

Overlapping  
**Wisdom**



**Rob Buurman**

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## A study into the value of religious arguments in a Dutch debate on embryo selection

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The photo on the cover is originally taken by Sage Ross and is free from copyright. The picture is taken at Linsly-Chittenden Hall at Yale University and is the centre of the stained glass window “Education” by Louis Comfort Tiffany made in 1890. It represents a harmony between Science and Religion over matters represented by the central personification of “Light-Love-Life”.



# Summary

In the spring of 2008, a lively debate on preimplantation genetic diagnosis (PGD) coloured the Dutch media. Jet Bussemaker, acting state secretary for Health, Welfare and Sport, kick-started the discussion when she issued a policy letter on PGD in which she consulted the parliament on the inclusion of the genetic defects BRCA 1/2 to PGD procedures. These genetic mutations are responsible for an aggressive form of breast and ovarian cancer. PGD can be used to select embryos to prevent the transfer of hereditary conditions from one generation to the next, and thus had appealing utility for several other hereditary diseases, among which Huntington's disease and Duchenne muscular dystrophy. While these diseases will develop with 100% certainty if the corresponding genetic mutation is present, the genes BRCA 1/2 indicate only a high chance for the development of breast and ovarian cancer.

The conservative ChristianUnion (CU) was unhappy with Bussemaker's move. This political party feels uncomfortable with any type of embryo selection because life is created, selected and also destroyed in the process. The bad embryos are simply thrown away in the PGD procedure and, valuing unborn human life from the moment of conception, the CU felt morally troubled by Bussemaker's letter. Being part of the government and being ill-informed by Bussemaker, the CU resisted the implications of the policy letter. To prevent a serious conflict, Bussemaker withdrew the letter and a period of internal deliberation was announced. This conflict sparked a colourful and emotional debate in the Dutch media centred on the topic of PGD, and the CU's opposition to it.

This study focuses on the role of religious arguments deployed in the PGD debate, as sketched above. The main question addressed throughout this thesis is: *Can religious arguments be valuable according to an analysis of a public debate on preimplantation genetic diagnosis in Dutch society?* This question is tackled in two main steps: The first step discusses whether there are reasons according to which religious-minded people should restrict their speech in public. The idea will be explored that religious reasoning might not be suitable for public discourse, especially when this reasoning implies a universality that dictates how other (non-religious) people should live their lives. The second approach to the main question seeks to identify a rationale by which one can say that religious arguments in some way offer a valuable contribution to the public debate and, consequently, public policy on PGD.

Liberal political philosophers in particular have argued for some version of religious restraint in public policy matters. In this study, I rely on the theory of John Rawls as expressed in *Political Liberalism* (PL). Chapter 2 contains an exposé of PL. According to Rawls, policy on matters of basic justice – and that includes PGD – can only be properly justified by appealing to political values. Because policy is essentially coercive, citizens expect from one another that they advance good reasons for their coercive actions. This means that arguments that limit someone's freedom need to express values that are equally fundamental and mutually embraced. Rawls argues that citizens already endorse this principle through the expression of reciprocity: Because citizens understand that other citizens do not share their comprehensive views on life, they feel they should advance reasons which they can reasonably expect other reasonable citizens to accept as

legitimate, justifying reasons for coercive policy measures. In practice, this means that it would be unreasonable to oppose gay marriage as an institution of the state because that would exemplify an inequality on the basis of sex-preference. Similarly, it would be unreasonable to restrict someone's freedom to vote on the grounds that he has a low IQ. The basic idea here is that of the golden rule: do not do to others what you would not like to be done to you. In the political arena, one can only truly apply this rule when one reasons according to the most fundamental liberal ideas of freedom, equality, justice and all that is necessary for a democratic society to prosper. Rawls offers a framework to assess the role of religion in public debate. Because the framework has a liberal character, the conclusions of that assessment should be particularly acceptable to those who generally appreciate liberal ideas.

In Chapter 3, I describe the debate on PGD for which I rely on an inventory of typical arguments and follow-up arguments drawn from scientific discussions on new and emerging science and technology. Such arguments can be categorized along traditional ethical categories of deontology, consequentialism, justice, virtue ethics and meta-ethics. Furthermore I have added a category for responses that focus on the role of the CU instead of PGD. By dividing the different arguments into different categories, the particular deontological, virtue ethical and meta-ethical styles of reasoning can be made explicit. Of those types of arguments, the practise of the debate shows how virtue ethical arguments are not confronted on their merits, but are instead delegitimized as the opinion of the religious few. The CU and their supporters are then labelled as fundamentalists who wish to conform the private lives of other people to their specific religious views.

In Chapter 4, the arguments proposed by the CU and their supporters are measured against the theory of PL in order to analyse whether they are proper political values. Meta-ethical arguments are excluded for this assessment. In the practise of the debate, meta-ethical arguments are more about logic and rhetoric, and the values found in those arguments can be placed in one of the standard ethical categories. Along the lines of deontology and ethics of the good life, arguments have been proposed against PGD. The deontological argument that suggests human life – and that includes an embryo – is worthy of protection, is generally accepted as a legitimate concern. Many disagree with the argument, but they accept it as a legitimate concern, and so would Rawls, on the grounds that respect for human life is a fundamental political value. The virtue ethical arguments are more controversial. The analysis of these arguments shows they express a sense of humility and solidarity. Solidarity is arguably a key element of a cooperative society, and humility is a good life-expression of the respect for human life. These arguments too express proper political values. According to the liberal theory of Rawls, religious-minded people have not been unreasonable by advancing these arguments.

The good life arguments are used to portray a society where solidarity and proper human relations are at stake. They point to a future where PGD becomes more widely accepted and where a chance for Alzheimer's or even hay fever might warrant the use of PGD. In this matter, it is not only important that these arguments express proper political values, but that they also satisfy some level of credibility. Think about the controversy over climate change. The idea is that people's lives and society at large is at stake and this rationale demands that action be taken. But action is really only necessary when the threat is serious and not imaginary.

For PGD, the imperative to take the good life concerns seriously depends on the existence of a slippery slope. The slippery slope is real when current decisions opt for similar decisions in the future. By discovering what values and principles inform a decision, it can be shown whether a future decision is already legitimized in advance. In the case of PGD, the slippery slope shows up by including the genetic mutation that causes breast cancer to the selection procedures. Because BRCA 1/2 only indicate a chance for development of the condition, a whole spectrum of new diseases becomes eligible for PGD. The idea here is that there really is no principled distinction at any point down the spectrum of chance: a chance of 50% is similar to one of 60%. Every decision implies the justification for the selection of another disease all the way down this slippery slope.

The slippery slope has been countered by suggesting that it does not exist because we as a society basically have enough sense and sensibility to prevent further developments. While it surely can be argued that the slippery slope does not make further developments necessary and the slippery slope in this case does not point to anything radical such as genetic enhancements, it is simply naïve to think that our future wisdom about PGD is a direct projection of our current moral ideas about it. Instead of refuting the slippery slope, one should explore how our present attitudes can shape future decisions. The good life concerns of the CU and their supporters should thus be taken seriously.

The exploration of the slippery slope is the task of Chapter 5. Here I ask whether religious arguments can be valuable. The question is a difficult one, for choosing a normative standard inevitably runs the risk of only convincing one side in the debate. After all, the different parties are in conflict exactly because they appear to have different ideas about the role of religion and religious arguments in the first place. I have avoided this dilemma with the idea of an *overlapping wisdom*: a spinoff from the concept of an overlapping consensus in PL. The overlapping wisdom is that area where both religious and nonreligious agree on how the matter of PGD should be governed. Crucial here is the proclaimed wisdom – the sense and sensibility – to stop at some point down the slippery slope. Chapter 5 explores how such an attitude can be fostered in light of the dynamics in the debate on PGD. The conclusion is that religious arguments – most notably those of the good life – *are* valuable in the discussion over PGD.

The research question addressed in this thesis is necessarily a broad one, and it produces a number of surprising conclusions. My aim is to invoke further curiosity about the topics raised in this summary, yet it is understandable that some readers might not wish to read through my extensive treatment of Rawlsian philosophy, nor my empirical description of the debate. Therefore I will suggest a short walkthrough by which readers with limited time can get acquainted with the fundamentals and the highlights of this study. Chapter 1-1.2 gives a broad idea about the main idea of the research. In Chapter 2, the introduction and Sections 2.5- 2.6 are especially informative, though a warning is in place for the understanding of these sections depends partially on those that precede them. Chapter 3 is a straightforward empirical analysis of the PGD debate drawing on a large sample of quotes from key actors. Sections 3-3.2 clarify the methodology behind the analysis. Where Chapter 2 provides a framework to measure the arguments found in Chapter 3, Chapters 4 and 5 take on the task of answering the main research question. Chapter 4 does not leave much room for skipping content, but Sections 4.2 and 4.3 are definitely the analytical highlight of this chapter. The same logic applies to Chapter 5, but if one lacks the time to read it all, I would certainly recommend reading its introduction and Sections 5.3-5.5.



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# Preface

Those who are close to me will acknowledge that I am what one might call a full-blown atheist. I do not believe in a supreme being (or supreme beings) as sketched by religions generally and I am convinced that people who do are mistaken. That said, I do have my own moral truths, which have their origin in the period of the Enlightenment. Those truths tell me to respect each and every person's search for meaning in life. I fully understand and respect that people can find comfort, peace and meaning in articles of faith and I do not wish to deprive anyone of their moral truths even though they may not resemble my own.

This all does not mean that I cannot give an informed value judgment about religion or religious institutions. Recently, the Catholic Church was severely criticized because of the widespread child abuse in traditional Catholic schools and churches. The attitude of the Vatican towards the many instances of abuse has been quite staggering. While acknowledging the horror of the abuse, the Vatican also holds that this matter bears no relation to the institution itself. Moreover, on Holy Friday, the Franciscan Capuchin Priest who serves under pope Benedict XVI likened the criticisms aimed at the Catholic Church with anti-Semitism, a statement for which he apologized shortly afterwards. Add to this the Vatican's view on condom use in Africa, and I must agree with one of my personal heroes, Stephen Fry, that the Catholic Church is not a force for good in the world. In a debate between supporters and opponents of the Catholic church in Central Hall Westminster in 2009, Fry convinced ninety percent of the audience of his views.

Having said this, I have taken up the task to explore possible valuable religious arguments by analyzing a debate on embryo selection. For the same reasons I can be critical of the Catholic Church, I feel I am equally able to support a case in favour of the value of religious arguments, if I were to discover it. This might feel a bit awkward for those who see liberal and religious ideas as opposing and conflicting. But although liberal and religious people are often each other's opponents in discussions, it is undeniably the case that they share many basic ideas about morality and the proper society. This overlap between people with different views on life and everything, will guide the assessment of religious arguments in this study. In that spirit, I attempt to convince both the religious and the nonreligious liberal-thinking readers of my argument, though the nature of the exploration requires that I be particularly convincing to liberal people like myself.

In the early stages of this study, I realized that I needed to be careful with my style of reasoning. My task resembled that of a tightrope walker, always struggling to keep the right balance when walking from one side to another. For this particular study, the balance would have to be struck between rational analytical arguments and simultaneous appeals to both religious and nonreligious people, who often profoundly disagree about what makes up a rational argument in the first place. I hope this study shows that I maintained my balance and made my way successfully to the other end of the rope.

I have a few people to thank for that. Intellectually, most important was Prof. dr. Tsjalling Swierstra, my first supervisor. Whenever I was adrift, Tsjalling's analytical capacity and his sense for overview helped to put me back on track. Our talks have been short, to the point, but always helpful. To Prof. dr. Jan Hoogland, my second supervisor, I do not only owe my thanks but also

an apology. After Jan agreed to be my second supervisor, he did not hear from me until I asked him to review the writings in their final phase. I am thankful for Jan's participation and his commentary that motivated me to clarify and adapt some of the writings.

On a more personal level I wish to express my gratitude to my housemates and my fellow PSTS students. I have always enjoyed the many nights in the Bolwerk where we sometimes seriously discussed philosophy or politics, usually failing to acknowledge that 3am in the morning is no time to think you have anything useful to say. Then there are my parents, for whom philosophy is sometimes just an awkward bunch of mumbo-jumbo, but who have always supported my efforts to develop my love for the discipline of analytical thought. Finally and most important is Floortje, the beautiful love of my life, who supports, accepts and loves me despite all of my flaws.

# Chapter 1

## Introduction

With new types of biomedical technologies come the potential to improve our lives significantly. Ripe with the promise to battle disease and cure ills, technological developments in the medical field can improve the quality and length of human life. Fundamental to the more recent developments in biomedical technology is the increasing understanding of the basic workings of the human body. The discovery of the double helix by Watson and Crick was an especially important step towards understanding how our genetic makeup influences our well-being. From this we have learned that, from the conception of human life onwards, the genes in our body tell us whether we may be at risk of disease. In some cases, such as cystic fibrosis and Huntington's disease, the genetic profile makes absolutely clear whether the disease will occur or not.

Half a century after Watson's and Crick's breakthrough, developments in embryonic stem cells and preimplantation genetic diagnosis (PGD) promise significant advancements in the treatments of disease. Stem cells have the ability to differentiate into a range of specialized cell types. For embryonic stem cells in particular, the possibilities to treat diseases such as Alzheimer or Parkinson might be even greater than with other types of stem cells. PGD allows for the differentiation between embryos such that the healthy can be selected and placed in the woman's womb with in vitro fertilization (IVF). In this case, such an intervention can result in the disease prevention. Developments in both types of embryonic technologies are subject to moral objections. At this point in time, research on embryonic stem cells and the procedure of PGD cannot proceed without simultaneously destroying embryos. Some uphold that these medical developments are therefore morally wrong. Another line of criticism focuses on the wider consequences for society once these biomedical technologies become commonplace. This criticism is best known as the Brave New World argument, named after the book by Aldous Huxley, first published in 1932 [1]. If we are not careful, so the argument goes, and we allow these technologies to become part of everyday society, they may pose threats to our present-day morals and values.

### 1.1 Should religion govern technology?

Religious institutions and individuals are often at the foreground of voicing concerns on cloning, stem cell research, IVF or PGD. Informed by holy scriptures and comprehensive ideas about life, objections are formulated against the use of embryos as a means to cure reproductive health maladies. Sometimes outright religious terminology is used and psalms or other scriptures are invoked to argue against technological and scientific developments in the field of medicine. A clear example that shows why Christians struggle with the destruction of embryos can be found in this passage: "Before I formed you in the womb I knew you." (Jeremiah 1.5) Also, the Vatican often expresses how new scientific findings and technological possibilities should be integrated within a religious view and society in general. In the *Dignitas Personae*, the Vatican formulates several fundamental goods that medical technologies should respect. Among others, new technologies should respect "human values of sexuality (...) which require that the procreation of a new human person come about as a result of the conjugal act specific to the love between a

husband and wife” [2]. It should be no surprise that the Vatican is no supporter of conception through IVF.

Such religious arguments, however, do not go unchallenged, and many opponents claim that religious speakers should not rely on their religious scriptures and comprehensive ideas of the good when they argue for a ban on stem cell research, PGD or IVF. Mostly liberal critics hold that it is inappropriate to influence policy on the basis of a particular religious view while many citizens who are subject to that policy do not share the same conviction. In a constitutional democracy, they argue, one should only try to justify policy on the basis of secular (nonreligious) values that all citizens can share. The arguments run even deeper when these values are historically placed in the period of the Enlightenment, which gave way to reason above belief. This milestone in history is used to explain how religious warfare made place for peaceful coexistence of different religions. The critics conclude that an involvement of religious thought into the public domain is not only unjustified but also jeopardizes the Enlightenment project of the past centuries.

What role, if any, should religious arguments play in public debate on new biomedical technologies? Over the past decades there has been substantial discussion on the proper role of religion when it comes to matters of policy. Although the discussions have been intense and the body of books and articles written about this topic has grown considerably, there is little sign of agreement. Progress has been made though. On the side of the critics, who usually reason from liberal grounds, it has been suggested that arguments based on secular ideologies such as utilitarianism are no less controversial than religious arguments [3]. On the religious side of the discussion, it has been suggested that religious thought can be most influential when translated into secular terms [4]. These examples show the heterogeneity of opinions on both the liberal and the religious side on the proper role of religious arguments. But when it comes to answering the normative question of whether religious arguments should influence policy, the two camps remain divided.

### 1.2 On the value of religious arguments

Could a study on religious arguments on biomedical technology add anything to what has already been said? Scholars of religion have already focused on: the history of religion in policy [5]; the ‘unliberal’ character of political theories such as that of Rawls [6] [7]; or even highlighted religious ethical principles that may suit liberal policy very well [8]. An analysis of religious arguments links up to this last type of study. It could be shown whether, and how, religious people endorse liberal principles when they argue in public debate. But an analysis of arguments in a debate on a biomedical technology has more potential. It offers an opportunity to identify and assess the dynamics of an actual debate including the role of religious arguments.

The discussions over the role of religion tend to work from principles in which the disagreement between the two disagreeing camps is already embedded. From a religious perspective, they might hail the freedom of speech, thereby reducing the relevance of asking whether they *ought* to restrain the religious element in their speech. Or, it is asked how other people dare to criticise the religious people for invoking religious reason because everyone relies on some sort of similar inspiration. From the other, liberal side, it is suggested that religious people do not respect the opinion of others when they try to enforce their specific ideas upon others. In any case, these arguments provide rational positions from which both camps continue keep the disagreement alive.

Simply to ask whether religious arguments are *valuable* helps to avoid getting too bogged down in this entrenched disagreement. Upfront, such a question allows for an approach that aims for consensus. The challenge in such a question lies in the rationale by which a religious argument can be considered valuable. I will return to that matter shortly, but first, I will discuss the research question that will guide me throughout the length of the chapters to come:

*Can religious arguments be valuable according to an analysis of a public debate on preimplantation genetic diagnosis in Dutch society?*

In this question, a few ideas and concepts arise that will be explained shortly. The technology of PGD is further introduced in 1.3. The focus on a public debate is original but logical, and offers an opportunity to look at the actual role of religious arguments. The concept and the analysis of a public debate will be discussed in 1.4. The concept of a religious argument will be discussed in 1.5. The topic of PGD is a suitable subject for there are still many uncertainties about its future applications and religious groups have voiced many concerns about it, in part because of those uncertainties. Most importantly, a value-based analysis of religious arguments is explored in the following section.

### 1.2.1 Two basic steps

Much weight rests on the connecting term ‘valuable’ in the research question. First, we should recognize that the use of terminology matters greatly in discussions over embryos. This much has become clear from debates in the United States, where abortion is often labelled as murder and where those who argue over it position themselves either as ‘pro-life’ or ‘pro-choice’ depending on which side they are on. Asking whether religious arguments can be valuable does not give preference to supporters or opponents of religious arguments in public debate. Instead, framing the disagreement over the role of religion in terms of value provides an analytical method that seeks consensus among competing parties. On a subject where liberals and people of faith deeply disagree, reaching an enduring consensus is admittedly difficult. On the liberal side it would demand openness to the possibility that liberal democracy may thrive well on a dose of religious influence. On the religious side it would require a deep respect for the liberal ideology so that the religious arguments proposed do not come in conflict with the most basic liberal values.

In *Political Liberalism* (1993) (PL), the most influential liberal political theorist of the 20<sup>th</sup> century, John Rawls, sets out his theory on public debates in liberal democratic society [3]. Rawls argues that any argument that does not reflect the values of a liberal political conception of justice has no legitimate place in the public forum.<sup>1</sup> Rawls calls this way of proper reasoning ‘public reason’. In practice, this means that arguments will have to rely on those few values that can be shared by all citizens such as freedom, equality and justice. These values can be shaped according to one’s own interpretation of them, such as freedom to vote, equality of opportunity or solidarity as an expression of both equality and justice. Arguments that rely only on cultural or metaphysical values are outside the scope of public reason and should not be used to justify policy.<sup>2</sup>

Rawls’s theory takes neutral ground because its principles aim to be acceptable to both religious and non-religious people. The theory of PL is a liberal theory and therefore, religious people might have their reservations. In the academic literature, furthermore, the demands of public reason are not endorsed by all [7] [9] [10]. Nonetheless, if we may believe Rawls, people understand that their specific system of belief is not shared by all. And furthermore, because of that awareness, they themselves feel it would be unreasonable to impose their religious ideas upon others. Only when those religious ideas support some idea or principle that is crucial to the

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<sup>1</sup> I will use the terms “public forum” and “public square” to refer to the arena or agora, which contains a plurality of arguments with the aim of justifying policy. It is different from Rawls’s ‘public reason.’ The latter makes expresses an ideal on the way the public forum should be morally governed.

<sup>2</sup> This only goes for constitutional essentials and matters of basic justice, which will be explained in Chapter 2. For now I will say that policy on PGD is arguably a matter of basic justice. As an additional note, throughout this thesis, the terms ‘policy’ or ‘law’ refer to matters of basic justice instead of other types of policy, unless specified otherwise.

existence and flourishing of liberal democracy will citizens endorse them in public debate. Hence, if one follows Rawls's line of reasoning, there really is no problem because reasonable people already endorse the limits of public reason.

Because PL is essentially a liberal theory and because it provides neutral ground, it is a perfect first step towards determining whether religious arguments can be valuable. The main question asks to explore whether a case can be made in favour of religious arguments. But since the purpose of asking whether these arguments can be valuable lies in the possibility of finding agreement among both sides, the rationale of public reason should be particularly acceptable to those who generally oppose the use of strictly religious arguments. Those arguments will thus be measured against the demands of public reason. Such an analysis provides the opportunity to conclude whether the religious arguments in this specific debate on PGD are legitimate arguments. The results of this analysis can be found in Chapter 4.

While this first step is about the possible reasons to exclude religious arguments, the second basic step focuses on the positive contribution of those arguments. A number of writers have already focused on the limited value of the standard types of secular reasoning, most notably when it comes to new biomedical technologies. Philosophers like Leon Kass and Michael Sandel have suggested that we are in need of a more comprehensive moral vocabulary. To talk about rights, freedom and justice, they argue, gives little guidance to the challenges that come with new developments in cloning, stem cell research and PGD. Kass makes a case for the preservation of human dignity and Sandel fears for the loss of softer values like solidarity, responsibility and humility [11] [12]. Biotechnology may be employed to produce better children, create ageless bodies and make happier souls. But while we try to combat imperfections and improve our human condition, do we not risk losing much that is of value?

Kass and Sandel have convincingly argued for a softer, perhaps more religious, approach to dealing with the challenges of new biomedical technologies. PGD is one of those technologies that could fundamentally change the way people see procreation or contribute to changing the relations between parents and children. Such concerns are abstract but there is good reason to take them seriously. Technology enters society and opens up new spaces for ethical deliberation. In those discussions, argumentative patterns emerge and some values will inevitably come in conflict, most notably, the values of equality and freedom. During those discussions, the balance between values is reaffirmed or realigned. Some arguments will win and others will lose. Kass and Sandel believe that we currently have a problem in our discussions on new biomedical technologies. In particular, the rationale to use technology as a means to reduce suffering is extremely powerful. With respect to the softer values in life, these thinkers hold that new technologies and the strong justification to use them threaten those softer, but important matters. Ethical discussions on new and emerging technologies reveal these softer values and it is here that religious arguments might be of particular value.

A positive conclusion on the value of religious arguments should be convincing to those who are most sceptical. The matter is difficult, for making a convincing argument implies persuading people – people who already endorse a well-reasoned position – that their judgments are in need of revision. It is not at all certain that such an argument can be made, but, if possible, it should reflect an *overlapping wisdom* between supporters and opponents to PGD. Where both camps argue according to their own rational views and disagree with one another, it will be my aim to identify those areas where they share an idea about PGD and its proper embedding in society. Finding that consensus among the two camps – the overlapping wisdom – might provide a rationale for discussing the religious arguments. Are these arguments necessary to guide PGD properly? And if so, could it be said they are valuable? Chapter 5 will pursue this matter.

### 1.3 Preimplantation genetic diagnosis

Preimplantation genetic diagnosis in the Netherlands is the topic of the public debate. The technology is an expansion to *in vitro* fertilization, which concerns the fertilization of eggs in a controlled environment, after which the fertilized egg – the embryo – is placed in a woman's womb. PGD is the screening of genetic deficits on embryos before they are implanted. A parent who carries a genetic mutation typically has a 50 percent chance of transferring it to his or her offspring. PGD allows for the selection between embryos to ensure that future children do not carry a genetic mutation that can eventually result in disease. Depending on the criteria for screening, PGD could also increase the likelihood for successful pregnancy (compared to IVF without selection). In the Netherlands, PGD is only performed on a case to case basis. Depending on the severity and nature of the disease and the possibilities for other types of treatment, a committee of the institution where the treatment can take place decides whether it is appropriate to screen and select embryos for their genetic deficits [13].

Depending on a woman's plans for future pregnancies, a number of eggs are harvested that varies between as much as a few to thirty and forty eggs [14]. A sufficient amount of eggs is fertilized and one or two of them, pre-screened for undesired genetic mutations, will be placed inside the woman's womb. Usually, three days after fertilization an embryo has grown to a size of eight cells. At this point, one or two cells are taken from the embryo to be screened for the particular genetic mutation. After the screening of the fertilized embryos, which is usually on the fourth or fifth day after fertilization, the embryos that do not carry the mutation are placed in the woman's womb. Remaining embryos may be frozen, which helps to save approximately 50% of these embryos.<sup>3</sup> If an embryo has a genetic deficit or some other irregularity, if the parents choose not to have another child, or if the state no longer subsidizes the expensive procedures, unused embryos might never be implanted.<sup>4</sup>

The technology of PGD that allows for the screening and selection of embryos can be applied in a number of situations. PGD can be applied for monogenetic diseases such as Huntington's disease and Duchenne muscular dystrophy. When the corresponding genetic mutation is diagnosed, eventual development of the disease is certain. PGD can also be used to screen for genetic mutations where a positive result does not give certainty about the development of the disease. The genetic mutations BRCA 1/2 fall under this category because approximately 65% of the female carriers will eventually develop breast cancer if no measures are taken [16]. In line with BCRA 1/2, other genetic mutations that indicate a chance for a disease can be included in a PGD procedure. Advancing one step further beyond the spectrum of disease, other human phenotypic traits can be identified and screened for in the genetic makeup of an embryo.

These possibilities give rise to controversy over the desirability of PGD. On the one hand, people wish to protect their future children from the diseases they themselves carry. If there is a technological possibility to prevent harm to one's children, it seems only right to pursue that option. On the other hand, PGD is not morally unproblematic. It is argued that embryos, being human life in its earliest phase but human life no less, deserve our respect. It is argued that although there is nothing wrong with trying to prevent one's children from harm, the morality of that action changes completely when it results in the destruction of embryos.

In the Netherlands, the policy on PGD is constrained by *Planningsbesluit klinisch genetisch onderzoek en erfelijkheidsadvisering* [17] (PKGOE). This regulation belongs to the law *Wet op*

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<sup>3</sup> Experiments are nowadays conducted to freeze unfertilized egg cells. While the general consensus was that only fertilized eggs, ergo embryos, were suitable for such a procedure, the academic hospital of Amsterdam (AZM) has the intention to start freezing eggs in 2010 [15].

<sup>4</sup> In the Netherlands, a procedure has a success rate of approximately 20%. The procedure is costly and the state subsidizes the first three procedures.

*bijzondere medische verrichtingen* [18] (WBMV). It was first promulgated on 14 January 2003 and was adapted on 16 February 2009 according to the regulation *Regeling preïmplantatie genetische diagnostiek* [13] (RPGD). Before 16 February, the criteria for PGD were formulated as follows: “for decisions on PGD, it is central that the individual parents have an elevated risk of transferring a serious genetic condition or disease to their child.” After 16 February, a more comprehensive framework with criteria for PGD was formulated. Now, not only the nature of the disease matters in the decision to warrant PGD, but so too do the possibilities for treatment, some additional medical criteria, and psychological and moral factors.

### 1.4 Analysis of a public debate on PGD

The term ‘public debate’ in the research question does not refer to just any kind of debate or to one specific debate for that matter. ‘Public debate’ refers to the collection of arguments used in debates to justify laws and to create policy. Typically, public debates on new and emerging technologies discuss whether the risks or moral problems of the topic under discussion justify some sort of policy. The public debate is not restricted by physical boundaries and arguments voiced on the radio may be just as relevant as those written in a column. But since the voices in such a debate intend to exercise influence over policy, it is restricted by the influence of the speaker. Practically this means that a comment in an internet forum holds little relevance, but a column of a member of parliament in a national newspaper carries significant weight.

The Dutch debate on PGD in the spring of 2008 will be the subject of analysis. The debate was kick-started when Jet Bussemaker, state secretary for Health, Welfare and Sport, issued a policy letter to the parliament on PGD [16]. In that letter she announced her intention to widen the use of PGD to protect against the genetic defects BRCA 1/2 that are responsible for a form of aggressive breast cancer. With this decision, she evoked irritation among those of the conservative Christian coalition partner, the Christian Union (CU). The inclusion of BRCA to PGD procedures means that, for the first time, a genetic mutation is included that does not give certainty about the development of disease. Due to a serious disagreement in the administration, Bussemaker withdrew the letter and a period of internal deliberation was announced. During that time, a vigorous debate coloured the Dutch media. On television, medical experts were positioned against people of faith and the newspapers contained many opinions from a variety of relevant actors.<sup>5</sup>

The analysis of this debate will be performed with the help of NEST-ethics [19]. NEST refers to New and Emerging Science and Technology, and NEST-ethics is basically an inventory of arguments that usually occur in debates about NEST. New technologies come with uncertainty about their possible implications and this characteristic drives specific lines of reasoning. For new science and technologies, a distinctive group of reoccurring arguments can then be identified. Arguments are used because they carry specific strength in specific situations and subsequently invoke typical responses because those too are particularly powerful. A debate is therefore much like an arena where strategic steps and countermeasures are taken to ensure victory.<sup>6</sup> For example, one can argue that a human embryo is human and therefore deserves protection. A typical response would be to suggest that it really is no more than a mere bunch of cells and it would be silly to assign moral rights to it.

NEST-ethics helps to structure the debate in the newspapers and on television, and compare the two camps’ arguments face-to-face. Along different ethical categories, the relation between arguments and responses are easily identified. However, people who express arguments do not always say against whom or against which position they exactly argue. Therefore, one might

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<sup>5</sup> There are basically two sides in the discussion which I will label as ‘religious’ and ‘liberal’ throughout this research. Naturally, this distinction does not mean that opponents of PGD do not share liberal principles, or that supporters of PGD are all non-religious liberals.

<sup>6</sup> The arena-metaphor is borrowed from Swierstra’s and Rip’s article on NEST-ethics.

wonder whether the reconstruction by means of NEST-ethics is true to the intentions of those who argue. Does the NEST-ethics approach possibly produce already biased information? This is a serious concern which should be answered. The inventory of NEST-ethics relies on the idea that arguments are used in specific situations because that is when they are most powerful. Patterning the arguments to make them interlock only means that the specific strength of each specific argument is respected. If we may assume that actors in a debate voice particular arguments because they feel that an argument is particularly appropriate (an easily defended assumption), NEST-ethics only helps to reconstruct a debate to match the intentions of the actors.

NEST-ethics plays a crucial role in this research and is more than just a way to categorize arguments in the debate. The identification of argumentative patterns helps to identify the position of religious arguments. If religious arguments carry little value, one might expect to see striking counterarguments. However, from typical argumentative patterns on NEST, it is also clear that some arguments are not really countered but are marginalized. Those arguments are seen as inappropriate for public deliberation because they reflect personal and private matters. This rhetorical move appears to be particularly prominent in the debate on PGD where the CU is blamed for imposing their Christian ideas upon others.<sup>7</sup> Whether this is a reasonable attitude will be discussed in the section on Rawlsian public reason. But first, it is my aim to explore the value of religious arguments. Here too, NEST-ethics will prove its worth. PGD, like any other new and controversial technology, opens up spaces for ethical deliberation. In those spaces values come in conflict which can clearly be identified with NEST-ethics. An analysis of the debate makes clear how some values win and others lose.

### 1.5 Religious arguments

So far I have used the term ‘religious argument’ freely without explaining what is exactly meant by it. Intuitively, the reader will be able to grasp a general idea about it, but an elaboration is in place: Encyclopaedia Britannica describes ‘religion’ as: “Human beings’ relation to that which they regard as holy, sacred, spiritual, or divine. Religion is commonly regarded as consisting of a person’s relation to God or to gods or spirits” [20]. A search in a dictionary provides several results of which the first two are: “a set of beliefs concerning the cause, nature, and purpose of the universe, esp. when considered as the creation of a superhuman agency or agencies, usually involving devotional and ritual observances, and often containing a moral code governing the conduct of human affairs,” and: “a specific fundamental set of beliefs and practices generally agreed upon by a number of persons or sects: the Christian religion; the Buddhist religion” [21].

God. Nature. The purpose of the universe. Rituals. Fundamental sets of beliefs. Practices and beliefs agreed upon by a number of persons. Religion can be described in many ways and it does not seem possible to give a strict definition of it but most people would be able to identify it when they see it. Just as there is no generally accepted, satisfactory definition of religion, so is there no satisfactory definition for a religious argument. But that does not mean that religious arguments cannot be identified. See, for example, how a follower of Christianity could argue both in a religious or a nonreligious way: Think of Peter Singer’s example of the drowning child in a shallow pond. Singer argues that it is one’s duty to “wade in and pull the child out.” The muddy clothes are a small price to pay considering the death of the child would have been significantly worse [22]. A different argument for the same action could be made, for example, by appealing to the parable of the Good Samaritan in Christian scripture.

In the latter case, a religious argument is an argument that relies on religious scripture. But for many arguments, this link is not easily established. Morality itself is continuously changing such that a man held to be good a couple of centuries ago is vilified today. The words in religious scriptures remain the same yet with each passing year, religious books appear to be holding more

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<sup>7</sup> Chapters 3 and 4 discuss these rhetorical moves.

and more evils. Therefore, reinterpretation is necessary as time passes and morality changes. Over the years, religion has become an institution which has often evolved with the spirit of the time. Scriptures are reinterpreted and the answers towards life, the universe and everything else are constantly changing. Stories such as that of the Good Samaritan are still referred to constantly, and many verses or psalms will always contain some moral wisdom. Nonetheless, religious arguments, or arguments inspired by religion, are often not mere evocations of words from the past.

So, the question remains: how do we recognize religious arguments as such? The answer lies in the practice of the debate. Where conflicts emerge and people fight over the legitimacy of one another's position, controversial arguments – like those voiced by religious people – are likely to be found. In the debate on PGD, the conflict broils over the role of those who reason from a religious background. It is difficult, however, to argue when an argument is religious or not, for there remains no general consensus on what religion really is. Therefore, it would be good to look at the actors in the debate and see what they find problematic about religion. The general idea would be that religious people appear to 'tell other people how to live their lives.' More than others, people of faith tend to base their arguments on ideas of the good life and the proper society. These are the arguments that others often find problematic and, as such, will be of particular interest in this research.

### 1.6 Overview

Chapter 2 contains a thorough investigation of Rawls's *Political Liberalism*. A few concepts stand central, of which overlapping consensus and public reason are most relevant. In this chapter, I will make explicit how Rawls's liberal theory argues that all citizens should be motivated to exercise some restraint when justifying coercive laws. I will also make clear the ways in which the theory helps to demarcate between proper arguments for public debate and arguments that might be 'too religious.' Chapter 3 offers a description of the debate along the lines of NEST-ethics. Arguments in the debate on PGD are clustered in different ethical categories and they are discussed in relation to each other. By virtue of the plurality of arguments and the aim to provide a thorough and accurate description of the debate, this chapter is an extensive one. Chapter 4 endeavours to discuss the role of religious arguments in the debate on PGD. First the question is raised as to whether those arguments can live up to the demands of public reason. Second, I consider whether those arguments should be taken seriously. Chapter 5 completes the assessment on religious arguments and asks whether they are valuable. The idea here is to search for a rationale by which critics of religion in public might conclude that religious arguments can be valuable. Chapter 6 closes off with a discussion.

## Chapter 2

# Rawls and the Public Forum

John Rawls played a decisive role in liberal political thinking of the twentieth century. In particular the volumes *A Theory of Justice* (TJ) [23] and *Political Liberalism* (PL) [3] have been very influential. In the first volume, Rawls sets out his idea of justice as fairness, which he considers to be morally superior to utilitarianism, the other well-known liberal doctrine. In TJ it is assumed that citizens will accept the two governing principles of justice as fairness in a well-ordered society.<sup>8</sup> In reality, however, a well-ordered society where all citizens happily endorse the principles of TJ is unrealistic. People always have and always will disagree on principles of justice and the general good. In PL, Rawls recognizes this problem and reconceptualises justice as fairness of TJ as a moral conception of justice<sup>9</sup> ([3], p. xvii), which can be distinguished from a political conception of justice, which is the focus of PL.

Citizens affirm different worldviews, or doctrines as Rawls calls it, which may inform people's views on every aspect of life. The more a doctrine tells about preferable ways of life and living, the more comprehensive it is. Prime examples of partially or fully comprehensive doctrines are religions, but also Marxism or more liberal ideologies such as Kantianism or utilitarianism, are comprehensive doctrines. Rawls defines a doctrine as comprehensive when "it includes conceptions of what is of value in human life, and ideals of personal character, as well as ideals of friendship and of familial and associational relationships and much else that is to inform our conduct, and in the limit to our life as a whole." ([3], p. 13) None of these doctrines command the support of citizens generally and it is unlikely that one will gain the allegiance of all citizens in the foreseeable future.

Consider the two worldviews of Christianity and utilitarianism. The latter dictates that the moral worth of an action follows from its contribution to happiness. It tells us whether actions are right or wrong and it poses a moral obligation upon people to act in a way that contributes to increased happiness. Christianity urges its followers to learn from the teachings of Jesus Christ, the Son of God, who, among other lessons, teaches about forgiveness, sin, humility and salvation. The followers of Christianity and utilitarianism are both convinced that the principles of their respective worldviews indicate proper moral actions. By what rationale, then, does it seem likely that all of the followers of Christianity will trade in their system of beliefs for utilitarianism? Or by what motivation may all utilitarians come to understand they have been wrong all along and admit that the teachings of Christianity are superior to that of utilitarianism?

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<sup>8</sup> "A. Each person has an equal right to a fully adequate scheme of equal basic liberties, which is compatible with a similar scheme of liberties for all.

B. Social and economic inequalities are to satisfy two conditions. First, they must be attached to offices and positions open to all under conditions of fair equality of opportunity; and second, they must be to the greatest benefit of the least advantaged members of society." [3]

<sup>9</sup> Moreover, in PL, Rawls uses the fact of reasonable pluralism to change the idea of justice as fairness so that it can be a proper political conception of justice. In particular, the role of the original position by which Rawls determines how rational citizens will uphold the same principles of justice, has changed. I will come back to this point in my discussion of the original position in 2.3.

The problem is the following: To put it in Rawls's words, "a modern democratic society is characterized not simply by a pluralism of comprehensive religious, philosophical, and moral doctrines but by a pluralism of incompatible yet reasonable comprehensive doctrines." ([3], p. xvi) A reasonable doctrine would be one that accepts the essentials of a democratic society which always considers people to be free and equal. It is first and foremost free democratic society that allows citizens to confirm either Christianity, Islam, Judaism, Marxism or a Kantian doctrine under one and the same democratic regime.<sup>10</sup> Yet, and I wish to emphasize what follows now, while these people disagree on many aspects of life, including justice, they also affirm the same political conception of justice (as opposed to the moral conception of justice). Citizens accept the constitution, the laws, the institutions and the standards that make up political justice in a democratic regime. It is this dualism between the stable political society supported by all citizens and the private worldviews about which citizens are deeply divided, that is the problem and inspiration of PL.

In this chapter, a complete overview of PL is given. The aim is not only to provide a thorough description of the theory, but simultaneously to show the relevance of the theory in connection to a debate on PGD. It will become clear how and why PL provides a convincing framework for the evaluation of religious arguments.

### 2.1 Political Liberalism

PL tries to uncover the conditions and content of a political conception of justice that is acceptable to free and equal citizens who affirm different comprehensive, religious, philosophical and moral doctrines. *Always*, the answers can be found by looking at what principles are implicit in democratic regimes for it is here where free and equal citizens live in a stable society with legitimate law. These ideas of stability and legitimacy are essential because they arise as problems from the dualism between citizens accepting law and simultaneously affirming different comprehensive views. The problem of PL can then be formulated in the question: "how is it possible that there may exist over time a stable and just society of free and equal citizens profoundly divided by reasonable though incompatible religious, philosophical and moral doctrines?" ([3], p. xviii)

The answer to this question starts with an assumption of the citizen as possessing two moral powers – a capacity for a sense of justice and for a conception of the good. It is fully rational for citizens to accept different and competing principles of the good, whether it be utilitarian or Christian. In justice as fairness in TJ, however, the rational good and the capacity for a sense of justice belong to one theory of justice. PL recognizes that justice in a society with a plurality of doctrines can never rely on a single rational idea. So instead, Rawls prioritizes the reasonable above the rational. This means that citizens may pursue their own ideas of the good insofar as they recognize that others citizens may do the same. Within a reasonable scope, there are then only a few principles about which we can say that they apply to all and restrict the pursuit of the good.

In the end, Rawls builds towards an understanding of the political relation among citizens: a relation that does not specify that citizens should accept rational principles of the good, as comprehensive doctrines usually do, but specifies how citizens may live together while accepting that they disagree and respect another's ideas of the good. Rawls captures the political relation among citizens under the idea of public reason. Public reason aims to specify how the political relation is to be understood between citizens in accordance with the ideals and the reality of a democratic society. This means that public reason builds upon the idea that citizens are free and equal and accepts that they all endorse different and incompatible comprehensive views. In view of this, the citizens are considered to have the moral and intellectual capacities to distinguish between the reasons they may propose on fundamental political questions, which are public

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<sup>10</sup> Not to say that all doctrines have only reasonable elements or are equally reasonable.

reasons, and those reasons that concern any other matter. In the following sections, I will make clear exactly what counts as a good reason, what kind of policy it may address, and how this fair system of cooperation works.

### 2.2 Principles of democracy

One of the ideas implicit in the idea of democracy is that of “society as a fair system of cooperation over time, from one generation to the next” ([3], p. 15). Democracies in Western Europe and Northern America are prime examples where citizens are engaged in a system of fair cooperation. People here accept and respect the rules and procedures that legitimate law places upon them. Whenever efforts are made to change existing laws or introduce new ones, citizens do not use methods of revolution or rebellion but instead make use of the opportunities available within democracy such as free speech, the right to public assembly, the right to demonstrate or the ability to become politically active. Whenever citizens are not able to achieve desirable changes such as a higher minimum wage or lower health care costs, they consider the laws in place to be legitimate despite their own opposition, and will obey them. Note that in a democracy, despite fundamental differences between ideas on proper economic policy, citizens work together under law and procedures that are acceptable to all citizens. The idea of society as a fair system of cooperation is not just an ideal, but is a reality that is confirmed daily in Western democracies.

Another idea implicit in the idea of democracy and the idea of society as a fair system of cooperation is that of the reasonable citizen. Citizens who underline democracy as a fair system of cooperation respect their fellow citizens as free and equal human beings. Rawls formulates this respect according to a principle of reciprocity, which means that one should be prepared to “propose principles and standards as fair terms of cooperation and to abide by them willingly, given the assurance that others will likewise do so.” ([3], p. 49) The idea of reciprocity expresses the relation between citizens in a democracy who as free and equal citizens exercise political power over one another. It can furthermore be formulated as a criterion which says: “our exercise of political power is proper only when we sincerely believe that the reasons we offer for our political action may reasonably be accepted by other citizens as a justification of those actions.” ([3], p. xlv) It basically says that political power (condensed in laws and institutions and enacted by citizens, politicians and judges) can only be properly justified if is exercised in accordance with conditions that are acceptable to all citizens. In ethics and religion this principle is often better known as the golden rule.<sup>11</sup>

Two remarks about the reasonable citizen: first, it should be stressed that the reasonable citizen is not just a concept present in the ideal of democracy. Rather, people accept that their full outlook on life may not be shared by all citizens. Citizens accept that policy that applies to all should not involve those ideas that only a few may share, but should consist of those values citizens share generally, including the conditions necessary to ensure them.<sup>12</sup> Then, in the ideas of society as a fair system of cooperation and the reasonable citizen we can see how citizens who affirm different comprehensive doctrines nonetheless accept that there are limits to the policy they can reasonably impose upon each other. Second, to define citizens as reasonable means that they are defined as political beings. Here, the term ‘reasonable’ says little about one’s character concerning non-political affairs such as the stereotypical well-intentioned, but overprotective father who is seen as unreasonable in his daughter’s eyes. Reasonableness, as meant in the context of PL, is thus a moral political conception that only suggests that citizens (are willing to) act according to a principle of reciprocity that is informed by the values of freedom and equality.

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<sup>11</sup> An example in Luke 6:31: “And as ye would that men should do to you, do ye also to them likewise.”

<sup>12</sup> For example, because citizens in a democracy are involved in collective self-rule, they should have the possibilities to exercise their power and be given the means to vote.

### 2.3 A political conception of justice

We can see that citizens are in agreement on fair terms of cooperation, which finds its inspiration in a respect for all citizens as being free and equal and a natural tendency to only accept policy that satisfies the principle of reciprocity. Rawls captures this idea under a political conception of justice that is shared by all citizens. In the introduction to this chapter, I distinguished the political from the moral conception of justice. The latter is on par with any other reasonable comprehensive view in the sense that it gives a special position for values and norms that not everyone may share. In contrast, the political conception of justice only aims to specify those values and standards (which we can call political values) that are necessary for a stable and just society to exist over time, always assuming there is a pluralism of comprehensive doctrines. A political conception of justice then can be defined in the features that separate it from comprehensive doctrines. Such is the task of PL and it will be discussed shortly according to: 1) the subject or scope; 2) the mode of representation; and, 3) the content of a political conception of justice.

To continue, a first characteristic of a political conception of justice is that it applies to the “basic structure of society, which (...) I take to be a modern constitutional democracy” ([3], p. 11). By this, Rawls means that it concerns only those institutions, rules of law and principles in general that collectively govern conduct in society according to a fair system of cooperation. To explain, not just any coercive law falls under the scope of public reason. Only those “constitutional essentials and questions of basic justice” ([3], p. 214), on the principles of which citizens should agree, can belong to a political conception of justice. Remember that reasonable citizens willingly conform to the demands of reciprocity when it concerns the exercise of political power over those who live under the same rule of law. Those citizens agree that comprehensive values, such as religious ones on salvation or eternal life, or other values such as love, friendship or altruism, form no legitimate basis for the exercise of political power and would not qualify as a public reason.

Then the question might be raised how we can demarcate between constitutional essentials or matters of basic justice and other types of policy? The constitutional essentials specify the relation between citizens on the most fundamental level of rights and duties in light of a fair system of cooperation. Citizens agree on these principles, for they concern the most basic interpretations of freedom and equality, including freedom of speech or equal suffrage, as well as standards to secure these principles, including the ability to change constitutional essentials only when mandated by a large majority. Note that I have merely applied the democratic principles discussed in 2.2 to the idea of the overarching constitutional law that specifies the relation between free and equal citizens on the most fundamental level.

The idea of “basic justice”, however, is less straightforward. In the additional sections added to PL, namely “Introduction to the Paperback Edition” and “The Idea of Public Reason” [3], Rawls makes clear what he understands matters of basic justice to be. In a footnote, Rawls suggests that “matters of basic justice relate to the basic structure of society and so would concern questions of basic economic and social justice and other things not covered by a constitution” ([3], p. xviii, 442). But this category remains very abstract, and whenever Rawls considers matters that may be categorized as basic justice, there is no explanation as to why that would be. Consider the case of abortion, which Rawls also discusses by appealing to political values only ([3], p. 243 footnote:32). I agree (and I assume that I agree with Rawls) that policy on abortion should be considered as a matter of basic justice. But instead of arguing why abortion would qualify as a question of basic justice, Rawls simply assumes this is the case ([3], p. 244 footnote: 32).

To see what counts as a matter of basic justice, we should return, as I often do in my assessment of Rawls’s PL, to the basic principles of democratic society. To recap, people are free and equal citizens who work together in a fair system of cooperation. Whenever citizens argue that a certain principle should inform policy, given that the principle *unmistakably influences* the

freedom or equality of citizens, they should argue along the lines of the principle of reciprocity, which suggests that they need to offer reasons which they reasonably believe other citizens will reasonably accept as relevant arguments. In this statement, I have italicized the principle that distinguishes matters of basic justice from other matters of justice, as I understand it (and as I believe Rawls understands it).<sup>13</sup>

Whether something is a matter of basic justice is a matter of degree. When applied to the case of abortion, we can understand that any law that prohibits or constrains abortion is a matter of basic justice because it can be of *great influence* to a woman's freedom and equality as a citizen. Therefore, reasons to constrain abortion need to express political values that all citizens may share. On abortion, that principle would be the due protection of human life. Whether this means that abortion should be illegal, simply possible, or allowed under some restrictions, is negotiable in normal political process. Concerning the question of pollution, it may rightly be argued that because pollution is of influence to citizens' health, it qualifies as a matter of basic justice. But much depends on the degree of pollution. Not any political decision that brings about a level pollution, such as licensing a power plant, falls under the scope of basic justice, and, hence, public reason. To some degree all citizens pollute. The question is whether that pollution may be of such influence to the health of citizens that it should be constrained by the principle of reciprocity. To conclude this discussion on constitutional essentials and matters of basic justice, I wish to remark that there are certain rights that are easily specified, such as freedom of speech or equal suffrage, which can be embedded in the constitution. Then there are those cases where citizens are motivated to argue reciprocally when the policy at hand may have significant influence on the citizens who will be affected most by it. Citizens are, however, less likely to consider it their duty to reason reciprocally when the matters of basic justice are less visible.

Second, the political conception of justice should be seen as a 'freestanding view.' ([3], p. 10) As discussed, citizens agree about the basic principles of justice that should inform political power. Because these principles do not rely on other comprehensive views, it should be seen as unattached (freestanding) from them. Furthermore, the political conception of justice is 'neutral' towards the wider systems of belief that citizens may maintain. It is neutral in the sense that it does not aim to prefer any comprehensive doctrine over another. That, however, does not imply comprehensive views find equal currency in a political conception of justice. It is likely that a religious perspective may find the political to conflict with some religious values. In Christianity, for example, it is often valued that marriage is reserved for people who wish to marry somebody of the opposite sex. But because marriage has a particular status in the political domain and certain rights are connected to it, it would be unreasonable to oppose to such marriage on gender grounds. Marriage is also a political institution, and the state cannot legitimately make distinctions between people's sexual preference for that would violate the fundamental idea of all citizens being free and equal.<sup>14</sup> Nonetheless, Christians are also motivated to accept the values and standard presented in a political conception of justice. For by the same standards that Christians are expected to keep their comprehensive ideals for themselves, others cannot deny them the right to exercise their religious freedom.

The final and third feature that I discuss here concerns the content of a political conception of justice. Rawls mentions three features that should specify its content when viewing people as free and equal reciprocal citizens:

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<sup>13</sup> To prevent any misunderstanding, I do not pretend that my formulation of legitimate justification according to the principle of reciprocity is sufficient to sustain the full scope of public reason. Nor do I suggest that my formulation of legitimacy in the perspective of matters of basic justice, would be the best interpretation of PL.

<sup>14</sup> I realize that especially people of faith may have difficulties with same sex marriage. Although I do not wish to say that these religious people are unreasonable in general, it would be difficult to find a reason that reflects a political conception of justice to deny gay people the privilege of marriage. For marriage as a matter of the Church, the arguments would not need to reflect the values of a political conception of justice.

- 1) a specification of certain basic rights, liberties and opportunities (of a kind familiar from constitutional democratic regimes);
- 2) an assignment of special priority to those rights, liberties, and opportunities, especially with respect to claims of the general good and of perfectionist values;
- 3) and third, measures assuring to all citizens adequate all-purpose means to make effective use of their liberties and opportunities. ([3], p. 6)

So far I have maintained that the political conception of justice is shared by all reasonable citizens. But there is also room for different interpretations of values that inform political justice. Citizens may thus disagree on the way the principles of freedom and equality should be formulated, how they may relate to each other, or what standards are most suitable to guarantee these values. A well-known problem in democratic society concerns the level of democracy a society can accept and still be effective. A very direct democracy could use the tool of referendum to decide most policy matters. But that would ask a much greater involvement of the citizens and could reduce the effectiveness of the political system. Whatever the preferable level of ‘direct democracy’ is, citizens would nonetheless agree that all have an equal say in it.

Throughout history, democratic societies have all developed particular liberal political conceptions of justice that may differ from each other in the relative weight they attribute to substantive principles of justice. Events in the past and cultural traditions change the way people understand how freedom and equality among citizens is safeguarded best. As an example, the differences between the priority of freedom of speech can be shown by comparing the constitution of the Netherlands and the Bill of Rights of the United States. For the Netherlands, freedom of speech (article 7 of the Constitution of the Netherlands) is limited by the first article of the constitution that forbids discrimination on the basis of all citizens being equal. Freedom of speech in the United States is protected in the First Amendment and is not restricted by an article similar to that of the first article of the Dutch constitution.

The content of a political conception may thus change, but only within certain limits. Those limits are expressed by what Rawls calls “the priority of the right” ([3], p. 176). This means that “admissible ideas of the good must respect the limits of, and serve a role within, the political conception of justice.” ([3], p. 176) Ideas of the good are then worked-out expressions of citizens being free and equal including the means to support those values, standards and institutions that allow for a society as a fair system of cooperation. Other ideas of the good may always be pursued, but only insofar as these do not come in conflict with the political conceptions of justice. One may, for example, argue for allowing prayer in school insofar as it does not replace the curriculum that is necessary for a child to become a fully informed, autonomous citizen. Furthermore, that a society may consider freedom in all its forms to be the highest good, such as is embedded in the constitution of the United States, which is consistent with the priority of the right, does not mean that discriminatory expressions, protected under the right to freedom of speech, is also consistent with the priority of the right.

As a way to develop the content and principles of a political conception that is undistorted from cultural preferences or personal gain, Rawls goes over the “original position” ([3], p. 22-28), originally developed in TJ. The original position is a way to identify principles that one could consider to belong to a political conception of justice if one would imagine oneself detached from the current social position. A person is supposed to imagine what a just society would look like from a position where one is entirely ignorant of one’s own inherited race, gender, ethnicity, intelligence, disposition to disease, or any other characteristic relevant to the role of a citizen in that society. The idea is that the content of a political conception of justice can be achieved by pure reason when one thinks about the principles that would be to one’s own advantage. When people reason in accordance with their own interests from the original position, they will come to

the best – though others may disagree – principles for a political conception of justice that should govern the relation between free and equal citizens in a system of fair cooperation.

But while the original position may be a perfectly sound rational way to determine the most preferable conception of the good, it makes no distinction between the reasonable and the rational, or the priority of the right over ideas of the good. Because reasonable pluralism means that different rational ideas of the good are a fact of society, the idea of TJ to provide a rational moral framework that should govern justice needed to be replaced by a political framework that prioritizes the reasonable over the rational. Justice as fairness has thus been reformulated to express that society should not be remodelled in the image determined by the original position, but according to a proper civic relation among reasonable citizens. Then, justice as fairness is a moral conception that may fit a political conception perfectly, but is nonetheless constrained by political values. The content of a political conception may be given by justice as fairness, but only insofar as it reflects the relation among free and equal citizens.<sup>15</sup>

To summarize this section: citizens are free and equal and recognize that this applies to fellow citizens equally. Citizens confirm different incompatible but nonetheless reasonable comprehensive doctrines. Therefore, citizens accept that ultimate political power (constitutional essentials and matters of basic justice) can only be legitimately invoked if they reasonably think that other reasonable people can accept the reasons for the use of democratic power. These principles underlie the idea of democracy and are used to explain the character (freestanding view & subject or scope) and content of a political conception of justice that would be endorsed by those who reason within the limits of public reason. Such a conception of justice is the focus of proper legitimate reasoning and justification of laws, so essentially, it organizes the ideas of reciprocity and that of free and equal citizens, which can be used as justifications for policy or standards and institutions necessary to regulate democracy effectively. The political conception of justice is not merely an ideal that would be present in an ideal society but is present in democratic societies. Rawls ‘merely’ identified how and why we as citizens reason according to the values and standards of a political conception of justice.

### 2.4 The overlapping consensus

To preserve the unity and stability of a democratic society, Rawls argues, the political conception of justice should be the focus of an overlapping consensus. The general idea of the overlapping consensus is that each reasonable doctrine endorses the liberal political conception of justice from its own point of view. The Vatican, for example, endorses the idea that all people have a right to religious freedom. “The [Vatican] council (...) declares that the right to religious freedom has its foundation in the very dignity of the human person as this dignity is known through the revealed word of God and by reason itself (...) This right of the human person to religious freedom is to be recognized in the constitutional law whereby society is governed and thus it is to become a civil right.” [24]

According to Rawls it is furthermore important that the political conception of justice is not merely accepted as a *modus vivendi*, but is in fact wholeheartedly embraced. To explain what he means by a *modus vivendi*, Rawls traces the origins of a pluralist democratic society of toleration back to the Reformation and the Enlightenment. The conflicts in the Catholic Church during the Reformation and the conflicts between the legitimacy of reason and the authority of the Church during the Enlightenment had enormous consequences for societies in the years to follow. Centuries of wars and intolerance made way for a minimalistic conception of toleration. To avoid

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<sup>15</sup> It is then also interesting to point out how the role of the original position has changed. While the original position was initially intended to specify the relation between citizens on a most fundamental level, in PL, the fundamental level is constructed upon an idea of the reasonable citizen in a fair system of cooperation. Only with due respect to this idea can the original position be called upon.

a clash between the competing comprehensive doctrines, which ran the risk of destroying society altogether, the diversity of religions had little choice but to tolerate their opponents. This *modus vivendi*, in which religious doctrines only tolerate other comprehensive doctrines for their own interests, may very well produce a just society. But as long as a religious doctrine, for example, only tolerates other worldviews out of mere self-preservation, the just society is not a very stable one. In contrast, when a political conception of justice is endorsed from one's own comprehensive worldview, citizens will accept it for the right reasons (wholeheartedly) and are more likely to resist injustice.

So basically, the idea of the overlapping consensus explains the stability of democratic society where the content of a political conception of justice reflects values and standards that are also present in a reasonable comprehensive doctrine. But remember that comprehensive doctrines such as Christianity say a great deal more than those values and standards that are supposed to reflect a political conception of justice. By what rationale, then, should Christians decide that only political values present in their religion are proper justifications for constitutional essentials and matters of basic justice? In view of the coercive nature of law that can only be legitimized with due respect to citizens being free and equal, Rawls says it is unreasonable if a comprehensive doctrine is forced upon others, for that would violate a criterion of reciprocity. But the case is not that simple for those who affirm a religious doctrine. While people of faith may sincerely value the political conception of justice including its criterion of reciprocity, they, as reasonable and rational citizens, may also value competing religious ideas.

The problem is the following: why should somebody who affirms a reasonable comprehensive view (and this holds particularly for those who affirm a religious doctrine) judge the values expressed in a political conception of justice to outweigh whatever other values that may conflict with them? Rawls gives two reasons. The first is that the liberal values of a political conception of justice are "very great values [that] govern the basic framework of social life – the very groundwork of our existence." ([3], p. 139, 157-158) These values are the focus of a fair system of cooperation. By assigning a special priority to the values and standards of a political conception of justice, citizens can cooperate with mutual respect and with reasonableness. The second reason suggests that the problem proposed is less serious than might be imagined. Conflicts with other values are likely to be reduced because citizens endorse the political conception of justice from their own comprehensive view. That is the idea of an overlapping consensus.

### 2.5 Public reason

With the exception of the original position, all of the previously discussed ideas are related to ideas of reasonable pluralism and the legitimacy of coercive democratic power of a collective body of free and equal citizens. The purpose is to identify the most reasonable basis upon which citizens who affirm a pluralism of comprehensive doctrines can cooperate. That basis is reflected in a political conception of justice. The formulation of the nature and the content of a political conception of justice has been the focus of PL throughout the ideas discussed. In this matter, the greatest challenge Rawls faced was to propose a workable liberal political theory that would be acceptable to those citizens who affirm non-liberal but nonetheless reasonable comprehensive views (especially religious ones). Further, Rawls had to explain why a citizen's first allegiance should be to the value of a political conception of justice, regardless of whatever other values might be specified in the comprehensive doctrines to which one subscribes.

The terms upon which citizens cooperate can be found in an ideal of public reason. A discussion of the idea of public reason adds little to what has already been said. Both the problems of legitimacy and stability have been discussed and I have already alluded to the duties (which are also specified in the idea of public reason) this places upon citizens. Nonetheless, public reason is

in some way the culmination of all the other ideas. PL aims to materialize the ideals and the practice of democracy in a coherent family of ideas that may be supported by all citizens. Public reason is then the final idea under which the other ideas come together. Hence, it is also the focus of most criticisms when it concerns the basic project of PL. It is these criticisms that give meaning to this section and which compelled Rawls to revise his idea of public reason slightly.

It is necessary to briefly explain the idea of public reason more thoroughly before addressing the the concept's most relevant critics. First to define the term: "public reason is the reason of equal citizens who, as a collective body, exercise final political and coercive power over one another in enacting laws and in amending their constitution." ([3], p. 214) Public reason is then an ideal of reason that citizens would uphold if they respect each other as free and equal citizens, to whom they have the civil duty to properly explain their supporting reasons for coercive policy. There are two types of reasons that would satisfy the demands of public reason. First, citizens may appeal to the "substantive principle of justice for the basic structure" ([3], p. 224), which are exponents of citizens regarding each other as free and equal such as equal suffrage, equal opportunity, freedom of speech, right to education. Second, citizens may appeal to the values of public reason. These "fall under the guidelines for public inquiry, which make that inquiry free and public." ([3], p. 224) That includes standards of proper reasoning such as principles found in common sense or logical ways of reasoning, or conclusions of uncontroversial scientific facts, or political virtues such as a willingness to change one's opinion in the light of new arguments.

Public reason does not aim to say whether comprehensive doctrines are right or wrong. Rather, it starts from the idea of citizens in a fair system of cooperation and suggests that the two types of reasons mentioned are the only reasonable ground for free and equal citizens to justify political power. Citizens can endorse these principles as the focus of an overlapping consensus and are compelled to give these principles priority over other ideas of the good. This, however, does not fully exclude ideas of the good as I remarked in my discussion on the priority of the right in Section 2.3. PL suggests that ideas of the good are permissible, as long as they belong to a reasonable political conception of justice, meaning that they can be shared by citizens regarded as free and equal and that they do not presuppose any particular fully comprehensive doctrine ([3], p. 176). It could be suggested that calls for allowing religious instruction in public schools would be valuable in itself. It would even be legitimate to argue that it would be more valuable to teach about Christianity in a dominantly Christian society than it would be to teach about Islam or Judaism.

Remember that the biggest challenge Rawls faced was to convince those people who affirm religious doctrines to accept a liberal political conception of justice, even if this sometimes means that they cannot justify matters of basic justice by appealing to the reasons they find within their comprehensive views. It should be no surprise that the most persuasive criticisms to PL relate to the demands that public reason place upon citizens who affirm non-liberal comprehensive views. Rawls himself deals with many criticisms in PL, and there are two types of criticism that are of particular importance which I will discuss here. First, there is the suggestion that public reason is unfairly biased in favor of secular (nonreligious) doctrines by excluding religious arguments from the public forum. The second line of criticism suggests that public reason is too strict for those who endorse comprehensive views. As we shall see, this type of criticism comes in different forms.

The first criticism suggests that public reason creates an unfair advantage for those doctrines who justify their ideas with secular reasons. I will split this question up in two parts: 1) do secular doctrines have an advantage compared to religious doctrines?; 2) if the answer is affirmative, is there reason to assume that this advantage is unfair? To the first question, Rawls says that with respect to religious comprehensive views, secular doctrines such as Kantianism or utilitarianism may have more common ground with the liberal principles of a political conception of justice. But why would that need to be a criticism? The demands of public reason apply equally to all

doctrines and it seems only logical that those doctrines who are closest to the views of a political conception of justice will find the principle of reciprocity to be the least conflicting with the whole of their doctrine. But to suggest that an advantage for any doctrine is a criticism is to beg the question. Any standard will fit one doctrine better than another.

Genuine criticisms should therefore come from the second part of the question. Is it unfair to religious doctrines that the demands of public reason do not constrain utilitarian reasons as much as reasons inspired by, for example, Christianity or Islam? To get a positive answer to this question, one should prove that the standards of public reason cannot be seen as belonging to a freestanding view that is acceptable to all, but to liberal ideology in its broader sense, rather than a political conception of justice that is liberal in its character. In other words, one should be able to question the aim of a political conception of justice and conclude that it does not intend to provide (or succeed in providing) the most reasonable basis for fair cooperation among free and equal citizens. To this, Rawls argues that the political conception of justice is neutral in the sense that it does not prefer any comprehensive doctrine beyond what is specified in the conception itself. Just as a Christian should not argue that the state ought not to recognize gay marriage (as I argued before), so too a secular Marxist should not seek to restructure society when this threatens basic human rights.

Finally, to close off this first line of criticism, it is worthwhile to point out that public reason only demands citizens to offer proper reasons insofar it concerns policy on matters of basic justice or constitutional essentials. Its demands only intend to guarantee the most fundamental principles of a democratic society that citizens can agree upon. To this extent, it aims to safeguard the absolute minimum that can sustain an overlapping consensus. Whenever citizens have difficulties respecting these limits and insist on advancing their comprehensive ideas of the good from the private to the public domain, Rawls labels these citizens as unreasonable, for they do not respect that other citizens may reasonably disagree about ideas of the good. These notions should guarantee that public reason supports a political conception as a freestanding view and does not aim to support secular comprehensive views over religious views.<sup>16</sup>

The second line of criticism suggests that public reason is too strict. It implies that people of faith cannot voice their religious opinions in public, for that seems to violate the criterion of reciprocity, even if those opinions could be supportive of a political conception of justice. André Rouvoet, the Minister of Youth and Family, expressed his grounding reasons for his position in a debate on embryo screenings [25]. Rouvoet referred to Psalm 139, which contains the following passages (Rouvoet cited a smaller part of this psalm):

- 13) For you created my inmost being;  
you knit me together in my mother's womb.
- 14) I praise you because I am fearfully and wonderfully made;  
your works are wonderful,  
I know that full well.
- 15) My frame was not hidden from you  
when I was made in the secret place.  
When I was woven together in the depths of the earth,
- 16) your eyes saw my unformed body.  
All the days ordained for me  
were written in your book  
before one of them came to be.

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<sup>16</sup> Although I try to interpret Rawls to the best of my ability, it is worth reading Rawls's defense of this line of criticism in PL, V:5 190-195 [3].

These passages do not formulate political reasons one may expect a non-religious fellow citizen to reasonably accept. Hence, the criterion of reciprocity appears to be violated here. Yet, although no political reason is given, these passages are accessible to religious and nonreligious people. People of faith may embrace these passages and suggest that human life in the womb is worthy of protection since God's work is involved, which can be translated in a political reason that expresses the due respect to human life.

Rawls recognizes the value of sharing one's fundamental inspiration (such as Rouvoet did) for an open debate where trust and honesty may lead to a better understanding among citizens. Rawls therefore suggests that it is in the interest of the political culture that citizens advance their grounding ideas only insofar as they can be supported by proper political reasons, cf. Rouvoet. This is what Rawls calls the *proviso*. Constitutional essentials and matters of basic justice then still need to be justified by political values, which can be provided in 'due time'. Rawls's example of the abolitionists, who based their argument for the abolishment of slavery on religious grounds, can be used to explain this principle. Rawls cites from William Ellery Channing's *Slavery*, 3d ed. (1836): "I come now to what is to my own mind the great argument against seizing and using a man as property. He cannot be property in the sight of God and justice, because he is a Rational, Moral, Immortal Being, because created in God's image, and therefore in the highest sense his child, because created to unfold godlike faculties, and to govern himself by a Divine Law written on his heart, and republished in God's word. From his very nature it follows that so to seize him is to offer an insult to his Maker, and to inflict aggravated social wrong. Into every human being God has breathed an immortal spirit, more precious than the whole outward creation (...) Did God create such a being to be owned as a tree or a brute?" ([3], footnote 38, p. 249) Although the abolitionists didn't know how to satisfy the proviso, their religious views are fully compatible with the basic values of a constitutional democracy.

Critics might argue that we may not know whether a religious argument may eventually be satisfied by the proviso, just as the abolitionists did not know that their arguments would eventually be supported by proper political values expressing the freedom and equality of all citizens. Rawls recognizes such questions but instead of solving the problem, he suggests that the "proviso is to be appropriately satisfied in good faith." ([3], p. 462) The problem, however, can be easily answered. The question is this: how can one know whether the proviso will eventually be satisfied, or how can one know that the religious reasons proposed have a corresponding political argument? But to answer this question seems to imply that citizens have no knowledge on the basic political values of freedom and equality, respect for which should guide all citizens to reason reciprocally. To take this question seriously is to mistake modern constitutional democracies with the society in which the abolitionists had to reason. If the religious reasons have a political counterpart, the proviso can be easily satisfied, as the proper political reasons can already be found in the idea of a democratic society as a cooperation among free and equal citizens.

Public reason is furthermore supposed to be too strict to resolve all matters of basic justice. But to prove this point, one has to establish that there are cases where public reason fails to do justice to the matter. Furthermore, one needs to point out in which ways it would be resolved in a better fashion. Rawls does not deny that there may be stand-offs such as in the case of abortion. But why should that be a fault of the theory? Political liberalism does not suggest that public reason must lead to the best outcome of conflicts over matters of basic justice. Instead, the outcome is considered to be legitimate if it is supported in accordance with principles of public reason.

## 2.6 Rawls and the public debate

The idea behind this thorough explanation on political liberalism and the concept of public reason is to explain its credibility as a liberal standard by which arguments in a public debate on PGD can be measured. Nonetheless, it is not at all taken for granted that Rawls's theory can be used to reflect upon an actual debate on PGD. In the formulation of public reason and how it applies, Rawls has been careful not to create a theory that demands the ordering of every debate on every policy matter. Not every subject should be the concern of public reason, nor should everyone always feel obliged to reason reciprocally. These notions will be discussed because they determine whether PGD is a suitable subject and which opinions and arguments make up the content of the public debate.

For Rawls, public reason applies only to those debates about constitutional essentials and matters of basic justice. Whether or not PGD should be pursued is clearly not a matter of constitutional relevance. It then remains to ask whether it is a matter of basic justice. In Section 2.3, I introduced the following quote: "matters of basic justice relate to the basic structure of society and so would concern questions of basic economic and social justice and other things not covered by an institution" ([3], p. 442). This quote is the most complete description Rawls offers on matters of basic justice. Unfortunately, it only tells us which types of justice we should think of, but it gives no direction to decide whether a matter of justice is 'basic enough' to fall under the scope of public reason.

Remember that Rawls uses abortion as a prime example to explain public reason ([3], p. 243). It would be safe to assume that the question of abortion is in fact a matter of basic justice. What does not fall under the scope of public reason is "much tax legislation and many laws regulating property; statutes protecting the environment and controlling pollution; establishing national parks and preserving wilderness areas and animal and plant species; and laying aside funds for museums and the arts" ([3], p. 214). To this, Rawls adds that "sometimes, these do involve fundamental matters" ([3], p. 214). In Section 2.3, I argued that the difference between a matter of basic justice and other political matters seems to depend on the prominence of basic liberal values such as freedom and equality. In the case of abortion, a policy that forbids abortion has direct and significant influence on the freedom of a woman with an unwanted pregnancy. A tax increase of only a few percentage points does not have the same impact on someone's freedom.<sup>17</sup>

Now, if abortion is a matter of basic justice, could this mean that PGD is as well? In both cases, the controversy exists over the destruction of unborn human life. For abortion, the freedom and self-determination of the pregnant women are the values that work in favour of abortion. For PGD, these values are also applicable for those people who wish to make use of the procedure, but are, perhaps, less compelling. More importantly, PGD is justified by referring to the harm that can be undone to future children. If anything, it is difficult to say which controversial policy is a more 'basic' matter of justice. It should be clear that PGD, just like abortion, is a subject for public reason.

Determining who is subject to public reason is a more difficult matter. Rawls suggests that the idea of public reason does not apply to all citizens in all positions equally. It concerns "the discourse of judges in their decisions, and especially of the judges of a supreme court; the discourse of government officials, especially chief executives and legislators; and finally, the discourse of candidates for public office and their campaign managers, especially in their public oratory, party platforms, and political statements" ([3], p. 443). It therefore seems that a public debate should thus only be subjected to public reason if it is held among these kinds of citizens. To continue, Rawls makes a distinction between the idea and the ideal of public reason. The latter

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<sup>17</sup> It could be argued, however, that a tax increase that would make it impossible for some citizens to live a self-determined life *is* a matter of basic justice.

is realized when those persons in legislative and juridical power follow the idea of public reason. But ordinary citizens should also feel moved to live up to the ideal of public reason. Ideally, citizens “think of themselves *as if they were legislators* and ask themselves what statutes, supported by what reasons satisfying the criterion of reciprocity, they would think it most reasonable to enact” ([3], p. 444-445).

The distinction between the idea of reciprocity for legislators and judges on the one hand, and the ideal of reciprocity for citizens on the other, is a bit brusque. To explain: if citizens really do think as legislators, this implies, according to Rawls, that “citizens fulfil their duty of civility and support the idea of public reason by doing what they can to hold governmental officials to it” ([3], p. 445). Rawls considers public reason to be the morally right way of reasoning for members of parliament, judges and other officials because they are in a position to create and enforce policies and laws. That is inferred from the principle of reciprocity. The citizen is relevant insofar it is involved in the control of those powers. Hence, when elections come up, they should vote consciously and give and take away power where it is believed to be necessary. Now, in reality, debates on public matters are mostly not held among politicians or judges. Instead, experts are by far the most prominent actors in the media judged by airtime or number of words published. Not only politicians, but scientists, medical practitioners, political philosophers, most of whom are professors, religious spokespersons and finally, victims of cancer, are prominent in these debates. When politicians argue for their viewpoints in the parliament, it are these other people they refer to for support. It are these people who create the arguments and give members of the parliament the tools they need to debate. Point is, if politicians are morally obliged to reason reciprocally because of their legislative power, the same moral obligation applies to those prominent experts in a public debate.

Perhaps, because Rawls values open debates in the media and does not wish to imply that such is no longer a possibility, he is hesitant about the formulation of the citizen’s moral duty. It seems that Rawls is concerned that critics misunderstand his theory of public reason and think that its aim is also to constrain deliberation in the background culture. Hence, Rawls goes to great lengths to restrict the theory to those persons and those subjects where the theory of public reason is most difficult to reject. It would, however, be a mistake to suggest that a prominent scientific researcher or a medical specialist is not bound by the same moral duties when they voice their influential opinions in a newspaper or on a talk show. I believe Rawls would agree with this point, and the following quote of Rawls displays the best interpretation of the citizen’s duty. “Public reason sees the office of citizen with its duty of civility as analogous to that of judge with its duty of deciding cases. Just as judges are to decide cases by legal grounds or precedent, recognized canons of statutory interpretations, and other relevant grounds, so citizens are to reason by public reason and to be guided by the criterion of reciprocity, whenever constitutional essentials and matters of basic justice are at stake” ([3], p. 478).

These considerations have implications for the scope of the public debate that will be analyzed. Were public reason only a theory for judicial and legislative power, the public debate would be restricted to parliamentary discussions, verdicts of judges or advisory reports of governmental institutes, and the few occasions where relevant political figures express themselves in the media. Now that we have established that some groups of influential citizens also have a moral duty to reason reciprocally, the media itself becomes the main element of the public forum. In newspapers and television broadcasts, new actors are brought to the stage offering a wide range of perspectives and arguments aimed at influencing policy in different ways. All relevant actors in the debate on PGD, whether members of parliament, political spokespersons, medical experts, philosophers, scientists, employees of research institutions or mothers with a transferrable genetic deficit, use the media as a platform from which to voice their opinions. In the analysis of the public debate on PGD in Chapter 3, I will engage this variety of opinions.

### 2.7 Some final remarks

I have presented the reader with a summary of what I hold to be the complete theory of PL. The key concepts necessary for understanding PL have been included. Wherever the theory itself is unclear, I have filled in the gaps while maintaining analytical faith in the idea of PL. Where matters become too abstract, I have introduced examples to clarify the theory. And finally, I have connected the theory of PL to the practice of a debate on PGD.

PL is a very convincing theory. For those who value liberal ideology, it offers a well-thought-out idea of why liberal principles should be at the core of political justification. A respect for those principles is nothing less than a respect for democratic society and the plurality of religions and other systems of belief. Religious people are motivated to accept the idea of PL and the limits of public reason. The idea of reciprocity, which is also a prominent idea in religion, merely asks one to argue in such a way that one can reasonably expect another reasonable citizen to accept. The voicing of religious ideas is fully compatible with PL, as long as this can be translated into terms of political values, or in a way that does not conflict with such values.

For the evaluation of religious arguments, PL offers an ideal of a public forum based on liberal terms where also religious arguments are not upfront excluded. Due precisely to these liberal constraints, the terms should be acceptable to those who criticise the role of religion. Criticisms to PL in the academic literature never really opted for a more restrictive theory. The criticisms that were voiced, both from religious and liberal perspectives, considered PL and its idea of public reason to be too strict. In any case, if religious arguments in a debate on PGD can satisfy the norm of public reason, there is little ground to exclude them. In that case, those arguments reflect political values and deserve to be included.

## Chapter 3

# Debate on PGD

Theories on public debates, such as that of PL, impose moral duties upon those who wish to voice their opinions. Citizens should give each other good reasons when they argue for coercive policy. For people of faith, this means that they should not support matters of basic justice *only* on the basis of a religious doctrine. The idea is that it would be unreasonable if someone tries to justify laws on the basis of principles that others might reasonably not share, which would be a violation of the criterion of reciprocity. In the chapter on Rawls, I explained how it would be unreasonable for people of faith to reject gay marriage as an institution of the government, on the grounds that people cannot reasonably assume that those who love a person of the same sex are treated differently by the state (while, correspondingly, it can be argued that the marriage in the Church should exclusively exist as the holy matrimony between man and woman).

The idea of this chapter is to observe and classify the diverse arguments in a real debate. The first motive for doing so is to connect Rawls's theory on public debate to an actual debate where, in particular, people of faith play a prominent role in the policy debate. Religious people may have many different kinds of inspiration for their arguments of which some may transgress the limits of public reason as formulated by Rawls. An analysis of the debate will help to provide answers to several important questions: First, do religious citizens reason reciprocally? Do they give reasons, of which they can reasonably expect other reasonable citizens to accept them? Second, do other citizens feel that religious people owe them 'good' public reasons for the policy they try to impose? These questions are important, for they define the character of the debate and help determine whether religious arguments are accepted as legitimate and possibly even valuable arguments.

Religious people are often wary of new types of biomedical technology because they entail the destruction of embryos. Because these new technologies are understood to redefine and influence the fundamentals of life itself, particularly people of faith fear that certain biomedical practices redefine our very conception of ourselves as human beings. Values that we currently take for granted might well be challenged as result of such technological developments. In Section 1.2.1, I have suggested that these values become especially explicit in the discussions on PGD. Analyzing the debate helps to see which values are uncovered and show what their role is. Do these values and the corresponding arguments possibly play a key role in sensible policy in the discussions on PGD? To explore this matter – and to say whether those arguments might be valuable – it is first and foremost important to see how this debate on PGD really develops. This is the second motive for analysing the debate on PGD.

The debate is categorized by means of NEST-ethics. NEST-ethics provides an inventory of typical, often-invoked arguments on new and emerging science and technology. These arguments tend to follow up on one another. Logical patterns then emerge between arguments, and, depending on the technology, some arguments succeed in eventually steering the development of technology. NEST-ethics can then be seen as an algorithm with two unknowns: the values that inform the arguments, and the specific workings of the technology. By filling in these blank spots,

a plausible story on the interaction between arguments can be created. In the context of a new technology, scenarios can be developed for the future – or in the case of PGD, NEST-ethics helps to cluster and interlock the diversity of arguments that have already appeared in the debate. In this way, a trustworthy story can be developed upon the diversity of opinions that colour the debate.

I have chosen for a debate in the Netherlands on preimplantation genetic diagnosis as a suitable subject to which to apply the NEST method. In other debates on new genetic technologies, religious groups have taken a firm stand against use of technology that brings about the destruction or selection of human life in its embryonic phase. In line with other discussions on abortion and in vitro fertilization, the ability to screen embryos before they are implemented in the woman's womb gives rise to moral objections. New technologies such as IVF and PGD force us to rethink our attitude towards human life in its earliest phase. New areas for moral discussions are opened and a plethora of differing opinions are voiced in public debate. In the Netherlands, such a debate started when the State Secretary of Health, Welfare and Sport, Jet Bussemaker proposed to include screening on genes that *may* (as opposed to *will*) cause breast and ovary cancer. This specific policy proposition is very interesting because it is the first time that non-conclusive evidence of an as-yet-undeveloped genetic disorder was included as a valid subject of screening. Not surprisingly, this leads to much discussion on further developments.

### 3.1 An ethical debate

Politicians and, in particular, liberal politicians go to great lengths to distance themselves from a moralist label. Yet, all political parties exist because they have different ideas on what morals and ideals for which a society ought to strive. Labour parties may particularly value solidarity with the working class, while neoliberal parties might emphasize the importance of individual responsibility. Whether one agrees with policy is then often a matter of identifying the values that are implicitly being safeguarded by the policy. The debate on PGD is no different. The debate is not about the validity of scientific data, the costs of the procedure, or the number of people that may wish to make use of PGD. Facts can, however, be brought into the discussion to develop a moral viewpoint. A fact often cited, for example, holds that the embryo is no more than a clump of cells, so one really cannot classify it as 'a human being'. The point is that a debate on PGD does not revolve around the correct facts, but that different actors marshal different fact in order to serve a particular moral viewpoint. Debates on policy are thus essentially ethical debates where moral views compete with each other.

Ethical arguments can be divided along four lines of ethical reasoning: consequentialism, deontology, justice and virtue ethics. For consequentialism, the moral worth of an action depends on its consequences. A morally preferable action is thus an action that provides a good outcome. A familiar branch of consequentialism is utilitarianism, which suggests that the morally favourable action is that which leads to the greatest utility of pleasure over pain, often understood as the greatest happiness overall. The second line of ethical reasoning, deontology, suggests that the moral worth of an action is intrinsic to the action itself. In daily practice, this type of ethics is best translated into duties and rights. For example, it is immoral when one violates another person's autonomy. Or: someone should (has a duty to) always speak the truth. Arguments derived from distributive justice pronounce a view on the distribution of goods. In *A Theory of Justice*, John Rawls sets out a theory of justice as fairness, where inequalities may only exist insofar they are of the greatest benefit to the worst off. Finally, virtue ethics defines the moral worth of an action in terms of how it helps to realize a good life. Virtue ethics may ask what kinds of actions help to realize a moral character. For a nurse, compassion would be a particularly desirable virtue, while for a scientist, a critical attitude is more apt. In a broader perspective, one may also suggest how developments in society may contribute to the good life. So it may be argued that subsidizing culture or art helps us to lead better lives.

Arguments can belong to one of these four ethical dimensions, but they can also be meta-ethical. This latter type of arguments do not express any ethical position, but are appealing lines of reasoning that may give weight to a particular ethical view. They do not address our moral intuitions directly, but can appeal to our sense of logic. One type of meta-ethical reasoning might appeal to moral intuitions and thereby support an ethical argument that fits with a conservative perspective. The ‘slippery slope’ argument, for example, is often used to warn of possible moral corruption, as is the case when one argues that if we allow the birth control pill to become commonplace, more and more people will have sex for pleasure. In this particular case, we might nowadays rather speak of moral development instead of moral corruption. In any case, the argument favours some kind of morality of the present, which in the case of the birth control pill is exemplified by a particular conception of the good life: sex is for making babies, not for pleasure. Good life arguments can clearly benefit from the argument of the slippery slope.

Consequential and deontological reasoning can be contrasted in the sense that they emphasize different aspects of the moral worth of an action. Ethical dilemmas may occur where the consequences of an action do not line up with the ‘rightness’ of that action. Should one lie if doing so results in greater happiness for the people involved? A justice perspective values the consequential outcome in terms of benefits and risks, but only insofar the action itself is a display of justice. In this sense, it combines consequences with the intrinsic value of the action. Although these ethical frameworks are different, they can also be grouped together. All three determine the morality of an action by looking at the action only. General principles or rules can then easily be formulated which would apply in all kinds of situations where the morality of an action is to be determined. In deontology, principles are often formulated in this way: you should never do x, or; you should always do y. The consequential doctrine of utilitarianism is even simpler in that it applies one general principle of greatest happiness. And a perspective from justice could apply the Rawlsian difference principle, which only permits inequalities in the distribution of goods insofar these differences benefit the worst off. We can cluster these ethical arguments as belonging to the category of rule ethics.<sup>18</sup>

For the analysis of the debate, it is worthwhile to point out the differences between rule ethics and virtue ethics. Consequential, deontological or justice arguments are widely accepted and are used by all groups in a debate. Liberals who wish to avoid being seen as moralists will only use arguments that belong to rule ethics. Refraining from engaging in a virtue ethical perspective means that liberals give great value to the idea that people can individually decide how they wish to live the good life in private. Those who do wish to voice arguments belonging to virtue ethics consider the spectrum of rule ethics too narrow to deal with all matters of importance. It might be suggested that without wanting to infringe on people’s desires to live their own lives, what would be wrong with laws and policy that help to create a better society where people can lead better lives? To some degree most politicians can accept the thick morality of virtue ethics, such as in the case of subsidizing culture or art. However, when it comes to matters of justice or constitutional essentials, as formulated by Rawls, virtue ethical arguments can become highly controversial.

Distinguishing rule ethics from virtue ethics helps to emphasize the differences between the two sides in the debate on PGD. Liberals and simply nonreligious people are likely to rely on arguments that can be identified as belonging to rule ethics. Religious people are more likely to be motivated by virtue ethical arguments rather than consequential or deontological arguments. This division also links up to the demands of public reason as proposed by Rawls. Virtue ethical arguments are suspect when it comes to matters of basic justice. Some can rely on proper political values, but other arguments might rely on principles that other citizens are unlikely to endorse. In contrast, deontological reasoning and perspectives from justice easily express the core liberal

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<sup>18</sup> I cluster consequentialism, deontology and justice perspectives together into a heuristic category based on the idea that the morality of an action follows from that action. The idea of ‘rule ethics’ here should not be confused with rule ethics as another term for deontology or categorical ethics.

values of a political conception of justice. Consequential arguments, although not always particularly sensitive, are usually applicable in many policy matters. In cases where treatments are financed by the public health system, benefits and costs will have to be weighed in relation to the good of all citizens. It is known that deontological principles may function as a check on consequential reasoning, but the opposite is thus equally true.

Because of this separation between types of reasoning, friction between the actors is likely to occur. Those who reason exclusively in rule-ethical terms often find it problematic that others counter their reason by appealing to virtue ethical considerations. Those considerations are often interpreted as an intrusion into one's private life. As a result, emotions tend to run high when matters of importance, such as PGD, are at stake. In that case, it is not PGD itself that becomes a topic to be discussed, but rather the position of the CU. The opinion exchanges between actors about the CU form a significant part of the debate on PGD. The character of the debate at large is coloured by those opinions, and they help to point out whether good life principles are part of the debate. One finds, for example, that religious ideas often fall under the category of good life principles. In cases where religious people have fundamental objections on matters of basic justice, one can expect that others do not always respond with the outmost subtlety or understanding. Therefore, a final category that contains such emotional responses towards the position of the CU is included in the analysis.

### 3.2 Methodology

I have limited the body of debate to be analysed according to several factors. First, the subject of the public debate concerns policy on PGD in the Netherlands. Second, the starting point of the debate is the letter which Jet Bussemaker, the State Secretary of Health, Welfare and Sport, sent to the Dutch parliament in May 2008 [16]. Most of the debate took place in the first few weeks after this letter, but because Bussemaker's proposition mostly concerns the matter of adding the genes BRCA 1/2 for screenings, and PGD itself is broader than this matter only, I will not exclude more recent contributions to the debate, even if they are few. Third, only the following types of sources/opinions are included:

- Transcripts of parliamentary discussions on PGD.
- Policy propositions on PGD as proposed to the Dutch parliament.
- Television broadcast shows where a number of prominent actors on PGD are engaged in discussion.
- Newspaper articles on PGD.
- Opinions voiced in the newspapers on PGD by columnists and prominent actors.

I do not include the whole of opinions voiced on internet forums, nor do I include relatively short contributions in the newspapers. The reason for this is the following: The media structure the debate depending on a number of factors such as the relevance of an actor, the goal of allowing a plurality of opinions to enter the debate, or the quality of a commentary. Such factors separate the influential opinions and actors from those who carry little to no weight. Forums on the internet, for example, do not hold such a structure and it is often unknown whose opinions are voiced. It is thus difficult to see how such writings could have a considerable influence. Drawing the line here also ensures that the corpus does not become too big to handle. I do intend to give a complete overview of the debate, but I will not claim that there are no other valuable newspaper articles or television discussions that deserve to be included.

Swierstra and Rip have developed a useful toolbox to analyse ethical debates on new and emerging science and technology [19]. NEST-ethics is characterized by specific tropes and

argumentative patterns that show up due to the uncertainty that comes with the introduction of new technologies. NEST-ethics plays a central role in answering the main question. Importantly, it helps to reconstruct a debate that is fragmented over a spectrum of media appearances into a debate *as if* the actors are involved in a face-to-face discussion. This patterning is only possible because arguments typically carry a certain intentionality, a directedness. Furthermore, some arguments are more likely to be decisive because of the moral landscape in which they work. In Western societies, values of freedom and autonomy are particularly strong and argumentative patterns that appeal to such principles are thus likely to be very powerful. By patterning plausible ways of argumentation, decisive arguments can be expected upfront. NEST-ethics provides a trustworthy method to identify the patterns in arguments, not simply because the analytical analysis is logical, but also because that analysis perfectly aligns with the intentions of an actor. By means of NEST-ethics, the particular intention and strength of an argument is respected and thus the intentions of the person who voices the argument are also respected. This reconstruction then helps to create a plausible story on the actual role of religious arguments. What responses do they invoke? Are they accepted or rejected? Second, a study on the role of religious arguments in the debate could reveal whether, and how, religious arguments are valuable. Do certain religiously-expressed reasons possibly contribute to the discussions in a way that other reasons do not, and which can be considered valuable? This latter point is introduced more extensively in Section 1.4 and will be discussed in Chapter 5.

### 3.3 Analysis of the debate

The analysis of the debate on PGD in the Netherlands consists of two parts. The first, with which I am concerned in this chapter, is the description and the classification of the arguments according to their ethical meaning. The second part, to which I will come in Chapters 4 & 5, discusses the religious arguments and concludes by considering whether they can be valuable. While the first part of the analysis is descriptive, the second part is analytical. In what follows now, I will describe the debate according to the different ethical categories addressed above: consequentialism, deontology, justice, and virtue ethics, as well as meta-ethics, and responses focussing explicitly on the CU, respectively. To ensure a chronological treatment of the debate, an overview of the debate is given before the arguments are clustered in categories. As a final remark, it is worthwhile to note the language of the debate is Dutch. Any excerpts appearing below have been translated from Dutch to English by the author. The original quotes can be found in the Appendix.

#### 3.3.1 *The start of a debate on preimplantation genetic diagnosis*

In the spring of 2008 emotions were running high when André Rouvoet, Minister of Youth and Family and the political leader of the CU, ‘forced’ the State Secretary of Health, Welfare and Sport, Jet Bussemaker of the Labour Party (PvdA), to withdraw a letter she sent to the Dutch parliament. In that letter [16], sent on 26 May 2010, she proposed to include the genes BRCA 1/2 for preimplantation genetic screening. Previous to this, embryo selection had already been routinely performed in a number few very serious cases, of which Huntington’s disease, cystic fibrosis and Duchenne muscular dystrophy are well known. Not only do these hereditary diseases cause severe suffering, they can also be conclusively detected using PGD procedures. Carriers of BRCA 1/2 have a 65 percent chance of developing breast cancer and a 10-60 percent chance of developing ovarian cancer [16]. To give prospective parents the chance to save their future children from this burden, Bussemaker decided to include these genes in PGD procedures. While the law on PGD (PKGOE) already allowed a hospital in Maastricht to pursue such procedures, Rouvoet objected to the policy proposition and suggested that such sensitive policy should first be

discussed internally (in the government) before consulting the parliament. Valuing the sanctity of life from conception onwards, the conservative CU felt morally troubled about broadening the policy on PGD and any other policy that sanctions the destruction of any form of embryonic life. The public reacted with resentment and bewilderment towards Rouvoet. Who could reasonably disagree with such a humane policy proposition?

In the letter, Bussemaker explains on what grounds she wishes to include the genetic mutations BRCA 1/2 for PGD. First and foremost, she agrees with her predecessor, the former State Secretary for Health, Welfare and Sport, Clémence Ross, who argued that the interests of the future child should be decisive ethical choices regarding PGD. This leads to the consideration that PGD is only warranted when it benefits the future child. Bussemaker qualifies the impact of BRCA 1/2 as substantial and therefore suggest that these genetic mutations warrant the use of PGD. Furthermore, Bussemaker also suggests that the interests of the woman who considers PGD is of importance. An alternative to PGD is prenatal diagnosis, which would require an abortion if one desires to terminate the pregnancy. PGD is thus also an alternative for women object to having an abortion if the foetus carries the genetic mutation [16].

Bussemaker also accounted for alternatives such as breast amputation or the removal of the ovary. Half of the women with BRCA 1/2 choose to have the breasts removed, often in combination with breast reconstruction [16]. Pre-emptive breast amputation reduces the chance of breast cancer to almost zero percent. The removal of the ovary reduces the chance for ovary cancer to 5 percent on average and, in addition, reduces the chance of breast cancer by 50 percent due to hormonal changes [16]. The decision to remove breasts or ovaries is difficult to make, and it does not reduce the chance to transfer the gene to the next generation. Considering that the interests of particularly the child, but also the mother should be guiding these matters, Bussemaker does not consider these options as full alternatives for PGD [16].

André Rouvoet objected to the letter on the grounds that such matters first need to be discussed in the cabinet before sending it to the parliament. The conservative CU is against any form of embryo selection and considered the proposed measures to be an expansion of existing regulation. Furthermore, in the negotiations leading to the formation of the government, the CU stipulated that no expansions of policy on embryos would be pursued during the rule of this government [26]. Although the relevant regulation, the PKGOE, did not exclude any type of serious genetic disease for PGD, Rouvoet suggested that the inclusion of BRCA 1/2 is not merely a decision within the scope of the PKGOE, but is basically against the 'spirit' of the agreements made in the formation of the government [27]. On Friday the 30<sup>th</sup> of May, Bussemaker withdrew the letter to parliament she sent the previous Monday. For several weeks the cabinet would discuss the topic internally.

In those following weeks, newspapers and television talk shows offered a podium to a variety of opinions on the matter. Finally, a month after the initial letter, Bussemaker and Rouvoet reached consensus and a compromise, in the form of a new letter, was presented to the Dutch parliament [28]. The genes BRCA 1/2 would be included for PGD but every case would have to be reviewed by a medical-ethical committee. During this period, only a very sporadic, minimalistic ethical debate was waged in parliament, where the sanctity of life and the duty to reduce harm were sidelined by the suggestion of power politics. The public, however, mostly inspired by discontent of Rouvoet's ways, engaged in an emotional debate on television and in the national newspapers. While the government played down the controversy by suggesting that Bussemaker had been a bit gauche in raising the subject in the first place, the 'real' debate was highly ethical and found its stage in the Dutch media.

Prominent in this debate was the outrage about the religious perspective. It is fine if religious people consider an embryo to be valuable human life, so it is widely suggested, but it is even better if they keep their opinions to themselves. After all, we are talking about a mere hump of 8 cells (which, according to the argument, disqualifies an embryo as valuable human life). Some

supporters of the CU tried to bring the debate beyond the initial arguments and called upon the argument of the slippery slope. They suggested that it might be right to accept the policy as proposed by Bussemaker, but warned of repeating the same argument in similar cases where a smaller chance to develop a disease is also present. People were hasty to disqualify this argument as irrelevant and not applicable in the situation.

The debate on PGD has its origin in a political disagreement between Bussemaker and Rouvoet, but this matter is itself irrelevant for the purpose of this research. The focus is on a debate on PGD where in particular religious people are moved to voice their opinions. It does not matter whether Bussemaker was clumsy in raising the question, or whether Rouvoet exaggerated his response to it. Of more interest are the arguments that favour an inclusion of BRCA 1/2 for embryo selection, which can be found in the letter to the parliament, as well as the reasons according to which the CU and others take issue with PGD. Most prominent here are the arguments with a deontological signature, to which I will now turn.

### *3.3.2 Deontological arguments*

The ethical branch of deontology suggests that the morality of an action is intrinsic to the action itself and does not depend on its consequences. Morality is thus not formulated in terms of cost or benefit, as is often the case with consequentialism, but is translated as duties or rights. In everyday society we can find a plurality of rules that can be formulated as either duties (e.g. you should not lie) or rights (e.g. the right to freely express one's opinion). Deontological arguments typically come forward when people's most basic beliefs and outlooks on life are at stake. For many people and in particular people of faith, PGD challenges our ideas on unborn human life in its first days, and the respect that should be afforded to it. For some, it is clear that all human life is in principle inviolable and PGD, which comes at the cost of a few embryos, is inherently wrong. In this section, I will deal with all kinds of deontological arguments voiced. There are only a few ways in which deontological arguments can be contested. Swierstra and Rip [19] have identified three main ways to counter deontological principles and these will prove apt to deal with the arguments identified in the debate on PGD.

The debate starts with Bussemaker's letter to the parliament in which she agrees with her predecessor, Clémence Ross-van Dorp, on the principle motivation that should inform PGD. Referring to the policy on PGD under Ross-van Dorp, she suggests that: "The interests of the future child are the starting point from which to decide whether PGD is an appropriate possibility. That includes the motive to prevent (very) serious suffering" [16]. As a secondary consideration, Bussemaker includes the interests of the women who wish to make use of PGD. "I wish to point out the interests of the woman who considers PGD. Together with her partner, she will have to make a choice between PGD and prenatal diagnosis" [16]. Basically, this means that when PGD contributes to a diminishing of suffering, the interests of the woman who considers PGD, becomes an additional relevant factor. Nowhere in Bussemaker's letter is any other type of ethical argument pronounced.<sup>19</sup>

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<sup>19</sup> The argument that the interests of the child should be guiding in these matters also has metaphysical problems. It can be asked whether it is in the child's interest not to exist if she carries a serious chance for a disease. Possibly this is the wrong question to ask because existence, from the perspective of reproduction, is always an extremely coincidental matter, or perhaps this is a matter of splitting hairs and we should see it from the parents' perspective who do not feel they have exchanged one child for another. On the other hand, possibly this is a question that has received too little attention and should be guiding in the matter of PGD. In any case, the interests of the child is a relevant consideration no matter the metaphysical difficulties simply because the participants in the debate think it is. I do not attempt to tackle this topic philosophically. I will say that it is a

The motive to prevent suffering could very well be explained according to deontological or consequential principles. Either it could be seen as a duty to prevent serious suffering or it could be judged according to the utilitarian ‘greatest happiness principle’ where suffering leads to less happiness. To be exact, in none of the letters to the parliament [16] [28] or the parliamentary debates [29] [30], and not even on a television show in the matter [31], did Bussemaker make it clear whether she specifically endorses one of these two ethical approaches. Still I have classified the interests of the child with the idea to prevent serious suffering in this deontological section. Usually, such matters over life and death are initially justified according to deontological principles. It simply seems a bit obtuse to talk about it in a consequentialist manner. Doing so would mean that, for example, financial costs would also need to be included. Although a relevant consideration, in none of Bussemaker’s letters or performances in the parliament or media did she include this concern. And although a decision on PGD will always be a balance of competing values, there was no sign of a rationalistic-consequential type of calculation. A consequential perspective is an extremely inclusive perspective aimed at making sure all factors that may contribute to the greatest benefit are accounted for. When there is no sign of such an approach, it is difficult to classify the motivation as, for example, utilitarian.

In the second letter to the parliament, which carried the support of the entire cabinet, the following argument was detected: “For PGD, both the autonomy, and the protection of early human life should be weighed. In other words, preventing a very large risk of very serious suffering for a possible future child should be weighed against the selection of embryos and eventually possible options for treatment” [28]. The keyword is autonomy. While it can be argued that a consequentialist perspective could fully endorse this value, it does fit better in a deontological frame of reference. The term expresses a respect for the intrinsic qualities of a human being and therefore corresponds better with a categorical type of ethics. Furthermore, in the overall debate, several metaphors are used to make clear how strongly people feel about this matter. References to the sword of Damocles occur multiple times and sometimes there is talk of ‘rights’ (those arguments will be introduced in this chapter), and people are truly offended by the position of the CU (see section 3.3.7). This does not sound like the language of people who endorse a calculative consequentialist perspective. People feel so strongly about this matter because they feel it is only *right* to support Bussemaker’s proposal. If others particularly talk in ‘a deontological way’, it seems unlikely that Bussemaker endorses a different ethical framework.

In the public debate, the arguments that indicate a duty to act in the interest of the future child and to diminish suffering are often multi-layered and hence, complicated. For Bussemaker, it is clear that the interests of the child should be the first rationale and many actors in the debate seem to share this opinion. Additionally, the arguments that relate to a diminishing of suffering place the interests of the child in a context of a family history, or connect it to the parents’ desire to save their children from BRCA 1/2. This is not at all strange, for actors in a debate rarely follow strict philosophical categories. The words and the sentences they formulate can express multiple principles as people feel it expresses their opinion. In any case, the following arguments express the idea that PGD is warranted because it is a procedure carried out in the interest of the child, which could be understood in terms of averted suffering or translated in an idea about autonomy of the future child.

The spokesperson of PvdA, Khadija Arib, suggests that, “[a] large group of women know they carry this hereditary disease and want to save their children from this burden” [32]. In an editorial commentary about the matter, *NRC* states: “Women who have a large chance to develop hereditary breast cancer have to go through pre-emptive breast amputation. The ChristianUnion is reluctant to recognize that parents wish to save their children this misery” [33]. Emma van Leeuwen, carrier of BRCA-1 says: “The genetic mutation is a destructive gene. We know families

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consideration that is endorsed among policymakers and all sorts of actors in the debate and is the main principle that guides the use of PGD.

where the grandmother, mother and all daughters died as result of hereditary breast cancer” [34]. In an editorial commentary, *de Volkskrant* states: “Because the chance for cancer is so significant, 60 to 80 percent, the disease hangs over the heads of these women like a sword of Damocles (...) PGD makes it possible to ban the disease from the lives of families who have feared for generations for a premature death of their loved ones. This is why this suffering should outweigh the abstract worries about the future” [35]. Political columnist Marc Chavannes of the NRC concludes: “Anyone who has read the stories of women who have lost their grandmothers, mothers or aunts to this disease and themselves have had their breasts pre-emptively amputated before the age of thirty, must conclude: give her the right *not* to transfer the disease to the next generation. Pre-emptive amputation is an amputation of womanhood and does not reduce the chance to transfer the disease. We should not weigh this matter too lightly” [36].

Often, arguments are intended to support the idea that the impact of the disease is greater than is commonly presumed. The transfer of mutations in BRCA 1/2 covers many generations, destroys entire families and does damage long before breast cancer has even developed. In the television programme *Netwerk*, a video was shown of Els Westerhof, who died of hereditary breast cancer several years ago. In this video, she talks about the impact of breast cancer on her life. “From puberty onwards I have been confronted with this disease. For me, breasts are no sign of feminine beauty. For me, they are bombs” [37]. Caroline Haasbroek, carrier of a hereditary form of breast cancer, argues how only the presence of the genetic defect, is already a heavy burden. “Even if you belong to the twenty percent who will never develop the disease, the psychological impact on your life still is very great. There is the constant insecurity, there are all sorts of research like mammographic scans which are done every year. The people who do not develop the disease also suffer from a serious burden” [38]. Hans Evers, professor in gynaecology states in the television show *NOVA*: “The breasts of these women are a time bomb and the ticking clock is a psychologically heavy burden” [39]. In an interview with *Algemeen Dagblad* (AD), Ellen Groenewold, carrier of genetic mutation of either BRCA 1/2, suggests that “Breast cancer is devastating for families where it occurs. All women are struck by it, even those who do not get breast cancer” [40]. Esther Leeninga-Tijmes, carrier of a genetic mutation BRCA-1, tells in an interview with *de Volkskrant* that her daughter understands why PGD is so important. “It is important that it is not transmitted, she said, otherwise women will keep getting cancer” [41]. The message is clear, hereditary breast cancer causes suffering even before the disease occurs. Furthermore, it is ‘our’ duty to future generations to prevent the transfer of BRCA 1/2.

No one disagrees that hereditary breast cancer is indeed the cause of much pain. But for many people, the idea that it concerns a serious disease does not necessarily mean that it *beseches* a duty to diminish suffering by means of PGD. These opinions are also forwarded by women who carry BRCA 1/2. Esther Leeninga-Tijmes asks: “Does an embryo with a genetic defect not have a right to live? I was once such an embryo and I am alive and happy (...) I went through chemotherapy, had both breast removed and reconstructed. Of course I have been angry, sad and scared. Yes, it was tough but I am still happy that I am here” [41]. In a similar vein, Mariska Scheuer, surgical oncologist and carrier of either BRCA 1/2, talks about her son. “My son is an amazing person. In the sixth grade, he played the leading role in a school musical, he loves to play football, has twenty tennis trophies and passed his VWO exam with a 10 for math. He knows exactly what he wants to be (cardiac surgeon), belongs to a nice student club, lives in a nice house, has good friends and was independent from the moment he went to university. This child of mine should have been removed when he was still an embryo?” [42] In an interview with *Nederlands Dagblad* (ND), Marijke (who wishes to remain anonymous in her children’s interests), carrier of a breast cancer gene, is optimistic about medical treatments. “Previously, women would almost certainly die of cancer because of a defect gene, but nowadays, that can be prevented. The threat of cancer does not hang over you like a sword of Damocles. For a gene carrier, it is possible to live a good life” [43].

So far, the debate is sketched as one that revolves around the matter of suffering. It is clear that the defective genes BRCA 1/2 cause much pain and PGD is seen as a method to protect the next generations from the misery that previous generations had to endure. In response, it is suggested that although these pains are real, they do not preclude one from living a normal and happy life. Furthermore, one cannot disconnect the selection of embryos from the selection of life. The rhetorical question “Would someone who suffers from the genetic defect rather not be here?” is asked.

Although people agree that BRCA 1/2 cause much pain that could be averted by PGD, it is sometimes also considered blatantly immoral to pursue PGD because it comes with the destruction of embryos. No matter what the benefits may be, an embryo is still human and embryo selection comes with the loss of fully alive embryos. Embryos are first fertilized, knowing that some will never be allowed to grow and become a full human being. In ethical deliberation, this idea is reflected by the principle of nonmaleficence, to do no harm, which has a higher priority than the principle of beneficence. Sure, much pain and suffering might be prevented by means of embryo selection, but it is categorically wrong to kill the embryo, it would be suggested. Whether this type of argument is useful depends on the status of an embryo. In which way can people make a convincing case that embryos deserve such respect, that it would be a matter of harm if they would be submitted for selection?

In NOVA, Esmé Wiegman, a member of parliament for the CU, points out her principled objection to PGD. “My troubles with the technology is that it requires IVF. In that procedure, some embryos are selected and placed in the womb, but there are also the remaining embryos which are likely to be destroyed” [44]. André Rouvoet, the political leader of the CU who ‘forced’ Bussemaker to withdraw her letter to the parliament on PGD, considers the embryo to be worthy of protection.<sup>20</sup> Referring to the agreements made between the political parties in the government, Rouvoet suggests: “For the first time in a ‘coalition agreement’, the embryo has been considered as being worthy of protection” [27]. Rouvoet’s political party states on its website that it considers “embryos to be early human life that must be protected” [45]. Bas van der Vlies, political leader for the Political Reformed Party (SGP) is clear on their political views: “For the SGP it is a core value that all human life deserves to be protected. God is at the origin of human life. Embryos should be protected and not killed” [29].<sup>21</sup>

Henk Jochemsen, director of the Lindeboom institute, a study centre advocating a Christian-oriented medical ethics, argues that days-old embryos are just like older embryos, worthy of protection. “When fertilization has taken place, a human child is on its way” [46]. So far, the idea that an embryo is human life has been used to claim that it is worthy of protection. R. Seldenrijk, director of the Dutch association for patients and lecturer of ethics, offers a more comprehensive version of this idea. “All life on earth deserves to be protected. But only human life is inviolable from conception onwards. The status of the embryo is embodied in its intrinsic value: there is an internal intentionality, a program of development that is determined from the very beginning. Without external interference, it grows to become a complete human” [47].<sup>22</sup>

The status of the embryo is a passionately debated topic and many people argue that, although the embryo is human in a biological sense, this offers little to no ground for protecting it. Abeltje Hoogenkamp, hospital minister, says: “We should be sober about the matter. We are talking about a clump of cells. That is not a child yet. In such ethical matters I ask myself: do I have a bond with the child?” [49] In an article in *NRC*, Marcel Zuijderland, philosopher and writer, denies that

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<sup>20</sup> The discussion on the protection of embryos in this section on deontological arguments does not discuss arguments which would say that the embryo deserves protection for other reasons than the intrinsic value of the embryo itself. To go beyond this topic would be to go beyond the scope of deontology.

<sup>21</sup> Little more than a month later, Van der Vlies of the SGP voiced a similar opinion in another parliamentary debate [30].

<sup>22</sup> In *ND*, R. Seldenrijk published a similar opinion [48].

embryos deserve to be protected. “To qualify an embryo as ‘early human life’ is ridiculous. An embryo is not a human being, but a bunch of cells. It knows no pain, has no experiences, and it cannot think. It lacks everything what gives a living being its moral rights” [50]. Zuijderland also attacks the idea that a human embryo deserves protection because of its potential to become fully human. If that would be the case: “Then all those million sperm cells that are lost at each ejaculation and all of those unfertilized eggs that women lose every month should also be cause of moral exasperation, because ‘potential human life’ is being wasted. The range of the argument from potency is too wide to imply that we should adjust our moral ways” [50]. Similarly, Koos de Geest, general practitioner, asks to which degree we should consider the embryo worthy of protection. “Many early embryos are lost because they fail to attach to the womb. These embryos often have some kind of deficit. Therefore, it is difficult to see human life in an early embryo” [51].<sup>23</sup> The view that an embryo deserves our respect and should be protected is especially common among people of faith, such as Rouvoet and Jochemsen, both prominent actors in the debate. Their moral positions are (also) grounded in their convictions. In an earlier debate on a law concerning embryos (PKGOE), Rouvoet expressed one of his principle motivations by citing a few lines from Psalm 139: “For you created my inmost being; you knit me together in my mother's womb (...) your works are wonderful (...) your eyes saw my unformed body” [25].

The second type of argument that pleads for PGD, besides the duty to diminish suffering, is the idea that women, or parents, should be free to pursue what they consider best for their children. Just like anyone else is free to use a mobile phone or drive a car, one should be able to decide for oneself whether PGD should be pursued. Of course, freedom is always limited by other principles and it could be argued that a person's freedom to make use of technology is constrained by the principle of nonmaleficence. One is, for example, only allowed to drive a car after demonstrating that this can be done in a safe manner. If an embryo is indeed worthy of protection, it could be argued that a woman should not have the freedom to make use of PGD. In what follows, however, I wish to deal with this argument on its own merits. Critics of PGD have done so by interpreting and applying the deontological principle of freedom differently.

The freedom argument suggests that a woman should be able to choose PGD simply because the choice is hers to make. If a woman values that her children will not suffer from hereditary breast cancer, she should be able to choose for PGD. For the Labour Party, this principle carries much weight. Khadija Arib, spokesperson of the party, formulates it as follows: “This is about the right of self-determination and the woman's freedom to choose. That is for us just as important as the protection of life” [52]. In NOVA, Jan Maarten Kommen, clinical geneticist at the Emma Childs hospital in the AMC, questions the reasons put forth by the CU to prohibit PGD for BRCA 1/2. In a question directed toward Esmé Wiegman of the ChristianUnion, he asks: “How do you justify taking away the parent's autonomy? Of course, there are many people who do not choose for PGD. In reality, there are only a few who do, but you want to take away their options and I ask myself on what grounds?” [44] Caroline Haasbroek, carrier of the genetic mutation, feels that she should be able to decide on this matter herself: “I am angry with the ChristianUnion because it is ridiculous that politicians now decide about my future and the future of my family” [38]. In a similar vein, Elisa Klapheck, a rabbi by occupation, considers it important that “women are free to decide for PGD” [49]. But she realises that women should also be free to refuse PGD: “Parents should be free to say no to research without having to be scared that the medical bill for health care will not be paid by the insurance company if the child eventually proves to have the disease” [49]. In short, the freedom argument can be countered by the idea that one person's freedom might become restrictive for others.

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<sup>23</sup> In section 3.3.6 on meta-ethics, I will return more extensively to this type and other variants of arguments from precedent. They prove to be a very strong argument against the idea that an embryo deserves to be protected.

The deontological arguments in the debate correspond with the findings of Swierstra and Rip in their study on NEST-ethics. They list three main ways in which deontological principles can be contested [19]. The first way is to invoke a principle with a higher priority; the principle of nonmaleficence in this case versus the duty to reduce suffering, which is the main argument to choose for PGD in the first place. A second way is to argue that a deontological principle does not apply in this particular case, which is reflected by the question: do embryos, just like older human beings, really deserve protection? It is argued that the principle of nonmaleficence, which purportedly outweighs the duty to reduce suffering, is not applicable. The third way to counter a deontological argument is by interpreting a deontological principle differently. This line of argumentation is visible when one questions whether one woman's freedom might restrict the freedom of another.

### *3.3.3 Arguments from consequence*

Swierstra and Rip point out that ethical debates on new and emerging technology usually begin from a consequentialist starting point [19]. Most often, new technological developments are first judged on the desirability of the consequences they bring about. This seems to be the case for technologies that represent truly new developments that open up a world of possibilities bridging the gap between science fiction and reality. Swierstra's and Rip's article uses nanotechnology as a suitable test case to highlight the diverse arguments in NEST-ethics. Nanotechnological developments and their future offspring may be so revolutionary different from our current technological standard that we can only begin to imagine the consequential benefits of the technology. A decision will have to be made: Do we pursue what is promising but uncertain, or do we proceed cautiously to hedge the risks inherent in developing new technology, accepting that we may never reap the benefits of new developments as the trade-off for manageability, stability and predictability?

The discussions on PGD have a different dynamic than those on nanotechnology. This is (partially) due to the difference between the level of novelty, and hence, uncertainty between the respective technologies. In the case of nanotechnology, it remains to be seen whether nanosubmarines will ever target inflamed cells in our vessels or whether the risks of nanotoxicity will be manageable. But, whatever the future role of PGD may be, the technology itself is available and is well established in medical practice. When PGD is applied to pick out the embryos without the genetic deficit, it is certain that this disease will not transfer from parent to child. In this sense, the benefits of the technology are clear. The occurrence of hereditary breast cancer will in fact be prevented if PGD is applied in the case of BRCA 1/2. Where the discussion on nanotechnology starts with consequential promises, PGD is already robbed of its technological uncertainty and is settled in the technological landscape. The starting point of the ethical discussion, therefore, is also different and has, in this particular case, been deontological, as shown in the previous section.

Swierstra and Rip identify three axes along which consequential arguments can be contested. Consequentialist arguments are usually challenged on 1) plausibility; 2) whether benefits promised are really benefits; and 3) the ratio of the benefits and costs [19]. Whether a consequentialist argument is plausible or not, depends on whether there is uncertainty regarding the anticipated benefits or risks. In the case of PGD for BRCA 1/2, it is clear that hereditary breast cancer will in fact be prevented. There is no uncertainty regarding the benefits promised, hence it is redundant to discuss the plausibility of the promises. However, those who argue against PGD often refer to treatments that might become available in the future. Such expectations are uncertain, and are contested on their plausibility, as we shall see.

Second, are the benefits promised really benefits? One could imagine an argument that questions whether PGD really is beneficial because the success rates of IVF are fairly low. Or it

could be argued that people with breast cancer can still live a good and enjoyable life, thereby creating doubt whether PGD really is beneficial. The problem with this type of question is its normative character while in the case of PGD subjectivity seems to be more appropriate. Because people tend to disagree on values such as what makes a life enjoyable and worthwhile, and to which lengths we can go to pursue it, it is difficult to decide for one another whether PGD creates benefits. No one wishes to argue that parents are not acting in a beneficial way when they consider PGD. Possibly, the argument could become more prominent if the topic would concern a less destructive disease with a lower chance of developing it.

This leads us to the third axis mentioned, that of the ratio between benefits and costs. In the case of hereditary breast cancer, it is difficult to contest whether PGD delivers benefits. People may disagree on it, but it is mostly a personal and subjective matter as I have argued in the previous paragraph. Costs, however, are easier to point out. After a PGD procedure has been completed, what did it cost? What is the price to be paid to prevent the transfer of hereditary breast cancer? Cost-benefit analyses are the most calculative type of ethics and are not easily formulated when applied to a sensitive matter such as PGD. To make such a perspective work, both benefits and costs need to be quantified before one can be divided by the other to get a ratio. A number will appear only if we assume that benefits and costs can indeed be compared to each other. They, so to speak, will need to be quantified in the same Cartesian coordinate system and be composed of the same units of measurement if they are to be divided into one another. For ultraorthodox consequentialists, this is a basic condition to practicing ethics. Those who see an embryo as a mere hump of cells will also have little trouble accepting a cost-benefit analysis about PGD. The desires of the parents and the duty to reduce harm justify the use of embryos. The costs are considered to be low, hence the benefits easily outweigh them. But those who consider an embryo to be inviolable cannot place benefits on one side of the scale and costs on the other. For them, the status of the embryo is a purely deontological matter and transcends the logic of consequentialism.

Typical consequential arguments are unlikely to be very prominent in a debate on PGD. Nonetheless, all three types can be identified, if sometimes only minimally. The first type of argument, which concerns contestation over matters that concern plausibility, is visible for proposed alternatives to PGD. Henk Jochemsen and Matthijs van den Berg, whose doctoral dissertation addressed the subject of prenatal screening, focus on future treatments as alternatives for PGD: “Breast cancer and other hereditary cancers only occur in a later stadium of life and can be treated. Furthermore, this is about the selection of embryos which have an increased chance to develop breast cancer or ovary cancer in 30 or 40 years time. By then it seems plausible that early diagnostics and treatments have improved. Should we not focus on the treatment of people who carry a disease instead of eliminating early human life, because it might have a condition?” [53] Esther Leeninga-Tijmes, carrier of BRCA-1, is also of the opinion that “treatments will only improve in the future” [41]. Jan Mol, molecular biological researcher, supports this train of thought with recent developments in research on cancer: “Much research on the prevention of hereditary breast cancer has been performed. (...) Results of research on mice which carry the gene responsible for breast cancer show that all possible tumours in the mammary glands can be prevented by administering a synthetic steroid. To the best of my knowledge, these procedures have not been tested on humans, but if similar effects could be achieved, it becomes increasingly urgent to ask whether embryo selection is a proper solution. There is enough reason for further debate and more research on the prevention of and therapy for cancer” [54].

While appearing on the television show NOVA, emeritus professor in humane genetics, Hans Galjaard, and professor in gynaecology, Hans Evers, discussed the plausibility of alternatives to PGD. Galjaard, is confident in future medical possibilities to treat BRCA 1/2. “We are discussing the prediction whether an embryo, a little girl later, will develop breast cancer in 40, 50, 60, 70 years (...) I just wrote a book titled *Gezondheid kent geen grenzen*, in which I reflected upon what happened in the past 40 years, and I must say, I was deeply impressed with all the past

developments. Thus, in 40-50 years from now, I also expect that spectacular developments will have taken place” [39]. In response, Evers, is reluctant to jump to any conclusions about past developments. “It is possible that no developments will be made at all” [39], Evers replied. In an interview with *AD*, professor and clinical geneticist Martinus Niermeijer, said he was bothered by the argument that in fifty years there will be a treatment for BRCA 1/2. “Often, cancer damages healthy tissue between the age of twenty and twenty-five (...) It is also difficult to treat cancer, which makes it unlikely that there will be a breakthrough in twenty years. But more importantly, parents want to make an informed decision with today’s facts” [55]. In a discussion on television with Henk Jochemsen, Caroline Haasbroek, carrier of a breast cancer gene, denies that there are viable alternatives to PGD. To Jochemsen she says: “You make it seem as if new and better techniques to treat breast cancer will become available. But in these discussions I miss that there is also a strongly elevated chance for ovarian cancer where screenings are not that good, meaning that many women die of ovarian cancer every year because it is detected when it is already too late” [38]. For Nicky Westerhof, carrier of a breast cancer gene, it is hard to believe that people can have so much trust in currently fictional treatments. “How can they argue that there should be more attention for treatments? (...) If my disease could be treated, my grandmother would still be alive, my mother would still be alive, and I would not have amputated my breasts” [56].

The second and third types of consequential contestation are only minimally present. Only once does an argument appear to question whether the proposed benefits are indeed benefits. Jochemsen and Van den Berg seem to provide that argument when they suggest that “PGD is not an easy technology which guarantees success” [53]. Here, they appear to question the use of PGD as a useful method to deal with hereditary breast cancer. However, sometimes it is difficult to separate this type of argument from cost-benefit arguments. In the latter case, the argument could be interpreted as one which questions the effectiveness of the technology. Without asking the actor who voiced the argument it is impossible to say which interpretation is correct, but this is really a matter of splitting hairs. One clear example of a reason that displays a cost-benefit argument can be identified: Karin Janssen van Doorn, a Dutch medical specialist and ethicist in Brussels, argues that: “Embryo selection in this particular case will not only prevent much pain, but also saves a great deal of money. Money which can be used for a new medication which is effective but presently still too expensive” [57].

In fundamental discussions where topics such as self-determination, reduction of suffering, and the status of an embryo are at stake, the role of consequentialist arguments are limited. When deontological principles are prominent, arguments based on consequence seem to be secondary. Only where the plausibility of a proposition can be doubted is there a lively discussion.

### *3.3.4 Arguments from justice*

How do we achieve a just distribution of benefits and costs? For a follower of Robert Nozick, the ownership of property could never be sacrificed for a social redistribution the goods. Thus, to tax somebody for someone else’s welfare is a wrongful intrusion to one right to property. In the same case, a Rawlsian would uphold the difference principle, which only permits inequalities in the distribution of goods insofar these differences benefit the worst off. The Rawlsian position is more suitable to traditional left-leaning parties, while right-leaning parties might have more in common with Nozick. Fortunately, whatever the idea of justice someone may endorse, the arguments made on its behalf can still be clearly identified.

A few arguments derived from a justice-informed logic can be identified in the PGD debate. The question of whether the use of PGD by one person will lead to injustice for others is a highly speculative matter. This uncertainty makes it difficult to distinguish a problem of justice from good life concerns. The following multi-interpretable argument of the ChristianUnion is a perfect

example: On the website of the CU it is stated: “The Christian Union fears the selection of embryos may have questionable consequences for society. Will there still be room for people with diseases, handicaps or congenital defects? (...) Health is important, but should not be overrated” [45]. What is the CU really saying here? Should one be careful with PGD because people with a disease might eventually run the risk of having to pay higher medical insurance? Or are they trying to say that the social climate may be less supportive of people with a disease? I will consider the argument to mean both and, hence, it will be used in a perspective of justice now, and in the context of good life arguments in the next section.

To continue, similar arguments of justice can be identified. Frank G. Bosman, theologian at the University of Tilburg, fears for solidarity and the role of insurance companies in a society with PGD. “Selection of embryos jeopardizes solidarity in society. Yesterday, Henk Jochemsen, head of the Lindenboom Institute, warned in *Trouw* that ‘blame’ is already ascribed upon parents who chose to go through with a pregnancy without seeking to know whether their child would be born with Down syndrome. Parents are blamed that ‘they could have known.’ Not just between adults but even by children towards their parents. I also fear that health care insurance companies will refuse to pay the high medical costs of certain groups, with the argument that ‘it’ could have been prevented. The parents will have to pay the bill” [58]. In a parliamentary debate, Henk Jan Ormel, spokesperson for the Christian Democratic Appeal (CDA), said: “The CDA faction dearly values equality of opportunity, including for people with a disability, whether that is genetically determined or occurs in a later stadium. One of the areas where future tension may occur is in that of access to insurance and inspections [of hospital records]. The law on medical inspections guarantees that not everyone may ask for a medical file. We wish to see a reinforcement of these guarantees, especially in the light of the discussions held” [30]. In the same debate, the political leader of the Socialist Party (SP), Agnes Kant, shares Ormel’s worries: “In politics, we should make sure that new opportunities do not lead to a reduction of freedom. The availability of embryo selection may never imply that people are forced or feel forced to make use of the same technology. The administration should ensure that new technologies benefit people and cannot be used against people. It must be prevented that new technology and knowledge lead to unequal access to work or insurance, and should not be able to conclude that children with a congenital defect not be compensated based on their parents’ decision not to terminate a pregnancy while the disabled child was still in the womb” [30]. Esther Ouwehand, spokesperson for the Party for Animals (PvdD), is also worried. “To say it frankly, how will our health care insurers respond when diseases could have been prevented?” [29]

The matter of justice is limited to this type of argument, which is shared by multiple actors in the debate.<sup>24</sup> People are concerned that further use of PGD may eventually lead to future injustice. Counterarguments have not been given and the general consensus was that it would be a display of injustice if governmental institutions were to ascribe some sort of blame, or even deny coverage, based on the argument that a hereditary disease could have been prevented *in vitro* but was not.

### 3.3.5 Arguments from virtue ethics

Unlike deontology, consequentialism and forms of distributive justice, virtue ethics does not concern itself with right actions. For Kantians (deontology), the morality of an action is intrinsic to it; for consequentialists it depends on the outcome of the action and for those who adhere to a theory of justice, and so morality is a combination of both intrinsic elements and consequence. In contrast, virtue ethics, or ethics of the good life, shifts the focus of morality to the actor himself

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<sup>24</sup> Among others, Bas van der Vlies [29] and Henk Jochemsen and Matthijs van den Berg [53] have argued along similar lines.

and asks ‘how should one live?’ To know whether an action is good or not can then be judged by asking how it contributes to one’s flourishing, or how it helps cultivate a virtuous character. In broader terms, virtue ethics can be used to reflect on society at large to see what terms of cooperation among citizens allows citizens to lead the good life. Should society, for example, particularly foster family life because it leads to overall better outcomes, as a utilitarian would say, or should society do so because people value family and thereby become better people?

Swierstra and Rip have categorized these arguments in two ways. One group of good life arguments focuses on human character. These arguments express “culturally shaped identities and aspirations: who are we and who do we want to be?” [19] Or, in addition: what should society look like to facilitate the good life? In discussions on new and emerging science and technology, conservative and optimistic views on the role of technology have a different view of what that good life exactly is. Well known is the debate between posthumanists, who see genetic technologies as a means to speed up human evolution, and more conservative thinkers who fear that, as a result of that ‘speeding up’, we might lose much of what we currently consider meaningful. The second group of arguments of the good life are translated into limits. What great divide should not be crossed to preserve the good life? Desirable limits may be inspired on the religious notion that we ‘should not play god’, which is particularly prominent in debates on biotechnology. Or, limits can be drawn by what is deemed natural by arguing, for example, that something is unnatural or fabricated and is thus not worthy to pursue. On the divide between posthumanists and their critics, the argument over limits could suggest that humans should not try to transgress their natural limitations. Part of what makes life valuable are what humans struggle with most, like death and disease.

In the debate on PGD such arguments appear to be almost exclusively the domain of religious people. Religious doctrines contain a plurality of moral positions on the good life and life itself. New developments in science and technology can challenge and confront those values. In Copernican times, the authority of the Church and God himself was at stake when Earth was losing its central place in the universe. More recent developments in biotechnology might change the way we look at life. Should it be protected in its earliest phase? Should one be humble towards the miracle of life, or is such an attitude inappropriate now that new technologies allow for a reduction of suffering? Framing life in terms of a gift (from God), rather than something to be recreated according to human standards, exemplifies a characterization of the good life that is inspired by religious thought. This does not mean that Christians are the only ones endorsing a particular model of the good life, but in practice it seems that nonreligious groups are less motivated to express this type of ethics. There are a few exceptions, but it remains mostly religious people who put forward virtue ethical arguments in the debate on PGD.

Now, to the debate. The first type of good life arguments that will be handled are those arguments that frame a perspective of the good life in terms of our identities and aspirations. In a statement, the CU suggests: “The ChristianUnion feels the selection of embryo’s may have questionable consequences for society. Will there still be room for people with disease, handicaps or congenital defects? (...) Health is important, but should not be overrated” [45].<sup>25</sup> The editors of *ND* argue in a similar way. “A society which tries to prevent the birth of disabled or diseased people technically, opens the door for a social climate where it eventually becomes unacceptable that people are still born with congenital defects or a hereditary aberration. After all, they could have been prevented. Just like some parents of children with Down syndrome already hear” [59]. In a similar vein, Jochemsen suggests: “If we head towards a society where embryos are selected on the basis of an increased chance for a hereditary disease, then that looks like an undesirable society to me” [38].<sup>26</sup> Professor Galjaard warns: “By closing off risks, life might become less enjoyable. We should

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<sup>25</sup> This quote is also used in the section on arguments from justice.

<sup>26</sup> Frank G. Bosman, theologian at the University of Tilburg, argues in a similar vein (see also section 3.3.4) [58].

accept certain risks and be careful that we do not medicalize the entire society” [60]. These arguments share that they perceive a change in the character and meaning of human life if PGD becomes daily routine. It is not just that people will be free from disease, but disease itself will be considered to be a choice. How will people’s character be formed by that understanding? In an editorial commentary, the newspaper *Trouw* questions the previous arguments. Referring to the viewpoints of the CU, the commentary suggests: “[The CU] fears the future will hold no place for people with disease or handicap. However, it lacks proof to support that hypothesis” [61].<sup>27</sup>

The following group of good life arguments is similar to that described above, but is more difficult to dismiss as mere speculation. First, in a joint commentary in *NRC*, Jochemsen and van den Berg change the angle of the argument: “The selection of unborn human life with a condition, sends out the wrong message to society: we really feel that such people should not be born. We acknowledge the fact that future parents want to use PGD to prevent the birth of a child with a genetic burden. But the fact that this method is financed with public money unmistakably makes this selection a societal matter (...) Are we not going towards a society where you are only born when you have no disposition for (serious) conditions? International research has shown that an increasing part of children who are prenatally diagnosed with Down syndrome or a neural tube defect are aborted” [53]. At the debate in the parliament on PGD, where the revised letter on PGD was discussed, the spokesperson of the CDA, Henk Jan Ormel, stated: “The CDA feels that the possibility to make use of PGD should never lead to the signal that it is better to be dead than alive with such a disease” [29]. State Secretary Jet Bussemaker agreed with Ormel and said: “The use of embryo selection must never lead to the signal that someone should not have been born” [30].

One question remains, however: How will the character and aspirations of future children be influenced by the possibility of PGD? The matter is highly speculative and philosopher and columnist Désanne van Brederode sarcastically hints at the good life of a child who has been saved from breast cancer. “What?! Skydiving? Smoking? Unhappy about your figure? A depression. You?! All this while your parents made sure you could not get breast cancer! How dare you!” [62]. Another kind of good life argument is forwarded by Esther Ouwehand, spokesperson for the PvdD: “In a broader perspective, the societal implications deserve our attention. An example would be the risk of holding parents liable for the increasing number of detailed choices they can make about new life. What responsibilities will become the burden of future parents now that they have many more choices to make? The centre for ethics and health remarked that the continuous increase of choice in healthcare is moving towards a duty to choose. What consequences will that have for the individuals in our society?”<sup>28</sup> [29] From a personal perspective, Esther Leeninga, carrier of BRCA-1, says in the television programme *NOVA*: “It almost seems as if you should feel guilty when you have a child and choose not to do selection” [41].

*NRC* contains an elaborate response from Roel Kuiper, member of the Senate for the CU and professor reformational philosophy. In that article, Kuiper gives an account of a Christian good life perspective on the matter of PGD: “The world as a creation is a ‘date’ and not a coincidental ‘fact’. The world is given; the order and the mystery of that world makes human beings realize that they aren’t the creator of all that exists, but that the world has been given. This realization gives a specific experience to things. He who sees the world as a miracle, the miracle of a gift, will not be able to exploit the world in an individualistic utilitarian way (...) The relation to nature

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<sup>27</sup> Note that this question could also create doubt on the feared role of insurance companies, which was prominent in the section on arguments from justice.

<sup>28</sup> This argument, as well as some of the arguments just mentioned, might appear to be deontological in nature. There is talk of duties and people are worried whether society will still be hospitable to people with a defect. I have categorized these arguments as good life arguments for these arguments do not express a duty to say whether the policy is good or bad, or say that the policy measure does not respect people with a condition. Instead they point towards a society which is seen as undesirable. One type of such a society is one where people do not endorse these deontological concerns that worry us today. That, most certainly, is a good life concern.

should be one of respect for what has been given in the processes of creation. Human beings do not exploit, instead they answer. Answering is in particular the right attitude in relation to God and fellow human beings. Answering means to acknowledge the authority of someone else. For Christians, this means to acknowledge the authority of God, who speaks in many ways. This is the source of moral responsibility for one's actions" [63].

In general, and particularly when proposed by people of faith, good life arguments support a conservative view on life. In an interview with *Trouw*, rabbi Elisa Klapheck endorses a more progressive religious viewpoint. "In the book Ezekiel," rabbi Klapheck says, "it is written that God will give people a new heart and a new spirit. This is not medically but spiritually intended, and it tries to say that improvement and renewal is possible. God speaks to the prophet there as son of man, responsible for the godlike in life. All developments are frightening, but we should not be led by fear, but by faith in progress" [49].

The second type of framing of the good life occurs through the identification of limits. With respect to modern technology, it is often suggested that humans should not play God for that will eventually lead to the corruption of much that we hold valuable. This argument has been particularly prominent in the debate between trans- and post-humanists and their critics, to which I referred earlier. By taking too much control of human life with new genetic technologies, the critics suggest, many values among which humility and solidarity are in danger. The editors of *ND* support a similar opinion. "Humans can't handle playing God. That will corrupt eventually. The weaker people in society can hardly be considered human 'gods'" [59]. The same kind of argument is also forwarded by Kuiper: "Christians are deeply sceptical about the utopian projects of modernity. Science and technology are able to create, but can derail when they are not attached to any moral framework. Many Christians have identified the criticisms of the postmodernists as their criticism to the pretensions of modernity. They have an insurmountable hubris to play God (...) It thus becomes paramount to identify and critically examine the perspective through which science and technology are used. A technologically reshaped world is no perspective. The meaning of life will be lost here. Opposite to this is the perspective whereby every human being is accepted as an intended and desired person" [63]. In an article in *NRC*, Marcel Zuijderland, publicist and philosopher, responds to this type of argument: "The argument that we 'should not play God' is unfounded. Nowhere in the human genome shall we find anything that points to a divine plan" [50].

A different opinion is forwarded by Hospital Minister Abeltje Hoogenkamp. From a biblical perspective, she questions the limits that are supposed to benefit the good life. In favour of PGD, she asks: "Is the human being allowed to interfere in the natural cause of things? Certainly (...) Nature is not pleasant at all. Why should we be so stubborn about this point, while for insemination, the best seeds are selected with a centrifuge, and we do not make a problem about that? Most of all, the argument is untenable with the bible as starting-point. The natural way of things is not sacred in the Bible" [49].

### 3.3.6 *Meta-ethical arguments*

Meta-ethical arguments are not ethical arguments themselves, but are rhetorical methods or logical lines of reasoning to give weight and credibility to one's ethical position, which itself is an expression of consequentialism, deontology, justice, or the good life. Meta-ethical arguments are powerful when they contextualize ethical arguments, giving a fuller and more credible account of one's opinion. Swierstra and Rip mention three different kinds of meta-ethical arguments [19]. The first concerns the degree of influence 'we' (as actors) have to steer the path of the technology. On the extreme side of the spectrum, denying human agency should convince the audience that whatever views they have, it is futile to try to steer or stop the introduction, development or use of

the technology. Less extreme positions affirm human agency, even though path dependencies make it difficult to influence the directions of technological development.

In the debate, a few of these arguments are visible. The bottom line is: these developments will not, or cannot be stopped. Technology just fits too perfectly into the general developments happening in contemporary society. In *Trouw*, rabbi Klapheck argues: “It does not help to forbid selection. People want it, they are consumers in health care” [49]. In an interview in *NRC*, Hans Galjaard shares his thoughts on the matter. “The application of PGD cannot be stopped, and that is no blessing, neither financially nor for society (...) In my book you can see the government struggling to keep control of the costs of reproductive technologies. There is no medical method where it is said: we will not do it (...) To my surprise, last year fifteen diseases were added to the Guthrie test. Some of those diseases occur less than once a year, with little possibility for treatment. But since we can determine it all in one moment, we say: why not? That’s part of your generation” [64].<sup>29</sup> This type of argument can be used in combination with diverse ethical positions. It can be used to reflect on the morality of present-day society and thereby forward questions of justice or the good life. Or it can simply be used to suggest that people should simply accept the implications that come with PGD and stop moaning about it.

The second form of meta-ethical arguments concerns the use of past experiences. Previous experiences may suggest that technology is either used for good or bad, is beneficial or disastrous, or offers a reason to sustain, or reconsider, our current moral ideas. Particularly this last type of argument is prominent in the debate on PGD. In the media, the CU was often blamed for trying to force their ‘pre-historical’ ideas on the citizens of the Netherlands. The rhetorical question is begged, “How can the people of the CU still have trouble with this policy proposition on PGD after all the moral progress of the past decades?” While all other arguments from precedent are in favour of PGD, I will start this matter with the single example that supports the position of the CU. In *NRC*, Henk Jochemsen and Matthijs van den Berg comment on the matter. “It should be realized that the previous Secretary of State, Ross van Dorp (CDA), wanted to forbid the selection that Bussemaker wants to allow. So, in this matter, it would be wrong to suggest that the ChristianUnion holds a wicked opinion” [53]. Proponents of PGD respond by suggesting that the condoned practice of IVF already allows selection of embryos for other reasons than the identification of genetic mutations. Professor Hans Evers speaks from personal experience: “Recently I had a patient for IVF because of her infertility, but she also carried the BRCA-1 gene. For IVF, we were allowed to select the embryos on appearance (to place the prettiest one back in the ovary) but not whether it carries the gene. An absurd situation” [65]. In a similar vein, Joep Geraedts, head of the department of clinical genetics at the Academic Hospital Maastricht, says: “It would be strange not to select for a serious hereditary condition. With regular IVF you also make a choice because there is a surplus of embryos” [66].

The argument from precedent is widely endorsed by supporters of PGD. They refer to the moral development we have already made by allowing abortion. Furthermore, they refer to other ways in which embryos are lost every day. Both types of argument are aimed to delegitimize the so-called right of the embryo to protection. The leader of the Socialist Party, Agnes Kant, was one of the first to compare PGD to abortion: “It is strange to consider that you do not allow this and you do allow abortion, for the self-same reasons” [32]. *De Volkskrant* poses the similar dilemma in an editorial commentary. “The ChristianUnion objects to the destruction of embryos which carry the gene that corresponds to hereditary breast cancer. But Dutch law already allows amniocentesis for women who have this hereditary form of breast cancer. When the foetus turns out to carry the disease, it can be aborted, sixteen weeks after fertilization. Which is worse, according to the logic of the ChristianUnion? Abortion after four months or the destruction of an embryo in a laboratory?” [35] In the television show *NOVA*, Hans Evers points out this moral inconsistency by comparing embryo selection to abortion. “People already have aborted

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<sup>29</sup> The book Galjaard refers to is: *Gezondheid kent geen grenzen* (2008).

spontaneous pregnancies for 2-3 times, because amniocentesis showed that the child carried the breast cancer gene. When I am abroad for a congress, I cannot explain to my colleagues that we are allowed to carry out amniocentesis and abort the pregnancy, while we are not allowed to prevent a pregnancy from occurring in the first place” [39]. Karin Janssen van Doorn argues: “Politicians think up all sorts of doubtful counterarguments, such as: ‘this conflicts with the due respect for all forms of beginning human life’, ‘this leads to the medicalization of society’, ‘the chance that hereditary breast cancer will develop is not 100 percent’, or: ‘this undermines the solidarity in society’. When such arguments are proposed, it also seems logical that the laws on abortion and euthanasia are abolished” [57]. Previous minister of Health, Welfare and Sport, and member of D66, Els Borst, is equally disturbed with the position of the CU. “Many people are principally against abortion and say: I would rather destroy an embryo than a three month old foetus” [67].

The previous paragraph contained only a selection of the arguments found in the PGD debate.<sup>30</sup> An equivalent amount of arguments from precedent were given to delegitimize the status of the embryo as something that inherently deserves to be protected.<sup>31</sup> In NOVA, Hans Galjaard who is in fact a critic of PGD, considers the deontological motivations of the CU to be outdated. “Prenatal diagnostics have existed for 30 years. So you can’t just say now ‘you think the embryo is worthy of protection from conception onwards.’ Only in Rotterdam, already sixty thousand prenatal diagnoses have already been performed” [39]. Hans Evers says: “In the Netherlands, every year 10,000 IVF treatments are performed. With each treatment embryos are selected. The good ones are placed in the ovary or are frozen and stored, the bad ones are thrown away, which amounts to a few dozen each day. In the Netherlands about 150,000 women use the coil (intrauterine device) for birth control. The coil prevents the nesting of embryos in the ovary. So each month, about 150,000 good embryos are lost. That’s a couple of thousands per day” [65]. Zuijderland endorses the same kind argument but approaches it from a different angle. “‘God’ himself seems to be quite wasteful with embryos. The destiny of most embryos is a premature death. Of all the eggs that are fertilized in a natural way, seventy-five percent die before the pregnancy ends” [50]. As a final example of this type of argument, I wish to quote emirate professor of gynaecology P.E. Treffers, who points out that human intervention is no different than what already happens in nature. “The ChristianUnion regards an embryo in the first stadium of life to be worthy of our protection: it cannot be destroyed and selection of embryos on grounds of hereditary deformities cannot take place. This thought is opposite to what happens in normal reproduction. An embryo is a clump of cells that comes to exist from cell division after fertilization in the fallopian tube. The fallopian tube transports it to the womb where it might eventually get the chance to settle in the inner membrane of the womb. Many embryos never settle and are lost; and even if they do settle, a great deal still goes to waste as result of a spontaneous abortion” [72].

The third type of meta-ethical arguments concern the projection of moral change in the future. It could be argued that such change will become habitual and is seen as moral development. Oppositely, the perceived moral change can be seen as moral corruption. This latter interpretation proves to be prominent in the debate on PGD and comes in the rhetorical form of the slippery slope. In its strongest form, the argument suggests that when some boundary is crossed, it will

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<sup>30</sup> Additional arguments have been given by: Senno Verhoef, head of department familiar tumours of the Dutch Cancer Institute – Antoni van Leeuwenhoek Hospital in Amsterdam [55]; Alexander Pechtold, political leader D66 and member of parliament [68]; and Ellen Groenewold, carrier of hereditary breast cancer [44].

<sup>31</sup> A selection of these arguments that will not be mentioned in the text are given by: Clare Wesselius; publicist [69]; Simone Hof, carrier of gene that causes colorectal cancer [43]; Marc Chavannes, columnist [36]; Guido de Wert and Inez de Beaufort, professors in Biomedical Ethics and Health Ethics at the University of Utrecht and Erasmus Medical Centre Rotterdam [70]; and Christine de Die-Smulders, medical coordinator PGD on the department Clinical genetics AZM [71].

inevitably lead to further steps down the road. In a weaker form, the argument is about the logic of justification. The latter version means to ask whether the principles used to justify a decision can also be used to justify similar decisions in advance. This brings us to an important matter in the discussions on PGD to which I have, until now, only given passing reference. Much of the debate on PGD revolves around the *chance* to develop breast cancer. So far, the only diseases that were allowed for selection, such as Huntington's disease and Duchenne muscular dystrophy, are very devastating diseases that would certainly develop over lifetime if the relevant gene is found. In the case of breast cancer, certainty cannot be guaranteed and it thus can be argued that it does not prevent one from living a good life, which has been proposed in section on deontological arguments. But more importantly, a carrier of BRCA 1/2 need not necessarily develop breast cancer. There is a chance of approximately 65 percent that it will occur during the length of one's life, and additionally, there is a 10 to 60 percent chance of developing ovarian cancer [16]. The step from certainty to chance gives rise to the argument of the slippery slope.<sup>32</sup>

On to the debate: Henk Jochemsen is one of the first to forward the argument of the slippery slope: "We will come in a situation where, in principle, everything can be selected (...) There are so many genes that can lead to a disease. How serious must the disease be and how severe should the treatment be and how big should the chance be to justify embryo selection?" [46] In a similar vein: "The ChristianUnion points out that it is not 100 percent certain that the defective genes will lead to breast- or colorectal cancer. Therefore, André Rouvoet feels that state of secretary Bussemaker crosses a fundamental line and opens the door for further embryo selection" [87]. Galjaard sketches a situation in which the slippery slope might work in this case: "Carriers of the hereditary breast cancer gene have eighty percent chance to develop the disease. What risk is serious enough to close it off upfront? A risk of eighty percent, sixty, ten? Step by step this goes further. There are people who do not believe in the slippery slope, but this decision shows that it really exists" [60].<sup>33</sup> Furthermore, in an interview with *NRC*, Hans Galjaard says: "All embryos carry risks to develop a disease (...) We have to realize that people in the future will also wish to eliminate smaller chances for disease. In the end, who do you have left?" [64] Annemiek Nelis, general director of the Centre for Society and Genomics, shares Galjaard's fears: "What type of new boundaries are we seeking? What does it mean for the future if we also start selecting for genes that do not always lead to a disease? It means that in due time, more diseases will be screened for, because the suffering of the patient keeps forcing us to push further" [66]. More imaginatively, René Cuperus, political ideologist and columnist of *de Volkskrant*, portrays a Brave New World scenario: "You don't have to be a great futurologist to establish that future human production will take place in a laboratory without love and without sex (...) You don't have to believe in the God of Genesis, to believe in the slippery slope and the manipulation of the quality of life" [74].

Naturally, there is much disagreement about the slippery slope and whether it really exists. Christine de Die, a clinical geneticist, does not see a slippery slope. "An IVF treatment is an intensive procedure. Women think for months about it. Science itself is not that far advanced just yet. For every woman, for every mutation, a specific test needs to be developed" [75]. From Evers' experience there is no reason to fear a slippery slope: "For fourteen years have we been doing preimplantation genetic diagnosis (...) and in those fourteen years we have never had someone who came with the request to apply this diagnostics for a disease with a risk of 10 percent" [39]. At the other side of the table, Galjaard was quick to reply that such is not very strange, as the possibilities are still limited. A bit further in the same debate, Evers counters

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<sup>32</sup> Other arguments that indicate a slippery slope which will not be mentioned in the text are suggested by: Esmé Wiegman, member of parliament for the CU [44]; Maarten Keulemans, scientific journalist, final editor for the popular scientific monthly magazine *NWT Natuurwetenschap & Techniek* and columnist of *Volkskrant* [73]; and Frank G. Bosman, theologian at the University of Tilburg [58].

<sup>33</sup> Galjaard refers to Bussemaker's first letter to the parliament [16] in which she announces to include BRCA 1/2 for embryo screening.

Galjaard's expectations that people will want screening for a variety of diseases and advances another argument from experience: "But Mr. Galjaard, if that would be the case, then we should have already seen similar developments in antenatal diagnosis, which is amniocentesis (AFT). You can have amniocentesis performed for a variety of diseases but in the thirty years that AFT's have been performed in the Netherlands, there has been no trend where people ask to screen for less serious diseases. People are very thoughtful about these matters and that goes all the more for preimplantation genetic diagnosis" [39]. J.G. Nijhuis, gynaecologist, draws on data from prenatal diagnosis to counter the idea of a slippery slope. "In 25 years, prenatal diagnostics, the research of the child in the womb has expanded enormously. Nonetheless, the number of abortions due to a child's disease or aberration did not grow. For years it has been between 400 and 600 cases. There is no slippery slope" [71]. Publicist Clare Wesselius has faith in contemporary morality: "There is no slippery slope", she argues. "We are in full control and looking at the way questions of life and death have been handled in the past years; we can be confident there is no slippery slope" [69]. Finally, *ND* reports on a publication in *Nederlands Tijdschrift voor Geneeskunde*: "There is no single piece of evidence that suggests that future parents are quicker to abort if the unborn child has a minor shortcoming" [76].

Other arguments against the idea of the slippery slope refer to the solid measures taken in the policy on PGD. In the television show *Knevel & Van den Brink*, State Secretary Jet Bussemaker, was a guest. Van den Brink, one of the interviewers, asked whether Bussemaker agreed that the decision to include hereditary breast cancer to PGD procedures might open the door for the inclusion of other diseases. Bussemaker made it clear that there is no slippery slope because: "These are very specific cases which are judged individually." Van den Brink continued the interview and suggested: "Your predecessor was against PGD for hereditary breast cancer (...) So it matters who holds that office and possibly the next state secretary will allow PGD for more diseases." Bussemaker replied: "No. It is most important that you choose a process where sensible and careful judgments are made" [31].

In an editorial commentary, *NRC* responds to the fears of the CU: "The argument of the ChristianUnion which suggests that Bussemaker's proposition will lead to a slippery slope of eugenics is a fallacy. The Secretary of State makes it painfully clear under which circumstances this technology is allowed" [33]. Elsbeth Ety, columnist of *NRC*, endorses the same argument. "The slippery slope makes no sense because the existing law on PGD draws sharp boundaries" [77]. Evers adds that not only are the measures solid, but the medical practice itself is also very rigid.<sup>34</sup> "The slippery slope does not exist. It's a political invention. Embryo selection only takes place after many talks with the parents and after thorough deliberation of a special committee. Every application is reviewed independently on risk of transferability, the impact of the disease and the options for treatment. Is it only about a great-aunt who developed the disease or is half of the family involved? Does the disease develop at a young age? How does the disease progress over time? After intensive talks, of the 1250 pairs who applied in the past fourteen years, only 250 remained. In the United States, there are commercial clinics who select for Alzheimer and other conditions that are perfectly treatable. We will never go that far" [78].

Despite such common sense arguments, particular cases also give rise to much doubt according to the following arguments.<sup>35</sup> Marijke, carrier of the gene that causes breast cancer, has a strong opinion on the matter: "I am totally against selection of embryos, because I feel that we should not select human life (...) Besides that, I don't think my situation is any worse than that of a mother with autistic children. Autism probably also has a heritable component and in due time, it will be

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<sup>34</sup> A similar opinion is endorsed by Caroline Haasbroek, carrier of a hereditary breast cancer gene [38].

<sup>35</sup> Perhaps comically, the decision to change the policy and allow for the selection of BRCA 1/2, was rapidly followed by an article on further genetic disorders. Guido de Wert and Inez de Beaufort, respectively professor Biomedical ethics and Health ethics at the University Maastricht and Erasmus Medical Centre Rotterdam, wrote an article on exclusion-PGD and HLA detection and opted for the inclusion of these methods to the policy on PGD [70].

possible to detect it in an embryo's genetic profile. If you allow selection for a breast cancer gene now, where does it finally end?" [43] Galjaard is certain that in the future, more diseases will become eligible for selection. "There are rapid developments in DNA chip technology. The coming ten-to-twenty years you can expect that many gene variants will be found that lead to higher risks. Sometimes it will be a small risk, other times it will be larger. I don't see how we say 'yes' now, and 'no' later. Every one of us has an increased chance for something, whether it is dementia, Parkinson's or vascular disease. In this way, not many people will be left" [39]. René Franssen, science journalist, also fears for selection for less serious diseases. "What if the future holds that somebody suffers under the thought that his or her child has an increased chance for autism or an increased chance for Rhinitis (hay fever). Hay fever can really poison your life, right? What if a deaf couple wants a deaf child because that would be good for their family life? This is no farfetched situation; there has already been a lawsuit about it" [79].

There are a few final remarks in order. The meta-ethical arguments that we have seen thusfar are either intended to delegitimize or strengthen an ethical view. The argument from precedent has been used to counter the deontological idea that embryos are worthy of protection. These arguments works very well when the protection of the embryo is seen as a deontological matter, which is consistent with my own categorization. But what is the value of an embryo when the argument for protection is endorsed from a good life perspective? What does it mean to develop a theory based on the respect for an embryo, linked not to its biological status but to the potentiality of its growing into a flourishing human? This will be one of the concerns in Chapter 5. The other argument—that of the slippery slope—intends to give way to good life arguments. The slippery slope itself is merely a vehicle to give a podium to considerations of the good life. The opposite argument—that of habituation—could argue that the use of PGD for an increasing number of disorders is a sign of moral development. This argument, however, has not yet been made. To some extent, the daily practice of politics is about governing a slippery slope and proponents of PGD have suggested that the medical practice of PGD, the law on embryo selection, and the intensity of the procedure make the slippery slope similar to a bad science-fiction scenario. Whether those criticisms are correct will be discussed in Chapter 4.

### *3.3.7 Responses to the ChristianUnion*

The role of the ChristianUnion has been met with hostility. There are basically two camps: those who consider PGD to be an excellent solution to the problem of breast cancer and those who oppose PGD in this particular case. Those who endorse the latter position need to forward good reasons why, because it implies that PGD is not automatically a decision that falls within the autonomy of a woman with hereditary breast cancer. Add to this the idea that PGD prevents serious suffering, and a negative attitude towards PGD could be considered little else than unethical, so it appears. As a result, the CU has been subject to emotionally charged attacks in the media. Variations of the question "On what grounds does the CU think they can impose their private religious ideas onto others?" are widely asked. Religious people surely must know that many people do not share their outlook on life, so why do they insist on mingling into matters that should be kept in the private sphere? This line of thought often leads to the conclusion that the CU and its followers are tyrants who are not susceptible to any rational argument. There are basically two categories of arguments that are supposed to delegitimize the position of the CU. The first category concerns those arguments that reduce the position of the CU to an ostracized religious position. It is argued that no proper morality can be implied by a Christian perspective. The arguments of the CU are, in this formulation, simply too unreasonable or irrational to uphold. The second category concerns the idea that the CU is a disgrace to the idea democracy. Here it is argued that the advocates of the CU wish to impose their private ideas upon the majority of people who do not share the same system of belief.

Mark Rutte, the political leader of the VVD, is annoyed with the position of the CU. In the parliament he asks: “Who is the ChristianUnion to impose such a moral judgment about the quality of life and health on the people of the Netherlands?” [29] In *NRC*, Els Borst expresses her problems with the CU’s position. “The ChristianUnion gives the impression that it has a direct connection to the heavenly and that we are all misguided. While the position of State Secretary Bussemaker is logical and thoughtful. (...) Being devoted Christians, the politicians of the ChristianUnion believe that they have access to the wisdom of the ages. (...) The ChristianUnion uses the parliament as a missionary post, but that is not the purpose of the parliament. In the parliament you are supposed to convince each other by argument” [67]. In response to minister Rouvoet of the CU, Karin Janssen van Doorn, suggest what the primary concerns of Rouvoet ought to be. “Minister Rouvoet should worry about a government which considers the family to be the cornerstone of society, forces women to mutilate themselves and remain childless to prevent breast cancer” [57]. Ben Crul, medical doctor and main editor of the magazine *Medisch Contact*, asks: “What fundamentalist country do I live in? Will it soon become mandatory to grow a beard? (...) According to my Bible, the reduction of unnecessary human suffering is still a good thing” [55].

These arguments do not simply argue against a moral point of view. Rather, they intend to dismiss the position of the CU completely. The ways in which that is achieved is often based on little more than insults and mere rhetoric. Elsbeth Etty is on the foreground of attacking the CU on their integrity. “Bussemaker assumed that politicians of the ChristianUnion are rational and humane people and that you can cooperate with them. A mistake: they are not rational politicians, they are fanatics, fundamentalists and tyrants (...) They appeal to their God who wants people to suffer and get cancer because that is all part of the greater plan” [77]. In the television show NOVA, Henk Jochemsen, a clear opponent of PGD, and Caroline Haasbroek, carrier of a hereditary form of breast cancer and supporter of PGD, were invited to discuss the matter. Citing a poll that shows that 66% of the population supports PGD in the specific case of hereditary breast cancer, the host of the show, Twan Huys, turns to Jochemsen and says: “Sir Jochemsen, 66% of the Netherlands feels you are talking rubbish and that this technology should be allowed” [38]. In the television show Knevel & Van den Brink, political leader of the CU, Arie Slob, says he was astonished by the attention the CU received. In *NRC*, political columnist Marc Chavannes responds with little sympathy: “Whomever imposes a hereditary ‘almost-death warrant’ on women who do not share one’s beliefs has quite a lot to explain” [36].

The CU and its supporters appear dumbfounded by these fierce responses to their position. Roel Kuiper says in an article in *NRC*: “I am not a Christian fundamentalist and I will not be told off like that. I am bothered by the ideas and images provoked into existence as if we are cold-blooded Christians who wield some sort of a ‘Befehl ist Befehl’-ethics simply because we rely on the Bible. Christians who find authority in the Bible have populated this country for centuries and now we should shut up because we are Christian fundamentalists?” [63] In an interview with *NRC*, Arie Slob says he is hurt by the ‘anger’ and ‘bitterness’ that is directed towards his party. “For example, Elsbeth Etty, who writes that we are ‘fanatics, fundamentalists and tyrants.’ That is absolutely absurd. Or Els Borst who accuses us of ‘arrogant smugness.’ Wasn’t she the one who said ‘It has been accomplished’ when she finished the law on euthanasia? And she dares to say that we use the parliament as a missionary post?” [80] Also in an interview with *NRC*, minister Rouvout of the CU talks about the hostile responses the CU received. “Many of these opinions were not so much about what we said, but about our suspected motivation. That was sometimes quite staggering” [81].

It is also questioned why the views of the CU are met with such hostility. M.J. Schuurman, preacher at the reformed congregation Ipendam-Watergang, gives his idea on the problem. “For Dutch people, faith is little more than a projection. God and belief are nothing more than a fairytale. They consider it appalling that this outdated position seems to have some influence (...)”

But restraint in the field of medical ethics is not the sole right of orthodox protestants” [82]. Roel Kuiper suggests that you do not need to be a Christian to share their viewpoints. “Christians are not the only group that sees experimental genetic science as a risky instrumentalization of life. In philosophy and ethics, similar critical argumentative patterns can be found. Why should the discussion on the limits of technical instrumentalism, which is held in all places in the world and in science, be reduced to bickering about forms of fundamentalism?” [63] In *NRC*, André Rouvoet argues for the proper place of a religious viewpoint in the public debate. “It seems that people think the ChristianUnion should not be allowed to introduce their viewpoints on this subject because they are founded upon the Bible and are of no relevance to the rest of the world. This is really remarkable. You also don’t say: ‘I can’t take a liberal politician seriously because he appeals to John Locke or Rousseau and they do no interest me?’ If you deny the public place for some viewpoints because of their ideological origins, then you destroy the heart of democracy.” Rouvoet goes even further and suggests: “If you appeal to the universal declaration of human rights, it is also dogmatic to believe that it should never be subject of discussion. Every human being holds on to something. It is difficult to have a political debate on the level of convictions, but it does offer insight in how people stand in life. I do not leave my faith at home when I go to Den Hague” [81]. In the same newspaper Arie Slob also provides this argument. “On environmental issues, GroenLinks and D66 also endorse positions that restrict the freedom of citizens, but apparently people have no problem with that. It seems ok to do politics from all sorts of viewpoints, except from the Christian religion” [80].

The second type of response towards the CU concerns their apparent desire to force their ideas onto other people with power politics. These arguments rely on an idea of democracy by which policy decisions should reflect the opinion of the majority. Therefore, it would suit the CU to be more modest, small as the political party is. Elsbeth Ety endorses this argument as follows: “For fundamentalists, arguments fall on deaf ears. How can we possibly govern together with them? They don’t feel obliged to justify their decisions in a democratic fashion, they are only beholden to their God” [77]. Less offensive is the argument of columnist Sylvain Ephimenco: “When the ChristianUnion strongly opposes embryo selection, you naturally can’t force a religious mother to make use of that procedure. And the other way around? How can a small minority (4% of the electorate) commit obstruction and punish women with a genetic aberration who have little to do with orthodox convictions?” [83] An editorial commentary of *de Volkskrant* shares Ephimenco’s opinion. “Christians have the right”, the editors suggest, “not to make use of prenatal research. But it is undemocratic for them to force their ideas upon others, while it is only supported by a minority” [35]. The day after the editorial commentary, the newspaper placed an article of Eva Asscher, working for the Faculty of Law at the University of Tilburg: “There are multiple aspects to a democracy. That decisions are made by the majority is one aspect. The power of this majority is limited by constitutional rights that guarantee the individual freedoms of minorities. This, however, does not mean that a minority can force the majority to follow their specific set of rules. That would mean tyranny of the minority” [84].

In an interview with *NRC*, Arie Slob responds to these accusations. “The idea that this small party with six members in parliament forces its principles on others does not reflect what happens in reality. The way in which the ChristianUnion became part of the government was fully legitimate. People with a libertarian outlook are now suddenly concerned about their ideals. The strongest opposition comes from that area. “How do you dare to limit our autonomy?” it is asked. But we only try to find a majority for our point of view within the limits of the law. We follow the rules of democracy, which, I hope, all parties endorse” [80]. Roel Kuipers is afraid that democracy is seen as the mere rule of majority. He argues: “I do not consider democracy as a mere tool to make policy because it is the wish of the majority. Democracy is also intended to allow for a plurality of opinions. Fundamental to democracy is the idea that a plurality of ideas will improve the quality of decision-making. That plurality should be heard and only those who are convinced of their own

opinions will disagree. If democracy is solely seen as a way to govern power, it may function to eliminate other opinions. That is the ‘knock-out-democracy’, aimed to silence the ideas of others. When democracy becomes an instrument of a self-appointed elite to discipline political views, it becomes impossible to have an open dialogue in society” [63].

While the dust around the debate on PGD was settling, Rouvoet looked back on this period. In an interview with NRC he says: “Liberals accuse us for trying to impose our religious convictions on others. But it is the other way around: the intolerance comes from the secular majority in this country which does not accept political views because they come from religion (...) The political arena is not an instrument to spread my faith. If I wanted to do that, I would have become missionary. Nonetheless, I am a Christian, no matter where I am or what I do (...) My contribution to the debate on the ‘embryo law’ in 2001 started with a reference to Psalm 139, a very beautiful psalm, which starts with the miracle of life woven together in the mother’s womb. I did not make this reference to convince my opponents but to show something of my inner motives. It is funny that the spokespersons of the VVD and D66 understood this very well. It touched them and they even asked for the specific text” [81].

This exposé intends to show how a small religious party itself becomes the focus of a debate on PGD. Often, criticisms on the role of the ChristianUnion are formulated as direct insults. Still, it would be wrong to dismiss these opinions because they come with a temper. For this research, these voices are valuable exactly because they are deep-felt emotions. They drive the conflict over the limits of the debate, the limits which are supposed to divide the reasonable positions one can endorse in public from those positions which are only suitable in private. When the Christian perspective becomes the focus of the discussion, these limits are at stake. One then questions how people can rely on the Bible for their inspiration and feel it is legitimate to make their private ideas part of coercive, public laws. These conflicts result directly from the good life principles people of faith endorse. Those principles are seen as belonging to one’s private life and are considered not suitable for public deliberation. It is then said that Christians should not try to impose their personal beliefs upon others and that they should not try to tell other people how to live their lives.

### 3.4 Final thoughts

The bulk of this chapter was devoted to presenting a clear-cut description and categorization of the diverse ethical arguments and other relevant types of arguments present in the PGD debate. Although the overview is elaborate, it does not include all of the arguments I encountered. Sometimes, the same arguments are repeatedly made by a variety of actors. Repetition of some arguments helps to emphasize its prominence, but style and readability are also fair virtues for an analysis. The inherent risk in this is that the selection might appear to be somewhat arbitrary, though the variety and the number of arguments that have ‘made it through the filter’ should suggest otherwise.

In the coming chapters, my analysis will take on a more analytical and normative character. This chapter provided the empirical input, already nicely chopped up in valuable argumentative patterns. For each type of argument, I have listed the counterarguments and, when it concerned meta-ethics, I clarified the ethical viewpoints those arguments aim to support or counter. For virtue ethical arguments, I observed no counterarguments, except for the emotional responses categorized in Section 3.3.7. In Chapter 4, I focus on the limits of the debate. Good life arguments are of particular interest because in them we find the root source of disagreement and controversy over public reasoning. Good life arguments rely on the idea of the slippery slope for their credibility and meaning. The Christian good life arguments focus on the prospect of an increasingly undesirable society should the practice of PGD continue to expand. Whether those

concerns are realistic depends on how the argument of the slippery slope is fashioned. The argumentative patterns identified in this chapter will be of additional value in Chapter 5, where I will explore the question of whether religious arguments are a valuable contribution to policy on PGD. The focus will be on the differences between the good life arguments and the arguments that belong to rule ethics. Can a plausible argument be made that rule ethics alone provides too shallow a moral inventory to deal with the challenges that PGD presents to us? An affirmative answer to this question also helps to answer the main question affirmatively.



## Chapter 4

# The Limits of the Debate

Over the past decades, Dutch society experienced a steady secularization.<sup>36</sup> While originally being a Christian country with mostly Catholics and Protestants, the group of nonbelievers is nowadays almost as large as all Christians combined. Not surprisingly, several matters that are still controversial in other countries are becoming part of the Dutch moral landscape. Particularly those matters which are of great concern to religious groups, such as abortion or euthanasia, meet less resistance in the Netherlands than in, for example, the United States. Abortion, while legally permitted in both the countries, appears to be far more controversial in the United States. Euthanasia, which is criminal in most countries, including the United States with the exception of Oregon, is allowed in the Netherlands under the law *Toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*. Today, many aspects of Dutch society clearly reflect the decreasing influence of traditional Christian values. The debate on PGD is no exception.

To ask whether religious arguments can be valuable is a particularly interesting question in light of the consideration that these arguments are somewhat controversial. In contrast to the United States, religious spokespeople in the Netherlands are more cautious when advocating their particular comprehensive worldview. Talking in a religious way in the public forum may be supported by their followers, but will influence public opinion very little. Then how is it that the debate on PGD has been coloured by so little understanding as we saw in Chapter 3? Much of the discontent with the position of the ChristianUnion was directed toward their alleged attempts to force their particular ideas upon others who do not share the same religious worldview. It should be asked how the CU and its close supporters use the public forum. Do they not operate within reasonable liberal limits, including the limits proposed by Rawls's idea of public reason? Do they actually try to impose their comprehensive views on others? Or have people become deaf to their arguments precisely because Christians are the ones expressing them? Or it is because 'we' have become 'moral strangers' who are unable to understand the moral perspective of our fellow citizens?<sup>37</sup>

The limits of the debate are at stake in these discussions. It is the task of this chapter to identify the ways in which these limits are drawn and to consider whether those limits are reasonable. One way of identifying reasonable boundaries can be done on the basis of public reason. But doing so draws a tough line for the CU and their supporters. Religious scholars in the United States have vigorously and compellingly argued against the demands of Rawls's public reason [6] [7]. Many religious people simply consider the demands to be too strict. On the other hand, if it turns out that the CU in practice complies with the demands of public reason, a very appealing case can be made for them to introduce their ideas into the public forum. If even Rawls can be pleased – that towering figure of liberal political philosophy – which liberal could still reject the arguments of the CU?

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<sup>36</sup> 42% of the Dutch population is not religious while this was only 18% in 1960 [85].

<sup>37</sup> Roel Kuiper, senator for the CU, coined the term 'moral strangers' in an article in *NRC* [63].

Then there is also *credibility*. Surely, an argument could reflect political values, and thereby, according to Rawls, have a legitimate place in the public forum, but such an argument also needs to connect to the actual situation under consideration. At this very moment in time, there is much debate and controversy over global warming. By human hand the earth is warming up and the prospects are a rising sea level, an increase in natural disasters, the extinction of animals and the shift of ecological habitats. The imperative to act is very clear: there are human lives at stake and, more dramatically, our civilisation itself and earth as we know it are in jeopardy. The motive (the political values) is provided, but whether these concerns demand us to respond depends on the perceived role of us, the people, in all of this. We as citizens only need to act if we indeed influence the climate in a dramatic way. Whether action is taken depends on the credibility of human agency, which in the case of the climate should be fostered by scientific research. Returning to PGD, one can understand that future concerns need some level of credibility. The slippery slope is called upon to support those concerns and the inclusion of the genetic mutations BRCA 1/2 are at the origin of the slippery slope argument. Whether the good life arguments of the CU deserve to be taken seriously depends not only on an idea of public reason, but those arguments should reflect serious and not merely fictional concerns if they are to be taken seriously and not merely dismissed.

It is time to increase the focus on the main question and ask again: can religious arguments be valuable according to an analysis of a public debate on preimplantation genetic diagnosis in Dutch society? The first analytical step towards answering this question consists of scrutinizing the religious arguments in the debate. What do these arguments really say and are the critics right to simply dismiss them as belonging to one's private views?<sup>38</sup> Or should they be accepted as legitimate positions and hence be discussed on their merits? The arguments from deontology, the good life, and meta-ethics are of particular importance. The Christian case for the protection of early embryonic life is thoroughly criticized and their ideas on the good life and their concerns about a slippery slope are generally dismissed. To say whether religious arguments may be valuable, these arguments and the responses to them will be the subject of analysis.

Before that analysis starts, there is a final comment I need to make to prevent possible misunderstandings. The main question requires me to thoroughly assess the role of religious arguments in public debate. To live up to this question I sometimes need to abandon the bird's eye perspective and say whether an argument makes sense. Abandoning my role as an observer, I then become much like a participant in the debate. Sometimes this is a necessary part of the analysis, but I do not intend to assume the role of the referee for the mere sake of it. Sometimes arguments have been coined in the debate that are weak or deserve to be discussed, but that need not be the task of this study and it surely is not my intention to declare who is right and who is wrong. Only where the purpose of this study is served by scrutinizing arguments will I take on that task. This notion goes for both Chapters 4 & 5.

### 4.1 Managing the debate

In a debate there are basically two ways of dealing with arguments. One way is to confront them on their merits. Depending on the type of ethics to which an argument belongs, the responses vary along the different argumentative patterns. It is possible to counter an argument from a consequentialist perspective to question it on its plausibility, the ratio of benefits and costs, or by asking whether the promised benefits are really benefits. Another way of dealing with arguments is by delegitimizing them. The logic of the argument itself does not become the focus of the response, but instead the argument is considered irrelevant or inappropriate. The example of John

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<sup>38</sup> The translations of arguments have been provided in chapter 3. This chapter (chapter 4) will only make reference to those positions.

Harris's survival lottery will help to illustrate this point. This thought experiment asks people to think of a situation where organ donation is expected to save more lives. The sacrifice of one person could save the lives of two or more people [86]. To justify the experiment, it would be necessary to do it on utilitarian grounds, but such a justification would seem very inappropriate. The argument could be discussed on its validity. It could be questioned whether a utilitarian perspective would indeed opt for organ lottery, but that is beside the point. Nobody really takes this argument seriously. It is preposterous to even consider that humans may be harmed in such a way to safeguard the greater good. The argument is delegitimized, rather than confronted.

The limits of the debate are at stake when arguments are dismissed and not confronted. In the matter of PGD it is very clear that some religious arguments are accepted, while others are simply rejected. The first method, to confront the argument on its qualities, has been particularly prominent when it concerned the status of the embryo. In Chapter 3 we saw how opponents of PGD for breast cancer argue in favour of the protection of the embryo. André Rouvoet and Esmé Wiegman, both prominent spokespersons for the CU, have pointed out that PGD requires IVF where spare embryos are likely to be destroyed. Because the embryo is very early human life but human life no less, it deserves to be protected, according to these politicians [27] [44] [45]. The status of the embryo is also defended by referring to its intentionality, its program of development which allows it to become a complete human being [47] [48]. So, while PGD might be used for good, it comes with the destruction of human life, which is intrinsically wrong. In ethical terms: the principle of nonmaleficence is invoked by the CU to overrule the principle of beneficence.

Responses to these arguments follow a typical way of argumentation outlined by Swierstra and Rip [19]. The argument in favour of the protection of the embryo is countered by suggesting that the principle of nonmaleficence does not apply in this case. Although human, this biological fact does not lead to the conclusion that it deserves to be protected, the argument goes. A prominent trope in these responses is the description of the embryo as a 'clump of cells'. Although human in its DNA, everything else that makes us human is not visible in a few cells. It does not think like a human, it does not feel like a human, and most of all, it does not even look like something human. Both religious and nonreligious people have proposed such views [38] [49] [50] [68] [72].

References to nature and measures that already come with the destruction of massive amounts of embryos are another way of suggesting that the principle of nonmaleficence does not apply. Nature is extremely wasteful with embryos. When nature does its work, most embryos will die too. The journey of the embryo towards babyhood is a dangerous one and most embryos will die long before they start to even look like a human. Why should we feel inclined to protect a few embryos on the idea that it is human life, while the entire existence of the human race also comes with the mass destruction of such embryos? [43] [50] [72] The argument becomes even more forceful when this meta-ethical argument of precedent reflects our own human actions. It calls in previous dealings with embryos and suggests that not only nature, but humans themselves have been responsible for the loss of many embryos. Particularly the use of the coil provides a powerful argument. In the Netherlands alone, many thousands of embryos are prevented from growing to become full little human beings by means of the coil. For decades, there has been no talk of mass murder nor has there been much concern about the loss of these embryos. To make fuss about the loss of embryos in relation to PGD seems to ignore the moral landscape of the society we live in [36] [39] [64] [65] [70] [71].

Many of the religious arguments rely on some perspective from the good life. People often feel that religious people wrongfully mingle in their private lives and, hence, responses to these arguments are less respectful than those arguments expressed against the deontological perspective just discussed. It is here that the limits of the debate are at stake. Section 3.3.5, which deals with arguments from a virtue ethical perspective, shows no arguments that confront the religious good life arguments on their validity, use, strength, plausibility, or any other way in

which arguments are normally countered. Instead, the arguments of the good life are dismissed. They are the mere opinions of religious people whose beliefs are not shared and, hence, whose opinions on the good life are not relevant, so it seems. In Chapter 3 I discussed the arguments about the role of the CU (section 3.3.7) in a separate section. In reality, this disapproval of the religious perspective is closely related to the religious arguments that rely on principles of the good life.

Those who oppose PGD are often sympathetic with the good life position of the CU. They feel that arguments from freedom, the protection of the embryo and the duty to diminish suffering, are only minimally useful in discerning what is troubling about PGD. Their concerns are about the type of society in which we want to live, what kind of people we wish to be, and how PGD forms a risk for these softer matters. The good life concerns of the CU are endorsed particularly in religious circles [38] [43] [45] [48] [53] [58] [59] [63], but also Hans Galjaard, emeritus professor in humane genetics, Annemiek Nelis, general director of the Centre for Society and Genomics, and René Cuperus, political columnist, have voiced doubts that implicitly support a good life position [39] [60] [64] [66] [74]. These actors are mostly concerned about the slippery slope and argue minimally from a good life perspective themselves. But the very fact that they worry about the slippery slope shows they have concerns for future prospects. Galjaard's position is particularly interesting because he has explicitly rejected the idea that the embryo itself deserves to be protected, a position he regards as untenable [39]. One can thus share the concerns of the CU without agreeing with their ideas on the protection of an embryo.

One of the concerns mentioned by the CU, and several others, focuses on the changing attitudes towards parents. They ask the question, "Will parents become responsible for the genetic deficits of their children?" Whether a child will carry a disease increasingly becomes a parent's choice. Furthermore, funding that choice with public money gives it a societal character. Society sends out a message: if you prevent your child from having hereditary breast cancer you make the *right* choice. From this perspective, it is argued, does it not seem likely that parents will increasingly be held responsible for the diseases of their children? After all, they could have prevented it [29] [30] [45] [58]. Another good life dilemma focuses on us, humans, as inventors and creators, who increasingly try to solve the problems of the world but simultaneously fail to see what else of value we might lose in the process. The problem is that it is difficult to see what is at stake, for these are soft matters while the benefits of PGD are hard facts. One question would be: how will PGD shape our perspective on the creation and mystery of life? Differently put, when human life becomes increasingly the product of human work, what could that mean for our attitude towards life and each other? [38] [53] [59] [60] [63].

The discussions on PGD have often been depicted as a religious versus a liberal conflict. That is largely the picture I have painted here as well. Although many of the arguments against PGD are indeed proposed by religious people, some of these appear to be acceptable to others. Particularly the distinction of Galjaard between the untenable deontological arguments from the CU and the appreciation for their concerns is telling. So is the commentary of political columnists René Cuperus who argues that one does not need to believe in a God to see how PGD might lead to a Brave New World [74]. Also on the liberal side of the dispute the arguments are heterogeneous. Not only liberal principles may plead for PGD, but a religious perspective can support the same cause. Based on the book Ezekiel, rabbi Elisa Klapheck proposed to have faith in progress rather than fear for new developments [49].

Most often though, the supporters of PGD try to set limits on the content of the debate. Arguments of the good life that question the use of PGD in the particular case of hereditary breast cancer are dismissed. They are not seen as relevant or appropriate. In Section 3.3.7, I have divided these responses into two categories. One way of dealing with this matter is to suggest that no proper moral argument can be derived from a Christian perspective. Another way is to portray the position of the CU as inherently undemocratic. Either the political party itself is too small to defend their position so rigidly, or it is simply seen as undemocratic because most of the people

do not support the position of the CU. Many have resorted to either or both of these responses [35] [55] [57] [67] [77] [83] [84]. According to these critics, the CU has a problem with the justification of their position. Along both axes, the CU refuses to be placed outside of the debate. First, the CU insists their position is compatible with democratic principles. They were democratically chosen, they formed a coalition and within the space and the tools of legitimate decision making, they are fully entitled to exercise their democratic right. Second, the CU sees no difference between their religious motivation and other sources of inspiration. In an interview, André Rouvoet referred to Locke and Rousseau to make clear that liberal politicians also have their sources of inspiration. For Rouvoet, a Christian perspective is no more dogmatic than a liberal one. Allowing all sorts of positions access to the debate is the heart of democracy. Destroy that and democracy itself is in danger [81].

Finally, there is another consideration that determines where the limits of the debate might justifiably be. Whether matters of the good life deserve to be taken seriously in the case of PGD depends on the argument of the slippery slope. This argument is important because the inclusion of hereditary breast cancer to PGD policy will not by itself change society in a very worrying way. The number of cases is simply too low to expect significant changes on a societal level. Furthermore, in line with Huntington's disease and Duchenne muscular dystrophy, breast cancer is seen as a very, very serious disease. But the matter becomes different when PGD clears the way for the introduction of other diseases to PGD. Therefore, much depends on the nature of the disease and the logic of justification by which hereditary breast cancer should be included. Is there reason to assume that a decision in this case will clear the way for the inclusion of other diseases and is it subsequently possible and not too farfetched that the good life-concerns point towards a dauntingly realistic future?

In the public debate, many focus on the slippery slope. Those who resist PGD for breast cancer emphasize that the nature of this disease places PGD into a whole new ballgame [38] [39] [43] [46] [53] [60] [64] [66] [74] [79] [87]. The shift from selecting for diseases such as Huntington's disease or Duchenne muscular dystrophy and now also for hereditary breast cancer is a shift from certainty to risk. The genetic mutation for Duchenne indicates the disease will, in fact, occur. The genetic mutations BRCA 1/2 only indicate a risk for development of breast cancer. A high risk, but a risk no less. Policy needs to be consistent with its supporting principles, which means so much as: if we allow this, we should make the same judgment for similar cases. The same logic that is responsible for the inclusion of breast cancer to PGD should apply for other similar hereditary genetic diseases too. André Rouvoet of the CU pointed out that a fundamental line is crossed with the inclusion of hereditary breast cancer [87]. Annemiek Nelis, general director of the Centre for Society and Genomics, suggested that the logic of the duty to diminish suffering will demand the screening for more and more diseases [66]. The idea is that there really are no more fundamental boundaries left. The logic that applies for a serious disease with an 80 percent chance also applies to a serious disease with a chance of 50 percent. The rules of the ballgame – to stick with the metaphor – will continue to change, for what is the difference between 50 percent and 40 percent?

If there is no slippery slope, it is far easier to point out the insignificance of the arguments from the good life. No longer do the arguments of the CU address serious concerns of an upcoming reality, instead they mistakenly ground their objections on a fictional idea of the future. Not only is it possible to say their concerns should be private and not public, but there is also little reason to take them seriously since the topic is nonexistent. While the slippery slope is about predicting and projecting the future, the conditions required to speak of a slippery slope are more concrete. Opponents of PGD have focused on the nature of the disease and the logical development of further selection in the future. Supporters of PGD have questioned whether such a development is likely. Christine de Die, clinical geneticist, made reference to the intensity of the procedure and the difficult decision for PGD. It is her experience that women do not take a decision for PGD lightly [75]. Hans Evers, professor in gynaecology, pointed towards past

experiences. In the years these procedures have been around, no further demands for less than serious diseases were made. Also, for prenatal diagnosis, which has been around for a much longer period than PGD, no such developments were observed [39]. Similarly, according to J.G. Nijhuis, gynaecologist, parents are no quicker to abort even though prenatal diagnosis allows for the detection of more diseases than before [71]. State Secretary of Health, Welfare and Sport, Jet Bussemaker, trusts the solid structure of the law and the current procedures. Every case is judged individually where sensible and careful judgments are made, it is argued [31].

Most of the debate on PGD focuses on 1) the status of the embryo as something that is intrinsically worth protecting; 2) the good life arguments, or the ‘thicker’ morality of the CU and their supporters, and; 3) the slippery slope, a necessary step for those good life concerns to acquire their relevance. The first point was heavily discussed, but within respectful limits. The arguments of the CU were accepted as the exponent of legitimate concerns. People may not agree with the specific view of the CU and have even convincingly argued that their perspective is outdated, but those ideas were always a direct response to the arguments of the CU. The focus on the second point was a display of disagreement on the limits of the debate. The CU felt they should be able to voice their specific good life ideas, while others did not even want to take them seriously and dismissed them. The third point was widely discussed. The slippery slope is a necessary step for the good life arguments to carry any weight. But because the legitimacy of those arguments was denied, the slippery slope was viewed to be little more than the trick of a con artist in a final attempt to convince the audience. The following section will discuss the first two points with Rawls’s theory on the public debate. The section afterwards focuses on the role of the slippery slope.

### **4.2 Rawls, religious arguments and the limits of the debate**

Many political thinkers and in particular liberal philosophers have argued for some version of religious restraint. Government officials and citizens should not try to justify coercive laws by appealing to some sort of religious rationale. That would be a disrespect of one’s fellow citizen because they might not share the same grounds of faith. So, citizens should only appeal to those values that they share and/or understand. Depending on the philosopher that opts for the theory, there are some fine distinctions detectable in their views.

Robert Audi argues that secular (nonreligious) reasons are the only acceptable kind of reasons to foster the separation of church and state. Just like the state fosters the liberty of religious practice, religion should not try to interfere in the affairs of the state. Citizens owe each other good reasons for the policy they try to impose on one another, and a reason that derives its truth from a religious point of view cannot be considered a good reason [88]. Rawls’s theory is more strict than Audi’s and more comprehensive too. Not only should religious reasons be excluded, but any reason which is not an expression of shared values should not inform coercive policy (read: matters of basic justice). By this standard, utilitarians, Marxists, neoliberals or perfectionists should also be careful with the reasons they propose. One can be sure that one’s fellow citizen shares the values of freedom and equality and has a sense of justice. Only reasons that are direct expressions of these values or reasons that aim to preserve them are proper arguments in matters of basic justice. If religious reasons can satisfy these demands, Rawls would see no reason to object proposing them in the public domain [3].

The arguments against the use of PGD can be reviewed according to the demands of public reason, as proposed by Rawls and explained in Chapter 2. Placing these arguments in the context of the theory of one of the most influential political philosophers of the 20<sup>th</sup> century could provide an intriguing perspective. Public reason is a strict theory but, simultaneously, it is a particularly forceful one. Christians, Kantians, atheists—people from all sorts of backgrounds—are all

compelled to accept that their own truths are not always shared by others in society. It requires citizens to respect one's fellow citizen as a free and equal individual. That respect is best fostered when one lives up to the criterion of reciprocity. According to this criterion it would be unreasonable to justify coercive policy, or matters of basic justice, by those reasons which one can expect another *not* to endorse. That is the heart of public reason and it is a very powerful principle. Political Liberalism really does not need to convince people that they ought to live up to the criterion of reciprocity. If citizens in a pluralistic society value democracy with its pillars of freedom and equality, they see it as only normal that they do not try to enforce their comprehensive worldviews upon others. Instead, really important matters of justice are only decided by appealing to those shared values such as freedom, equality and the general workings necessary for democratic society to prosper.

Consequentialist arguments and arguments from justice have played a minimal role in the debate on PGD. Moreover, the arguments that were proposed showed little signs of a religious sensibility. Thus, the focus is on those arguments that reflect deontological ethics or good life-ethics. About deontological arguments, it is no secret that conservative Christians dearly value unborn human life, often from the moment of conception. In a parliamentary debate in 2001, André Rouvoet, at that point Member of Parliament for the CU, cited from Psalm 139, an important source of inspiration for Christians to protect embryonic life. In the debate on PGD this source is not mentioned. Nor did the CU make reference to any Christian source of belief whatsoever. Nonetheless, that an embryo deserves protection is exclusively argued by people with a Christian background like André Rouvoet [27] and Esmé Wiegman [44], both spokespersons for the CU<sup>39</sup>, Henk Jochemsen [46], the director of Prof. dr. G.A. Lindeboom Institute, a study centre for a Christian oriented medical ethics, and R. Seldenrijk [47] who wrote a book in which he combines the rejection of homosexual praxis while accepting that people can have homosexual feelings.<sup>40</sup> A position that is often endorsed amongst conservative reformed Christians.

Interestingly, *Nederlands Dagblad* and *Reformatorisch Dagblad*, the two Christian national newspapers that reported on the matter, did contain articles with references to the Bible. However, not so much with the intention to support coercive policy but to question the fundamentals of their own Christian position. Koos de Geest, a general practitioner, argued for a less conservative Christian view on the status of embryos and used religious scriptures to support his point. In *ND*, de Geest argues: "Psalm 139 says: 'For you created my inmost being; you knit me together in my mother's womb (...) your eyes saw my unformed body. All the days ordained for me were written in your book before one of them came to be.' Jeremiah 1:4-5 says: 'The word of the LORD came to me, saying, Before I formed you in the womb I knew you, before you were born I set you apart.' (...) The Bible and the tradition offer space for a vision that the early embryo is the material from which a human can develop during the pregnancy. Although the early embryo should be protected, it cannot have the same rights as a human" [51]. After the government took the final decision to include hereditary breast cancer in PGD [26], *RD* engaged in an intensive discussion on the status of the embryo from a Christian perspective. Also here, the idea was not so much to influence policy but to discuss its own religious position [47] [89] [90] [91] [92].

In Section 4.1 and in Chapter 3 we saw how supporters of PGD are willing to accept deontological arguments of the CU as legitimate concerns. Although these arguments are not endorsed on the liberal side and they feel it is outdated to protect the embryo on deontological grounds, the arguments of the opposition are nonetheless accepted as genuine and proper concerns. The arguments are discussed and are therefore treated as legitimate, though mistaken, points of view. Now, when those arguments are reviewed in light of the demands of public reason, the conclusion is the same. Rawls would feel it is completely legitimate to argue for the protection

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<sup>39</sup> On the website of the CU the official position of the party was described as one that considers embryo's to be early human life that must be protected [45].

<sup>40</sup> *Als je je Anders Voelt* (2005).

of unborn human life. To show respect to one's fellow human citizen is crucial to the idea of reciprocity. A lack of respect for human life might endanger the relation of citizens as cooperating members of society. How that respect is best served can be discussed because the principle can be interpreted in different ways. But the fact that religious people find their inspiration for the protection of all human life in the Bible, including an embryo, makes little difference. For Rawls it is important that they can support their ideas with relating political values.

Section 4.1 also explains how the general discontent with the position of the CU relates to their thicker and more comprehensive views on life. People with a liberal point of view feel it is unjustified if religious views are imposed. But in Rawls' view, the good—which also includes the religious perspective on the good—is not simply a matter that must be excluded from the public forum. Ideas of the good may be freely introduced if they express proper political values. That is what Rawls calls priority of the right.<sup>41</sup> So what would Rawls say about the CU's good life arguments in the debate?

The website of the CU stated that the continuous efforts to eradicate disease in every way possible might lead to a society that is hostile to people with a disease, handicaps or congenital defect [45]. I will not repeat their and their supporters' specific statements, those can be found in Section 3.3.5, but they can be summarized as follows: When it becomes acceptable to prevent disease by technologically preventing people from existing, we run the risk of creating a society which is hostile to people with a disease. Subsidizing the matter sends out the signal that society feels children with a genetic defect should not be born. What will that signal mean for the role of the parents, burdened with the choice to do what is best for their children? And how will children with a genetic defect be looked upon when someone else without that defect could have been born in their place?

To continue, in an article in *NRC*, Roel Kuiper, member of the Senate for the CU and professor of reformational philosophy, elaborated on a Christian good life perspective. To summarize a long contribution, Kuiper plead for a Christian-like humbleness towards the miracle of creation. People who stand in awe of life do not exploit it but respect what has been given [63]. Kuiper's point forms a bridge to the 'we should not play God' argument. While arrogantly trying to control and manipulate nature to the fullest of our technological potentials, we allow ourselves to be blind for other matters of importance. While scientists are fiddling with the origin and workings of life itself, which used to be the domain of God, they are simultaneously reshaping the world. What will that world look like and how will we fit in it? These new technologies reshape our morality and that does not seem like a desirable perspective. The aspiration to prevent disease by all means possible might very well end in tragedy. While trying to help people, these technological advancements are likely to endanger human relationships. By means of PGD people may no longer be seen as intended and desired persons. What will be the meaning and experience of life in that world? The Christian perspective holds that meaning will be lost.

Now, how would Rawls feel about these Christian worries? The answer to this question depends on whether the arguments of the CU and those who have endorsed similar opinions are properly political. For the above good life arguments to qualify as political, they need to express or safeguard those values of which one can reasonably expect that other reasonable citizens will endorse. People do not need to draw the same conclusions and they do not even need to support the argument of the CU. People can disagree about an argument and weigh it differently while simultaneously accepting the opposite position as legitimate. Rawls has argued that although people can have very different views on the good society and the whole of life itself, they, when reasonable, will still reason according to the principle of reciprocity. That is one's citizen's duty towards another citizen.

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<sup>41</sup> For a fuller account of how this works, see Sections 2.3 and 2.5.

The question becomes: did the CU, with their (religious) good life ideas, cross the limits of public reason? Have they proposed any arguments of which they could reasonably expect others to reasonably accept as legitimate (or reject as illegitimate)? The Christians have argued against PGD because they fear for a loss of solidarity with parents and children. Solidarity can be seen as one of those binding factors for society to function. It refers to the relation between citizens and how citizens should treat one another. A sense of solidarity, the argument could go, reinforces the idea of citizens together trying to cooperate in society, which is a fundamental principle in Rawls's idea of a cooperative democratic society. Without solidarity, this idea might very well be in danger, thus, an argument against PGD to preserve the value of solidarity is appropriately political.

Another argument put forth by Christians concerns the appropriate awe-inspired humbleness one should hold for creation. Should we indeed be humble and is that a political value? Probably not everyone will feel that humbleness is a suitable way to deal with new technologies. Perhaps bravery is more in order in these times, particularly against the background of great problems such as climate change, overpopulation and the depletion of fossil fuels. But the fact that other people might not agree with a humble attitude does not render it illegitimate any more than an argument in support of one's freedom to use a car delegitimizes environmental policy measures that tax the use of cars. What is important is that the argument from humbleness supports or expresses a political value that one can expect to be shared by all citizens. Here, just like the deontological argument the Christians endorse, the political value is that of respect towards human life. While the deontological argument expressed this value in terms of what an embryo deserves because it is an embryo, the good life perspective comes from a different angle. To respect the miracle of life is to be humble towards it. It is about having doubts about one's own capacities to change society for the better. It is about worrying how our own character and identities are shaped when PGD is allowed. To show respect for human life as an embryo, to be humble before its creation, is to show respect for human relationships and for human society. It is also to accept that a technological fix may threaten these soft matters that make society worth living in.

Do people need to agree with this humble attitude to make it a proper political statement? Not at all. It is about the proper political values that are expressed or supported by a humble attitude. To show respect for human creation could very well be interpreted as being humble towards it, no different than fostering that respect by selecting life and diminishing suffering. The supporting principles are, of course, different and to say that one should be humble is in itself a hollow statement. The Christians have connected this point to concerns about human relationships and human character and the society we seek to live in. Because these matters such as solidarity and humbleness are tools to nurture the cooperative society where people are seen as full and intended free and equal persons, they can be seen as legitimate political concerns to bring into a debate.

Supporters of PGD are likely to have a different view on how respect for a human being is best served. By dealing with disease, by taking away the misery that hereditary breast cancer inflicts on current and future generations, the human being is respected best. Also by allowing people to make their own choice in this matter as free, rational and moral human beings, respect is shown for people's autonomy. To decide that people cannot make use of PGD would be a lack of respect for those people who wish to save their children from genetic burdens. However, that people endorse these opinions and disagree with the Christian view on the respect for human life does not render their arguments illegitimate in the way Rawls would judge it. Just like the value of freedom could have a positive or a negative interpretation – 'freedom to' and 'freedom from' – about which people may argue freely [93], the value of due respect for human life can also be interpreted in multiple ways. Some interpretations may fit better against particular moral or political landscapes. And surely, the elimination of disease and the respect for people's autonomy, both fit perfectly within the secular development in the Netherlands over the past decades. It would, however, be wrong to conceptualize other views on the due respect for human life as illegitimate.

### 4.3 The role of the slippery slope

It is often unclear how the argument of the slippery slope works or how it can be appropriately applied. The argument frequently shows up in debates, often in absurd ways, sometimes fittingly. The slippery slope is a complex argument indeed, but it basically comes in two forms. In its strongest form, the argument suggests that action A initiates a domino effect that will inevitably lead to outcome Z. Not rarely do these arguments portrayed to be the words of a prophet. Such arguments are usually fallacious, for it is unlikely that all the steps in between are necessary steps. In its weaker form, the argument suggests that action A provides a justification for further steps all the way down to outcome Z. Here, the outcome does not necessarily follow from action A, instead, the slippery slope argument in this form suggests that outcome Z has become a realistic scenario. Depending on the number and the likelihood of the intermediate steps towards Z, the argument of the slippery slope gains or loses strength.

The slippery slope plays a key role in determining whether the good life-concerns are mostly fictional or point to some disturbingly realistic future. But slippery slope arguments about PGD are received with a great variety of criticisms. Are the critics right and is the CU grasping at straws or is there reasonable ground to take their concerns seriously? One type of criticism, expressed by columnist Elsbeth Ety, interprets the concerns of the CU as the future telling where the CU arrogantly claims a wisdom they could not possibly know [77]. This criticism mistakenly interprets the arguments of the CU as a stronger version of the slippery slope. Professor Herman Philipse, philosopher and atheist, provides a second type of criticism which does not counter the existence of a slippery slope but suggests that it is inherent to politics to govern that slope [94]. It can be agreed to that the existence of a slippery slope does not lead to the conclusion that a specific policy should be abandoned. That, however, does not really delegitimize the slippery slope as such. And if it indeed really is inherent to politics, this merely suggests it is something real that needs to be taken seriously.

The third and most wide-ranging line of criticism focuses on the applicability of the slippery slope. The CU uses the slippery slope to portray possible societal and moral change which many people would call undesirable. But, as came forward in Section 4.1, critics suggest this scenario is a bit farfetched. The careful attitude towards life in society and the daily practice of PGD clearly show that nobody really wishes to include genetic defects which aren't life threatening or only indicate a minor chance of developing [39] [71] [69] [76] [78]. Parents do not ask to screen for less than very serious diseases. In thirty years of amniocentesis in the Netherlands, no such trend has been shown. Why would PGD be any different? Moreover, it is a difficult procedure. Parents do not take such a serious step for a less serious hereditary genetic defect [38] [39]. Finally, references are made to the solid measures taken right now. When laws are put together with the greatest care, no one needs to worry about the slippery slope [31] [35] [77]. In general, these lines of criticism suggest there is far too much common sense among the people of the Netherlands to fear for far-reaching genetic selection.

These responses seem to assume some kind of independent wisdom within Dutch society. They assume a Dutch morality that is lifted above those of other countries and one that will remain fixed during changes to come. Ethics does show some rigidity. The millennia-old principle of reciprocity is arguably the foundation of most ethical thought today. But the use of ethical principles surely is highly contingent and develops over time. The world changes, society changes, people change, and morality does not stay behind. The study on the interaction between ethics and technology shows how technology is also very capable of influencing morality. The birth control pill not only empowered women, but also helped to make sex for pleasure acceptable beside sex for procreation. And the recent controversy over illegal downloads is not just a matter of right versus wrong, but is equally a conflict between morality condensed in laws that guarantee a right to property and the duties one can expect a citizen to uphold. Is downloading a film

illegally really as bad as stealing it from the supermarket? Intellectual property could very possibly become a fluid concept as a result of the facilitated ease with which information spreads.

PGD, if widely applied, could change morality in a very significant way. A first hints towards such developments have, strangely enough, been given by supporters of PGD in the debate. Decades ago it could have been a perfectly consistent argument to oppose the use of IVF or the use of the coil as a measure for birth control on the grounds that an embryo deserves protection because of its intrinsic qualities. But nowadays, the status of the embryo is partially determined by the normalization of these technologies. How can one still consider the embryo intrinsically worthy of protection, no different than a human, without being outraged about the biggest 'mass-murder' of all time? Rightly, these arguments have been proposed to counter the deontological perspective of the CU. But at the same time, it also becomes clear how the morality of the doctors, the patients, the politicians and the public is influenced by these developments. The fact that people refer to the developments of the past decades for support of a particular moral view shows how technology influences morality in a very definite way. Indeed, the deontological argument of the CU is problematic. But this necessarily also means that technological developments have a tremendous influence on the things we feel are acceptable or meaningful. No doubt, it is naïve to expect the current Dutch moral attitude to steer all future technological developments.

It is also argued that the slippery slope is not applicable because the PGD procedures are very complicated and intensive. No one would undergo such a procedure for lousy reasons. But does this really defy the idea of a slippery slope? First, it is not at all certain that these procedures will remain as difficult as they are now. But moreover, should one put the faith of morality and our future dealings with technology into the limits of current technology? That is not a very reassuring thought considering past technological developments. It is also awkward because usually it is scientists in the medical sector who try to secure funds for research on the basis of technological developments and promises. No limits are perceived when funds are needed for projected therapy of cancer, Alzheimer's, or vascular diseases. If only enough money and time is given, treatments and cures will become available. If this is the usual rhetoric in the world of medical research, does it not seem inappropriate to use a new set of arguments which is exactly the opposite of their previously endorsed arguments?

More important than pointing out this opportunism is, again, the moral rigidity that is assumed when it is expected that people will not desire to use PGD for lousy reasons. What exactly would count as a bad reason and would that same judgment be made in twenty years from now? The point that an appeal to the slippery slope makes, is that to allow PGD for hereditary breast cancer does justify further steps down the road of eliminating disease by use of this technology. Those steps in turn justify further steps. Continuously a precedent is created to go one step further, for there is no real difference between a disease with a 60% or 55% chance of contraction and one with a 40% or 35% chance. Can anyone at all distinguish a good from a bad reason at any point down the slippery slope? All intermediate steps are reasonable steps and while our current morality tells us that a 10% chance for transferring a disease might be a lousy reason, this thought slowly evaporates with the inclusion of every new disease.

In the beginning of the debate when the initial decision was made to allow PGD for hereditary breast cancer, State Secretary of Health, Welfare and Sport, Jet Bussemaker, rejected the argument of the slippery slope. She referred to the new solid policy measures to determine whether a case is eligible for PGD. Some firm criteria have been formalized which require a very thoughtful assessment of each individual case [31]. Bussemaker is probably right when she feels that good criteria have been established. This, however, does not undo the problem the slippery slope poses. Even though it is a perfect example of how society can manage the slippery slope and even though the current criteria would not allow the selection of a disease with only 10% chance of contraction, the logic of the slippery slope remains unaffected. By taking the step to allow for

the selection of hereditary breast cancer, a justification is created to allow for similar diseases to enter the procedure. Once the boundary from certainty to chance is crossed, a reason has been given to include other diseases with only a chance of development over life. Morality changes, policy can be adapted and new secretaries of state are installed with upcoming elections.

### 4.4 Conclusion

Some remarkable conclusions have been drawn in this chapter. First of all, the complaints about the role of the CU and their desires to impose their specific worldviews upon others are overshadowed by the political character of their arguments. Rawls, who proposes a rather strict but reasonable theory on the public forum and their limits, would see no problem with the position of the CU. Rawls also does not appreciate stubborn religious fundamentalists who do only what the Bible tells and show no concern for other views. But, because the CU advocates in fact base their arguments exclusively on grounds that express political values, values of which it might be expected that other citizens share, it should be asked what the problem really is?

Secondly, the slippery slope is shown to be a valid argument in the debate on PGD. The change from certainty to chance by including the genetic mutations BRCA 1/2 gives way to the argument of the slippery slope. The most pervasive criticisms claim the slippery slope is not applicable in this situation. The argument for this position is to say that people simply have too much sense and the PGD procedures are too demanding, making it very unlikely that people will wish to make use of PGD for anything other than very serious diseases. The problems with this type of argument are: 1) What counts as a serious disease can change over time; 2) morality changes over time. To project current moral sensibility into the future is naïve, so much should be clear from the study on the interaction of technology and morality, and; 3) It is, to say the least, somewhat awkward to put faith in the limits of current technological procedures. This conclusion is important, for not only are the good life concerns now properly political, but there is also reason to take them seriously. To recognize the slippery slope as a valid argument does not at all mean that we are in fact heading towards a Brave New World where all meaning is lost. Instead, it makes it reasonable to believe that the use of PGD, when widespread, can very well lead to undesirable changes in society. Instead of dismissing the religiously inspired good life position, it should be explored.

This chapter has played a key role in disentangling a restrictive view on the main question: can religious arguments be valuable according to an analysis of a debate on PGD? If an argument should lead to the conclusion that the religious arguments of the CU are not valuable, it cannot be reasonably held on restrictive grounds. Accepting Rawls's theory as authoritative, there is no reason to exclude the arguments forwarded in the debate on PGD. But to make an appealing case to say whether religious arguments can indeed be valuable, a positive account is necessary. The following chapter will discuss the value of the Christian perspective. If the religious arguments make an appealing case for a 'shared wisdom', the main question can be answered positively.

## Chapter 5

# Overlapping Wisdom

Until now I have tried to dismantle the self-assured attitude of both the Christians and the more secularly oriented people. Christians might all too easily find it acceptable to bring their religious beliefs into the public domain.<sup>42</sup> Rawls, however, has made a very appealing case that there are limits. Christians, like any other group, are first and foremost citizens of a society in which other people do not always share their views. Therefore they ought to restrain themselves not to impose the whole truth as they see it in the public debate, but only to forward views that can find support among people who do not share their doctrine of faith. On the other side, the liberals appear all too confident that religious views hold no value whatsoever. Moreover, the liberals have all too willingly depicted Christians as fundamentalists that try to tell other people how to live their lives. By analysing the debate it became clear how this picture does not reflect their actions.

But there is more. To ask whether religious arguments can be valuable is a tricky question for it is difficult to decide on the rationale by which the respective value should be measured. Relying on a normative standard runs the risk of only convincing the liberals or the Christians. After all, they are in disagreement about what is and what is not acceptable, and hence, they already endorse some sort of normative view. In a very Rawlsian way, the standard will therefore be of a pragmatic kind. In PL, Rawls accepts the multicultural society as a fact and accepts that there are many rational outlooks on life and everything else. But when it concerns the fundamental relation of citizens who govern themselves, only a limited amount of ideas can reasonably be held. Only ideas that reflect fundamental values that are inherent to democratic society such as freedom and equality are acceptable as legitimate support for matters of basic justice. By virtue of its pragmatic character, the idea of PL can be upheld as normative because it takes neutral, or mutually acceptable, ground between competing views. There is, in Rawls's terminology, an overlapping consensus.

Similarly, a plausible argument for the value of religious arguments would be particularly forceful if it would be the focus of an overlapping *wisdom*. Chapter 4 shows how religious arguments are proper political arguments and can thus be the focus of an overlapping consensus. The discussion on the slippery slope clearly demonstrates that they deserve to be discussed rather than dismissed. This chapter – the chapter you are reading – takes on the task of exploring the good life concerns on PGD. In Section 1.2.1 I presented Leon Kass and Michael Sandel as thinkers who worry that our moral vocabulary is not well equipped to deal with all matters of importance. They worry about the drive of new technology and the loss of values, particularly where new technologies help to reconceptualise our ideas on human life. They hold that talk on rights, duties, consequences and justice is too shallow to account for the challenges that technologies like PGD bring. This chapter aims to identify the area where those arguments of rule ethics offer little guidance. Very importantly, in the debate it was suggested that ‘we’ have too

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<sup>42</sup> Although the previous chapter showed how the Christians of the CU respect the limits of public reason, it has also been argued that they are just as much entitled to bring their religious views into the debate as a liberal is entitled to appeal to a liberal source of inspiration [81]. Although Rawls would not deny it is their right to do so, they *ought* to act some restraint when their views do not support or reflect political values.

much sense, too much wisdom, to allow for a far-reaching selection of embryos. This chapter asks whether such wisdom can be found in rule ethics or perhaps relies on an idea of the good life.

The controversy over PGD opens up new spaces for deliberation and may require a different approach than other ethical dilemmas. It is not at all certain that methods belonging to rule ethics can properly address the problems this technology poses. The following sections work towards an exploration of this idea. First, the role of technology in society will be discussed. Over time, many philosophers and social scientists have tried to understand technology. I intend to give a short overview of twentieth-century thought on technology to see how it raises concerns and how we should understand the role of technology nowadays. Section 5.2 focuses on the general attitude that PGD is only warranted for very serious diseases and asks how this attitude can be fostered. Section 5.3 discusses those values that inform the case of PGD and Section 5.4 addresses the ways in which the acceptance and rejection of the different principles influence our future dealings with PGD and assesses whether religious arguments can be valuable. Finally, Section 5.5 draws lessons for public deliberation.

### 5.1 The role of technology

Technology is part of the human condition. From early times on, humans have used their intellectual competences to deal with nature's challenges. Spears were crafted for hunting. Knives for cutting. Needles for stitching. The more humans surrounded themselves with their own inventions the further they came crafting a variety of technologies. Challenges from nature were complemented by challenges from society. Bureaucracy is needed to govern the masses. Spears or guns are needed to wage war. And sewage systems are very useful to prevent the spreading of disease. The final and most modern type of challenges come from within. These challenges refer to our emotions, our will to understand, our autonomy to choose. In short, our desire to find out and control. Against boredom there is television. For muscle ache there is tiger balm. For electricity there are fossil fuels or durable resources. Starting with the urge to survive, man invented stone technology and the power to wield fire. Now, a few million years later, technology is part of daily life and daily life has changed because of it.

In many ways technology has improved human life. Without it we would lead shorter lives in a smaller world. Those who like to read *The Hitchhiker's Guide to the Galaxy* should surely appreciate the invention of ink, paper, printing, or the trucks and roads to transport the book, the lights under which it can be read, the power plants which supply the electricity or the coal diggers to provide the fossil fuel. The point is, without technology, there is no fine arts and certainly no books. And without technology I would not have devoted these few lines to show my gratitude to Douglas Adams, let alone write the remainder of this thesis. But to be very, very clear, without technology there would be no society and possibly even no humanity. Technology is good. Now the blessings of technology have been praised sufficiently, the road ahead is free to address the more interesting part of technology. The part of technology which provides us with challenges.

Air pollution. Ozone depletion. Nuclear war. Climate change. These challenges are intimately connected with the further advancement of technology. They are practical problems though, and the solutions to which, although sometimes difficult to achieve, are often clear. The depletion of the ozone layer can be managed by reducing the emission of freons and halons, and the prevention of a nuclear war 'merely' needs some international goodwill. While these challenges are serious and concern us all, they simply need to be governed appropriately. There is nothing mystical about these undesired consequences of technology. They are for all to see and when such challenges are not addressed appropriately, this is in essence a failure of human agents. The problem is not technology as such, but society's inability to take adequate action.

According to many a philosopher the problem of technology runs much deeper. For one, Jacques Ellul argues that technology itself demands the ordering of society according to its own rationality which is always done in service of greater efficiency. But efficiency is also the trademark of technology so that makes this is a matter of begging the question. For Ellul technology is an autonomous force, but by no means does this circular argument explain why this is so ([95], p. 194). Differently, Martin Heidegger understands the problem of technology in its relation to nature; that which is 'concealed'. Technology is a way of revealing or unclinking the world. It makes the world accessible, but does so in a very particular way. It forms a bridge between the human and the world, but in doing so the world is not merely revealed, but is 'ordered'. Technology dictates nature to show its secrets. But whatever is found is never the true being of what was really concealed. Therefore it is not so much a matter of revealing what technology does, but it is an ordering. The world is approached as 'Bestand', as standing reserve, as raw matter for manipulation. For Heidegger, just like it becomes more difficult to uncloak the world as anything else but raw matter, humans themselves run the risk only to be understood as Bestand ([95], p. 63-71).

Both Ellul and Heidegger understand the problem of technology as something that is innate to technology. For Ellul, technology comes with the reconfiguration of society where people are reduced to mere cogs in a machine in service of greater efficiency. Heidegger understands the problem of technology through the relationship humans have with the world. Technology discloses the world in a specific way and this type of relation also endangers humans to exist as intended persons instead of raw matter. Both philosophers rightly go beyond the perspective of desirable and undesirable consequences and try to look at what technology really does. But in that assessment they reduce the role of technology to something abstract. In doing so, these philosophers fail to see how technology does not simply determine life, but offers opportunities to interact with society and with the world. In interaction with technology, these thinkers believe people are assimilated or blinded by it. While it is true that society sometimes looks very much like a machine and technology does influence the way we look at the world, this does not mean we become the cog in the machine nor does it mean that technology prevents meaningful existence.

As a general rule it would be good to distrust any view on technology that reduces it to a specific conception of it and tries to draw inevitable conclusions from it. Technology works on society and it is philosophy's task to figure out these relations. The story is different for different types of technology. Some technologies can resemble Ellul's view, such as large industrial factories with conveyor belts or bureaucratic tax systems that conceptualize the citizen according to its financial contribution to society. Other technologies, such as the hydroelectric power plant fit well within Heidegger's view such as the power plant that orders nature according to techno-logic. Nature here is approached in terms of its function, its potential to provide electricity. This all does not mean that technology is good or bad, but it does help to understand it better and to see how it affects human beings. Coming to terms with the specificity of different types of technology is crucial if we are to understand its role in society. Particularly for controversial new and emerging technologies, such steps will have to be made for there is much at stake.

Heidegger and Ellul saw technology essentially as a problem, as something inherently dangerous and out of our control. In response to these views, social scientists delegated autonomy back to the people. Technology might sometimes appear to be autonomous, but this results only from interests, networks and engagement with the technology. With the well known example of the bicycle, Trevor Pinch and Wiebe Bijker show how different people themselves define technology differently, and thereby influence its development in different decisive ways [96]. A bit differently, Bruno Latour, understands the interaction between people and technology as one of equals. Both are *actants* and are capable of engaging in networks [97]. The historian Thomas P. Hughes takes middle ground (sort of) between the idea of autonomous technology and the idea

that people are in control. Hughes developed the thesis of technological momentum and argues that although technology can be steered early on, as time passes, it gains more and more momentum making it increasingly unstoppable like a speeding train [98].

More recently, philosophers of technology and researchers on the interaction between science, technology and society turned their focus to technology itself. In the tradition of Heidegger and Ellul, postphenomenological philosophers like Don Ihde and Peter-Paul Verbeek look at what technology actually does. Of course, without making the mistakes of their predecessors. They understand technology in relations and how this relation should be seen depends on the person, the technology and the world. Both the subject and the object are not merely related to each other but they help to shape and constitute one another. Just like many modern gadgets are used to establish someone's identity, or how a pair of glasses offers a different perception of the world. Technology has no essence of its own (or at least, no essence that we know of), nor is it merely the result of social construction, but technology *works*. Depending on the social context *and* the technology, technology acquires its meaning in society [95].

Technology and society are engaged in a dynamic process of mutual interaction. To understand how this process develops one needs to accept there is no force that is a priori in control. The role of technology in society has become highly contingent. A multitude of factors play a role, such as geographical situatedness, perception of technology, or the moral landscape against which technology develops. But also from a technological perspective it can be asked what specific technologies really do and how they work on people. This means that insights from both science and technology studies and the philosophy of technology help to shape a narrative about technology. The role of technology has become a complex story but it has also become a story that reflects common sense. No, we are not slaves of technology. Yes, we should be careful with new and emerging technologies because they sometimes come with great uncertainty and great consequences. No, we are not always able to be aware of all of technology's implications. But yes, we can make scenarios and estimate how present attitudes help to shape the role of future technologies. It is this attitude that will guide the reflections on PGD in the following sections.

## 5.2 Future PGD: 'We know better than that'

If there is a problem with PGD, it is a moral problem. The application of PGD knows its practical problems and one of them would be the fairly low success rate of pregnancy. Another practical problem would be the demanding procedure for women, which in itself might be a reason to refrain from it. But these problems are not the reasons for the emotional debate in the spring of 2008, and are certainly not the problems I am interested in. The debate started with a difference of opinion in the Dutch government. State Secretary Jet Bussemaker issued a letter to the parliament in which she said that the genetic mutations that are responsible for a serious form of hereditary breast cancer would be included in PGD procedures. Deeply valuing the sanctity of life and not being informed by Bussemaker, the CU pulled the brakes and Bussemaker had to withdraw the letter. The CU questioned the use of PGD because they considered it morally problematic. In response, many considered the position of the CU itself to be problematic.

For some, the fact that embryo selection also comes with the destruction of embryos means that it is wrong, no matter what the benefits are. The problem of PGD is here that early human life is destroyed, a problem that appears to be inevitable with the procedures. Those who endorse this position can never see PGD as a truly humanitarian tool. But also, at the other extreme there are those who see no problems with the selection of embryos. For these people, an embryo is a just a bunch of cells and it would be silly to attach any moral conclusions to it. Other possible problems focus on the possible injustice that might come with PGD. Particularly members of parliament expressed fears for injustice to those who carry diseases that could have been prevented. While

such concerns are real, they do not immediately point to a problem. First of all, the matter is highly hypothetical. Second, justice issues about PGD do not opt for current actions. Whatever unfairness might occur in the future can be dealt with in that future.

But there is another type of concern which is more difficult to define because it seems to be so vague and abstract. This type of concern, argued by those who have doubts about PGD, appeals to our hesitation about a future society where the use of PGD has become commonplace. They wonder whether decisions made today lead up to future steps towards that scenario. A perspective which nobody, as of yet, seems to favour.<sup>43</sup> Section 4.3 on the slippery slope shows how actors in favour of PGD explicitly and implicitly argue that PGD will not become commonplace. By refuting the concerns that a decision on PGD opens the door for similar future decisions, they hold that embryo selection is something exceptional. They argue that PGD is not something that would become an ordinary part of dealing with disease but is only applicable in cases of very serious suffering. What decisions are made today do not support future decisions on other genetic transferrable diseases or conditions like autism or hay fever. Basically, these arguments rely on the idea that ‘we’ the society, ‘we’ the doctors, ‘we’ the politicians, and ‘we’ the citizens, have too much common sense to let this happen. Nobody argues for such a society, so why be suspicious that it is could be our future?

In the section on the slippery slope I argued that this attitude is fairly naïve. Morality is not a matter that is fixed and settled for all eternity and we might think differently about PGD in a couple of decades. Nor is it merely the result from pure rational reasoning. In interaction with the environment, whether that concerns people or things, or both, we continuously redefine our morality. These processes generally go slowly and only in retrospect by means of sociological, philosophical and historical studies, we are able to identify a morality from the past, and moreover, we are able to contextualize it in the appropriate timeframe. This second part is important because it helps to realize that the development of morality need not be a one-way street from what we would consider right or proper at this exact moment in time. In retrospect, it is difficult to see when, if ever, we were more moral than we are today. But overconfidence is not in place for it is difficult to see how present ideas will inform future decisions. Rather than refuting the slippery slope, we should explore how present attitudes help to shape future developments.

Possibly nobody ever wishes to make genetic selection a common and widespread process in reproduction, except for the occasional radical viewpoint.<sup>44</sup> Possibly PGD will never become a standard procedure. Then, if this wisdom is shared among the people in society, one can expect that people endorse expressions of that cautious attitude. It would be perfectly fine for that attitude to favour genetic selection in some cases. But more importantly it should also provide the argument against selection in other cases. The idea that we are wise enough to make the right decisions about these matters should be grounded in a balance of principles where at some point down the slippery slope, we will say ‘no, this has gone far enough’. If ‘we’ indeed carry that sense and sensibility to make those decisions, it should be asked which values and principles are supportive of that attitude.

I believe that proponents of PGD have difficulties arguing against the use of PGD at any point down that slippery slope. Their wisdom to allow PGD only for very serious diseases finds little resonance in the values and principles they argue by. To support this thought, I will use the debate to identify how certain arguments support far-reaching selection as opposed to a sense of wisdom to stop at some point. It is my contention that their rule ethical style of reasoning does not support

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<sup>43</sup> Besides the occasional overly optimistic philosopher.

<sup>44</sup> In these discussions, a few rare examples are often introduced of a son suing his parents for not being aborted or a couple asking for far going medical measures for only a minor genetic inflection. These examples stimulate our imagination, but they hardly are indicators for moral change. In every society some people are exponents of the most radical position one could imagine. The fact that such cases exist is more an example of the inherent plurality in the massive world-society than an indicator of changing attitudes.

the wisdom they proclaim to have. If PGD proponents at all wish to ground their sense of wisdom in solid principles, they need to turn their focus to those who have opposed PGD. This is no easy request. Yet, if they are serious about their feelings on the selection of embryos, they can find solid ground for their ideas without needing to accept the dogmatism they identify among the opponents of PGD. A reorientation on the idea of human respect can be the focus of a shared wisdom on PGD. This reorientation means that one should understand this respect according to a good life perspective and not in terms of rule ethics. A few religious arguments already endorsed a good life perspective, but by no means does one need to be religious to endorse the wisdom of these arguments. I will point out how secular liberals too should be motivated to accept these arguments.

The religious good life arguments can then be seen as valuable. The idea of a valuable argument is tricky, because different parties in the debate on PGD are likely to have different ideas about what makes an argument valuable and whether a particular argument is valuable. The rationale by which one could say religious arguments are valuable is therefore also likely to be the rationale that finds little support among those who have little affinity with religious principles. After all, the debate on PGD is conflicted over exactly the role of those who oppose PGD and endorse religious views. However, if we may believe the different attitudes on PGD, there is a shared wisdom among parties in the debate, namely, the shared feeling that embryo selection cannot be appropriate for anything less than very serious diseases. If this wisdom finds solid ground in arguments that rely on an idea of the good life, both sides in the debate can agree on its value.

### 5.3 Shared values

The parliamentary letters from Jet Bussemaker contain some key principles that guide the thinking on PGD. A moral landscape can be drawn in combination with the description of the debate on NEST-ethics we saw in Chapter 3. By identifying how some basic principles clash in the discussions on PGD, it becomes clear how different styles of reasoning are able to support different positions on embryo selection. Some principles only opt for an extension of procedures on PGD while other principles suggest a restriction. By identifying the dynamics between those principles, we might be able to identify how present attitudes help to shape future policy on PGD and consequently answer whether the religious view and their arguments play a valuable role in those dynamics.

Just like matters over abortion or euthanasia, the case on PGD is coloured by venerable values. In the second letter to the parliament dated June 27, 2008, State Secretary of Health, Welfare and Sport Jet Bussemaker, states three main principles that should guide medical ethical matters [28]. These principles were first formulated in the Policy Letter on Ethics in 2007 [99], and are autonomy, the status of human life as something that is worthy of protection (In Dutch: 'beschermwaardigheid'), and good care. For the controversy over PGD, the principle of good care is not relevant. It should also be noted that most ethical arguments (meaning that the argument expresses a type of ethics) in favour of PGD have focused on the welfare of the future child. Furthermore, in the two letters on PGD, Bussemaker makes clear that the interests of the child should be guiding in this matter ([16], p. 5; [28], p.2). The idea is that it's in the future child's benefit to prevent a large chance for very serious suffering. We can then relate the diverse positions and arguments to three worked-out principles that clearly inform the policy on PGD. First there is the autonomy of the parents. As free human beings they are entitled to decide what is best for their child. Second, there is the principle to act in the interests of the future child. That includes the idea of suffering. The third principle refers to unborn human life as something that should be treated with respect. These principles are so-called shared principles meaning that they generally are endorsed by all participants in the debate. In Rawls's terminology they would be called political values.

No doubt, parents have an important say in deciding the future of their children. What a child wears or eats, what school he attends, which church he belongs to (if any), or whether he is vaccinated against the Mexican flue are all (partially) determined by the parents. Of course, parents cannot just do whatever they feel is right or necessary. A child can be disciplined but that does not mean a smack with a ruler is allowed. The legitimate position of the parents as decision makers is evident but that does not mean PGD is evidently a choice that should be available to parents. The autonomy of the parents as a relevant consideration has not been challenged in the debate. Instead, several sometimes opposing arguments are weighed and this can lead to the position that parents should not be able to make use of PGD.

The interests of the child, or the rationale to reduce suffering, suggests that parents should be given the choice for PGD. Curing disease has, since ancient times, been one of the nobler activities. Regardless of the many diseases the medical profession can already combat, there always remains a strong desire to eliminate those remaining causes of suffering and death. Nowadays, armed with a better understanding of the human physiology and a wider array of medical tools, diseases such as Duchenne muscular dystrophy, Huntington's disease and hereditary breast- and ovarian cancer are not simply confronted but prevented. Going upstream in the path of disease development has many benefits. For one, the prevention of disease prevents suffering in a way that treatments might never be able to do. The entire prospect of developing the disease is taken away. Prevention of disease equals the prevention of suffering even if it is uncertain whether the disease will occur and even if there are other ways for treatment besides prevention. Additionally, the prevention of hereditary genetic mutation transfer is attractive because it prevents further transfers down future generations. Also in this sense, PGD is a highly effective way of dealing with disease.

It is not questioned whether the reduction of suffering is a legitimate reason to support PGD. It has been suggested that PGD does not provide the certainty of a pregnancy [53], but this is not so much a disqualification of the supporting reasons. It merely tries to debunk the idea that PGD is always a fail-safe solution. Opponents to PGD have suggested how a focus on treatment would be preferable over the use of PGD [29] [30] [39] [41] [45] [53] [54], but by means of this argument, the motive to reduce suffering is also recognized as a legitimate concern. It is by invoking another principle, i.e. the protection of the embryo, that different options are highlighted, but by no means does this deny the legitimacy of the idea that future children can be saved from a lot of misery. While this principle is quite obvious, it needs to be stressed that it is the main justification for allowing PGD. So much is clear from the several policy letters that State Secretary of Health, Welfare and Sport, Jet Bussemaker, sent to the parliament, but also from the many responses in the newspapers and on television. To allow PGD necessarily means that the choice will be made by the parents, for there is almost unanimous objection to transferring this decision to others. But the decision to allow it, is made first and foremost with the interests of the child as its prime justification.

The third principle concerns the status of the embryo. In the several documents on medical ethics and policy on PGD which Bussemaker sent to the parliament [16] [28] [99], she endorses the idea that all human life, and that includes embryos, should be protected. In the Dutch formulation, it is suggested that embryos are *worthy* of protection, meaning that embryos deserve to be protected because of their 'embryonic being'. The status of the embryo as a guiding principle in the matter on PGD is thus founded upon traits that are intrinsic to the embryo. Several views on the embryo could be supportive of this view. Naturally, there is the idea that an embryo deserves to be protected because it is human [27] [29] [30] [44] [45] [47]. A bit less obvious, but also suggested, is that the embryo deserves to be protected because of its intentionality that allows it to grow to a full human being. It is not human life as such that is being defended here, but rather the miracle of human life [48].

Expressed in policy letters and endorsed by the opposition to PGD, the status of the embryo seems to matter in the case of PGD. The CU and religious people in general value unborn human life and have problems with many decisions that come with the destruction of embryos. That human life should be respected and protected would be a generally acceptable view. How this principle applies to unborn human life is open for discussion. There are a few logical and biological dividing lines that can be seen as appropriate in deciding in the matter. An obvious distinction can be made between born and unborn human life; another one can be made at the moment of conception; yet another can depend on the level of embryonic development. Has the embryo developed to a human-like stage? Could it be self-sustaining if born? Can it learn? In this entire spectrum, from conception to birth, from a few cells to a little boy or girl, the idea that human life deserves to be protected knows a wide variety of support and opposition. Generally speaking, there really is no solid principle that outranks all other principles. Therefore, in public debate and in policy justification, a diversity of positions is seen as a legitimate expression of the basic principle that demands the protection of human life.

But this is not the end of this matter. To recognize a position as legitimate is far different from finding it coherent, acceptable or well-founded. For Rawls, finding an argument to be legitimate means as much as saying that citizens can reasonably accept that other reasonable citizens endorse and subscribe to that argument when policy matters are at stake. The logic behind the legitimacy of this argument relies on it being an expression of a shared value, which is the respect and the protection of (unborn) human life in this specific case. Now, at the same time that citizens 'accept' one's fellow citizen's argument to endorse the idea that an embryo deserves to be protected, the argument was also refuted. Because abortions are also allowed and considering the loss of embryo in normal natural processes, or those massive amounts of embryos that are lost due to the intrauterine device or normal IVF procedures, people argue that it is ridiculous to ascribe any value to an embryo: a 'mere' clump of cells [29] [30] [32] [35] [39] [49] [50] [51] [57] [65] [67] [69] [72].

Something paradoxical is surfaces here. On one hand, there is the idea that people can genuinely have different opinions about the status of unborn human life. On the other hand, increasing knowledge and previous actions lead some to suggest that one of those positions has become untenable. Sure, people may attach value to a mere clump of cells, but doing so means they are blind to the world in which they live – the verdict rules. While this section discussed three 'shared' values, it becomes clear how one of those values is under pressure.

### **5.4 Respect for human life**

Something is at stake where friction occurs and self-evident morality is challenged. For PGD, the protection of unborn human life becomes a matter to be discussed rather than accepted. The arguments from those who support PGD have been merciless. Their logic is clear: over the past several decades, we as a society have already accepted the destruction of embryos. Either we have made huge mistakes and we need to lift ourselves above these inhuman processes, even though natural processes already cost staggering quantities of embryos. Or, in favour of some very high-minded values, we have weighed the status of the embryo and found it to be too light. Although policy on PGD still talks about the embryo as being worthy of protection [13] [16] [28], many arguments in favour of PGD bluntly refute that opinion. Indeed, it is difficult to see intrinsic value in something that consists of only a few cells. It is difficult to understand why one ought to see the intrinsic value of something that is not allowed to grow because of birth control. There are several other ways to prevent an unwanted pregnancy, but nonetheless, the intrauterine device remains an acceptable alternative. Should we then speak of moral corruption or is this a sensible moral development?

I do not attempt to give an answer to this last question, nor do I believe I can give little more than a personal opinion on the matter. More important for this research is the recognition that this development in morality is inspired by our knowledge of nature and the technological powers at our disposition. The more we learn about our own human makeup and origins and the more we are able to exercise control over our world, the greater authority we give ourselves to decide over the status of an embryo. PGD then becomes a milestone where previous developments lead to a reorientation of moral principles. Shreds of information collected over the past decades have allowed for a moral separation of the human embryo from the human being. Everything that makes us human seems to disappear at the cellular level when a few cells tucked together, is all that is supposed to be human, science provides a reason to change one's attitude about it.

It is difficult to establish moral judgments on the natural qualities of the embryo. The natural world has always provided a hostile but fertile soil for life to grow. Both qualities have led to the evolutionary development of life. Nature facilitated the growth and adaptation of life and simultaneously provided the environment in which those changes would be tested. Most adaptations proved unsuccessful, but sometimes they helped the organism to grow and reproduce better than its ancestors. This factor in nature that challenges organisms, the factor that makes nature sometimes seem so cruel, is also the root of our existence as homo sapiens. Billions of years of two main processes—biologically typified as random mutation and natural selection—have led to the development of the human. Now, should we stand in awe and reverence of these processes? Should we respect the idea of natural selection and throw out our ideas on justice and solidarity because they do not fit well with the idea of survival of the fittest? Not even remotely.

To say that an embryo should be protected because it is essentially human also points to nature as morality. Because an embryo is our biological equivalent, it is supposed to have some intrinsic value. But to say that it is human is to beg the question. Just like saying that cannibalism is repulsive because it is human flesh being eaten. That explains nothing. The idea that an embryo should get our respect is not simply determined because it is human in the biological sense. Nor is it necessary to assume that embryos deserve protection on the basis of its own programme of development. A little miracle in itself, but awe and wonder alone do not feed morality. Oppositely, the mere fact that embryos are flushed down the toilet by millions does not simply mean it is only silly to show some respect towards the embryo.

Arguments that deny that an embryo *deserves* to be protected are here to stay. Then, by virtue of this ruthless logic that denies an embryo it is worthy of protection, the question becomes by what rationale, if any, should one be hesitant about the destruction of embryos? Accepting that we are talking about a mere bunch of cells, it seems only logical that further steps for policy on PGD are accepted. Autism. Alzheimers. Hay fever. By what principle should one object to the inclusion of these conditions to PGD? Some questions have been raised suggesting that the use of PGD might lead to injustice, but injustice is a social phenomenon, not a technological one. Here, the question is not whether PGD should be allowed nor whether certain diseases are 'serious enough' to be eligible for PGD. Instead, what is questioned are the social conditions PGD affects and how they influence society's perception of justice. Perhaps insurance companies should be left uninformed or perhaps only the less fortunate in society should be subsidized to make use of PGD or perhaps we should accept that people are consumers in a liberalized health care market.

Despite all of the arguments that conceptualize the embryo as a mere bunch of cells, nobody wishes to support PGD for anything that does not resemble a very serious disease. Supporters of PGD go to great lengths to deny further steps down the slippery slope [31] [33] [39] [71] [75] [76] [77] [78]. These arguments are weak, but their implicit message is powerful. They show to understand that somewhere down that slope, the act of beneficence no longer justifies the selection of embryos. They assume we have the wisdom to manage that slippery slope. It should be of no worry to anyone because nobody really wants the widespread use of embryo selection, it is suggested. Sometimes, this attitude is also expressed more explicitly [39] [77] [78]. It is

obvious that people are hesitant about instrumentalizing the embryo. But what is the source of this wisdom? An embryo might not be 'worthy' of protection but is there perhaps another source of this moral hesitation about embryos?

It is time to raise the stakes and confront the problem. Remember that there are three main principles that guide the arguments on PGD. Two of those principles are basically supportive of PGD, that is, the autonomy of the parents and the reduction of suffering. Only the respect for unborn human life tells people to be careful with this technology. Then, exactly because people have doubts about the manipulation and control of embryos, the cold, hard reductive logic that conceptualizes an embryo according to its biological status should be resisted. If one subscribes to the idea that an embryo is *only* a bunch of cells, there is basically no limit to manipulating it. In favour of nothing less than humanitarianism, the embryo becomes a normal tool to reduce suffering, support justice and give freedom wherever possible without the slightest hesitation. But equally, to submit to the idea that an embryo is worthy of protection because it is human and nothing less makes any IVF or PGD procedure a trade-off. Every act of beneficence is then necessary also a wicked one. The good-wishing doctor is also the villain. The first scientific perspective ignores real moral concerns. The second perspective is blind for moral development. More importantly, both perspectives are essentially meaningless.

There is, however, a different argument in favour of respecting an embryo. I believe this argument points to the doubts people might have about PGD. I believe it is this type of concern that feeds the wisdom which supporters of PGD also claim to have. This argument asks that one understands the respect for an embryo in our *relation* to it. The embryo should not be respected for what it is biologically but because the embryo plays a crucial role in our identity, our moral ways, our society. To respect an embryo means to recognize that human relations can be redefined through the embryo. The fact that we never had to think about such a role for the embryo means that this respect is difficult to articulate. To see the problem, one needs to be imaginative. One needs to be willing to ask how it could matter whether all embryos or whether only a few are conceived in the laboratory. One needs to imagine how the relation between parents and child might change because the child was not conceived but 'fabricated'. How is that relation shaped by the fact that people have little to no control over the genetic makeup of their children? With present-day morality, such matters seem quaint and unreal. But the idea is exactly that morality will change and whether such matters will become future reality depends on the way we think about these matters now.

Supporters of PGD have generally been dismissive of these softer matters. Emotionally they responded with outrage. Against the background of the interests of the future child, it seems obtuse and overly moralistic to talk about soft and abstract matters like lineage or the instrumentalization of embryos. But to refute those principles completely opens the door for unlimited selection. To choose for a scientific view of the embryo is to dismiss the moral concerns that we all seem to experience. There is no moral hesitation in the idea that an embryo is a mere bunch of cells. Sure, the embryo is a bunch of cells, but this fact says nothing and it means nothing.

The moral vocabulary of rule ethics is too shallow to address the concerns of PGD. The deontological perspective on the embryo suggests that an embryo is intrinsically worthy of protection, but this view becomes increasingly difficult to uphold. Many have good reasons to dismiss this view and yet they do not simply support a common and widespread use of PGD. Another moral principle is at work here, a principle that reflects a thicker morality, an idea about the good life, an idea about a desirable society and proper human relations. To understand this perspective, people should not reason in terms of rights, consequences or benefits. Instead, they need to ask how their moral being is not only the result of rational thought, but of growing up, experiencing life and developing human relations. It asks people to understand that these matters can change as result of far-reaching manipulation of embryos. The *overlapping wisdom* that we

should not use embryo selection for anything but a very serious disease finds solid ground in these softer matters.

Religious people have been more prominent in voicing these good life concerns but also they have defended an intrinsic idea on the worth of an embryo. People of faith would do good to realize that this argument has become unconvincing for those who do not share their system of belief. Surely, they are entitled to their views about the embryo and it is by no means my aim to suggest that they are not. I do hold that a public reorientation on the respect for an embryo could win the hearts and the minds of those who share their concerns about dealings with embryos. Detached from religious thought, the embryo also should be respected. This is a difficult message, but one which reflects an overlapping wisdom, even though some might initially find that hard to accept in this polarized debate.

### 5.5 The public arena

In this essay I relied on an inventory of ethical arguments about new and emerging technologies, the so-called NEST-ethics. In that article, the authors study patterns of ethical arguments and come to a rather surprising conclusion about NEST-discussions. Because an argument precedes *and* evokes a typical follow up argument, these discussions are not so much aimed at seeking consensus but are steps towards victory. Arguments are then tools to outmanoeuvre the opposing party. The ideal of the agora where wise men deliberate to come to the most informed and well-reasoned solution thus becomes the arena where some may win and others will lose.

To conceptualize a debate as a battle in an arena makes sense when one describes a debate. Also in the case of PGD, the steps which actors took were motivated by their position on the matter. An opinion is formed and it is consequently defended. Sometimes that defence even meant that actors endorsed unusual arguments. The Christians having faith in technological progress while medical professionals refuse to endorse this optimism, is a typical example of reversed roles for the sake of victory. But then there remains the normative aspect of a debate, which also should be appealing to the actors. This aspect asks actors to present reasonable arguments and to be open to each other's positions. The actors are expected to present views which the other party is least likely to reject. That is not only a normative view, but also a rhetorically strong view. By providing a reasonable ground for the other party and also for the audience to accept one's position, one does not only make a logical step towards consensus, but also a step towards victory.

The debate on PGD reflects the metaphor of the arena. Every possible means towards success was used, even when that meant to offend and insult the opponent in the debate. But what the analysis with NEST-ethics also helped to uncover is how this knock-out structure of the debate seems to miss a valuable opportunity, an opportunity to reach consensus. While parties are involved in defeating the opponent, they are blind for the values they share. Those values, the values on human respect and consequently the respect for an embryo may very well be forgotten. Heavy punches are thrown when the embryo is repeatedly conceptualized as a mere bunch of cells. It would be a tragedy to conclude that a knock-out victory for the humanitarian goal to reduce suffering can eventually lead to the dehumanization of all.

For both sides in the debate, a task awaits to explore the unease that comes with the selection of embryos. This unease might very well be translated in terms of respect. To really see what is at stake, this respect is perhaps best seen as self-respect or a respect for humanity. But to ignore this unease in favour of victory can eventually be self-defeating. To stimulate such thought, one only needs to read *Brave New World*, in which a human's *being* is sacrificed for mere human existence. Or one can think about the difficult-to-explain unease that people might have with cannibalism or incest. These matters too are connected to the softer interpretations of human relations, but we do not consider them irrelevant. With dialogue, imagination and realism about our dynamic morality

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including a role for science and technology, possibly something like an overlapping wisdom about PGD finds fertile ground.

## Chapter 6

# Conclusion

Now and again, new scientific and technological developments give rise to much controversy and disagreement. When it concerns the sciences of life, the discussions often go between the usual liberal enthusiasts and the more conservative religious critics. The debate on PGD was no exception. Typically these debates are not merely about the exchange of arguments on technological- or policy matters, but simultaneously they develop into a discussion on the position of religious critics. Here too, the debate on PGD was no exception. Just as many other actors in that debate, it was my intention to discuss the role of those religious critics, though I have approached the task a bit differently.

I have asked whether religious arguments can be valuable according to a study on PGD. As a first step, it was necessary to discuss what types of arguments can reasonably be upheld when it comes to policy on PGD. Often, the idea is that religious people wish to shape society to their religious ideas, ideas that others do not share. I relied on the liberal philosopher John Rawls' theoretical insights into public justification to explore whether the religious arguments are suitable expressions on policy matters. I defined suitable expressions to be reasons by which one can expect a fellow citizen to see that reason as an expression of shared values. That appeared to be the case in the debate on PGD. The shared values of solidarity and respect for human life were identified in this assessment. This step opened the door for a further assessment of the religious critiques of PGD. Sure, those reasons have a legitimate place in the public forum but can we say they are also valuable?

To answer this question I searched for a positive explanation of the role of religion in public debate. In academic literature, several thinkers, using terms of justice, consequence, or duties, have questioned whether traditional styles of ethical reasoning are able to deal with new technological challenges that constantly redefine human relations. The idea is that a reorientation on more traditional, cultural, or even religious values is necessary to deal with the problems that developments in cloning, stem cell research, or PGD pose. Further technological developments appear unavoidable because liberal thought justifies virtually every new available technology in life sciences. The reduction of suffering and the idea that people are free to use technology as they please provide a strong imperative to support new developments. If a religious argument could be of particular value, it would have to function as a stop to this 'liberal juggernaut' (the term is borrowed from Leon Kass).

Much of the discussion on PGD was about the slippery slope. Critics of PGD were concerned that present decisions on hereditary breast cancer would lead to similar future decisions for other diseases. A carrier of the genetic risk for hereditary breast cancer only has a chance—not the certainty—of developing the disease. To include high-risk but non-conclusive diseases then also provides an argument for including diseases with a slightly smaller chance for development, and so the story continues all the way down this slippery slope. At each instance down that slope the duty to reduce suffering justifies every next step. But there is no need to worry, it is told. From the debate it becomes clear that nobody really wishes to include other diseases in the procedures of PGD. Supporters of PGD have generally argued that we possess the wisdom, the sense and sensibility to decide differently for future diseases. Even those proponents of PGD, the same

group of people who have been so critical on the role of religion in this matter, make it perfectly clear that there are limits. What a relief!

But hold your horses. Much of the discussion revolved around the status of the embryo. In the debate, the ChristianUnion made it clear that they value unborn human life from the moment of conception. They consider the embryo to be *worthy* of protection. Supporters of PGD have argued clearly and convincingly that this view is outdated. In nature, but also by human hand, embryos already parish in high quantities. The intrauterine device, the coil, prevents the nesting of an embryo in the woman's womb. If the embryo is worthy of protection, one should be outraged by this means of birth control. But the fact remains that society already has taken significant steps in morality and does not pity the loss of embryos through contraception. If, then, the supporters are right and the embryo is a mere bunch of cells, this idea takes away all moral hesitation one can harbour about embryo selection. The duty to reduce suffering and the freedom of parents to make use of IVF only demands further and increased use of PGD.

The liberal juggernaut is gaining momentum. If one accepts that an embryo is a mere bunch of cells, there really is no principle left that says 'no, we should not make this next step.' Therefore, if people value their sense of wisdom on the limits of PGD, they need to wonder where that hesitation resides. One needs to ask how the embryo plays a role in human identity, human relations and the good society. One needs to ask how our own moral human being can change because of far-reaching manipulation of embryos. These questions invite people to turn their focus to good life principles. Indeed, this means that supporters of PGD need to take their opponents seriously. Not so much for the views they consider to be dogmatic, which are the views that say an embryo should be protected simply because it is human life – but for the religious views that express a sense of humility, carefulness, a sense of hesitation when it comes to taking part in the fabrication of life. One does not need to be religious to see the wisdom in these views, and to see how this wisdom is shared by supporters and opponents of PGD. Imagination is enough.

Religious arguments can be valuable according to this study of a debate on PGD. They have uniquely expressed a thicker type of morality that certainly is not dogmatic, nor merely religious, but is part of the moral landscape that makes up a sense of shared wisdom in society. To ignore the value of this type of argument would be to give way to the slippery slope. To only endorse a scientific view, to see the embryo as a mere bunch of cells, revokes any objections to PGD at any point down the slippery slope.

In this study I combined empirical data with a philosophical style of reasoning. This methodology has led to a solid analysis of public discourse on PGD. In that analysis, the dynamics of a debate on PGD are drawn to see how some arguments are decisive, and how they may eventually lead to future policy. NEST-ethics was of great value because it helped to describe and bring order to a fragmented debate and, in doing so, it simultaneously offered the tools to ask philosophical questions. By means of NEST-ethics, I could ask a normative question—"Can religious arguments be valuable?"—even though the debate in which those arguments figured would first need to be described and patterned.

I wish to highlight three steps that would have been impossible without this combination of empirical research and analytical philosophy. First, this approach allowed me to connect Rawls's theory of public reason to an actual public debate. Rawls's theory is highly philosophical, but if understood correctly, it is a very useful method to reflect on the legitimacy of religion in an actual public debate. Second, it was necessary not only to describe how people fight over the idea of the slippery slope, but also to analyse and weigh the arguments on the slippery slope themselves. And third, this combination of philosophy and empirical research allowed me to identify how actors can claim to decide wisely while simultaneously offering inadequate arguments for their ostensibly wise decisions.

I have not tried to argue either in favour of supporters or opponents to PGD. Where necessary I became a participant in the debate and pointed out where people's arguments are weak, strong or flawed. Wherever I have done so, I merely reasoned from academic facts or general logical principles, such as in the case of the slippery slope where counterarguments simply did not counter the idea of the slippery slope. I did, however, actively seek to find the most reasonable basis upon which people can agree that a religious argument is convincingly valuable. The rationale for deciding on their value would have to be appealing to those who criticise religion in public debate. The use of the liberal theory of Rawls, and also the search for a shared sense of wisdom, were necessary steps towards that aim. In these proceedings I also acknowledged that it becomes difficult to see the embryo as something that deserves to be protected. In the general dealings with embryos over the past couple of decades, we as a society have already allowed for some sort of moral detachment along those lines. The widespread use and acceptance of the intrauterine device makes clear that this moral development has become part of the general moral landscape.

This study into the value of religious arguments on the matter of PGD is complete. The analysis of the debate could have been complemented by interviews with the actors in the debate to make sure that the perceived argumentative patterns are correct and match the intentions of the actors. But time constraints made such an approach impossible and, in lieu of exhaustive interviews, Chapter 3 provides an accurate description of the debate. I do believe that this study provides a reason for further research if only because the methodology sets itself apart from other studies and allows for unique results. The analysis shows how our ideas about the status of the embryo might be changing and raises the question of why exactly people are hesitant to instrumentalize embryos to limit human suffering. Other discussions on technologies that deal with embryos, such as those on embryonic stem cells, might be guided by similar argumentative patterns. Those discussions are surely characterized by a similar battle over the status of the embryo. Morality is changing right under our noses and it is up to philosophers to provide the theoretical tools to guide it appropriately. People will have to make up their mind about the embryo and the ways in which it should be respected, if any. To philosophers is left the task of stimulating imaginations and allowing for an informed debate.



# List of References

- [1] A. Huxley, *Brave New World*. London: Penguin Books, 1963.
- [2] Congregation for the Doctrine of the Faith, "Dignitas Personae: On Certain Bioethical Questions," ed, 2008.
- [3] J. Rawls, *Political liberalism*, Expanded ed. New York: Columbia University Press, 2005.
- [4] Nigel M. de S. Cameron, "On One Path or the Other," in *Handbook of bioethics and religion*, D. E. Guinn, Ed., ed Oxford ; New York: Oxford University Press, 2006, pp. xv, 437 p.
- [5] A. R. Jonsen, "A History of Religion and Bioethics," in *Handbook of bioethics and religion*, D. E. Guinn, Ed., ed Oxford ; New York: Oxford University Press, 2006, pp. xv, 437 p.
- [6] C. B. Cohen, "Religion, Public Reason, and Embryonic Stem Cell Research," in *Handbook of bioethics and religion*, D. E. Guinn, Ed., ed Oxford ; New York: Oxford University Press, 2006, pp. xv, 437 p.
- [7] H. T. Engelhardt, "Public Reason and Reasonable Pluralism: Rethinking the Requirements of Neutrality," in *Handbook of bioethics and religion*, D. E. Guinn, Ed., ed Oxford ; New York: Oxford University Press, 2006, pp. xv, 437 p.
- [8] E. N. Dorff, ""These and Those are the Words of the Living God": Talmudic Sound and Fury in Shaping National Policy," in *Handbook of bioethics and religion*, D. E. Guinn, Ed., ed Oxford ; New York: Oxford University Press, 2006, pp. xv, 437 p.
- [9] J. Stout, *Democracy and tradition*. Princeton, N.J. Cincinnati: Princeton University Press ; Hebrew Union College Press, 2004.
- [10] A. Gutmann and D. Thompson, *Why deliberative democracy?* Princeton, N.J.: Princeton University Press, 2004.
- [11] L. Kass, *Life, liberty, and the defense of dignity : the challenge for bioethics*, 1st ed. San Francisco: Encounter Books, 2002.
- [12] M. J. Sandel, "The Case Against Perfection: What's wrong with designer children, bionic athletes, and genetic engineering," *Atlantic Monthly*, April 2004.
- [13] *Regeling preïmplantatie genetische diagnostiek*, Ministerie van Volksgezondheid, Welzijn en Sport, 2009.
- [14] N. Righton, "Vijf vragen over het invriezen van eicellen," in *de Volkskrant*, ed, 2009.
- [15] F. Baltesen and W. Köhler, "Ingevroren eicel al geen experiment meer," in *NRC*, ed, 2009.
- [16] J. Bussemaker, "Standpunt Preïmplantatie Genetische Diagnostiek," Ministerie van Volksgezondheid, Welzijn en Sport, ed, 26 May 2008.
- [17] *Planningsbesluit klinisch genetisch onderzoek en erfelijkheidsadvisering*, Ministerie van Volksgezondheid, Welzijn en Sport, 2003.
- [18] *Wet op bijzondere medische verrichtingen*, 1997.
- [19] T. Swierstra and A. Rip, "Nano-ethics as NEST-ethics: Patterns of Moral Argumentation About New and Emerging Science and Technology," *NanoEthics*, vol. 1, pp. 3-20, 2007.
- [20] Website, [www.britannica.com](http://www.britannica.com). Accessed 1 February 2010, *Religion*. Available: <http://www.britannica.com/EBchecked/topic/497082/religion>

- [21] Website, [www.dictionary.com](http://www.dictionary.com). Accessed 1 february 2010, *Religion*.
- [22] P. Singer, "Famine, Affluence, and Morality," *Philosophy & Public Affairs*, vol. 1, pp. 229-243, 1972.
- [23] J. Rawls, *A theory of justice*. Cambridge, Mass.: Belknap Press of Harvard University Press, 1971.
- [24] Second Vatican Council, "Dignitas Humanae," 1965.
- [25] S. Generaal, "Behandeling van: het wetsvoorstel Wet houdende regels inzake handelingen met geslachtscellen en embryo's," ed, 2 oktober 2001.
- [26] CDA, PvdA, CU, "Coalitieakkoord tussen de Tweede Kamerfracties van CDA, PvdA en ChristenUnie," ed, 2007.
- [27] W. Breedveld and C. v. d. Laan, "Rouvoet zet conflict op scherp," in *Trouw*, ed, 7 June 2008.
- [28] J. Bussemaker, "Kabinetstandpunt preimplantatie genetische diagnostiek," ed, 27 June 2008.
- [29] Staten Generaal, "debat over de gang van zaken rond de brief over pre-implantatie genetische diagnostiek," vol. 93ste vergadering, ed, 2008.
- [30] Staten Generaal, "debat over pre-implantatie genetische diagnostiek," vol. 104de vergadering, ed, 2008.
- [31] "Knevel & Van de Brink," ed, 27 May 2008.
- [32] G. Herderschêe, "Coalitie sterk verdeeld over selectie embryo's; Embryo-selectie Heikel onderwerp in de politiek: de ChristenUnie is tegen, het CDA weifelt en de PvdA is voor," in *de Volkskrant*, ed, 28 May 2008.
- [33] Editorial commentary, "Embryopolitiek," in *NRC*, ed, 2 June 2008.
- [34] E. de Visser, "Vergis je er niet in hoe zwaar die behandeling is," in *de Volkskrant*, ed, 4 June 2008.
- [35] Editorial commentary, "Medische praktijk heeft principes al ingehaald," in *de Volkskrant*, ed, 6 June 2008.
- [36] M. Chavannes, "Een slagboom bemand door Rouvoet c.s.," in *NRC*, ed, 7 June 2008.
- [37] "Netwerk," ed, 26 May 2008.
- [38] "NOVA," ed, 30 May 2008.
- [39] "NOVA," ed, 31 May 2008.
- [40] "Ellen laat haar embryo's wél onderzoeken - De zware last van een gendrager," in *Algemeen Dagblad*, ed, 5 June 2008.
- [41] E. de Visser, "Natuurlijk ben ik boos geweest, en verdrietig," in *de Volkskrant*, ed, 4 June 2008.
- [42] M. Scheuer, "Opinie," in *NRC*, ed, 4 June 2008.
- [43] "Borstkankergen is geen zwaard van Damocles meer," in *Nederlands Dagblad*, ed, 6 June 2008.
- [44] "NOVA," ed, 28 May 2008.
- [45] ChristenUnie. (29 May 2008, 27 August 2009). *Embryo's: 'Bescherm beginnend menselijk leven*.
- [46] "'Doden van Embryo's is geen oplossing'," in *Nederlands Dagblad*, ed, 28 May 2008.
- [47] R. Seldenrijk, "Embryo bezielt menselijk leven vanaf conceptie," in *Reformatorisch Dagblad*, ed, 8 July 2008.
- [48] R. Seldenrijk, "Embryoselectie: wie houd je nog over?," in *Nederlands Dagblad*, ed, 17 July 2008.
- [49] M. Slingerland, "Testen is zoiets als inenten," in *Trouw*, ed, 4 June 2008.
- [50] M. Zijderland, "Een embryo is maar een klomp cellen," in *NRC*, ed, 3 June 2008.
- [51] K. de Geest, "Embryoselectie in eerste plaats zaak van arts en patient " in *Nederlands Dagblad*, ed, 25 June 2008.
- [52] "Impasse in coalitie over embryoselectie PvdA en CU moeten denken aan achterban," in *NRC*, ed, 3 June 2008.

- [53] H. Jochemsen and M. v. d. Berg, "Gaan we nu ieder ziek kind wegselecteren?," in *NRC*, ed, 3 June 2008.
- [54] J. Mol, "Embryoselectie is niet de enige weg," in *Nederlands Dagblad*, ed, 6 June 2008.
- [55] R. van Geenen and K. Wessels, "'Politiek moet afblijven van medisch probleem' - Embryotest mag niet, abortus wel," in *Algemeen Dagblad*, ed, 4 June 2008.
- [56] D. Stokmans, "Onbegrip bij draagster borstkankergen," in *NRC*, ed, 5 June 2008.
- [57] K. J. v. Doorn, "Je dochter borstkanker besparen, mag dat niet?," in *Trouw*, ed, 2 June 2008.
- [58] F. G. Bosman, "Embryoselectie ondergraaft solidariteit," in *Trouw*, ed, 29 May 2008.
- [59] Editorial commentary, "God spelen," *Nederlands Dagblad*, 31 May 2008.
- [60] "Galjaard: het leven is niet zonder risico's," in *Nederlands Dagblad*, ed, 30 May 2008.
- [61] E. commentary, "Met embryoselectie kiest Bussemaker terecht voor het voorkomen van leed," in *Trouw*, ed, 30 May 2008.
- [62] D. v. Brederode, "Embryoselectie," in *Buitenhof*, ed, 8 June 2008.
- [63] R. Kuiper, "Ik ben geen christenfundamentalist en wil niet dat we moral strangers worden," in *NRC*, ed, 7 June NRC.
- [64] H. van Santen, "Humaan geneticus," in *NRC*, ed, 7 June 2008.
- [65] H. Evers, "Rouvoet haalt gelijk over de rug van zieken," in *NRC*, ed, 3 June 2008.
- [66] "Kader nodig voor embryoselectie," in *Nederlands Dagblad*, ed, 19 June 2008.
- [67] A. Reerink, "Els Borst: ChristenUnie is arrogant Twee oplossingen; D66'er en oud-minister van Volksgezondheid hekelst optreden coalitiepartij," in *NRC*, ed, 4 June 2008.
- [68] "Geen keuzes in venijnig embryodebat CDA onder vuur in spoeddebat; PvdA en CU wachten op kabinet," in *NRC*, ed, 5 June 2008.
- [69] C. Wesselius, "V O O R De natuur is ook zo," in *Trouw*, ed, 4 June 2008.
- [70] G. de Wert and I. de Beaufort, "Sta nú ook andere varianten van PGD toe," in *NRC*, ed, 1 July 2008.
- [71] S. Kooke, "Het gaat om de nood van de ouders," in *Trouw*, ed, 7 June 2008.
- [72] P.E. Treffers, "Zijn embryo's beschermwaardig?," in *NRC*, ed, 4 June 2008.
- [73] M. Keulemans, "Embryovrees," in *de Volkskrant*, ed, 7 June 2008.
- [74] R. Cuperus, "Embryonale selectie is pure vooruitgang," in *de Volkskrant*, ed, 31 May 2008.
- [75] B. Scholtens, "Bijzondere techniek met veel ethische dilemma's," in *de Volkskrant*, ed, 28 May 2008.
- [76] "Artsen: geen hellend vlak," in *Nederlands Dagblad*, ed, 17 June 2008.
- [77] E. Ety, "Krijg dan maar borstkanker," in *NRC*, ed, 3 June 2008.
- [78] E. de Visser, "Geen hellend vlak bij embryoselectie," in *de Volkskrant*, ed, 5 June 2008.
- [79] R. Franssen, "Embryodebat staat bol van simplismen," in *Nederlands Dagblad*, ed, 12 June 2008.
- [80] S. H. van Voss and D. Stokmans, "Wij fanaten en tirannen? Ongelofelijk," in *NRC*, ed, 7 June 2008.
- [81] S. H. van Voss and A. Reerink, "Geloof is een andere vorm van wetenschap," in *NRC*, ed, 26 July 2008.
- [82] M. J. Schuurman, "Embryodebat legt zwaktes bloot," in *Reformatorisch Dagblad*, ed, 13 June 2008.
- [83] S. Ephimenco, "Pijl en boog," in *Trouw*, ed, 31 may 2008.
- [84] "Dit is knielen voor een minderheid van 4 procent," in *de Volkskrant*, ed, 7 June 2008.
- [85] Centraal Bureau voor de Statistiek, "Religie aan het begin van de 21ste eeuw," Centraal Bureau voor de Statistiek2009.
- [86] J. Harris, "Survival Lottery," *Philosophy*, vol. 50, pp. 81-87, 1975.
- [87] "Vicepremier Rouvoet woedend op Bussemaker; Staatssecretaris heeft geen overleg gepleegd in kabinet over voorstel," in *Parool*, ed, 30 May 2008.

- [88] R. Audi, "The Separation of Church and State and the Obligations of Citizenship," *Philosophy & Public Affairs*, vol. 18, pp. 259-296, Sum 1989.
- [89] D. v. Schalkwijk, "Beziëld embryo redelijke gedachte," in *Reformatorisch Dagblad*, ed, 27 June 2008.
- [90] A. A. Teeuw, "Embryo niet beziëld, wel beschermwaardig," in *Reformatorisch Dagblad*, ed, 2 July 2008.
- [91] A. A. Teeuw, "Embryo een onbegrijpelijk wonder," in *Reformatorisch Dagblad*, ed, 9 July 2008.
- [92] C. Sonneveld and T. W. Sonneveld-Kraaijeveld, "Embryo beziëld en daarom beschermwaardig," in *Reformatorisch Dagblad*, ed, 8 July 2008.
- [93] I. Berlin, "Two concepts of liberty," in *Four Essays on Liberty*, I. Berlin, ed London: Oxford University Press, 1969.
- [94] H. Philipse, "Het André-dilemma," in *NRC Next*, ed, 31 July 2008.
- [95] P.-P. Verbeek, *De daadkracht der dingen*. Enschede: Boom Amsterdam, 2000.
- [96] T. J. Pinch and W. E. Bijker, "The Social Construction of Facts and Artifacts - or How the Sociology of Science and the Sociology of Technology Might Benefit Each Other," *Social Studies of Science*, vol. 14, pp. 399-441, 1984.
- [97] B. Latour, "Where Are the Missing Masses? The Sociology of a Few Mundane Artifacts", in *Shaping technology/building society : studies in sociotechnical change*, W. E. Bijker and J. Law, Eds., ed Cambridge, Mass.: MIT Press, 1992, pp. vii, 341 p.
- [98] T. P. Hughes, "Technological Momentum in History - Hydrogenation in Germany 1898-1933," *Past & Present*, pp. 106-132, 1969.
- [99] J. Bussemaker, "Beleidsbrief ethiek," Ministerie van Volksgezondheid Welzijn en Sport, ed, 7 September 2007.

# Appendix

Below are all the original quotation listed (according to chronology of appearance) that have been translated into English. For each quote the reference is given which can be looked up in the list of references.

## Section 3.3.2

- [16] “Aansluitend bij het standpunt van mijn voorgangster: bij de ethische keuzes is daar steeds, en mijns inziens terecht, uitgegaan van het belang van het toekomstige kind. Daarbij is inbegrepen het motief van voorkómen van (zeer) ernstig lijden.”
- [16] “Daarnaast wijs ik graag op het belang van de vrouw die PGD overweegt. Daarbij zal ze, samen met haar partner, een afweging maken tussen prenatale diagnostiek en PGD.”
- [28] “Bij PGD bijvoorbeeld moeten zowel autonomie als beschermwaardigheid van leven worden afgewogen, oftewel het voorkomen van een (grote) kans op (zeer) ernstig lijden voor het eventuele toekomstige kind moet worden afgewogen tegen het uitselecteren van embryo’s, en tegen eventueel beschikbare behandelperspectieven.”
- [32] “Een grote groep vrouwen weet dat ze drager zijn van deze erfelijke ziekte en wil hun kinderen daar niet mee belasten.”
- [33] “De ChristenUnie gaat gemakkelijk voorbij aan het feit dat vrouwen die grote kans hebben op het ontwikkelen van erfelijk borstkanker nu genoodzaakt zijn over te gaan tot bijvoorbeeld borstamputaties als preventieve ingreep. De partij heeft er te weinig oog voor dat ouders hun kinderen deze ellende willen besparen.”
- [34] “Het borstkankergen is, als het defect is, een verwoestend gen. We kennen families waarvan oma, moeder en alle dochters aan erfelijke borstkanker zijn overleden.”
- [35] “Omdat de kans op kanker zo groot is, 60 tot 80 procent, hangt de ziekte als een zwaard van Damocles boven het hoofd van deze vrouwen, ook in hun gezonde jaren, en ook als ze uiteindelijk niet ziek zullen worden. Embryoselectie maakt het mogelijk de ziekte uit het leven van families, die al generaties moeten vrezen voor een voortijdige dood van hun dierbaren, te laten verdwijnen. Daarom moet het voorkomen van dit concrete leed zwaarder wegen dan de abstracte zorg over de toekomst.”
- [36] “Wie deze week de levensverhalen hoorde of las van vrouwen die hun oma, moeder, tante verloren aan de ziekte en zelf vóór zij dertig waren uit voorzorg hun borsten lieten amputeren, moet bijna concluderen: gun haar het recht dat níet door te geven aan weer een generatie. Denk er niet gering over. Preventieve amputatie (vaak op latere leeftijd gevolgd door het weghalen van de eierstokken) is een amputatie van het vrouwzijn. Met behoud van de grote kans het gen door te geven.”
- [37] “Ik ben er al vanaf de puberteit mee geconfronteerd en voor mij zijn borsten geen mooie vrouwelijke dingen meer. Voor mij zijn het bommen.”
- [38] “Ja, ik vind dat het percentage van 80% een beetje gebagatelliseerd wordt, want al zou je die ziekte niet krijgen, al behoor je tot de twintig procent die het misschien niet krijgt,

- maar als je drager bent dan heeft het zo'n enorme psychische impact op je leven, constant de onzekerheid of je kanker krijgt, je hebt allerlei onderzoeken, mammografie scans waar je jaarlijks mee te maken krijgt, dus dan denk ik dat de mensen die de ziekte niet krijgen ook met een hele zware belasting zitten.”
- [39] “De borsten van deze vrouwen zijn vanaf jonge leeftijd een tijdbom en de tikkende klok is psychologisch zwaar.”
- [40] “Borstkanker slaat hard toe in families waar het voorkomt. Alle vrouwen worden erdoor getroffen, zelf degenen die niet ziek worden.”
- [41] “Maar de oudste snapt al precies waar het over gaat. Het is belangrijk dat het niet steeds wordt doorgegeven, zei ze laatst, anders blijven vrouwen kanker krijgen.”
- [41] “Heeft een embryo met een genafwijking geen recht op leven? Ik was ook ooit zo'n embryo en ik leef en ik ben gelukkig (...) Ik heb een chemokuur gehad, beide borsten laten verwijderen en meteen voor een reconstructie gekozen. Natuurlijk ben ik boos geweest, en verdrietig en bang. Ja, het was zwaar maar ik ben toch blij dat ik er ben.”
- [42] “Mijn zoon is een bijzonder mens: hij had de hoofdrol in een musical in groep acht, houdt van voetballen, heeft 20 tennisbekers op zijn kamer en haalde zijn vwo met een 10 voor wiskunde. Hij weet precies wat hij wil worden (cardiochirurg), heeft een leuke jaarclub, een leuk huis, goede vrienden, stond direct op eigen benen toen hij ging studeren en zeurde niet. Dit kind van mij had als embryo weggegooid moeten worden?”
- [43] “Vroeger stierven vrouwen vrijwel zeker aan kanker door het defecte gen, maar medisch gezien kan dat nu voorkomen worden. Je kunt als drager van het gen goed leven en de dreiging van kanker hangt veel minder als een zwaard van Damocles boven je hoofd.”
- [44] “Mijn grote moeite met de techniek is dat er IVF toegepast gaat worden waar dus sprake is van meerdere embryos. Dat er vervolgens een selectie plaats gaat vinden met die embryos en dan worden de goed bevonden embryos zonder dat erfelijke gen teruggeplaatst, maar vervolgens is er wel sprake van restembryos die waarschijnlijk vernietigd zullen worden.”
- [27] “In dit coalitieakkoord is, voor het eerst, de beschermwaardigheid van het leven opgenomen.”
- [45] “De ChristenUnie beschouwt die embryo's als beginnend menselijk leven dat moet worden beschermd.”
- [29] “Iedereen kan weten dat beschermwaardigheid van ieder menselijk leven voor de SGP-fractie een kernwaarde is. Menselijk leven is door God geschapen leven. Embryo's moeten worden beschermd en niet uiteindelijk gedood.”
- [30] “Het selecteren van embryo's en het vernietigen van dit jonge menselijk leven is voor de SGP in strijd met de waardigheid van de mens. God, onze Schepper, geeft het nieuwe leven; wij mensen mogen daar onze vingers niet aan branden. Ieder embryo is een unieke creatie die volledige bescherming verdient.”
- [46] “Als de bevruchting heeft plaatsgevonden, is er een mensenkind op komst.”
- [47] “Alle leven op aarde is beschermwaardig. Alleen de levende mens is onschendbaar vanaf de conceptie. De status van het embryo ligt in zijn intrinsieke waarde: er is een innerlijke doelgerichtheid, een vanaf het begin vaststaand ontwikkelingsprogramma. Zonder ingrijpen van buiten groeit het uit tot een volwassen mens.”
- [48] “De status van het embryo ligt in zijn intrinsieke waarde: er is een innerlijke doelgerichtheid, een vanaf het begin vaststaand ontwikkelingsprogramma. Zonder ingrijpen van buiten groeit het uit tot uitsluitend een volwassen mens. Uitgangspunt van de discussie moet zijn dat embryologisch gezien er bij een menselijk embryo sprake is van menselijk leven. En de gelovige embryoloog kent en erkent God, Die het leven geeft en neemt. Ook in onze christelijke levensovertuiging begint menselijk leven bij de conceptie. Het embryo is menselijk leven, omdat het menselijk leven is beziel. Daarvan geeft de Bijbel getuigenis. Denk alleen al aan de ontmoeting van de zes maanden zwangere Elisabeth met haar nicht Maria. Verbluffend relevant is dat Maria nog maar enkele dagen zwanger is van de Heer van het leven (Lucas 1:26-56).”

- [49] “Daar moeten we heel nuchter in zijn. Het gaat dan nog om een klompje cellen. Dat is nog geen kind. Ik laat me bij zulke ethische vragen leiden door het relationele: heb ik een band?”
- [50] “Een embryo kwalificeren als ‘beginnend menselijk leven’ is volslagen absurd. Een embryo is geen mens, maar een klomp cellen. Het kent geen pijn, heeft geen ervaringen en kan niet denken. Het ontbeert, kortom, alles wat een levend wezen aanspraak geeft op morele rechten.”
- [50] “Waarschijnlijk omdat een embryo de potentie heeft om een mens te worden. Dat klopt. Maar verdient het daarom bescherming? Dan is het einde zoek. Want dan zouden al die miljoenen spermacellen die bij iedere zaadlozing verloren gaan en al die onbevuchte eitjes die vrouwen maandelijks verliezen, voortaan ook morele verontwaardiging moeten oproepen, omdat er ‘potentieel menselijk leven’ wordt verspild. Het potentiëargument heeft gewoonweg een te breed bereik om ons morele handelen op af te stemmen.”
- [51] “Veel vroege embryo's gaan weer verloren, ze kunnen niet innestelen of worden spontaan afgedreven. Het betreft hier vaak embryo's die afwijkend zijn aangelegd. Het is daarom moeilijk menselijk leven te herkennen in het vroege embryo. De waarde lijkt te liggen in wat het kan worden, niet in wat het op dat moment is.”
- [25] “U hebt mij prachtig gemaakt; U zag mij al toen ogen mij nog niet konden zien.”
- [52] “Het gaat hier om het zelfbeschikkingsrecht van vrouwen en hun keuzevrijheid. Dat weegt voor ons even zwaar als de beschermwaardigheid van het leven.”
- [44] “Maar u zegt, voor al die ouders tegelijk, zij mogen die keuze niet maken, wij vinden dat dat in Nederland niet kan, bijvoorbeeld in België kan dat wel en in Engeland kan dat ook, maar wij vinden in Nederland dat dat niet kan. En dan denk ik, waar haalt u het recht vandaan om die autonomie bij ouders, die ervaringsdeskundigen zijn, weg te halen. Natuurlijk zijn er mensen die niet voor die techniek kiezen, heel veel. In werkelijkheid zijn er weinig mensen die er wel voor kiezen, maar u wilt hen die keuze ontnemen en ik vraag mij dan af op grond waarvan u dat doet.”
- [38] “Ik ben boos op de ChristenUnie omdat ik het eigenlijk belachelijk vind dat politici nu beslissen over mijn toekomst en de toekomst van mijn gezin.”
- [49] “Wat vooral van belang is, vindt Elisa Klapheck, is dat ouders vrij moeten zijn in het nemen van beslissingen bij prenatale diagnostiek en dat zij beschermd worden als zij dit soort onderzoeken niet doen. “Ouders moeten vrij zijn om nee te zeggen tegen onderzoek en later niet hoeven opdraaien voor eventuele ziektekosten die door de verzekering betaald worden. Ouders moeten ook vrij zijn van angst.”

### Section 3.3.3

- [53] “Borstkanker en andere mede erfelijk bepaalde kankers treden later in het leven op en zijn in principe behandelbaar... Ten tweede gaat het nu over selectie van embryo's die een sterk verhoogde kans hebben over 30 of 40 jaar borstkanker of eierstokkanker te krijgen. Maar het is zeer aannemelijk dat in die periode de vroegtijdige diagnostiek en behandelmethoden zullen verbeteren. Moeten we niet juist inzetten op behandeling van mensen met aandoeningen en niet op het elimineren van pril mensenleven, omdat het een aandoening kan hebben?”
- [41] “behandelmethode zullen bovendien in de toekomst alleen maar verbeteren.”
- [54] “Er wordt veel onderzoek verricht naar preventie van het ontstaan van borstkanker bij deze groep. De mogelijkheden die zich aandienen lijken ook sneller binnen handbereik dan voor andere ziektebeelden waarvoor nu al embryoselectie plaatsvindt. Onderzoek bij muizen met het borstkankergen BRCA1 heeft bijvoorbeeld een volledig voorkomen van melkkliertumoren aangetoond door het toedienen van een antiprogesteron. Bij mensen wordt, voor zover ik weet, deze bevinding nog niet toegepast. Maar als dezelfde effecten

- zouden kunnen worden verkregen bij de mens, dan kan je met nog meer nadruk de vraag stellen of embryoselectie de oplossing is. Er is dus alle reden voor een verdergaand debat en zeker voor meer onderzoek naar preventie van en therapie bij kanker.”
- [39] “Maar waar we nu over discussiëren is de voorspelling van een vruchtje wat al dan of niet teruggeplaatst moet worden en dan gaat het over dit meisje, als ze dat gen draagt, over 40,50, 60, 70 jaar borstkanker kan ontwikkelen, want dat risico waar het over gaat is een levenslang risico (...) Ik heb net een boek geschreven, dat heeft, *gezondheid kent geen grenzen*, daarin heb ik teruggekeken wat er in de laatste 40 jaar is gebeurd, ik moet zeggen, ik was onder de indruk, dat wist ik niet eens allemaal. Dan verwacht ik, dat over 40-50 jaar van nu ook geweldige ontwikkelingen plaatsvinden.”
- [39] “Possibly no developments are made at all”
- [55] “De klinisch geneticus heeft zich gestoord aan de argumenten die tegenstanders van embryoselectie hebben aangevoerd. Zoals: over vijftig jaar kan er een behandeling tegen erfelijke kanker zijn. “Vaak tast de kanker al weefsel aan tussen het 20<sup>ste</sup> en 25<sup>ste</sup> levensjaar,” zegt Niermeijer. “Kanker blijkt ook heel moeilijk te bestrijden te zijn, wat het niet aannemelijk maakt dat er over twintig jaar een doorbraak is. Maar belangrijker: ouders willen met de feiten van nú een verantwoorde beslissing nemen.”
- [38] “U doet voorkomen alsof er steeds betere technieken komen om borstkanker te behandelen. Maar wat ik mis in de discussies is dat er ook een sterk verhoogde kans is op eierstokkanker en daar is de screening op dit moment nog niet goed, dus dat houdt in dat heel veel vrouwen jaarlijks sterven aan eierstokkanker omdat te laat ontdekt wordt dat ze dat hebben.”
- [56] “Hoe kan ze zeggen dat er meer aandacht moet komen voor behandeling, en dat gezondheid niet overgewaardeerd moet worden? Als mijn ziekte behandelbaar was, dan zou mijn oma nog leven, dan zou mijn moeder nog leven, en dan zou ik mijn borsten niet geamputeerd hebben.”
- [53] “De PGD is geen gemakkelijke techniek die succes verzekert.”
- [57] “Door embryoselectie in dit specifieke geval, wordt naast het voorkomen van leed ook veel geld uitgespaard, geld dat bijvoorbeeld aangewend kan worden voor nieuwe medicatie, die doeltreffend, maar nu nog onbetaalbaar is. De solidariteit gaat er met sprongen op vooruit.”

### Section 3.3.4

- [45] “Het selecteren van embryo's heeft maatschappelijke gevolgen waar de ChristenUnie haar vraagtekens bij plaatst. Is er nog wel ruimte voor mensen met ziektes, handicaps en aangeboren afwijkingen? "Gezondheid is belangrijk, maar moet niet overgewaardeerd worden", stelde Wiegman.””
- [58] “In de eerste plaats ondergraaft embryoselectie de solidariteit in de samenleving. Henk Jochemsen, directeur van het Lindenboom Instituut, waarschuwde gisteren al reeds in Trouw voor het risico van ‘verwijtbaarheid’, zoals nu gebeurt met ouders die hun kind met Down niet ‘hebben weggemaakt’. ‘Je had het toch kunnen weten’, is dan het verwijt. En niet alleen van volwassenen onder elkaar, maar zelfs van kind tegen ouders. Ik vrees ook dat de zorgverzekeraars zullen gaan weigeren de hoge gezondheidskosten van bepaalde groepen te vergoeden met als argument dat ‘het’ immers voorkomen had kunnen worden. De rekening is dan voor de ouders.”
- [30] “De CDA-fractie hecht zeer aan gelijke kansen, ook voor mensen met een beperking, of die nu genetisch bepaald is of later gekregen. Een van de velden waar in de toekomst druk kan ontstaan, is dat van de toegang tot verzekeringen en keuringen. Nu borgt de Wet op de medische keuringen dat niet iedereen mag vragen naar het medisch dossier. Wij willen dat deze garanties worden versterkt, zeker ook in het licht van de discussie.”

- [30] “Een voortschrijdende technologie brengt ons nieuwe mogelijkheden en kansen en tegelijk nieuwe moeilijke keuzes die zorgvuldige afweging vereisen. De politiek moet bewaken dat nieuwe keuzes niet leiden tot onvrijheid. Zo mag de beschikbaarheid van embryoselectie er nooit toe leiden dat mensen ook gedwongen worden of zich gedwongen voelen daarvan gebruik te maken. De politiek moet bewaken dat nieuwe technieken ten goede komen aan de mensen en ook aan alle mensen en niet tegen mensen kunnen worden gebruikt. Voorkomen moet worden dat nieuwe technologie en kennis leiden tot ongelijke toegankelijkheid van werk of verzekeringen, dat verzekeraars bijvoorbeeld zeggen dat het laten geboren worden van een kind met een aangeboren afwijking een eigen keuze is en derhalve niet wordt vergoed.”
- [29] “En om het ook maar even plat te benoemen, hoe zullen zorgverzekeraars reageren op ziekten die voorkomen hadden kunnen worden?”
- [29] “Hoe zal zij voorkomen dat mensen en ouders van mensen met welke ziekte of handicap ook, worden gestigmatiseerd omdat het kind toch had kunnen worden weggehaald of voorkomen?”
- [53] “Hoe langer een prenataal screeningsprogramma bestaat, hoe gewoner het wordt om aan de screening deel te nemen (...) Wat betekent dat voor mensen met die aandoeningen die er toch zijn? Juist voor deze kwetsbare mensen en groepen patiënten, moeten we ons tegen de voorgestelde uitbreiding van de PGD verzetten.”

### Section 3.3.5

- [45] “Het selecteren van embryo's heeft maatschappelijke gevolgen waar de ChristenUnie haar vraagtekens bij plaatst. Is er nog wel ruimte voor mensen met ziektes, handicaps en aangeboren afwijkingen? "Gezondheid is belangrijk, maar moet niet overgewaardeerd worden", stelde Wiegman.””
- [59] “Maar de consequenties gaan hier veel verder. Een samenleving die geboorten van 'gemankeerde' mensen technisch kan voorkomen, zet de deur open voor een sociaal klimaat waarin het op den duur niet meer geaccepteerd wordt dat er mensen met een aangeboren afwijking of erfelijke aandoening rondlopen. Die hadden immers 'voorkomen' kunnen worden? Zoals nu ouders van kinderen met het syndroom van Down soms al kunnen horen.”
- [38] “Ik vind dat, als wij toe gaan naar een samenleving waarin vóór de geboorte kinderen, embryo's, geselecteerd worden op erfelijke aanleg van een ziekte en dan weggeselecteerd worden als er een verhoogde kans is op een bepaalde ziekte, dan vind ik dat een samenleving die niet wenselijk is.”
- [58] “In de eerste plaats ondergraaft embryoselectie de solidariteit in de samenleving. Henk Jochemsen, directeur van het Lindenboom Instituut, waarschuwde gisteren al reeds in Trouw voor het risico van ‘verwijtbaarheid’, zoals nu gebeurt met ouders die hun kind met Down niet ‘hebben weggemaakt’. ‘Je had het toch kunnen weten’, is dan het verwijt. En niet alleen van volwassenen onder elkaar, maar zelfs van kind tegen ouders. Ik vrees ook dat de zorgverzekeraars zullen gaan weigeren de hoge gezondheidskosten van bepaalde groepen te vergoeden met als argument dat ‘het’ immers voorkomen had kunnen worden. De rekening is dan voor de ouders.”
- [60] “Galjaard waarschuwt dat het leven door risico-uitsluiting minder aangenaam kan worden. „We moeten bepaalde risico's accepteren en ervoor waken dat we niet de hele samenleving gaan medicaliseren.””
- [61] “Zij vreest ook dat voor mensen met een ziekte of handicap in de toekomst geen plaats meer is als embryoselectie wordt toegestaan. Bewijzen voor die stelling heeft ze niet.”
- [53] “Van de selectie van ongeboren leven op grond van aanleg voor een aandoening gaat een verkeerd signaal uit naar de samenleving: we vinden eigenlijk dat zulke mensen niet

- geboren mogen worden. We erkennen dat aanstaande ouders van PGD gebruik willen maken om de geboorte te voorkomen van een kind met de belastende erfelijke aanleg. Maar het feit dat die methode in de gezondheidszorg collectief gefinancierd aangeboden wordt, geeft die selectie onmiskenbaar ook een maatschappelijk karakter (...) Gaan we niet toe naar een samenleving waarin je alleen geboren mag worden als je geen aanleg hebt voor (ernstige) aandoeningen? Uit internationaal onderzoek blijkt dat steeds een groter deel van de kinderen met aandoeningen als downsyndroom of een neuralebuisdefectie prenataal opgespoord en geaborteerd wordt.”
- [29] “De CDA-fractie is van mening dat van de mogelijkheid van pre-implantatie genetische diagnostiek voor bepaalde ziektes absoluut nooit het signaal mag uitgaan dat je beter niet kunt leven dan met zo’n ziekte leven.”
- [30] “Bovendien mag van het bestaan van embryoselectie nooit het signaal uitgaan dat iemand niet geboren had mogen worden.”
- [62] “Wat?! Parachutespringen? Roken? Ontevreden over je figuur? Een depressie, jij?! Terwijl je ouders ervoor hebben gezorgd dat je geen borstkanker kunt krijgen? Hoe durf je!”
- [29] “Breder gezien, verdienen de maatschappelijke implicaties onze aandacht. Een voorbeeld hiervan is het risico op verwijtbaarheid als wij steeds meer en steeds gedetailleerdere keuzen moeten maken over nieuw leven. Met welke verantwoordelijkheden worden aanstaande ouders opgepadeld nu zij steeds meer keuzen moeten maken? Datzelfde Centrum voor ethiek en gezondheid merkte op dat de almaar groter wordende keuzevrijheid in de zorg dreigt om te slaan in een kiesplicht. Welke gevolgen heeft dat voor de individuen in onze samenleving?”
- [41] “Het lijkt onderhand alsof je je schuldig moet voelen wanneer je als gendraagster met een kinderwens niet voor selectie kiest.”
- [63] “De wereld is als schepping een ‘datum’ en geen toevallig ‘feit’. De wereld is gegeven; de orde en het mysterie van die wereld confronteren de mens met het besef dat niet hij de schepper is van alles wat bestaat, maar dat hij die wereld heeft ontvangen. Dat besef geeft een specifieke ervaring van de dingen. Wie de wereld als wonder blijft zien – de wonder van het geschenk – zal haar niet in een zelfbetrokken utilistische houding kunnen exploiteren...De verhouding tot de natuur dient er een te zijn van respect voor wat in de schepping gegeven is. De mens exploiteert niet, maar antwoordt. Dat antwoorden is bij uitstek de houding die past in de relatie tot God en medemensen. Antwoorden betekent de erkenning van het gezag van de ander. Voor christenen betekent dit de erkenning van het gezag van God, die op vele manieren spreekt. Hier ligt de bron van de morele verantwoording van het handelen.”
- [49] “In het boek Ezechiël, zegt rabbijn Klapheck, staat dat God de mensen een nieuw hart zal geven en een nieuwe geest. “Dat is spiritueel bedoeld en niet medisch, maar het geeft aan dat er verbetering en vernieuwing mogelijk is. God spreekt de profeet daar aan als mensenzoon, verantwoordelijk voor het goddelijke in het leven. Elke vernieuwing is angstaanjagend, maar wij moeten ons niet door angst laten leiden, maar door geloof in vooruitgang.”
- [59] “Volgens de voorstanders 'lijkt' dit scenario 'onrealistisch'. Maar voor God spelen kunnen mensen niet aan. Dat corrupteert een keer. Want bij menselijke 'goden' zijn zwakken nooit in tel geweest.”
- [63] “Onder christenen bestaat een diepe scepsis met betrekking tot de utopische projecten van de moderniteit. Wetenschap en techniek zijn scheppingsgaven, maar kunnen ontsporen als ze worden losgemaakt van morele kaders. Veel christenen hebben de kritiek van de postmodernen herkend als hun kritiek op de pretenties van de moderniteit. Zij hebben een onoverkomelijk hybris om voor God te spelen. (...) Het komt er op aan in welk perspectief wetenschap en techniek worden ingezet. Een door de techniek herschapen wereld is geen perspectief. Daarin gaat het besef van de zin van het bestaan verloren.

Hiertegenover staat het perspectief waarin ieder mens wordt geaccepteerd als een gewild en bedoeld persoon.”

- [50] “Het argument dat we ‘niet voor God mogen spelen’ heeft dan ook geen enkele grond. We zullen in de menselijke genenkaart niets ontdekken dat de verwezenlijking is van een goddelijk plan.”
- [49] “De natuur is helemaal niet leuk. En waarom doen we hier wel moeilijk over, terwijl we bij het selecteren van zaad bij inseminatie de beste zaadjes eruit centrifugeren, zonder daar een probleem van de maken? Maar vooral: het is geen houdbaar argument met de Bijbel als uitgangspunt. De natuurlijke gang van zaken is bijbels gezien niet heilig.”

### Section 3.3.6

- [49] “Maar puncties verbieden, dat werkt niet. Mensen willen het. Ze zijn consumenten in de gezondheidszorg, zegt ze.”
- [64] “De toepassing ervan is niet tegen te houden, betoogt de hoogleraar, en dat is geen zegen. Financieel niet, en maatschappelijk niet (...) In mijn boek zie je hoe de overheid worstelt om de kosten van voortplantingstechnologie te beheersen. Er is geen medische methode waartegen gezegd is: we doen het niet (...) Vorig jaar is, tot mijn verbijstering, het hielprikkpakket uitgebreid met vijftien ziektes. Daar zijn ziektes bij die minder dan eens per jaar voorkomen, en waarbij de behandeling helemaal niet veel beter wordt als je bloed prikt. Maar we kunnen het in één ruk allemaal bepalen. Dus we zeggen: waarom niet? Dat hoort bij uw generatie.”
- [53] “Overigens zij opgemerkt dat het vorige kabinet, op dit punt vertegenwoordigd door staatssecretaris Ross van Dorp (CDA), de embryoselectie die Bussemaker nu wil toestaan, wilde verbieden. Het is dus niet juist te doen alsof het hier gaat om een buitenissige opvatting van de ChristenUnie.”
- [65] “Onlangs had ik een patiënte die IVF nodig had vanwege haar onvruchtbaarheid, terwijl ze tevens het BRCA-1 gen droeg. Bij de IVF mochten we de embryo’s wel op uiterlijk selecteren (om de mooiste terug te plaatsen) maar niet op dragerschap van het gen. Een absurde situatie.”
- [66] “Het zou raar zijn om embryo's met een ernstige erfelijke aandoening níét uit te selecteren, vond Joep Geraedts. „Bij reguliere ivf maak je ook een keuze, omdat je meer embryo's hebt.””
- [32] “Als je dit niet toestaat en abortus om deze reden wel, dan is dat gek.”
- [35] “De ChristenUnie wil niet dat embryo’s met een borstkanker-gen worden vernietigd. Wat volgens de Nederlandse wet allang mag: een vruchtwaterpunctie bij zwangere vrouwen in wier familie deze erfelijke vorm van borstkanker voorkomt. Als de vrucht drager van de ziekte blijkt, mag zij na zestien weken worden geaborteerd. Wat is erger, ook volgens de logica van de ChristenUnie: abortus na vier maanden of de vernietiging van een embryo in een laboratorium?”
- [39] “Mensen hebben al 2-3 keer een spontane zwangerschap gehad die ze hebben moeten afbreken met een abortus omdat bij vruchtwaterpunctie bleek dat het kind in de zwangerschap dat borstkankergen had. Als ik in het buitenland op congres ben kan ik niet aan mijn collega’s verklaren dat we wel vruchtwaterpunctie mogen doen en de zwangerschap afbreken maar dat we niet mogen voorkomen dat een zwangerschap ontstaat.”
- [57] “Politici uiten bedenkelijke tegenargumenten zoals ‘Dit botst met de eerbied voor alle vormen van menselijk beginnend leven’, ‘Dit leidt tot de medicalisering van het leven’, ‘De kans dat een erfelijke borstkanker zich ontwikkelt is niet 100 procent’ of: ‘Dit ondergraaft de solidariteit in de samenleving’. Als zulke argumenten worden aangevoerd

- is het in feite ook logisch dat ook de abortuswet als de euthanasiewet weer worden afgeschaft.”
- [67] “Veel mensen zijn principieel tegen abortus en zeggen: liever een embryo vernietigen dan een foetus van drie maanden.”
- [55] “Abortus is ook toegestaan als bij een test blijkt dat het kind verhoogde kans loopt op een ernstige vorm van erfelijke borstkanker. Verhoef: Dat is als arts niet uit te leggen. Abortus mag wel, maar embryoselectie niet.”
- [68] “Kunt u het uitleggen dat met úw goedkeuring na drie maanden wél een zwangerschap mag worden afgebroken, maar geen embryoselectie zou mogen worden gedaan? Als de bevruchte eicel nog niet eens ingenesteld is, en nog maar ácht cellen klein is.”
- [44] “Dat is voor ons ook het frustrerende. Je mag inderdaad wel tijdens de zwangerschap, terwijl zo’n kindje al helemaal compleet is, abortus plegen, en inderdaad, in een eerdere fase mag het niet. Dat is voor ons gewoon onbegrijpelijk.”
- [69] “Vernietiging van de overige (foute) embryo’s is een daad van mensen die vergelijkbaar is met de wijze waarop de natuur met fouten omgaat. Niets meer en niets minder.”
- [43] “Bij ivf kunnen embryo's weggegooid worden, maar in de natuur gaan ook embryo's verloren.”
- [36] “Zwangere vrouwen mogen wel via een vruchtwaterpunctie hun wekenoude vrucht laten onderzoeken en eventueel aborteren als het syndroom van Down of het erfelijke borstkanker-gen wordt geconstateerd. De 150.000 draagsters van een spiraaltje in Nederland beletten iedere maand dat een gezond embryo zich verder ontwikkelt. Bij iedere IVF-behandeling worden de meest kansrijke embryo’s geselecteerd, de overige op termijn weggegooid. De natuur selecteert iedere dag embryo’s op massale schaal. Hebben de Rouvoets twaalf kinderen?”
- [70] “Een ander argument van Ross is dat mogelijk ‘zonder noodzaak’ embryo’s tot stand worden gebracht die, als ze niet voor plaatsing in de baarmoeder in aanmerking komen, zullen worden vernietigd. Maar hoe zwaar moeten we daar aan tillen als dagelijks duizenden embryo’s verdwijnen door het gebruik van het spiraaltje? Overigens: is het niet vreemd de exclusie-PGD te verbieden, terwijl vrouwen ook in ons land tijdens de zwangerschap recht hebben op de prenatale exclusietest, die vaak wordt gevolgd door abortus als de kans op dragerschap 50 procent is?”
- [71] “Ik hang de theorie aan van de toenemende beschermwaardigheid: hoe ontwikkelder het ongeboren kind, hoe beschermwaardiger het is. Ook een embryo is beschermwaardig, al moeten we niet vergeten dat zo’n embryo in hetzelfde stadium is als de bevruchte eicel die door het spiraaltje niet kan innestelen. Zo’n spiraaltje doet dus hetzelfde als wij en daar kunnen we als samenleving al decennia mee leven.”
- [39] “Er wordt al 30 jaar prenatale diagnostiek gedaan, dus dan kan je nu niet ineens zeggen: ‘wij vinden het embryo beschermwaardig vanaf het moment v.d. bevruchting.’ Want er zijn geloof ik zestigduizend prenatale diagnoses alleen in al Rotterdam gedaan.”
- [65] “In Nederland worden 10.000 IVF-behandelingen per jaar uitgevoerd. Bij iedere behandeling selecteert men embryo’s. De goede worden in de baarmoeder geplaatst of ingevroren, de slechte worden weggegooid. Dat zijn er enkele tientallen per dag. In Nederland gebruiken 150.000 vrouwen een spiraaltje als anticonceptiemiddel. Het spiraaltje werkt door te verhinderen dat het embryo inde baarmoeder innestelt. Per maand gaan er aldus 150.000 goede embryo’s verloren. Dat zijn er enkele duizenden per dag.”
- [50] “God’ zelf lijkt er ook nogal kwistig mee om te springen. Het lot van de meeste embryo’s is namelijk een voortijdige dood. Van alle eitjes die op natuurlijk wijze worden bevrucht, sterft 75 procent nog voor de zwangerschap is voltooid.”
- [72] “De ChristenUnie acht een embryo als eerste stadium van menselijk leven beschermwaardig: het mag niet vernietigd worden en selectie van embryo’s op grond van erfelijke afwijkingen mag niet plaatsvinden. Die opvatting staat haaks op wat gebeurt bij het normale voortplantingsproces. Een embryo is een klompje cellen dat ontstaat door

- celdeling na de bevruchting in de eileider. Het wordt door de eileider vervoerd naar de baarmoeder waar het eventueel de kans krijgt in te nestelen in het baarmoederslijmvlies. Veel embryo's nestelen niet in en gaan dus verloren; als er wel innestelen gaat een groot deel alsnog verloren als spontane abortus.”
- [44] “Er wordt gezegd, de ziekte wordt al toegepast bij ziektes die dodelijk zijn waar ook echt honderd procent zekerheid is dat de ziekte zal gaan optreden, maar wat bijzonder is aan het voorstel van de staatssecretaris is dat een verruimde toepassing van de techniek gaat plaatsvinden bij een ziekte die op latere leeftijd waarschijnlijk zich zal voordoen en waar het ook nog gaat om een grote kans dat die ziekte zich zal voordoen. Dan is dus mijn vraag, op het moment dat je zegt, we achten het hier noodzakelijk: hoe ernstig moet de ziekte zijn en hoe groot het risico om te zeggen ‘we kiezen voor deze techniek en voor deze manier van selecteren’ en als je dan nog veel verder doordenkt, dat je dan ook gaat afvragen, wat betekent dit voor de samenleving?”
- [73] “Natuurlijk is het toestaan van embryoselectie bij ernstige erfelijke kanker een glijdende schaal. Met embryoselectie is het als met die felgekleurde stortkokers die je soms ziet in het zwembad: de enige zekerheid is dat het heel hard gaat, maar waar je precies uitkomt, dat weet niemand. In Amerika en Australië meldden zich destijds enkele dove ouderparen die ook graag een embryo wilden selecteren. Ze wilden een doof kind.”
- [58] “Bussemaker bezweert haar tegenstanders in de Tweede Kamer dat het gaat om een beperkte lijst genetisch bepaalde ziekten, die in aanmerking komen voor preselectie van embryo's. Het grote probleem met dit soort lijsten is dat er geen weg terug meer is. Als eenmaal preselectie van embryo's op deze ziekten is toegestaan, zullen er maatschappelijke en medische lobbygroepen ontstaan die zich zullen inzetten om ook hun 'ziekte' op de lijst voor preselectie te krijgen. Waar eindigt het? Het uiteindelijke criterium van de staatssecretaris, 'ernstige erfelijke ziekten', is een zeer vloeiende waarde, potentieel zonder einde. Wie de uitzondering toestaat, zet de deur open voor algemene aanvaarding.”
- [46] “„We komen in een situatie waarin op van alles en nog wat geselecteerd kan worden,” zegt directeur prof. dr. Henk Jochemsen van het Lindeboom Instituut, een studiecentrum voor medische ethiek. Er zijn zoveel meer genen die tot een ziekte kunnen leiden. „Hoe ernstig moet de ziekte en hoe zwaar de behandeling zijn en hoe groot de kans erop om embryoselectie te rechtvaardigen?”, is een van de vragen die het Lindeboom Instituut en de NPV in hun reactie opwerpen.”
- [87] “De ChristenUnie wijst erop dat niet honderd procent aantoonbaar is dat afwijkende genen leiden tot het ontstaan van borst- of darmkanker. André Rouvoet vindt dat staatssecretaris Bussemaker daarom een principiële grens overschrijdt en dat haar plan de weg opent voor nog verdergaande selectie van embryo's op afwijkingen.”
- [60] “Dragers van het erfelijke borstkankergen hebben tachtig procent kans de ziekte te krijgen. Welk risico is ernstig genoeg om het vooraf uit te sluiten? Een kans van tachtig procent, zestig, tien? Zo ga je stap voor stap verder. Er zijn mensen die niet geloven in een hellend vlak, maar deze beslissing laat zien dat dat hellend vlak er wel is.”
- [64] “Hans Galjaard, humaan geneticus, vindt dat met uitbreiding van embryoselectie een grens wordt overschreden. Alle embryo's dragen risico op een ziekte, dus: ‘Wie hou je dan nog over?... En dat er nú rekening mee gehouden moet worden dat mensen in de toekomst ook kleinere kansen op ziekte bij hun nageslacht willen uitbannen. “En wie hou je dan nog over?” vroeg hij retorisch.””
- [66] “Wat voor nieuwe grenzen zijn we aan het opzoeken? Wat betekent het voor de toekomst als we ook gaan selecteren op genen die niet in 100 procent van de gevallen tot een ziekte leiden? Dat betekent dat er op meer ziektes gescreend gaat worden, want het leed van de patiënten zal ons telkens dwingen ermee door te gaan.”
- [74] “Je hoeft geen groot futuroloog te zijn om vast te stellen dat de menselijke voortplanting van de toekomst seks- en liefdeloos in een laboratorium zal plaatsvinden (...) Je hoeft niet

- in een Scheppende God te geloven, om te geloven in het hellende vlak van de manipulatie van levenskwaliteit.”
- [75] “Een ivf behandeling is niet niks. Vrouwen denken er maanden over na. Ook de wetenschap is nog niet zover: voor iedere vrouw, voor elke mutatie moet een specifieke test worden ontwikkeld.”
- [39] “Ja ik ben daar helemaal niet bang voor. Wij doen nu veertien jaar preïmplantatie genetische diagnostiek, dus dat embryo onderzoek, wij hebben in die veertien jaar nog nooit iemand gehad die is gekomen met het verzoek om deze diagnostiek toe te passen voor een ziekte die een 10 procent verhoogd risico geeft.”
- [39] “Maar meneer Galjaard, dan hadden we dat toch ook gezien bij de antenatale diagnostiek, dat is vruchtwaterpunctie. Je kunt vruchtwaterpunctie laten doen op allerlei ziektes, er is in de 30 jaar dat er vruchtwaterpuncties in Nederland gebeuren helemaal geen trend naar mensen die met minder ernstige ziektes komen en een vruchtwaterpunctie vragen. Daar zit helemaal geen trend in. Mensen denken daar ontzettend goed over na wat ze willen en dat geldt nog veel meer voor preïmplantatie diagnostiek.”
- [71] “In 25 jaar is de prenatale diagnostiek (onderzoek van het kind in de baarmoeder) enorm uitgebreid, maar het aantal abortussen vanwege een ziekte of afwijking bij het kind groeit niet. Het zit al jaren tussen de 400 à 600 gevallen. Die glijdende schaal is er niet, omdat ouders graag een kind willen.”
- [69] “Dat er een hellend vlak zou dreigen, is ongegronde angst. Daar is iedereen zelf bij. Gezien de wijze waarop er de laatste jaren met vragen van leven en dood is omgegaan, kan er ook op vertrouwd worden dat dit niet gebeurt.”
- [76] “Er is geen enkele aanwijzing dat aanstaande ouders sneller abortus laten plegen als blijkt dat hun ongeboren vrucht iets kleins mankeert. Dat heeft een groep artsen dinsdag op de website van het Nederlands Tijdschrift voor Geneeskunde geschreven. Volgens de artsen blijkt ook nergens uit dat mensen sneller tot abortus overgaan als hun vrucht een kleine kans op kanker heeft.”
- [31] Van den Brink: De vraag is of er niet meer ziektes ontstaan waarbij je PGD kan doen. Sluit u dat uit?”  
 Bussemaker: “Het kan zijn dat er andere genen worden ontdekt.”  
 Van den Brink: “Maar dan ga je toch steeds een stapje verder.”  
 Bussemaker: “nee, je gaat niet steeds een stapje verder omdat je zegt: hier is de kans dat iemand dat krijgt in die individuele beoordeling (...) en alleen in die specifieke gevallen dat we te maken hebben met dit verwoestende gen, dat in zijn uitwerking identiek is aan de andere ziektes, mag het.”  
 Van den Brink: “Uw voorganger vond dat dit niet mocht, u vindt dat dit mag maar dat andere dingen niet mogen, en uw opvolger vindt misschien dat die dingen weer wel mogen (...) Het maakt dus uit wie daar zit en misschien zegt de volgende staatssecretaris wel, er komen nog meer ziektes bij.”  
 Bussemaker: “Nee, het belangrijkste is dat je een proces kiest waarin je zeker weet dat de beoordeling die gekozen wordt dat die zorgvuldig is. En ik heb me niet voor niks bij dit proces heel nadrukkelijk bemoeid met al die deskundigen. Ik heb presentaties gekregen van het academisch ziekenhuis in maastricht om mij ervan te overtuigen dat ik niet de weg open om te zeggen ‘u heeft een vlekje, misschien kunt u maar beter niet geboren worden.’”
- [33] “Het door de ChristenUnie gehanteerde argument dat het voorstel van Bussemaker leidt tot een hellend vlak van eugenetica is een drogredenering. De staatssecretaris bakent juist pijnlijk nauwkeurig af onder welke omstandigheden deze medische techniek wordt toegestaan.”
- [77] “Het hellend vlak slaat in dit geval nergens op omdat de bestaande embryowet scherpe grenzen trekt.”

- [38] “En bovendien, op het moment dat je kiest voor embryoselectie dan ga je een heel traject in met allemaal gesprekken en onderzoeken dus het is niet zo van.. we gaan even naar Maastricht en we willen een jongetje met blond haar en blauwe ogen. Zo gaat het niet en zo wordt het nu wel een beetje voorgesteld met het hellend vlak. Daar komt heel veel bij kijken. De ouders die het overwegen – en zo heel veel gevallen zal het niet betreffen, die een beroep doen op Maastricht, die mensen met deze erfelijke ziekte hebben er een lange lijdensweg op zitten en hebben dit als laatste hoop.”
- [78] “Het hellend vlak bestaat niet, betoogt hij: 'Dat is een politieke vinding.' Embryoselectie vindt pas plaats na vele gesprekken met de ouders en na uitvoerig overleg in een speciale commissie, zegt hij. Iedere aanvraag wordt apart beoordeeld, waarbij wordt gekeken naar het risico op overdracht, de ernst van de ziekte, de behandelopties. Gaat het alleen om een oudtante die de ziekte heeft gekregen of om de halve familie? Openbaart de ziekte zich op jonge leeftijd en hoe ernstig is het verloop? Van de 1.250 paren die zich de afgelopen veertien jaar aanmeldden, bleven er na intensieve gesprekken 250 over voor embryoselectie. Hij weet dat in de Verenigde Staten commerciële klinieken embryo's selecteren op de ziekte van Alzheimer en op aandoeningen die prima te behandelen zijn. 'Zover zullen wij nooit gaan. Wij denken niet commercieel en willen patiënten niet blootstellen aan onnodige medische technieken. Nederlandse patiënten zijn nuchter, die kiezen niet voor een langdurige belastende behandeling als daar niet voldoende gezondheidswinst tegenover staat.’”
- [43] “Ik ben absoluut tegen selectie van embryo's, omdat ik geloof dat we menselijk leven niet mogen uitselecteren (...) Daarnaast denk ik niet dat mijn situatie zwaarder is dan die van bijvoorbeeld een moeder met autistische kinderen. Ook aan autisme zit waarschijnlijk een erfelijke component en mogelijk kan zoiets straks ook genetisch vastgesteld worden bij embryo's. Als je nu toestaat te selecteren op het borstkankergeen, waar ligt dan de grens?”
- [39] “er is een geweldige ontwikkeling in de chip DNA technologie. Dus de komende 10-20 jaar kun je verwachten dat er voor ik weet niet voor hoeveel ziektes genenvarianten gevonden worden die tot een hoger risico leiden. En soms zal dat een heel geringe verhoging zijn, soms zal dat meer zijn,.En dan zie ik niet als je nu ‘ja’ zegt, hoe je dan nog ‘nee’ kan zeggen. En omdat ieder van ons wel een verhoogd risico heeft op iets, van dementie tot Parkinson en van diabetes tot hart en vaatziekten. Denk ik dat er dan weinig mensen overblijven.”
- [79] “Maar wat als in de toekomst iemand lijdt onder de gedachte dat zijn of haar kind een verhoogde kans heeft autistisch te zijn of een verhoogde kans heeft op hooikoorts? Hooikoorts kan je leven flink vergallen, toch? Wat als een doof echtpaar een doof kind wil, omdat dit zo goed is voor hun gezinsleven? Dat is geen vergezochte casus, er is al eens een rechtszaak over geweest.”

### Section 3.3.7

- [29] “Wie, mevrouw Wiegman, is de ChristenUnie om een dergelijk moreel oordeel over de kwaliteit van leven en gezondheid op te willen leggen aan de rest van Nederland?”
- [67] “De ChristenUnie straalt uit dat zij een direct lijntje heeft met boven en dat wij allemaal dwaallichten zijn. Terwijl het standpunt van staatssecretaris Bussemaker heel logisch en weldoordacht is... De politici van de ChristenUnie menen dat zij als zeer gelovige christenen de wijsheid in pacht hebben. Het is het willen opleggen van een opvatting die berust op een levensovertuiging. De ChristenUnie gebruikt de Tweede Kamer als missiepost, maar daar is het parlement niet voor. Dan moet je het zendingswerk in gaan. In het parlement dien je elkaar te overtuigen met argumenten.”

- [57] “Minister Rouvoet zou zich er beter over kunnen opwinden dat een regering die het gezin als hoeksteen van de samenleving beschouwt, vrouwen dwingt zich te laten verminken en kinderloos te blijven om borstkanker te voorkomen.”
- [55] “‘In welk fundamentalistisch land leef ik? Moet ik binnenkort mijn baard verplicht laten staan?’ briest hij. Crul is woedend over de politieke rel die is ontstaan over embryoselectie bij vrouwen met erfelijke borstkanker. In het blad van artsenorganisatie KNMG, wekelijks gelezen door circa 40.000 medici in ons land, trekt hij fel van leer. ‘In mijn bijbel staat het besparen van onnodig, menselijk leed nog steeds als ‘goed’ te boek.’”
- [77] “Bussemaker is ervan uit gegaan dat de politici van de ChristenUnie rationele en humaan denken mensen zijn. En dat eer normaal met hen te werken valt. Een vergissing: het zijn geen rationele politici, het zijn fanaten, fundamentalisten en tirannen (...) Zij beroepen zich op hun God, die wil dat de mensen lijden en dat zij kanker krijgen omdat het in zijn grote plan met ons past.”
- [38] “Meneer Jochemsen: 66% van Nederland vindt dat u onzin uitkraamt en dat deze techniek moet kunnen”
- [36] “Wie vrouwen die jouw geloof niet delen een erfelijk bijna-doodvonnis wil opleggen, heeft wel wat uit te leggen.”
- [63] “Ik ben geen christenfundamentalist en wil me dat verwijt niet laten maken. Ik ben verontwaardigd over de gemakkelijke beelden die worden opgeroepen over hardvochtige christenen die een soort ‘Befehl ist Befehl’- ethiek hanteren, omdat ze zich op de Bijbel beroepen. Christenen die de Bijbel gezag toekennen hebben sinds eeuwen dit land bevolkt en zouden zich nu als christenfundamentalist buiten de orde moeten laten verklaren?”
- [80] “Elsbeth Etty, die in haar column schrijft dat wij ‘fanaten, fundamentalisten en tirannen’ zijn. Ik vind dat echt ongelofelijk. Of Els Borst (voormalig minister van Volksgezondheid en lid van D66), die ons beticht van ‘arrogante zelfvoldaanheid’. Het eerste dat ik dan denk is: was Borst niet die vrouw die in 2001 zei ‘Het is volbracht’, toen ze klaar was met de Euthanasiewet? En dan zegt ze dat wij de Tweede Kamer als missiepost gebruiken.”
- [81] “Veel van de tegengeluiden gingen niet zozeer over wat wij als ChristenUnie zeiden, als wel over de uitgangspunten die men erachter vermoedde. Dat was soms onthutsend om te zien.”
- [82] “Voor veel Nederlanders is geloof niet meer dan een projectie. God en geloof zijn voor hen niet meer dan een sprookje, een verzinsel. Zij vinden het stuitend dat deze achterhaalde zienswijze toch enige invloed lijkt te hebben (...) Maar zij vergeet de andere kant te belichten: terughoudendheid op het vlak van medische ethiek is geen alleenrecht van orthodoxe protestanten.”
- [63] “Niet alleen Christenen beschouwen de experimentele genetische wetenschap als een riskante instrumentalisering van het leven, ook binnen de filosofie en de ethiek bestaan verwante cultuurkritische denkpatronen... Waarom zou de discussie over de grenzen van het technischinstrumentalisme, dat op alle plaatsen in de wereld en in de wetenschap wordt gevoerd, moeten worden versmald tot een gekibbel over vormen van fundamentalisme?”
- [81] “Als je je beroept op de Universele Verklaring van de Rechten van de Mens en van mening bent dat die niet ter discussie gesteld mag worden, dan is dat net zo goed een dogma. Ieder mens houdt zich uiteindelijk ergens aan vast. Je kunt op het niveau van overtuigingen heel moeilijk een politiek debat voeren, maar het biedt wel inzicht in hoe mensen in het leven staan. Ik laat mijn geloof niet op mijn nachtkastje liggen als ik naar Den Haag ga.”
- [80] “GroenLinks en D66 hebben op milieugebied ook standpunten die de vrijheden van burgers beperken, maar kennelijk vindt men dat onverdacht. Kennelijk mag je vanuit allerlei invalshoeken politiek bedrijven, maar niet vanuit de christelijke religie.”

- [77] “Fundamentalisten zijn doof voor argumenten. Hoe valt er dan met hen te regeren? Zij missen het vermogen om hun keuzes democratisch te verantwoorden, aangezien zij alleen aan hun God verantwoording schuldig zijn.”
- [83] “Als de ChristenUnie mordicus tegen embryoselectie is, kun je natuurlijk geen moeder uit diezelfde kringen verplichten deze handeling bij haarzelf toe te passen. Maar andersom? Hoe kan een kleine minderheid (4% van het electoraat) obstructie plegen en vrouwen met genetische afwijkingen, die niets met orthodoxe overtuigingen te maken hebben, toch straffen?”
- [35] “Het staat de ChristenUnie uiteraard vrij om hier anders over te denken. Christenen hebben het volste recht om van prenataal onderzoek af te zien. Maar het is ondemocratisch als zij hun minderheidsstandpunt aan anderen willen opleggen.”
- [84] “Democratie heeft meerdere aspecten. Eén aspect is dat de meerderheid uiteindelijk beslist. De macht van deze meerderheid wordt beperkt door de grondrechten die individuele vrijheden van minderheidsgroepen waarborgen. Dat betekent overigens niet dat een minderheid de eigen beperkende regels aan de meerderheid kan opleggen. Dat zou tirannie van de minderheid betekenen.”
- [80] “Het beeld van een partijtje met zes mensen in de Kamer en drie in de coalitie dat zijn wil aan de anderen oplegt, doet geen enkel recht aan de werkelijkheid. De ChristenUnie is op volkomen legitieme wijze in de coalitie gekomen. Nu zijn de mensen die libertair zijn ingesteld, opeens bezorgd dat hen terrein wordt afgepakt. Uit die hoek klinken de felste woorden: hoe durf je grenzen te stellen aan onze autonomie. Maar het enige dat wij doen, is een meerderheid voor ons standpunt proberen te vinden binnen de ruimte die de rechtsstaat daarvoor biedt. We volgen de democratische spelregels waarvan ik hoop dat elke partij ze onderschrijft.”
- [63] “Ik beschouw democratie niet louter als een manier om via meerderheden tot machtsvorming te komen. Democratie is er om een pluraliteit aan opvattingen tot uitdrukking te brengen. Aan de democratie ligt de idee ten grondslag dat het de kwaliteit van de besluitvorming ten goede komt als er verscheidenheid van opvatting is. Die verscheidenheid moet tot klinken worden gebracht. Alleen wie overtuigd is van eigen gelijk zal hier geen behoefte aan hebben. Wordt democratie louter als middel tot machtsvorming, dan kan zij ook gaan functioneren om opvattingen van anderen uit te schakelen. Dat is de ‘knock-out-democratie’, die erop gericht is stemmen tot zwijgen te brengen. Wanneer democratie verwordt tot een instrument van een zelfbenoemde elite om politieke opvattingen te disciplineren, wordt het onmogelijk een open dialoog te voeren in de samenleving.”
- [81] “Liberalen verwijten ons dat wij onze christelijke overtuiging willen opdringen aan anderen. Maar het is eerder omgekeerd: de intolerantie komt van de seculiere meerderheid in dit land die politieke opvattingen buiten de democratische orde verklaart, omdat ze voortkomen uit een bepaalde geloofsovertuiging. De politiek is geen instrument om mijn geloof te verbreiden. Dan had ik zendeling moeten worden. Maar ik ben christen, waar ik ook ben, wat ik ook doe. Ik spreek liever over getuigen dan over evangeliseren. Mijn bijdrage aan het debat over de embryowet in 2001 ben ik begonnen met een verwijzing naar Psalm 139. Een heel mooie psalm, die begint met het wonder van het nieuwe leven, dat in de moederschoot geweven wordt. Dat deed ik niet om zo mijn tegenstanders te overtuigen, maar om iets van mijn diepste motieven te laten zien. En het grappige was dat het heel goed werd aangevoeld door de toenmalige woordvoerders van VVD en D66. Dat had ze geraakt, ze vroegen zelfs om de teksten.”

### **Section 5.3**

- [28] “Bij PGD bijvoorbeeld moeten zowel autonomie als beschermwaardigheid van leven worden afgewogen, oftewel het voorkomen van een (grote) kans op (zeer) ernstig lijden voor het eventuele toekomstige kind moet worden afgewogen tegen het uitselecteren van embryo's, en tegen eventueel beschikbare behandelperspectieven.”