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From Human Nature to Moral Judgments

Reframing Debates about Disability and Enhancement

Van menselijke aard tot morele oordelen
Een frisse blik op debatten over handicap en enhancement
(met een samenvatting in het Nederlands)

Von der menschlichen Natur zu moralischen Urteilen
Eine Neuausrichtung von Debatten
über Behinderung und Enhancement
(mit einer Zusammenfassung in deutscher Sprache)

Proefschrift

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¹ <http://phdcomics.com/comics/archive.php?comicaid=1784> (by Jorge Cham)

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Introduction

Human beings are imperfect, although we have always tried to improve ourselves by different means. We come to terms with our shortcomings and learn to value human diversity up to a certain extent. But in recent years, the life sciences have significantly broadened the possibilities for influencing human beings. This development has led to an ever-increasing number of different bioethical challenges. These challenges are illustrated in movies, thought experiments, and general developments as well as in paradigmatic real-life cases. Consider the following three cases.

1. Gattaca and desiring disability

In the movie *Gattaca* (1997), the parents of Vincent Freeman visit a geneticist when they want to conceive a second child, just as all potential parents in their society do. The geneticist explains that he has identified four embryos that possess the best hereditary traits of both parents: these embryos carry no diseases and will not make children prone to early baldness, addiction, violence, or obesity. All that Vincent's parents have to do is select the most compatible embryo. They decide that they would like to have a boy with hazel eyes, dark hair, and fair skin. A few months later, Anton is born.

Some forms of preimplantation screening (PGS), though not as advanced as demonstrated in the movie, have become commonplace. For carriers of major heritable diseases such as Huntington's disease, it is possible to choose to implant only healthy embryos. A few years ago, there was an unexpected development in the debate

about designer babies: a lesbian deaf couple turned to a sperm donor with a clear family history of deafness in the hope of conceiving a deaf child (Teather 2002). Like many other parents, the couple were motivated by what they believed was best for the child and their future family. They considered that a hearing baby would be a blessing and that a deaf baby would be a special blessing. The child born to them did indeed turn out to be deaf, as did their second child, conceived with the help of the same sperm donor. Even if not everyone accepts the use of PGS to allow couples to have a baby free from a specific hereditary disease, most people at least understand the prospective parents' desire to have a healthy child. Most will understand the intention of Vincent and Anton's parents in *Gattaca* when they choose the genes for their child, even though, for some, the practice might go a step too far. But as the controversy following the deaf couple's decision showed, only few understand why someone would wish to bring a disabled child into the world, such as the deaf couple desired to do. How can the different intuitions in the two cases be explained? What limits are there to accessing reproductive and genetic techniques for designing children?

2. Antidepressants and love pills

Serious depression accounts for as great a part of the total overall global disease burden as the most common heart diseases or diarrheal diseases (Mann 2005, 1819). In *The Noonday Demon* (Solomon 2001), Andrew Solomon provides a vivid description of his episodes of depression. When the first symptoms started, his first novel had recently been published and had received a favorable reception. However, this success did little for him. He started to feel constantly bored and numb. Instead of enjoying parties and having fun, as he used to do, he failed to connect with friends and family. His work slowed down and then stopped completely. He was losing himself. After a while, he became too scared to even take a shower or eat. Finally, his father took him to a psychopharmacologist and Solomon received medication. With antidepressants, his days became manageable. He would still wake up panicked, but the medication would relieve the anxiety. Solomon tried several kinds of antidepressants over the following months, and they helped him become the person he used to be. This is not meant to indicate

that antidepressants are a simple cure for depression, and Solomon would not argue for this claim. However, about half of moderate to severe episodes of depression improve with medication (Mann 2005, 1821). These mood improvements are relatively uncontroversial.

Now imagine a different kind of pharmaceutical cocktail, a 'love pill' designed to boost affection between partners (for this thought experiment see Savulescu and Sandberg 2008; Earp et al. 2013). Maintaining a long-term relationship is not always easy. Struggling with the relationship and then breaking up can have devastating effects on the personal and professional life of both partners and on the lives of any children they may have. Some couples seek counseling to remedy their difficulties, but this is a time-consuming process that often does not deliver the desired result. Fine-tuned emotional engineering achieved by taking a safe and cheap love pill could be more effective and efficient in helping couples to maintain the magical elements of love. Everyone would gain from it. Nevertheless, putting a chemical Band-Aid on a relationship leaves most people with quite an uncomfortable feeling, much more so than using antidepressants to be able to function in everyday life. What is the difference between such a love pill and antidepressants?

3. The blade runner

Before making headlines for his implication in the shooting to death of his girlfriend, Oscar Pistorius was known as the 'blade runner.' Pistorius was born with several deviations in his lower legs and feet and had both legs amputated below the knee as a baby (Longman 2007). Sprinting on carbon-fiber prostheses, he met the Olympic qualifying standards for able-bodied men and wanted to participate in the Olympics. However, his participation was legally challenged on the grounds that his prostheses might give him an unfair advantage over runners with natural legs. Whereas in most situations, Pistorius would be a paradigm example of a disabled person, he was now considered *too* able. Pistorius's case blurs the lines between abled and disabled. Pistorius appealed against the decision not to let him compete, and succeeded. During the 2012 Summer Olympics, he was the first amputee sprinter to compete in

the Olympics against able-bodied runners. Would future athletes be disabled or enhanced if they deliberately amputated and replaced their healthy extremities to achieve better results?

These three examples illustrate the kind of bioethical issues with which this dissertation is primarily concerned. Should parents be able to rule out inheritable traits of their offspring, and should they be morally allowed to actively seek traits such as deafness? Should we endorse the use of antidepressants and a love pill, and what—if anything—distinguishes these two cases? Should we consider Pistorius disabled, abled, or too abled? These are examples of questions that ask which treatments or enhancements are morally permissible, what we are morally permitted to do when making decisions about the characteristics of our offspring, and where we should draw the line between a disabled or an able-bodied person. All these questions are related to disability and enhancement. I will not be providing a straightforward solution for any of these cases, but I aim to provide a tool to help us to systematically and carefully analyze these and similar issues.

One approach to these issues is to employ the established standard bioethical approaches of ethical analysis and decision making, such as utilitarian or deontological principles or risk assessments. And this employment of standard analytical tools is precisely what dominates current bioethics discussions. Some bioethicists take a utilitarian perspective, for instance, when investigating whether, by preventing the birth of children with similar conditions, PGS causes harm to existing disabled individuals (Edwards 2004). Similarly, utilitarian principles are applied to debates about mood enhancers, such as antidepressants and love pills, by focusing on their impact on our well-being (Savulescu, Meulen, and Kahane 2011, especially chapter 1). Some bioethicists apply a deontological perspective to focus on children's rights to an open future (Feinberg 1980) and on the extent to which manipulating genes has a negative impact on such an open future (D. S. Davis 2009). Rights theorists debate what respect for people with disabilities entails and which specific rights they should have (Degener and Quinn 2002). Risk ethicists debate the legitimate and illegitimate risks of using new technologies and the danger of being pressured to use technologies. Clearly, these are all important questions that deserve to be discussed.

Nevertheless, the starting point of this dissertation is the claim that these standard bioethical approaches fall short of providing a satisfactory basis for treating bioethical issues such as those outlined above. Instead of criticizing the existing approaches individually, however, I shall put forward a constructive proposal to approach the issues. This proposal will be developed in

more detail in chapter one: in debates about disability and enhancement, the very idea of the human being itself needs to be discussed. Why is this the case?

To begin with, enhancement and disability affect individuals' lived experience in particularly profound ways. Biomedical enhancements improve human capacities by directly influencing the body or the brain (Buchanan 2011, xi). Enhancement, for instance, promises to improve our mood and physical capacities; it influences parent-child relationships as well as romantic relationships. And enhancement technologies are becoming increasingly available. The disabled human being, in comparison to the enhanced human being, is at the other end of the spectrum of the 'normal' human being in terms of ability and is presumed to be in some sense 'less abled.' The experience of disability can turn our world upside down: disabled people do not have some of the capacities that human beings normally take for granted, but at least some disabled people do not miss these capacities and flourish in diverse ways. Like enhancement, disability is also becoming more prevalent. But nowadays people with disabilities live longer lives and are more visible in society than they used to be.

Enhancement and disability are, increasingly, domains of complex and ethically difficult choices. Enhancement and disability both demonstrate that our capacities and traits are not only much more heterogeneous than often thought, but that capacities and traits can also be altered to some extent. Capacities that we have always simply taken for granted can be taken away, reduced, or improved, which forces us to rethink what having ability and less ability in terms of dis-ability means for human beings. Disability and enhancement require reflection on the question of which of our traits we consider it essential or important to preserve and support. They force us to think about how we relate to biological aspects of our existence and the connection of these aspects to what gives us meaning. In the light of disability and enhancement, it becomes clear that an understanding of human nature is contingent. Disability and enhancement change how we see ourselves. These two phenomena drive us to rethink ourselves and question our existence as human beings. The bioethical questions that were sketched out at the beginning of this introduction are, therefore, in many respects not analogous to other issues in applied ethics. Instead, they demand in addition that we reconsider what it means to be human.²

² See chapter one for a more detailed reasoning for this claim.

Take, for instance, the case with which I started this chapter: *Gattaca* and desiring disability. To answer the moral questions these cases raise, we need to consider which of our traits are good ones that we want to keep and which traits we are happy to alter and, most of all, how these decisions should be made. Is deafness a valuable trait because some deaf people are convinced that it is? Is there any value in ‘normal’ traits, and what makes a trait normal? What do we decide about our offspring when we design or modify their genetic make up—do we *design children* at all when we modify their genes? Furthermore, what is the value of the original genetic make up of a human being, or is there even such a thing as an original genetic make up? Questions like these will be investigated in more detail in chapter six, where I analyze the debate about designing children.

My goal in this dissertation is to develop an account of how a theory of human nature should be integrated into bioethics and to show what bioethics can gain from using this account. I explore the relevance of human nature for moral argumentation, and especially for bioethics. I develop and apply a theoretical framework that takes the contingency of human nature seriously. This framework can be used to approach questions regarding bioethical issues about enhancement and disability. Bioethics is in need of a discussion of conceptions of human nature, as I will argue, to better justify moral judgments in bioethics. Questions about human nature are essential to an adequate understanding and discussion of bioethical issues. These questions about human nature, or issues of philosophical anthropology, have so far not been systematically discussed or integrated into bioethics. As a consequence, the issues with which this dissertation is concerned have been given insufficient attention.

I begin the development of the theoretical framework by identifying the very different conceptions of the human being implicit in discussions of ‘human nature.’ Once one distinguishes between naturalistic, metaphysical, and normative conceptions of the human being, it becomes clear that one cannot simply choose one of these conceptions to employ in a moral argument. These conceptions are not directly comparable to each other, because they are not simply alternatives for each other. I will also show that conceptions of the human being can—and, in effect, *do*—play a role in moral arguments. These roles go beyond the much-criticized idea that approaches to human nature can serve as a sufficient basis for making moral judgments. In particular, as I show, there are several indirect argumentative functions for conceptions of human nature in moral arguments. This dissertation develops a systematic and detailed inquiry into the relationship between accounts of human nature and bioethics. My discussion should contribute to reflection

on the philosophical assumptions in bioethics in general, and special attention will be paid to the impact on discussions about disability and enhancement.

1 Method

This dissertation aims to contribute to the debate on the methods of applied ethics. However, as with any other scholarly work, I too have to use a certain method. How will I proceed?

It is not my aim to argue for specific answers to moral questions such as those sketched out at the beginning of the introduction. Rather, I want to show how we should fruitfully integrate an account of human nature into arguments about bioethical cases that involve disability and enhancement. I want to demonstrate how sound arguments can be made and what role an account of human nature plays in these arguments. Such a strategy is meaningful, because it develops a perspective on the relation between an account of human nature and bioethics, a perspective that has been neglected in the literature to date. This perspective serves to shed light on a variety of bioethical cases. I will argue that taking conceptions of human nature into account is necessary to make progress in many debates in bioethics. In chapters two and three, I will, therefore, develop a theoretical framework that works out a taxonomy of different understandings of human nature and the corresponding argumentative functions that they can carry out in moral arguments.

In chapters four to six, this framework will be applied to three debates about disability and enhancement. These chapters assess the extent to which employing my framework improves the moral debate in question or allows better arguments to be made.³ The applications should clarify the meaning, relevance, and implications for bioethical debates of the theoretical distinctions and insights developed in the theoretical framework. Applying a theory to a case is always a matter of striking a balance between doing justice to the specific characteristics of the case and assessing the fruitfulness of applying the framework to that case. For this reason, I have chosen to analyze detailed as well as broader bioethical issues, and I will employ different types of

³ After having developed and applied the theoretical framework in chapters two to six, I will evaluate more precisely the aims for which the framework can be employed (see chapter seven, section 1.2). I believe that this evaluation will be more fruitful and clearer after having developed the full framework and after having seen it in action.

applications when I apply the theoretical framework to these moral issues. I will explain in the following what this means:

First, I will examine the choice of the moral issues. I start in chapter four with a real-life case in which a decision has to be made concerning the treatment of an individual. This case concerns Ashley, a severely disabled girl. She received a controversial medical intervention to keep her child-sized and to restrict her female bodily development, with the intention of improving her long-term quality of life. Chapter five challenges the common assumption in debates about disability, which is that as soon as we know what the correct ‘model of disability’ is, we have an answer to the question of what justice for disabled people entails. Models of disability are taken to have strong normative implications. In chapter six, I discuss a more general moral debate: the fascinating debate about designer babies. The moral issue under scrutiny is the most abstract in chapter six, and has the most details in chapter four. The moral issue in chapter five is situated in between an abstract case and a case with many details. In chapter four, the discussion and evaluation of the ethical issue is dependent on the many particularities of Ashley’s situation. The arguments in chapter six, however, are less constrained by such situation-specific details. The reason for choosing detail-dependent as well as more abstract ethical cases is to analyze whether the theoretical framework can contribute, at least in some sense, to a wide range of bioethical issues. All of these case studies, as I will call them, are taken from the spectrum of debates in disability and enhancement. Chapter six is mostly concerned with enhancement and chapter five with disability, and chapter four discusses both disability and enhancement.

Second, I will explain the different types of applications. The more our judgments regarding a moral issue hinge on specific particularities of the case, the more attention needs to be paid to considering those details. Accordingly, the role of the theoretical framework will be less central in case studies in which the details of the case are particularly significant. For this reason, I start in chapter four with a rather loose application of the theoretical framework. Chapter five employs the framework more strictly. Chapter six, which is concerned with the most abstract moral issue of the three chapters, has the strongest focus on the theoretical framework. In all three cases, the moral framework will be used to analyze the cases, but the degree to which the theoretical framework is explicitly applied and moves to the forefront of the application differs between the cases. In chapter four, the framework plays only a limited and rather implicit role in the case study, whereas in chapter six the theoretical framework will be very prominent in

the analysis of the case study. In chapter seven, I will reflect on these different types of applications.

2 Target audience

The main target audience for this dissertation are bioethicists, especially those working on disability, disease, and enhancement. As I understand it, the discipline of bioethics is concerned with how to respond appropriately to the possibilities and challenges resulting from the life sciences. This makes it a broad and diverse field. Scholars in philosophy departments, as well as in medical and engineering schools, engage in bioethics through their teaching and publications. Policymakers seek out effective ways to regulate the innovations generated by the life sciences. Clinical ethics committees have to make decisions about how to treat a patient or whether to treat them at all. Physicians and laboratory researchers develop responses to ethical challenges that arise in their daily work. I think that this diversity of bioethics is a good thing, for the broad range of bioethical issues calls for a broad range of methodological resources. After all, bioethical questions also concern a variety of disciplines: they combine at the very least the medical and technical facts of the matter, an estimation of possibilities and risks, a moral justification, and an embedding in a system of laws and regulations. Bioethics demands knowledge stemming from a number of perspectives. It also demands a methodological account of how this knowledge can be combined to lead to moral judgments.

In this dissertation, I aim to contribute to the methods of bioethics in a general sense. My dissertation reflects on the role of specific philosophical assumptions in bioethics. In chapters two and three, I present a theoretical framework regarding the relation between conceptions of human nature and moral judgments. This theoretical framework is a philosophical piece of work. I argue that philosophy can provide distinctions that are essential to understand bioethical discussions and provide valid arguments. Specifically, without these crucial distinctions and their implications, there is little hope of an adequate and fruitful debate on bioethical questions such as those related to enhancement and disability. In this regard, the dissertation offers further evidence that bioethics cannot do without philosophy. Although bioethics is not an exclusively philosophical discipline, it cannot be conducted solely as an empirical discipline or as an analysis of what happens in practice. My dissertation demonstrates that, for specific discussions at least, engaging in bioethics means engaging in philosophy. It is not only worth the

effort, but also needed in order to provide sound justifications for moral judgments defended in bioethical discussions and to understand these discussions at all. If I manage to convince some skeptics on this point, I have achieved an important aim.

If bioethics requires a philosophical theory of human nature, this applies to bioethics throughout society: in the classroom, at the bedside, and in parliament. The bioethical questions that benefit from a philosophical discussion are present in these different settings. Even a clinical ethics committee, for instance, cannot discard these philosophical questions, put them aside, and proceed on different grounds. That said, the main audience for this discussion of the framework is an academic—and specifically philosophical—audience. I do not expect that parents of children like Ashley will read my dissertation before they make a treatment decision for their children. Similarly, the style and level of abstractness of this presentation might need to be adapted to make it suitable for many practitioners in the field of bioethics, such as physicians or politicians. A simple analogy can illustrate this point. Finer points in discussions among car mechanics will probably be lost on many car drivers, but that does not mean that knowledge about cars is irrelevant to car drivers. Ordinary drivers should be able to understand and apply a basic knowledge of mechanics, though not necessarily be aware of the technical details. The same holds for the translation of the theoretical framework.

The second target audience are philosophers who are engaged in research on questions of human nature. Questions of human nature include parts of philosophy of science, discussions about accounts of personhood and, generally, philosophical anthropology. The message for these philosophers is that what they do makes a difference in relation to bioethical issues. The separation of philosophical work on human nature and bioethics is an issue for this reason. Furthermore, the importance of a number of the distinctions that I make in chapters two and three only becomes only apparent by considering their value for bioethical cases. A practical context can illuminate philosophical theories about human nature. Therefore, philosophers of human nature should feel encouraged to contribute to bioethics.

3 Outline

In chapter one, the relation between disability, enhancement, and a theory of human nature is explored. Chapters two and three develop a strategy to

connect applied ethics with fundamental questions about human nature. In chapters four to six, this strategy is applied to three debates in disability and enhancement. Chapter seven pulls the discussion together and provides general recommendations on how the conversation about enhancement and disability should be changed. Next, I provide a more specific overview of the chapters of my dissertation.

Chapter one introduces the enhancement and disability debate. As human beings, we diagnose deviance and improve ourselves in many ways. Some of these ways are taken as self-evident, some are partly accepted, and others are controversial. I show that enhancement and disability (including disease) are closely related to each other by analyzing three subjects that are important in both debates: species-typical functioning, the role that technology plays in our identity, and well-being.

I argue that an account of human nature has a normative-legitimizing role in debates about disability and enhancement. Disability and enhancement define the limits of being human. We need to understand who we are to make sense of our existence's limits and to deal with these limits. By themselves, concepts of disability and enhancement cannot, I submit, provide such an understanding of human nature. We are, therefore, in need of a broader perspective on the human being to deal adequately with disability and enhancement. For this broader perspective, we need theoretical insights from ethics and theories of human nature.

In *chapters two and three*, I develop such a broader perspective. The aim in these two chapters is to develop a theoretical framework to analyze the relation between accounts of human nature and moral judgments.

Chapter two discusses different meanings of 'the human being.' We can see ourselves as animals, as rational beings, and as language-using and tool-making beings. We study ourselves from different perspectives: from the perspective of a biologist, a sociologist, a cultural anthropologist, or a philosopher. The reference to 'the human being' has various meanings according to each perspective. I distinguish between naturalistic, metaphysical, and normative conceptions of the human being. Naturalistic conceptions define the human being using naturalistic methods. The human being is then understood as the species *Homo sapiens* or as a being with an innate nature. Metaphysical conceptions answer metaphysical questions about human beings. For instance, they can take a stance on personhood. Normative conceptions employ normative justifications. They provide an account of human characteristics or what we value about ourselves. I do not aim at

developing a fully-fledged philosophical anthropology (or even showing this to be possible at all) but at articulating diverse conceptions of the human so as to render their applicability in ethical contexts visible.

In *chapter three*, I relate the various conceptions of the human being to moral judgments. A particular conception of the human being does not necessarily lead to a particular moral judgment. I argue that conceptions of human nature interact with moral theory and other considerations to arrive at a moral judgment. Different elements in a moral judgment, accordingly, have different argumentative functions. However, it is not possible for all understandings of human nature to have all of the argumentative functions. I distinguish five different argumentative functions that conceptions of the human can have: forming a foundation, being a constraint, creating a specification, determining scope, and describing the circumstances of morality. First, a moral judgment could be justified by reference to an understanding of human nature. Substantive moral judgments follow from a conception of the human being. Second, conceptions of the human can function as a constraint on moral judgments. In such cases, the moral judgment is shown to be wrong if it refers to an implausible conception of the human being. Conceptions of the human being can, thirdly, be used to specify our moral demands. Particular conceptions of the human being guide the practical application of normative theories and principles. Fourth, conceptions of the human being can also determine the scope of normative-ethical theories. They can give an account of who is addressed by certain theories or principles. A fifth function of conceptions of the human being in moral judgments is describing the circumstances of morality. These are features of human beings that facilitate thinking about possible moral judgments but do not make a case for any one of them.

But the proof of the pudding is in the eating. The theoretical framework developed in chapters two and three should make a difference to debates about disability and enhancement. In *chapters four to six*, I therefore apply the theoretical framework to three specific debates, with the aim of demonstrating its fruitfulness for those debates. I analyze one case study on disability (chapter five), one on enhancement (chapter six), and one that refers to aspects of both disability and enhancement (chapter four). In addition, the three case studies are situated on different levels of the discussion. Chapter four discusses an individual treatment decision, chapter five analyzes a specific question in a debate, and chapter six is concerned with a particular debate as a whole.

Chapter four is concerned with the ‘Ashley treatment.’ Ashley is a girl with severe cognitive and physical disabilities. When she was six years old, she received controversial treatment, including growth attenuation through high-dose estrogen therapy to keep her child-sized, as well as surgical removal of her womb and breast buds. The aim of the treatment was to provide Ashley with the best possible quality of life. The case has sparked a vigorous ethical controversy. This chapter starts with the observation that the debate on the Ashley treatment has paid insufficient attention to a careful philosophical analysis, which I show to be essential for a sound ethical assessment. I explain what form good arguments for and against the treatment could take. I argue that arguments for both sides necessarily have to make controversial assumptions about our relationship to our body. The relationship to our body, as I argue, is an aspect of a normative conception of the human being. The debate about the Ashley treatment would, therefore, be improved if this aspect of an understanding of the human being were part of the argument.

Chapter five analyzes the relation between models of disability and social policy claims about disability. Since the introduction of the social model of disability, there has been extensive debate about the various models of disability. The social model attributes disability at least partly to the environment instead of seeing disability as a trait of a person. The assumption underlying the debate seems to be that if only we could agree on a model of disability, we could tackle widespread and persistent injustices against people with disabilities. This idea presupposes that models of disability have a large impact on the moral judgments that are defended. Against this presupposition, I argue that models of disability cannot themselves ground social justice claims. I show that models of disability should rather be understood as metaphysical conceptions of the human being. However, that does not mean that they play no role at all in normative analysis on disability policy. They can have indirect argumentative functions in interaction with moral principles. I discuss the form such defensible arguments can take and the claims to justice that they raise for disabled people. These arguments employ several of the indirect argumentative functions that are analyzed in chapter three.

Chapter six is devoted to the debate about designing children. Fetal genes can be tested, a couple can choose to implant an embryo expected to be a compatible blood donor for an older sibling, and gamete donors can be specifically selected for certain talents. The future holds even more dramatic possibilities for increasing the chance of having a child with desired traits. Is this allowed, or is it even obligatory? In this chapter, I suggest that distinguishing between naturalistic and normative references to the human being in the debate helps to gain clarity. I argue that naturalistic conceptions of the hu-

man being are necessary for understanding what it means to ‘design children.’ However, only specific normative conceptions can determine a moral judgment and, therefore, play a significant role in evaluating an attempt to design children. I explain how specific positions in the debate can be understood better by making these distinctions. Thereby, the debate can move beyond opposing, entrenched positions.

Finally, *chapter seven* draws more general conclusions. I discuss the lessons to be learned from the discussion so far and the implications for other discussions in bioethics. I extend the theoretical framework that was developed in chapters two and three, and describe its practical applicability. I build, thereby, on the results of the application of the theoretical framework in chapters four to six. I describe how issues around enhancement and disability should be approached by integrating accounts of human nature. I show how arguments in bioethics should be constructed, and what role ideas on human nature should play in bioethics. The aim of the dissertation is to open up and facilitate a change in the conversation about enhancement and disability.

Part I – Background

Chapter 1

Disability and enhancement⁴

Human beings have long been concerned with improving themselves. We fix broken bones with metal plates, pins, and screws, we use pacemakers, and have laser surgery on our eyes. We drink coffee and take medication to stay alert longer, we take doping to improve our results in sports, and manipulate the genes of unborn children. We diagnose deviance and try to make ourselves better in all kinds of ways. How can it be explained that some biomedical improvements of ourselves are apparently accepted and others are the subject of ethical debates?

Many people tend to think that disability and disease should be eradicated, but that enhancements are problematic or should at least not be publicly financed. But the distinctions are not so neat and uncontested as one might think. In this chapter, I will suggest that to deal adequately with disability and enhancement, we need to understand better who we are. In the first section, I will explain how enhancement and disability are related to each other. Next, I will focus on the understanding of the human being in these debates by analyzing concepts of disease, disability, and enhancement. I will end by indicating the direction in which the following chapters will develop. First, I want to briefly introduce enhancement and disability.

The notion of enhancement includes a variety of issues. It ranges from the creation of cyborgs, for example, which are human beings with bionic legs, to the optimization of a biological process by using doping and neuroen-

⁴ Section one of this chapter is a revised version of the second section of (Harnacke 2013) and also builds on parts Caroline Harnacke wrote in (Harnacke and Bolt 2015).

enhancement and the genetic engineering of organisms (Heilinger 2010, 26–32). Many of the debates under the heading ‘enhancement’ do not have much in common. Yet they all engage with our ability to construct our own capacities. And this is, I think, what is so fascinating about enhancement for many people: suddenly, moral questions no longer concern what we owe to each other or how to shape the world we are living in. Rather, moral questions in these debates concern what kind of beings we are and want to be—our self-understanding as human beings is unavoidably on the agenda. Enhancement offers a point of entry into the fundamental problem of philosophical anthropology: what is a human being?

Whereas many enhancements are still a long way off, living with a disability is the reality for the “world’s largest minority” (United Nations 2007, III). Like enhancement, disability is a broad category. Experiences differ vastly between, for example, people born with cognitive levels significantly below that of the average, those unable to walk after an accident, and those who slowly lose their sense of hearing. Some of these people, such as some deaf people, do not identify as disabled, but instead as part of a minority culture (L. J. Davis 1997; Doe 2007). Moreover, many ethical problems that are not directly concerned with disability are nevertheless related to it: think of prenatal testing, euthanasia, and body identity disorder. Nowadays, people with disabilities have become more visible than they used to be. Due to medical progress, many, who for much of human history had to die early, can live full lives now. In addition, as the recent UN Convention on the Rights of Persons with Disabilities (CRPD) testifies, society has become more open to accommodating disabled people (though there is still a long way to go for equality to be reached). Disability, I believe, is a test case for understanding and living with human diversity.

1 The relation between disability and enhancement

The academic debates about enhancement and disability have been developing in parallel. Both ethical debates gained prominence in the late 1990s with the publication of the first books (e.g. for the enhancement debate Erik Parens’ *Enhancing Human Traits* (Parens 1998) and for the disability ethics debate Lennard Davis’s *The Disability Studies Reader* (L. J. Davis 1997)). Right from the start, there was also an interaction between the two debates. This interaction consisted mainly of scholars in disability ethics being deeply critical of enhancement (see, for example, articles in Buchanan et al. 2001; and Harris 2007 who both discuss concerns put forward by disability ethics

scholars; also see Glover 2008). For example, John Harris discusses and refutes the claim that enhancement would create a risk of intolerance towards disabled people (Harris 2007, chapter 6).

Even though some interaction between these two debates certainly took place, I will suggest that the ethical issues regarding disability and enhancement are intertwined even more closely. This will be elaborated by means of four subjects that I will show to be important in both debates: species-typical functioning, the role of the environment, technology and identity, and well-being. These are examples of themes that connect debates about disability with debates about enhancement and emerge at the interface of both debates.

1.1 *Species-typical functioning*

Both disability and enhancement are what we, intuitively, consider as ‘not normal.’ Being disabled is commonly understood as missing some capacities that most human beings typically have. Disabled people, for instance, cannot walk, hear, or see. They might be unable to manage their financial matters by themselves or generally struggle to navigate independently in everyday life. The enhanced human being, on the contrary, is often described as a superhuman with extraordinary abilities or even as a posthuman (Fukuyama 2003). This superhuman is “better at experiencing the world through all of the senses, better at assimilating and processing what we experience, better at remembering and understanding things, stronger, more competent, more of everything we want to be” (Harris 2007, 1). Whereas the disabled human being is less of a ‘normal’ human being, the enhanced human being is more of one. Such an approach to enhancement and disability suggests that there is a middle ground from which enhancement and disability are both deviations. Indeed, a notion of normal functioning as *species-typical functioning* is often invoked to characterize such a middle ground. Whereas treatments would be directed at reaching species-typical functioning, enhancement is supposed to move beyond species-typical functioning. Enhancement and disability describe, then, two different ways in which human beings can deviate from species-typical functioning.

Despite forceful criticism from disability scholars, the idea of species-typical functioning is still influential in understanding enhancement (for a limited defense see Daniels 2000; for a recent discussion see Savulescu, Meulen, and Kahane 2011, chapter 1.1). Eric Juengst explains that enhancements are

often understood as those interventions that are “designed to improve human form of functioning beyond what is necessary to sustain or restore good health” (Juengst 1998, 29). An influential understanding of this state of good health is Christopher Boorse’s biostatistical account of species-typical functioning (Boorse 1977; Boorse 1997; Boorse 2014). Boorse’s analysis of species-typical functioning was meant to describe health as understood by traditional physiological medicine (Boorse 1977, 543). Independently from Boorse’s analysis, species-typical functioning has become an important notion for the enhancement debate. Species-typical functioning is understood as an objective matter of fact that can be discovered by statistical investigations.

“Normal functioning in a member of the reference class is the performance by each internal part of all its statistically typical functions with at least statistically typical efficiency, i.e. at efficiency levels within or above some chosen central region of their population distribution.” (Boorse 1977, 558ff)

For Boorse, functions are contributions to individual survival or reproduction (Boorse 2014, 685). Sex and age determine different reference classes for individuals (Boorse 1977, 558). Introducing reference classes avoids a toddler, who cannot talk or walk, being seen as not functioning normally in comparison to most humans, and allows for comparing a toddler only to other toddlers. Abnormal functioning occurs, then, “when some function’s efficiency falls more than a certain distance below the population mean” (Boorse 1977, 559). What is “a certain distance”? For Boorse, this distance is simply conventionally chosen (Boorse 1977, 559). A biological notion of function and a statistical notion of normality set the standard of species-typical functioning.

Importantly, Boorse stresses that his account of normal species-functioning is value-free (Boorse 1977, 542/543; Boorse 2014, 684). Normal species-functioning is a matter of science and not of evaluative decisions. To avoid misinterpretations of Boorse, it should be added that Boorse does not think that a commitment to medical intervention is value-free in the same way as the description of a state of health and disease. Whereas the concepts of health and disease themselves are value-free, what we do about them is a normative decision (Boorse 2014, 694). We could just as easily decide to cause diseases instead of cure them. It might sometimes even be preferable to have a disease instead of being healthy. Infertility, for instance, could be a blessing if contraceptives are unavailable. To what extent a state below species-typical functioning is disadvantageous depends on an individual’s envi-

ronment and goals. These are value-laden considerations, even for most Boorsians.

Following an interpretation of Boorse's account, all deviations from the norm that alleviate or augment species-typical characteristics to a certain extent are correspondingly diseases/disabilities or enhancements.⁵ Within this account, it could, for example, be normal for adult human beings to talk, walk, and run (at what speed?), see, use instruments, and maybe to swim, but it would not be normal for them to have an IQ of 150, to have telepathic powers, or to be able to fly. The latter list of abilities are enhancements. Norman Daniels defends such an account of species-typical functioning to conceptualize disability (Daniels 1985). Deviations below normal functioning for humans are, accordingly, diseases or disabilities. The normal human being can walk, but a person with Amyotrophic lateral sclerosis (ALS) cannot, so she is disabled. A normal human being has an IQ of around 100, but a person with Down Syndrome has a lower IQ, so she is disabled. Is species-typical functioning a convincing notion for understanding disability/disease and enhancement?

Even though the notion of species-typical functioning has some intuitive appeal, it is the main target of criticism in the debate.⁶ In particular, the success of Boorse's attempt to remain value-free has been questioned (Cooper 2002a; Hausman 2014; Kingma 2007; Kingma 2010; Krag 2013). From a disability ethics perspective, Jackie Leach Scully and Christoph Rehmann-Suter argue, for instance, that Boorse's account has serious difficulties in setting the cut-off point for species-typical functioning (Scully and Rehmann-Sutter 2001, 91–93). Looking at the human species with all its impairments or variations shows us that variation is actually the norm. People have a different level of intelligence, are better or worse athletes, and are in any case all somehow limited by their bodies and brains. There is almost always a continuous variation with respect to any trait. Some people have a higher IQ than others, and it is a social convention to define a person with an IQ below a certain threshold as cognitively disabled. Some children can concentrate better than others, and for more and more children in the latter category, we conclude that they have Attention Deficit Hyperactivity Disorder (ADHD). This practice challenges the idea that there is a value-free cut-off point through which we can understand disability, which is exactly what an account of species-typical functioning aims to accomplish. Excluding some variations but not others from the category of species-typical function-

⁵ For a discussion of the distinction between disease and disability, see section 2.2.

⁶ Different kinds of criticisms from a disability perspective are possible. I will focus here on the most frequent and influential points in the literature.

ing cannot be done if it is based on an uncontested biological criterion. This distinction cannot simply be rooted in nature. There is no division between species-typical and atypical functioning that we can discover by looking at nature (Parens 2011, 3). Rather, a criterion for the distinction must be deliberately chosen. This means that the criterion is not descriptive, but a value statement, which is in need of a value-based justification.

This discussion of the notion of species-typical functioning is not meant to solve all of the problems regarding the notion, or even to come to a final judgment about it. Rather, my discussion is meant to indicate that the notion of species-typical functioning is one of the bridges between the enhancement debate on one side and the disability debate on the other. Species-typical functioning is, however, a controversial notion and it needs to be critically analyzed and reflected on before it can be employed in either debate.

1.2 *The role of the environment*

I argued that an attempt to understand disability by referring to species-typical functioning is criticized in the disability ethics debate. How else, then, do authors in the disability ethics debate want to understand disability? In disability ethics, the widespread understanding is that disability is not only determined by the traits of an individual, but that it is also influenced by factors outside of the individual. This is the point of departure for the *social model of disability*, which was developed in the late 1980s and which is now the preeminent model for understanding disability (Oliver 1990; Silvers, Wasserman, and Mahowald 1998; Shakespeare 2006a; Sisti 2015, 553). According to the social model of disability, the environment is an important factor that causes disability. The environment, I submit, is in a similar way relevant to the evaluation of enhancement interventions. For this reason, the role of the environment emerges as the second concept at the interface between enhancement and disability. But let me first explain the social model of disability.

Before the social model emerged, what is today known as the medical model was taken for granted when approaching the phenomenon of disability (Wasserman et al. 2011, section 2). According to the medical model, limitations that people with disabilities face are regarded solely as a consequence of an inherent attribute of the individual. Disability would be explained by pointing at limitations, weaknesses, or other negative deviations that could be found in the individuals themselves, such as not-species-typical function-

ing. The social model of disability identified serious shortcomings in this traditional approach, arguing that what makes a person disabled is not some inherent trait of that person, but only the interaction between a trait of a person and the environment in which a person lives. The environment needs to be understood in a broad way; it incorporates not only the physical environment, but also, for example, the design of institutions and the attitudes of other people. It is this environment *together* with an impairment that disables a person and not the person who is disabled per se. A deaf person is certainly not disabled in the same way if everyone uses sign language compared with a situation in which no one does. Consequently, we need to distinguish between an impairment that is the characteristic of the individual that can, but need not necessarily, lead to a disability, and the actual disability that describes the limitations a person faces (Oliver 1990; Silvers, Wasserman, and Mahowald 1998).

In disability studies—and, more specifically, disability ethics—the exact interaction between an impairment and the environment has become a focus of discussion. On the one hand, it is argued that what constitutes an impairment also depends on social arrangements (Amundson 2000; Tremain 2001). The idea is that everyone has deficits to a certain extent. Yet, for example, in a world in which everyone signs, people who cannot sign are disabled rather than those who cannot hear. On the other hand, it is also argued that impairments themselves are often limiting or difficult (Shakespeare 2006a; Terzi 2004). Even in a perfectly adapted environment, a person with an impairment might still have less energy and have pain and so on as a result of the impairment, because this is independent of the environment. For Shakespeare in particular, impairment and disability are difficult to separate from each other, conceptually as well as empirically, and hence it is better to understand them as a fluid continuum rather than as a polar dichotomy (Shakespeare 2006a, 54ff; Shakespeare 2013, 72ff). However, even a perfectly adapted environment will still leave some severely impaired persons disabled. Imagine, for instance, a person with impairments that leave her unable to communicate, ambulate, or eat on her own. Can we really adapt the environment in a way that means that this person is not disabled anymore? Accordingly, stronger and weaker versions of the social model of disability can be distinguished. ‘Stronger’ versions, as I understand them, attempt to explain disability by pointing (almost) exclusively at the environment, whereas weaker versions acknowledge that impairments can also be problematic in themselves. In the following, I will refer to the ‘social model of disability’ as encompassing both stronger and weaker versions, unless I indicate otherwise.

If the insights of the social model of disability are accepted, it is apparent that the environment, or the context more generally, can in the same way be important for understanding enhancement. The discussion about enhancement technologies focuses on changing the individual for various purposes. However, the need for and experience of enhancement also depends on the environment, just as the experience of disability by persons with an impairment is influenced by the environment to some extent. The environment can either strengthen or diminish the value of an enhancement (Rehmann-Sutter 2012, 80–84). Accordingly, changing the environment might be as effective as using enhancement technologies to reach an improvement of human functioning. In their discussion of enhancement to improve well-being, Savulescu and colleagues acknowledge that changing the environment might also improve well-being, but they do not develop this line of argument further (Savulescu, Sandberg, and Kahane 2011, 15). Within disability ethics, authors largely agree on some form of the social model of disability. Similarly, the enhancement discussion should avoid using a medical model of functional capabilities to understand and evaluate enhancement interventions.

1.3 *Technology and identity*

I want to analyze the role of technologies in our identity as a third theme that connects the enhancement and disability debate. Just as the environment has an influence on an evaluation of human functionings, technologies also play a role in our functionings. In Andy Clark’s words, we have already become “natural-born cyborgs” (Clark 2004). We are human-technology symbionts because our thinking and reasoning takes place not only in our biological brain, but is distributed across our brain, body, and world (Clark 2004, 33). Just as we take it for granted that we use our vocal chords to speak to someone next to us, we take it for granted that we use our phones to send a message to someone further away (Clark 2004, 9) and use our computers to organize our research output. Our mind is extended to the non-biological world and embedded in this world (Clark and Chalmers 1998; Clark 2007). Many types of enhancements, those possible now and those that are future promises, are technologies that function in very close intertwinement with human beings. Virtual-reality eyeglasses, for instance, need to be worn to function. Brain-machine interfaces to stimulate the brain, such as those available for Parkinson’s patients (Okun 2012) and imagined in the future as enhancements, are even implanted under the skin. They are intended to improve, for example, senses, or to manipulate our mood. Robotic-like devices such as bionic legs (Kiss 2015) become part of the person.

Authors contributing to the enhancement debate raise concerns about how these technologies change us as human beings. Worries are expressed concerning how to deal with these types of enhancing technologies and how the borders between human beings and technologies are increasingly dissolving. Peter-Paul Verbeek conceives technologies not simply as additional instruments, but as entities that radically change us. Without the fire, the script, the airplane, or phone, we would not be the kind of persons we are (Verbeek 2011, 27). According to him, human beings and technologies become more and more intertwined with the increasing development and use of technologies. This even makes it difficult to make a distinction between the two (Verbeek 2011, 14). As a new relationship emerges, a radically new conceptualization of the relation between human beings and technologies would be needed (Verbeek 2011, 26/27).

The new conceptualization to which Verbeek refers could benefit from a disability perspective. In studying physical disability, we find a great deal of experience with enhancing technologies: think about hearing aids, battery-powered wheelchairs, myoelectric prostheses, or speech recognition software. Disabled people have been using technology in collaborative, intimate ways in their lives to move, communicate, and interact with the world for a long time. Thus, the current discussions about technology in the enhancement debate do not deal with fundamentally new issues. There are several studies reflecting on how life is lived through bodies coupled with technology (e.g. Gibson et al. 2007; Lupton and Seymour 2000; Hillhorst 2005). Studies like these can provide answers to or at least offer guidance for a possible conceptualization of the relation between human beings and technology in the enhancement debate.

A study by Gibson et al. suggests that invasive technologies become incorporated into people's self-understanding and are largely taken for granted (Gibson et al. 2007, 13). Bodies and technologies are intimately intertwined. This intertwining does not only concern technologies that are invisible from the outside and mainly imperceptible for the person, such as artificial joints. It also concerns electric wheelchairs and ventilators, as Gibson and colleagues describe. Severely disabled people see their devices as embodied extensions of the self until something occurs to bring their ventilators or wheelchairs into consciousness, for example when the device fails. The technologies become part of the person. People's descriptions of them can be likened to how persons commonly describe biological body parts (Gibson et al. 2007, 16).

Based on these findings, one could assume that a similar process would also be likely to happen with the adaption to enhancement technologies. After a while, we might no longer realize that we see through augmented reality eyeglasses, and it will become the standard way of seeing—until the glasses suddenly break. Just as it is common to state, “My back is bothering me today,” it would become common to state, “My left augmented reality eyeglass is bothering me today.” It would then be true that the borders between human and technology disappear more and more, but this would make enhancement technologies a lot less special than is sometimes assumed.

The findings of Lupton and Seymour support this view. They analyze how technology used by disabled people fulfills the function of a number of attributes, among others mobility, physical safety, personal autonomy, independence, and the ability to better engage in social relationships, the workforce, and the wider community (Lupton and Seymour 2000, 1860). These are not disability-specific attributes that a technology can offer, but they are still attractive attributes for non-disabled people. The use of technology by disabled and non-disabled people is at least in this regard apparently comparable. In addition, Lupton and Seymour stress the importance of the social acceptability of the technologies. Sensory-impaired persons were treated in a more friendly way and felt more accepted when they used a guide dog instead of a cane or an electronic sensor (Lupton and Seymour 2000, 1858). Walking around with a dog is socially acceptable, whereas electronic aids seem to frighten or unsettle people. Comparable issues might arise with the use of enhancement technologies in an early phase when people are not used to them. Yet, contrary to the use of assistive technologies for disabled people, which will in most cases only be used by a minority, enhancement technologies might become even more prevalent.

The controversy around cochlear implants can be interpreted as a debate about the role of technology in our identity (for an overview of the debate see Robert Sparrow 2010). Cochlear implants aim to be a (partial) cure for some forms of deafness. Part of the device is surgically implanted into the middle ear of the recipient which is not how other hearing aids work. To the surprise of many, the device was not as enthusiastically received by its target group as was presented by its developers. In fact, a considerably large group of deaf people refuse to have the implant. They see themselves as part of the Deaf culture (with a capital ‘D’) that uses its own language for communication and deserves protection. According to them, deafness is not a miserable impairment that should be overcome by modern technology. Rather, it is a way of being and forms an important part of their identity (L. J. Davis 2007; Doe 2007). Based on the reception of the cochlear implants, we can antici-

pate that a similar development could also occur in the case of some enhancement technologies. People might not feel the need for a certain enhancement even though this need is detected from outside that particular community. Some technologies could simply be misplaced and not be accepted because people feel that their assumed shortcomings form an essential part of who they are.

As in the case of people with a hearing impairment, the choice of a prosthesis is a question of how one perceives oneself and how one wants to be perceived by others (Hilhorst 2005). For some persons, Medard Hilhorst argues, a brightly colored prosthesis with the look of a cute toy may fit better than a prosthesis that resembles as closely as possible a ‘real’ hand. A colorful prosthesis needs to be worn with self-awareness and self-confidence. It immediately attracts attention and certainly does not aim at hiding the disability. It suggests that a missing hand cannot be denied and does not need to be. Rather, it emphasizes the value of bodily difference. However, persons choosing a hand-like prosthesis might not want to place too much emphasis on their bodily difference. They might try to avoid bringing special attention to their impairment and thereby minimize their difference from others (Hilhorst 2005, 306). Likewise, choosing or not choosing a certain enhancement might also relate to how people understand themselves.

The preceding discussion shows that the role of technologies in our identity is a central topic for both the enhancement debate and the disability debate. For many disabled people, living closely connected with invasive technology is not as special as it is for able-bodied people. As John Hockenberry claims: “We live at a time when the disabled are on the leading edge of a broader societal trend toward the use of assistive technology” (Hockenberry 2011). The enhancement debate can make use of these experiences. We may learn about how we will adapt to biomedical enhancements by considering how we adapt to technologies to cope with disabilities.

1.4 *Assumptions about well-being*

A fourth common theme for both disability and enhancement debates are assumptions about well-being, on which the debates typically rely. Whereas disability is often problematized because it would reduce well-being, enhancement is justified on the grounds that it contributes to well-being.

One common conception of enhancement is that enhancement improves a person's well-being. Julian Savulescu, John Harris, and others, defend such a welfarist definition of enhancement. Enhancement describes "any change in the biology or psychology of a person which increases the chances of leading a good life in the relevant set of circumstances" (Savulescu, Meulen, and Kahane 2011, chapter 1). Similarly, Harris argues that "[i]f it wasn't good for you, it wouldn't be enhancement" (Harris 2007, 9). Such an understanding of enhancement is inherently normative from the start. However, it needs to be shown that either seemingly clear paradigm instances of enhancement, such as doping, are indeed contributing to well-being, or it needs to be accepted that such instances should no longer be included within the class of enhancement. Savulescu and his colleagues accept that seemingly clear instances of enhancement do not count as enhancements on their account, but they assert that most of these paradigm enhancements will be enhancements in their sense most of the time.

Not all authors argue for a conceptual connection between enhancement and well-being. Some authors are simply willing to accept that, generally speaking, enhancement contributes positively to a person's well-being. More intelligence, more muscles, or in general a higher performance would allegedly make one better off. However, it is pivotal to ask what conception of well-being or a good life lies behind the claim that enhancement would make a contribution to welfare. As Immaculada de Melo-Martín points out, "[I]t is at least not obvious in what sense reading a book in 20 seconds, or enhanced physical strength or numeric capacity, contributes to a more fulfilling life" (Melo-Martín 2010, 485). A particular theory of well-being is presupposed by understanding these capacities as beneficial. Typically, theories of well-being can be distinguished in hedonistic theories, desire theories, and objective list theories (Parfit 1984; see Griffin 1986 for a more detailed discussion based on Parfit's account). In hedonistic theories, well-being exists in experiences that consist of more pleasure than pain. Desire-based theories focus on the satisfaction of the desires of an individual. Objective list theories argue that some things, for instance knowledge, friendships, or love, benefit us independently of our attitudes or feelings towards them.

Julian Savulescu's strategy, which he developed with several co-authors, is especially interesting and promising at this point: Savulescu and colleagues want to be neutral concerning the question of what constitutes a good life or well-being (Savulescu and Kahane 2009, 279).⁷ Even though they remain

⁷ In other writings, Savulescu supports a mixed hedonistic and objective account of well-being:

agnostic regarding a theory of well-being, they maintain that there would be a considerable consensus about the particular traits that make a life better or worse. They call these “all-purpose goods.”⁸ All-purpose goods are goods that contribute to the good life independently of the question of what kind of life is considered a good life. Examples of all-purpose goods include memory, self-discipline, patience, empathy, humor, optimism, and a sunny temperament (Savulescu, Sandberg, and Kahane 2011, 11). The main examples of all-purpose goods that Savulescu and co-authors focus on are cognitive capacities. They argue that cognition increases well-being according to all major theories of well-being (Savulescu, Sandberg, and Kahane 2011, 11). For some theories of well-being, cognitive capacities would be necessary requirements, for instance for objective list theories that include items such as knowledge. For all theories of well-being, cognitive capacities would be instrumentally valuable. Independent of the goals someone has, cognitive capacities would be necessary to choose the right means to reach those goals. Savulescu and his co-authors admit that ultimately it is an empirical question as to whether more cognitive capacities do indeed lead to more well-being and not a question that can be decided by armchair reflection.

This empirical claim is questionable when taking empirical research on people with disabilities into account. Disabled people themselves, generally, judge their own well-being much more positively than non-disabled people making a judgment about a disabled person’s well-being (Asch and Wasserman 2005, 175; Goering 2008, 125/126; Tännsjö 2009; Ubel, Loewenstein, and Jepson 2003, 605; Ubel et al. 2005). Even significant limitations of body and mind do not need to be an obstacle to well-being. In the following, I will argue that the disability debate sheds a critical light on assumptions about well-being as put forward in the enhancement debate. It is not my aim to prove that the enhancement debate makes wrong assumptions about well-

“I hold a mixed hedonistic and objective account of well-being. Well-being is in part constituted by hedonic states like pleasure and absence of pain. But it is also associated with engaging in objectively valuable activities, like gaining knowledge, developing one’s talents, having deep personal relationships, appreciating beauty, and so on. One item on the objective list is autonomy. Our lives go better when they are autonomously authored.” (Savulescu 2009, 64)
 However, this does not stand in contradiction with his argumentative effort to employ a neutral conception of well-being here. With this neutral conception, he aims to offer an account that can be valid for very different conceptions of well-being.

⁸ Here, Savulescu builds upon earlier work by Allen Buchanan and co-authors (Buchanan et al. 2001, 167ff), which in turn is based on John Rawls’ concept of ‘primary goods.’ Buchanan et al. argue that eyesight, for example, is an all-purpose means. There are few perspectives from which the loss of eyesight does not constitute a harm, and equally few perspectives from which eyesight is not an advantage that helps one to realize one’s plan of life. A similar argument applies to memory. Buchanan et al. recognize that the relative advantage of these capabilities may differ and that people can adapt to changing circumstances. Unlike Buchanan, Savulescu et al. employ all-purpose goods to construct an argument for enhancement. This makes Savulescu’s account particularly suitable to analyze regarding enhancement and well-being.

being, because it is often unclear to which account of well-being the empirical studies relate. But I want to demonstrate that the engagement with disability is at least thought provoking regarding some expectations of enhancement. If disability makes it clear that there is no direct relation between functionings and well-being, enhancement might not make its promises come true.

Regarding cognitive disabilities, empirical research shows that people with cognitive disabilities might even be happier than others (Verri et al. 1999). They report a high quality of life (Hensel et al. 2002). In addition, some years after being treated for a brain tumor, participants from another study noted a quality of life that is independent of their degree of cognitive impairment (Lannering et al. 1990).

The majority of empirical research regarding disability and well-being focuses on physical disabilities. In a famous study, the self-reported happiness of people who had recently developed paraplegia or quadriplegia following an accident was much higher than one might expect. They rated their own happiness at this stage of their life, that is, at a rehabilitation institute shortly after their accident, still above the midpoint of a scale between ‘not at all’ to ‘very much’ (Brickman, Coates, and Janoff-Bulman 1978, 919). People with a spinal cord injury disclose in general a lower subjective well-being than the general population, but the difference is not dramatic (Dijkers 1999, 867). Other studies compare the self-reported well-being of patients in a certain condition and the well-being that other individuals assume they have. The results show that healthy individuals consistently attribute a lower well-being to patients’ quality of life than the patients themselves. Patients who received life-long dialysis in a hospital rated their quality of life at a value of 0.52 (where 0 stands for death and 1 for perfect health) in comparison with healthy individuals who estimated the patients’ quality of life at only 0.32 (Sackett and Torrance 1978, 702). Similarly, in another study, patients with a colostomy, an artificial anus at the front of the stomach, valued the quality of life with a colostomy a lot more than people did who only imagined this situation (N. F. Boyd et al. 1990). Another indication for the high level of well-being of people with impairments is the fact that many disabled people do not feel the need to be healed.⁹ They argue that even if it was available, they would not want to take a ‘magic pill’ to eliminate their impairments (Hahn and Belt 2004; S. Morris 2006, 11).

⁹ Note that the reason for this behavior might also lie in their identification as disabled and not in the absence of welfare improvements.

Even though it is often unclear exactly which theory of well-being is presumed in these studies, these results make clear that discussions of disability and enhancement pose profound questions regarding the relationship between functionings and well-being. If disability is not an impediment to well-being, enhancement might not lead to higher well-being either. Both the enhancement and the disability debate would benefit from a reconstruction and critical discussion of well-being as well as a systematic interpretation of empirical studies. Assumptions about the effect of functionings on well-being are, therefore, a common theme in both enhancement and disability debates.

2 Human nature in debates about disability and enhancement

2.1 *Human nature as a norm*

In the first section, I discussed four different topics that connect the disability debate and the enhancement debate. First, disability and enhancement can be understood as deviations from species-typical functioning. Yet the notion of species-typical functioning is also criticized. Second, the environment plays a role in our attempts to understand and evaluate disability as well as enhancement. The social model of disability emphasizes this role of the environment. Third, the role of technologies in our identity is relevant in both debates. We could learn how to adapt to biomedical enhancements by considering how disabled people adapt to technologies designed for them. Fourth, both the disability and the enhancement debate make and discuss assumptions about the relation between functions and well-being. Accordingly, these four common topics indicate that the two debates are intertwined. What is it exactly that connects the two debates on a more abstract level?

All four topics that connect the debates cover aspects of what it means to be human. They reflect upon normality, the interaction with the environment, identity, and the constitution of well-being. The central question for debates about disability and enhancement, I submit, is how to understand who we are and what consequences that has for our actions. As we learn that human beings can be different from what we are normally used to (disability) and that we are able to fundamentally change ourselves (enhancement), we have to reflect upon our way of being and which capacities and traits are important for us. We have to think about what it means to be human and how we want to relate to this. Disability and enhancement are both deviations

from what we, intuitively, consider to be ‘normal.’ That does not mean that a disabled human being is always a ‘less normal’ human and that the enhanced human is a ‘more normal’ one. Consider, for instance, the case of Oscar Pistorius that was discussed in the introduction of my dissertation. Despite having prostheses, he attempted to enter the able-bodied Olympics. Before he could eventually take part, he had to face a legal dispute because his prostheses would give him an advantage in comparison with able-bodied people. Arguably, he is disabled, but is he also enhanced? Similarly, the neurodiversity community empathically denies that people with autism are disabled in all respects.¹⁰ They argue that being autistic is simply another way of being that might even be beneficial for performing certain mental tasks. But the general idea is that ‘human nature’ has a normative-legitimizing role in debates about disability and enhancement.

For this reason, I want to suggest that debating ‘human nature’ is what connects the enhancement debate and the disability debate. If this is indeed the case, we need to understand who we are to become clear about and to deal responsibly with disability and enhancement. I do not aim at bringing forward a full argument for this claim at this point. Instead, my claim should be understood as a tentative suggestion. It will be developed further on a theoretical level in chapters two and three, and applied to practical debates in chapters four to six. Finally, the merits of approaching debates about disability and enhancement by using theories of human nature will be evaluated in chapter seven.

2.2 *Concepts of disease, disability, and enhancement*

Recently, a major effort has been made to develop convincing conceptions that demarcate disease and disability from health, on the one hand, and that draw a line between health and enhancement, on the other hand. One might argue that ‘debating human nature’ is exactly what happens in these debates. When we are discussing what constitutes disability, disease, and enhancement, one might think that we are to a certain extent putting forward an understanding of what it means to be human. Different conceptions of disease, disability, and enhancement have to provide criteria to differentiate between deviant characteristics of humans and, thereby, debate human nature, or so one could say. To relate to such a possible argument, this section is dedicated to different notions of disease, disability, and enhancement and

¹⁰ See, for instance, www.neurodiversity.com and www.wrongplanet.net

what they can do. The aim is not to defend a specific conception of disease, disability, or enhancement, but to show how normative questions regarding disease, disability, and enhancement relate to these conceptual debates.

Note that in the preceding discussion I have not distinguished disability from disease, illness, injuries, traumas, or other typically pathological states. This is common practice in debates on moral questions regarding atypical persons because the moral issues that are raised are similar enough to put this demarcation problem aside (see also Cooper 2002a, 264; Kingma 2014, 592). Also, colloquially, disease and disability are not completely distinct concepts. Of course, diseases are typically taken to be relatively short, be reversible, and be a disruption of an ongoing identity instead of being a constitutive part of it (Scully 2004, 651). But a disease can lead to a disability, and the transition is often continuous (see also Nordenfelt 1993, 21). Is MS, for instance, a disease or a disability, or both? Conceptually speaking, however, disease and disability could be separated. Diseases could be understood as being much closer to a biological account than disabilities. Boorse himself defends such an idea (Boorse 2009). He does not believe that disability is a medical notion in the sense that the same impairment might leave one person disabled, but not another. Losing a ring finger, for example, disables the violinist, but not the English professor (Boorse 2009, 69). In the discussion of Boorse's work, his account is often taken to defend an objective notion of disability in the same way that it argues for an objective notion of disease. For the purpose of my analysis, however, I will not distinguish between disabilities, diseases, and injuries, and so on.

In general, we can distinguish between naturalistic and constructivist approaches to understanding disease and health (for an overview see Ereshefsky 2009, 221–224; Murphy 2009, section 2), and disability and enhancement. Among naturalistic approaches, Boorse's biostatistical theory that was outlined above is the most prominent one (also, for instance, Schramme 2007; Wakefield 2014). It can be employed to understand disease as well as disability as states in which one is below species-typical functioning and enhancement as pushing the limits of species-typical functioning. Naturalistic accounts, generally, refer to natural or objective features of the human body that depart from natural functions. They are based on scientific theory. This means, henceforth, that a notion of disease, disability, and enhancement is based on descriptive facts about the human body that we can discover. The medical model of disability also falls into this category.

A considerable number of participants in the discourse defend instead a constructivist account of disease, disability, and enhancement (for example

Cooper 2002a; Engelhardt 1976; Engelhardt 1986; Nordenfelt 1995; Nordenfelt 2007). The basic idea is contrary to naturalism: our understanding of disease, disability, and enhancement reflects values. Of course, empirical factors can still play a role too, but the point constructivists emphasize is that one cannot talk about health and disease without making evaluations of these states (Engelhardt 1976, 276). The historical development of our understanding of atypical human beings is often cited as supporting constructivism. In 1843, Samuel Cartwright argued that, unknown to medical authorities, many slaves were affected by ‘drapetomania,’ which caused them to run away (Cartwright 2004, 33–35). What we think of as diseases and disabilities, it is argued, is normatively loaded and socially constructed.

Diverse notions of disease, disability, and enhancements are constructivist. The social model of disability and its variants (for an overview of different social models see Shakespeare 2013, 11–46) are included in this description. Welfarist definitions of enhancement and disability, such as those often defended by utilitarians, employ even stronger value statements and are clearly normative from the start. Lennard Nordenfelt defends an influential normative account of disease and health (Nordenfelt 1993; Nordenfelt 1995; Nordenfelt 2007). Health is, according to him, the ability to reach one’s vital goals in standard circumstances. Some constructivists, inspired by Michel Foucault, even go as far as claiming that some types of disease, for example mental diseases, do not exist at all, but are nothing more than constructions (Szasz 1960).

Much more could be said about constructivist and naturalistic notions of disease, disability, and enhancement, and advantages and problems for both sides, as well as possible answers. At this point, it seems, instead, worth approaching this topic from a different perspective. I think that we should consider what we want these concepts to do for us. Sally Haslanger calls this the “analytic approach” (Haslanger 2000, 33) in her analysis of race and gender. Her analysis starts by inquiring what the point is of having these concepts and what purpose they should serve. I think that it is helpful to side step the debate about the appropriate conceptions of disease, disability, and enhancement and examine the aspect that Haslanger mentions.

In bioethics, we expect that knowing whether something is a disability or an enhancement tells us what a proper reaction to it should be. Explicitly or implicitly, it is assumed that if we can find out whether certain states count as either pathological or better than normal, we will know how to deal with them. The hope is that we can answer a range of important ethical questions by figuring out what exactly the subject matter is and how other authors

analyze it (Anderson 2008, 259; Scully 2004, 650; Schramme 2013, 171/172). Conceptions of health and disease, thus, guide our actions.

Charles Rosenberg's impressive historical studies (Rosenberg and Golden 1992; Rosenberg 2002; Rosenberg 2007) demonstrate how concepts of disease are used to perform the work of "enforcing norms and defining deviance" (Rosenberg 2002, 251). Disease categories are important for physicians, because they guide the treatment, and for patients, because they guide their expectations (Rosenberg and Golden 1992, xviii). Diagnoses label, define, and predict.¹¹ Homosexuality, for instance, was for a long time considered a sin (Hansen 1992) and is among some populations still considered as such. When homosexuality was established as a medical diagnosis, this was a relief for the new patients: suddenly, they could explain their guilt-inducing desires and had found the source of their troubles. Identifying as being diagnosed with a disease gave them the possibility to frame their behavior, its nature, and its meaning. Accordingly, what we consider the right reaction towards people with recurrent, unprovoked seizures depends on how we frame their condition (Parens 2011, 5): 150 years ago, we thought that they were a divine gift. At the beginning of the last century, it was considered a psychological disorder, and now we are convinced that this is epilepsy, which is an actual medical disorder (Chang and Lowenstein 2003).

The idea that a conceptual distinction should also be an ethical one at the same time, I submit, allows for a better understanding of the debate about the treatment-enhancement distinction.¹² As soon as an intervention qualifies as a treatment, the suggestion is that it should be morally evaluated in a different way from an enhancement. We expect that there is a dividing line between treatments and enhancements and that this line tells us which interventions we have a right to have or are at least allowed to have—namely, treatments—and which need to be regulated or even forbidden—that is, enhancements. The conceptual distinction is taken to be relevant to morality. This means that a clear grasp of the concept of enhancement is assumed to be necessary for deciding on the moral permissibility of specific instances of it. This is what we want these concepts to do for us.

Norman Daniels provides a "limited defense" (Daniels 2000, 309) of the treatment-enhancement distinction as a tool to delineate the moral bounda-

¹¹ See also Björn Hofmann (Hofmann 2001), who argues that technology is constitutive of the concept of disease and establishes how we act towards disease.

¹² Note that most scholars who define enhancement and disability in terms of addition or loss of welfare do not make a distinction between treatment and enhancement (for example John Harris). Constructivist accounts of health and disease are, generally, less prone to subscribe to this distinction.

ries between acceptable or necessary interventions and unnecessary or unacceptable ones. He argues that even if the treatment-enhancement distinction is not a sharp instrument, it has a useful and modest bearing on morality. Daniels defends species-typical functioning as the dividing line between treatment and enhancement. Species-typical functioning protects normal opportunities and this, in turn, is what we owe to each other, as Daniels has argued extensively elsewhere (Daniels 1985; Daniels 2008). Daniels claims that treatments are the “primary rationale” for healthcare (Daniels 2000, 314). In some cases, we have obligations to offer healthcare beyond treatment, for instance to perform an abortion. The existence of a treatment is, therefore, not a sufficient condition of an obligation to provide it, the primary justification for healthcare is treatments. Consequently, knowing that a certain intervention is an enhancement should “raise a moral warning flag” (Daniels 2000, 320).

Daniels weakens the connection between conceptual distinctions and answers the difficult ethical questions, at least to an extent. For his argument, protecting normal opportunities is, ultimately, the decisive consideration. I think that it would prove fruitful to go one step further than Daniels suggests. We should not only acknowledge that the treatment-enhancement distinction is of only restricted value, but should also understand that the really decisive questions for ethics do not lie here. If we want to find out how we best react to atypical human beings and traits, wondering about what exactly constitutes atypical does not lead us straight to a conclusion. Concepts of disease, disability, and enhancement cannot do for us what we want them to do. Normative questions need to be disentangled from the theoretical questions about the concepts of disease and enhancement. The important considerations for ethics do not simply lie in a conceptual distinction between disease, disability, and enhancement (Anderson 2008, 268; Schramme 2013, 172). This leaves room for an influence of the conceptual questions about the normative problems. But the right way to find out what influence conceptual distinctions can have, I think, is to consider conceptual and normative questions separately and only then relate the answers to each other.¹³

Germund Hesslow shows that a concept of disease is not crucial for different considerations that we take the concept to determine (Hesslow 1993). It would not be helpful to decide whether someone is in need of a medical intervention, whether an insurance policy should cover the costs, or whether

¹³ As elaborated above, Boorse also wants to distinguish between the conceptual question of what disease is and the normative question of how to react to it. At this point, I support Boorse. Yet Daniels, for instance, employs Boorse’s account to make a normative distinction.

the person should be relieved of an obligation to work or carries less moral responsibility and legal liability. For all these questions, different kinds of considerations would be necessary. For instance, to decide about the need for medical interventions, the question should be whether an intervention is beneficial for the patient. Medical insurance works by spreading certain costly and unforeseen risks evenly. And we grant special rights not to work not because people have a disease, but because it would be too risky, demanding, or harmful for them to work just as it is for pregnant women and older people. And so on. Consequently, Hesslow argues that we do not need an exact conception of disease. There is too much emphasis on the concepts, and too little on the really important questions (Hesslow 1993, 12/13).

Along these lines, Marc Ereshefsky suggests framing bioethical discussion not in terms of health and disease, but by referring to ‘state descriptions’ and ‘normative claims’ (Ereshefsky 2009). State descriptions are descriptions of physiological or psychological states and normative claims are value judgments regarding these states. This, and not the debate between naturalists and constructivists about disease, he argues, is what really matters for ethical problems and what makes points of agreement and disagreement in the debate explicit. For example, whereas naturalists and constructivists both acknowledge that deafness involves a physiological state regarding hearing, they disagree about its value—the normative claim. This opposition is relevant to ethical questions regarding deafness, but not to whether it qualifies as a disease or disability. Correspondingly, we cannot answer any ethical question if we know whether obesity, criminality, or aging are diseases. What matters is what kind of state these conditions describe—a medical one?—and how we evaluate this state.

So far, we can conclude that concepts of disease, disability, and enhancement are employed to delineate ethical boundary lines, but they are unsuited for this task. The important considerations for normative questions lie elsewhere. If we want to know how to react to typical human beings, we will not find an answer in a metaphysical discussion about the nature of disease, disability, and enhancement. These metaphysical and conceptual distinctions are not sufficient to ‘debate the human being,’ contrary to what some might assume.

This conclusion, of course, does not imply that concepts of disease are irrelevant to all kinds of considerations, such as describing the traditional understanding of disease (Khushf 1997, 147–155). Yet in order to think about normative questions, it does not even seem necessary to argue that there are

conceptions that unify different kinds of atypical states and make them worth talking about them as a type.¹⁴

It is also important to note that I do not want to suggest that we should clear our language of the terms disease, disability, and enhancement. Like Hesslow and Ereshefsky, I believe that these notions are helpful to give a brief reference to a certain class of descriptions. Colloquially, we understand what is meant by ‘disability’ just as we understand what is meant by ‘summer.’ Most of the time, it is irrelevant that these concepts are vague to some extent. Generally, concepts of disease and disability might even give us an idea about why someone receives medical interventions or has rights other do not enjoy. But my claim is that reflection on the concepts does not help to clarify or answer difficult and new ethical problems.¹⁵

3 Conclusion: making sense of disability and enhancement

So far, it has become clear that metaphysical analyses of disease, disability, and enhancement are not the right way of providing a better understanding of human nature for debating disability and enhancement. We want these concepts to guide our actions. Yet the important considerations for ethics are to be found elsewhere. How, then, can we understand the reference to the human being in debates about disability and enhancement? I want to suggest that we should try to develop a broader perspective on the human being.

However, such broader discussion of human nature, or problems of philosophical anthropology, other than concepts of disability and enhancement, are unfashionable in bioethics. Most authors feel that they are on safer ground either by staying neutral towards it or by neglecting an explicit discussion of the old philosophical question of who we are (Roughley 2005, 133). Clearly, this has not always been the case. A brief look at the history of moral philosophy leads to the conclusion that it was common to develop complete philosophical systems (Noggle 2001, 533–534). A theory of morality had to be integrated with a theory of human nature. Thomas Hobbes’

¹⁴ Hence my approach is different from that of Elizabeth Barnes, for example, who wants to make general statements about disability (E. Barnes 2014a).

¹⁵ Analogously, Jeff McMahan argues that we do not need to discuss the conditions for a condition to qualify as a war to decide about the permissibility of killing (McMahan 2011). Whether a country is at war or not, he claims, does not make a difference regarding the justification of killing. The moral question, he argues, cannot be answered by a conceptual distinction between just and unjust wars.

contractualism, for instance, presupposes an egoistic human being who is in a war of all against all. Therefore, the Leviathan has to rule. Jean-Jacques Rousseau, on the contrary, believed that the human being is essentially good and retrieved all kinds of political and educational conclusions from this starting point. But, despite regular criticism (Anscombe 1958), modern ethics mainly tries not to make explicit assumptions about human nature. This strategy might have been sufficient to answer many ethical questions.

But currently, disability and enhancement provide us with reasons to reconsider human nature. I want to suggest tentatively that to deal adequately with disability and enhancement we need to think about how we understand ourselves. We should discuss the limits of the human being to make sense of disability and enhancement. At the same time, disability and enhancement demand that we acknowledge the contingency of our self-understanding. Answers to questions about human nature that we used to feel comfortable with are not sufficient anymore in the light of biotechnological development. Disability and enhancement have implications for our self-understanding. Hence, debating disability and enhancement can become an entry point for studying the relation between questions about human nature and applied ethics. This relation is, most likely, also relevant to other questions in applied ethics, but it is especially vivid for disability and enhancement. Jan-Christoph Heilinger summarizes this point and his summary is, therefore, worth quoting in full:

“Because it matters for human beings to conceive of themselves as human beings, a thorough discussion of the descriptive and normative components of being a human being is indispensable. The relevance of the human self-understanding is particularly salient under the current conditions, in which new biotechnological interventions may factually change what is considered to be a human being. What is ultimately needed is a theoretical framework within which the substantial debate about the content of anthropological arguments can be lead in a well-ordered way.” (Heilinger 2014, 100)

I want to develop such a theoretical framework in the following two chapters. I want to bring questions about human nature back into bioethics. In chapter two, I will analyze different notions of ‘human nature.’ Chapter three, which is closely related to chapter two, connects these different notions to moral judgments by identifying several argumentative functions of human nature.

Part II –
Theoretical Framework

Chapter 2

From human nature to moral judgments: human nature¹⁶

What is the human being? We can see ourselves as rational beings, as images of God, or as creative, language-using, tool-making, laughing and crying, or self-designing beings. We can study human beings from different perspectives: from the perspective of a biologist, a sociologist, a cultural anthropologist, or a philosopher. Accordingly, the reference to ‘the human being’ can have various meanings. In this chapter, I will investigate these different understandings.

I do not aim at developing a fully-fledged philosophical anthropology (even if this were possible). My focus will be on understanding what it means to refer to the human being in a moral judgment. For reasons specified in chapter one, I am interested in bioethics, and particularly in moral judgments regarding disability, disease, and enhancement. I suggest that quite different notions of human nature are put forward in ethical arguments. In this chapter, I aim to investigate a number of different possibilities regarding how the human being can be discussed. This implies that the discussion that follows will, for the most part, be situated on a meta-level. I want to show what different understandings of the human being are possible. I indicate what argumentative steps are necessary to defend any such understanding and what the challenges and limits of the diverse understandings are. A number

¹⁶ Section one of this chapter is based upon section three, which Caroline Harnacke wrote, in (Düwell and Harnacke 2013).

of examples are analyzed in which the author's notion of human nature is made explicit and discussed. Importantly, it is not my aim to defend one specific understanding of human nature. Rather, it is my aim to show what difference it makes if one chooses one rather than another understanding of human nature, and what is needed in order to properly defend any specific understandings. My aims are thus primarily methodological and meta-theoretical. Yet by analyzing and criticizing diverse understandings of human nature, some of these understandings become more plausible than others. Nevertheless, the most important aim in this chapter is to find out what, exactly, the reference to the human being can mean in moral arguments. In the next chapter, which is closely related to the current chapter, I will investigate which *role* these different notions of human nature play in moral judgments. It is only in the third chapter that the general evaluation of different notions of human nature in moral judgments can become fully clear. But to analyze the reference to the human being in moral judgments, we first need to understand the meaning of the reference to the human being.

The structure of this chapter is as follows: first, I will make some preliminary remarks regarding what it means to discuss the human being. I will then investigate five different possibilities to understand the reference to the human being in moral judgments.

1 A blind spot and naming is framing

First of all, it should be clear that the question 'What is a human being?' is quite unlike the questions 'What is a chair?,' 'What is water?,' or 'What is a fish?' (see also Frierson 2013, 3). It is our own perspective that makes the first question special for us. From which perspective or discipline whatsoever we want to ask this question, asking it from within ourselves remains unavoidable. We cannot shy away from the fact that it is ourselves that we are reflecting upon. We cannot step outside our body and mind and adopt the perspective we use to inquire into what chairs, water, or a fish are, but we have to remain at the same time the very object of research. Our understanding of the human being is relative to our own perspective. For this reason, we might not be able to reach a full understanding of the human being, and a blind spot might always remain. This restriction needs to be kept in mind for every analysis of the human being, regardless of one's particular views on the question of what it means to be a human being. We have to accept it as a precondition for any study of the human being (Frierson 2013, 3).

Before we can delve into the study of the human being, a second problematic aspect concerns the vocabulary the research uses. Are we discussing how to ‘understand the human being’? Do we debate various ‘conceptions of the human’? Are we talking about ‘mankind’? Or are we figuring out how ‘human nature’ is constituted? Although each and all of these terms are clearly in need of further explanation and specification to understand which perspective is taken on the research subject, every term already suggests a certain direction of the investigation. In that sense, naming the problem under scrutiny already frames it in a specific way. Various terms are employed to characterize this anthropological element. These terms are not only used in very different ways, but they also suggest certain meanings and make other associations less likely.

Why can we not simply stick to philosophical anthropology? There are several reasons why I do not want to endorse this term. First of all, anthropology in a general sense is quite well established as cultural anthropology specifically, which is a descriptive study of human beings in their social and cultural environment. This is not the right term to use at this point in the dissertation. Furthermore, philosophical anthropology is typically associated with a philosophical movement in the continental tradition in the 1950s and 1960s, which mainly took place in Germany, involving Gehlen, Schelling, and Plessner. Therefore, this term also narrows the research to a certain tradition that is not desirable for the aim of this dissertation.

Using the term ‘mankind’ could be understood to refer to the collective of human beings rather than to individual members. In addition, in any discussion that goes beyond the development of sexual organs or the like, it needs to be assumed that it not only relates to men, but to women as well. Hence, using ‘mankind’ as a term is in any case inappropriate for discussing the human being.

As for ‘human nature,’ one could assume that debating this topic concerns biological questions, or matters of fact that can only be investigated using natural-scientific methods. This association is even stronger in bioethics, where physicians and other researchers from the natural sciences are also involved in discussions. However, this association of ‘human nature’ with natural-scientific methods is not present in every discussion. For instance, Aristotle’s discussions about ‘human nature’ were also meant to be evaluative. He and other philosophers who came after him included normative ideas about the human being, how we should live, what we should do, and how we should relate to each other (see sections 2.4 and 2.5 for further elaboration). In the same vein, the discussion about ‘natural’ rights is a nor-

mative-ethical discussion. Whenever I refer to ‘human nature,’ I also want to include at least the possibility of such a normative aspect. Referring to ‘the human being’ might be the most neutral approach, though it is clearly a somewhat long and rather uncommon expression. In the following, I will use these two expressions—though neither of them is perfect.

Like Rawls (Rawls 1971, 9/10), I also choose to refer to a concept and specific conception of the human being instead of an image or an idea. Different terms also have different connotations here. The term for an image indicates that something is directly, almost at a glance, visible and knowable. It suggest that something exists as a unit and is complete. All components as well as their relation to each other must be simultaneously detectable; otherwise, we could not speak of an image. A concept/conception, however, clearly has the character of something that is theoretically constructed. It does not need to be completed or comprehensive; it does not even need to be fully understood immediately. However, it is in a certain way more than an idea that might be either a sudden flash of brilliance or a useless thought.

This short discussion of the terminology that we could use to study the human shows that choosing the right term is not a trivial task. The choice of terminology has implications for which theoretical frameworks are likely to be used for the analysis and which are not. Therefore, it must be carefully considered which term is most appropriate for the aim of the argumentation. Note that the problem is even more pressing if one operates in the context of multiple languages. It is not only that a translation is typically difficult, but each language uses its own vocabulary that again has different connotations. For example, in the German discussion, the term *Menschenbild* (roughly: image of the human) is widely used. Here, this term is employed very broadly and it seems to be able to mediate between different levels of description and normative justification at the same time. However, how this is done exactly often remains rather unclear, and one could argue that this term simply hides various meanings and functions from a clear discussion (for a discussion see Düwell and Harnacke 2013). A Christian image of the human is, for example, invoked to argue against euthanasia (but interestingly enough, it is also invoked by those arguing *for* euthanasia). To avoid such a problem here, I work with the following terms in my analysis: ‘conception of the human being’ or an understanding, account, a notion of ‘human nature.’

2 Diverse conceptions of the human being

The human being can be studied as an animal, as a cultural and meaning-generating being, or as an accountable agent. To investigate these different perspectives, I will distinguish naturalistic, metaphysical, and normative conceptions of the human being. For naturalistic and normative conceptions, I make another distinction between two different conceptions: naturalistic conceptions that discuss the human being as a biological species and naturalistic conceptions that discuss the human being as a being with an innate nature. For normative conceptions, I want to distinguish between conceptions that discuss the characteristic human form of life and those that refer to what we value about ourselves.

The following five sections classify, then, five different understandings of human nature. Yet this does not imply that one can make a choice between one of these references to human nature as if they were alternatives for each other. As will be explained, these conceptions answer rather different questions about the human being. In addition, the different conceptions do not necessarily exclude each other. As these conceptions only refer to aspects of a comprehensive idea of the human being, moral arguments can, at least in principle, employ several understandings of the human being.

I do not claim that distinguishing between various notions of human nature is a new thing to do. Aristotle made similar distinctions in his *Metaphysics*, *Book V* (J. Barnes 2014, 3442–3483), though of course they remain within his teleological view of nature. In contemporary philosophy, Neil Roughley probably develops the most extensive categorizations of references to human nature (Roughley 2000; Endress and Roughley 2000; Roughley 2005). My own analysis will build upon that work.

However, in discussions about what it means to be human for bioethical debates, and specifically for enhancement debates, these distinctions have so far not become sufficiently clear. Here, I will briefly provide a few examples of where authors started to make distinctions between various conceptions of the human but where the distinctions are in my view have not yet sufficiently been considered. In sections 2.1 to 2.5, I will return to these examples and similar ones and argue in full for the necessity of clarifying distinctions. For the time being, I merely want to use these cases to illustrate the claim that various notions of human nature are so far only partly distinguished from each other.

A first example is David Heyd (Heyd 2003), who discusses the problematic use of ideas about human nature in bioethical debates but does not explicitly separate different perspectives that can be taken on being human. He refers to biological and psychological studies, the idea of unnaturalness as artificial, and the ability to make autonomous choices, all under the heading of 'human nature.' Yet it is not evident from the start that all these different aspects refer to the same conception of the human being. Instead, it seems to me that we should consider the possibility of very different kinds of conceptions of the human being that need to be separated to analyze their power to be used in an ethical evaluation.

Similarly, Kurt Bayertz observes various difficulties in formulating the concept of human nature in discussions about the moral status of human nature (Bayertz 2003). He discusses several possible understandings, their starting points, challenges, and limits. However, when he turns to ethical questions, he puts this analysis aside and concludes for the remainder of his paper that he has to assume that a good concept of human nature has been found. Here, apparently, his preceding analysis and careful distinctions seem not to be necessary anymore. It is at this point not clear why this is the case.

Allen Buchanan, who usefully tries to evaluate appeals to human nature and how they relate to the ethics of enhancement (Buchanan 2009; Buchanan 2011, chapter 4), makes a distinction between philosophical, folk, evolutionary, and religious conceptions of human nature. Taking the next step to evaluating enhancement, he employs a general conception of human nature that combines a number of aspects. Such a synthetic conception should have a number of advantages that would make the relevance of scientific knowledge clear, be general enough to cover a range of other more specific conceptions, and be uncontroversial in certain respects (Buchanan 2011, 118). Yet, just as in the case of Heyd and Bayertz, it seems to me that it could be useful to hold on to the previously made distinctions between different kinds of conceptions of human nature. It does not seem obvious that the previously made distinctions are not relevant to evaluating enhancement.

In a similar way, Jan-Christoph Heilinger connects philosophical anthropology with the enhancement discussion (Heilinger 2010; Heilinger 2014). Yet he proceeds with a very specific and special understanding of human nature and, thereby, neglects other aspects of how we see ourselves as human beings. It seems to me that these other aspects of our understanding of ourselves could just as well be relevant to evaluating enhancement. It is not clear from the start which understanding of human nature proves to be relevant

to moral thinking. If my idea seems *prima facie* reasonable, then I think that we should not neglect some conceptions of the human being from the beginning.

Tim Lewens does indeed discuss different understandings of human nature to apply them to the enhancement discussion (T. Lewens 2012). However, he dismisses the majority of attempts to understand human nature. As I will show below, he does so too quickly.

I think that the discussion would benefit from a clearer separation and discussion of different notions of human nature. I agree with Maria Kronfeldner and her co-authors that there is a plurality of concepts of human nature that has to be distinguished and that different concepts can have legitimate roles in respective contexts (Kronfeldner, Roughley, and Toepfer 2014). Accordingly, I will develop the diverse conceptions of the human to make their applicability and usefulness in ethical contexts visible. As I am engaging with bioethics, my examples and illustrations will mainly be drawn from bioethics, but it should be possible to extend the theoretical analysis to different domains.

The discussion that follows will have to cover diverse aspects of and theoretical approaches to the human being. I am not able to do justice, and do not even come close to doing justice, to the various proposals and authors that I discuss. Here, the aim is not to debate whether the proposals are correct as they stand. The aim in this chapter is to distinguish between various meanings of ‘human nature.’ In chapter three, we can proceed to find out what roles these different understandings can play in moral judgments.

2.1 *Naturalistic conceptions 1: A species concept*

The first use of a conception of the human is a reference to a biological human nature. This association is relevant for debating the human being within non-academic discussions, though clearly it is not limited to this use. The human being as an animal can also be studied. Accordingly, the use of natural-scientific methods is necessary to conduct the research and justify the results.¹⁷ I will distinguish two different naturalistic conceptions of the human being. First, I will investigate understanding the human being as the species *Homo sapiens*. Second, in the next section, I will analyze the question

¹⁷ Of course, one could also claim to use natural-scientific methods to answer other kinds of questions, namely normative questions. For a discussion of such attempts see section 2.5.1.

of whether human beings can be ascribed an innate nature. These two discussions are intertwined. But it should be remembered that the point of making the following distinctions is to make them useful for ethics. As will be shown, for this purpose, referring to a species conception of the human is not equivalent to discussing the innate nature of humans.

For the first naturalistic conception, the question ‘What is the human being?’ is specified as a question about a species. More precisely, it asks us to find the necessary and sufficient conditions for belonging to the species *Homo sapiens* (call this conception the *naturalistic-species* or *naturalistic-s conception of the human*). On the one hand, this is a biological question and a question about other natural-scientific disciplines, but on the other hand, it demands an analysis and interpretation of the concept of ‘species’ as applied to human animals. The latter question is for the most part a discussion in the philosophy of science.

What makes a ‘species’? Commonly, a species is understood as a “certain segment of a phylogenetic tree” (Roughley 2005, 137 my translation). This is not a characteristic of individual members of a species, but a matter of evolutionary relations. Presently, only few deny that the human being is in a certain sense the result of evolutionary developments. When we try to capture more precisely what these evolutionary relations are, we run into many different definitions of species. The question under scrutiny is what the glue of each lineage segment, so to speak, is—the taxon. The species’ taxa can be defined in terms of reproductive isolation, genetic isolation, shared ancestry, or homeostatic property clusters, and none of these definitions takes precedence over the others (Robert and Baylis 2003, 3–5). Tim Lewens sketches the philosophical consensus regarding biological species as follows:

“Most taxonomic philosophies [...] regard species members as united not by virtue of possessing similar intrinsic properties, but instead by virtue of the relations they stand in to each other [...] What these relations may be is contested: some take it to be a matter of breeding relations, others take it to be a matter of the niche they occupy, for others it is a matter of ancestry.” (Lewens 2012, 461)

In all of these cases, it is clear that a species taxon is, then, not a stable and timeless category within the range of thousands of years. All of these different understandings acknowledge that as a species, human beings are the result of an evolutionary process. Fitness and survival are the motor of evolution. Evolution teaches us that species, understood in such a relational

way, develop, separate from each other, and become distinct. Although it clearly takes a long time, accordingly, the characteristics of a species can change over time. A species can evolve into another without there being clear dividing lines. Biological species are characterized by their very variability in the extreme long run (Hauskeller 2009, 100/101).

This consensus about species is not compatible with the idea that a species category possesses essential intrinsic properties (Robert and Baylis 2003, 5; Bird and Tobin 2012, section 2.1).¹⁸ Imagine that we found a dog-like organism on a different planet. This dog-like being would not be a dog unless it had a common ancestor with our dogs. Just as intrinsic similarity is not sufficient, it is not necessary either. There is no sequence of genes or genetic material that all and only members of one species share, but instead, there is a high degree of variation (Bird and Tobin 2012, section 2.1). Species cannot, therefore, be considered a natural kind, at least if one maintains a traditional view of what a natural kind requires: “a set of intrinsic natural properties that are individually necessary and jointly sufficient for a particular to be a member of the kind” (Bird and Tobin 2012, section 2.1). For instance, gold is understood as such a natural kind: if the atomic number of this metal is changed from 79, it would no longer be gold, but would be a different natural kind (T. Lewens 2012, 460). In this case, the atomic number is the essence of gold. Such an explanatory essence is what the species *Homo sapiens* is generally not considered to possess.¹⁹

This understanding of species as a non-natural kind in the traditional understanding developed in the 1970s and 1980s, and was especially based on works by David Hull and Michael Ghiselin (Hull 1978; Ghiselin 1987). Hull argues that “species are temporary, contingent, and relatively rare” (Hull 1986, 3). Evolutionary theory, he argues, teaches us that our traits are likely to vary. Therefore, biological species should rather be interpreted as individuals who are born and die. Individual organisms are, then, parts of species, and not members of the species kind. What makes organisms part of the same species is not that they share certain common features, though they might, indeed, share features. What makes them part of the same species is that they are parts of the same lineage. Similarly, a number of philosophers

¹⁸ Of course, there are a few scholars who argue for something like intrinsic biological essentialism (such as, for example, Devitt 2008).

¹⁹ Note that on an alternative conception of natural kinds, the homeostatic property clusters theory of Richard Boyd, species count as a natural kind (R. Boyd 1999). Natural kinds are, here, characterized as groups of entities that share stable similarities. Just as in a traditional understanding, natural kinds corresponds to a grouping or ordering that does not depend on humans, but does not hold that natural kinds have an essence. For a short explanation and discussion of this theory, see (Robert and Baylis 2003, 3).

of biology defend a version of pluralism regarding the concept of species (Dupré 1981; Kitcher 1984; Ereshefsky 2001). They argue that various concepts of species are legitimate. There are countless ways of taxonomizing the world into kinds and there is not one right way to do so. Rather, they argue that different classifications are useful for different purposes and are open to modification and criticism.

What does all this mean for understanding the human being in the sense of naturalistic-s? It means that even in this sense, it is at least controversial, if not impossible, to claim that the human being is a natural kind in the traditional sense. One could assume that an understanding of the human being as a natural kind is still closest to an investigation from the perspective of naturalistic-s, but even here, this does not seem to be the case. There are currently no instantiated properties of human beings that are necessary and sufficient to characterize the human being as a species (Roughley 2000, 383; Roughley 2005, 137/138).

How can such a naturalistic-s conception be used in ethical debates? In general, there are two options: such a conception can be employed to understand certain concepts used in ethical debates, or ethical implications can be drawn from it. I will have a brief look at both options. A more extensive evaluation will follow in the next chapter.

Regarding the first option, naturalistic-s conceptions are regularly invoked to make sense of enhancement. Enhancement is then understood as the idea of controlling the development of the species or controlling evolution. For instance, John Harris argues that enhancement would “replace natural selection with deliberate selection, Darwinian evolution with enhancement evolution” (Harris 2007, 4). We can even make ourselves better to the point of changing into a new species—and according to Harris certainly a better one (Harris 2007, 4/5). More specifically, enhancement and disability are often understood as deviations from species-typical functioning (as was elaborated in the first chapter). But what exactly is species-typical functioning in relation to a species?

Take the example of life expectancy. Living longer is often mentioned as a possible enhancement. Even during the last 250 years, we have experienced a tremendous rise in life expectancy for human beings. However, we are still (and have been for much longer) the same species. Species are defined by certain relations in which they stand to each other and not by certain traits of their members. So at what threshold does being “species-typical” stop? The reference to the species *Homo sapiens* does not provide much support here—

unless we agree on setting a time and place as a reference class such as, for example, in developed societies after the industrial revolution. Deciding upon such a reference class with a naturalistic-s conception of the human, however, means that there is no objective and value-free fact about enhancement that we can discover in nature. We could just as well decide upon a different reference class. Of course, the challenge of choosing a reference class does not mean that such an approach to understanding enhancement is doomed to fail. It only means that it is a methodological problem that such approaches need to solve (see Kingma 2010 for a discussion of setting reference classes; for a similar criticism from a disability perspective see Scully and Rehmann-Sutter 2001).

Regarding the second option of deriving ethical implications from a naturalistic-s conception of the human, David Hull tries to probe what would follow from assuming a naturalistic-s conception for moral principles. He wonders why naturalistic-s conceptions are considered important at all, and goes on:

“One likely answer is to provide a foundation for ethics and morals. If one wants to found ethics on human nature and human nature is to be at least consistent with current biological knowledge, then it follows that the resulting ethical system will be composed largely of contingent claims.” (Hull 1986, 11)

Hull hints here at a certain tension between naturalistic-s conceptions and moral justifications. Because a species is not a stable criterion and in his view no natural kind, a morality that is based upon it could also not be stable. Though I agree that the prospect is dim for grounding normative claims about what we should do on such a species concept (see chapter three, section 2.1), I think that we need to be rather careful in relating a naturalistic-s conception to moral judgments. For example, it seems reasonable to claim that normative-ethical reasoning should be consistent with the fact that human beings need food and oxygen to survive. In chapter three, I will distinguish several argumentative functions for different conceptions of the human being and come back to that point (chapter three, section 2.2-2.5). But before that, more needs to be said about other conceptions of the human being.

2.2 *Naturalistic conceptions 2: Innate traits*

Understanding the human being as an evolving species is not the only possible naturalistic conception of the human being. Instead of investigating the type to which human beings belong, which naturalistic-s conceptions do, one can investigate individual organisms. For instance, one could try to capture what the human being is with naturalistic-scientific methods by analyzing which traits are innate traits (*naturalistic-innate* or *naturalistic-i*). Here, the human being is explained by its intrinsic nature while other traits reflect the influence of the environment.

A naturalistic-i understanding of the human being can also be distilled from folk debates about the human being. It is the idea that living beings have an essence that makes them the beings that they are. Our imagination of what is truly the core of our untouched nature regularly gets inspired by real-life Mowgli stories that hit the news every once in a while. Understanding the human being in terms of innate traits is also a widespread strategy in folk discussions (Griffiths 2002). If one argues in science talk attended by the public that, for instance, addictive behavior is part of human nature, the audience will most likely interpret this to mean that addictive behavior is innate. This fact makes naturalistic-i conceptions important and interesting ones to analyze.

But what makes a trait innate? Paul Griffiths has shown that people without a formal biology education seem to uphold the implicit belief that a being has an inner nature that makes it the kind of being it is and that this explains certain traits that typify the being (Griffiths 2009a, 37).²⁰ The folk conception of innateness bundles together three different concepts. An innate trait can be a trait that is hard to change (*fixity*), is typical or universal for the species (*typicality*), or it relates to how an organism is meant to develop (*teleology*) (Griffiths 2002; Griffiths 2009a). With these criteria, traits such as jealousy or gender differences are assumed to be part of ‘human nature.’ Griffiths goes on to evaluate that this picture of the living world is not borne out by biology (Griffiths 2009a, 37). The problem is that these three concepts are empirically disassociated (see also Mamelì 2008). They do not appear together, but describe different properties. Therefore, it is undesirable to conflate them under the term ‘innateness.’ If such a folk biological view of innateness is unsatisfactory, what would be a better suggestion for understanding the human being in terms of innate traits?

²⁰ An analysis of the judgments made, which come from biologically naive research subjects, produces similar results to the findings of Griffiths (Linguist et al. 2011).

The concept of innateness is widely discussed in philosophy of biology, probably starting with Stephen Stich's paper 'The idea of innateness' (Stich 1975), in which he makes different tentative suggestions about the structure of the concept. Next, I want to comment briefly on the most important proposals.

First, 'innate' could be understood in contrast to 'acquired.' This attempt can be understood as placing a conception of the human being on the spectrum between nature and nurture. The nature of the human being would be what developed by itself without environmental or human intervention. However, it is immediately clear that it is conceptually difficult to investigate what develops without intervention. After all, we grow up in a world that is to a large extent designed by humans. Most forests are not natural anymore and animals have been bred for a long time. We exert influence upon the climate, which affects the seas and creates deserts, and have learned to grow and harvest our food (see also Heilinger 2010, 88). In that sense, there is hardly anything anymore that is completely free from intervention (see also Roughley 2005, 144). In the same vein, as Richard Samuels explains, there is always a point at which we 'acquire' something that we did not have before (Samuels 2004, 136). The cell ball that develops into a human being 'acquires' cognitive structures in the course of its development that it did not have before. Hence, it needs to be specified what acquiring something attempts to capture. Additional constraints are needed to describe innateness more specifically than simply saying that innate means not acquired.

Let us therefore look at a second notion of innateness. Others argue that innate traits should satisfy certain temporal constraints (Samuels 2004, 137). They should be present at birth or at least 'early' in the normal course of early development. Secondary sexual characteristics are plausibly innate and reliably appear at a reasonably early point in development. However, Stich already offers a counterexample to this proposal: in the normal course of development, children learn that night follows day and day follows night or that water is wet (Stich 1975, 9). These universally held beliefs would count as innate traits on this proposal, but that seems counterintuitive.

A third way to understand innateness would be to conceptualize innate traits as genetic traits. But biologists and philosophers of biology are skeptical about this distinction between genes and the environment: it is not that some traits are expressions of genes while others result from the action of the environment (Griffiths 2009a, 47; Samuels 2004, 137/138). It is (almost) agreed upon that all traits result from the interaction of genes and environment. This is referred to as the 'interactionist consensus' (Kitcher 2001). If a

gene produces an enzyme that only works below a certain temperature, a warmer environment will eliminate the genetic influence. Thus, the effect of a genetic difference on a trait sometimes depends on the environment (Griffiths 2009b, section 2). Genetic influence and accordingly heritability are difficult concepts.²¹ Using a comparison to describe the difficulties should suffice at this point (Bateson 2013, 153): the development of a living being is not like a fixed musical score that specifies how the performance starts, when the different instruments come in, and how it slows down and reaches full blast. Rather, development can be compared to a form of jazz in which musicians improvise and react to each other. New themes appear and the performance might take a turn that no one had thought of at the outset. It is only constrained by the kind of instruments available and general musical rules. Hence, it is conceptually difficult to understand innateness as genetic determination.

Fourth, in a similar way, it is suggested that innateness should be understood as canalization. An innate trait is, then, a trait that an individual tends to exhibit in a wide range of initial environmental conditions and regardless of environmental changes during the development (Ariew 1996, S25). Thus, a genetically canalized developmental system takes development to the same endpoint from many different genetic starting points. This is an old idea ('old' for biology, not for philosophy, of course) that was first developed by Conrad Waddington (Waddington 1959), but it still retains considerable validity in light of recent research (Griffiths 2009b, section 4.3). Generally, canalization is a matter of degree. For example, limbs or secondary sexual characteristics develop in almost all environments and are therefore highly canalized or innate. This understanding of innateness is the sense in which Noam Chomsky's work about the 'innateness' of our universal grammar can be understood. Chomsky argues that there is a non-acquired cognitive structure present at birth that can produce normal linguistic development in various, though maybe not all, environments (Griffiths 2009b, section 4.3). However, the idea of canalization probably cannot capture what everyday speakers of English mean when they use the word 'innate' (Mameli and Bateson 2006, 172). It is not the folk concept of innateness. Nevertheless, it is so far the most promising candidate that can be used to understand the concept of innateness.

Clearly, there are more possibilities for analyzing the concept of innateness; for example, that innate traits are those that are found in all cultures or those

²¹ See Richard Lewontin (Lewontin 1974) for a seminal paper on criticism of heritability studies and Stephen Downes (Downes 2014b) for the consensus that broad heritability measures are uninformative.

that are hard to change (see Mameli and Bateson 2006 for a comprehensive summary and analysis of different suggestions). Yet, for the current purpose, the most important thing to understand is that innateness can mean many different things. These various conceptualizations do not pick out the same traits; the different proposals are not equivalent to each other (Mameli and Bateson 2006). Hence, if one wants to understand the human being in terms of innate traits, it should at least be clear what ‘innate’ refers to in the relevant context. As Paul Griffiths argues:

“Substituting what you actually mean whenever you feel tempted to use the word ‘innate’ is an excellent way to resist this slippage of meaning. If a trait is found in all healthy individuals or is pan-cultural, then say so. If it has an adaptive-historical explanation, then say that. If it is developmentally canalized with respect to some set of inputs or is generatively entrenched, then say that it is. If the best explanation of a certain trait differences in a certain population is genetic, then call this a genetic difference. If you mean that the trait is present early in development, what could be simpler than to say so?” (Griffiths 2002, 81)

The term ‘innate’ itself only confuses the issue. It carries many different connotations and should therefore be avoided. In the following, innateness will be understood as canalization. Canalization turns out to be the best candidate that can be used to understand what the concept of innateness tries to capture.

If we understand the innate nature of human beings as those traits that are canalized, that is, what an individual tends to exhibit in a wide range of environments, how can it be used in ethical debates? First of all, it needs to be clear that canalization is not a dichotomous concept. A trait can be more or less canalized, but there is no clear cut-off point at which a trait cannot be seen as canalized anymore. For almost all traits, we could then argue that they are in certain respects at least partly canalized. Hence, if human nature is understood as comprising all canalized traits, almost all traits could be understood as belonging to human nature. The concept does not, then, function to single out human nature. Yet, secondly, canalization helps us to understand how human beings are constituted. It helps us to understand the interplay between genetic and environmental conditions and our possibilities for influencing the end result of the development of an organism. Most of all, it makes clear how flexible developmental systems are. This, in turn, shows how difficult predictions about the development of an organism are after its genetic and environmental conditions have been influenced. To

debate the contingency of human nature, the concept of canalization is, therefore, important for understanding what this contingency really is.

In bioethics, canalization is, for example, important to understand debates about reproductive decisions. In a time when not only gamete donors can be chosen, but even specific sperms can be selected, and preferred embryos are placed in the womb after a genetic screening, we need to understand how human beings evolve to make responsible decisions. This will be investigated in more detail in chapter six.

Another example of an application of canalization in moral debates concerns the distinction between natural and social inequalities in political philosophy. The underlying idea is that there is an important difference between two types of inequalities: some inequalities are not morally permissible because they derive from the 'natural lottery.' To draw the distinction between the natural and social, it is tempting to rely on an interpretation of innate traits as describing 'the natural' (for a discussion see Lippert-Rasmussen 2004; T. Lewens 2010).

2.3 *Metaphysical conceptions*

Next, I want to consider a very different way of talking about human beings. It is not an empirical description of what the human being is like in a naturalistic sense, but a metaphysical claim about human beings. Metaphysical conceptions make statements about the metaphysical nature and structure of human beings. They give an account of what human beings are like and provide a metaphysical justification for this account. Metaphysical notions of personhood and how it is instantiated, for instance, are such conceptions of human beings.

Metaphysical accounts of human beings are, of course, not at the same time value-laden claims. There are, generally, no direct normative consequences for metaphysical conceptions of human beings. But a metaphysical account can be relevant to an ethical problem after the moral importance of the metaphysical conception is established with a moral argument. How exactly this interaction between conceptions of the human and normative-ethical principles can be understood will be investigated in the next chapter. Here, I will provide a few examples of some of the most relevant metaphysical conceptions.

Within the scope of the current inquiry, it is first of all necessary to note that models of disability and notions of disease are meant to be such metaphysical conceptions (see chapter one, especially section 2.2. for an elaboration of disease and disability). Importantly, how models of disability are transformed in the discussion, and what problems this raises, will be investigated in chapter five. However, in general, a model of disability is supposed to give an account of what disability essentially is. It describes the ontology and etiology of disability. In general, discussing such a model is equivalent to discussing a conceptual framework that can be used to approach the phenomenon of disability. This is what these models describe. Although the various models differ concerning which specific aspects of such a metaphysical account they cover, most of them try to explain how disability is caused and of what, exactly, it consists of. Their underlying question can be phrased as ‘What is disability?’

Metaphysical conceptions also concern questions regarding the relation between the body, the mind, and the world. There are numerous sophisticated philosophical approaches to these kinds of questions. It is impossible to give them the space they deserve here. Instead, I have to constrain myself to mentioning a few aspects to provide a general understanding of metaphysical conceptions of the human being. At least two branches of research are directly relevant to questions of disability and enhancement: the extended mind thesis and embodied cognition.

The extended mind thesis, developed by Andy Clark and David Chalmers (Clark and Chalmers 1998), claims that minds are not limited to the body or brain, but are extended into the world. Objects within the environment can function as part of the mind. We not only calculate with our brains, but learn to do it with pen and paper and using calculators and computers. We incorporate tools into our existence to the extent that the gap between user and tools grows smaller and smaller. Our technology has become inseparable from who we are and how we think. We have become human-technology symbionts or natural-born cyborgs (Clark 2004). This has implications for questions regarding disability and enhancement: for instance, if technological tools are in any case part of ourselves, the status of a prosthetic limb, a white cane, or a wheelchair is not different from the status of other parts of ourselves. They become just as much a part of ourselves. Furthermore, if you accept the extended mind thesis, it does not matter whether data is stored inside the brain, in the external world, or in a brain implant. What matters is how fast and with what specific requirements the information can be retrieved (Clark 2004, 69). This means that the alleged problematic character

of enhancement and disability cannot be found within the nature of the device that enhanced or disabled people rely upon (Anderson 2008).

Embodied cognition theory argues that cognition is influenced by aspects of the body. Again, the body does not need to be defined by the boundary of the skin, but, according to Merleau-Ponty, can be extended to include some external objects within those boundaries, such as the white cane of a blind person (Merleau-Ponty 1962, 165/166). The significance of the body for cognition indicates that the experience of atypical embodiment, such as the experience of enhancement or disability, has an influence on cognition (which is to be specified). Similarly, Jackie Leach Scully argues that disability and impairment contribute to a difference in the perception and interpretation of morally relevant features of life (Scully 2008, 56). A specific cognitive capacity, such as imagining oneself in a different situation or being a different person, can also be seen as being constrained by embodied experience (Mackenzie and Scully 2007). It would mean that non-disabled and non-enhanced persons have at least crucial difficulties or even encounter limits in judging the well-being or the lives of disabled or enhanced persons.

A more general debate about metaphysical conceptions is the debate about personal identity. It is about the question of what makes a person who changes over time the same person: what makes me ‘me.’ Derek Parfit, for example, argues that what matters is “relation-R,” which he defines as psychological connectedness and continuity (Parfit 1984, 205/206). A person is the same person if overlapping chains of strong connections exist between the two. This means that, first, a psychological state that exists at one time is causally related in an appropriate way to a psychological state that exists at an earlier time and that, second, there are many of these connections and they are overlapping. For example, I am still the same person that I was as a child if I now remember something because little-Caroline experienced it and if there are many of those connections between me and little-Caroline.²²

Why is this of relevance to bioethics? There are a number of cases in bioethics in which the question of up to what point a person is still the same person is crucial for an argument. David DeGrazia identifies four different

²² Clearly, this is a huge question, and there are many other theories that have been developed about personal identity that disagree with that of Parfit (see for example Korsgaard 1989; and Shoemaker 2007; for an overview see Shoemaker 2012; and also see Schechtman 2007 who distinguishes two questions in the debate, the “reidentification question”, which is about the metaphysics of identity, and the “characterization question”, which is about beliefs and values and then develops a narrative account of characterization.) What is important at this point is simply that metaphysical conceptions of the human being are invoked in the debate and how such an argument is constituted.

issues: death, advance directives, enhancement, and reproductive decisions (DeGrazia 2005 and in various articles). For example, regarding exercising advance directives, we have to make sure that the person who is treated on the basis of the advance directive is still the same person as the person who signed the advance directive. Given that a person's characteristics and habits can change fundamentally in the light of, for instance, dementia, this is a pressing question for medical practice.

Scholars who support more specific metaphysical conceptions that are concerned with the identity of human beings make statements about the structure and freedom of the will, for example. Here, Harry Frankfurt is influential. He argues that human beings are able to form "second-order desires." Humans not only have certain desires and motives, but also have the capacity to ask whether they want to have or not to have certain desires and motives (Frankfurt 1971, 7). We are capable of wanting to have different preferences: this is reflective self-evaluation in action. Second-order volitions are those second-order desires that a person wants to be her or his will. Such an identification is, ideally, 'wholehearted.' This means that we must take this decision without reservation; it must be a stable decision.

Consideration of our will, among other issues, is important in bioethics in relation to questions about authenticity. Authenticity matters in psychiatry as well as for questions of pharmacological enhancement: does medication obscure or reveal the true self (see Bolt and Schermer 2009 for an extensive discussion of such a case; for a discussion of authenticity in the enhancement debate Parens 2005; also Kraemer 2011)? Imagine a drug addict who has a desire for a drug and a second-order desire to resist that desire. His second-order desire is even a second-order volition that he identifies with: he does not want to take the drug. If he nevertheless gives in to his first-order desire and takes the drug, this action is not really his own. It is not an act done of his own free will. Imagine now that psychopharmacological medication is available that helps the addict to adhere to his second-order desire and not take the drug. For Frankfurt, this would then not threaten authenticity, but support it because it allows the addict to act on the desire he identifies with. Needless to say, different accounts about the will might come to the opposite conclusion.

Although Frankfurt makes claims that I classify as metaphysical claims, his conception of the person can even be understood to reach further than that and give a comprehensive account of the essential nature of human beings. His account of the will is not only understood as part and parcel of a metaphysical conception of the person, but as a description of what it means to

be human. Such a conception of the human being will be evaluated in the next section.

2.4 *Normative conceptions 1: The characteristic human form of life*

Normative conceptions of the human being aim at giving a more complete account of what it means to be human. They can be taken to have explanatory power about human beings. By looking at the work of Neil Roughley, I want to understand such a conception of the human as “the characteristic human form of life” (Roughley 2000, 385) (*normative-characteristic* or *normative-c*). It is something that is constitutive of the human way of life.

As I already indicated, Frankfurt’s conception of the human being can be understood in this sense. His account about second-order volitions is not only taken as a description of the will of persons, but as grasping the essential differences between persons and other creatures. Frankfurt argues that many animals have the capacity to have desires of the first order, but only human beings have the capacity for reflective self-evaluation. This is “peculiarly characteristic of humans” (Frankfurt 1971, 6).

This shows that normative-c conceptions of the human being can employ metaphysical facts to make a case for the most fundamental nature of human beings. In the same way, biological factors can play a role. But understanding human nature in the sense of a normative-c conception entails more than picking out the right object among others. It contains an evaluative moment. It describes something that is important for us as the beings we are. This importance is not to be understood as important because we evaluate it positively. It is important in the sense that it significantly affects the character of its bearer or is causally important for explaining behavior (Roughley 2005, 141). In that sense, as David Hull remarks: “If all and only human beings were able to digest Nutrasweet, this ability would still not be a very good candidate for the property which makes us peculiarly human” (Hull 1986, 6). Here, Hull apparently employs a normative-c conception of human nature.²³ What makes us human is supposed to be in some sense ‘more’ than being able to digest Nutrasweet. Furthermore, each and every member of the human species does not need to exhibit the property the normative-c con-

²³ One could argue that this understanding of human nature is not in line with Hull’s earlier analysis of a naturalistic conception of the human.

ception describes, but it does need to be at a “significant level of statistically generality” (Roughley 2000, 385). Strict universality is not needed.

Understanding a conception of the human as the characteristic human form of life is obviously not a new idea, and many candidates for such a property were developed in the history of philosophy. Being equipped with reason is often seen as typical of the human being, as is being a ‘social animal’ with the capability of living in a society or a *Homo faber* that uses tools (for a summary and discussion see Heilinger 2010, 85–89). Thomas Hobbes famously described the human being as above all interested in self-preservation, and for this reason being aggressive and involved in a war of all against all in the state of nature (Hobbes and Malcolm 2012, 104–124). Economic theories are known—and criticized—for assuming that the human being is a *Homo economicus*, a rational and narrowly self-interested actor (for a well-known criticism see Sen 1977).

More fundamentally, the idea that there is a characteristic human form of life is already a normative-c conception itself. Existentialists such as Jean-Paul Sartre deny this and think that we have the ability to freely form ourselves when they claim that “there is no human nature [...] Man is nothing else but that which he makes of himself” (Sartre 1946). Similarly, Norman Daniels argues that human beings have no fixed nature, but that features of our nature vary in degree depending on the features of the basis institutions (Daniels 1979). Human nature is plastic and is shaped to have different continuities. This can be linked to certain ideas in enhancement debates: here, the human being is sometimes characterized as a being that essentially changes its body and mind according to its own tastes: we cut our hair and have tattoos done for aesthetic reasons; we follow religious rituals, such as circumcision; and we train our brains and have established institutional arrangements to do this on a large scale (Bayertz 2003, 139). Modern enhancement is, then, simply seen as a continuation of this development.

Importantly, these characteristics, no matter which one is chosen, do not need to be in agreement with an understanding of the human being as a naturalistic being. We can understand the human being as a species that, as the *Homo sapiens*, evolved between 400,000 and 250,000 years ago and at the same time acknowledge that some specifically human characteristics, such as culture, language, and technology ‘only’ evolved around 50,000 years ago. A naturalistic-s conception of the human being and a normative-c conception are simply not identical. They describe different perspectives from which to look at the human being. This shows at the same time that the characteristic

human form of life is not a timeless property. It must therefore be clear what time frame is considered here.

How does all this relate to an ethical evaluation? Importantly, it is clear that the characteristic human form of life could also consist of pervasive and bad habits (Roughley 2005, 149). If social cooperation is understood as characteristically human, aggression and fraud could as well. Once again, it does not need to be a property that is evaluated positively, but it must have explanatory power regarding what is characteristically human. In that sense, this understanding of a conception of the human is only of normative significance in a derivative sense. Knowing what defines the characteristic human form of life does not give an account of how we should evaluate these properties. A characteristically human property is not necessarily good. Roughley acknowledges this problem. He explains the normative importance of the characteristic human form of life in the following way:

“A plausible universal morality cannot avoid demanding attention for the characteristic human form of life. What this attention consists of and why these demands exist, these are questions that no theory of human nature can answer. These are questions of normative-ethical theories.” (Roughley 2005, 153)²⁴

Understanding what is characteristic of human life is somehow important for normative-ethical problems. However, in what way it is important, whether we should value it or ignore it, hinges on the normative-ethical theory or principles. How the interaction between conceptions of the human being and normative-ethical principles can be understood exactly and can lead to judgments about cases remains to be seen in chapter three.

Before that, I want to investigate one possible strategy that could be used to work with normative-conceptions of the human being. The ideas of neo-Aristotelian Michael Thompson are at this point especially interesting in terms of the link he makes between human nature and normative aspects that can be analyzed regarding disease and disability. I understand Thompson's analysis of the concept of a human life-form to provide a normative-conception of the human as I have described it so far. Thompson investigates systems of concepts that articulate the common-sense world within which we operate. Lastly, inspired by the work of Elizabeth Anscombe

²⁴ My translation. In the original: “Eine plausible universalistische Moral kann nicht umhin, die Beachtung von strukturellen Eigenschaften der charakteristischen menschlichen Lebensform zu fordern. Worin ‚Beachtung‘ hier besteht und warum die Forderungen bestehen, kann aber keine Theorie der menschlichen Natur beantworten. Das sind Fragen der normativen Moraltheorie.“

(Anscombe 1958), Thompson aims at an ethics as approached through an understanding of the human life-form. His ethics will be investigated in section 2.5. Here, the focus will be on the life-form.

Thompson argues that living beings should be understood through the concept of a life-form (Thompson 2008, first essay; Thompson 2004): not through a list of characteristics that they all fulfill, but by a reference to a 'wider context.' When we look at a wider context, we acknowledge, for example, that oaks come from acorns and acorns come from oaks. Thus, an acorn is generative of an oak whether or not it does indeed generate an oak. How exactly can we understand the life-form? Thompson argues that we should not ask what a life-form is, but should ask how such a thing is described (Thompson 2008, 62). The answer to that question is reached through recourse to 'natural-historical judgments.' These are the kinds of judgments that one finds in nature documentaries: the domestic cat has four legs; the iris blooms in the spring. This is compatible with some cats missing a leg or an iris that actually blooms earlier or later. Natural-historical judgments do not even require statistical majorities. They cannot be translated as 'most cats have four legs.' They are statements about classes, and not about individuals. There might not be a single cat that is exactly as a documentary describes cats to be. Yet these statements ultimately result from observations of individual organisms and provide a general description about the essential nature of the being.

Though Thompson limits his examples at this point mainly to non-human animals, he later extends it to human beings. His account of natural-historical judgments is in accordance with my analysis of normative-conceptions. They are not purely empirical or biological concepts, but contain an evaluation. It is interesting for my purpose here that Thompson connects his analysis with an analysis of normativity. Thompson stresses that natural-historical judgments are themselves not normative (Thompson 2008, 74). It does not hold to state 'the domestic cat ought to have four legs.' Nevertheless, they set a standard of goodness for the individual. They allow for a critique or evaluation of individual organisms (Thompson 2008, 80). This means that we can make a natural-historical judgment such as *human beings can walk*. We can then observe a specific human being: *this human being cannot walk*; and conclude: *this human being is defective in that it cannot walk*. Thompson explains that 'judgments of natural badness,' such as lameness and blindness, are invented to capture defects that occur more frequently (Thompson 2004, 8). Clearly, these judgments are life-form relative. What is bad sight for a human might be just average sight for cats.

What ought we to think about this? Though I am convinced that Thompson's general analysis of life-forms is illuminating regarding understanding normative-c conceptions, I think that his introduction of judgments of natural badness proceeds too quickly. First of all, we would have to accept that we can make statements about deviations from the life-form. But Thompson stresses that there is no particular number of individual beings that do indeed possess the necessary criterion in question that means that they belong to the life-form. This raises the question of at what point we know that something is a deviation from the general description of the life-form. Is red hair also a deviation from the life-form? Baldness in older men? Infertility? One could also think that deviations simply make for different life-forms. Men and women, for instance, could be considered significantly different enough from each other to be two life-forms. Yet even if we accept for a moment the general possibility of describing deviations within a life-form, a second point is even more pressing: how ought we to know whether a deviation is for the worse or the better? It is not clear to me that judgments of deviation are judgments about badness. A human being who can breathe under water differs from the human life-form, but I doubt that we would consider that person defective. However, enhanced human beings are also defective according to Thompson. What is even more difficult is what ought we to think of a human being who runs faster with his prostheses than almost everyone else with natural legs (of course, I have Oscar Pistorius in mind)? Thompson's theory, therefore, has difficulties in accounting for disease, disability, and enhancement.

These difficulties indicate that it could prove useful to look at conceptions of the human being that are more explicit about normative requirements. This will be the subject of the next section.

2.5 Normative conceptions 2: What we value about ourselves

Normative conceptions of the human being can also reach further than normative-c conceptions. We can understand an analysis of human nature that gives an account of what we value about ourselves (*normative-value* or *normative-v*). This corresponds on the one hand to the former weaker normative-c conception, but on the other hand, it adds another component, and this is the direct reference to a theory of value. Hence, the status of normative-v conceptions is different from that of normative-c conceptions.

Patrick Frierson wants to understand human nature as such a normative-v conception. He explains that it is a question “not merely about the structure of our brain or society, but about the implications of that structure for human choices, for what we should do with ourselves” (Frierson 2013, 3). It is a question about what is important about us and for us, so about our values, prospects, and aspirations. It is fundamentally about what we can do and should make of ourselves. It is thus clearly a very comprehensive concept. We have to make sense of ourselves and we do that from within. Views about human nature are, then, understood to have normative force as they have consequences for how we should live our lives.

Similarly, Michael Hauskeller argues that ‘human’ has a strong prescriptive dimension but cannot be understood as merely descriptive (Hauskeller 2009, 97). It is not so much an account of how we think we are, but rather how we think we ought to be or how we aspire to be. Hauskeller explains that this is the reason why we are not at ease with Plato’s famous definition of the human being as a featherless two-legged being: it fails to signal the significance of what it means to be human (Hauskeller 2009, 102). The issue at stake, Hauskeller explains, can be compared to our expectations regarding art. People who wonder whether something is indeed art when they are confronted with contemporary art convey the understanding that art should be something valuable in itself and something worth looking at. The term ‘art’ as well as the term ‘human’ cannot be used solely in a descriptive manner.

However, this does not mean that descriptive elements do not play any role. A description of human beings can be integrated into a normative conception. Frierson acknowledges that an answer to the question ‘what is the human being?’ “combines careful description of human characteristics with a normative, aspirational account of what about ‘us’ is or would be truly valuable” (Frierson 2013, 4). Hence, just as with normative-c conceptions, normative-v conceptions can also refer to naturalistic facts and metaphysical descriptions. Yet they should not be confused with either naturalistic or metaphysical conceptions: they are meant to be normative. Accordingly, they are in need of normative justifications. If the difference in a normative conception lies in the justification of the statement, the pure content of a normative conception can be the same as the content of a descriptive conception. An assertion such as ‘the human being walks’ could be read either as a descriptive, naturalistic understanding of human nature or as a normative evaluation. The former relies upon a description of human beings. The latter is in need of a normative justification. Hence, the different kinds of conceptions of the human being are not alternatives for each other.

By way of the different normative justifications used for them, different normative-v conceptions are linked to different normative-ethical backgrounds. In one way or another, moral theories have to incorporate specific normative ideas about human beings. Christine Korsgaard argues that utilitarians characteristically emphasize that the human being is a subject of experiences who can be pleased or dissatisfied, whereas Kantians highlight that the human being is first and foremost an agent (Korsgaard 1989, 101). Clearly, this does not entail that Kantians deny the passive, receiving aspect of human beings and that utilitarians refute that human beings are agents, but they place a different emphasis on these two aspects. Both kinds of theories put forward how we should understand ourselves in practice. This is a normative-v conception of the human being. These are the kind of conceptions of human nature we find in moral theories.

Indeed, some moral theories primarily embody and explicate a normative-v conception of the human being. Moral demands are then directly derived from a conception of human beings. Aristotelian theories, which will be investigated in section 2.5.2, are an example of this strategy. However, specifying certain features of human beings that are to be the primary concern for morality is only part of what most moral theories do (Noggle 2001, 551). Typically, moral theories do more than that. The exact relation between the moral theory and a conception of the human being is in these cases rather indirect. Yet what I call a normative-v conception of the human being is necessary to build any moral theory. As the purpose of a moral theory is to tell us how to express our concern for human beings, we need to know which features of human beings we should care about (Noggle 2001, 551). Once again, utilitarians focus on bringing about pleasure or satisfying preferences, whereas Kantians, broadly conceived, want to respect decisions and refrain from treating human beings as mere means.

The different relation to normative-v conceptions of the human indicates already that moral theories differ in a number of aspects. There is a gap—wider or smaller—between the understanding of the human being a moral theory puts forward and the theory's moral principles themselves. At this point, however, I am less interested in questions about the nature and construction of moral theories, and more in the normative-ethical judgments that those theories lead to and which role human nature plays here.

Following on from this, there are different strategies that it is possible to use to proceed with such a normative justification. One could, for instance, derive an ideal of the human being from an explicit idea of flourishing, rely upon a transcendental argument, an overlapping consensus or, once again,

scientific justifications. I will follow up some of these different possibilities and thereby make a global distinction between naturalistic and explicitly normative methods.

2.5.1 *Naturalistic methods*

First of all, it is interesting to look at attempts to develop a normative-v conception by using natural-scientific methods. On the one hand, this is important to better grasp challenges arising from biomedical (hence naturalistic) advances such as those related to disability and enhancement. On the other hand, it is just as necessary for understanding the intertwinement of and distinction between descriptive and normative aspects of conceptions of the human.

The natural sciences, especially evolutionary biology, neurobiology, and cognitive psychology, might be better able to provide a crystal-clear answer to the question about the human being. They might put an end to our “nebulous self-explanations” (Illies’ term: Illies 2006, 9) that characterize philosophy.²⁵ Indeed, many efforts of this sort can be recognized. Naturalistic explanations of human beings are very popular, and this is not only regarding giving an answer to the question of what the human being is as an animal, but also in terms of providing almost comprehensive normative accounts. Hence, the human being is studied using natural-scientific methods to make inferences regarding what I call a normative-v conception of the human being.

However, most of these attempts do not aim at providing a full normative-v conception of the human being. I concluded that normative-v conceptions can also contain naturalistic elements. These are the elements that are under scrutiny here—at least in the majority of cases. In addition, these naturalistic aspects can be informative in relation to a normative conception of the human on different levels: metaethical arguments aim to discuss metaethical problems, but, thereby, they have implications for a number of normative possibilities that are connected with those metaethical positions. Here, I will not investigate or test whether the examples I provide in the following sections for these argumentative strategies are correct as they stand. I aim at

²⁵ My translation: “Die Biologie, vor allem die Evolutionsbiologie und Neurobiologie beanspruchen, unsere nebulösen Selbstverklärungen zu beenden; nach so vielen Mythen winkt endlich eine wissenschaftliche Antwort auf die Frage nach dem Menschen.” Illies is clearly critical of these attempts.

understanding methodologically how these strategies proceed and on which levels they interfere.

For instance, famously, psychological experiments are used to argue for important constraints on how free will operates (Libet 1999; for normative consequences Pereboom 2006). If this is indeed correct, then it has implications for all kinds of normative conceptions of human beings. Ethics as we know it would then broadly be in vain. In addition, a number of evolutionary approaches aim at debunking metaethics and argue, for example, that in light of evolution, moral realism cannot be supported (famously argued by Street 2006).

Others argue for a different view on moral judgments than we are accustomed to and base this on cognitive neuroscience and psychological experiments. In the same way, Jonathan Haidt argues that moral judgments are only gut feelings (Haidt 2001). Emotion-related neural activation often occurs when we make moral judgments, and all we do when we are trying to provide reasons for our moral beliefs is render those emotional judgments *ex post* intelligible to ourselves. This means that it would not be the case that a belief causes a certain emotion, but that, vice versa, because of an emotion, we form a belief. If this is true, ethics should rather be concerned with the study of emotions instead of giving justificatory reasons for beliefs, as it traditionally does. Such an approach might in addition inform our understanding of psychopathy and the study of autism, as psychopaths as well as autistic people are often understood as lacking certain emotions such as empathy (Kennett 2002; Schramme 2014).

On a different level, naturalistic methods are taken to support utilitarian ethical theories over deontological ones (J. Greene 2003; J. Greene 2008; Singer 2005). Here, psychological studies of people's intuitions regarding a number of moral dilemmas are linked to their emotional responses, which are in turn tied to evolutionary explanations. Utilitarian thinking would employ the 'rational part' of the brain instead of the emotional part. Moral judgments based on deontological reasoning are, then, discarded and we should instead focus on utilitarian accounts. The idea is that evolution proves utilitarians right.

In these cases, naturalistic approaches to the human being are generally employed to support, criticize, or otherwise inform aspects of a normative-conception of the human being. Yet sometimes, the naturalistic aspects seem to become dominant. The idea then is that everything that is real is part of the world investigated by natural sciences (Frierson 2013, 166). A compre-

hensive scientific naturalism about what it means to be human seems, then, to be advanced. The question of normative-v conceptions of the human being is in this case reduced to the same level as a question such as ‘What is oxygen?’ Generally, these kinds of accounts are characterized by materialism and reductionism (Frierson 2013, 166). Materialism claims that there is nothing that is non-material, such as a soul. Reductionists hold that non-physical processes can be reduced to physical processes, biology to neurobiology, and neurobiology to chemistry and so on.

Within those approaches, the step from a natural-scientific description of the human being to a normative conception of the human being in the sense sketched out above is made seemingly effortlessly. However, it is questionable whether this is actually fruitful or even possible at all. Clearly, natural-scientific conceptions of the human being are informative for some kinds of questions, but they cannot answer normative questions. In general, normative questions cannot be answered by using natural-scientific methods. To make a case that supports that point, Frierson makes a distinction between explanatory causes and justificatory causes (Frierson 2013, 182). Explanatory causes provide reasons why something developed or happened in a certain way, whereas justificatory causes provide reasons why something should be done or should be developed in a certain way. Naturalistic-scientific approaches can provide explanatory causes, but no justificatory ones. For instance, evolution might explain why art or music matters to us, but it cannot even attempt to show what makes these goods genuinely important. In a similar way, neurobiology can explain what causes us to experience different feelings when we see pictures of loved ones in comparison to seeing pictures of strangers, but it cannot explain whether we should care about them differently. To answer these normative questions, we are in need of normative justifications. As William FitzPatrick puts it:

“Normative ethical conclusions are justified through first-order ethical reflection and argument, just as mathematical propositions are justified through mathematical reasoning (...) It would seem to be as much of a mistake to try to answer ethical questions by examining fMRI scans or studying our evolutionary history as it would be to try to solve mathematical problems by such means.” (FitzPatrick 2014, section 3.2)

To the extent that philosophers refer to naturalistic elements in a normative-v conception of the human being, they cannot ignore results from cognitive neuroscience, psychology, and other broadly naturalistic disciplines. Philosophers need to relate to those results, and some of the approaches I discuss

might be more challenging than others for specific normative-ethical accounts. At least in some way, normative claims need to be compatible with explanatory claims, as I will show in the next chapter. But naturalistic results cannot construct normative-v conceptions on their own. If the question ‘What is the human being?’ is not merely a question about the distinctive features of a certain type of natural entity, then naturalism is simply insufficient to answer it (Frierson 2013, 198).

2.5.2 *Normative methods*

Other normative accounts of the human being treat these accounts explicitly as normative problems. In this section, I will have a closer look at two different normative justification strategies, namely Aristotelian and Kantian ones. Aristotelian theories are interesting because they take a thick normative account of the human to be at the center of their moral philosophy. Kantian theories, on the contrary, manage to do with thin and merely formal assumptions about human beings. Both theories are relevant to questions regarding disability and enhancement. As we will see, Aristotelian theories are applied to ethical questions regarding atypical human beings. Kantian theories are especially important for (human) rights frameworks as well as for discussions about agency, and these are often employed in disability debates. Of course, a number of other justification strategies remain that I do not delve into at this point. For instance, Jan-Christoph Heilinger sketches a quasi-democratic process broadly in the spirit of an overlapping consensus to decide which features of human beings are most significant (Heilinger 2010, 199ff; Heilinger 2014, 104–111). In addition, religious conceptions about the human being could be understood as such normative-v conceptions. But for now, I want to focus on Aristotelian and Kantian approaches.

I want to start with the Aristotelian Michael Thompson, as I have already analyzed the first stage of his theory when I discussed normative-c conceptions. In the second stage, he connects his analysis with a normative-ethical theory. This step is made seemingly effortlessly. Ethical judgments, Thompson argues, are the same kind of judgments as judgments about good sight (Thompson 2004, 60). Natural-historical judgments should set a standard for the goodness or badness of individuals. Accordingly, a special form of judgments of natural goodness or badness can be used to criticize the actions of individual persons as unjust or prudent. It means that the concept ‘human’ is “the highest concept of practical philosophy, one which all of our genuinely normative predication implicitly involves” (Thompson 2004, 62/63). As I

analyzed it, the human life-form is not simply an empirical observation, but rather a normative-c conception of the human being, as I analyzed it.

Philippa Foot makes a very similar move (Foot 2001): she follows Thompson's analysis of the life-forms in his earlier work. She argues that to arrive at a moral theory, all we have to do is to consider "what kind of living thing a human being is" (Foot 2001, 51). Morality is rooted in human needs, just as plants and animals have specific physical needs.

For both Foot and Thompson, this means that the normative-c conceptions of the human being are employed as a foundation for an ethical theory. Thereby, the normative-c conception is transformed to a normative-v conception with just a few words and, most importantly, without adapting its justification. Yet why should ethical standards follow from a description of the human being? Neo-Aristotelians argue, importantly, that the notion of a moral 'ought' rests on a mistake and that ought-statements should rather take the form of an ought-statement such as 'the plant ought to have water' (Anscombe 1958, 7). Therefore, the life-form is not itself again in need of a normative foundation to be able to provide normative reasons.

However, as both Buchanan and Lewens point out, an account of the life-form is unhelpful for a number of enhancement debates. Enhancement, especially genetic enhancement and certainly far-reaching enhancements, could be understood as changing the human life-form. Even if we take a life-form to specify ethical standards for its members, this does not have any implications for altering the human life-form (Buchanan 2009, 144ff; T. Lewens 2012, 469). A different life-form might entail different standards.

Martha Nussbaum is an Aristotelian of a different kind, at least in her early writings. She is also interesting at this point because she and others apply her moral theory to questions regarding disability. For disability scholars, the focus on capabilities and on what one is able to do and to be is a welcome alternative to the usual focus on resources as political entitlements.

Nussbaum develops an account of "what we essentially are" (M. Nussbaum 1992a, 91) as a foundation for her type of capabilities approach. The guiding question of this endeavor is, as she explains:

"What are the features of our common humanity, features that lead us to recognize certain others, however distant their location and their forms of life, as humans and, on the other hand, to de-

cide that certain other beings who resemble us superficially could not possibly be human?” (M. Nussbaum 1990, 219)

This is a description of a normative-c conception of the human being. Such a conception of the human being, she argues, is internal to the human practices and evaluative from the start. What does this mean? Nussbaum argues that human nature is not something that science can reveal. A completely external perspective on human nature is not possible (M. Nussbaum 1995, 94). Instead, it is “an inside perspective, (...) the most fundamental and broadly shared experiences of human beings living and reasoning together” (M. Nussbaum 1995, 121). What it is to be human is evaluated by testing whether or not we can agree with certain judgments about human beings spelled out, for example, by mythological stories. Thereby, certain functions are singled out as more basic than others. The question is simply whether the critic would seriously disagree with those judgments.

Moral judgments are directly linked to this understanding of human nature. The selection of capabilities that are the building blocks of Nussbaum’s normative-ethical theory is based on this understanding of a truly human life. A life that lacks any of the capabilities, “no matter what else it has, will be lacking in humanness” (M. Nussbaum 1992b, 222). That means that her account of human nature not only works as normative-c conception of human nature, but at the same time also works as a normative-v conception.

Just as for Thompson and Foot, the move from a normative-c conception to a normative-v conception is challenging. For all of the above-mentioned authors, normative-c conceptions seem to have direct normative significance. This means either that the normative-c conception is loaded with normative commitments that are themselves in need of a normative justification or that the normative-v conception is a thin normative conception, but then it is questionable to what extent it can ground normative rules (Buchanan 2009, 147 with a similar remark). This criticism is not meant to show that these kinds of projects are necessarily flawed, but merely to point to methodological problems that should be addressed by any such project to be successful (for further discussion see Antony 2000; Claassen and Düwell 2012).

Lastly, I want to investigate the justification strategy for normative-v conceptions put forward by Kantians. Intentionally, they try to work with a thin understanding of what it means to be human, but nevertheless they attempt to draw substantial normative commitments from it. As noted earlier, Kantians see the human being primarily as an agent. Broadly summarized, they

argue that human beings have a necessary reason to see themselves as agents. This, in turn, has certain normative implications that are spelled out in a moral theory.

In this way, Alan Gewirth developed the ‘principle of generic consistency’ (Gewirth 1978). Gewirth begins with the concept of action. All actions necessarily require two fundamental qualities: freedom and well-being. These qualities should not be understood too comprehensively, but more narrowly as meaning generally that without a fundamental sense of being free and a certain level of well-being, such as physical integrity, no action is possible. Because freedom and well-being are necessary for any action, an agent, simply by being an agent, has to value them. From this valuation it follows that the agent claims a prudential right, rather than a moral right, to freedom and well-being. And this is the crucial point: the claiming of those rights is solely based on the fact that they are claimed by someone who is an agent. Therefore, logic demands that the agent accepts that other agents also claim a prudential right to their freedom and well-being. If an agent does not want to contradict herself as an agent, she has the duty to accept those rights of all agents (Düwell 2006, 160). This step of universalization means that rights are moved from the prudential realm to the moral realm (Gewirth 1978, 73). All agents must make a claim to a right to these generic goods of action and must also grant these rights to other agents. This is the ‘principle of generic consistency.’ According to Gewirth, this cannot be logically be denied from any agent's point of view without denying the grounds of his own agency. From here on, Gewirth develops a comprehensive account of morality.

Such an understanding of morality has implications for a variety of domains of social life, as Gewirth also pointed out in his analysis (Gewirth 1978; Gewirth 1996). For instance, according to Gewirth, it can justify and interpret a framework of human rights. Human rights are then understood as generic rights to agency. Of course, it needs to be spelled out which rights exactly that covers. The ‘principle of generic consistency’ even allows the setting of priorities between various rights in relation to their centrality for human agency (Harnacke 2012). Clearly, how exactly priorities should be determined in relation to other demands of justice and additional non-moral background assumptions would demand a more extensive analysis. But for now, it should be sufficient to indicate how, generally, such an argumentation strategy could proceed.

At this point, Gewirth can be representative of Kantian positions. Other Kantians proceed in a broadly similar way. For Christine Korsgaard, for instance, reasons for actions arise from practical identities, “description[s]

under which you value yourself and find your life worth living” (Korsgaard 1996, 101). Most of those practical identities, such as an identity as a philosopher, a friend, or a mountain climber, are contingent. However, to be able to value any practical identity at all, to be able to act at all, one has to value one’s identity as a human being. This is an identity as a reflective being that needs reasons to act and to live. Hence, humanity is the source of all reasons.

This means that for Kantians, generally speaking, there is a rational and universal necessity for a specific normative-v conception of the human being that does not include thick assumptions about a human life. It is not the case that a moral theory follows directly from it, but it is informative about morality in a non-contingent way.

3 Conclusion: additional questions

This chapter aimed at understanding the reference to the human being in moral judgments. I distinguished three general, or five more specific, possible ways to talk about the human being. I indicated how the different conceptions of the human being can be useful in different contexts and different debates. Therefore, we can conclude already here that as a minimum, it needs to be clear what kind of conception one employs.

In this chapter, I did not argue that one specific perspective on the human being is correct, but showed which different understandings are possible. I sketched which methodological implications and options but also problems follow from certain positions and what questions need to be addressed. How a conception of the human being should be used in bioethical judgments depends on the specific debates and questions such a conception engages with. I could only hint at some options. These distinctions between various conceptions of the human will be applied to case studies in chapters four to six, where I will show that these distinctions are necessary and relevant for a proper analysis and understanding of those case studies. But before that, I want to extend the theoretical framework that I developed in the current chapter. The evaluation of a specific conception of the human also depends on its function in a moral argument. For this reason, I will investigate a variety of argumentative functions in the next chapter. It will then become much clearer, I hope, how the various distinctions that have been made up to this point are necessary in practical evaluations.

Chapter 3

From human nature to moral judgments: argumentative functions

Having an account of different understandings of the human being does not take us all the way to moral judgments. Various elements of a moral judgment can have different argumentative functions. It is like baking a cake: knowing that you need butter, eggs, flour, and chocolate sprinkles is not enough. If you start by mixing sprinkles and egg together, you will not end up with a good cake. A list of the different ingredients for making a cake is not sufficient: we need to know how to put them together.

I will analyze moral judgments in a similar way here. Which function can different conceptions of the human plausibly have in a moral judgment? Such a function is obviously not independent from a specific conception of human nature. I will investigate a number of possibilities for argumentative functions and connect them to diverse conceptions of the human being that were distinguished in the previous chapter. I want to analyze different possibilities for how to incorporate the human being in moral judgments. Thereby, I will focus on cases related to disability, disease, and enhancement to make my arguments as specific as possible. However, I hope to be able to make a more general point rather than being limited to enhancement and disability. Just as in chapter two, my aim in this chapter is to show how to defend different positions instead of arguing for a specific position myself.

This should, I hope, prove to present a useful theoretical framework for debates in applied ethics. In chapters four to six, I will apply this framework to practical debates and cases to indicate why such a theoretical framework is useful and necessary.

I think that reflection on argumentative functions can be useful in a number of ways. Such reflection is not only relevant to a better understanding of the reference to human nature in a moral judgment. In addition, it could, for instance, prove helpful in understanding how normative-v conceptions are constituted. Alternatively, it could be employed to understand the general organization of moral arguments. But I will focus here on an analysis of the role of a conception of the human in a moral judgment.

I will briefly reflect upon moral judgments and their relationship with conceptions of the human in section one. In section two, I will analyze five different argumentative functions of conceptions of the human.

1 Moral judgments

Even though conceptions of the human being play a role in moral judgments, this does not mean that moral judgments are simply an application of conceptions of the human being to specific cases. First of all, a complete philosophical anthropology can be a lot more comprehensive than moral judgments. In the discussion of conceptions of the human being, I did not propose such comprehensive conceptions of the human being. I want to stay agnostic on the question of whether these conceptions are possible at all. Moral judgments do a lot less: they specify what should be done in a certain situation. Only some aspects of conceptions of the human will be relevant here, but not a complete philosophical anthropology.

Furthermore, a conception of the human is in most cases not sufficient to instruct us what to do in a specific situation. In other words, it can be unspecific with regard to moral judgments. A conception of the human can be compatible with very diverse ideas about morally right conduct. It underdetermines the moral domain. Generally, more than a conception of the human being is needed to justify moral obligations. Clearly, a moral theory or at least some moral principles are also necessary here. As I concluded in relation to normative-v conceptions of the human, moral theories also rely upon conceptions of the human. But moral theories should not be the focus here. I am only interested in moral theories to the extent that they are relevant to

understanding the right place for a conception of the human in a moral judgment. For this purpose, it needs to be clear that a moral theory in itself is not the same as a moral judgment. Moral theories are to a greater or lesser extent indeterminate. They are in need of enactment. Conceptions of the human interact with a moral theory or principles and other considerations such as factual descriptions of a situation to form a moral judgment. This happens in the process of practical judgment. I will investigate in this section what, exactly, that entails.

When we are discussing moral judgments on abstract and general levels from a philosophical perspective, we tend to refer to this as a discussion of moral theories. However, first, moral theories are not identical to moral judgments. And second, moral theories differ in a number of important ways. They vary considerably in terms of their aspiration towards generalization, abstractness, systematic organization, and comprehensiveness (Arras 2010, supplement section 2). Like Arras, we can say that moral theory leads to the derivation of moral principles (such as ‘respect the autonomy of rational agents’), general rules (such as ‘do not enlist patients in medical research without their consent’), and, ultimately, moral judgments (such as ‘the Tuskegee syphilis study was morally wrong’). Moral theories are indeterminate: they do not directly show what must be done. Hence, they do not provide complete guidance (O’Neill 2000, 54). There are many possible ways in which moral theories can be enacted and in the end lead to moral judgments (O’Neill 2009, 225). Furthermore, several moral principles are typically justified by a moral theory. Importantly, authors with identical moral theories, that means with identical starting points, can arrive at different moral judgments if they differ in their assessment of the process of practical judgment (Düwell 2013, 66). How to apply a moral theory or, if the notion of ‘application’ is already considered misleading, how it can guide action is controversial and certainly not easy (O’Neill 2009, 223/224). However, this does not mean that we should aim for moral theories that circumvent this methodological challenge by avoiding the openness of a plurality of indeterminate principles. It is rather as O’Neill says: “Normativity requires indeterminacy because it requires relevance to situations that are still open and unresolved” (O’Neill 2009, 225/226). In that sense, the openness of moral theories is a strength instead of a weakness.

Practical reasoning fills the gap between moral theories and a moral judgment. It is during the process of practical reasoning that we have to bridge factual and normative, and probabilistic and evaluative convictions to reach a moral judgment. To be able to do so, we need the competence to use moral knowledge in a judgment and an action: we need “moral literacy” as Barbara

Herman phrases it (Herman 2007, 81). Yet a general description of the process of practical reasoning proves difficult. How it works exactly is again dependent on the moral theory that is presupposed. And most theories about practical reasoning develop and operate within the context of a moral theory. As I explained previously, moral theories differ in a number of important characteristics and, therefore, have different requirements in terms of practical reasoning. Different ideas about practical reasoning can be traced back to disagreements about the right moral theory. Note that some moral theories, such as particularism or case-based judgments, even refrain from formulating any more abstract and general principles, but only recognize descriptions of situations and moral judgments. Claims about what it means to make a moral judgment are thus tied to specific normative-ethical assumptions about the right conduct and are not agnostic regarding moral theories (Richardson 2013, section 2).

However, I am not specifically interested in an extended discussion and justification of moral theories. I am interested in moral judgments, particularly in what role a conception of the human plays in a moral judgment. Hence, I will leave open the question of justification of moral theories and more detailed questions about the process of practical reasoning. Let us now focus on one of the elements of a moral judgment: the role of conceptions of the human.

2 Argumentative functions

What function do conceptions of the human have in moral judgments? With very few exceptions, the different roles that references to human nature in a moral judgment can play are not systematically discussed in applied ethics. A notable exception is Buchanan's account, which analyzes the fruitfulness of human-nature arguments in the enhancement debate (Buchanan 2009). Buchanan distinguishes a number of possible roles for such a reference. I will build upon his categorization and develop it further. Most importantly, I will add some indirect argumentative functions. Thereby, we will see that I come to quite different conclusions regarding the usefulness of human-nature arguments for applied ethics.

In the following, I aim at showing in a systematic way how conceptions of the human can be employed in moral judgments. I will distinguish five possible roles. I will show that moral judgments hinge in different ways on an understanding of human nature. Conceptions of the human can come into

play at different points and thus interact in different ways with various other elements of the moral judgment. Accordingly, they are of different importance for the outcome of the moral deliberation process. In most cases, the relation between moral judgments and conceptions of the human is best understood as an indirect relation.

2.1 Foundation

First, a moral judgment could be justified by reference to a conception of the human being. Only one moral judgment is compatible with a conception of the human. That means that a conception of the human is the immediate source of substantial normative principles. This is the most direct way in which conceptions of the human being could relate to moral judgments, and at the same time it is also the strongest function possible. Here, the content of morality is derived from a certain understanding of what the human being is. An account of human nature, thus, works as a normative justification.

Such an argument could be presented in bold statements such as ‘homosexual relationships are against human nature.’ Yet it could also be expressed rather subconsciously if specific ideas about the human being are taken as sufficient to justify a moral judgment. In that sense, employing human dignity to argue against (or for) euthanasia is one possible strategy. The idea here is either that euthanasia would be incompatible with an understanding of human dignity or that the right to euthanasia would be incorporated in such an understanding of dignity. Correspondingly, a standpoint against organ donation could be based on the view that organ donation presupposes an unduly mechanistic understanding of the human being. Because this is not how the human being should be seen, organ donation is rejected. Of course, the defender of such a position would have to show that the practice of organ donation in all possible forms does indeed necessarily entail this mechanistic view of the human being.

In addition, this is the argumentation strategy that Aristotelians work with, as I concluded in the last chapter. For them, the concept of the human being is the highest concept of practical philosophy. Aristotelians try to establish thick essential conceptions of the human from which substantial normative principles are deduced. Here, all a moral theory has to do is to explicate a conception of the human being. Most moral theories other than Aristotelian ones manage with a thinner conception of the human being. Alongside this, they establish a conception of the human being that is indeed informative

for moral theory, but not without taking several other argumentative steps. Therefore, I do not understand them as taking up a conception of the human as a foundation for their moral judgments, although, in general, they also make use of normative-v conceptions, as I call them.

Allen Buchanan analyses such a role of human nature in the context of debating human enhancement technologies (Buchanan 2009, 145). In his evaluation of such a role, he states:

“[I]f the concept of human nature from which controversial substantive moral rules (prohibiting asexual reproduction or enhancement, or procreation by same sex partners, etc.) are supposed to be derived is itself normatively rich enough to ground those rules, then that highly normative concept of human nature will itself be equally controversial and no argumentative leverage will be gained.” (Buchanan 2009, 147)

Buchanan argues that such an argument against enhancement needs to be developed in more detail. Simply referring to a normatively rich conception of the human is not sufficient. *Pace* Buchanan, if a conception of the human being is used as a foundation for a moral judgment, it is in need of a normative justification. This is the methodological challenge that Aristotelians face, which is also analyzed what I analyzed in the preceding chapter.

This remark leads us to another point: it clearly matters what kind of conception of the human is taken up as a foundation for a moral judgment. At least in principle, it is possible to refer to a normative-v conception. But no other conceptions of the human can fulfill this role. Similarly, naturalistic methods cannot justify normative-v conceptions. We cannot move from a descriptive conception to a moral judgment.

An attempt to do so can be criticized from different perspectives (Heilinger 2014, 102/103): first, as Heilinger formulates it, it is unclear what is part of human nature and what is not. All kinds of human traits could be included as being parts of human nature. I would like to formulate it differently: it is unclear which descriptive conception of the human overrules the others, as several could fulfill this role. Second, and more importantly, such an argument falls prey to the naturalistic fallacy. Claiming that something is the case, as in saying that something is part of a description of human nature, does not say anything about normative relevance at that point. This is the problem that causes some critics of enhancement to be attacked. Sometimes, they seem to presume that our natural evolutionary development is normatively

good. This should make enhancement, which intentionally changes this development, repellent. But evolution only aims at survival and fitness. This is not necessarily, without further argument, morally good (Buchanan 2011, 4). Heilinger mentions a third, almost obvious point: facts about human nature can stand in contradiction to what moral theories declare to be good. Human aggression, for instance, could be considered a trait of human nature as much as any other trait, but most would argue that we should overcome aggression instead of valuing it.

To avoid all these problems, we have to move to normative-v conceptions of the human. They are the only conceptions of human nature that can be a foundation of a moral judgment. Normative-v conceptions have their place in moral theories. This means, in turn, that moral theories are the foundation of a moral judgment.

2.2 Constraint

Related to the function of the conception of human nature as a foundation for a moral judgment, but less comprehensively, is the function of a constraint. Here, the moral judgment is not justified by a reference to a conception of the human being, but is shown to be wrong or at least deeply problematic if it refers to a problematic conception of the human being. The idea is that if a moral judgment makes assumptions about the human that are implausible, this moral judgment is defeated. Thus, employing a conception of the human in relation to this function constrains the number of possible moral judgments. Only a few moral judgments are compatible with a conception of the human.

For instance, moral judgments that are incompatible with the idea that human beings need food and oxygen to survive are clearly defective. Of course, these facts cannot by themselves establish normative obligations. Human beings have a right to food and oxygen just because they need it to survive. However, if we formulate duties towards future generations that are incompatible with the fact that they will, in all likelihood, also need clear air, then these moral judgments are flawed.

Nikolai Münch takes up such a strategy in his criticism of transhumanism (Münch 2012). Transhumanists are particularly extreme enhancement defenders who argue out of different considerations for wide-ranging enhancement technologies. Their arguments are commonly illustrated by the

most creative science-fiction examples. A frequently used example is ‘uploading,’ a process by which our mind is transferred from the biological brain to a computer in the same way as a file or program can be uploaded. Just like a file, a program, the software, or the hardware could then be updated. One could increase the memory, install a faster processor, and use more efficient algorithms. In short, the human mind could improve considerably. Münch concludes that this idea requires a functionalist mind-body theory, such as that advocated by Jerry Fodor and Hilary Putnam (Münch 2012, 296). Here, the mind is seen as the software of the brain and human thought is considered to be a calculation, a formal, rule-governed management of symbols. Substantial objections arise against such dualist conceptions as they cannot make sense of our bodily self-awareness, for instance, or various aspects of cognitive and emotional experiences. The problems of this theory, however, are necessarily connected with positions that work with the idea of uploading. That does not necessarily defeat these transhumanist ideas, but it shows that they have to confront these kinds of problems. If they cannot adequately deal with them, it is an argument against them. Here, a conception of the human as a constraint on morality is a claim about implausible presuppositions that refer to how human beings are constituted.

Similarly, Leon Culbertson engages an understanding of the human being as a constraint for transhumanism. He connects Sartre’s philosophy with transhumanist ideas (Culbertson 2011). Sartre would reject the existence of human nature in the sense that it is employed by transhumanists. To summarize, Culbertson argues that Sartre has a point and that if Sartre is correct, then transhumanism is not.

More generally, the moral implications of Darwinism could be understood as a constraint on morality. It is, then, not the case that our evolutionary development determines a moral theory, but only that our moral theories need to be developed within the constraints of evolution. For instance, to the extent that views on the different moral status between animals and humans are justified by reference to the creation of a divine designer, these views lose at least some of their support in the light of Darwin’s theory (Rachels 1990).

In all these cases, the argument needs to show that the normative-ethical view that is criticized depends in a necessary and not just a contingent way upon the conception of the human that is put forward. It needs to be shown that the argument does not work without assuming a specific conception of the human that is then shown to be controversial.

The role of constraint could also be brought to bear on the level of moral theory construction and not only on the level of moral judgments. Robert Noggle discusses this argumentative function as “the conditional claim” in the context of the justification of moral theories (Noggle 2001, 536). If a moral theory is linked to specific claims about human nature and these claims turn out to be false, then the moral theory loses credibility. For instance, the development of care ethics could be interpreted as a criticism of contractarian theories (Held 1995; Held 2006; Kittay 1999; Kittay and Feder 2002; Noddings 1984). Contractarian theories, as care ethicists argue, proceed from the idea of a strong, self-sustaining, and independent human being, which does not reflect the characteristics of weaker members of society. Leaving open whether this criticism is correct as it stands, it is supposed to show that contractarian theories can be defeated.

Using an account of human nature as a constraint is definitely prevalent. There seems to be a reasonable idea behind it: on the one hand, the conviction that our moral judgments should take human nature in some way into account, combined with, on the other hand, the suspicion about whether a particular account of human nature can justify moral claims (Horton 1999, 453). One possibility is understanding the constraint of human nature in the light of the ought-implies-can principle. Ought-implies-can establishes a link between one’s obligations and one’s abilities. In its simplest form, it says that what we should do needs to be something that we actually can do. Morality can only demand from us what is possible for us as the sort of beings we are. As Robert Noggle formulates it: “[0]ne ceases to provide guidance if one recommends the impossible” (Noggle 2001, 542). Morality needs to accommodate human limitations and thus needs to be feasible for us (for the debate see Martin 2009; Graham 2011; Greve 2014; Stocker 1971; Vranas 2007; for a discussion on Kant see Stern 2004).

This problem provides the background needed to understand a debate on utilitarianism. It is often argued that utilitarianism demands too much. For instance, according to Peter Singer, we should give away part of our income to charity (Singer 1972). Utilitarians ask us to behave in a similar way towards strangers as we do towards our family and friends. Critics argue that this demands too much from us: human beings are not constituted that way. Human beings do want to be partial to those who are closest to them, such as their kin and friends. Because we do not have the ability to act as utilitarianism demands from us, we should also not be obliged to do so (Scheffler 1982).

Buchanan discusses ought-implies-can in the context of the enhancement debate (Buchanan 2009, 143). He thinks that it is a valid principle, at least to a certain extent, but that it is meaningless for arguing against enhancements. As Buchanan analyzes it, enhancement involves the removal or relaxing of perceived human limitations. If we have trouble behaving in the same way towards strangers as we do to our loved ones, then a pill could enhance our empathy. Enhancement would help to shift the limits of what we can do and implies fewer constraints on morality. This, however, might not be a bad thing in itself.

Even though most would agree on some interpretations of ought-implies-can, other interpretations are certainly controversial. The discussion in the last chapter regarding different understandings of human nature leads immediately to a subsequent question: what kind of claims about human nature should be invoked? It is controversial which human limitations are among the limitations that morality has to accommodate. If it means that morality cannot demand that we are beamed from one place to another as happens in *Star Trek* and the like, then this might be reasonable. A compliance with such demands is indeed impossible for human beings and hence meaningless. But how should morality deal with jealousy, problems with motivating oneself, or other generally unwelcome but all-too-human features? Is it really the task of moral demands to take these features into account or should morality not also demand that we overcome them, at least to a certain extent? Both Keith Horton and Sanjay Reddy argue that ought-implies-can is prone to underestimate what human beings are able to do and thus arrives at views that are too limited regarding an agent's obligations (Horton 1999; Reddy 2005). Though human beings have a tendency both to age and to be selfish, these two predispositions probably demand different interpretations here. What notion of 'can' we should work with and what its conditions are is the subject of both interpretation and discussion.

Although it is debatable which specific claims about human nature can be invoked as a constraint on moral judgments, these can, at least in principle, be claims on the level of all conceptions of the human being. Münch and Culbertson, for example, employ metaphysical conceptions of the human in their criticism of transhumanism. Though I do not want to debate at this point whether their analysis really hits the mark, it could work methodologically. Ought-implies-can, on the contrary, typically refers to naturalistic or normative-c conceptions.

Importantly, although a conception of the human as a constraint on moral demands can exclude certain specific moral judgments, it underdetermines

the moral domain. A constraint is only directed at those options that are excluded, not at those that are morally indicated. Various moral judgments could be compatible with a specific conception of the human. Even though one can decide on a specific conception of the human, further considerations would be needed to determine what one should do. Using a conception of the human as a constraint on moral judgments is, therefore, in most cases not sufficient to come to a normative conclusion. It might be interesting to use this argumentation strategy to critically analyze certain moral judgments and to test whether they are implausible in a certain sense. However, a constraint cannot provide in most cases the tools with which to develop a constructive account about how a moral problem should be dealt with. It can play part of a constructive project, but in most cases it will not be a sufficient element.

2.3 *Specification*

Conceptions of the human being can also come into play at a later point in moral judgments. One of these possibilities is using conceptions of the human to specify a moral judgment. That means that an idea of human nature guides the practical application of a normative theory or principle. Here, the correct normative theory or principle is already determined. But to bring these principles to bear in guiding the action regarding a particular case, it is necessary to specify them by employing a conception of the human.

Noggle discusses this as a “very common and very unproblematic” function (Noggle 2001, 541). We need to tailor moral principles to be able to apply them, and in doing so we should not ignore relevant information. That means that we need to know what sort of things are harms and benefits. Specifying moral principles involves conceptual and normative work. For instance, knowing that we should support people in trouble only takes us so far in actions of everyday life. If we see someone thrashing about in deep water, we need to understand that human beings lack gills, which means that this person might be in dire need of assistance. Here, facts about human beings help to specify a moral judgment.

Regarding disability and enhancement, specification is also a relevant argumentative function. For discussions about well-being, we need to understand exactly what well-being means to be able to promote it adequately either for a disabled person or for superman and superwoman. It is, for instance, not

self-evident that limitations of body or mind are an obstacle to happiness or, more generally, to quality of life (see chapter one, section 1.4). Disabled people argue vehemently that able-bodied persons commonly misjudge a disabled person's level of well-being and what contributes to it. Against all odds, even severely disabled people typically report a high quality of life (Asch and Wasserman 2005, 175; Goering 2008, 125/126; Tännsjö 2009; Ubel, Loewenstein, and Jepson 2003). This is known as the 'disability paradox.' It challenges us to think twice about how to conceptualize well-being. The problem of adaptation also contributes to this paradox. We quickly get used to either apparently good or bad circumstances and are prone to falling back to our original level of happiness quite quickly (Hope 2011, 236–239). Of course, these discussions already presume that well-being understood in a certain sense is the relevant indicator. But to act according to well-being, this needs to be specified. A conception of the human could fulfill this role. We need to have information about the constitution of the well-being of disabled persons to be able to specify the determinants of well-being in their situation. A conception of the human can provide this information. An example of how, exactly, well-being can be specified for a disabled person will be investigated in chapter four.

A similar specification could be imagined for the moral principle of respecting a person's self-determination or autonomy. To apply this principle in practice, it is necessary that we understand which beings are capable of autonomy, have an idea of the development of autonomy in children, and can understand the limitations and scope of the autonomy of psychiatric patients and the cognitively disabled. We need to have knowledge about the human being to specify how we can respect autonomy. Clearly, we also need to reflect on the significance of the empirical research for the moral demands, but we do need answers to some empirical questions.

It seems that it is always necessary to have a general specification to arrive at any more specific moral judgment. Even if one presupposes certain moral theories or principles that are already justified, they are formulated in a general way and always need to be specified for the case in point. This happens in the process of practical judgment, as I explained at the outset (section 1). It is difficult to imagine a moral judgment that does not have some kind of specification. This makes specification an important argumentative function. Not surprisingly, specification is employed by various ethicists (Beauchamp 2003; DeGrazia 1992; Richardson 1990; Richardson 2000). However, none of them discusses the possibility of specifying a principle using a conception of the human on a theoretical level, although this does in fact happen in practical discussions in applied ethics.

All kinds of conceptions of the human that were distinguished in the last chapter can take the role of a specification. Yet, importantly, a conception of the human as a specification is not sufficient to provide guidance on what we should do. We need to start with a moral principle that is the subject of the specification.

2.4 *Scope*

A moral judgment also has to determine the scope of moral demands, rights, and duties. Here, a conception of the human can provide an account of who is addressed by certain moral theories or principles. This role does not concern the content of moral obligations, but the question of who is morally indebted to whom, for what, and in what context.

This is, for example, relevant for exercising advance directives, as already discussed under metaphysical conceptions of the human being. We have to decide what we owe to the person who can no longer decide for herself. Should she be treated according to the advance directive? Does she fall under the scope of moral requirements that the advance directive formulates? To make this decision and to formulate the conditions for a responsible decision, typically, a metaphysical conception of the person is invoked.

Not only for the practice of advance directives, but for questions of life and death in general, it is relevant that we develop an idea about the appropriate way to relate to someone. We normally think that we have different and more encompassing duties towards living persons than towards dead bodies. This presupposes an understanding of the limits between life and death. However, our definition of death has changed with the development of modern medicine. Whereas for a long time, the cessation of the heartbeat was considered sufficient for the declaration of death, we now think that certain brain functions should have stopped. With ever more precise instruments to measure brain function, it is not impossible that, one day, we might not consider someone dead whom we now think it is safe to bury. Here, naturalistic facts are used to provide an account of conditions for personhood.

Likewise, during the development of the UN Convention on the Rights of Persons with Disabilities (CRPD), disabled people made a forceful claim that so far they had not been sufficiently considered within the scope of human rights. Whereas human rights instruments were clearly meant to include

disabled persons as well as women and children, these groups were in fact not visible within the existing systems (Kayess and French 2008, 12). To make sure that the general rights regime was tailored to them, they were considered to be in need of conventions directed at them.

More generally, questions of moral status fall under discussions of the scope of moral requirements. We have to think about in what sense a being should be taken morally into consideration for its own sake at all. Thereby, we can distinguish full moral status from a partial or lower moral status and no moral status at all. Non-disabled adult human beings are normally considered to have full moral status. Sometimes, such a full moral status is described as having dignity. We have to reflect upon the criteria for having dignity or moral status in general. How inclusive do we want to be regarding non-human beings such as animals, but also regarding atypical humans or humans at the limits of life, such as embryos, people in a coma, those with severe disabilities, or future generations? These questions are especially relevant to questions relating to the beginning of life, as in assisted reproduction, and to the end of life. Scholars continue to discuss what the relevant criterion is to attribute a certain moral status to a being (for a review of different criteria see Düwell 2013, 109–125; Wasserman et al. 2012, section 3–5). Here, anthropological background assumptions always play a role, but it is not enough to simply refer to ‘the human being,’ as this is exactly what is under discussion. There are three broad possibilities to accord a being moral status.²⁶

First, one could argue that a being has the relevant capacities. Here, a common argumentation strategy is to refer to various different cognitive or psychological attributes that give one a high moral status: autonomy, rationality, self-determination, the capacity to act for reasons, and self-consciousness, etc. A normative justification for the choice of the relevant criterion needs to be added. It is sometimes argued that there is no need to actually possess the capacity in question, but that it is enough to stand in a suitable relation to that criterion. That means that the potential to have that capacity, ever having had the capacity in question, or having it to a certain degree would suffice. This would then be more inclusive towards young children and people with dementia who might only possess the criterion in question to a degree or might only have had it in the past.

Second, a being could be granted a high moral status simply due to the fact that it belongs to the human species. This would invoke a naturalistic con-

²⁶ These criteria will be tested and elaborated in chapter three, section 3.2.

ception of the human. Peter Singer famously argued that such an argument to justify the special treatment of a certain biological species is not any better than racism or sexism (Singer 1975). But Singer's conclusion is reached too fast. To avoid it, a further reason needs to be provided about why species membership is normatively relevant (Düwell 2013, 109–121). We could argue in the following direction: certain cognitive capacities could be qualifications for having a high moral status in combination with a principle of precaution that demands that those human beings who do not actually have the capacity in question are also included (Graumann 2014, 487/488). Defining a threshold for who is and who is not included is notoriously difficult and maybe also unavoidably arbitrary. Therefore, it might be safest to include the whole species. Such an argument allows a more inclusive approach than demanding a simple cognitive or psychological capacity. Yet even some severely disabled people, and certainly embryos and gametes, do not fall into such a gray area, but instead are clear instances of not having the capacity in question. The need to include the whole species does not automatically follow from precautionary considerations. But species membership might be important on different grounds: allowing a threshold to be established for those falling within the scope of moral status on the basis of certain capacities would imply that someone or some institution has the authority to make that judgment. This could be considered undesirable (Who should make this decision? How can we avoid abuse of power?) and therefore a reason to include the whole species. Species membership is, then, the best way to determine the scope of the validity of moral requirements.

Third, moral status could be justified on the basis of a practice of recognition. Moral status would be accorded because others recognize and value a being as having such a status (Williams 2006; Forst 2007). Here, moral status is not based within the individual, but comes into existence because others treat and value her as such. The moral status is gained through the way in which others treat someone.

As we have seen, determining the scope of moral principles is possible by using all kinds of conceptions of the human being. This function of a conception of the human in moral judgments is clearly important in a number of applications to understand what morality demands from us. However, the scope of moral duties is not always the subject of debate and argument. There are many moral problems in relation to which the scope of various debated principles is clear (for instance, problems regarding the use of enhancement by students) and, accordingly, this argumentative function is then not necessary.

2.5 *Circumstances of morality*

There is still another, more general, function of conceptions of the human for moral judgments. This is capturing the circumstances of morality. These are the features of human beings that make moral judgments possible and relevant in the first place. Therefore, this role can be described as a necessary precondition for discussing different moral judgments. In this function, a conception of the human does not determine the result of moral deliberations; it only opens up a range of possibilities of moral judgments. A conception of the human can help to identify possible moral judgments that would have been inaccessible otherwise. It is thus relevant for all kinds of moral debates, but it does not suggest or determine any more specific moral judgments. It provides a frame for the next step in debating moral judgments. Such a role of human nature broadly follows in the footsteps of Hume's description of the circumstances of justice and Rawls' later elaboration (Rawls 1971, 126–130). They describe the conditions under which the very idea of rules of justice makes practical sense, such as in terms of selfishness and limited altruism of human beings on the one hand and scarcity of resources on the other.

Similarly, we have to make some assumptions about human beings if ethics, and accordingly any moral judgment, is to make sense at all. As Buchanan also argues, human beings have to be capable of morality (Buchanan 2009, 143). Although the specific content of the circumstances of morality is not uncontroversial, it seems that one necessarily has to assume at least some specific conditions of moral agency and some kind of interdependence between human beings to make debating moral judgments a worthwhile endeavor. Specifically, human beings have to be able to act in some way and make decisions to be able to be held responsible for their actions and be obliged to act according to certain standards. Furthermore, we have to assume that human beings can reflect on their actions and norms in a basic sense to make moral judgments meaningful. We also have to presuppose that human beings are vulnerable (at least in a limited sense) because otherwise it would not matter how we treat each other or whether we take into account someone's rights, well-being, or any other moral principles.

However, and importantly, it should be emphasized that the circumstances of morality cannot justify any normative claims. The fact that we are vulnerable does not entail that our vulnerability deserves protection. This fact in itself has no moral implications. An additional argumentative step is needed. This is the reason why Buchanan is opposed to using such a role of human nature to decide on the permissibility of enhancement (Buchanan 2009, 143).

Indeed, knowing the circumstances of morality might not shed any light on the answers to normative questions. Instead, it is a background assumption that makes thinking at all about these questions possible and meaningful.

In addition to these very general understandings of the circumstances of morality, I want to distinguish a second kind of circumstance of morality: this is the idea that a reflection on the human being allows for moral judgments that were not considered before. This means that a conception of the human being not only provides the possibility for morality in general, but also the possibility for a number of more specific moral judgments. For instance, thinking about an embryo as a potential person instead of a bunch of cells is necessary to understand that radical pro-life activists want to defend a number of obligations we should have towards embryos. Similarly, understanding the impact (and its limits) of genes on the development of a human being is necessary to capture appropriately the ethical dimensions of donor conception and to understand this discussion in the first place.

Certain moral questions and controversial standpoints remain invisible unless we develop an understanding of what kind of beings we are. This understanding gives us an idea of what we have to consider and debate. All kinds of conceptions of human beings can be invoked here. Of course, sketching the circumstances of morality either in the first or second sense does not entail any moral obligations so far. To justify moral obligations, we need moral principles.

3 Conclusion: evaluation

In section one, I showed that during the process of practical reasoning, conceptions of human nature interact with moral theory and possibly a number of other considerations to reach a moral judgment. Subsequently, I investigated in section two which kind of argumentative functions conceptions of the human can have. I distinguished five argumentative functions. First, a moral judgment could be justified by reference to the nature of human beings. This *foundational role* of conceptions of the human being can, for example, be found in Aristotelian ethics. Second, conceptions of the human can function as a *constraint* on moral judgments. That means that the moral judgment is not justified by a reference to a conception of the human being, but is shown to be wrong if it refers to a 'wrong' conception of the human being. This is, for instance, the case if one argues that morality can only demand from us what we are reasonable able to do. Conceptions of the

human being can also come into play at a later point in moral judgments. Third, they can be used to *specify* our moral demands. Specification means that an idea about what the human being is guides the practical application of a normative theory or principle. For example, it gives us an idea of what it means to contribute to well-being or what the empirical conditions for autonomy are. Fourth, conceptions of the human being can also determine the *scope* of normative-ethical theories. They can give an account of who is addressed by certain theories or principles. A fifth function of conceptions of the human being in moral judgments can be describing the *circumstances of morality*. These are the features of human beings that make thinking about morality generally possible and relevant and that allow us to consider certain specific moral judgments at all.

I argued that not all kinds of conceptions of the human can take all of these roles. It is clear that naturalistic, metaphysical, and normative-c conceptions are all evaluated in the same way. They do not function as a justification for a moral judgment, but can fulfill a number of indirect functions. These conceptions are not directly normative, but can be informative for normative problems. Only normative-v conceptions can function as a foundation for a moral judgment. They can occur in all types of argumentative functions.

What is the general upshot of this analysis up to this point? In all cases, the reference to the human being in a moral argument needs to be made explicit. The reference to the human being can be understood as quite different notions and can fulfill different argumentative functions. If we do not know what, exactly, is argued for, we cannot even start discussing it. For example, it is not surprising that the role of a foundation is unpopular in ethical debates, given that, first, it often remains unclear which conception of the human is invoked and, second, most conceptions of the human being, indeed, cannot provide such a foundation.

Furthermore, just as the different kinds of conceptions of the human are not alternatives for each other, the different argumentative functions should not be considered to be alternatives for each other. They do not make the same contribution to the moral judgment, but come into play at a different point in the process of moral reasoning. An account of human nature can only be decisive in relation to a moral issue in a foundational role. Whereas a conception of human nature in a foundational role is sufficient to argue for a moral judgment, a scope can only specify some aspects of a moral judgment. The indirect argumentative functions cannot be neglected, but, at the same time, they should also not be overrated in terms of the importance of the outcome.

In addition, it is possible to use several conceptions of the human in a moral judgment. For instance, an analysis of innate traits can be combined with an account of the inherent dignity of the human being. As long as different understandings of being human do not contradict each other, this is unproblematic. If it is possible to employ several conceptions of the human being, is it necessary to incorporate any conception of the human being at all? Depending on the moral issue in question, it might be possible to avoid naturalistic or metaphysical conceptions. However, I argued that for all kinds of moral judgments we are in need of a moral theory or at least moral principles. As moral theories entail normative-v conceptions of the human, this means that we cannot make any moral judgments without using these kinds of conceptions. Even if a metaphysical conception, for instance, is employed as a specification, an argument also has to exercise a normative-v conception. Being human and what makes us human is not only a question of fact, but a question of value, and it is of fundamental importance for what we should do. This means that debating about a notion of human nature in ethics has to involve a normative perspective. At least implicitly, we take up such a perspective whenever we are making moral judgments. Hence, we cannot stay neutral on a normative-v conception of a human being. As concluded in chapter two, such a conception is difficult to argue for.

The most important outcome of this discussion, however, I submit, needs to be derived from the application of this theoretical framework to debates in bioethics and applied ethics. But one cannot judge the suitability of something before it has been tested. The usefulness of the different distinctions and clarifications will be clear if they prove helpful or even necessary in relation to real ethical problems. Therefore, I want to apply the theoretical framework to three different bioethical debates in the following part of the thesis, in chapters four to six. In chapter four, I will analyze the Ashley treatment, which relates to the case of a severely disabled girl. Ashley received a controversial medical intervention to keep her child-sized and to restrict her biological development as a female, with the intention of improving her long-term quality of life. Chapter five elaborates a common assumption in debates about disability. In this chapter, I aim at finding out what implications a ‘model of disability’ has for the question of what justice for disabled people entails. In chapter six, I analyze the debate about designing children.

Part III – Case Studies

Chapter 4

The Ashley treatment²⁷

Ashley is a girl with severe cognitive and physical disabilities. Her last name was never revealed for reasons of privacy, but her first name is by now “synonymous with the debate about the acceptable limits of medical intervention in the care of disabled people” (Pilkington 2007). Ashley has been diagnosed with static encephalopathy. This means, roughly, that she remains at the developmental stage of a three-month-old child. Her parents describe her as follows: “Ashley cannot keep her head up, roll or change her sleeping position, hold a toy, or sit up by herself, let alone walk or talk. She is tube fed and depends on her caregivers in every way” (Ashley’s Mom and Dad 2012, 1). Ashley cannot talk, but she does vocalize and smile in response to others. Her parents are not sure she recognizes them. Even though the reason for her developmental delay is unclear, no significant future improvements of her capacities are expected. Despite her profound disability, she is expected to live a full-length life and was also expected to attain an adult’s weight and height. However, when she was six years old, her parents started a controversial treatment, now known as ‘the Ashley treatment.’ The treatment included growth attenuation through high-dose estrogen therapy to keep her child-sized, a hysterectomy (surgical removal of the womb), and breast bud removal (Gunther and Diekema 2006, 1014). The aim of the treatment was, as her parents continually maintain, to provide Ashley with the best possible quality of life (Ashley’s Mom and Dad 2012, 3).

The treatment was conducted as planned and was, according to Ashley’s parents and physicians, a great success (Pilkington 2012). Yet the first publi-

²⁷ A slightly revised version of this chapter has been accepted for publication in *Bioethics*.

cation about the case in 2006 sparked an outburst in the media: outrage from disability rights activists on the one hand and support from families with severely disabled children on the other. Academic discussions about ethical perspectives followed. The case has raised a vigorous ethical controversy.

This chapter starts from the observation that the debate on the Ashley treatment does not include a careful philosophical analysis of the positions that are defended in this debate. Yet this philosophical analysis is essential for a good understanding of the different ethical positions, as I will show in this chapter. Proponents and opponents of the Ashley treatment debate often fail to make their underlying assumptions explicit. In addition, it is also frequently unclear how the arguments proceed exactly, and hence it is difficult to judge whether they are sound. To give just one example, it is striking that a number of authors—who are either for or against the treatment—discuss the Ashley treatment as a package of the threefold treatment of the hormone treatment, the hysterectomy, and the breast bud removal (Asch and Stubblefield 2010; Brosco and Feudtner 2006; Edwards 2008).²⁸ However, the three different interventions subsumed under the heading ‘the Ashley treatment’ demand a differential analysis and judgment. Deciding to use skin patches to keep someone at their current height and weight involves different considerations than deciding for a surgery that leads to infertility. It is possible to argue that one intervention is morally permitted whereas the other might not be. Not all authors separate these points. This is unfortunate because a more detailed analysis of the philosophical issues could be helpful for caretakers of children in a similar situation to Ashley who wonder about how best to take care of them.

I will show what form good arguments for and against the treatment could take. By doing so, I develop the philosophical context in which the empirical facts regarding the case can be interpreted. I focus on a family of arguments for the treatment based on quality of life (section 2) and a family of arguments against it from a perspective of dignity and rights (section 3). I will argue that arguments about the case have to make controversial assumptions about our relationship to our body that are in need of further discussion. In the debate as it stands, these arguments stay mainly implicit. This is unfortunate because crucial issues cannot be brought to light if these aspects of a normative conception of the human, as I will identify them, are ignored. I will make these assumptions explicit, discuss their role for the moral judg-

²⁸ Asch and Stubblefield, as well as Brosco and Feudtner, only analyze growth attenuation, but they derive a judgment about the Ashley treatment from an analysis of growth attenuation. Edwards bundles the different aspects of the treatment together.

ment on the case, and show which implications they have under which conditions.

The Ashley case is at this point an interesting case for my dissertation because aspects of both disability and enhancement play a role. Without a doubt, Ashley is a severely disabled person. But her treatment is not a straightforward medical treatment. It goes in some sense beyond medicine as traditionally conceived and could also be understood as a form of enhancement.

The Ashley case is a specific individual treatment decision, and its many particular details are decisive for a sensitive moral judgment. The more our judgments regarding a moral issue hinge on specific particularities of the case, the more attention needs to be paid to considering those details. In the Ashley case, it is especially important to do justice to the many specific characteristics of the case, more than, for instance, to the analysis of a rather general moral issue. For this reason, I do not want to extract the specific particularities of Ashley's situation in my analysis. The theoretical framework, which was developed in chapters two and three, will, therefore, only be applied carefully. The theoretical framework is less central in this chapter than it is in the preceding chapters, five and six, where it moves more to the forefront of the application. In the analysis of the Ashley treatment, the framework plays only a limited and rather implicit role. But as we will see, the analysis of the Ashley treatment will clarify the meaning, relevance, and implications of some of the theoretical distinctions developed in chapters two and three.

1 The debate

The Ashley treatment was published first in a medical journal at the end of 2006 by her attending physicians. By then, Ashley had already gone through surgery a couple of years before and was almost finished with the growth hormone treatment. The case was published as an attempt to introduce the Ashley treatment for children in a similar situation and was therefore entitled 'A new approach to an old dilemma.'²⁹ Shortly after the publication, the well-known disability rights scholar Tom Shakespeare posted a cynical negative

²⁹ The article made no reference to the breast bud removal. This was, as the authors declared later on, because they wanted to focus on the growth attenuation therapy as beneficial for children with similar disabilities to Ashley instead of on the threefold treatment that Ashley received. It was, however, necessary to mention the hysterectomy because if this surgery is carried out, major side effects of hormone therapy, such as the development of malign tumors, can be avoided.

reaction on a BBC blog (Shakespeare 2006b). In January 2007, discussions in newspapers such as the *Guardian* and in *Time* followed. Other bioethicists joined in the discussion with Arthur Caplan, who argued against the treatment on a weblog (Caplan 2007) and Peter Singer, who supported it on an opinion page in the *New York Times* (Singer 2007). At this point, Ashley's parents decided to set up a weblog about the treatment to make clear what their intentions were and to provide information on the treatment for parents of children in a similar situation. Many more reactions, in newspapers and weblogs, medical journals, journals in ethics, and those at the intersection between both, and from families in similar situations, disabled people themselves, medical practitioners, ethicists, and philosophers followed. A few years later, two bioethicists involved in the case offered a defense of the treatment by discussing an impressive number of critical arguments (Diekema and Fost 2010). As Tan and Brassington rightly evaluate: "Although the intensity of reactions both for and against growth attenuation therapy suggests that an ethical dilemma may be involved, the source of the issue is not unequivocal" (Tan and Brassington 2009, 659).

What is the debate about? In this section, I will sketch an overview about the discussion to show the direction in which it is going. I do not aim at comprehensiveness, but rather at trying to prepare the ground for a deeper investigation of some of the arguments in the debate in the next part of the dissertation. I refrain from judging the arguments made by both sides, but merely aim at reconstructing them. I will present the overview as a debate, that is, as a question-and-answer session between the proponents and opponents of the treatment.

The treatment was mainly motivated by the wish *to improve Ashley's future quality of life*. Authors argue that the treatment will eventually be beneficial for her if harms and benefits are balanced (Ashley's Mom and Dad 2012; Gunther and Diekema 2006). They describe how keeping Ashley at the height and weight of an infant of approximately 1.30m and 30kg respectively will allow one person to carry Ashley instead of two or having to use assistive devices. This will also keep her moving. It contributes to her health in terms of better blood circulation and gastrointestinal function, the motion of her joints, and less danger of infections caused by her being bedridden. It also contributes to her well-being as she apparently enjoys being taken on trips, being with her family, being held in someone's arms, being in a swing, and being in the bath (Ashley's Mom and Dad 2012, 8). In the view of its defenders, a further substantial benefit of the growth attenuation is that it will make it possible for parents to continue caring for an older profoundly disabled child at home (Gunther and Diekema 2006, 1016). As many testi-

monies on Ashley's website passionately indicate, parents understandably struggle to care for their severely disabled children as they grow to adult size and weight. With the treatment, the children stay child-sized, which would give parents the opportunity not to put their child in an institution, but to continue with home-based care. The removal of the breast buds lets Ashley's chest remain flat and, according to her caretakers, avoids uneasiness about lying down and being strapped in a wheelchair with the big breasts that she was likely to develop given her family history. As it is about a benefit-harm balance, the harms, authors argue, are minimal in this case. What the hormone therapy actually does is speed up puberty. That means that it leads to the stagnation of the growth of the body and the development of the womb and breasts, as happens in puberty. Because this process is speeded up, there is a greater risk of developing a tumor in the womb. This is one of the reasons for the hysterectomy that was performed on Ashley before the hormone treatment started. The main reason for this part of the intervention, according to Ashley's parents, is that it frees her from menstrual pain and cramps. These benefits, they argue, are greater than the harm induced by the surgery. Thus, on balance, this treatment would provide Ashley with the highest possible quality of life, given her situation.

Against this argumentation, opponents argue that Ashley was only *used as a means for the convenience of her caregivers*. Making it easier to carry her would not be an advantage for Ashley, but solely an advantage for those who take care of her (for example Bennett 2009; Coleman 2007; Ellis 2007; Sobsey 2010). It would certainly still be possible to move Ashley as a full-sized woman and include her in social activities, but it would be more difficult for those doing it. The intervention is not a benefit for Ashley, but only for others. This renders the interventions illegitimate. It is not permissible to impose such a radical intervention on one person to make the job of another person easier (as discussed by Tan and Brassington 2009, 659).

Again, proponents counter that the *interests of the parent and the child are intertwined* (Allen et al. 2009; Diekema and Fost 2010; Singer 2007; Solomon 2012). Ashley is thus not used as a means for the convenience of her parents, even though the treatment is also for their benefit and not solely for Ashley's benefit. Authors argue that is difficult to separate whose interests are being served. What is good for one is also good for the other. Their interests are thus congruent: "the line between improving Ashley's life and making it easier for her parents to handle her scarcely exists, because anything that makes it possible for Ashley's parents to involve her in family life is in her interest" (Singer 2007).

Closely connected to the question of whose interests are actually served by the treatment is the accusation of opponents that the treatment would be *an attempt to infantilize Ashley* (Shakespeare 2006b). After all, she will stay child-sized and her body will look like the body of a child because she is small and has no breasts. Caregivers will also not have to deal with menstruation. They will feel as if they are not caring for a woman, but for a child.³⁰ It might give caretakers a better feeling about their job, as Shakespeare frames it (Shakespeare 2006b). At least for most people, it is easier to change the diapers of a child than those of an adult. However, even if it is acknowledged that this treatment is infantilization, it needs to be shown why this makes it wrong. This remains unclear in the literature. I see two main possibilities for making this argument: it could be argued that infantilizing is wrong because it would only be in the interests of Ashley's parents and thus Ashley would be used as a means, as shown above. It could also be argued that infantilizing Ashley violates her dignity, rights, or a combination of both.

This is a fairly common argument made by opponents of the treatment. They make the case that the treatment is *incompatible with Ashley's dignity and/or that it trespasses certain rights*, such as rights to bodily integrity or rights to grow and develop (Coleman 2007; Edwards 2008; Kittay and Kittay 2007; Kittay 2011; Smith 2012; Sobsey 2010). At this point, I will only provide a very broad (and certainly not satisfactory) overview of this line of argumentation. Some authors argue that human rights are grounded in dignity. Treating a person accordingly, then, includes providing someone with the means to reach their full potential (Coleman 2007) or treating people "as human beings with their own agency" (Smith 2012). The Ashley treatment would be an instance where this is not safeguarded (how this works exactly still needs to be seen). Some authors, in a way that is compatible with this interpretation, or is in addition to it, try to interpret legal human rights instruments and argue that, for instance, the treatment is not in accordance with certain articles of the UN Convention of the Rights of the Child (CRC) or of the UN Convention of the Rights of People with Disabilities (CRPD) (Sobsey 2010). Others argue that all living beings have a species-specific dignity that is somehow linked to their body and would thus not allow the kind of body modification that happened in Ashley's case (Kittay and Kittay 2007; Kittay 2011). I will analyze these kinds of arguments below in section 3 more extensively.

³⁰ Keeping Ashley small forever will of course not keep her young forever. Ashley will age and this will also be visible, for example in her face. In pictures on her website, it is visible that by the time she is a teenager, the childishness of her face has faded.

Proponents of the treatment hold against considering rights or dignity that it does not make sense to talk about in terms of rights of bodily integrity or the like. Ashley cannot value growth and sexual maturity and whatever comes with it because she *cannot make use of those functionings that were taken from her* (Diekema and Fost 2010; Solomon 2012; Spriggs 2010). Regardless of her size and degree of sexual maturity, many opportunities that are normally connected to these qualities that were taken away remain in any case unavailable to her. As Diekema and Fost explain:

“Most of the usual features that distinguish a woman from a girl—the opportunity to marry, procreate, work, lead an autonomous life—would not have been available to Ashley with or without a uterus, fully developed breasts, or normal stature.”
(Diekema and Fost 2010, 34)

Ashley clearly lost attainments that most other people develop during the life cycle, but, as some authors argue, these features are only valuable because they allow us to do other things. This means that they only have instrumental value. However, those values for which these features are a surrogate would in any case be impossible to reach for Ashley. Hence, she does not need these functionings and might even benefit from not having them.

Critics argue that *this instrumental approach to the body is essentially wrong* (Kittay and Kittay 2007; Kittay 2011). Eva Kittay states that “we cannot attend to the body without attending to the person, and we cannot care for a person without attention to their bodily integrity and well-being” (Kittay 2011, 616). According to this point, our body belongs to what constitutes who we are. That means that the body does not just have a certain function for the individual, for instance being a surrogate for other values, such as being a source of pleasant and painful experiences. The body needs to be valued as someone’s body. Respecting someone’s bodily integrity should go beyond valuing her or his bodily functionings. Thus, all kinds of developmental changes of the body, such as growth and puberty, should be accepted as they are whether or not they allow us to do other things.

Linked to these discussions about the value of the body and the question of rights and dignity is the more fundamental *question of moral status*. Proponents of the treatment counter arguments that refer to rights, dignity, and the inherent value of the body by arguing that Ashley and others in a similar situation need to be treated according to a different standard because they are fundamentally different morally (Singer 2007; Tan and Brassington 2009). That is, because of their different moral status, considerations of

rights, dignity, or an inherent value of the body that might or might not apply to other persons are in any case meaningless in Ashley's and other similar cases. Peter Singer, who in every sense does not find dignity in the sense of an intrinsic and unconditioned notion a relevant concept, states very clearly that he accords a different moral status to Ashley: "she is precious not so much for what she is, but because her parents and siblings love her and care about her" (Singer 2007). For him, Ashley's moral status, that is, to what extent she is to be taken into account morally, is derived from the way in which others value her. Therefore, she can be treated according to a different standard than is used for other persons.³¹ It is clear that an argument needs to be put forward about why Ashley has a different moral status, that is, on which attributes moral status in general is based and why she does not fulfill these criteria. I will here only briefly elaborate on it. Quite a common argumentation strategy, first used by Immanuel Kant, is to employ capacities of agency and autonomy to argue about why someone has a special moral standing. In her case, one could argue straightforwardly that whatever agential capacities are, she clearly does not have them, and thus she has a different moral status that deserves a different treatment (Tan and Brassington 2009, 659/660).

However, opponents' criticism is that Ashley might have *more cognitive capacities or develop them*. Therefore, one could not argue that she has a different moral status and needs to be treated according to a different standard. Authors argue either that Ashley might be more self-aware than we think (Asch and Stubblefield 2010, 47) or that her physicians underestimate her potential development (Bersani 2007, 521). Even though all professionals involved in the case agree that Ashley's development will not proceed, and even though her parents look continually for any signs of cognitive functionings, authors argue that there is still a chance, albeit a small one, that Ashley will gain cognitive and motor functionings. Obviously, most, if not all, decisions for and against medical treatments are made under uncertain conditions facing the risk that things develop differently than expected. However, it seems that here this uncertainty is considered such a fundamental problem that the intervention should not be conducted.

Other arguments raise objections against the treatment, not on an individual level, but on a social level. The outrage of disability activists can at least partly be explained by referring to the *potential for misuse* (Bersani 2007; Ellis

³¹ This ascertainment is perfectly compatible with treating two beings differently even though they have the same moral status. Having the same moral status only means being taken into account morally to the same degree, but that can mean different things if background considerations are different.

2007). People with disabilities face a history of forced sterilizations in the nineteenth and twentieth centuries. The people affected were able to live independently and to make the decision to raise children, yet it was considered not to be in the interest of society to have them pass their ‘defects’ on. Against this background of eugenics, the fear of stepping on a slippery slope is raised. If the treatment is justified for *one* disabled person, it might soon be available for all disabled people even if the nature of their impairment is fundamentally different. It is clear that the treatment is not justifiable for a person with a mild cognitive impairment, because in such a case, more is lost than gained. Authors argue that it would be impossible to establish a threshold between cases in terms of when the treatment is allowed and when it is not. Therefore, the treatment should be forbidden.

Another, and maybe even more common, objection on a social level sees the Ashley treatment as a *medical response to a social problem* (Caplan 2007; Goering 2010; Shakespeare 2006b; Stein 2010). In one of the first reactions on the Ashley treatment, Arthur Caplan argues that

“a decent society should be able to provide appropriately sized wheelchairs and bathtubs and home-health assistance to families like this one. Keeping Ashley small is a pharmacological solution for a social failure—the fact that American society does not do what it should to help severely disabled children and their families.” (Caplan 2007)

The idea is that other options should be available to relieve Ashley and her family, but against a background of a lack of sufficient social services, Ashley’s family is more or less forced to choose invasive measures. However, considering Ashley’s profound disability, it is questionable to what extent social change will be able to resolve all of the problems that Ashley and her family are facing. Yet, as some authors argue, at least some changes should be made that would make the Ashley treatment at least less attractive to concerned parents (Goering 2010, 54).

More arguments from the literature could be set out, but I hope that this suffices as a short (though much too quick) overview about the discussion of the case. For the remainder of the chapter, I will focus on two central families of arguments in the debate, namely arguments defending the treatment based on quality of life considerations (section 2) and arguments against the treatment based on dignity and rights considerations (section 3).

I choose these two families of arguments because they both play an important role in the debate on the Ashley treatment. As I reconstruct the debate, these are the two central kinds of arguments on which it hinges. Starting somewhere in the middle of my reconstruction, the accusation that the treatment causes *infantilization* can be understood in two ways: either this is problematic because it is a violation of *dignity and rights* or because it shows that the treatment is only for the benefit and in the *interests of Ashley's caregiver*. To follow up on the latter, one could discuss to what extent Ashley's interests and the interests of her caregivers are *intertwined*. However, these two arguments are only relevant if one is prepared to assume that interests and benefits, or, in general, *quality of life*, are what we should look at in this case. Thus, arguments about quality of life play a central role.

Similarly, if one thinks that infantilization interferes with *dignity and rights*, one can dispute how rights and dignity should be understood and what the scope of such rights is. Here, the argument that Ashley can make *no use of these functionalities* comes into play, which denies that considerations of rights are applicable in this case. Likewise, the argument that such an *instrumental approach to the body* is wrong holds that these considerations are in any case nonetheless applicable. Yet both of the last two arguments are only worth mentioning if thinking in terms of rights and dignity is considered the correct approach. Arguments about *moral status* could be understood as a generalization of dignity arguments. Having dignity describes in this case a specific high moral status (but not every author who works with the concept of moral status needs to employ the term 'dignity' at all).

2 Quality of life

The contribution of the treatment to Ashley's quality of life is still one of the main kinds of arguments discussed. Being smaller and lighter will make it easier for Ashley to be carried around and will keep her moving. She will have no menstrual cramps or uneasiness about lying down with the big breasts she is likely to have had. In comparison to these benefits, the operation that is necessary for the treatment would induce only a small harm according to proponents of this line of argumentation.

Most of this discussion revolves around the question of whether the treatment did indeed improve Ashley's quality of life (Ashley's Mom and Dad 2012; Diekema and Fost 2010; Gunther and Diekema 2006; Singer 2007). Yet there are many different conceptions of 'quality of life.' To make a dis-

discussion about quality of life possible, it needs to be clear which particular conceptions are referred to. Only then, as the next step, can it be evaluated whether the treatment contributes to quality of life. Which of these notions of quality of life is used in the Ashley debate has so far not been sufficiently clear. I would like to fill this lacuna. Furthermore, I would like to reflect on the fundamental assumption of this type of argument that quality of life should be the decisive reason that is employed in making a decision about the treatment. As quality of life is predominantly cited to argue in defense of the treatment, I will also focus on that side of the debate.

Arguing for the Ashley treatment based on quality of life considerations has to start by explaining why quality of life should be the decisive reason in the first place. How could such an argument proceed? Clearly, the decision to undergo or forego the treatment cannot be left to the patient as is commonly required in the name of ‘informed consent,’ because Ashley is unable to make her own decision (for a discussion of informed consent see Eyal 2012). Therefore, her parents have to act as guardians. They cannot reflect on Ashley’s values and way of life to make a decision that she would agree with because she has never been autonomous, not even in a minimal sense. However, Ashley has certain interests, at least an interest in avoiding pain, and she enjoys certain things, such as being cuddled by her parents and siblings. The best her parents can do is to protect her interests and make a decision for her regarding what is in her best interests.

This still leaves open the question of what best interests, well-being, or quality of life specifically mean for Ashley.³² If we act in line with the best interests standard, this is defined as “acting so as to promote maximally the good of the individual” (Buchanan and Brock 1989, 88). Yet this definition still leaves open what ‘the good’ in this case is. The notion of interests is open to different interpretations, generally called subjectivist and objectivist interpretations (Archard 2011, section 7). Subjectivist interpretations refer to what the child would choose for herself under specified hypothetical circumstances. However, we know nothing about Ashley’s except that in all likelihood she will stay in the same condition as she is in now and has always been. Therefore, we are left with an objectivist interpretation of interests that refers to what is best for her independent of her choices in hypothetical circumstances. But what is it that is best for Ashley?

In the philosophical literature, three prominent accounts of well-being are discussed (Parfit 1984, 493–502): hedonistic theories, desire theories, and

³² These terms are interchangeable here (Schües and Rehmann-Sutter 2013, 198).

objective list theories. I will examine all three theories in turn to see how they specify the well-being of someone like Ashley, and what each of these particular accounts of well-being imply for arguments defending this treatment.³³ The analysis that I will conduct here is a matter of specifying a moral principle as defined in chapter three, section 2.3.

First, hedonistic theories determine well-being in terms of mental states, that is, in terms of experiences of pleasure. A good quality of life is understood as a positive pleasure-pain balance. In that sense, Ashley might have a good quality of life as she can apparently experience pleasure in terms of enjoyable activities such as being on a swing or having a bath. Ashley can also experience physical pain. What does it mean, then, to apply a hedonistic theory to this case? Even though the best interest standard is sometimes discussed in the literature as *maximizing* the fulfillment of someone's interests, it is commonly not understood as such (Kopelman 1997, 283). For example, it does not seem reasonable to ask Ashley's parents to quit their jobs, leave their country, and move somewhere else only because a different climate might be slightly better for Ashley. This introduces a difficulty for the best interest standard: there are often different interests at stake. First, the interests of others will at some point provide a limitation for the interests of the child. Second, interests can be intertwined, which makes it unclear for whose pleasure-pain balance they should count. Whereas the first problem is not important for the Ashley treatment, the second one plays a role. The treatment makes caring for Ashley less difficult for her caregivers. It is sometimes argued that this advances the interests of Ashley's parents, but not the interests of Ashley (Coleman 2007; Ellis 2007; Sobsey 2010). Letting someone who has no power of veto undergo an operation for the sake of someone else is difficult to defend. In defense of the Ashley treatment, it needs to be argued that the treatment serves Ashley's interests at least as well. That means that the degree to which her needs are met and her interests are protected and fostered is greater in the state with treatment than in the state without treatment. It is defensible to argue that using mechanical support and pulley systems for transport to bed and bath provides less pleasure or comfort than being carried and cuddled by a parent. Even if mechanical support systems are in general available, first, they cannot support every need, such as diaper changes, positional changes at night, or being carried into a friend's inaccessible home, and second, they simply feel different compared to human arms.³⁴ It is sensible to assume that most of us prefer

³³ There is some discussion on the application of these theories of well-being in the case of children (see especially Archard 1993; Bagattini and Macleod 2014; Skelton forthcoming).

³⁴ Compare the narrative of Sandy Walker in (Wilfond et al., Seattle Growth Attenuation and Ethics Working Group 2010, 36).

human touch to mechanical support (Solomon 2012, 389/390). Besides, this argument assumes that if Ashley does not have the treatment and does indeed have to live in an institution because her parents cannot handle her care anymore, this is worse for her pleasure-pain balance. Again, though difficult to prove, this seems reasonable.

Concerning the potential harms of the treatment, Ashley will be deprived of some bodily functionings that other women have. Specifically, she will be extraordinarily small, she will have no breasts, will not menstruate, and will be infertile. Losing these functionings should not be considered a substantial enough harm to oppose the treatment. A defender of the treatment within a hedonistic account could say that Ashley will in any case not be able to make use of those functionings. Normally, a full-grown and developed body is at least advantageous, if not necessary, for doing certain things, such as having children and a sexual life or even applying for a job. Regardless of her bodily size and degree of sexual maturity, many opportunities such as these remain in all likelihood unavailable to her. Of course, we cannot completely exclude the possibility that one day, Ashley's capacities could develop and these could then be real opportunities for her. Yet despite the stimulating environment that has been provided for Ashley since her birth, her capacities remain as limited as they are and, as far as we know, they will not develop further. As Ashley has no use for growth and sexual maturity, one could argue that they have no value to her (Diekema and Fost 2010; Solomon 2012; Spriggs 2010). This means that bodily functionings have a merely instrumental value. These functionings only have a value in relation to something else, but do not have an intrinsic value. Alternatively, one could claim that these functionings do have an intrinsic value (Kittay and Kittay 2007; Kittay 2011).³⁵ Independent of the question of what use Ashley could make of these functionings, being as tall as other women and having breasts and a womb would be considered good. Clearly, a reason needs to be given as to why this should generally be the case and why this should be the case for a severely disabled child. It raises questions about the relationship between the person and the body. It is questionable what exactly the intrinsic value of functionings means and whether it can be justified. Leaving those questions aside, in order to argue for the treatment, losing these functionings should be outweighed by the benefits of the treatment. Hence, if these functionings are valuable in themselves, this has to be a relative value that can be balanced against other values, but only a comparatively low one as it is outweighed by other values.

³⁵ In the next section, I provide a more substantial analysis of the argument given by the Kittays.

Yet further argumentation will be needed. Suppose that within a hedonistic conceptualization of well-being the posttreatment state is better for Ashley than the no-treatment state. It would still need to be the case that the difference in quality of life between these two states is great enough to warrant surgical intervention, which clearly involves temporary pain and discomfort. Only if the pleasure-pain balance is positive is the treatment warranted. After all, if the philosophical analysis is accepted up to this point, more empirical information is needed to draw a definite conclusion. For example, we need to understand better how high the risk of developing a tumor in the womb as a result of the hormone treatment is and how great the risk would be of having such bad menstrual cramps that birth control pills would not be sufficient to alleviate them. Ashley's parents and doctors maintain that these are sufficient enough risks to justify a hysterectomy, but others question these empirical facts (Liao, Savulescu, and Sheehan 2007, 18). However, it is not unreasonable to believe that the empirical evidence can be supplied, which makes the pro-intervention claim based on quality of life considerations, if properly spelled out and backed up with evidence, a plausible argument.

The second set of well-being theories holds that what is best for someone is that her desires should be satisfied.³⁶ However, it is not at all clear how Ashley's desires can be determined in a straightforward way. There are certain activities that Ashley enjoys, but desires are not simply what provides one with pleasure. Desires and pleasures are conceptually distinct. Fulfilling a desire does not necessarily provide one with pleasure. For example, satisfying a desire to climb Mount Everest will most likely go together with stress and anguish, a fear of failure, and an austere experience. Desires are not valued, or at least not all desires, for the sort of experiences that result from them. Different conceptualizations of desire are discussed in the literature, but they all associate desiring with acting, feeling, and thinking in certain ways (Schroeder 2009, section 1). As far as we know, Ashley does not act or think in the relevant sense of these terms, and if she does, we have no means of having access to this. If a desire is only connected to feeling a certain way, Ashley's desires would have to be interpreted as what she apparently enjoys. The desire account would then boil down to a mere hedonistic account. That means that desire theories of well-being are not applicable to Ashley and have to be omitted.

³⁶ Christopher Heathwood discusses various problems of desire theories, most of which do not play a role in Ashley's case, for example the difference between current and future desires or hypothetical circumstances such as having full information that might change an evaluation of the situation (Heathwood 2010, 650–652).

Third, objective list theories argue that some things are good for a person independent of that person's attitude towards them. Typical items on such a list are friendship, love, and knowledge. It is possible that these things are in accordance with what one desires or what brings one pleasure, but the important difference between hedonistic and desire theories is that the 'good-maker' of items on an objective list has to be an objective reason, such as an account of human nature (see, for examples of such an account, Kraut 2007; also M. Nussbaum and Sen 1993).

Using an objective list avoids the problem of assigning certain subjective states to a severely cognitively disabled person like Ashley. Whether an objective list theory of well-being provides a reason for the treatment or not depends ultimately on the more specific conceptualization of the list. To employ such a theory to argue for the treatment, a few assumptions should be made. First, even though not all items on such a list are probably reasonably attainable for Ashley, one has to assume that at least some items are attainable for her, such as giving and receiving love, having a bond with the family, and laughing. Second, if not all items on the list are attainable for Ashley, it needs to be assumed that the merely partial applicability does not make the whole list irrelevant. It must be valuable to attain only some of the items on the list; it is not an all-or-nothing question. Third, one has to select and weight the items on the list in a way that suits the Ashley treatment. The capacities that were just mentioned would probably all be improved as a result of Ashley undergoing the treatment. Yet items such as 'having a mature body' or 'growing,' would be reasons against the treatment. If those items are represented on the list at all, they have to be weighted in a way that means that the treatment provides Ashley with a higher well-being than the choice of not treating her. Thus, they cannot be understood as absolute entitlements, but should have a relative weight and also a comparatively low one. In the aggregate evaluation, they should be discounted. Again, this means that these bodily functionings cannot be considered as having a high intrinsic value. Alternatively, these items cannot be represented on the list at all. This is the case when they are considered only to be valuable *for* something, for example, for sexual relationships, but not as valuable in themselves. In this case, they have only an instrumental value. If all this is given, the Ashley treatment could be justified by reference to an objective list.

In my analysis of the application and specification of all three theories of well-being, and I think in any reasonable analysis of well-being, Ashley's disability is central. Because she is different from other children, quality of life means something else for her. Her disability is, thus, morally significant. Importantly, the moral significance of her disability does not have to imply

that Ashley has a lower moral status. She might have to be taken into account morally to the same degree, but because her quality of life is determined by different factors due to her disability, accounting for quality of life simply means something else. I have argued that desire theories are not applicable to the case, but both hedonistic and objective list theories could be used to argue in support of the Ashley treatment if a few qualifications are made. Most importantly, both of these arguments have to assume that bodily functionings have either an instrumental value or a relative and comparatively low intrinsic value.

3 Rights and dignity

3.1 *The argument in the literature*

What do authors who think that the treatment interferes with Ashley's dignity or rights argue? Two rights are primarily taken to be relevant: a right to bodily integrity and a right to grow and develop. It is certainly correct that the treatment interferes with bodily integrity—as does Ashley's feeding tube, which is virtually never disputed for comparable severely disabled people. It is also correct that Ashley no longer grows and that her body will not reach puberty as other children's bodies do—as it is true that her body does not work in many ways like other children's bodies. Hence, it is questionable what the nature of these rights in general is and what they should protect in Ashley's case.

Eric Schmidt argues that a developmentally disabled child has only a minimal right against interference with her growth (Schmidt 2007).³⁷ He thinks that there is a right to grow and develop but that this right only exists in a weak form for cognitively disabled children. He claims that if the child does not have a personal interest in developing a body of adult size, growth may be stunted to facilitate care (provided that this is the least intrusive means to facilitate that care). This still leaves open how such a minimal right can be justified. Apparently, having a personal interest in growth and bodily development is part of a justification, but it is neither a necessary nor a sufficient condition. If this condition is no longer fulfilled, the right may be invaded under certain provisions. That means that in this situation, the right still exists in a weaker form. Yet how is this weaker right justified? Schmidt does not provide such an account.

³⁷ Schmidt argues for the Ashley treatment out of considerations of rights, and thereby represents an exception to other authors who mainly refer to rights to argue against the treatment.

Rights to bodily integrity and development are established in legal human rights documents such as the UN Convention on the Rights of the Child (CRC) and the UN Convention on the Rights of Persons with Disabilities (CRPD). Here, rights are established as an especially important rights category, namely as human rights. Some authors refer to these conventions that are signed and ratified by the vast majority of world countries (discussed by Edwards 2008, 342; Sobsey 2010, 59). In the relevant article, the CRC claims that we must “ensure to the maximum extent possible the survival and development of the child” (CRC, article 6.2), which includes, according to Dick Sobsey, physical growth and sexual development (Sobsey 2010, 59). The CRPD states that “every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others” (CRPD, article 17). Edwards and Sobsey then go on to simply claim that, henceforward, the Ashley treatment is not allowed.

Yet referring to a legal right embodied in a treaty is an authority argument: it is not a philosophically robust argument, since, as far as we know, some rights protected by such treaties may not be morally defensible in the way stated in those conventions and declarations. Nevertheless, moral rights might be in need of a legal implementation to be effective. Yet, in order to provide a robust ethical argument, it is essential to provide an ethical justification and interpretation of these legal articles and explain why exactly the Ashley treatment is incompatible with them. Why, for example, should ‘survival and development’ be interpreted regarding developing a full-grown body instead of regarding being able to participate in social activities? And how can we understand the requirement to be ‘on an equal basis with others’ mentioned in the CRPD given that things are in a relevant sense necessarily different for profoundly disabled people? An ethical discussion of these legal articles could indeed prove interesting for the Ashley case, but simply stating the relevant articles does not provide much insight and does not amount to an argument showing that the Ashley treatment is not morally allowed.

A discussion about human rights is often linked to a discussion about dignity. This can also be observed in the debate about the Ashley treatment (Coleman 2007; Smith 2012; Kittay 2011; Kittay and Kittay 2007). These authors do not clarify the relation between rights and dignity, but they explain that certain normative requirements follow from dignity and rights. They argue that having dignity and human rights means being treated “as human beings with their own agency” (Smith 2012) and being provided with the means to reach one’s full human potential (Coleman 2007). How can these claims be understood?

First, it is questionable how someone like Ashley can be treated as having agency. Normally, treating a person with regard to her agency is understood as being allowed to make autonomous decisions about one's life without manipulation or interference and to live one's life in accordance with motives and reasons that are one's own. This presupposes that someone is an agent. There is philosophical disagreement on the question of what exactly autonomy or agency is and what conditions need to be fulfilled to have it. Yet whatever epistemic criteria are used to determine agency—for example, autonomy, rationality, or self-determination—it seems reasonably clear that, because of what we know, Ashley does not qualify as having agency (see also Tan and Brassington 2009, 659/660). However, it is sometimes argued that there is no need to actually possess the capacity in question, but that it is enough to stand in a suitable relation to that criterion. That means that the potential for that capacity, ever having had the capacity in question, or having it to a certain degree would suffice. Thereby, newborn infants, who will in all likelihood become autonomous, self-conscious, or rational, as well as children who are so to a degree, and people with dementia who were once autonomous and self-conscious would qualify as having human dignity. Ashley has never been autonomous and, given the description of her range of capacities, we cannot even consider that she is autonomous to a certain degree. Albeit we can never be certain that a future development of her capacities is impossible, as far as we know her capacities will remain unchanged. Hence, Ashley does not stand in a relation to any of the proposed cognitive or psychological criteria. It would be quite astonishing to believe that Ashley should be treated according to her own agency if she lacks agency.

Second, it is similarly dubious why providing Ashley with the means to reach her full human potential (Coleman 2007) would mean being against the Ashley treatment. At no point does Coleman explain what he means by this statement. If 'full human potential' consists in a grown and sexually mature body, then she has been deprived of the opportunity to reach that potential. However, due to her condition, her body and mind do not function according to this dubious criterion of 'full human potential,' which is understood in many different ways. What this potential should be 'potential for' in her case is another question. As I argued earlier (see section 2), many opportunities such as having a sexual life or deciding to have children are in all likelihood not available for Ashley regardless of the treatment decision. It is difficult to say that Ashley can make use of having a tall and mature body. In another interpretation of full human potential, one could argue that full potential is exactly what her parents are trying to develop by providing her with the

treatment. They aim at exposing her to physical contact, activities, and social contact, and relieving her from discomfort. These are all very human needs, and the treatment is providing her with the potential to have those needs and interests met. Coleman's account thus hinges on the interpretation of full human potential. Without giving an explanation of and justification for why this potential is good and what it is good for, his argument cannot convince.

Eva Feder Kittay and Jeffrey Kittay employ a conception of dignity to argue against the Ashley treatment. They claim that "all individuals have intrinsic worth, the source of their dignity" (Kittay and Kittay 2007). Intrinsic worth seems to be different from dignity if intrinsic worth is the source of dignity. But what is it, then, that makes for intrinsic worth and, accordingly, dignity? This is left open. Furthermore, they argue that there are different kinds of dignity for different species. Even an elephant can have dignity, which is, however, a different kind of dignity from human dignity. This makes it even more difficult to specify a conception of dignity and reasons for attributing dignity. They at least make it clear that intellectual capacities are not the right place to search for it, but this leaves many questions open.

Concerning the normative requirements that follow from having dignity, the Kittays, letting the body be as it is or at least not engaging in extensive body modification, see it as a normative consequence of dignity. Eva Kittay argues that bodily integrity is an intrinsic good (Kittay 2011, 620). It is not decisive whether someone can make use of her bodily functions, such as an ability to procreate. Kittay writes: "We take pleasure and pride in our bodies as they grow and mature because ... we do. Full stop. It needs no further justification" (Kittay 2011, 621). Our bodies are constitutive of ourselves. If we treat the body as an instrument, we treat the person as an instrument. On the other hand, valuing bodily integrity is not equivalent to never invading the body. A broken leg should be operated on and a tumor removed. If imminent danger to life, health, or function—however these concepts are precisely understood—is present, an intervention is justified (Kittay 2011, 618).

This account is employed as an argument against the Ashley treatment. Ashley could survive without the treatment, and Kittay also seems to assume that her health and function were not (sufficiently?) affected to justify the Ashley treatment. According to Kittay, attention to Ashley's thriving, flourishing, and well-being would have been possible, even though maybe more difficult, without the treatment (Kittay 2011, 619). Yet it remains unclear at what point a body modification is allowed or even obligatory and why this is not the case for Ashley. Claiming this requires a more specific conception of

human flourishing and the role of the body in human flourishing than Kittay provides.

To conclude, so far none of the arguments against the Ashley treatment based on rights and dignity convince. The arguments that I have analyzed leave many questions open and are not sufficiently developed to make a case against the treatment. One would expect an account of human dignity and rights to be provided and an explanation of why Ashley qualifies for them and to what extent dignity and rights are violated by the treatment. To be fair, such an elaborate argument cannot be expected from parents who are blogging about their disabled children or newspaper reporters who write a short note on the case or on the controversy. But it is reasonable to expect such robust analysis from ethicists who get involved.

3.2 What should a dignity- and rights-based argument look like?

To test the plausibility of an argument against the Ashley treatment based on dignity and rights, the argument should be presented in its strongest possible form. I will, in this section, develop such an argument and then critically analyze it. This will allow us to judge the validity and plausibility of this argument. I conclude in my analysis that it is indeed possible to construct an argument against the Ashley treatment based on rights and dignity. However, for this argument to work, one needs to make certain controversial assumptions about human embodiment and its role in social practices.

An argument against the Ashley treatment in terms of dignity and human rights would have to discuss and justify

- why Ashley has dignity
- the relation between dignity and human rights
- which specific rights are concerned in this case
- why these are human rights
- how and to what extent the treatment does not respect those rights.

Initially, two general points concerning my approach are that, first, even though not all authors talk in terms of (moral) human rights rather than only rights, I assume that the vocabulary of human rights as especially important rights that human beings have as human beings is adequate (and maybe also what most authors mean). Second, I am referring to a will theory of rights rather than an interest theory. Will theorists maintain that rights protect the will. Rights are seen as giving the right's holder control over another's duty. Interest theorists hold that rights promote the holder's interests (for an overview of different right theories see Wenar 2011, section 2.2; Kramer 1998). I choose a will theory because the reference to human dignity is commonly used within such a theory of rights.

There are several possibilities for according dignity to Ashley.³⁸ First, one could argue that Ashley has the relevant capacities (call these *dignity-capacities* or *dignity-c*). A common argumentation strategy is to refer to various cognitive or psychological attributes that give one dignity: autonomy, rationality, self-determination, the capacity to act for reasons, and self-consciousness, etc. Given Ashley's severely limited capacities, it seems reasonably sensitive to argue that whatever that capacity is, Ashley does not possess it despite all the efforts of her caretakers to develop her capacities. In addition, she does not even stand in a suitable relationship to agency because, unlike babies and small children, as far as we know she is not expected to acquire it and, unlike people in a coma or demented people, she has never had it in the past.³⁹ Ashley has no *dignity-c*.

Second, Ashley could be granted dignity because she is a human being (*dignity-species* or *dignity-s*). This is a biological criterion of species membership. That is not to say that species membership alone provides the ground for normative claims. Such an argument would fall prey to the famous counter-argument provided by Peter Singer, who explained in what sense the special treatment of a certain biological species is not any better than racism or sexism (Singer 1975). Rather, a further reason needs to be provided as to

³⁸ The different criteria were introduced in chapter three, section 2.4.

³⁹ In addition, more sophisticated accounts that refer to capacities are proposed in the literature. Agnieszka Jaworska and Julie Tannenbaum, for example, also argue that Ashley has a higher moral status—yet not necessarily full moral status—than an animal that is cognitively similar to her. This is due to the value of her capacity to engage in certain activities within a person-rearing relationship. These are activities that model what a self-standing person does and are transformed by the person-rearing relationship into an incomplete realization of what a self-standing person does (Jaworska and Tannenbaum 2014). To my mind, their account seems promising concerning the moral status of small children and babies, but it is unclear to me why, as they argue, “Ashley’s flourishing involves her becoming an SSP [self-standing person]” (Jaworska and Tannenbaum 2014, 263). David DeGrazia also argues that their account is unconvincing (DeGrazia 2014, 550–553). A more detailed analysis of the account of Jaworska and Tannenbaum falls outside the scope of this chapter.

why species membership is normatively relevant. Sigrid Graumann argues in the following way (Graumann 2014, 487/488): certain cognitive capacities could be qualifications for having human dignity in combination with a principle of precaution that demands that those human beings who do not have the capacity in question are also included. Defining a threshold for who is and who is not included is notoriously difficult and maybe also unavoidably arbitrary. Therefore, it might be safest to include the whole species. Yet even then, it is clear that Ashley does not fall into such a gray area, but that she is a clear case of not having the criteria in question. The need to include the whole species does not automatically follow from precautionary considerations. Yet *dignity-s* might be accorded to Ashley on different grounds: allowing the establishment of a threshold for who falls within the scope of dignity on the basis of certain capacities would imply that someone or some institution has the authority to make that judgment. This could be considered too dangerous and therefore be a reason to include the whole species (Düwell 2013, 109–121). Based on this line of argumentation, one could conclude that Ashley has *dignity-s*.

There is still a third way in which Ashley could be seen as endowed with dignity. Ashley could be seen as having dignity because others recognize and value her for what she is (Williams 2006; Forst 2007). Dignity is then an attribute that Ashley has because of a social practice of recognition (call this *dignity-practice* or *dignity-p*). Here, dignity is not based within the individual, but it comes into existence because others treat and value her as having dignity. This understanding of dignity, admittedly, stretches the notion of dignity. After all, we also show care towards our pets without necessarily according them dignity. However, note that Ashley is a full member of her family just as her other siblings are. Her parents lovingly describe how she fulfills a binding role within their family and takes part in their activities. A certain attitude is taken towards her and this goes beyond an attitude that is taken towards non-human animals. At least in a charitable interpretation, Ashley has *dignity-p*.

I will bracket a discussion about the relation between human dignity and human rights and assume that dignity is understood as the foundation of human rights. Human rights protect dignity. If a being has dignity, it needs to be treated according to human rights.⁴⁰

⁴⁰ Alan Gewirth and Jürgen Habermas provide arguments which establish this relationship between dignity and human rights by building on Kantian theory (Gewirth 1984; Habermas 2010). One could argue for human rights out of different considerations, and one could argue that having dignity has normative implications that cannot be grasped in the language of human

Next, it needs to be clear which specific rights are relevant in Ashley's case. The main aim of the treatment is that Ashley does not grow or mature bodily. To argue against the Ashley treatment, one would therefore have to establish the right to grow and the right to develop to sexual maturity. On what grounds could these rights be human rights? I assumed earlier that human rights protect dignity. The justification of specific human rights thus refers to a specific conceptualization of dignity. I argued above that there are two possibilities for granting Ashley dignity. Ashley can be seen as having *dignity-p* and as having *dignity-s*. I will consider the implications of these two options in turn.

First, Ashley has dignity in the sense of *dignity-p* because others value her as what she is and their attitude towards her reflects this. Human rights should protect this social practice. This means that the social practice is considered valuable. Something must make this practice normatively good. There are two possibilities. Firstly, Rainer Forst argues that the practice of recognition is self-evident (Forst 2007, 70). It is inherent in the concept of a human being that it needs to be treated in a certain way, but this is not something we can provide arguments for. As such, the practice is ultimately groundless. Consequently, Forst does not provide further reasons for it, nor does he believe that one *should* provide reasons for it. Admittedly, this approach cannot convince those who do not believe in the social practice, and can hardly be seen as an argument for it. Secondly, one can argue that the social practice has a normatively important aim and is therefore valuable in itself. Axel Honneth holds that a praxis of recognition is important for the development and maintenance of a person's identity (Honneth 1996). This praxis is a precondition for self-realization: "the conditions for autonomously leading one's own life turn out to be dependent on the establishment of relationships of mutual recognition" (Anderson and Honneth 2005, 131). Leaving out the question of whether this is an empirical or a normative claim or a combination of both, the argument still does not seem to hold. Even if it is accepted that the development and maintenance of identity is important, we do not accept everything that contributes to this aim. If a social practice is in itself repugnant, its aim does not make it acceptable. If a violent drug-dealing gang has a social practice of only considering someone a recognized and valued member of the gang after they have raped a few young girls, and

rights. But this will not be the subject of my concern. In addition, here, I rely upon a non-comparative notion of dignity instead of a social-comparative one (see for the distinction Buchanan 2010, 690/691). A non-comparative notion of dignity argues that being treated in certain ways is not fitting in terms of the kind of beings that humans are. In a social-comparative sense, on the other hand, an affront to dignity is understood as being wrongly relegated to a position of inferiority in comparison to others. This latter notion is not at stake in the Ashley case.

if belonging to that gang helps to develop and maintain an identity, this does not mean that we approve of the social practice of the gang. It is still unclear why a social practice is valuable. We cannot make a valid argument against the Ashley treatment based on granting Ashley *dignity-p*.

Second, I argued that Ashley can be considered as having *dignity-s*. Every member of the human species would be accorded dignity in this sense because no one should be authorized to judge whether an individual falls above the threshold of a certain capacity. Even though *dignity-s* is not directly explained by reference to capacities, capacities are indirectly important. Why is this? Ultimately, which normative implications follow from *dignity-s* depend on which capacity is protected. To argue against the Ashley treatment, an argument should be provided showing that a grown and fully developed body is required to protect a life that is appropriate in relation to the relevant capacity. It does not make a difference that Ashley might never be able to live a life in accordance with that capacity due to her condition. She cannot be treated differently compared to other human beings because no one should make the decision who falls under the scope of human rights. There are three different ways to expand such an argument.

The first possibility is to argue that autonomy or self-determination is the relevant capacity and that a mature body gives one the opportunity to live an autonomous life. It is clearly convenient to have a mature body if one wants to be recognized and treated as an autonomous person. This might be sufficient reason to establish a right to such a body. Clearly, the Ashley treatment would be an immoral bodily deformation if it were administered to a non-disabled child. If no distinction should be made between Ashley and healthy children, that is, that a mature body is as good for Ashley as for every other child, then the treatment should never be morally allowed.

Such an argument runs into two problems: first, it has to explain how Ashley can be treated at all differently from other children. We think that Ashley should be treated differently in many ways. For example, her parents cannot demand that she helps to set the table for dinner as her siblings probably do, tidies her room, or gets dressed on her own. They could still provide her with a pacifier if this soothes her, and so on. Ashley is treated differently all the time because, due to her disability, she is different from other children. Hence, the treatment might be indicated for her, but not for other non-disabled children. Second, even if a right to a mature body is recognized because of its value for an autonomous life, Ashley's parents could say that in Ashley's case, other considerations are more important and that therefore the right needs to be waived. A right is not a duty; it does not need to be

exercised. In Ashley's case, there might be good reasons not to make use of it. To argue that the right cannot be waived, it needs to be shown that a mature body is not only convenient for living a life in accordance with a specific capacity, but that it is a *necessary* condition for such a life.

There is a second way to develop an argument against the Ashley treatment based on *dignity*-s: a full-grown and developed body should be a necessary precondition for living a life in accordance with a specific capacity. Not just any body can fulfill this requirement, only a mature and developed one. The only capacity that I can think of here is procreation. It seems that it is possible to do everything else, though it may be more difficult with just any body rather than a specific one. Clearly, we need a body to navigate in this world and to act, but we do not need any particular body to do so. It is only procreation that demands a particular body, namely a sexually mature and fertile female body. This argument could be used against the hysterectomy, but not against the breast bud removal and growth attenuation. More importantly, it is difficult to accept this argument given that it is probable that Ashley will never have a chance to choose to procreate. I therefore doubt that it is a truly convincing argument.

A third way to provide more detail on the argument would specify an earlier argument made by the Kittays (see above). This argument relies on the idea that the body is in general of special value for the person. Such an argument would have to claim that the person cannot be distinguished from the body because the person is essentially the body. To intervene in the development of the body, imminent dangers to life or a conceptualization of flourishing should be present. It needs to be shown that this is not the case for Ashley. The cut-off point above which intervention is allowed needs to be set so that the Ashley treatment is excluded. This could, in principle, be a cut-off point that only allows interventions to save life. But then the use of that cut-off point could no longer be justified in relation to operating on a broken leg, for example, and is thus not convincing. It might be possible to define a cut-off point in the spirit of a Boorsian account of species-typical functioning (see chapter one for an elaboration). According to Boorse's theory, health is a statistical normality of biological functions (Boorse 1977; Boorse 1997). If this is the standard according to which Ashley should be treated, one could argue that she and her body should resemble the statistically normal person as closely as possible because this is in itself valuable. This could be used to argue against the treatment as Ashley will look different and develop differently compared to the average person as an intended result of the treatment.

Yet this account has to find answers to the numerous general criticisms that Boorse's and other naturalistic accounts encounter.⁴¹

To conclude, I think that this last option is the strongest possible way to argue against the Ashley treatment based on dignity and rights. As I made clear, this argument encounters various problems and might not be convincing. For one thing, one would have to assume that statistically normal functioning is normatively valuable. In addition, I hope that it has become clear that providing such an argument requires the further development of various argumentative steps. The current literature does not accomplish this in a satisfactory way.

4 Conclusion: assumptions about the human being

I have analyzed two central families of arguments in the debate on the Ashley treatment to raise doubts about whether the debate as it stands is philosophically robust. I have shown what form good arguments for and against the Ashley treatment can take. I did not put forward a conclusive argument for or against the Ashley treatment. But I have argued that an argument against the Ashley treatment from a perspective of dignity and rights is rather difficult to maintain. On the other hand, an argument for the treatment based on quality of life seems reasonable if a few empirical facts hold, although this could not be tested sufficiently. It has become clear that both types of arguments have to make substantial and controversial assumptions concerning the value of bodily functionings. In the light of the theoretical framework, these assumptions can be understood as aspects of normative-conceptions of the human as developed in chapter two, section 2.5. A normative-conception describes what we value about being human and has a prescriptive dimension. In the discussion on the Ashley treatment as it stands, these assumptions about the value of bodily functionings remain mostly implicit. This is problematic because these assumptions need to be justified and their validity should be discussed.

Even though these two positions on the treatment depend on such controversial assumptions, the assumptions play different roles within the different kinds of arguments. For a dignity- and rights-based argument, the assump-

⁴¹ Most objections argue that Boorse's account fails in various regards concerning its general commitment to be objective and value-free (Amundson 2000; Cooper 2002b; Kingma 2007; Kingma 2010; for a helpful summary of various criticisms see Krag 2013). For further elaboration and discussion of Boorse's account, see chapter one.

tion about the necessity of a statistically normal body plays a *foundational* role. The moral objection against the Ashley treatment follows directly from the idea that a statistically normal body is essential for someone to have dignity and rights. The moral judgment is, thus, derived from a specific understanding of rights and dignity. The corresponding normative-v conception of the human being—in which the necessity of a statistically normal body is one aspect among others—is, therefore, the source of a substantial moral judgment. Such an argumentative function was developed and discussed in chapter three, section 2.1. Arguments based on quality of life illustrated a different argumentative function. The idea of an instrumental value or a comparatively low intrinsic value of bodily functionings is employed to *specify* what quality of life or well-being means in Ashley's case (see chapter three, section 2.3 for details regarding specification). If quality of life is established as the guiding moral concern, we need to understand what promoting well-being implies for Ashley and how it is related to bodily functionings.

A philosophical debate about the assumptions of the arguments is needed to provide sound recommendations for how children with severe disabilities should be treated. Thereby, aspects of a normative conception of the human play a role. I conclude that philosophy and philosophers can and should contribute more to the debate than is currently the case. Robust philosophical arguments could clear up certain confusions in the debate and support caretakers as well as policymakers in making responsible treatment decisions for severely disabled children.

Chapter 5

Disability in social policy

Models of disability have been dominant in all kinds of debates about disability. It seems that there is almost no publication about disability ethics that does not start with remarks about the social model of disability. The social model of disability, as I introduced it in chapter one (section 1.2), argues that what makes a person disabled is not some inherent trait of that person, but only the interaction between a trait of a person and the environment in which a person lives. But what, if anything, do models of disability imply for social policy regarding disability? In this chapter, I will analyze the relation between models of disability and what is considered an appropriate moral response to disability. I do not aim at finding the correct or best model of disability, but I will investigate how, if at all, models of disability relate to moral judgments about justice for disabled people.

At first sight, one would assume that there is at least some kind of relation between the question of how one views the nature of disability and how one thinks that one ought to react to the phenomenon of disability. Models of disability and social policy claims do not seem to be completely independent from each other. Consider, for example, debates about prenatal testing (Wasserman and Asch 2013, 4/5): standard justifications for this practice and the corresponding choice of a selective abortion invoke the suffering in the life of the disabled child as well as the material and psychological burden on the family. Against this, Wasserman and Asch find that critics regard the underlying assumptions about the hardship and costs of disability as false or at least exaggerated. Critics argue that disability would be close to unproblematic if only disabled people were not discriminated against by society.

That means that these authors understand themselves as subscribing to a strong social model of disability and accuse the other side of the debate of not recognizing this model as the right conceptualization of disability. Here, a different understanding of disability is thus taken to explain the difference in the normative positions of defenders and critics of prenatal testing. Similarly, in the debate about euthanasia and assisted suicide (Wasserman and Asch 2013, 6), authors argue that disabled people's request for a termination of their life can only be understood in the light of the discrimination they have experienced, the lack of information about life possibilities, and an inability to receive appropriate support. Acknowledging these reasons seems to be compatible only within a social model of disability. This is because a medical model of disability does not accord any relevance to the adaptation to the environment. In these two examples, it is the models of disability that explain the normative claims. In general, different models of disability seem to favor different moral responses to disability (see also Wasserman et al. 2011, section 2.1). The medical model seems to support a medical cure of impairments whereas the social model appears to favor reconstruction of the physical and social environments. Disagreement about how to react to disability can, then, be traced back to the support of different models of disability.

This brief summary of how one can analyze the debate explains at least partly the extensive discussion in disability ethics about models of disability. Even though some authors are clearly interested in understanding the phenomenon of disability for its own sake, many are motivated to discuss disability because they want to tackle widespread and persistent injustices against people with disabilities. The underlying idea seems to be that if only we could agree on a model of disability, we would also agree upon a social policy for disabled persons. This presupposes that models of disability have a strong force for moral judgments. Yet exactly how models of disability lead to moral judgments or indicate specific directions for such judgments to take is an open question. This is the question I want to investigate.

I will argue that we cannot substitute a discussion about moral principles with models of disability. Models of disability interact in a number of specific ways, which I will work out in detail, with moral principles to arrive at moral judgments. I reach this conclusion by applying the theoretical framework that I devised in chapters two and three. I identify models of disability as metaphysical conceptions of the human (see chapter two, section 2.3 for an analysis of such metaphysical conceptions). Subsequently, I analyze various argumentative functions, as they were argued for in chapter three, that models of disability can have. This chapter shows, therefore, in what sense

the various theoretical distinctions and insights of the theoretical framework can be necessary for a practical moral debate. Employing my theoretical framework makes clear how an important assumption made by the disability debate can be better understood and what kind of argumentative steps are necessary to raise claims of justice for disabled people.

In the first section, I analyze models of disability. In the next section, I show that reviewing the disability ethics literature gives the impression that normative claims for the social justice of disabled people follow immediately from acknowledging the social model of disability. Against this traditional understanding in the literature, I will argue in section three that models of disability cannot ground social justice claims. In section four, I demonstrate that models of disability interact in a number of specific ways with moral principles to arrive at moral judgments. I will end in section five with a critical note on the notion of ‘models of disability.’

1 Models of disability

Although this is not the place for a general discussion of models of disability (see chapter one, section 1.2), it is necessary to make a few remarks here. These remarks are not only meant as a reminder from chapter one, but also to specify key points that are important for the following discussion.

Many models of disability discussed in the literature can be arranged on a continuum between a medical model of disability and a social model of disability. I will focus on these models in this chapter as they are the most common ones in general and the most relevant ones in the context of social policy. These models incorporate two common features, as understood here by Wasserman: “(i) a physical or mental characteristic labeled or perceived as an impairment or dysfunction; (ii) some personal or social limitation associated with that impairment” (Wasserman et al. 2011, section 1). Clearly, the characterization of both features is disputed and the relationship between the two is even more so.

The medical model regards the limitations that people with disabilities face solely as a consequence of an inherent attribute of the individual. Disability is, then, explained by pointing at limitations, weaknesses, or other negative deviations of individuals. In Wasserman’s general characterization, the second feature (the limitation) is explained by referring only to the first feature

(physical or mental characteristic). This model of disability was dominant until the late 1980s.

The social model of disability introduced a change because the former approach was considered to be too limited. Social model theorists argue that what makes a person disabled is not some inherent trait of that person, but only the interaction between a trait of a person and the environment in which a person lives. It is the environment together with an impairment that disable a person. Disability is not only due to a trait of a person. The social model of disability in one variant or another has become the preeminent model for explaining disability in scholarly and advocacy work. The different social models provide different answers regarding how exactly the interaction between an impairment and the environment can be understood and what precisely the role of these two elements is. In the strong social model of disability, as I understand it, the limitations associated with disability are regarded as being caused solely by the environment, and the impairment is viewed as neutral (Silvers, Wasserman, and Mahowald 1998). A social model could thus still attribute some kind of inherent limitation to a trait of an individual. Some authors argue that what constitutes an impairment also depends on social arrangements (Amundson 2000; Tremain 2001). Others hold that impairments themselves are often limiting or difficult (Shakespeare 2006a; Terzi 2004).

Leaving these disagreements aside for now, how can we understand the general idea behind models of disability? What is it that models of disability do? Commonly, models of disability want to unify various kinds of paradigm cases of disability, such as deafness, paraplegia, or cognitive impairments, but also multiple sclerosis or autism. In general, discussing a model of disability is equivalent to discussing a conceptual framework that can be used to approach the phenomenon of disability. Specifically, models of disability describe the constitutive features of disability or how disability is caused. The underlying question of models of disability can be phrased as 'What is disability?' They are the etiological study of disability. Models of disability provide an ontological account of disability. Therefore, I want to understand models of disability as putting forward a specific metaphysical conception of the human. Metaphysical conceptions of the human were developed in chapter two, section 2.3. I argued that metaphysical conceptions make statements about the metaphysical nature and structure of human beings.

Finally, it is essential to understand that not every model of disability covers the same aspects or proceeds in the same way. Although the term 'model of disability' is a shared and common term in the literature, there is no clear

definition of what a ‘model of disability’ essentially is. Thus, what I have described up to this point is, roughly, a shared understanding that can be distilled from the literature. A model of disability is not a sharp scientific concept. It is rather a dynamic working concept that was introduced in the literature at some point and that several authors employ. In addition, as we will see, models of disability are used in academic discourse as well as in the political discourse of disability activists.

2 Impression from the literature: from a model to an imperative for change

In the literature, a prescription for reconstructing the physical environment and changing social policy and laws often follows smoothly on from a discussion of the social model (Barclay 2011, 273–277; Samaha 2007, 1267–1269). Without further discussion, a social model of disability is commonly taken to entail certain obligations of justice for society to improve the position of disabled people. Only if it is acknowledged that disability is not the result of an inherent trait of a person, and hence if it is recognized that society is at least partly responsible for constituting disability, does it seem to become possible to recognize that the state has a duty to alleviate the disadvantages of disabled people. If society has no role here, it seems to be impossible to demand that the state has to change something. This gives the impression of an obvious connection between the social model of disability and a need for social change. For Barclay, proponents of the social model often (wrongly) assume that “there is a clear normative imperative to change society once we recognize the social aspect to disability” (Barclay 2011, 275). The idea is that these elements not only fit together, but that the social model *logically entails* the social justice claims. Sometimes, this seems to be the reason why the move from a medical model of disability to a social one is regarded as such an important change.

This is how Michael Oliver, as one of the first defenders of a strong social model of disability, discusses the connection between models of disability and social policy claims in his influential book (Oliver 1996). Anita Silvers argues in the same way that “the medical model proposes to solve the problem [of misalignment between individuals and social practice] by realigning (eligible) individuals, while on the social model it is society that should be reshaped” (Silvers 1998, 85). To provide a charitable interpretation of Silvers’ account, it is important to note that in other places she sees the need for a separate justification of the moral obligation to rectify disadvantage

connected with disability.⁴² Nevertheless, she does not devote much attention to the move from the social model of disability to social justice claims in her book. With this strategy, she gives the impression that this step is made effortlessly. Both Jenny Morris and Colin Barnes see the social model of disability as a tool to generate policies that try to prevent discrimination against disabled people (J. Morris 2001, 1; C. Barnes 2012, 18). However, they do not make clear how exactly these policies follow from the social model. Morris's reasoning moves from a social model of disability to the rights of disabled people without explaining this step at all.

In the same vein, Tom Shakespeare employs a line of reasoning that establishes a strong link between models of disability and social policy responses. He assumes that normative claims follow simply from accepting a social model of disability, and this is something he values in the social model (though he later rejects certain social models of disability). However, he does not explain how to proceed from a model of disability to a social policy response. The latter simply seems to follow from the former. Specifically, he argues that the social model of disability has two impacts. First, it identifies the removal of barriers as a political strategy: “[i]f people with impairments are disabled by society, then the priority is to dismantle these disabling barriers, in order to promote the inclusion of people with impairments” (Shakespeare 2006a, 30). According to him, disability would then primarily be a discrimination issue. Second, and clearly related to the first point, it would allow disabled people to stop feeling sorry for themselves and instead be angry about the fact that they are facing discrimination. For Shakespeare, these are implications of the social model in the sense that these claims directly follow from the social model. He might have some general principles, such as principles of equality or non-discrimination, in the background.⁴³ Yet even if this is the case, those principles are neither made explicit and conceptually elaborated nor are they related to a conception of disability and the ultimate normative judgments regarding how to react to disability. In that sense, he gives the impression that the social model of disability is directly connected to a specific social policy.

⁴² “First, we must decide whether the disadvantages characteristically associated with those differences we identify as physical, sensory, or cognitive impairments are artificial or natural. Second, we must come to terms with whether we are morally or politically obligated to mitigate or rectify the specific kind(s) of disadvantage occasioned by those sorts of difference – that is, whether we are required to equalize people because of their disabilities.” (Sivers 1998, 15)

⁴³ Certain passages lend support to such an interpretation; compare, for example:

“If disabled people have equal moral worth to non-disabled people – and are viewed politically as equal citizens – then justice demands social arrangements that compensate for both the natural lottery and socially caused injury.” (Shakespeare 2006a, 67; Shakespeare 2013, 91)

Shakespeare's own model of disability is, in the same way, open to different interpretations. He argues for certain normative implications of his model, for example that curing disabled people is to a certain extent justified if the voices of disabled people themselves are heard and if it is not seen as an alternative to barrier removal (Shakespeare 2013, 137–154), but it is unclear how this conclusion really relates to his model of disability. He does not provide any other normative principles or a normative framework at any point, but only relies on his understanding of disability. Thereby, he gives the impression that this model of disability already incorporates a certain policy response.

The impression gained from reading the literature that recognizing a social model of disability leads to certain social policy claims is also confirmed in the recent discussion of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). This international convention, which was adopted in 2008, makes the rights of persons with disabilities a matter of human rights. It grants persons with disabilities a number of civil and political, but also economic, social, and cultural, rights. It is widely agreed that this is a groundbreaking agreement for all persons with an impairment and that it has far-reaching implications (see, for a philosophical discussion, Anderson and Philips 2012). The CRPD sees disability not as an inherent attribute of an individual, but as the result of an interaction of this attribute with an inaccessible environment (United Nations 2006, 1). The environment is understood here in a wide sense as comprising the physical environment, but also social policy, laws, and the attitudes and behavior of other people. The CRPD thus adopts the social model of disability.

A great part of the philosophical literature on the CRPD now gives the impression that the convention is the logical consequence of supporting the social model of disability. Most authors discuss the social model of disability, and then move on to a discussion of the convention without explaining the relationship between the social model of disability and the normative implications that the CRPD legally establishes (for example Degener and Quinn 2002, 14/15; Kayess and French 2008, 5–7; 20–22). This argumentative step and the focus on the social model of disability gives the impression to the reader that the convention logically follows from a social model of disability. This model of disability seems to be employed to justify social policy claims.

In general, an argument that establishes such a strong and direct connection between models of disability and certain moral judgments commonly remains implicit in the sense that it is taken for granted that the normative claims follow if a specific model of disability is acknowledged. Typically,

such an argument reasons from the social model of disability to the need for a proactive social policy. It is therefore common in the disability rights movement. One could also assume that a medical model of disability justifies in a similar way the need to cure individuals. But which normative claims are really implied by a model of disability and which need to be argued for in another argumentative step? In the following section, I will take a critical stance towards the impression raised in the literature.

3 What models of disability cannot do

Contrary to the impression gained from the literature that a model of disability entails social policy claims, I will argue here that models of disability cannot justify normative claims. First of all, it should be considered that models of disability are logically compatible with different normative claims, contrary to the impression given in the current literature. For instance, one could argue that impairments exclude the possibility of having certain valuable experiences.⁴⁴ A physical disability, for instance, would make it impossible to enjoy climbing mountains. However, this claim does not necessarily mean that living with a disability is therefore less valuable; it could mean that there are many ways in which human beings can flourish (Wasserman 2001, 222). Additional normative arguments are necessary to draw this normative conclusion.

In general, I described models of disability as metaphysical conceptions of the human or ontological accounts of disability. They provide causal accounts to explain how a disability is constituted and what it consists of. They answer the question ‘What is disability?’ If this description of models of disability is taken seriously, it is clear that it means that a model alone cannot make normative claims about how to react to disability. Just as I concluded in relation to my theoretical framework that metaphysical conceptions of the human cannot provide the foundation for moral judgments, models of disability as such metaphysical conceptions cannot provide the foundation for claims of justice for disabled people. A model of disability explains the constitutive features of a disability, but it cannot inform us about responsible actions and obligations towards people with disabilities. A model of disability can only make a statement about causation (i.e. the constitutive features of disability), but not about responsibility (Barclay 2011, 273–283; Samaha 2007, 1252–1255; Wasserman 2001, 225–229; Wasserman et al. 2013, section

⁴⁴ Note that many variants of the social model would not agree with that claim.

2). And causation is not on a par with responsibility. I understand responsibility here as a prospective and current moral responsibility in the sense that a responsible agent is answerable for something and that there are things for the agent to attend to (Duff 1998).

By analyzing the social model of disability, I will explain why there is no conceptual necessary link between causation and responsibility: although society does play a role in causing the problems that some people face—this is the social model—it does not follow that society has to do something about it. Not all social contributions to disadvantage can be deemed to be the responsibility of society to address (Barclay 2011, 276). An additional moral principle needs to be introduced to draw that conclusion. There are several reasons for this.

First, we need to show that moral responsibilities regarding disabled people exist. For a long time, we have not assumed that anyone has moral responsibilities towards persons with disabilities, independent of the constitutive features of that disability. Even if nowadays most people are prepared to think that we have certain responsibilities towards disabled persons, just as we assume that we have special responsibilities towards children and general responsibilities towards each other as human beings, this is not self-evident. Initially, an argument regarding responsibility needs to be put forward.

Second, one could argue that it is more important that social justice focuses on other problems. In some situations, for instance, providing accessible public transport might not be a priority for social policy if there are still greater injustices in place. If a society sets other priorities, it does not necessarily mean that society is at fault (Barclay 2011, 277). Needless to say, a number of disadvantages that disabled people face could be corrected by relatively minor adjustments. For these problems, it is simply no justification to say that they are overruled. But it is at least possible and relevant in some situations to acknowledge that priorities must be set and that sometimes ameliorating the situation of disabled persons might not be among those priorities. To provide an argument for what should receive priority, we are in need of a moral argument.

Third, and related to the problem of setting priorities, one could pragmatically argue that alleviating these problems is too costly for what is gained. If that is the case, the budget should be spent on other things. To make the case that this is an unjust discrimination, we are in need of moral principles about what discrimination amounts to and why it is problematic. Simply

referring to the cause of the disadvantage, namely a social model of disability, is not sufficient.

Fourth, following Shakespeare's arguments, Barclay argues that full inclusion is practically impossible (Barclay 2011, 276). As much as we try, it will remain impossible to fully include all severely cognitively impaired persons in society. In addition, it is sometimes impossible to accommodate all kinds of impairments at the same time. Tactile guiding systems for blind people make it more difficult for wheelchair users to navigate, for example. As it is not possible to design a society without features that impact differently on some people because of their inherent traits, it is therefore not reasonable to accuse society of a failure when it does not do so.

Fifth, it might be questioned whether it is indeed very problematic that some people are disadvantaged or whether this is simply a regrettable but unavoidable side effect of the otherwise satisfactory organization of society—you might think that it is difficult to achieve something that is satisfactory without causing some undesired effects.

Hence, even if one sees a relation between causation and responsibility in the sense that causation changes the burden of proof, these examples indicate that there can be several reasons why a person, institution, or society is not responsible for alleviating the problematic situation despite having caused it. Responsibility could be overruled or be erased by either pragmatic or practical reasons. Hence, the social model does not have such far-reaching implications as is often assumed by its defenders.⁴⁵ Another argumentative step is necessary to argue that barrier removal by society is what needs to be promoted. Causation can occur without any responsibility to address it.

Vice versa, responsibility is not necessarily connected to causation. One could be seen as being responsible for relieving a disadvantage even though one is not guilty of having caused it. For example, a state might have a duty to support the victims of hurricanes and tsunamis even if that state did not cause or exacerbate the natural catastrophe (Wasserman et al. 2013, section 2). In general, no matter which position one defends on this point, the social model of disability cannot take a stance on it because it only answers questions of causation and does not address questions of responsibility.

A model of disability provides an account of the cause of the disadvantage that some people experience. As Adam Samaha argues, one can accept that

⁴⁵ Barclay also thinks that the power of the medical model to address injustice in society is regularly underestimated.

insight, but is not automatically committed to a specific normative response (Samaha 2007, 1253). A model of disability only “suggests causes of disadvantage, but what we do about it is a matter of contested norms” (Samaha 2007, 1275). Arguing about causation needs to be separated from arguing about responsibility and justice. One can decide to take causation into account or neglect the cause of disadvantage, but this decision is in itself already a normative judgment. Only a normative framework is able to justify a social policy on disability. Models of disability do not provide such a normative framework. An answer to the responsibility question cannot lie in the question of which model of disability one supports. Hence, models of disability cannot justify social policy claims.

4 The indirect relation between models of disability and social policy claims

If models of disability cannot justify social policy claims, what force do they have for the content of moral judgments? Before I provide my own answer to this question, I want to consider two authors who engage with this issue.

Linda Barclay could be understood as opting to leave models of disability completely aside in moral judgments: she concludes that theories of justice are at the heart of discussions about the just entitlements of people with disabilities (Barclay 2011, 285). For her, models of disability are less important for settling normative questions. She finds it “more fruitful” to concentrate directly on the question of social justice for disabled people rather than on a discussion about how disability should be understood (Barclay 2011, 286). Should we, therefore, omit debating about models of disability? Barclay is careful not to fully draw that conclusion. She only suggests that, rather, we should discuss questions of social justice. This is not the same as arguing that the social model is in all respects irrelevant to moral judgments. The exact relation between models of disability and moral judgments remains, then, an open question. How can the relation between conceptualizing disability and an appropriate response to disability be adequately understood?

Adam Samaha argues that “a normative framework is mediating a logical gap between causes of disadvantage and the appropriate response” (Samaha 2007, 1276). He shows how a social model of disability can interact with three different normative frameworks—a libertarian, a utilitarian, and an egalitarian one—and that it is the normative framework and not the model

of disability that mainly determines normative claims (Samaha 2007, 1286–1306). Specifically, libertarians could accept the social model of disability without embracing social change because they can deny any governmental duty to assist the disadvantaged. For utilitarians, the social model could be significant in terms of its power to identify causes of welfare loss that should be rectified by state action. Egalitarians would in any case advise alleviating the disadvantage that disabled people face simply because they are motivated by egalitarian concerns. But for egalitarians, it does not matter how this disadvantage comes about, and therefore the social model is not of any importance here. The social model of disability thus influences only very little of the overall ethical analysis, Samaha argues, and if it has any influence, this is only as the consequence of the defended normative framework. Samaha concludes that the social model of disability by itself cannot underwrite “any policy, in any direction” (Samaha 2007, 1275).

Yet if we accept that normative frameworks as well as causes of disadvantage as represented in models of disability both play a role in determining the appropriate normative response to disability, then we need to understand better how moral judgments about disability are made. Samaha’s analysis of an interaction between normative frameworks and models of disability is not yet specific enough to understand how justified moral judgments are formed. I want to inquire, therefore, what specific role models of disability play in interaction with normative frameworks. I will argue that models of disability do have an important influence on normative claims even though they do *not* provide a foundation for social policy claims. Denying such a foundational role does not mean that models of disability do not play any role at all. I will argue that their role is rather indirect. Models of disability are thus influential, but in a way that is different from what is commonly assumed. They do not stand alone, but interact with moral theory. In my theoretical framework, I identified several of those indirect argumentative functions (chapter three, sections 2.2–2.5). In the following subsection, I will outline and illustrate these argumentative functions in the context of models of disability and social policy. I will, thereby, show that the argumentative functions I identified on a theoretical level do indeed play a role in decisions about practical moral issues.

4.1 *Specifying policy*

A model of disability could be taken to specify policy claims (see chapter three, section 2.3 for a theoretical elaboration of specification). In this role, it

guides the practical application of moral principles. That means that the moral principle needs to be justified separately. The model of disability is then analyzed to make clear what a moral principle means in a specific situation. The model of disability is taken to provide information on the conception of disability, and this information is what is needed to enact the moral principle.

For instance, we could imagine a social justice theory that makes two assumptions: first, that something should be done about the disadvantage of disabled people and second, that causing disadvantage establishes a responsibility to alleviate it (see also Wasserman et al. 2013, section 3). The second assumption can be illustrated using Peter Singer's famous example: if I push a child into the pond, I might have a greater responsibility to save that child from drowning than an innocent bystander.⁴⁶ This, clearly, is already a normative judgment that needs to be argued for. In the case of disability policies, a social model of disability can be taken to specify these moral principles. The social model makes explicit how the disadvantage of persons with disabilities is caused and how it can be alleviated. It can show what the rather abstract moral principles mean in practice. Knowing the cause of a disadvantage—which the social model claims it can—is then important if it is also decided that the disadvantage should be alleviated. This means that “[t]he causation claim on its own will not establish the normative claim, while the normative claim can, if accepted, make the causation claim important” (Samaha 2007, 1284). Such a reasoning could substantiate the argument made by those who start by arguing from a model of disability and move immediately on to an imperative for social change. They could be interpreted as assuming such a normative framework without explicitly arguing for it.

To give another example, one could support the normative principle that intentionally created disadvantages that could relatively easily be avoided should be alleviated.⁴⁷ The social model now claims that the disadvantage that disabled people face belongs at least partly in that category. Think, for example, about the creation of steps in front of new buildings rather than ramps, which are arguably not more expensive or more difficult, or in any other way less feasible to install. Again, the social model can specify the

⁴⁶ Of course, the point of Singer's discussion of this example was to show that this assumption does not hold.

⁴⁷ Wasserman and his co-authors discuss prejudice and stigma under the heading of innocently-created disadvantage and argue that one could therefore accord priority to alleviating those disadvantages (Wasserman et al. 2013, section 2). However, while I think that the general point of distinguishing between innocently created and intentionally created disadvantage is worth considering, I am not convinced that prejudice and stigma belong in the first category.

moral principle. It leads to the moral judgment that disabled persons' disadvantages should be addressed whenever new buildings are constructed. These deliberations will yield a policy response to disability that refers to normative principles about economic feasibility and practical possibility, but specifies them with a social model of disability.

This theoretical background also provides a better understanding of the CRPD. In contrast to the impression that one gains from most of the literature about the CRPD, the convention should not be understood as being based solely on the social model of disability, but as employing a social model to *specify* a theory of human rights (for a comparable interpretation see Graumann 2011). It still holds that the shift in an understanding of disability from a medical model to a social model made the CRPD possible. That is, without such a new way of thinking about what disability is, the necessity for disability human rights would not have existed. However, a theory of human rights is needed initially. To understand this interpretation, it is necessary to understand in more detail how the reasoning of the CRPD works.

The CRPD is a human rights convention, but as human beings, disabled people are obviously also covered by all other, existing human rights conventions that are not specially designed for disabled people. So why was a disability human rights convention needed? The CRPD starts from the idea that disabled people do not deserve different, exclusive human rights. But up to that point, they seem to have been insufficiently protected by the general human rights legislation (Office of the High Commissioner of Human Rights 2010, 5). What they needed, therefore, was an application of the well-known canon of human rights to their specific situation. This is what the CRPD aims to achieve. Therefore, it does not aim at bringing new rights into existence, but at framing human rights in such a way that they also protect disabled people. Disability rights are still human rights—"specific to persons with disabilities, yet rooted in the universality of rights" (Mégret 2008, 516).⁴⁸

What does it mean, then, to frame rights in a way that means that they also protect disabled people? One of the most important aims of the CRPD is "full and effective participation and inclusion in society" (United Nations 2006, sec. 3c). The state is seen as having additional obligations to ensure

⁴⁸ This reasoning holds not only for disabled people, but also for children or women. Therefore, these groups require a tailoring of the general rights regime to their needs. This is exactly what is accomplished by special conventions such as the Convention on the Rights of the Child (CRC) and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).

that human rights are also guaranteed for persons with impairments. The underlying idea is that disabled people need something else or need more resources to be able to enjoy rights to the same degree as non-disabled people. That means that additional resources have the capacity to make a change in disabled people's lives and, specifically, to make a change in the extent of their enjoyment of rights. To make this possible, it is a precondition that at least part of the reason why disabled people do not enjoy their human rights to the fullest extent also lies in external conditions. Otherwise, changing external conditions would not make a change in a life with an impairment. Troublesome external conditions need to be at least part of the reason why people with an impairment face disadvantages. And this is exactly what a social model of disability claims. It explains disability as resulting from an interaction between individual characteristics and external conditions. Only by assuming that understanding of disability could the empowerment of individuals with impairments, leading to their inclusion in society, be possible. Thus, understanding the CRPD is only possible in the light of a social model of disability, but it needs to assume first an account of human rights. Thus, the CRPD specifies what human rights mean for disabled people, and it does so with a social model of disability. We need to tailor moral principles to be able to apply them, and by doing so, we should not ignore relevant information, which in this case is an ontology of disability.

4.2 *Constraining policy choices*

Another possibility regarding the interaction between moral principles and models of disability is to argue that models of disability constrain moral judgments (see chapter three, section 2.2 for a theoretical elaboration of constraining). That means that models do not determine which policy response is the right one, but only that they reduce the number of choices of possible policy responses. Some policy responses would be 'defeated' because they are not compatible with the defended model of disability. The idea is that if moral judgments make assumptions about the ontology of disability that are implausible, the moral judgment is shown to be wrong.

In this role, models of disability underdetermine moral judgments. A constraint is only directed at those options that are excluded, but not at those that are morally indicated. There might still be many possibilities for policy claims that are compatible with the defended model of disability. Hence, to come to a final moral judgment, other considerations need to come into play.

For example, a medical model of disability would exclude environmental reconstruction as a possible social policy claim to change the situation of disabled persons for the better. This is because within a medical model, the environment is not decisive regarding the disadvantage of disability. A medical model gives an account of the cause of disability, namely it sees it as rooted in specific traits of an individual. Hence, the disability is solely dependent on the medical condition of the individual. Choosing environmental reconstruction is therefore not a valid option if a medical model is defended at the same time. However, opting for a medical model does not prescribe what exactly to do in a certain case. It is not even clear that something should be done at all to address the disadvantage of disabled people. There are still many possible options of action—including not doing anything—that are compatible with a medical model of disability. To make a decision between those options, moral theory is necessary.

The argumentative function of a constraint is sometimes employed in the disability rights movement. However, it is not the case here that a model of disability narrows the range of possible social policy claims as I described models of disability, but that social policy claims determine which models of disability are acceptable. Thus, the reasoning is, effectively, turned around. Shakespeare provides such an argument in the revised version of his monograph (Shakespeare 2013).⁴⁹ He starts his book by claiming that

“[t]here seems to have been an assumption that without the 'strong' social model, there can be no political progress and no social movement of disabled people. If I believed that this was the case, it would be very much more difficult for me to suggest that the social model should be revised.” (Shakespeare 2013, 1)

This suggests that Shakespeare reasons from an imperative for social change back to certain conceptualizations of disability. He argues that he would not dismiss the strong social model if it were the only model that could apprehend certain policy responses to the phenomenon of disability. In the same vein, Shakespeare also dismisses what he calls “cultural disability studies”,⁵⁰ because they would “not offer much in the way of practical help in understanding the lives of disabled people, let alone changing them for the better” (Shakespeare 2013, 3). Cultural disability studies are rejected because they do

⁴⁹ At the same time, he still uses other argumentation strategies that can already be found in the original version (Shakespeare 2013, 11–46). One could wonder whether the two different argumentation strategies as they appear in the revised version can actually be reconciled.

⁵⁰ He means disability scholars informed by post-structuralist and postmodernist authors (Shakespeare 2013, 47–71).

not incorporate certain implications. That means that the possibility of dealing with a phenomenon in a certain way determines how it can adequately be captured. From a disability activist goal follows a certain model of disability.

Within this argumentation, the statement that disabled people's lives should be changed for the better cannot be supported by an argument in which the conceptualization of disability plays any role. This is because the conceptualization of disability is proven wrong if it does not support this moral judgment, and therefore it cannot justify the very same judgment without avoiding a circular argument. Why society owes something to disabled people has to be defended independently from an understanding of what disability actually is. It is therefore even more surprising that Shakespeare does not devote much attention in his book to a justification of the moral judgments. It seems as if, here, the focus is so concentrated on the political aims of the disability rights movement that the philosophical task of providing justifications has been lost sight of.

4.3 *Circumstances of policy*

Models of disability can also open up a range of possible policy options and, thereby, describe the circumstances of policy (see chapter three, section 2.5 for a theoretical elaboration of the circumstances of morality). They provide an account of what disability is. Thereby, they can indicate what action can be undertaken to address the disadvantage of disability. They can give an idea of which action could be effective and in what way. In this role, models of disability do not determine or justify social justice claims, but they make it possible to think about disability as a particular question of social justice. Models of disability develop a framework for considering questions of justice.

Wasserman and his co-authors see such a relevance of the social model of disability. They argue that

“for most theories of justice, the mere fact that the social environment can be modified in ways that alleviate the disadvantages associated with impairment places demands for their alleviation within the scope of justice – as claims that a theory of justice must consider and weigh.” (Wasserman et al. 2013, section 2)

If a social model of disability is assumed, we know that it is at least possible to address the disadvantage of disabled people by adapting the environment. This is not automatically a moral imperative to adapt it because this would need a moral justification. Knowing the causes of disadvantages only tells us where it would be possible to look for a remedy. It makes certain policy directions options to consider. Clearly, debating the necessity of environmental reconstruction only makes sense at all if one thinks in terms of a social model of disability. Before the social model became popular, this possibility was not considered at all. In general, if one finds it important to address disability-related disadvantage on the basis of moral principles, the circumstance of policy provide information about the question of how to address that disadvantage. It gives us an idea of what we have to consider and debate. A social model of disability has a different answer to that question from a medical model. Yet to make moral judgments, models of disability need to be supported by moral principles.

5 Conclusion: what models of disability can do

By applying the theoretical framework that was developed in chapters two and three, I analyzed different ways of capturing the relation between models of disability and policy responses. First, models of disability can *specify* social policy claims. They make explicit what it means to enact a moral principle. A second possibility for the interaction between moral principles and models of disability is to argue that models of disability *constrain* the number of reasonable policy responses. Some policy responses are 'defeated' because they are not compatible with the defended model of disability. Third, models of disability can depict the *circumstances of policy*. Models of disability describe what action can be undertaken to address disability-related disadvantage and hence make it possible to think about disability as a question of social justice. Hence, models of disability do have an influence on the question of what we think we owe to disabled people, but it is only an indirect influence. What the different argumentative functions of models of disability have in common is that moral principles are necessary to yield a normative claim. Models of disability cannot be substitutes for those moral principles; as metaphysical conceptions of the human being, they cannot have a *foundational* role. These different argumentative functionings are not to be understood as an exhaustive list, but only as a starting point for a more structured way of thinking about the relation between models of disability and social policy claims. In addition, they are of different importance for an actual social policy claim. A

constraining function is more powerful than describing the circumstances of policy.

Furthermore, in the analysis it has become clear that discussing models of disability is not without obstacles. Models of disability are used to incorporate many different aspects. They are employed to cover ethical as well as normative-political aspects. All kinds of different types of considerations are hidden under this general notion. Models of disability are, thereby, transformed from their original meaning and become something quite different: they become models* of disability. Strictly speaking, a model of disability was solely meant to provide an account of how disability is caused. Yet in the discussion, the new models* of disability are used in a more general way. This does not facilitate a reasonable and sensible discussion about the ethical issues surrounding disability. What models describe, what they can accomplish, and what they cannot do is lost sight of. Employing the term ‘models of disability’ in such a broad sense of models* of disability only confuses the issues in a philosophical analysis. Instead, we should be explicit about what kind of knowledge a model of disability can provide. What exactly do we discuss when we are discussing a model of disability? It would be necessary not to put all kinds of different discussion around disability into such a model, but to make it possible to debate ontological, moral, and normative-political questions separately. In a next step, these different aspects could then be related to each other.

It might be the case that this is an idealized understanding of models of disability. Maybe models of disability, or least the social model of disability, should not be understood as the ontological account of what disability is that I described at the beginning of this chapter. This impression is affirmed by Phillip Cole (Cole 2007). He argues that the social model of disability cannot be comprehended as a philosophical project, but only as a political one. For him, it is more a political tool for action than a theory of disability. Cole argues that the social model of disability “is designed for a particular purpose in a particular kind of society, one in which social oppression through disability exists” (Cole 2007, 176). For him, this model was only invented to serve a certain policy claim.

Indeed, in the history of the disability rights movement there has been an entanglement between defenders of the social model of disability and disability rights activists, and often such an entanglement can take place within one person (also see Samaha 2007, 1280–1285). It is understandable that the original meaning of an ontological account of disability might have been transformed to a certain extent in the course of debate. It has therefore

become less a model of disability as an ontological project, which was my analysis of it, and more a model* of disability that has, primarily, a political function. A model* of disability is something other than an answer to the question ‘What is disability?’, and is instead “a normative orientation emphasizing respect for people with disabilities and their integration with nondisabled people” (Samaha 2007, 1267). If that is the case, the term ‘model of disability’ in the literature must be understood very differently and certainly not as an ontological conception but rather as a normative-v conception of the human that can provide such a broad idea of the human being (see chapter two, section 2.5 for an analysis of normative-v conceptions). However, we would still be in need of a conception of disability as an ontological description. We would just have to assert that the label ‘model of disability’ is rather confusing as the term seems to live its own life in the debate—and simply give it a different name for the sake of philosophical analysis.

Chapter 6

Designing children

Prospective parents are willing to go a long way to have the children they crave. Nowadays, 1–3 percent of all children born in the United States and Europe are the result of assisted reproductive technology ranging from fertility medication to sperm or egg donation and surrogacy (M. F. Greene 2012, 1737). Since the birth of the first test-tube baby in 1978, more than 200,000 IVF babies have been born in the United States alone (Todd 2015). All these treatments involve psychological burdens, a time investment, and, in many cases, high costs that the prospective parents have to bear. Many procedures seem worth trying for those who aim to have a child. But parents-to-be do not just want children; sometimes, they want a child with specific characteristics.

In addition, all parents want the best for their children. They send them to the best schools, they pay for their musical education, they read them bedtime stories, and they are ready to accept an infringement of their own interests for the sake of their children. It is only comprehensible that parents also want to give their children a good—if not the best—start in life. They hope for children without devastating medical conditions, and many want intelligent children or, more specifically, children with a particular talent or children that share certain physical traits with them.

With current advances in technology, it is becoming more and more possible to design future children in these ways. But is it morally acceptable to seek a particular kind of child? As John Harris provokingly asks:

“If it's not wrong to wish for a bonny, bouncing, brown-eyed baby girl, why or how would it become wrong if we had the technology, the choice, to play fairy grandmother to ourselves and grant our own wishes?” (Harris 2007, 145)

The possibility of designing children has given rise to a widespread debate.⁵¹ Designing children is a subtopic in the enhancement discussion that is typically integrated in the seminal enhancement literature (for example Fukuyama 2003; Habermas 2001; Harris 2007; Sandel 2007). In this chapter, I want to clarify and discuss the reference to the human being in the debate. As we will see, just as in the general debate about enhancement, human nature or a conception of the human being in general plays an important role in the debate on designing babies. However, it is often unclear exactly what is meant by that reference and how it should be used. This suggests that gaining clarity about diverse conceptions of the human that are put forward could help to move beyond a situation in which there are entrenched positions of defender and critics. I want to test whether distinguishing between different conceptions of human nature could indeed take the debate further and whether the use of different conceptions of human nature has an effect on the normative conclusions that are reached. Being clear about the role that the choice of a particular conception of the human plays can also help to better understand, and perhaps even solve, disputes between different philosophers in this debate. This means that I want to apply the theoretical framework that I developed in chapters two and three in the debate of designing children. I will, thereby, focus on naturalistic and normative conceptions of the human as these are the most relevant and widely used in this debate (see chapter two, sections 2.1, 2.2, 2.4, and 2.5).

In the first section of this chapter, I will briefly look at the actual and likely future possibilities for designing children. The second section applies naturalistic conceptions of the human being. The third section turns to different normative conceptions. In the fourth section, I illustrate how different moral positions in the debate on designing children can be better understood within my theoretical framework and its elaboration in this chapter.

My discussion cannot (and does not attempt to) provide a decisive argument about whether and to what extent designing children is morally permitted. However, it indicates the limits of and prospects for different argumentation strategies. I will argue that naturalistic conceptions of the human being are

⁵¹ For a general introduction to a number of important ethical questions in the debate about designing children, for example questions of fairness and justice or the nature of family bonds (see, for instance, Buchanan et al. 2001, 156–203).

necessary to understand what designing children means. However, only normative-v conceptions can provide the normative grounding that is needed for a moral judgment in this debate; hence, they play a crucial role in the different positions that are defended. The debate as it stands would benefit from distinguishing between the different functions that conceptions of the human can play, and from being more aware of the importance of the endorsement of a particular conception for the moral views that are defended.

1 Possibilities for designing children

To discuss designing children, we first need to understand what this debate is actually about. As Adrienne Asch and David Wasserman explain, fetuses can be tested for Huntington's gene, a couple can choose to implant an embryo that is expected to be a compatible blood donor for an older sibling, and gamete donors can specifically be selected for certain physical characteristics and talents. Though clearly different, these are all means by which to increase the chance of having a child with desirable traits or avoiding having a child with undesirable traits (Asch and Wasserman 2013, 7/8).

Admittedly, there could be important moral differences between different ways of designing children. I want to distinguish between bringing children into existence in the following ways:

- (a) without paradigmatic cases of disease and disability
- (b) with traits that are generally considered advantageous, such as high intelligence or beauty
- (c) with neutral traits such as a specific gender, hair, or skin color (Harris 2007, 147, distinguishes these neutral traits from other ones).

Though the different categories are not always clear—is height neutral or advantageous?—some would argue that disability is inherently neutral (for example E. Barnes 2014b). I hope that the general idea proves to be helpful. Here, my examples will mainly be drawn from designing children in the sense of options (b) and (c) because my inquiry is based in the context of the enhancement debate. However, I believe that the general analysis has important implications for all three of these cases.

What are the real possibilities for designing children currently? We can distinguish between designing before conception and after conception. Before conception, it seems that there are two methods used to design children: first, by sorting sperm, and second, by choosing gamete donors. First, sorting sperm only allows for gender selection. As the second sex chromosome, either a Y chromosome or an X chromosome is chosen. Current methods for sorting sperm have different success rates of around 70—90 percent,⁵² but these methods might become more accurate in the future (Gil et al. 2013; Mayor 2001 critical on sperm selection). Second, choosing gamete donors is similarly unreliable. Even though it is well-known that some traits are inherited, for example skin and eye color, it is clear that choosing gamete donors delivers fairly random results in most cases.⁵³ This is especially the case for traits that are generally considered more relevant than physical traits, such as musical abilities or athletic skills. Designing children before conception is more of a future possibility than a reality.

Assessing what might be possible in the future is a daunting task (especially for philosophers). For the most part, the enhancement debate suffers from inflated expectations and a hyping of technology instead of being based on a realistic evaluation of the expected possibilities (see for such a criticism Nordmann 2007; Schermer et al. 2009). Yet it seems that among the future possibilities for designing children are somatic cell nuclear transfer (SCNT) cloning, recombinant DNA technology, and in vitro eugenics (Robert Sparrow 2013, 4/5). Cloning, if it is ever possible for humans, would allow a human being to be brought into existence with the same genotype as another one. Recombinant DNA technology, which is already widely used in non-humans, brings together genetic material from multiple sources by using genetic recombination methods. It can potentially introduce new genes into a specific location of the genome. Clearly, it is a difficult method for human enhancement as the new gene should bring about the intended result without interrupting the functioning of the rest of the genetic system. In vitro eugenics works in the same way as the breeding of plants: a human embryo would be created by fusing the egg and sperm derived from different stem-cell lines; subsequently, gametes from the stem-cell lines of this embryo would be used to create another embryo, and so on. These are all future possibilities, and it is unclear whether they will ever become real options.

⁵² Note that the chances of having a child with the desired gender without active intervention is around 50 percent.

⁵³ However, remember the case that I described in the introduction, in which a couple chose a sperm donor who was part of a family that included five generations of deafness. Even though they did not know for sure that the child would turn out to be deaf, we can assume that the likelihood of deafness was quite high.

After conception, there are real opportunities to make a selection between potential children (Dayal 2013). First, different forms of prenatal testing are possible (chorionic villus sampling, amniocentesis, serum screening, or ultrasound), followed by the option of abortion. In these cases, selecting or not selecting a potential child happens relatively late in the development process of the child. Because of the associated psychological burdens, this cannot be considered an option apt for all but the most severe cases. It goes without saying that if possible it is preferable to select earlier rather than later. A second possibility is using in vitro fertilization (IVF) in combination with preimplantation genetic screening (PGS) and then deciding which embryo should be placed in the womb. PGS, an embryo biopsy of one or two cells at the eight-cell stage to diagnose a range of chromosomal and single-gene defects, is already widely used (Van Voorhis 2007, 384). Though most countries restrict the use of PGS to cases of severe genetic conditions and recurrent miscarriages, a much wider application is clearly possible. The sex of the child can be determined fairly reliably; in fact, the whole genome of the child can be read, with the only hindrances being that it is costly and time intensive. Embryos could then be selected according to their original genetic make up.

In addition, women can then choose how many embryos they want to have implanted in their womb. Placing two or more embryos increases the chance (or the risk) of having multiple children (Van Voorhis 2007, 382).⁵⁴ In rare cases, the development of twins takes place after the embryos are placed in the womb, when they are usually already blastocysts.

However, it should be clear that a round of IVF, with the associated burdens for women, produces at best about five embryos. Although some of these embryos might be judged to be ‘better’ than others according to certain criteria, it is likely that a perfect embryo—without diseases and undesirable traits, but with the right gender, eye and hair color, and with specifically chosen talents—is not to be found among them. Furthermore, going through IVF is far from providing a guarantee that a baby will be taken home after nine months. Depending mainly on the medical diagnosis of the fertility problems and the woman’s age, only about a third of all women who go through IVF are expected to have a child (Society for Reproductive Medicine 2013). The majority of all IVF cycles do not even result in a pregnancy. Hence, the real possibilities for designing children are actually quite meager. There are clearly certain ways to influence what kind of children

⁵⁴ To minimize the associated risks of carrying more than one child, many countries only allow one embryo to be put back.

come into existence. But the greatest part of the discussion about the real possibilities for designing children should be understood as anticipating future developments.

References to human nature occur are used for two purposes in the debate: first, to understand what we are doing when we are designing children and second, to morally evaluate this practice. Regarding the first instance, even though I described the possibilities for designing children, we need to understand what, exactly, these possibilities enable us to do. We should understand what we are doing when we are designing children. What is the human being that we are influencing? Regarding the second question, we need to become clear about whether it is morally allowed or even obligatory to design children. I will show that this presumes an understanding of what it means to be human in a morally relevant sense. I will analyze naturalistic and normative conceptions of the human being regarding these two questions of understanding and evaluating designing children.

2 Naturalistic conceptions of the human being

According to my analysis in chapter two, naturalistic accounts describe the human being using natural-scientific arguments as a certain type of natural entity. First, naturalistic-s conceptions look for the necessary and sufficient conditions for belonging to the species *Homo sapiens* (chapter two, section 2.1). Second, naturalistic-i conceptions analyze innate traits of humans (chapter two, section 2.2). In the following two sections, I want to find out whether understanding the human being in the sense of these naturalistic conceptions of the human contributes to producing better arguments and more plausible moral judgments in the debate.

2.1 Understanding designing children

What, if anything, do we gain if we try to understand the designed human being I just described in the sense of a naturalistic-s conception of the human? It is quite clear that most parents are not attempting to develop members of a new species. We do not need to consider the challenge of demarcating the point of death of one species and the birth of another, along an unpunctuated lineage of change. Rather, the concept of species-typical functioning is common in the enhancement debate (see chapter 1 for an elabora-

tion). Designing children would then mean selecting embryos that would in all likelihood develop in ways that are currently not within the normal range of *Homo sapiens*. Examples are enormously high intelligence, or the creation of human-animal chimeras. However, before we even need to consider how to determine a ‘normal’ range, it is clear that this is not debated when designing children is debated. At least currently, the debate on designing children concerns children as we know them, with a ‘normal’ functioning but with specially chosen traits and talents. Most parents do not aim to have children with an outstandingly high intelligence or talents we cannot even think of, but aim to have children with athletic and musical abilities, or with a specific appearance or gender. Understanding the reference to the human being as a reference to species is thus not helpful.⁵⁵

A second possibility for understanding the designed human being is in terms of innate traits. Designing children would then be understood as enabling us to influence their innate nature. In chapter 2, I argued that the best way to understand innateness is the concept of canalization (section 2.2). A canalized trait is robust in its development. It is almost bound to appear, regardless of the precise environment in which the being lives. If height is relatively independent from nutrition and other external influences, then it is an innate trait. If intelligence can only be influenced in a minor way by upbringing, then it is also innate. Clearly, canalization is not a dichotomous concept. Many traits can be seen as innate to a certain extent, but we know of only a few that are fully canalized.

Nevertheless, innate traits seem to be those traits at which designing children is directed. When selecting a specific embryo, parents are interested in influencing what their children will be like. Henceforward, they are interested in those traits that are canalized. A naïve genetic determinism then lurks around the corner: all that parents can hope to know about their future children at this stage is their genetic endowment. This does not determine the child-to-be. The interactionist consensus tells us that many other factors are important (see chapter 2). One trait that seems to be strongly canalized is per-

⁵⁵ Note that, on the contrary, the reference to species might be helpful for debating designing children without certain paradigmatic cases of diseases and disabilities. Disease and disability do not fall into the range of normal species functioning according to Boorse’s famous theory (see the first chapter). The concept of the human being as a species might therefore be helpful to delineate the boundaries of what we are doing when we are designing children. However, I excluded designing without diseases and disabilities from my inquiry. Nevertheless, this short analysis might be enough to raise the question of at which threshold high intelligence does not count as species-typical anymore, which is relevant for the current inquiry. Within this understanding, an IQ above, say, 120, might not count as species-typical, or an extraordinary musical talent might not be statistically typical. In this case, the concept of species might be helpful to understand parents’ ambitions. But I will leave it aside for now.

fect pitch (Robertson 2003, 215). It is suggested that this involves only a single gene and, though not mapped yet, this could become the object of selection by PGS. In the future, we might even know more about the genetic starting points that take us fairly reliably to certain developmental end points. Imagine finding single genes that are associated with a high risk of becoming obese, genes for intelligence as well as for athletic skills, or genes for sexual orientation or vulnerability to addiction.

I have argued that the reference to innate traits and their analysis as canalized traits is necessary to understand what we are doing when we are designing children. Let us now consider evaluating designing children.

2.2 *Evaluating designing children*

Can naturalistic conceptions of the human also be informative for deciding whether and to what extent we should design children? When developing the theoretical framework in chapters 2 and 3, I argued that it is not possible to infer a moral judgment directly from a naturalistic understanding of human nature. A moral judgment is in need of a moral justification. Understanding which traits count as innate traits cannot deliver a verdict regarding the question of what we should do about those traits. Accordingly, a naturalistic conception of the human can only have an indirect role in evaluating any enhancement intervention.

I distinguished four possible indirect roles: constraint, specification, scope, and the circumstances of morality (chapter three). All of them can be combined with a naturalistic conception of the human. The discussion that follows will not be complete; there are too many possibilities to be tested to make that claim. But it should be sufficient to show in general and with a few examples how naturalistic conceptions can be used in the debate about designing children.

First, I want to look at the understanding of the human being as a species (naturalistic-s conceptions as developed in chapter two). In what way can this be informative regarding the question of how to go about designing children? As with any moral argument, an argument for or against enhancement has to determine the scope of its validity. It needs to be clear for whom or what it is valid. When we are discussing the question of how to treat cells in a laboratory, we have to make sure that we know what we are talking about to determine the right moral framework to refer to.

Here, the idea that the cells are actually an embryo can come into play. The status of cells that can potentially develop into a human being is controversial. It is questionable whether we should treat an embryo at an advanced state differently to an embryo just after fertilization, and if not, at what point of development the moral status of the entity in question changes. According to the species criterion, human embryos are all part of the human species and have the same moral status as adult human beings. From an extreme position, this might even raise questions concerning the treatment of gametes. This has implications for designing children: for one thing, it is necessary that research is done on embryos in the process of designing children. In addition, it is common and maybe inevitable that embryos are frozen for couple of years and even more, and, of course, that embryos are discarded when they are no longer needed (Van Voorhis 2007, 382). If the moral status of embryos is determined using a species criterion, which implies that human embryos have full moral status immediately after fertilization, this might put a narrow limit on the practice of designing children. Yet what moral duties this entails exactly is of course a question of the moral principles and their application and cannot be answered by only referring to their scope.

Furthermore, using the species criterion as a scope implies that human embryos could be treated differently from non-human embryos. At least, the same regulations are not automatically applicable. Although some animal rights activists might argue that the breeding of animals should be regulated in a much more similar manner to the breeding of humans, even they agree that animals and human beings are in some sense distinct categories. The criterion of species could be helpful for the debate on designing children, for example concerning the question of how to treat so-called three-parent embryos.⁵⁶ Clearly, they would still fulfill almost any criterion that is suggested as a criterion of species. This would be different for an embryo from a human-animal chimera.⁵⁷ Here, we would be dealing with a new species, and therefore, according to the argument, different moral principles might apply to it. However, the discussion of species in the preceding chapters showed that all relevant criteria, whether they were reproductive or genetic isolation, shared ancestry, or other properties, are relational and contain spatiotem-

⁵⁶ It is possible to extract defective mitochondria from a woman's egg and replace them with healthy mitochondria from a donor egg. A resulting child has three genetic parents. The procedure was recently permitted in Britain to prevent incurable genetic diseases (Devlin 2015).

⁵⁷ Chimeras are organisms composed of cells with different embryonic origins (Streiffer 2011, section 1). The most famous laboratory-created chimera is probably the geep, which was created by fusing a sheep embryo with a goat embryo or by transplanting cells from one embryo into another. Human-animal chimeras exist, but not in the sense of a whole new being that is brought into existence, only in the sense of human stem cells that are injected or implanted into non-human embryos to analyze the new cell structures that develop.

poral specifications. This means that our understanding of the human species could shift. In the future, chimeras might be included in our conception of the human being as a species.

Importantly, determining the scope of moral principles delivers only limited insights regarding the right treatment of living beings. It only provides an account of the circle of entities that are protected by moral principles. But we need a different strategy to determine the correct moral principles and the details of their application. In most cases, it will leave researchers in the laboratory and parents and policymakers undecided regarding the majority of ethical questions.

However, as I see it, functioning as a scope is the only argumentative function that is sensible for a species conception of the human being in this context. The reason for this is that belonging to *Homo sapiens* does not really say much about beings like us. It only describes certain relations in which we stand to each other; it does not even say anything about the traits we share. The earliest *Homo sapiens* might have behaved quite differently to existing humans and not exhibited language, abstract thought, or creativity as we understand these concepts today. But argumentative functions such as a constraint, specification, or a description of the circumstances of morality are more substantive and hence need the specific traits of the human being for them to exist. Therefore, these functions cannot be fulfilled by such a vacuous conception of the human being.

Second, a naturalistic-i conception of the human captures canalized traits. This turned out to be essential to understand the human being as an object to design. I will argue that it can also fulfill various argumentative functions when evaluating designing children.

A naturalistic-i conception of the human can function as a constraint when evaluating designing children. An argument is shown to be wrong if it relies on an implausible conception of innate traits. Some versions of naïve genetic determinism presuppose a much too broad vision of innate traits (also see, for a criticism, Asch and Wasserman 2013, 8). Here, arguments assume that the life of a person is completely predictable if only one looks at his or her genes. For example, it could be argued that a gene for criminal behavior should be altered. However, most likely, a tendency for criminal behavior is not sufficiently canalized. Furthermore, tracing a genetic influence is very complex (Wasserman and Wachbroit 2001). Whether or not a person turns out to be a criminal depends more on the environment and personal experi-

ences than on genetics. This makes a ‘criminal-behavior gene’ and accordingly an argument for a duty or a permissibility to remove it highly unlikely.

In addition, innate traits could specify the moral argument. Take for example the argument provided by Savulescu and Kahane, who maintain a ‘principle of procreative beneficence’:

“If couples (or single reproducers) have decided to have a child, and selection is possible, then they have a significant moral reason to select the child, of the possible children they could have, whose life can be expected, in light of the relevant available information, to go best or at least not worse than any of the others.” (Savulescu and Kahane 2009, 274)⁵⁸

According to them, selecting the child who is likely to have the best life is not only permissible, but an ethical duty. To apply their principle, we need to have some knowledge about the conditions for the ‘best life.’ Besides a theory of well-being, that is, an idea about what makes a life a good life, we also need empirical facts about human beings. This is where innate traits can come into play. Imagine, for example, that being homosexual is an innate trait. In a homophobic society, one could argue that a gay person lives a worse life in regarding the relevant conception of well-being in comparison to the life the very same person could have if they were not gay. Such an argument needs to be based on empirical information, for example on experiences of persons in comparable situations. This does not take away the possibility that this specific gay person-to-be could have a good life or maybe even a better life, all other things being equal, if, for example, living with that sexuality and striving for equal rights provides a deep meaning to that person’s life. The only assumption this argument makes is that in all likelihood, not being gay will be advantageous. It seems that according to Savulescu and Kahane, a gene that means a person is gay, if it exists and is ever found, should thus be eliminated. Here, the ‘principle of procreative beneficence’ is specified by a conception of the human in terms of innate traits.

Furthermore, a description of innate traits of human beings can determine the scope of moral principles. In this case, an embryo is treated according to certain moral standards if it has specific canalized traits. In practice, this implies that some embryos, but not others, are no longer used in the IVF procedure and are either discarded or dedicated to research. Such an innate trait can have a comparatively low threshold, such as the capacity to develop

⁵⁸ The principle was first presented in a slightly revised version (Savulescu 2001).

into a baby. After the embryos have grown in the laboratory for three to five days, scientists select embryos that are of sufficient quality to be transferred to the womb. The remaining embryos will in all likelihood either not be implanted in the womb or will lead to a miscarriage. They would then be treated differently. For instance, research on embryos might in general be prohibited except on these bad-quality embryos that will (in all likelihood) not develop into children. But the threshold could be set higher. This is, for example, the case when it is determined that only male embryos will be placed in the womb, as is frequently demanded in China and India (UNFPA Asia and the Pacific Regional Office 2012, 2). Sometimes, only embryos with an HLA-match for a sick sibling are transferred, and several IVF cycles might even be necessary to create such an embryo.

Finally, the last possible argumentative function for innate traits concerns establishing possibilities for action or describing the circumstances of morality. Here, innate traits are also important. Knowledge about which traits are canalized is the precondition for even starting considering designing children. As soon as we learn that other innate traits also have a genetic basis, we can debate about the question of whether we are allowed or even have a duty to select for them: think of a gene for altruism or proneness to addiction. If there were no innate traits at all, the discussion would at best have the status of a thought experiment.

To sum up, I argued that the notion of species can determine the scope of moral principles. A naturalistic-i conception can play a role in all indirect argumentative functions that I distinguished. Positions in the enhancement debate do not merely rely on moral arguments, but are at the same time in need of scientifically sound background descriptions. However, it is important to keep in mind that these indirect functions can never determine a moral judgment, but are only influential for a part of this judgment.

3 Normative conceptions of the human being

In the literature, an idea of what it means to be human is often invoked in an argument for or against enhancement. What do we gain if we understand this notion of the human being as a normative conception of the human?

Normative conceptions do more than naturalistic conceptions: they not only provide a description of the human being, but they provide a normative-evaluative view of what human beings are and should make of themselves.

Hence, this understanding of human nature provides a quite different perspective on designing children. I distinguished two types of normative conceptions: normative-c conceptions describe the characteristic human form of life (chapter two, section 2.4) and normative-v conceptions give an account of what we value about ourselves (chapter two, section 2.5). As I argued in chapter two, both conceptions can incorporate naturalistic facts. But normative-v conceptions spell out the features of human beings that are the primary concern for morality. Hence, this is the understanding of human nature that we find in moral theory.

Contrary to my analysis of naturalistic conceptions, I will omit an analysis of understanding the designed human being in the sense of a normative conception. The reason for this is that employing such a conception to understand enhancement has unavoidable implications for the evaluation of enhancement. This is especially so if a normative-v conception is used to understand what we are doing when we are designing children, because this inevitably implies that a particular course of action is recommended. Think, for instance, of a normative-v conception of the human being that is directly linked to designing ourselves: such a conception could claim that human beings are essentially designers; we should influence who we are and make ourselves better.⁵⁹ Enhancement is then, accordingly, positively evaluated morally. Therefore, I will in the following section concentrate on evaluating designing children.

3.1 Evaluating designing children

I will first evaluate normative-c conceptions and then turn to normative-v conceptions.

A normative-c conception, which describes the characteristic human form of life, cannot work as either a constraint on or a foundation for a moral argument on designing children. This is because it is unclear how we should relate to an interpretation of the characteristic human form of life. Understanding human beings as aggressive or as social beings or as in need of love does not tell us anything about how we should evaluate these interpretations. As I described it in the enhancement discussion, some authors claim that human beings have always tried to influence who they are, that this is also what the enhancement project is about, and hence that we should, in princi-

⁵⁹ Peter-Paul Verbeek could be understood as putting forward such a conception (Verbeek 2011, 79/ 136).

ple, welcome enhancements. Here, a normative-c conception is used as a foundation for a moral argument. Indeed, most parents try to form their children: they teach them manners and rules, they challenge their ideas, and they send them to schools and sport clubs. Some even become “tiger parents,” (Chua 2011) as Amy Chua describes herself: they engage in strict and disciplinary parenting with the aim of bringing out the best in their child. The attempt to design children before they are born can be interpreted in this direction. However, the interpretation that designing children is something typical for humans is unhelpful when we are trying to evaluate these efforts. We might just as well conclude that hyperparenting, as well as some attempts to influence our nature, are problematic, although they still occur. Michael Sandel argues partly in this direction (Sandel 2007, chapter 3). For this argument to hold, an independent moral reason is needed.

This seems to be a general problem for a normative-c conception: it is situated between a stronger normative-v conception and a merely descriptive conception. On the one hand, it is not evaluative enough to declare whether it provides an ideal of being human or, on the contrary, traits of being human that we should overcome. On the other hand, it is not descriptive enough to only provide the empirical facts that could matter for a moral judgment and to add something to naturalistic conceptions. Its ambiguous status makes it impossible to apply a normative-c conception in any indirect argumentative function in this debate. This conclusion has not yet been developed in the theoretical framework, in which I argued that normative-c conceptions can at least theoretically be applied just as naturalistic and metaphysical conceptions can. Only the practical context, and one example of a practical context is discussed in this chapter, makes the ambiguous status of normative-c conceptions clear.

However, it might be more promising to use normative-v conceptions to understand what defenders and critics mean when they argue about what it means to be human in the context of the enhancement debate. Indeed, a normative-v conception can provide a foundation for an argument for or against designing children. Typically, it is used to condemn and stop the practice. A specific idea of human nature is then put forward that is incompatible with designing children. The inherent value of human nature is taken to put a limit on manipulation and enhancement (Bayertz 2003, 131–133 describes such a strategy). Such an account establishes an idea of how we should understand ourselves and which ideal of being human we should strive for. If we know what we should make of ourselves, we can understand how we should approach enhancement.

For instance, Jürgen Habermas argues for an understanding of the human being that he sees as incompatible with designing children regarding autonomy and moral equality (Habermas 2001). Parents who genetically enhance their children would, through the control they exert, undermine their children's ability to be autonomous and prevent them from entering relationships of moral equality. Designing children would restrict the child's freedom to choose a life of her or his own due to the irrevocable character of the demands resulting from being designed. These children could not regard themselves as free. In addition, it would jeopardize the foundations of moral equity and make the child an impaired moral agent. Hence, enhancement would endanger crucial aspects of our self-understanding. Leaving aside whether these objections against enhancement are valid (for a discussion see Buchanan 2011, 5–7), this is an example of an account of human nature as a source of substantial moral judgments. Michael Sandel's anti-enhancement project, which I will analyze below, goes in a similar direction.

Such an argumentation strategy is especially relevant to the debate on designing children in comparison to other enhancement discussions. It is clear that those who are affected by the selection procedure cannot decide for themselves. Hence, a libertarian framework that argues that everyone has to make her or his own decision about enhancement is impossible. Of course, parents can take over the responsibility of deciding for their children. Yet parental autonomy typically has limits as children are not considered to be their parents' property. A normative account of what human beings should make of themselves is then especially valuable.

In the same way, such a normative conception could also be employed to constrain the number of reasonable options for action. It would in this case not be used to indicate what should be done, but it would exclude some possibilities. For instance, it could be argued that selecting an embryo because of its specific neutral traits is not justified. One could argue that selecting an embryo because of a trait such as gender would express sexism and spreads a society-wide message that one gender is in some respect superior to another. This critique could be supported by a normative conception of the human that emphasizes the moral equality of the sexes. Such a conception should, of course, be worked out more specifically, but it seems to be possible in principle. The very same normative conception could, at the same time, be indecisive about the question of selecting because of traits that are generally considered advantageous, such as athletic or musical talents. The normative conception is then informing for the designing of children, but not decisive enough to tell us what, exactly, we should do.

A normative conception of the human being could decide for whom an argument about designing children is valid. This is determining the scope of an argument. In the debate about designing children, it means that an argument holds for all embryos who fulfill certain normative criteria and will be human beings in the relevant sense. What this exactly implies depends, of course, on the normative conception of the human. If certain standards of agency are used, it could, for example, mean that embryos with certain severe (genetic) conditions, which make it impossible to live up to these standards, are excluded from being treated according to the moral principles. An argument about the illegitimacy of designing children or, on the contrary, for a moral duty to design children might then not apply to them, since the concept of the human that has been used in the argument places them outside the scope of the argument.

After having considered the argumentative function of a scope, the next possible function that I would like to consider is specification. Here, an account of what we value about ourselves would make clear what a rather general moral principle entails for designing children. Of course, every moral principle must in some way or another be specified to be applied to a certain situation. Yet it is questionable how a normative conception of the human could carry out this function. A normative conception of the human being itself has to be specified to be applied or it already needs to be specific enough to be directly applied to the moral problem at hand. It cannot be employed to specify a more general principle.

The last role describes the circumstances of morality. Here, an account of what we value about being human would indicate new possibilities for what we could do. However, it is an argumentative function that comes into play at a very early point in the reasoning process because it makes thinking at all about morality possible. It is relevant before normative considerations can become relevant. This is why a normative conception of the human cannot describe the circumstance of morality.

Up to this point, we have seen that a normative conception of the human as an account of what we value about ourselves can fulfill a number of vital argumentative functions for discussing designing children. However, a normative-c conception is unhelpful for a moral evaluation of enhancement. This can be explained by the fact that this conception moves between a naturalistic conception and a stronger normative-v conception. It might be understood as existing between a naturalistic and a strong normative conception rather than as a conception in its own right.

4 Conceptions of the human in the debate

After having shown what distinguishing between different understandings of being human contributes to the analysis, I want to test to what extent these conceptions can indeed be found in the debate as it stands. I will show that naturalistic as well as normative conceptions play a role and that separating them provides clarity. These two conceptions are of different importance for the debate. Supporters and critics refer to different conceptions of the human being and thereby misunderstand each other. This diagnosis makes it difficult, if not impossible, to settle on a safe ground for reasoned disagreement before conceptions of the human are systematically discussed. The result is a confusing debate, which can only be clarified if both critics and supporters of designing children are fully aware of the notions of human nature that they are using and the argumentative functions that the different notions can and cannot play. To show in detail how different notions of the human being are being used in debates between critics and opponents, I will focus on John Harris's defense of enhancement and Michael Sandel's case against enhancement.

4.1 *Harris's defense of enhancement*

Harris defines enhancement as an improvement of human functioning that is by definition good for a person: “[i]f it wasn't good for you, it wouldn't be enhancement” (Harris 2007, 9). Hence, his definition of enhancement already contains an ethical evaluation. Genetic technologies, he argues, are no different from other methods used to promote people's interests. In combination with utilitarian principles, it follows logically for Harris that enhancement should be pursued out of a concern for welfare.

In addition to utilitarian elements, Harris's defense of enhancement also employs libertarian aspects.⁶⁰ As a libertarian, he is not much concerned with possible risks. Citizens should decide for themselves as long as there is no “serious real and present danger to either other citizens or to society” (Harris 2007, 72). Accordingly, he has far-reaching ideas of parental autonomy concerning designing children. Reproductive technologies should be accessible unless good and sufficient reasons can be shown against doing so (Harris 2007, 74). And the standards of danger should be set high (Harris 2007, 83).

⁶⁰ These two theories might even be in opposition to each other, but that is not relevant for the analysis I am pursuing in this chapter (for a criticism in this direction see R. Sparrow 2011).

Harris argues that it would be absurd to be on principle against changes in our nature (Harris 2007, 40). We are simply the product of an evolutionary process that has fundamentally changed us. Therefore, it would certainly be morally permissible to change ourselves for the better. Enhancing ourselves means intervening in the natural lottery of life for the sake of the good that this will bring about. We would “replace natural selection with deliberate selection, Darwinian evolution with enhancement evolution” (Harris 2007, 4). So we would improve evolution. We can even make ourselves better to the point that the human species changes into a new—and according to Harris certainly better—species (Harris 2007, 4/5). This could, for example, happen if we become immortal (Harris 2005, 15). Following Harris’s argumentation, there is nothing wrong with this consequence; instead, it is merely an acceptable side effect of the enhancement project.

In the same way, he argues in favor of designing children. He stresses that, naturally, we are simply a random combination of genes and asks: “[C]ould it be ethical not to be a designer?” (Harris 2007, 143). To him, the case seems to be clear. Designing children is allowed or even obligatory to gain beneficial traits. It is also permissible regarding the selection of neutral traits such as gender (Harris 2007, 143–159). These traits do not make an individual worse off. For Harris, these choices lie within the realm of parental autonomy.

Thus, in his case for enhancement, Harris refers to a naturalistic conception of the human. More specifically, his argument can be traced back to a species conception, as the title of his monograph, *Enhancing Evolution*, indicates. Harris stresses that no moral demands follow from this understanding of the human being. Morally speaking, evolution delivers random results and belonging to a certain species is neither good nor bad. This is also in accordance with my earlier analysis. Harris shows that, indeed, a naturalistic-s conception cannot be employed as a foundation for a moral argument (see for a similar interpretation T. Lewens 2012). He merely uses it to exclude the claim that any moral demands can be based on this understanding of who we are. Such a conception, he shows, does not provide good enough arguments to counter enhancement. Hence, Harris argues that we could be a better species than we are (or a worse one). From here on, he builds up his argument for enhancement based on utilitarian and libertarian principles. For his justification of enhancement, these various principles are much more decisive than his conception of the human.

So far, Harris’s conclusions follow from his premises. I have just argued that a naturalistic-s conception of the human being can only be employed as a

scope to determine for whom an argument is valid (section two). Harris could have used it in this way, but it would not have added anything to his conclusion that we have a moral duty to design children. The only contribution of the endorsement of the naturalistic-s conception to Harris's argument is that it holds for all *Homo sapiens*, but this is not very enlightening.

Clearly, if one is convinced that a naturalistic conception of the human being provides a sufficient understanding of who we are, then the argument could hold. But do we really see ourselves as nothing more than members of a species? Not even Harris seems to believe that. After all, his defense of enhancement relies on a utilitarian and libertarian framework. And these moral theories, in turn, have to put forward an account of how human beings should understand themselves in moral practice. For utilitarians, welfare is the central value. Human beings are essentially beings who can experience pleasure and whose quality of life can be better or worse. Libertarian theories see human liberty as most important. Safeguarding our autonomy and liberties are the guiding principles. It follows that Harris does make value judgments about human beings. His perspective on the human being is not purely a naturalistic one. But, *implicitly*, he puts forward a normative-v conception of human beings by using these moral principles.

I do not want to suggest that this is a problematic feature of Harris's argument. Rather, as I argued in my theoretical framework, it is inevitable that any moral argument refers to some kind of normative-v conception. Yet Harris apparently overlooks this point. He dismisses all kinds of normative-v conceptions of the human being: "many people talk as though being human was a moral imperative" (Harris 2007, 39). He acknowledges that 'human' or 'inhuman' are used as indices of morality or culture, but he finds this close to absurd. He stresses that evolution delivers only random results. Hence, he criticizes a normative-v conception on the basis of a naturalistic-s conception. Thereby, he seems to miss that these are two different and not two alternative ways to understand who we are as human beings. In addition, he does not seem to be aware that he himself *necessarily* has to use such a normative-v conception.

4.2 Sandel's case against enhancement

I will now proceed to show that Michael Sandel provides an argument against enhancement on the basis of a normative-v conception of the human being. According to him, a normative-v conception of the human being

works as a foundation for the moral judgment. I do not aim to scrutinize Sandel's full argument, but I want to show how he methodologically proceeds and what kind of steps in relation to a conception of the human are necessary for his argument to hold.

According to Sandel, enhancement is an attempt at mastery. It makes us fail to appreciate the giftedness of life (Sandel 2007, 26/27). Not appreciating the giftedness of life is problematic because it will change three fundamental values: humility, responsibility, and solidarity (Sandel 2007, 86). We lose something important, perhaps even essential to our lives, when we seek enhancement (see Hauskeller 2011, 77, whose paper is an excellent reconstruction of Sandel's argument). Of course, it needs to be understood better how those values change (see Sandel 2007, chapter 5) and, of particular importance here, what appreciating the giftedness of life involves.

First of all, seeing life as a gift is not necessarily a religious notion, according to Sandel (Sandel 2007, 93). Yet if we see life as a gift, we understand that our talents are not completely our own doing (Sandel 2007, 27). Though we know that an Olympic medalist puts hard work into getting that far, we believe that she or he also needs to be equipped with talents for which that person is not responsible. Seeing life as a gift means that we realize that there are things in this world that we should not use in any way we want to even if we can. A gift cannot be demanded, acquired, or earned, but it has to be accepted and kept (Hauskeller 2011, 63).

In the same way, parents should appreciate their children as a gift. Parental love is not dependent on certain characteristics of a child, but is unconditional (Sandel 2007, 45). Designing children stands in opposition to that insight because here, parents want to change what their children are like. Again, life is something we ought not to alter, and we should be open to the unbidden. But what exactly does this imply? On the one hand, Sandel argues that it is acceptable to intervene in life for the sake of health. Of course, parents should take a sick child to a doctor and they should strive for their children to be healthy. On the other hand, Sandel thinks that children should not be enhanced and made better than well. The norm of treatment is to preserve the "natural human functions that constitute health" (Sandel 2007, 47). Treatment is morally permitted, if not obligatory, but enhancement is not. This should make all attempts to design babies illegitimate. In the same way, the acceptable promotion of the development of one's child's talents does have certain limits (Sandel 2007, 46–52).

Therefore, what is needed for Sandel's project is a convincing account of this 'giftedness of human life.' It is essential to understand what exactly it is that we have to appreciate. He presupposes a specific understanding of the human being that is a normative reference point for his case against enhancement. The 'gift' or 'given' should be understood in a normative sense if it provides an account of the moral badness of enhancement. Naturalistic elements such as an account of natural functioning, which is his account of health as something we should strive for, can play a role in this conception of the human. But in any case, it needs a normative justification. Sandel himself argues that "it is not only a biological question" (Sandel 2007, 47). He strives to provide such a normative justification by referring to humility, responsibility, and solidarity. Hence, he turns against enhancement because of the moral status of human nature and an appropriate attitude towards it. Enhancement would make us view ourselves in the wrong way. This is a normative conception of the human that works as a foundation for a moral judgment against enhancement.

4.3 *Naturalistic versus normative conceptions*

I sketched two prominent arguments in the debate on designing children. Harris argues for enhancement and explicitly takes a naturalistic conception of the human into account. I argued that, at least implicitly, he also has to make use of a normative-v conception of the human. Sandel, in turn, explicitly outlines a normative-v conception. His argument against designing children is based on this understanding of what it means to be human.

Hence, Harris's understanding of the human being cannot be contrasted with Sandel's because they ask two different questions. This can at least partly explain their misunderstanding of each other's position. Harris, for instance, criticizes Sandel and asks: "Why [...] do we have to recognize and accept the gifted nature of normalcy but not the gifted nature of disease?" (Harris 2007, 112). Here, Harris does not acknowledge that Sandel's conception of giftedness refers to a normative instead of a naturalistic notion. Of course, this is not to say that Sandel's argument is convincing, but it makes clear that they pursue different argumentation strategies.

Tim Lewens makes the same argumentative mistake in his criticism of Sandel (T. Lewens 2009). As a philosopher of science, Lewens understands human nature in the naturalistic sense of the term and overlooks that Sandel employs a normative conception instead. For Lewens, human nature should be

understood as naming “all the typical features of human populations” (T. Lewens 2009, 354). He then decides that this is not helpful for distinguishing between interventions that permit natural capacities to flourish and those that override natural capacities. ‘Natural capacities’ are for Lewens simply those capacities “that a person could attain, given the right inventions” (T. Lewens 2009, 355). This comes very close to a description of canalized traits. If this is how we understand natural capacities, giving a person a special diet is just the same as giving a person special genes. Both are interventions that can allow the development of certain capacities. Hence, according to Lewens, Sandel does not succeed in putting forward an argument against enhancement.

Yet Sandel does not think of the ‘given’ as natural capacities in the sense that Lewens does. Sandel’s notion of the given is not the same as canalized traits, but, as I described it, it is a normative conception. Therefore, Lewens’ criticism misses the point of Sandel’s argument. Of course, once again, this does not mean that Sandel’s argument holds as it stands, but it indicates that Lewens’ critique is misunderstanding Sandel’s argument and hence that his criticism misses the point.

The analysis of the arguments of Sandel, Harris, and Lewens has shown that the distinctions between different notions of the human, and the argumentative roles they can play, are important to avoid misunderstandings. In addition, the foregoing discussion also indicated that different conceptions of the human being are not alternatives for each other. One cannot simply choose to employ either a normative or a naturalistic notion. Instead, these conceptions have different roles and functions in an argument, and one has to use a notion of the human being that will deliver the function one wants it to carry out. Importantly, I argued that any moral judgment needs to refer to a normative-v conception of what it means to be human. Whereas naturalistic conceptions are necessary to *understand* designing children, only normative ones can *justify* a moral statement on the problem. Normative conceptions are the kind of conceptions many who oppose designing children are apparently thinking of whenever they refer to “the human being.”

5 Conclusion: the force of different conceptions of the human

What can we conclude? First of all, it should be made explicit what kind of questions are debated when the human being is debated. A naturalistic conception does contribute to answering the same questions as a normative

conception. In the current debate on designing children, this often remains unclear. For this reason, critics of enhancement, such as Sandel, are attacked by supporters, such as Harris, on the grounds of a conception of the human to which they do not refer. This leads to misunderstandings and critiques that are missing the point.

Naturalistic and normative conceptions have different purposes. Naturalistic conceptions can be important for bioethical inquiries as they concern understanding the life sciences. Yet I showed that naturalistic conceptions have limits in terms of evaluating moral questions. These limits should be acknowledged whenever naturalistic conceptions are employed. The reference to the human being might in many cases be better understood as a reference to a normative-v conception. I argued that these normative conceptions are not merely informative, but are also *necessary* for moral arguments. Those who argue that enhancement endangers human nature or a core of being human are thinking of such a normative conception. Only normative-v conceptions can be employed to defend such a position. Clearly, justifying such a normative conception is far from trivial. Yet, given that we think that we are more than naturalistic beings, and given that normative conceptions of the human being are vital for our self-understanding, we have to discuss these normative conceptions to adequately discuss enhancement.

Part IV – Moving Forward

Chapter 7

Lessons for bioethics

Non-philosophers commonly demand that philosophy must be ‘relevant,’ which is, in most cases, taken to imply that philosophy should provide direct and quick answers to important questions about everyday life (Stevenson 1970, 258). Philosophers commonly reply in the one way or another that this demand is misconceived: just as theoretical physics or molecular biology need not be directly applicable, philosophy has its own specialized concerns. Philosophy might not always have a direct benefit, but is necessary as self-reflection, to clarify our thinking, to provide insightful critiques, and to satisfy our curiosity as human beings. Some philosophers even argue that the humanities and philosophy are necessary for a democracy, because humanities train critical thinking, transcending local loyalties and imagining the predicament of another person (M. Nussbaum 2010, 7). In my view, all these reactions are worth considering. Yet even though the public’s demand that philosophy should supply quick and easy answers to important questions of everyday life is misconceived, there is a sense in which philosophy is relevant to and necessary for such questions. The previous chapters tried to develop how philosophy, and more specifically theories of human nature, can and should be applied to moral questions. In the preceding chapters four to six, I showed how my theoretical framework can help to illuminate three debates in bioethics, how it clarifies misunderstandings between scholars holding different positions in those debates, and how it is necessary to understand the arguments put forward in the debates. As these case studies show, a choice of a particular account of human nature makes a difference when dealing with practical moral issues. We need such an account to make sensi-

ble moral judgments, but also to understand discussions properly and to understand disagreements about moral issues at all.

What have we learned from this? In this chapter, I will draw general conclusions: first, regarding the results from the previous chapters, and, second, regarding employing these results in other debates. In the first section of this chapter, I will discuss the conclusions that have been drawn so far and present them in a new structure, which starts with the different aims of the theoretical framework. The purpose of the first section is to provide the ground for extending these results to make them useful for future discussions. The second section will provide more details of such a future application of the theoretical framework. In this latter section, I want to extend the theoretical framework and describe its practical applicability. The aim is to develop an alternative at a most general level for dealing responsibly with accounts of human nature in normative debates in bioethics and applied ethics. Thereby, I will mainly focus on bioethics and questions related to disease, disability, and enhancement to render the conclusions as specific as possible.

1 Results

1.1 *Impetus*

Western culture likes binaries (Solomon 2012, 599): we divide the world into normal and abnormal, healthy and sick, beautiful and ugly, and good and bad. It simplifies life and provides us with control over what we think it is right to aim for and right to do. Disability and enhancement are commonly constructed as such a binary. Disability is loss, and disability is sad and bad for you. Enhancement, by contrast, is reaching for more, is being better and stronger. Disability is less of all that we want to be and enhancement is more of it. This dissertation had its starting point in debates about disability and enhancement. Enhancement allows us to construct our own capacities to some extent. Disability is perceived as the awkward, undesired flip side of a plea about being special. But disability and enhancement converge at an understanding of what it means to be human. I argued in chapter one that to deal adequately with disability and enhancement, we should understand better who we are.

The discussion of concepts of disability, disease, and enhancement in the current literature could be understood as a solution for this quest to under-

stand who we are. But in chapter one, we have seen that an analysis of these concepts is not sufficient to provide answers to ethical questions. We are in need of a broader perspective on the human being. So far, such a broader perspective is not adequately taken into consideration in bioethics. Bioethicists try to stay neutral about theories of human nature, or at least avoid an explicit discussion about it. Yet this strategy is not sufficient in the light of enhancement and disability. On the one hand, disability and enhancement make it necessary to consider a broader perspective on accounts of human nature. If we want to be able to deal adequately with disability and enhancement, we cannot stay neutral on accounts of human nature. On the other hand, the possibility of enhancement and the reality of disability both demonstrate that our view of the human being is changing. Our understanding of ourselves as human beings is challenged. Disability and enhancement change how we see ourselves. Human nature has become ever more contingent. In that sense, disability and enhancement not only demand a broader perspective on human nature, but they also have implications for such a perspective.

It is, therefore, necessary to analyze the relation between questions about human nature and bioethics. This is needed to make progress in bioethics. Accomplishing such an analysis is the main purpose of the dissertation.

1.2 *General aims*

In chapters two and three, I provided a theoretical framework to analyze and understand the role of accounts of human nature in moral judgments. This framework was then used to analyze three cases in chapters four to six. The theoretical framework does not attempt to argue for or against particular accounts of human nature as such, but it discusses *how to integrate* accounts of human nature in applied ethics. It distinguishes and reconstructs different roles that accounts of human nature are factually playing in applied ethics to evaluate how convincing these roles are and tries to make a proposal about what a plausible role for those accounts could be. The theoretical framework starts with questions on a meta-level. An investigation on a meta-level means that the theoretical framework attempts to answer the question of how theories of human nature should be made fruitful in applied ethics. The theoretical framework does not defend one specific position on the relation between theories of human nature and moral judgments. Yet such a strategy does not continuously remain on a meta-level—in fact, I assume it can never completely ignore other levels—but it also has implications for other levels

of discussion as will be made explicit shortly. These different levels of discussion are not independent from each other and, therefore, the argument trickles down. The argument has an impact on several dimensions of ethical analysis, all informed by conceptions of human nature. The theoretical framework fulfills different aims for debates in applied ethics:

1. *Diagnostic aim*: It is a tool for locating a source of a moral disagreement.
2. *Elucidative aim*: It shows how various normative positions can be defended.
3. *Advisory aim*: It makes arguments for more substantial moral judgments.

These different aims of the foregoing discussion can be distinguished from each other amid their relation to each other. Before I expand on these different aims on the basis of the case studies in chapters four to six, I will clarify their general meaning.

First, the theoretical framework has a *diagnostic aim* as it is a tool for locating a source of a moral disagreement. Particular moral judgments require that one endorses particular kinds of notions of the human. The endorsement of a particular notion of the human being that is included (whether implicitly or explicitly) in one's argument has important normative implications. The theoretical framework can be used to detect conceptions of the human being that are put forward in a justification of a moral judgment and identify the conceptions' argumentative functions. As was demonstrated in chapters four to six, different conceptions of the human being and their different argumentative functions are often not adequately distinguished in moral debates as they stand. The unclear uses of references to the human being are problematic within debates in applied ethics. The lack of adequate distinctions blurs the understanding of different positions on a moral question. It veils the reasons scholars have for defending a particular standpoint in a debate and the grounds they have on which to justify their moral judgment. In that respect, the theoretical framework is a diagnostic tool for understanding better how and why participants in bioethical debates defend their position and where a source of their disagreements is located.

Second, the theoretical framework shows how various positions can be defended in relation to issues in applied ethics and, thereby, it has an *elucidative aim*. This may well be the most important function of the theoretical

framework. Its purpose is to show what difference being explicit about references to human nature makes and the different argumentative functions these references can have. I try to show what different positions in bioethics entail and on what assumptions they rest. Thereby, I want to give an account of what is needed to defend certain moral judgments and how and to what extent it is possible to make certain arguments. The distinctions made in the theoretical framework should lead to a higher-level discussion of bioethical issues. In that sense, the theoretical framework makes meta-interventions in bioethical debates. These meta-interventions are, then, not meant to justify specific normative standpoints, but to illuminate routes towards a number of normative standpoints. Disagreement with what has been said should, accordingly, not be situated merely at the level of moral judgments, but in the first place at the level of the strategies that are identified to defend specific moral judgments.

Third, these aims also lead to another aim. The theoretical framework has an *advisory aim* and makes arguments for more substantial positions. In the light of the first and second aim, I wanted to develop a taxonomy of possible understandings of human nature and their role in moral arguments. Yet by sketching possibilities and impossibilities to defend some positions, the theoretical framework does not stay completely neutral regarding different moral judgments. It does more than making possible argumentative routes and moral judgments visible. The theoretical framework indicates which argumentative routes are more problematic than others and which routes look promising. Thereby, it also excludes some moral judgments. It gives reasons for believing that a justification is going to be successful if it is made in one way rather than another. Even if the framework does not develop a complete substantial argument on a moral issue, at least it works out directions that such an argument might take and gives guidance about deciding what to defend in specific cases.

1.3 *General conclusions*

The general conclusions that I have drawn in the theoretical framework, as well as in the case studies and partly already in the theoretical framework, are in line with all three of the dissertation's aims. In this section, I will sum up, generalize, and extend these conclusions.

Diagnostic aim

All three case studies benefited from an analysis of the roots of disagreement between participants in the debates. I identified the disagreement as lying in the presuppositions about human nature and in which role these presuppositions play. Such an analysis is necessary to understand the nature of the disagreement between defenders of different positions on a case. This analysis is, therefore, the first step to starting to discuss difficult ethical issues.

In relation to the Ashley treatment, I argued that the debate suffers from a lack of solid philosophical arguments. The debate seems to be stuck between entrenched positions. A detailed analysis of arguments in the debate is required to find a sensible solution for Ashley and children in a similar situation. I demonstrated that arguments either in favor of or against the treatment have to make controversial assumptions about our relationship to our body. These assumptions are important, because they are necessarily presupposed as part of a justification strategy in favor of or against a therapeutic intervention, but they remain mostly implicit. This essential disparity should be made explicit and be put up for discussion to further the debate.

A similar point was analyzed in chapter five. Disagreements about social policies on disability are commonly regarded as disagreements about what is the right model of disability to use. Accordingly, models of disability are debated as if these would yield the solution to finding out what society owes to disabled people. Yet the notion ‘model of disability’ is an unclear notion. It is far from evident that a model has the force that the debate assumes it has. It is, therefore, important to understand what kind of claims are incorporated in a model of disability and how such a model can be employed in an ethical argument. The theoretical framework clarifies these points. With the help of the theoretical framework, I argued that models of disability should be understood as metaphysical accounts of disability. Nonetheless, these models are regularly applied in the discussion as if they incorporated moral as well as political aspects. Their original meaning seems to be lost in the debate. Furthermore, the debate, as it stands, suggests a dichotomy: either models of disability should comprehensively determine social policy, or they are taken to be irrelevant to policy questions. My theoretical framework shows that this is an invalid dichotomy. The theoretical framework, therefore, provides the tools for understanding and discussing the crucial relationship between models of disability and social policy.

In chapter six, I argued that the unclear reference to the human being is an important source of misunderstandings in the debate on designing children.

Both defenders and critics of designing children build their arguments on specific but different conceptions of the human being. They, accordingly, accuse the other side of making invalid assumptions about the human being. Yet both defenders and critics fail to see that they employ distinct conceptions of the human being. This obstructs understanding each other's positions and settling on safe grounds for reasoned disagreement. The theoretical framework can be employed to confirm that different kinds of conceptions of the human play a role and, thereby, to understand why participants in the debate disagree with each other. I identified both naturalistic and normative conceptions. Whereas defenders of designing children typically work with a naturalistic conception, critics aim at developing normative conceptions. Their reference to the human being is located at two different levels. These different conceptions of the human being can be distinguished and evaluated separately within the theoretical framework.

Elucidative aim

The theoretical framework cannot only be used to deconstruct arguments as they are currently defended in debates. More importantly, it indicates how better arguments can be developed, as these give a reflective function to accounts of human nature. For the Ashley treatment, I showed what form robust arguments for and against the treatment can take. I made the assumptions of the arguments explicit and showed which implications follow from them under which conditions. In the most general way, I tested different routes to justify and argue for and against the treatment to make explicit which argumentative steps every argument has to make. It has become clear, thereby, that aspects of a normative conception of the human being determine a moral judgment on the Ashley treatment. Such a normative conception of the human is controversial and, therefore, it should be made explicit to find a sensible treatment solution for children in a situation such as Ashley's.

In chapter five, I argued that models of disability cannot be the sole basis on which moral claims rest, which is against the common implicit understanding in much of the literature. The theoretical framework identified models of disability as metaphysical conceptions of the human being. For this reason, models of disability can only have various indirect argumentative functions to justify a social policy. Although models of disability are not sufficient alone to be used to form a moral judgment, they can interact with moral principles to formulate claims of justice for disabled people. I sketched a

number of possibilities for these argumentative functions and how such an argument could then be completed. These argumentative functions stem from the theoretical framework.

In relation to the debate on designing children, I demonstrated, with the help of the theoretical framework, how the reference to the human being can be used responsibly. Conceptions of the human are invoked in two steps of an argument: first, to understand an attempt to design children, and second, to evaluate this attempt. I analyzed what naturalistic and normative conceptions of the human being can mean in various argumentative functions regarding understanding and evaluating an attempt to design children. Using the theoretical framework, I presented possible ways to construct valid arguments that integrate conceptions of the human being.

Advisory aim

My analysis is elucidative yet also advisory in nature. The analysis showed that certain positions can be better justified than others. At a minimum, I hinted at more substantial positions that are justified better than others. In chapter four, I did not put forward a conclusive argument for or against the Ashley treatment. But I showed that an argument against the Ashley treatment from a perspective of dignity and rights seems to encounter difficulties. The assumptions that have to be made along the route of this argument are difficult to defend. As I analyzed it, though, an argument for the treatment that starts from an account of quality of life seems reasonable if a few empirical facts hold. However, whether these facts hold is something that falls outside the scope of this dissertation.

In the chapter five, it turned out that the term ‘models of disability’ is confusing. This term seems to have lost its original meaning in the discussion and is now used as a broader notion. It is used widely as if the distinction between ontological, moral, and political aspects was not necessary. This, I think, is problematic at least. Ultimately, these are very different aspects that need different justifications. This is the reason why the theoretical framework distinguishes between different kinds of conceptions of the human in the first place. Hiding these differences under the notion ‘models of disability’ hinders a critical discussion of what we owe to people with disabilities. I argued that different kinds of conceptions of the human relate in different ways to substantive moral judgments. These different possible argumentative functions become invisible in the debate as it stands, and this is problematic.

For this reason, the notion ‘models of disability’ is problematic and should only be used carefully.

Regarding the discussion about designing children, it has become clear that normative conceptions of the human are essential for the debate. Whereas naturalistic conceptions are necessary to understand the possibilities for designing children, only normative ones can justify a moral statement in this regard. Normative conceptions are the kind of conceptions many opponents of enhancement seem to have in mind when they refer to the human being.



Taking into account everything that has been considered so far, we have seen that practical and real bioethical issues are in need of a fundamental analysis of the role they give to accounts of human nature. Such fundamental philosophical work is necessary, first of all, to understand bioethical discussions, but, secondly, to justify diverse moral judgments on bioethical questions. Specifically, distinguishing between different understandings of the human and different argumentative functions allows better arguments to be made in bioethics. This is the reason for the relevance of the theoretical framework as it was developed.

Currently, it is often unclear in debates what it means when ‘the human being’ is invoked and which argumentative role such a reference can indicate. However, as my theoretical framework made explicit, only some of the combinations of kinds of conceptions and argumentative functions make sense in specific contexts. Naturalistic and metaphysical conceptions of the human being, generally, should not be overrated. On their own, they cannot justify a moral judgment. Yet they can have various indirect argumentative functions in interaction with moral principles. Finally, we cannot make any moral judgments without employing a normative conception of the human being. I showed that arguments for and against the Ashley treatment have to refer to aspects of such a normative conception. Disability models, being metaphysical accounts of the human being, are not sufficient to justify a social policy. Only normative conceptions of the human being can be used to evaluate designing children. That means that we have to argue for a normative conception of the human being if we want to be able to deal responsibly with bioethical challenges. Within a normative conception of the hu-

man, the question of the human being is not only a matter of descriptive facts. It is a normative question and it is of fundamental importance for what we should do.

My dissertation has shown that conceptions of the human being are essential for moral reflection and for a normative justification of our actions. At the same time, however, it is not sufficient in the majority of cases to rely on these conceptions of the human being to come to substantive moral judgments. In addition, my discussion focused on and was motivated by debates about enhancement and disability. The preceding discussion made clear that these debates have important implications for our general understanding of the human being. These cases on the limits of what it means to be human are more central to our self-understanding than one might have assumed.

2 Further applications

What do these results entail for future debates in bioethics? I think that the theoretical framework taken together with the insights of the case studies reveal a number of lessons for bioethics and applied ethics more generally. In this section, I will discuss the possibility and plausibility of and the conditions for moving forward with the results established up to this point. I will address a number of points that are crucial for the future application of the framework.

Who can make use of the theoretical framework?

The theoretical framework is intended to be useful for the target audience of this dissertation. The framework is mainly targeted at bioethicists, and especially at those working on disability, disease, and enhancement. I demonstrated in this dissertation that bioethics is in need of a discussion about human nature. I presented an account of how a theory of human nature should be integrated into bioethics and what bioethics can gain from it.

The theoretical framework on accounts of human nature in moral judgments presents a fundamentally philosophical account. This philosophical account is relevant to bioethics. It is one instance that shows that engaging with bioethics also includes an engagement with philosophy. Engaging with philosophy is, therefore, necessary to be able to justify bioethical judgments. All

kinds of bioethical questions can benefit from it. This means, in turn, that bioethicists working on all levels in bioethics can make use of it. It is not only relevant for academic bioethics, but at the same time for clinical bioethicists, policymakers, and laypersons, and so on. Yet this is a dissertation in philosophy and, accordingly, the presentation of the framework is aimed at a philosophically inclined audience. Even though the content of the theoretical framework is relevant for all bioethicists, the style of presentation is not suited to all of them. After all, I cannot reasonably expect that parents of children such as Ashley will read this dissertation before they make a treatment decision for their child. Instead, I think that it is the task of the clinical ethicists in such a case to explain the philosophical background to caretakers to enable them to make responsible decisions. Most importantly, bioethics as a discipline should make my distinctions on human nature part of the general discourse. I want to make available a more nuanced conceptual vocabulary to help to sort out the complexities of bioethical cases.

A second group that can make use of the theoretical framework is philosophers working on theories of human nature. So far, much of this research has taken place separately from bioethics. In the light of what has been argued thus far, this is precarious. Standpoints on theories of human nature actually make a difference for bioethical issues. In addition, the distinctions that I made in the theoretical framework are not sufficiently available in the philosophical literature. The importance of these distinctions only becomes fully clear in their application to practical cases. In that sense, the practical context is necessary to illuminate philosophical theories of human nature. Accordingly, philosophical anthropologists should feel encouraged to engage with bioethical questions.

Which debates is the framework relevant for?

I applied the theoretical framework to three problematic questions that are present in real life and the literature and that are all related to disease, disability, and enhancement. I analyzed these three problematic bioethical issues and concluded that the distinctions made in the theoretical framework are relevant in a proper analysis and understanding of the bioethical issues. It seems, first, that the framework can also be applied to other debates that engage with disease, disability, and enhancement. After all, the framework could have been applied to any other debate in these fields. In addition, there are a number of debates that do not explicitly discuss disability and enhancement, but that actually refer to issues as they are raised in those de-

bates. Debates about moral status, discrimination, genetic testing, prenatal technologies, and sex-changing surgery are just some examples. They all engage with a notion of an atypical human being and its implications for moral questions. Sex-changing surgery undergone by transgender people, for instance, raises the question of what aim surgical interventions to change our body have and under which conditions they are justified or should even be publicly financed. We can assume, therefore, that these kinds of debates would benefit from a theoretical framework to reason from accounts of human nature to moral judgments.

Second, more generally, the theoretical framework is relevant whenever ‘the human being’ is invoked within a justification of a moral judgment. It can help to provide clarity about the reference to the human being. General and unclear notions, such as ‘models of disability’ or *Menschenbild* in German [image of the human], should alert us that an explicit discussion is necessary. The theoretical framework can provide the tools for such an explicit discussion. Moreover, there could be new or ongoing debates in which it seems that the human *should* be used as a reference point, but it is not yet employed as such. These are debates in which the contingency of human nature is at stake.

A third area of application is bioethics more generally. As bioethics is concerned with the life sciences, the human being is in many cases central to the enquiry. Henceforth, the theoretical framework might prove useful for achieving clarity about the understanding and the role of the human being in a moral justification. Consider, for example, organ transplantation: suspicions against organ transplantation are raised from the perspective that the human being should not be seen as a machine with parts that can be replaced by other parts. This would not be an understanding of the human being that is in accordance with human dignity. Yet it is questionable, first, whether the practice of organ transplantation necessarily relies on such a mechanistic view of the human being and second, what human dignity implies for organ donation. In such a debate, the theoretical framework can help to identify sources of disagreement between various positions and shed light on possible argumentation strategies to justify divergent moral judgments.

What level of concreteness should issues for the application of the framework have?

The three case studies that I analyzed in the preceding chapters differ regarding the abstractness of the moral issue they discuss. Chapter four discusses individual treatment decisions, chapter five analyzes a specific question in a debate, and chapter six is concerned with a debate as a whole. Chapter four, for example, has to take many particularities of Ashley's situation into account that are absent in chapter six. The question at stake was becoming less and less specific as the dissertation proceeded. I used the framework for all these different kinds of debates. I reached results in all cases. It seems, therefore, that none of these different types of moral issues needs to be left out in future applications. However, a different mode of application might be advisable for different kinds of cases. I will now turn to that question.

In what sense should the framework be applied?

This dissertation is situated within the debate on methods in applied ethics. But it also has to make use of certain methods itself. In chapters four to six, I addressed three case studies by applying the theoretical framework that I developed in chapters two and three. How, exactly, do I apply the theoretical framework to the case studies? I have to take a stance on what 'applied' in applied ethics means. For all three cases, I show why the distinctions I make in the theoretical framework are relevant in a proper analysis and understanding of those cases. The applications should clarify the meaning, relevance, and implications for bioethical debates of the theoretical distinctions and insights developed in the theoretical framework. Beyond this general methodological diagnosis, I tried several ways of applying the theoretical framework to the case studies. The degree to which the theoretical framework is applied and moves to the forefront differs between the cases. I started in chapter four by giving the theoretical framework only a limited role in the analysis of how concepts of the human being are used in the discussion about the Ashley treatment. For instance, metaphysical and naturalistic conceptions of the human are not mentioned here, and the different argumentative functions are only analyzed at the end of the chapter. In chapter five, I employed the framework in a somewhat stronger sense. Here, several argumentative functions are systematically assessed to understand the relation between models of disability and social policy claims. In chapter six, I investigated the 'designing children' debate from the perspective of the framework. In this chapter, the theoretical framework is very prominent. This chapter starts with conceptions of the human as they were identified in

the theoretical framework. I continued by identifying several of these conceptions in the debate on designing children. The more abstract the guiding question of the case study was, the stronger the focus on the theoretical framework became, and vice versa. All strategies proved possible in the sense that it was indicated that the theoretical framework provided a viable and important alternative for approaching the case in question.

Applying a theory to a case is always a matter of keeping a balance between doing justice to the specific characteristics of the case and assessing to what extent a particular approach to the case can make a difference. For an individual treatment decision with many specific particularities, more attention must be paid to the particular details of the case. Yet for a very general debate, the application of the framework might feel almost forced and abstracted from the discussion as it is taking place. A middle ground in all respects is probably most convincing. However, from just three chapters that use different applications, it is difficult to say something in general about this problem. Most importantly, for future applications it is necessary to keep in mind that different methods of application exist. The method that is best suited to moving the case forward should be chosen as this is what the theoretical framework was constructed for.

How should one proceed to apply the framework?

After having identified the target audience, the right debates, and the method of application, the framework can be employed. Thereby, it is helpful to distinguish the three different aims of the framework as they are outlined in the first section of this chapter. It is not always necessary to apply the framework in all of its dimensions and in accordance with its different aims, and it could, for instance, also be used to only show how to defend certain positions on a bioethical issue. This acknowledgment also includes the consequence that the framework can still partly be applied if one disagrees with parts of it (and I like disagreement—it is what philosophy is all about). Those who do not trust my analysis of normative conceptions, for instance, can still apply the sections on naturalistic and metaphysical conceptions.

3 Conclusion: directions for further research

In this chapter, I have reflected on the main results of this dissertation and provided a strategy for the future application of these results to other debates in applied ethics. By way of conclusion, I want to investigate directions for further research that aim at such an application of the theoretical framework. I will distinguish, therefore, between research questions on the level of the theoretical framework itself and those on the level of the application of the framework.

In relation to the theoretical framework, it could, first, be investigated whether there are additional kinds of conceptions and argumentative functions that have been left out so far. For example, it might be fruitful to develop an evolutionary conception of the human being as a third naturalistic conception. I included ideas about evolution within an understanding of the human being as a species (naturalistic-s conceptions), but these ideas might be comprehensive enough to stand on their own. Such an evolutionary conception could also be informative for ethical debates, as ideas about evolution are regularly invoked. This presumes, however, that a valid evolutionary conception can be developed that can still be distinguished from the naturalistic conceptions already mentioned. Evolutionary psychology as represented by Leda Cosmides and John Tooby (Cosmides and Tooby 1997; Tooby and Cosmides 2005), for instance, puts forward such a conception of the human. Yet the basic tenets of evolutionary psychology are often criticized already (Bolhuis et al. 2011; Downes 2014a).

Second, in chapters two and three, I started to evaluate in a general sense which combinations of kinds of conceptions and argumentative functionings prove useful under which conditions. I argued, for example, that only normative-v conceptions, which provide an account of what we value about ourselves, can be used as a foundation. Such an analysis, which links kinds of conceptions with argumentative functions even more explicitly, could be extended. This would facilitate a simpler application of the theoretical framework to new debates.

Third, I identified normative conceptions of the human as especially important for applied ethics. In chapter two, I discussed several strategies to provide more detail about these conceptions and what methodological challenges these strategies encounter. It would be important for ethical discussion to develop these kinds of conceptions.

Regarding the future application of the framework, it would first of all be necessary to make the framework available in an accessible way for all diverse bioethicists. If the framework can indeed be useful for bioethics on all levels, it should also be able to reach bioethicists working on all levels. This dissertation cannot accomplish this aim on its own. Writing geared at different audiences would be needed in addition. Secondly, whether the framework can also be adopted for discussions in applied ethics as broadly understood should be tested. In this dissertation, the main part of the discussion focused on bioethics, as the issues that were analyzed are especially vivid here. But, as was argued in the last section, this approach could also prove insightful for social and political ethics. Lastly, it would be helpful to achieve more clarity as to which method of application is best under which conditions. I tried several methods of application for different kinds of cases. The application was more rigid the more abstract the case in question was. My discussion, after all, could not prove that one method is superior to another.

For now, let us not focus on what remains to be done, but on what has been done. Philosophy might not, or at least not always, be able to supply quick and simple answers to difficult questions about everyday life. However, I hope to have shown that there is a sense in which philosophy is relevant and even necessary to answer those questions.

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Samenvatting

Van menselijke aard tot morele oordelen Een frisse blik op debatten over handicap en enhancement

Als mensen zijn we niet perfect. Voor een deel leren we met die imperfectie te leven. Misschien waarderen we onze grenzen zelfs of ervaren die niet eens als zodanig. Veel gehandicapte mensen willen bijvoorbeeld niet worden ‘genezen’ omdat hun handicap deel van hun identiteit uitmaakt. Niet iedereen wil onsterfelijk worden of het vermogen hebben om een heel boek in een paar seconden te lezen. Desondanks proberen we onszelf al sinds mensenheugenis op verschillende manieren te verbeteren. In de afgelopen jaren zijn de mogelijkheden voor zulke verbeteringen uitgebreid en diepgaander van aard geworden. Mensen die eigenlijk gezond zijn gebruiken geneesmiddelen en medische technologieën om slimmer, sneller en attentier te worden: enhancement oftewel mensverbetering. Een veelgebruikt voorbeeld van enhancement is doping. Ook het selecteren van embryo’s met bepaalde eigenschappen is een vorm van enhancement van de mens en sommigen vinden dat antidepressiva evengoed enhancement zijn. Vaak is de grens tussen medisch ingrijpen bij een ziek of gehandicapt mens en enhancement niet duidelijk. Oscar Pistorius, de hardloper met twee beenprothesen, werd plotseling als ‘enhanced’ beschouwd toen hij bij de Olympische Spelen voor niet-gehandicapte sporters wilde starten. Zijn prothesen zouden hem een oneerlijk voordeel geven.

Deze en vergelijkbare debatten over handicap en enhancement vormen het startpunt voor mijn onderzoek. In debatten over handicap en enhancement staat een aantal bioethische problemen centraal. Deze problemen hebben als centrale vraag hoe we ons moeten verhouden tegenover mensen met een handicap en tegenover de wenselijkheid van enhancement. Ik geef in mijn

proefschrift geen kant-en-klaar antwoord op deze vraag maar ik ontwikkel een hulpmiddel om deze en soortgelijke vragen met een frisse blik systematisch te analyseren. Ik denk namelijk dat een beschouwing van de menselijke aard in deze debatten over het hoofd wordt gezien. Het is mijn doel om in het proefschrift te beargumenteren hoe ideeën over menselijke aard in de bioethiek geïntegreerd kunnen en moeten worden en wat de bioethiek hiermee opschiet. Ik toon hoe overtuigende morele argumenten gemaakt kunnen worden en welke rol ideeën over de menselijke aard hierbij spelen. Ik laat zien dat verschillende ideeën over de menselijke aard in de bioethiek bediscussieerd zouden moeten worden om morele oordelen beter te kunnen rechtvaardigen. Vragen over de menselijke aard zijn essentieel om bioethische debatten te kunnen begrijpen en op een adequaat niveau te bediscussieren. Tot nu toe werden deze vragen niet systematisch geïntegreerd in de bioethiek.

In het eerste hoofdstuk begin ik met de stelling dat de aard van de mens, of hoe we onszelf als mens zien, centraal zou moeten staan in debatten over handicap en enhancement. Ik zie debatten over handicap en enhancement als sterk met elkaar verbonden. Enhancement en handicap veranderen ons lichaam of onze geest. Eigenschappen die we als vanzelfsprekend beschouwen kunnen verdwijnen, verminderd of worden versterkt. Dat betekent dat we na moeten denken welke van onze eigenschappen we belangrijk vinden om te herstellen, behouden of zelfs willen versterken. Met andere woorden, we moeten oog hebben voor de diversiteit van onze menselijke eigenschappen voordat we kunnen oordelen over het aanpassen van die eigenschappen. We moeten nadenken over hoe we ons tot de biologische aspecten van ons mens-zijn willen verhouden en hoe deze aspecten op hun beurt gerelateerd zijn aan wat we als waardevol beschouwen. Debatten rondom enhancement en handicap zetten daarmee de vraag naar de mens zelf opnieuw op de agenda.

Vervolgens pak ik de centrale probleemstelling van mijn proefschrift op een theoretische manier aan. Ik vraag me af wat we eigenlijk bedoelen als we over ‘de menselijke aard’ spreken. Ik onderscheid in hoofdstuk twee drie verschillende betekenissen die ik in de literatuur terugvind. Ten eerste praten we praten over de mens als een soort dier en bestuderen onszelf natuurwetenschappelijk. Ten tweede benaderen we de mens vanuit de metafysica. Wat maakt bijvoorbeeld dat een mens door de tijd heen dezelfde identiteit behoudt? In een derde betekenis van de mens hanteren we een normatief perspectief. Het begrip mens zegt in die betekenis iets over een status van waarde. Net als het woord ‘pad’ in het Nederlands zowel een smalle weg als een amfibie kan betekenen, kan ‘de mens’ dus ook verschillende betekenis-

sen hebben in een moreel debat. Deze betekenissen moeten niet slechts als simpele alternatieven van elkaar worden gezien, want het verschil in betekenis zit op een dieper niveau.

In hoofdstuk drie ga ik na welke rol of argumentatieve functie de verwijzing naar de menselijke aard in een moreel argument kan spelen. Het inzicht uit het tweede hoofdstuk dat ‘de menselijke aard’ verschillende betekenissen kan hebben is niet voldoende voor het ontwikkelen van een valide argument in een moreel debat. Om een valide argument voor een moreel oordeel te maken moeten we weten hoe we de verschillende aspecten van het argument precies moeten gebruiken. Vergelijk het met het bakken van een taart: als je weet dat je er zowel suiker als chocoladeglazuur voor nodig hebt, dan weet je nog steeds niet hoe je een goede taart moet bakken. We moeten dus begrijpen welke rol de verschillende betekenissen van de mens kunnen spelen. Ik werk vijf verschillende rollen uit, waarbij ik toelicht dat niet elke betekenis van ‘de mens’ elke rol in een argument kan spelen. Mijn theoretisch kader in hoofdstuk twee en drie neemt uitdrukkelijk geen stelling voor of tegen bepaalde ideeën over de menselijke aard. Ik werk verschillende opties uit om op deze manier ideeën over de menselijke aard in morele oordelen te integreren en ik laat zien hoe die integratie precies in zijn werk gaat.

In hoofdstukken vier tot zes pas ik het theoretisch kader uit de hoofdstukken twee en drie toe. Elk hoofdstuk behandelt één specifiek debat over handicap en enhancement. In deze hoofdstukken test ik in hoeverre mijn theoretisch kader daadwerkelijk een verschil kan maken voor bio-ethische debatten en of dit kader het mogelijk maakt om morele oordelen beter te rechtvaardigen.

In het vierde hoofdstuk analyseer ik de behandeling van het ernstig meervoudig gehandicapt meisje Ashley, een inmiddels bekende casus in de bio-ethiek. Door haar handicap is Ashley kortgezegd geestelijk en motorisch ongeveer even ver ontwikkeld als een baby van drie maanden. Toen ze zes jaar oud was, kreeg ze een hormoontherapie om niet verder te groeien en werden in een operatie haar baarmoeder en borstknopen verwijderd. Het doel van deze behandeling was om Ashley een zo hoog mogelijke kwaliteit van leven te geven. Omdat ze op deze manier relatief klein zou blijven, werd het mogelijk voor haar ouders om haar thuis te blijven verzorgen. Ook zou ze geen last krijgen van menstruatiekrampen of borsten die storend zouden kunnen zijn. Ashley's behandeling is omstreden. Ik laat zien dat een grondige filosofische analyse nodig is om een goed moreel oordeel, zowel positief als negatief, over deze behandeling te kunnen vellen. Sterker nog, argumenten voor en tegen de behandeling berusten allebei op specifieke controversiële assumpties over onze relatie met ons lichaam. In dit hoofdstuk verbind ik

deze assumpties met verwijzingen naar de mens die ik eerder in het tweede hoofdstuk heb geanalyseerd. Ik concludeer dat het nodig is om verwijzingen naar de mens te bespreken als we de behandeling van Ashley op een adequate manier willen bediscussiëren.

In hoofdstuk vijf kijk ik naar de implicaties van verschillende manieren om een handicap te zien. In de jaren '80 en '90 van de vorige eeuw hebben gehandicaptenactivisten en onderzoekers zich sterk gemaakt om een handicap niet langer als alleen een medisch probleem te zien. Ze stelden dat de omgeving ook bepaalt wat we als een handicap beschouwen. Personen die niet kunnen lopen zijn niet per se gehandicapt omdat ze een probleem met hun benen hebben, maar omdat we trappen bouwen in plaats van liften en hellingbanen en omdat rekken in de supermarkt twee meter hoog zijn. Deze manier om over handicap na te denken vinden velen overtuigend. Ik zie dit perspectief als een specifieke verwijzing naar de mens. In het debat wordt vaak verondersteld dat deze manier om een handicap te zien automatisch ook betekent dat we bepaalde dingen voor mensen met een handicap zouden moeten doen. Als iemand bijvoorbeeld door het bouwen van trappen gehandicapt wordt, dan zou dit betekenen dat het bouwen van trappen niet gerechtvaardigd kan worden. Ik beargumenteer dat een begrip van handicap niet zulke sterke implicaties kan hebben. Abstracter gezegd kan deze verwijzing naar de mens niet zo'n sterke argumentatieve functie in een moreel oordeel krijgen. Dit heb ik in mijn theoretisch kader laten zien en kan ik nu op een enigszins praktische vraag toepassen. Uiteraard kunnen begrippen van handicap wel andere, zwakkere argumentatieve functies hebben die in het debat tot nu toe over het hoofd worden gezien.

Hoofdstuk zes behandelt het debat over designerbaby's. De meeste ouders willen dat hun kinderen intelligent, sympathiek en gezond zijn. Een goede opvoeding kan een steentje bijdragen, maar inmiddels wordt ook genetische aanleg niet meer alleen aan de natuur overgelaten. We kunnen embryo's vóór terugplaatsing selecteren en zaad- en eiceldonoren met specifieke eigenschappen gebruiken. In de toekomst is wellicht nog meer mogelijk. Mag dat, of zijn we misschien zelfs verplicht om dit te doen als we het beste voor onze kinderen willen? Ik laat zien dat verschillende posities in dit debat duidelijker worden als we een onderscheid maken tussen verschillende betekenissen van menselijk aard. Het is belangrijk om de verschillende betekenissen uit elkaar te halen omdat ze andere rollen in het debat spelen. Op dit moment gebeurt dit nog niet. Het gebruik van deze verschillende betekenissen leidt tot misverstanden in het debat wat een goede discussie niet meer mogelijk maakt. Als de verschillen die ik in mijn theoretisch kader maak in

het debat over designerbaby's worden gehanteerd, dan kunnen we het debat over designerbaby's verbeteren.

In het laatste hoofdstuk verbind ik de resultaten uit de toepassingen van het theoretisch kader met elkaar en met het theoretische kader zelf. Ik vraag me af wat deze resultaten op een algemeen niveau voor andere, vergelijkbare casussen betekenen. Ik beschrijf hoe mijn theoretisch kader precies kan worden toegepast. Ik laat zien hoe ideeën over menselijke aard geïntegreerd kunnen en moeten worden in de bio-ethiek en waarom dit belangrijk is. Als we over enhancement en handicap discussiëren, dan kunnen we een expliciete discussie over de menselijke aard niet vermijden. De mogelijkheid van enhancement en de realiteit van handicap maken ook duidelijk dat onze manier om over de mens na te denken veranderbaar is en verandert. In dit opzicht maken enhancement en handicap het niet alleen noodzakelijk om over de mens na te denken, maar hebben ze ook implicaties voor ons denken over de mens.

Zusammenfassung

Von der menschlichen Natur zu moralischen Urteilen Eine Neuausrichtung von Debatten über Behinderung und Enhancement

Als Menschen sind wir nicht perfekt. Zum Teil können wir mit unseren Unvollkommenheiten leben. Vielleicht schätzen wir unsere Grenzen sogar oder erfahren sie nicht einmal als solche. Viele behinderte Menschen wollen zum Beispiel nicht „geheilt“ werden, weil ihre Behinderung Teil ihrer Identität ist. Nicht jeder würde gerne unsterblich sein oder die Fähigkeit haben, ein ganzes Buch in wenigen Sekunden zu lesen. Dennoch versuchen wir seit Menschengedenken uns in unterschiedlichen Weisen zu verbessern. In den letzten Jahren sind die Möglichkeiten hierfür nicht nur zahlreicher geworden, sondern auch weitreichender. Menschen, die eigentlich gesund sind, nehmen Medikamente und machen Gebrauch von medizinischen Technologien, um schneller, intelligenter und aufmerksamer zu werden: Enhancement. Ein häufig verwendetes Beispiel für Enhancement ist Doping. Auch die Selektion von Embryonen mit bestimmten Eigenschaften ist eine Form von Enhancement. Nach Einschätzung einiger Fachleute handelt es sich bei der Einnahme von Antidepressiva ebenso um Enhancement. Häufig kann die Grenze zwischen einem medizinischen Eingriff an kranken oder behinderten Personen auf der einen Seite und Enhancement auf der anderen Seite nicht eindeutig gezogen werden. Oscar Pistorius, der Sprinter mit zwei Beinprothesen, galt plötzlich als „enhanced“, als er an den Olympischen Spielen für nicht-behinderte Sportler teilnehmen wollte. Der Einwand lautete, seine Prothesen gewährten ihm einen unfairen Vorteil gegenüber gewöhnlichen Beinen.

Diese und ähnliche Debatten über Behinderung und Enhancement bilden den Ausgangspunkt meiner Dissertation. In Debatten über Behinderung und Enhancement nehmen eine Reihe von bioethischen Problemen einen zentralen Platz ein. Diesen Problemen liegt die gemeinsame Frage zugrunde, wie wir uns gegenüber Menschen mit Behinderung und dem Wunsch nach Enhancement verhalten sollen. Ich gebe in meiner Dissertation keine abschließende Antwort auf diese Frage. Stattdessen entwickle ich ein Hilfsmittel, um diese und vergleichbare Fragen auf eine neue Art und Weise systematisch zu analysieren. Ziel meiner Dissertation ist zu zeigen, wie Ideen von der menschlichen Natur in bioethische Debatten integriert werden können und sollten und was die Bioethik hierdurch gewinnt. Ich arbeite heraus, wie überzeugende moralische Argumente aussehen und welche Rolle Ideen von der menschlichen Natur hierbei spielen. Verschiedene Ideen von der menschlichen Natur müssen in der Bioethik diskutiert werden, um moralische Urteile besser rechtfertigen zu können. Fragen über die menschliche Natur sind damit entscheidend für das Verständnis bioethischer Debatten, und um diese Debatten auf einem angemessenen Niveau führen zu können. Bislang wurden diese Fragen jedoch nicht systematisch in die Bioethik integriert.

Im ersten Kapitel stelle ich die These auf, dass der Natur des Menschen, oder unserem Selbstverständnis als menschliche Wesen, in Debatten über Behinderung und Enhancement ein zentraler Stellenwert zukommen sollte. Debatten über Behinderung und Enhancement sind aus meiner Sicht stark miteinander verbunden. Enhancement und Behinderung beeinflussen unseren Körper oder Geist. Eigenschaften, die wir für selbstverständlich hielten, können verschwinden, verringert oder verstärkt werden. Das bedeutet, dass wir darüber nachdenken sollten, welche unserer Eigenschaften wir gegebenenfalls wiederherstellen, behalten oder verändern wollen. Mit anderen Worten: Wir müssen die Diversität unserer menschlichen Eigenschaften anerkennen und hierauf reflektieren, bevor wir über unseren Umgang mit diesen Eigenschaften hinreichend differenziert nachdenken können. Wir müssen darüber nachdenken, wie wir uns gegenüber den biologischen Aspekten unseres Menschseins verhalten wollen und wie diese Aspekte wiederum damit zusammenhängen, was wir als wertvoll erachten. Mit den Debatten über Behinderungen und Enhancement rückt damit auch die Frage nach dem Menschen selbst in den Fokus.

Anschließend widme ich mich der zentralen Problemstellung meiner Dissertation. Was meinen wir eigentlich damit, wenn wir von „dem Menschen“ oder „der menschlichen Natur“ sprechen? Im zweiten Kapitel unterscheide ich drei verschiedene Weisen, diese Frage zu verstehen. Wir beziehen uns

erstens auf den Menschen als eine Art Tier und studieren ihn naturwissenschaftlich. Zweitens können wir den Menschen in einer metaphysischen Betrachtungsweise in den Blick nehmen. Was macht beispielsweise die Identität eines Menschen aus? Schließlich können wir, drittens, aus einer normativen Perspektive über den Menschen nachdenken. Aus dieser Perspektive ist mit dem Begriff des Menschen zugleich eine normative Aussage über dessen spezifischen Wert oder Status verbunden. So wie der Begriff „Ball“ im Deutschen sowohl ein kugelförmiges Spielzeug als auch eine Tanzveranstaltung bezeichnen kann, können dem Begriff „Mensch“ in einer ethischen Debatte unterschiedliche Bedeutungen zukommen. Diese verschiedenen Bedeutungen können nicht einfach als Alternativen füreinander betrachtet werden, denn dafür ist der Bedeutungsunterschied zu groß.

Im dritten Kapitel untersuche ich, welche Rolle oder argumentative Funktion dem Verweis auf den Menschen in einem moralischen Argument zukommen kann. Das Ergebnis des zweiten Kapitels, dass der Verweis nach der menschlichen Natur verschiedene Bedeutungen haben kann, reicht für sich genommen nicht aus, um ein gültiges Argument in einer ethischen Debatte zu entwickeln. Hierfür müssen wir genau wissen, welche Rolle der Verweis nach der menschlichen Natur in einem gültigen Argument spielen kann. Dies kann mit dem Backen eines Kuchens verglichen werden: Wenn wir wissen, dass wir sowohl Zucker als auch Schokoladenglasur benötigen, wissen wir noch nicht, wie man einen Kuchen backen muss. Wir müssen daher verstehen, wie die verschiedenen Zutaten gebraucht werden sollen oder wie die verschiedenen Bedeutungen des Menschen in einem ethischen Argument verwendet werden können. Ich arbeite fünf solcher Rollen heraus, wobei ich zeige, dass nicht jede Bedeutung der menschlichen Natur jede dieser Rollen einnehmen kann. In dem theoretischen Teil in Kapitel zwei und drei argumentiere ich ausdrücklich nicht für oder gegen bestimmte Möglichkeiten, den Begriff der menschlichen Natur zu verstehen. Stattdessen entwickle ich verschiedene Möglichkeiten, diese Ideen von der menschlichen Natur in moralische Urteile zu integrieren.

In den Kapiteln vier bis sechs wende ich den theoretischen Teil aus den Kapiteln zwei und drei praktisch an. In jedem dieser Kapitel wird eine spezifische Debatte über Behinderung und Enhancement behandelt. Das Ziel besteht hier darin zu untersuchen, inwieweit mein Theorierteil bioethische Debatten tatsächlich verändert und ob es so möglich wird, moralische Urteile besser zu rechtfertigen.

Im vierten Kapitel analysiere ich die Behandlung des schwerst mehrfachbehinderten Mädchens Ashley, ein bekannter Fall in der Bioethik. Etwas ver-

einfach formuliert ist Ashley durch ihre Behinderung sowohl motorisch als auch geistig etwa auf dem Entwicklungsstand eines drei Monate alten Babys. Im Alter von sechs Jahren bekam sie eine Hormonbehandlung, um ihr weiteres Wachstum zu verhindern. Zudem wurden in einer Operation ihre Gebärmutter und ihre Brustgewebe entfernt. Das Ziel dieser Behandlung bestand darin, eine höchstmögliche Lebensqualität für Ashley zu gewährleisten. Da sie nun relativ klein bleiben wird, ist es ihren Eltern möglich, die aufwendige Pflege weiterhin zuhause durchzuführen. Außerdem wird Ashley keine Menstruationsbeschwerden haben oder Brüste, die sie eventuell stören könnten. Ashleys Behandlung ist umstritten. Ich zeige, dass eine systematische philosophische Analyse notwendig ist, um ein moralisches Urteil über diese Behandlung zu fällen. Argumente für und gegen die Behandlung basieren auf bestimmten umstrittenen Annahmen über unser Verhältnis zu unserem eigenen Körper. Ich verbinde diese Annahmen mit Verweisen auf den Menschen, die ich im zweiten Kapitel analysiert habe. Ich schließe daraus, dass es notwendig ist, diese Verweise auf den Menschen zu besprechen, wenn wir über die Behandlung von Ashley in einer adäquaten Weise diskutieren möchten.

Im fünften Kapitel beschäftige ich mich mit den praktischen Konsequenzen verschiedener Möglichkeiten, Behinderung zu verstehen. In den 80er und 90er Jahren des letzten Jahrhunderts haben Behindertenrechtsaktivisten und Forscher sich verstärkt dafür eingesetzt, eine Behinderung nicht länger als ein rein medizinisches Problem einer Person zu betrachten. Sie argumentierten, dass die Umgebung zumindest mitbestimmt, was wir als Behinderung ansehen. Personen, die nicht laufen können, sind nicht unbedingt darum benachteiligt, weil ihre Beine nicht adäquat funktionieren, sondern auch, weil wir Treppen bauen anstatt Aufzüge und Rampen und weil die Regale im Supermarkt zwei Meter hoch sind. Diese Art, Behinderung zu verstehen, finden viele überzeugend. Ich analysiere diese Position als eine bestimmte Weise, über den Menschen zu sprechen. In der ethischen Debatte über Behinderungen wird nun häufig angenommen, dass diese Weise über Behinderung nachzudenken zugleich impliziert, dass wir Menschen mit Behinderungen bestimmte Handlungen schuldig sind. Wenn jemand etwa durch das Bauen von Treppen behindert wird, dann dürfen nicht mehr ausschließlich Treppen gebaut werden. Ich argumentiere, dass ein Verständnis von Behinderung nicht solche weitreichenden Konsequenzen mit sich trägt. Abstrakter formuliert, kann dieser Verweis auf den Menschen nicht so eine starke argumentative Funktion in einem moralischen Urteil einnehmen. Das habe ich in meinem Theorieteil gezeigt und kann dieses Ergebnis nun auf eine praktische Frage anwenden. Jedoch können Konzepte von Behinderung andere,

schwächere argumentative Funktionen erfüllen, die in der Debatte bislang übersehen wurden.

Im sechsten Kapitel befasse ich mich mit der Debatte über Designer-Babys. Die meisten Eltern möchten, dass ihre Kinder intelligent, sympathisch und gesund sind. Eine gute Erziehung kann hierzu einen Beitrag leisten. Aber mittlerweile braucht auch die genetische Ausstattung nicht mehr ganz der Natur überlassen zu werden. Wir können Embryonen vor dem Transfer in die Gebärmutter auswählen und Samen- und Eizellspender mit bestimmten Eigenschaften verwenden. In der Zukunft ist vermutlich noch viel mehr möglich. Dürfen wir von diesen Möglichkeiten Gebrauch machen oder sollten wir es sogar, wenn wir das Beste für unsere Kinder wollen? Ich zeige, dass verschiedene Positionen in der Debatte besser zu verstehen sind, wenn wir verschiedene Bedeutungen der menschlichen Natur unterscheiden. Dies ist deshalb wichtig, weil diese Bedeutungen jeweils unterschiedliche Rollen in der Debatte spielen. Bislang wurden diese Bedeutungen jedoch nicht hinreichend differenziert. Dadurch kommt es zu Missverständnissen in der Debatte, was einer produktiven Diskussion entgegensteht. Wenn die verschiedenen Bedeutungen, die ich in meinem Theorieteil herausgearbeitet habe, in der Debatte über Designer-Babys unterschieden werden, würde dies dazu beitragen, der Debatte eine differenzierte Form zu verleihen.

Im letzten Kapitel verbinde ich die Ergebnisse aus der Anwendung des theoretischen Teils miteinander und mit dem theoretischen Teil selbst. Ich gehe der Frage nach, was diese Ergebnisse auf einer allgemeinen Ebene für vergleichbare Fälle bedeuten können, und lege dar, wie mein Theorieteil auf diese Fälle angewandt werden kann. Schließlich erläutere ich, auf welche Weise Ideen von der menschlichen Natur in die Bioethik integriert werden können und warum dies wichtig ist. Wenn wir über Enhancement und Behinderung angemessen diskutieren wollen, dann ist eine Diskussion über die menschliche Natur unvermeidlich. Die Möglichkeit von Enhancement und die Realität von Behinderung machen auch deutlich, dass unsere Art über den Menschen nachzudenken veränderbar ist und sich verändert. In dieser Hinsicht machen Enhancement und Behinderung es nicht nur nötig, über den Menschen nachzudenken, sondern haben auch Konsequenzen für unser Denken über den Menschen.

Curriculum Vitae

Caroline Harnacke was born in Aachen, Germany, on April 19, 1985. She earned a Bachelor degree in Philosophy & Economics (2007) and a Master's degree in Applied Ethics (2010, *cum laude*). During her Bachelor studies, she spent a year abroad in South Africa. After her Bachelor's graduation, she worked for nearly two years at Rambøll Management GmbH, Berlin, a consultancy for the public sector. For her Master's studies, she lived in Linköping (Sweden), Stellenbosch (South Africa) and Utrecht (The Netherlands). After her studies, she conducted research at the Institute for Biomedical Ethics in Zurich, Switzerland. From June 2011 until May 2015 she wrote her dissertation at the Ethics Institute, Utrecht University. Her dissertation was supervised by Prof. dr. Marcus Düwell, Prof. dr. Ingrid Robeyns and Dr. Joel Anderson and financed by the Netherlands Organisation for Scientific Research (NWO). Caroline is now a postdoctoral researcher at the Ethics Institute, Utrecht University.

Quaestiones Infinitae

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