



Universiteit Utrecht

## **Thesis Applied Ethics**

### ***Selective abortion of Down Syndrome & Alasdair MacIntyre***

By: Remi Leroy

Date of birth: 3<sup>th</sup> April 1995

Born: Ghent, Belgium

Student number: 6455980

MA Applied Ethics

University of Utrecht

Academic year: 2018-2019

Submitted on: 20/06/2019

Supervisor: dr. Van Den Hoven, Mariëtte

Second reader: Naomi Van Steenbergen

Word count: 21.487



## Abstract

Non-invasive prenatal testing (NIPT) is increasingly used to screen for Down Syndrome. As a result, NIPT could prevent almost every child with Down Children to be born when people are open to selective abortion after testing. The main research question is whether this *combination* of NIPT and abortion is morally problematic. Both can of course be valued by themselves, NIPT for informative purposes and abortion as a right of bodily integrity. But nonetheless, there's a separate concern about whether both procedures should be combined to decrease the number of Down children. Some find this wanted because Down children experience more suffering, whereas others point out that society should focus on reducing their suffering instead of avoiding their birth.

Observing that society remains divided over this dispute, one could argue from a liberal perspective that only future parents as individuals should decide whether abortion and NIPT should be combined. Yet this thesis uses the virtue ethics of Alasdair MacIntyre to contest this liberal division between public institutions and personal decision making. This implies that the research question must be answered by pointing out what the virtues of good parents *and* medical practice are. First, by adding the work of different virtue ethicists it will be argued that the combination of NIPT and abortion is wrongful because future parents have a *prima facie duty* to accept their child the way it is. Secondly, virtue ethics learns that the end of medical practice is benevolence. So when NIPT and abortion are *only* used to pursue ideals of family planning, medical practice is outstepping its legitimate boundaries.

Nonetheless, whether these virtues can be applicable in case of prenatal care will eventually depend on whether some moral status is assigned to the fetus. MacIntyre recognizes that there'll remain disputes on that matter, but also points out that dialogue is this still more reasonable than moral relativism or institutional neutrality. In case of Down Syndrome, prenatal counselling should be for example try to avoid that future parents have a stigmatized view on the disorder of the fetus.

## Table of contents

Abstract .....	3
Table of contents.....	4
Chapter 1. NIPT.....	8
1.1 What is NIPT? .....	8
1.2 Advantages of NIPT .....	9
Chapter 2. Changing attitudes towards Down Syndrome and selective abortion.....	11
2.1. Introducing NIPT as a first-tier test causes future parents to deliberate not well enough. ....	12
2.2 Introducing NIPT as a first-tier test pressures future parents to do the test when they actually don't want to.....	14
2.3 Introducing NIPT as a first-tier test will make Down Syndrome largely disappear.....	15
2.4 Summary.....	16
Chapter 3. Ethical perspectives on selective abortion .....	17
3.1 The utilitarian argument .....	17
3.2 The argument of the disability right movement .....	19
3.3 The conflict between utilitarianism & the disability right movement .....	22
3.4 Conclusion: compromise rather than concensus.....	24
Chapter 4. Dworkin & Liberalism .....	27
4.1 Dworkin's defence of reproductive autonomy .....	27
4.2 Criticism to Dworkin's defence of reproductive autonomy .....	28
Chapter 5. Alasdair MacIntyre.....	31
5.1 Introduction: Alasdair MacIntyre .....	31
5.2 Criticism on the Enlightenment.....	31
5.3 Aristotelian virtue ethics .....	33
5.4 Crisis of modernity .....	34
5.4.1 Persistence of the Enlightenment project.....	35
5.4.2 Recognition of the failure of the Enlightenment project .....	35
5.5 Conclusion .....	37
Chapter 6. Validity of MacIntyre's criticism .....	39
6.1 Interpretation of MacIntyre's criticism .....	39
6.2 The post familial family .....	41
6.3 Ethical problems concerning the post-familial family.....	43

6.4 Conclusion .....	47
PART 3. Virtue ethics and selective abortion .....	48
7. Virtue ethics & Selective abortion.....	48
7.1 The virtues of good parenting .....	48
7.2 Criticism to the prima facie duty of acceptingness .....	50
7.2.1 Is Down Syndrome to severe to be acceptable? .....	50
7.2.2 Are parental virtues applicable in case of abortion? .....	51
7.2.3 Counter criticism: the experience of pregnancy .....	52
Chapter 8. Medical practice as a Moral Community.....	56
Final reflexion .....	59
Suggestions for further debate .....	61
Bibliography.....	62

## **Introduction**

The first part of this thesis will address the problem analysis, showing why it's important to ask whether NIPT and abortion should be combined so often to avoid the birth of Down children. At the end the conclusion follows that unsolvable moral dispute exists on this question.

The first chapter of this thesis gives a descriptive analysis of the evolving practice of NIPT as a prenatal test. Because of its advantages over other prenatal tests, NIPT is said to largely replace them in the near future. This is already taking place in certain countries where NIPT is offered as a free first-tier test.

The second chapter predicts that as a result, the selective abortion of fetuses with Down Syndrome will also increase, making it continuously a more common and normal practice. Healthcare professionals warn that pregnant women feel a pressure to opt for NIPT, and sometimes also to abort a fetus with Down Syndrome. The increasing popularity of NIPT thus seems to affect the choices of future parents in ethically questionable ways. Most of all, the freedom of choice is contested.

In chapter three, different perspectives on this progress are therefore discussed. Some claim that the diminution of Down children is good because this results in greater wellbeing. Yet there's also negative criticism on NIPT and selective abortion. Parents of Down children for example argue that it's not self-evident to screen and abort fetuses with Down Syndrome, especially because future parents have no idea what it's like to have a Down child. Chapter three will conclude that moral diversity stands in the way of finding a common agreed consensus and policy on NIPT. To answer the question of what policy on NIPT to adopt, it must be asked whether a compromise may be found to overcome conflict.

Part two focusses on the question whether reproductive autonomy is a good solution for the moral dispute on NIPT and abortion, which entails that medical practice as a public institution should remain neutral regarding people's personal opinion on selective abortion. This second part will conclude to the contrary by pointing out the importance of virtue ethics.

Chapter four will discuss the liberalism of Ronald Dworkin, because it explains how reproductive autonomy is valued in modern society to answer to the moral diversity on abortion. Unfortunately, his argument fails on basis of its own commitment: providing a neutral institutional policy that respects everybody's interest and opinion. Some people namely argue that selective abortion of Down Syndrome should not be a matter of compromise in the first place.

To solve and explain these shortcomings of liberalism, the work of Alasdair MacIntyre is introduced step by step in chapter five. First, his criticism to liberalism is discussed. MacIntyre shows

how the plan to find a consensus is not possible in contemporary society, and that trying to do so in fact disturbs the debate. Yet his emphasis on moral diversity does not make him a moral sceptic, for he believes that Aristotelian virtue ethics is valuable for any culture and any philosophical tradition no matter how different they are. MacIntyre's version of Aristotelian virtue ethics is therefore discussed in greater depth.

Chapter six concludes that his account does bring a sensible solution to moral diversity, but also that MacIntyre's depiction of liberal society is overly one-sided. The way he uses the term 'liberal' is highly misleading, and so it's important to see to what aspects of liberal society his criticism does or does not apply. To do so, sociological and psychological research is used to see why what MacIntyre's criticism is applicable to modern conceptions on family planning. This analysis will make clear that emphasis on reproductive autonomy neglects virtues of parenthood and medical practice.

Finally, in the last part it will be explained what answers virtue ethics brings to the question whether and when abortion and NIPT should be combined. Looking back at the previous part, it's clear that the research question must be answered by pointing out the virtues of future parents and medical practice.

In chapter seven, different virtue ethicists will be discussed to argue why acceptingness ought to be a parental virtue. On such understanding, it follows that parents have a prima facie duty to accept their fetus with Down Syndrome. Nonetheless, being pregnant of a child and raising a child are two different modes of being its parent. Especially in contemporary society, the connection between the biological fact of parenthood and its sociocultural meaning is no longer self-evident. Therefore, some might argue that being pregnant does not necessarily imply that one ought to behave as a virtuous parent.

Because MacIntyre learns that virtuous decision making is only possible with the help of institutions, this thesis will conclude in last chapter that future parents need help and advise for good decision making. Conversely, the integrity of medical practice depends on whether good prenatal decision making is made. When parents decide to abort their fetus with Down Syndrome for the wrong reason, for example because they want their child to excel, it must be asked whether this is the kind of thing that medicine should comply with. Like Pellegrino and Thomasma point out, benevolence is the end of medicine and so should not actively contribute to ideals of family that have nothing to do with the child's wellbeing. Moreover, most parents are happy with their Down child, so counselling should focus on conveying this message before considering the option of selective abortion.

## PART 1. Problem analysis

### Chapter 1. NIPT

This first introductory chapter explains what NIPT is, why it's so popular and how it's implemented in the Dutch and Belgian medical practice.

#### 1.1 What is NIPT?

Non-invasive prenatal testing (NIPT) is a screening method for chromosomal disorders of the fetus. Pregnant women's bloodstream contains cell free DNA (cfDNA) coming from the placenta, which is normally identical to the DNA of the fetus<sup>1</sup>. After the tenth week of pregnancy a blood test of the mother is therefore an indicator of possible chromosomal disorders of the fetus, such as trisomy 21 (Down Syndrome). Down Syndrome is the most common chromosomal disorder, occurring mostly when the fetus has three copies of chromosome 21 instead of the normal two<sup>2</sup>. Every woman has a small chance of having a child with Down Syndrome, varying around 1 in 1500 for healthy women aged under 20<sup>3</sup>. Yet this chance increases when there's an inherited genetic defect in at least one of the parents or when the mother grows older<sup>4</sup>. Women aged over 35 have a chance of 1 in 174 to have a child with Down Syndrome, going up until 1 in 11 when they reach the age of 45. Since women in western society decide to have children later in life, the prevalence of Down Syndrome increases as a result<sup>5</sup>.

NIPT is becoming more and more common as different countries are lowering the costs of the procedure or are making it entirely free like Belgium<sup>6</sup>. Whether this leads to more selective abortions strongly depends on the countries cultural attitude towards the status of the fetus, the institutional arrangement of prenatal testing (including counselling) and the costs of NIPT<sup>7</sup>.

As for The Netherlands, the implementation of NIPT as a first-tier test for all pregnant women is still under consideration. NIPT is currently only possible by the TRIDENT 1 and 2 studies ("*Trial by Dutch laboratories for Evaluation of Non-invasive prenatal Testing*") who are evaluating this new practice since 2014 in eight university hospitals. Within these studies, women with a high chance of having a child with Down Syndrome can have the test for free with the TRIDENT 1

---

<sup>1</sup> Dierickx, Vandenakker, en Bekedam, "The first 3,000 Non-Invasive Prenatal Tests (NIPT) with the Harmony test in Belgium and the Netherlands". p8

<sup>2</sup> Hook E.B., "Rates of chromosome abnormalities at different maternal ages". p3

<sup>3</sup> J. L. Hamerton N. Canning M. Ray S. Smith, "I. Incidence of chromosome abnormalities".

<sup>4</sup> Verweij, "NIPT : non-invasive prenatal testing : towards implementation in the Netherlands", 2014.p117

<sup>5</sup> Shin, Mikyong, "Prevalence of Down syndrome among children and adolescents in 10 regions of the United States".

<sup>6</sup> Beel, "Regering maakt downtest (bijna) gratis voor iedereen".

<sup>7</sup> X. Zeng a, L. Zannoni b, I. Löwyc en , S. Camporesi D., "Localizing NIPT: Practices and meanings of non-invasive prenatal testing in China, Italy, Brazil and the UK".



program, others have to pay €175 and belong to the second TRIDENT study. Annually, 3.000 women choose to participate in the TRIDENT 1 study whereas 73.000 opted for the TRIDENT 2 study. This amounted to non-invasive prenatal testing for 42% of all pregnancies in The Netherlands, which is a surprisingly low percentage compared to neighbouring countries such as Belgium<sup>8</sup> or the UK<sup>9</sup>.

## **1.2 Advantages of NIPT**

NIPT is generally preferred by future parents because it involves no possible harm to the fetus, unlike invasive diagnostic testing<sup>10,11</sup>. Also, because NIPT has a failure rate under 0.90%<sup>12</sup>, many future parents are deciding to do the latter conclusive test only in case when the NIPT indicated a chromosomal disorder<sup>13</sup>. Such strategy is less preferred when instead of NIPT the combination test, which encompasses a blood test and an ultrasound scan, is used to detect chromosomal disorders. It has a false-negative rate between 20 and 25% and more than 95% of the abnormal results are false-positive<sup>14</sup>. This means that on the one hand, more people relying on the combination test wrongly believe their child to be without disorder when this is not so, making them not choose for an invasive test because it's potentially harmful. On the other hand many pregnant women have an abortion after the combination test while their child actually has no disorder at all. It's namely observed that some pregnant women abort their fetus without having a conclusive diagnostic test<sup>15,16,17</sup>, mostly because they want to get things over with as quickly as possible. This can be explained by research that shows that abortion in early pregnancy invokes less psychological suffering of the mother<sup>18</sup>. Yet precisely because it is hard for mothers to have an abortion, the aborting of fetuses that are actually without a disorder is an unnecessary harm. As the goal of prenatal screening is to help couples have healthy babies, NIPT can be seen as an improvement to the combination test.

---

<sup>8</sup> R. Devlieger, E. Martens, R. Goemaes, H. Cammu, "Perinatale Activiteiten in Vlaanderen 2017".

<sup>9</sup> X. Zeng a, L. Zannoni b, I. Löwyc en , S. Camporesi D., "Localizing NIPT: Practices and meanings of non-invasive prenatal testing in China, Italy, Brazil and the UK".

<sup>10</sup> Li G, Chandrasekharan S, en Allyse M, "'The top priority is a healthy baby': narratives of health, disability, and abortion in online pregnancy forum discussions in the US and China."

<sup>11</sup> Rachèl V. van Schendel e.a., "Women's Experience with Non-Invasive Prenatal Testing and Emotional Well-being and Satisfaction after Test-Results". p1355

<sup>12</sup> Dierickx, Vandenakker, en Bekedam, "The first 3,000 Non-Invasive Prenatal Tests (NIPT) with the Harmony test in Belgium and the Netherlands".

<sup>13</sup> Lewis C, Silcock C, Chitty LS., "Non-invasive prenatal testing for Down's syndrome: pregnant women's views and likely uptake."

<sup>14</sup> Dierickx, Vandenakker, en Bekedam, "The first 3,000 Non-Invasive Prenatal Tests (NIPT) with the Harmony test in Belgium and the Netherlands". p7

<sup>15</sup> Ontario Health Technology Advisory Committee, "Perspectives of Pregnant People and Clinicians on Noninvasive Prenatal Testing: A Systematic Review and Qualitative Meta-synthesis". p17

<sup>16</sup> Rachèl V. van Schendel e.a., "Women's Experience with Non-Invasive Prenatal Testing and Emotional Well-being and Satisfaction after Test-Results". p1347

<sup>17</sup> Mertes, "Is de hype rond de NIPT terecht? De Maakbare Mens".

<sup>18</sup> Korenromp MJ, Christiaens GC, van den BJ, Mulder EJ, Hunfeld JA, Bilardo CM e.a., "Long-term psychological consequences of pregnancy termination for fetal abnormality: a cross-sectional study".

Another opportunity of NIPT is that it can help parents to prepare for their Down child, which is also why many parents say that they choose to do it<sup>19</sup>. Unsurprisingly, most couples say that they would choose NIPT even if they would not choose the combination test<sup>20</sup>. Also 72% of Dutch reproductive healthcare professionals wish to replace the combination test with NIPT<sup>21,22</sup>. This is not to say that when NIPT indicates a disorder, no diagnostic test should be advised to obtain certainty<sup>23,24</sup>. Rather, NIPT improves the process of decision making by its higher reliability and safety. In sum, NIPT seems to have many advantages in comparison to previous reproductive technology.

---

<sup>19</sup> Crombag en Boeije, "Reasons for accepting or declining Down syndrome screening in Dutch prospective mothers within the context of national policy and healthcare system characteristics: a qualitative study."

<sup>20</sup> van Schendel RV, Kleinveld, en Dondorp, "Attitudes of pregnant women and male partners towards non-invasive prenatal testing and widening the scope of prenatal screening".

<sup>21</sup> Tamminga, Van Schendel, en Rommers, "Changing to NIPT as a first-tier screening test and future perspectives: opinions of health professionals". p1318

<sup>22</sup> Although 43% preferred to maintain nuchal translucency measurement as a standard test.

<sup>23</sup> Benn, Borrell, en Chiu, "Position statement from the chromosome abnormality screening committee on behalf of the board of the International Society for Prenatal Diagnosis."

<sup>24</sup> Bowman-Smart, H e.a., "'Is it better not to know certain things?': views of women who have undergone non-invasive prenatal testing on its possible future applications". p231

## **Chapter 2. Changing attitudes towards Down Syndrome and selective abortion**

As the previous chapter outlined what the benefits of NIPT are, this section will discuss some hypothetical claims about what would happen if these benefits are pursued by making NIPT the new standard test for all pregnant women in The Netherlands. It's expected that when NIPT becomes the norm, this will change the attitudes people have towards Down Syndrome and selective abortion. For example, although the majority of Dutch parents of Down children, pregnant women using NIPT and healthcare professionals in the field of reproductive technology say that NIPT has great advantages and should therefore be available to pregnant women, many of these people also predict some attitude changes that come about by doing this<sup>25,26</sup>. Specifically, they believe that the implementation of NIPT as a free first-tier test would make people perceive it as just another routine test. When almost everybody does it, the costs are reimbursed and all doctors advise it, such a simple routine test would be seen as something normal and legitimate. This is said to have three different effects: future parents will not deliberate well enough about their decision to choose NIPT, they will experience pressure from others to choose NIPT and Down Syndrome will largely disappear. This chapter will discuss these three predictions in depth and check them for their validity, to show how NIPT could change the landscape of human reproduction.

Note that although these fears mentioned above are not entirely new, they're specifically applicable to NIPT because it's such a safe and reliable test that is possible during early pregnancy. Whereas the drawbacks of other prenatal tests made people reflect more over what they were doing, and because previous tests included different steps which allowed for reflection over time, the increased use of NIPT as a one-step test could change the way people think about prenatal testing. Moreover, parents of Down children for example point out that when the disorder is discovered earlier because of NIPT, people will be more willing to abort their disordered fetus because there's less bonding with it<sup>27</sup>. In sum, it is expected that the combined effect of these attitude changes could make Down syndrome largely disappear. Whether this is ethically problematic, will be discussed in the third chapter.

---

<sup>25</sup> Rachèl V. van Schendel e.a., "Women's Experience with Non-Invasive Prenatal Testing and Emotional Well-being and Satisfaction after Test-Results". p1347

<sup>26</sup> Rachèl V. van Schendel e.a.

<sup>27</sup> Kater-Kuipers, Van Schendel, en Dondorp, "What Do Parents of Children with Down Syndrome Think about Non-Invasive Prenatal Testing (NIPT)?" p525

## **2.1. Introducing NIPT as a first-tier test causes future parents to deliberate not well enough.**

First of all, The Dutch Healthcare Counsel warns that if NIPT becomes a routine test it's possible that pregnant women become *inconsiderate* in giving their consent to it<sup>28</sup>. Since it's just a 'simple blood-test', The Counsel warns that the possible harms that come about by knowing its results might very well be overlooked by future parents. For some part this is already the case, because research shows that many parents don't perceive the current prenatal screening tests as a choice or potential problem<sup>29,30</sup>. Yet good consideration is required for screening, because hearing the news of probably having a child with Down Syndrome often causes great distress and doubts<sup>31</sup>. Researchers and parents of Down children therefore argue that future parents should deliberate well about what they want to know<sup>32,33</sup>. Sometimes, it might be better not to be burdened with the information and the decision of continuing the pregnancy or not.

The neglect of these downsides may also be caused by healthcare professionals who become less explicit in mentioning them during counselling, because Lewis et al. argue that also they can come to see NIPT as a routine test<sup>34</sup>. Concerning the Netherlands specifically, Van Schendel et al. found that 57% of Dutch reproductive healthcare professionals believe that NIPT only has advantages<sup>35</sup>. Hence it's likely that they won't press future parents to reflect on the possible downsides of NIPT, which will substantially influence their decision making. Billen et al. namely show that physicians feel that their job is fulfilled when they correctly communicate the statistical probability of genetic disorders, whereas parents understand such advice in binary terms: will my child have a disorder yes or no<sup>36</sup>. So when the physician judges that the odds are very small, parents are very likely to reflect overly positive over this advice.

Moreover, The Dutch Healthcare Council warns that selective abortion might be equally normalized by what is often called the 'technological imperative'<sup>37</sup>: the idea that a medical defect requires some technological solution, simply because this is how it's normally done. A future parent

---

<sup>28</sup> Nederlandse Gezondheidsraad, "NIPT: dynamiek en ethiek van prenatale screening". p11

<sup>29</sup> Billen, Evers-Kiebooms, en d'Ydewalle, "Risico-perceptie en erfelijkheid: een benadering vanuit de cognitieve psychologie".

<sup>30</sup> Scholz, "On the interactive accomplishment of decision in genetic counseling before prenatal diagnosis",.

<sup>31</sup> Kater-Kuipers, Van Schendel, en Dondorp, "What Do Parents of Children with Down Syndrome Think about Non-Invasive Prenatal Testing (NIPT)?" p525

<sup>32</sup> Deans en Newson, "Should non-invasiveness change informed consent procedures for prenatal diagnosis?"

<sup>33</sup> Campbell K. Brasington, "What I Wish I Knew Then...Reflections from Personal Experiences in Counseling about Down Syndrome", 2007.

<sup>34</sup> Lewis C, Silcock C, Chitty LS., "Non-invasive prenatal testing for Down's syndrome: pregnant women's views and likely uptake."

<sup>35</sup> Tamminga, Van Schendel, en Rommers, "Changing to NIPT as a first-tier screening test and future perspectives: opinions of health professionals".p1316

<sup>36</sup> Billen, Evers-Kiebooms, en d'Ydewalle, "Risico-perceptie en erfelijkheid: een benadering vanuit de cognitieve psychologie".

<sup>37</sup> Nederlandse Gezondheidsraad, "NIPT: dynamiek en ethiek van prenatale screening". p18

faced with uncertainty might feel the urge to simply do something to respond to what is perceived as an abnormality. Yet, this would imply blind compliance to a perceived norm and so no case of genuine informed consent<sup>38</sup>. Therefore, some doubt whether NIPT should be a standard and free first-tier test, advocating for the right not to know as a protection of reproductive autonomy<sup>39</sup>.

The importance of careful deliberation and good counselling is uncontested. Favre et al. for example studied prenatal screening in France and found that poor counselling (besides educational level and belonging to the high risk group) left many women poorly informed. Many didn't realize that the test was optional, and 15% even thought that abortion was obligated when it was diagnosed that the child had Down Syndrome. Favre et al. concluded that this lack of adequate information made many of their decisions inconsistent with their reported values. Other research shows similar problems in the counselling practice in Germany<sup>40</sup>.

Yet the results of the TRIDENT 1 study point out that as far as the Netherlands is concerned, counselling does succeed in obtaining good informed consent for NIPT. Using a questionnaire, van Schendel et al. found that 77.9% made an informed choice, 89.8% had sufficient knowledge and 90.5% had positive attitudes towards NIPT<sup>41</sup>. Compared to Germany and France these are good results. Kater-Kuipers et al confirm that the counselling practice in the Netherlands indeed succeeds in avoiding inconsiderate decision making, but also point out that since NIPT is advised within a study setting people are more cautious as to what they consent to<sup>42</sup>. Now when the TRIDENT studies finish and conclude that NIPT should be offered to all pregnant women, the pre-test counselling will (if any at all) take place outside the current study setting. Counseling will then mostly be done by primary care midwives who so far have limited experience with NIPT compared to the professionals working within the TRIDENT studies. So it's unsure whether they will adequately communicate the risks involved to make people reflect about their decision.

Moreover, the TRIDENT 1 study only concerned women within the high-risk group, who are therefore presumably more actively concerned with the chance of having a child with Down Syndrome. The TRIDENT 2 study is still ongoing, yet since these participants paid €175 for the NIPT

---

<sup>38</sup> Shuster, "Microarray genetic screening: a prenatal roadblock for life?" p526

<sup>39</sup> Deans Z, Clarke A.J. Newson, A.J., "For your interest? The ethical acceptability of using non-invasive prenatal testing to test 'purely for information.'"p11

<sup>40</sup> Ilona Renner, "Schwangerschaftserleben und Pränataldiagnostik: Repräsentative Befragung Schwangerer zum Thema Pränataldiagnostik".

<sup>41</sup> Rachèl V. van Schendel e.a., "Women's Experience with Non-Invasive Prenatal Testing and Emotional Well-being and Satisfaction after Test-Results".

<sup>42</sup> Kater-Kuipers e.a., "Ethics of routine: a critical analysis of the concept of 'routinisation' in prenatal screening". p628

it's highly likely that they don't perceive it as just another blood test. If NIPT would become freely available for all, the overall decision making might become less fully deliberate.

In short, good counselling can overcome the danger of inconsiderate decision making. But for counselling to be successful, it's highly important about how NIPT is offered and perceived. Besides, the following section shows that even with all of this in mind, not yet all problems concerning informed consent are overcome.

## ***2.2 Introducing NIPT as a first-tier test pressures future parents to do the test when they actually don't want to***

Fishbein and Ajzen show how prenatal decision-making by future parents is mostly determined by social components, like the expected reaction of significant others in their surrounding like family-members<sup>43</sup>. So to think that only rational self-interest and knowledge of medical facts guide the decision, is unwarranted. The second point of concern is thus that when NIPT becomes popular and normalized, those parents who don't want to be tested feel obliged to do so, albeit unconsciously. Hence Michael Sandel says:

*"Once, giving birth to a child with Down syndrome was considered a matter of chance; today many parents of children with Down syndrome or other genetic disabilities feel judged or blamed. (...) The advent of genetic testing creates a burden of decision that did not exist before. (...) When genetic screening becomes a routine part of pregnancy, parents who eschew it are regarded as "flying blind" and are held responsible for whatever genetic defect befalls their child."*<sup>44</sup>

Sandel is not alone in seeing this new sense of responsibility that comes about with prenatal testing<sup>45,46</sup>. Research shows that some pregnant women do experience pressure from their social surrounding to opt for NIPT, and many of them report that they believe that this pressure will increase if NIPT becomes a first-tier and low cost test<sup>47,48,49</sup>. Since NIPT has these advantages, it might be felt that only a careless and therefore bad parent would not take the test. The concern is also

---

<sup>43</sup> Fishbein en Ajzen, "Belief, attitude, intention and behaviour: An introduction to theory and research".

<sup>44</sup> Sandel, "The Case Against Perfection: Ethics in the Age of Genetic Engineering". p87-88

<sup>45</sup> Suster, "The Routinization of Prenatal Testing".

<sup>46</sup> Dierickx, "Prenatale Diagnostiek, Nieuwe technologische mogelijkheden en ethische uitdagingen".

<sup>47</sup> M. Vanstone, "Women's perspectives on the ethical implications of non-invasive prenatal testing: a qualitative analysis to inform health policy decisions". p8-9

<sup>48</sup> van Schendel RV, Kleinveld, en Dondorp, "Attitudes of pregnant women and male partners towards non-invasive prenatal testing and widening the scope of prenatal screening". p1345

<sup>49</sup> Lewis C, Silcock C, Chitty LS., "Non-invasive prenatal testing for Down's syndrome: pregnant women's views and likely uptake."

heard from the Belgian Bioethics Committee<sup>50</sup>. Of course the presence of such pressure to test does not necessarily mean that parents will eventually take the test when they believe they actually shouldn't. But the possibility that they do is a threat to informed consent, and thus this involves an area of concern.

Compared to the previous section, this problem lies predominantly with the attitudes present in society. Therefore, the next section further addresses the attitudes on Down Syndrome.

### ***2.3 Introducing NIPT as a first-tier test will make Down Syndrome largely disappear***

Fetuses with Down Syndrome are often aborted, especially in China<sup>51</sup> and Europe<sup>52</sup>. Kater-Kuipers et al. show that between 1990 and 2009 (before NIPT that is) 47% of diagnosed cases of Down Syndrome were aborted in European countries<sup>53</sup>. Concerning The Netherlands specifically, it's observed that roughly 90% of diagnosed fetuses with Down Syndrome is aborted<sup>54</sup>. The Dutch Health Counsel predicts that the total amount of such abortions will rise because more people will attend to prenatal screening because of the more advantageous technique of NIPT<sup>55</sup>. Note that the combination test allows for more Down children to be born because not all of them are detected, whereas NIPT is almost flawless. The only drawback to this progress seems to be the current costs of NIPT for women who are not in the high-risk group, as was seen above by comparison of the Netherlands with other countries. If costs are fully reimbursed for all, it's possible that the Netherlands will follow the path of Denmark and Iceland where Down Syndrome is almost entirely disappearing because of selective abortion<sup>56,57</sup>. Finally, note that this is a dynamic progress: the prevalence of a practice can increase its popularity. In case of selective abortion for Down Syndrome, some make the prediction that the less children with Down Syndrome are being born, the more people will be inclined to also abort their fetus with Down Syndrome.

---

<sup>50</sup> Belgisch Raadgevend Comité voor Bio-Ethiek, "Advies nr. 59 van 27 januari 2014 betreffende de ethische aspecten van de toepassing van de wet van 28 mei 2002 betreffende de euthanasie". p11

<sup>51</sup> Li G, Chandrasekharan S, en Allyse M, "'The top priority is a healthy baby': narratives of health, disability, and abortion in online pregnancy forum discussions in the US and China."

<sup>52</sup> Kater-Kuipers e.a., "Ethics of routine: a critical analysis of the concept of 'routinisation' in prenatal screening". p629

<sup>53</sup> de Graaf, Engelen, en Gijsbers, "Estimates of live birth prevalence of children with Down syndrome in the period 1991-2015 in the Netherlands."

<sup>54</sup> Nagel H e.a., "Invasieve prenatale diagnostiek in Nederland, 1991-2000: aantallen ingrepen, indicaties en gevonden afwijkingen."

<sup>55</sup> Nederlandse Gezondheidsraad, "NIPT: dynamiek en ethiek van prenatale screening". p91

<sup>56</sup> Nonetheless, both countries have a relatively small population, so the total number of newborns with Down Syndrome is no direct indication of a changing attitude.

<sup>57</sup> J. Quinones, "'What kind of society do you want to live in?': Inside the country where Down syndrome is disappearing".

## **2.4 Summary**

This section highlighted the expected attitude changes that come about when introducing NIPT a first-tier test. First, it was argued that future parents might not deliberate well enough about their decision to choose for NIPT because it becomes to be seen as a routine test. Secondly, it was shown that some parents experience pressure to choose NIPT. Thirdly, it was shown that more abortions of Down children are likely to follow the increased use of NIPT.

This short overview allows us to see how these three aspects are related. Both the pressure to test and the perception of NIPT as a routine test are likely to increase uptake, especially if NIPT becomes freely available. This increased uptake will result in more people coming to know that their fetus has Down Syndrome. As Down is generally seen as something negative for the family<sup>58</sup>, less children with Down Syndrome are expected to be born.

These predictions raise a series of ethical questions, especially concerning the *freedom of decision making* that is granted to future parents. First, the routinization is likely to effect the *quality of the decision making* because future parents don't reflect well enough or under pressure. This raises the question how and whether NIPT should be offered to all future parents. Secondly, one may ask whether it is really necessarily to avoid so many Down children to be born, since so many parents of Down children say that they're happy with their child. These questions contest the freedom of choice, which will be of central importance in the following chapters. Since it's still under consideration how NIPT will find a place in Dutch society, an answer to these ethical concerns is important and insightful to guide medical practice.

---

<sup>58</sup> Gilmore L, Campbell J, en Brasington K, "M. Developmental expectations, personality stereotypes and attitudes towards inclusive education: Community and teacher views of Down syndrome."



### **Chapter 3. Ethical perspectives on selective abortion**

The ethical debate on NIPT relates to the ethical problems concerning abortion, because NIPT is often used for the selective abortion of Down children. Therefore, anyone who defends a definite position in the NIPT debate will also have a correlated stance on the general issue of abortion. Yet arguments pro and against abortion per se fall outside of the scope of the current discussion. Because the question in this chapter will be that *if* abortion is justifiable, *whether* and *when* the same goes for *selective* abortion of Down children. Answers to the questions of abortion and selective abortion are namely not straightforwardly related, because to argue that a woman should not be obligated to have *a* child when she is pregnant, is not always the same as to say that she may choose *which* child she gives birth to. The practice of selecting the most wanted fetus for birth is therefore partly outside of the abortion debate, because in this case it's also common that the woman already decided to become pregnant. Therefore an 'unwanted pregnancy' gets a different meaning, and so too the content of the debate changes.

For some this separation of the two debates is unwarranted, because they advocate for the fundamental right of bodily integrity in both instances for example. Yet this overlap between the two debates would then only apply in so far as abortion is considered as a political right. Now besides arguing who should get the final authority on the legitimacy of abortion, there's still space and need for ethical reflection to help people make good decisions and more specific policy decisions.

To do so, this chapter focuses on two constrating positions: the utilitarianism of Julian Savulescu and the disability right critique of Arienne Ash. Both answer the questions formulated in chapter two, *should Down children be born* and *what should be advised by prenatal counselling*. Therefore they are useful for the current discussion. Analyzing their constrating positions is interesting to show how people can differ about the moral status of the fetus, the conception of the good life and how prenatal counselling takes place. Their differences allow to understand the core ethical dispute of selective abortion, and therefore serve to get a good overview of the debate.

The conclusion of this chapter will be that these perspectives are mutually incompatible so that, nor in theory nor in practice, there's consensus on the use of NIPT. Part two will therefore consider exactly why moral disagreement arises in this debate, and so too how moral diversity must be responded to.

#### **3.1 The utilitarian argument**

Julian Savulescu, Peter Singer and Etienne Vermeersch argue from a utilitarian perspective to promote selective abortion and NIPT. They believe that there's nothing wrong per se with aborting disordered fetuses, and argue that it would be best to do so in order to only give birth to

nondisordered fetuses. Because Down children experience a lot of suffering, the principle of wellbeing justifies selective abortion according to them. This section summarizes their arguments, to see what different emphasize they introduce.

Concerning the use of NIPT in Belgium, Belgian philosopher Etienne Vermeersch made the unambiguous statement that Down Syndrome must be exterminated for the same reason as it was done with smallpox<sup>59</sup>. Hence, NIPT should not only be made freely available but also mandatory for all pregnant women according to him. Refuting the claim that he did not value the life of people with Down Syndrome, Vermeersch argued that the decrease of their numbers makes extra care available for those left. Similar arguments are heard from Peter Singer, who points out that there are no good reasons not to select for a non-disordered child<sup>60</sup>. He argues along the lines of Vermeersch, saying that the disappearance of Down Syndrome is a goal to be strived for because this results in less suffering. He emphasizes the physical pain that Down children experience, mostly because of their many physical defects like breathing. Indeed, Cuskelly et al. their analysis confirmed that Down children generally face lower wellbeing<sup>61</sup>.

Now both Vermeersch and Singer are very straightforward in their reasoning, claiming that's there's actually no moral conflict at all in 'exterminating' Down Syndrome by reproductive technology. Counterarguments are merely empowered by religious or religiously inspired beliefs, but anyhow not rational<sup>62</sup>. Selective abortion is thus completely rational since the fetus has no value on its own. This is how Singer sees it:

*"The decision to abort a fetus that has, say, Down syndrome, is ... a decision that says: "Since I will only have two children, I want them to have the best possible prospects for a full and rich life. And if, at the outset, those prospects are seriously clouded, I would rather start again."<sup>63</sup>*

Vermeersch says that since the majority of future parents do decide to abort their fetus when it's diagnosed with Down Syndrome, he's defending the opinion of the general public<sup>64</sup>.

Finally, Julian Savulescu his argument parallels to a great with the positions of Vermeersch and Singer, as the essence of his argument depends on his 'Procreative Beneficence Principle':

---

<sup>59</sup> Vermeersch, "Pleidooi voor vrije keuze".

<sup>60</sup> Singer en Kuhse, "Should the Baby Live? The Problem of Handicapped Infants."

<sup>61</sup> Cuskelly, Hauser-Cram, en Van Riper, "Families of children with Down syndrome: What we know and what we need to know". p105-106

<sup>62</sup> Rogiers en Verhoeven, "Filosofen Hebben Woorden. Interview: Etienne Vermeersch & Ignaas Devisch".

<sup>63</sup> Singer, "Severe Impairment and the Beginning of Life".

<sup>64</sup> Rogiers en Verhoeven, "Filosofen Hebben Woorden. Interview: Etienne Vermeersch & Ignaas Devisch".

*“Couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information”.*<sup>65</sup>

He clarifies that ‘choosing genes’ is like playing with ‘a Wheel of Fortune’<sup>66</sup>. It’s always uncertain how the child will turn out to be. But if the odds to have a healthy child can be improved, it’s rational to do so. So this argument is clearly in line with the other two philosophers. Yet unlike them, Savulescu puts great emphasis on the indisputable right of reproductive autonomy that comes into conflict with the principle of beneficence. He namely holds that within liberal society people should be free to make their own choices on family planning<sup>67</sup>. Later on it will be shown why this specific argument is of great importance to understand the conflict on selective abortion. So for it suffices to show that Savulescu relies on the principle of reproductive autonomy, to argue that institutional reform but not interference with reproduction is required. Eventually, he advocates that prenatal counselling should be directed at promoting selective abortion.

### **3.2 The argument of the disability right movement**

The disability right movement advocates against NIPT and selective abortion because they see it as unequal treatment of disabled people<sup>68,69</sup>. They claim that Down Syndrome is no disease to be prevented, but an indispensable part of people’s identity and therefore also of the family and the community that the child belongs to<sup>70,71,72</sup>. To abort and even to screen for Down Syndrome is wrong according to them, because it enforces the already existing stigmatization surrounding it. Not only does this stigmatization wrongfully influence future parents to choose for selective abortion, it also forms a symbolic and substantive discrimination of people with Down Syndrome. This argumentation will be discussed in depth, starting with the claim that there effectively is a stigma on Down Syndrome.

---

<sup>65</sup> Savulescu, “Procreative Beneficence: Why We Should Select The Best Children”, 2001. p415

<sup>66</sup> Savulescu. p416

<sup>67</sup> It unfortunately remains unclear whether Savulescu means to say that procreative autonomy is valuable in itself, or that it must be respected simply because it’s a value of liberal society. Now the later statement can be defended on libertarian as well as on utilitarian grounds, meaning that autonomy can be valued intrinsically or instrumentally. Yet it’s unclear which one Savulescu has in mind, and so whether he’s a pure utilitarian.

<sup>68</sup> Nelson, “The Meaning of the Act: Reflections on the Expressive Force of Reproductive Decision Making and Policies”.

<sup>69</sup> With this is meant disabled people, their care workers, their close relatives and friends.

<sup>70</sup> Taylor, “Non-Invasive Prenatal Testing”.

<sup>71</sup> Parens en Asch, “Disability rights critique of prenatal genetic testing: reflections and recommendations”.

<sup>72</sup> Campbell K. Brasington, “What I Wish I Knew Then...Reflections from Personal Experiences in Counseling about Down Syndrome”, 2007.

Parents of Down children claim that most people don't know what it's like to have a child with Down Syndrome<sup>73</sup>, which refutes the claim that future parents are well informed during their prenatal decision making. Indeed, it's well documented that the general public does have a very negative view on having a child with Down Syndrome<sup>74</sup>, which doesn't match the attitudes of families who do have a Down child. In their meta-analysis, Cuskelly et al. namely describe the different experiences of families with Down children, showing how the manageability of the child and the happiness of the family highly varies across families<sup>75</sup>. A lot depends on having sufficient financial means, other children in the family and whether the Down child has side conditions like autism. Cuskelly et al. show that although the negative effects of having a child with Down Syndrome on the family's wellbeing are significant, many families are satisfied and do feel empowered by taking care of a Down child. Besides, the idea that marital bonds would be negatively affected or that the mother has to give up her career are also proven not to be true. So to conclude, although having a Down child is often a hard burden, to automatically suppose that the family cannot fare well because of this is generally mistaken.

As long as the stigmatization of Down Syndrome is addressed adequately, it still seems warranted that NIPT can be justified as a means to secure optimal wellbeing. When future parents rightfully observe that they don't have the means for taking care of a Down child, screening and selective abortion can make sure that they don't have to. Yet this way of reasoning would assume that the problem to the child's and the family's wellbeing is the disorder in the first place. Now this assumption is questionable. For if society would provide the means for adjusted care, the Down child and its family could flourish just as well. Admundson explains why this view is often overlooked:

*"People think of disabled people not as having specific disabilities, but as being generally incompetent. This social image reinforces the illusion that global disadvantages and handicaps flow from nature itself".<sup>76</sup>*

He concludes that this perception blocks off institutional change towards the solving of discrimination, because people are not eager to recognize that the institutional setting is the core of the problem. Arienne Ash agrees, adding that nondisabled people understand a disorder by thinking how their life would be if they would lose the capacities and opportunities that the disorder

---

<sup>73</sup> Kater-Kuipers, Van Schendel, en Dondorp, "What Do Parents of Children with Down Syndrome Think about Non-Invasive Prenatal Testing (NIPT)?" p528

<sup>74</sup> Gilmore L, Campbell J, en Brasington K, "M. Developmental expectations, personality stereotypes and attitudes towards inclusive education: Community and teacher views of Down syndrome."

<sup>75</sup> Cuskelly, Hauser-Cram, en Van Riper, "Families of children with Down syndrome: What we know and what we need to know".

<sup>76</sup> Admundson, "Disability, Handicap and the Environment". p114

precludes<sup>77</sup>. This is a flawed understanding according to her. First of all, for people with congenital disorders like Down Syndrome this sense of loss is meaningless. To take the example of Down Syndrome, it's obvious that they don't miss the joys of great intellectual accomplishment. It's simply an end that they cannot pursue. Yet there's no problem to this when they can enjoy others and don't miss the ones they can't. For it would be senseless to say that all possible ends that humans can theoretically pursue ought to be pursued. No one pursues all ends that are upon to him or her given his or her capacities. Like Ash says, the most passionate reader will not read all books and the best sportsman will not practice every sport. Therefore, it would also be senseless to say that every human being ought to pursue great intellectual accomplishment. Down children have a different set of goals, and since these goals can be recognized as being valuable, so too are Down children. Ash concludes that Down is not the problem to the child's good life. Rather, it's the institutional setting and attitude of society that make his or her life goals difficult to obtain.

It's documented that disabled people, including people with Down Syndrome, are still discriminated in society. Leenmans et al. for example researched three European countries, including the Netherlands, to show how discrimination of disabled people is real and persistent<sup>78</sup>. In the Netherlands, Stichting Down Syndrome (SDS) and others also complain that Down children don't get fair educational opportunities<sup>79,80</sup>.

Now to come back to NIPT, Ash argues that prenatal diagnosis reinforces the idea mentioned by Admundson, that disability itself and not the societal discrimination of disabled people is the problem to be solved<sup>81</sup>. She supports her claim by a research of Lippman & Wilfond that compared prenatal and postnatal counselling on Down Syndrome. It was found that the former was highly negative by focusing on all the difficulties, whereas during the postnatal counselling parents with a Down child were told that the disorder is not that bad at all. Means were advised for making good care possible, which was often not mentioned during prenatal counselling<sup>82</sup>. So indeed, it can be said that prenatal counselling is directive, contrary to the official norm<sup>83</sup>. But Ash seems to overlook the fact that it might simply be the postnatal counselling that is biased in being overly positive, instead of the prenatal counselling being overly negative. In order to support her argument in another way, it's

---

<sup>77</sup> Ash, "Disability Equality & Prenatal Testing: Contradictory Or Compatible?", 2003.p324-325

<sup>78</sup> Wilken e.a., "Community Support and Participation Among Persons With Disabilities. A Study In Three European Countries."

<sup>79</sup> Schuman, "Passend Onderwijs – pas op de plaats of stap vooruit?"

<sup>80</sup> Lamberts, "Special DU overgang SVO naar werk".

<sup>81</sup> Ash, "Disability Equality & Prenatal Testing: Contradictory Or Compatible?", 2003.p316

<sup>82</sup> Lippman en Wilfond, "Twice-told Tales: Stories about Genetic Disorders".

<sup>83</sup> Ministerie VWS, "Kwaliteitseisen counseling prenatale screening".

important to see that parents of Down children say that their prenatal counselling gave a misinterpretation on living with Down Syndrome<sup>84</sup>.

So Ash formulates a justified demand when saying that prenatal counselors should correctly understand and explain how a life with Down Syndrome can be worthwhile<sup>85</sup>. Yet more importantly, she argues that the attitude of society towards disability is the main obstacle to good prenatal decision making. Like Ash says:

*"I believe that it will be very difficult for most families to consider bringing children with diagnosable disabilities into the world if they know that the society believes that their births should have been prevented".*<sup>86</sup>

Only after the stigma has disappeared, NIPT and selective abortion can become informed and valuable choices according to her. Yet, although she does seem to recognize this herself, it seems hard how this might ever be so. For selective abortion always causes some stigmatization of Down Syndrome, and so to its use she would always have to protest.

Finally, it's understandable that given the persistent discrimination and stigma, prenatal screening for Down Syndrome can be felt as an insult in itself<sup>87</sup>. Many people with Down syndrome and their family members, seem to identify with disabled fetuses<sup>88</sup>. For some of them, selective abortion signifies a transgression of their right to live. So even when counselors would do the best they can to make future parents correctly understand Down Syndrome, the existence of selective abortion would always be a symbolic insult to them.

### **3.3 The conflict between utilitarianism & the disability right movement**

The first question here is how a utilitarian can respond to the disability right critique. Because Savulescu addresses this critique directly, his argument is useful to discuss the matter. It's obvious why he believes that fetuses with Down Syndrome ought not to be selected: greater intelligence directly and indirectly contributes to greater wellbeing<sup>89</sup>. To defend his argument, he relies on Newson her meta-analysis of empirical literature on intelligence, which concludes that:

---

<sup>84</sup> Kater-Kuipers, Van Schendel, en Dondorp, "What Do Parents of Children with Down Syndrome Think about Non-Invasive Prenatal Testing (NIPT)?" p527

<sup>85</sup> Ash, "Disability Equality & Prenatal Testing: Contradictory Or Compatible?", 2003.p338-339

<sup>86</sup> Ash.p340

<sup>87</sup> Nelson, "The Meaning of the Act: Reflections on the Expressive Force of Reproductive Decision Making and Policies".

<sup>88</sup> Campbell K. Brasington, "What I Wish I Knew Then...Reflections from Personal Experiences in Counseling about Down Syndrome", 2007.

<sup>89</sup> Savulescu, "Procreative Beneficence: Why We Should Select The Best Children", 2001. p420

*“Intelligence has a high instrumental value for persons in giving them a large amount of complexity with which to approach their everyday lives, and that it equips them with a tool which can lead to the provision of many other personal and social goods”.*<sup>90</sup>

Therefore, Savulescu goes so far as to argue that even non-disordered fetuses ought to be aborted when it's possible to create and select fetuses with even greater dispositions for intelligence. Now when replying to the criticism from the disability right movement, Savulescu recognizes that substantial discrimination of Down Syndrome is a real problem that must be solved<sup>91</sup>. Yet he holds that other means must be used instead of a different policy on NIPT, for it would be unjust to solve the discrimination by means of disallowing, restricting or counselling differently about NIPT and selective abortion. Not only would it be in breach with reproductive autonomy, so to it would result in the birth of children with less capacity for happiness.

It's obvious that the utilitarian interpretation of Savulescu misses the point that Ash and Admundson are trying to make. First, for him it's irrelevant that prenatal screening and selective abortion take place in a society where disabled people are discriminated. Both are *separate problems that require separate solutions* according to him. To solve one problem by giving up the other, is invalid because only the consequences and not the symbolic significance of the act is what matters. Here there's a fundamental conflict about what the focus and goal of ethics should be.

Secondly, Ash also holds that it's simply untrue that the less Down children there are, the greater care is made available to them<sup>92</sup>. She points out that the rise of selection abortion was not followed by more care or opportunities for disabled people. Yet also here, the utilitarians might once again argue that the existent discrimination is a separate problem from prenatal practice.

Thirdly, for Savulescu the good life consists in achieving as much happiness as possible, whereas Ash her conception of the good life was defined by the achievement of different inconsumable goals.

Fourthly, Ash, many parents of Down children and advocates of the disability right movement, argued that there's an epistemical boundry to knowing what it's like to have a child with Down Syndrome. The utilitarians in this discussion don't consider such limitations, but merely point out that it's only relevant to asses what conditions can be reasonably *expected* to contribute the *most* to wellbeing. Also here, the conception of the good life fundamentally differs.

Finally, for Ash the disabled fetus is already part of the disabled community, whereas Savulescu and other utilitarians mention no such identification.

---

<sup>90</sup> Savulescu. p421

<sup>91</sup> Savulescu. p423

<sup>92</sup> Ash, “Disability Equality & Prenatal Testing: Contradictory Or Compatible?”, 2003. p317;329

To summaries, both positions differ on what solution ought to fit with what problem, what the good life is and on the moral status of the fetus. Therefore they don't come to a reasonable agreement about whether Down children should live, and what should be advised during counselling.

### **3.4 Conclusion: compromise rather than consensus**

Many other utilitarians or advocates of the disability right movement can be found that have different opinions on the ethical assumptions and proposed solutions listed above. Furthermore, the debate could also be extended still further by adding different perspectives like Feminism, Catholicism or Kantianism. Also many subdivisions could then be formulated by combining or deepening these theories and perspectives. Only such an extensive list could rightfully accommodate for all the different perspectives on NIPT and abortion. Yet there's no need for discussing the debate still further, for it would only show what's already clear: that there's no consensus on the use of NIPT.

Still seeking for an answer to the questions *should Down children be born and what should be advised by prenatal counselling*, the following question is whether reasonable and justifiable *compromise* on these issues may be found since *consensus* remains unattainable. Of course such compromise already exists in the form of the institutionalized right of reproductive autonomy. Liberal democracies like Belgium<sup>93</sup>, The Netherlands<sup>94,95</sup>, the UK<sup>96</sup> and the USA<sup>97</sup> for example acknowledge that there's no final truth on what choices on selective abortion or NIPT are right. According to their laws, counselling should be non-directive, everyone's decision ought to be respected and the final authority lies with the mother because she has a right to bodily integrity. This way, everyone can make his own decisions concerning his own family, while no final consensus is found on what good decisions really are.

To know whether and why this form of compromise is ethically justifiable or not, one must assess the assumptions and justifications behind these laws. Yet laws are upon to different interpretations and justifications, and so they are not straightforwardly related to ethical theory. Nonetheless it seems that the above justification of reproductive autonomy as a fundamental right is a highly liberal conception, because freedom choice is valued as the prime ethical standard. Therefore the next part will focus on liberalism and its philosophical and cultural underpinning in Western society, in order to assess its justification of reproductive autonomy. Two philosophers who

---

<sup>93</sup> Belgisch Raadgevend Comité voor Bio-Ethiek, "Advies nr. 59 van 27 januari 2014 betreffende de ethische aspecten van de toepassing van de wet van 28 mei 2002 betreffende de euthanasie". p10

<sup>94</sup> Ministerie VWS, "Kwaliteitseisen counseling prenatale screening".

<sup>95</sup> Nederlandse Gezondheidsraad, "NIPT: dynamiek en ethiek van prenatale screening". p72

<sup>96</sup> Human Fertilisation and Embryology (Disclosure of Information) Act. c. 54.

<sup>97</sup> Human Fertilisation and Embryology Authorit, "Sex selection: options for regulation".



have a contrasting vision on this point are discussed: Ronald Dworkin (1931-2013) and Alasdair MacIntyre (1929-).

Dworkin's liberal justification of reproductive autonomy is useful for the current discussion, because it justifies the right to reproductive autonomy like it's known in Western countries such as Belgium and The Netherlands. Therefore, he's a useful candidate to understand, defend and appreciate the current institutional arrangement. Of course, many other liberal philosophers could be useful candidates as well, because it's a common liberal assumption that the state ought to be neutral concerning personal and ethically dubious matter. Yet Dworkin is especially useful and interesting. First of all, because he defends the idea that there does exist moral consensus on a deeper level. This idea is interesting because it sheds a different light on the ethical conflict, as will be shown in the following chapter. Secondly, because Dworkin's popularity made him a core proponent of liberalism<sup>98</sup>. His work is still very influential among liberal scholars. Thirdly, MacIntyre directly criticizes Dworkin's liberalism, which criticism is essential for understanding MacIntyre's own position.

MacIntyre his work is highly valuable because he explains how conflicting ethical perspectives can each be intelligible and rational, emphasizing the validity of different modes of rationality. Yet simultaneously, his theory does not result in moral relativism. On his account, no perspective is fully coherent and some more than others. So reasonable debate is useful and possible.

The following part will evaluate Dworkin's and MacIntyre's position in turn, to see whose answer must be applied to answer the question of what policy on NIPT to adopt. The conclusion will be that Dworkin's account fails to find reasonable agreement, and so that MacIntyre's virtue ethics is more appropriate to answer to the different critiques on NIPT.

---

<sup>98</sup> Neal, "Dworkin on the Foundations of Liberal Equality".

## **PART 2. Reproductive autonomy**

This part focuses on the principle reproductive autonomy in modern society and how it came to be valued. To circumscribe this principle more clearly, it basically entails that all future parents may make their own choices regarding reproduction in line with their own values. Essential is that anything that falls within the scope of this principle, be it the future parents' choice for a screening test or abortion, is ethically justified and must be respected. The act itself, abortion for example, is not what justifies the choice. Rather, the choice is justified because it's in line with the values of the future parents, making this a *sufficient* instead of only a *necessary* condition. Hence, the specific application of this principle, abortion or selective abortion, is only of secondary concern during this second part. The question in this part namely is whether reproductive autonomy is a legitimate compromise to solve the controversy surrounding NIPT and selective abortion. It's only in the third and final part that the differences between the applications of the principle will be of primary concern.

First, Dworkin's liberal defence of reproductive autonomy is formulated, assessed and criticized. It will be shown that his argumentation fails on the basis of its own goal, which is to provide a neutral institutional setting that respects everyone's opinion.

## Chapter 4. Dworkin & Liberalism

### 4.1 Dworkin's defence of reproductive autonomy

Ronald Dworkin believes that underlying the dispute on abortion<sup>99</sup>, there exists fundamental moral agreement that can serve as a legitimate basis for respecting reproductive autonomy<sup>100</sup>. He leaves the discussions on particular principles and the status of the fetus aside, because he remarks that these don't explain the intuitions everyone has concerning life and death. Yet intuitions are of central importance according to Dworkin, because he believes that they reveal overall and fundamental agreement. To prove his point, he starts of arguing that there are many totally different ways to value life. But nonetheless, he concludes that all people eventually regard human life as *intrinsically valuable* in some way. Dworkin identifies two forms of intrinsic human value, to which he says anyone aspires, no matter what their stance on abortion is. First, everyone acknowledges that human life is intrinsically valuable, because even the most surefooted proponents of abortion recognize that aborting a fetus is unlike cutting hair. Secondly, Dworkin claims that everyone values human creation and life investment as intrinsically valuable<sup>101</sup>. Now Dworkin connects these two forms of intrinsic value by observing:

*"...an inarticulate, unchallenged, almost unnoticed, but nevertheless absolute premise of our political and economic planning that the human race must survive and prosper".<sup>102</sup>*

Humans must survive biologically and culturally, as is assumed by all he says. Logically, this conviction forms the fundamental justification of society because everyone ascribes to it. Important is how Dworkin proceeds his argument. He argues that the relative weight given to some principle or value in favour of others, originates from contrasting religious and philosophical orientations. These orientations signify how the two forms of intrinsic value ought to be valued and how they relate to each other. Yet remarkable about Dworkin's thesis is that all moral conflict on life and death can be reduced to unanimous consensus, concerning the intrinsic value of human life. As a result, Dworkin defends the right to abortion as an extension of the fundamental right of freedom of religious belief. This right must be respected by all he says, because it allows everyone to value the two forms of the sacred in his or her own way. So eventually, denying this is to deny one's own commitment. Although

---

<sup>99</sup> Because Dworkin does not address the question of selective abortion specifically, his arguments on abortion are used here.

<sup>100</sup> Dworkin, "What's Sacred?"

<sup>101</sup> Because on the one hand, the death of an old man is less bad when he accomplished a lot in his life. On the other, the death of a baby is less worse than the death of an adolescent, Dworkin observes, because the latter made unaccomplished investment in his or her life. She or he has build up a family, made friends, acquired skills and had plans for the future that are frustrated by death.

<sup>102</sup> Dworkin, "What's Sacred?"

societies differ on this precept, Dworkin maintains that any society can only be just in so far as it respects this basic value of equality and mutual respect like he describes it<sup>103</sup>.

To come back to NIPT, Dworkin his argument gives reason to value reproductive autonomy over other considerations, making it a fundamental value. Such proposal is, at least so far in theory, a solution that respects everyone's values. Everyone can act on one's own values during prenatal decision making, and so everyone is treated as an equal. The free availability of NIPT as a first-tier test thus seems to be a good proposal. As long as counselling is non-directive, and the price is also affordable for the less fortunate, reproductive autonomy can be guaranteed for all.

Like shown in the first chapter, there's a wide appreciation of NIPT and respect for reproductive autonomy. Now although it's questionable whether Dworkin adequately describes everyone's intuition on life and death, especially because it's quite vague, his defence of reproductive autonomy as a political right does serve as a possible explanation of this general appreciation.

Yet because his argument focusses on intuitions, it leaves out two essential gaps: why the intuitions and the philosophical or religious orientations are what they are, and why reproductive autonomy in particular should be the ground for respecting other people's opinion. The following section will investigate these matters, in order to show that the defence of reproductive autonomy is not the only conclusion to be drawn from the respect of human life that Dworkin observes to be essential.

#### ***4.2 Criticism to Dworkin's defence of reproductive autonomy***

Looking back at the third chapter, it's clear that many adherents of the disability-right movement like Ash would dispute Dworkin's liberal justification of reproductive autonomy<sup>104,105</sup>. Not because they believe that future parents should have no autonomy rights at all, but because considerations on equality should not limit itself to their decision making. To grant that future parents may do whatever they want with their fetus, is disrespecting the equality of disabled people according to them. So their position refutes the claim that reproductive autonomy, which is restricted to choices regarding one's own family, is the *only* basis on which equality must be respected. Thus Dworkin stands in need of justifying why equality should only concern reproductive autonomy.

---

<sup>103</sup> Dworkin, "Chapter 1. Equality".

<sup>104</sup> Ash, "Disability Equality & Prenatal Testing: Contradictory Or Compatible?", 2003.

<sup>105</sup> Bringman, "Invasive prenatal genetic testing: A Catholic healthcare provider's perspective", 2014.

Interesting on this regard is Slavoj Žižek's criticism to liberalism<sup>106</sup>. This criticism can be translated to the NIPT debate, by stating that the defence of reproductive autonomy as an equal right is a way of protecting abortion and selective abortion from scrutiny and criticism<sup>107</sup>. To say that everyone has an equal right to decide freely on one type of choices, Žižek explains, is putting these choices and the motives underlying them out of the public debate. When religious groups for example, criticize those choices to which everyone is assigned an equal right, Žižek remarks that they are all too quickly labelled as being 'intolerant'. To translate this to the NIPT debate: those liberals who think that selective abortion and NIPT is right can respond to a religious critique, by saying that they allow religious groups reproductive autonomy as well. Hence, the liberal camp can perceive itself as treating its opponent more equal, respectful and tolerant than the opponent treats them. This creates a sense of supreme legitimacy of the liberal position in contrast to its opponents, whereas a justification for those choices that reproductive autonomy protects is actually lacking. The respect for equality namely has nothing to do with the question whether abortion is murder, or how valuable a life with Down Syndrome is. Yet these questions are what religious groups, and the disability right movement, want to highlight in public debate. Importantly, abortion is no valuable choice for Catholics or Protestants. Hence, they are granted nothing by the respect for reproductive autonomy while their arguments are not heard.

Observe that the same goes for the disability right movement. Savulescu responded to them that in a liberal society the choice of future parents on family planning must be respected, even when those choices are irrational. He namely contends that selective abortion is completely rational and unproblematic, and that parents who deny this are wrong. Interestingly, counterarguments against reproductive autonomy are thus also placed outside rational debate. This way Savulescu can defend the possibility of selective abortion, without fully answering to his critics.

This idea is also present in Dworkin's argument: disputing reproductive autonomy, no matter for what reason, is necessarily a self-defeating argument. In order to make a valid argument in the public discourse on reproduction, one must first acknowledge the liberal stance on equality and freedom of personal choice. Yet now it's clear that not everyone has the same interest in allowing reproductive autonomy, and so that there's no equality for all.

Now it remains the question exactly how many people have such closed-minded attitude and are not upon to critical debate on moral principles like Žižek argues. His argument is eventually somewhat speculative, and he bluntly generalizes the opinion of all liberals. But it's clear that

---

<sup>106</sup> Žižek writes about autonomy in liberal society in general, and not specifically about reproduction.

<sup>107</sup> Žižek, "Tolerance as an Ideological Category".p665

reproductive autonomy is a fundamental and almost uncontested value in liberal society that is strongly embedded and protected within medical institutions and legislations. Now Zizek is right in arguing that when (reproductive) autonomy is not put under scrutiny, it's simply legitimate by majority rule instead of being founded on genuine consensus. Prenatal care policy is never neutral, because even allowing a procedure comes down to defending its legitimacy. The disabled and religious community are indeed marginal groups whose call for equality is not conclusive for policy decision-making on prenatal care. Yet, this is still no argument to say that reproductive autonomy shouldn't be a core value of prenatal care. Many parents of Down children and virtue ethicists like Hursthouse for example still argue that reproductive autonomy has importance<sup>108,109</sup>. So far, Zizek only makes clear that the liberal mode of argumentation, like Dworkin's defines of reproductive autonomy, puts many assumptions out of discussion by emphasizing the inviolability and legitimacy of personal decision making. This is a serious flaw to Dworkin's argument, because the institutional arrangement of respecting reproductive autonomy is not neutral and so does not mirror and respect everyone's opinion in society.

To clear out this shortcoming, it must be argued why reproductive autonomy should be a fundamental value. Therefore, the following chapter discusses MacIntyre's explanation of why autonomy is seen as such a fundamental value in contemporary society. The conclusion will follow that autonomy is wrongfully understood on the liberal account, because it formulates it as a sufficient condition for good decision making instead of a necessary one. MacIntyre shows how also the virtues are necessary for good decision making, enlarging the discussion to the questions what the role of future parents and physicians requires and disallows.

---

<sup>108</sup> Kater-Kuipers, Van Schendel, en Dondorp, "What Do Parents of Children with Down Syndrome Think about Non-Invasive Prenatal Testing (NIPT)?"

<sup>109</sup> Hursthouse, "Virtue Theory & Abortion".

## Chapter 5. Alasdair MacIntyre

This chapter analyses MacIntyre's criticism to individualism, which he sees as the cultural underpinning of the fundamental right of autonomy. His socio-historical method means to dissect liberal culture as a way to scrutinize its philosophical assumptions, instead of directly addressing the consistency of liberal arguments like Dworkin's. Tracing back the roots of contemporary society to the Enlightenment, MacIntyre shows how virtue ethics has become neglected and needs to be revived in order to detain moral decline. Afterwards it's possible to understand why his account of virtue ethics is a valuable alternative to understand and partly solve the moral dispute on NIPT. This chapter will substantiate MacIntyre's arguments by referring to other philosophers. Criticism to his arguments are not mentioned here, but are discussed in the next chapter.

### 5.1 Introduction: Alasdair MacIntyre

MacIntyre points out that contemporary modern society has no means for rationally solving moral debate, like abortion<sup>110</sup>. Rather, only hard fought and unfair compromise may be reached without the basis of genuine consensus. Moral debate nowadays is therefore best described as an arena according to him, with everyone trying to protect his own opinion by advocating for individual rights. MacIntyre denies that there's any common ground available that could serve as a basis for consensus. It's only within one and the same cultural tradition, that moral consensus can to some extent arise. Yet liberal society does not have any such cultural coherence, as too many different cultures live together and because liberalism is not an intelligible cultural tradition. It is unintelligible because it denies moral diversity, says MacIntyre, by defending the idea that all people have the same basic moral precepts. This liberal idea defines morality above and beyond culture, as if it were an autonomous sphere separate from historical progress. Arguments are namely defended by precepts of universal rationality. To understand MacIntyre's critique to this meta-ethical stance, his historical analysis of liberalism is insightful.

### 5.2 Criticism on the Enlightenment

This section analysis the origin of liberalism, which MacIntyre traces back to the late Middle-Ages. He observes that it was only then that people started to speak of '*morality as such*'<sup>111</sup>, which implies a distinction between factual statements and moral judgments<sup>112</sup>. This use of language originated from the belief that God's commands should be respected even when they cannot be

---

<sup>110</sup> MacIntyre, *After Virtue*, 1981. p22-24

<sup>111</sup> MacIntyre. p63-66; 149

<sup>112</sup> Also, whereas previously a 'fact' was meant to refer to an event, it was now being used to refer to a thing that is known or proved to be true. Out of this follows that moral judgments concerned the question whether moral facts were present or not. This also comes from the fact that Gods commands are given. MacIntyre, *Whose Justice? Which Rationality?*, 1988. p358

comprehended by human reasoning. Moral rules are simply constituted by Him for all of humanity, time and place alike. Consequently, actions are good or bad in themselves. They are no longer grounded in anything earthly or human like pleasure, desire or social status. So one may be ethically virtuous but unsuccessful or happy in life, because to be good is to be directly responsive to God's commands. Therefore the *self*, conceptualized as the soul, *is defined prior to societal roles*. Therefore MacIntyre places the origin of modern individualism in the Middle-Ages.

The above conception of morality is predominantly present in Protestantism, whereas Catholic morality also incorporates many lessons of how to succeed and flourish during life<sup>113</sup>. MacIntyre observes here that Catholicism was still influenced by Aristotelianism, for whom morality was all about human flourishing and not about blind compliance to moral rules.

From this observations stems MacIntyre's criticism on the Enlightenment philosophers who, after banning the church out of moral debate, inherited from Christianity the belief that morality exists as an autonomous sphere<sup>114</sup>. When they took human reason as a means for rejustifying morality, they also presupposed that moral rules are valid irrespective of desire, pleasure and social status. Immanuel Kant gives the best synthesis of the Enlightenment project, MacIntyre says, because his work was all about rejustifying his protestant beliefs in terms of universal logic. Robert Solomon confirms this analysis, highlighting the historical development of the conception of the self that culminates in Kantian ethics<sup>115</sup>. As a result, MacIntyre, Cassirer and Solomon conclude that the Enlightenment philosophers saw themselves as transcending history<sup>116,117,118</sup>. There could be only one true conception of morality, applicable to all humans and situations alike. This, on MacIntyre's view, makes their project flawed. Moral rules are only intelligible when applied in the right context, because it's in response to concrete problems that they're formed and shaped.

In summary, the Enlightenment philosophers failed to understand morality because they neglected the socio-historical origin of their values and principles. The search for the rational justification of universal moral principles made them avers to any form of traditionalist thinking. Yet every tradition has embedded in itself a conception of right conduct, says MacIntyre, encompassing historically developed practical knowledge of how to apply moral rules and principles<sup>119</sup>. This entails that different societies have different modes of rationality and understanding, which diversity was

---

<sup>113</sup> MacIntyre, *After Virtue*, 1981. p155

<sup>114</sup> MacIntyre. p58-63

<sup>115</sup> Solomon, *Continental Philosophy Since 1750: The Rise and Fall of the Self*, 1988. Chapter 2: *Modern Continental Philosophy and the Transcendental Pretence*.

<sup>116</sup> Cassirer, *The philosophy of the enlightenment*.

<sup>117</sup> Solomon, *Continental Philosophy Since 1750: The Rise and Fall of the Self*, 1988.

<sup>118</sup> MacIntyre, *After Virtue*, 1981.

<sup>119</sup> MacIntyre, *Whose Justice? Which Rationality?*, 1988. p349-352



overlooked by Enlightenment philosophers. MacIntyre thus calls their project wrongful, dangerous and pretentious. A better understanding of morality is a return to pre-modern moral philosophy, like Aristotle's virtue ethics.

### **5.3 Aristotelian virtue ethics**

To understand why MacIntyre believes that modernity faces moral decline, one must first apprehend his adoration for Aristotelian virtue ethics which he contrasts to liberalism. Unlike modern philosophers, Aristotle made no difference between descriptive and prescriptive ethics<sup>120</sup>. Moral evaluations are factual statements, concerning the question whether someone acts like his position and situation prescribes. A good physician, for example, is a physician who possesses in high degree those qualities that make the ends of medicine pursuable. He or she knows the means for treating a disease and when and how to use them. Such qualities make it possible to preserve wellbeing, which is the essential end of medicine.

Wellbeing is at first sight an *external good*, which means that its value does not consist in the activity of pursuing it. It's the patient who values his or her wellbeing and the means for preserving it, like operations, are only valuable in so far as they reach this goal. To explain, the opposite is an internal good, like sports: although the goal of the activity is winning, the value of sports does not arise from victory but from the pleasure of the activity itself. This difference between internal and external goods is easily confused, because almost all specific actions are aimed at pursuing some external good. Yet it's because of pursuing external goods that the prospering life in a community is possible. The latter is, on the Aristotelian view, the one and only pure internal good<sup>121</sup>. To live out and develop one's capacities in the *polis*, means living out the goal of human nature. Just like a bee lives out its nature by living in its colony, humans live out their essential nature by a prospering in their community. Aristotle sees this as the highest form of happiness and flourishing that humans can achieve. Observe that because medicine is a necessary means for sustaining the life of the community, the good physician at work is also pursuing the supreme internal good of being a good citizen. Therefore, the job of the physician is also intrinsically valuable, unlike a robber who only pursues external goods by profiting from the community. Therefore, seeing the difference between internal and external goods is crucial for understanding what the good life consists in.

Ethics is thus the science of the virtues: those qualities that makes someone a good citizen<sup>122</sup>. To become virtuous requires learning and habituation, so that passions become directed at preserving the good of society. Because when someone only does what one's role prescribes in order

---

<sup>120</sup> MacIntyre, *After Virtue*, 1981. p82

<sup>121</sup> MacIntyre, *Whose Justice? Which Rationality?*, 1988. p133-134

<sup>122</sup> MacIntyre, *After Virtue*, 1981. p59

to achieve external goods, meaning that the passions do not aim at the good of society, then no internal good is pursuit. The internal good namely isn't something tangible, but a form of contemplation on Aristotle's account. One must do the right thing for the right reason, to become virtuous and so to know and experience what the good life is. Nonetheless, doing the right thing for the right reason is eventually what holds society together. Therefore, the pursuit of internal goods is not merely about contemplation.

This makes it clear why the Enlightenment project is flawed according to MacIntyre. Its conception of the self as existing prior to societal roles, which grounds contemporary individualism, makes it impossible to appreciate the flourishing in society as the essence of human life. Virtues are not the essence of morality for the modern philosopher, because they are only derivative from a pre-defined conception of rational action and judgment.

#### **5.4 Crisis of modernity**

The following step in MacIntyre's argument is analysing how the Enlightenment project influenced the forming of 20<sup>th</sup> century society and philosophy. He argues that people, and especially analytic philosophers, still think and speak about morality as being an autonomous sphere<sup>123</sup>. John Mackie, Richard Joyce and Urban Walker agree on this observation, by showing how moral judgments seem to refer to objectively true non-natural properties<sup>124,125,126,127</sup>. All agree along the lines of MacIntyre that this use of language is mistaken. Like Mackie concludes: it's unexplainable how such properties could exist on their own, relate to the natural world and be known by humans.

Although the same linguistic errors are still in the same use, MacIntyre argues that contemporary modern society is even more alienated from any intelligible conception of morality than its 18<sup>th</sup> century predecessor<sup>128</sup>. Some still pursue the Enlightenment project in the face of persisting philosophical and political failure, while others give up the possibility of constructive moral debate. Both tendencies result in what MacIntyre calls the fragmentation of modern society. This progress is further explained below.

---

<sup>123</sup> MacIntyre, "Does Applied Ethics Rest On A Mistake?" p512

<sup>124</sup> Yet Mackie and Joyce take this to be the case for all of morality, which is flawed on MacIntyre's account.

<sup>125</sup> Mackie, "Error- Theorie, inventing right and wrong".

<sup>126</sup> Joyce, "Moral Fictionalism".

<sup>127</sup> Walker, "Keeping moral space open".

<sup>128</sup> MacIntyre, *After Virtue*, 1981. p35-42

#### 5.4.1 Persistence of the Enlightenment project

Utilitarianism was once an intelligible critique to monarchical rule<sup>129</sup>. The greatest happiness for the greatest number was meant as a rhetoric tool to criticize the unfair institutional setting, which concrete goal made early utilitarianism still a slightly intelligible philosophical tradition<sup>130</sup>. But nowadays, MacIntyre argues, utilitarianism is used to criticize against all traditionalist values<sup>131</sup>. Everything must be assessed by the same principle of utility, which gives an impoverished conception of morality that is unable to understand different ethical perspectives. More importantly, this is so because utilitarianism confuses internal and external goods by equating them.

The same can be said about contemporary deontological theories. MacIntyre heavily criticizes the idea of Human Rights for example, because they are said to apply to all societies and cultures alike<sup>132</sup>. Just like with utilitarianism, traditionalist values are not understood and infringed

#### 5.4.2 Recognition of the failure of the Enlightenment project

MacIntyre's criticism on the Enlightenment is anything but new. Many have recognized the failure of the Enlightenment project, and have therefore rejected the idea that morality can be justified on universal rationalistic terms. Engelhardt for example, has argued that there's only a 'mirror of consensus' on the rational standards for ethical debate<sup>133</sup>. Instead, he wants ethicists to realize that: *"moral diversity exists as a sociological condition and as a moral epistemological constraint"*<sup>134</sup>. Hence, pluralism must be recognized.

Yet MacIntyre despises the term pluralism, because also this conception forms a mirror of consensus<sup>135</sup>: agreeing to disagree on important topics of debate. The fault here according to him is that this term implies a rejection of the possibility of reasonable philosophical debate, which he still believes in. He's anything but a sceptic when refuting the possibility of finding overall consensus. On the contrary, the whole idea that there's only one right conception of ethics from which all moral rules must be derived is what's withholding reasonable debate. MacIntyre criticizes how liberals believe that they can understand everyone's perspective, because they hold that the essence of morality is the same everywhere. Unsolvable conflict then arises, because the validity of the other's viewpoint is too quickly framed in the simplistic terms of right or wrong in relation to this perceived essence of morality<sup>136</sup>. MacIntyre's solution is to stop deducing rules from a core conception of

---

<sup>129</sup> MacIntyre. p67-68

<sup>130</sup> MacIntyre, *Against The Self-Images of The Age. Essays on Ideology and Philosophy*. p120-123

<sup>131</sup> MacIntyre, *After Virtue*, 1981. p174

<sup>132</sup> MacIntyre.p68-69

<sup>133</sup> Engelhardt, "Bioethics in the Third Millenium: Some Critical Anticipations", 1999.p231-235

<sup>134</sup> Engelhardt. p225

<sup>135</sup> MacIntyre, *Whose Justice? Which Rationality?*, 1988. p335

<sup>136</sup> MacIntyre. p345

ethics, and to argue the other way around: observing what values a practice promotes, and how this might be safeguarded or optimized by the virtues<sup>137,138</sup>. Discussions would then arise within the background of commonly accepted beliefs, because these beliefs define the medical practice in a particular cultural or society. Maxims like promoting wellbeing for example, are already accepted and specified within a medical setting<sup>139</sup>.

Rationality thus has many forms because it's constituted by different traditions of philosophical enquiry which guide and instruct cultures through history and conflict. Different traditions might sometimes overlap or contribute to each other's understanding of the virtues, because none is fully coherent and some more than others. Therefore the conception of the virtues is constantly adapted to deal with these challenges. According to MacIntyre, this learning through conflict process is necessary for both individuals and society at large<sup>140</sup>. It contributes to a more coherent and developed understanding of the virtues, and so the openness to critique and change is also a virtuous attitude itself. Different cultures ought to learn from each other to solve their own internal struggles, leaving aside the idea that one conception of the virtues is the ultimate right one for any given community or practice. Any culture has some basic agreement on the virtues, and so there is a baseline of communal understanding that makes debate possible in spite of all differences<sup>141</sup>.

MacIntyre concludes that being virtuous implies partaking in one's tradition, which means acknowledging that the currently held conception of the virtues is the best version found so far. Hence self-scrutiny remains essential, but must also be constructively aimed at achieving new consensus and the prospering of the community. Here it becomes clear why MacIntyre believes that modernity is in crisis. The failure of the Enlightenment culminated in Emotivism and Existentialism, which contributed to the moral relativism present in modern society. Both philosophical movements mistakenly rejected morality all together when recognizing the limits of pure rationality, because just as the Enlightenment philosophers, they equate morality with those rules that can be rationally justified irrespective of contextual factors<sup>142</sup>. Yet instead of their complete rejection of the possibility of intelligible moral debate, they should have returned to virtue ethics<sup>143</sup>.

---

<sup>137</sup> MacIntyre's direction of argumentation, from factual observation to value judgment, might be criticized for being a natural fallacy. But MacIntyre refutes such criticism on basis of Aristotelianism: there's no difference between factual and value judgments.

<sup>138</sup> MacIntyre, *Whose Justice? Which Rationality?*, 1988. p141

<sup>139</sup> MacIntyre, "How Virtues Become Vices: Values, Medicine and Social Context", z.d. p99-101

<sup>140</sup> MacIntyre, *Whose Justice? Which Rationality?*, 1988.

<sup>141</sup> MacIntyre, "How Virtues Become Vices: Values, Medicine and Social Context", z.d. p102-105

<sup>142</sup> MacIntyre, *After Virtue*, 1981. p35-40

<sup>143</sup> This is not also Zizek's opinion.

The logical counterpart of Aristotelianism is of course individualism, which is omnipresent today according to MacIntyre<sup>144</sup>. This viewpoint implies that making one's own choices is not only a necessary, but also a sufficient condition for the choice to be right. Self-development is the true ethical goal to strive for, and it's defined in contrast with traditional norms. Note that for Aristotle, the virtuous person doesn't decide what is good, he knows it by knowing his or her position in society. There's really nothing left to decide after becoming virtuous. Now the fact that individualism reigns, according to MacIntyre, can only indicate that society has gone out of touch with the virtues and therefore too with human flourishing. He criticizes how schools and the state refuse to educate moral values to the public because this is found wrongful from an individualist point of view, which says that education ought to be neutral<sup>145</sup>. MacIntyre also concludes that this implies giving up the Enlightenment project of creating a rational and publicly shared conception of morality.

### **5.5 Conclusion**

Concerning the unsolvable conflict between the utilitarians, such as Savulescu, and the disability right critiques, like Ash, MacIntyre has a better explanation and solution than Dworkin. On the one hand, MacIntyre allows that conflicting perspectives can all be intelligible and rational, because there's not only one consistent conception of rationality. Yet on the other, he emphasizes that no perspective is fully coherent and that reasonable debate can take place. A liberal might respond and say that conflict will always be there, no matter how much meaningful debate takes place. So there must always be some form of compromise, and the best solution is at least that everybody can decide for his or her own family.

This liberal response does have its worth. In case of unsolvable conflict, granting final authority to the people who have the greatest concern in the outcome of the decision, seems warranted. So too, a legal right to abortion seems justifiable. But MacIntyre detests that liberals are so quick in framing any ethical debate as an unsolvable conflict. Concerning the debate on Down Syndrome this criticism is highly valuable, for its highly questionable that giving birth to a Down child is always a problem. Furthermore, if it's unproblematic it cannot be argued that restricting or guiding people their decisions on this matter is a violation of their interest. Subsequently, it becomes hard to argue why people should always have the right to choose.

Similarly, Zizek criticizes those liberals that block off moral debate by labelling all criticism on autonomy as paternalistic<sup>146</sup>. This creates the wrongful impression that every opinion is just an expression of personal preference, equal in content to any other. As a result, the compromise of mutual respect becomes immune from criticism.

---

<sup>144</sup> MacIntyre, *After Virtue*, 1981.

<sup>145</sup> MacIntyre, *Whose Justice? Which Rationality?*, 1988. p400-403

<sup>146</sup> Zizek, "Multiculturalism, or, the cultural logic of multinational capitalism".

Nonetheless, raising a Down child is though and valuable at the same time. Hence selective abortion remains a difficult matter. Especially when the family doesn't have the right means or when there's only one parent, the decision will confront an even more difficult dilemma. Tension and conflict will therefore persist, but it's in the face of such conflict that virtue ethics has its worth. Before discussing this matter in full length, it must first be analysed how MacIntyre's virtue ethics relates to the constitution of the family. Until now his criticism has been highly abstract, and so it must be specified what the effects of individualism on reproduction and the family are and to what extend these effects take place. The goal of the next chapter is therefore to make a first step towards the normative debate, by showing how reproduction fits into MacIntyre's sociohistorical analysis.

## Chapter 6. Validity of MacIntyre's criticism

The first section will address how MacIntyre's criticism must be interpreted to make good use of it. In sum, his characterisation of contemporary society as liberal and individualistic is rather blunt. To a great extent, society still allows for flourishing and virtuous decision making. So his criticism is rhetorical rather than a valid description. With this in mind, it's clear that the relation between individualism and the different institutions in contemporary society, like medical practice or the family, is not straightforward nor necessarily negative. So although this chapter will substantiate MacIntyre's criticism on the liberal conception of the family, in order to understand it, the conclusion will follow that this characterisation is one-sided. New technologies and new norms of family planning can be ethically justified from a virtue ethical perspective, so these opportunities should therefore be embraced. Nonetheless, liberal proposals like neutral prenatal counselling are present and do disturb virtuous decision making in some instances. This chapter will conclude that medical profession must take a stance on what good parental virtues are, in order to make good decision making possible.

### 6.1 Interpretation of MacIntyre's criticism

MacIntyre played a vital role for the revival of virtue ethics in the 80s<sup>147,148</sup>. Yet it's important to ask how MacIntyre's success, and the success of those who argue along the same lines like Steven Toulmin, can be explained. For MacIntyre noted himself that if his hypothesis in *After Virtue* (1981) is correct that modern society has a flawed understanding of morality, then people will reject it<sup>149</sup>. So on basis of his own argument, MacIntyre's relative popularity might simply be explained by the fact that his main contention, that modern society is fractioned and alienated from a genuine conception of morality, is largely invalid.

MacIntyre does acknowledge that many people do still know how to act and judge intelligibly<sup>150</sup>. This is only possible because they, like MacIntyre says himself, still hold on to those 'fragments of virtue based traditions' that still survive or pop-up in liberal society. Now his definition of virtue based traditions is quite large, as it covers any tradition that gives enough prominence to the virtues. These might be the Ancient Greeks, suburban subcultures and also 20th century Catholics like himself<sup>151</sup>. In short, he seems to mean any culture or philosophical tradition that is simply not liberal. But now the term liberal becomes quite vague and unprecise, making it quite difficult to specify what type of society or practice is essentially liberal. More importantly, 'liberal'

---

<sup>147</sup> Mortier, Freddy en Raes, *Een kwestie van behoren*.

<sup>148</sup> Solomon, "MacIntyre and Contemporary Moral Philosophy".

<sup>149</sup> MacIntyre, *After Virtue*, 1981. p19;24

<sup>150</sup> MacIntyre, *Whose Justice? Which Rationality?*, 1988. p397

<sup>151</sup> MacIntyre, "Catholic Instead of What?"

society does not seem to be very liberal at all, when it's observed that most people still endorse to these 'virtue based traditions', like MacIntyre admits himself.

Such observations show that MacIntyre's use of the term 'liberal' is misleading. It's rather a rhetorical tool to show how philosophy often goes wrong and that this is also happening right now, rather than a valid description of contemporary society<sup>152</sup>. He uses the term to depict those aspects of liberal philosophers and institutions that are detestable, like disrespecting other cultural norms or neglecting the historical origin of one's own values. But these aspects seem to be characteristic of many philosophers in any cultural, like also Kulenovic rightfully observes<sup>153</sup>. It's important to note that MacIntyre acknowledges that even Aristotle himself made such mistakes, like having a flawed understanding of history and metaphysical conceptions of the self<sup>154</sup>. Observe that MacIntyre only defends *his own corrected version of Aristotelianism*, because many aspects of Aristotle and Ancient Greek society he finds detestable, like slavery<sup>155</sup>. Most importantly, he contests Aristotle's account of the virtues because this conception entails that the virtues form a perfect harmony<sup>156</sup>. To take the example of the good physician again, his or her technical skills are of no value when he or she neglects the trust of the patient. The patient would not allow the procedure, and so wellbeing is not obtained as a result. Technical skills are therefore only virtuous skills in so far as the physician is trustworthy, just, etc. Now the same goes for all the virtues, that they require one another. For Aristotle this interrelatedness between the virtues means that they form a perfect and definite harmony. This is where MacIntyre corrects Aristotle<sup>157,158</sup>. To presuppose *perfect* harmony is to presuppose that the ordering and moral framework of a society remains, or should remain, *completely* unaltered. So Aristotle also wrongfully pretends to transcend history as well, just like the Enlightenment philosophers.

Now it seems difficult to argue why liberalism is necessarily any less of an intelligible philosophical tradition than Aristotelianism. To be fair and consistent, it would now seem that also liberalism should be corrected on basis of its wrongful aspects, just like Aristotelianism. Specifically, it seems that the moral authority that is assigned to the individual in liberal society is no problem in itself, but rather that it may obstruct meaningful debate, like was shown by the criticism to Dworkin. Useful on this regard is Jeffrey Stout's proposal that it would be better to stop talking about liberal society on MacIntyre's definition<sup>159</sup>. Instead, one should focus on those aspects of contemporary

---

<sup>152</sup> The same can be said about Zizek's argument.

<sup>153</sup> Enes Kulenovic, "Pluralist Response to MacIntyre's Critique of Liberalism", 2007.

<sup>154</sup> MacIntyre, *Whose Justice? Which Rationality?*, 1988.

<sup>155</sup> MacIntyre. p144

<sup>156</sup> MacIntyre, *After Virtue*, 1981. p130

<sup>157</sup> MacIntyre, *Whose Justice? Which Rationality?*, 1988. p350-360

<sup>158</sup> MacIntyre, *After Virtue*, 1981. p145-147

<sup>159</sup> Stout, "Homeward Bound: MacIntyre on Liberal Society and the History of Ethics". p229



society that MacIntyre rightfully criticizes and how these can be overcome. On that line of criticism, both the individualistic tendencies in society and those so-called fragments of virtue based traditions are part of 'liberal' society. The question is thus what virtues are lacking or neglected and how this might be overcome, instead of abandoning liberal thought all together.

So far this seems to be a mere matter of applying the right definitions, and so no direct criticism to MacIntyre. But David Solomon and Kulenovic criticize MacIntyre for ascribing one and the same flawed conception of the self to all liberal philosophers<sup>160,161</sup>. In fact, many of these philosophers are not liberal on MacIntyre's definition, because they reject the premises that grounded the Enlightenment project like its conception of the self. Unsurprisingly, Solomon and Kulenovic object to him when they don't recognize all the flaws that he attributes to contemporary moral debate. This objection is important, because MacIntyre's definition of contemporary society as liberal serves to demarcate fields of legitimate authority. For example, he's very clear that philosophers have no moral expertise that can rightfully serve medical ethics<sup>162,163</sup>. With 'philosopher' in this context he clearly means anyone who's not a virtue ethicist. For example, he aims to attack the liberal theories of Dworkin and John Rawls<sup>164</sup>. Now the practice of respecting reproductive autonomy might be labelled 'liberal' and be rejected as a result, just like MacIntyre rejects Dworkin's liberalism. But so far it's unclear whether reproductive autonomy means that no intelligible decisions are made, and whether it poses a problem to the internal goods of the family and medical practice. Of course, he's right in saying that society becomes more individualistic. But to say that this is a moral decay, is begging the question. MacIntyre would have to show that people fail to make intelligible moral decisions and that they cannot flourish well in liberal society, directly because of individualism. Unfortunately, that scope of research is way too large to carry out and there would be too many different ways to investigate it. But the next chapters will focus on the selective abortion debate specifically with its substantial concerns. There it can be seen how MacIntyre's criticism can be of use.

## **6.2 The post familial family**

Having outlined MacIntyre's history of modernity, the question now is how reproductive autonomy fits into this story. The following section serves to validate MacIntyre's critique for the current debate, starting off with a sociological explanation of why reproductive autonomy is found so important in contemporary liberal society. Volkmar Sigush his analysis of the sexual revolutions of the 20<sup>th</sup> century is used to see how the ideal of autonomy, defended by liberals, has intersected with

---

<sup>160</sup> Enes Kulenovic, "Pluralist Response to MacIntyre's Critique of Liberalism", 2007. p140-142

<sup>161</sup> Solomon, "MacIntyre and Contemporary Moral Philosophy". p143

<sup>162</sup> MacIntyre, "Does Applied Ethics Rest On A Mistake?"

<sup>163</sup> MacIntyre, "How Virtues Become Vices: Values, Medicine and Social Context", z.d.

<sup>164</sup> MacIntyre, *After Virtue*, 1981. p73

technological and demographic changes, to finally become institutionalized in the form of the right to reproductive autonomy. After validating this analysis by qualitative research, the final section will discuss what ethical problems and threats can be located here.

Sigush starts of explaining how the institution of the family and the values underlying it have significantly changed from the 60's onwards, by showing how the traditional connection between the family, sexuality, marriage and reproduction has been fragmented into separate spheres<sup>165</sup>. First, the introduction of reproductive technology broke down old barriers of family planning, especially contraception. Women in western society, who had already gained more political rights and financial independence after WO II, were finally able to complete this new life style by birth control. As a result, family size decreased, women came to have children with the man they want and they finally had the opportunity to start their own career. The means to freedom and the new ideal of liberty were mutually reinforcing, of which the legalization of abortion in many Western countries is the most important example. As a result, the traditional connection between marriage and family, and between motherhood and femininity, disappeared and lead to what many sociologist call the '*post-familial family*'. Marriages without children came into being, and later on families without marriages. So too did several different forms of household emerge, including divorced couples and gay marriage.

Leslie Cannold her qualitative research is most interesting to prove the existence of these changes<sup>166</sup>. She investigated the attitudes of women on the choice to have children by using semi-structured interviews. First of all, Cannold found that none of the women she interviewed saw motherhood as an intrinsic part of female identity, which she argues is a unique aspect of modern Western culture. Motherhood was also said to be a choice and no mandate. Secondly and more importantly, Cannold found that although women could easily come up with bad reasons for having children, like to safe the marriage, they had problems defining what good reasons for having children actually are. Although they recognized some of the benefits that it could have, they were incapable of explaining why these benefits could outweigh the many downsides. Furthermore, when questioned about what explains the thrive to have children, almost all women said that this is a blind biological phenomenon. Therefore they concluded that the motives and the choice to have children are irrational, whereas remaining childfree was spoken of as rational and well deliberative. Rational choices were thus defined by these women as choices that promote self-interest and self-development. On the one hand, the women said that choosing to have time for a career and self-development is rational. On the other, many women said that remaining childfree allows them to

---

<sup>165</sup> Sigush, "The Neosexual Revolution". p331-358

<sup>166</sup> Cannold, "Do We Need a Normative Account of the Decision to Parent?"

have a 'pure relationship'. Cannold uses this term to depict those relationships that are purely constituted on mutual love, and so not on communal care for children, social obligations or finance.

Sigush his analysis strongly parallels to these findings. He notes that the family and love relationships become all the more founded on personal preference and serve the goal of enriching the life of the individual<sup>167</sup>. The best example is the idea that couples ought to *fit together*, in the sense that they empower each other in defining themselves. Sigush calls this process, led by increased liberty, the 'diversification of intimate relationships': "*The diminution, deregulation, and devaluation of the traditional family and the diversification of life-styles and types of relationship*"<sup>168</sup>. The new norm is individualized morality, Sigush concludes, which comes down to the conviction that everyone ought to decide for themselves what choices on family planning are correct. The women in Cannold her studies confirm to this norm, by emphasizing that when women decide to have children because they think that they ought to, such choices are necessarily irrational and wrong<sup>169,170</sup>.

This analysis explained why reproductive autonomy is of fundamental importance in contemporary society. Compared to the first half of the 20<sup>th</sup> century, the new norm is to have the means and liberty to engage in self-chosen relationships. This doesn't mean that all traditional forms of family have disappeared, but rather that they are no longer perceived of as being self-evident.

### **6.3 Ethical problems concerning the post-familial family**

This section serves to highlight what ethical challenge arise because of the decline of traditional family values. Sigush argues that many people wrongfully believe that the abandonment of traditional family and relationship values has liberated them, because the ideal of liberty and self-empowerment itself is coercive as it obstructs a great many people of living a good life<sup>171</sup>. For those people who are lucky enough to constitute and sustain the relationships that they prefer, the ideal of liberty will be autonomy enhancing and therefore effectively liberating. But most people, Sigush remarks, now face many forms of anxiety and loneliness. Whereas the old back-drop of the large traditional family ensured that relationships and family ties were solid, people are now faced with the burden of constantly having to maintain their more fragile relationships on their own. This leads to anxiety for most people, and to loneliness for those who fail to maintain or find relationships.

---

<sup>167</sup> Sigush, "The Neosexual Revolution".342

<sup>168</sup> Sigush. p346

<sup>169</sup> Cannold, "Do We Need a Normative Account of the Decision to Parent?"

<sup>170</sup> Cannold.

<sup>171</sup> Sigusch, "The Neosexual Revolution", 1998. p350-355

Overall, Sigush his analysis is very one sighted and negative. He leaves out mentioning any positive opportunity that the new norms of family planning might have. Perhaps this is only a rhetorical trick to signalize some under recognized problems, and not so much an empirical claim about the amount of loneliness and anxiety that results from individualism. Anyhow, the precise prevalence of all those forms of anxiety and loneliness is only of secondary importance. More important is that Sigush and Cannold make a valuable observation about individualism its hostile attitude towards traditional values: the traditional values are perceived of as being coercive, whereas the ideals of individualism, like self-creativity and independence, are not. This clearly applies for the women in Cannold her study, and so presumably too for many more women in Western society.

Zizek is able to explain this phenomenon, saying that the coercive strength of liberalism is not commonly recognized, because the norms that are truly embedded in society are always so intuitively clear, good and rational that they're easy to lose perception of<sup>172</sup>. Premodern societies did not perceive of the family as a coercive norm, just as people nowadays don't have the perception of being coerced by the ideal of liberty and self-empowerment. MacIntyre his socio-historical perspective is insightful here, because it urges to recognize that the meaning of liberation and autonomy, like any other ethical concept, is always designated by culture. The important conclusion from all of this, is that the individualist ideal of freeing oneself from any societal norm is quite contradictory. Like MacIntyre explains, liberalism is a tradition that proclaims not to be one<sup>173</sup>. Its conception of autonomy as self-creation is therefore also flawed. Autonomy, properly understood on MacIntyre's account, requires that one can integrate and identify with the values of one's society or practice. Only then can acting and interacting with others become an intelligible and meaningful life investment, which interaction is necessary for learning to become virtuous.

Note that the virtue ethical view entails that the individual, with his or her spontaneous inclinations, is unable of being autonomous by itself. Institutions are required for moral guidance, which is why the liberal ideal of neutral institutions is so problematic. Sigush explains this individualist attitude, by saying that the ideal of autonomy is a make up for hiding people their inward insecurities<sup>174</sup>. Institutional control and scrutiny on personal decision making are thus labelled as paternalistic or backward, he says, so that inward feelings and convictions lose their irrationality. So by denying that any moral code can or ought to be formalized, especially by institutions, people avoid self-scrutiny of their values and beliefs.

---

<sup>172</sup> Zizek, "Multiculturalism, or, the cultural logic of multinational capitalism".

<sup>173</sup> MacIntyre, *Whose Justice? Which Rationality?*, 1988.

<sup>174</sup> Sigusch, "The Neosexual Revolution", 1998. p356

Likewise, the conception of prenatal counselling and care as a neutral practice is a misconception. Offering a test doesn't simply allow future parents to make decisions in line with their own values, rather it promotes some particular values and choices over others. Choosing to abort a Down fetus is not motivated by a mere preference, like cutting away one's hair, but involves a value judgment on what is good for the family. Medical practice is actively involved in enforcing those ideals by offering and performing procedures, and is therefore anything but neutral. MacIntyre, Pellegrino and Thomasma agree that liberalism ignores this insight by narrowing down the patient-physician relationship to a contractual agreement<sup>175,176</sup>. On such a view, both parties engage with each other out of mutual benefit. This perception leaves out many important facts about the physician-patient relationship, especially the special nature of the decisions being made.

This leads the discussion back to the institution of the family, which according to MacIntyre is of fundamental importance for educating the virtues. Although he doesn't write about reproductive technology, MacIntyre does clearly advocate that the institution of the family in liberal society is in crisis<sup>177</sup>. Just like Cannold and Sigush, he observes that traditional family values are disappearing to make place for liberal values of self-empowerment. Because the family forms the basis for every child to learn to become virtuous, MacIntyre claims that the crisis of the family is a crisis for society at large. To explain, he says that from a liberal perspective the independence of individuals is of sole importance. As a result, those who are dependent of others are the ones benefiting from help and care. MacIntyre notes that such conception of relationships works unidirectional: one serves the other. According to him, this way of thinking disturbs the understanding of virtuous learning and the internal goods of the family and society at large. In order to become virtuous, one must be educated virtuous. Because learning requires active experience on MacIntyre's account. Now it is within the family that one learns that humans are dependent from others for a big part of their life, which lesson is central to MacIntyre's conception of the virtuous. A family only holds together because it's recognised that the common good of all lies in caring and being taken care of by others. On this virtue ethical view, those in need of help are necessary for those independent to become and grow more virtuous. Individualism is therefore a threat to the internal goods of the family, which like MacIntyre says forms a small kind of polis.

From a MacIntyrean perspective, one could now argue that NIPT is so popular because people in liberal society want to pursue the ideal of the self-chosen family. In consonance with Sigush, MacIntyre namely states that relationships in liberal society are only there to serve the

---

<sup>175</sup> MacIntyre, "How Virtues Become Vices: Values, Medicine and Social Context", z.d.

<sup>176</sup> Pellegrino en Thomasma, *The Virtues in Medical Practice*.

<sup>177</sup> MacIntyre, *Dependent Rational Animals: Why Human Beings Need The Virtues*. p129-148

individual who engages in them<sup>178</sup>. Hence the choice for having a non-disordered child is found rational, on that type of reasoning, because the extra care needed for a raising Down child is only seen as an unwanted and superfluous burden. MacIntyre would probably protest to this, because the instrumental usage of family bounds weakens them by degrading the meaning of what a family is. Hence selective abortion is wrong, because it's wrongful to think that a child that requires more care, like a Down child, has less value. In sum, a non-disordered child that grows out to be independent and self-creative, is not any more important to the family than a child with Down Syndrome.

Yet MacIntyre gives a very narrow interpretation of the transition towards new forms of family planning. It's important here to remember Stout's advice not to overgeneralize MacIntyre's criticism. The motive behind the act of selective abortion must be closely analysed before coming up to hasty conclusions. Sigush's analysis does give a reason to hypothesize that there is some connection between the rise of individualistic tendencies and the popularity of NIPT and selective abortion. Especially because he describes how technology and cultural norms are strongly mutually reinforcing, this hypothesis seems important to investigate. But there's no proof that the increased use of selective abortion is the result of, what MacIntyre describes as, liberalism. Another explanation of the popularity of NIPT and selective abortion is that many families cannot take care for a Down child, and so use reproductive technology in order to get a child that they can take care of. Selective abortion can thus be in the interest of the whole family.

Yet looking back at the first chapter, it's questionable whether all selective abortions are done out of such motive. It was shown that many future parents feel pressure to test, don't know what they're applying for and that Down is often seen as something negative and necessarily problematic. Taking these three facts together, it's clear that future parents are actually in a situation of uncertainty. This is exactly where virtues are required, in order to guide decisions in function of the prospering of the family. The liberal ideal of neutral counselling is no good on this regard, because future parents need guidance to make the best decision for their family. MacIntyre stressed the indispensable role of institutions for making virtuous decision making possible. This conviction is echoed by Pellegrino, who refers to MacIntyre when stating that medical practice loses its moral force by passively giving in to everyone's preference<sup>179</sup>.

To conclude, since offering prenatal tests is not a value neutral decision, medical practice ought to take a stance on what a good family is and when a Down child can or cannot contribute to it. This task is addressed in the following chapter.

---

<sup>178</sup> MacIntyre. p127-130

<sup>179</sup> Pellegrino en Thomasma, *The Virtues in Medical Practice*.

#### **6.4 Conclusion**

This chapter applied MacIntyre's criticism on liberal family values. MacIntyre has quite a negative view, saying that family relationships become increasingly fragile and empty because of the influence of individualism. Relating this to the NIPT debate, it can be hypothesized that selective abortion is one such result of individualism. Yet from a virtue ethical perspective, a specific act or procedure does not have a determinate meaning. Rather, its meaning is derived from the context, consequences and the motives of those who perform the act. So selective abortion might be done for virtue ethical reasons, like considerations of manageability in case of poverty for example. The next chapter will look at what such good reasons might be, and how medical profession can and must guarantee that good decisions are made.

## **PART 3. Virtue ethics and selective abortion**

Most central to the conflict on selective abortion is the question whether a Down child ought to be accepted or not. This chapter will therefore discuss the parental virtue of acceptingness and how it relates to prenatal decision making. Virtue ethicists Rosalind Hursthouse and Rosalind McDougall are discussed because MacIntyre himself doesn't write much directly on reproductive technology. Their argument on the virtue of acceptingness will be defended to argue why selective abortion can sometimes be a wrongful means for pursuing the good of the family. Yet despite recognizing the value of their argument, this part will also conclude that virtue ethics faces the same difficult question of what value should be attributed to the fetus. In short, their argument says that the fetus ought to be accepted by the parents because it's their child. But the difficulty is that a fetus only becomes their child, both symbolically and literally, when it's accepted as such (meaning when it's not aborted). Nonetheless, future parents do connect to their unborn child, so there's no black and white answer here.

As medical practice is the setting wherein prenatal decision making takes place, it will be argued how a physician ought to respond to this ambiguity. Although society might be divided on the question of selective abortion, the uncontested virtue of the physician remains benevolence. To prove this point this part will focus on the work of Thomasma and Pellegrino. Now the virtue of benevolence does also allow for multiple interpretations, but this doesn't imply that a physician or the practice he or she works at ought to accept any such interpretation. Offering NIPT as a first-tier test for any pregnant women might be seen as outstepping the end of benevolence, just as the abortion of all fetuses with Down Syndrome might be. Medical practice as a community ought to be open to public debate on these interpretations, but will eventually have to adopt one such interpretation and take responsibility for it.

Conflict with at least some future parents coming for counselling will thus be inevitable. In order to make the best out of such conflict, a MacIntyrean perspective on ethical debate will be given to show how both parties can retain their integrity.

## **7. Virtue ethics & Selective abortion**

### ***7.1 The virtues of good parenting***

On an Aristotelian account, to answer a moral question implies referring to roles and responsibilities<sup>180</sup>. the first question to be asked is what a good parent would do when faced with the

---

<sup>180</sup> MacIntyre, *Whose Justice? Which Rationality?*, 1988.



choices concerning NIPT. A good parent is a parent who exercises the parental virtues, McDougall argues, which are those character traits conducive to the child its flourishing<sup>181</sup>. Yet the good parent also has obligations to the rest of his or her family, which considerations must also be taken into account. McDougall and MacIntyre emphasize that the flourishing of the whole family is what eventually matters for the good parent<sup>182,183</sup>. So the choice for a Down child can only be answered by reference to the good of the family as a whole.

This approach has a clear advantage over other positions on the value of the fetus. Much of the debate on abortion namely gets stuck on the question whether and when the growing fetus is a person with independent moral worth, like MacIntyre analyses<sup>184</sup>. Yet it's here that virtue ethics makes the interesting attempt to shift away from such conflict. Like McDougall explains, the starting point of the discussion ought to be the future parents who asks him or herself: what ought I to do, to be a good parent?<sup>185</sup> Now this question is independent from the debate of the ethical status of the fetus, because it concerns the actions of the future parent as being virtuous or not. Consequently, a comparison that shows which fetuses have better characteristic does not exhaust the discussion, because the question is whether a parent ought to make such comparison in the first place. Now McDougall argues that they don't.

McDougall states that acceptingness is an indispensable virtue of every parent, implying that parents have a prima facie duty to accept their fetus the way it is<sup>186</sup>. It's namely an immutable fact of human nature that any child has unpredictable characteristics. No matter how reproductive technology might further develop, parents will always have to deal with certain unwanted characteristics of the child. These might be diseases, difficult character traits or genetic disorders. Some children will of course be healthier or easier to take care of than others, but this will always depend on chance to some extent. So choosing to have a child remains a risk. On the condition that a parent accepts the child the way it is and the consequent duties of parenthood, taking that risk of having a potentially troublesome child, is justified. But in any case, if a parent doesn't want a child with negative characteristics then he or she ought not to choose to have one. Therefore McDougall concludes that the uncertainty involved requires that a good parent already accepts the child its characteristics even before having it. That's why selective abortion is wrongful.

Note that selective abortion is not characterized as wrongful because it straightforwardly relates to some harm or injustice that occurs as a result. Although such results are of paramount

---

<sup>181</sup> McDougall, "Parental Virtue: A new way of thinking about the morality of reproduction". p182

<sup>182</sup> MacIntyre, *Dependent Rational Animals: Why Human Beings Need The Virtues*. p119-132

<sup>183</sup> McDougall, "Parental Virtue: A new way of thinking about the morality of reproduction". p185-186

<sup>184</sup> MacIntyre, *After Virtue*, 1981.

<sup>185</sup> McDougall, "Parental Virtue: A new way of thinking about the morality of reproduction". p184

<sup>186</sup> McDougall, "an argument against sex selection". p603

importance for virtue ethical deliberation, the good parent doesn't just think about the consequences of his or her choice. Rather, he or she asks him or herself whether a good parent ought to be aborting a fetus when he or she is capable of caring for it. Recognizing one's role is the starting point of discussion, unlike the utilitarian point of view for example.

Now this line of reasoning stems closely to MacIntyre's criticism in the previous chapter. A good parent does not perceive the care of his or her child only as a necessary burden that ought to be outweighed by the benefits of parenthood. Rather, the child is accepted with its good and bad aspects alike. No one would deny that raising a child, and especially a Down child, is a hard task. But dealing with these difficulties is valuable, because it learns what the value of family is.

This doesn't mean that every pregnancy ought to be carried out. Like Hursthouse and McDougall argue equivocally, the conflict with other virtues might imply that abortion is more appropriate given certain circumstances<sup>187,188</sup>. For example, McDougall says that future-agent-focus is also a parental virtue, which implies that a future parent must consider whether the child can have a decent life. Moreover, the future parent ought to think of other responsibilities including the ones to oneself. So the virtue of acceptingness only *amounts to a prima facie duty* to accept the fetus. It's only in some circumstances, like when the family is capable of taking care of a Down child, that abortion would be a wrongful grasp of the good life. Parenthood, on Hursthouse her view, is namely essential of the good life. Although she recognizes other forms of flourishing and modes of living besides parenthood, this doesn't take away the fact that abortion is sometimes a wrongful means for pursuing the important good of the family.

## **7.2 Criticism to the *prima facie* duty of acceptingness**

Two counterarguments might be made here to show that selective abortion of fetuses with Down Syndrome is not in violation with the parental virtue of acceptingness. First, it might be said that Down Syndrome is too severe to be acceptable. Secondly, it's contestable whether parental virtues are always applicable, because the fetus is not yet someone's child.

### 7.2.1 Is Down Syndrome too severe to be acceptable?

To start off with the first question, McDougall argues that serious genetic disorders are a good reason for selective abortion, because they necessarily lead to great suffering<sup>189</sup>. Yet she doesn't mention Down Syndrome specifically, and there's no clue that she would intend to do so. Moreover, given the experience of parents with Down children, it seems wrongful to think that Down is always too severe to justify an abortion. Most of the time, their child is well and manageable. Of

---

<sup>187</sup> Hursthouse, "Virtue Theory & Abortion".

<sup>188</sup> Hursthouse.

<sup>189</sup> McDougall, "Parental Virtue: A new way of thinking about the morality of reproduction".

course Cuskelly et al. showed that in combination with other disorders like autism, the matter changes<sup>190</sup>. But the same might be said about other combinations of characteristics like personality or physical condition, which are also unpredictable. Therefore, unpredictability applies for Down Syndrome as well as for any characteristic, and it cannot be said why Down Syndrome *necessarily and specifically* should be prevented instead of these other disorders. Note that from the virtue ethical point of view, the right choice depends on the means and capabilities of the family for raising a Down child, instead of on the disorder per se. This stems closely to Ash her outlook.

Interestingly, Savulescu claims that there's 'good reason' to select for all beneficial characteristics<sup>191</sup>. So he's not inconsistent if he's unable to say why Down Syndrome is especially problematic. Yet then the worth of his argument is even more under threat, because it seems that what he calls a *good reason* to screen and abort means very little. It does not seem to relate to anything what's essential to the values of the family. Of course many parents would want to have a healthy, intelligent and stable child. But this preference is merely just that, and shouldn't affect their love for their child when it's born otherwise.

#### 7.2.2 Are parental virtues applicable in case of abortion?

Yet the second critique also relates to Savulescu's argument and is a bit more troublesome. It's one thing to say that the preference for a non-disordered child is not essential to family values, but that doesn't imply that such preference is always in breach with those values. Whether the fetus will grow out to be a child is namely still under considerations. So too is the question whether a couple should behave as good future parents.

To explain, a very realistic scenario is an older couple of whom one person is a carrier of Down syndrome, which is often known by occurrence of Down Syndrome in the family. This couple knows that the chance of having a Down child is very high, given the fact that the age of the mother also increases this chance<sup>192</sup>. Therefore this risk will probably play a role during their decision making. Now it might be possible that even before becoming pregnant, this couple already decides to abort the fetus when Down Syndrome would be diagnosed. From a virtue ethical perspective making such a deliberation before pregnancy is wise, because it shows that the couple is consciously preoccupied with the responsibilities of parenthood.

Hursthouse namely makes a similar argument concerning abortion, saying that a virtuous attitude implies avoiding an unwanted pregnancy in the first place<sup>193</sup>. Because even when the

---

<sup>190</sup> Cuskelly, Hauser-Cram, en Van Riper, "Families of children with Down syndrome: What we know and what we need to know".

<sup>191</sup> Savulescu, "Procreative Beneficence: Why We Should Select The Best Children", 2001.

<sup>192</sup> Verweij, "NIPT : non-invasive prenatal testing : towards implementation in the Netherlands", 2014.

<sup>193</sup> Hursthouse, "Virtue Theory & Abortion".

abortion is more justified than having a child, it remains a tragic and sometimes traumatic event that ought therefore to be avoided. So before becoming pregnant, careful deliberation must be made on whether the pregnancy is wanted. Now concerning NIPT, the tragic at hand is not only the potential abortion, but sometimes also the fact of being unprepared to make that decision. The time to decide whether to abort the Down fetus is scarce after diagnosis, so deliberating calmly on this matter beforehand is better. Moreover, when the woman is already pregnant there will be some emotional bonding with the child, making the decision harder to make. So all of this points out that the most virtuous attitude is deciding over selective abortion in advance.

Having made this point clear, it can be understood why virtue ethics is unable to avoid the troublesome discussion on the value of the fetus. Hursthouse and McDougall namely argued that the fetus has no independent value, but gets valued because it's part of the family. Yet since the decision on selective abortion ought to be made before becoming pregnant, it can be decided that the fetus with Down Syndrome will not be part of the family. Therefore, it's wrongful to say that parental virtues ought to be exercised. The pregnant woman is a *potential* parent, but no *future* parent in any literal sense. Now the crux is that it seems absurd to say that *potential* parents ought to behave like good parents. They simply aren't parents. Therefore the virtue of acceptingness seems inapplicable.

Now the importance of this criticism is to show that contextual factors, unlike McDougall's position, don't seem to matter at all under these circumstances. It might be so that the couple is highly adequate and capable for taking care of a Down child. Now in such a situation McDougall would say that there's a *prima facie* duty to give birth to the child, because not doing so would be a failure of the virtue of acceptingness. But despite the fact that this is a good parental virtue in general, it doesn't seem to apply to the couple who decides not to become parent of this child.

Moreover, this preference for a non-disordered child does not arise from a wrongful understanding of the virtues. It might be so that this couple would actually love and accept the Down child if it was born, and so they possess the necessary virtues for becoming a good parent. But nonetheless, they simply prefer a nondisabled child. Now this preference is what's guiding their decision, without arising from a flawed understanding of the parental virtues. Hence in this situation, selective abortion does not conflict with the virtues of parenthood in any sense.

### 7.2.3 Counter criticism: the experience of pregnancy

Although initially plausible, the above criticism is only valid to a very limited extent. The virtue ethicists namely place a high value on how biological facts are experienced and how they influence decision making, which is where the above criticism goes wrong. Of course, the difference between the future parent and the potential parent might be theoretically valid, but this distinction has limited correspondence to the experienced reality of pregnancy and abortion. For to say that

someone is only a potential parent when he or she decides to abort his or her fetus, is to equate this person with any other who's capable of having children. Both are indeed no future parents in the literal sense. But it would be absurd to equate a pregnant woman with any other fertile woman, because the monthly loss of an ovum is not the same as the loss of a fetus by abortion. Also Hursthouse points out that the relationship with the unborn child develops over time, which is why abortion is more troublesome in late pregnancy<sup>194</sup>. Now this experienced relationship is of ethical importance, because it indicates that someone ought to behave as a future parent, making the virtue of acceptingness applicable. The above example of the older couple deciding over abortion was thus highly speculative. Even when a couple makes a decision beforehand, it's unlikely that everyone will still have the same attitude and opinion when actually being confronted with the diagnosis of Down Syndrome. Being pregnant will namely involve at least some bonding with the fetus, whether it's wanted or not.

Yet still, not every pregnant woman will experience the exact same bond with her unborn child. Therefore McDougall her argument remains to be somewhat incomplete, for it wholly relies on the presence of contextual factors, like the fact whether the parents have the means for taking care of a Down child. But now it seems that highly personal attitudes are of ethical importance. These personal attitude highly differ nowadays, because like Sigush argued, the connection between reproduction and parenthood is becoming less and less self-evident. So too is the value of parenthood itself, like Cannold observed. Now virtue ethics is less able to give clear and direct guidance, like MacIntyre said, within a fragmented value framework. Eventually, the virtue ethical approach of avoiding the troublesome question when or whether the fetus becomes a person with independent moral worth, has limited advantage. Its solution of relying on the relational value of the fetus with the parent, namely seems to confront great ambiguity.

Nonetheless, it can be apprehended why attitudes differ the way they do. Conflict will persist, but understanding the conflict allows for at least some virtue ethical guidance. Illuminating to understand the ambiguity surrounding the experienced relationship with the fetus, is the story of an interviewed father of child with Down Syndrome:

*"I would probably (have) terminated our pregnancy (out of ignorance) had I known our baby had DS. I cannot say for sure as I did not have to make that decision. But not knowing allowed our girl to be born and she is the foundation of our family's love (along with her brother). To us she is not our*

---

<sup>194</sup> Hursthouse.

*DS child... She is our child with DS. I am thankful we did not test but it is not my place to take that option from others.*"<sup>195</sup>

This quote shows how the parent perceives the disorder differently before and after birth. When becoming a parent, the Down child is retrospectively identified with the fetus it was back then. Down Syndrome, like the father says, is thus a characteristic of the child. Now although the precise attitude of this father is not deducible from the quote, the following attitude seems to be applicable to the point that he's making: before becoming a parent, Down Syndrome is seen as a characteristic of a fetus, but not as a characteristic of a future child to be. Instead, the disorder determines whether the fetus will become a child.

This seems to be what ultimately divides Savulescu and Ash. Savulescu said that future parents ought to *select out the best characteristics of the child*<sup>196</sup>, whereas Ash says that *children with Down Syndrome are selected out*<sup>197</sup>. Disabled people identify with disabled fetuses, because they identify themselves by their disorder. So just as cutting hair is unlike an abortion, Down Syndrome is part of someone's identity unlike a haircut. But not every future parent will identify the fetus as a person, being his or her child. This is understandable, like the father of the Down child recognizes.

Now the fact that each position has some credibility, as they reflect an experienced reality of pregnancy, implies that virtue ethics can still have its worth here. Guidance and reflection are still possible to help people understand and work with the dilemma's that they face. Giving attention to personal and cultural differences, like MacIntyre does, is clearly not the same as the moral relativist stance: everything goes.

The following question concerns how one ought to deal with all this ambiguity, indicating what the obligations of medical practice are. Like Pellegrino and Thomasma clarify, a MacIntyrean perspective on medical practice implies seeing it as a moral community<sup>198</sup>. This viewpoint is legitimate, for no physician learns medical skills and knowledge by his or her own, but acquires these by serving the role of apprentice in a medical practice. Partaking in that practice requires accepting the institutional goals, moral codes and responsibilities towards society. Although every physician ought to retain his or her own integrity, it's only by acknowledgement of the shared commitment that medicine is possible.

---

<sup>195</sup> Inglis, Hippman, en Austin, "Prenatal testing for Down syndrome: The perspectives of parents of individuals with Down syndrome".p6

<sup>196</sup> Savulescu, "Procreative Beneficence: Why We Should Select The Best Children", 2001.

<sup>197</sup> Ash, "Disability Equality & Prenatal Testing: Contradictory Or Compatible?", 2003.

<sup>198</sup> Pellegrino en Thomasma, *The Virtues in Medical Practice*.

Such a virtue ethical perspective implies that the physician-patient relationship is not the only thing that matters. Physicians also have a communal obligation and responsibility to serve the end of medicine, namely benevolence. Maintaining that end requires setting clear boundaries to what means are appropriate for pursuing it. The fact that contemporary society solves moral dispute by democracy, Pellegrino and Thomasma say, does not violate the legitimacy of those boundaries. Of course dialogue is necessary and beneficial, but to let everything be decided by majority rule would deny the inviolable credibility of the end that makes medicine possible.

## Chapter 8. Medical practice as a Moral Community

This chapter will answer how medical practice ought to face moral controversy. The proposal of Jay Bringman is discussed, because it's a good example of how a physician can balance the demands of integrity and medical practice. His emphasis on reasonable debate stems close to MacIntyre's virtue ethics, allowing to see what MacIntyre's abstract ideas might mean for medical practice.

So far the above discussions have made clear that medical practice ought to take a stance on the selective abortion of Down children. Such stance will be partly constituted by a particular culture, but also by the moral codes specific to medical practice. Concerning the latter, medicine would not be medicine, Pellegrino and Thomasma agree, if benevolence does not remain the central end of the practice<sup>199</sup>. Now when a hospital is highly Catholic for example, benevolence will imply that abortion is always wrongful. The unborn fetus, no matter what disorder, is regarded by Catholicism as a subject entrusted to the physicians care. Now in such a scenario, it seems that either some future parents won't get the information and help that they want, or that the physician must put aside his or her integrity in order to fulfil the future parents' wishes.

Engelhardt emphasizes that it's highly wrongful to think that such conflicts can be avoided in contemporary Western society, which is too divers to sustain moral consensus<sup>200</sup>. Each country, hospital and physician has its own moral outlook and precepts. The search for a common ground of agreement or a universal moral code, he contends, only obscures this fact. Engelhardt concludes that people will just have to accept the fact that their hospital in town might not provide euthanasia or abortion.

Yet a middle route is possible. Even when a hospital agrees that they disapprove of selective abortion, it's questionable whether this stance ought necessarily to imply that NIPT and selective abortion ought to be banned. Interesting on this regard is namely the argument of Bringman, who as a devoted Catholic opposes any kind of abortion<sup>201</sup>. Interestingly, he claims that a Catholic physician in contemporary society ought not to refuse prenatal screening, even when it's unsure whether the couple coming up for counselling will carry out the pregnancy when a disorder is diagnosed. For Bringman observes that the couple might go to another physician or hospital where prenatal screening is available. Therefore, the refusal to screen avoids no abortion. This was common in the Netherlands before the start of the TRIDENT studies, with many women having their test in

---

<sup>199</sup> Pellegrino en Thomasma.

<sup>200</sup> Engelhardt, "Bioethics in the Third Millenium: Some Critical Anticipations", 1999.

<sup>201</sup> Bringman, "Invasive prenatal genetic testing: A Catholic healthcare provider's perspective", 2014.



Belgium<sup>202</sup>. Now Bringman argues that it's better to be open to prenatal screening, so that at least good counselling is possible. This does not mean preaching according to him, but providing information about families living with Down children that is obtained from accurate empirical research. Only on the basis of such information, a meaningful discussion on the choice may arise and contribute to prevent an abortion. Interestingly, although Bringman his stance on abortion is definite, he still seems to believe that meaningful debate is possible and necessary. Such attitude stems with MacIntyre's argument on the possibility of rational debate between conflicting cultures<sup>203</sup>. Emphasizing the importance of debate, Bringman learns how medical practice can retain integrity in the face of moral diversity, while not restricting reproductive autonomy.

At first sight, Bringman's argument seems to be a mere proposal for more pragmatism and compromise. Like the criticism on Dworkin's position made clear, the dispute is precisely that not everything should be a matter of compromise. But at closer look, this criticism does not seem to apply to Bringman's proposal. First of all, the physician or the medical practice on his view is not torn between the demands of the patient and its own ethical standards. So in no sense there's a solution by compromise. Rather, the conflict he describes is between retaining integrity and pursuing the goal of medicine. On the one hand, the Catholic physician detests cooperating with the screening for Down Syndrome. For when it results to an abortion, he or she will have violated his or her own integrity. Yet on the other hand, risking one's own integrity to do good is virtuous, because the fetus could be saved.

Now Bringman's Catholic position might be replaced by another, like the disability right criticism. Just like Bringman, Ash argues that counselling should aim at providing accurate information on living with a Down child<sup>204</sup>. Yet her argument is still somewhat different than his, because she emphasizes that screening necessarily entails the stigmatization of Down Syndrome. No matter how good counselling is, the fact that screening for Down is popular depicts the disorder as negative. Indeed Ash makes a good point, since it would be highly idealistic to think that the stigma can disappear while screening takes place.

Yet like Bringman argued, a restrictive policy on prenatal screening is still of no use. The very same practice that causes the stigma is the most apt in overcoming it. Note that this approach is totally different from Savulescu's point of view, for whom prenatal counselling was not the right

---

<sup>202</sup> Luc, "NIPT".

<sup>203</sup> MacIntyre, *Whose Justice? Which Rationality?*, 1988.

<sup>204</sup> Ash, "Disability Equality & Prenatal Testing: Contradictory Or Compatible?", 2003.

means for preventing the discrimination of disabled people. Like Pellegrino and Thomasma would agree, Bringman acknowledges the duties of medical practice as a moral community<sup>205</sup>.

Relating Bringman's stance to the virtue of acceptingness and selective abortion, the final conclusion is that also here a careful balance between integrity and the goal of medicine must be made. With the introduction of prenatal screening, medical care is already pushing the boundaries of what medicine is for. Although the screening for Down Syndrome can be seen as contributing to wellbeing, given that Down children suffer from severe medical conditions, this can only be so when one accepts the highly contested precept that abortion is not contrary to the goal benevolence. The previous chapter argued that virtue ethics is unable to completely solve the controversy over that precept, because the moral status of the fetus remains disputable.

Moreover, parents that want to abort their Down fetus are not exclusively motivated by considerations over their child's wellbeing. Although these considerations will most likely be the most decisive, the stigma on Down Syndrome will also play its part. People with Down Syndrome are sometimes mocked for being 'retarded', whereas many parents would probably want their child to excel. Of course it's hardly possible to indicate what parent is motivated by such a stigma and which one is not. Furthermore, restricting reproductive autonomy will not do away with the stigmatisation. But medical practice ought at least to prevent that this stigma becomes decisive in decision making. Otherwise, the goal of prenatal screening is not benevolence but sustaining unscrutinised ideals of family planning.

Given the fact that medical decisions and procedures are often very influential on people their personal lives, it's of course true that secondary causes besides benevolence are commonly served. Whether this is to be a threat to a medical practice its integrity, will depend on the matter at hand. In case of selective abortion, medical practice cannot but consider what ideals on family planning it wishes to allow and support or not. It namely remains medicine its responsibility that the number of Down children is decreasing, and so how families are organised and perceived. On McDougall her perspectives, selective abortion in so many cases entailed a loss of recognition what family is for. People ought to learn to deal with and accept family members the way they are. Referring back to MacIntyre, he holds that such a loss of recognition implies a deep crisis of society, because families ought to teach everyone that no human can prosper without taking care of others.

---

<sup>205</sup> Pellegrino en Thomasma, *The Virtues in Medical Practice*.

### ***Final reflexion***

Some might object to MacIntyre's use of Aristotelian virtue ethics, because it implies that autonomous decision making requires so much guidance and control by institutions. One must accept and practice the virtues, in order to understand and value them afterwards. Although virtues can be explained and scrutinized by outsiders, one must eventually *assume* that what virtue ethicists proclaim to be the good life, will eventually be so when put into practice. Everyone will of course add something new to the understanding of the good life, but such understanding will only be possible after being educated the norms and values of cultural tradition. Now such reliance is what some people might still feel uncomfortable with. MacIntyre wants people to continuously acknowledge that their beliefs and values are shaped by a particular culture which is never fully coherent or rational. Such openness to critique might be hard to endure, because it will always entails facing one's own deficits and weaknesses. Nonetheless the virtue ethics is empowering as well, because it defends institutions, like the family and medical practice, that despite moral controversy have been proven to be valuable.

## Conclusion

The main research question was whether it's morally problematic to combine abortion and NIPT in order to avoid the birth of Down Syndrome.

The first part discussed why this question is important but also why it remains largely unsolvable.

An explanation of what NIPT and its benefits are was given in the first chapter, in order to understand how it signifies a gradual change in the landscape of prenatal care.

The second chapter proceeded this analysis by pointing out that the increasing popularity of NIPT changes the way people think about and deal with prenatal care and counselling. In sum, screening gradually becomes a routine practice so that some future parents don't deliberate well enough about its possible downsides. Simultaneously, their social surrounding or physician might pressure them to do the test because taking it is seen as responsible behaviour. Combined with the existing stigma on Down Syndrome, these changes can result in almost no more new-borns with Down Syndrome to be born.

The third chapter criticized whether this progress is wanted, by questioning the boundaries of parental autonomy and the way prenatal counselling informs future parents about Down Syndrome. First, utilitarians Savulescu, Singer and Vermeersch were discussed to defend NIPT and selective abortion. Secondly, this position was opposed by disability right critiques. Both have a fundamentally different opinion on how the discrimination of disabled people has to be overcome and what the good life amounts to. The conclusion was reached that this controversy cannot come to a reasonable consensus, because they don't even agree on what the problem surrounding selective abortion really is. Disabled people identify themselves with their disability, whereas the utilitarians define the disability as a characteristic of a fetus. Moreover, it was shown that many more perspectives on selective abortion can be brought into the debate, showing how little consensus exists on selective abortion.

Because consensus cannot be found, it was discussed in the second part whether compromise might be found instead in the form of reproductive autonomy.

In chapter four, Dworkin's liberal defence of reproductive autonomy was discussed, because it matches the justification of abortion in Western countries like Belgium and The Netherlands. Dworkin's account has some intuitive appeal, but failed on basis of its own commitment: providing an outline for a neutral institutional setting that respects everyone's opinion. The problem is not that reproductive autonomy should be of importance, but rather that equality should also be respected on other grounds. The disability right critiques namely contested whether selective abortion is the kind of procedure that should be compromised on in the first place.

MacIntyre his work was discussed as an alternative to liberalism in chapter five. His sociohistorical analysis helped to understand moral diversity in contemporary society, while his virtue ethical stance was used as a joint response to this diversity.

In order to translate MacIntyre's work to the selective abortion debate, the work of Sigush and Cannold was discussed in chapter six to show how individualism affects family planning in contemporary society. Although insightful, it was argued that such criticism tends to overshadow new forms of family planning that are consistent with virtue ethics. A better approach is observing what virtue is neglected in the debate on selective abortion, and how future parents and medical practice can learn from this approach. This conclusion sets out the task of the final part.

First, chapter seven was discussed to defend the virtue ethics of McDougall and Hursthouse. The parental virtue of acceptingness was analysed as a means for instructing when and whether selective abortion of Down Syndrome is an appropriate means for pursuing the good of the family. It was shown that future parents have a prima facie duty to accept their child, meaning that selective abortion is only justified under those circumstances that would make care for a Down child impossible. Although McDougall gives a good argument, it was shown that dispute still arises as to when this virtue is applicable. Whether the fetus should be regarded as a child, cannot be fully answered by virtue ethics.

Secondly, in the final chapter it was discussed how medical practice ought to respond to this ambiguity. All controversy aside, benevolence remains the most essential goal of medicine. It was argued that selective abortion is done out of several motives besides benevolence, and also that some people think that it's always in violation of that end. So even trying to stay close at the central end of medical practice requires interpretation, scrutiny and defence of particularist values. Bringman his stance was shown as a good example of how a MacIntyrean attitude helps to guarantee virtuous decision making under such situations of complexity. His emphasis lies on the balance that must be made between the integrity of the physician and the end of medicine. All controversy aside, it was argued that prenatal counselling should be aimed at overcoming the stigma on Down Syndrome in order to make good decision making possible.

### ***Suggestions for further debate***

Further research should focus on how NIPT should be offered. Low or no costs could make prenatal decision making undeliberate, like argued in the first chapter. But introducing high costs can also be discriminative, making Down Syndrome a disability that's associated with poverty. Low or no costs with emphasis on good counselling thus seems to be the best solution. Yet many questions are still left open on how good counselling should take place. Foremost, further research should focus on what specific conditions require that the prima facie duty of acceptingness must be overruled. This

implies a closer perspective on what makes care for Down children possible or not, ranging from the stability of the relationship to emotional and financial resources. Only then can future parents decide whether giving birth to a Down child is worthwhile.

## Bibliography

1. Admundson, Ron. "Disability, Handicap and the Environment". *J. SOC. PHIL*, nr. 23 (1992).
2. Ash, Arienne. "Disability Equality & Prenatal Testing: Contradictory Or Compatible?" *Florida State University Law Review*, nr. Vol.30:315 (2003): 315–43.
3. ———. "Disability Equality & Prenatal Testing: Contradictory Or Compatible?" *Florida State University Law Review*, nr. Vol.30:315 (2003): 315–43.
4. Beel, Veerle. "Regering maakt downtest (bijna) gratis voor iedereen". *DeStandaard*, 29 mei 2017. [http://www.standaard.be/cnt/dmf20170528\\_02901527](http://www.standaard.be/cnt/dmf20170528_02901527).
5. Belgisch Raadgevend Comité voor Bio-Ethiek. "Advies nr. 59 van 27 januari 2014 betreffende de ethische aspecten van de toepassing van de wet van 28 mei 2002 betreffende de euthanasie", z.d.
6. Benn, P, A Borrell, en RW Chiu. "Position statement from the chromosome abnormality screening committee on behalf of the board of the International Society for Prenatal Diagnosis." *Prenat Diagn*, 2015, 725–34.
7. Billen, A, G Evers-Kiebooms, en G d'Ydewalle. "Risico-perceptie en erfelijkheid: een benadering vanuit de cognitieve psychologie". *Lisse: Swets & Zeitlinger*, 1987.
8. Bowman-Smart, H, J Savulescu, C Mand, en S Lewis. "'Is it better not to know certain things?': views of women who have undergone non-invasive prenatal testing on its possible future applications". *J Med Ethics*, nr. 45 (2019): 231–38.
9. Bringman, J.J. "Invasive prenatal genetic testing: A Catholic healthcare provider's perspective". *Linacre Q*, nr. 81(4) (2014): 302–313.
10. ———. "Invasive prenatal genetic testing: A Catholic healthcare provider's perspective". *Linacre Q*, nr. 81(4) (2014): 302–313.
11. Campbell K. Brasington. "What I Wish I Knew Then...Reflections from Personal Experiences in Counseling about Down Syndrome". *J Genet Counsel*, nr. 16 (2007): 731–734.
12. ———. "What I Wish I Knew Then...Reflections from Personal Experiences in Counseling about Down Syndrome". *J Genet Counsel*, nr. 16 (2007): 731–734.
13. Cannold, L. "Do We Need a Normative Account of the Decision to Parent?", nr. Working Paper Number 2002/4 (z.d.): 2002.

14. Cassirer, Ernst. *The philosophy of the enlightenment*. Princeton University Press, 1951.
15. Crombag, NM, en H Boeijs. "Reasons for accepting or declining Down syndrome screening in Dutch prospective mothers within the context of national policy and healthcare system characteristics: a qualitative study." *BMC Pregnancy Childbirth*, 2016, 121.
16. Cuskelly, M, P Hauser-Cram, en M Van Riper. "Families of children with Down syndrome: What we know and what we need to know". *Families. Down Syndrome Research and Practice*, z.d.
17. Deans Z, Clarke A.J. Newson, A.J. "For your interest? The ethical acceptability of using non-invasive prenatal testing to test 'purely for information.'" *Bioethics*, 17 augustus 2014.
18. Deans, Z, en A.J. Newson. "Should non-invasiveness change informed consent procedures for prenatal diagnosis?" *Health Care Anal*, 2011, 122–32.
19. Dierickx, H., E.S. Vandenakker, en D Bekedam. "The first 3,000 Non-Invasive Prenatal Tests (NIPT) with the Harmony test in Belgium and the Netherlands", 2014.
20. Dierickx, Kris. "Prenatale Diagnostiek, Nieuwe technologische mogelijkheden en ethische uitdagingen". *Ethische Perspectieven/ KU Leuven*, nr. 21 (2) (2011). <https://doi.org/10.2143>.
21. Dworkin, R. "Chapter 1. Equality". In *Political Philosophy in the Twenty-First Century: Essential Essays*. Westview Press, 2013.
22. ———. "What's Sacred?" In *Life's Dominion: : An Argument about Abortion, Euthanasia, and Individual Freedom*, Volume 3 Issue 2. New York: Alfred A. Knopf, 2011.
23. Enes Kulenovic. "Pluralist Response to MacIntyre's Critique of Liberalism". *Politička misao*, nr. Vol. XLIV No.5 (2007).
24. ———. "Pluralist Response to MacIntyre's Critique of Liberalism". *Politička misao*, nr. Vol. XLIV No.5 (2007).
25. Engelhardt, Tristram H. Jr. "Bioethics in the Third Millenium: Some Critical Anticipations". *Kennedy Institute of Ethics Journal* 9.3, 1999, 225–43.
26. ———. "Bioethics in the Third Millenium: Some Critical Anticipations". *Kennedy Institute of Ethics Journal* 9.3, 1999, 225–43.
27. Fishbein, M.A, en Icek Ajzen. "Belief, attitude, intention and behaviour: An introduction to theory and research". *MA: Addison-Wesley*, 1975, 512–19.
28. Gilmore L, Campbell J, en Brasington K. "M. Developmental expectations, personality stereotypes and attitudes towards inclusive education: Community and teacher views of Down syndrome." *International Journal of Disability, Development and Education*, 2003, 67–78.

29. Graaf, G de, JJM Engelen, en ACJ Gijsbers. "Estimates of live birth prevalence of children with Down syndrome in the period 1991-2015 in the Netherlands." *J Intellect Disabil Res*, nr. 61 (2017): 461–70.
30. Hook E.B. "Rates of chromosome abnormalities at different maternal ages". *Obstetrics and Gynecology*, nr. 58(3) (1981): 282–85.
31. Human Fertilisation and Embryology Authorit. "Sex selection: options for regulation", 2003. <http://www.hfea.gov.uk/AboutHFEA/Consultations>.
32. Human Fertilisation and Embryology (Disclosure of Information) Act. c. 54 (1992). <https://www.legislation.gov.uk/ukpga/1992/54/contents>.
33. Hursthouse, Rosalin. "Virtue Theory & Abortion". *Philos Public Aff.*, nr. Summer;20(3) (1991): 223–46.
34. Ilona Renner. "Schwangerschaftserleben und Pränataldiagnostik: Repräsentative Befragung Schwangerer zum Thema Pränataldiagnostik". *r Bundeszentrale für gesundheitliche Aufklärung*, 2006.
35. Inglis, A., C Hippman, en J Austin. "Prenatal testing for Down syndrome: The perspectives of parents of individuals with Down syndrome". *Am J Med Genet A.*, nr. 158A(4) (2012): 743–50.
36. J. L. Hamerton N. Canning M. Ray S. Smith. "I. Incidence of chromosome abnormalities". *Clinical Genetics*, nr. Volume8, Issue4 (2008).
37. J. Quinones. "'What kind of society do you want to live in?': Inside the country where Down syndrome is disappearing". *CBS News*, 14 augustus 2017. <https://www.cbsnews.com/news/down-syndrome-iceland/>.
38. Joyce, Richard. "Moral Fictionalism". *Fictionalism in Metaphysics*, nr. M.E.Kalderon (2005): 287–313.
39. Kater-Kuipers, A, I de Beaufort, RJH Galjaard, en E Bunnik. "Ethics of routine: a critical analysis of the concept of 'routinisation' in prenatal screening". *J Med Ethics*, nr. 44 (2018): 626–31.
40. Kater-Kuipers, RV Van Schendel, en WJ Dondorp. "What Do Parents of Children with Down Syndrome Think about Non-Invasive Prenatal Testing (NIPT)?" *J Genet Counsel*, 2017, 522–31.
41. Korenromp MJ, Christiaens GC, van den BJ, Mulder EJ, Hunfeld JA, Bilardo CM e.a. "Long-term psychological consequences of pregnancy termination for fetal abnormality: a cross-sectional study". *Prenat Diagn*, nr. 25(3) (2005): 253–60.
42. Lamberts, R. "Special DU overgang SVO naar werk". *Stichting Down Syndrome*, nr. Down+Up 124 (z.d.).



43. Lewis C, Silcock C, Chitty LS. "Non-invasive prenatal testing for Down's syndrome: pregnant women's views and likely uptake." *Public Health Genomics*, nr. 16(5) (2013): 223–32.
44. Li G, Chandrasekharan S, en Allyse M. "'The top priority is a healthy baby': narratives of health, disability, and abortion in online pregnancy forum discussions in the US and China." *J Genet Couns*, nr. 26(1) (2017): 32–39.
45. Lippman, A, en A.S. Wilfond. "Twice-told Tales: Stories about Genetic Disorders". *Am. J. Hum. Genet.* 51, 1992, 936–37.
46. Luc, Bonneux. "NIPT", 15 november 2017.
47. M. Vanstone, A. Cernat. "Women's perspectives on the ethical implications of non-invasive prenatal testing: a qualitative analysis to inform health policy decisions". *BMC Medical Ethics*, 2018. <https://doi.org/10.1186/s12910-018-0267-4>.
48. MacIntyre, Alasdair. *After Virtue*. London: Bloomsbury, 1981.
49. ———. *After Virtue*. London: Bloomsbury, 1981.
50. ———. *Against The Self-Images of The Age. Essays on Ideology and Philosophy*. Duckworth. London: The Trinity Press, z.d.
51. ———. "Catholic Instead of What?" Notre Dame, Paris, 9 november 2012. <https://brandon.multics.org/library/macintyre/macintyre2012catholic.html>.
52. ———. *Dependent Rational Animals: Why Human Beings Need The Virtues*. The Paul Carus Lectures, 2002.
53. ———. "Does Applied Ethics Rest On A Mistake?" *The Monist. Ethics and the Modern World*, nr. Vol. 67, No. 4, (1984): 498–513.
54. ———. "How Virtues Become Vices: Values, Medicine and Social Context". In *Evaluation and Explanation in the Biomedical Sciences.*, 97–111. Vol 1. Dordrecht: Philosophy and Medicine., z.d.
55. ———. "How Virtues Become Vices: Values, Medicine and Social Context". In *Evaluation and Explanation in the Biomedical Sciences.*, 97–111. Vol 1. Dordrecht: Philosophy and Medicine., z.d.
56. ———. *Whose Justice? Which Rationality?* Duckworth. London: Redwood Burn Limited, 1988.
57. ———. *Whose Justice? Which Rationality?* Duckworth. London: Redwood Burn Limited, 1988.
58. Mackie, John. "Error- Theorie, inventing right and wrong", z.d.
59. McDougall, Rosalind. "an argument against sex selection". *J Med Ethics*, 2004, 601–5.
60. ———. "Parental Virtue: A new way of thinking about the morality of reproduction". *Bioethics*, nr. Volume 32, No. 4 (2007): 181–90.

61. Mertes, Heidi. "Is de hype rond de NIPT terecht? De Maakbare Mens". Gent, 27 juli 2017. <https://www.demaakbaremens.org/is-hype-rond-nipt-terecht/>.
62. Ministerie VWS. "Kwaliteitseisen counseling prenatale screening". *Versie 10, vastgesteld door het RIVM-CvB na advisering door de Programmacommissie Prenatale Screening*), 21 juli 2018.
63. Mortier, Freddy, en Koen Raes. *Een kwestie van behoren*. Gent: Mys & Breesch, 1992.
64. Nagel H, A Knegt, M Kloosterman, H Wildschut, en N Leschot. "Invasieve prenatale diagnostiek in Nederland, 1991-2000: aantallen ingrepen, indicaties en gevonden afwijkingen." *Ned Tijdschrif Geneesk*, nr. 148(31) (2004): 1538–43.
65. Neal, P. "Dworkin on the Foundations of Liberal Equality". *Cambridge University Press*, nr. Volume 1, Issue 2 (1995): 205–26.
66. Nederlandse Gezondheidsraad. "NIPT: dynamiek en ethiek van prenatale screening", nr. U-8009/LvR/bp/894-A63 (2013).
67. Nelson, L.J. "The Meaning of the Act: Reflections on the Expressive Force of Reproductive Decision Making and Policies". *Kennedy Institute of Ethics Journal*, nr. Vol. 8 Issue 2 (1998): 165–82.
68. Ontario Health Technology Advisory Committee. "Perspectives of Pregnant People and Clinicians on Noninvasive Prenatal Testing: A Systematic Review and Qualitative Meta-synthesis". *Ontario Health Technology Assessment Series*, nr. Volume 19, Number 5 (2019): 1–38.
69. Parens, E, en A Asch. "Disability rights critique of prenatal genetic testing: reflections and recommendations". *Ment Retard Dev Disabil Res Rev.*, nr. 9(1) (2003): 40–47.
70. Pellegrino, E, en D Thomasma. *The Virtues in Medical Practice*. New York: Oxford University Press, 1993.
71. R. Devlieger, E. Martens, R. Goemaes, H. Cammu. "Perinatale Activiteiten in Vlaanderen 2017". Vzw Studiecentrum voor Perinatale Epidemiologie (SPE). Brussel, 2017.
72. Rachèl V. van Schendel, G. C. M. Lieve Page-Christiaens, Lean Beulen, en Dutch NIPT Consortium. "Women's Experience with Non-Invasive Prenatal Testing and Emotional Well-being and Satisfaction after Test-Results". *Journal of Genetic Counseling*, nr. 26(6) (z.d.): 1348–56.
73. Rogiers, F, en K Verhoeven. "Filosofen Hebben Woorden. Interview: Etienne Vermeersch & Ignaas Devisch". *DS Weekblad*, 24 juli 2017. [http://www.standaard.be/cnt/dmf20170622\\_02936822](http://www.standaard.be/cnt/dmf20170622_02936822).
74. Sandel, M. "The Case Against Perfection: Ethics in the Age of Genetic Engineering". *Cambridge: Harvard University Press.*, 2007.

75. Savulescu, J. "Procreative Beneficence: Why We Should Select The Best Children". *Bioethics*, nr. Volume 15 Number 5/6 (2001).
76. ———. "Procreative Beneficence: Why We Should Select The Best Children". *Bioethics*, nr. Volume 15 Number 5/6 (2001).
77. Scholz, C. "On the interactive accomplishment of decision in genetic counseling before prenatal diagnosis", *Birth Defects Orig Artic Ser.*, nr. 28(1) (1992): 47–55.
78. Schuman, H. "Passend Onderwijs – pas op de plaats of stap vooruit?" *Tijdschrift voor orthopedagogiek*, nr. 46 (2007).
79. Shin, Mikyong. "Prevalence of Down syndrome among children and adolescents in 10 regions of the United States". *Pediatrics*, nr. 124(6) (2009): 1565–71.
80. Shuster, Evelyne. "Microarray genetic screening: a prenatal roadblock for life?" *Lancet*, 2007, 526–29.
81. Sigush, Volkmar. "The Neosexual Revolution". *Archives of Sexual Behavior*, nr. Vol. 27, No.4 (1998): 331–58.
82. Singer, Peter. "Severe Impairment and the Beginning of Life". *APA NEWSL. on Phil. & Med.*, 2000, 247–48.
83. Singer, Peter, en Helga Kuhse. "Should the Baby Live? The Problem of Handicapped Infants." *Oxford University Press*, 1985.
84. Solomon, D. "MacIntyre and Contemporary Moral Philosophy". In *Alasdair MacIntyre*. Washington DC: Cambridge University Press, 2003.
85. Solomon, Robert C. *Continental Philosophy Since 1750: The Rise and Fall of the Self*. Volume 28, Number 3. Oxford University Press, 1988.
86. ———. *Continental Philosophy Since 1750: The Rise and Fall of the Self*. Volume 28, Number 3. Oxford University Press, 1988.
87. Stout, Jeffrey. "Homeward Bound: MacIntyre on Liberal Society and the History of Ethics". *The Journal of Religion*, nr. Vol. 69, No. 2 (1989): 220–32.
88. Suster, MS. "The Routinization of Prenatal Testing". *American Journal of Law & Medicine*, nr. Vol 28. No. 2&3 (2002): 233–70.
89. Tamminga, S, RV Van Schendel, en W Rommers. "Changing to NIPT as a first-tier screening test and future perspectives: opinions of health professionals". *Prenatal Diagnosis*, nr. 35 (2015): 1316–23.
90. Taylor, P. "Non-Invasive Prenatal Testing". *CMF Files*, nr. No.6 (2017).
91. van Schendel RV, JH Kleinveld, en WJ Dondorp. "Attitudes of pregnant women and male partners towards non-invasive prenatal testing and widening the scope of prenatal screening". *Eur J Hum Genet*, nr. 22 (2014): 1345–50.

92. Vermeersch, Etienne. "Pleidooi voor vrije keuze". *De Standaard*, 10 juli 2019. [http://www.standaard.be/cnt/dmf20170609\\_02919564](http://www.standaard.be/cnt/dmf20170609_02919564).
93. Verweij, Joanne. "NIPT: non-invasive prenatal testing: towards implementation in the Netherlands". *PROEFSCHRIFT ter verkrijging van de graad van Doctor aan de Universiteit Leiden*, 2014.
94. ———. "NIPT: non-invasive prenatal testing: towards implementation in the Netherlands". *PROEFSCHRIFT ter verkrijging van de graad van Doctor aan de Universiteit Leiden*, 2014.
95. Walker, Margaret Urban. "Keeping moral space open". *Hastings Center Report*, nr. Vol. 23 Issue 2 (2016).
96. Wilken, Jean-Paul, Marju Medar, Zsolt Bugarszki, en Frans Leenders. "Community Support and Participation Among Persons With Disabilities. A Study In Three European Countries." *Journal of Social Intervention; Theory & Practice*, nr. Volume 23, Issue 3 (2014): 44–59.
97. X. Zeng a, L. Zannoni b, I. Löwyc, en , S. Camporesi D. "Localizing NIPT: Practices and meanings of non-invasive prenatal testing in China, Italy, Brazil and the UK". *Ethics, Medicine and Public Health*, 2016, 2352–5525.
98. Žižek, Slavoj. "Multiculturalism, or, the cultural logic of multinational capitalism". *New Left Review*, 1997, 28–51.
99. ———. "Tolerance as an Ideological Category". *Critical Inquiry*, nr. 34 No. 4 (2008): 660–82.