragraphs, I approach reproductive autonomy from a liberal perspective, as the common understanding of reproductive autonomy in prenatal screening practices.

3.1 Why reproductive autonomy matters

The right to have control over one's fertility and body, and to be able to decide when and how to start or grow a family, has not always been taken for granted. In the twentieth century, the enforcement of this right to reproductive autonomy saw important social developments in the Netherlands (Historiek, 2021).

Early in the 20th century, contraceptive education and its sale were prohibited, and abortion was considered a crime. Contraception was still a sensitive topic for many years after World War II. Nearly 200 letters to the editor were written by family physicians who felt that an article by two female doctors on contraceptives in the 1949 Dutch Journal of Medicine went against the moral standards on which their profession was based (Historiek, 2021). The sexual revolution and a social conversation about abortion both began in the 1960s. Professor of gynecology Gerrit Jan Kloosterman made the following statement on national television on May 9th, 1967: "The only justification I see for terminating a pregnancy is when the carrier of that pregnancy is in a situation that could be described, perhaps with a thick word, as an existential distress." (Ruigrok, 2007, 12:43). His phone rang nonstop the next day with requests for abortions. In response, Kloosterman established the first abortion committee with medical professionals to discuss specific cases of women seeking abortions and decide whether to grant those requests (Ruigrok, 2007).

The Partij van de Arbeid (Dutch Labour Party, PVDA) submitted an initiative bill in 1970 to limit the criminalization of abortion in response to the legalization of abortion in neighboring countries such as Denmark and the United Kingdom (Bol, 1970). After an interview with a qualified physician, the woman would decide whether to have an abortion. Dolle Mina, a feminist advocacy organization, ran a pro-abortion campaign at the time. With slogans such as "Baas in eigen buik" (Boss in your own belly) and "Women decide," see figure 4, they emphasized that a woman could make her own decisions about her life, including carrying a pregnancy to term, (Historiek, 2021). The first abortion law was finally passed in the 1980s, and in November 1984 the Netherlands passed the Wet Afbreking Zwangerschap (Termination of Pregnancy Act), making abortion legal there (Treffers, 2006).

Countless generations of women, thanks to this legal availability of abortion, have been able to plan and choose when to start a family. This form of control over a woman's

Figure 4: Dolle Mina launches the slogan “Baas in eigen buik” during a raid on a gynecologists’ congress in Utrecht, March 14, 1970. Copyright 1970 by Herschel, Spaarnestad / Collection IAV - Atria.

own body, life, and future can be guaranteed in the Netherlands by two different laws. Legal information about these two laws is provided on RIVM’s Dutch Pre- and Neonatal Screening (PNS) website. First, the Wet op het Bevolkingsonderzoek (Population Screening Law, WBO) imposes strict quality standards for screening.

This law defines NIPT as “population screening for serious diseases or abnormalities for which no treatment or prevention is possible,” with which it seeks to emphasize the protection of the population from the risks associated with screening through NIPT. This law seeks to assure persons participating in NIPT of “a sufficient utility of the research in question,” thereby ensuring that the benefits of participating in NIPT outweigh the harms. The second law protecting reproductive autonomy has to do with informed decision-making, which is emphasized in NIPT. However, according to the Wet op de Geneeskundige behandelingsovereenkomst (Medical Treatment Agreement Act, WGBO), elderly couples also have the “right not to know.” Consequently, the new NIPT protocol, therefore, includes asking parents first if they want to undergo the test before providing further information about NIPT (RIVM, n.d.-b).

Today, the right to choose, such as the freedom to choose whether to have children and to have control over one's own reproductive and medical care, is legally protected by several laws, which are important in shaping the NIPT program. In the following sections of this chapter, I discuss in more detail how different perspectives view reproductive autonomy to help shape the understanding of reproductive autonomy in relation to NIPT and prenatal screening. Through the examination of liberal bioethics, a critique of the disability rights movement, and feminist ideologies, I contribute to the understanding of reproductive freedom and informed choice which helps to better understand the concept of reproductive autonomy. In this way, I can explore reproductive ethical issues in the Netherlands - such as how routine NIPT affects women's reproductive autonomy and informed decision-making, particularly regarding the decision of expectant parents to have or not have children with characteristics typically associated with disabilities, such as Down Syndrome.

3.2 The liberal understanding of reproductive autonomy

Free will and the non-interference principle define the typical liberal understanding of reproductive autonomy (John & Robertson, 1982; Purdy, 2006, p. 287). Reproductive autonomy, according to Johnston and Zacharias (2017, p. s7), is related to the idea that people should have self-governance over their reproductive options and decisions, including the ability to choose when to have children. The idea of liberal reproductive autonomy can be interpreted broadly, raising the issue of just what choices individuals should have. This can be demonstrated by the fact that parents have the "freedom to choose against disability" (Harris, 2005, p. 13), in which the right to abortion plays a key role because this increases women's autonomy by giving them more control over their own bodies and lives (Denbow, 2014, p. 415). This reflects the liberal perspective that a woman is an autonomous individual and a free chooser in terms of reproductive practices. She has the power to decide and control what she wants to happen or not happen to her body.

Professor of Bioethics Catherine Mills addresses this problem in reproductive bioethics as the problem of parents being able to "choose children", in her work *Futures of Repro-*

duction (Mills, 2011, p. 9). She examines how social norms affect decisions about who is born or not and discusses her thoughts on this freedom. The concepts of value pluralism and the harm principle are discussed in this. As this is the terrain of new reproductive practices, Mills first elaborates on the idea of liberal eugenics.

3.2.1 Liberal eugenics

Francis Galton coined the term eugenics in 1883, referring to the scientific study of methods of improving genetic qualities through selective breeding. Eugenics gained worldwide popularity in the early 20th century when eugenicists believed they could perfect humans and eliminate so-called social ills through genetics and heredity (National Human Genome Research Institute (NHGRI), 2022). Partly because of this, eugenics has an unreliable history.

The term has mostly been associated with German National Socialism in the Third Reich in which eugenics was part of Nazi Germany's population policy between 1933 and 1945. Efforts were made during this period to improve the genetic makeup of the German people to create a pure Aryan race: a group of people who would be superior to others. To this end, a form of eugenics, which was also called "Racial Hygiene," was used, with the intention of eliminating an entire inferior "race." To create a genetically healthy Aryan people according to Nazi eugenics, a ban on marriage between Aryans and non-Aryans, forced sterilization, euthanasia and later the killing of people who did not conform to the National Socialist ideal was used (Mills, 2011).

Although the term eugenics was abandoned after World War II because the term was associated with moral condemnation, technological developments in genetics and related prenatal screening methods have rekindled interest in eugenics. Liberal or laissez-faire eugenics are other names for contemporary eugenic practices (Mills, 2011, p. 6).

Whereas in earlier eugenics, the coercive and interventionist role of the state was the main flaw, in contemporary eugenic practices, the very notion of freedom forms an important role. This implies that the population should not be forced to make decisions, as this would hinder efforts to achieve reproductive autonomy. In current framing, it is no longer appropriate to shape certain beliefs about how people should live, or the reproductive choices of citizens, because coercion limits the possibilities of expectant parents and individual autonomy. Mills articulates this as follows: the "final arbiter of moral acceptability" in the new liberal eugenics, is "unrestricted parental choice, in which state regulation and coercion must be minimized" (Mills, 2011, p. 13). Mills claims that freedoms related to parenthood and reproduction will become stronger if the state maintains its neutrality because parents will have more choice and control over the offspring born (Mills, 2011). To conclude: New liberal eugenic practices may be considered appropriate for Dutch society where individual freedoms extend to reproductive choices. In this, liberal eugenics adheres to two core principles that are important to explore in the context of current the NIPT: value pluralism and the harm principle.

3.2.2 Value pluralism

Value pluralism refers to the general view that liberal eugenic practices should remain neutral and allow everyone to decide their own value orientations and course of action. This is directly related to people's political freedom because political freedom gives people the choice to live according to their own morals and ideas about what is right (Mills, 2011, p. 13). In this sense, then, political freedom is linked to eugenic practices because it protects and enhances the freedom of individuals to make important reproductive decisions for themselves, consistent with their own values and deeply held beliefs around reproductivity. In the context of prenatal screening as a liberal eugenic practice, this can be understood as follows: the NIPT ensures the protection of individual freedom because it allows individuals to make reproductive choices that are consistent with a person's own values.

Following the concept of value pluralism, NIPT increases individual freedom rather than restricting it. For example: A person can make the choice to participate in NIPT, or not to participate based on one's own values and beliefs. Someone can make the choice to have an abortion in case of an abnormal result, or to continue the pregnancy: also, in this, choices offer the relevant freedom and thus autonomy. Neutrality is essential in this because neutrality can ensure that people make decisions based on their own beliefs.

Thus, in the context of prenatal screening, it is important that the practices of NIPT be free of political, or governmental interference, to guarantee individual freedom. This makes the eugenic practices of NIPT according to the concept of value pluralism paradoxical: Although the conception of value pluralism guarantees the protection of individual freedom to be able to make choices that fit a person's own values, it can never be carried out that prenatal screening happens completely without restrictions on freedom because it is the government that offers this test and determines what choices can be made and determines what values underlie them. This makes pluralism a necessary concept in discussions about autonomy in NIPT because NIPT can never be performed with complete neutrality and freedom and thus paradoxically can also restrict individual autonomy.

At this point, it is important to discuss the concept of harm principle. Indeed, the harm principle is founded on the idea of preventing harm to others and constitutes a limitation on individual freedom as it is understood in value pluralism. This makes it interesting to further discuss the idea of the harm principle, looking more closely at the concept of others and harm and how it relates to autonomy in NIPT.

3.2.3 Harm principle

The idea of the harm principle states that every person should be allowed to act as he or she wishes and that every person has control over his or her own body and mind. A person is free to pursue ideas or choices without interference, even if a person's course of action is contrary to his or her own interest from the perspective of others. This applies, however, if an action or choice does not harm other people. Through this figurative boundary, the harm principle places limitations on personal freedom and determines one's behavior in prenatal screening (Mills, 2011).

In the case of NIPT, an individual choice that can be made, such as whether to interrupt a pregnancy, is related to harm to 'the other', to the unborn child, such as a child with Down Syndrome. The harm principle constitutes the only justification for the restriction of freedom of individual autonomy and, as a result, 'clashes' with value pluralism. In reflecting on this 'clash,' it is useful to examine the concept of harm in more detail to identify when interference with individual liberty may be justified and constitute a justifiable restriction on reproductive autonomy.

The following illustration may clarify the discussion of the idea of harm: A pregnant woman is told that her unborn child has an abnormality that will cause her child to be born with a disability. However, if she decides quickly, her unborn child will still be able to be aborted and her child will not be born, and therefore will not have a disability. Although at first, it may seem that abortion is harmful to the unborn child, this is not the case. Because if the woman aborts, this child will simply not exist. And in continuing the pregnancy, the child would be worse off because it has a disability with which it will be born. This dilemma is also called the non-identity problem, based on the work of British philosopher Parfit (1986).

The non-identity problem states that if a person is not born in the month of its conception, it does not exist; instead, another person would exist. Mills (2011) includes the work of Parfit (1986) in her description of harm because it provides a framework for decisions related to prenatal screening: aborting upon the discovery of a chromosomal abnormality is not bad according to the harm principle, because this act ensures that a person is not born so they cannot be harmed by their disability. The non-identity problem thus states very black and white that if a fetus is not born in the month of conception, he or she does not exist and therefore the decision to abort is a correct one in the case of discovering a disability.

The above example establishes a figurative threshold of harm, at the point at which a person is worse off purely by birth. But when is a child better off without birth, than being born and living with a disability? When is a child ”not worth living?”, Mills succinctly answers this question: “Only when the discovered disability is so severe that it makes life unlivable and the child is better off not being born, can it only be said that the child was harmed by being born” (Mills, 2011, p. 58).

A possible response to this statement by Mills might be: There will be very few situations that are harmful if you accept the harm threshold of ‘not worth living,’ and there will be very few cases where a child is in such bad shape that it can be said that the child is worse off for being born. This makes the harm principle very important in discussions about NIPT, because individual choices that can be made, for example interrupting a pregnancy with Down Syndrome, relates to ‘the other,’ to the unborn child with Down Syndrome. The question of what disability is acceptable to live with, and whether, for example, being born with and living with Down Syndrome harms a child, is a very personal and sensitive subject and cannot be answered lightly. Therefore, it is important to look at the target audience itself; children and parents with Down Syndrome, to give them a voice in this discussion as well.

3.3 Conclusion

Both the concept of value pluralism and the harm principle is crucial in the discussion of reproductive autonomy within NIPT, but both concepts conflict with each other. Namely, in value pluralism, restricting reproductive choices is seen as a violation of individual autonomy and because of this, NIPT constitutes a necessary test to protect individual reproductive freedom. However, the harm principle justifies precisely limiting individual choices to protect 'the other,' the unborn child from harm. In both concepts, state neutrality, and underlying individual values play a major role. According to the idea of value pluralism, neutrality is essential to guarantee individual freedom. When neutrality cannot be guaranteed, it constitutes a restriction on individual freedom, which can be seen as a violation of reproductive autonomy.

Thus, NIPT, offered by the government, constitutes a paradox for reproductive autonomy, because political beliefs and/or state interference are inseparable from enabling and offering NIPT. In addition, the question is whether unique parental choices in the process of participating in NIPT can be made with complete freedom. Is there neutrality and complete individual freedom when a test is offered by the government and in which choices are predetermined? And who determines what constitutes harm, and to what extent an abnormal test result provides grounds for interrupting a pregnancy?

While selection against disability is almost taken for granted and considered morally acceptable, disability critics have shown that this selection can lead to discriminatory attitudes that ultimately lead to a form of (morally unacceptable) eugenics (Mills, 2011). In the following section, I expand on this, by addressing the question of whether a pregnancy should be terminated due to having Down Syndrome. While it is crucial to defend women's autonomy and their right to access abortion, it may also be ethically acceptable to question the standards and principles that guide certain decisions that at first glance appear to be reasonable. I investigate this from the disability rights critique, in which the expressivist critique by Parens and Asch (1999) provides important insights.

4 Voices of disability

One of the key assumptions of the liberal approach to reproductive autonomy discussed in the previous chapter is that a life with a disability is less desirable than a life without a disability. In this approach, the value of a life with a disability is compared to a nominal (and idealized) life without a disability, and reproductive choices, such as choosing prenatal screening and abortion, fit within the freedom of choice idea central to liberal beliefs. In this chapter, I address the question of the moral prerogative to choose against children with disabilities, which tests the outer limits of reproductive autonomy. I do so by discussing an alternative approach to disability that assumes the value of disabled people's lives.

4.1 Disability rights critique

An alternative perspective on disability and reproductive freedom that highlights the benefits and opportunities of having a disability is called the disability rights critique (Parens & Asch, 1999). The idea that “a life with a disability can be valuable and worthwhile” (Parens & Asch, 1999, p. s1), is the foundation of the disability rights movement's critique of prenatal testing. This critique relies on the claim that the widespread use of prenatal testing technologies, and subsequent selective abortion, conveys a negative message about disability and thereby perpetuates disrespectful attitudes toward existing disabilities and influences parents' informed choice (Mills, 2011). In other words: the routine use of NIPT, followed by selective abortion in the case when Down Syndrome is detected, sends a negative message about the disability, and maintains disrespectful or disparaging attitudes toward those who are already living with Down Syndrome. This position has been advanced by several disability activists and theorists as the expressivist critique.

4.1.1 The expressivist critique

The expressivist critique, as outlined by Parens and Asch (1999), centers on the argument that prenatal screenings for traits commonly associated with disabilities “express a hurtful attitude and send a hurtful message to people living with those same traits” (Parens & Asch, 1999, p. s2). Prenatal testing does this by focusing on a single characteristic that ”represents” the whole person (Parens & Asch, 1999, p. s2), which, when combined with the termination of pregnancy, creates the reason to end that life. In other words, discrimination occurs when a particular characteristic is associated with a set of norms and assumptions, effectively making it impossible to recognize the person whose characteristic is the only one (Mills, 2011).

Prenatal tests thereby ‘send a message’ or ‘express an attitude’ (Parens & Asch, 1999, p. s2) about disability, making the social significance of disability and discrimination inextricably linked. The criticism here focuses on the background conditions that shape one’s behavior and beliefs regarding prenatal testing and selective abortion. This implies the widespread rejection of disability that characterizes contemporary Western culture, which influences people’s beliefs, motivations, and intentions when they decide to terminate a pregnancy. This also implies that information is based in part on a distorted or misunderstanding of what it is like to live with a disability if health professionals involved in NIPT view disability primarily as negative. In other words: Background conditions, or ableism, influence individual decisions, which cannot be made independently. Ableism is the social prejudice and discrimination against people with disabilities, labeling entire populations as ‘less than’ based on preconceived ideas and stereotypes. It only takes a person’s disability into account when defining it (Allyse & Michie, 2021).

In relation to the NIPT, it can be argued that societal misconceptions about Down Syndrome and this idea of ableism are inextricably linked to decisions to terminate pregnancies. These myths influence one’s personal values and worldview, so decisions are never solely based on personal principles and are always influenced by societal norms and attitudes toward disability. Therefore, the relationship between the woman and the fetus is not only an interpersonal one but also a societal one. In other words, the effects of societal norms regarding disability support individual beliefs and societal legitimacy regarding abortion decisions (Parens & Asch, 1999). The expressivist critique illustrates the importance of societal norms and assumptions and their implications through prenatal testing, which is characterized by prejudice against people with disabilities. This recognizes the operation of societal norms in making reproductive choices, which is particularly relevant in making informed choices in the process of NIPT. Using an example from the disability rights movement in the Netherlands, I explain this in more detail.

4.1.2 Dutch Downpride

Families of individuals with Down Syndrome were the first formal organizations to voice opposition to prenatal genetic testing. This is not surprising considering that Down Syndrome was one of the first conditions to be tested for during pregnancy and continues to be used as a lens to view both prenatal testing and genetic disorders in general (Allyse & Michie, 2021, p. 8). The Nederlandse Tweede Kamer (Dutch House of Representatives) received the Zwartboek Downsyndroom: Alle mensen zijn ongelijk en gelijkwaardig (Black Book Down Syndrome: All people are unequal and equal) from Stichting Downsyndroom and Downpride (The Dutch Down Syndrome Foundation) on February 16, 2016, as a response to concerns about the emergence of NIPT in the Netherlands.

In opposition to the NIPT, parents of Down Syndrome children created this Zwartboek. They did this to draw attention to the moral and societal pressures a mother might encounter when deciding whether to keep or abort a child who has a disability. Mothers, according to Downpride, are torn between two options: stop testing and you are the one who did not test; or have an abortion and you are the one who did. Using statistics from Denmark and Iceland, where nearly all pregnancies diagnosed with Down Syndrome are terminated since the routine (and free) provision of NIPT, Downpride expresses concern that the pressure to abort will only grow with the routine provision of NIPT.

The Zwartboek, which contains the stories of parents of Down Syndrome children who deal with pre-existing negative attitudes toward the condition, was published because of this fear. These accounts demonstrate how negatively society views those who have Down Syndrome. The book's premise is based on criticism of disability rights and attempts to change perceptions about those living with Down Syndrome. According to Downpride, the fear, prejudice, eugenics, and ableism of society are to blame for the abortion of a child who has Down Syndrome, for instance. In addition, Downpride contends that the treatment of people with Down Syndrome in Dutch society differs from that of people without disabilities, leading to a situation where parents worry, they will not be able to provide a child with Down Syndrome with the necessary care (Lindeman et al., 2016).

The Zwartboek, figure 5, provides an overview of the sometimes positive, sometimes negative coverage of Down Syndrome in Dutch media, in which the benefits of NIPT are widely praised and Down Syndrome is portrayed as a syndrome that is challenging to live with. According to Downprides' parents, NIPT is primarily portrayed in the media as a test for Down Syndrome, and many parents feel that this is done at the expense of their child who has the condition.

The Zwartboek also purposefully highlights the benefits of having the condition: "People with Down Syndrome today lead socially active lives; they attend school, participate in extracurricular activities, go out, work, and are content" (Lindeman et al., 2016, p. 3).

Prenatale screening.
Doordat mensen met downsyndroom in de samenleving (nog) niet als gelijkwaardig worden gezien, voelen veel vrouwen druk vanuit de omgeving om tijdens hun zwangerschap te screenen en te selecteren.

'Het is niet het kind met down dat het leven met down zo moeilijk maakt, het is de buitenwereld.'

Figure 5: The Down Syndrome Zwartboek. In the book, parents of children with Down Syndrome share their experiences, mostly showing how negatively society relates to standing children with Down Syndrome. Reprinted with permission of Slager, 2016, Downpride.

Although Downpride acknowledges the value of NIPT for a mother's reproductive autonomy, the real issue is whether it is even acceptable to decide to carry a Down Syndrome pregnancy to term. According to Downpride, the risk of routinizing NIPT is that fewer mothers will refuse the test, preventing the unintentional birth of a child with Down Syndrome. In doing so, Downpride acknowledges the danger of growing stigma and discrimination against people with Down Syndrome in society, which exerts moral pressure on mothers participating in the NIPT process and influences their informed decision-making.

4.1.3 A glimpse of the future

To complement Downpride's views, I briefly add insight from *Born Well: Prenatal Genetics and the Future of Having Children* (Allyse & Michie, 2021). They argue that if there are fewer people with Down Syndrome in the population (due to the widespread use of prenatal testing), there will be less demand to invest in quality services for those who remain. Allyse and Michie argue that "as the number of people with disabilities declines, it is likely that the acceptance, support, and resources provided to these people will also decline as they become less visible and less pronounced" (Allyse & Michie, 2021, p. 51). It is interesting to think about the effect of the routine use of NIPT, which could possibly lead to a future in which few babies are born with Down Syndrome and possibly reduces the need for specialist skills in health care. In other words: Does the routinization of NIPT lead to a reduction in the disabled population and therefore a lower quality of life for disabled people? This is a question that I do not fully address in this thesis, but it may take part in the cyclical dynamics between the routinization of NIPT and the societal norms surrounding Down Syndrome, and how this is related to informed choice.

4.1.4 Conclusion

Technologies such as NIPT seem to contribute to limiting the acceptance of disabled bodies, as a kind of social distinction between those who are desirable and accepted, and those who are socially rejected. This raises the question of how the routine use of NIPT affects how society views Down Syndrome, how information about the syndrome is disseminated, and how individual decisions about prenatal testing and whether to perform or terminate a pregnancy are affected. It could be hypothesized that when disabilities are viewed primarily as negative, predominantly these views prevail, and people make decisions based on this information.

Thus, disability rights critics criticize NIPT not only because it discriminates against people with disabilities, but also because it negatively affects the informed choice and thus reproductive autonomy of pregnant women. Indeed, as I indicated in this paragraph, NIPT contributes to stigma and prejudice about living with Down Syndrome by framing the syndrome as a life not worth living. In addition to this idea about societal norms, the routinization of NIPT is seen as a threat to reproductive autonomy because routinization can create moral pressure in the selection of parents; in the possible abortion of children usually considered disabled. However, because reproductive autonomy is strongly related to "freedom of choice, control, the ability to choose to take into account one's own preferences and beliefs about what is right, and rights over one's own body with respect to reproduction" (Lee, 2022, p. 524), the choice to have children is considered something legitimate, up to the individual and subject to personal responsibility. According to this liberal conception of reproductive autonomy, it would be morally wrong to deny women the option of an abortion. Therefore, the use of NIPT can also be seen as something positive, as a "moral license" to promote reproductive autonomy (Lee, 2022, p. 524).

In the past chapters, I approached reproductive autonomy from the liberal perspective that emphasizes individual aspects, and from the disability rights critique that emphasizes societal norms. Both perspectives seem to rub shoulders with each other, as enabling NIPT for the right to individual freedom and reproductive autonomy seems to negatively impact society's view of Down Syndrome and thus could potentially influence decisions about abortion. With that, both perspectives also seem to influence each other mutually and cannot be interpreted in isolation regarding the notion of reproductive autonomy in NIPT. After all, the question is how much freedom a person enjoys by participating in NIPT if the choices are already determined in advance and how a syndrome is viewed socially. How much reproductive autonomy exists when a pregnant woman participates in NIPT?

In the next chapter, I look at autonomy from a feminist perspective, in which the concept of autonomy is defined relationally, and argue that a relational interpretation of autonomy helps explain this apparent above paradox that women choose freely in NIPT, but in which NIPT also affects reproductive autonomy.

5 A feminist perspective

The work of Susan Sherwin (1998) provides the basis of this chapter. Sherwin is a Canadian philosopher whose writings have influenced bioethics, ethics, and feminist theory. Sherwin is regarded as one of the foremost feminist ethicists in the world. In this chapter, I focus on Sherwin's critique of the predominant biomedical practice of Western medicine, in her work "*The politics of women's health: exploring agency and autonomy*" (Sherwin, 1998). From this feminist approach, Sherwin offers perspectives on health ethics, concentrating particularly on women's health. It is interesting to understand how the biomedical practice functions in relation to women's health needs. Indeed, Sherwin acknowledges that the social organization of health services has great potential to exacerbate the oppression of women in society. To comprehend the role of being a woman, in relation to health care, Sherwin specifically focuses on two key themes in women's empowerment: Autonomy and agency. Sherwin emphasizes the importance of social conditions to counterbalance the prevalent liberal method of contemporary health care in which the individual is the focus of attention and social conditions are not considered. Although her work dates from the 1990s, this work offers excellent insights into the dynamics of the current non-invasive prenatal test, in which autonomy is a key aspect for expecting parents entering the Dutch healthcare system.

5.1 Autonomy and agency

Western conceptions of autonomy often focus on the individual and the freedom to choose. Sherwin rejects the idea that autonomy means only “being able to actively choose” (Sherwin, 1998, p. 12). She points out that the problem of autonomy, as currently conceived in Western liberal medicine, ignores oppression’s influence. One example of oppression in the context of women’s health identified by Sherwin, is the way cultural norms and values reinforce negative stereotypes about women. For example, women may be seen as emotional and irrational, which can lead to dismissing or ignoring their emotions by healthcare professionals. As a result, women may be subject to not being taken seriously which can lead to inadequate treatment because needs or wants may be overlooked. Sherwin also refers to the effect of having to completely surrender the pregnant body to the “tools and knowledge of the medical experts” (Sherwin, 1998, p. 13) which maintains power and control over the woman and her body.

Indeed, in the context of NIPT, the pregnant woman is dependent on the provision of information and knowledge by the healthcare professional, and the medical tools needed to examine the health of the fetus, which perpetuates a power differential and perpetuates oppression. Sherwin relates oppression to the design of healthcare systems, which can be clarified from the core value of autonomy in the current NIPT. Respect for personal autonomy is a dominant value in the Netherlands and plays a central role in the constitution of NIPT. Yet the protection of autonomy is at risk because a pregnant woman is dependent on access to the medical system because she needs help from healthcare professionals to get more information about the health of her fetus. This “power of the system” according to Sherwin (1998, p. 13), makes the woman vulnerable to manipulation, as the woman is more likely to set aside her own preferences and follow the advice of experts because she does not want to risk being abandoned by a healthcare professional if she were to reject the professional’s advice.

Sherwin argues that “people comply with the demands of healthcare professionals to access necessary services”, such as prenatal screening services. Even though the pregnant woman can make choices, the presence of oppression affects the extent to which she can “freely choose” (Sherwin, 1998, p. 13) and thus the autonomy of the woman. Being able to choose constitutes an apparent paradox because full autonomy requires that barriers of oppression disappear. By this, Sherwin means that oppression determines a person’s available choices and therefore affects the actual options a person has. In her argument, Sherwin refers specifically to the concept of agency, which she deliberately separates from, but links to, the concept of autonomy. Indeed, according to Sherwin, agency involves the ideal of informed choice, in which healthcare professionals consider and consult specific treatments appropriate and which can be accepted or refused by patients. By this, she refers to the apparent paradox of "being able to choose" (Sherwin, 1998, p. 14) as mentioned above, and the influence of oppression in which women have the authority to make choices but from limited options.

In addition to the examples above, Sherwin focuses on the relationship between the pregnant woman and the healthcare system, in which there is a danger to paternalism; healthcare professionals assume from their technical expertise, that they are better able to judge what is in the best interest of the patient than the patient themselves. The following example in relation to the NIPT clarifies this risk, that affects the notion of autonomy and informed choice: Taking part in the NIPT determines the pregnancy experience because the expectant mother suddenly must start thinking about risks, is monitored, and is exposed to technical knowledge.

As a result, it is not the woman's (experiential) knowledge or underlying values that are central, but the knowledge and methods of healthcare professionals. Indirectly, healthcare professionals in this situation ignore the values of the pregnant woman, which has a paternalistic effect. When information about Down Syndrome is limited or one-sided, as put forward by disability critics, the health care system indirectly determines what information the pregnant woman makes choices based on. This is especially harmful when women are faced with possible choices surrounding a pregnancy detected for Down Syndrome, which can have long-lasting psychological and physical consequences when a choice is made to terminate a pregnancy.

However, prenatal screening concerns such intimate and central aspects of a person's life that it is difficult for anyone other than the pregnant woman herself to make choices that are compatible with the woman's personal value system. These examples are just a few of the ways in which women can be oppressed in the healthcare system of the NIPT, which is mostly related to the relationship between the pregnant woman and the healthcare system and its professionals. In the following paragraph, I briefly elaborate on this relational aspect.

5.2 A relational approach to autonomy

Autonomy is commonly understood as the freedom of action in which individuals are considered independent. In the Netherlands, this view of autonomy is part of a larger cultural ideal of individualism in which each citizen has the freedom to make choices in social, economic, and political life. But, Sherwin argues, no one is completely independent. “Much of who we are and what we value is rooted in our relationships and affinities with others; we are never completely self-interested,” Sherwin (1998, p. 34) says. With this, much of our experience is related to building and/or maintaining relationships. Therefore, Sherwin argues, we must move away from the view of autonomy as a self-centered concept. Sherwin defines the relational nature of autonomy from a structure of autonomy-heteronomy, in which she rejects the general idea of autonomy based on the idea that the individual exists independently of the larger society. This way of thinking does not consider the complexity of relationships between individuals and their (cultural) backgrounds and the medical system; according to this way, decisions are free of outside influences. Instead, Sherwin recognizes that every human being is socially constructed. By this, she means that an individual cannot be separated from social relationships and is shaped, as it were, by his or her environment. A person’s identity is therefore, as it were, a product of the social environment. Thus, norms and values never exist in isolation but are shaped by social relationships, as are perceptions about concepts in the world (Sherwin, 1998). With relational autonomy, Sherwin offers an alternative view of the concept of autonomy that recognizes the importance of the social forces that shape each person’s identity and personality.

Relational autonomy refers to all the influential human, personal, and public relationships that shape an individual’s sense of self. As a result, autonomy is not something purely private and is not free from the influence of others. With respect to NIPT, the pregnant woman can be seen as a social being shaped by the entanglement of interpersonal and political power relations within the medical system. Looking at Sherwin’s recognition of oppression, the autonomy of pregnant women can be hindered by the forces of power relations between the pregnant woman and the health care system, for example, the health care professionals working in the practice of prenatal screening health care. The notion of autonomy in NIPT is developed within social relationships but is thus also dependent on them. For example, the social relationships a pregnant woman faces can either promote or inhibit the ability to act autonomously. Indeed, the fact that women have the power to make choices does not directly indicate the promotion of autonomy, since they can only make choices from limited options. This points to the apparent paradox of “being able to choose” (Sherwin, 1998, p. 14) and the influence of oppression as explained earlier. Since having children is well and truly about parents’ desire to start a family together, the relationship with the partner should certainly not be underestimated either. A pregnant woman is not an individual in her own right but is in a human relationship with her partner and will make decisions based on this relationship. Thus, the presence or absence of autonomy is not just a matter of being able to make choices but is partly a result of experiences of making decisions and having them respected and encouraged based on one’s values, as Sherwin also explains in her work.

5.3 Conclusion

While there is broad consensus on the value of and respect for autonomy, there are issues about its interpretation and application in current health care and the provision of NIPT. In her discussion of autonomy and agency, Sherwin (1998) argues that social and political relationships should not be ignored and that it is interesting to question how much autonomy pregnant women truly have over the determination of their reproductive choices, and, how this works within a stressful situation such as NIPT. When thinking about relational autonomy, it is worthwhile to look critically at the role of relationships and how pregnant women’s choices are viewed within the NIPT decision-making process. For example, to illustrate, we might ask how stereotypes about Down Syndrome or existing societal expectations about whether to choose to test or not to test with NIPT affect the choices women make or how the relationship with the healthcare professional enables the pregnant woman to act autonomously. In this, Sherwin recognizes the importance of the social context and does not attempt to ignore the needs and interests of individuals.

In this chapter I emphasized that relationships could influence pregnant women’s autonomy within NIPT. NIPT centers on the relationship between humans and the healthcare system in which the relationship between healthcare professionals and pregnant women can influence informed choice.

6 A multilayered discussion

In the literature review of this thesis, I have focused on the notions of reproductive autonomy and informed choice within prenatal screening. Examining how different perspectives understand the notion of reproductive autonomy and informed choice, can support the understanding of these notions in relation to the routinization of non-invasive prenatal testing for Down Syndrome in the Netherlands. Briefly, a few main points emerged from my literature review. Mills (2011) indicates that the individual prerogative to make choices is a central issue in liberal bioethics. I want to explore in the discussion whether, and if so, what the limits to the freedom of choice are, within the context of Dutch NIPT. Parens and Asch (1999) examined the discriminatory effect of mass prenatal testing on disabilities that are framed as severe and what this means for the perception of certain groups of people in society. In this discussion, I want to question whether it is at all possible, in the face of a negative societal perception of Down Syndrome, to still have an informed choice. And what is the effect of social norms on the moral pressure women might experience in participating in prenatal screening?

Sherwin (1998) focuses from a feminist perspective on the relationship between healthcare professionals within the healthcare system and the recipient of care, in this case, the expecting woman. She indicates that this relationship greatly affects women’s autonomy. I, therefore, focus the discussion on the relational aspect of autonomy by asking myself how much control women, and expectant parents, have over determining their choices within the routinization of NIPT.

In the upcoming discussion section, I elaborate on the significance, importance, and relevance of the results from my literature review. This section focuses on explaining and evaluating the moral pros and cons of the routine offering of the NIPT, interpreted by different perspectives, with which I provide arguments to support my overall conclusion. After all, I want to be able to interpret what my results mean for the situation of the NIPT in the Netherlands and contribute to this with my own reflection.

6.1 The limits of freedom of choice

The liberal viewpoint strongly emphasizes expectant parents’ freedom of choice as a requirement for the protection of reproductive autonomy. Not providing NIPT would severely restrict this freedom of choice and thereby the autonomy, because there would be no options at all.

Additionally, limiting the use of NIPT by, for instance, making people pay for it, also limits freedom of choice. Because of this, not everyone would have the same equal access to the test, which would also constitute a restriction on one's right to reproductive autonomy. In other words: Routine providing NIPT promotes equal opportunities for people to make reproductive decisions, partly because the test is free of charge.

Following the liberal understanding of freedom of choice by Mills (2011), a pregnant woman must have options to choose, to support autonomy. The set-up of the current NIPT program offers the option to decide whether to take the NIPT test, which safeguards both the right to choose and the 'recht op niet weten' (right to not know). In doing so, expectant parents keep control of their own reproductive and medical care.

Subsequently, a person should then be allowed to respond however she pleases to the test result. I believe that this is where NIPT's liberal bent breaks down. One could argue that since there are only two options available following a test result—to abort or not to abort—the choice is too limited. Nonetheless, NIPT can also be appealing to women who do not want to terminate their pregnancy at risk of Down Syndrome but want more information about what this will mean for their future child and parenthood. As a result, it is not accurate to state that a person can only choose between having an abortion or not because the NIPT program ensures that pregnant women's needs and preferences can be respected in various ways.

Also, according to Mills' liberal interpretation of reproductive autonomy, expectant parents should be free to make any decisions they see fit without being constrained or influenced in any way. It is crucial to understand that just because NIPT offers choices, it does not necessarily follow that those choices are limitless. This takes no account of the fact that offering the test deprives expectant parents of the opportunity to question whether they want to engage in prenatal screening at all, in violation of their 'recht op niet weten'. Even though NIPT is offered to every pregnant woman, giving her a free choice and would promote reproductive autonomy, it does take place with the presupposition that someone wants to engage in it at all during pregnancy.

The advantages of NIPT, such as being relatively easy to test, with no risk of miscarriage and accurate test results, and therefore offering it routinely, are at the same time, in my opinion, an important moral drawback. Recognizing the likelihood of having a child with a disability is increasingly difficult for expectant parents because the widespread offering of NIPT emphasizes the importance of disease prevention. As a result, refusing to participate in the test, on personal grounds, is becoming increasingly difficult. Previously, the disadvantages of prenatal screening, such as the risk of miscarriage, offered parents the option of not participating in screening based on personal reasons.

Thus, because of routinization, there seem to be no barriers to participation in the NIPT procedure, and NIPT has been integrated into standard prenatal care. Just as having an ultrasound or measuring blood pressure are considered standard prenatal care, and home births are generally considered impractical, women cannot refuse NIPT thanks to its general acceptance and popularity. This unintentionally gives the pregnancy a medical character, potentially psychologically affecting a personal life event in which expectant parents must make important choices.

Moreover, because participation in NIPT is no longer an active decision that expectant parents make for themselves in an informed and deliberate manner, routinely offering NIPT paradoxically undermines freedom of choice, preventing the screening goal of reproductive autonomy from being achieved. In other words: While increasing reproductive autonomy may seem like a good idea, routine government use of NIPT may limit rather than expand personal choice.

What worries me, is that the liberal understanding of reproductive autonomy, in my opinion, provides only a limited understanding of what is involved in the routinization of NIPT and its impact on informed choice and reproductive autonomy. This is due to the liberal framework's failure to adequately account for who gains from which reproductive options, the risks and negative effects of various reproductive interventions, and the motivations behind reproductive decisions.

6.2 Individual control within the Dutch NIPT

The individualistic ideals associated with liberal autonomy are rejected by relational viewpoints, as mentiond by Sherwin (1998). She contends that women's interactions with healthcare professionals are largely characterized by hierarchy and that oppressive and unequal social environments make it difficult for women to maintain complete autonomy. Professionals do, in fact, play a crucial role in guiding expectant mothers in prenatal research. The Dutch government places a strong emphasis on the right of pregnant women to freely make decisions based on accurate information. Professionals like the gynecologist, the midwife, or a specially trained counselor can assist them in this. However, because of the hierarchical relationship between women and health professionals, the professional's opinions can be very influential because they are regarded as authoritative. As Sherwin (1998) contends, because of the use of medical technology healthcare runs the risk of becoming authoritative because it prioritizes medical knowledge and concerns over the personal and emotional requirements of the woman. Women are heavily reliant on NIPT technology when I consider the transfer of knowledge and practices. As a result, medicine becomes a dominant and potent institution, and doctors gain power because of having access to this medical data. The following example can clarify the operation of this hierarchical relationship specifically in effect within NIPT.

As a patient in health care, in the case of one's own physical complaints, one can stay close to one's own experiences and a doctor is partly dependent on personal information from the patient. Thus, a patient preserves to a large extent his own control. However, within prenatal care and specifically NIPT, this is different. As a pregnant woman, knowledge about the screening technique is lacking and insight into what it means for her is a lot more difficult. The woman is no longer an expert by experience, so to speak, but is at the mercy of the (technical) expertise and must trust what the medical specialist knows and says about it. Of course, someone can always refuse the NIPT and thus maintain their own autonomy, but this example indicates the power relation between the pregnant woman and the medical specialist that is specifically in force within the NIPT.

The assertion of Sherwin (1998), that physicians have more power than patients is one with which I generally agree. However, I want to begin by acknowledging that both patients and healthcare providers are in social contexts that can reflect oppressive expectations. Physicians are products of society, as are women, and prenatal screening is not just a preventive measure that women must undergo in the name of health care. Women themselves have reproductive goals, and they demand access to reproductive technologies to achieve these goals. In fact, eliminating the possibility of prenatal screening for women is therefore unthinkable; it would be a serious violation of women's autonomy and control over their own bodies. One could argue that there is a tension between freely accessible prenatal care to support the reproductive goals of women which subsequently causes moral pressure to participate in the practice of prenatal screening because of this routine and accessible offering.

I contend that the position of healthcare professionals can also be suppressed as an alternative to the idea of a hierarchical relationship between a doctor and a patient. Patients may have less power than doctors, but they do have agency; they bargain, demand health care, and work with doctors to get what they need. Moreover, doctors, like women, are products of the society in which they live and must deal with norms that shape their work and form an expectation of how they should behave.

Nationwide uniform guidelines have been established that optimize the quality, safety, and efficiency of prenatal care and prevent variation in the basic prenatal care provided by doctors. These guidelines form a national standard for doctors and ensure appropriate care because they are expected to use these guidelines. An example comes from the guideline *"Testing for Down, Edwards and Patau Syndrome The NIPT,"* a leaflet on NIPT from the Rijksinstituut voor Volksgezondheid en Milieu (RIVM, 2023), that describes how to inform parents about NIPT and the process of NIPT. For example, this leaflet includes an explanation of Down Syndrome, which is initially quoted with the following sentences: "What is Down Syndrome? Down Syndrome is a condition that a child is born with. It does not go away. People with Down Syndrome have intellectual disabilities. And they often look different. How severe the disability will be, you don't know in advance" (RIVM, 2023, p. 6). This information provides an initial norm about Down Syndrome that healthcare professionals are expected to follow, which forms a standard in the NIPT process, so to speak. It is crucial to understand that in the context of NIPT, what a healthcare professional can or cannot do or say is constrained by these (moral) standards regarding NIPT and testing for Down Syndrome.

Given the discussion above, I want to acknowledge that it is uncommon for women and healthcare professionals in NIPT to have a straightforward relationship in which one party has total control over the other and vice versa. In a nutshell, neither a woman nor a doctor can ever be completely powerless. But in medical examination, a patient is and will always be reliant on the medical expert's knowledge and the provision of information, which puts pressure on making an informed decision. During the process of decision-making within the NIPT, it is crucial to understand women's needs and desires, but it is also a delicate subject. As I already mentioned, Sherwin (1998) asserts that a patient is entirely dependent on the judgment of the medical professional. In this, the professionals' perception of women, in general, is influenced by negative stereotypes about women in society, such as the idea that women are emotional and irrational in comparison to men. Thus, making (emotional) decisions during the NIPT process based on one's own feelings, intuition, or beliefs may therefore be perceived as irrational by medical professionals. Because of this, pregnant women run the risk of having their needs to be suppressed, not being taken seriously, or having the opinion of a health professional take precedence over their own.

However, according to how I see it, this patient's relationship with the medical professional opens' opportunities for fostering autonomy because they can assist the expectant mother in receiving NIPT counseling. Additionally, women maintain their autonomy by having the choice to accept or reject the advice and consideration of healthcare professionals during counseling; in this way, the woman maintains her agency and is unhindered by any influence. Full autonomy, however, is not possible due to the ongoing power disparity between women and healthcare professionals and the woman's reliance on their knowledge. Because the informed decision is constrained and dependent on the interpretation of the healthcare professional, one's agency is still in doubt.

Additionally, a variety of options provided by medical specialists make up the current NIPT program. These options, in my opinion, have a constraining impact on the individual choices of the pregnant woman. Should I perform NIPT or not? Whether or not to abort if the Down Syndrome test result is positive. These are intrusive choices that might be stressful. Premature exclusion of options that the expectant mother may have preferred to avoid. For instance, not being asked if you want to take part in NIPT. Or only being able to obtain the NIPT in cases where a child is incapable of living after birth or for a short period of time. In my opinion, women agree to a small number of options even though they are given the chance to choose. In other words, I agree with the claim made by Sherwin (1998) about individual control: Women in the NIPT program run the risk of losing their own control, and thus their autonomy, because they can only select from a small number of options.

As a final thought, I contemplate whether it is possible to determine whether someone is oppressed and whether they can exercise a choice and keep individual control. Women might decide to have an abortion, for instance, if they are concerned that having a child with Down Syndrome will cause them to experience unwanted and enduring social issues in society. Or some pregnant women proactively request a prenatal diagnosis because they understand that they cannot pedagogically raise a child with a disability nor afford the additional financial care costs associated with caring for a disability, even if they themselves would place great value on such a child. When a pregnant woman is reliant on the medical system and its professionals, how free does she feel to express her wants and needs? I pose this question aloud in this. And if there are at odds ideas about, say, Down Syndrome and the decision to have an abortion, what impact does that have on a person's sense of control? These seem to be very pertinent questions for further investigation to learn how women themselves experience the decision-making process within the current Dutch NIPT program.

6.3 Informed choice with a negative societal perception of Down Syndrome

It is interesting to note that according to Parens and Asch (1999), abortion based on prenatal testing displays a hurtful attitude toward people with disabilities. Indeed, through routinely offering the NIPT for conditions that are thought to be severe disabilities, NIPT is accepted as a responsible - and natural - practice. As a result, pregnant women may feel compelled to check for specific conditions as a result. The burden of choice that results from NIPT is caused by the fact that knowledge of risks and potential abnormalities can make expectant parents more anxious and force them to make difficult reproductive decisions, decisions that they would not have had to make if they had opted out of the NIPT. Having options and being able to make an informed decision can strengthen parents' sense of autonomy but this does not imply that it always has a positive effect.

Another risk of routinely offering the NIPT is that the routine use seems to imply that there is something wrong with people with Down Syndrome. I agree with this expressive criticism of prenatal testing, as the NIPT implies that Down Syndrome is a condition you would not want to have. Therefore, there is a risk that expectant parents who are unaware of or have little experience with Down Syndrome will already be influenced by this when making the decision to continue or end a pregnancy. It is already being framed negatively because it is already being screened for. Normalizing prenatal screening and abortion for people with Down Syndrome will, inadvertently, increase stigma for those who do have the condition. Thus, routinely providing NIPT not only endangers reproductive autonomy but also puts society at risk.

As Sherwin (1998) asserted, decisions made by women are never solely guided by their own moral convictions; they are also influenced by societal expectations and attitudes toward people with Down Syndrome. Besides, one's behavior and beliefs regarding prenatal testing and selective abortion depend on their social background. I contend that people's beliefs, motives, and intentions are impacted by NIPT's widespread rejection of Down Syndrome. It has an impact on how people perceive what it is like to live with a (child with a) disability and what qualifies as a severe one, leading to information that is partially based on a skewed or incorrect understanding of disability. As a result, NIPT-involved medical professionals might have a negative opinion of Down Syndrome that impacts the provision of information to expectant parents.

Consequently, women's personal values may be entwined with societal values, and they are no longer completely free to make their own decisions. Women may be burdened with the duty of making decisions that are in line with society or the healthcare professional. In my opinion, the answers to these issues undermine the fundamental purpose of NIPT, which is to guarantee that women are free to make their own decisions through informed choice. In other words, by making the NIPT test available to screen for Down Syndrome as a serious condition, the societal stigma associated with the Syndrome is maintained, which means an individual's decision is not fully informed. Therefore, the routine offering of the NIPT poses a risk to informed decision-making and, consequently, reproductive autonomy.

In this conversation about informed decision-making, I also want to partially counter the claim of Sherwin (1998) using the harm principle (Mills, 2011). Although the harm principle appears straightforward, the principle itself does not immediately clarify what constitutes harm. In fact, it is difficult to define what constitutes harm or injustice because the concept of harm in everyday life is so nebulous and highly subjective. The harm principle raises a moral conundrum regarding reproductive autonomy. Having options and being able to make an informed decision can strengthen parents' sense of autonomy but this does not imply that it always has a positive effect. However, parents are free to choose abortion even if the unborn child has less than ideal chances of survival. The choice of whether to have a child is entirely up to the parents; the harm principle places no restrictions on what they can decide. This makes reproductive autonomy a very liberal concept, in which there appear to be no restrictions on the individuality of reproductive choices because even if a person with a disability in society suffers harm because of the decision to terminate the pregnancy due to the disability, this does not necessarily imply that the moral imperative to avoid causing harm to others takes precedence over the individual's right to reproductive autonomy.

Of course, a person is required by the harm principle to consider how a condition will affect the child in the future, but this does not imply that the harm has a higher moral value than the restriction of one's freedom of choice. My understanding of Mills' argument regarding the harm principle, is that one's autonomy and free will should not be curtailed just because another person does not agree with that choice, such as the decision to abort a fetus with Down Syndrome.

Another argument on the potentially discriminatory impact of the NIPT as described by Parens and Asch (1999), is that the Dutch government incorporated the NIPT program under the new title 'screening for severe chromosomal abnormalities'. Through this, the NIPT does not solely concentrate on Down Syndrome. However, it still suggests that Down Syndrome is a serious abnormality given that it is still tested for. Considering this approach to Down Syndrome, I agree with Parens and Asch (1999) on this point. Due to this one-sided medical perspective on Down Syndrome, there is a risk that people's perceptions of what life with a child with Down Syndrome entails may influence their decision to take part in prenatal screening. I think it is hard to define what "severe" or "non-serious" illnesses are. I seriously question whether the NIPT policy should determine a condition's severity. I want to emphasize that in my view, expecting parents should set their own boundaries regarding whether they view a disorder as serious or not. Besides, I believe that a person is quite capable of choosing abortion while simultaneously devaluing the disability itself and valuing a person with a disability in society. The two are not mutually exclusive.

To counter my own claims made above, I want to say that feeling responsible for your child as a parent is also a very natural and human emotion. Just as the desire for bearing and raising a healthy child. Therefore, this can also refer to choosing to have an abortion if you want your child to grow up without Down Syndrome and have a life like other children. This is why I am wondering now if the decision to end a Down syndrome child's pregnancy implies that the choice is one made of disrespect for that condition or with the intention of sending that message to those who have disabilities, as the expressionist critique claims.

In conclusion, NIPT is not about a pregnant woman's desire to have a child but rather about her desire to have a child with or without abnormalities. This, in my opinion, emphasizes how crucial it is to lessen the stigma attached to having children who have Down Syndrome. Despite the moral acceptance of the routine offering of the NIPT, do expectant parents still choose to have a child with a disability? In my view, this query emphasizes how crucial it is to lessen the stigma attached to having a child with Down Syndrome so that parents' reproductive decisions can be supported. Indeed, the risk of a lack of adequate and complete information about Down Syndrome may impact informed decision-making, a prerequisite for reproductive autonomy that therefore cannot be adequately guaranteed.

7 Conclusion

The routine practice of the non-invasive prenatal test in the Netherlands invigorated the start of this thesis. The central question of this thesis was how to understand the routinization of the NIPT test in The Netherlands in relation to the notions of reproductive autonomy and informed choice. With my research, I contribute to the ongoing discussion about prenatal screening.

The goal of prenatal testing is to promote autonomy, by providing reproductive choice options. With that, the benefits of the Dutch NIPT program, with respect to the autonomy of expectant parents, are significant. It could be argued that not offering the test, therefore, would be a violation of reproductive autonomy because it does not offer reproductive choice options at all. However, while the benefits of NIPT are clear, this thesis focused on the implications of routinely offering it for reproductive autonomy. Two main issues appeared to be at stake: the reproductive autonomy of expectant parents and the impact of routinely offering NIPT on informed choice, and the dignity of people with Down Syndrome. The actual consequences of routine testing for Down Syndrome with the possible decline of this group of people in Dutch society and its long psychosocial consequences were not discussed, as this discussion needs a separate study.

After the discussion about individual freedom of choice, it can be assumed that expectant parents have fictitious freedom to choose within the current Dutch NIPT program. In fact, decisions are influenced by what society, and as a result healthcare professionals, expect of a person. The routine offering of the NIPT endangers expectant parents' decision-making by establishing a new societal expectation. As an illustration, if expecting parents decide to keep a child with Down Syndrome after receiving a favorable NIPT result, this may spark stressful conversations in the social setting. In contrast, the reality is that parents can fully preserve reproductive autonomy, by choosing to keep a child with Down Syndrome even within the regular NIPT provision. To be able to make decisions that they feel are necessary for themselves, however, is something crucial, which leads to the next important point.

My analysis has shown that NIPT seems to contribute to limiting the acceptance of disabled bodies, as a kind of social distinction between those who are desirable and accepted, and those who are socially rejected. It can be argued that the routine provision of NIPT affects how society views Down Syndrome with which NIPT maintains a vicious cycle. According to Dutch government documents, the NIPT's regular availability has nothing to do with the judgment of disability. However, by allowing the test, the government has decided that it is morally acceptable to find out if a child has Down Syndrome and to allow abortions if the test is positive. This completely refutes the claim that the Dutch government has no opinion about people with disabilities.

In fact, there is no longer any question of promoting reproductive autonomy because the free choice within NIPT is an imposed choice because of the strong government involvement and because NIPT is routinely provided. Of course, the abortion of several Down Syndrome children does not necessarily change society, but if this occurs frequently, it can undoubtedly have an impact on societal norms regarding living with a disability. Making an autonomous decision in this dynamic will always be biased, making this one of the biggest threats to being able to make an informed choice in the NIPT process. On the one hand, a negative societal view of Down Syndrome results in an informed choice based on the dissemination of negative information, possibly resulting in the choice of abortion. This perpetuates the stigma about Down Syndrome as a syndrome you are better off not being born with.

This means that offering the NIPT thus perpetuates a negative societal image of Down

Syndrome. However, on the other hand, this way of thinking also offers opportunities. For if society's view of Down Syndrome is positive, choices could also be positively influenced, reducing the choice of abortion. Thus, in summary, NIPT affects reproductive autonomy because it influences informed choice. In the process of NIPT, how information about Down Syndrome is disseminated is very important because it influences decisions about whether to test and/or abort at the individual level. In addition, it is very important that initiatives from different disciplines continue to contribute to society's perception of Down Syndrome, framing it not only as a serious abnormality that is not worth living but also as a condition that allows a person to increasingly integrate and participate in society today.

My analysis has shown that increasing autonomy is a matter of increasing the social power of expectant parents to ensure that the social relationship meets the needs of expectant parents in the process of NIPT. The fact that expectant parents in NIPT retain the power to make choices does not directly indicate the promotion of autonomy, as they have limited options to choose from and depend on social relationships with health professionals. NIPT is not a completely neutral practice and therefore it is questionable whether informed choice can be met. Individual autonomy may be undermined rather than promoted in practice because both health professionals and the pregnant woman and her partner are influenced by prevailing stigmas about Down Syndrome.

In conclusion, NIPT can be seen as a paradoxical practice in which the routinization of the test threatens informed choice and reproductive autonomy. It is essential that testing for Down Syndrome be presented as a choice to be considered and that information about this syndrome be provided in a multifaceted manner during counseling in which prospective parents are given the time and space to act from their own norms and values. In this, however, it is very questionable whether complete neutrality is possible, because each person thinks and acts from his or her own norms and values, and therefore there is no neutrality at all. Nor is it possible for the government to be neutral, or for healthcare professionals working within NIPT.

A general conclusion about the current routine implementation of NIPT is that it poses a challenge to respecting women's reproductive autonomy. Pregnant women may not perceive informed choice as free. There is a gap between policy (free choice) and practice (perceived pressure). The decision to terminate or continue a pregnancy is not primarily medical in nature, but deeply imbued with personal interests and moral beliefs.

What we may face due to the routine implementation of NIPT in the Netherlands is that women may have regrets after participating in NIPT because they did not have full autonomy of choice and action. Because the test is offered by the health care system, as an arm of the government, women see it as logical and good to participate and will consider it irresponsible behavior if they do not do the test. It can increase pregnant women's sense of responsibility to society and the population and result in them feeling compelled to participate. Or it may even go so far that women may experience moral pressure to abort upon discovering Down Syndrome. Routinely offering the NIPT reinforces this idea that getting tested is something that naturally normalizes abortion upon detection of Down Syndrome.

We must first wait and see what impact routinely providing the test has on the number of abortions and/or children born with Down Syndrome. Does routine cause a decline in the number of disabled people? Does this continue the vicious cycle whereby, as fewer individuals with Down Syndrome are born, they are less likely to integrate into society and, consequently, less is known about them? As a result, making an informed decision may be impacted because having a disability is becoming less common, which forms a threat to reproductive autonomy. What is most at stake in the current Dutch NIPT program, is that there is a great risk that choices made by the expectant parent(s) will become ill-considered choices.

Finally, in the end, I think most parents wish to raise a child who can live a normal life as an integrated member of society. Therefore, the ability to be concerned with the health and future of an unborn child during pregnancy is supportive of reproductive autonomy. However, it is crucial to consider the Down Syndrome population in the Netherlands in this context. I contest the validity of Down Syndrome testing because the condition is manageable and does not make a child's life unworthy of living or worse off than having been born. The challenging aspect of this is that one's opinion on whether someone with Down Syndrome can simply go through life depends heavily on their own circumstances.

So perhaps it would be better to examine the NIPT from a meta-level rather than a personal one. For instance, by looking into how Dutch society affects people with Down Syndrome or how the word "disability" is understood there. Because only from a global (i.e.: Dutch) understanding of disability can the NIPT's Down Syndrome testing and potential abortion be approved as a legitimate practice.

Let me add the following to this. Pregnancy seems to have become medicalized due to the development of technology, and, due to this, seems to be approached as a potential risk or danger and precautions can be taken. I want to make moral arguments about whether NIPT is appropriate for fiddling with pregnancy. By routinely offering the NIPT, it seems as if we thereby accept that there is always room for, or need for, (genetic) improvement in pregnancy or a fetus. In the NIPT program, healthy people are routinely and proactively involved in the healthcare system. That has the benefit of allowing parents to foresee issues there in advance and prevent some, but living a healthy life has thereby become the norm. And I consider that to be very unhealthy on its own. Nevertheless, I continue to think that an essential component of quality prenatal care is the principle of respect for reproductive autonomy, in which the range of potential restrictions on autonomy needs to be carefully interpreted.

Precisely because the NIPT test is so embedded in Dutch society, this thesis emphasizes the importance of continuing critical research on NIPT. More research is needed on the decisions made by expectant parents during NIPT, and the context that influences and sometimes limits these decisions. This research should focus on the decision-making process itself, with the relationship between expectant parents and medical professionals playing a crucial role. Especially the human and social aspects of the experiences of parents in the current NIPT program are important in this. Personal experiences are not included in the research of this thesis, as are, for example, the experiences of people with Down Syndrome, who are central to the context of prenatal testing and who can judge better than anyone else what life with Down Syndrome is like.

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