Prenatal Testing and Reproductive Freedom

A Mother’s Right to Choose

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Presented August 2014

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ISRN: LIU-CTE-AE-EX--14/04--SE
Abstract

The aim of this thesis is to analyse and examine the debate on prenatal testing in Western countries, with a special focus on my own country, Sweden. In the near future it might be possible for a pregnant woman to profile the DNA of her foetus with a simple blood test early in pregnancy. This method of prenatal testing – Non Invasive Prenatal Diagnosis (NIPD) – could potentially detect the genetic causes of almost every disease. I will argue that prenatal testing should be offered by society to all pregnant women, not only to those at highest risk of giving birth to children with severe conditions. I will do that from a perspective of reproductive freedom. Furthermore, I will argue that offering prenatal testing for some conditions (such as Downs’s syndrome) and not for others, is conflicting with the autonomous choice of the pregnant woman.

Key words: prenatal testing, reproductive freedom, autonomy, severe diseases
Table of Contents

Introduction ............................................................................................................................................. 4

Autonomy and Informed Consent ........................................................................................................... 5

Reproductive Freedom .......................................................................................................................... 7

Discrimination ......................................................................................................................................... 12

Playing God .......................................................................................................................................... 16

The Child’s Right to an Open Future ..................................................................................................... 20

Why offering NIPD to all women? .......................................................................................................... 22

For which conditions? ............................................................................................................................ 25

Conclusion ........................................................................................................................................... 28

Bibliography .......................................................................................................................................... 31
Introduction

Our knowledge of the human genome has developed rapidly in the last decades. We are now living in an age where it is possible to profile DNA and reveal a complete set of information for all human beings. This has contributed to significant scientific and medical progress, for example, the ability to identify which of our genes trigger diseases as well as better medical treatments. It also raises some extremely difficult ethical questions about life and death, human value and what kind of life is to be perceived as worth living. Both the scientific advances in this field and the ethical dilemmas they raise will have a major impact on individuals as well as society. In the near future it might be possible for a pregnant woman to profile the DNA of her foetus by a simple blood test. This method of testing – Non Invasive Prenatal Diagnosis (NIPD) – could be used in the early stages of pregnancy (from the seventh week) and could potentially detect the genetic causes of almost every disease.¹

In this thesis I will examine and analyse the debate on prenatal testing in Western countries with a special focus on my own country, Sweden. I will refer to Swedish policies but also to Swedish and international literature.

In Sweden debates has focused on which conditions prenatal testing should detect. Rolf Zetterström for instance, claims that the debate concerning prenatal testing put too much focus on Down’s syndrome (a chromosomal abnormality) and therefore neglects other severe medical conditions.² I support this view, and, furthermore I argue that offering prenatal testing for some conditions (as Down’s syndrome) and not for others, is conflicting with the autonomous choice of the pregnant woman. I will argue that prenatal testing should be offered by society to all pregnant women, not only to those at highest risk of giving birth to children with severe conditions (based on age or family history). I will do so from the perspective of reproductive freedom. As I consider the woman to be the owner of her body I argue that the decision to use or not use prenatal testing should be her own and nobody else’s, even though I recognise the prospective father to be a part of the procedure leading to whatever decision she chooses. But what does reproductive freedom mean? Obviously it is closely related to individual autonomy regarding reproductive choices.

¹ SMER, 2011, p.26
² Zetterström, 2008, pp.304-5
I will begin this paper with discussing views on autonomy and informed consent followed by debates on reproductive freedom. Thereafter, I will proceed with discussions on reproductive freedom. After investigating autonomy and reproductive freedom, I will then examine three common arguments frequently used in debates concerning prenatal testing. The first argument holds that prenatal testing is discriminatory against people already living with a disability. In selecting against disability (in cases of abortion), society sends a signal that these people are unwanted in the society. The second argument holds that selecting against disability by using prenatal testing is equivalent to Playing God. The proponents of this view argue against autonomous choice for pregnant women, stating that choices are already done by a higher power, as God or nature. The third argument concerns the child’s right to an open future. This argument holds that parental freedom, in some cases, should be restricted to protect the future freedom of the child.

In the following section of this paper I will discuss why I consider it to be morally justified to offer NIPD to all pregnant women. I will here argue that severe disease could be seen as a genuine harm that we all have experienced in some way or another. In using our imagination we can understand how it would be to live with severe disease on permanent bases.

Next section, before concluding remarks, will present some suggestions of examples of which conditions that could be candidates for NIPD. They should only be seen as possible examples of conditions, there are indeed many more conditions that would be on the list for NIPD. However, I don’t have the expertise required in this field so further examples would not be helpful.

**Autonomy and Informed Consent**

The principle of autonomy has an important value in modern society. In healthcare for example, an adult patient has the right to refuse treatment, for whatever reason, if that is what the patient chooses (with the exception of patients with some psychiatric disorders or contagious diseases). But what is autonomy?

Autonomy can be defined as self-rule or self-governance. In other words, a person who is autonomous is, at the very least, free from controlling interference from others and is also
capable of making meaningful choices. Freedom and capacity are necessary in order to make one’s own choices and to pursue one’s own elected life ambitions and aspirations. Opinions and interpretations differ with regard to the relationship between autonomy and physical and mental health – and which conditions affect a person’s autonomy or not. According to Stanley Benn’s theory, the autonomous person is; “…consistent, independent, in command, resistant to control by authorities, and the source of his or hers basic values and beliefs”. This kind of person is what he calls an “ideal chooser” to be distinguished from a “normal chooser”. The ideal chooser would then be fully autonomous. The problem with the theory of the ideal autonomous person is that it is too demanding. Few persons could be defined as being autonomous persons (with the ability make autonomous choices) according to his definition. Hardly anyone could be consistent all the time and no one is totally independent of others. Indeed, we interact with other people, and therefore reciprocity is necessary for living according to one’s own life plan. It is in fact very hard to determine which values and beliefs are exclusively ones one. Your upbringing and culture certainly forms your values and beliefs. Therefore, we need a more inclusive conception of autonomy.

The fully autonomous person (one that makes fully autonomous choices) could then be considered a myth. What we instead should look for – according to Tom L. Beauchamp and James F. Childress, is *substantial autonomy*. In their view an action that would be considered autonomous, does not need to be fully understood nor be completely free of influence. Instead there has to be a substantial degree of understanding and freedom from constraint. For example, a person could be considered to be autonomous if she or he chooses to adopt religious views in guiding her or his decisions.

In healthcare, respecting a patient’s autonomous choice is a professional obligation. From the patient’s perspective, autonomous choice is a right. This does not mean that the patient has a duty to choose. Regarding prenatal testing this means that a woman have the right to choose if she wants to use it or not. Moreover, should a patient wish to make a choice they must have access to relevant information.

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3 Beauchamp and Childress, 2009, p.99
4 Faden and Beauchamp, p.236
5 Ibid
6 Beauchamp and Childress, 2009, p.102
7 Ibid
8 Ibid, p.107
Existing guidelines in Sweden recommends that pregnant women be offered the possibility of receiving information about prenatal testing during their first prenatal care appointment (10–12 weeks of pregnancy). If the possibility of receiving such is declined, only medically motivated examinations and ultrasounds should be offered. If it is not, more extensive information should be offered. It is important that this information not only focuses on medical issues. Psychosocial aspects are important as well. For example, should a test reveal a medical condition, what kind of support can society offer a disabled a child? In what way would the disability restrict the child’s life? As we can see, prenatal testing is a complex issue and rises difficult – including emotionally difficult – questions for prospective mothers. Therefore, information should be presented gradually and be adjusted to each individual case in order for a woman to be given the possibility to make an autonomous choice about whether or not, to use prenatal testing.

Reproductive Freedom

What does reproductive freedom mean? Reproductive freedom is generally understood as the right of every human being to decide if they want to have children or not, without interference from society. Article 16 of The Universal Declaration of Human Rights for example states that; “(1) Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and found a family”. From this perspective reproductive freedom is a human right enshrined in international law. The right to have children without interference from society means that it is a negative right, i.e. a right to be free of actions from others. Positive rights, on the other hand, are rights to receive help or service from others. Concerning reproductive freedom this could mean that the state offers assisted reproduction, economical subsidies to families and so on. However rights on reproductive freedom have limits as well. I will here investigate some suggestions about where to draw the line for reproductive freedom.

9 SMER, 2011, p.7
10 Ibid, pp. 7-8
11 The Universal Declaration of Human Rights, Article 16
12 Beauchamp and Childress, 2009, p.352
John Roberson and Bonnie Steinbock argue for reproductive freedom as a negative right, i.e. a right not to be interfered with from society. They also argue that it should include the right to genetic reproduction (to pass on one’s genes). On Robertson’s view, the right to reproductive freedom means that it is morally permissible to use assisted reproduction as gamete and surrogacy processes. Here reproductive freedom is understood in genetic terms (the right to pass on one’s genes), an interpretation which doesn’t necessarily connect reproduction with child rearing. It could of course mean child rearing but it isn’t a necessary condition for reproductive freedom. Steinbock, on the other hand resists the idea of reproductive rights based on purely genetic reasons. Instead she argues that procreation is deeply connected with raising children and that the latter is valuable. For her the right to have a child to rear is a central component of reproductive rights. According to Steinbock the right to reproduce should only be restricted if individuals interested in having children lacks the ability to raise a child. Although Robertson argues that the right to reproductive freedom requires an understanding of what reproductions means, he doesn’t include child rearing as necessary.

As we can see above, Roberson strongly believes in the idea of autonomous choice as an element of reproductive freedom. Hence it’s morally permissible to donate egg and sperm to help people that need assisted fertilisation for example. In contrast Steinbock believes reproductive freedom should only extend to people who have the intention and ability to rear children. In her view egg and sperm donation without any intention to play a role in rearing the child is morally impermissible. Nonetheless, they both argue for reproductive freedom from the perspective of negative rights.

Having the possibility of using assisted fertilisation depends on having access to actors providing these services, such as public health institutions. This can be defined as a positive right.

In Sweden it’s legal to donate as well as to use donated eggs and sperm with the purpose of assisting reproduction in cases where it is otherwise impossible. There are however restrictions on both donors and recipients. Donors and recipients undergo both medical and psychological evaluation before assisted reproduction can proceed. In addition, recipients also undergo social evaluation with the purpose of investigate if recipients are able to provide for

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13 Quigley, 2010, p. 403-11
14 Ibid, p. 404-5
15 Ibid, p. 406-7
the child’s well-being. If prospective recipients do not meet the required criteria they are not allowed to benefit from assisted reproduction. In addition to donors and recipients being required to meet a range of physical and mental criteria, a key determinant of reproductive rights in the case of assisted reproduction is the ability of recipients to provide for a child’s well-being. In Sweden most cases of assisted reproduction is provided by public health. There are only two private clinics that have permission to provide these services. Permission is hard to get and can only be granted by the Swedish National Board of Health and Welfare. The private clinics have the same requirements as clinics in public health.

With regard to restriction on reproductive freedom involuntary fertility is the main factor to emerge so far in the above discussion. Fertile persons that do not require assisted reproduction – and therefore don’t have to depend on healthcare services to reproduce – do not hinge upon meeting different physical, mental and social criteria. In other words their reproductive rights are not curtailed by legal restrictions. But could there be moral restrictions on reproductive freedom?

Laura M. Purdy argues that it indeed can be immoral to have children. She argues, for example, that it is morally wrong to reproduce if there is a known risk of transferring a severe disease or disability. In some cases, the heredity of genetic diseases makes conception itself too risky. The exception according to Purdy, are those persons who are willing to employ genetic screening and selective abortion. In short, prospective parents should not bring children into the world if they don’t have the possibility to live a minimally satisfying life. She gives Huntington’s disease (a severe late-onset disease leading to death) as an example of such a case. Beyond this it is not clear what she takes a minimally satisfying life to mean, but she rejects the view that it is morally right to bring children into the world as long as they are not likely to lead a life so miserable that they wished they were dead. Although she recognizes that her claim conflicts with the idea of reproductive freedom, she nevertheless argues that carriers of severe diseases that are opposed to abortion should avoid conception.

Purdy on the other hand claims that even though people have an individual duty to avoid transmitting genetic diseases, society also has a corresponding duty to make individual responsibility possible, for example by providing genetic testing and counselling for all

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16 SMER, 2014
17 RFSL, 2013, p.2-4
18 Purdy, 2006, p.115-120
19 Ibid p.118-19
women. In Purdy’s view there are therefore moral restrictions on reproductive freedom. In other words, it is a moral duty to avoid transmitting genetic diseases. Interestingly she argues strongly for positive rights in the sense of ensuring all women have the possibility to access to genetic testing and counselling. Society she believes has a moral duty to provide these tools.

This is in line with my own claim, namely that prenatal testing should be offered to all women regardless of age or medical family history. However I don’t believe that avoiding transmitting genetic diseases is a moral duty that the prospective parents has. Although I do recognise that this could be problematic with regards to the suffering of the child potentially endure, but I argue that it is too demanding to put such a burden of responsibility on prospective parents. Society should, as Purdy argues, offer prenatal testing and counselling to all women, but women should have the freedom to choose whether and how to use such service and what action to take should a test result show disease in the foetus. In other words, I disagree with Purdy on her view that it is prospective parent’s moral duty to avoid genetic diseases. But I agree on her view that that society has a moral duty to provide genetic testing and counselling. Only then a woman has the possibly to make an autonomous choice concerning her own future as well as her potentially child’s future.

So far I have investigated a number of suggestions regarding where (morally) to draw the line concerning reproductive freedom. In Purdy’s case for example there is indeed a clear line in reproductive freedom when it comes to genetic diseases. Another philosopher who argues for even more restrictions on reproductive freedom is David Benetar.

According to Benetar reproductive freedom should be restricted when it inflicts harms on the people brought into existence by it. If we agree that it is wrong to inflict harm on others in non-reproductive contexts, we should not have the right to inflict harm on others in reproductive contexts. He claims that those in favour of reproductive freedom employ a double standard if they argue on the basis of the principle of autonomy. This is because one’s autonomy, or freedom to do what one wishes interference from others, is limited by the right of others.

When it comes to reproduction we should consider the risks for our off-springs. This is important, because, even if we can never be completely sure that our children will be born healthy, it is necessary to distinguish between the ordinary chance to be born healthy and

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20 Ibid, p.120
21 Benetar, 2006, pp.2491-93
having an increased risk of being born unhealthy or disabled. Examples of increased risk, according to Benetar, include carriers of certain severe genetic conditions, being HIV-positive as well as being an elderly woman (still fertile). Another example of increased risk put forward by Benetar is poverty. Poor people that cannot provide for their own basic needs are also at higher risk of doing harm to their off-spring.²²

A minimum condition of procreation is that it should be consistent with the judgements we make in non-procreative contexts. These judgements should then be linked with the conditions regarding reasonableness. How we should respond to risky and harmful procreation depends on how severe the harm is expected to be. In cases of mild harms it will be enough to only desist from assisting reproduction. In worse cases it could be appropriate to condemn procreation. In some cases it might be even right to consider prohibiting or preventing it (depending on if the expected moral benefits are higher than the expected moral costs).²³

In Benetar’s view therefore there are important restrictions to the principle of autonomy in relation to reproduction. Indeed, the reproductive rights of a significant number of people would be restricted if one follows his line of argument. Not only would the reproductive rights of persons carrying genetic diseases and older (but still fertile) women be curtailed, but so would the rights of those afflicted by poverty. His views on the use of prenatal testing to detect genetic disorders and, for example, PGD (Preimplantation Genetic Diagnosis) are unclear however. If testing were offered by society to people that are carriers of genetic diseases they wouldn’t increase risks for their off-springs (if they abort a damaged foetus). He doesn’t even mention positive rights, he only restrict the negative right to reproduction. For example, states have a duty help poor people out of poverty.²⁴ To place such hard restrictions on reproductive freedom could lead to a society where only the healthy and rich would have the privilege of making autonomous choices regarding procreation.

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²² Ibid
²³ Ibid
²⁴ The Universal Declaration of Human Rights, Article 22
Discrimination

When a woman is confronted by a prenatal test result indicating a defect of the foetus, she has two options, to continue with the pregnancy or to terminate it. Some choose the former, others choose the latter. Abortion on the grounds of a disability in the foetus is sometimes called selective abortion. A common argument from opponents of prenatal testing is that it could lead to selective abortion and selective abortion is discriminatory, per se, against people already living with disabilities. As Adrianne Asch writes:

> What differentiates prenatal testing followed by abortion from other forms of disability prevention and medical treatment is that prenatal testing followed by abortion is intended not to prevent the disability or illness of born or future human being but to prevent the birth of a human being who will have one of these undesired characteristics.\(^{25}\)

Through this statement Asch puts the focus on society and what kind of message it sends to pregnant women, as well as society as a whole, to offer these tests. She claims that, when society offers women these tests – and indeed, urges women to use them – it sends the message that disabled people are a burden to society. Moreover, offering prenatal testing comes in conflict with the stated goal of public health, namely, to improve social justice and equality for people living with disabilities. Especially important, according to Asch, is how medical practitioners inform about impairments detected in foetuses. For example, not only focus on costs of disability, but also on the contribution that people with disability make to their families, friends, economy and society as a whole.\(^{26}\)

In Sweden there is a public debate concerning prenatal testing and how it affects people living with disabilities. Much of the debate focuses on testing for Down’s syndrome, something which has been offered to all pregnant women from age 35\(>\) (the risk for Down’s syndrome rises with the mothers age) since the1980s. In those days the only way to test for this condition was to use amniocentesis which is an invasive test. Using amniocentesis to detect foetus abnormalities increases the risk for having a miscarriage 0,5–1\%\(^\).\(^{27}\) In 2007 a new non-invasive form of testing for chromosomal abnormalities was introduced and is offered to all women regardless of their age in the county of Stockholm. Combined ultrasound and biomedical test (Swedish translation: kombinerat ultraljud och biokemitest. Abbreviated KUB). It is a testing method that is carried out during test the first trimester of pregnancy in

\(^{25}\) Asch, 2006, p.126  
\(^{26}\) Ibid, pp. 126-7  
\(^{27}\) Hau, 2008, p.401
order to reveal the extent to which there is an increased risk of chromosomal abnormalities. Parents confronting a decreased risk then have to decide for or against amniocentesis to get a definite diagnosis. As we can see amniocentesis is still necessary to get a definite diagnosis and therefore the small risk for miscarriage cannot be avoided. If the new kind of prenatal testing, NIPD, is going to be introduced and thereby replace invasive tests, the risk for miscarriage is reduced.

The introduction of the KUB test led to an intensification in the ongoing debate about prenatal testing in Swedish society. In particular, questions were raised why prenatal testing is so focused on Down’s syndrome. This has caused people with this condition and their families to feel unwanted in society. As a father of a boy with Down’s syndrome expresses in a Swedish newspaper; “why is society making so much effort to develop technologies to search for a disability the biggest problem of which is cognitive impairment?” The cognitive impairment didn’t stop his son from living a rich and fulfilling life. He goes on explaining that they have no problem with prenatal testing in general, but on the focus on this particular condition because there are so many other and more severe disabilities that deserve greater attention. Furthermore, they expressed how his son’s disability was not a problem for them – he was deeply loved and a great joy to the family. The problem rather was how he was treated by institutions within society, for example at school. The fact that his son was not allowed continuing an ordinary school (which he was placed in until fourth grade) and instead being placed in special school was, they said, a great disappointment to them and their son.

Experiences like these are commonly found in articles on this subject. They illustrate some of the problem associated with focusing on Down’s syndrome in the context of prenatal testing. If society offers genetic testing for specific conditions, it can increase the risk that people born with these conditions feel unwanted and discriminated against. Furthermore, it seems that conditions that, for example, Down’s syndrome is more connected to identity than, for example, conditions like Huntington’s disease or cystic fibrosis. A strong connection between condition and identity increases the risk for people with these conditions to feel discriminated against.

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28 Ibid, p.399-400
29 Hofman, 2014, p.74
30 Lerner, 2011, Translated from Swedish by the author of this paper
31 Lerner, 2011
32 Hofmann, 2014, p.76
33 Ibid, pp.78-79
One of the reasons for the focus on Down’s syndrome within prenatal testing could be that it is the most common cause of disability in foetuses. Another reason could be that today we have more knowledge as well as new methods for discovering other conditions, that wasn’t available in the early days of prenatal testing. The introduction of the KUB test in Sweden has indeed led to more early abortions (in counties where the test is offered as routine) in findings of risk for Down’s syndrome. But on the other hand, it hasn’t changed, to any appreciable extent, the numbers of children born with this condition (in counties where the test is offered as routine). One explanation could be that some of the pregnancies identified with chromosomal abnormalities – and then terminated – could otherwise have resulted in spontaneous abortion, i.e. miscarriages, later on in pregnancy. However it could also indicate that women who undergo the test in many cases prefer to terminate the pregnancy in findings of Down’s syndrome. On the other hand, the introduction of KUB-testing and subsequent increase in numbers of women choosing to terminate their pregnancies has not led to any measurable decrease in the number of children born with this condition. This also suggests there will not necessarily be less people born with this condition in future. It is therefore important to emphasise that not all women choose to undergo this test and that among those women who do and are told that there is a high risk of Down’s syndrome some choose not to terminate their pregnancy.

However, as we can see from the discussion above, prenatal testing for non-life threatening types of disability, such as Down’s syndrome, linked to selective abortion, could be seen as being discriminating against people already living with the same disability as well as their families. Indeed, to convey the message that foetuses with disabilities are selected against, i.e. are not wanted, could be potentially harmful for these persons. However, it is also worth asking whether focusing on how the above is harmful to people living with disabilities, because it conveys the message that they are “worth less” to society, is in fact misguided? This is what Dan W Brock claims in his discussion of selection of children. He notes that women who choose to terminate a pregnancy of a healthy foetus for whatever reason doesn’t send a message that children in general have lower moral status, nor do they send the message that children in general are unwanted, whether they are born with a disability or without. Nevertheless, it can’t be denied that some people find it morally offensive when women

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34 Socialstyrelsen, 2012,
36 Brock, 2009, pp.251-271
decide to select against disabled foetuses. However, these people then have misread the message. In Brock’s view, selecting against disability as well as terminating a pregnancy for other reasons, is compatible with the rights to reproductive freedom.\textsuperscript{37} As he notes:

> Women are neither morally nor legally obliged to bring an unwanted child into the world just because the child would be valuable to society. This means that her action need imply nothing about the value or moral status of others who have a similar disability to what her child would have.\textsuperscript{38}

I agree with Brock’s view while recognising that being made aware that foetuses with disabilities are selected against could be hurtful to people already living with disability. There are additional examples to the one discussed that illustrates how complicated these questions – the decision to abort and the potential harm resulting from this decision – are. One concerns the case of a woman that chose to terminate her pregnancy because a close family member – her brother – suffered from the hereditary disease haemophilia. Traumatic memories from her childhood – dealing with the disease in the family – made her decide for abortion when prenatal testing revealed the condition within her foetus. Her brother was hurt by her decision interpreting it as meaning she didn’t want people like him to live. This was very hard for her, it was only after psychoanalysis that she was able to talk with him and explain that her decision was not directed against him as a person. It was directed against the disease.\textsuperscript{39}

As we can see above there are different opinions concerning whether prenatal testing linked to selective abortion actually is discriminatory against people already living with disability (Asch) or whether it instead stands for a misinterpretation that causes hurt feelings (Brock). As I myself argue that the society should offer prenatal testing for all pregnant women regardless of age or family history, I agree on Brock’s view. However, hurt feelings still have to be dealt with. Most people do not want to hurt other people, or for that matter, be hurt themselves. What is needed is an open discussion about prenatal testing in society. This is of utmost importance, especially if NIPD is going to be introduced that makes it possible to search for almost every condition. For example, as Björn Hofman notes, if NIPD would lead to an increased number of selective abortions there would be less people born with disabilities which could mean a decrease in competence and recourses for people with disabilities.\textsuperscript{40} This would indeed be discriminatory and therefore it is important for society to secure competence

\begin{thebibliography}{9}
\bibitem{37} Ibid
\bibitem{38} Ibid, p.262
\bibitem{39} Leuzinger-Bohleber, et al, 2008, p. 191
\bibitem{40} Hofmann, p.79
\end{thebibliography}
and resources to these groups. There will always be people born with disabilities and diseases regardless of prenatal testing, therefore, society would still have the responsibility to provide for example medical treatment as well as environmental adjustments so that these people can interact in society as everybody else. However, there are no indications that resources to people with disabilities have decreased since genetic testing was introduced in Sweden for several decades ago. Nor have discrimination or stigmatizing increased in other countries that offer extensive prenatal testing.\textsuperscript{41}

\subsection*{Playing God}

The notion of playing God could be articulated as a \textit{religious} argument but also as a \textit{non-religious} argument to not violate the “natural order” in our world.\textsuperscript{42} The argument is often used by opponents of the use of science and technology that would lead to dramatic changes in how we live our lives.\textsuperscript{43} Obviously, prenatal testing has given humans possibility to intervene in the “natural” course of pregnancy and hence intervene with the outcome of pregnancy. I will therefore start this section by giving a short overview of how this argument could be interpreted.

In the religious interpretation it holds that it is God – not humans – that should determine the nature of our children that are a gift from God. To intervene in the pregnancy process by using prenatal testing would then be interfering with God and therefore morally wrong.\textsuperscript{44} This argument makes it really hard to know what kind of interventions that would be morally wrong. Considering prenatal testing leading to negative selection, abortion it is always wrong even if it concerns extremely serious diseases like Tay Sachs that is hereditary degenerative disease leading to death in early childhood. However the Plying God argument is seldom applied in other technical developments as for example cars or aeroplanes. If God has given humans capacity to develop a technology like prenatal testing – as well as technology to use for cars and aeroplanes – how should we then know that it against Gods will to use it?\textsuperscript{45}

\textsuperscript{41} SMER, 2006, p.17
\textsuperscript{42} Brock, 2009, pp.266-9
\textsuperscript{43} Coady, 2009, pp. 155-80
\textsuperscript{44} Brock, 2009, pp.266-7
\textsuperscript{45} Ibid
Prenatal testing can lead to abortion which in this view is considered to be killing an innocent human being. Given that abortion, according to this view, is morally wrongful killing, the conclusion will be that prenatal testing that leads to abortion is morally wrong because it is wrongful killing. That would of course lead to condemning all abortions, not only those of disabled foetuses. For example, the official Roman Catholic Church claims that human life begins with conception; therefore, foetuses have the same moral status as all other humans.\textsuperscript{46} In Swedish policy on the other hand the fertilized egg has \textit{some} moral value that increases during development of pregnancy and after birth the child have full human moral value.\textsuperscript{47} In other words, this means that the woman has the right to decide if she wants to continue a pregnancy or not for whatever reason. In Sweden she has the lawful right to abortion until the 18\textsuperscript{th} week of pregnancy without giving any reason at all.\textsuperscript{48} It seems to me that it is hard to separate selective abortion from social abortion (abortion grounded on social circumstances, for example, that the woman considers that carrying for a child would be too burdensome for economic reasons) in the religious interpretation of the Playing God argument. Abortion is always morally wrong whatever reason because it is wrongful killing. It is not in human power to decide when life is going to be over – only God has the power over life and death – therefore selective abortion and social abortion would then be equally wrong. Considering that Sweden is a secular democracy it would then seem wrong to base any public policies regarding reproductive choices on religious arguments.

In the non-religious version of this argument, children are still seen as a gift, not from God, but from nature. Reproduction is a gift from nature that ought not to be inferred with. Selecting children is a morally wrong action where we (wrongfully) try to control the nature and characteristics of our children and it can undermine parents’ unconditional love for their children. Selective abortion could be considering children to be consumer’s products that could be destroyed before birth if they are defected.\textsuperscript{49}

Unconditional love is indeed important for children in developing into healthy individuals. But this argument focuses only on that unconditional love is something that has to start with pregnancy and neglects the bonding between mother and child after birth during the process in fostering of the child.\textsuperscript{50} Even if the bonding between the mother and child starts in

\begin{thebibliography}{99}
\item Beauchamp and Childress, 2009, p.83
\item SMER, 2006, p.13
\item Socialstyrelsen, 2011, p.8
\item Brock, pp. 268-9
\item Ibid
\end{thebibliography}
pregnancy it is indeed not necessary for feeling unconditional love for the child. If pregnancy would be considered to be a necessary condition for unconditional love to a child it would lead to the false conclusion that adopted children have no possibility to be loved unconditionally by their adoptive parents. Hence, pregnancy is not a necessary condition for the unconditional love a parent should have to a child. This argument rather expresses a biased view of what motherhood is supposed to be. Rather the ability to give a child unconditional love is depending on several different factors interacting with each other, as for example, emotional stability and socio-economic circumstances.

However, as the religious interpretation of the Playing God argument strongly condemns prenatal testing linked to selective abortion, the non-religious interpretation is no different. John Finnis, an advocate of the non-religious interpretation, argues that any test and examination is justified only if the purpose is preparing for a safe pregnancy and delivery and only if the tests don’t involve risks for the child. As he writes:

…anyone who does or accepts a test or examination with the thought of perhaps suggestion or arranging or carrying out an abortion if the results show something undesirable, is already willing, conditionally, abortion, and so is already making himself or herself into a violators of principles non-maleficence and justice.51

According to Finnis, health professionals respecting the principles of justice and non-maleficence should refrain from conducting or recommending prenatal testing. They also have the responsibility to inform pregnant women in their care that any prenatal tests that she could be offered by others are for an immoral purpose.52 This view clearly states that the principle of autonomy is ruled out by the principles of non-maleficence and justice. Not only should health professionals avoid prenatal testing, they should also inform women that it is immoral.

I find this type of arguing problematic with regard to women in general. It presupposes that women (in this case pregnant women) have no right to actively make their own decisions regarding their pregnancies. Rather it demands that she should be a passive carrier of the foetus that without any complaint should welcome whatever destiny brings her. However, if the woman herself, let her beliefs in God or nature determine her choice, it still is an autonomous choice. Therefore, it is necessary that she will be offered prenatal testing as well as information about the tests. Health professionals should not impose their own moral values

51 Finnis, 2006, p.22
52 Ibid
or giving advices concerning this issue. Instead they should provide adequate information, assisting in decision-making and give psycho-social support.  

I have so far presented some views of the theoretical debate concerning prenatal testing and the moral authority of nature (both religious and non-religious). But how does this argument influence women in practise when they are in the situation where they have to decide to use prenatal testing or not?

It does not provide sufficient guidance when women themselves decide to use or not use prenatal testing. The concept of nature is dim and holds different concepts of what we ought or not ought to control. This is what the results of a study from Netherlands in 2011 showed. In this study, a group of women were interviewed about ethical considerations when they were offered prenatal testing. Both acceptors and decliners of the test answered that they believed that the most ethical option was to let pregnancy has its natural course without trying to control everything. Nevertheless both accepters and decliners claimed that parents have the right to decide if they want (or no want) the birth of a severe disabled child. Neither acceptors nor decliners saw disability as something that always had to be avoided. A difference in acceptors and decliners concerning disability in the child was their expectations about parenting a child with a disability. Decliners considered themselves to be able to care for a child with a disability while acceptors considered themselves unable to care for a disabled child. Nevertheless, in cases of severe disability abortion was morally acceptable and it was described that it was done in the best interest of the child. It should also be noted that considerations about well-being in the family also played an important role in this decision.

This study definitely shows the complexity in how women make decisions about prenatal testing and handle the results of the testing. It shows how hard such a decision is and that the well-being of the child to be as well as of the family seems to be in the focus of women. Therefore research on acceptability of prenatal testing should not focus on the moral authority of nature; instead it should focus on how women shape their moral beliefs concerning responsible parenthood.

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53 Nordgren, 2008, p.324
55 Ibid, pp. 461-64
56 Ibid
The Child’s Right to an Open Future

The argument from the child’s right to an open future is developed by Joel Feinberg to basically restrict parental freedom to protect the future freedom of the child, meaning, that the child will have the possibility as an adult, to live according his/her own conception of a good life.\textsuperscript{57} For example, to allow Amish community to not sending their children to school until age 16 could restrict these children’s right to an open future by limiting their options as adults.

To restrict parental freedom could also be extended to limit reproductive freedom of parents to be as a purpose to protect the freedom of the ones not yet born. For example, parents using reproductive technologies should see to that they are neutral with respect of the possible future life-plans of the child to be.\textsuperscript{58}

Dena S. Davis argues that using reproductive technologies for selecting for a deaf child is a moral harm and inflicts with the child’s right to an open future.\textsuperscript{59} Spokesmen for deaf community claims, on the other hand, that deafness should not be seen as a disability but a different culture. Therefore, a deaf child growing up in a deaf community would rather have better options than a hearing child in same circumstances.\textsuperscript{60} Davis reply to this argument is that regardless of whether deafness is considered a disability or a culture, it is narrowing down future options in other surroundings than deaf community for deaf children. Therefore it’s morally wrong to let parents to be, to choose deafness in their children by using reproductive technologies.\textsuperscript{61}

To use prenatal testing to find out the health status of the expected child seems to be morally justified and even in line with responsible parenthood according to the child’s right to an open future argument. A severe disease or disability would indeed limit a child’s possibility to live according her/his own plan of life as an adult. For example it would limit options in carrier choices, family planning and other important choices in human life. However, I don’t consider it morally justified to use prenatal testing (or other reproductive technologies) in other areas than health issues. Therefore, to use prenatal testing in selecting for sex or characteristics of the child is not included in my own view of reproductive freedom. This

\begin{itemize}
\item \textsuperscript{57} Malmqvist, 2008, p. 73
\item \textsuperscript{58} Ibid
\item \textsuperscript{59} Davis, 2006, pp.246-255
\item \textsuperscript{60} Ibid
\item \textsuperscript{61} Ibid
\end{itemize}
view is also consistent with the guidelines from The Swedish National Board of Health and Welfare. These guidelines hold that prenatal diagnostics should always see to that the medical utility outweigh the predictive risks. Furthermore, prenatal diagnosis should not be offered in determine the sex of the foetus if there isn’t any hereditary genetic sex-linked disease in the parents’ families.62

So far the argument from the child’s right to an open future seems to justify prenatal testing as means to protect children’s future autonomous choices by selecting for health by avoiding disease and disability. We don’t know what future children’s preferences of a good life will be; therefore, prospective parents have a strong reason to give their future children a wide range of options.63 But could prenatal testing also lead to a less open future of the child?

In using NIPD there are indeed huge amounts of information concerning the child to be. This means that parents and health institutions has access to information about the child (and future adult) that is out of control of that particular person.64 It seems that reproductive autonomous choices of persons today (parents) reduce autonomy in future persons (children). For example, it could be in conflict with the right not to know. In this case, health institutions may have access to information that is of importance for the person’s health and at the same time it could be interfering with the person’s right not to know.65

This is indeed problematic. Even if some persons would welcome the possibility to have access to their own genetic profile there would be many people that doesn’t want to have that information. For example, if an adult want to find out about her/his genetic profile that would be unproblematic, because it is an autonomous choice by an autonomous person. In case of foetuses and children we don’t know how this is going to affect them in the future. A recent discussion in the UK about genotyping children as a screening program for common cancer, this problem was discussed.66 One of the possible harms mentioned was indirect psychological harm to children by increase of anxiety for developing disease. Therefore, if NIPD is going to replace invasive tests it is of utmost importance to regulate what conditions that the test is going to reveal.

62 Socialstyrelsen, 2013, pp.1-2
63 Malmqvist, 2008, p.78
64 Hofmann, 2014, p.76
65 Ibid
Why offering NIPD to all women?

As mentioned before I defend the view that prenatal testing should be offered to all pregnant women from a perspective of reproductive freedom. However I don’t find it morally permissible to use prenatal testing to select for sex or for characteristics that have no significance for the child’s health. There are several reasons why I consider non-health characteristics not to be considered morally permissible in using prenatal testing. This is, however, beyond the scope of this paper. Instead, before staring the discussion on what kind of conditions to focus on in prenatal testing I consider it to be important to explain why I consider it to be morally permissible to use prenatal testing to detect diseases in foetuses.

For this purpose I am going to use Erik Malmquist’s view on this issue. According to him severe diseases could be seen as a genuine harm that stands in the way and also deprives us of the capacity of getting a good life.67 Most of us have experienced illness that at least temporary deprived us the capacity to strive for a good life. Therefore, by using our imagination we can understand how it would be to live with a severe disease on permanent basis. Furthermore most of us have seen severe illness in others, sometimes in near and dear ones. So we have all experienced suffering of severe disease.68

This view is compatible with what the women in the study presented above answered when they were interviewed on ethical questions concerning prenatal testing. It was the well-being of the child to be as well as the well-being of the family that was in focus when they decide to use or not use prenatal testing. In other words, a severe disease does not only harm the person with the disease, it also has a large impact on the life within the family. For example, let us once again think of the example of the woman who used genetic testing to find out if her foetus was affected by haemophilia. Her choice in using prenatal testing was influenced by her experience of this disease within her family.

In Swedish regulation pregnant women with a known family history of genetic disease are already offered prenatal testing for the condition in question. Indeed they are both at a high risk of transmitting that condition to their foetus and they do have experienced how the condition affects both the child and the family. However, what I myself argue is instead that all pregnant women should be offered prenatal testing regardless of family history or age. As

67 Malmqvist, 2008, pp.171-2
68 Ibid
mentioned above, I agree with Malmqvist that the harm of severe disease is something we all can relate to by experience. It might be by experience in family but it could also be in other contexts. Regarding risk factors such as age and family history it is indeed important to offer prenatal testing. On the other hand, women that don’t belong to these risk groups may still be at some risk for giving birth to children with severe diseases, for example, some diseases, for example, due to new mutations. Furthermore, one can be a healthy carrier of a severe disease without knowing about it and therefore run the risk of transmitting disease to the child. But before further discussion, let’s take a look on different ways of how genetic diseases pass on to the next generation.

Many severe genetic diseases are caused by a mutation in a single gene, i.e. monogenetic diseases. These diseases are inherited in predictable patterns.69

To inherit an autosomal recessive condition the defected gene has to be passed in two copies, one from each parent. However if the defected gene passes on in one copy (from one of the parents), the person doesn’t develop the disease herself but may pass it on to the next generation. An example of such disease is cystic fibrosis.

To inherit an autosomal dominant condition only one copy of the defected gene is passed on from either parent. Huntington disease is an example of such disease.

Some diseases are sex-linked disorders which mean that they expresses differently between males and females. The reason is that males inherit one X-chromosome from the mother and one Y-chromosome from the father, while daughters inherit two X-chromosomes, one from each parent. An example of such disease is Duchenne muscular dystrophy. In this disease sons are affected from the mother who is a healthy carrier of the disease whilst daughters doesn’t get affected by disease but becomes carriers.

A condition like Down’s syndrome is caused by abnormalities in the chromosomes. Chromosomal disorders can sometimes transmit from parent to child but occurs mostly by accidents at cell division.

Mutations in mitochondrial DNA also cause some inhered disorders. These disorders can only be inherited from the mother.70

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69 Ibid, pp. 12-3
70 Ibid
As we can see from the presentation above there are predictable heredity patterns presented in genetic disease. But in some cases the mutation occurs for the first time in a family, i.e. it was impossible to predict. If we consider severe disease to be a genuine harm (as I do), the harm is still a suffering for the individual with the disease regardless causes. Therefore, all pregnant women should have equal right to avoid severe disease in their future children as well as having equal right to prepare themselves and their family for carrying for a child with a severe disease. Furthermore prospective parents can be healthy carriers of severe diseases without knowing. To be offered prenatal testing for severe diseases there has to be known cases of severe diseases in family or relatives. Sometimes there are no known cases of severe disease in the family. The mutation that causes the disease hasn’t led to the actual severe disease for several generations but the mutation is still transferred by healthy carriers. An example of such disease could be Fragile X which is an X-linked syndrome that causes mental retardation, autism and hyperactivity.\footnote{Finance, 2013} This particular condition was considered until recently to be a straightforward X-linked condition causing mental retardation in boys. However recent research has linked Fragile X to complex adult-onset conditions. This complicates the concept of who is considered to be a healthy carrier as the symptoms manifests in so many different ways.\footnote{Ibid}

In offering NIPD to all pregnant women they could be prepared at an early stage of pregnancy – as it could be used in earlier stages of pregnancy than other invasive methods – on how to deal with a situation where the test reveals a severe disease in the foetus. If the woman chooses to continue the pregnancy there would be additional time to prepare for the situation of caring for a child with special needs as well as prepare herself (and her family) psychologically for this situation.\footnote{Hau, 2008, p.403} If she on the other hand chooses to terminate the pregnancy she can have an abortion at an earlier stage of pregnancy which means a less complicated abortion for the woman. I do not by less complicated abortions suggest that any abortions are easy for the woman, but for obvious reason, it is harder, both physically and psychologically to undergo an abortion at later stage when the foetus has developed more.

However, as NIPD could be used as early as within the seventh week of pregnancy there might be concerns if it is appropriate to offer women the test that early within pregnancy. Consider, for example, that chromosomal abnormalities increase the risk for spontaneous
abortions within the first 12 weeks of pregnancy. A test showing abnormalities at this early stage could then put the woman in a position of an unnecessary burden if she chooses to terminate the pregnancy.\textsuperscript{74} This might sound contradictive as I argue that prenatal testing should be offered to all women from a perspective of reproductive freedom. Here it is most important to keep in mind that even if it is the woman herself that choose to use prenatal testing, it is nevertheless a complex and emotionally difficult procedure for the woman to decide what to do with the result of the test. If NIPD is going to be introduced (as I suggest it should) to all women, it is therefore of utmost importance to discuss the issue of at which stage of pregnancy it serves its purpose best.

\textbf{For which conditions?}

In the section above I presented hereditary patterns presented in severe genetic diseases. Testing foetuses with NIPD would reveal these conditions and furthermore, the test could also reveal information about genes that increase the risk for many common diseases as for example, diabetes, cardiovascular diseases and Alzheimer. These conditions are however complex compared to monogenetic conditions as they are multifactorial, i.e. depends on interaction between genes and environmental factors. The complexity makes it hard to predict if a person with a specific genetic profile that increases the risk for these conditions actually is going to develop the disease.\textsuperscript{75} Therefore, to use NIPD to search for a predictive increased risk for common diseases would not be effective, nor would it be morally defensible. Even if these conditions, for example cardiovascular diseases, indeed could be described as severe diseases, NIPD will only reveal an increased risk for developing these conditions, not a definite diagnosis of disease, to be compared with for example Huntington’s disease – a monogenetic condition – where it could be predicted with certainty that a foetus carrying the defected gene, will with certainty develop this severe disease later in life. In other words, I argue, that NIPD should be used to revile mutations that with certainty causes severe conditions, not for detect increased risk for common diseases.

So far I argued for what NIPD should \textit{not} be used for to reveal, i.e. common diseases, sex or characteristics of the child. It should only be used to detect mutations that with certainty cause

\textsuperscript{74} Deans and Newson, 2012, p. 612  
\textsuperscript{75} SMER, 2006, p.11
severe conditions. However, there are about 6000 inherited monogenetic inherited diseases, all of them rare and most of them extremely rare.\textsuperscript{76} Furthermore some are early-onset diseases; others are late-onset diseases. The diseases also vary in how and to what degree they cause disability, suffering or risk for premature death. Some of the diseases can be cured or at least be treated to decrease symptoms. An example of such disease is PKU (phenylketonuria) which can be treated with a special diet. However, for most monogenetic diseases there are no effective medical treatments.\textsuperscript{77} Using NIPD for revealing each and every one of these conditions therefore seems to be overwhelming and probably not wished for.\textsuperscript{78} That leads to the question; what conditions should we search for with NIPD? It seems obvious that NIPD should be used to detect severe diseases and leave out diseases with mild symptoms.

However, as I don’t have the expertise required in medicine and genetics, I don’t intend to present a list of conditions that would be suitable to detect by testing with NIPD. Instead I will present some examples of conditions often referred to in debates concerning prenatal testing.

According a proposal in UK 1997, foetal defects can grouped in four different groups depending on their clinical consequences:\textsuperscript{79}

- defects not compatible with life (lethal);
- defects associated with possible survival but with high morbidity and long-term disability;
- foetal conditions that might be amenable to intrauterine therapy;
- foetal conditions that will require postnatal investigation or treatment.\textsuperscript{80}

Considering the first two groups there are no doubt that these kinds of conditions would be of high importance to detect. For example, Edwards’s syndrome (trisomy 18) is a condition leading to severe mental retardation and multiple defects on inner organs, where most children die during the first month of life and only 5\% survive their first year.\textsuperscript{81} In Crabbe’s disease, the child seems to be healthy at birth but at three to six months of age symptoms start to be seen. Brain functions disperse gradually and the child becomes blind, deaf and loose

\textsuperscript{76} Ibid
\textsuperscript{77} Ibid
\textsuperscript{78} Bui and Meiner, 2008, p.80
\textsuperscript{79} Ibid, p.64
\textsuperscript{80} Ibid
\textsuperscript{81} Socialstyrelsen, 2014
ability to talk and swallow. Most children die before two years of age and it is often required palliative care to make their last time as painless as possible.\textsuperscript{82}

The examples above are referred to as severe early-onset diseases. There are also other early-onset diseases which indeed are severe with a shortened lifespan, but with the possibility to extend lifespan as well increase quality of life with medical treatment. An example of such disease is cystic fibrosis.\textsuperscript{83} This disease causes mucus production in lungs, pancreas and other organs. Medical treatment with multiple medications and chest drainage manoeuvres several times a day is necessary to decrease mucus in the lungs. Declining capacity of the lungs is the most common cause of death. The predictive survival for affected persons was 37.4 years in 2009.\textsuperscript{84}

Not all severe genetic diseases are early-onset conditions. Some are late-onset conditions in which symptoms of the disease occur in late adulthood. Huntington’s disease is an example of such disease.\textsuperscript{85} This degenerative disease starts in age 30–50 and leads to death usually in 20–25 years after first symptoms. The symptoms are a combination of neurological problems, motor problems and cognitive problems, for example, involuntary writing movements, depression, anxiety and behavioural problems. In the last stage of the disease the declining of mental capacities often leads to dementia.\textsuperscript{86}

As we can see above there are differences in when severe diseases occur, i.e. early-onset to late-onset. There are also large differences in how they affect the sick person’s quality of life. However, they all have in common that they are severe diseases and therefore I claim that these conditions – and other conditions with similar outcome – are candidates for NIPD.

However, with the medical development and the possibility to achieve early prenatal diagnosis, it could also lead to potential benefits in foetal therapy, for example, in utero transplantation of stem cells or endoscopic foetal surgery.\textsuperscript{87} In Sweden scientists are conducting research in methods that would make it possible to use foetal cardiac surgery in treating severe cardiac conditions.\textsuperscript{88} Furthermore, detection before birth of severe cardiac

\begin{itemize}
  \item \textsuperscript{82} Ibid
  \item \textsuperscript{83} Bosslet, 2014, pp.280-81
  \item \textsuperscript{84} Ibid
  \item \textsuperscript{85} Socialstyrelsen, 2014
  \item \textsuperscript{86} Ibid
  \item \textsuperscript{87} Ibid
  \item \textsuperscript{88} Medicinsk access, 2014
\end{itemize}
conditions actually saves lives as the delivery of the affected child then could be organized to take place in special medical centres with specialised care for these conditions.89

Conclusion

In this thesis I have examined and analysed the debate on prenatal testing in Western countries with a special attention to the current state in my own country, Sweden. As new methods as NIPD have been developed – a non-invasive prenatal test – we can now profile the whole DNA of the foetus with a simple blood test on the mother at an early stage pregnancy. Furthermore NIPD can potentially detect the genetic causes of almost every disease.

I have tried to argue that prenatal testing should be offered to all pregnant women, not only to those that to those at highest risk of giving birth to children with severe conditions (based on age or family history). I have done so from a perspective of reproductive freedom. Furthermore I claim that that offering prenatal testing for some conditions (such as Down’s syndrome) and not for others is conflicting with the autonomous choice of the pregnant women.

In the first section I examined and analysed views on the concept of autonomy and informed consent. As the fully autonomous person could be considered a myth, we should instead look for substantial autonomy. In making an autonomous choice one has to have relevant information on the subject for the choice. In Swedish policies concerning prenatal testing, the pregnant woman should be told at her first appointment at prenatal care about the possibility of receiving information of prenatal testing. If she accepts the offer of getting information about prenatal testing she will have that information otherwise no further information about prenatal testing is offered. How the information is provided is also of importance, medical issues should not be the only focus, psychosocial aspects is of importance as well.

In the second section I have focused on debates concerning reproductive freedom. Reproductive freedom is generally understood as a right of every human being to decide if they want to have children without interference from society. This right is a negative right and does not include positive rights as, for example, society offering health services such as

89 Ibid
prenatal testing or assistance in reproduction for infertile couples. However, in getting assistance for reproduction there are different physical, mental and social criteria that are necessary to be meet before society offers assistance. As negative rights hold that there should be no legal restrictions on reproduction there are indeed different opinions concerning moral restrictions on reproductive freedom. For example, there are different views on if intention and ability to rear a child is necessary condition. Concerning the issue of transmitting severe genetic diseases it could also be seen as an obligation to avoid to procreate if there is an increased risk to transmit severe disease.

After discussions on reproductive freedom I examined three common arguments frequently used in the debate concerning prenatal testing. The first argument holds that prenatal testing is discriminatory against people already living with a disability. Adrianne Asch argues that when prenatal testing is linked with selective abortion it is discriminatory against people already living with disability. Dan W Brock opposes this view and argues that selective abortions do not send the message that people with disability have lower moral status comparing with other people. Selective abortions as well as abortions for other reasons are compatible with the rights to reproductive freedom. It would indeed be discriminatory if selective abortions lead to fewer resources for people living with disability. However, there are no indications of decline in resources to these groups in countries offering prenatal testing. Nor have discrimination or stigmatizing increased.

The second argument, Playing God, holds that prenatal testing – in its religious interpretation – would be morally wrong as it is God, not humans that should determine the nature of our children. The non-religious interpretation of the Playing God argument holds that reproduction is a gift from nature that ought not to be interfered with. In selecting children we undermine parents’ unconditional love for their children. In other words both the religious as well as the the non-religious interpretation of the Playing God have in common that they presuppose that women have no right to actively make their own decisions regarding their pregnancies, instead they ought to welcome whatever destiny brings them. However, the argument (both religious and non-religious) does not provide sufficient guidance when women themselves decide to use or not to use prenatal testing. According to a recent study from the Netherlands, the concept of nature is too dim and holds different concepts of what we ought or not ought to control.
The third argument, The Child’s Right to an Open Future, is basically to restrict parental freedom to protect the future freedom of the child. Using prenatal testing to detect health status seems to be morally justified according to this argument as severe disease or disability would limit a child’s possibility to live according her/his own plan of life as an adult. However in using NIPD there would be a vast amount of information of the child to be that health institutions and parents have access to that is out of control of the particular person. This could lead to a less open future for the child. Therefore, if NIPD is going to replace invasive tests it is of utmost importance to regulate what conditions the test should reveal.

In the following section of this thesis I discussed why I consider it to be morally justified to offer NIPD to all women. I argued that severe disease could be seen as genuine harm that deprives us the capacity of living a good life. We have all experienced illness and by using our imagination we can understand how it would be to live with severe disease on permanent basis.

In Swedish regulation, women with a known family history of genetic disease are already offered prenatal testing for the condition in question. However, in some cases the mutation occurs for the first time in a family. Furthermore parents can be healthy carriers of a disease and therefore transmitting the condition to the next generation without knowing it. Therefore, all women should have equal right to avoid severe disease in their future children as well as equal right to prepare themselves and their families in caring for a child with a severe disease.

In the last section I discussed for which conditions NIPD could be used. I argued that NIPD should not be used to detect sex or characteristics of the child, nor should it be used to predict risk for common diseases with multifactorial causes. The complexity of these diseases makes it hard to predict if a person with a genetic profile that increases the risk for these conditions actually is going to develop the disease. Therefore, I argue, that NIPD should only be used to detect severe monogenetic diseases that with certainty are going to affect the child to be.
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