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Rethinking Well-being in Biomedical Ethics

Barbara Stroop

Fach: Philosophie

Making Sense of Well-being in Biomedical Ethics

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1. Introduction

'It shouldn't be about life at any cost but about someone's quality of life'[1]

These words spoken by the wife of the British man Tony Nicklinson before her husband eventually died in August 2012 have received attention around the world. Tony Nicklinson suffered from Locked-in Syndrome after having had a stroke in 2005. Ever since then he had wanted to die and considered his well-being as severely diminished due to the 'increasing indignity and misery' (The Telegraph 2012b) which he went through. Because he was suffering from almost total paralysis, he was physically not able to commit suicide. Nicklinson thus started a legal battle for a right to assistance in dying. Shortly after losing the campaign, Nicklinson died of pneumonia. His case once again raised public awareness to the already contentious debate on whether there should be a moral and legal right to assistance in dying in situations in which patients request it, since they judge their well-being as diminished to such an extent that they wish to die.

The notion of well-being not only plays an important role in bioethical issues dealing with the final phase of life as in the case of Tony Nicklinson: when browsing through well-known newspapers such as *The New York Times* one comes across a great number of articles such as 'Should a Fetus's Well-being Override a Mother's Rights?' (Greenhouse 2000), which obviously alludes to the field of reproduction and the beginning of life. The German weekly newspaper *Die Zeit* raises the question, 'In the Interest of the Patient's Well-being?'[2] (Reuter 2011) when dealing with the topic of appropriate treatment for patients suffering from mental illness. The notion of well-being accompanies us in bioethical discussions right from the beginning of our lives and through to their end. This holds true for the media but also for conversations in everyday life about difficult decisions which have or had to be taken. We might, for instance, chat with our neighbour over the garden fence about the recent death of our great Aunt Margaret, who suffered from severe dementia, and the difficul-

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[1] The Telegraph 2012a

[2] Translation by author. Original title: 'Zum Wohl des Patienten?'.

ties we had to face when deciding whether to forego life-sustaining treatment prior to her death. In this case we might make comments such as: ‘it was for the best since her life was not worth living anymore’, ‘it was a happy release’ or ‘it is good that her suffering has ended’ in order to ease our conscience and justify our decision. These remarks inevitably allude to the notion of well-being and the case described is just one of many examples of dilemmatic situations in everyday life in which we apply the concept of well-being as an argument or within a justification for a decision we have already taken.

Also in political and academic deliberations within the context of biomedical ethics the notion of well-being constitutes an important point of reference. This was clearly noticeable in the discussions which took place when the German Parliament passed a new law allowing preimplantation genetic diagnosis, albeit within strict limits, in July 2011. Participants in the debate from various disciplines such as medicine, law, philosophy and theology as well as politicians from different parties made frequent references to the well-being of the prospective parent and the future child.

Taking a step back from everyday discussions about well-being and delving into the philosophical appraisal of the concept, it becomes clear that well-being is, above all, applied when utilitarian approaches underlie the arguments, which maintain that the collective overall well-being is to be maximized. Nonetheless, the notion of well-being also comes into play within lines of reasoning tied to other approaches such as deontological theories. In addition to being an *explicit* point of reference in many bioethical[3] debates, well-being is frequently also considered *implicitly* where other lines of argumentation are concerned, as in, for instance, discussions about the notion of autonomy. In these cases of implicit reference, well-being has a rather hidden presence which one might easily overlook. Furthermore, there are a number of concepts applied in medical ethics that are closely related to – or appear to be used as if they are equivalent to – the notion of well-being as for example *quality of life*, *welfare*, *flourishing* or the notion of *a good life*. Although obviously not identical in meaning, these various terms and concepts still refer to one specific idea rather than to a manifold variety of related concepts. Overall, against the background of the furnished tapestry regarding the reference to the notion of well-being it be-

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[3] The book focuses on the field of medical ethics. Therefore, in the following the term *bioethics* is applied with a narrow connotation in order to refer to the domain of medical ethics.

comes apparent that it enjoys great popularity in current bioethical debates, both in academia and everyday life.

The notion of well-being is vague

When analysing the way in which the concept of well-being (and related terms) is applied in bioethical debates, it is recognizable that it has a broad connotation and is referred to in many different ways. Sometimes it is applied with reference to the feelings of the patient and at other times to refer to his/her health status determined by medical facts without taking into account the subjective experience of the patient, to mention just one example. Although well-being establishes an important point of reference, there appears to be not a suggestion of agreement as to what *well-being* actually is. Different concepts are used as a matter of course. We can therefore claim that there is an equivocation present with regard to the application of the term well-being in biomedical ethics. The term is used in order to refer to a plethora of different meanings. In consequence, the concept remains vague within this field and is a matter of constant contest.

One of the most controversial issues is the basic question as to whether the notion of well-being is correctly captured by subjectivist or objectivist approaches or a combination of both. According to subjective accounts, that which contributes to a person's well-being depends on what he/she desires or what makes him/her happy.[4] Objectivist accounts, on the other hand, refer to specific objective goods as requirements for well-being, which do not depend on a person's desires or on what makes him/her happy. When surveying the distribution of alternative concepts of well-being we can ascertain that in the various debates in biomedical ethics there are different concepts prevalent. There appear to be discussions in which subjective conceptions prevail whereas in others objective accounts of well-being are predominant. Tensions between rival concepts even occur within some of the debates themselves. Despite the prevalent ambiguities, the different concepts of well-being are often applied as a matter of course within the respective debates and there are rarely clear reasons provided for the choice of a specific approach. Sometimes even discus-

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[4] However, there are a number of different ways of understanding the subjective/objective differentiation and this is simply one way of making a distinction. We will come back to this distinction in due course.

sions at cross purposes within biomedical ethics appear to be the consequence of the vagueness of the concept of well-being.

However, the realization that there are alternative concepts of well-being and that these are a matter of dispute does not in any way break new ground. Different concepts of the essence of well-being have been at the centre of debates in ethical theory since antiquity. There are a number of sustained philosophical reflections on this matter (Griffin 1996; Sumner 2003). Issues linked to these reflections deal with, for example, what we should improve in our lives in order to live well, and whether the components of a good life are universal or culturally variant. The differentiation between three major kinds of theories has become a standard: hedonism, the desire-fulfilment theory and, finally, the objective list theory.[5] Hence, we can conclude that there are various approaches to the notion of well-being present in the field of biomedical ethics as well as in the philosophical discussions dealing with this notion.

The need for a common language

There are various ways of dealing with the presence of alternative conceptions of well-being and the vagueness of the notion within biomedical ethics: one could, for instance, argue that the existence of various concepts is a good thing since it does justice to the pluralism with regard to the notion of a good life which is to be found in our society. However, there appear to be a number of practical reasons why there is a need for clarification and a reduction of the plurality of concepts within the realm of biomedical ethics. In order to avoid discussions at cross purposes, it is vital that there is a common language concerning the notion of well-being. In health care many comparative statements with regard to well-being are made, which have far reaching implications for the individuals concerned and in many cases effect large numbers of people. This, for instance, is the case when scarce medical resources are allocated or when different medical procedures are evaluated in terms of their efficacy in adding quality to a patient's life. The outcome of such comparisons should serve as guidance for health and medical care. If the assessments reached by practitioners are based on different concepts of well-being or quality of life, they could easily be misleading. This would, in turn, have serious consequences and, as in

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[5] This three-way division is taken from Derek Parfit (1984): Appendix I. A detailed discussion can be found in chapter 2.

the case of the allocation of donor organs, could even include questions of life or death.

Furthermore, the equivocation of the term well-being leads to problems in the context of medical treatment when it comes to resolving cases of high urgency. Too great a demand is placed upon health professionals if they are asked to differentiate between different concepts of well-being when making decisions as to how particular patients should be treated. As John Arras points out: 'They have neither the time nor the inclination to discuss matters on this level …' (Arras 2010). Taking all these different aspects into consideration, the field of biomedical ethics obviously is in need of clarification with regard to the notion of well-being and strongly requires a common language. The meaning ascribed to well-being in the various debates cannot and should not be left to chance. Well-being needs to have a clearly defined character so that the notion can have a meaningful function within biomedical ethics and to avoid the potential for discussions at cross purposes. This proposition constitutes the underlying hypothesis and starting point of this book. But how are we to tackle this problem and how can we identify what kind of concept of well-being would be appropriate for the context of biomedical ethics?

1.1. The goal and methodology

Obviously the development of an adequate concept of well-being constitutes a demanding and comprehensive task which can only be accomplished step-by-step. This book sets out to provide an initial step towards this comprehensive task by establishing a critical analysis of the present state of affairs with regard to the role which well-being currently plays in biomedical ethics. Therefore, the central question which this book aims to approach is: what role does well-being play in the realm of biomedical ethics? In answering this question we will try to *rethink the notion of well-being within the context of biomedical ethics*.

But what exactly are we to understand by the expression *role of well-being*? Within this book the term role is used in a specific connotation that encompasses two dimensions: the *presence* and the *character* of well-being. When examining the presence of well-being it is investigated whether well-being plays an overt or a subliminal role in bioethical discussions: it has already been briefly mentioned in the above that the notion of well-being sometimes appears to have a hidden presence. It will be investigated where exactly this subliminal presence occurs and why that is. In addition, the presence of well-being in the face of other prevalent notions in the respective debates is explored. When enquiring into the *character* of well-being within biomedical ethics the meaning which the term has will be analysed in the various debates. Do subjective or objective dimensions prevail? Are narrow or broad concepts of well-being applied? Are the discussions mainly concerned with the restoration, the protection or the promotion of well-being? These are the questions on which we focus where the character of well-being is concerned in the following. Furthermore, it is examined why exactly the character of well-being adopts specific attributes. Also the underlying reasons for changes which occur with regard to well-being's character will be analysed.

Over the course of four analytic chapters the argument will be established that the concept of well-being plays manifold roles in the context of biomedical ethics and is subject to the influence of other notions prevalent in the various debates, namely the notions of *moral status*, *human nature*, *justice* and *autonomy*. The influences deriving from the respective notions occur with regard to the presence as well as to the character of well-being. On the grounds of our findings three different types of influences will be identified: requirements, instrumentalisations and interferences. It is argued that especially the latter two kinds of impact are troublesome since they provoke illusions about the character of well-being in biomedical ethics. Influences which are classified as requirements, in contrast, are considered to be of a different kind since they express specific needs on a concept of well-being to function in biomedical ethics and thus bring us closer to the 'true' character of well-being within this field.

Identifying the role of well-being and the influences depicted above requires a critical review of the literature on major debates in biomedical ethics, which will be provided in the following chapters. As a detailed examination of well-being within the whole literature on the broad field of biomedical ethics cannot be accomplished within the scope of this book, a careful selection of specific debates to be analysed has been carried out. For this reason, the following provides an exemplary analysis of four major biomedical topics, namely discussions concerning the *beginning of life*, *enhancement*, the *allocation of scarce goods* and those dealing with the *end of life*. There are several reasons underlying the selection of these four debates: first of all, the subjects listed can be considered eminent controversial issues discussed in the present context of biomedical ethics. All of them have received considerable attention and are present to a great extent in the literature within the field of biomedical ethics. Hence, in order for the analysis of the role of well-being to grasp the main points of contention, these four debates form the basis of the examination. Moreover, in each of the debates well-being appears to have, at least to some extent, a changing presence: in some debates the reference to the notion is immediately apparent whereas in others it is not directly recognizable. Hence, the exploration of the four debates is likely to provide us with a diverse picture of the role of well-being within biomedical ethics. Finally, the exploration of the listed debates is biographically comprehensive since the discussions placed under scrutiny range from the beginning to the end of life.

In addition, it should be noted that in the following chapters we will not embark upon a comprehensive analysis of the four broad fields of discussion mentioned in the above but rather set a specific focus within each debate. When dealing with discussions concerning the beginning of life we will concentrate on the role of well-being within the debate on prenatal testing and selection. In the case of the enhancement debate the main concern will be procedures of non-therapeutic mood enhancement. Within the chapter on the role of well-being in discussions on the allocation of scarce goods the example of organ allocation is dealt with and finally, in the context of end of life issues we concentrate on the role of well-being in the debates on assistance in dying and foregoing life-sustaining treatment. These respective focuses are set to enable a detailed and in-depth analysis of the role of well-being in the various debates.

The literature-selection is for the most part taken from the academic debates dealing with the four bioethical subjects under consideration, that is to say the works of scholars from the fields of philosophy, medicine, law and theology. Nonetheless, chapters 5 and 6, which concentrate on debates on organ allocation and euthanasia, also include an analysis of the role of well-being within the criteria as applied in practice. This is due to the fact that in both cases the academic debates are held against the background of the specific criteria applied in practice and are strongly influenced by them. Hence, in order to gain a better understanding and to provide a complete picture, the analysis of the role of well-being within discussions on organ allocation and euthanasia also takes into account the criteria as applied in practice. Since the practical aspect is of lesser importance within the other two debates, namely prenatal testing and selection and mood-enhancement, the exploration of these discussions is only concerned with the academic debate.

In the chapters dealing with prenatal testing and selection and on euthanasia special attention is drawn to discussions in Germany. This is in order to examine how events during the Nazi era influence the reference to well-being in biomedical ethics, above all, in this country.

1.2. The structure of the book

In order to pave the way for the analysis of the four major bioethical debates chapter 2 provides preliminaries with regard to the concept of well-being. It gives an initial idea of the character of well-being, thus equipping the reader with a provisional and rough idea about the philosophical discussions dealing with this matter. In addition, this chapter lays a first foundation for the analysis of the role of well-being by establishing the analytical framework that will be put to use. This framework is based upon the three-way division of approaches to well-being which constitutes a standard point of reference in the philosophical discussions. Thus, the main body of this chapter provides a taxonomy of the major kinds of theories of well-being deployed in ethical theory. The taxonomy encompasses the three standard theories of well-being: hedonism, the desire-fulfilment theory and the objective list theory. This classification functions as a framework for the analysis carried out in the following part of the book. Moreover, it is depicted that the three alternative theories can, to varying degrees and in different respects, be classified as objective or subjective accounts of well-being. On the grounds of this finding, also close attention is paid to the objective/subjective divide when dealing with well-being. All of these aspects need to be addressed prior to embarking upon an investigation into the different bioethical discussions since a coherent analysis of the character of well-being requires a framework by means of which we can identify and classify alternative concepts.

In chapter 3 the journey through the four bioethical debates starts covering the various stages of life. The point of departure is the discourse dealing with prenatal testing and selection. Before a detailed exemplary analysis of the reference to the notion of well-being in the debates dealing with the practice of prenatal diagnosis (PND) and selective abortion and the procedure of preimplantation genetic diagnosis (PGD) is established, the procedures in question are characterized in a first step (3.1.). After these preliminaries have been furnished, the analysis of the role of well-being in debates on prenatal testing and selection is carried out against the background of the framework consisting of the conceived philosophical theories of well-being (3.2.). Thereby, the focus is first set upon the consideration of the well-being of the prospective parents. The findings of the analysis illustrate that the notion of well-being often has a concealed presence hidden behind the principle of procreative autonomy which has an overriding importance within the debate on prenatal testing and selection. The reference to the future child's well-being constitutes the next point of interest. Whereas considerations of the future child's well-being frequently occur in the Anglo-American debate, they are rarely to be found within the German discussions. It is shown that the role which well-being plays where the future child is concerned strongly depends on the notion of moral status (3.3.). This notion is found to influence well-being's presence as well as its character. Also the identified opposition between objectivist and subjectivist concepts of well-being is attributed to differing notions of prenatal moral status. On the basis of the findings, it is concluded that the framework for analysis provided in chapter 2, which consists of the three alternative theories, is not sufficient for our goal. This is due to the fact that it cannot provide a clear insight into the opposition of subjective and objective concepts of well-being. For this reason, it is then supplemented by a subjective/objective scheme which enables us to differentiate between the ontological, the epistemic and the evaluative level. This amendment will also be applied in the subsequent chapters.

Within chapter 4 the journey through the various fields of discussion reaches the middle phase of life. The role of well-being in the debate on so-called 'mood enhancement' is explored within this chapter. After a short introduction as well as a brief summary of preliminary definitions (4.1.), the examination concentrates on well-being based lines of reasoning within opposing arguments in the discussion on enhancement (4.2.). First of all the focus is set on arguments which reject the procedures in question as brought forward by the so-called bioconservatives such as *The President's Council on Bioethics*. In a second step, the consideration of well-being within contentions in favour of mood enhancement are scrutinized. Within this section we take a closer look at arguments purported by transhumanists such as Nick Bostrom and Julian Savulescu and at the lines of reasoning of the American psychiatrist Peter D.

Kramer. The findings suggest that, contrary to expectations, rival lines of argumentation in the debate on mood enhancement do not necessarily rest upon rival concepts of well-being. With regard to the character of well-being, there is a prevalence of broad objective concepts. Finally, this chapter pays special attention to the relationship of the concept of well-being and the notion of human nature within the debate on mood enhancement (4.3.). It is extrapolated that the essentialist notion of human nature leads to a prevalence of objective concepts of the character of well-being in the realm of debates on enhancement.

In Chapter 5 the role of well-being in the context of organ allocation is explored. As in the previous chapters, first of all a short introduction to the subject is provided, namely the quandary of organ allocation (5.1.). It has already received a short mention in the above, that the academic debate on organ allocation is held against the background of the criteria currently applied in practice. For this reason we explore, to begin with, the role of well-being within the criteria and models currently applied (5.2.). Having ascertained a first impression of the subordinate role which well-being has within this context, the focus is set on the examination of well-being as a consideration in the broader academic debate (5.3.). Above all, the role of well-being within two specific criteria, that is to say the criteria of *outcome* and *patient need*, is explored. The findings of the analysis illustrate that rather than playing a prominent role, the concept of well-being constitutes one of many considerations in the context of organ allocation. With regard to the character of well-being, there is a striking prevalence of narrow objectivist concepts. Moreover, the results suggest that, within the context of organ allocation, the concept of well-being cultivates a special relationship with the principle of justice. In a next step, this relationship is subject to a more detailed examination (5.4.). It is shown that the principle of justice is very powerful within the debate on organ allocation and strongly influences the presence and character of well-being. The prevalence of objective concepts of well-being is attributed to the weight given to the notion of justice.

The journey through bioethical issues in the various phases of life finally reaches the end of life in chapter 6. The role of well-being in discussions on euthanasia or, to be more precise, the debates on assistance in dying and foregoing life-sustaining treatment is explored. First of all some introductory facts about the various practices concerned in discussions on euthanasia are furnished (6.1.). As in the case of the analysis of the role of well-being in organ allocation, we take a look at two examples of practice (6.2.): physician-assisted dying in the Netherlands and physician-assisted suicide in the U.S. state of Oregon. After having dealt with the role well-being plays in these two jurisdictions, the analysis concentrates on the academic discussions (6.3.). Two parts constitute this section: the first part examines the reference to well-being in discussions on assistance in dying in the case of competent patients while the second deals with well-being in debates on foregoing life-sustaining treatment in the case of incompetent patients. The results of the examination indicate that well-being has a partly subliminal presence and that further investigation is needed with regard to the relationship between well-being and the notion of autonomy. This is accomplished in a next step (6.4.). On the grounds of the findings, this chapter closes with the diagnosis that the major weight given to autonomy within the context of euthanasia leads, above all, to interferences in the character of well-being and to the prevalence of subjective concepts of well-being. All in all, the results of the examination within this chapter support the hypothesis established over the course of the analyses in the previous chapters that the concept of well-being appears to be vulnerable to influences from other dominant notions and principles in biomedical ethics.

After having reached the end of the journey through the four major fields of discussion, chapter 7 recapitulates the findings with regard to the role of well-being in the various debates and thereby provides a first attempt to rethink well-being within biomedical ethics. Firstly, it focuses on the way in which the other notions and principles impact on the role of well-being in biomedical ethics (7.1.). It is shown in detail how the presence and the character of the concept of well-being are affected by the influences. Three different kinds of impact should be distinguished, namely instrumentalisations, interferences and requirements. The latter two (instrumentalisations and interferences) are considered as leading to a ‘false’ character of well-being, whereas the requirements express demands which the field of biomedical ethics has on a concept of well-being and are thereby of help when rethinking well-being within biomedical ethics. Section 7.1 deals with the impact of instrumentalisations and interferences on the concept of well-being. In a second step, further attributes of the character of well-being, which are not subject to the impact of other notions but rather derive from the specific content under consideration are scrutinized (7.2.). They are attributed to the category ‘requirements for a concept of well-being’. The chapter closes with an elaboration on the implications of our results and an outlook (7.3.). Tentative requirements for an adequate concept of well-being within biomedical ethics are developed on the grounds of the findings. It is argued that the requirements do indeed suggest that there is a need for a more comprehensive concept if well-being is to function in the field of biomedical ethics.

2. Paving the way for the analysis — preliminaries with regard to the concept of well-being

Before the journey through the four debates in biomedical ethics starts it is important to gain a clearer picture of our object of enquiry, namely the concept of well-being. This chapter is primarily concerned with an initial approximation of the character of well-being. By depicting the current state of the philosophical debate with regard to alternative theories of well-being, a preliminary theoretical background for the analysis is provided. We take a closer look at the three-way division of theories which constitutes a standard point of reference in discussions on the notion of well-being as well as at the subjective/objective distinction.

2.1. Well-being and related concepts

It has been already suggested in the introduction that the term ‘well-being’ is just one of many expressions in use to allude to the idea of a good life, which is in itself vague and applied in many different ways. This holds true for its use in the field of biomedical ethics, the broader context of philosophy and for everyday life in general. Albert W. Musschenga describes a similar impression and provides a host of examples:

> In everyday common language as well as in philosophical literature, there are several terms available for evaluating the quality or goodness of a person's life, including happiness, well-being, welfare, contentment, satisfaction, pleasure, flourishing, and excellence. None of these terms has a fixed meaning. Their meaning (their connotation - defining characteristics - and also their denotation - range of application) and the relation between them is highly culture and theory dependent. (Musschenga 1997: 17)

Musschenga draws attention to two distinct observations: 1. The existence of a plurality of terms in use to refer to one idea and 2. the perception that none of these expressions is consistently defined and that the idea they refer to is in itself vague. Let us first of all concentrate on Musschenga's first observation that various terms are applied to refer to one idea. This indeed is a quite commonly held view: L. W. Sumner, for instance, maintains that 'a person's welfare is more or less the same as her well-being or interest or (in one of its many meanings) her good' (Sumner 2003: 1). He, thus, supports the impression that the different terms and concepts are applied to refer to one idea rather than to a manifold variety of related concepts. Moore and Crisp provide an even longer list of near-equivalents of well-being. 'The numerous near-equivalents to well-being include a person's good, benefit, advantage, interest, prudential value, welfare, happiness, flourishing, eudaimonia, and utility.' (Moore and Crisp 1996: 599) We can, hence, observe that there are, indeed, a great number of different terms applied to refer to one idea. Above all, the expressions *quality of life* and *well-being* find wide application within the context of biomedical ethics.[6] For this reason, this book is primarily concerned with these two terms. Nonetheless, it should be noted that in the course of our analysis we will also take into account those lines of reasoning in which the concept of well-being is not explicitly referred to but near-equivalents are applied or the notion is implicitly suggested. There is, however, another important conception prominent in the context of biomedical ethics which ought to be addressed before commencing our analysis.

Health and well-being

In the context of biomedical ethics, above all, the concept of health is a central issue. This concept is closely linked to well-being. Thus, it is important to lay down how we are to define the notion of health and the relationship between the notions of health and well-being for the task in hand. Health is considered to be 'the absence of disease so if disease is biological malfunction or abnormality, it follows that a healthy person is someone whose biological systems are all in order' (Murphy 2009). However, the concepts of *health* and *disease* are in themselves highly contested matters and rival conceptions exist.[7] The

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[6] See, for instance, Veatch 1991c; Wasserman et al. 2005; Brock 2009.

[7] See, for instance, Schramme 2012.

traditional debate deals with the opposition between naturalist and normative approaches. Naturalists such as Christopher Boorse (1977, 1997) and Norman Daniels (1985) base their definition of health on conceptions of biological functioning which they consider purely descriptive. Hence, health and disease are viewed as objective conditions. Normativist approaches, in contrast, are based upon the assumption that conceptions of health and disease are inherently value-laden since they are derived from specific social and moral values and norms.

The relationship of both well-being and health is also defined in different ways. The well-known, often cited and highly criticized definition of health as ‘a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity’ (WHO 2006) provided by *The World Health Organization* suggests that both concepts have a similar scope and puts them on an equal footing.[8] More often health is viewed as a central component among others of individual well-being such as in the accounts of Wayne Sumner (2003) or Martha Nussbaum (2000). This view will be followed in the subsequent analysis. Arguments which refer to health are classified as dealing with one important dimension of well-being. Hence, the notion of well-being is considered to have a broad scope encompassing more than just health. Our perception of the notion of well-being involves both negative dimensions such as the absence of disease, pain and suffering as well as positive aspects such as pleasure and components which extend beyond the restoration and protection of health. That is to say, in our investigation we are concerned with the restoration, the protection and the promotion of well-being. In the respective debates we will scrutinize which of these dimensions of well-being prevail.

2.2. An initial insight into the character of well-being

Since it is the aim of this book to provide a clearer picture of the character of well-being in biomedical ethics, we are not, at the moment, in a position to give a distinct and clear-cut definition. To have a starting point, however, we can follow Dan Brock (2009: 96) and take an utterly broad conception of well-being as a working definition based on Derek Parfit’s words ‘what makes a life

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[8] For a critical perspective on the definition of health provided by the WHO see, for instance, Callahan 1973.

go best' (Parfit 1984: app.). This working definition is rough and broad and encompasses a multitude of things. However, in the course of the analysis we will continually reveal dimensions which will provide a deeper understanding of the character of well-being.

In addition, there are some philosophical deliberations which we can fall back on, for the time being, in order to gain a first insight into alternative approaches to well-being. These deliberations will serve as a background for classification within the analysis. It has already been mentioned in the introduction that the philosophical discussion on the notion of well-being is by no means a new endeavour. In contrast, '[m]odels of the good life (for human beings) are as old as philosophy itself' (Sumner 2003: 26). Philip Brey provides the following overview of the history of well-being within philosophical deliberation:

> In philosophy, well-being (the good life, happiness) has been studied since the ancient Greeks. It is an important theme in the works of Aristotle, as it is in ancient Greek philosophy throughout. In modern philosophy, well-being and happiness take center stage in the works of the 18th- and 19th-century philosophers Jeremy Bentham and John Stuart Mill, who present a modern version as part of their theory of utilitarianism. (Brey 2012: 15)

After a period of respite it is again at the centre of interest (cf. Bayertz 2010). Alternative theories of well-being have been developed and there are ongoing discussions as to which of them is most appropriate. A three-way division of theories, that is to say hedonism, desire-fulfilment theories and objective list accounts, which was first purported by Derek Parfit (1984) has become a standard model for differentiation in the discussions dealing with alternative approaches to well-being and is often referred to (cf. Griffin 1986; Sumner 2003; Fenner 2007; Brock 2009). In the subsequent sections the three alternative theories are briefly presented in order to be au fait with the philosophical discussions and to have a background for classification when examining the well-being based lines of reasoning within biomedical ethics.

Hedonism

Hedonic accounts of well-being have a long history. The beginnings of this doctrine go back to the fourth century B.C. when Aristippus stated that experiencing the maximum amount of pleasure is the goal of life. In his view happiness was the totality of one's hedonic moments. Above all, Hedonism has been an essential element of classical utilitarianism (cf. Shafer-Landau 2007: 281). Whereas hedonist accounts in antiquity, as for instance in the works of Aristippus and Epicurus, were of an egoistic nature, utilitarian accounts focus on the promotion of happiness of all persons affected. Generally speaking, hedonist doctrines are based on the assumption that experiential quality constitutes our well-being. Since they presuppose that there is a connection between well-being and different mental states, they have also received attention under the title *mental state accounts* (cf. Adler 2012: 162). Put simply, the hedonist doctrine considers well-being to consist of the greatest balance of pleasure over pain. Hedonists 'hold that only pleasure is intrinsically good, and pain is the only intrinsic bad. A person's life therefore goes well to the extent that he or she is able to accumulate pleasure and avoid pain.' (Brey 2012: 16) Nonetheless, as Fred Feldman points out, there are various forms of hedonism and many representations and formulations of what is essential to the hedonist doctrine (cf. Feldman 2004: 1). Andrew Moore differentiates between two rival hedonist accounts: the *experience account* and the *attitude account* (Moore 2011). Approaches to experiential hedonism derive especially from the works of the classical hedonistic utilitarians such as Jeremy Bentham and John Stuart Mill. The experience account is based on the notion that there are experiences of pleasure and pain of varying intensity (cf. Tännsjö 2013). Accounts of experiential hedonism, in turn, can be divided in to those of *quantitative hedonism* and others, which have been classified as *qualitative hedonism*. According to the quantitative approach, which was purported by Jeremy Bentham (1789), duration and the intensity are the central features to determine the value of pleasure. Qualitative accounts such as the hedonism found within the works of Mill, in contrast, differentiated between higher and lower pleasures. A contemporary approach to experiential hedonism can be found in the works of Torbjörn Tännsjö (1998). A different form of hedonism called *attitudinal hedonism* also identifies well-being with a pleasurable life. According to this kind of hedonism, pleasure is not a feeling or sensation but rather an attitude of enjoyment. This view is put forward by Fred Feldman (2004). However, hedonism has often been subject to fierce criticism like, for instance, the objection that we care about other things apart from pleasure such as connection to reality. This objection is often brought forward with regard to Robert Nozick's thought experiment known as the ‘Experience Machine’ (Nozick 1974: 42-5). In this the reader is asked to imagine a machine which is directly attached to the brain and able to provide any kind of experience one wants. Would people choose to be hooked on to the machine for the rest of their lives? Nozick argues that people would not want to hook on to the machine as they want their experiences to be real and to have contact with reality: ‘We want to *do* certain things, and not just have the experience of doing them. … [W]e want to *be* a certain way, to be a certain sort of person … plugging into an experience machine limits us to a man-made reality.’ (Nozick 1974: 43)

Desire-fulfilment theories

As Roger Crisp points out ‘[t]he experience machine is one motivation for the adoption of a desire theory’ (Crisp 2008) since this theory is in a position to circumvent the criticism with which hedonism is confronted. Desire-fulfilment theories ‘emerged in the 19th century, in part as an outgrowth of welfare economics’ (Brey 2012: 17) and have recently enjoyed great popularity. The central notion of desire-fulfilment theories is that well-being results from the satisfaction of personal desires and preferences. Hence, within these approaches to well-being there is no “experience requirement” involved. Desire-fulfilment theories do justice to pluralism with regard to well-being since individual desires and preferences constitute their basis (cf. Steinfath 2011: 297). ‘The simplest version of a desire theory one might call the *present desire* theory, according to which someone is made better off to the extent that their current desires are fulfilled.’ (Crisp 2008) However, this simple version is confronted with the problem that we often desire things which to not contribute to our long-term interests and our well-being in the long run. Philip Brey provides the following example for such a case: ‘An angry and impulsive adolescent, who chooses a life of crime and substance abuse and engages in reckless acts, may follow his short-term desires but is not likely to be better off by following them in the long run’ (Brey 2012: 18). In recent times more elaborate versions of fulfilment theories have been expressed within philosophical discussions. These are based upon *informed* desires and are able to provide an explanation for the fact that we are frequently mistaken about what might promote our well-being since this is viewed as a result of a lack of information. ‘According to the informed desire account, the best life is the one I would desire if I were fully informed about all the (non-evaluative) facts.' (Crisp 2008) Informed desires have to meet specific requirements such as the fact that they are based upon full information and rationality (cf. Adler 2012: 160). 'Relevant information could include information about possible alternative courses of action and objects of desire, about possible and likely consequences of actions, and about one's own psychological makeup and behavioural tendencies.' (Brey 2012: 18) Examples of informed desire accounts can, for instance, be found within the works of Griffin (1986), and Stemmer (1998). Although desire-fulfilment theories provide us with information about the 'necessary and sufficient conditions of well-being', namely that our desires are fulfilled, they have been criticized since they do 'not tell us anything about the source of these desires' (Brey 2012: 18).

Objective list theories

Objective list accounts of well-being, in contrast, offer information with regard to the source of our desires. They take the opposite view to desire fulfilment theories: rather than presupposing that things are valued because they are desired, they are tied to the assumption that the recognition of an objective good leads to the development of a preference or desire for it: 'Friendship and love may also seem to be things whose goodness explains, rather than results from, people's preference' (Wolf 1997: 208). In this context Griffin differentiates between the *taste model* and the *perception model* (cf. Griffin 1991). In following the taste model specific goods are valuable because they are desired, whereas the perception model is based on the notion that specific goods are desired because they are valuable. The latter represents the stance taken within objective list accounts. 'The lists is objective in the sense that items on the list increase the value of one's life independently of one's tastes, attitudes, traits, or interests.' (Brey 2012: 19) Hence, these theories are tied to the notion that goods can promote our well-being even if they are not desired and do not lead to more experiential quality. Nonetheless, mental states and preference satisfaction are not necessarily absent within objective list accounts (cf. Adler 2012: 167). As the name of the theory implies, lists of goods which are considered as intrinsic constituents of well-being are provided (cf. ibid.: 165). However, it should be noted that these lists differ with regard to their scope and content. Examples of such lists can be found in Finnis 1980, Parfit 1984 and Nussbaum 2000. When purporting a neo-Aristotelian approach Martha Nussbaum, for instance, lists the following capabilities: life, bodily health, bodily integrity, the senses, imagination and thought, emotions, practical reason, affiliation, other species, play and control over one's environment. Her list is tied to the anthropological assumption that all human beings share certain essential capabilities. Objective list accounts are often linked to the notion of perfectionism 'according to which what makes things constituents of well-being is their perfecting human nature' (Crisp 2008). Thomas Hurka (1996) has purported such an account which is based on the assumption that components contribute to our well-being if they perfect human nature. Objective list accounts often are faced with the accusation that they throw the doors wide open to paternalism[9], since specific goods are considered as contributing to individual well-being even if the person concerned does not enjoy or desire them. For this reason they are also frequently considered elitist (cf. Crisp 2008).

This three-way division of theories constitutes a standard point of reference whenever the question of the character of well-being arises. For this reason we will adopt the three-tiered framework for our analysis of the role of well-being in biomedical ethics. It is to function as a yardstick in order to classify the well-being based lines of reasoning in the various debates which we will be exploring. We will investigate in which debates the respective theories are applied and whether a particular theory is predominant in the field of biomedical ethics. Nevertheless, the three major philosophical theories can – to varying degrees and in different respects – be classified as objective or subjective accounts of well-being (cf. Brock 2009). Since this differentiation might also be of assistance within the analysis it is briefly elucidated in the subsequent section.

Subjective versus objective concepts of well-being

When exploring the discussions dealing with the character of well-being it becomes evident that also the opposition between subjective and objective conceptions is a major point of reference.[10] Brock states: 'A major issue concerning ethical judgements generally, and judgements concerning a good life in particular, is the sense and extent to which such judgements are objective and sub-

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[9] For information on the concept of paternalism and the problems associated with it see section 6.4.1. of chapter 6.

[10] See Sumner 2003; Schramme 2008; Brock 2009; Schaber 2013.

jective' (Brock 2009: 97). Generally speaking, the terms *subjective* and *objective* have various meanings (cf. Birnbacher 2007: 251) and are therefore not precise. What exactly is meant when the terms subjective and objective are applied in connection with alternative concepts of well-being? When referring to the term *subjective* Sumner states 'the kind of subjectivity I have in mind here is the dependence of the prudential value of a life on the feelings, or aims, or preferences' (Sumner 1992: 5). Hence, what is viewed as the essence of well-being depends on the subject under consideration. The term *objective* within this context, in contrast, refers to approaches which deny the dependence of values on feelings and preferences. Objectivist conceptions, thus, consider the components of well-being as subject independent. They often stem from anthropological theses from which specific needs are derived (cf. Siep 2004: 279). 'Thus, when our task is to determine whether some particular thing or activity is good for an agent or not, the subjective theories of well-being advise us to consult the agent whose well-being is being assessed, to pay attention to her own preferences and attitudes of favor and disfavor.' (Varelius 2003: 364) Objective accounts are based upon the assumption that we can also estimate the well-being of a person from an external point of view by determining if specific components of a good life are present and human needs are fulfilled. On the grounds of these elaborations we can observe that '[h]edonist and preference theories are both subjective in the sense that both hold that what is good for a particular person depends on what in fact makes that person happy or what that person in fact (with appropriate corrections) desires' (Brock 2009: 98). Due to the fact that objective list theories set down specific components which are viewed as promoting individual well-being independent of the desires and experiential quality they constitute a form of objective theories of well-being.

We have already obtained a preliminary insight into the character of well-being and existing alternative approaches to it. The information gained so far provides a framework for the analysis of the role of well-being within biomedical ethics, which will now follow.

3. Well-being in debates concerning the beginning of life: prenatal testing and selection

We have gained first insights into the theoretical discussion on the nature of well-being as well as existent alternative theories and are now equipped with a framework which aids orientation when tackling the goal of this book: to analyse the role of well-being in biomedical ethics. The point of departure is the beginning of life or more precisely debates about reproductive technology.

Rapid developments in the field of genetics as well as reproductive technology have brought about many changes in the field of human reproduction. New methods of assisted reproduction, for instance, have provided hitherto infertile or gay couples or single women with the opportunity to conceive children which are biologically related to them. By means of egg-freezing women are in a position to conceive even after the menopause. Furthermore, new as well as in the meantime well established techniques also give the means to detect certain diseases and impairments in utero or even prior to conception and also to reduce their occurrence. Procedures of *prenatal diagnosis* (PND) for example have become well-established practices in pregnancy care. More recently, however, the method of *preimplantation genetic diagnosis* (PGD) has, above all in Germany, augmented the debate. To a greater degree the process of human reproduction is becoming easier to influence and control at different stages.

However, the various technologies in the field of reproduction have raised a host of challenging and profound ethical as well as a number of social issues. Arguments which oppose the new or already established practices refer, for example, to the *moral status* of the embryo or foetus, the notion that mankind should not interfere with *human nature* or the *social implications* these procedures might have in the long run. Proponents of the reproductive techniques, on the other hand, call attention to the *procreative autonomy* of the parents. It is argued, for instance, that parents should have the opportunity to make decisions about having children and, furthermore, that they should be in a position to decide to have a child without a disorder or disability (cf. Glover 2006: 39).

When taking a closer look at the arguments put forward in favour of or against these technologies in the field of reproduction, it becomes obvious that the notion of *well-being* is also concerned. Even though, at first glance, well-being does not constitute one of the pivotal arguments in debates on the ethical acceptability of the various technologies in the field of reproduction, on closer examination it appears, nevertheless, to be an important point of reference. Sometimes it comes into play implicitly whereas in other instances it is explicitly addressed. On the one hand the well-being of the *prospective parents* is alluded to; on the other hand the well-being of the *future child* plays an important role in the discussions.[11] As a broader analysis of the role of well-being in the various bioethical discussions encompassed by the phrase *beginning of life* would go beyond the scope of this book, the focus of the following is centred on debates concerning *prenatal testing and selection*.

This chapter provides a detailed exemplary analysis of the presence and character of the notion of well-being in the debates dealing with the practice of PND and selective abortion and the comparatively new procedure PGD.[12] In a first step the practices in question are characterized. Having laid out these preliminaries, the exploration of the role of well-being in debates on prenatal testing and selection is the focus of interest. First of all, the analysis concentrates on the reference to the well-being of the prospective parents. In a next step the consideration of the future child's well-being in discussions on prenatal testing and selection is examined.

3.1. A short introduction to techniques and practices

There is hardly any other area in modern medicine which has developed as rapidly as the field of reproductive technology (cf. Schramme 2002: 52). The various practices of prenatal testing and selection, which constitute one part of re-

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[11] In some cases also the well-being of siblings of the future child is concerned or that of other interest groups such as people who live with a disability in the case of the so-called *expressivist argument*. This argument states that procedures of prenatal testing and selective abortion express hurtful attitudes and messages to people who live with a disability or severe disease and thus reduce their well-being (cf. Parens and Asch 2000: 13). However, in order to keep this analysis concise, the following concentrates on arguments based on the well-being of the prospective parents and the future child.

[12] In the following the expression *prenatal testing and selection* is applied in order to refer to the procedures of PGD and PND followed by selective abortion.

productive technology, have created the possibility for parents to be advised of disabling conditions or predispositions to illness and to select embryos or foetuses which do not have these conditions. There are in particular two practices, the moral legitimacy of which has been a much discussed topic in bioethical debates:

1. PND, followed by abortion if a foetus is found to be affected by certain genetic or chromosomal abnormalities and
2. the selection of embryos which have been created through *in vitro fertilization* (IVF) by means of PGD.

It should, however, be noted that 'the existence of genetically compromised children can be prevented not only by aborting already existing fetuses [or selecting embryos *ex utero*] but also by preventing conception in the first place' (Purdy 1996: 40).[13] Due to the fact that the two alternative procedures of prenatal testing and selection have received considerable attention lately, the analysis of the role of well-being in debates on the beginning of life provided in this chapter primarily focuses on PND followed by abortion and PGD. The subsequent section furnishes a short overview of both interventions in order to gain a more vivid picture of the techniques and practices under consideration in the debate on prenatal testing and selection before the analysis of the role of well-being in the discussions is provided.

Prenatal diagnosis and selective abortion

PND is used for the early detection of high-risk pregnancies and births as well as in cases in which there are indications of a genetic risk in the family. The term *prenatal diagnosis* is applied to a variety of non-invasive as well as invasive techniques which are employed to detect disabling conditions or those which cause illness of the foetus *in utero*. Generally speaking, '[t]he type of procedure undertaken depends on the stage of pregnancy, the nature of the test and personal preferences' (Bankier and Cram 2008: 12). Whereas the invasive techniques involve an intrusion into the abdomen of the pregnant woman and, therefore, carry to varying degrees a risk to the unborn baby[14], non-invasive

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[13] See also Schöne-Seifert and Krüger 1993.

[14] These risks include, for instance, the danger of miscarriage or of infection and leakage of amniotic fluid. However, generally speaking, there is just a low probability that these

techniques are comparatively safer and encompass, for example, the detection of foetal DNA present in maternal blood or *ultrasonography*, which has become a standard procedure in pregnancy care. Through ultrasound scans a visual representation of the developing embryo or foetus is provided and anatomical abnormalities can be detected (cf. DeGrazia et al. 2010: 525). The *nuchal scan*, for instance, constitutes one form of prenatal screening and is used in order to identify a higher risk of chromosomal defect that might lead to malformations such as *Down's Syndrome* or *Turner's syndrome*. This test is performed in weeks 11–13 of pregnancy.

If the non-invasive tests detect anatomical abnormalities or, in the case of advanced maternal age (over 35) or a family history of certain diseases or disabilities, the pregnant woman might in some cases be advised to have invasive tests for further and more detailed detection of genetic diseases. Among the invasive methods is the procedure of *amniocentesis*. Under ultrasound guidance, a needle is inserted through the woman's abdomen in order to obtain foetal cells from amniotic fluid (cf. Bankier and Cram 2008: 13). The foetal cells obtained in this way are tested. Apart from genetic diseases it also identifies other conditions such as an abnormal number or arrangement of chromosomes or neural-tube defects (DeGrazia et al. 2010: 525). This method is not performed before the 15th week of gestation. As the results might not be available before the 20th week, the procedure of selective abortion is administered in some cases at a more advanced developmental stage of the foetus. For this reason abortions following amniocentesis are considered even more problematic in moral, psychological or social terms in comparison to abortions at an earlier developmental stage (cf. ibid).

Chorionic villi sampling, in contrast, can be applied during early pregnancy and provides an alternative to amniocentesis. It is administered in the first trimester mostly between the 10th and 12th week and allows for an earlier decision as whether to continue or terminate the pregnancy if a disabling condition is diagnosed. It is also used to detect chromosomal or genetic abnormalities in the foetus. Samples of the placental tissue (chorionic villus cells) are obtained for biopsy from the placenta either through the cervix or through the abdomen.

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phenomena might occur. For more detailed information and statistics see German National Ethics Council 2003: 24.

For all these various procedures of PND it is the case that, if the foetus is found to have a genetic disease or chromosomal abnormality, the selective process which sometimes follows is accomplished through abortion (cf. PCB 2004: 89).[15] The way in which the pregnancy is terminated depends upon the gestational age of the embryo or foetus.[16] It is especially this combination of PND and selective abortion which raises ethical issues. DeGrazia et al. maintain that 'since prenatal diagnosis is ordinarily undertaken with an eye towards selective abortion, the practice of prenatal diagnosis clearly confronts us with one particular aspect of the more general problem of abortion […]' (DeGrazia et al. 2010: 525; see also Nippert 1998; Siep 2004: 324). Thus, on the one hand, the combination of PND and selective abortion is confronted with the objections to abortion in general, such as the argument of the *moral status*[17] of the foetus and the psychological and physical burdens caused by the intervention. On the other hand, there are also objections formulated specifically against the procedure of selective abortion as, for instance, the disability rights critique, which is dealt with in the following. However, PND followed by abortion is not the only practice of prenatal testing and selection which has been confronted with criticism. Recently the discussion has also focused on PGD.

Preimplantation genetic diagnosis

In Germany especially the procedure of PGD has received much attention since the decision was taken to make it legal (albeit within strict limits) in July 2011.[18] In other countries such as Great Britain, PGD has been permitted in li-

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[15] It is important to note, however, that prospective parents seek the practice of PND during pregnancy for different reasons: PND might facilitate, for instance, the medical treatment *in utero* in a case of disease. It might also enable parents to prepare themselves for the potential risk of a stillbirth or life with a child with a disability or severe disease. In some cases of positive diagnosis after PND parents are confronted with the challenge of deciding if the foetus should be aborted. Above all the combination of prenatal diagnosis and selective abortion often faces fierce criticism. The following concentrates primarily on the combination of both procedures.

[16] For further information on the alternative procedures see for instance DeGrazia et al. 2010: 457-458.

[17] For a more detailed description of arguments which refer to the moral status see, for instance Schöne-Seifert 2007: 155pp. and section 3.3.1. in this chapter.

[18] As the German Ethics Council states, '[u]ntil recently, PGD was largely regarded as incompatible with the German Embryo Protection Act. However, in a decision of July 2010, the *Bundesgerichtshof* (Federal Court of Justice) held that PGD carried out after

censed centres for many years. Couples at risk of transmitting certain genetic diseases consider the procedure of PGD to be a better alternative to selective abortion with regard to the physical and psychological burdens and also in moral terms (cf. Schöne-Seifert 2007: 173). ‘The couples who choose the reproductive option usually have either a moral objection to termination of pregnancy, have had one or more terminations in the past, have recently lost a child to a genetic disease or hold great hope that the new technology will deliver them an unaffected child.’ (Bankier and Cram 2008: 14)

PGD has been developed against the background of IVF and aims at selecting early-stage embryos in vitro. As the procedure of PGD requires IVF or alternatively *intracytoplasmic sperm injection*[19] it faces the risks and side effects of this technique such as the *ovarian hyperstimulation syndrome*[20] or the risk of infection through the withdrawal of egg cells. The procedure is often criticized for requiring the *artificial* as opposed to *natural* creation of life which is said to conflict with central values such as the value of the natural (cf. Schramme 2002: 51).[21] Embryonic cells are extracted from the embryos obtained by IVF. In the most common form of PGD one or two cells are removed from the embryo which is at approximately the eight-cell stage (cf. DeGrazia et al. 2010: 531).[22] The cells are screened for a specific genetic disease or chromosomal abnormality. The procedure can detect the conditions for certain and immediate diseases such as Tay-Sachs or Down’s Syndrome, but also diseases

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extracorporeal fertilization by means of blastocyst biopsy and subsequent examination of the harvested pluripotent trophoblast cells for serious genetic damage does not constitute an offence under the Embryo Protection Act […]’ (German Ethics Council 2012: 7).

[19] If this method is applied ‘a single sperm is directly injected into the oocyte under the microscope’ (German Ethics Council 2012: 10).

[20] Ovarian hyperstimulation syndrome results from the injection of hormones for triggering the oocyte release. The symptoms range from mild to severe and encompass, for instance, abdominal bloating, pain in the abdomen or weight gain.

[21] For more detailed information on the notion of the natural and the differentiation between the *natural* and the *artificial* see chapter 4.

[22] It should be noted that in the eight-cell stage many of the embryonic cells are *totipotent* which means that they are capable of developing into a human organism. For this reason the destruction of totipotent cells is regarded as problematic in legal and moral terms. In Germany PGD of totipotent cells is prohibited by the Embryo Protection Act. *Pluripotent* embryonic cells, in contrast, have a limited developmental capacity since they can only develop into various organs. For this reason they are considered to have a different moral status and are, therefore, not subject to moral or legal prohibition. Medical progress has made it possible to apply PGD methods which can exclusively be carried out on pluripotent embryonic cells (cf. Leopoldina 2011: 13).

that will occur later in life such as Huntington's Disease (cf. PCB 2004). In the international literature dealing with the subject of PGD the following indications are listed among others: the presence of monogenic diseases in family such as Cystic Fibrosis, Myotonic Dystrophy, Spinal Muscular Atrophy, Sickle-cell Disease, Thalassemia, Huntington's Disease, Epidermolysis bullosa and the Marker X Syndrome (cf. DRZE 2013). After the process of screening, affected embryos are discarded while those unaffected are implanted into the womb to initiate a pregnancy (cf. Siep 2004: 324). Due to the fact that embryos are created with the aim of selection, the procedure of PGD is often confronted with the charge of creating 'lives on trial' (Schramme 2002: 51)[23] and is for this reason highly controversial.

There is also the possibility that PGD might be used for purposes which go beyond the reduction or elimination of disabilities and diseases. This issue is discussed under the title 'designer babies' (Schöne-Seifert 2007: 171) and refers to selecting embryos for desired traits such as height, muscularity, cognitive capacity or a strong immune system – procedures of so-called enhancement.[24] However, as Bankier and Cram maintain, 'in reality the complexity of the determinants of traits [such as height and intelligence]…severely limits the potential of such options' (Bankier and Cram 2008: 17). Sex-selection is possible by means of PGD although it should be noted that it is usually used to avoid sex-linked diseases. 'More rarely and above all outside Europe [it is also used] for what is known as *social sexing* or *family balancing* in accordance with the parent's desire for a female or male child.' (German Ethics Council 2012: 19) Moreover, in the US and Great Britain the technique is applied in order to create so-called *saviour siblings*. Embryos with the best genetic match are selected and transferred into the womb so that the future child can provide an organ or cell transplant to an older sibling that is affected with a fatal disease. However, the following analysis concentrates primarily on the debate dealing with PND and PGD as a means for preventing the birth of children with severe disabilities and diseases and does not consider other cases such as saviour siblings or sex-selection for family balancing.

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[23] Linked to this charge is the question of whether it is a morally legitimate act to discard embryos and the question with regard to the moral status of the embryo *ex utero*.

[24] However, the question as to where one crosses the boundary between medical interventions and enhancement is a moot point. For an extensive discussion of this problem, the topic of enhancement in general and definitions see chapter 4.

Generally speaking, one should bear in mind that procedures of prenatal testing and selection still do not give a guarantee that a healthy and non-disabled child will be born. This is the case for a number of reasons, among others that the birth process in itself presents risks and that genetic testing is not in a position to detect every possible disabling condition. Furthermore, the class of disabilities and diseases which are reduced or eliminated through PND and selective abortion as well as by means of PGD is heterogeneous. 'Prenatal diagnosis [for instance] can now detect conditions as different as Lesch-Nyhan syndrome and ectrodactyly (a trait involving a partial fusion on bones of fingers and toes). Further, not only are the traits heterogeneous, but so are perceptions of their significance and/or seriousness.' (Parens/Asch 2000: 8) In addition, 'the number and variety of conditions for which tests are available grow daily' (ibid.: 3). As both methods, PND in combination with selective abortion as well as PGD, provide means for selection in the case of disability and disease, their administration has been very controversial. Especially advocates of the disability rights have strongly criticized these techniques for, among other things, their alleged discriminatory impact. We will come back to this issue in due course. Before embarking on the analysis one should be aware of the fact that the question of the moral permissibility of prenatal testing and selection involves *two* different issues, namely whether the embryo or foetus is allowed to be discarded in the first place and secondly, whether it is morally legitimate to select against disability and illness. As will be discovered both issues are deeply interwoven.

3.2. The reference to well-being in the debate on prenatal testing and selection

When dealing with the moral acceptability of procedures such as PGD and PND followed by selective abortion, there are especially two lines of reasoning which prevail: the argument of the *procreative autonomy* of potential parents as an assertion in favour of these procedures and the argument of the *moral status* of the embryo or foetus as an objection to the legitimacy of these techniques. This has already received a short mention in the introduction to this chapter. Nonetheless, when taking a closer look at the various arguments in the debate, or alternative ways in which the pivotal arguments in the discussions are characterized, it is clearly discernible that the notion of well-being also plays a prominent role. Equally, we can encounter presentations of the central arguments such as the following by *the Ethic-Task Force* of the *European Society of Human Reproduction and Embryology* (ESHRE) concerning PGD:

> At stake are two main principles. Firstly, the technology is justified by referring to the welfare of the child by avoiding harm to the future offspring. Secondly, the application of PGD increases the autonomy of the parents, both by allowing them to choose a technique that better fits their moral principles and reduces the psychological burden (by avoiding repeated terminations of pregnancy) and by giving them the possibility to protect their interest in favouring the health of their offspring. (ESHRE 2003: 650)[25]

According to these lines, well-being does indeed play an important role in debates on the moral acceptability of procedures such as PGD. For the time being we can maintain that the well-being of the future child is considered in order to argue in favour of PGD as disability and disease appear to be widely associated with a reduction in well-being. However, is that all that is to be said about the role of well-being in debates on prenatal testing and selection? The following analysis goes into more detail concerning this matter. It focuses primarily on the consideration of the well-being of the potential parents and the future child. Thereby, it explores the presence of well-being and the character it is ascribed within the arguments against the background of the alternative theories portrayed in chapter 2.[26]

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[25] For a critical comment on this statement see Thomas Gutmann 2010: 89. Gutmann points out that the argument of the well-being of the child no longer holds water if one takes Derek Parfit's Non-identity problem into account. We will come to the Non-identity problem in due course.

[26] The following analysis does not deal with considerations of well-being which are based upon safety concerns such as medical risks which accompany procedures of prenatal testing and selection. In the debate attention is frequently drawn to the fact that medical side-effects might endanger the well-being of the prospective mother or the future child (see PCB 2004). However, these arguments are not of central importance for the purpose of this chapter.

3.2.1. The well-being of the prospective parents

When taking a closer look at the debate on prenatal testing and selection, there are lines of argumentation to be found which draw attention to the well-being of the potential parents, although this is not encompassed in the quote of the ESHRE. In order to shed light on the role which well-being plays in the debate on prenatal testing and selection, the subsequent section places these assertions under scrutiny and, above all, examines the character of well-being under consideration.[27]

The desire for a biological child

An argument frequently encountered, primarily in the debates on the ethical acceptability of PGD, is the line of reasoning that PGD is said to provide couples who are 'genetically at risk' with the opportunity to conceive children who are biologically related to them and not affected by the disability or disease in question: '[w]omen or couples, the argument continues, in having recourse to PGD, wish to realize their legitimate desire for a biological child which is not genetically impaired' (German Ethics Council 2012: 56). Sigrid Graumann also describes the fulfilment of a couple's desire to have a biological child as one of the classic arguments in the debate on PGD: 'PGD is a procedure which should help towards fulfilling the desire for a child of couples at risk'[28] (Graumann 2001: thesis 3). However, to her mind this line of reasoning does not constitute one of the pivotal arguments in the debate. It rather is of secondary importance. All in all, it becomes evident that especially the procedure of PGD appears to be viewed as a practice which enables parents to fulfil their dearest wish, provided that IVF and PGD lead to a pregnancy despite the risks linked to the technique of IVF and the low prospects of success. It is frequently pointed out that unwanted childlessness can diminish the well-being of those concerned. When dealing with the argument of *parental reproductive freedom* the German National Ethics Council, for instance, maintains: 'an unfulfilled wish for a child can permanently impair people's happiness' (German National Ethics Council 2003: 108). Thus, one common line of argumentation in the debate, which pri-

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[27] Some of the elaborations in the following section can also be found in Stroop 2013.

[28] Translation by author. Original quote: 'Die PID ist ein Verfahren, das dazu dienen soll, den Kinderwunsch von Risikopaaren zu erfüllen.'

marily concentrates on the technique PGD, is based upon the assumption that, in the case of a successful application, the administration of PGD preserves the well-being of the parents through sparing them the painful experience of unwanted childlessness or even promotes their well-being through providing them with the opportunity to have a biological child. This, in turn, is said to be an important part of their procreative autonomy.

Nevertheless, opponents of this line of reasoning claim that this strong desire for a biological child is a result of the broadened possibilities provided by the new reproductive technology (cf. Schräer 2009: 130).[29] Ulrich Eibach maintains, that the broadened possibilities in terms of reproduction brought about by technological development have increased the psychological as well as social pressure on women or couples, respectively, to allow these new practices to be applied in cases in which natural procreation is not possible. Therefore, according to him, the willingness declines ‘to accept such hard fate – as for instance childlessness or the birth of a disabled child – as a challenge of life’[30] (Eibach 2000). The use of the expression ‘hard fate’ illustrates that Eibach, too, appears to consider unwanted childlessness as a factor which has a negative impact on well-being. However, the fact that it is in the nature of a hard fate that it is not easy to accept makes his argument appear contradictory. Nonetheless, it can be observed that modern techniques of reproductive technology are not only considered to *fulfil* the desire for a biological child but also to *generate* it in its intensity.

The depicted arguments all focus on the relationship between well-being and unwanted childlessness or the realisation of the desire for a biological child, respectively. The conception of a healthy biological child is considered as having a tremendously positive impact on the well-being of the parents, whereas unwanted childlessness is viewed as leading to a drastic reduction with regard to well-being. Therefore, both positive as well as negative dimensions of well-being come into play. In addition, the desires of the couples and the fact that they should be provided with the opportunity to fulfil their desires is an important point of reference within these arguments. Nevertheless, the deliberate application of the practices of prenatal testing and selection is said to pre-

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[29] See for instance the lines of argumentation put forward by Schockenhoff 2000: 101.

[30] Translation by author. Original quote: ’in schweres Geschick – z.B. Kinderlosigkeit und die Geburt eines behinderten Kindes – als Herausforderung des Lebens anzunehmen‘.

vent unreasonable burdens on parents – and therefore preserve their well-being – in a second but different way.

Avoiding the burdens of raising a disabled or an ill child

In the debates it is frequently argued, that the birth of a child with a severe disease or disability puts a strain on the parents in psychological as well as physical terms. The President's Council on Bioethics (PCB), for example, draws attention to the fact that 'PGD, when effective, enables parents to avoid the deep grief and hardship that accompany the birth of a child with dreaded and incurable diseases such as cystic fibrosis and Tay Sachs' (PCB 2004: 94).[31] But what exactly are the strains and hardships which parents with disabled or ill children face, or rather prospective parents anticipate when they decide against having a child with a disability or disease? Bettina Schöne-Seifert and Lorenz Krüger list the following reasons parents might have for avoiding the procreation of a child likely to be disabled: disabled children require a greater amount of care and energy on the part of their parents. Furthermore, parents are afraid of the responsibility and of enormous burdens which might endanger their social and family life. Another reason might be the unsatisfied desire for a child which is in a position to translate the parental encouragement into action and to return the love which it has received in a 'normal' way. (cf. Schöne-Seifert and Krüger 1993: 259)

While being concerned with the *procreative liberty* of potential parents, Jonathan Glover states that 'where a child has a very severe disability, much of the parental burden may be empathy for the child's own distress' (Glover 2006: 41). In order to give a more vivid picture of the emotional and physical burdens placed on the parents of disabled children, Glover refers to the case of Julia Hollander, a mother who describes her experiences of life with her daughter Imogen, who suffered significant brain damage. In her article Julia Hollander depicts her emotions as follows. 'The future terrified me. Along with the practical toll Imogen's condition would take, there was the enormity of the emotional one – caring for a young child who should be smiling and running around, but instead would be suffering terribly because of what had happened to her inside my body.' (Hollander 2010) Above all, Hollander stresses the fact

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[31] It is important to note that, generally speaking, the PCB primarily deals with the ethical concerns linked to the new technologies such as PGD and takes a critical stance.

that social support in such cases is limited and hard to get. Further burdens imposed on the parents which are mentioned in the debate on prenatal testing and selection are, for instance, limited future prospects because of the unpredictability in terms of the development of the disease or disability, limited possibilities to hold down a job and increased financial burdens. Thus, couples who seek prenatal testing and selection to avoid the birth of potentially ill or disabled children are afraid of the excessive psychological as well as physical demands which they might otherwise have to face. They fear that these demands might significantly diminish their well-being. It is argued that because of these fears, they should have the freedom to decide in favour of techniques such as PGD or PND followed by selective abortion.

In addition, those who already have a severely disabled or ill child and are at high risk of this situation repeating itself are mentioned frequently in the debate.[32] As these parents already take care of a disabled or ill child it is maintained that they might be overtaxed if they have a second child which requires such intensive and extraordinary care.

All these lines of reasoning refer to the various ways in which the birth of a child with a severe disease or disability might put a strain on the parents. Emphasis is placed on the subjective experience of the parents such as negative emotions through empathy for the child. In connection with the argument of *procreative liberty,* it is pointed out that parents should have the freedom of choice to avoid these hardships without the necessity of having to avoid having a biological child altogether. Again the desires of the future parents are central to the arguments and the subjective dimensions of well-being are placed in the foreground.

Preventing PND followed by abortion

A different line of argument which is especially linked to the well-being of the potential mother is that ‘by screening out embryos with genetic abnormalties before a pregnancy begins, [PGD] prevents many women from having to decide whether to abort an abnormal fetus’ (PCB 2004: 94). Many couples with an increased risk have experienced the burden of selective abortions several times and could be spared the hardship of a further abortion through the appli-

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[32] See for instance Glover 2006: 28.

cation of PGD. In addition, the practice of PGD is said to prevent parents from being confronted with a stillbirth or the early death of their child, which might otherwise happen to them a second time. These are further ways in which procedures of prenatal testing and selection are depicted as means of protecting parental well-being. These arguments focus primarily on the protection of well-being, stating that PGD avoids suffering and pain for the potential mother. Again it is pointed out that PGD provides opportunities to couples for conceiving a biological child without having to face major hardship. However, the procedures of prenatal testing and selection have also been subject to fierce criticism and the depicted lines of reasoning which refer to the parental well-being have been highly contested.

Criticism by the disability rights activists

The various lines of argumentation portrayed above, which are mainly put forward in order to approve practices such as PGD and PND followed by selective abortion, have been criticized especially by the so-called *disability rights activists*[33]. Generally speaking, they maintain that those parents who seek procedures which select against disability and disease, because they fear that their well-being might diminish if they have to care for a disabled or ill child, are driven by misinformation. When portraying the stance of the disability rights activist, Eric Parens and Adrienne Asch describe their assertion the following way.

> The prospective parent who wants to avoid raising a child with a diagnosable disability forgets that along with disabling trait come other traits, many of which are likely to be enjoyable, pride-giving, positive (and as problematic, annoying, and complicated) as any other child's trait. If prospective parents imagine that disability precludes everything else that could be wonderful about the child, they are likely acting on misinformation and stereotypes. (Parens and Asch 2000: 17)

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[33] The disability rights activists argue for the equality of people with disabilities. They place emphasis on the negative impact of prenatal testing and selection. Many participants of this movement themselves live with a disability or have close relationships to disabled people. They claim that there are many clichés about disability and life with a disability to be found in our society which need to be eliminated (cf. Parens/Asch 2000: Introduction IV)

They draw attention to the fact that prospective parents are apt to change their attitude if they obtain information about what life with a disability is like and how parents who have disabled children enjoy caring for them just like parents with non-disabled children do (cf. Parens and Asch 2000: 8). Hence, critics such as the disability rights activists call in question the notion that caring for a disabled or severely ill child leads to major reduction of well-being on the part of the parents. Couples who seek procedures of prenatal testing and selection in order to avoid the birth of a disabled or ill child are considered to be driven by misinformation. Thus, the disability rights activists tie their argument to the assumption that these couples are not able to anticipate their future well-being in the event that they conceive a disabled or ill child. Accordingly, they distance themselves indirectly from an utterly subjective stance in terms of the character of well-being.

Interim results

Returning to the quote of the ESHRE provided at the beginning of this chapter, which implies that the well-being of the future child and the reproductive autonomy of prospective parents are the two central arguments brought forward in favour of prenatal testing and selection, we can now conclude that well-being appears to play a more substantial role than suggested.

The notion of well-being not only comes into play when the future child is concerned, it is also referred to when the potential parents are considered. As indicated in the above, many lines of argumentation allude to the various ways in which practices of prenatal testing and selection can be viewed as preserving or even promoting parental well-being. However, one is apt to overlook these lines of argumentation which are based upon the concept of parental well-being and they have not received a lot attention. But what is the reason for this?

When taking a closer look at the context in which the well-being based lines of reasoning appear, one notices that they frequently – or even principally – occur when the notions of *reproductive autonomy* or *reproductive freedom,* respectively, are considered. When arguing that parental reproductive autonomy should also, for instance, include the choice of having a child without a disability or disorder (cf. Glover 2006: 39) the underlying reasons and interest parents might have for this choice are addressed. The preservation or promotion of their well-being appears to constitute a central reason in this context. Thus, failing to take into account the potential parents' fear that caring for a disabled or ill child might diminish their well-being, would constitute an infringement of their autonomy. The argument of parental well-being is, therefore, not only linked to the reference to the principle of reproductive autonomy or freedom but also appears to be concealed behind it. The promotion or preservation of well-being is, for the most part, merely implicitly addressed. The overriding importance of *reproductive autonomy* and the resulting *subliminal* presence of the concept of parental well-being might explain why the latter has not received a lot of attention so far, and why parental well-being as an argument in favour of prenatal testing and selection is frequently overlooked.

Nonetheless, the answer to the question as to what kind of character well-being has when the prospective parents are concerned, proves to be difficult to pinpoint against the background of the framework for analysis which consists of the three alternative theories of well-being and was provided in chapter 2. The various lines of argumentation do not contain a lot of information about which of the three alternative theories is underlying. Broadly speaking, it can be maintained that the desires and interests of the parents appear to play a major role within the arguments. This finding might indicate that the arguments are primarily based upon the desire-fulfilment theory of well-being. It should, however, also be noted that the mental state and the emotions of prospective parents are a consideration which could indicate that the arguments are tied to the hedonist doctrine. As a consequence it can be concluded that different *subjective* concepts of well-being prevail if parental well-being is referred to, but that is about all which can be said when using the framework provided in chapter 2 as a yardstick.

It is often pointed out in the discussions that the potential parents *should* have the freedom to make procreative decisions in order to promote their well-being in a way they see fit. This can be classified as the normative claim. The normative claim, above all, seems to result from the substantial weight given to reproductive autonomy in the context of prenatal testing and selection and has little to do with the question as to what is the essence of well-being. This finding suggests that the weight given to autonomy might have an impact on the character of well-being under consideration (namely a subjective character) and that it is important to provide a detailed exploration of the relationship between the principles of *respecting autonomy* and *promoting well-being* within this book.

Arising from the above is the impression that the three alternative theories of well-being illustrated in chapter 2 do not suffice as a framework when classifying the character of well-being in the various debates of biomedical ethics. At the moment there are no precise results which emerge with regard to the character of well-being suggesting the need for a more extensive framework when addressing the question as to the role of well-being in biomedical ethics.

3.2.2. The well-being of the future child

It has already received a short mention above that, in contrast to parental well-being, the well-being of the future child is explicitly addressed in the debates on prenatal testing and selection. As Michael Parker illustrates, John Stuart Mill has already placed emphasis on the fact that the well-being of the future child and the responsibility linked to it constitute an important consideration in human reproduction (cf. Parker 2005: 13). ‘The fact itself, of causing the existence of a human being, is one of the most responsible actions in the range of human life. To undertake this responsibility – to bestow a life which may be either a curse or a blessing – unless the being upon whom it is to be bestowed will have at least the ordinary chances of a desirable existence, is a crime against that being.’ (Mill 1859: Chapter 5) When writing these lines Mill obviously did not have in mind the various new procedures in the field of reproduction brought about by technological advances. Nevertheless, the more extensive possibilities provided by the new reproductive technology such as the possibility of selecting against disability and disease have made his statement of current interest. There are a great number of arguments to be found in the debate on prenatal testing and selection which are formulated in a similar fashion and are thus based on the assumption that the well-being of the future child is to be protected or even promoted. On the one hand, the procedures of prenatal testing and selection are viewed as a means for protecting the well-being of the future child. On the other hand, critics consider them to be a danger to well-being as the estimation or anticipation of the well-being of future children should not be undertaken by third parties. The following provides a more detailed examination of various lines of argumentation which refer to the well-being of the future child.

The zero-line stance

In the debate attention is drawn to the fact that PGD as well as PND followed by selective abortion can protect the well-being of future children by avoiding the birth of children with severe disabilities or diseases. Thereby, assumptions are made about the well-being of the prospective children. The underlying supposition is that diseases or disabilities could have a negative impact on it. Proponents of this line of reasoning presuppose that embryos or foetuses respectively do not have a *full moral status*. Therefore, in following their argumentation, aborting a foetus with a disability or discarding embryos with specific conditions cannot, in terms of moral acceptability be equated with killing a person born with a similar disability (cf. Brock 2005: 77pp.). Brock refers to 'the concept of personhood, or person, as a moral concept to designate a being who has the moral standing that persons are typically accorded in common moral theories' (ibid.). Since, according to Brock and the like-minded, the embryo and foetus are not persons, they do not have a right to life. An instance of a well-being based line of reasoning in favour of prenatal testing and selection can be found in Jonathan Glover's book *Choosing Children*. Under the heading *What We Owe to Our Children* Glover provides the following explanation.

> The case for optimism is not hard to see. Disabilities and disorders often (though not always) mean that people have less good lives than they would have had. They may have lives with more pain and more periods in hospital than others have. They may find many things harder to achieve than others do. These disadvantages can be seen as a huge natural injustice, affecting many people, which wherever possible should be removed. (Glover 2006: 1)

He considers prenatal testing and selective abortion as a means to avoid the hardships caused by disability and disease. Glover appears to be representing a common opinion with this quote. Julian Savulescu also views the protection of well-being as the central aim when procedures of prenatal testing and selection are administered. 'In the case of selection and reproductive decision-making, one important outcome of interest is how well a person's whole life goes, that is, wellbeing. We use this approach often in our decision in a rough and ready way.' (Savulescu 2008: 53) Thus, in following this line of reasoning, if chromosomal or genetic abnormalities of the embryo or foetus are detected which appear to preclude a life of reasonable well-being, it would be appropriate to discard the embryo or to abort the foetus respectively. Frances Kamm for instance suggests that '[o]ut of concern for the person who have [sic!] to live with a clubfoot, [I] believe it would be permissible to abort the fetus that would develop into a person' (Kamm 2002: 384) because he/she would have an additional difficulty in life.[34] Thereby, disability and disease appear to be viewed as conditions which, at least in many cases, diminish well-being. When dealing with the impact of serious disabilities such as blindness and serious mental retardation on quality of life, Dan Brock states that a decrease in the quality of life of a disabled person could be possible even though the person him-/herself describes his/her life as being pleasant.

> Serious disabilities can have a negative impact on people's lives by significantly restricting their opportunities even if, through adjustment to their disability, their subjective satisfaction with their lives is undiminished. Thus, when I use the term "quality of life" in what follows, I refer to an overall assessment of how good a person's life is, one that includes the person's own subjective assessment of or [sic] happiness with his life as well as objective components such as accomplishments, personal relations, and self-determination, including having the reasonable array of opportunities that self-determination requires. (Brock 2005: 70)

Glover also draws attention to the fact that the well-being of a person might be diminished through having to cope with a severe disability or illness even if the person experiences contentment that comes from adjustment to his/her condition (cf. Glover 2006: 52). In the last chapter of his book he maintains that he bases his arguments on a concept of well-being which takes into account two strands — in a similar fashion to Brock:

> The binocular vision we need corresponds to two strands of the good life. One strand is about the fit between what you want and value and what your life is like. Part of having a good life is being happy, in the

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[34] The appropriateness of Kamm's club foot example is highly debatable since one could argue that this disability should not be viewed as severe. Common examples of severe disabilities or diseases which are referred to in the debate are for example Huntington's disease or Tay Sachs. Both cause a lot of suffering and an early death.

> (limited) sense of being reasonably content with how your life is going. The second strand is about how rich your life is in human goods: what relationships you have with other people, your state of health, how much you are in charge of your own life, how much scope for creativity you have, and so on. (Glover 2006: 93)

Thus, according to these lines of reasoning, although subjective dimensions constitute a component of well-being, there are for the most part objective dimensions important for it. Both Glover and Brock place emphasis on the objective measures such as individual functioning when stating that severe disability and disease diminish individual well-being. Due to the fact that they list specific components which they consider as important for individual well-being, they could possibly be classified as purporting an objective list theory against the background of the three alternative theories provided in chapter 2. Subjective satisfaction or subjective well-being constitutes one element among others on the list. It should, however, be noted that the depicted lines of reasoning occur for the most part within the Anglo-American debate on prenatal testing and selection and are rarely to be found in the German debate. We will return to this matter in a later section of this chapter.

In discussing arguments in favour of prenatal testing and selection which refer to the well-being of the future child, Wassermann maintains that this stance views the resulting responsibility of potential parents as the function of "gatekeepers" selecting against suffering and limitation caused by disability and disease (cf. Wassermann 2005: 133).[35] Most of these lines of argumentation draw attention to the fact that 'we ought to try to provide every child with something like a minimally satisfying life' (Purdy 1996: 45). Glover calls this the *zero-line stance* as it refers to a level where the child's life is just about worth living (cf. Glover 2006: 52). However, a closer look at the arguments present in the debate on prenatal testing and selection suggests that there are lines of reasoning to be found which go a step further, stating that we ought to provide children with the *best* opportunity of a good life.

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[35] However, Wassermann questions this view.

Procreative perfectionism

An instance of this can be found within the works of Julian Savulescu. He endorses a stance which Glover terms 'procreative perfectionism' (Glover 2006: 53).[36] Savulescu's elaborations are mainly, but not exclusively, concerned with PGD since 'selection by abortion has greater psychological harms than selection by PGD and these need to be considered' (Savulescu 2001: 421). Savulescu too appears to presuppose that embryos or foetuses respectively do not have a full moral status and that, consequently, procedures which involve the discarding of the embryo or foetus are permissible and cannot be equated with killing a person who has already been born. But which notions of well-being does Savulescu's stance encompass?

When arguing for the principle of procreative beneficence, Savulescu maintains that potential parents have the duty to select the child with the *best* opportunity of a good life by means such as PGD. 'Couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information.' (Savulescu 2001: 415) He explains that by applying the expression 'best life' he is referring to the maximum of well-being possible. In addition to genetic dispositions for disease and disability, potential parents should also select for traits which could be considered as non pathological such as intelligence, memory and height. These traits are said to have a great impact on well-being just like disability and disease. Parents should opt for the most advantaged child, which is to say 'the child, of those possible for the parents, whose life can be expected to go best' (Savulescu and Kahane 2009: 275). Thus, Savulescu can be considered a proponent of so-called 'genetic enhancement', the improvement of the human body beyond the reduction or elimination of disabilities and diseases by means of reproductive technology.[37] According to Savulescu, the thesis that non-pathological genetic dispositions have an impact on the likelihood of leading a good life is compatible with all

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[36] As explained in chapter 2, perfectionism is an ethical theory which endorses the view that a good life consists in the promotion of certain aspects of human nature, which should be cultivated in as far as possible (cf. Hurka 1996). For further examples of perfectionist theories see chapter 4.

[37] For a detailed analysis of the enhancement debate and the reference to well-being see chapter 4.

alternative theories of well-being.[38] However, while arguing that there are specific human capacities which universally contribute to well-being, he presupposes a conception of well-being which can be classified as objective. Like Brock and Glover he lists specific goods which ought to be promoted in order to increase well-being.

John Harris purports a similar argument when dealing with the subject of PGD stating that 'she [a woman who seeks PGD] has a reason therefore to choose the embryo that is not already harmed in any particular way and that will have the best possible chance of a long and healthy life and the best possible chance of contributing positively to the world it will inhabit' (Harris 2001: 385). Also Harris appears to base his argument on the assumption that we are able to anticipate which condition will harm or benefit the future child and that the estimation of well-being is not an utterly subjective venture. He defines disability as a 'harmed condition' and provides the following elaborations: 'a harmed condition is one which if a patient was brought unconscious into the accident and emergency department of a hospital in such a condition and it could be reversed or removed the medical staff would be negligent if they failed to reverse or remove it' (ibid.: 384). Hence, he can be classified as taking an objective or at least intersubjective[39] stance concerning the well-being or harm respectively of the future child.[40] Both Harris and Savulescu presuppose that the embryo and foetus have *not* got a full moral status and that they can be subject to selection procedures which involve their discarding. Harris, for in-

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[38] Chapter 4 provides critical reflection of this claim illustrating that Savulescu implicitly ties his arguments to an objectivist concept of well-being.

[39] Intersubjective concepts of well-being are based on the assumption that there are certain components of well-being which can be considered trans-individual and can be classified as one form of objectivism. This is due to the fact that there are socially shared ideas of what promotes or diminishes our well-being. Intersubjective conceptions of well-being are, therefore, not linked to realism.

[40] Nevertheless, Harris appears to consider himself as moving in a subjective direction in terms of well-being when stating: 'I have defined disability as a condition that someone has a strong rational preference not to be in and one that is in some sense a harmed condition. For me then a harmed condition is defined relative both to one's rational preferences and to conditions which might be described as harmful, not relative to normal species functioning but relative to possible alternative.' (Harris 2001: 384) However, alone the mere concept of *rationality* can be considered an objective dimension which enters Harris's argument. In addition, Robert Sparrow maintains: 'What is far less clear is whether we can in fact, as Harris intends, assess whether someone is in a harmed condition without making reference to an idea of the normal capacities of a human body' (Sparrow 2011: 277).

stance, states that ‘none of the embryos has a right or an entitlement to be chosen rather than the other, since none is a person, nor yet a moral agent’ (ibid.: 385). He equates being a person with having full moral status.

To conclude, we can observe that also proponents of ‘procreative perfectionism’ are mainly to be found within the Anglo-American discussions on prenatal testing and selection and rarely in the German debate. Savulescu and Harris also appear to base their arguments on concepts of well-being which can be classified as objective with regard to the character. They presuppose that potential parents are in a position to anticipate which traits will contribute or diminish well-being due to its objective nature. Owing to the fact that Savulescu lists specific components which he views as universally contributing to individual well-being, he might also be classified as purporting an objective list theory. Again it is striking that arguments of this kind only appear to occur in the Anglo-American debate and rarely within the German discussions.

In addition, Harris and Savulescu mention components of well-being which should be promoted by means of prenatal testing and selection which go beyond the preservation of health and the alleviation of pain and suffering. Hence, they can be said to refer to positive as well as negative dimensions of well-being, that is to say the protection as well as the promotion of well-being. They apply a comparatively broad conception of well-being within their arguments which is not limited to health-related dimensions.

Both Savulescu and Harris assume that the embryo and the foetus do not have the same moral status as a human being which has already been born.

However, generally speaking, arguments in favour of prenatal testing and selection which refer to the well-being of the future child have been confronted with the charge that they lead to a paradox.

The non-identity problem and different people choices

Derek Parfit has drawn attention to the fact that in the debates on the moral acceptability of prenatal testing and selective abortion, it is important to be aware of the differentiation between *same people choices* and *different people choices* (cf. Parfit 1984). In same people choices there are two possible futures for the same child and the question to be asked, when considering the well-being of the child is: which possible future is better for the child? Different people choices, in contrast, do not focus on two possible futures for one child.[41] They are rather a choice between different possible children. According to Parfit, the choices which occur when procedures of prenatal testing and selective abortion are administered constitute different people choices since the well-being of different children is concerned. In the case of prenatal diagnosis, for example, a pregnancy is terminated after the foetus has been diagnosed with a disabling condition. The woman might become pregnant again at a later point in time with the aim of conceiving a different child which has not got the disabling condition. Therefore, there is the choice between conceiving two different potential children.

Thus, the means for preventing the disability such as PND and selective abortion, do not promote or protect the well-being of the future child with the disability; instead they would prevent the existence of this child. In terms of the consideration of the well-being of the future child, therefore, Parfit states that apart from few extreme cases of exception (such as a case in which the life of an expected child is brief and painful), cases in which an individual is preserved from harm through an action which at the same time prevents its existence lead to a paradox (see Parfit 1987: 351pp.).

This problem has received a lot of attention under the heading of 'the non-identity problem'. Thus, according to the non-identity problem, the consideration of the well-being of the future child in the debate on the moral acceptability of prenatal testing and selective abortion cannot be viewed as referring to the well-being of the child who would be born with the disability. After having dealt with the consequences of the non-identity problem, Brock claims that when applying means for preventing disability, prospective parents should act 'for the sake of a world with less diminishment of well-being or limitation in opportunity' (Brock 2005: 87). This leads to the conclusion that it only makes sense to consider prenatal testing and selection as means for promoting well-

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[41] It is important to bear in mind that, as Wasserman puts it, '[t]ypically, the issue has been framed somewhat differently: should the presumed wrong in choosing to have or failing to avoid having an impaired child be understood in person-affecting or impersonal terms? If parents who make that choice act wrongly, do they wrong the child, giving him a complaint, or do they commit only a more impersonal wrong? Philosophers who take the latter view argue that a parent violates an impersonal duty in creating a child significantly less happy than one she might have created with little additional burden' (Wasserman 2005:133).

being *in the world* and not the well-being of *a future child*.[42] Since utilitarianism maintains that the well-being in the world is to be maximized, this can be considered a utilitarian line of reasoning.[43] However, the consideration of the well-being of the future child in debates on prenatal testing and selection has, above all, been confronted with much criticism of a different kind.

The disability rights critique

Here again the disability rights activists are among the fiercest critics. According to Eric Parens and Adrienne Asch, disability rights advocates criticize the fact that 'using prenatal tests to prevent the birth of babies with disabilities seems to be self-evidently good to many people' (Parens and Asch 2000: 4). However, for a number of reasons the disability advocates raise doubts about this widespread notion. They primarily refer to the so-called 'expressivist critique'.[44] As Sparrow points out this critique 'derives from a concern that selection against embryos with genetic disorder, or terminating pregnancies on the basis that they are likely to result in the birth of a child with a disability, express morally reprehensible negative attitudes towards people with disabilities' (Sparrow 2008: 112). Disability rights advocates also place emphasis on the fact that the degree to which specific traits are experienced as disabling factors which diminish well-being, depends on societal factors and organization such as education and employment (cf. idid: 6). 'Many of the limits on quality of life come not from medical burdens, but from barriers set up by society, from stigmatization to elevators that don't work.'[45] (Lehrman 2000) Thus, according to

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[42] For a similar line of reasoning see John Harris 1998: '[d]eliberately choosing to increase suffering in the world when [one] could avoided so doing' (ibid.: 91) is doing a moral wrong.

[43] For a critical perspective on Brock's utilitarian line of reasoning see Siep 2003.

[44] Above all, the so-called 'expressivist critique' of members of the disability community has received a lot of attention. Due to the fact that within these lines of reasoning the well-being of the future child is not directly concerned, a close examination of the expressivist critique at this point would not serve our central aim in this section, namely the analysis of the role of the future child's well-being in the debate on parental testing and selection. Nonetheless, we will come back to the espressivist critique in section 3.3.2..

[45] This stance is frequently referred to as the 'social model of disability'. The traditional model, in contrast, which considers disabilities as properties of individuals, is termed the 'medical model' (cf. Amundson 2005: 102).

the disability rights activists, the prevention of a decrease in well-being due to disability and disease can best be accomplished through social changes.

Furthermore, members of the disability community argue that underlying (mis)assumptions, misinformation and stereotypical thinking about disability influence proponents of procedures for prenatal testing and selection and the women who undergo these procedures. They claim that it is a mistake to believe that disability and disease inevitably diminish individual well-being by causing suffering. This is said to be a view that is primarily held by non-disabled people who have no experience of what life with a disability is like (cf. Amundson 2005: 103) and are guided by misinformation.

> Many clinicians and bioethicists take it for granted that health status is mostly responsible for the reduced life chances of people with disability […]. [T]hese clinicians and bioethicists often discount data indicating that people with disabilities and their families do not view their lives in solely or even predominantly negative terms; instead, they may insist that such data reflect a denial of reality or an exceptional ability to cope with problems. (Parens and Asch 2000: 6)

As the quote illustrates the disability advocates draw attention to a number of studies which have shown how well people with significant impairments can live and also that disabled or ill people rate their well-being higher than non-disabled people would expect them to do. ‘When asked about the quality of their own lives, disabled people report a quality only slightly lower than that reported by nondisabled people, and much higher than projected by nondisabled people.’ (Amundson 2005: 103) Furthermore, Ron Amundson states that ‘the Standard View [that disabilities have very strong negative impacts on well-being] is an *expression* of the stigma of disability. It is not (as it presents itself to be) an estimate of the objective consequences of impairments’ (ibid.: 104).

Hence, critics seem to reject the objective stance with regard to well-being and the impact of disability taken by proponents of prenatal testing and selection. As illustrated in the above, proponents such as Brock and Harris presuppose that disability has a negative impact on well-being and should for this reason be avoided by means of prenatal testing and selection. We can observe that the disability rights activists, above all, criticize the view that impairments and disabilities necessarily diminish the well-being of the persons affected by them. Nevertheless, they do not appear to imply that disabilities and impairments *never* diminish individual well-being, rather they state that they do *not necessarily* do so. When expressing their critical arguments, they appear to move more in a subjectivist direction in terms of the character of well-being stating that there are considerable differences as to how disability influences the well-being of different persons and that these should be taken into account. However, some disability rights activists cannot be considered as taking an utterly subjectivist stance which would imply that we cannot make general statements such as: condition X often (though not always) has a negative impact on well-being. Adrienne Asch for instance states:

> [y]es, disability might mean shorter-than-average life expectancies; might entail living with weakness, pain, or fatigue; might require more time than is typical for medical visits or hospital stays; might preclude seeing, hearing, or speaking; might require moving with wheelchairs, crutches, or braces; or might prevent some people from reading, writing, or participating in activities using numbers. (Asch 2003: 319-20)

Furthermore, she states '[i]t is possible to acknowledge that disabilities may preclude some activities that many people find worthwhile' (ibid.: 324). As her quotation indicates she thereby affirms that there are some specific conditions which might be classified as often having a negative impact on well-being. Some of the disability activists explicitly point out that they do not fundamentally reject procedures such as abortion, but rather their administration with the aim of selecting against disability: 'women or couples should be free to reject becoming parents for whatever reason they wish, and thus they should be able to use techniques like abortion to fulfil their familial goals. The conviction that a life with a disabling trait is so distressing that it should not be undertaken if it can be avoided is quite different [...].' (Asch 2000: 239) By providing these lines Asch intends to indicate that she does not generally reject procedures which involve the discarding of the embryo or foetus, but only if these are applied with the aim of selecting against disability. Hence, she does not appear to ascribe a full moral status to prenatal entities. As a consequence the impression arises that the argument of moral status is not the foundation of the stance which Asch takes. The plausibility of this will be placed under close scrutiny at a later point.

All in all, with regard to the character of well-being we can perceive that there appears to be tension between subjective and objective concepts where the well-being of the future child is concerned. Whereas proponents of prenatal testing and selection tie their arguments to objective concepts of well-being such as objective list accounts, the opponents of the procedures in question place emphasis on the subjective dimensions. This finding suggests that the tense relationship between proponents and opponents of prenatal testing and selection might also result from the fact that they purport rival concepts of well-being. We will place this hypothesis under scrutiny in the following.

We are, nevertheless, not in a position to determine which of the two alternative subjective theories (hedonism or desire theory) depicted in chapter 2 is presupposed within the arguments by the disability rights advocates since these do not provide us with much information concerning this matter. Again the three-tiered framework provided in chapter 2 reaches its limits and the impression seems to be reinforced that there is a need for supplementation.

Nevertheless, the examination of the role of well-being in debates on prenatal testing and selection suggests that it is not solely the disability advocates who refer to the subjectivity of well-being in order to criticise arguments in favour of parental testing and selection.

The impossibility of anticipating the well-being of a future child

If one takes a closer look at the critical arguments put forward in the debate on the moral acceptability of procedures for prenatal testing and selection, one can find similar lines of reasoning to the above depicted arguments brought forward by the disability advocates. The lines of reasoning are, above all, purported by theologians such as Eberhard Schockenhoff and Peter Fonk in the German discussions. Before dealing with their well-being-based arguments, it should be noted that their theological background as well as the elaborations they provide clearly indicate that they ascribe a full moral status to the embryo and foetus. Fonk speaks repetitively of the ‘killing’ (Fonk 1999a: 36) carried out by the administration of PND and selective abortion which suggests that he considers the foetus to have the same moral status as a person who has already been born. He therefore considers procedures which involve the discarding of the embryo and foetus such as prenatal testing and selection as impermissible.

With regard to the future child's well-being, Schockenhoff and Fonk maintain that the suffering caused by disease and disability and the resulting reduction of well-being are subjective quantities which should not and cannot be assessed from the outside. Like the disability advocates they refer to studies which illustrate that, where the well-being of people who live with a disease and disability is concerned, there is a large discrepancy between the first person perspective and the estimations of third parties. In order to provide an example, Schockenhoff refers to the differences in terms of well-being between physical and mental disabilities (cf. Schockenhoff 2000: 102-103 and also Fonk 1999b: 153). Most people would evaluate life with a physical disability as being less burdensome in comparison to a life with a mental disability such as Down's syndrome from the outward perspective. However, Schockenhoff claims that from the first person perspective it is exactly the opposite way around: in many cases of mental disability, contrary to common expectations, the subjective ability to experience well-being is not impaired (cf. ibid.). It is pointed out in the literature that there are also large discrepancies between the subjective estimation of the well-being of different individuals, who are affected by the same disease or disability. In addition, critics point out that experts of various disciplines come to a totally different evaluation in terms of the seriousness of certain disabilities (cf. Schockenhoff 2000: 98). In only a few cases are the development of a disease and the impact of the symptoms predictable. Anticipations of well-being by third parties, therefore, run the risk of drawing false conclusions. This evaluation of the well-being of the future child is said to constitute a paternalistic estimation of the worthwhileness of the life of a human being (cf. ibid.).

Thus, in the debate on prenatal testing and selection other critics of the argument which is based upon the well-being of the future child apart from the disability advocates also draw attention to the fact that the objective scaling of the suffering and pain to be expected by certain disabilities and diseases is impossible. These critics, who often have a theological background, ascribe a full moral status to the embryo and the foetus. Like the disability advocates they move in a subjectivist direction with regard to the character of well-being within their lines of reasoning. This observation merely strengthens the impression expounded above that there is tension between the subjective and objective concepts of well-being within the debate on prenatal testing and selection. We can conclude by saying that proponents of prenatal testing and selection, such as Brock, Glover and the like-minded, base their lines of reasoning on objective concepts of well-being, whereas opponents such as the disability rights advocates or thinkers with a theological background purport subjective conceptions.

The phenomenon of adaptation

The examination of the above depicted arguments in favour of and against prenatal testing and selection, which consider the well-being of the future child, illustrates that the process of adaptation is widely referred to. Generally speaking, approaches to the phenomenon of adaptation deal with the ability of the human psyche to adjust to difficult circumstances in life and to withstand severe personal tragedies successfully (cf. Taylor 1983: 1161). The mechanism of adaptation suggests that 'people who lose functioning as a result of disease or accident typically report, despite initial disruption and feelings of loss, increasing satisfaction and proficiency with the passage of time' (Wasserman et al. 2005: 11). This phenomenon is also known as the 'disability paradox'. On closer scrutiny two ways can be identified in which the process of adaptation is applied in the debate on prenatal testing and selective abortion:

On the one hand, as already suggested in their lines of argumentation portrayed above, the critics of procedures such as PGD and PND followed by abortion, such as some of the disability rights advocates or Schockenhoff and Fonk, place emphasis on this mechanism in order to strengthen their argument that disability does not necessarily lead to a diminishment of well-being. By referring to the phenomenon of adaptation they maintain that disabled or ill people often succeed in coping with their disability or illness after a period of time. According to Asch, this means that although affected by disability many individuals do not experience a diminishment in their well-being, at least not in the long run (cf. Asch 2003: 327). In addition, the disability advocates refer to studies which indicate that being able to cope with impairments might even strengthen the character of the person affected. They deal with the phenomenon of adaptation within their arguments to buttress the subjective stance they take with regard to the character of well-being and the impact of disability.

On the other hand, Glover and Brock and like-minded thinkers who, as illustrated, tie their arguments to the objective concepts of well-being, refer to the phenomenon of adaptation as evidence of the fact that the first person perspective is not an adequate measure when evaluating the well-being of persons with disability. Brock, for instance, maintains: '[n]evertheless, if the disability substantially limits a major life activity, then it still limits or closes off an important area of functioning and the activities that such functioning makes possible, even if the person may not 'miss' them' (Brock 2005: 75). According to Brock, subjective satisfaction constitutes only one aspect of quality of life. There are other important components of well-being and if these are missing due to disability or illness, we can determine from an external point of view that the well-being of the person concerned is diminished. When referring to the problem of scaled-down preferences[46], which Amartya Sen has dealt with, Glover claims that '[g]etting what you want is not all there is to a good life. A lot depends on whether your preferences and hopes are themselves impoverished.' (Glover 2006: 18) This impoverishment of preferences is viewed as resulting from the mechanism of adaptation. Consequently, due to the possibly impoverished desires of persons who lead a life with a disability, their first-hand experiences and evaluation of their well-being should be treated with caution. When dealing with this line of reasoning Wasserman summarises it as follows:

> [t]he lives of people with disabilities are assumed to be of low quality, whatever environmental factors mediate the impact of impairments, and their own testimony to the contrary is seen as inherently unreliable. Their adaptations to their impairments appear not as instances of the universal processes of adjustment to changed circumstances, but as disability-specific strategies for recovering the ground that has been lost, or for covering up its loss through benign self-deception. (Wasserman et al. 2005: 11)

For the time being it can be concluded that proponents of prenatal testing and selection consider the phenomenon of adaptation when they argue that we are in a position to anticipate the future child's well-being in order to strengthen their objectivist stance with regard to well-being. The two different ways in which the critics and proponents of prenatal testing and selection refer to the phenomenon of adaptation illustrate precisely the above-mentioned tension

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[46] Scaled-down preferences refer to preferences which are adjusted to the restricted options and deprived circumstances in which the individuals concerned find themselves. See Sen 1993.

which appears to exist between subjectivist and objectivist conceptions of well-being in the debate on prenatal testing and selection.

Interim results

The consideration of the well-being of the future child is a much more complex as well as controversial matter than one would assume at first glance. Firstly, the results of the analysis indicate that it is important to differentiate between the Anglo-American and the German debate on prenatal testing and selection: Whereas the well-being of the future child is overtly referred to in the Anglo-American debate, thinkers in the German discussions exercise greater caution concerning this matter. In the German discourse the well-being of the prospective child is mainly considered within arguments which reject the procedures in question. It is pointed out that disability does not necessarily diminish well-being and for this reason, we are not in a position to anticipate the well-being of future children on grounds of genetic testing. Schockenhoff and the like-minded place much emphasis on the fact that one should refrain from passing judgement on the worthiness of life. This argument appears to be a line of reasoning which enjoys widespread popularity in the German debate on prenatal testing and selection. However, the opponents of these procedures, who criticize the reference to the well-being of the future child, appear to attack a stance which is hardly ever to be found in the German debate since proponents of prenatal testing and selection mainly base their arguments on the procreative autonomy of the parents. Thus, the discussion is at cross purposes.

A finding of interest with regard to the character of well-being is the fact that there are various ways in which the concept is applied in order to argue in favour of prenatal testing and selection. On the one hand, PGD and PND followed by selective abortion are considered as a means for *protecting* the well-being of future children – the zero-line view. Within these arguments the concept of well-being is applied with reference to its *protection*, namely the prevention of pain and suffering. On the other hand, proponents of procreative perfectionism allude to the *promotion* of the well-being of future children by referring to our obligation to increase such traits as intelligence, memory and height. Consequently, positive dimensions of well-being also come into play, which go beyond the reduction of pain and suffering.

An additional observation to be made with regard to the character of well-being is that proponents and critics of prenatal testing and selection appear to base their arguments on different concepts – that is to say *subjectivist* and *objectivist* concepts. When proponents of the procedures, such as Brock and Glover, argue that prenatal testing and selection provide means for preventing suffering and the diminishment of the well-being of a future child, they take it for granted that the well-being of a child which has not yet been born can be anticipated by third parties. They assume that the mere detection of a disposition for a severe disability or disease provides us with sufficient information to estimate that the future child will lead a life with diminished well-being. Savulescu and Harris even go a step further in stating that also non-disabling traits such as intelligence and height enable us to judge that the future child can be expected to experience a life with maximum well-being. Thus, in following the lines of reasoning of Brock, Glover, Savulescu, Harris and like-minded colleagues, well-being can be estimated by third parties on the grounds of objective criteria. The quotations of Brock and Glover provided in the above, however, illustrate that both maintain that there is a necessity to take the subjective as well as objective components of well-being into account.

Nevertheless, the concept of well-being applied appears to be for the most part objective. According to the stance of the above thinkers, in the case of severe disability or disease, the first person perspective is not an adequate measure for well-being. This is rendered particularly clearly by their remarks concerning the phenomenon of adaptation. The character of the concept of well-being on which proponents of prenatal testing and selection base their argument can therefore be considered as, for the most part, objective. As illustrated, there are some hints to suggest that the stance they take can be classified as an objective list account of well-being. However, there is a lack of further evidence to enable us to make a more valid classification. Furthermore, analysis indicates that when the well-being of the future child is considered by proponents of prenatal testing and selection the term *quality of life* is applied with a great frequency. One attempt at an explanation might be that especially the term *quality of life* creates the impression that the notion of well-being can be applied as an objective operational measure in order to decide in which cases prenatal selection should be considered. This would contradict the thesis mentioned in the introduction that the terms well-being and quality of life are used interchangeably.

Critics of the consideration of the well-being of the future child as an argument in favour of prenatal testing and selection, in contrast, maintain that the estimation of the harm and suffering (and therefore the diminishment of well-being) caused by disability and disease is an exclusively subjective procedure which cannot, and therefore, should not be undertaken by third parties. Accordingly, judgements concerning well-being can only be made from a first person perspective and not through anticipation by third parties. As illustrated, the disability advocates draw attention to the phenomenon of adaptation to illustrate that people who argue that disability and disease necessarily lead to a diminishment in well-being are wrong. Nonetheless, it is difficult to provide a clear testimony for the theory of well-being to which they tie their argument against the background of the three alternative theories since the critics' arguments do not contain enough information concerning this matter. There are a few passages to be found which hint that the critics might base their arguments on desire-fulfilment theories, but that is the sum total of what they permit to be said about their stance.

In summary, we can observe that there are tensions between objective and subjective concepts with regard to the character of well-being. Proponents of prenatal testing and selection often tie their argument to objective concepts whereas opponents presuppose subjective theories. The impression arises that the relationship of tension between proponents of prenatal testing and selection and opponents of these procedures appears to rest upon the rival concepts of well-being which underlie their arguments. This impression will be placed under scrutiny in the following section.

In addition, the results of the examination indicate that it is impossible to categorize all of the arguments illustrated above against the background of the three alternative theories (hedonisms, desire-fulfilment and objectivist list theories). This confirms the suspicion that the framework for the analysis provided in chapter 2 is not sufficient for the examination of the role of well-being in biomedical ethics. There is a need for a more suitable and more differentiated framework for analysis.

There remains one final observation which should receive attention: obviously the question as to whether or not the embryo and foetus have a full *moral status* is of major importance in the debate on prenatal testing and selection.

The results of the examination indicate that the notion of prenatal moral status[47] also plays a central role where the well-being of the future child is concerned. Objective accounts of well-being tend to be tied to the assumption that embryos or foetuses do not have a full moral status, whereas subjective concepts of well-being, at least at a first glance, appear to be tied to no specific conception of moral status. Subjective approaches are referred to within arguments which are based on both kinds of assumption: either that the embryo and foetus have full moral status or that they do not. In order to attain a clearer picture of the role which well-being plays in discussions of prenatal testing and selection it seems to be fruitful to place the relationship of the notion of moral status and the concept of well-being under scrutiny. This is done in the following section.

3.3. Results arising from the analysis and the issues it raises

The exploration of the role of well-being in discussions dealing with prenatal testing and selection suggests that the concept of well-being interacts with other predominant principles and notions, namely the principle of *reproductive autonomy* where the well-being of the prospective parents is concerned and the notion of *moral status* where the well-being of the future child is considered. This indicates that it is important to examine more closely the presence which well-being has in the face of the principle of autonomy and the notion of prenatal moral status, respectively, in the debate. To begin with, the following section provides a closer examination of the presence of well-being in the face of the notion of prenatal moral status within the discussions. Due to the fact that the principle of respecting autonomy also is predominant and influential in other debates such as the discourse on euthanasia, which we will examine with a little later, we return to the relationship of autonomy and well-being at a more suitable point.

Another striking finding of the analysis with regard to the character of well-being is the existing tension between subjectivist and objectivist concepts in the debate. The idea has evolved in the above that we need a more suitable and differentiated framework for the analysis of the character of well-being in

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[47] The expression ‘prenatal moral status’ is borrowed from DeGrazia 2012. In the following it is used to refer to the moral status of the embryo and foetus.

biomedical ethics since the framework provided in chapter 2 is not sufficient. Section 3.3.2. provides a finely differentiated framework based on the subjective/objective differentiation which complements the former scheme of examination during the analysis in the chapters to come.

3.3.1. The presence of well-being in the face of the notion of moral status

Generally speaking, if the concept of moral status is concerned in discussions on prenatal testing and selection, it refers to the question as to what kind of moral obligations we have with regard to the embryo or foetus for its own sake (cf. Ach, Schöne-Seifert and Siep 2006: 267; Schöne-Seifert 2007: 155). To put this more explicitly existing or non-existent protection claims which we concede to the embryo or foetus are dealt with (cf. Ach, Schöne-Seifert and Siep 2006: 267). With regard to the question of prenatal moral status various stances can be taken: it can, for instance, be argued that embryos and foetuses have a *full* moral status, a *partial* moral status or *no* moral status at all. Nevertheless, the embryo and foetus do not necessarily have the same moral status since both are at different developmental stages. In order to examine the presence of well-being in the face of prenatal moral status in the above depicted arguments, it is worthwhile taking a closer look at existing alternative concepts of moral status; this then provides a foundation for classifying the specific stance in the previous well-being based arguments. In addition, it is illustrated how the alternative notions of moral status relate to the concept of well-being within the discussions dealt with in this chapter.

Three alternative stances with regard to prenatal moral status

When dealing with the subject of abortion and moral status, Bonnie Steinbock (2008) distinguishes between three camps, namely the conservatives, the liberals, and the moderates (or gradualists).[48]

The conservative stance: according to the conservative perspective, the embryo and foetus have a full moral status which means that, like human be-

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[48] In the following I apply her tripartite scheme to discussions dealing with the moral status of the embryos *and* the foetus and supplement some important points and advocates of the particular stances.

ings who have already been born, they have a right to life. Hence, the embryo and the foetus are on an equal footing with them regarding their dignity and claims of protection (cf. Schöne-Seifert 2007:157). Consequently it is morally impermissible to discard embryos and foetuses by means of PGD or abortion. The process of implantation in the uterus is viewed as the decisive stage for a full moral status. However, as Steinbock states, the Catholic Church considers an earlier phase of development important. ‘Conception is regarded as the significant point because that is when the embryo develops its own unique genetic code, distinct from that of its mother or father, and thus from the egg or sperm.’ (Steinbock 2008: 1) Generally speaking, four different arguments are brought forward to justify that embryos and foetuses have a full (or at least a partial moral status), namely the arguments of species, of continuity, of identity and of potentiality (cf. Damschen and Schönecker 2003; Schöne-Seifert 2007: 157).[49] According to the conservative stance, prenatal entities such as the embryo and foetus have a full moral status and therefore are not permitted to be discarded. As a consequence of this, procedures which imply the discarding of these entities such as PGD and selective abortion are morally impermissible. For this reason the question as to whether or not well-being can be promoted or protected by these interventions does not, in fact, arise. The same holds true for the questions as to whether or not the well-being of the future child can be anticipated or whether the essence of well-being is objective or subjective. Hence, advocates of the conservative stance, who object to procedures of prenatal testing and selection do not necessarily need to consider the notion of well-being and do not need to take a position with regard to alternative concepts.

The liberal stance: the liberal approach does not view unborn life as having a full moral status from the outset. Instead full moral status is attained at a specific point later during development. Hence, the embryo and, according to some approaches, also the foetus are not worthy of protection and do not have a right to life. As a consequence, a comparatively liberal attitude is taken towards procedures such as PGD and abortion (cf. DeGrazia 2012: 17). The specific stage of development at which entities are ascribed full moral status is dependent upon the properties considered as the deciding factor. Various properties such as ‘sentience, rationality, or moral agency’ (Beauchamp and Childress

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[49] Due to the limited scope of the book I cannot provide a more detailed presentation of the four alternative arguments. For a thorough discussion and criticism see Damschen and Schönecker 2003; Schöne-Seifert 2007: 157.

2013: 65) have been brought forward to confer moral status. There are advocates of a liberal stance, such as Peter Singer (1979), who consider the possession of subjective interests as decisive, which in turn requires sentience. Due to the fact that embryos and foetuses do not have an interest in their future, according to Singer's stance, procedures such as abortion and PGD cannot be considered morally impermissible (cf. Singer 1979). In common with a few other thinkers, Singer links the attribution of a full moral status to the notion of personhood, which in turn is based on the requirement of certain properties.

What are the implications of the liberal stance for the presence of well-being? First of all, it should be noted that the answer to this question depends on when prenatal entities are said to have full moral status. If this point in development is deemed to be in the foetal phase, this has different implications for the permissibility of PGD in contrast to PND followed by selective abortion. Whereas the former is considered permissible the latter is classified as impermissible. Let us assume, for the sake of argument, that a full moral status is only attained at birth and that, as a consequence, procedures of PGD and abortion are permissible since the discarding of the embryo and foetus is allowed. In this case the consideration of the well-being of future children is likely to play an important role since it could be argued that the procedures in question are in a position to protect or promote their well-being. If this is so, then the questions as to whether or not the well-being of future children can be anticipated or whether the essence of well-being is objective or subjective gain a great significance. All things considered, it is possible to observe that the notion of well-being becomes relevant in the context of prenatal testing and selective abortion since prenatal entities are not ascribed full moral status.

The gradualist stance: in following the gradualist approach,[50] the moral status of prenatal entities steadily increases during their development and there is no such thing as a specific point at which the embryo or foetus, respectively, is suddenly ascribed full moral status. The more advanced the developmental stage, the higher is its moral status and thus the claim of protection. As Steinbock points out, 'the moderate, or gradualist, agrees with the liberal that a one-celled zygote is not a human person, but agrees with the conservative that the late-gestation fetus is virtually identical to a born infant' (Steinbock 2008: 3). Thus, according the gradualist view, PGD is better in moral terms than early

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[50] See for instance Siep 2004.

abortion which in turn is better than an abortion at a later stage (cf. ibid.). The question as to whether PGD and PND followed by selective abortion can be considered morally permissible procedures on grounds of a gradualist perspective is difficult to answer since it depends on the degree of moral status ascribed to the various developmental phases and the stage at which the prenatal entity is ascribed a right to life. These matters, in turn, influence the answer to the question under consideration in this section: the presence of well-being in the face of the notion of moral status. If the right to life can be claimed at a comparatively early stage (similar to the conservative view), then well-being plays no role due to the prohibition of prenatal selection and discarding. Alternatively, if the right to life is not ascribed until a later stage of foetal development, the concept of well-being becomes as significant as in the case of the liberal stance.

From these reflections it becomes evident that the question of moral status has priority over the consideration of the well-being of future children in the debate on prenatal testing and selection.

If prenatal entities are ascribed a full moral status, then procedures such as PGD and abortion, which imply their discarding, are inadmissible and the consideration of the well-being of future children is not of primary importance within the argumentation. In contrast, well-being is likely to constitute an important concern if prenatal entities are not attributed full moral status and there is no general prohibition on discarding the embryo or the foetus. We can observe that before participants in the debate address the topic of the well-being of future children, it is important that they explain the stance which they take in terms of moral status, so that one is in a position to grasp the implications of their well-being based arguments. Hence, the concept of well-being has a *subordinate presence* in the face of the notion of prenatal moral status. At this point the following now turns to the alternative considerations of the well-being of the future child in the above section and explores the stance regarding moral status which are contained therein.

Classifying the well-being-based lines of reasoning

Concerning the proponents of the zero-line stance and procreative perfectionism, lines of reasoning have been discovered which indicate that Brock, Glover, Savulescu, Harris and other like-minded thinkers do not ascribe a full moral status to the embryo or foetus. References can frequently be found to the concept of personhood and the statement that embryos and foetuses do not have the status of a person. Consequently, they consider interventions which entail the discarding of embryos and foetuses as morally permissible. We can, therefore, maintain that advocates of the zero-line stance and procreative perfectionism can be classified as *liberals* with regard to prenatal moral status. This opens the door for the question as to whether it is morally acceptable to administer PGD or PND followed by abortion with the aim of selecting against disease and disability and hence the deliberation about the well-being of the future child with or without disability. As illustrated, these liberal thinkers view procedures of prenatal testing and selective abortion as protecting and promoting well-being respectively. Their well-being based lines of reasoning are the decisive points within their argumentation in favour of prenatal testing and selection.

We now come to those critics who have a theological background such as Schockenhoff and Fonk, who argue that we cannot anticipate the well-being of the future child. As already suggested in the above, they ascribe a full moral status to prenatal entities. This full moral status is conferred from conception onwards and rooted in the biblical belief that human beings are created in the image of God and as a result of the Divine will (cf. Siep 2003: 13). This renders the discarding of the embryo and foetus as impermissible and thus makes the question of the moral acceptability of prenatal testing and selection redundant. It goes without saying that this can be classified as a conservative stance and hence the consideration of the well-being of the future child is superfluous. Nonetheless, as indicated in the above, the conservative thinkers do address the question as to whether well-being can be anticipated, which they then negate.

In the case of the well-being based arguments of the disability rights advocates, the classification proves to be more difficult. Asch and the like-minded state explicitly that they do not object in general to procedures which lead to the destruction of unborn life such as abortion. They therefore give the indication that they take a liberal stance but are opposed to prenatal testing and selection on other grounds. One of these reasons is their criticism of the view that well-being is necessarily diminished by the presence of disability. The following section, however, questions whether or not their position in terms of prenatal moral status is really a liberal one.

3.3.2. Tension between objectivist and subjectivist concepts of well-being

Results indicate that there is a need for a more suitable and more differentiated framework for the analysis of the role of well-being in biomedical ethics or, to be more precise, the character of well-being. In biomedical ethics (as in the traditional philosophical debate) the following questions with regard to the notion well-being are of central importance: What is the very essence of well-being? According to which criteria should it be evaluated? And who should have the ultimate authority to determine it? These issues have received various answers and competing concepts exist.

As illustrated in chapter 2, a great deal of the tension rests upon the question as to whether the notion of well-being is correctly captured by *subjectivist* or *objectivist* approaches. It has been extrapolated that the opposition of these two different approaches to the notion of well-being is central to the debate on prenatal testing and selection. This might well be the case in bioethical debates. Consequently, it appears to be fruitful to supplement the subjective/objective differentiation in our framework for analysis (provided in chapter 2) which is applied in order to attain our central aim. However, as mentioned in the above, the terms *subjective* and *objective* have various meanings and are apt to be vague. Chapter 2 has merely provided a preliminary approximation to the objective/subjective distinction. If it is to function as a yardstick for the analyses of the character of well-being provided in the subsequent chapters, both terms require a more precise definition and clarification of their different meanings. Various plausible attempts to systematize the different ways of understanding the subjective/objective distinction have been made.[51] The subsequent section focuses on a scheme of classification as provided by Thomas Schramme (2008: 1501). In following his endeavour there are three different levels to the objective/subjective differentiation. 1. the *ontological*, 2. the *evaluative* and 3. the *epistemic* level.

1. On the ontological level the central question is: What is the essence of well-being? One might ask whether well-being is a specific mental state or rather some other condition such as being equipped with certain mate-

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[51] See for instance Sumner 1996; Kühler 2006; Birnbacher 2007; Schramme 2008 and Bayertz 2010.

rial goods. The ontological level refers to the source of value. It queries where the value comes from. Is the value intrinsic to what is being prized or does it depend on the person who values it (cf. Birnbacher 2007: 251)?

2. What are appropriate criteria for estimating well-being? This is the question with which the evaluative level is concerned. Should subjective estimations, intersubjective or objective determinants be decisive?
3. The epistemic level deals with the question as to who has the best access to individual well-being – the individual him/herself or his/her social environment from an external point of view? Who can be considered the expert? Is it possible to have a false impression of one's well-being? Whereas subjectivist conceptions represent the view that only the person him-/herself has access to his/her well-being, objectivist approaches are linked to the notion that it is possible to determine the well-being of a person from an external point of view and that the person concerned can indeed have a false impression of his/her well-being.

However, all of these levels are interconnected and overlap to some degree: if one, for instance, presupposes a subjective concept of well-being with regard to the ontological level, this has implications on the evaluative and epistemic level and allows for subjective dimensions on these levels.

As already mentioned, the scheme provided, based on the subjective/objective distinction with regard to well-being, appears for various reasons to be more appropriate and suitable for our aim in comparison to the framework furnished in chapter 2: Firstly, it is broader than the three-tiered framework and because of its alternative levels allows for a more precise classification of the well-being-based lines of reasoning. It permits us to ascertain directly which of the alternative levels is present when subjective or objective dimensions of well-being come into play. The three alternative theories, in contrast, do not amplify the alternative levels and provide a comparatively undifferentiated picture. In addition, it has been illustrated that they are rarely referred to within the arguments. The reference to objective as well as subjective dimensions of well-being can easily be recognized within the arguments brought forward. Nevertheless, the three-tiered system will not completely lose its significance in the following chapters, but will be supplemented by the subjective/objective scheme provided.

Applying the scheme to the arguments which refer to the well-being of the future child

If one examines the various arguments which refer to the well-being of the future child by means of the new framework, a number of further details with regard to the character of well-being are provided: The opposition between objective and subjective concepts of well-being is mainly expressed by differing answers to the question as to whether we can anticipate the well-being of the future child, especially in the case of children with a disabling condition. This question can be categorized as operating on the *epistemic level* as it mainly deals with the query as to whether the well-being of disabled and ill individuals can be determined by outsiders who have no experience of life under such conditions. This comes down to the question who has the best access to individual well-being. By taking an objective stance, proponents of prenatal testing and selection argue that a third party *is* able to determine the well-being of a (potential) individual. The above mentioned opponents of the procedures concerned, such as the disability rights advocates or Schockenhoff and the like-minded, move in a more subjective direction arguing that third parties are not able to anticipate or determine well-being. They appear to take the view that only the person him- or herself is able to express his/her level of well-being. Although the discussion principally takes place at the epistemic level the opposing views are also evident at the other two levels.

At the ontological level, the advocates of the zero-line stance and procreative perfectionism tie their arguments to a concept of well-being which appears to be to a great extent objective as specific universal goods of well-being are listed. Nevertheless, their lines of reasoning are also linked to the notion that pleasurable experiences are one component on the list. The disability rights advocates and other critics such as Schockenhoff clearly take a more subjectivist stance with regard to the ontological level, placing emphasis on the various ways in which disability might influence well-being and the subjectivity of well-being.

When the evaluative level is concerned, Brock, Glover, Savulescu, Harris and the like-minded can also be considered to move in an objectivist direction. This, above all, becomes clear by their elaborations concerning the phenomenon of adaptation. The criterion which they implicitly apply when determining the impact of disability and illness on individual well-being focuses on objective determinants such as the provision of certain goods. The other camps, who object to prenatal testing and selection, evaluate well-being by focusing on the first person perspective. Their stance in terms of the evaluative level also becomes obvious through the way they deal with the phenomenon of adaptation. Hence, the relationship of tension between subjectivist and objectivist concepts of well-being is, above all, present at the epistemic level. The impression is reinforced that the tense relationship between proponents of prenatal testing and selection and opponents of these procedures seems to rest upon the rival concepts of well-being which underlie their arguments. But does this hypothesis indeed hold water?

Putting the hypothesis to the test

If one studies the results gained up to now concerning the opposition of subjectivist and objectivist concepts of well-being and the presence of the concept of well-being in the face of the notion of moral status, certain inconsistencies and conspicuous findings become apparent. These could call into question the hypothesis we have so far developed, namely that the tense relationship between proponents of prenatal testing and selection and opponents of these procedures appears to rest upon the rival concepts of well-being to which they tie their arguments. The inconsistencies and conspicuous findings are chiefly to be found within the well-being based lines of reasoning which reject prenatal testing and selective abortion, that is to say the arguments put forward by the disability rights advocates as well as the critics with a theological background.

First of all, the findings concerning the arguments given by Adrienne Asch as an eminent representative of the disability rights advocates are analysed in detail. In the above it has been illustrated that she claims to take a liberal stance with regard to prenatal moral status since she maintains that she does not reject procedures such as abortion in general. Nonetheless, she considers techniques of prenatal testing and selection as impermissible on other grounds dealing with the selection against disability. As illustrated, one important reason which she provides is the fact that disability does *not necessarily* diminish individual well-being. It has been extrapolated that Asch can, thereby, be considered as moving in a subjectivist direction especially at the epistemic level in terms of well-being. As already mentioned in the above, however, she does not take an utterly subjectivist stance since she does indeed affirm that there are some specific disabling conditions which might be classified as frequently having a negative impact on well-being. This is precisely the point at which an inconsistency occurs: if Asch admits that there are disabling conditions which often (although not always) diminish well-being, while at the same time taking a liberal stance with regard to prenatal moral status, one would expect her to argue that by means of prenatal testing and selection to prevent disability, the chances of a good life for the future child are definitely increased (but obviously not guaranteed). For this reason she *ought* to consider the procedures in question permissible. However, as we have already seen this is not the case. Thus, the impression could arise that Asch does indeed acknowledge prenatal entities as having a right to life and thereby a higher moral status than she claims, otherwise this would render her argumentation against prenatal testing and selection against disability inconsistent.

There is, however, still 'one route of escape' which Asch could take: she could maintain that this argument 'from misinformation about disability' (Asch 2003: 316) is not her chief argument but that the so-called *expressivist critique* is her main concern with regard to prenatal testing and selection and that both arguments function in tandem when arguing for a prohibition of the procedures in question. As already mentioned, the expressivist critique considers prenatal testing and selection against disability as transmitting the message to individuals who live with the disability in question that they would have been better off if they had not been born. However, when dealing with this line of reasoning Bonnie Steinbock (2000) claims that prenatal testing and selection constitute simply one form of prevention of illness and disability. In this respect the procedures in question can be equated with taking folic acid and abstinence from smoking and alcohol during pregnancy to prevent disorders of the future child. Steinbock points out that these preventive actions are generally accepted and not criticized for their discriminatory impact on, or message to the disabled (ibid.: 117). In a next step she provides the following elaborations:

> [a]dmittedly, abortion prevents this outcome by terminating a pregnancy, by killing a fetus. In this respect, it differs from giving the pregnant women folic acid, which does not kill but rather promotes healthy development in, the fetus. Obviously, if the fetuses have the same moral status as born children, then this difference is crucial. It is permissible to reduce the incidence of disability by keeping people healthy; it is not permissible to reduce the incidence of disability by

> killing people with disabilities. But if the embryos and foetuses are not people (something a pro-choicer like Asch concedes), then the impermissibilty of killing people to prevent or reduce the incidence of disability is irrelevant to the permissibility of abortion or embryo selection. (Steinbock 2000: 118)

Hence, on the grounds of Steinbock's argument it can be claimed that also the expressivist critique comes under suspicion of ultimately resting upon the assumption that the embryo and foetus have a right to life and a moral status which is comparable to that of already born persons. If Asch claims to take a liberal stance with regard to prenatal moral status, her argument against the permissibility of prenatal testing and selection can be proven to be inconsistent. The impression that she does indeed presuppose a full (or at any rate a higher) moral status of the embryo or foetus is supported by other remarks of hers such as the following: '[p]renatal testing is a clear case of first impression [with regard to disability], and as with any such impression, it is an incomplete impression; when followed by selective abortion or by discarding an otherwise implantable embryo, that first impression includes a decision never to learn about the rest of who that embryo or fetus could become after its birth.' (Asch 2000: 235) Within these lines of reasoning Asch refers to the potential of the embryo and foetus to develop into an individual with a full range of character traits. It has already received a short mention in the above that arguments of potentiality are generally applied when taking a liberal or gradualist stance with regard to moral status. If Asch's arguments do indeed implicitly rest upon the assumption that the embryo and foetus have a full moral status, which appears to be the case, then her elaborations as to whether or not the well-being of future children who have a disability can be anticipated, become redundant since foetuses and embryos are not permitted to be discarded. All in all, it can be concluded that there are several indications that Asch's argumentation is more about a full prenatal moral status than about the well-being of future children.

Now it is time to concentrate on the well-being-based lines of reasoning purported by the critics of prenatal testing and selection who have a theological background such as Schockenhoff and Fonk. They can be classified as taking a conservative stance with regard to prenatal moral status. This implies that any procedure which involves the discarding of the embryo or foetus is impermissible. It has already been illustrated that this directly provides a negative answer to the question of the moral acceptability of prenatal testing and selection. Hence, the consideration of the well-being of the future child in this context is rendered obsolete. Nevertheless, Schockenhoff and the like-minded are at great pains to argue that we cannot anticipate the well-being of future children with a disability and tie their arguments to a subjective concept of well-being, as illustrated. Their well-being based lines of reasoning can, however, be considered superfluous in the light of the deliberations provided in the above. Thus, the suspicion arises that the well-being-based lines of reasoning are only an alleged argument contra prenatal testing and selection since the deciding factor within the argumentation is the full moral status ascribed to prenatal entities. As a consequence, the depicted lines of reasoning which are based on a subjective notion of well-being are of no significance within the theological arguments against prenatal testing and selection. One reason why Schockenhoff and Fonk still refer to the future child's well-being might be that they want to create the impression that they can offer a variety of different arguments against the moral permissibility of prenatal testing and selection other than the conservative argument of prenatal moral status. By moving in a subjectivist direction in terms of well-being and opposing the objectivist stance taken by proponents, they provoke one to think that the fact that we are said not to be able to anticipate the well-being of future children with a disability constitutes a major reason as to why they reject the procedures in question.

All in all, it has been shown that the well-being-based lines of reasoning brought forward by the disability advocates and critics with a theological background are based on the argument of *prenatal moral status* and, contrary to expectations, not on a subjective conception of well-being at the epistemic level. The critical arguments which refer to subjective dimensions of well-being have been proven to be specious. This has been indicated by the inconsistencies and conspicuous findings we have encountered after having carried out a more detailed investigation of the well-being based lines of reasoning and their dependence on alternative concepts of prenatal moral status.

This finding refutes the initial hypothesis that the tense relationship between proponents of prenatal testing and selection and opponents of these procedures appears to rest upon the rival concepts of well-being to which they tie their arguments. With regard to the opponents of prenatal testing and selection such as Asch and Schockenhoff, the discussions implicitly restrict themselves to the matter of moral status. It can nonetheless be maintained that the well-being of future children plays a major role within the arguments brought forward by the proponents of prenatal testing and selection such as Brock, Glover, Harris and Savulescu. Since they take a liberal stance with regard to prenatal moral status (and, therefore, generally allow the discarding of the embryo and foetus), their deliberations concerning the well-being of future children can be considered as having substance and great significance within their argumentations.

The fact that the question of moral permissibility with regard to prenatal testing and selection is entwined with the moot point of the moral acceptability of discarding the embryo and the foetus is clearly reflected by our findings. Laura M. Purdy states that there is a risk present of falling 'into the trap of letting the abortion question swallow up all others' (Purdy 1996: 40). On the basis of our results it can be claimed that opponents of prenatal testing such as the disability rights advocates and theological thinkers are caught in this trap. Nonetheless, they seek to conceal this by making constant reference to the future child's well-being and by emphasizing the subjective nature of this. Hence, subjective concepts of well-being appear to be *instrumentalised* within the argumentation of critics for the sake of the argument of moral status. In returning to our central question dealing with the role of well-being in biomedical ethics we can maintain that the notion of moral status has a strong impact on the presence of well-being as well as on its character within the debates on prenatal testing and selection.

3.4. Findings: well-being in the debates concerning the beginning of life

Generally speaking, the results of the examination provided in this chapter show that well-being plays a *prominent* role in the debate on prenatal testing and selection. There are many thinkers to be found (such as, for example, the members of the ESHRE, Glover and Savulescu), who view the future child's well-being as belonging to the prevalent arguments in the debate alongside the reproductive autonomy of the prospective parents. Nonetheless, it is noteworthy that precisely the future child's well-being tends to be circumnavigated within arguments in favour of prenatal testing and selection in the German discussions. One major underlying reason for this appears to be the fact that estimations of well-being by third parties in the case of illness and disability provoke recollections of the classification of ‘worthless lives’ as against ‘worthwhile lives’ during the Nazi era. The differences between the German and Anglo-American debate in terms of the application of concepts of well-being, mirror the societal deviations in dealing with topics such as prenatal testing and selection. Whereas the Anglo-American debate takes, for the most part, a more liberal stance, the discussions in Germany are held in a comparatively cautious manner always drawing attention to human dignity and the danger of a slippery slope leading to eugenics. This is due to the circumstances during the Nazi era and the policy which selected against minority groups such as people with mental or physical disabilities among others.

The examination has furthermore illustrated that well-being also frequently comes into play where the prospective parents are concerned, notwithstanding its, at times, *subliminal presence*. In this case it almost always occurs together with the argument of *reproductive autonomy*. This appears to be of such significance that it ‘obscures’ the reference to parental well-being. Whereas the notion of autonomy strongly influences the presence of well-being where the prospective parents are concerned, the concept of *prenatal moral status* has a strong impact on the presence of well-being where the future child is concerned. It has been shown that before participants in the debate address the topic of the well-being of future children, it is important that they expound the stance they take in terms of moral status. This is owing to the fact that the question of prenatal moral status is of greater importance than the consideration of well-being and the specific stance adopted determines the implications of the well-being based arguments brought forward. It has, therefore, been concluded that the concept of well-being has a *subordinate presence* in the face of the notion of moral status. Nonetheless, above all opponents of the procedures in question appear to ignore the subordinate presence of well-being based lines of reasoning and place them in the foreground in order to conceal the fact that at the heart of their arguments is the full moral status which they ascribe to prenatal entities.

The analysis has also revealed another important aspect with regard to the character of well-being, namely that there is an opposition between *subjective* and *objective* approaches particularly where the future child’s well-being is concerned. We have ascertained that the three-tiered framework for analysis provided in chapter 2 rapidly reaches its limits. For this reason it has been supplemented by the subjective/objective scheme of alternative levels. Both schemes will be put to good use in the investigations of the character of well-being in the following chapters. When applying the subjective/objective scheme to the lines of reasoning referring to the future child's well-being, it becomes obvious that the identified antagonism of subjective and objective concepts of well-being operates, for the most part, at the *epistemic level*. It has, however, been shown that appearances are deceptive especially where the opponents of prenatal testing and selection are concerned since, at bottom, the argument is not about well-being but rather about *prenatal moral status*. Their lines of reasoning, which refer to subjective concepts of well-being, have been identified as alleged arguments which are directed against the objectivist stance of proponents of prenatal testing and selection. It has been shown that subjective concepts of well-being are *instrumentalised* in order to conceal lines of reasoning which are tied to the notion of a full prenatal moral status. All things considered, the findings illustrate that the notion of prenatal moral status has a major impact on the presence and character of well-being within the debate on prenatal testing and selection.

A further important finding should receive a mention here: the term *quality of life* appears to take preference over the expression *well-being* when objective concepts of well-being are referred to. In the following chapters it will be investigated whether this is a mere coincidence or whether this is also a finding in the other debates and if so, whether there is a purpose behind it.

The results of the analysis show that discussions on prenatal testing and selection are first and foremost concerned with the *protection* of well-being and the prevention of suffering. Nonetheless, the depicted arguments by the procreative perfectionists such as Savulescu and Harris reveal that the consideration of well-being is not restricted to the realm of health and the prevention of suffering. These dimensions of well-being will be thoroughly examined in the subsequent chapter dealing with the role of well-being in the debate on enhancement.

4. The role of well-being in the discussion on enhancement: the case of non therapeutic mood-improvement

The previous chapter dealing with the role of well-being at the beginning of life has already hinted at the fact that discussions in the realm of biomedical ethics are not exclusively concerned with the restoration and protection of health. The targets sometimes extend beyond this scope especially (but obviously not solely) where the middle phase of life is concerned. This chapter sets out to analyse the role of well-being in the debate on so-called ‘enhancement’.

During the last few decades man’s potential for the enhancement of human capacities and traits such as physical ability and appearance, cognitive capacity or mood has increased tremendously. Thus, more and more human desires for improvement beyond ‘natural limits’ can be fulfilled with the help of advances in biotechnology: the desire for ‘ageless bodies’, ‘superior performance’ and ‘happy souls’ are just some examples mentioned in the words of PCB (2003). The different procedures resulting from these developments, as for instance memory blunting through drugs or increasing height by growth hormones, raise ethical and social questions which are discussed principally under the term ‘enhancement’. Recently the topic of enhancement has received a lot of attention and is in the focus of many works in the field of biomedical ethics.[52] As the concept of enhancement is very broad, there is much confusion in the literature with regard to a uniform definition of enhancement and the term is indeed applied in many different ways (cf. Parens 1998). However, in its broadest sense, enhancement means ‘increase’ or ‘improvement’ (cf. Savulescu, Sandberg and Kahane 2011: 6).

It is visible at first glance, that the concept of well-being plays a major role where enhancement is concerned. The different human capacities and traits such as outward appearance, concentration, mood or physical ability, which are enhanced with the help of biotechnological procedures, are considered to con-

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[52] See for example Parens 1998; The President’s Council on Bioethics 2003; Schöne-Seifert and Talbot 2009; Nagel 2010; Suvulescu, ter Meulen and Kahane 2011; Buchanan 2011.

stitute important parameters for individual well-being. Proponents as well as opponents of enhancement refer to *well-being* in order to argue that the different procedures in question are morally acceptable or unacceptable as the case may be. Broadly speaking, proponents argue that enhancement will promote individual well-being, whereas critics do not abide by the notion that the enhancement of the human body and mind will actually increase well-being. The PCB, whose attitude towards enhancement is critical, maintains that 'in the end, it is happiness understood as complete and comprehensive well-being […] that we seek' (PCB 2003: 270) when enhancing the human body. Thus, implicitly or explicitly it is frequently argued that traits such as beauty, high cognitive or physical abilities contribute to the overall goal, the promotion of well-being. Accordingly, the enhancement of outward appearance, physical or cognitive ability indirectly propagates the well-being of the individual concerned. The term 'indirectly' refers to the way in which the intervention affects well-being. In the case of enhancement through plastic surgery, for instance, interventions are viewed as enhancing outward appearance which in turn contributes to individual well-being. Therefore, a connection between the improvement of beauty and an increase in well-being is assumed. Mood enhancement establishes a special case: apart from contributing indirectly to the pursuit of well-being, various mood-brightening technologies are frequently viewed as having a direct influence on individual well-being – as 'a pharmaceutical shortcut to happiness' (Juengst 1998: 38).[53] By utilizing pharmacological assistance some people believe that they are in a position to regulate their emotions directly and thereby improve their well-being. The notion of well-being plays a major role in these discussions and specific concepts of well-being are applied with great awareness. As it is such a wide field the following analysis of the presence and character of well-being will be restricted to the debate on *non therapeutic mood-improvement*.[54]

In a first step, a short introduction to the theme of mood enhancement as well as preliminary definitions are provided. The main part of this chapter fur-

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[53] Juengst applies this expression when depicting a line of argumentations put forward by critics of enhancement. This kind of view is based on a very narrow concept of well-being, which is of a hedonist nature referring to the subjective experience of happiness and well-being.

[54] Sections 4.1. as well as 4.2.1. of this chapter provide information which overlaps to a certain degree with the content in the following article: Beck and Stroop 2015.

nishes an analysis of the role of well-being within opposing arguments in the debate on mood enhancement. On the one hand, the concepts of well-being which are the basis of arguments brought forward in order to criticize enhancement procedures are placed under scrutiny. The examination primarily concentrates on lines of reasoning brought forward by the so-called bio conservatives such as *The President's Council on Bioethics* (2003). On the other hand, the role of well-being within contentions in favour of mood enhancement is examined. Here the exploration focuses on arguments purported by transhumanists[55] such as Nick Bostrom and Julian Savulescu and by the American psychiatrist Peter D. Kramer.

4.1. The subject of mood enhancement

The so-called 'mood enhancers' were originally developed as antidepressants to treat recognized mental illnesses like major depression. Nonetheless, they are being taken increasingly for non-therapeutic purposes in order to promote feelings 'better than well' (Kramer 1997: xii). Apart from being a common theme in science fiction, the use of mood-brightening technology for purposes of enhancement is said to be becoming a familiar aspect of contemporary life (cf. PCB 2003; Merkel et al. 2007). Due to various ethical concerns such as the problem of social conformity, distributive justice or the alleged personality changing effect of the substances (cf. Merkel et al. 2007) discussions have erupted as to whether there should be a moral or even legal ban on mood enhancement.

Among the most common methods of enhancing mood is the taking of psychiatric drugs such as *selective serotonin reuptake inhibitors* (SSRIs) and recreational drugs. In addition, memory-blunting drugs have increasingly entered the discussion (cf. PCB 2003). Other procedures, besides pharmacological interventions, which have a mood altering effect are, for instance, deep brain

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[55] According to Dieter Birnbacher '[i]t should be borne in mind, however, that the terms "transhumanist" and "bioconservative" describe ideal types rather than the concrete realities. There is a broad range of positions between the extremes, and it will be no less hard to find a "bioconservative" opposed to literally *any* attempt to improve the human condition by medical and non-medical techniques than to find a "transhumanist" in favour of literally all such attempts. As it is usually the case with polar opposites, most people can be expected to adopt some kind of intermediate position.' (Birnbacher 2008: 95)

stimulation and transcranial direct current stimulation (cf. Schermer 2011).[56] So far, these interventions have mainly been utilized for therapeutic purposes and not for enhancement. Looking into the future one can expect that 'the existing repertoire of interventions will most likely be expanded by e.g. genetic engineering, nanotechnologies, neural interfaces, rational drug design, trascranial magnetic stimulation, and "neuroceuticals"' (Brülde 2011: 218). With the help of these advances mankind might be able to regulate mood more effectively, with fewer side effects and with greater precision (cf. Lynch 2004). These methods will then tend also to be used for purposes of enhancement. Although it is a matter of dispute as to how far the enhancement of mood beyond the restoration of health has been a common practice up till now, advances in technology as well as changes in the attitude of society towards these technologies will most likely lead to a wider administration of mood enhancers. There is already significant evidence of a growth in the sales of SSRIs (cf. Pratt et al. 2011), for instance, and of the fact that gradually more and more people ingest SSRIs for less severe mental states than depression (cf. Farah 2002). Therefore, what are currently considered 'normal' emotions or moods might in future be treated as mental illnesses (cf. PCB 2003: 241).[57] However, what exactly is mood enhancement?

Two alternative definitions of enhancement

First of all, in order to obtain a clearer picture of mood enhancement it would appear to be advantageous to approach the broader notion of *enhancement*. 'The term *enhancement* is usually used in bioethics to characterize interventions designed to improve human form or functioning beyond what is necessary to sustain or restore good health.' (Juengst 1998: 29) This treatment/enhancement-approach distinguishes between *therapeutic interventions*, which sustain and restore health, and *enhancement procedures* which go beyond the restoration of health. But this differentiation in turn depends on concepts such as *disease*, *health* and *normalcy* which are equally broad and unspecified terms since they are strongly influenced by cultural, societal and historical factors (Merkel et al.

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[56] These are different forms of neurostimulation. For deep brain stimulation and enhancement see Schermer 2011.

[57] This development that conditions which previously were considered as 'normal' are gradually treated like illnesses is widely discussed under the title 'medicalization'.

2007: 305).[58] There have been criticisms that there is no clear line between interventions which count as treatment and those which should be considered as enhancement. For this reason, the treatment/enhancement distinction is highly contested. Discussions dealing with this differentiation have developed into a specific debate of their own and much has been written on this topic.[59]

Alternatively, participants in the enhancement debate, for the most part proponents of enhancement, have proposed the so-called ‘welfarist-definition’ of enhancement, clearly demarcating it from the treatment/enhancement-distinction. According to the welfarist approach any improvement of the human body and mind constitutes a form of enhancement if it increases the well-being of the individual concerned. When arguing for medical interventions considered as enhancement, Savulescu, Sandberg and Kahane give the following definition of ‘human enhancement’[60] from a welfarist perspective: ‘[a]ny change in biology or psychology of a person which increases the chances of leading a good life in the relevant set of circumstances’ (Savulescu, Sandberg and Kahane 2011: 7). A similar definition can be found within the works of John Harris: ‘[i]f it wasn’t good for you it wouldn’t be enhancement’ (Harris 2009: 131). Thus, in following this definition if an intervention does not succeed in increasing well-being, this would not be a case of enhancement. Nevertheless, this definition appears to be too widely based and thus, does not allow for a concrete definition of what kind of interventions should count as enhancement. Whether or not something is considered as human enhancement depends on how we understand the notion of well-being. Alternative theories of well-being are likely to result in divergent classifications. Moreover, if all interventions which improve the human body and mind and thereby promote individual well-being are considered as enhancement, then there can be no possible objection to procedures of enhancement since they are per definition good (cf. Merkel 2009:

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[58] For an overview of alternative concepts of health and disease see Schramme 2012.

[59] As this is not the debate this chapter aims to illustrate, further reference to this topic will not be pursued. For further details see for instance Parens 1998; Daniels 2000; Bostrom and Roache 2007; Heilinger 2010; Savulescu, Sandberg and Kahane 2011.

[60] Savulescu, Sandberg and Kahane provide the following definition of the term ‘human enhancement’: ‘[b]ut when we are considering human enhancement, we are considering improvement of the person's life. The improvement is some change in state of the person - biological or psychological - which is good. Which changes are good depends on the value we are seeking to promote or maximize. In the context of human enhancement, the value immediately in question is the goodness of a person's life, that is, his or her well-being.’ (Savulescu, Sandberg and Kahane 2011: 7)

177). The welfarist definition of enhancement, therefore, already encompasses the value judgement that the enhancement procedure under consideration is good (cf. Heilinger 2010: 114). Hence, it does not allow for discussions concerning the moral or legal legitimacy of these procedures.

Although the treatment/enhancement distinction presents many problems and is highly contested, in the following elaborations the differentiation between therapy and enhancement beyond the restoration of health shall function as a preliminary definition. There are, indeed, borderline cases in which it is difficult to tell whether an intervention should be considered as therapy or as enhancement. However, this chapter acts on the assumption that the distinction, nonetheless, seems meaningful and compelling in most contexts as there are many cases which can be classified relatively clearly as therapy (such as chemotherapy for cancer) or enhancement (for instance botox treatment). The same holds true for the concepts disease and health: it is taken for granted that, although there are no precise definitions and a grey area notwithstanding, we can generally speaking distinguish between disease and health.

The various biotechnological interventions concerned in the enhancement debate can be used for different purposes. They can be utilized for purely therapeutic purposes or for enhancing the human body beyond the restoration of health: '[t]hus, the same technology – [the antidepressant] Paxil, for example – will count as an enhancement technology in certain contexts (when used for enhancement purposes), but not in others (when used to treat a psychiatric illness)' (DeGrazia 2005a: 262). Originally most of the technologies in question had actually been developed for the treatment of recognized diseases, before they were utilized for enhancement.

Characterizing mood enhancement

What exactly is meant by referring to the term "mood" and what characterizes interventions which are considered as mood enhancement? Guy Kahane (2011: 167) provides the following definition of the term 'mood' when distinguishing it from the other two key notions 'feeling' and 'emotion': '[moods are] dispositions that govern one's entire emotional orientation for a certain period'. Feelings in contrast 'are episodes of consciousness. There is something it feels like to feel angry or sad. Emotions are broader behavioural dispositions which include dispositions to have certain feelings, as well as dispositions to behave, think, and attend in certain ways.’ (ibid.)

The question as to what exactly characterizes interventions which are considered as mood-enhancement is, as in the case of enhancement in general, difficult to answer. If one takes the definition of enhancement given above, which focuses on the distinction between therapy and enhancement, as a starting point and applies it to the case of mood, it would be the improvement of mood beyond what is necessary to sustain or restore health. Following this definition, the ingestion of antidepressants in order to improve mood in a case of severe or persistent suicidal depression clearly is not an example of enhancement. Instances of this kind can be considered as straightforward therapeutic intervention. In numerous other cases, however, it might not be so evident whether the improvement of mood has therapeutic purposes or can be considered as enhancement. Let us imagine in a case of fear of examinations that a person takes antidepressants in order to reduce his/her anxiety and feel better. Should one consider this as therapy or as an instance of enhancement? This, in turn, depends on the degree of anxiety present and where one draws the line between a pathological anxiety and a common degree of apprehension before an exam. This case illustrates the importance of cultural and societal factors which strongly influence the conceptualization of psychiatric illness vs. a normal state of mind.

An example to be found in the literature on mood enhancement is the case of a person who is too stressed about work to enjoy a friend’s wedding celebration (cf. Liao and Roache 2011; Wassermann and Liao 2008). In order to bring about the feelings appropriate for the wedding – feelings of joy and pleasure – she takes psychiatric drugs.[61] Thus, a desired feeling which the person lacks in a specific situation because of her particular circumstances is induced artificially[62]. There are many occasions in everyday life in which people desire emotions which seem appropriate and are not forthcoming naturally for a variety of different nonmedical reasons and might consider inducing them artificially. Cases of this kind are considered as examples of mood enhancement in the following.

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[61] At this point it is important to note that most psychiatric drugs such as antidepressants do not have an immediate effect. They need to be taken for several weeks until the desired effects occur. Therefore, one might call this example into question.

[62] The term ‘artificially’ is applied in order to refer to things humanly contrived.

Frequently when giving examples of cases of mood enhancement, authors refer to instances described by the American psychiatrist Peter D. Kramer (1997). In these cases people, who are not considered to suffer from an illness but want to change specific habits and skills in order to lead a better life, seek a psychiatric medication. Examples are habitually timid people who want to gain social confidence, sensitive persons who want to become brash or introvert individuals who want to improve their social skills (cf. Kramer 1997: xii). Kramer considers feelings resulting from mood enhancement as 'better than well' (ibid.). However, as DeGrazia points out, 'one might argue that, since such patients struggle with psychological phenomena that can be ameliorated with medication, it means little to say that they are not ill whereas someone who, say, barely qualifies as having depression or clinical anxiety is ill' (DeGrazia 2005a: 263).

Certainly, it remains a matter of dispute whether the depicted examples are cases of enhancement since, as illustrated, the treatment/enhancement distinction does not provide a concept with clear boundaries. Nevertheless, these cases shall function as examples of mood enhancement for the following.

4.2. The role of well-being in the debate on mood enhancement – an analysis

On taking a closer look at the arguments in the debate on mood enhancement, it becomes obvious that the reference to well-being and the question of what constitutes a good life play a major role in these discussions. Many authors point out explicitly that the question as to whether or not mood enhancement is a morally justified procedure relates directly to the question about the essence of well-being and the existing alternative concepts.[63] Furthermore, Nagel points out that 'people seek to achieve more well-being by using enhancement interventions' (Nagel 2010: 72). However, emphasis is placed on the fact that it is the well-being of the individual concerned (as opposed to overall well-being) which plays a central role in the discussions on enhancement (cf. Mieth 2011: 370). It has already been mentioned briefly in the introduction to this chapter

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[63] See for instance PCB 2003: 210; Brülde 2007; Berghmans et al. 2011: 161; Kipke 2011: 18; Schermer 2011.

that proponents as well as opponents of enhancement refer to well-being in their arguments. Savulescu et al. provide the following précis.

> Proponents of enhancement see these [technological advances] as positive developments. They argue that it is high time that we used biomedical science, not only to fight disease, but also to positively enhance human capacities and well-being. But opponents of enhancement see these developments as a grave threat to what is most dear in human life. These contrasting hopes and fears have already generated intense controversy. (Savulescu et al. 2011: preface)

The tension between rival lines of argumentation which refer to well-being is clearly perceptible in the debate on mood enhancement. There are two opposing camps: on the one hand, the bio conservatives[64] (as they are called by their critics) who state that enhancement procedures do not promote and even endanger our well-being and on the other hand, the proponents, who claim that mood enhancers, or enhancement in general, constitute a new way for promoting well-being. Among them are the so-called transhumanists.

The following section depicts the different lines of argumentation put forward by the opposing camps and analyses the way in which the notion of well-being is applied in their arguments.[65]

4.2.1. Critical attitudes towards mood enhancement

Generally speaking, the various procedures for mood enhancement have encountered much criticism. Many objections refer directly to the well-being of the persons who consume mood enhancers. If one takes a closer look at the critical lines of argumentation, they generally maintain that mood enhancement

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[64] The term 'bio-conservatives' usually is applied to refer to the PCB (2003) and thinkers such as the chairman of the PCB Leon R. Kass (2003), Francis Fukuyama (2002), Jürgen Habermas (2003) and Michael Sandel (2007), who are considered as moral conservatives where procedures such as enhancement are concerned. Due to the fact that the PCB has provided a detailed discussion and study of the subject of mood enhancement the following primarily focuses on their arguments.

[65] In the following I will not concentrate on arguments referring to medical side-effects or long term safety as these arguments are of lesser interest to the central question of this chapter.

does not promote individual well-being as we are ‘missing something important’ (Cole-Turner 1998: 153). This appears to be a common line of argumentation. The assumed elements of well-being which are said to be missing are different in nature. In order to examine what exactly is said to be missing, the following section focuses primarily on the argumentation as represented by the PCB (2003) but also refers to critical lines of reasoning brought forward by other participants in the debate.[66] Attention is, above all, paid to the specific concepts of well-being underlying the various objections.

Mood enhancement as an alleged ‘shortcut’ to well-being

In their report the PCB state first of all that the development of mood enhancing technologies is apt to provoke the following question, provided that the pursuit of well-being constitutes the overarching interest of mankind. ‘Indeed, why would one need to discipline one’s passions, refine one’s sentiments, and cultivate one’s virtues, in short, to organize one’s soul for action in the world, when one’s aspiration to happiness[67] could be satisfied by drugs in a quick, consistent, and cost-effective manner?’ (PCB 2003: 208) According to the PCB, some people are likely to view mood enhancing technologies as a useful means for *directly* increasing well-being with lesser effort compared to traditional means. Cole-Turner expounds a similar idea when maintaining that it is a common belief on the part of proponents of mood-enhancement that ‘the new means seek the same goals [as the old means], but they achieve them more quickly or efficiently; therefore, the new means are good, perhaps even better than the old means’ (Cole-Turner 1998: 153). Hence, mood enhancement is often related to the notion of a ‘shortcut’ to happiness providing a quick way to well-being which requires less effort. However, this notion has been strongly opposed, above all, by critics of mood enhancement such as the PCB.[68] The criticism is that this notion of a shortcut reduces the concept of well-being to its hedonic content, namely pleasure and pain. This notion is based on the assumption that well-being is merely the product of our present mood, which can be

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[66] The differentiations provided in this section have arisen in the course of discussions with Birgit Beck to whom I owe my sincere thanks.

[67] It is important to note here that the PCB uses the terms ‘well-being’ and ‘happiness’ interchangeably. Happiness is therefore applied in a broader sense.

[68] For a more detailed and critical discussion of the objection that enhancement does not provide an ‘easy shortcut’ see Schermer 2008.

directly increased through mood enhancing interventions. The PCB classifies this as a common misconception since well-being is more than ‘good mood’ (cf. PCB 2003: 235). Hence, good mood in itself is not a sufficient condition for well-being. Therefore, according to the PCB, if we try to increase our well-being through mood brighteners something important is missing since well-being encompasses far more than hedonic components. So what exactly is missing according to the PCB?

Missing components of well-being where mood enhancement is concerned

Critics frequently maintain that we desire other goods than mere pleasure and that often we strive for things even though we do not expect them to give us pleasure. Thus, there appear to be other important components of well-being apart from good mood. The PCB states that ‘we desire not simply to be satisfied with ourselves and the world, but to have this satisfaction as a result of deeds and loves and lives worthy of such self-satisfaction’ (PCB 2003: 251) and that ‘the happiness of the soul is inseparable from the pleasure that comes from perfecting our natures and living fruitfully with our families, friends, and fellow citizens’ (ibid.: 270). The PCB places emphasis on the fact that, due to our *human nature*[69], the listed aspects are important components of individual well-being. By applying enhancement procedures we run the risk of losing what it means to be human. This notion, that the listed aspects are important for the pursuit of well-being, can also be found in the arguments of other authors in the literature on mood enhancement such as Berghmans et al. (2011: 161). They maintain that individual well-being depends on factors such as ‘individual striving’ and ‘effort’, ‘being connected to other people by way of social relationships and interactions’. Furthermore, Berghmans et al. state that as mood brighteners do not depend on these important factors, consuming them is apt to result ultimately in a ‘shallower life, instead of a richer life’ (ibid.). As Dan W. Brock maintains ‘[t]here is a widespread popular conception that using drugs for pleasure interferes with developing each of these components [such as friendship, love, intellectual capacities, activities and autonomy] of our good’

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[69] See also PCB 2003: 7 and 289 f. on the importance of the concept of *human nature*.

(Brock 1983: 33).[70] Hence, in the discussion of mood enhancement these components are widely considered as important factors which influence individual well-being. According to the critics, these aspects are not promoted when mood enhancers are applied. Therefore, mood enhancing procedures are not in a position to increase individual well-being.

All things considered, we can observe that some critics stress the importance of other components apart from pleasure when the character of well-being is concerned. They list specific components which are of importance for individual well-being and stress the fact that these are missing when mood enhancement is applied. Their argumentation appears to be based upon the assumption that the nature of well-being is not entirely subjective. There are important objective components which set limits to the promotion of well-being by means of mood enhancers. As illustrated, they explicitly list these components.

The following question seems to be of central importance for the analysis: what is the relationship between pleasure and well-being? Critics point out that there are other important aspects of well-being apart from pleasure which proponents of mood enhancement ignore. Moreover, critics might even go as far as to dispute the fact that pleasure is of importance for well-being. As Brock points out '[w]hen disapproval of the use of drugs for pleasure derives from a general disapproval of pleasure, it often takes some form of the "swine objection". That is, people are capable of many higher activities, and to view them as merely pleasure-seeking beings is to debase their nature.' (Brock 1983: 31) Furthermore, it is claimed that if one recognizes the fact that pleasure is a component of wellbeing, there appear to be qualitative differences in terms of pleasure which depend on whether or not our emotions are connected to reality and that pleasure induced by means of mood enhancement is of a lesser quality due to the fact that we have no contact to reality.

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[70] Note that Dan W. Brock is concerned with the legal prohibition on the use of drugs merely for pleasure and does not directly address the broader subject of mood enhancement. At the time his paper was published enhancement had not yet developed into a major debate. Nonetheless, his discussion of drug induced pleasure can fruitfully be transferred to the subject of mood enhancement.

Mood enhancers and the danger of losing contact to reality

It is frequently maintained that apart from the fact that other components of well-being are missing, the pleasure resulting from mood enhancement is no real pleasure but rather a 'fraudulent happiness' (PCB 2003: 212): according to the PCB, we desire our experiences of pleasure to be real. It is a widespread concern that mood enhancers might distort our feelings and that there is a risk of 'mistaking some lesser substitute for real happiness' (PCB 2003: 252). Mood enhancers are said to be not in a position to induce real happiness, rather they provoke an illusion of it. The connection is frequently made to a common objection against ethical hedonism[71] which we already encountered in chapter 2, namely Robert Nozick's thought experiment known as the 'Experience Machine'. When referring to this thought experiment it is maintained that 'real well-being is not only "in the mind" but also "in the world"' (Schermer 2013: 441). *Soma,* the pleasure drug in Aldous Huxley's *Brave New World* (1932), which creates a spurious happy and superficial environment, also constitutes a familiar point of reference in the debate. The analogy is applied in order to illustrate what kind of impact mood enhancement might have.[72] As Roland Kipke maintains, the central concern is the absence of the *connection* between the emotion and reality (cf. Kipke 2011: 265). If this connection is missing, our emotional experiences cannot be considered authentic. Such kinds of emotions which lack contact to reality run the risk of leading to solipsism in terms of happiness: the happy individual being remote from the external world outside of her mind. But, according to some critics 'we not only want to be happy, rather happy in an authentic way'[73] (ibid.). Since this cannot be accomplished by mood enhancers they are viewed as leading to 'fraudulent happiness'.

If we compare this objection with the criticism directed against hedonism illustrated in chapter 2 we can observe that there are many similarities. These critical lines of reasoning rely upon the assumption that being connected to reality is an objective requirement for 'real' pleasure. Thus, once again some critics distance themselves from a subjectivist conception referring to objective dimensions with respect to the character of well-being. Furthermore, they cre-

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[71] See for instance Schermer 2011.

[72] See for instance PCB 2003; Merkel et al. 2007 and Roache 2007.

[73] Translation by author. Original quote: 'Wir wollen nicht nur glücklich, sondern authentisch glücklich sein.'

ate the impression that proponents of well-being do not attach any importance to being connected to reality.

Pleasure derived from a false origin

The charge of a ‘fraudulent happiness’, however, refers to another objection to mood-enhancement: the pleasure resulting from mood enhancement is no ‘real pleasure’ since it is artificially induced and for this reason not authentic. According to the critics of mood enhancement it is important to distinguish between the *natural* as opposed to the *artificial* origin of an emotion. ‘In their eyes, those who take psychotropic drugs and employ other technical devices necessarily end up in an inauthentic emotional state.’ (Krämer 2011: 54) Thus, the pleasure resulting from mood enhancement has a ‘false’ origin since it is artificially induced and not naturally produced. Frequently the term ‘natural’ is equated with ‘authentic’ and ‘artificial’ with ‘inauthentic’. However, the critics are not very explicit about what exactly they mean when distinguishing the natural from the artificial and also the concept of authenticity, which is often referred to, is far too vague and, therefore, does not contribute to comprehensibility. Thus, the question remains open as to why exactly naturally produced pleasure is to be preferred in the face of artificially induced pleasure.[74] We will come back to the concept of the natural and the value which is attributed to it in due course.

Another reason which is brought forward in order to argue that mood enhancers lead to pleasure which has a ‘false’ origin is the fact that ‘real’ pleasure results from efforts, deeds and actions. The notion is criticised that pleasure is ‘logically detachable from the activities that produce it. It is the pleasurable sensations or feelings that are liked for their own sake, and the activities that produce the pleasure are only contingently necessary to the pleasure’. (Brock 1983: 31) The PCB envisages a risk that mood enhancers ‘create the possibility of severing the link between feelings of happiness[75] and our actions […]’ (PCB 2003: 207-8) and a risk of a ‘fraudulent happiness’ (ibid.: 212). This line of ar-

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[74] For a more detailed and critical discussion of causal connection between the artificiality of the means and the inauthenticity of the resulting emotions see Krämer 2009 and 2011.

[75] In this quotation the term happiness seems to refer to pleasure and not to the broader concept of well-being. However, the PCB acknowledges that in cases of therapeutic use mood enhancers might, on the contrary, re-link feelings and activities (cf. PCB 2003: 260).

gumentation implies that feelings of pleasure without the activities which usually arouse this pleasure are not considered ‘real’ pleasures. ‘Real pleasures’ need to result from actions and activities: ‘[w]e do not want the pleasure of playing baseball without playing baseball, the pleasure of listening to music without the music, the satisfaction of having learned something without knowing anything’ (ibid: 265). Once again the PCB appeals to human nature when stating that there is a ‘danger of violating or deforming the nature of human agency and the dignity of the naturally human way of activity’ (ibid.: 292).

Furthermore, the critics mentioned suggest that we do not mind making efforts in order to experience pleasure and that we should earn the pleasure we feel from our actions. As Martha J. Farah maintains ‘[m]ost people in our society feel there is value to earning one’s happiness, success, and so on’ (Farah 2002: 1125). *Directly* inducing pleasure by means of mood enhancement without having earned it and thereby taking the ‘easy shortcut’ is considered cheating. Mood enhancers ‘estrange us from the forms of pleasure that depend upon discipline and devotion’ (PCB 2003: 208). This objection is discussed under the title *no pain, no gain-argument*. Schermer points out ‘“no pain, no gain” implies that one *ought* not to have any gains without having worked or suffered for them’ (Schermer 2008: 358). Thus, the happiness resulting from mood enhancement is considered ‘fraudulent’ as it is neither deserved nor linked to specific deeds or actions.

In summary, according to critical lines of reasoning, the origin of pleasure appears to have an impact on the quality of that pleasure and whether or not it is considered ‘fraudulent’ or ‘real pleasure’. Since mood enhancement induces pleasure with the help of artificial means and, as critics claim, thereby detaches it from any activity it leads to fraudulent happiness. Thus, there are some further objective requirements at stake which ‘real pleasure’ needs to fulfil: it needs to have the right origin which means that it should have a natural source such as activities, actions and hard work. These requirements operate on the ontological level. Pleasure is not considered as ‘real’ pleasure if these requirements are not fulfilled. The PCB appeals to nature and ‘our human nature’ when justifying these requirements for real happiness. All in all, even though it is recognized that pleasure constitutes a component of well-being it is does not have an utterly subjective essence. The arguments depicted are based on the underlying assumption that there are important objective dimensions where the character of well-being is concerned.

The importance of sorrow and sadness

Another objection to mood enhancement, which has received attention in the literature, is the concern that mood brighteners might undermine character formation and thereby our ability to cope with difficult or more challenging phases in life.[76] The PCB, for instance, states that sorrow 'courageously confronted, can make us stronger, wiser, and more compassionate' (PCB 2003: 293). When critically examining this argument Schermer states it is a common view that suffering 'can … enable learning, personal growth, or the development of wisdom and life-experience' (Schermer 2008: 359). Experiences of coping and struggling with the darker aspects of life are said to be especially important for character formation. In a nutshell: 'struggling with pain builds character, and eliminating that pain undermines good character' (Chatterjee 2004: 971). The formation of a strong and good character in turn is considered as a precondition for individual well-being. People need to develop character traits and coping mechanisms which are important for their future well-being. The reliance on mood enhancers in difficult situations in life does not provide an alternative since they impede character formation. Hence, it is maintained that mood enhancers are frequently considered 'the easy way out' in difficult situations in life and that this notion might, in the long run, lead to a decrease in well-being as learning how to struggle and cope with pain and sorrow is important for the promotion of well-being. Furthermore, the PCB places emphasis on the fact that 'distress, anxiety, and sorrow [are] appropriate reflections of the fragility of human life and inseparable from the setbacks and heartbreaks that accompany the pursuit of happiness and the love of fellow mortals' (PCB 2003: 213). Instead of trying to eliminate these feelings we should recognize that they are part of our human nature.

In addition, the so-called 'contrast experiences' are said to enable individuals to appreciate positive feelings of happiness and contentment more fully. When referring to this objection Berghmans et al. give the following argument:

> [...] leading a good life and being happy seems to depend also on so-called contrast experiences. Sadness, grief, and suffering are inherently part of human life, as much as feelings of joy, happiness, and elevated mood are. They are like two sides of a coin. Trying to elimi-

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[76] For a critical discussion of this argument see Chatterjee 2004: 971.

> nate negatively valued experiences may ultimately and paradoxically lead to a lower level of well-being. (Berghmans et al. 2011: 161)

Hence, for two reasons states of mood such as sorrow and sadness are viewed as important components of individual well-being: firstly, they foster character formation which is important for individual well-being and secondly, they provide contrast experiences which are also said to be important for well-being. Since mood enhancement aims at alleviating these states of mood they are viewed as endangering the pursuit of well-being in the long run.

The examination of these arguments once again illustrates that the critical lines of reasoning place emphasis on objective dimensions of the character of well-being. Sorrow and sadness are considered universally important elements since ultimately they help to promote well-being and are inevitable and ultimately helpful emotions resulting from the characteristics of human nature.

Interim results

All things considered, we can observe that there is a variety of arguments against mood enhancement in which well-being plays a prominent role and has an overt presence. However, although not explicitly stated, the critical arguments are based upon a specific notion of the character of well-being, namely objectivist conceptions. Within the arguments it is assumed that there are some objective goods such as social relationships and a number of objective requirements, such as having contact to reality, which need to be involved if well-being is to be promoted since they are tied to our human nature. Due to the fact that mood enhancement does not incorporate these goods and since the resulting pleasure does not fulfil the listed requirement, it is alleged not to be in a position to promote well-being. These assumptions operate on the ontological level since it is presupposed that certain goods constitute the essence of well-being independent of whether or not the subjects concerned desire them. Since these goods encompass a broad variety of different things such as friendship or love relationships which are important for well-being, we can conclude regarding the character of well-being that they presuppose a broad objective concept similar to an objective list theory when propounding their critical lines of reasoning.

Although critics might not reject the importance of pleasure, which is generally considered a subjective dimension of well-being, they state that 'real pleasure' is connected to objective requirements such as being connected to reality. Thus, they move the generally subjective notion of pleasure into a more objectivist direction binding objective requirements to it. Furthermore, we can ascertain that throughout the various well-being-based arguments the concept of *human nature* or the *value of the natural* is referred to. Human nature is seen as setting limits to our abilities to control our well-being. Factors such as social relationships and 'real' activities are considered to be integral parts of well-being by our very nature. Hence, the well-being based arguments appear to be tied to a specific normative conception of human nature. All things considered it might be fruitful to pay more attention to this relationship of the concept of well-being and the notion of human nature in the debate on mood enhancement.

There is, moreover, another interesting observation to be made: the critical arguments towards mood enhancement rest upon the assumption that mood brighteners cannot function as a *direct* shortcut to well-being mainly for two reasons:

1a: Well-being consists of more than 'good mood'. Important aspects such as social relationships, real deeds, activities and contrast experiences are missing if mood brighteners are administered.

2a: The pleasure produced through mood enhancement is no 'real' pleasure as it does not result from contact with the 'real' world and has a false origin. This 'fraudulent' pleasure does not contribute to individual well-being.

These two central arguments put forward contra mood enhancement are directed towards proponents of these interventions who argue that mood enhancement gives people the opportunity to increase their well-being. Against the background of these two central critical arguments outlined above, critics seem to imply that authors arguing for the enhancement of mood take a directly opposite stance stating that

1b: 'good mood' is the one and only component of individual well-being

and

2b: that it does not make a difference whether the pleasure results from activities and interaction with the 'real' world or whether it is *directly* produced through artificial means such as mood brighteners.

Taken together, these two assumptions can be classified as representing the core thesis of the hedonist doctrine. Therefore, it appears as if critics accredit a hedonist stance to proponents of mood enhancement. The opposing lines of argumentation applied closely resemble the disapproval directed towards the hedonist doctrine. Instances of this are the criticism that pleasure and pain is not of primary importance to well-being since well-being is dependent upon various other factors. Also, the objection that experiences of pleasure must essentially be real, emphasized by the reference to Nozick's experience machine, is a classical line of argumentation contra hedonism. Thus, according to critics, proponents of mood enhancement are apt to take a hedonist stance in questions as to what constitutes the character of well-being. This alleged link between a favourable attitude towards mood enhancement and a hedonist stance is also explicitly pointed out: '[m]any supporters of the biomedical enhancement of mood explicitly or implicitly base their case on such appeal to hedonic reasons' (Kahane 2011: 167).

Having ascertained this perspective, one would imagine that rival lines of argumentation in the debate on mood enhancement rest in their core upon rival concepts of well-being, that is to say subjective hedonist concepts and objectivist approaches. But does this hold water? Are the lines of argumentation in favour of mood brightening procedures really based on a purely hedonist concept of well-being which views mood enhancement as a direct shortcut to well-being?

4.2.2. Argumentations in favour of mood enhancement

After having dealt with the objections with which mood enhancing procedures have been confronted, it is now time to turn to the arguments of the other camp, of the proponents of mood enhancement. When doing so, first of all, it is important to point out that the literature on the ethics of mood enhancement is, for the most part, critical. There do not appear to be very many supporters of these kinds of intervention. Among the most eminent of the proponents of mood enhancement are the so-called 'transhumanists'[77], who argue that recent enhancing technologies offer new or even easier opportunities for enhancing well-being than the usual means. Therefore, according to them there should not be a ban on such new technologies. Julian Savulescu (2005; Savulescu and Kahane 2009) and John Harris (2007 and 2009) even go as far as to argue for a moral obligation to pursue enhancement. Another eminent proponent of mood enhancement is the American psychiatrist Peter D. Kramer. As will be illustrated in the ensuing section, he argues that mood enhancers *indirectly* promote individual well-being. The following analysis of well-being-based arguments in favour of mood enhancement primarily concentrates on the lines of reasoning brought forward by the transhumanists and by Peter D. Kramer. Special attention is paid to the character of well-being considered in their arguments in order to examine whether proponents really do take a hedonist stance, which the critics of mood enhancement accredit to them.

Pleasure as one among other important components of well-being

To begin with when dealing with the assertions of the transhumanists, it is important to point out that it is difficult to find detailed lines of argumentation regarding the specific case of mood enhancement. Most of their works deal with the general theme of enhancement ethics and provide general lines of argumentation which are to be applied to specific cases such as the procedure of enhancing mood.[78] Nevertheless, there are a few lines of argumentation to be found which clearly illustrate that members of the group such as Julian Savulescu and Nick Bostrom do indeed argue in favour of mood enhancement.[79] In order to elucidate this, the following, first of all, depicts the argument for human enhancement in general proposed by Savulescu, Sandberg and Kahane (2011) and will then apply it to the case of mood brighteners.

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[77] Hughes defines the movement of transhumanism as 'the idea of using reason to transcend the limitations of the human condition' (Hughes 2004: 155). Among the members of this group are Nick Bostrom and Julian Savulescu. John Harris is also frequently considered to be a member of the group as he takes a similar stance. However, he distances himself from the transhumanist programme. The following focuses mainly on the works of Savulescu and Bostrom where the transhumanists are concerned.

[78] See for instance Savulescu 2005; Bostrom 2008; Savulescu, Sandberg and Kahane 2011.

[79] See for instance Ranisch and Savulescu 2007: 49; Bostrom 2008: 12.

Savulescu et al. take the welfarist definition as their starting point, which has already been portrayed above. According to this account, enhancement procedures do by definition increase the chances of leading a good life. Interventions, in contrast, which raise the person to a level beyond normal functioning, but are not beneficial to the person concerned should not be considered as enhancement. Hence, whether or not specific procedures are viewed as human enhancement depends on the empirical question as to what impact they have on well-being. Savulescu et al. conclude: '[b]y accepting the welfarist definition of enhancement, the question of when should we enhance becomes: when should we increase human well-being?' (Savulescu, Sandberg and Kahane 2011: 8).

If one applies the welfarist account to the case of mood brighteners the central question is: are individuals who apply mood brighteners likely to lead a better life? Are they likely to lead a life with more well-being (cf. Ibid.: 10)? Paragraphs to be found in other works by the authors illustrate that they consider the application of mood brighteners as interventions which enable people to brighten their mood and foster their *subjective well-being* (see Ranisch and Savulescu 2007: 49 and Bostrom 2008: 12). However, the question as to how they define the relationship of *subjective well-being* and the more broader concept of *well-being* then arises. Savulescu et al. explicitly point out that 'whether, on the welfarist account, something counts as a human enhancement depends on how we understand the notion of well-being' (Savulescu, Sandberg and Kahane 2011: 10). They depict the three alternative theories of well-being and the specific aspects on which they lay emphasis. Concerning the role which subjective well-being plays in each of the alternative theories they state: 'subjective well-being is the whole of well-being only on hedonist theories, although it is a significant component of well-being on all plausible views' (ibid.: 11). Hence, subjective well-being is used to refer to the hedonic quality of experiences and viewed as having a positive impact on overall well-being irrespective of which of the alternative theories is endorsed. Elsewhere one can find a similar line of argumentation put forward by Savulescu and Kahane.

> But although there is this philosophical disagreement [concerning the concept of well-being], there is considerable consensus about the particular traits or states that make life better or worse […]. Few if any would deny that chronic pain tends to make a life worse or that joy makes a life better. All plausible moral theories have to make such

> judgments – judgments about harms and benefits, or things that make a life go better or worse. (Savulescu and Kahane 2009: 279)

Thus, according to Savulescu and Kahane pleasure and joy are important aspects in each of the three alternative theories (hedonism, desire-fulfilment and objective list theories). There are also other authors to be found in the debate on mood enhancement who point out that even if one maintains that well-being consists of more than good mood it is beyond doubt that the experience of pleasure is an important component of individual well-being. If one presupposes that mood brighteners are indeed in a position to elevate subjective well-being, as the transhumanists appear to suggest, then they should be considered as promoting well-being in all three alternative theories. Therefore, in following the welfarist definition of enhancement they should be classified as interventions of human enhancement. Nick Bostrom demonstrates a similar line of contention when arguing for the enhancement of the emotional capacity. ‘One dimension of emotional capacity that we can imagine enhanced is subjective well-being and its various flavors: joy, comfort, sensual pleasure, fun, positive interest and excitement. Hedonists claim that pleasure is the only intrinsic good, but one need not be a hedonist to appreciate pleasure as important component of the good.’ (Bostrom 2008: 11-2) In summary, we learn that proponents of mood enhancement such as Bostrom and Savulescu argue that mood brighteners promote pleasure and joy. Due to the fact that these are important components of individual well-being according to all three alternative theories, administering mood brighteners promotes well-being and for this reason can be considered as human enhancement.

Furthermore, Savulescu, Sandberg and Kahane state that there are a number of traits such as ‘memory’, ‘self-discipline’, ‘patience’ and ‘having a sunny temperament’ which are ‘valuable on all plausible conceptions of well-being’ (Savulescu, Sandberg and Kahane 2011: 11) and due to this fact their promotion always has a positive impact on well-being. Bostrom provides a similar line of reasoning when referring to the promotion of our basic human capacities such as healthspan, cognition and emotion (cf. Bostrom 2008). Since ‘[a]ll of these characteristics ... may have some biological and psychological basis capable of manipulation with technology’ (Savulescu, Sandberg and Kahane 2011: 11) they can be modified and thereby promote individual well-being. Bostrom states that ‘[t]ranshumanists view human nature as a work-in-progress, a half-baked beginning that we can learn to remold in desirable ways' (Bostrom 2005: 4) or in the words of Savulescu 'to choose to be better is to be human' (Savulescu, Foddy and Clayton 2004: 670). Although the transhumanists criticize the opponents of mood enhancement for tying their arguments to old-fashioned concepts of human nature and allegedly reject the moral relevance of the notion, they themselves make reference to human nature within the argumentation. In following the transhumanists, the ingestion of mood brightening pills to increase our well-being can be considered part of our human nature which aims at progress and improvement. The various procedures of enhancement are viewed as enabling us to improve ourselves and, above all, our well-being. When applying enhancement procedures we are considered to live in accordance with our human nature. Hence, as in the case of the critics of mood enhancement the impression arises that the well-being-based lines of reasoning are tied to a normative concept of human nature.

It has been argued above that critics seem to presuppose that authors arguing for the enhancement of mood would take a hedonist stance basing their arguments on the following assumptions: 1b*'good mood' is the one and only component of individual well-being* and 2b *that it does not make a difference whether the pleasure results from activities and interaction with the 'real' world or whether it is produced artificially through mood brighteners.* In fact, the arguments presented so far in favour of mood enhancement do not support these assumptions. In the case of 1b transhumanists such as Savulescu and Bostrom do not argue that 'good mood' is the one and only component of well-being. Instead they take a different stance stating that 'good mood' is an important factor for well-being in all alternative theories of well-being. Thereby, it can be just one component among many others contributing to well-being.

Assumption 2b, on the other hand, is difficult to prove as Savulescu et al. as well as Bostrom do not deal with the specific kind of pleasure (or subjective well-being as they call it) resulting from mood brighteners and allegedly do not take a specific stance concerning the three alternative theories of well-being. Since they relate to the notion that mood enhancers do in fact promote pleasure, they would possibly support the view that it does not make a difference whether the pleasure results from activities and interaction with the 'real' world or whether it is produced 'artificially' through mood brighteners.

All in all, the transhumanist approach to the character of well-being appears in no way to be a purely hedonist or an utterly subjectivist stance. In contrast, even though they themselves maintain that their arguments are not based upon any specific conceptions of well-being their considerations suggest that they adopt an approach which tends towards objectivism. They list specific goods – among them subjective well-being – which are viewed as universally having a positive impact on individual well-being and these do not depend on the specific individual concerned. Hence, they appear to make commitments on the ontological level with regard to the character of well-being which tend towards objectivism. Furthermore, our findings indicate that also within the transhumanist well-being-based lines of reasoning the concept of *human nature* is implicitly and sometimes explicitly addressed. It is argued that our human nature forces us in the direction of improvement with regard to our human capacities which in turn is considered promoting our well-being. This is an interesting observation since the transhumanists claim that their arguments are not based on a normative conception of human nature. After having dealt with the transhumanist assertions, the subsequent section now takes a closer look at the arguments in favour of mood enhancement as provided by Kramer.

Indirect promotion of well-being through mood enhancement

In his book *Listening to Prozac* (1997) the American psychiatrist Peter D. Kramer deals with the effects of psychiatric medications which were new at the time. His description of the story of Tess, a woman who starts to take Prozac, has received a lot of attention. Through telling her story, Kramer wants to illustrate the positive impact the ingestion of Prozac has and the changes it brings about. The following will also concentrate on Kramer's example of Tess (1997: 7-8) and the way he applies her story as an argument in favour of mood enhancement. But before doing so, it is important to point out that it is open to dispute whether the case of Tess does in fact provide an example of enhancement. According to the definition of enhancement given above, Tess's case would not be an instance of enhancement since she contacted Kramer for the treatment of her clinical depression. Nevertheless, Kramer himself maintains that he does not deal with the impact of Prozac on major mental illnesses; rather he focuses on 'fairly healthy people who show dramatically good responses to Prozac, people who are not so much cured of illness as transformed' (ibid.: xvi). He uses the term 'better than well' (ibid.: vii) to describe the state which Prozac brought about.

Kramer describes Tess's childhood as difficult since she took over the responsibility for her nine younger siblings and was physically and sexually abused as a child. Her mother suffered from clinical depression and her father, who died when Tess was twelve, was an alcoholic. At the age of seventeen Tess got married in order provide a family environment for her siblings. Her marriage was very problematic as her husband was abusive. Kramer illustrates that although there were these huge challenges Tess coped amazingly well. She managed to achieve a highly responsible position in a large corporation and cared for her mother. Although she appeared to be coping well and seemed be a successful person, Tess did not consider her life in that way. She was suffering from a clinical depression. After two weeks of treatment with Prozac Kramer observed remarkable changes. Tess's improved mental state had a great impact on many other aspects of her life. She gained confidence, started dating men and experienced the fact that people approached her more readily. Also, she was able to handle stress and conflict more easily which made her working life easier for her. The application of Prozac made her feel more energetic. Kramer describes the transformation the following way: 'I had never seen a patient's social life reshape so rapidly and dramatically. Low self-worth, competitiveness, jealousy, poor inter-personal skills, shyness, fear of intimacy – the usual causes of social awkwardness – are so deeply ingrained and so difficult to influence that ordinarily change comes gradually if at all. But Tess blossomed all at once.' (ibid: 7-8) He stresses the fact that Prozac not only brought Tess out of her depression, but is also in a position to change people's habits and social skills. 'Prozac seemed to give social confidence to the habitually timid, to make the sensitive brash, to lend the introvert social skills of salesman' (ibid.: xii). His argumentation suggests that he implicitly considers people's habits and social skills as having great impact on individual well-being and flourishing. Concerning this matter Stefan Schleim places emphasis on the importance of distinguishing between a *direct* and an *indirect* way in which pharmaceuticals influence well-being: 'When we discuss the possibility of pharmaceuticals, the means in question can *directly* or *indirectly* aim at increasing happiness. The latter is achieved by influencing other dimensions which in turn increase well-being'[80] (Schleim 2011: 384). According to Kramer, rather than *directly* influ-

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[80] Translation by author. Original quote: ‚Wenn wir die Möglichkeiten von Psychopharmaka diskutieren, dann kann das Mittel *direkt* auf eine Steigerung des Glücks zielen oder

encing people’s happiness Prozac *indirectly* promotes their well-being by modifying their habits and social skills. Thus, by changing character traits mood enhancers indirectly lead to a state which Kramer considers ‘better than well’. He does not appear to view Prozac as a ‘pharmaceutical shortcut’ to happiness but rather as an indirect way of promoting well-being. Kramer’s lines of argumentation are compared with the assumptions 1b and 2b of the critics, namely: 1b:*’good mood’ is the one and only component of individual well-being,* and 2b: *that it does not make a difference whether the pleasure results from activities and interaction with the ‘real’ world or whether it is directly produced through artificial means such as mood brighteners*. With regard to 1b, Kramer mainly stresses the fact that the ingestion of Prozac and the resulting improvement of mood change individual habits and skills such as social abilities. His reflections illustrate that he presupposes that these skills and abilities have an impact on individual well-being. Therefore, the underlying assumption of his argument seems to be that factors such as social relations, love attachments and career are important factors for well-being. Rather than maintaining that ‘good mood’ or pleasure is the one and only component of individual well-being, Kramer appears to presuppose that there are various factors. Hence, he would not agree with assumption 1b.

Concerning 2b, Kramer’s argumentation also points in a different direction: As illustrated, his main thesis is that the ingestion of Prozac has a positive impact on social interactions and the way certain activities are performed. These, in turn, have a positive effect on individual well-being. Thus, according to Kramer the increase of well-being results from activities and interactions with the ‘real’ world. Kramer’s stance does not necessarily imply assumption 2b *that it does not make a difference whether the pleasure results from activities and interaction with the ‘real’ world or whether it is produced artificially through mood brighteners.*

Furthermore, Kramer does not take a hedonist stance in terms of the character of well-being. There are some lines of reasoning to be found in which he appears to refer to the desires which people have and things which persons strive for. This suggests that he bases his argument on a subjective conception such as desire fulfilment theory. However, he does not bind his argument to an

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indirekt Glück versprechen, indem es eine andere Größe beeinflusst, die wiederum zu mehr Glück führt‘.

utterly subjectivist conception of well-being since he also refers to goods such as social relationships, love attachments and career fulfilment which people desire and strive for. For this reason we can observe that he appears to move in an intersubjective direction in terms of well-being. Although Kramer's well-being-based arguments are not explicitly based upon a specific conception of human nature, he also pays attention to the concept: 'I have focused on this phenomenon because I find it intriguing and because I believe it has power to influence the way we understand human nature' (Kramer 1997: xvi). He appears to presuppose a more flexible and not rigid concept of human nature which allows for transformations by Prozac as in the case of Tess.

Interim Results

In conclusion, it can be stated that, as in the opposing arguments brought forward by the critics of mood enhancement, well-being plays a prominent role and has an overt presence within the lines of reasoning in favour of these procedures. Especially the argument of the transhumanists, in which they claim that mood enhancement is a legitimate procedure, is directly tied to the value they ascribe to the promotion of well-being. Although Kramer refers to well-being in a comparatively more subtle way, the concept nonetheless is of major importance within his lines of reasoning. This is chiefly suggested by the fact that he considers pharmaceuticals as means which elevate persons to a state 'better than well'.

In the section dealing with the objection to mood enhancement it was made plain with regard to the character of well-being that critics ascribe a hedonist and utterly subjective stance to proponents of the interventions in question. They themselves tie their arguments to objectivist conceptions of well-being, as illustrated. One would imagine that rival lines of argumentation in the debate on mood enhancement rest in their core upon rival concepts of well-being (objective list concepts versus hedonism). However, the analysis of the arguments advanced by proponents of mood brightening procedures proves that this is not the case. First of all, it can be extrapolated that the two contentions 1b and 2b are not to be found in the argumentation in favour of mood enhancement. Neither the transhumanists nor Kramer state that 1b *'good mood' is the one and only component of individual well-being* and 2b *that it does not make a difference whether the pleasure results from activities and interaction* *with the 'real' world or whether it is produced artificially through mood brighteners*. It must, however, be mentioned that it is in the nature of the transhumanists' argument for it to remain vague especially with regard to 2b. Nevertheless, it is evident that the lines of argumentation in favour of mood brightening procedures are not based on a purely hedonist and utterly subjectivist concept of the character of well-being.

The transhumanists expressly do not limit themselves to a specific concept of well-being when stating that the improvement of mood should be undertaken which ever concept of well-being is applied. However, it has been illustrated that their considerations on the issue of enhancement suggest that the approach they adopt in terms of the character of well-being, especially with regard to the ontological level, tends towards objectivism since they list goods which they view as universally important for well-being. Hence, although they state explicitly that their argument is not tied to any specific concept of well-being, the transhumanists make conceptual commitments which enter through the backdoor, so to speak. Based on the assumption that striving for improvement and perfection of these goods in order to increase well-being is part of our human nature, they can be considered to take a perfectionist stance regarding the character of well-being. Moreover, we can observe that they refer to broad conceptions of well-being which encompass a variety of different things. These things which are considered important for well-being are not limited to health and medical matters.

Peter Kramer, in contrast, cannot be straightforwardly classified as a proponent of a specific conception of well-being. There are lines of reasoning which suggest that the concept of well-being underlying his arguments is a desire-fulfilment theory. Nonetheless, due to the fact that he refers to goods such as social relationships, love attachments and career fulfilment which he considers as intersubjectively shared values he seems to base his argument on an intersubjective concept of well-being in ontological terms. Kramer does not tie his arguments to the view that well-being has an utterly subjective nature. Rather, in his assertions he presupposes that there is a set of important components of well-being which can be promoted by administering mood enhancers. As illustrated above, he claims that mood enhancers *indirectly* have a positive impact on the promotion of well-being since these components in turn influence individual well-being.

All in all, hedonism does not seem to be represented within the arguments in favour of mood enhancement in any great measure. The case is rather that supportive lines of argumentation also appear to be founded on broad objective (and intersubjective) concepts for the main part. Therefore, contrary to expectations, opponents and proponents of mood enhancement do not base their contentions on rival concepts of well-being. They are, in fact, more or less of one opinion if one considers the PCB and the transhumanists. Hence, critics appear to refute a line of argumentation and linked to it a specific concept of the character of well-being, namely hedonism, which seems to be non-existent in the debate and are therefore, found to be 'attacking a hedonist straw man'.

In addition, the results of the examination of the role of well-being in the debate on mood enhancement suggest that both opponents and proponents of mood enhancement frequently appeal to *human nature* when dealing with the essence of individual well-being in the enhancement debate. They both appear to apply this concept in a normative fashion. This is an interesting finding since the transhumanists themselves claim to reject normative conceptions of human nature. However, the impression arises that proponents and opponents of mood enhancement presuppose alternative notions when using the term 'human nature'. Furthermore, the underlying notion of what it means to be human seems to be tied to the specific stance taken as to whether or not mood enhancers are in a position to promote well-being. Hence, the relationship of the notion of human nature and the concept of well-being appear to require further examination.

4.3. Results arising from the analysis and the issues it raises

The analysis provided in the above has shown that the notion of *human nature* is not only central to the debate on mood enhancement but also appears to be closely involved with the arguments (pro as well as con) which relate to individual well-being. However, the critics and proponents of mood enhancement seem to have diverging ideas of what is meant by the term *human nature* and the impact it has on promoting well-being by means of enhancement. As in the previous chapter dealing with the role of well-being in debates at the beginning of life, it appears to be worthwhile analysing more closely the presence of well-being in the face of the other major concept with which well-being occurs. This will help clarifying the role which well-being plays in the debate on mood enhancement. How exactly is the concept of human nature applied in the respective arguments and in what way does this relate to the notion of well-being?

Moreover, the analysis has shown with respect to the character of well-being that there is a predominance of broad objective concepts and that subjective notions are only peripheral in the debate on mood enhancement. The subsequent section also sets out to explore the underlying reasons of the predominance of broad objective concepts of well-being in the debate on mood enhancement.

4.3.1. The value of (human) nature and the notion of well-being

In order to have a starting point when dealing with the relationship between the notion of *human nature* and the concept of *well-being*, it is necessary to illustrate the meaning and the notions tied to the term human nature. This also provides a background for classifying the alternative conceptions of human nature purported by critics and proponents of mood enhancement. Nevertheless, the term *human nature* is highly ambiguous and can refer to a variety of different things (cf. Bayertz 2003). With regard to the application in the enhancement debate, Lisbeth Witthoff Nielsen maintains that '[t]he problem, however, is that "nature" and/or "human nature" is referred to as if it were a clearly defined concept, and not a nebulous concept that embraces a host of meanings' (Witthoff Nielsen 2011: 22). In order to get a clearer picture of what is at stake when the notion of human nature is referred to in the debate of mood enhancement, it is necessary to take a closer look at its various meanings.

Material versus formal sense of the concept

When dealing with the notion of human nature, according to Dieter Birnbacher (2008), it is important to distinguish between two principal meanings which are above all present in the debate on enhancement: 1. human nature is used to refer to the natural side of mankind and to purely biological aspects. In this sense the concept of human nature is applied in a *material* way (cf. ibid.: 100). Thereby, the 'natural' is often viewed as the opposite concept of the artificial (cf. Bayertz 2003: 134). 2. However, human nature can also refer to the characteristics which humans share. 'In this sense, "nature" refers to the essential, necessary or constitutive features of a thing' (Birnbacher 2008: 101). Dieter Birnbacher refers to the *formal* sense of the term human nature. 'Taken in this sense, the "nature of man", even on a minimalistic understanding, involves a number of non-biological factors such as the ability to make and to use tools, to use language, to build complex social structures and to regulate his behavior by a system of internalized norms'. (ibid.) If we recall the above depicted arguments by the critics and proponents of mood enhancement and classify them against the background of these two principal meanings, we can, first of all, observe that both opponents and proponents apply the terms 'human nature' and 'nature' with a material *and* a formal sense. Nonetheless, they do so in a different manner. When referring to the material sense critics such as the PCB distinguish between natural and artificial means for promoting well-being and ascribe different values to them. Only natural means are in a position to promote well-being. Nevertheless, as the arguments depicted in the above illustrate, they also constantly use the term 'human nature' to allude to the essence of what it means to be human. Hence, the concept is also applied in a formal sense by the critics of mood enhancement. In following the above-mentioned lines of reasoning of the PCB, our human nature has an intrinsic value and needs to be protected. Enhancement procedures are considered as constituting a threat to our human nature.

It is important to take a look at the arguments of the proponents in order to see in which way they apply the terms 'human nature' and 'nature'. Nevertheless, it is difficult to assign a specific stance to Peter Kramer since he barely refers to the concept of human nature and his arguments do not provide enough information to function as a basis for classification. For this reason the following, for the most part, refers to the transhumanists when the proponents of mood enhancement are concerned. The arguments of proponents of mood enhancement provided in the above suggest that they apply the term in its material sense when illustrating which conditions have to be overcome by means of enhancement. 'The rise of modern science and technology has radically transformed the relation between human beings and nature. Nature, which for millennia had seemed all powerful and immutable, has suddenly become an object for control and manipulation, something that can be systematically shaped to human ends.' (Savulescu et al. 2011: preface) Nature applied in its material sense is viewed as setting limits which ought to be conquered. The transhumanists thereby explicitly reject arguments which ascribe value to human nature or nature in terms of the material sense. However, they also apply the term human nature in order to refer to its formal dimension stating that improvement, development and progress are a fundamental element of our human nature. Although not always explicitly mentioned, choosing to be better is considered a constitutive element of our human nature. Hence, we can ascertain that both the critics and the proponents apply the concept of human nature in order to refer to its formal sense. However, this merely provides a first imprecise answer to the question as to what proponents and opponents of enhancement mean exactly when they refer to the concepts of human nature. It appears to be helpful to take a closer look at the alternative ways in which they deal with 'what it means to be human' within their arguments.

The gratitude and the creativity framework

Eric Parens (2005, 2006) differentiates between two divergent ethical frameworks which underlie the arguments in favour of and against enhancement and might help to clarify the specific concepts of human nature to which the alternative arguments are tied. Parens distinguishes between the *gratitude* and the *creativity* framework. The gratitude framework 'emphazises our obligation to remember that life is a gift and that we need to learn to let things be' (Parens 2005: 38). Parens points out that this stance is often taken by critics of enhancement. Proponents, in contrast, frequently base their arguments on the creativity model which 'emphasizes our obligation to transform that gift and to exhibit our creativity' (ibid.).

The above-depicted arguments of the critics and proponents of mood enhancement can easily be assigned to the two alternative frameworks. Critics such as the PCB, who view mood enhancement as an intrusion upon human nature, clearly adhere to the gratitude framework. Thereby, they 'tend to indirectly presume that there is a certain state of "naturalness", or a "human nature" essence, which can be applied as a reference state in the assessment of the use of a particular technology' (Witthoefft Nielsen 2011: 26). They ascribe intrinsic value to this state of naturalness implying 'that [the value] is inherent to human nature "in itself", independent of what any individual or all humans accept as valuable' (Bayertz 2003: 143). Due to its intrinsic value critics place emphasis on the importance of protecting human nature from intrusions.

Proponents such as the transhumanists, in contrast, tie their arguments to conceptions of human nature as an evolutionary process. Their stance can be classified as a creativity approach stating that we have the obligation to transform our human capacities by means of enhancement. Thus, when propounding their arguments, the transhumanists presuppose a dynamic concept of human nature. Proponents such as Savulescu and Bostrom consider the improvement of our body as resulting from our *reason* which is directed to self-improvement and part of our human nature (cf. Hauskeller 2009: 11). However, 'the idea [of this kind of] inherent value of nature is not a new invention' (Bayertz 2003: 144). By referring to the *telos* of rationality and our obligation to develop and exercise it, the proponents of enhancement allude to the ancient argument of *ergon*, 'according to which a human being can only lead a good life if he realizes and cultivates his own specific potentials – his rationality – in the best possible way' (ibid.: 145). Hence, in following the transhumanists the promotion of our human capacities by means such as mood enhancers results from our rationality and, thus, can be considered part of our human nature. Due to this fact the ingestion of mood enhancers cannot be classified as artificial. In following the creativity stance the differentiation between the *natural* and the *artificial* loses credibility.

For the time being we can conclude that both critics and proponents of mood enhancement apply normative concepts of human nature, but these, however, are of a different kind. Michael Hauskeller points out that '[t]hey assign moral authority to different conceptions of human nature and see different things as valuable' (Hauskeller 2009: 5). Whereas critics such as the PCB adhere to the gratitude framework, proponents of mood enhancement tie their arguments to the creativity approach. In both approaches 'nature' or 'human nature' is considered an objective point of reference for normative claims with regard to the legitimacy of the application of enhancement procedures.

Moreover, a closer scrutiny reveals that the alternative concepts of human nature purported by critics and proponents determine what is considered to be the essence of well-being. Whereas critics of enhancement view the constituents of well-being as static and worthy of protection, the proponents maintain that the continuous improvement of our human capacities constitutes a basic requisite of well-being. In a nutshell: *we can increase well-being by sustaining* *our human nature* versus *we can increase well-being by transforming ourselves.* The alternative notions of the essence of well-being mirror the above depicted two different approaches to human nature, the gratitude and the creativity framework. Thus, both critics and proponents of mood enhancement consider human nature as a guide telling us what we need to do in order to promote our well-being. But what precisely does this imply with regard to the relationship of the concept of human nature and well-being within the arguments of critics and proponents?

The alternative concepts of human nature and their relationship to well-being

The concept of human nature can relate in different ways to the notion of well-being. The presence of well-being when occurring with the notion of human nature depends on the kind of value which is attributed to both human nature and well-being. To begin with we take a cursory glance at the different values which can be ascribed to human nature and the impact this has on its relationship to well-being.

1. The intrinsic value of human nature: As hinted above, human nature can be considered to have an intrinsic value. That is to say, human nature has a value 'in itself' and for its own sake. Thus, it is not valuable for the sake of anything else and its value does not depend on individual preferences. If the intrinsic value of human nature is presupposed and the striving to promote our well-being is considered part of human nature then the promotion of well-being ultimately has instrumental value for the sake of the realization of human nature. In this case individual well-being can only be promoted if we comply with our human nature. There are specific values embedded in human nature which need to be promoted if well-being is to be increased. Hence, whatever has a positive influence on our well-being can be directly derived from our human nature. In turn, human nature is viewed as an objective yardstick for what will promote our well-being.

2. *The derivative value of human nature*: If a derivative value is attributed to human nature, the latter is only of value in as far as it succeeds in promoting something else. Specific dimensions of human nature could be valued for the sake of increasing our well-being: '[i]t would show certain intuitive, well-founded ideals of "naturalness" to be elements of a good life and a prerequisite

of human flourishing' (Bayertz 2003: 148). In following this notion, well-being is attributed intrinsic value, whereas human nature has a derivate value. The concept of well-being thereby is not completely determined by our human nature since it consists of further dimensions. Human nature only has a *prima facie* value which can be outweighed by other aspects of well-being. Therefore, it cannot function as a yardstick for our well-being.

Having contemplated these two different values which can be attributed to human nature, and the resultant alternative ways in which human nature and well-being can relate to each other, it is now time to establish the notions to which proponents and opponents of mood enhancement adhere. When investigating the lines of reasoning purported by the critics of mood enhancement one can easily ascertain that they attribute an intrinsic value to the notion of human nature. Striving to promote our well-being is considered part of our human nature and, furthermore, our human nature determines what promotes our well-being. We can, thus, conclude that the notion of well-being is attributed derivative value within the arguments of opponents of mood enhancement. Well-being, therefore, has a subordinate presence in the face of human nature where the opponents of mood enhancement are concerned.

It has been illustrated that the transhumanists place emphasis on the fact that the promotion of well-being is their central argument in favour of enhancement. At first sight, one therefore gets the impression that the notion of human nature is of lesser relevance to their argumentation or even of no importance at all, since the transhumanists explicitly distance themselves from a normative conception of human nature. The promotion of well-being, in contrast, appears to be at the heart of their argument. Nonetheless, the analysis in the above has indicated that the notion of human nature is of greater importance within their arguments than the transhumanists might want to admit. As we have seen, closer inspection shows that it even determines what is considered as promoting our well-being, namely the improvement of our human capacities. Thus, it can be concluded that, contrary to what the transhumanists assert, they also ascribe intrinsic value to the concept of human nature and instrumental value to the notion of well-being. Proponents of enhancement consider human nature to be continually evolving and, therefore, self-improvement by means of enhancement is deemed promoting our well-being. Although not immediately visible, well-being also has a subordinate presence within the arguments of the transhumanists whereas the notion of human nature enjoys an intrinsic value and is of primary importance. Hence, both proponents and opponents of mood enhancement explicitly or implicitly attribute intrinsic value to the notion of human nature and merely instrumental value to the notion of well-being. On the grounds of this finding, it can even be conclude that the transhumanists seek to conceal the major importance which they ascribe to the notion of human nature by constantly placing the promotion of well-being in the foreground. These results concerning the relationship between human nature and well-being within the arguments of the opposing camps already hint at possible reasons why broad objective concepts of well-being prevail in the debate on mood enhancement.

4.3.2. The prevalence of broad objective conceptions of well-being

In the above analysis it has been observed that critics of mood enhancement intimate that the proponents of these procedures take a subjective stance with regard to well-being. It has been shown, however, that the approaches to well-being of critics and proponents of mood enhancement are actually not worlds apart as they both tend towards an objective direction. Where the ontological level is concerned, both appear to presuppose broad objective conceptions of the character of well-being. But what is the reason for this tendency?

Bare versus explanatory objectivism

Generally speaking, there are various explanations for the adherence to objective concepts of well-being. In order to shed some light on this issue, Philipp Kitcher (1999) distinguishes between *bare* and *explanatory* objectivism. Whereas the latter explains and justifies the specific goods which are considered components of well-being by referring to a theory which unifies the different elements, the former merely provides lists of goods which contribute to well-being without justifying them. Concerning the presence of bare objectivist theories Wayne Sumner offers the following comment: '[a]lthough it is easy to find philosophers who count themselves as objectivist about welfare, it is surprising how few of them have anything like a genuine theory to offer' (Sumner 2003: 45). Hence, it frequently appears to be the case that objectivists do not provide us with explanations as to why the specific goods they list should be considered as components of well-being. But what about the opponents and proponents of mood enhancement? Do they provide explanations for their objectivist conceptions? The analysis has shown that proponents as well as opponents continuously refer to human nature when maintaining that specific elements promote individual well-being. Our human nature is the explanation which they offer when claiming that specific goods constitute well-being. It should, however, be recalled that the transhumanists do not explicitly take an objectivist stance and also do not explicitly tie their arguments to the notion of human nature. As illustrated, this is often conveyed indirectly in the course of their argumentation. Nonetheless, we can conclude that both proponents as well as opponents adhere to explanatory objectivism since they give human nature as an explanation. But what is the relationship between objectivist concepts of well-being and the notion of human nature?

Objective concepts of well-being and essentialism

It has been shown that both proponents and critics of mood enhancement presuppose within their arguments that our human nature has a specific underlying essence and specific features. For this reason, they can both be considered to take an essentialist stance. Martha C. Nussbaum claims essentialism is 'the view that human life has certain central defining features' (Nussbaum 1992: 205).[81] Essentialist approaches often presuppose that there is a link between the essence of human nature and the components which promote our well-being. A well-known representative of this stance, which is based on the assumption that our human nature specifies what a good life consists of, is Aristotle. 'On one interpretation of his writings, Aristotle supplied the model for this type of theory, proposing that the human species has an essence and that this essence determines what contributes to the goodness of a human life.' (Kitcher 1999: 60) Contemporary accounts of this kind are to be found within the works of Thomas Hurka (1996). In following these approaches, well-being is promoted when we live according to our human nature and realize those capacities which are

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[81] Nonetheless, the essentialist stance which opponents and proponents of mood enhancement take is of a different kind. Whereas the biconservatives make substantial commitments with regard to the concept of human nature, the transhumanist commitments, for the most part, refer to the superordinate level describing formal features of human nature. Nonetheless, also the transhumanists list specific capacities and features which they appear to consider part of human nature.

part of the essence of human nature. Human nature is considered a given fact which constitutes an objective point of reference when determining what promotes our well-being. This means also the constituents of well-being are objective and, therefore, not subject to our individual preferences and desires. We can ascertain that there is a strong connection between essentialist concepts of human nature and objective conceptions of well-being. Especially with regard to the ontological level what constitutes well-being is viewed as being determined by our human nature.

Transposing the insights to the case of mood enhancement

By bringing together these elaborations with the results obtained so far concerning the relationship of well-being and the notion of human nature within the arguments of opponents and proponents of mood enhancement, we can clearly ascertain the possible underlying reason for the predominance of objective dimensions of well-being in the discussions. The overriding importance given to the concept of human nature by proponents as well as opponents of mood enhancement and their essentialist stance provide us with a convincing explanation with regard to the prevalence of objective conceptions. Within the arguments of both camps, human nature is attributed an intrinsic value and the specific concept of human nature under consideration determines in each case what is to be understood as the essence of well-being. Both critics and proponents list specific goods, human traits or capacities which they consider as important for individual well-being. Their alternative concepts of human nature, above all, lead to different ideas as to how we should treat these elements of our human nature. As already mentioned, critics state that we increase well-being by sustaining our human traits and characteristics, whereas proponents of enhancement maintain that we promote well-being by transforming and perfecting our human capacities. This indicates that transhumanists take a perfectionist stance with regard to well-being, as already suggested. This is in keeping with the evidence that within their arguments the transhumanists frequently allude to the teaching of Aristotle, who also establishes a link between essence and perfection. They appear to establish a connection with Aristotle's contemplations to give their arguments, as Bostrom terms it 'a distinguished pedigree' (Bostrom 2008: 19). All in all, we can conclude by saying that objective concepts of well-being prevail in the debate on mood enhancement because of the substantial weight given to human nature. The character of well-being can, therefore, be considered as being subject to the influence of the notion of human nature within the debate on mood enhancement. The essentialist concepts of human nature, which are ascribed intrinsic value, appear to *require* objective concepts of well-being.

Nonetheless, one issue remains to be resolved – why are the concepts of well-being which are applied in the enhancement debate comparatively broad?

The prevalence of broad conceptions of well-being

Apart from the fact that objective concepts of well-being prevail in the debate on mood enhancement, we have also observed that where well-being is referred to, a variety of aspects are concerned which are not limited to health-related well-being. In addition, they extend beyond the reduction of pain and suffering since they refer to positive dimensions of well-being such as pleasure. The quality of pleasure is an important issue and alleged components of well-being such as social relationships, love attachments and career fulfilment are also of relevance. The listed elements of well-being exceed the realm of health and apparent medical need. This is not surprising, however, since, as we have already shown, the core definition of enhancement is that it is concerned with 'interventions designed to improve human form or functioning beyond what is necessary to sustain or restore good health' (Juengst 1998: 29). Hence, enhancement is also aimed at other components of a good life apart from merely health, health-related well-being and the reduction of pain and suffering. It is often classified as 'wish-fulfilling medicine' as opposed to traditional curative medicine which is primarily concerned with the sustainment and restoration of health (cf. Kettner 2006). Obviously our wishes and desires go beyond the restoration of our health and demand various components of well-being some of which are a central theme in the enhancement debate such as pleasure and good mood. For this reason, broad concepts of well-being are applied in the debate. Nonetheless, due to the fact that enhancement interventions are concerned with matters other than health, they have received a lot of criticism and the question is frequently raised whether or not enhancement should be included in the targets of medicine.

4.4. Drawing conclusions with regard to the role of well-being in the debate on mood enhancement

It is now time to take a look at what results emerge from the analysis of the consideration of well-being in the debate on mood enhancement. What do our present findings contribute to our central theme of *rethinking well-being in biomedical ethics*?

It is directly noticeable, even at first glance, that the concept of well-being plays a *prominent* role in the current debate. Both proponents as well as opponents make frequent reference to the concept in order to support their argumentation concerning mood enhancement. Contrary to the debate on prenatal testing and selective abortion, well-being is almost always explicitly cited. Consequently, it can be considered to have an *overt* presence. In addition, it has been extrapolated that the concept of well-being has a *subordinate* presence in the face of the notion of human nature. Although proponents and opponents of enhancement frequently refer to the concept of well-being they both ascribe a derivative value to it whereas human nature enjoys an intrinsic value. Nonetheless, the transhumanists try to conceal the value they ascribe to human nature by placing well-being in the foreground of their argumentation.

In the debate on mood enhancement the discussions revolve around the question: What is the essence of well-being? Hence, it is possible to observe against the background of the subjective/objective scheme of alternative levels provided in the previous chapter, that in the debate on mood enhancement the *ontological* level in terms of well-being is primarily involved and that the epistemic and evaluative levels are of secondary importance. Moreover, the investigation of the arguments of both critics and proponents of mood enhancement reveals that the three alternative theories from chapter two, namely hedonism, desire-fulfilment theories and objective list theories are indeed present. Nevertheless, the differentiation between the three alternative levels introduced at the end of chapter 3 provides a helpful means of gaining a clearer insight into the specific concept of well-being applied in the discussions.

It became evident in the analysis of the character of well-being within debates on prenatal testing and selective abortion that there is tension between subjectivist and objectivist notions of well-being. We can also recognise this clearly in the debate on mood enhancement. It is interesting to note that opponents of mood enhancement actually criticise subjectivist theories of well-being, that is to say hedonist theories, within their arguments contra enhancement while purporting an objectivist stance. However, this has been proved to be ‘attacking a hedonist straw man’ since proponents of mood enhancement do not take the alleged subjectivist stance. It could, therefore, almost be maintained that critics specifically make use of the tension between subjective and objective concepts of well-being for their own arguments.

Another striking result of the analysis of the character of well-being in the context of mood enhancement is the prevalence of *broad objective* conceptions of well-being. The broadness of the conception of well-being has been shown as resulting from the fact that enhancement targets a broad variety of components of well-being which are not directly related to health. Furthermore, whereas the debates dealing with the beginning of life were found to be primarily concerned with the protection of well-being by the prevention of pain and suffering, the enhancement debate clearly focuses on the promotion of well-being beyond the restoration and protection of health.

Concerning the predominance of objective concepts, it has been concluded that this is a consequence of the weight and value given to the notion of *human nature* by both proponents and opponents of mood enhancement. There are influences from the notion of human nature on the concept of well-being: both critics and proponents of mood enhancement bind their arguments to essentialist concepts of human nature. These determine in each case that there are specific objective components of well-being and what these are. Thus, in the debate on mood enhancement the essentialist concepts of human nature require the character of well-being to be objective. On a more general level, the impression becomes strengthened that the concept of well-being is vulnerable to influences by other notions dominant in the respective debates. The fact there appears to be an impact from the other prevalent notions on the concept of well-being has already been suggested by the findings in chapter 3 dealing with debates concerning prenatal testing and selection.

5. The reference to well-being in debates on the allocation of scarce goods within medicine: the example of kidney allocation

The previous chapter dealing with the role of well-being within the discussion on enhancement has, for the most part, focused on the effect of enhancement procedures on the well-being of the *specific individual* concerned. In medicine and healthcare, however, decisions often have to be taken which have an impact on *various persons* and their well-being. This is, for example, the case when scarce resources have to be allocated. Problems arising from the allocation of scarce resources appear in various ways and on various levels: the question arises, for instance, whether financial resources should be spent on preventive medicine or rather on the care of patients who are already ill. At a lower level, the question might also arise as to which specific institutes such as cardiac or obstetric units should receive financial support if only one can be supported. Priority setting in the case of funding alternative forms of treatment such as kidney transplantation or renal dialysis might also represent a challenge if there are not enough financial resources to fully fund both. These are all examples of problems on the so-called level of *macroallocation* and priority setting decisions concerning these matters always affect the well-being of patients who depend on the specific forms of treatment under consideration. The level of *microallocation*[82] is concerned with dilemmas in which medical resources which are scarce, because of limitations in natural supply or economic constraints, have to be distributed among patients who need them but will inevitably not all receive them. A case in which treatment is not readily available to all patients in need means that decisions have to be taken about which patients should be given priority provides an example of this.[83]

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[82] The differentiation between macro- and microallocation stems from Engelhardt 1996.

[83] Beauchamp and Childress furnish a more detailed picture of the various allocation forms distinguishing between four types: 1. partitioning the comprehensive social budget, 2. allocating with the health budget, 3. allocating within targeted budgets and 4. allocating scarce treatments for patients (see Beauchamp and Childress 2013: 279-80).

Irrespective of whether they occur on the level of micro- or macroallocation, priority setting choices always and unavoidably constitute decisions which directly or indirectly influence the well-being of the individuals who are in need of the specific treatments or resources concerned. These decisions have far-reaching implications and can, of course, constitute 'tragic choices' (Calabresi and Bobbitt 1978) of life or death such as in the case of organ allocation or the allocation of beds in an intensive care unit. The question arises as to who should receive priority and which standards would be appropriate for priority setting in the first place. A wide range of differing criteria exist or have been proposed for this matter.

There is a common reflex reaction to the problem of resource allocation in healthcare both on the macro- as well as on the micro level. Lockwood describes this the following way: '[it is frequently argued that] one should put one's resources where they do the most good' (Lockwood 1988: 34). At a first glance, this utilitarian line of reasoning might, indeed, appear to be quite compelling and justified in the process of allocating scarce goods (cf. Gutmann and Land 1997: 193). In the case of scarcity why not try to achieve the most good? Veatch maintains with a focus on organ transplantation that '[i]t is obvious that we are interested in organ transplant because we are convinced that it can be beneficial to those in need of organs' (Veatch 2000: 288). In following this argument, clearly the saving of lives is viewed as an important good and as effective when allocating scarce medical resources.

Nonetheless, it is also a widely held view that resources should be distributed in such a way that they, in addition to prolonging life, should also promote the *well-being* of the persons concerned. In many cases of health care an extension of life is not accompanied by an improvement of well-being. Sometimes it might even decrease the well-being of the person concerned. Consequently, both the anticipated quantity and quality of life should be considered and are said to be relevant factors in setting priority. Thus, at a first glance the 'simple strategy' of putting one's resources where they do the most good in terms of longevity and well-being has a lot of intuitive appeal. Hence, the notion of well-being appears to play a major role. Nonetheless, we need to examine in depth whether or not the 'simple strategy' is indeed applied in practice and whether or not this is all to be said about the role played by well-being in debates on the allocation of scarce goods in health care.

This chapter attempts to provide a detailed picture of the presence and character of well-being in debates on microallocation. A prominent case has been singled out: the subsequent analysis places a focus on the subject of organ allocation as this matter often serves as a paradigm case at hand in academic and public discussions about resource allocation in healthcare (cf. Childress 1991: 182). The focus is set on kidney allocation. After a short introduction to the quandary of organ allocation this chapter considers the criteria and concepts applied in practice as an initial approximation to the role of well-being in the allocation of kidneys. In a second step, the chapter focuses on an examination of well-being as a consideration in the broader academic debate on appropriate standards for organ allocation. Two specific criteria in which the concept well-being appears to be an important consideration fall under scrutiny, namely the criteria of *outcome* and *patient need*.

5.1. The quandary of organ allocation

Since the 1960s organ transplantations have become common practice (cf. Schöne-Seifert 2007: 137). The list of organs which can be transplanted includes kidneys, lungs, intestines, the liver, the heart and the pancreas. These are transferred as a matter of routine practice and with increasing success nowadays. Apart from being life saving interventions, transplantations improve the quality of life of the patients concerned. This is especially the case with kidney transplantations which provide a better alternative to renal dialysis. Furthermore, tissue, bone marrow and corneas are transplanted. However, 'because they are not functional wholes, they are not considered organs' (Munson 2009: 211). Living donors are only eligible for regenerative tissue such as bone marrow, paired organs such as kidneys or organs which can be transplanted in sections like the liver. Most grafts are procured from deceased donors who have been diagnosed as brain dead[84], this refers to the irreversible loss of brain function, including the brainstem (cf. American Academy of Neurology 1994). Due to the growing discrepancy between the demand for organs and their availabil-

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[84] However, the criterion of 'brain death' as an indicator for death has received fierce criticism from many sides (see for instance Veatch 1993; Shewmon 1992). Deviating from the standard definition, irreversible brain stem dysfunction is considered the indicator of death in the United Kingdom.

ity, in many countries (with the exception of Germany) transplants are also increasingly taken from non-heart-beating-donors (donors after circulatory death).

Transplants are ‘by their nature a scarce commodity’[85] (Ach 1997 and Fuchs 1993). There are not enough organs available to fully supply all persons waiting for a transplant since the number of patients in need by far exceeds the number of organs available for transplantation.[86] ‘Every year nearly 10,000 people on the United States’ United Network for Organ Sharing (UNOS) national waiting list die without getting the organ they need to survive’ (Munson 2009: 212). Thus, as already mentioned in the above, the allocation decisions which have to be taken are, because of their existential importance for the potential recipients, ‘tragic choices’ or even a ‘fatal decision’[87] as Weyma Lübbe (2004) terms them. We are facing a moral dilemma since we are not in a position to provide all persons with a transplant who need one (cf. Gutmann and Fateh-Moghadam 2002). Furthermore, it can be assumed that as a result of our ageing population the list of people waiting to receive an implant will grow even longer. Other procedures such as xenotransplantation (the transplantation of organs from one species to another) or the use of artificial organs for transplantation have, because of their early developmental stage, not been in a position to provide a viable alternative so far and thus, at the moment there remains no solution to the ongoing problem of scarcity. The demand for transplants by far exceeds the supply.

All in all, there are two central questions especially arising from the problem of scarcity which receive society’s attention: ‘(1) how can the organ supply be increased, and (2) how should the available organs be allocated?’ (Childress 1996: 397).

Specifically the question as to how the limited number of organs available for transplantation should be allocated among the many patients in need constitutes a normative problem rather than being a medical question (cf. Gutmann

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[85] Translation by author. Original title of the article: ‘Von Natur aus knapp’.

[86] Nevertheless, the scarcity of organs does not present such a great problem in countries such as Spain or Austria in which the *opt-out legislative system* for organ donation is operated. In following this system, anyone who has not declined is considered a donor. It is said to increase rates of consent for donation. Thus, the scarcity of donor organs represents a problem especially in countries such as Germany, in which only those who have given explicit consent to donation are considered donors (*the opt-in legislative system*).

[87] Translation by author. Original title of the book:‘Tödliche Entscheidung‘.

and Land 1997: 192). Dan Brock states that '[it] is important to emphasize that there are *no* value-neutral selection criteria that could permit bypassing the need to make ethical judgements in the recipient selection process' (Brock 1988: 88). There is no such thing as objective medical criteria to tackle the problem of priority setting since value judgements are always implicitly present.[88] Thus, physicians, as such, have no special competence in providing an answer to the question of appropriate criteria for allocation (cf. Veatch 1991b). Instead, it is pointed out by many participants in the debate on organ allocation that the donated organs should be viewed as public property and a matter of public responsibility and that the public should formulate criteria for allocation (see for instance Childress 1991; Land and Dossetor 1991; Veatch 1991a). At this point the question arises: What are the criteria according to which organs should be allocated? This presents a significant problem since, as Thomas Gutmann states 'some norms for distribution are less unfair than others and some might have more and stronger moral conviction in a coherent entirety than others'[89] (Gutmann 1998: 64). Various proposals for appropriate criteria have been made, some of which have attracted a great deal of interest and have been implemented in allocation practice, while others have been duly rejected for a number of reasons such as unfair consequences or because they are based on non-compelling premises.

In order to map out the terrain for our central aim of analysing what kind of role well-being might play in the process of organ allocation and the way the concept is considered in the criteria for allocation, let us first of all consider the criteria which are applied in practice.

5.2. Criteria used in allocation practice: *Eurotransplant* and *United Network of Organ Sharing*

Various networks have been set up for the mediation and allocation of organs in different parts of the world. They operate according to different criteria and have differing practices for allocation. The following provides an illustration of

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[88] One instance of this is the value judgment about what should be considered good outcome (cf. Brock 1988: 89).

[89] Translation by author. Original quote: 'Doch manche Verteilungsnormen sind weniger ungerecht, manche bringen mehr und stärkere moralische Überzeugungen in ein kohärentes Ganzes als andere'.

the actual allocation practices as carried out by the two major organisations: *Eurotransplant International Foundation* (hereafter ET) and *United Network of Organ Sharing* (hereafter UNOS). In the above it has been pointed out that one would expect the 'simple strategy' of maximizing good in terms of longevity and well-being to be commonplace in allocation practice and one would therefore assume that well-being is to play a major role. The following aims to discover whether or not this is indeed the case. Whenever the concept 'well-being' is referred to, we will pay attention to the context and the criteria within which it constitutes a consideration. This could provide a first idea of where the notion of well-being comes into play and the way it might be linked to specific criteria applied in practice.

However, it is important to bear in mind that the various organs are allocated according to alternative criteria. Owing to the vast scope of this field, the following concentrates on the allocation of kidneys.

Eurotransplant International Foundation

ET constitutes an international non-profit making organization, which was established in 1967 and is situated in Leiden in the Netherlands. The foundation is responsible for the allocation of organs in its member states 'Austria, Belgium, Croatia, Germany, Luxembourg, the Netherlands and Slovenia' (ET 2015).[90] With the aim of distributing all donated organs among a pool of recipients as broad as possible, these countries have agreed by treaty to register all patients in need of transplant as well as all cases of organ donation at ET via their transplantation centres (cf. Conrads 1996: 300). In order to generate a waiting list of potential recipients, ET provides a central computer database to which the transplantation centres within the member states have access. The profile supplying general and medical information about patients in need, such as the organ required, status of urgency, blood group and tissue characteristics is transferred onto the data base by the respective transplantation centres. The data base also contains the profile of donors so that, according to the ET, the 'best match' between donor organs and potential recipients can be ascertained (cf. ET 2015). For each donor organ a so-called match list is generated by a specific computer algorithm (cf. ibid.). But what exactly are the relevant crite-

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[90] Similar networks for other countries are *Scandiatransplant* for Iceland, Norway, Finland, Denmark and Sweden, and *Balttransplant* for Estonia, Latvia and Lithuania.

ria for the selection of the recipients of donated organs? The foundation itself only provides brief information about its general aims and relevant criteria for allocation. ET places emphasis on the fact that '[i]n all deliberations and recommendations of the Ethics Committee the need and well-being of the patient (as well as the donor) is a key focus' (ET 2011: 3).

On their website ET state that generally speaking '[t]he match is based upon two general principles:

1. Expected outcome
2. Urgency (as determined by experts in an objective and transparent way)

Furthermore, the following is taken into account:

1. National organ balance - for Eurotransplant pursuits a reasonable balance in the exchange of organs between countries
2. Waiting time'

(ET 2015)

According to the German Medical Association the criterion of expected outcome refers to the long-term functioning of the graft and the thereby ensured survival of the recipient with an improved quality of life (cf. Bundesärztekammer 2010: 1533). Urgency, in contrast, focuses on the damage to health which is to be avoided by means of the transplantation (cf. ibid.). It has already been mentioned briefly in the above that the criteria for allocation are organ-specific. Each type of organ has a special set of criteria tailored to its specific properties. In order to obtain a more detailed picture of how these general factors are taken into account, let us take a look at a more concrete example: the case of kidney allocation.[91] ET's rules which are currently in use for kidney allocation are integrated into a model called the *Eurotransplant Kidney Allocation System* (ETKAS). After having been implemented in 1996, ETKAS has been continuously refined and operates now according to a point system. The total amount of

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[91] As already mentioned, there are striking differences between the sets of criteria applied for the various organs. The analysis of the relevance of well-being focuses on criteria applied for the allocation of kidneys. Nonetheless, priority setting decisions in the case of kidney allocation are not representative for all grafts since (in contrast to heart and liver transplants) they involve decisions of life and death to a lesser degree. There is always the alternative of renal dialysis.

points a potential recipient receives is the decisive factor for priority-setting among all candidates. The following provides a simplified outline[92] of the order of allocation and the criteria in operation:

Order of allocation in the case of kidneys

- Acceptable mismatch-patients (highly immunized patients)[93]
- High HLA-match[94] ("full house"- compatibility)
- All other patients

ETKAS point score system

- Tissue matching (HLA-Match grade) (max. 400 points)
- Low probability of ever finding a suitable HLA-Match (Mismatch Probability[95]) (max. 100 points)
- Waiting time for renal transplantation (33.33 points/year, max. 200 points, bonus to children[96])
- Distance between donor and recipient centre (max. 260 points)
- National Import/Export Balance (max. 200 points)

With reference to the order of allocation, highly immunized patients and those with a high HLA-match are given priority over all other patients on the waiting list who are in the ETKAS point score system. Furthermore, the so-called *high*

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[92] This outline is based upon a model provided by Johann Ach (Ach 1997: 35) and recent refinements as portrayed in Bundesärztekammer (2010) and Mayer and Persijn (2006).

[93] Highly sensitized patients have a low chance of finding a compatible donor organ since they have developed antibodies against various HLA antigens. Because of their low chance of transplantation they are treated in separate program called the 'acceptable mismatch program'.

[94] Human leukocyte antigens (HLA) are proteins which the immune system uses to recognize which cells belong to the body and which do not. HLAs are an indicator of tissue compatibility between a donor and a potential recipient. A close match between HLA markers of the recipient and the donor reduces the likelihood that the transplant will be rejected. It is an important factor in kidney and pancreas allocation. (cf. Davis and Wolitz 2006). Patients with a high HLA-match receive priority.

[95] There are potential recipients with a lower probability of receiving a suitable organ due to rare tissue types or their blood group (Type O), for instance. This problem frequently occurs with first and second generation immigrants from a different ethnic background. Thus, in following ETKAS these low probability-recipients should be taken into account in a special way.

[96] Children who are over the age of 16 at the time of registration receive a bonus.

urgency patients whose life is in danger are treated preferentially by receiving 500 additional points.

In taking a look at the various criteria applied one can recognize that there are two central principles underlying them: the principle of *maximizing utility* and the principle of *justice* (Ach 1997: 36; Gutmann and Land 1997: 193-6; ET 2010: 1).

The principle of maximizing utility[97] stresses the importance of using the transplants as effectively and efficiently[98] as possible focusing on the prospective medical benefit. This is, above all, expressed by the application of the criterion of *HLA-matching*, which reduces the risk of rejection of the transplant and, therefore, increases the likelihood of medical benefit to the patient. According to ET the medical benefit 'might include preserving life, reduction in morbidity, relief of pain and relief of suffering caused by illness' (ET 2010). A 'full house match' constitutes a case for mandatory exchange since it is considered as an indicator for high medical benefit. The factor of *distance between donor and recipient centre* aims at lowering the risk of graft quality loss by long transportation times. Here again the underlying principle is gaining the most positive outcome and thus, maximizing utility.

The other three criteria as well as the rule of giving priority in cases of high urgency, in contrast, are linked to the principle of justice. *High Urgency* cases concentrate on patients with special neediness[99]. The term 'special neediness' is often used to indicate the patients in danger of losing their lives. None-

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[97] However, the notion of utility maximizing encompasses various notions: It can refer to *social utility*, which is the social usefulness of the person receiving benefits or *medical utility* referring to the medical benefit (cf. Veatch 2004: 59). Especially the first notion has received fierce criticism for having unfair consequences. Therefore, the prevailing opinion continues to be that in the process of organ allocation only the concept of medical utility should be applied.

[98] The term 'efficiency' is primarily used in economy to refer to the relation of the use of resources and the extent to which the objectives can be attained.

[99] It should be taken into account, however, that there are different interpretations of the term 'need' in the debate on organ allocation. Kamm, for example, differentiates between 'urgency' and 'need'. The neediest person is the one who has had the least adequate conscious life. Urgency, in contrast, is more focused on the person's medical future such as the question 'how soon someone will die without a transplant' (Kamm 1993: 234). However, her definition of need diverges from the standard usage in which the terms *urgency* and *need* are used interchangeably. Gutmann and Land also point out that the criterion of high urgency can also be characterized by a line of reasoning which is based upon the principle of utility (cf. Gutmann and Land 1997: 194).

theless, as Frances Kamm points out it can also be used to indicate that a person needs an organ because she has very low quality of life (hereafter QoL) or to avoid a grossly diminished QoL in future (cf. Kamm 1993: 234). Especially in the case of renal transplantation, urgency in terms of QoL might be concerned since there is always the possibility of dialysis which means it is not necessarily a life or death decision. The elaborations of the German Medical Association indicate, however, that the criterion of high urgency refers to patients with a high likelihood of death (cf. Bundesärtzekammer 2010: 1536). As is illustrated in the following, giving priority to the most urgent cases or neediest patients frequently conflicts with the principle of utility since taking care of patients with urgent need might not result in the most favourable outcome possible.

The consideration of the factor of a *low probability of ever finding a suitable HLA-Match* aims at increasing the equality of opportunity in the process of allocation. African Americans and Hispanics or patients with the blood group O, for instance, are difficult to match (cf. Veatch 1991c: 211). The criterion of *waiting time* implies that the notion of deserving something after a long period of waiting plays an important role and is taken into account in the process of allocation (cf. Gutmann and Land 1997: 195). The standard of *National Import/Export Balance* is taken as a guideline by ET in order to secure a balance in the exchange of organs between the various countries.

As we have shown, ET maintains that in the process of deliberation and recommendation, the well-being of the patient constitutes their key focus. At a first glance this statement suggests that the concept of well-being (or quality of life, the term which is more widely applied in the debate) is to play a major role within the criteria for allocation as applied by ET. This would fit with the intuition mentioned at the beginning of this chapter. However, as elucidated, the criteria take into account a variety of factors which ultimately come down to the two central principles: utility and justice. Thus, the 'simple strategy' of maximizing good in terms of longevity and well-being rather is one principle among others applied in allocation practice. What remains of the claim by ET that well-being should constitute the key focus in the criteria for allocation is, above all, the consideration of maximizing the outcome in terms of prospects of individual benefit. The grade of HLA-match is taken as an indicator for the probability of realizing the aim of maximizing the outcome in terms of *medical benefit*. ET is not precise concerning the question as to what exactly the term *medi-*

cal benefit encompasses and how it is estimated. According to them, apart from the prolongation of life, medical benefit also refers to the reduction of pain, suffering and illness. Thus, the health-related QoL appears to be a matter of concern. In this way, the protection and promotion of well-being through ET is for the most part spelled out as the reduction of illness and suffering through a successful transplantation. However, we do not learn according to which standards and in what ratio the expected quantity and quality of life are calculated.

In summary, it can be said that the examination of the criteria for organ allocation as applied by ET illustrates that a comparatively narrow concept of well-being is used which refers to the health-related QoL of the patients. It comes into play when the principle of utility is concerned. Nevertheless, in contrast to notions mentioned at the beginning of this chapter, well-being does not appear to be a major consideration in the process of allocation. Let us see if we reach a different conclusion in the case of the criteria as applied in practice by UNOS.

United Network of Organ Sharing

UNOS is a private, non-profit-making organization that manages the organ transplant system in the United States. It administers the *Organ Procurement and Transplantation Network* (OPTN), which in turn is responsible for the development of the criteria for allocation. UNOS maintains the database which contains information about all patients waiting for a graft as well as information on the organs donated for transplantation. It generates a national waiting list of all patients in need. The best match between donor organs and potential recipients is ascertained by a procedure similar to that of ET. *Independent Organ Procurements Organisations* provide the information (such as medical history, physical measurements and blood type) of donors in their service areas and lists of potential recipients with the best match are generated. The system also operates on point-based criteria. Generally speaking, the standards which are applied by UNOS are based upon three principles: 1. *patient need*, 2. *probability of a successful outcome* and 3. *time on the waiting list* (cf. Childress 2001: 368). The way in which they are specified and the weight given to each of them depends on the organ distributed. Thus, as in the case of ET, for each type of organ, there is a specific set of criteria setting different priorities. These might change over time since they are always modified according to the current cutting edge of science and technology:

> Kidneys [, for instance,] are currently allocated based primarily on how long a candidate has been waiting. This is not how the kidney allocation system was initially designed. Initially, allocation priority was heavily weighted based on closely a candidate 'matched' a kidney by tissue type testing. In the past, closer matching was necessary for acceptable results. With improvement in anti-rejection medications, the priority for tissue typing has been decreased greatly over the last several decades. (OPTN 2011: 6)

OPTN Board of Directors has approved a new system in June 2013 which ought to improve kidney allocation (cf. OPTN 2014: 1). This system was implemented in December 2014 and has the following key features:

- Individual calculations of the likely length of function of a donor kidney and of the expected length of time an adult candidate may need a kidney transplant
- Priority matching of kidneys likely to function the longest with candidates likely to need a kidney for the longest amount of time
- Revisions to blood type matching to provide more opportunities to candidates with more rare types
- Increased priority for candidates whose immune system is not compatible with most donor kidneys
- Calculation of transplant waiting time (a key factor in allocation priority) from the date a patient begins dialysis, even if he or she started dialysis before being accepted for listing at a transplant center
- Elimination of kidney payback offers and local logistical exceptions to the national system

(UNOS Transplant Pro 2014)

Based on the principle of utility this new model takes greater account of the number of years a patient is expected to live after transplantation. 'The allocation rules are designed to promote better longevity matching between donor and recipient in order to utilize the maximum amount of graft years through an estimated post transplant survival or EPTS score' (OPTN 2014: 6). Two new standards for allocation have been introduced. A *Kidney Donor Profile Index* (KDPI) is applied in order to rank donor kidneys according to the length of time that they are expected to function in an average transplant recipient. The index is combined with a calculated *Estimated Post-Transplant Survival Score* (EPTSS) of the potential recipients. The top quintile of donor kidneys with the best expected graft survival is allocated to the top quintile of potential recipients with the highest Estimated Post-Transplant Survival score.

Two rules are based on different forms of equity (Veatch and Ross 2015: 347). Highly sensitized patients have improved access, a change which is based on the principle of equal opportunity. Also '[b]oth wait list time and dialysis time can be considered to be grounded in equity' (ibid.). Nonetheless, the kidney allocation system of the OPTN pays lesser attention to equity/justice aspects and gives prominence to the probability of a successful outcome. Hence, it appears as if the principle of justice takes a back seat in favour of the principle of utility. Priority is given to those patients who have a high probability of benefit. Although utility in terms of potential outcome plays the major role in this allocation system, the expected well-being or QoL after the transplantation appears to be of minor relevance within the criteria for kidney allocation. Utility is merely spelled out in terms of overall survival of patients after kidney transplantation by improved matching of donor longevity with recipient's longevity. Thus, in the allocation system as implemented by OPTN well-being appears to be of minimal importance. This result again conflicts with our initial intuition.

All things considered, the analysis of the criteria for kidney allocation as applied by ET and the criteria as developed by the OPTN demonstrate that the notion of well-being does, to varying degrees, represent a concern. However, it appears to be of considerably lesser importance than we expected. Within ET-KAS well-being plays a role (although not a major one) especially when the criterion of potential outcome is applied. Since the allocation system of the OPTN focuses on the standard of maximizing the potential outcome, one would expect that well-being is to be of major importance. However, the OPTN mainly refers to longevity and well-being appears to be of less importance. This lesser role of well-being contradicts the idea formulated in the introduction to this chapter. Especially in the case of kidney allocation this is an astounding finding, since as there is the possibility of renal dialysis, renal transplantations are primarily aimed at improving the quality of life of patients rather than saving their lives. For this reason, one would expect the promotion of well-being to constitute an important consideration in the process of allocation.

Furthermore, the first examination of the criteria as applied in practice has shown that where the character of well-being is concerned, comparatively narrow concepts are applied. These basically refer to an adequate life in medical terms, such as a life without severe pain, suffering and illness, not taking into account any further aspects.

5.3. Well-being as a consideration in debates on organ allocation

The examination of the criteria applied in practice for organ allocation could create the impression that the concept is of little relevance when allocation decisions are being taken. However, well-being (or the notion of QoL) might not constitute a major consideration at a first glance, but it does come into play especially if the standards *potential outcome* and *need (or urgency)* are referred to. Although only sporadically applied in the current systems for allocation, QoL[100] has received more attention in the academic reflections on appropriate standards for organ allocation (see for instance: Ach 1997; Ach and Quante 1994; AMA 1993; Bullinger 1993). This chapter now moves away from the systems applied in practice, changing its focus to the academic debate in which well-being constitutes a consideration. When dealing with the concept of QoL as a rationale for organ allocation, Johann S. Ach and Monika Bullinger stress the moral importance of differentiating between various points of reference when estimating QoL (Ach 1998 and 1997; Bullinger 1993). Estimations can refer (1) to the present QoL of a potential recipient before the process of transplantation, (2) to the QoL of the patient *after* the transplantation or (3) the difference in terms of QoL before and after the transplantation – the ‘surplus’ of QoL as Ach calls it (cf. Ach 1997: 44). Estimates of the first kind (the present QoL) are to be found in the context of the criteria *urgency* and *need*. The last

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[100] Since the expression ‘well-being’ is rarely applied and quality of life plays a pivotal role in the debate in the following, the term ‘quality of life’ is mainly used. If not explicitly otherwise indicated, the terms well-being and quality of life are applied interchangeably.

two (QoL after transplantation and surplus), in contrast are potential candidates for standards when dealing with outcome.

The concept of QoL has, on the one hand, received a lot of attention as a potential measure when evaluating the outcome or benefit in the process of organ allocation. On the other hand, its consideration within the criterion of need has kindled intense discussions. For this reason the following focuses first of all on QoL as a *potential measure for outcome* and then, in a second step, takes into account its role where the *criterion of need* is concerned. It is examined in which way the notion of QoL is referred to in the alternative criteria and what kind of concepts are applied.

5.3.1. Quality of life as a rationale for outcome in organ allocation

As James F. Childress points out even if the successful outcome constitutes the central criterion for allocating scarce goods, 'there is debate about what will count as success – such as length of graft survival, length of patient survival, quality of life, rehabilitation – and about the factors that influence the probability of success' (Childress 1991: 188). The concept of QoL is among the contenders as an essential measure for successful outcome. This has already been indicated by the examination of ET's criteria for allocation. Concerning the role that QoL plays where outcome is concerned, Kamm states that 'emphasis on outcome indicates a concern for the best possible future state of affairs where the standard for judging states of affairs is narrow, i.e., how many additionally medically adequate life years can we produce' (Kamm 1993: 257). Thus, apart from the quantity of life, its quality is also taken into account, although, as Kamm points out, it is applied in a narrow sense referring merely to its medical adequacy. The notion that apart from the quantity of life also its quality should be taken into account has received a lot of attention – above all in the shape of *quality-adjusted life-years*, the so-called QALY (cf. for example Zeckhauser and Shepard 1976; Waring 2005; Broome 2008).

The QALY approach to allocation

When the outcome or productivity is concerned in health care, it has been argued that not only the gained *quantity* of life but also its *quality* ought to be taken into account since the prolongation of life is not the sole aim of medicine (Hanson and Callahan 1999: 60). ‘A person’s quality-adjusted life years are the number of years she lives, adjusted for their quality’ (Broome 2008: 261). The concept of QALY constitutes a metric which combines both expected years of life as well as the expected quality. Broome states that the fundamental precept that guides the practical use of QALYs is the following: ‘[o]ne action is better than another if and only if it leads to more qalys’ (Broome 1993: 160). This particular view is called the ‘principle of QALY maximization’ (Cubbon 1991). The QALY[101] calculus is applied above all in the field of health economics. It primarily serves on the macro level of allocation but is also considered on the micro level: on the one hand, QALYs are applied to determine what kind of treatment to give a patient with a specific disease in order to achieve the best outcome. Thereby, the QALY calculus is also used to determine the cost-effectiveness of various forms of treatment. On the other hand, QALYs are employed for priority-setting in the allocation of health care resources with the aim of obtaining as many QALYS as possible in the process of allocation. In the debate on organ allocation the QALY calculus has been proposed as a way of deciding how organs should be distributed and as a better alternative to the current system (cf. Veatch 2004). A QALY-based system would allocate the organ to the patient on the waiting list who would gain the largest number of QALYs by the transplantation. ‘[QALYs] acquire plausibility on the assumption that any rational person would prefer a shorter, healthier life to a longer life of severe discomfort and disability’ (Waring 2005: 100). The QALY calculus considers QoL in terms of the person’s health status and links it to questions such as whether or not the patient is in pain or what degree of mobility he/she has, or the capacity to perform social interactions and actions of daily life (cf. Beauchamp and Childress 2013: 239). Hence, rather than concentrating on the broad concept of QoL, the QALY measure for the most part is concerned with health-related QoL. The central idea is that ‘for all alike a year of healthy life is

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[101] QALYs must be distinguished from the metric of disability-adjusted life years, the so-called DALY. The DALY calculus focuses on the overall disease burden combining mortality and morbidity. ‘DALYs for a disease or health condition are calculated as the sum of the Years of Life Lost (YLL) due to premature mortality in the population and the Years Lost due to Disability (YLD) for incident cases of the health condition’ (WHO 2012b). Since these are of lesser importance in the context of organ allocation the following deals primarily with the metric of QALYs. For a comparison of the QALY and the DALY metric see Brock 2006: 191.

equally valuable' (Menzel 1990: 79). One QALY is attributed to a year of good health whereas a year of less good health receives less than one QALY (cf. ibid). The state of death has a QALY of 0. A 'quality-adjustment factor' is used to calculate the QALY score. Thus, '[v]arious states of illness or disability better than death but short of full health receive a value between zero and one. Health conditions assessed as worse than death receive a negative value.' (Beauchamp and Childress 2013: 239)

Generally speaking, it is left open to conjecture on which basis the QALY system assigns value to various states of health (cf. Broome 1993: 159). It is not pre-defined 'whether these values are determined by how people feel when they are in these states, by their preferences about them, or perhaps by some objective principles' (Broome 1993: 159).

Michael Lockwood maintains that some factors are based on empirical findings which analyse how people view the severity of various states of health. When dealing with the example of the *Rosser distress and disability index*[102] he states that 'the factors and their associated weightings are mostly so chosen as to reflect the feelings and considered judgments which the average or representative patient is likely to evince in practice, when faced with various forms of disability or discomfort, either in prospect or, better, having actually experienced them'. (Lockwood 1988: 37)

Thus, the criteria that are used in practice for calculating QALYS might, for instance, be grounded in people's expressed values and preferences. Both Broome and Lockwood state that, notwithstanding the various ways in which the QALY is put into practice, the criterion is based upon a very narrow concept considering QoL simply as it is affected by health status. Lockwood suggests that 'this at any rate makes it something relatively objective, and something regarding which the doctor may at least claim some professional expertise' (Lockwood 1988: 44).

QALYs and the problem of unjust discrimination

One of the main objections to the use of the QALY measure (as well as the standard of QoL) as a criterion for priority-setting and interpersonal compari-

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[102] The Rosser distress and disability index was developed for the qualitative patient-derived classification of health states. For further information on the Rosser distress and disability index see Rosser and Watts 1972.

sons in the process of organ allocation (and microallocation in general) has been formulated by John Harris (1987). He criticizes the fact that a system based on the QALY calculus does not properly take justice into account since it is indefensibly discriminatory. 'The idea, which is at the root of both democratic theory and of most conceptions of justice, that each person is as morally important as any other and hence, that the life and interests of each is to be given equal weight, [...] plays no part at all in the theory of QALYS.' (Harris 1987: 118) One of the discriminatory features which the QALY criterion is accused of possessing is an inclination to *ageism*, as Harris puts it: available resources are allocated to those who will gain the greatest amount of QALYS, which are primarily the young and not the elderly since young people generally have better prospects for QoL and longevity (cf. ibid.). Hence, in many cases the increased age of the patient correlates negatively with expected QALY outcome. In following Harris, transferring the QALY measure to the problem of organ allocation would lead to a situation in which young people receive most of the grafts and the elderly are left empty-handed. Furthermore, Harris maintains that a QALY based allocation system might lead to racial discrimination (cf. ibid. 119). The various races have a different genetic make-up and medical characteristics which have an impact on the estimated QALY outcome after medical interventions. African Americans and Hispanics, for instance, often have antigens that are very difficult to match (cf. Veatch 1991c: 211) and thus, additional criteria, apart from the QALY calculus, are needed to ensure a fair distribution of organs in their case.

Another associated problem has received attention under the label of 'double jeopardy' (Harris 1987: 119): if a heart transplant could be given to either a blind person or a sighted person (all else being equal) the QALY rationale would clearly imply that it should be allocated to the latter (cf. Nord 2005: 131). Harris asks: '[i]s it clear that the candidate with most QALYs on offer should always and inevitably be the one to have priority?' (Harris 1987: 120). According to the objection, the QALY rationale does not give equal weight to preferences of all the individuals concerned and puts disabled or ill people at a disadvantage. Individuals who have been unfortunate (because of being blind, for instance, or being disabled in some other way) are, on the strength of this, ill-fated for a second time in a QALY based system. Harris elaborates: '[h]er first disaster leaves her with a poor quality of life and when she presents herself for help, along come QALYs and finish her off!' (ibid.).

Thus, according to Harris QALYs should not be considered an appropriate basis for priority-setting when allocating scarce goods since they involve profound injustice. The following also depicts the criticism levelled at QoL as a consideration in organ allocation since this might draw the attention to problems connected to the application of the concept.

Conflicts with the principle of need

Another respect in which the QALY system can be viewed as unjust is pointed out by Lockwood (1988). By focusing on the aggregation of QALYs, the approach frequently comes into conflict with the principle of *need*. The principle of need 'represents concern for fairness as taking care of the worst off overall' (Kamm 1993: 255). However, in many cases giving preference to patients in need does not lead to the greatest QALY outcome. As patients with urgent need are commonly more ill they are likely to score significantly lower on the scale than others. Thus, the QALY criterion 'is inherently insensitive to differences in degree of need' (Lockwood 1988: 46) and can therefore, result in processes of allocation which appear intuitively to be unjust. Whether or not a person has greater or lesser need for a scarce medical resource such as an organ is not mirrored by the QALYs assigned to her. The QALY system has inherent problems in accounting for the fact that someone who will die without a transplant has a stronger claim than someone else who is not in danger of losing his/her life. As Lockwood points out, there is, however, a way in which a QALY based system and the principle of need do not conflict. This is the case when a person's need for something is viewed as a limitation to his/her well-being or QoL. 'Someone, then, who will die without some particular treatment needs it in the strongest possible sense; for one cannot flourish at all if one is dead' (Lockwood 1988: 45).

Life-saving should have priority over life-enhancement

A further objection formulated by Harris, among others, refers to the assertion that life-saving should have priority over the promotion of QoL (or *life-enhancement*[103] as Harris terms it) in resource allocation. Harris states: '[m]ost

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[103] Harris applies the term 'enhancement' in a way which differs from its typical definition and usage (the improvement of the human body and mind beyond what is necessary to

people think, and for good as well as for prudential reasons, that life-saving has priority over life-enhancement and that we should first allocate resources to those areas where they are immediately needed to save life and only when this has been done should the remainder be allocated to alleviate non-fatal conditions' (Harris 1987: 120).

As Thomas Nagel points out, it is a common conception 'that life is all we have and the loss of it is the greatest loss we can sustain' (Nagel 1979: 1). Therefore, saving life[104] appears to be the most obvious medical benefit in the process of organ allocation (cf. Veatch 2000: 289). In addition, the life of an individual can be said to constitute the precondition of his/her experience of well-being and QoL and patient survival should thus have highest priority. The QALY calculus and other systems which are grounded in the notion of maximizing QoL are not in a position to take into account the greater importance of the gain of life. However, Harris allows for the fact that there might be exceptions in which a person is in such poor health that he/she suffers to such a degree that he/she should be given priority (cf. Harris 1987: 120).

The problem of measuring QoL

The QALY measure as well as the consideration of QoL in general in organ allocation are based on the assumption that we can estimate the (future) well-being of a person and make comparisons between different individuals. Generally speaking, this notion of measuring (or anticipating) the QoL of a person and comparing it with the QoL of another has received a lot of criticism (cf. Gutmann 2006: 36). Lockwood depicts this scepticism in the following way: '[f]rom a certain point of view, the idea of putting a yardstick up against a life, whether real or hypothetical, and reading off some numerical value representing its quality or degree of worthwhileness, may seem simply preposterous' (Lockwood 1988:40). One reason for the lack of conviction is the fundamental problem that there is no standard definition for QoL when it is used for comparing the potential benefit different patients would have from a specific form of treatment (cf. AMA 1993; Edlund and Tancredi 1985). Since the concept QoL

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restore and sustain health). He uses the term in order to refer to the promotion of QoL in general.

[104] Note that it is a further point of controversy 'whether it is lives saved or years of life added that should be counted' (Veatch 2000: 289).

is used in a similar fashion to the term well-being it also has no clearly defined meaning and different things are meant when it is applied. ‘Quality of life has many other components: enjoyment derived from one's customary activities, relationships with others, protection from the elements, and so on. It would have to be measured, if indeed it can be at all, by a hotch-potch of disparate scales, which would vary from culture to culture, from sub-culture to subculture and even from individual to individual.’ (Cubbon 1991: 81)

Johann S. Ach, Michael Anderheiden and Michael Quante elaborate on the fact that there is no generally accepted definition of the term QoL stating that the concept is vague but also multidimensional in a positive sense (cf. Ach, Anderheiden and Quante 2000: 124). In this instance a reliable foundation for measurement and interpersonal comparison is said to be missing. For this reason some authors even go as far as to state that we should therefore refrain from such comparisons and the application of the criterion of QoL or QALY when allocating vital grafts (see for instance Feuerstein 1995: 244). QoL cannot be put into operation in such a way that it could function as a reliable yardstick for expected outcome in the process of organ allocation. One should be aware of the fact that the concept is not merely applied in a descriptive sense. Its application in the process of organ allocation also has far reaching normative implications.

Lockwood maintains, however, that even if measures for QoL are not in a position to provide accurate information, they should not be completely disregarded. ‘[T]he fact that any assignment of precise QALY values is bound, in practice, to involve a degree of arbitrariness need not invalidate the qualitative conclusions that emerge, to the extent that the latter prove robust.’ (Lockwood 1988: 41) Even if welfarist considerations are not regarded as the decisive factor they should be given weight.

A narrow concept of QoL

Nevertheless, it is pointed out that especially ‘[a]llocation decisions that put too much weight on non-medical contributions to a patient's likelihood of benefit run the risk of arbitrariness and overgeneralization’ (AMA 1993: 3). There is a need for an objective standard. This, in turn, is said only to be able to be provided by focusing on medical standards when estimating QoL to determine potential outcome in the process of organ allocation. Hence, instead of applying a measure which is based upon a broad approach to QoL, a comparatively narrow concept forms the basis of QoL estimations. This has already been alluded to in the definition of *medical benefit* as provided by ET in the above. Empirical factors which are considered as indicators for high medical benefit (such as immunologic factors) become 'crude surrogates' for predicting the expected outcome in terms of QoL (cf. Veatch 2000: 291).

In addition, voices in the philosophical debate on appropriate criteria for organ allocation adhere to similar concepts. Frances Kamm, for example, relies on the concept of a 'medical adequate conscious life' in order to avoid refined QoL judgments (cf. Kamm 1993: 256pp.). She points out that especially hedonist and desire-fulfilment theories 'raise problems about the interpersonal comparison of utility. That is, if we want to decide whose life is better we will, for example, have to compare the degree of intensity of desires and their satisfaction.' (ibid.) A similar line of reasoning can be found within the report of the American Medical Association: '[p]rioritizing candidates for treatment on the basis of their subjective preferences, however, would be impossible in practice. It would be extremely difficult to assess patients' individual preferences, and even more difficult to make useful comparisons among patients on that basis.' (AMA 1993) Thus, there appears to be a necessity to apply standards which are independent of subjective measures such as patients' feelings or desires and to adhere to an objective and narrow concept of QoL.

For this reason QoL judgments in terms of changes in functional status have been viewed as an attractive approach to the problem of allocation (cf. AMA 1993). 'By this definition, improvements in quality of life would be measured for each patient by comparing functional status with treatment to functional status without treatment.' (ibid: 3) The patient with the expected greatest improvement on the functional level is likely to receive the graft. QoL is equated with functional status.

Nevertheless, there are thinkers, who argue that standards should not be too 'remote' from the subjective perspective of the patients concerned and that this perspective should be taken into account in QoL estimations and comparisons (Waring 2004: 102; Ach 1997; Feuerstein 1995). People differ greatly in the way they perceive the specific functional conditions with which they have to live and the implications these have in everyday life. 'Though change in functional status is an important factor in defining improvements in a patient's quality of life, it is less important than the patient's *attitude* towards his or her change in functional status.' (AMA 1993: 4) Therefore, in following this line of reasoning medical-objective as well as patient orientated-subjective factors should be considered. Johann Ach refers to the normative/descriptive dual character (Ach 1997: 43; see also Ach, Anderheiden and Quante 2000: 134ff.) of QoL as an operational concept in organ allocation since, according to him, the concept takes into account the subjective QoL experience and estimation of the patient concerned and is made ascertainable by means of intersubjective or objective standards which are to be normatively determined.

Interim results

Placing the opening intuition under scrutiny again, the impression arises that even though well-being/QoL does not constitute a major consideration in the criteria as currently applied, it does emerge that it is a widely debated aspect of organ allocation when the criterion of potential outcome is concerned. The lines of reasoning which refer to the maximisation of outcome can clearly be identified as utilitarian lines of reasoning. The notion of utilitarianism focuses on the maximisation of overall utility.[105] Since well-being frequently comes into play where utilitarianism is concerned, the idea could arise, at a first glance, that the decision as to how much weight should be given to utilitarian considerations determines the role which the concept of well-being is to play in the process of organ allocation. We will come back to this idea in due course after having gained a clearer picture of the role of well-being in the two different theories of justice.

As previously illustrated, the proposal to use QoL as a standard (by itself and as a part of the QALY) has received extensive criticism. This leads to speculation as to whether this could provide us with a reason why it is apparently of minor importance in the criteria in use. To draw a conclusion, the doubts levelled against QoL as a measure for outcome in the allocation of grafts can be divided into three different sets of objections: 1. *QoL as a measure for outcome leads to injustice*, 2. *The specification of the criterion outcome* and 3. *The lack of a conceptual foundation*.

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[105] Section 5.4.1. on the relationship between well-being and alternative theories of justice provides detailed information on utilitarian theories of justice and the role of well-being within them.

Concerning 1: As illustrated, one of the main objections consists in the charge that if decisions are concerned which affect several people, the QALY or the QoL measure for outcome in general runs the risk of leading to situations perceived as grossly unjust because of its discriminatory impact and its disregard of patients in need.

Concerning 2: When the potential outcome constitutes an important criterion for organ allocation the question arises as to how outcome should be defined. Should it merely be a matter of saving life or is the improvement of QoL to play a role? As elucidated in the above, there are thinkers who argue that in the process of allocating scarce resources, we should primarily be concerned with saving life and only in a second step with the improvement of its quality. Thus, there is a serious dilemma in deciding how much weight to give improvement of QoL in the face of saving life (cf. Veatch 2000: 290). There is increasing controversy concerning the place well-being should occupy when maximizing outcome.

Concerning 3: As we have seen, there is, above all, considerable disagreement on the most basic level which is concerned with the questions as to how QoL should be defined. This, in turn, has great impact on the answer to the important question as to how it could be measured and compared in the process of organ allocation. The measurability and interpersonal comparability of QoL constitute pre-conditions for the operationability of the concept in organ allocation. The lack of conceptual clarification has led some participants in the debate to refrain completely from QoL estimations in organ allocation. These are the three main objections with which QoL as a measure for outcome is confronted.

Since one of our main interests is the character of well-being in the discussions, the following scrutinizes which solutions to the problem of *the lack of a conceptual foundation* are proposed by proponents of QoL as a measure for outcome in organ allocation and the specific concepts of well-being which underlie their argumentation. As previously illustrated, many participants in the discussions refer to objective functioning models or adhere to comparatively narrow concepts focusing on purported medical criteria in order to avoid any commitment to a specific concept of QoL or value judgments (an example thereof being ET). First of all, it is important to note that this can be considered short-sighted since the adherence to 'medical' criteria or very narrow concepts (such as 'objective medical adequacy' in the case of Kamm) already involve specific conceptual commitments and value judgments which are claimed to be bypassed. Approaches of this kind are based on the assumption that health constitutes a necessary, but not sufficient condition for QoL and on the value judgment that health is an adequate measure for QoL. On the basis of this commitment health status is applied as an objective indicator for QoL.

If we consider the three alternative levels of dimensions with regard to the character of well-being (the ontological, the evaluative and the epistemic level) it becomes obvious that the discussions are primarily concerned with the evaluative level dealing with appropriate criteria for evaluating and comparing the well-being of potential recipients. Moreover, we can identify a striking predominance of objective dimensions at all three levels. We have seen that the functioning model of well-being is often considered in discussions on organ allocation. This model relies on the assumption that there is so-called 'species-typical functioning' (Daniels 2000) and that disease and disability represent a departure from normal functioning. The alleged medical criteria which are referred to in the discussions work in a similar fashion: they are based upon specific concepts and notions of a 'normal' health status. Whether or not transplantation is expected to be efficient is determined by anticipated changes in the patient health status. Hence, at the ontological level these are objectivist conceptions of well-being. Appropriately, on the evaluative level, objective standards which are developed and applied by medical professionals are considered for the determination of the QoL of the patients concerned. Thus, the patients themselves do not have the ultimate authority to determine their well-being in the process of organ allocation. In terms of the epistemic level it is understood that medical professionals have access to a person's QoL from an external perspective.

As illustrated, there are sometimes concepts of QoL in use which allow for the fact that well-being includes subjective components such as positive experiences in addition to the objective dimensions such as a person's health status. Accordingly, it appears to be a common assumption that both the objective standard of health status and the subjective experience of a person correlate and that the health status, therefore, can also be applied as an indicator for subjective dimensions of well-being. Hence, it is argued that the adherence to objective medical criteria also allows for taking into account the subjective dimensions. In this case we have an objective as well as subjective concept of well-being at the ontological level and, for the most part, objectivist conceptions of well-being on the evaluative and epistemic level. Nonetheless, it is important to bear in mind that, as Brock elucidates, 'medicine provides many examples which show it is a mistake to assume that the subjective happiness component correlates closely and invariably with other objective functional measures' (Brock 2009: 119).

All in all, if QoL is applied as a measure for outcome, it appears as if there is no alternative route past specific conceptual commitments as well as value judgements. Thus, the notion that the application of purportedly 'medical' criteria provides a possibility to obviate the problem of lack of conceptual clarity and conceptual commitments is mistaken. The specific conceptual commitments made should be clearly elucidated so that the instruments in use for evaluating QoL have a firm foundation notwithstanding rival concepts. Furthermore, the analysis of the various proposals for QoL as a measure for outcome indicates that if the concept is proposed to function as an operational measure for allocating organs, objective dimensions of well-being clearly prevail at all three levels.

5.3.2. Quality of life as a measure for patient need

So far, we have explored the role which well-being plays within rationales for organ allocation, that is to say within utilitarian approaches to the problem of organ allocation. However, while dealing with the criteria applied in practice we have recognized that well-being might also come into play when the criteria *need* and *urgency* are concerned. The standards of need and urgency are generally grounded in the egalitarian principle of justice. Thus, the decision as to how much weight should be given to utilitarian consideration does not fully determine the role which the concept of well-being is to play in the process of organ allocation. This is because well-being also appears to constitute a consideration where other approaches to justice are concerned, which focus on the pattern of distribution rather than on potential outcome. Nonetheless, in the academic debate on organ allocation the consideration of well-being within egalitarian approaches has received considerably less attention than the application of the concept within utilitarian approaches. Robert M. Veatch (2000) and Frances Kamm (1993) have developed egalitarian approaches to the problem of organ allocation in which the QoL concept is applied. The following examines these approaches in more detail in order to gain an impression of the relevance of well-being within the measure of patient need. What exactly is meant by the reference to theories of justice which concentrate on the pattern of distribution when allocating organs? Veatch elaborates that theories of justice ‘consider a pattern of distribution to be just insofar as it contributes to giving people opportunities for equality of outcome. In health care that often means targeting those who are medically worst off to give them the opportunity, as far as possible, to be as healthy as other people’ (Veatch 2000: 295).

So far, we have seen that terms such as *need* and *urgency* are frequently used interchangeably without a concrete definition. Veatch provides a clearer picture identifying three notions which are linked to the expression ‘worst off’ and to the broader concept of need[106]: *present need*, *urgency* and *need over lifetime* (ibid.). The following sets out to determine the role of well-being within these three notions.

Present need

The criterion of *present need* is frequently applied in allocation systems currently in practice such as those applied by ET. Present need refers to the current medical status and condition of the potential recipient. The criterion operates on the assumption that ‘those who are the sickest or worst-off deserve first consideration’ (Veatch 2000: 295). In following this concept, patients in need are in severe danger of losing their lives and in very bad health. Where the criterion of present need is concerned, QoL is viewed as an indicator apart from the probability of patient death. However, here again the probability of patient death is viewed as the more important consideration when it comes to present need. Estimations of QoL refer to the present QoL of a potential recipient before the process of transplantation. As in the case of potential outcome, a very narrow concept of QoL, which is for the most part based on medical criteria, finds application in order to avoid more substantial QoL evaluations. Whereas this standard focuses on the present, there are those which are more future orientated.

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[106] In the following the concept of *need* is applied in a broad sense encompassing the three notions *present need*, *urgency* and *need over lifetime*.

Urgency

If we look at the arguments of Frances Kamm the concept of *urgency* relates to the future in contrast to the criterion of present need (cf. Kamm 2003: 234). Veatch points out: '[t]he crucial point is that some patients on the waiting list may need a transplant urgently even though they are not presently among the sickest categories of patients' (Veatch 2000: 296). They might have a low status of priority according to the criterion of present need but their health status might decline very rapidly as for instance in the case of cancer of the liver. The criterion of urgency takes account of this fact by focusing on the expected condition in the future. Kamm differentiates between two dimensions of urgency: *urgency t* and *urgency q*. Urgency t (*t* for time) refers to 'how soon someone will die without a transplant' (Kamm 1993: 234). Urgency q (*q* for quality of life), in contrast, is linked to the question as to 'how *badly off* someone will be without it' (ibid.).[107] Urgency q is concerned with the expected future QoL as the point of reference of evaluation. However, it is important to bear in mind that rather than focusing on the expected QoL after transplantation it focuses on the future QoL of the potential recipient *without* a transplant. Veatch proposes to apply the QALY calculus to determine the degree of urgency: 'I would measure this in QALYs, but because we are concerned about identifying who has a claim of justice (rather than a claim based on medical utility) we are not focusing on the expected number of QALYs added by the transplant but rather who has the smallest number of QALYs expected in the future – that is, who is worst off from a "future QALYs" perspective' (Veatch 2000: 297). This kind of application of the QALY calculus would avoid the above-mentioned objections (such as the alleged discriminatory impact) as put forward by Harris since the QALY approach is incorporated into a system of distribution which focuses on equality and need by giving priority to those patients who are expected to be worst off in the future.

However, in current allocation practice urgency is frequently only considered in terms of urgency t, and urgency q is disregarded since the probability of death is considered as the only indicator for high urgency. Nonetheless, the way in which the criterion urgency is specified also depends on the organs concerned. In the case of kidney transplantation, where there is the alternative of

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[107] Dan Brock provides a similar differentiation (cf. Brock 2004: 42).

dialysis, urgency q plays a major role. However, Veatch distinguishes yet another alternative notion of need.

Need over a lifetime

A third way of conceptualizing need is in terms of *need over a lifetime* incorporating the quantity and quality of life a person previously had. In order to illustrate what is meant by need over a life time, Veatch describes the following situation:

> [c]onsider, for example whether we would view two persons with end-stage liver disease to have lives that are equally desirable if one develops her disease at age 80 and the other develops his at age 30. Even if the two persons were equal in their present need and had equal urgency (i.e., had the same number of predicted future QALYs without treatment), we are likely to have little difficulty concluding that the person getting her disease at 80 has had a much better life, overall, than the one who develops his at the age 30. One might plausibly say that the 30-year-old is much needier than the 80-year-old. (Veatch 2000: 299)

The concept of *need over a lifetime* captures this intuition. It takes into account that some patients 'very poorly off in a given moment may nevertheless have had [a comparatively long life and] considerable opportunity for well-being over their lifetimes' (Veatch 1988: 39) whereas others might be less poorly at a given moment, but have had a short life with less opportunity for well-being over their lifetime. The approach is based on the assumption that there is a specific span of life years with a certain degree of well-being[108] that we consider a reasonable life (a fair innings).[109] This notion has also received attention under

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[108] Cf. Harris 1985: 91. However, Harris only refers to the span of life years we consider a fair innings and not to the degree of well-being when dealing with this argument.

[109] Note that this approach clearly implies age-weighting since need is viewed as inversely proportional to age (cf. Waring 2004: 71). There are some thinkers such as Robert Veatch (2000) and Norman Daniels (2008) who have argued that *age* is different from other properties such as gender and race and that age-weighting can be considered fair in some domains of health care. Veatch elucidates: 'it turns out that there is also a strong case to be made in the name of justice or equity for giving allocation priority for younger people since it is more fair as well as more efficient' (Veatch 2000: 300).

the title 'the fair innings argument' (Williams 1997), which was first defined by John Harris (1985: 91-4). To be more precise, there are two different versions of the fair innings argument (cf. Waring 2004: 89): 1. the first version focuses on equal opportunity for well-being over a lifetime. 2. The second is concerned with equal opportunity in terms of living to the same age as others. Here again the concrete way in which need over a lifetime is specified depends on the weight given to QoL in the face of quantity of life and the way in which both are balanced. The first version of the fair innings argument, which has been above all supported by Veatch (1991c; 1988), is of special interest to us since it directly refers to the well-being of potential recipients. According to this argument 'one right-making characteristic of an allocation practice would be that it gives people an opportunity for equality of well-being' (Veatch 1991c: 206). Veatch terms this the *egalitarian principle of justice* (ibid.). He maintains, however, that the broad notion of providing opportunities for equality of well-being (not equality of health status) leads to problems in healthcare. The egalitarian principle of justice could imply that inequality in terms of health status could be compensated by advantages in other spheres of well-being and thus 'any discussion of justice in health policy has to take into account that unequal health can be compatible with the principle of justice' (Veatch 1991c: 208). This constitutes a major problem especially for the field of health care since resources are distributed utterly unequally (as also in the sphere of education) (cf. ibid.). For this reason Veatch maintains that 'in health policy, we should strive for opportunities for equality of health insofar as this is possible, leaving other social practices to deal with the best strategy for providing equality opportunities in other spheres of life' (ibid.). Thus, in health care the egalitarian principle of justice is specified as 'opportunities for equality of health'. Following Veatch, when allocating organs (and in the field of healthcare in general) we should provide people with opportunities for equality of health. Nevertheless, people have the possibility to trade their health resources for other goods in the various spheres of well-being (cf. ibid.).

Veatch identifies a theoretical problem: 'people evaluate purported benefits very differently' (ibid.). In order to provide opportunities for equality of well-being in other spheres (of well-being) apart from health care, and to avoid the problem of inherent subjective variation we should adhere to the equal distribution of primary goods. However, Veatch states that in health care things are different:

> In healthcare, however, that clearly will not work. We simply must introduce a concept of objective well-being in the health sphere. People should have no moral claim of justice to a health resource – Laetrile, for example—simply because they believe it will increase their opportunity for well-being. Society will have to tackle the very difficult problem of determining what will be taken as contributing to objective rather than subjective well-being. (Veatch 1991c: 208)

Veatch, therefore, comes to the conclusion that in health care we decide how to promote opportunities for objective well-being in terms of health.[110] Nevertheless, he does not provide us with more concrete information as to how objective well-being is to be estimated in health care. Frances Kamm takes a similar stance as Veatch. She maintains that the *need over a lifetime* concept should be the primary interpretation of patient need (cf. Kamm 1993) and defines it as how much adequate conscious life a person will have had before he/she dies (cf. ibid.: 234). As in the case of outcome Kamm states that her concept of need refrains from refined quality-of-life judgements focusing on the adequate conscious life.

Although some participants in the debate on organ allocation have laid emphasis on the advantages of an over-a-lifetime perspective '[a]t present this over-a-lifetime notion of need is almost never taken into account in organ allocation' (Veatch 2000: 300).

Interim results

To summarize the main results of the analysis in the theoretical discussions on organ allocation when patient need is concerned: the analysis illustrates that if well-being is concerned within the three alternative concepts of need, its evaluation has different points of reference. In the case of *present need* the current QoL of the potential recipient is concerned. The concept of *urgency*, in contrast, focuses on the future QoL the potential recipient will have *without* a transplant. The *need over a lifetime* concept takes an utterly different point of reference: the QoL over a lifetime. Thus, the above mentioned three way division as provided by Ach and Bullinger does not encompass all points of refer-

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[110] The latest proposal for the application of the fair innings approach for kidney allocation is to be found in Ross, Parker and Veatch et al. (2012).

ence for QoL estimations in the debate on organ allocation since it does not properly take into account QoL evaluations within the criterion of patient need. It should be supplemented by at least two additional points of reference: 1. *The future QoL of the potential recipient without a transplant*, which comes into play when the criterion of urgency is concerned and 2. *QoL from an over a lifetime perspective* which is considered when the criterion of need over a lifetime is applied. All things considered, we end up with the following points of reference for QoL estimations in organ allocation: (1) the present QoL of a potential recipient before the process of transplantation, (2a) to the QoL of the patient *after* the transplantation, (2b) the future QoL of the potential recipient without a transplant, (3) the difference in terms of QoL before and after the transplantation (the *surplus* of QoL) and (4) QoL from an over a lifetime perspective. There is, however, a lack of more concrete information about how QoL over a lifetime should be estimated.

Furthermore, the exploration indicates that if well-being is referred to when the concept of need is concerned, similar subjects of concern occur as with QoL as a measure for outcome. This applies especially to the above-mentioned points of controversy *the specification of the criterion outcome* and *the lack of a conceptual foundation*. In the above analysis of the alternative concepts of need, it becomes obvious that if their specification is concerned, the standard of QoL always competes with the measure quantity of life or probability of patient's death respectively. Thus, also in the case of the specification of the criterion of patient need, it appears to be a moot point whether need in terms of quantity of life/the probability of patient's death should have priority over need in terms of QoL.

The lack of a conceptual foundation also clearly represents a problem in the case of patient need. This is, above all, apparent in the elucidation provided by Veatch. When dealing with the character of well-being he maintains that the concept of well-being/QoL is too broad by far to function within a justice-based criterion for organ allocation and even for the field of healthcare in general and that, for this reason, the concept of health-related well-being should be applied. In addition, it is striking that also in the case of QoL as a measure for need, the adherence to medical criteria is common in order to avoid conceptual commitments owing to the concept of well-being being too broad as well as too vague.

Veatch places emphasis on the requirement for an objective concept of well-being in the field of health care. As we have seen, the need for objective standards in the case of QoL/well-being also clearly emerges in the debate on QoL as a measure for outcome.

Concerning the above-mentioned objection that QoL judgments or estimations lead to unjust consequences, the examination of QoL as a measure within the criterion of need provides us with a more differentiated picture. The concepts of present need and urgency clearly are not confronted with the problem of unjust discrimination or ‘double jeopardy’ as they give priority to patients who are worst off. This, however, does not completely hold true for the concept of *need over a lifetime* since this approach implies age-weighting. Yet, Veatch and others maintain that there are instances in which age-weighting constitutes a just procedure and organ allocation provides an instance of this (cf. Veatch 2000). Hence, whether or not QoL estimations can be viewed as having unjust implications (such as a discriminatory impact) appears to depend on both their point of reference and whether they are applied within an outcome-orientated or a need-based approach.

5.4. Results arising from the analysis and the issues it raises

So far, the analysis has shown that the relationship between the concept of well-being and the principle of justice appears to be of major importance in the debate on organ allocation. This has become especially apparent through the criticism with which the concept of well-being has been confronted when applied has a measure for outcome. Efforts have been made to incorporate well-being within the approaches to the problem of allocation that focus on the pattern of distribution rather than on the maximization of individual benefit. In order to elucidate the role of well-being in the debate on organ allocation even further, the following examines how precisely well-being relates to, and is incorporated in, theories of justice. To accomplish this, section 5.4.1 analyses the way in which the concept of well-being is applied in the two alternative theories of justice, utilitarianism and egalitarianism, in the discussions on organ allocation.

Furthermore, it has become apparent that narrow objectivist concepts of the character of well-being predominate in the discussions. The ensuing sections investigate the reasons for the prevalence of narrow objectivist concepts in organ allocation.

5.4.1. Well-being and the principle(s) of justice

So far we have seen that in the context of organ allocation, well-being often is involved with the principle of justice: sometimes the consideration of well-being is criticized for having unjust consequences and at other times the concept is incorporated into approaches in which the emphasis is placed on the aim of a just distribution of the grafts. The results of the analysis indicate that it is indispensible to place the relationship between well-being and principles of justice, or theories of justice respectively, under scrutiny when attempting to render the role of well-being in the debate on organ allocation in concrete terms. In order to get a clearer picture of how well-being and the principle of justice relate to each other, we first of all need to come to terms with the general notion of *justice* and the principles and alternative theories linked to it.

Alternative theories of justice

There are various kinds of concepts of justice. However, for the context of organ allocation we can state that we are primarily concerned with *distributive justice*, a concept which was discussed as long ago as in Aristotle's Nicomachean Ethic[111] (cf. Aristotle, NE, book 5). 'The term distributive justice refers to fair, equitable, and appropriate distribution of benefits and burdens determined by norms that structure the term of social cooperation.' (Beauchamp and Childress 2013: 250) Usually differentiations are made between the *formal* and *material* dimensions of distributive justice (cf. ibid.). The formal dimension refers to the principle of formal justice, namely: equals must be treated equally, and unequals must be treated unequally. This principle constitutes the core of our concept of justice (cf. Höffe 2002: 82). Since there are no specific criteria listed which determine when individuals should be considered as equals and in which way they should be treated equally, this principle lacks all substance (cf. Beauchamp and Childress 2013: 251). Thus, there is a need for addi-

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[111] Aristotle differentiates between *universal* and *particular* justice. Particular justice in turn encompasses two forms: distributive and rectifiable justice.

tional *material* principles which specify the *formal* principle of justice in order to make it applicable. Various material principles of distributive justice have been proposed. Beauchamp and Childress distinguish between six alternative material principles of distributive justice (ibid: 253). These principles are in turn derived from six alternative theories.[112] Hence, on the material level there does not appear to be *one* sole principle of justice, but rather *various* different principles of justice. Since a detailed description of all of these principles and theories would exceed the scope of this chapter, the subsequent part merely deals with those principles and theories of justice which are of relevance for our analysis and have been alluded to in the above. These are *utilitarian* and *egalitarian* theories of justice. In order to clarify the role which well-being plays in the discussions on organ allocation, the way in which the concept of well-being relates to and is incorporated into these alternative theories of justice is examined. Due to the fact that a great number of the previously depicted lines of reasoning which refer to the potential outcome in the debate on organ allocation can be assigned to utilitarian theories of justice, we will focus first of all on utilitarianism and the way in which the concept of well-being relates to this specific theory of justice.

Well-being embedded in utilitarian theories of justice

When considering utilitarian theories 'we seek to produce the maximal balance of positive value over disvalue' (Beauchamp and Childress 2013: 254). The central goal is to maximize utility and the sole and final measure when determining what is considered to be right or wrong or even just, is the moral principle of maximizing utility, 'which holds that a practice or rule tends to be correct if it results in as much or more aggregated good that any alternative action or practice' (Gutmann and Land 1997: 193). Hence, in following utilitarian lines of reasoning, and one of their main proponents, John Stuart Mill, if a practice or rule maximizes the most utility it can be considered just. Utility is often defined as the *overall well-being* which results from an action. Thus, generally speaking, the concept of well-being is of central relevance within utilitarian ap-

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[112] Beauchamp and Childress refer to the four traditional theories of justice: utilitarian, libertarian, communitarian and egalitarian theories and to two recent theories, namely capabilities theories and well-being theories (cf. Beauchamp and Childress 2013: 252 ff.). Obviously, not all of these alternative theories and related principles have been applied in the context of organ allocation

proaches. Traditionally, subjectivist theories of well-being such as hedonism or desire-fulfilment theories have been applied within utilitarianism. As Dieter Birnbacher maintains, the notion of utilitarianism is frequently characterized by the three central features (cf. Birnbacher 1992: 69f.): 1. *Consequentialism*: utilitarian theories are consequentialist approaches, which means that when the moral quality of an action is evaluated it is not the underlying intention which is decisive, but rather the actual results of the action. 2. *Subjectivism of values*: the measures which are applied in order to estimate the utility resulting from an action are utterly subjective referring to the well-being of the persons affected by an action in terms of the fulfilment of the desires and preferences or to the experiential quality resulting from an action. 3. *The principle of aggregation*: Utilitarianism is linked to the principle of interpersonal aggregation which implies that the collective overall benefit is to be maximized.[113] The way in which this benefit is distributed among the specific individuals is not taken into account.

The above analysis of the criteria as applied in practice as well as of the theoretical discussion on well-being in the debate on organ allocation, has illustrated that well-being/QoL is often referred to as a measure for outcome. As already suggested in the previous sections, we are clearly concerned here with utilitarian lines of reasoning, since the underlying assumption is that well-being (in terms of aggregated individual benefit) is to be maximized when organs are allocated.

However, it is important to note that when utilitarian lines of reasoning are to be found in the context of organ allocation there are some deviations from the above-mentioned general features: Firstly, utilitarian arguments which are to be found in the discussions on organ allocation primarily refer to aggregated individual benefit and not to other dimensions of utility such as the social worth[114] of the lives of the individuals concerned. ‘There is an almost total consensus that other aspects of utility, especially social usefulness of the lives of the potential recipients, should not be taken into account.’ (Gutmann and Land 1997: 193) Secondly, we have learned that in the context of organ allocation

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[113] As Birnbacher points out, there are, however, some current versions of utilitarianism which do not focus on the *aggregated overall-benefit* but rather on the *average benefit* (cf. Birnbacher 2007: 222).

[114] For further information on the concept of social utility and its history within the allocation of hemodialysis machines see Veatch 2000: 288-98.

narrow objectivist conceptions of well-being prevail. Thus, concepts which are based upon desire-fulfilment theories or hedonism rarely occur.

Above all the afore-mentioned third feature of utilitarianism *the principle of aggregation* has evoked harsh criticism. Since utilitarianism is only concerned with the overall maximization of utility and not with its distribution among the persons concerned, a standard objection to utilitarian theories is that they do not take sufficient account of distributive justice (cf. Schroth 2006). Interpersonal aggregation leads to problems concerning the rights, freedom and well-being of the specific individuals concerned. Rawls has provided a famous and detailed discussion of this problem stating that classical Utilitarianism does not take the separateness of persons seriously (Rawls 1971). When applying this line of reasoning, critics go as far as to discredit the fact that Utilitarianism can be considered a theory of justice.[115] After having ascertained a clearer picture of the reference to utilitarian theories of justice in organ allocation and the presence of well-being within these approaches, the depicted objections with which the well-being-based lines of reasoning have been confronted will be examined and it will be explored how these objections relate to utilitarian theories and their alleged weaknesses.

Well-being involved in the dispute on maximizing utility versus justice in distribution

We have learned that the consideration of well-being especially as a measure for outcome has been confronted with a great deal of criticism. One of the main objections concerning the consideration of well-being consists in the charge that where allocation decisions which affect several people are concerned, the QALY or well-being measures for outcome generally run the risk of leading to situations perceived as grossly unjust and unfair because of their discriminatory impact and their disregard of patients in need. Veatch points out that, when these concerns are cited, '[o]ur sense of justice has something to do with recognizing the fundamental equality of persons' (Veatch 1991c: 206). Well-being or QoL as a standard for outcome is accused of not taking the equality of persons into account. If one takes a closer look at the doubts expressed with regard to

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[115] It is not possible to give a more substantial and critical depiction of utilitarianism within the framework of this book. For a more detailed picture of the criticism leveled against utilitarianism and a defence against it see for instance Gesang 1998.

the consideration of well-being, one discovers that they appear to be familiar. Lockwood describes the following impression regarding the debate on the QALY: '[i]ndeed the QALY approach has a pleasantly nostalgic air, for those familiar with Jeremy Bentham's "felicific calculus". Most of the philosophical doubts about the QALY approach would be particular instances of familiar charges that have been laid against utilitarianism.' (Lockwood 1988: 39)

Thus, the criticism grounded in the notion of the equality of persons where justice in distribution is concerned does not relate to the QoL measures as such, but rather to the consideration of outcome in the dilemma of organ allocation in general and, furthermore, to the reference to utilitarianism in the debate. Veatch, for instance, maintains that theories of justice other than utilitarianism[116] focus on the pattern of distribution of the good rather than on the amount of good done and this is of major importance when grafts are allocated (cf. Veatch 2000: 295). We can determine that the objections facing QoL or well-being appear to be directed towards its consideration within a utilitarian approach to organ allocation rather than towards the concept itself. This observation fits in with the fact that, generally speaking, the debate on organ allocation is concerned with the familiar conflict between the two major principles *maximizing utility* and *justice in distribution*[117] (cf. Gutmann and Land 1997: 193; Veatch 2000: 287) and the appropriate relation of the goal of *utility maximization* on the one hand, and the allegedly competing aim of a *just distribution* of the grafts on the other hand.[118] Sometimes both principles work in the same direction, but in the context of organ allocation they often come into conflict where they have different implications. Dan Brock provides the following précis of

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[116] Veatch would probably even deny that utilitarianism can be classified as a theory of justice see Veatch 1991c: 209 ff.. When giving a response to an argument by James F. Childress he maintains that it is wrong to consider medical utility a criterion of fairness.

[117] Note that the reference to the principle of *justice in distribution* when describing the tension is rather vague and ambiguous, since above all utilitarians would argue that utilitarianism aims at increasing justice and for this reason the category *principles of justice in distribution* also encompass the utilitarian principle of *maximizing utility*. Nevertheless, as the statements by Veatch suggest in the context of organ allocation the expression *justice in distribution* appears to be widely used to consider the egalitarian principle of justice which refers to the notion of equality and need when distributing grafts. We will be coming back to this in more detail later.

[118] However, James F. Childress maintains that '[i]t is a fundamental mistake to suppose that "medical utility" and "fairness" are necessarily in tension so that if one is met, the other is infringed' (Childress 1991: 187).

the discussions involved: '[t]he fundamental ethical conflict in the distribution of scarce organs is between doing the most good with a scarce resource and ensuring that it is distributed fairly' (Brock 1988: 87). Hence, the classical competition between the two alternative sets of theories, *consequentialist* and *deontological* theories, is apparent in the debate on organ allocation.

Thus, in short, objections, which are based on the concern that well-being as a measure for outcome or the QALY calculus have unjust implications, operate on the theoretical level dealing with alternative approaches to the problem of allocation. QoL appears to be involved in the dispute on *utility maximisation* versus *justice in distribution* and on the superordinate level *consequentialist* versus *deontological* theories. As the concept is frequently embedded in utilitarian frameworks, it often becomes a victim of the criticism which is basically aimed at utilitarianism in the context of organ allocation. It is, however, important to keep the criticism which operates on the level of alternative theories (or divergent ethical traditions) separate from the conceptual level on which well-being is concerned. In the debate on organ allocation many, above all, critical voices appear not to succeed in distinguishing between the levels.

In addition, it is important to keep the objections on the theoretical level separate from the criticism on the conceptual level, since well-being measures need not necessarily be incorporated in a utilitarian line of reasoning. While dealing with the measure of *patient need* in 5.3.2. we have observed that QoL might also come into play when the criteria *need* and *urgency* are concerned. The various standards of patients' need, however, are generally grounded in egalitarian principles of justice. In order to further clarify the role which well-being plays in organ allocation, the subsequent section concentrates on the relevance of well-being within egalitarian theories of justice.

Well-being within egalitarian lines of reasoning

Generally speaking, egalitarian theories refer to material criteria of need and equality (cf. Beauchamp and Childress 2013: 252). 'These theories explicate the idea of equality in terms of treating persons as equals *in certain respects.*' (ibid.: 256) Various forms of egalitarianism have been brought forward and in these alternative forms the distribution of certain goods has various goals such as the equality of opportunity or the equality of well-being. Hence, in some egalitarian approaches well-being plays a central role. These approaches are often discussed under the title ‘welfare egalitarianism’ (cf. Keller 2002).

In *A Theory of Justice* (1971) John Rawls, developed his well-known egalitarian approach challenging utilitarian theories by focusing on the least well off when distributing goods in order to achieve more equality and to compensate for the inequality arising from nature. ‘Hence there is an effort to maximize the minimum, and the notion is often referred to as a “maximin”’ (Veatch 1998: 457). Rawls has argued for the ‘fair equality of opportunity’ rule, which Beauchamp and Childress classify as belonging to the group of ‘fair opportunity rules’ (Beauchamp and Childress 2013: 257). His approach and especially his principle of fair equality of opportunity have been transferred to the realm of healthcare.[119] Hoedemakers and Dekkers point out that ‘[a]n egalitarian justice model is based on a positive obligation on the part of the community to reduce differences in individual health and central to this model is determining of who is worst off’ (Hoedemaekers and Dekkers 2003: 228). We have seen that important voices in the debate on organ allocation such as Robert M. Veatch and Frances Kamm have developed, along the lines of Rawls, egalitarian approaches to the problem of organ allocation in which the QoL concept is applied. Within these egalitarian approaches the QALY measure and well-being measures (or in a more concrete form measures for opportunity for well-being over lifetime) do not face the above-mentioned problems of unjust discrimination or ‘double jeopardy’ as priority is given to patients who are worst off. Thus, a large number of the above depicted objections do not hold water when well-being has an embedded presence within egalitarian standards for the just distribution of grafts. This highlights the fact that the above depicted criticism referring to well-being and the QALY-measure is misdirected if it refers to the concept and not to the approach in which well-being is embedded. However, this does not in the least imply that the application of the concept of well-being within egalitarian theories is not without its problems. One instance of this is the previously mentioned challenge of ‘measuring’ and comparing well-being and the presence of alternative concepts. This obstacle and proposed ways to circumvent it by means of a narrow objectivist conception are the central theme of the following section.

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[119] See, for instance, Norman Daniels 1985.

5.4.2. The predominance of a narrow objective concept of well-being

The findings have indicated that in the practice of organ allocation as well as in the theoretical debate on this subject, objective dimensions of well-being prevail where the character is concerned. Furthermore, these concepts are comparatively narrow. This is the case when well-being is considered as a measure for outcome and as a rationale for patient need. In the enhancement debate we also discovered a predominance of objective dimensions. Nonetheless, these were broad and comprehensive concepts. We observed that the predominance of objective dimensions was due to the central role which the notion *of human nature* plays in the discussions on enhancement. However, this does not provide us with an explanation for the prevalence of objectivist concepts in the debate on organ allocation since the notion of human nature does not enjoy such relevance and there is also the distinguishing factor that the concepts of well-being applied in organ allocation are narrow. Thus, there seem to be other explanations for the predominance of narrow objective concepts within the context of organ allocation. The following sets out to examine these underlying reasons for the prevalence of narrow objectivist conceptions of well-being in the practice of organ allocation and in the theoretical discussions.

Facilitating the operationalizability and the application of standards of well-being

Although the proponents of narrow objective criteria for measuring well-being are often not very explicit about the reasons underlying their choice, there is evidence to suggest that narrow objective criteria increase the ease with which the concept of well-being/QoL can be put into operation when organs are allocated. This would serve us with a first reason as to why objective dimensions of well-being and narrow conceptions predominate. In order to examine the precise way in which narrow objectivist concepts might facilitate the application of well-being as a standard, we need to determine which conditions need to be met for the operationalizability of the concept of QoL.

The operationalizability and application of QoL in the process of organ allocation requires the following: since the priority-setting decision in organ allocation focuses on the differences of QoL among persons *the possibility of in-*

terpersonal comparability[120] of well-being is a necessary condition if QoL is to be put into operation. This, in turn, demands *a common standard for measuring QoL*, which facilitates its quantification and its empirical evaluation by means of instruments. A common standard and instruments for measurement need in turn to be based on *a firm conceptual foundation* of well-being. All of these requirements are closely intertwined and mutually dependent. A change in the conception of well-being leads to changes of shape in the standard for measuring it and in its interpersonal comparability. Also the adherence to a specific scale for measuring well-being has implications on the other two levels of requirements.

In addition to these requirements, emphasis is frequently placed on the fact that the system applied for organ allocation should be *transparent* since it is under pressure to prove its legitimacy as it is concerned with the sensitive decisions of life and death (cf. Ach 1998; Feuerstein 1995). This also holds true for the standards for measurement which are applied when determining the well-being of the potential recipients where individual well-being is being taken into consideration within the criteria for allocation. These standards for estimating and comparing well-being should also be transparent and easily comprehensible so that they evoke trustworthiness and reliability. The following considers the alternative concepts of well-being in the light of these requirements.

Before we commence, however, we should repeatedly call to mind that, concerning the requirement of a firm conceptual foundation, there does not seem to be a *single* substantiated theory of well-being, either in biomedical ethics or in the general theoretical debates on the nature of well-being. As demonstrated in chapter 2 the dispute about this is ongoing. The concepts underlying the standards for measuring and comparing well-being can be justified to a greater or lesser degree independent of whether they are subjective or objective, narrow or broad. Thus, the requirement that the standards applied when measuring and comparing the well-being of different individuals need to have a firm conceptual foundation does not in fact enlighten us as to whether standards should be objective or subjective, narrow or broad conceptions. Moreover, as we have already established, in the debate on organ allocation the experts who

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[120] The subject of interpersonal comparison of well-being has, as Matthew Adler points out, ‘not been much disputed by philosophers’ (Adler 2012: 157). For a more detailed picture see Elster and Roemer 1991, being one of the few works published on this topic.

are prepared to explain the conceptual foundation on which they base their measures for well-being, are few and far between. Hence, it is difficult to pinpoint whether or not their underlying conceptions are well-founded.

It is now important to return to the other requirements listed above in order to discover in how far narrow objectivist concepts (as opposed to subjectivist and broad concepts) are more likely to fulfil these. First of all, concerning the *narrowness* of the concept, generally speaking it becomes evident that the more comprehensive and person-directed the concept of well-being is, the more difficult it becomes to measure and compare the well-being of different individuals. This is due to the fact that comprehensive concepts of well-being take into account a variety of various aspects which all need to be estimated if the well-being of an individual is to be measured and compared. Thus, if a narrow concept is chosen, based solely on a limited number of medical criteria, for instance, measurement and interpersonal comparability are facilitated. Furthermore, we have seen that in the debates and practice of organ allocation comparatively narrow concepts focusing on purported medical criteria are mainly adhered to and that this is also done in order to avoid any commitment to a specific concept of QoL or value judgments. Nonetheless, it has been shown that the application of purported medical criteria in order to avoid conceptual commitments can be considered short-sighted since the adherence to them already involves specific conceptual commitments and value judgments which are claimed to be bypassed.

Moving to our primary concern, the underlying reasons for the predominance of *objectivist* conceptions in the context of organ allocation, it appears to be the case that these concepts of well-being more easily meet most of the requirements listed in the above in comparison to subjectivist conceptions. They facilitate the measurement of well-being because they allow the comparatively simple development of an easily applicable scale for measurement. This is due to the fact that objective concepts clearly list the relevant components which universally contribute to the well-being of the individual and thereby also provide a scale for interpersonal comparison. All this can be carried out by third parties, that is to say medical professionals, from an external perspective. As we have seen at the beginning of this chapter the different organisations which are responsible for the mediation and allocation of donor organs operate with the aid of a computer database, which contains the information of each potential recipient. The pieces of information about the patients are broken down into basic, for the most part medical, ‘facts’ which are easily accessible and comparable and do not contain many personalized details. The process of allocation is designed to take place impersonally. Standards for assessing the well-being of potential recipients need to function accordingly if they are to be integrated into the system. This can best be attained by objective measures as they disengage from the individual patient. In addition, the standards for measurement are tangible, which increases their transparency – also one of the above-mentioned requirements. Nonetheless, as shown, some participants in the debate on organ allocation consider it disadvantageous that objective criteria are distanced from the individual patient and his/her subjective perspective.

A more personal process however, could only be achieved by the help of subjective conceptions of well-being. Nonetheless, such concepts appear to have more difficulties to meet the above depicted requirements of QoL standards in organ allocation. Utterly subjective accounts in which well-being is considered subjective on all three levels, the ontological, the evaluative and the epistemic level, would complicate the application of well-being standards since the measurement and above all the interpersonal comparison become extremely challenging. In order to get a more vivid picture, it is worth considering *desire-fulfilment theories*, for instance, within the criterion of present need. In following this approach the patient who receives the graft is the one who is considered to be worst-off in terms of his/her actual well-being estimated from a subjective point of view focusing on his/her desires. For inter-personal comparison the estimations of the well-being of the potential recipients concerned are weighed up. However, in following an approach to allocation based on a desire-fulfilment theory what exactly is to be compared? What is the decisive *comparandum*? In the context of well-being and fair distribution Matthew Adler maintains: ‘[f]or anyone who adopts a view of well-being that makes preferences a central element, there is indeed a genuine intellectual puzzle about the possibility of interpersonal comparability’ (Adler 2012: 186). One could, for instance, focus on the *strength* of the desires of all potential recipients in order to determine who is the neediest person and should receive the graft. This, however, appears to be a very intransparent approach to the problem of organ allocation which inevitably complicates the measurement and inter-personal comparability and is vulnerable to abuse. The only way to integrate a more or less subjectivist conception of well-being would be a standard which is based upon average wishes and desires of reasonable patients, similar to the *reasona-*

ble person standard[121]. This, however, constitutes rather an objective or intersubjective concept of well-being which cannot be considered as entirely subjective. Thus, we can conclude that in order to facilitate the applicability to the context of organ allocation, the concept of well-being concerned needs to be narrow and (at least to a certain degree) objective.

The impression arises that apart from the technical problems mentioned in evaluating and comparing the strength of desires, there also appears to be a more profound problem involved when subjective concepts of well-being such as desire-fulfilment theories constitute the basis for standards in organ allocation especially when interpersonal comparability is concerned.

Justice leading to the requirement of a narrow objective concept of well-being

We have ascertained that when subjective concepts of well-being such as desire-fulfilment theories provide the basis of standards for measuring and comparing well-being in organ allocation, there are problems involved. In order to obtain a better understanding of the obstacles present an examination of the following case could be of assistance.

Two people are waiting for a donor kidney: Samantha is a demanding woman of 39. She has recently been diagnosed with renal failure and for this reason has now to rely on dialysis. Ever since then her world has simply caved in. She thinks it is terrible having to go to dialysis every three days, not being able to do the things she did before such as going on holiday spontaneously, working hard at her career and doing high-performance sports. Although her health status is comparatively good according to her physician, she is very unhappy not being able to maintain her former standard of life and is not overwilling to adapt to her current condition. For this reason she considers her well-being as diminished in the extreme and feels that she needs a kidney transplant very urgently. Therefore, we can conclude that her desire for a graft is strong.

On the other hand, Tom is around the same age as Samantha but of a more unassertive character. He has been living with dialysis for the past ten years and has come to terms with his condition. Because he is rather self-effacing, he is content with the things he is able to do like interaction with friends and watch-

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[121] The *reasonable person standard* will be dealt with in detail in the subsequent chapter 6.

ing TV and does not make other demands. His condition has gradually deteriorated to such an extent that from a medical point of view it is important for his future health condition[122] to receive a kidney transplant as soon as possible. Despite his condition Tom remains in character and still evaluates his well-being as being acceptable. He has requested a kidney transplant, but in comparison to Samantha his desire for a donor organ is more modest.

Tom and Samantha both require a matching donor kidney. The question arises: who is to be given priority. Let us imagine that, for the sake of argument, criteria such waiting time are omitted and that both have the same degree of tissue compatibility. The decisive factor when deciding who should be given priority is merely their *present need* in terms of the current strength of desire for a graft. Thus, this standard is based on a desire-fulfilment conception of well-being, functioning within an egalitarian approach to distributive justice. If this subjective standard of need is applied, it follows that Samantha is to be given priority since her desire is the strongest. But is this really a fair solution? Many have argued that this is not what distributive justice requires us to do.

Norman Daniels (1995; 2001) and Thomas M. Scanlon (1975) have given thought to this problem in great detail. When dealing with the uneasy feeling which arises if persons are given priority during allocation processes on the basis of their strength of desires, Daniels maintains that 'something seems clearly unjust if we deny the moderates equal claims on further distribution just because they have been modest in forming their tastes' (Daniels 2001: 332). Contemplating this in the face of our example we might get the impression that it would be *unjust* if Tom were not to receive the graft, solely because he is more modest. Samantha, in contrast, expects a great deal more from life. She could be held responsible for not having adjusted her preferences to her current condition so that she is in a position to endure her situation more easily.

In following arguments of John Rawls this phenomenon has been widely discussed under the title *expensive tastes* or *the social hijacking objection*.[123] It

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[122] Note that Tom is not suffering from an acutely life threatening condition. Thus, currently there is no life/death decision involved, but it goes without saying that his health and from an objective point of view his well-being, are steadily deteriorating under dialysis.

[123] See Rawls 1982: 168-9. Madison Powers and Ruth Faden provide the following description of the expensive taste objection: '[t]heories that employ a conception of individual well-being that depends inherently upon differences in personal satisfaction means that those with expensive tastes, say, for fine foods and wine, count on a par with those whose preferences are for the satisfaction of basic or more urgent needs. The more im-

is maintained that 'the special features of an individual's conception of the good – [such as] extravagant tastes and resulting dissatisfaction – do not give rise to any special claims of justice on social resources' (Daniels 2001: 333). Impartiality is a central factor within distributive justice. This implies that the subjective evaluation of well-being cannot be the decisive factor when goods are to be fairly distributed since this would jeopardize impartiality. Hence, when assessing the importance of competing claims on scarce goods, we cannot rely upon subjectivist conceptions of well-being such as desire-fulfilment theories because they are vulnerable to the problem of expensive tastes and biased. For these reasons they are apt to lead to decisions which could be considered unjust. It is, on the contrary, essential that a narrow objectivist approach to well-being is taken. Daniels points out that in contrast to subjective standards, '[a]n objective criterion invokes a measure of importance independent of the individual's own assessment, for example, independent of the strength of his preference' (Daniels 2001: 323). This concept is narrow (or *truncated* as Daniels calls it) because it is only concerned with needs such as health, food and social relationships which, according to Daniels, have objective importance since they establish the precondition for all other specific goals we have and a lack of them reduces our range of opportunity. In short, if resources are allocated, it is important that a narrow objective concept of well-being functions as a conceptual foundation to avoid unjust consequences (cf. Daniels 2001: 324; Scanlon 1975: 661). Scanlon states within his argument for narrow objective concepts: '[w]hat the examples show, however, is not that there is anything wrong with maximizing doctrines or with egalitarian doctrines per se but rather that a subjective criterion of well-being seems insensitive to differences between preferences that are of great relevance when these preferences are taken as the basis for moral claims' (Scanlon 1975: 659). Thus, according to Scanlon in cases of distributive justice approaches, independent of whether they are

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portant goal of morality, or of justice in particular, should be the narrower aim of helping those whose well-being is low, not the satisfaction of exotic tastes.' (Powers and Faden 2006: 33) There has been, above all, a debate between G.A. Cohen (2011) and Ronald Dworkin (2000) as to the question whether expensive tastes are really concerns of justice. However, the impression could arise that it is inappropriate to speak of 'expensive tastes' in the context of organ allocation, since the desire for a donor organ can be considered an essential desire for life. Thus, it could be considered more appropriate to differentiate between *moderate desires* and more *demanding desires*.

egalitarian or utilitarian, should adhere to narrow objective conceptions of well-being.

If we transfer this to our example and apply a narrow objectivist concept of well-being mainly referring to health related quality of life, Tom would be given priority because of his comparatively bad health status and would receive the kidney transplant. Obviously, this appears to be more in line with what distributive justice requires us to do. Thus, the great importance attached to the notion of justice in the context of organ allocation appears to influence conceptual choices in terms of well-being and sets limits to the applicability of subjectivist and broad concepts.

In summary, there are, above all, two reasons for the predominance of narrow objectivist conceptions of well-being where organ allocation is concerned: Firstly, narrow objective concepts of well-being facilitate the operationalizability and the application of well-being in organ allocation. Secondly, the importance of the notion of justice in organ allocation *requires* that narrow objective concepts of well-being are applied.

5.5. Drawing together the main findings concerning the role of well-being in the debate on organ allocation

At the beginning of this chapter on the role of well-being in the debate on organ allocation, we started with the notion that well-being is to play a prominent role in the debate on organ allocation since the ‘simple strategy’ of putting one’s resources where they do the most good in terms of longevity and well-being has much intuitive appeal. However, analysis has shown that the conception needs to be modified to a more modest view: *well-being constitutes one of many considerations in the debate on organ allocation.* It thereby plays a *subordinate* role. Nonetheless, where well-being does come into play it is explicitly mentioned and can, therefore, be said to have an *overt* presence. The subordinate role of well-being was suggested right at the beginning of the chapter by the results of the analysis of the criteria as applied by ET and UNOS. Thus, the results concerning the role of well-being in the debate on organ allocation are a marked contrast to the findings in the previous chapters – above all to the prominent role well-being plays in the enhancement debate. Especially the examination of the consideration of well-being in the academic debate on organ allocation indicated that the concept has, for the most part, received attention (mostly in terms of criticism) when functioning as a measure for outcome within utilitarian approaches and comparatively less attention within egalitarian approaches to the problem of organ allocation. The finding that well-being plays a subordinate role in the debate on organ allocation is in such stark contrast to the results so far with regard to the presence of well-being in the other debates, that it deserves some attention at this point before we come to our other findings concerning the presence and character of well-being. What exactly are the reasons for the subordinate role of well-being when guidance in organ allocation is concerned and why do opinions differ so greatly as to how much importance the promotion of well-being should have in organ allocation?

First of all, it has been observed that well-being is deeply involved in the dispute on alternative principles of justice, namely maximizing utility versus justice in distribution. Since well-being mainly occurs within utilitarian approaches to the problem of organ allocation, the decision as to how much weight should be given to utilitarian considerations does, at least to some degree, determine the role which the concept of well-being is to play in the process of organ allocation. Thus, if utilitarian approaches fade into the background, the concept of well-being does become, to a certain extent, less significant. As illustrated, the consideration of utilitarian approaches to the problem of organ allocation is highly controversial for its alleged unjust consequences and for this reason utilitarianism does not play the principal role within the criteria as applied in practice and in the academic debate. This provides a first reason as to why the concept of well-being is of subordinate importance in the context of organ allocation.

Moreover, it has been shown that the concept of well-being often becomes a victim of the criticism about unjust consequences which is basically aimed at utilitarianism in the context of organ allocation. This fosters a ‘negative reputation’ of the concept and especially of the QALY measure and might lead to situations in which people avoid the use of measures of well-being within standards for organ allocation. However, it has been pointed out that the criticism which operates on the theoretical level should be kept separate from objections which directly confront the concept of well-being itself.

There is, nonetheless, a further aspect: as we have seen, the concept of well-being does not necessarily need to be embedded in a utilitarian framework, although this is frequently the case. It can also occur within egalitarian approaches to organ allocation or even within an allocation system which is based upon a balanced application of various principles. However, the incorporation of well-being within these approaches to the problem of organ allocation has so far received comparatively little attention. This could possibly change since theories of justice which incorporate the concept of well-being other than utilitarianism are enjoying increasing popularity in the wider context of healthcare (see Powers and Faden 2006). Thus, if these approaches gain increased access to the context of organ allocation, the role which well-being plays might undergo a change.

There does, however, appear to be another important reason for the subordinate role of the concept of well-being in the context of organ allocation: the promotion of well-being competes with the predominant aim of saving life or prolonging life. We have learned that one major problem and point of controversy is the question as to how much weight should be given to improving well-being as opposed to the predominant aim of saving or prolonging life. Priority-setting decisions in organ allocation are for the most part ‘tragic choices’ or ‘fatal decisions’. For this reason it does not come as a surprise that many participants in the debate, such as Harris, give priority to the aim of saving life rather than improving its quality. This argument has received considerable attention under the title of *the moral uniqueness of life saving*[124]. In addition, being alive is viewed as the precondition for experiencing well-being. This provides us with a further explanation as to why well-being frequently appears to fade into the background in the debate on organ allocation. Especially the proposed allocation system provided by OPTN clearly reveals that the prolongation of life is often viewed as the major or even sole goal when distributing organs. Nevertheless, in the debate emphasis is also placed on the fact that criteria for organ allocation should not only be concerned with the prolongation of life, but also with the improvement and conservation of its quality. This, above all, is pointed out in the QALY debate. Having said that, one should bear in mind that the objection of well-being considerations based on the moral uniqueness of life saving might have a lesser importance in debates which focus on the allocation of scarce goods which are not as essential as organs and where priority-setting does not imply decisions of life and death but rather de-

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[124] See the deliberations provided by Madison Powers and Ruth Faden 2006: 171.

cisions of greater or lesser QoL. These elaborations made on the basis of the findings provide some possible reasons for the subordinate role of well-being in discussions on organ allocation.

With regard to the character of well-being the examination has revealed that there is a predominance of narrow objectivist concepts of well-being in the context of organ allocation. The exploration of the underlying reasons for this predominance has indicated that if the concept *is* to function as an operational measure for allocating organs, there needs to be some kind of narrow objective or intersubjective standard for interpersonal comparison. This is the case regardless of whether QoL as such is defined in objective terms (as in the case of the functioning model) or in a more subjective way. We have seen that this is due to the fact that objective or intersubjective concepts of well-being facilitate the operationalizability and the application of well-being in organ allocation and that they, furthermore, avoid unjust consequences due to partiality and the problem of 'expensive tastes'. Utterly subjective conceptions, in contrast, impede the ease with which well-being can be measured and compared and are likely to lead to unjust consequences. We can maintain that, above all, with regard to its objective character, the concept of well-being is strongly influenced by the notion of justice. We have ascertained that the concept of well-being is embedded in alternative theories of justice. Thus, as in the previous debates, the predominant notion referred to within the debate has a major impact on well-being.

In addition, it has been established that discussions dealing with the application of the concept of well-being within the context of organ allocation operate primarily at the *evaluative* level. Hence, the focus is set on appropriate criteria for the estimation and comparison of the well-being of potential recipients of a graft. Discussions are first and foremost concerned with the *restoration* of well-being of patients who are in need of a graft. Furthermore, it has been extrapolated that sometimes also the future well-being patients will have if they do not receive a graft is referred to and thus, the *protection* of well-being is involved.

Concerning the observation that that the term *QoL* is applied with higher frequency in the debate than the expression well-being: in the analysis of the discussion on prenatal testing and selective abortion we have already seen that the term 'QoL' is used in preference when important decisions have to be taken, precise estimations of well-being are required and an operational and transparent standard for evaluation is needed. This hypothesis becomes strengthened by the observations in this chapter.

6. Well-being in discussions concerning the end of life: the cases of assistance in dying and foregoing life-sustaining treatment

Our journey through bioethical issues in various phases of life has now reached the final stage of life. This chapter finally concentrates on the role of well-being in discussions dealing with the end of life.

Developments in modern medicine facilitate the possibility of resuscitation and life-sustaining treatment. Furthermore, new treatments in the field of palliative medicine have prevented and relieved the suffering of many patients at the end of life. At first glance, it appears as if the current developments have, above all, had a positive impact on patients' well-being in the final phase of life. However, there are also a variety of factors which have recently led to changes which could also be perceived as problematic. Among them are 'the increasing secularization of dying, the continuing dissolution of family life, the increasingly rapid development in possibilities to postpone dying until a stage of utter mental and physical deterioration, the increasing number of patients who know that they suffer from an incurable disease owing to medical diagnostics and prognostics and finally the physician-patient relation that exists today in which mostly silence is kept about the process of dying'[125] (Schöne-Seifert 2007: 109). These changes might have a negative impact on the well-being of the patients at the end of life making them feel lonely, hopeless, dependent, having no control over the circumstances of their death or concerned about being a burden to others. Above all, the developments on the medical front (notwithstanding all their advantages) have also influenced the process of dying negatively. 'Medical and technological progress means that there are more fre-

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[125] Translation by author. Original quote: 'die zunehmende Säkularisierung des Sterbens, die fortschreitende Auflösung engerer familiärer Lebensformen, die rasant gewachsenen Möglichkeiten, das Sterben bis in Phasen hochgradigen körperlichen und geistigen Verfalls aufzuschieben, die zunehmende Zahl von Patienten, die dank medizinischer Diagnostik und Prognostik um eine bei ihnen bestehende unheilbare Krankheit wissen und schließlich das Arzt-Patienten-Verhältnis heutiger Prägung, in dem über das Sterben doch wohl weitgehend geschwiegen wird'.

quently life situations in which the prolongation of life and the quality of life diverge.'[126] (Siep and Quante 1999: 38) This problem has already been indicated in the previous chapter with regard to organ allocation. Often the prolongation of life extends a burdensome period of physical and intellectual decline. As the *German National Ethics Council* depicts '[m]any people manifestly fear that such fate, might await them at the end of their lives and would prefer a non-lingering death without dependence on technical apparatus' (German National Ethics Council 2006: 9).

The problem of divergence between the prolongation of life and the quality of life and the fears linked to it have caused adverse reactions: on the one hand it is argued that terminally ill persons should have better access to palliative care including support from physician, nurses, social workers and psychologists. It is important to note that recently there has been progress in this field of end-of-life care as for instance permitting patients to die at home or in hospices with intensive palliative care and psychological support (cf. Schöne-Seifert 2007: 110). On the other hand it is argued that severely or terminally ill patients should have the possibility to end their life when they want 'in order to release the person from an incurable disease, intolerable suffering, or undignified death' (Beauchamp et al. 2007: 398). In some countries the decision to withhold or withdraw life-sustaining treatment has become a commonplace when the burdens of the prolongation of life outweigh its benefits to the patient. In addition, there is the call for the moral and legal right to physician-assisted suicide or voluntary active euthanasia.[127] Daniel Callahan (1993) uses the phrase 'a sea change in the climate of opinion' to describe the change in attitude which took place concerning the permissibility of physician-assisted suicide or voluntary active euthanasia instead of preserving life at all costs. As in the debates on the beginning of life dealt with in Chapter 3, proponents of eu-

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[126] Translation by author. Original quote: 'Der medizinisch-technische Fortschritt führt dazu, dass es immer häufiger Lebensumstände gibt, in denen Lebensverlängerung und Lebensqualität auseinandertreten'.

[127] As Bettina Schöne-Seifert points out, the call for the moral and legal right to physician-assisted suicide or voluntary active euthanasia would not die down even if everyone had access to comprehensive and the best possible end-of-life care since there are also other subjective values and notions at stake such as a self-determined death with dignity. (cf. Schöne-Seifert 2007: 110).

thanasia[128] for the most part base their arguments on the principle of *respect for autonomy*. Following this line of reasoning competent individuals should be able to decide autonomously how they wish to die. However, also the *prevention of major reductions in well-being* at the end of life presents a prominent argument in the debate and gives a reason why patients seek euthanasia.

This chapter sets out to analyse the role of well-being in discussions on euthanasia. After an introduction to the discussion about euthanasia, two examples of assistance in dying in practice are placed under scrutiny: physician-assisted dying in the Netherlands and physician-assisted suicide in the U.S. state of Oregon. It is examined which role well-being plays in the jurisdictions of each country/state. The focus then changes and encompasses the theoretical discussions: the role of well-being in the debates on assistance in dying and foregoing life-sustaining treatment is put under scrutiny. This section is divided into two parts, the first of which deals with the reference to well-being in discussions on assistance in dying in the case of competent patients. The second, in contrast, concentrates on well-being in debates on foregoing life-sustaining treatment in the case of incompetent patients.

6.1. An introduction to the discussion about euthanasia

Right up to the present there has been substantial debate concerning the ‘precise boundaries of the legitimate practice of medicine when patients [or surrogates] request help in ending their lives’ (Beauchamp et al. 2007: 397). The term ‘euthanasia’ originates from the Greek meaning ‘a good death’ and has been widely applied in connection with discussion on this matter. Albert R. Jonsen, Mark Siegler and William J. Winslade elaborate that ‘[i]n its original medical use, “euthanasia” implied the duty of a doctor to assure that his patients died as peacefully and comfortably as the medicine of the time could provide. … Later the term was used as a synonym for mercy killing, that is, deliberately and directly killing a sufferer to relieve pain, either by physician or by some other compassionate party.’ (Jonsen et al. 2010: 149) Euthanasia is considered in cases with the unfavourable prognosis that the therapeutic treatment of the patient is futile because of a terminal illness and in which his/her

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[128] If the term ‘euthanasia’ is used in the following, cases of involuntary euthanasia (cases in which individuals are killed against their will) are excluded.

death is approaching. Broadly speaking, this applies to dying patients, patients in the final phase of a serious illness, for those who are in a persistent vegetative state and for neonates with serious untreatable and incurable illnesses or malformations (cf. Schramme 2002: 110). It is, however, important to note that due to its negative connotations because of the term's misuse in the case of the horrors which took place during the Nazi era the usage of the expression 'euthanasia' is still avoided in Germany (cf. Schöne-Seifert 2007: 111; Schramme 2002: 109).[129]

Common classificatory schemes

In the discussion dealing with the topic of euthanasia there is usually a differentiation made between *voluntary*, *non-voluntary* and *in-voluntary euthanasia*. Whereas *voluntary euthanasia* refers to cases in which a competent person consciously and deliberately makes an enduring request for death, the expression *non-voluntary euthanasia* is applied to instances in which patients are decisionally incapacitated and have made no request for death (cf. Jonsen et al. 2010: 149). Cases of *in-voluntary euthanasia* occur in situations in which individuals have explicitly expressed opposition to euthanasia and are killed against their will as was the case during the Nazi era. Nowadays, involuntary euthanasia is universally condemned. As John Harris points out, '[w]henever the so-called problem of euthanasia is debated, or wherever it appears as an issue in morality generally or more particularly in medical ethics, the issue is almost always seen in terms of whether or not *voluntary euthanasia* is or is not justifiable, and so whether or not it should be permitted' (Harris 1985: 83; see also Schöne-Seifert 2000: 100). Nonetheless, it is important to bear in mind that in cases which deal with incompetent patients also non-voluntary euthanasia comes into play since these patients might not have been prepared (for example by means of an advance directive) for the condition they find themselves in.

Another widely applied differentiation is the one between *active* and *passive* euthanasia. This in turn rests upon the distinction between *killing* by a deliberate act and *letting die* by withholding (not starting) or withdrawal (stopping) of treatment. A case of active euthanasia constitutes, for instance, the administering of a lethal overdose of insulin or barbiturates (cf. Schöne-Seifert

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[129] In Germany debates are carried out under the title 'Sterbehilfe', since this term has fewer negative connotations.

2007: 114). Non-resuscitation in a case of cardiac arrest, in contrast, provides an example of passive euthanasia (cf. ibid.). Although, this distinction is said to function in a descriptive sense, it is based upon alleged normative differences of the practices (cf. Schöne-Seifert 2000: 99). It is a widely held view that there is a difference between active and passive euthanasia in terms of their moral and legal permissibility. Whereas the latter is sometimes viewed as permissible the former mainly is considered as inadmissible. This is due to the alleged moral difference between *carrying out an action* and *omitting to carry it out*. In this respect, it should be noted that in the Netherlands and Belgium physicians are permitted to perform acts of voluntary active euthanasia under specific conditions[130].

Further categories applied in the debate are *physician-assisted suicide* and *indirect euthanasia*. As Dan Brock maintains 'a paradigm case of physician-assisted suicide is a patient's ending his or her life with a lethal dose of a medication requested of and provided by a physician for that purpose' (Brock 2007: 437-438). Physician-assisted suicide has been made legal in the US states of Oregon, Washington and also in Montana since 2009. In Switzerland assisted suicide has also been legally tolerated for many years. In cases of indirect euthanasia physicians administer medication (sometimes in large doses) in order to alleviate the patient's pain with the unintended but foreseen consequence that it hastens death.[131] Instances of indirect euthanasia are frequently to be found involving patients suffering from terminal cancer, where 'there may come a point where the administration of pain-killing drugs hastens death' (Harris 1985: 84). This practice is not prohibited in many countries.

In the contemporary debate, the depicted classification schemes have for various reasons been strongly criticized and some participants in the discussions have moved away from these schemes (cf. Jonsen et al. 2010: 149;

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[130] A detailed analysis of these conditions is provided in the following.

[131] In connection with indirect euthanasia *the principle of double effect* is frequently referred to in order to justify this practice and distinguish it from VAE. Jonsen et al. provide the following description of this principle: '[t]he principle of double effect is a form of ethical reasoning that recognizes that persons may face an unavoidable decision which will bring about inextricably linked effects, some good and desirable and others bad and undesirable. The good effects are intended by the agent and are ethically permissible (e.g., relief of pain is a benefit); the bad effects are not intended by the agent and are ethically undesirable (e.g., depression of consciousness and risk of pulmonary infection).' (Jonsen et al. 2010: 145)

Schöne-Seifert 2007: 114-115). Nevertheless, the following analysis is based upon the differentiations as outlined in the above since they provide a rough orientation regarding the different practices in question. As Miller and Truog point out '[m]edical ethics has traditionally drawn a bright line between withholding and withdrawing treatment, on the one hand, and both assisted suicide and active euthanasia, on the other' (Miller and Truog 2012: 27). Whereas the former is permitted from an ethical point of view, the latter are frequently prohibited. A large part of the actual discussions has centred on the questions as to whether physician-assisted suicide (hereinafter PAS) and/or active voluntary euthanasia (hereinafter VAE) should also be legalized (cf. G. Dworkin 2009: 375). Gerald Dworkin points out that '[b]y definition, there is only one descriptive difference between assisted suicide and euthanasia. It lies in who performs the last causal act leading to death. In the case of assisted suicide it is the patient; in the case of euthanasia it is the physician.' (ibid.: 391) In the current discourse both practices are summarized under the expression 'assistance in dying' (hereinafter AiD) (cf. Schöne-Seifert 2000), the term which I also apply in the following to refer to both practices (PAS and VAE).

Having received a first impression of what kind of practices are under consideration when the theme of euthanasia is treated we will look of at two examples of assistance in dying in practice. This will illustrate how PAS and VAE are implemented in practical terms, what conditions prevail for it and whether or not well-being plays a role thereby.

6.2. Two examples of assistance in dying in practice

In the various industrialised countries patients who wish to die and request AiD name similar reasons for their decision such as their suffering and increasing dependency, but 'one finds striking differences in the extent to which this wish is recognised and reflected in public policy' (Birnbacher and Dahl 2008: preface V). In most parts of the world VAE as well as PAS are not permitted and are considered illegal acts. As mentioned in the above, countries such as the Netherlands and Belgium or the US states Oregon, Washington and Montana in which VAE or PAS respectively constitute regulated practices, are exceptions. In these countries and states various regulatory models with different guidelines and safeguards against potential abuse exist. Birnbacher and Dahl maintain that the following criteria are the ‘paradigmatic euthanasia conditions’: ‘(1) The patient is in an irreversible state of terminal illness, (2) The patient suffers intolerably, (3) The patient explicitly wishes to die, (4) This wish is not only momentary but also constant’ (ibid.). This list of paradigmatic conditions indicates, that patient’s well-being does come into play in terms of the degree of diminishment due to the patient’s suffering. In order to examine the role of well-being within the criteria for AiD as applied in practice in more detail, the ensuing part provides an exemplary analysis of the regulation of assisted dying in the two jurisdictions: the Dutch *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* and the Oregon's *Death with Dignity Act*. As in the previous chapter on organ allocation, the examination of the criteria as applied in practice provides us with an initial approximation concerning the role of well-being where euthanasia is concerned. In addition, the theoretical discussions are often conducted on the basis of practical experiences where AiD has been legalized. Thus, it is advisable to have taken note of the criteria as applied in practice and the role of well-being within these when reading the subsequent sections examining the theoretical discussions.

6.2.1. Physician-assisted dying in the Netherlands

In the Netherlands physician-assisted dying is regulated by the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*, which has been legally permitted since 2002. It legalizes VAE and PAS as administered by physicians in certain cases and under specific conditions. Both written directives as well as oral requests are considered in cases of AiD. Written directives apply in situations in which the patient is not in a position to voice or signal his/her desires and considered as incompetent as for instance in cases of persistent vegetative state. However, whether an act of AiD is performed or not also relies on the physician forming his/her own evaluation in the light of additional criteria. Concerning the legalization of physician assistance in dying *The Netherlands Ministry of Foreign Affairs* states that ‘[t]he inclusion in the Criminal Code of a special ground for exemption from criminal liability means that doctors who terminate life on request or assist in a patient’s suicide can no longer be prosecuted, provided they satisfy the statutory due care criteria … and notify death by non-natural causes to the appropriate regional euthanasia review committee.' (NMFA 2010: 3) In applying a uniform set of criteria to each case, it is the aim to reduce the number of unreported cases of AiD and to make the various practices more transparent (ibid.). The quotation highlights that when dealing with a patient's request for AiD the doctors concerned are monitored by review committees. These committees verify that they have acted in accordance with the criteria of due care (Article 2 of the Act). Namely:

> [Physicians] must:
>
> a. be satisfied that the patient's request is voluntary and well-considered;
> b. be satisfied that the patient's suffering is unbearable and that there is no prospect of improvement;
> c. inform the patient of his or her situation and further prognosis;
> d. discuss the situation with the patient and come to the joint conclusion that there is no other reasonable solution;
> e. consult at least one other physician with no connection to the case, who must then see the patient and state in writing that the attending physician has satisfied the due care criteria listed in the four points above;
> f. exercise due medical care and attention in terminating the patient's life or assisting in his/her suicide.
>
> (NMFA 2010: 3)

Buiting et al. maintain that '[a]lthough self-determination of the patient is a necessary condition to justify the termination of their life, in the final analysis the physician's responsibility to alleviate the patient's suffering is the most important principle underlying the Act' (Buiting et al. 2008: 2). Especially criterion b. and d. stress this and are of interest to us since they define the extent to which the well-being of the patient needs to be diminished in order to make physician AiD a legitimate act. The suffering and the resulting diminishment of well-being ought to be *unbearable* and *hopeless* and it is essential that there are no reasonable alternatives to alleviate it. Concerning the interpretation of the criterion b. Buiting et al. also state that although the suffering might have various causes, as for instance pain, increasing dependency and anxiety, in following 'a decision of the Supreme Court in 2002, the suffering should predominantly result from a medically classifiable disease or disorder: other forms of suffering do not justify euthanasia or assisted suicide' (Buiting et al. 2008: 1).

This especially refers to the ‘no prospect of improvement’ condition dealing with the anticipated medical situation of the patient in the foreseeable future (ibid.). The requirement that suffering is ‘unbearable’ also focuses on the patient’s subjective experience of his/her condition. ‘The physician only needs to be convinced that the patient is experiencing unbearable suffering.’ (ibid.) The criteria are worded in a very open way so that they have to be interpreted in the light of the specific circumstances of each new case. A study dealing with the physicians’ perspective on the criteria of due care conducted by Buiting et al. indicated that especially the evaluation of whether the criterion b. (the suffering is unbearable and hopeless) is fulfilled is problematic for many physicians: 79% of the physicians who stated that they experience problems when evaluating whether the criteria of due care are fulfilled maintained that especially the assessment of criterion b constituted an obstacle (cf. ibid.). Therein, according to the physicians, the main problem was to decide whether they themselves were convinced of the patient’s unbearable suffering. Buiting et al. state: ‘[h]owever, our results indicate that physicians predominantly experience problems with such subjective aspects. From a physician’s perspective, this is understandable because it is more difficult to rely on a patient’s experience and ideas than on one’s own medical-professional judgement’ (Buiting et al. 2008: 4).

Thus, the physician has to assume two different roles: an *empathising role* and a *medical-professional role*, the former of which appears to be the more difficult (cf. ibid). In addition, it is important to note that physicians have to make these decisions of AiD under very different conditions: in hospitals decisions have to be made quickly and when hardly acquainted with the patient and his/her values, whereas in nursing homes the medical professionals are well acquainted with their patients and their specific characters.

The confrontation with the Dutch jurisdiction has shown us that the patient’s well-being is of central importance within the criteria of due care and that the patient’s subjective perspective on his/her well-being plays a large role where AiD is concerned. Nonetheless, it becomes obvious that in order to be in a position to receive AiD with the aim of ending suffering, the patient (or his/her suffering respectively) need to fulfil certain requirements. These are for example the criteria that the patient is competent, that the suffering results from an illness or disorder and cannot be alleviated by means other than the termination of life. Furthermore, the physician should be able to verify the unbearability of the patient’s suffering. Hence, the subjective perspective of the patient is only valid within a certain framework. We witness an interplay between the subjective and objective dimensions of well-being on the evaluative level. As we have ascertained, it is especially this interplay which represents a problem for physicians. The following now turns to the implementation of PAS in the state of Oregon in order to be in a position to compare the relevance of well-being and the concepts as applied in both practices.

6.2.2. Physician-assisted suicide in the U.S. state of Oregon

In 1997 Oregon's *Death with Dignity Act* was finally ratified to make PAS a legal practice for terminally-ill patients after first having been approved in 1994. Terminally-ill patients are, under a specific set of safeguards, allowed to end their life through using a prescription from their physicians for lethal medication and the voluntary self-administration of the medication (Oregon Death with Dignity Act (ORS) 1994: 127.800–127.867). Emphasis is placed on the fact that by the Act a terminally ill patient is enabled to ‘end his or her life in a humane and dignified manner’ (ORS 1994: 127.805§2.01.). In contrast to PAS, VAE is explicitly prohibited by the Act. It is pointed out, however, that in the state of Oregon only a small number of the patients who receive a prescription for lethal medication actually administer it. The feeling that they have the freedom to choose the time and the manner of their death (and therefore, the feeling that their autonomy is respected) is very often all the reassurance that patients need (cf. Ganzini and Dahl 2008: 67). The following conditions need to be met if terminally ill patients are allowed to obtain a prescription for lethal medication for the purpose of ending their lives:

- The patient must be adult (18 years of age or older) and a resident of Oregon.
- The patient must be capable (defined as able to make and communicate healthcare decisions).
- The prescribing physician and a consulting physician must confirm the diagnosis and prognosis.
- The patient must be diagnosed by two physicians as having a terminal illness (defined as 6 months or less to live).

- The patient must make two oral requests to his or her physician, separated by at least 15 days, and one witnessed written request.
- If either physician believes the patient's decision may be influenced by a mental disorder, the patient must be referred for a mental health evaluation.
- The patient must be informed by the prescribing physician of feasible alternatives, including comfort care, hospice care and pain control.
- The prescribing physician must request, but may not require, the patient to notify his or her next of kin of the request.
- The physician must report the prescription for lethal medication to the Oregon Department of Human Services (formerly the Oregon Health Division); and the Department must make available an annual statistical report of information collected under the Act.
- Pharmacies are required to report filling such prescriptions.
  (Battin et al. 2007: 593)

In contrast to the Dutch *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*, the *Death with Dignity Act* does not appear to have any kind of requirement directly referring to the well-being of the patient in terms of his/her pain and suffering. It is mainly concerned with the patient's competency for making a request for PAS. It is, however, stated that in order to have access to PAS, the patient needs to suffer from a terminal illness that will lead to death within six months.[132] One could get the impression that this criterion is also indirectly linked to the well-being of the patient since the nearer he/she gets to the point of death the more frequently his/her well-being tends to diminish. But this is not always the case. There are many illnesses which bring about drastic reductions in a patient's well-being, but do not directly lead to his/her death such as the Locked-in Syndrome[133] or forms of dementia as for

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[132] The criterion that the illness ought to be terminal is linked to the notion that the process of the patient's dying should have already begun and that when administering PAS the physician only hastens this process rather than bringing it about. The former is viewed as more compatible with the integrity of the medical profession.

[133] The term 'Locked-in Syndrome' is applied to a condition in which the patient suffers from an almost complete paralysis caused by damage to the lower brain and brainstem but is otherwise cognitively intact. Frequently the eyes are not affected by the paralysis. Patients are fully conscious while at the same time unable to move any of their muscles. Devices have been developed to help these patients communicate. Some patients die

instance Alzheimer's disease[134]. Thus, there are many cases in which the diminishment of well-being and the time until death do not correlate. Hence, Oregon's *Death with Dignity Act* has no specific requirements referring to the patient's well-being or to the degree to which it needs to be diminished.

Nevertheless, one could argue that indirectly it takes account of the patient's well-being by respecting his/her autonomous choice that he/she evaluates his/her well-being as diminished to such a degree that he/she prefers to die. Thus, if the patient is to die within six months (and if the other criteria of the Act such as the patient's competence are fulfilled) it is the subjective view of the patient of his/her well-being which is crucial and, in this respect, there are no objective limits set.

All in all, if one compares the reference to the patient's well-being in both Oregon's *Death with Dignity Act* and the Dutch *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*, it becomes obvious that the patient's well-being plays a central role in both, but that there also are differences. Although the Dutch law has no direct requirements concerning the severity of illness (as for example that it needs to be terminal) it demands that the suffering of the patient is unbearable and hopeless. Oregon's law, in contrast, requires that the illness of the patient is terminal and will presumably lead to death within six months, but has no criteria which refer to the degree of suffering or to the fact that it needs to be non-relievable. As indicated in the above, the suffering and therefore, the diminishment of well-being of the patient does, nevertheless, play an important role since it is likely to motivate his/her decision to request AiD. In the legislation both in Oregon and the Netherlands, it is apparent that with regard to the character of well-being a personalized perspective concerning patient well-being is, within different limits, overriding. Even though the Dutch law demands the presence of unbearable and non-relievable suffering, the estimation of the suffering as being unbearable is a highly patient-centred procedure. The physician must simply be in a position to reinforce this, which, as illustrated, nonetheless presents a great difficulty for many physicians. All in all, the subjective dimension of well-being is of great importance within the criteria for AiD in both the Netherlands and the state of Oregon. However, it is

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shortly after having lapsed into this state, but there are also numerous cases in which patients live for many years under this condition.

[134] For more detailed information on Alzheimer's disease see American Psychiatric Association 2000: 154-7.

important to be aware of the fact that in both jurisdictions the subjective perspective of the patient is only valid within a certain framework which requires, for instance, that the patient is competent.

In addition, it should be noted that, whereas in the Netherlands both PAS and VAE are decriminalised, in the state of Oregon only PAS is permitted. In the debate on AiD, PAS is frequently viewed as a practice with a lesser risk of abuse in comparison to VAE since the patient him/herself performs the last causal act which leads to his/her death. This might provide us with a reason as to why the Netherlands have additional requirements also focusing on the QoL of the patient.

6.3. The role of well-being in the debate on assistance in dying and foregoing life-sustaining treatment

So far, we have observed that the promotion of the patient's well-being plays a prominent role next to respecting his/her autonomy where the criteria as applied in practice are concerned and that there appears to be a predominance of subjective dimensions in terms of the character of well-being. The ensuing section is concerned with a detailed analysis of the considerations of the concept of well-being that arise in the theoretical discourse on euthanasia. As in the previous chapters, the examination is to show where exactly well-being comes into play in the debates and what kind of presence and character it has when it is considered. As the following will illustrate, it appears as if different concepts of well-being are considered depending on whether *competent* or *incompetent* patients, the latter lacking decision-making capacity, are concerned. Competent patients are primarily (but obviously not exclusively) involved in debates which deal with AiD, whereas discussions on forgoing life-sustaining treatment (FLT), above all, refer to incompetent patients since they frequently are in need of life-sustaining treatment. This shows a general tendency, but there are of course numerous exceptions.[135] Owing to this tendency, the upcoming analysis is divided into two separate sections: 6.3.1. concentrates on well-being in discussions on assistance in dying in the case of *competent* patients, whereas 6.3.2.

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[135] As illustrated in the above in the Netherlands, for instance, patients can request AiD by means of advance directives. Hence the question as to whether or not AiD should be administered also arises in cases of incompetent patients.

is concerned with the consideration of well-being in debates on forgoing life-sustaining treatment in the case of *incompetent* patients.

6.3.1. Well-being and assistance in dying in the case of competent patients

It has already been hinted at in the introductory part of this chapter that the principle of *respect for autonomy*[136] is a major argument brought forward in order to argue for the moral and legal permissibility of AiD. The argumentation on the basis of this principle has received much attention. Nonetheless, also lines of reasoning which focus on the *well-being* of patients at the end of life appear to play an important role. It is argued that terminally ill patients might evaluate their well-being as so diminished that they prefer to die and request AiD.[137] In this case AiD would be a relief for these patients. In the following this lines of reasoning in favour of AiD, the so-called *argument of mercy*, are placed under scrutiny.

The 'argument of mercy'[138]

There are many eminent voices to be found, above all in the current Anglo American debate on AiD, who state that *respect for autonomy* and *individual well-being* are the two central arguments applied when arguing in favour of AiD. Dan Brock, for instance, maintains that there are two central ethical arguments for VAE. 'These values are individual self-determination or autonomy and individual well-being.' (Brock 2007: 438) Margaret P. Battin paints a similar picture concerning PAS:

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[136] This principle and its relationship to the concept of well-being receive sustained attention, above all, in section 6.4.1..

[137] In connection with *Oregon's Death with Dignity Act*, which was enacted in 1997 and legalizes PAS, a survey dealing with reports of hospice nurses and social workers, who had been caring for patients who requested PAS, indicates that among the most important motivating factors for PAS were concerns about the loss of autonomy especially concerning the circumstances of their death, the decreased ability to participate in activities that make life enjoyable and a poor quality of life (cf. Ganzini et al. 2002). Hence, there is empirical evidence indicating that the diminishment of well-being constitutes one of the major reasons for requesting AiD.

[138] Nonetheless, it should be noted that the expression 'mercy' is for obvious reasons not widely used in Germany.

> [t]here are two mainstay issues in the 'pro'-PAS column: the autonomy argument and the one about 'mercy' or 'compassion' and the relief of pain and suffering. These two arguments jointly provide the foundations of the case for social acceptance and legalization of PAS, at least where both are the case — that is, where a patient wants to die and dying is the only way acceptable to him or her of avoiding pain and suffering. (Battin 2010: 406)

Battin refers to the second (the well-being based) assertion as the *argument of mercy*. John Harris elaborates on the notion of death as a mercy or as a release from suffering when stating: 'when it comes to the very old and infirm, or to individuals who are suffering from a painful and terminal illness, [death is regarded] as a "blessed release" or a "merciful and welcome end"' (Harris 1985: 64). The argument of mercy appears to be among the two central lines of reasoning for both procedures of AiD and seems to play an important role in the discussions. But what exactly does the *argument of mercy* encompass and in what condition does the patient need to be that his/her death can be considered as merciful? The following attempts to examine the argument in more detail.

One would expect that these well-being-based lines of reasoning have received considerable attention and are presented in detail as they play an important role in the discussions on AiD. This, however, is not the case. A more careful examination of the debate illustrates that '[g]iven the uncontroversial nature of the values [autonomy and individual well-being] invoked by supporters of physician-assisted suicide, their moral arguments are usually attempts to show that the arguments of the opponents are faulty rather than to present positive arguments in favor of physician-assisted suicide' (G. Dworkin 2009: 377). Thus, it is frequently taken for granted that the pro-arguments are not in need of elucidation since they are based upon the indisputable values autonomy and well-being.[139]

Bettina Schöne-Seifert confirms this impression that the values of autonomy and well-being are considered as self-explanatory when giving the following statement:

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[139] A great number of the discussions are rather concerned with typical counter-arguments against AiD such as the alleged normative difference between active vs. passive or intended vs. foreseen euthanasia and their refutation (see for instance Birnbacher 1995; Quante 1998; Siep and Quante 1999; Miller and Truog 2012).

> [i]t is scarcely necessary to explain assertions in favour of assistance in dying: respect in face of the autonomy of a patient, who wants to free himself (or to be freed) from his condition of understandably severe suffering. This is, therefore, the convergence of two moral principles – the obligations to respect autonomy and to promote well-being, which justifies assistance in dying in the eyes of the proponents.[140] (Schöne-Seifert 2000: 105)

It is worth pointing out that Bettina Schöne-Seifert is one of the few German participants in the debate who explicitly maintain that well-being-based assertions are among the two major arguments applied in order to argue in favour of AiD. There appear to be differences concerning the reference to well-being in the German debate and in Anglo-American discussions on AiD. The principle of respect for autonomy is said to be the paramount argument in the German discussions, in contrast to the Anglo-American discourse in which the importance of both arguments (the argument for mercy as well as the patient's autonomy) is stressed. Whereas the terms QoL and well-being are frequently applied in the Anglo-American discourse on AiD, the reference to them and the consideration of their assessment are obviously avoided in the German discussion. As the results of the analysis of the reference to well-being in discussions on prenatal testing and selective abortion in chapter 3 have already indicated, this is due to the tainted connotation of QoL estimations in the past. I shall be returning to this observation in due course.

Schöne-Seifert's quotation also provides further information as to what is at stake when the promotion of well-being is concerned in the context of AiD. The well-being of the patient is viewed as being endangered by severe suffering. Furthermore, her quotation draws attention to another interesting matter: she places emphasis on the fact that both lines of reasoning, the one which is based on respect of the patient's autonomy and the other which refers to individual well-being, are closely intertwined or even converge when applied as arguments in favour of AiD (see also Bleek 2012: 195; Battin 2010: 406).

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[140] Translation by author. Original quote: 'Was zugunsten von Sterbeassistenz angeführt werden kann, bedarf kaum der Erläuterung: Respekt vor der Selbstbestimmung eines Patienten, der sich aus einer Situation nachvollziehbaren schwersten Leidens durch den Tod befreien (lassen) möchte. Es ist also die Konvergenz zweier Moralprinzipien – des Gebotes, Autonomie zu respektieren und des Wohltätigkeitsgebotes, welche Sterbeassistenz in den Augen ihrer Befürworter rechtfertigt.'

The relationship of autonomy and well-being within the main argument for AiD

As the elaboration provided by Schöne-Seifert elucidates, the convergence of both arguments (autonomy and well-being) leads to the claim that one should comply with the request of the competent patient (respect of autonomy) to prevent a severe diminishment of his/her well-being (promotion of well-being) by means of AiD. Dan Brock provides the following description of the interdependence when dealing with the question as to how the principles of respecting autonomy and promoting well-being can lead to the conclusion that AiD is a legitimate act without being at variance to each other.

> It might seem that individual well-being conflicts with a person's self-determination when the person requests euthanasia. Life itself is commonly taken to be a central good for persons, often valued for its own sake, as well as necessary for pursuits of all other goods within life. But when a competent patient decides to forgo all further life-sustaining treatment, then the patient, either explicitly or implicitly, commonly decides that the best life possible for him or her with treatment is of sufficiently poor quality that it is worse than no further life at all. Life is no longer considered a benefit by the patient, but has now become a burden. (Brock 2007: 438)

Thus, at first glance, the reference to both principles when arguing for VAE (and AiD in general) seems contradictory. This is due to the fact that life is viewed as a necessary condition for experiencing individual well-being. Autonomously deciding to end one's life implies depriving oneself of the possibility of experiencing well-being. Brock, however, stresses the fact that the person who requests AiD evaluates his/her well-being as diminished to such a degree that he/she prefers to end this life. Rather than being a benefit, life is viewed as a burden by the patient. John Harris elucidates that '[what] is meant is simply that for a particular person the prospect of continuing to live under certain conditions is a worse prospect than immediate death' (Harris 1985: 78). In following these authors this dissolves the alleged contradiction. Margaret P. Battin, above all, stresses the fact that there is a necessity for both assertions to 'operate in tandem' (Battin 2008: 27) in an argumentation for AiD thereby providing us with a deeper insight to their interdependence: '[n]either provides an adequate basis for PAS by itself, but jointly they do. Each provides a safeguard against abuse: if PAS is either involuntary or if it is not a response to pain and suffering, the societal provision of PAS cannot be supported. Because this point is so often misunderstood, it is well to say it again: you need both.' (Battin 2010: 406) According to Battin, two requirements need to be fulfilled to have an adequate basis for PAS: 1. the principle of respect for autonomy lays down that PAS needs to be voluntary and 2. the argument from mercy requires that it is a response to pain and suffering. Although seldom explicitly mentioned, for reasons that have already been dealt with, this also appears to hold true for the German debate: both arguments operate in tandem. However, in the German discussion on AiD this is not directly ascertainable.

Death with Dignity

As already suggested in the above, there appear to be differences between the German and the Anglo-American debate on AiD. Whereas well-being is not frequently referred to in the German debate, the notion of 'dignity in dying' or a 'death with dignity'[141] finds wide application as an argument in favour of AiD.[142] It is also considered in the Anglo-American debate (as inter alia the title of Oregon's *Death with Dignity Act* indicates), but does not enjoy such a central role as in the German discourse. When this notion is concerned as an argument for AiD, it is maintained that at the end of their life, patients frequently find themselves in a state of pain, suffering and dependency which violates their dignity and is said to prohibit them from a death with dignity. AiD, in contrast, is said to give patients the opportunity to die with dignity. A closer examination of the application of this argument indicates that the expression 'death with dignity' is used in various ways[143]. For our purpose it is fruitful to

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[141] In German the phrase ‚Menschenwürdig sterben' or ‚das würdige Sterben' is widely applied. See for instance Jens and Küng 1995; Schöne-Seifert 2007: 109; Schaber 2012.

[142] In their study, which focuses on the representation of euthanasia and palliative care in German newspapers, Hahnen et al. (2009) make a similar diagnosis stating that the phrase 'death with dignity' is widely applied in the German media. It should, however, be noted that the expression 'death with dignity' is also used in a different sense referring to a process of dying in which the person concerned endures whatever destiny has in store without trying to hasten death. This constitutes an argument against AiD. An example of this line of reasoning can be found in Kass 1998.

[143] As Peter Schaber points out, some voices even go as far as to maintain that the term 'dignity' has no content at all since it is used utterly different ways (cf. Schaber 2012). How-

take two specific forms of applications of the term under scrutiny which are related in dissimilar ways to the well-being-based argument in favour of AiD: 1. dignity in terms of normative authority and 2. dignity in terms of freedom from severe pain and suffering.

Concerning 1.: the former is used to indicate that a patient experiences a death with dignity in the sense that he/she has control over the circumstances of his/her death due to the fact that he/she is not hooked up to life support machines, is not totally dependent or not in a state of severe debility or dementia. A death with dignity, therefore, is a death in which the normative authority over one's own life is preserved (cf. Schaber 2012: 304). Schaber points out that although a death with dignity might sometimes overlap with an autonomous death, both are not identical (ibid.). This usage of the expression 'death with dignity' does not directly relate to the patient's well-being.

Concerning 2.: the latter usage of the expression, on the contrary, encompasses other aspects than the normative authority over one's own life. It refers to the absence of severe pain, suffering and thus to a death without a major diminishment of the patient's well-being. A death with dignity is a death without severe suffering and pain (cf. Gentzler 2003: 466). This line of reasoning appears to be used in a similar way as the argument of mercy and for this reason refers directly to the patient's well-being. It is widely applied in the general discourse on AiD but above all in the German debate.[144] Concerning this application of the expression, Hillebrand points out that the value of freedom from pain and suffering is derived from the principle of *human dignity* (Hillebrand 2009). Human dignity is considered as being jeopardized through the prolongation of suffering in the process of dying and by grossly diminished QoL.

It appears as if well-being-based arguments tend to be concealed within arguments referring to a dignified death since the expression 'death with dignity' seems to be the more socially acceptable term. This is especially the case in Germany. Thus, in many instances the *argument of mercy* is masquerading behind the *death with dignity argument*. This might provide us with a reason as to why at a first glance well-being does not appear to play a prominent role in the

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ever, Schaber opposes this thesis attributing the term 'dignity' its own normative meaning.

[144] The results of the study conducted by Hahnen et al. (2009) indicate that the expression 'death with dignity' is also widely used in this way in the debates on AiD taking place in the German print media.

German debate on AiD. Well-being-based lines of reasoning are not directly identifiable and have a *subliminal* presence above all in the German debate. We have already learned in chapter 3, which deals with the role of well-being in debates concerning the beginning of life, that the explicit reference to QoL estimations is avoided due to their tainted past. This impression becomes reinforced by the hidden presence of well-being in discussions on euthanasia. Nevertheless, it is important to bear in mind that there are various ways of applying the death with dignity argument and that it is not always a disguised argument of mercy.

The above has illustrated, however, that in terms of the various considerations of well-being in the discussions on AiD the phrase 'pain and suffering' are often used. The following sets out to scrutinize what exactly is understood by 'pain and suffering' and what concepts of well-being predominate when they are referred to.

Alleviating pain and suffering

As Battin states '[p]ain and suffering are usually understood as central factors that contribute to reduced "quality of life", a standard notion in the medical and bioethics literatures' (Battin 2010: 406). However, especially the term 'suffering' is rather broad in meaning and different aspects could be concerned when it is applied. A passage from Gerald Dworkin might help to get a clearer picture of what exactly is meant when 'pain and suffering' are referred to in the debate on AiD: '[i]t is important, however, to note that pain is not the only issue. Those who are incontinent, or paralyzed, or unable to think clearly, or free from pain but in a mental state that is disconnected from reality, or slowly losing their ability to control their muscles, are not in pain. But they are suffering. And pain medication is not going to help them.' (G. Dworkin 2009: 386) G. Dworkin emphasizes that suffering encompasses far more than mere physical pain. There is also a further side to the matter involving suffering in terms of progressive mental and physical debility and the resulting psychological burdens. He thereby also pays attention to the fact that 'modes of indignity such as incontinence, paralysis, muscular wastage, and mental deterioration' (ibid.: 376) diminish the well-being of patients at the end of life. Also a definition provided by Eric. J. Cassell illustrates the various physical and psychological aspects the term *suffering* encompasses. 'It is an afflicted state of being, a specific distress that happens to a particular person on whom has been inflicted unendurable pain or other symptoms, losses, enduring fear, hardship, injury, disaster, grief, sorrow, or care and who has been changed as a result of the burden.' (Cassell 2004: 76) The *prospect* of deterioration is an additional factor which reduces the patient's well-being. Especially the importance of paying attention to the subjective experience of patient's suffering is accentuated and also its subject relativity. 'Whatever may be the origin of suffering (for example, pain or the depredations of disease), the loss of a person's intactness – the hallmark of suffering – is related to the specific nature of that person.' (Cassell 2004: 79) Thus, on the one hand it is stated that specific conditions at the end of life such as physical pain, dependency, mental and physical degeneration generally have a negative impact on individual well-being. On the other hand, it is pointed out that the subjective dimension in terms of the patient's experience of his/her condition and the pain and suffering is of major importance and that there are great differences in terms of this experience between different individuals. Hence, at the ontological level, well-being is considered as having intersubjective but above all subjective dimensions.

It is emphasized that it is up to the patient to decide at which point his/her well-being is diminished to such a degree that he/she would wish to make use of AiD. 'Deciding that the benefits [of continuing living] are proportionate requires the inherently nonmedical determination of how valuable it is to continue living. It should be obvious that these are judgments that no outsider should be able to make.' (Veatch 1989: 82) This line of reasoning is endorsed by Dan Brock who states that '[e]specially in the often severely compromised and debilitated states of many critically ill or dying patients, there is no objective standard, but only the competent patient's judgment of whether continued life is no longer a benefit' (Brock 2007: 438). Hence, the evaluation of well-being in connection with a request for AiD is considered a highly subjective procedure. In order to counter arguments of potential misuse it is repeatedly emphasized that it is the patient him-/herself who decides when his/her well-being is diminished to such an extent that he/she requests AiD. It is stressed that the patient *should* have the ultimate authority to determine his/her well-being. However, it is worth mentioning that there are some limits set to the subjective evaluation of the suffering and pain as a safeguard against misuse. This has already been hinted at in the previous section on AiD as applied in practice. PAS and VAE should only be administered if the patient can be considered competent and his/her choice autonomous. Thus, in a case in which a patient evaluates his/her well-being as grossly diminished due to the fact that he/she is suffering from depression, AiD is not considered a legitimate act. It is apparently a widely held view among the proponents of AiD that in these cases the patient's evaluation of his/her well-being should not have the ultimate authority. Thus, it is argued also in the theoretical debate that when AiD is to be considered, there should be additional criteria which must be fulfilled especially ensuring that the patient is competent before his/her subjective evaluation of his/her well-being is taken into account. We will come back to this observation in due course.

The argument of non-necessity[145]

The argument of mercy depicted in the above is frequently confronted with objections formulated, above all, from members of the hospice movement. It is argued that palliative and terminal care as well as an *ethics of solidarity* render AiD based on concerns about the well-being of terminally ill patients unnecessary. This is due to the fact that it is the aim of palliative care to improve the well-being of patients at the end of life (cf. Gutmann 2002: 176). In particular, it is stressed that in contrast to common opinion, palliative care encompasses far more than the alleviation of physical pain. In order to see what exactly it refers to, it is fruitful to make a closer examination of the definition of palliative care that the WHO provides: 'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.' (WHO 2012a) Thus, according to the WHO definition, palliative care not only aims at promoting the well-being of the patient concerned but also that of the family members involved. In addition, the WHO emphasizes that palliative care is not only concerned with the physical condition of the patient but also with psychological and spiritual matters. But what exactly does this mean? When expressing their aims in concrete terms, they state that palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;

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[145] Cf. Gutmann 2002: 176.

- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
  (WHO 2012a)

In following these explanations palliative care at the end of life is very comprehensive, encompassing many needs from the physical to the spiritual and thereby counteracting a diminishment of QoL. One can observe that many of the aforementioned factors which lead to a diminishment of well-being and therefore motivate a wish towards assistance in dying are treated by palliative care. On this basis it is argued that AiD is not necessary to safeguard well-being at the end of life. Furthermore, members of the hospice movement claim that a seriously ill patient's wish to die is a result of the lack of good palliative and psychological care. Thus, rather than legalizing procedures of AiD, substantial efforts should be made to improve palliative care as well as to increase the access to it.

We can ascertain that members of the hospice movement directly refer to the well-being of the patients when arguing that AiD is unnecessary. They also place emphasis on the subjective dimensions of well-being when referring to the various wishes patients might have and when claiming that palliative care encompasses far more than the alleviation of physical pain. It is pointed out that palliative care addresses a broad range of patients' wishes at the end of life and therefore, patients can request support for a variety of needs which they might have. They can do this in any way they see fit. Hence, the arguments are based on comparatively broad subjective concepts of well-being referring to a variety of aspects which patients might wish at the end of life.

Reactions to the argument of non-necessity

When responding to these objections to AiD proponents also appear to tie their argument to comparatively broad subjective conceptions of well-being. They respond that one should bear in mind that there are a considerable number of patients who have the wish to end their lives despite successful palliative care. This is due to the fact that there are further factors which cause the diminishment of well-being at the end of life and these are and cannot be encompassed by palliative or end-of-life care.

Many patients have the wish to control the circumstances of their death and want to avoid the loss of independence at the end of life. This has also been indicated by the survey conducted in connection with Oregon's *Death with Dignity Act* (cf. Ganzini et al. 2002). Apart from setting limits to patients' autonomy, the loss of independence also has a negative impact on their well-being. It is pointed out that patients also suffer from the feeling of being a burden to their family and others persons who are taking care of them (cf. Bleek 2012). Even successful palliative care is not in position to counteract this problem.

Increasing mental decline constitutes another reason why patients request AiD. Concerning this matter Gerald Dworkin maintains that 'there comes a point at which the life of the patient (in their eyes) is one of degradation and misery. What they want is to end their life, not to have it extended in a slightly improved fashion.' (G. Dworkin 2009: 386) Palliative care is only able in a limited way to prevent this from happening. In addition, it is stressed that pain medication can provide a relief from physical suffering but the downside is frequently that the patients live in a state of vegetation and lose 'contact with the world around them – in particular with those loved ones with whom they would like to communicate' (ibid.). Patients have the wish to die 'because their illness means the end of those things which make life meaningful and coherent according to their own personal basic desires: for instance physical activity, social interaction or intellectual participation in the world around them'[146] (Schöne-Seifert 2000: 107). The loss of these valued things and the resulting diminishment of well-being cannot be prevented by means of palliative and end-of-life

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[146] Translation by author. Original quote: 'weil ihre Krankheit das Ende dessen bedeutet, was nach den ganz persönlichen elementaren Vorstellungen das eigene Leben bedeutungsvoll und kohärent macht: etwas körperliche Aktivität, soziale Interaktion oder intellektuelle Teilnahme an der Welt'.

care. Cassell points out that '[t]he suffering of some patients cannot be relieved because its sources within the patient are inaccessible' (Cassell 2004: 79).

Moreover, it is emphasized that there are limits to the successful application of palliative care and the successful treatment of pain is not always possible (cf. Birnbacher 2005: 4). For these patients there is no other solution to avoid pain and suffering apart from their death. Furthermore, it is argued that the existent capacities of palliative care will not suffice on a medium-term basis and already existing trends such as the individualization in Western Society make 'dying in the bosom of one's family' an improbability (cf. Gutmann 2002: 176). Nevertheless, Thomas Gutmann maintains: '[i]ndeed the provision of hospices and palliative care units as well as the willingness of relatives to support dying patients should be the most important aims which should be focused on in society's attempts to deal with death...'[147] (Gutmann 2002: 176). It is important to note that most proponents of AiD share the view that palliative care should have priority over AiD (cf. Schöne-Seifert: 2000: 106). Dieter Birnbacher states that there should not be a polarized opposition between palliative care and AiD (cf. Birnbacher 2005: 4). Both practices should rather be viewed a complementing each other.

Once again, emphasis is placed on the variety of desires which persons might have at the end of life and the variety of things the lack of which reduces their well-being such as physical activity, social interaction or intellectual participation in the world. Arguments which refer to the desires for these aspects also for the most part rest upon broad subjective concepts of well-being.

Preliminary results

The analysis of the role of well-being in discussions of AiD in cases of competent patients has shown that the *well-being* of patients at the end of life plays a prominent role especially as an argument in favour of AiD. This is explicitly indicated in the Anglo-American discussion but well-being is, for the most part, only implicitly referred to in the German debate. It has been illustrated that, above all, in the German discourse well-being-based lines of reasoning are

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[147] Translation by author. Original quote: ‚In der Tat dürften der Ausbau von Hospizen und palliativmedizinischen Stationen sowie die Förderung der Bereitschaft von Angehörigen, Sterbenden beizustehen, die wichtigsten Ziele markieren, die es im gesellschaftlichen Umgang mit dem Tod zu erreichen gilt…‘.

masquerading behind the *death with dignity argument* and the reference to the *principle of autonomy* since these appear to be the more widely accepted assertions. Hence, it can be provisionally concluded that well-being has an *overt* as well as a *subliminal* presence in the debates dealing with AiD. Nonetheless, it can be said that the concept of well-being constitutes a prime reference in the discourse on AiD.

However, as we have seen, considerations of well-being occur in connection with autonomy-based lines of reasoning. Both principles, *the promotion of patients' well-being* and *respecting their autonomy*, are in a relationship of interdependence when applied as an argument in favour of AiD. In the discussions on AiD emphasis is placed on the fact that well-being does not by itself constitute an argument for AiD. It needs to be complemented by the principle of respect for autonomy since the mere reference to patients' well-being would throw the doors wide open to well-being evaluation by third-parties, which are to be avoided since they are highly susceptible to abuse. The principle of autonomy, on the other hand, is substituted by the principle of promoting well-being in order to ensure that the request for AiD results from severe pain and suffering. This aspect will be discussed in more detail later.

Regarding the character of well-being considered in the debate on AiD in cases of competent patients, it can clearly be said that the subjective dimensions of well-being are at the forefront. The importance of subjective dimensions of well-being in the debate on euthanasia also becomes evident from the way in which members of the hospice movement place emphasis on the fact that palliative care encompasses far more than the alleviation of physical pain. Much is done to address various needs patients might have and the end of life. Members of the hospice movement as well as critics of the argument of non-necessity often referred to the *desires* of the patients which clearly can be classified as subjective aspects of well-being. Furthermore, it is stressed that in psychological as well as spiritual aspects are of major importance when taking care of patients at the end of life. This refers to the subjective dimension of well-being focusing on the patient's experience of his/her situation. Moreover, we can observe that in the theoretical debate a comparatively broad concept of the character of well-being is applied, which refers to a variety of different desires patients at the end of life might have such as intellectual participation in the world. It is important to note that the aspects of well-being are viewed as health related. Hence, a broad concept of health-related well-being is applied.

However, it is necessary to provide a more detailed description of the concepts of well-being concerned on the different levels in the discussions: at the ontological level subjective dimensions appear to be of relevance. On the one hand, the patient's subjective experience of his/her condition and their desires play an important role. Especially the term 'suffering' is applied in a way in which it encompasses various elements which could be considered as subjective since they refer to the patients' feelings, personal experience of their condition and their mental state. On the other hand, specific goods such as freedom from pain, independence and having contact to reality, which are viewed as generally contributing to individual well-being, are listed. Hence, the arguments do not appear to be based upon an utterly subjectivist concept of well-being, but are tied to the assumption that there are certain goods which patients generally value in the final phase of life.

When the evaluative level is considered the subjective dimensions of well-being also clearly prevail. Emphasis is placed on the fact that the patient has and should have the ultimate authority to evaluate and determine his/her well-being. As the elucidations in the above indicate, this subjectivist perspective on the evaluative level is linked to the predominance of subjectivist dimensions at the epistemic level: it is often maintained that the patient him-/herself has the best access to his/her individual well-being. As afore-mentioned, this is only the case if the patient is considered competent. Thus, there are some formal criteria which need to be fulfilled before full account is taken of the patient's subjective evaluation of his/her diminishment in well-being.

The concept of competency thereby appears to be of central relevance. But what conditions need to be fulfilled when a patient is considered competent and what happens in cases in which he/she is regarded as incompetent and decisions whether to end life or not have to be taken?

6.3.2. The reference to well-being in the special case of incompetent patients in discussion on forgoing life-sustaining treatment

Many patients in the final phase of life are deprived of their decision-making capacity and unable to express the evaluation of their well-being in their current condition. Moreover, these patients frequently are not able to make decisions which serve their well-being (Buchanan and Brock 1990: 30). They are considered incompetent[148] since they lack the mental capacity for a given task such as making autonomous decisions (cf. Davis 2009: 350). Especially in cases in which decisions as to whether to withhold or withdraw life-sustaining treatment – cases of FLT – have to be taken, patients have frequently lost decision-making capacity. They might, for instance, be severely demented or in a persistent vegetative state. In these cases, in which the patients are incompetent, special standards are applied for decision-making to safeguard the patient's well-being and to extend his/her autonomy as far as possible. However, it is important to bear in mind that these cases are also often concerned with incapacitated patients who are severely debilitated but *not* terminally ill as in the case of patients in a persistent vegetative state.

The subsequent part sets out to analyze the role of the patient's well-being in discussions on foregoing life-sustaining treatment since these cases are frequently concerned with incompetent patients. It elaborates on the various standards for decision-making when patients have become incompetent. The analysis focuses on so-called *formerly competent patients* 'who used to have the relevant decision-making capacity, but lost it, for example, due to Alzheimer's disease or other medical problems (or procedures such as surgical anaesthesia) undermining normal brain functioning' (Jaworska 2009).[149] Due to the fact that in cases of FLT, patients have sometimes made no specific request for assistance in dying since they were unprepared for their current situation, *non-voluntary euthanasia* also comes into play. Attention is paid to the character of well-being under consideration in cases of incompetent patients in which the question of FLT arises and especially to divergences from cases of competent patients and AiD with regard to the concepts applied.

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[148] Although in the general debate on competency, such as in connection with the doctrine of informed consent, children (as so-called minors) play a large role, the subsequent part focuses primarily on incapacitated adult patients at the end of their life. However, it must be stressed that children could also be involved in end- of- life decisions, which raises divergent problems.

[149] Cases of patients who have never been competent, such as young children or patients with a severe mental retardation, are not considered in the following part.

The concept of competence and its gate keeping function

Due to the continually ageing society in which we live an increasing number of patients suffer from different forms of dementia at the end of their life. Thus, decisions concerning FLT and AiD are to an increasing extent concerned with so-called *incompetent* patients who lack decision-making capacity. The concept of *competency* has a gate-keeping function: complying with a request for AiD or FLT (in some countries) is only permitted if the patient is competent (or had requested AiD or FLT by means of an advance directive before he/she became incompetent). The underlying concern is that the decisions of the incompetent patient, provided that he/she is conscious and able make (as well as express) a decision, might fail to serve his/her well-being. As Buchanan and Brock (1990: 30) maintain, '[t]he same value of patient well-being that requires patients' participation in their own health care decision making sometimes also requires persons to be protected from the harmful consequences to them of their own choices'. For obvious reasons this holds especially true for decisions concerning AiD and FLT. Generally speaking, the concept of competence distinguishes 'persons whose decisions should be solicited or accepted from persons whose decisions need not or should be solicited or accepted' (Beauchamp and Childress 2013: 114). However, to what exactly does the concept of competence refer? Buchanan and Brock point out that 'competence is competence *for some task*, competence *to do something*' (Buchanan and Brock 1989: 84). Thus, a person may be considered incompetent for some special decision or task but at the same time competent with regard to another. 'So incompetency must be determined with regard to a particular set of choices.' (Veatch 1989: 107) If, for instance, decisions whether to withhold or withdraw life-sustaining treatment for terminally ill patients have to be taken, the term *incompetence* refers to a patient's lack of mental capacity with regard to making an autonomous decision about wanting to end his/her life.[150] Thus the concept of competence in terms of decision-making is closely linked to autonomous decision-making (cf. Beauchamp and Childress 2013: 116). 'Patients ... are competent to make a decision if they understand the material information, to make a judgement about

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[150] It should be noted that there are many participants in the debate who distinguish between *judgments of competence* and *judgments of capacity*: 'health professionals assess capacity and incapacity, whereas courts determine competence and incompetence' (Beauchamp and Childress 2013: 114). However, since the distinctions breaks down in practice (cf. ibid.) both terms (competence and capacity) are used interchangeably in the following.

this information in the light of their values, to intend a certain outcome, and to communicate freely their wishes to caregivers.' (ibid.) These are some general standards which are similar to the properties of autonomous persons. However, there is considerable controversy on the appropriateness of these and other standards for determining competency or incompetency respectively. Furthermore, it is important to note that there are different degrees of incompetency and it can have various causes.

> Incompetence may be limited or complete, chronic or intermittent, and it may be due to one or more of a diverse set of medical disorders, including: (1) degenerative neurological disorders such as Alzheimer's disease and Parkinson's disease, (2) single or multiple cerebrovascular accidents (stroke), (3) severe acute or chronic depression that impairs cognitive function, (4) temporary or permanent coma, (5) mental retardation, (6) psychosis, or (7) severe personality disorders. (Buchanan and Brock 1986: 17)

Nonetheless, it should be emphasized that for practical reasons *competence* is a threshold concept rather than a comparative one: patients are judged as either competent or incompetent with respect to a specific decision. Different guiding principles and standards have received considerable attention and are applied when patients are incompetent and the question of AiD or FLT arises. The controversy about appropriate standards for incapacitated patients in this context has also been treated at length in law. Generally speaking, the following hierarchy of decision-making standards applies (cf. DeGrazia 2005b: 163):

1. Informed consent.[151]
2. Advance directive
3. Substituted judgment.
4. Best interests.

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[151] The standard of *informed consent* is applied in cases in which the patient is competent. It refers to the voluntary consent of the patient to a medical intervention. However, since the debate on euthanasia is mainly concerned with voluntary requests for AiD and FLT as opposed to physicians' suggestions for a specific treatment, the standard of informed consent is not of crucial importance in the discussions. The debate rather focuses on the patient's competency when making a request for AiD or FLT.

The various standards for incompetent patients, namely the advance directive standard, the substituted judgment standard and the best interest standard, receive sustained attention in the following analysis of the role of well-being in the discussions at the end of life.

Advance directives

In order to clarify which actions (above all life-sustaining medical interventions) should be taken in the event that they become incapacitated, patients can make use of so-called advance directives. These encompass the expressed interests, preferences and values of the patient at a time when he/she was still competent. As Buchanan and Brock point out 'the advance directive principle offers the simplest extension of the competent patient's right of self-determination to the problem of decision making for incompetents' (Buchanan and Brock 1986: 57). The underlying assumption is that individuals should have the same moral authority over their *current* as over their *future* affairs – the so-called 'Extension View'[152] (Davis 2009: 350). Ronald Dworkin refers in this context to the 'precedent autonomy' of the patient, which is carried out by means of advance directives (cf. R. Dworkin 1993: 226). It provides patients with control over the circumstances of their death spelling out their wishes about when life-sustaining treatments should be initiated, forgone or ceased. According to PCB, advance directives mollify the following concerns.

> People worried especially that life-sustaining medical technologies might keep them alive for too long in what they perceived to be an undignified state, unrewarding to themselves and excessively burdensome to their loved ones. More generally, people worried that decisions might be made without sufficient regard to their own wishes and welfare. (PCB 2005: 54)

Thus, the quotation by the PCB indicates that advance directives are regarded as allowing for the application of the above-mentioned converging principles *respect for autonomy* and *promoting well-being* in the case of incompetent patients. There are two basic types of written instructions: 1. *instruction directives* and 2. *proxy directives*.

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[152] Proponents of the Extension View are among others Buchanan and Brock (1990) and R. Dworkin (1993).

1. *Instruction directives* express the competent patient's preferences about care such as life-sustaining treatments in the event that he/she becomes incompetent. They can be written (living will) or oral statements.[153] The declarant states which treatments he/she wants to receive or refuse in the event that he/she becomes incapacitated. 'More often, [advance directives] contain general statements, reflecting the person's basic values, about the considerations that should guide those at the bedside.' (PCB 2005: 57) However, the majority of people give oral statements rather than completing a written living will. Although living wills are also applied in order to request life-sustaining treatment, they are more frequently used to express decisions involving non-treatment. They provide evidence of the now incompetent patient's earlier wishes concerning specific circumstances e.g.: '[d]o not prolong my life if I enter persistent vegetative state.' (Jaworska 2009) Often informal documents provided by religious or right-to-die groups are used (cf. Davis 2009: 352).

2. *Proxy directives* (also referred to as *health care powers of attorney*) constitute the second type of advance directives. They can also be written or oral statements. A competent individual gives the authority to make health care decisions including terminating care and life support to another appointed, trusted individual (the proxy or surrogate) in the event he/she becomes incompetent. The proxy acts on the behalf of the then incompetent patient and as his/her representative in the decision-making process. 'Appointing a formal proxy can be especially valuable if a patient has no close family members, if the patient's relatives are dispersed, or if relatives disagree among themselves.' (PCB 2005: 58) Both instruction and proxy directives can be combined, for instance, the latter might help to resolve problems with the interpretation of the wishes formulated by the formerly competent patient in a living will.

The discussion of the advance directive standard manifests that also in the case of incompetent patients, autonomy and well-being are the two guiding principles. Furthermore, by focusing on the patients' former (when competent) desires and interests the subjective dimensions of well-being also prevail. As we will see, the constellation is similar where the substituted judgement standard is concerned.

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[153] It should, however, be noted that laws in various states and countries vary concerning this matter.

The substituted judgment standard

In cases in which patients have not executed an advance directive while competent, 'courts have generally appealed to the doctrine of *substituted judgment*, permitting a family member or another appropriate surrogate to attempt to determine what the patient would have wanted in the present circumstances' (DeGrazia 2005b: 161). Based on the values and interests of the formerly competent patient, the surrogate tries to decide in a way the patient would have decided him-/herself when competent. 'The "substituted judgment" principle states that a surrogate is to choose as the patient would choose if the patient were competent and aware both of the medical options and of the facts about his or her condition, including the fact that he or she is incompetent.' (Buchanan and Brock 1986: 56) This requires the surrogate to have a 'deep familiarity with the patient' (Beauchamp and Childress 2013: 227). He/she takes account of dimensions such as the patient's religious affiliation, cultural background or attitudes toward medical care (cf. PCB 2005: 63). On this basis the autonomous decision and the subjective point of view of the once-competent patient are reconstructed. Thus, both advance directives as well as the substituted judgment standard are *Extension Views* referring to the patients past wishes when he/she was competent in an attempt to extend the patient's autonomy now they have become incompetent. 'The goal is to determine the treatment alternative most consistent with the patient's earlier values and preferences.' (PCB 2005: 63) Thus, also in the case of the substituted judgment standard a subjectivist perspective is taken in terms of the patient's well-being, paying attention to his/her former desires.

The alleged shortcomings of advance directives and substituted judgments

For various reasons advance directives as well as the substituted judgment standard have received extensive criticism.[154] One problem which has received considerable attention is the 'past wishes versus present interests problem'

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[154] Both, advance directives and the substituted judgment standard, have been confronted with various objections. Nevertheless, I am only concentrating on the criticism in which the concept of well-being is involved. For a broader overview of the most common objections see for instance Mappes 1998; Jaworska 2009.

(Mappes 1998). In order to provide a more vivid picture of the problem, Thomas A. Mappes portrays the following case:

> [s]omeone has unambiguously stipulated in an advance directive that life-sustaining treatment should not be provided if she becomes seriously mentally debilitated; this patient is now severely mentally debilitated but is "pleasantly senile" and does not appear to be suffering. The problem is that life-sustaining treatment, although clearly incompatible with her *past wishes*, appears to be in her *present interests*. (Mappes 1998)

How are we to decide in these cases of the so-called ‘Happy Alzheimer’s Patients’ (Davis 2009: 355)? Recently the case of Walter Jens, a Professor of Rhetoric who fought for the legalization of VAE, has received considerable attention in Germany. Before he became severely demented, Jens said that he could not visualize a life without intellectual interaction and formulated his wish to forgo life-sustaining treatment in this event in an advance directive. But now in a state of severe dementia he appears to value his life and has uttered the following words: ‘Don’t kill me, please don’t kill me.’[155] (Die Berliner Literaturkritik 2009). Should the patient’s advance directive be binding or overridden in the event that he needs life-sustaining treatment?[156]

In this context Ronald Dworkin (1993) distinguishes the *critical life interests* of an individual which were expressed in a competent state from his/her *experiential interest* when incompetent. In cases of conflict he attributes higher value to the former. In following Rebecca S. Dresser and John A. Robertson, in contrast, the preferences which the patient stated when he/she was competent need no longer be valid when he/she becomes incompetent (cf. Dresser/Robertson 1989). According to them the ‘orthodox approach’ of giving priority to the preferences expressed in advance directives or by means of substituted judgments is misleading since the values and interest of the once competent patient are likely to have changed since he/she has become incompetent. ‘In giving priority to Advance Directives and Substituted Judgment, the ortho-

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[155] Translation by author. Original quote: ‘Nicht totmachen, bitte nicht totmachen.’

[156] These cases of conflict between the interests of the earlier and current self, above all, raise questions concerning the concept of *personal identity*. For a more elaborate analysis of this concept see Quante 2002 and DeGrazia 2005b.

dox view overlooks the possibility that the earlier competent self and the current incompetent self may have conflicting interests.' (Jaworska 2009) According to critical voices, referring to the earlier desires and values of the now-incapacitated patient does, contrary to common opinion, not respect his/her autonomy and might even cause harm when these wishes contradict his/her current welfare interests. Thus, it is argued that a more differentiated perspective is needed, which also takes into consideration the current interests of the now-incompetent patient. A close examination of the incompetent patient's actual/current situation is said to be of vital importance. Agnieszka Jaworska emphasizes the importance of paying attention to the specific circumstances of the incompetent patient in each case (cf. ibid.). Since patients in a vegetative state cannot have 'interests potentially different from the interests of the person he used to be' (ibid.) it is appropriate to focus on the wishes expressed in advance directives or surrogates. However, in cases of patients who are suffering from dementia the circumstances are often utterly different: these patients 'have simply lost the mental capacity to comprehend and reaffirm their earlier preferences' (David 2009: 359) and have developed new interests in their current condition which might conflict with their former interests when they were competent. 'Once mental deterioration progresses, the patient's universe of interests shrinks and new interests may become dominant.' (ibid.) In order to avoid harm, these new interests should be overriding in the process of decision-making.

Some critics state that 'advance directives fail on a *practical* level to effect a patient's autonomous choices because, for example, people cannot foresee their futures well enough to make informed decisions in advance' (Davis 2009: 350). This is, among other things, due to the fact that the therapeutic options might be improved by the time the patient becomes incompetent and the advance directive becomes viable. Furthermore, competent individuals might not be in a position to anticipate how their interests might change in the event that they become incompetent. Hence, in following this line of reasoning the individual him-/herself is not considered the best judge concerning his/her future interests after having become incompetent. For this reason, it is argued that rather than advance directives and substituted judgments the patient's 'best interests' should take effect when he/she has become incapacitated (cf. Dresser and Robertson 1989).

Hence, critics state that paying attention to the subjective perspective of the once competent patient is not appropriate in cases in which his/her desires and interests might have changed when becoming incompetent. They propound that it would be more appropriate to apply a standard which is based upon intersubjective (or even objective) criteria of well-being such as the best interest standard. But what exactly is the best interest standard and when is it applied?

Best Interest Standard

If there is a lack of information about the values and the preferences the patient had when he/she was competent, the so-called 'best interest standard' is applied in clinical decision-making.[157] Instead of focusing on the patient's former subjective perspective, this standard is based on a set of interests or elements which all humans appear to share (cf. Jonsen et al. 2010: 116). These are considered the interests of all reasonable persons. Jonsen et al. list the following interests for which this holds true:

> *It can be presumed that all humans have an interest in being alive, being capable of understanding and communicating their thoughts and feelings, being able to control and direct their lives, being free from pain and suffering, and being able to attain desired satisfaction.* It can be presumed that all humans would choose to avoid loss of these abilities.
> (Jonsen et al. 2010: 116)

The net benefit to the patient of each option is determined in the light of these various interests and the present circumstance of the patient. As the term *best* indicates the aim is to determine the highest benefit among the available options (cf. Beauchamp and Childress 2013: 228). It is asked how a 'reasonable' person would decide under the given circumstances and in how far widely valued goods such as freedom from pain and the ability to communicate are present. Thus, putatively objective or at least intersubjective measures are used to determine the patient's best interests. Beauchamp and Childress point out that 'the best interest standard protects an incompetent person's well-being by requiring surrogates to assess the risks and benefits of various treatments and al-

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[157] The best interest standard is also used in cases in which the patient has never been competent such as in cases of neonatal treatment or child custody.

ternatives to the treatment. It is therefore inescapably a quality-of-life criterion.' (Beauchamp and Childress 2013: 228) Furthermore, as illustrated the best interest standard operates on a more objective (in terms of intersubjective) concept of well-being in contrast to the advance directive or the substituted judgment standard.

Preliminary results

The analysis illustrates that, as in the discussions on AiD in the case of competent patients, well-being plays a prominent role, however, for the most part in connection with the principle of respecting the patient's autonomy. The above elucidations demonstrate that it is a crucial factor whether or not there is information about the now incapacitated patient's former desires and interests. This has a great impact on the role well-being is to play and the concepts applied.

First of all, the following takes a closer look at instances in which there *is* information available about the patient's former wishes and desires: in following the Extension View, the principle of respecting autonomy is extended, as far as possible, to the case of now incompetent individuals. This is accomplished through taking patients' former wishes and desires as a basis in the actual process of decision making for the now incapacitated patients. This course of action indicates that similar concepts of well-being as in the case of competent patients and AiD serve on the alternative levels: at the ontological level, above all, the subjective elements of well-being are stressed since the desires, values and interests of the once competent patient play a major role. This is also the case at the epistemic level. The patient him-/herself is considered to have the best access to his/her well-being and, furthermore, he/she is viewed as being in a position to anticipate his/her future well-being under specific conditions. Where the evaluative level is concerned, the ultimate authority is given to the once competent patient's desires and interests. Hence, the fact that the patient is incompetent now means that his/her former interests and desires by means of advance directives and substitutes judgments have the ultimate authority on the evaluative level. As we have seen in the above, this has evoked harsh criticism since in some cases the earlier interests of the competent patient might conflict with his/her current desires when incompetent. In these cases it is argued that it would be more appropriate to evaluate the patient's well-being with a focus on his/her current situation (or experiential interests) by means of objective or intersubjective criteria such as the best interest standard. It is maintained that patients can be mistaken about what might promote their well-being especially if their evaluation concerns specific future conditions which have not yet occurred.

As depicted in the above, this best interest standard is applied in cases in which there is *no* information about the patient's former interests and desires. Since there is no evidence of the once competent patient's desires and interests serving as a guideline for the patient's autonomous choice, the principle of respect for autonomy recedes and the promotion of well-being comes to the forefront. Thus, a shift takes place from the *Extension View* (which, as shown, also involves the principle of promoting well-being) to a purely *well-being based view*. The application of the best interest standard implies changes in terms of the concept of well-being under consideration: an objective or intersubjective stance is taken. It is not immediately apparent precisely whether it is an objective or intersubjective stance. Nonetheless, there are some indications which suggest that the perspective which prevails is intersubjective since the best interests standards is said to represent the standard desires of a reasonable person. There is no reference to an essentialist perspective in terms of well-being at the ontological level. Intersubjective standards are applied to evaluate the incompetent patient's well-being in order to determine whether or not foregoing life-sustaining treatment is a legitimate act. This change from a subjectivist to a more inter subjectivist stance is due to the lack of information about the patient's former values and preferences and therefore, was born out of necessity. Nevertheless, we can conclude that it acts on the assumption that the nature of well-being is not utterly subjective and that to a specific degree external evaluations of a person's well-being are possible, otherwise the application of the best interest standard would be rendered impossible.

6.4. Results arising from the analysis and the issues it raises

The results of the analysis so far clearly illustrate that where the role of well-being in discussions on euthanasia is concerned its relationship to the principle of *respect for autonomy* is of major importance. It appears to have a great impact on the role well-being plays and its character which is under consideration in the discussions on AiD and FLT. Hence, in order to clarify the role which well-being plays in the debate on euthanasia it would appear to be fruitful, as in the previous chapters, to analyze the relationship between well-being and the other major concept with which it appears to interact. Therefore, in this chapter we take a closer look at the presence of well-being when occurring with autonomy (6.4.1.). Furthermore, we have ascertained that there is a predominance of subjective dimensions of well-being in debates on euthanasia. But what are the underlying reasons for this prevalence of subjective conceptions? Section 6.4.2. involves itself with this question.

6.4.1. The presence of well-being when occurring with autonomy

When dealing with the relationship of well-being and autonomy, it is initially important to get a clearer picture of what exactly is meant by referring to the principle of respect for autonomy (or self-determination as maintained by Buchanan and Brock 1990) in the debate on euthanasia. On the authority of Beauchamp and Childress, 'to respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their personal values and beliefs' (2013: 106). They stress the fact that linked to this are *negative* as well as *positive* obligations. The negative ones mainly consist of the non-interference of physicians and other health care professionals in the autonomous actions and choices of the patient as long as these do not harm others (cf. ibid.: 107). The positive obligations, in contrast, refer to the disclosure of information and the assurance that the patient fully understands it so that he/she is in a position to make an autonomous choice. Of central interest to us, however, is the question as to how both principles, the respect for autonomy and the promotion of well-being, relate to each other in the context of discussions on euthanasia. In order to approach the answer to this question it appears to be fruitful, in a first step, to see how both autonomy and well-being can relate to each other and then, in a second step, to ascertain how exactly they relate in the discourse on euthanasia on the basis of this information.

Paternalism: well-being and autonomy in conflict

To begin with, it should be noted that especially in the realm of biomedical ethics there are often far-reaching discrepancies between the implications of the principles of respect for autonomy and promoting individual well-being (cf. Hildt 2006: 169). An example is the case of a patient who decides to act in a way which the physician views as harmful to his/her health and for this reason the physician meddles with the aim of protecting the patient's well-being. Cases of this kind are discussed under the title 'paternalism'. The field of medicine especially has a long tradition of paternalism. Beauchamp and Childress give the following definition of paternalism: 'the intentional overriding of one person's preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefiting or of preventing or mitigating harm to the person whose preferences or actions are overridden' (Beauchamp and Childress 2013: 215).[158] Thus, the concept of well-being is seen to play a central role since the patient's preferences or actions are overridden by the physician for the sake of the protection or promotion of the patient's well-being. Where paternalism is concerned, both the principles of autonomy and well-being conflict and autonomy is overridden by well-being. Let us consider whether the problem of paternalism plays an eminent role in the above depicted discussion on euthanasia. At a first glance, this does not appear to be the case since both principles, respect for autonomy and promoting or protecting individual well-being, work together in one direction: they both are used within the argument for AiD which, as described in the above, claims that one should comply with the request of the competent patient to prevent a severe diminishment of his or her well-being by means of AiD. Thus, both principles, well-being and autonomy, work in tandem and do not have conflicting implications. Nonetheless, in the case of incompetent patients, when the question as to whether FLT should be administered arises, it appears to be somewhat different. Let us investigate these cases more closely.

The differentiation between *hard* and *soft* paternalism, introduced by Joel Feinberg (1971), is of relevance here. Whereas hard paternalism refers to interferences with *autonomous* desires and decisions, in cases of soft paternalism

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[158] This is the so-called broader definition of paternalism. There is also a narrow one that paternalistic interventions restrict *autonomous* preferences, desires and actions (cf. Schöne-Seifert 2009: 109; Beauchamp and Childress 2013: 215).

the choices and desires of the individual concerned do not necessarily need to be autonomous. Thus, soft paternalism deals with intervention in cases of incompetent individuals. A mother who has her child vaccinated although the child is screaming provides an instance of soft paternalism (cf. Schöne-Seifert 2009: 110). 'A necessary condition for this variant of paternalism are currently uttered or perceivable wishes or intentions ..., which are not considered autonomous.'[159] (ibid.) Like Ronald Dworkin, Bettina Schöne-Seifert terms these 'empirical wishes' and intentions. In contrast to hard paternalism, soft paternalism is generally viewed as admissible. 'Soft paternalism only tries to prevent the harmful consequences of a patient's actions that the patient did not choose with substantial autonomy.' (Beauchamp and Childress 2013: 217). A special form of soft paternalism is called 'self-paternalism' or 'Odysseus paternalism' (Quante 2002; Schöne-Seifert 2009: 111): an incompetent person's empirical desires and intentions are interfered with for the sake of his/her well-being, since he/she has authorized somebody to do so when he/she was still in a competent state. Hence, self-paternalism comes into play when the advance directive and surrogate decision standards are concerned in cases of euthanasia. The afore-mentioned cases of the 'Happy Alzheimer's patients' constitute typical examples of self-paternalism if their prior decisions and wishes, as expressed in advance directives, are complied with. The special feature of self-paternalism is that the incompetent person him-/herself has authorized persons to act in a specific soft paternalistic manner in the event that he/she becomes incompetent. Taken together, when putting the relationship of well-being and autonomy in concrete terms one can say that soft paternalism in the form of self-paternalism plays a role in discussions on euthanasia whereas hard paternalism is rarely involved. On the contrary, substantial weight is given to the principle of respect for autonomy in cases of competent patients so that instances of hard paternalism are avoided. Hence, we can conclude that discrepancies between the implications of the principles of respect for autonomy and promoting individual well-being in terms of paternalism are not strongly represented in the discussions of euthanasia.

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[159] Translation by author. Original quote: 'Notwendige Bedingung für diese Paternalismusvariante sind aktuell geäußerte oder erkennbare Wünsche oder Absichten, … die nicht autonom sind.'

Possible relationships of autonomy and well-being

In order to clarify the role which well-being plays in the debate on euthanasia it is also worthwhile placing the axiological relationship of well-being and autonomy under scrutiny. Are both, well-being and autonomy, ascribed intrinsic value in the discussions or is one of the notions merely valued for the sake of the other? In order to shed light on our central interest at this point, the axiological relationship of well-being and autonomy, let us first of all scrutinize which reasons can be brought forward to justify why autonomy should be respected. Above all, two different reasons can be brought forward: 1. because of its *instrumental* value and 2. owing to its *intrinsic* value (cf. Buchanan and Brock 1990 and Schermer 2002). The following, first of all, portrays these two different approaches to the value of autonomy and, in a second step, classifies the value which is ascribed to autonomy in the debate on euthanasia against this background.

1. The instrumental value of autonomy: in following approaches which ascribe instrumental value to autonomy, autonomy is 'only valuable as an instrument to promote well-being' (Schermer 2002: 11). It is pointed out that this notion of autonomy and its relationship to well-being are based upon the assumption that competent individuals are in the best position to determine what will or will not promote their well-being and for this reason they should have the ultimate authority to evaluate their well-being. Their preferences resemble their best interests.[160] This view has received considerable attention under the heading 'the patient knows best' in medical contexts and constitutes a counter-movement to the long and powerful paternalistic tradition characterized by the idea that 'the physician knows best' what is good for their patients (cf. Buchanan and Brock 1990: 35). Thus, this approach relies on the notion that well-being has a clearly subjective nature. Various degrees of subjectivity can be distinguished: it could be based upon an utterly subjectivist stance in which at all three levels (the ontological, the evaluative and the epistemic level) well-being is viewed as exclusively subjective. In this case, the patient would *always* be considered the best judge in matters of his/her well-being. Alternatively, a view could be taken in which subjective dimensions of well-being are predominant at all three levels, but also objective dimensions play a sporadic role. This

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[160] Proponents of this view are for instance Edmund Pellegrino and David Thomasma (1988).

could lead to the conclusion that the person him-/herself is generally but *not always* the best judge in terms of his/her well-being and that there are instances in which others might be better judges. ‘This means that in as far as people’s choices do not promote their well-being, there is no reason to respect this right, so that interference with people’s choices becomes admissible.’ (Schermer 2002: 11) Thus, in following this approach if patients are not competent to make decisions which contribute to their well-being, there is no reason why their autonomy should be respected in these cases. One can maintain that the more clearly objective dimensions of well-being gain importance, the further autonomy drifts into the background. Hence, an approach which attributes instrumental value to autonomy and takes into account the objective dimensions of well-being is confronted with the protest that it is vulnerable to the problem of paternalism.

However, there is another slightly different view in which instrumental value could be attributed to autonomy when the promotion of well-being as the main goal is concerned. ‘This is the claim that making one’s own choices in itself contributes to a person’s good even if he does not always have the best knowledge of his own well-being, or of how to promote it.’ (Schermer 2002: 11-2) In this case a different, more objectivist concept of well-being is at stake: autonomy is viewed as one among various others on a list of components which promote individual well-being. Objective dimensions of well-being predominate especially on the ontological level. As Buchanan and Brock maintain ‘[t]his ideal of a self-determining agent presupposes the development of the capacities necessary for reflective choice. When these capacities are substantially limited or impaired, the value of choosing for oneself likewise is diminished because the ideal of the self-determining agent and the value it represents is less able to be realized.’ (Buchanan/Brock 1990: 39) Therefore, this approach is utterly vulnerable to paternalistic interventions.

2. Intrinsic value of autonomy: approaches which ascribe intrinsic value to autonomy refer to ‘the value that autonomy has in itself or for its own sake, as opposed to its being valuable for the sake of something else’ (Varelius 2006: 378). According to this approach, the value of autonomy is entirely independent of the value of well-being. The realization of autonomy is good in itself, regardless of whether or not it promotes individual well-being. Different notions of the intrinsic value of autonomy have been brought forward: Kantians, for instance, view the obligation to respect autonomy as a part of human dignity. John Harris derives the value of autonomy from the moral status of persons, who have the highest moral importance and value (cf. Harris 2003: 10). Proponents of the approach which attributes intrinsic value to autonomy maintain that especially in cases in which important decisions about our life have to be taken we want to make these decisions by ourselves and this is even the case when we believe that there are others who are in a better position to make the choice. 'Even when we believe that others may be able to decide for us better than we ourselves can, we often prefer to decide for ourselves.' (Buchanan and Brock 1990: 38) In following this concept of autonomy, patients should make their own choices irrespective of whether or not they have the best knowledge of their well-being. Thus, the approach requires that the autonomy of persons is always respected even if the patients have become incompetent and they themselves are not aware whether or not their autonomous choices are being respected.

Incidentally, it is interesting to note that John Harris views well-being as instrumentally valuable when attributing an intrinsic value to autonomy. 'We need welfare, broadly conceived in terms of health, freedom from pain, mobility, shelter, nourishment, and so on because these things create the conditions which not only maximize autonomy but also give autonomy minimum scope for operation.' (Harris 2003: 11) Hence, there is a third kind of relationship between well-being and autonomy attributing intrinsic value to well-being in order to promote autonomy. This opinion, however, appears to be rarely brought forward.

Putting the relationship of autonomy and well-being into concrete terms

After having dealt with the possible relationships between autonomy and well-being, in the following it is examined which relationship prevails in the above depicted arguments for AiD and FLT. Two observations can be made which suggest that most participants in the discussion act on the assumption that autonomy and well-being have an *intrinsic value* rather than being viewed as instrumentally valuable.

First of all, it is explicitly stated that *both* principles, the promotion of well-being and the respect for autonomy, are of central importance within the argument in favour of euthanasia. It does not appear to be the case that one of the two principles is merely valued for the sake of the other. Although both principles operate in tandem, the application of each of them has a very specific function. The principle of autonomy functions to ensure that it is the autonomous choice of the patient concerned to end his/her life. It thus provides a safeguard against paternalistic interventions, such as in a case in which a physician administers AiD in order to prevent the diminishment of a competent patient's well-being and the patient has not requested AiD. The principle of promoting well-being, in contrast, functions to ensure that the wish to die is brought about by the diminishment of the patient's well-being and not as a result of a sudden whim or random state of mind. The standards for AiD as applied in the Netherlands illustrate especially the way in which the principle of well-being sets limits to a patient's autonomy in terms of termination of life decisions. AiD is only administered if the patient is suffering unbearably and if this suffering cannot be alleviated by other means. Thus, the principle of well-being compliments the threshold concept of competence in as far as it presents a safeguard against misuse. Both principles set mutual limits in order to prevent different kinds of abuse or misuse. This observation suggests that although they operate in tandem both, autonomy and well-being, appear to be valued for their own sake and are, therefore, attributed intrinsic value.

However, there is a further observation which, above all, supports the thesis that in the debate on euthanasia intrinsic value is attributed to autonomy: it has been demonstrated earlier that the autonomy of the patient is also valued and respected by means of advance directives in cases in which he/she has become incompetent and is unaware of the fact that his/her autonomy is being respected owing to being in a vegetative state for example. In these instances, therefore, one could *not* argue that the autonomy of the patient is respected in order to promote the patient's well-being since respecting the patient's autonomy does not have a direct impact on the patient's current or future well-being.[161] This is at least the case if one takes an utterly subjectivist view in terms of well-being, which presupposes that the well-being of a person is only promoted if he/she perceives it in this way. An objectivist conception, in con-

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[161] It should be noted, however, that one could argue that the reassurance that a patient's autonomy will be respected even if they become incompetent has an impact on their present well-being when they are still competent. This is due to the fact that patients are not afraid of losing control over their life and the circumstances of their death if they should become incompetent.

trast, would allow for the fact that the well-being of the person concerned is promoted through respecting his/her autonomy although he/she does not perceive this. However, the results in the above elucidate that a strongly objectivist conception of well-being can be ruled out in the debate on euthanasia. Hence, standards such as advance directives, applied for incompetent patients in situations in which the question of FLT arises, indicate that autonomy appears to be valued for its own sake. Thereby, they provide us with further useful information in terms of the relationship between autonomy and well-being.

On the basis of the two observations it can, thus, be concluded that in the debates on euthanasia both autonomy and well-being are attributed intrinsic value. Although they both operate in tandem as an argument in favour of euthanasia their values are mutually independent and neither appears to have priority over the other.

Broadly speaking, the role of well-being is virtually as important as the role of autonomy within arguments in favour of euthanasia. Both are attributed intrinsic value and they enjoy a *nearly* non-competitive relationship. Well-being, therefore, appears to have a *dependent presence on an equal footing* with the notion of autonomy. However, as the following will illustrate the substantial weight given to the notion of autonomy leads to interference with the conceptual level in terms of well-being.

6.4.2. Predominance of subjective dimensions of well-being

The analysis provided in the above has made it plain that subjectivist dimensions predominate when the character of well-being is concerned within arguments in favour of euthanasia. In the discussions, much weight is placed on the fact that the patient has and should have the ultimate authority to evaluate and determine his/her well-being. However, a more careful scrutiny gives rise to the impression that different conceptual and theoretical aspects, which must be kept separate, are muddled up in the discussions and that some inconsistencies with regard to the conceptual level in terms of well-being are present.

Inconsistencies on the conceptual level of well-being

We have noted when dealing with the concepts of well-being concerned at the various levels that at the ontological level apart from subjective also intersubjective dimensions are concerned. The terms ‘pain’ and ‘suffering’ are used to refer to aspects which commonly diminish well-being particularly in the final phase of life. Although it is pointed out that attention needs to be paid to the fact that two patients in a similar terminal situation might experience it in an utterly different way, specific factors such as physical pain, mental degeneration and dependency are listed which are viewed as commonly causing suffering and therefore diminish individual well-being in this phase. This can especially be recognised by the fact that the best interest standard is applied in cases of incompetent patients in which their former preferences are unclear. As aforementioned, this standard is based on the assumption that the character of well-being has some kind of common denominator and that the nature of well-being is not utterly subjective. Thus, in order to remain consistent, the argument must follow that due to its intersubjective nature it is possible to evaluate well-being at least to a certain degree from a third-person perspective. This is, however, not often articulated. On the contrary, as shown and illustrated in the above quotations it is always emphasized in the discussion that at the evaluative and epistemic level, well-being is considered as completely subjective. This is not truly consistent and, furthermore, especially with respect to the evaluative level this is only a half-truth. First of all, in order for the patient’s subjective evaluation of his/her well-being to be taken seriously there are certain formal objective criteria derived from the notion of autonomy which need to be fulfilled. For instance, he/she needs to be competent. In addition, specific and substantial criteria come into play since the pain and suffering need to have convincing causes in order to be considered as legitimate reasons for administering euthanasia. Thus, the evaluation of pain and suffering is not viewed as a completely subjective endeavour. This, above all, becomes obvious in the paradigmatic euthanasia conditions we have been dealing with in the previous section on the two examples of assistance in dying in practice. As have been shown in the Netherlands the suffering should predominantly result from a medically classifiable disease or disorder (cf. Buiting et al. 2008: 1) in order to justify euthanasia or assisted suicide. Let me clarify the impact of this restriction through an example: 70 year old Mrs B. lost her husband two years ago and has considered her well-being to be severely diminished ever since despite not having any medically classifiable illness. Her life with her husband was of such value to her that nothing can now replace this and consequently she considers herself to be in a state of great suffering with no prospect of improvement. On these grounds she requests PAS. This is an instance in which the administration of PAS is not considered legitimate in the Netherlands (or elsewhere where PAS has been legalized). Her suffering does not constitute a sufficient reason for PAS since she has no medically classifiable illness causing it and she is not in a final stage of life. Thus, it becomes evident that the notion of suffering in the Dutch context of euthanasia is not taken to be entirely subjective. There are objective dimensions in terms of the evaluation of well-being involved and these place limitations on Mrs. B.'s potential to act or request assistance in putting her wishes into action.[162] This is not only the case where assistance in dying in practice is concerned, but also in the theoretical discussion on the legalisation of these procedures.[163] All in all, it appears as if objective dimensions of well-being play a larger part than hitherto supposed. Proponents of euthanasia invest much effort in attempting to conceal this fact either consciously or unconsciously. What is the reason for this? And why does subjectivism finds more favour than objectivism in discussions on euthanasia?

The interference of the principle of autonomy with the concept of well-being

As we have just ascertained, autonomy is attributed an intrinsic value when referred to in arguments for euthanasia. It plays a primary role in order to exclude heteronomous influences where euthanasia is concerned. This primary role is continually emphasized. This is especially due to the fact that during the Nazi era *involuntary euthanasia* was justified by referring to the allegedly reduced quality of life of those concerned. Thereby, from a third person perspective, the lives of human beings were classified as 'worthless lives' in contrast to 'worthwhile lives'. Ever since then objective evaluations of the quality of life or well-being, which do not take into account the perspective of the person concerned have been brought into disrepute. This provides a major reason why so much emphasis is placed on the patients' autonomy in the debate on euthanasia. On the normative level it is always maintained that the well-being of the

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[162] My sincere thanks to Peter Schaber for making me aware of this problem by means of this example.

[163] There are of course some exceptions. John Harris, for instance, argues that we should refrain from formulating any additional condition which place limitations on a patient's potential to undergo AiD. The patient should have the ultimate authority to decide.

patients concerned *should* not be determined externally. It is the patient's own personal perspective of their well-being which *ought* to count. However, this normative level should be separated from the question whether the nature of individual well-being is subjective or objective (the conceptual level). The impression arises that this does not always happen in the debate: the different levels, the normative level and the conceptual level, become muddled. Rather than merely stating that well-being *should* not be determined externally, it is maintained that the determination of individual well-being *is* a completely subjective endeavour. This has been illustrated by the quotations in the above such as the quotation by Veatch: '[d]eciding that the benefits [of continuing living] are proportionate requires the inherently nonmedical determination of how valuable it is to continue living. It should be obvious that these are judgments that no outsider should be able to make.' (Veatch 1989: 82) This quotation confuses two divergent statements: 1. No outsider *should* determine how valuable it is to continue living. 2. No outsider is *able to* determine how valuable it is to continue living. Whereas the former is a normative statement, the latter statement refers to the conceptual level of well-being, namely the epistemic level. Both statements operate on different levels which must be kept separate. This is, however, rarely done in the discussions on euthanasia. Hence, the aforementioned inconsistencies on the conceptual level arise because of the interference of the normative level with the principle of autonomy. Especially proponents of euthanasia appear to avoid objective dimensions of well-being due to the fact that the more objectivist the concept of well-being becomes, the more prone it is to heteronomous influences which are to be avoided especially when euthanasia is concerned.

However, it is of central importance to keep the *normative level* and the *conceptual level* in terms of well-being separate. Respect for autonomy leads to the fact that the competent patient has the ultimate authority to determine his/her wellbeing, but this should not be confused with commitments on the conceptual level stating (with regard to the epistemic level) that the patient him- or herself is the best judge of his/her well-being.

6.5. Findings in respect of the role of well-being in the discussions concerning the end of life

The analysis has shown, above all, that well-being plays a *prominent* role in debates on the end of life. The concept is a widely applied point of reference in arguments in favour of euthanasia. This finding can be maintained in both discussions on assistance in dying in the case of competent patients, as well as in debates on foregoing life-sustaining treatment in the case of incompetent patients. Nonetheless, it should be emphasized that the prominent role of well-being in these discussions is not as easily recognisable as in the enhancement-debate. The results of the examination suggest that there are manifold reasons for this. As in the case of the debates dealing with the beginning of life, it is essential to differentiate between the overt and the subliminal presence of well-being, which provides us with a second reason why the prominent role of well-being is not so easily recognisable. The results of the analysis clearly indicate that well-being has an *overt* as well as a *subliminal* status in debates on euthanasia. Within arguments in favour of euthanasia, well-being has its position *alongside autonomy*. Both are of central importance, are attributed intrinsic value and, as illustrated, operate in tandem. The analysis has revealed that autonomy is often given pride of place whereas the importance of well-being is disregarded. In these cases well-being has a subliminal presence. This is particularly true of debates in Germany.

Further instances of the subliminal presence can be found in the above-depicted well-being-based lines of reasoning concealed behind the *death with dignity* arguments, which are considered as more socially accepted. As already suggested, the subliminal presence of well-being behind arguments which refer to autonomy or a death with dignity appears to rest upon negative and traumatic experiences in which human lives were classified as ‘worthless lives’ in contrast to ‘worthwhile lives’ during the Nazi era. Thus, it becomes evident that there are many similarities to the role of well-being in the discussions at the beginning of life, where estimations of the QoL are a sensitive issue. Hence, above all, in German discussions well-being is not explicitly mentioned but implicitly referred to.

A major result of the analysis with regard to the character of well-being constitutes the *predominance of subjective dimensions*. This finding forms a stark contrast to those in the debates on enhancement and organ allocation, where we have ascertained a predominance of objective dimensions. However, it has been shown that the concepts of well-being under consideration in the discussions on euthanasia are not totally subjective and that also *intersubjective* dimensions are involved, which are based on the assumption that there are socially shared notions of what promotes or diminishes our well-being. This is especially the case in instances of incompetent patients when the question whether to forego life-sustaining treatment arises and the best interest standard is applied. The findings illustrate that the debate is mainly concerned with the *evaluative* and *epistemic level* with regard to well-being. Moreover, the investigation has revealed that inconsistencies exist on the conceptual level with regard to well-being. The underlying intersubjectivism, especially if incompetent patients are concerned, is not compatible with the radical subjectivism found within many arguments in favour of AiD where patients are competent. It has been shown that the concept of well-being is influenced by the major role which autonomy enjoys in discussions on euthanasia. This influence of autonomy could be described as an interference. This finding supports the already existing impression that the concept of well-being appears to be vulnerable to influences from other dominant notions and principles in biomedical ethics.

An additional observation is the fact that in debates on euthanasia a concept of well-being is used which is *broader* in comparison to the narrow concept applied in organ allocation, but can only be described as *narrower* in the face of the very broad concept of well-being which finds application in the enhancement debate. Hence, the concept of well-being under consideration in the (theoretical) discussions on euthanasia refers to health-related aspects of well-being, albeit in a broader sense. The debate is, above all, concerned with the protection of well-being. This protection is accomplished through the prevention of the major diminishment of well-being due to pain and suffering and also by the provision of the prospect that patients can determine an end to their suffering if it becomes unbearable. Having analysed the role of well-being in the final phase of life within this chapter, the journey has now come to an end. The task now is to recapitulate all the findings with regard to the role of well-being in the various debates in biomedical ethics.

7. Rethinking well-being in biomedical ethics – synopsis of the observations and issues raised by the analysis

It has been expounded in the introduction to this book that, although the concept of well-being seems to be an important point of reference within the field of biomedical ethics (and also in the general realm of ethics), there is not a suggestion of agreement as to what well-being actually is. This, as illustrated, constitutes a major problem since the notion of well-being comes into play where decisions with far reaching implications are taken. There is a need for both a common language and for clarification in terms of the concept. A vital step in achieving clarification with regard to the understanding of well-being is to establish a critical analysis of the present state of affairs concerning the role of well-being in biomedical ethics, which the previous chapters provided. All in all, the detailed exploration of the four debates has provided a varied and colourful tapestry of the presence and character of well-being within the extensive field of biomedical ethics. This chapter draws the threads together and takes stock of the results gained through the analysis in the four debates.

In the course of the examination it has become obvious, step by step, that rather than playing one specific role, well-being has various roles and manifold facets in the realm of biomedical ethics. It has gradually emerged that the concept of well-being is subject to the influence of other principles and notions prevalent in the various debates, that is to say the notions of moral status and human nature as well as the principles of justice and autonomy. These have a major impact on the presence of well-being in the discussions and on its very character. To put this in tangible terms: one main finding of the analysis provided in this book is that rather than playing an independent role, well-being strongly depends on the other principles and notions which are prevalent in the respective debates. The results illustrate that the dependence occurs on both levels, the level concerning the presence of well-being and the level dealing with the character of well-being.

7.1. The influence of predominant notions on the role of well-being

The results of our analysis clearly indicate that the concept of well-being enjoys a shifting presence in the respective bioethical debates and that it has an unstable character, which differs from debate to debate. It appears, however, that this variation in terms of presence and character is not a result of chance and rather that it has an underlying pattern. This section aims to extrapolate this pattern. As mentioned in the above, our findings appear to suggest that the role (that is to say: presence and character) which well-being plays in biomedical ethics is strongly influenced by the other predominant notions in the respective debates. The following aims to elaborate on this finding and to provide a clearer picture of it. We concentrate, first of all, on the influences which occur with regard to the *presence* of well-being in biomedical ethics. Another major part of this section examines the changing character of well-being with regard to its subjectivity and objectivity and the way in which it is determined by the other predominant notions.

7.1.1. The shifting presence of well-being in biomedical ethics

The examination of the four bioethical debates has shown that in each of them the concept of well-being is involved in a relationship with another prevalent notion. Nonetheless, the relationships which well-being cultivates with these are of an utterly different kind. First of all it is fruitful to recapitulate on these various kinds of relationships and then, in a second step, deal with the influence of the notions on the presence and character of well-being.

The presence of well-being in the face of other prevalent notions

Over the course of our analysis we have ascertained that the concept of well-being is involved in a special relationship with the notion of *moral status*. This was clearly indicated by our findings in the examination concentrating on the role of well-being in debates on prenatal testing and selective abortion. It has been shown that the question dealing with the moral status of prenatal entities is superordinate to the query as to the impact of illness and disability on the future child's well-being. As illustrated in chapter 3, it is important that participants in the debate expound the stance they take in terms of moral status before they address the topic of the well-being of future children, otherwise one is not in a position to grasp the implications of their well-being-based arguments. Hence, the consideration of well-being within debates on prenatal testing and selection heavily *depends on* the specific stance taken with regard to prenatal moral status. Thus, the concept of well-being has a *subordinate presence* in the face of the notion of prenatal moral status.

The findings have indicated that the relationship of the concept of well-being and the notion of *human nature* in the debate on mood enhancement is of a similar kind: although not always explicitly indicated, the notion of human nature is ascribed intrinsic value whereas the concept of well-being is attributed derivative value and strongly depends on the notion of human nature. We have, therefore, concluded in chapter 4 that the concept of well-being has a subordinate presence taking a back seat to the notion of human nature.

In the context of organ allocation, it has been extrapolated that the concept of well-being has a very close relationship with the notion of *justice*. To be more precise, well-being is deeply involved in the dispute of alternative principles of justice, namely utilitarian and egalitarian principles of justice, which in turn derive from different ethical traditions. The concept of well-being occurs within utilitarian and egalitarian approaches to the problem of organ allocation and can, therefore, be classified as having an *embedded presence* within alternative principles of justice. Hence, the consideration of well-being *strongly depends* on the alternative principles of justice.

In addition, it has emerged that the relationship of autonomy and well-being is important in the realm of biomedical ethics. This, above all, became obvious in our findings in chapter 6 dealing with the role of well-being in discussions concerning the end of life. We ascertained that in discussions dealing with euthanasia, autonomy and well-being operate in tandem and are both ascribed intrinsic value. On the grounds of our findings, well-being can be considered to have a *dependent presence on an equal footing* with autonomy in discussions at the end of life. It has also been illustrated in chapter 3 that the relationship of well-being and autonomy is likewise of importance in discussions dealing with prenatal testing and selection where the prospective parents are concerned. Nonetheless, it should be noted that in these instances the relationship of autonomy and well-being is of a different kind. The reference to the reproductive autonomy of the parents is superordinate to the consideration of their (the parents') well-being. Hence, as in the case of moral status, well-being can be classified as having a *subordinate presence* in the face of reproductive autonomy.

All in all, we can maintain that the relationship between well-being and other notions and principles not only depends on the other notion under consideration but also varies greatly from debate to debate as the example of the relationship between well-being and autonomy illustrates. As a result, there is great variation with regard to the presence of well-being in the face of other prevalent notions. Keeping this in mind, we will now turn to our central point of interest, that is to say, how the other notions influence the role of well-being in biomedical ethics.

An overt versus a subliminal presence of well-being

During the course of our analysis we have observed that the notion of well-being alternates between possessing an *overt* and a *subliminal* presence. Where well-being is considered in the debates on enhancement and organ allocation, it is overtly referred to and its presence within the lines of reasoning is directly recognisable. However, matters are more complicated in the discussions dealing with the beginning and end of life. Here the presence of well-being is, in turn, overt and subliminal. Where well-being plays a subliminal role, the reference to the concept is sometimes hardly recognizable. With regard to the discussions on prenatal testing and selection, it should be noted that the concept of well-being has, above all, a subliminal presence where the prospective parents are concerned. Generally speaking, the subliminal presence of well-being does not appear to correlate with the relevance (prominent or subordinate presence) which the concept has in the respective debates. It has, for instance, been shown that in the debates on organ allocation well-being has an overt presence although it merely plays a subordinate role. Hence, where well-being comes into play in the context of organ allocation, it is mentioned explicitly although it does not play a prominent role in general. In the debates dealing with the beginning and the end of life, in contrast, we have learned that well-being plays a prominent role but sometimes has a subliminal presence. For this reason there appears to be no connection between the weight given to consideration of well-being in the debate and its partly subliminal presence. But what are the underlying reasons for the sometimes subliminal presence of well-being and why does it only occur in the debates dealing with the beginning and the end of life?

It has already been suggested in the previous chapters that quality of life estimations, especially in the context of reproduction and euthanasia, provoke recollections of the atrocities which took place during the Nazi era, such as the eugenic programs and mass murder. These were justified by the reference to the classification of ‘worthless lives’ as against ‘worthwhile lives’. Especially in the German bioethical discussions, participants in the debate are very careful since they want to avoid their arguments being associated with the lines of reasoning brought forward by the Nazis. As elucidated, this is clearly mirrored by our findings concerning the role of well-being in the discussions dealing with the beginning and end of life. Furthermore, it provides us with an explanation as to why the concept of well-being, above all, has a subliminal presence within the German debates on these matters. However, it should be noted that the subliminal presence of well-being in discussion on prenatal testing and selection, above all, occurs where the prospective parents are concerned. These well-being based lines of reasoning have little to do with the negative recollections of Nazi atrocities. There does, therefore, appear to be another reason as to why well-being has a partly subliminal presence in the debates dealing with the beginning and the end of life.

The subliminal presence of well-being and the ‘triumph of autonomy’

If we examine where exactly the concept of well-being shifts into a subliminal role we can recognize that this frequently happens when it occurs together with the principle of autonomy. It has been shown that in these instances the reference to the principle of autonomy conceals the consideration of well-being. Thus, there seems to be a connection between the subliminal presence of well-being and the reference to autonomy. It is striking that this only appears to hold true for the relationship between well-being and autonomy and not elsewhere. In contrast, in the case of prenatal testing and selection, we have observed that the consideration of the future child’s well-being is even put forward as an alleged argument to conceal the reference to the notion of prenatal moral status since it is often considered as conservative and ‘old-fashioned’. The same holds true for the role of well-being in the debate on mood enhancement. The reference to well-being is placed in the foreground although the notion of human nature is at the core of the opposing arguments and well-being merely has a subordinate presence. Hence, in these cases the situation is reversed: well-being is in the forefront and moral status and human nature have a subliminal presence behind it, although, as shown, the reference to both notions constitutes the main part of the respective arguments.

Yet, why does the presence of autonomy in discussions lead to the subliminal role of well-being? If one studies the latest developments in the field of biomedical ethics, above all in the liberal Western tradition, one rapidly realizes that the principle of respecting autonomy has gained major importance. Some authors even go as far as to talk about a 'triumph of autonomy' in biomedical ethics (Wolpe 1998 and Beauchamp 2006). The principle of autonomy is highly respected in general, but most especially in the realm of biomedical ethics and is considered a powerful argument. Elisabeth Hildt points out that '[t]he argument of autonomy is frequently considered so strong and of such intuitive plausibility that it is accepted without further questioning' (Hildt 2002: 65). Although they constitute an important point of reference, well-being based lines of reasoning can obviously not be considered to have such a high standing within biomedical ethics. In contrast, as portrayed in chapter 6, the notion of well-being is often associated with medicine's long and problematic tradition of paternalism, in which the patient's preferences or actions were overridden by the physician for the sake of the patient's well-being. Thus, within bioethical discussions participants in the debates have good reason to place the principle of autonomy in the foreground while permitting the consideration of well-being to recede into the background. As a consequence, if the concept of well-being occurs together with the principle of autonomy it often takes a backseat and, therefore, it has a subliminal presence in these cases. It has been illustrated that the concept of well-being is present in different ways in the face of autonomy in the debate dealing with the beginning of life as opposed to the discourse on the end of life. Whereas well-being has a subordinate presence in the face of autonomy in the discussions on prenatal testing and selection, in discussions on the end of life it enjoys *a presence on an equal footing* with autonomy. Nonetheless, well-being has a subliminal presence in both debates. Hence, the subliminal presence of well-being does not appear to depend on the kind of relationship it has to autonomy in the respective debates. Due to the high standing of the principle of autonomy, well-being seems rather to recede into the background whenever both (well-being and autonomy) occur together within an argument.

In conclusion, it can be maintained that the presence of well-being within biomedical ethics, that is to say, whether it has a subliminal or overt presence, strongly depends on the other notions with which it occurs in the discussions as well as the specific standing of the respective notion under consideration. If the other notions have a very high standing within the field of biomedical ethics, such as the principle of autonomy, well-being is likely to have a subliminal presence. If, in contrast, the notion or principle with which well-being occurs has a comparatively ‘low’ standing or is viewed as old-fashioned such as the notions of moral status and human nature, the consideration of well-being is likely to be placed in the foreground within the arguments in order to conceal the alleged weaker line of reasoning.

It has already been suggested in the above that the other predominant notions not only influence the presence of well-being but also its character within the various debates in the field of biomedical ethics. The subsequent section sheds light upon this finding.

7.1.2. The changing character of well-being in the debates

One further significant observation during the course of our analysis is the finding that the notion of well-being has a changing character in the various discussions. It is clearly recognizable that the concept of well-being hovers between *subjective* and *objective* dimensions in the four debates. In the discussions dealing with prenatal testing and selection, we have extrapolated that there is tension between subjectivist and objectivist conceptions where the future child’s well-being is concerned. A striking prevalence of objective dimensions of well-being was identified in the debates dealing with mood enhancement and organ allocation. Within the discourse on the subject of euthanasia, in contrast, we discovered a predominance of subjective conceptions of well-being. However, the close examination of the respective prevalent conceptions of well-being within the specific bioethical discussions revealed that that the alternative conceptions of well-being do not have an arbitrary occurrence within the various debates. Within each of the four discourses it was possible to extrapolate specific reasons for the predominance of the respective subjective or objective conceptions of well-being. In all of the four debates the reasons identified were strongly associated with the respective other predominant notions. They appeared to determine, at least to a certain degree, whether subjective or objective dimensions prevailed in each discourse.

Connections between the prevalent notions and the changing character of well-being

In the discussions on prenatal testing and selection we have discovered that there is a strong connection between alternative attitudes with regard to prenatal moral status and the specific conceptions of well-being which are purported. Whereas thinkers who take a liberal stance with regard to prenatal moral status and argue in favour of prenatal testing and selection tend to base their arguments on objective conceptions of well-being, conservative thinkers in terms of moral status, tie their lines of reasoning to subjective approaches to well-being in order to argue against the permissibility of these procedures. We have, however, identified the latter well-being based lines of reasoning as *alleged* arguments since in their core they rest upon the notion of a full prenatal moral status. Hence, we can conclude that subjectivist conceptions are *instrumentalised* within the argumentations of critics of prenatal testing and selection.

In the debate on mood enhancement it has been concluded that the predominance of objectivist concepts of well-being results from the weight and value given to the notion of human nature by both proponents and opponents of the procedures in question. Both have been classified as taking an essentialist stance with regard to human nature. Since essentialist conceptions of human nature are objectivist, it does not come as a surprise that proponents as well as opponents of mood enhancement tie their arguments to objective conceptions of well-being. There appear to be *requirements,* deriving from the notion of human nature which they purport, to the concepts of well-being under consideration.

The predominance of objective conceptions of well-being in the context of organ allocation has been attributed to the importance which the principle of justice has within this field. In chapter 5 it was illustrated that the subjective evaluation of well-being cannot be the decisive factor where donor organs are allocated since subjective dimensions are vulnerable to the problem of expensive tastes and partial. Impartiality is a central aspect of distributive justice. As a result, the weight given to the notion of justice within the context of organ allocation *requires* that objective conceptions of well-being are prevalent.

In the discussions dealing with the end of life, the utterly subjectivist stance taken with regard to the character of well-being has been identified as resulting from *interferences* from the principle of autonomy. This has been suggested by inconsistencies which have been extrapolated with regard to the conceptual level of well-being: the radical subjectivism found within many arguments in favour of euthanasia has been shown to be inconsistent with the underlying intersubjectivism which is noticeable, especially where incompetent persons and the best interest standard are concerned. It has, above all, been pointed out that the normative level and the conceptual level in terms of well-being become confused and that they should preferably be kept separate.

Taking all these findings into consideration, we can maintain that, also with regard to its character, the concept of well-being is subject to influences from the other predominant notions. These influences appear to be the reason underlying the observation that the concept of well-being hovers between *subjective* and *objective* dimensions in the four debates. In each debate the character of well-being is, to a varying degree, determined by the respective predominant notion. Nonetheless, the impact on the character of well-being which derives from the respective notions in the various debates is each of a different kind. With regard to the influence of the notion of moral status in the discussions on prenatal testing and selection, it has been revealed that this can be classified as an *instrumentalisation* of the character of well-being. In the case of the principle of autonomy in the debate on euthanasia, the influence can be considered an *interference*. The impact of the notions of human nature and justice on the character of well-being within the contexts of mood enhancement and organ allocation is of a different kind: it has been revealed in the above that well-being has a subordinate presence in the face of human nature and an embedded presence within alternative principles of justice. In order for the concept of well-being to be compatible with the notions of human nature and of justice, well-being is required to have a character which is based upon objective dimensions. Hence, if well-being is to have a subordinate presence in the face of human nature or is to be embedded within the principle of justice, there is an *objectivity requirement* which it needs to fulfil.

Well-being – a chameleon in biomedical ethics?

On the grounds of these findings, the impression could arise that the character of well-being within biomedical ethics resembles the behaviour of a chameleon which adjusts its skin pattern and colour to correspond with its surroundings. In the case of the chameleon the colour change can obviously be considered a good thing since it has the function of camouflage which protects the animal from predators. However, in the case of the 'colour change' of well-being within biomedical ethics, things appear to be a bit different. Rather than being an advantage, the colour change of well-being brings a problem to our attention: the character of well-being can be considered vulnerable to external influences such as the impact of other predominant notions. Above all the kinds of impact which have been classified as *instrumentalisations* and *interferences* can be considered troublesome since they provoke an illusion that conceals the actual essence of well-being. They pass off attributes as components of the character of well-being which do not really belong to it but derive from other notions, thereby creating a 'false' character of well-being. Furthermore, if well-being is applied in a way in which it solely operates for the sake of other notions, one could argue that the concept itself is hollow and merely 'swimming with the tide'. Influences which can be classified as requirements, in contrast, appear to be of a different kind. They express specific needs which must be met if well-being occurs in connection with the notion under consideration. They do not provoke illusions of the character of well-being but appear to bring us closer to the 'true' character of well-being within biomedical ethics. It has already been portrayed in the introductory parts to this book that the character of well-being is rather vague within the field of biomedical ethics and also in general. The finding that the concept is vulnerable to instrumentalisations and interferences fits in with this vagueness. Nonetheless, the results do indeed suggest that the character of well-being is not totally subject to instumentalisations and interferences deriving from other notions within biomedical ethics. There are some other characteristics of well-being which cannot be attributed to the impact of other prevalent notions, as the results of our analysis show. These might be of assistance in clarifying the 'true' character of well-being in biomedical ethics. However, in order to rule out the possibility that these characteristics also result from interferences or instrumentalisations, we must examine their provenance. Thus, a more detailed exploration of these other traits is essential to attain the goal of *rethinking well-being within biomedical ethics* and is provided in the following section.

7.2. Attempts in revealing the 'true' character of well-being in biomedical ethics

So far we have ascertained that the character of well-being with regard to its subjectivity or objectivity is strongly influenced by the other notions predominant in the various debates within biomedical ethics. Impacts which we classified as interferences and instrumentalisations have been considered troublesome whereas impacts of the kind of requirements, in contrast, do not appear to provoke illusions but rather express specific needs which must be fulfilled if the concept of well-being is to be applied. As our findings suggest, there are further characteristics (apart from the subjective and objective dimensions) belonging to the notion of well-being such as the breadth of the concept, the consideration of alternative levels and the reference to the restoration, the protection and the promotion of well-being within biomedical ethics. In order to accomplish the endeavour *of rethinking well-being within biomedical ethics*, it is important that these other findings are also placed under scrutiny. We need to investigate whether these characteristics of well-being result from either instrumentalisations and interferences or requirements. This might help to identify further illusions and brings us closer to what could be considered the 'true' character of well-being if they can be identified as requirements.

Ontological, epistemic and evaluative level

The results of the analysis of the character of well-being against the background of the subjective/objective scheme of alternative levels provided in chapter 3 indicate that the reference to well-being within the realm of biomedical ethics occurs on the ontological, the epistemic and the evaluative level. However, a striking observation that we have made in the course of our journey through the four different debates is, that each debate has a different focus with regard to the three alternative levels. Discussions dealing with prenatal testing and selection have been identified as, for the most part, addressing the *epistemic level*. As portrayed in chapter 3, this level is concerned with the question of who has the best access to individual well-being. The major contentious issue between proponents and opponents is the question as to whether we can anticipate the well-being of future children, especially in cases in which they will have/have a disabling condition.

The debate on mood enhancement, in contrast, is mainly concerned with the *ontological level* in dealing with the essence of well-being. Proponents and opponents of mood enhancement have been proven to have different notions of the essence of well-being. They purport different objective conceptions of well-being with regard to the ontological level.

Discussions with regard to well-being in the context of organ allocation mainly operate on the *evaluative level* focusing on appropriate criteria for the estimation and comparison of the well-being of potential recipients who are waiting, as well as competing, for a graft. This is due to the fact that, generally speaking, the discourse on organ allocation is a debate on appropriate criteria for the distribution of grafts.

Both the evaluative and the epistemic level with regard to well-being are of central interest in discussions on euthanasia. Rather than dealing with the essence of well-being, participants in the debate place great emphasis on the fact that the well-being of patients at the end of life should be evaluated by means of subjective criteria because only the patient him-/herself has access to his/her well-being.

Taken together, all of these levels appear to constitute dimensions of the character of well-being. But what exactly determines which level is to predominate in the respective debates and are these dimensions components of the ‘true’ or ‘false’ character of well-being? Instead of resulting from the impact of other prevalent notions, these alternative levels of the consideration of well-being appear to be linked to the specific content of each debate. The content of a discussion encompasses the material facts under discussion as well as ethical aspects dealt with. If we take, for instance, the debate on organ allocation, the fact that this discourse is, mainly, concerned with criteria for the allocation of grafts and measures to put these criteria into operation results in discussions with regard to the concept of well-being which operate for the most part on the evaluative level. In each discourse the level on which well-being is considered results from the specific issues under discussion, that is to say its content. Therefore, the contents of the respective debates appear to have an impact on the character of well-being by determining the level at which well-being is discussed.

However, here the impact cannot be classified as an *instrumentalisation* or *interference*. The content of each debate rather seems to place specific *requirements* on the character of well-being to be a fruitful point of reference. If well-being does not fulfill the demands placed upon it by the content, it simply is not applicable to the context under consideration. Hence, if the concept of well-being is not open to the question e.g. 'who has the best access to individual well-being' (epistemic level), a discussion about prenatal testing and selection serves no purpose. Obviously, the same holds true for both other levels. Thus, the three alternative levels can be viewed as part of the 'true' character of well-being.

Broad versus narrow concepts of well-being

Within the four debates we have encountered both *broad* and *narrow* conceptions of well-being. It has been shown that, above all, in the enhancement debate a comparatively broad approach to well-being is taken, which is by no means limited to health-related aspects. The dimensions of well-being under consideration extend far beyond the reduction of pain and suffering and encompass aspects such as social relationships, love attachments and career fulfilment. The approach to well-being predominant in the enhancement debate can, for this reason, be classified as a broad concept of non-health related well-being. The approach to well-being concerned in the context of organ allocation, in contrast, is strikingly narrow. As the examination provided in chapter 5 has shown, the notion of well-being under consideration is, for the most part, based upon a limited number of health-related aspects. Truncated conceptions such as narrow models of 'species typical functioning' frequently come into play. A narrow conception of health-related well-being is referred to.

Discussions dealing with the beginning and end of life are tied to a concept of well-being lying between the two poles. Notions of well-being in these debates are not as broad as those concerned in the enhancement debate and not as narrow as approaches to well-being applied in the context of organ allocation. The dimensions of well-being under consideration in discussions on prenatal testing and selection and the subject of euthanasia are, for the most part, directly related to health. Instances of this are the future child's freedom from pain and suffering, but also the desire of patients at the end of life for intellectual participation in the world. Hence, a concept of health-related well-being of average breadth is applied.

In conclusion, it appears to be the case that also the breadth of the concept of well-being under consideration in the respective debates is determined by the specific content dealt with in the discussions. Therefore, the contents of the various debates also appear to have requirements with regard to the breadth of the concept of well-being. In order to gain a more vivid picture, two examples might be helpful: as illustrated in chapter 4, the enhancement debate is inherently concerned with aspects which extend beyond the protection and restoration of health. Hence, where well-being is concerned in the debate, dimensions of it are referred to which are not limited to the protection and restoration of health-related well-being. The content of the enhancement debate, therefore, determines which dimensions of well-being come into consideration. It requires a comparatively broad concept if well-being is to be applied. Also the context of organ allocation appears to have specific requirements with regard to the breadth: discussions on organ allocation focus on appropriate criteria for the distribution of grafts. The concept of well-being is referred to within these discussions on appropriate criteria. As shown in chapter 5, if the concept of well-being is to play a role within the criteria for organ allocation, it needs to be an operational measure. It has been shown that narrow concepts of well-being facilitate the operationalizability and application of well-being and are, for this reason, required where organ allocation is concerned. Also in debates on the beginning and the end of life, the contents under discussion determine what is to be understood as well-being. Since these debates are mainly concerned with health-related issues, health-related well-being comes into play. On the grounds of these elaborations, we can assert that this flexibility in breadth is an integral part of the 'true' character of well-being. However, the findings illustrate that there are still even more characteristics of well-being within biomedical ethics.

The restoration, protection and promotion of well-being

It has been extrapolated that negative as well as positive dimensions of well-being are referred to in the various debates, that is to say, the field of biomedical ethics is concerned with the *restoration*, the *protection* and the *promotion* of well-being. These three dimensions of well-being come into play to different degrees in the various debates. Discussions on prenatal testing and selection deal, above all, with the protection of well-being. The well-being of the prospective parents is to be protected by avoiding unwanted childlessness or the burdens of raising a severely disabled or ill child, also the well-being of future children is said to be protected by preventing the birth of children who have a comparatively low prospect of a good life due to disability and illness. Nonetheless, the promotion of well-being comes into play sporadically, too. This is the case when it is argued that procedures of prenatal testing and selection enable parents to fulfil their dearest wish for a biological child and also within the arguments of the so-called procreative perfectionists such as Harris and Savulescu, who argue that parents should select for the child with the *best* opportunity of a good life. Within the enhancement debate it is abundantly clear that the major concern is the promotion of well-being since, as mentioned in the above, it is inherently concerned with dimensions of well-being which extend beyond the restoration and protection of health. Conversely, deliberations in the context of organ allocation primarily focus on the restoration of well-being when distributing donor organ to patients in need who have a poor health status. Nonetheless, in discussions on organ allocation also the protection of well-being constitutes a consideration when the future well-being of patients if they do not receive a graft is taken into account. The debates at the end of life can, for the most part, be classified as focusing on the protection of well-being by preventing its substantial diminishment and furnishing the patients with the feeling and prospect that they can determine an end to their suffering if it becomes unbearable. On the grounds of these findings we can ascertain that also with regard to characteristics such as the restoration, protection and promotion of well-being, the respective contents of the four debates place requirements on the dimensions of well-being which come into play.

On the basis of this detailed representation of the findings, we have managed to come closer to the ‘true’ character of well-being within biomedical ethics. This is due to the fact that the characteristics have been identified as resulting from *requirements* (and not interferences or instrumentalisation) which derive from the contents of the four debates. Characteristics such as the breadth of the concept or the level of consideration are determined by the content of the specific discussion under consideration. Where the content exercises influence on the concept of well-being, there do not appear to be cases of interference or instrumentalisation. At this point it is important to emphasize once again that what is considered to be the ‘content’ of a discussion does not encompass the notions or principles referred to in the debate but must be regarded as being separate from it. As a consequence of these elaborations, it can be concluded that the character of well-being is constantly subject to influences within biomedical ethics. These influences derive either from other predominant notions in the discussions or from the specific content of the respective debates. However, it has already been argued in the above that it is vital to differentiate between the various kinds of influences to which well-being is exposed. Some of the influences which derive from the other predominant notions have been identified as instrumentalisations and interferences. These have been considered troublesome since they dilute what is considered to be the essence of well-being. They steer away from the ‘true’ character of well-being since they merely provoke illusions. The other influences, in contrast, which derive from the contents of the discussions and the notion of justice and human nature are of a different kind. They are indeed of assistance in reaching the goal of rethinking well-being in biomedical ethics. This is due to the fact that they provoke no illusions but rather express specific requirements which the realm of biomedical ethics makes on a concept of well-being. If well-being is to occur within these contexts and in connection with the specific contents, it needs to possess the characteristics we have extrapolated. If this is not the case the concept of well-being would be rendered inapplicable to the contexts concerned and to the field of biomedical ethics in general. The findings, therefore furnish a first insight into the development of a concept of well-being that actually is applicable to the realm of biomedical ethics. The following provides an outlook about what the findings might tell us with regard to this matter. However, the complete revelation of the ‘true’ character of well-being can be considered a huge task which cannot be completely accomplished within the frame of this book. Nonetheless, the above has furnished some initial steps in this direction.

7.3. Tentative requirements for a concept of well-being in biomedical ethics – an outlook

The present book has concentrated on the role of well-being in biomedical ethics. This is expressed in the main goal of *rethinking well-being in biomedical ethics*. The journey through the various debates has furnished a varied picture of the presence and character of well-being and underlying reasons for its changing role. However, the more fundamental question as to what *should* be the character of well-being within biomedical ethics remains open. Even so, the results provide an initial touchstone for the adequacy of conceptions of well-being which are to function within the field of biomedical ethics. The following requirements can be formulated on the basis of the findings:

1. *An adequate concept needs to encompass subjective as well as objective dimensions of well-being:* well-being is constantly shifting between its objective and subjective dimensions within biomedical ethics. Although we have attributed a great deal of this shifting to the interference of other prevalent notions and instrumentalisation, it becomes evident that there is more to be said about subjective and objective dimensions of well-being within biomedical ethics. There seem to be further and more substantial reasons why a concept of well-being which is adequate for the field of biomedical ethics needs to encompass subjective as well as objective dimensions. With regard to this aspect additional research is clearly needed. Moreover, the dualism of objective and subjective dimensions of well-being in biomedical ethics needs to be furnished with further refinements. The results of the analysis have shown that, above all, if the evaluative level is concerned, concepts of well-being which can be classified as intersubjective often come into play. Although these approaches constitute a form of objectivism they are not connected with realism. Instead they are tied to the assumption that there are socially shared ideas of what promotes or diminishes our well-being. These take an intermediate position in the face of subjective and objective conceptions. Therefore, there appears to be a need for a more subtle differentiation with regard to the subjective/objective distinction.

2. *An adequate concept needs to take account of the three alternative levels concerning the subjective/objective distinction:* the contents of the various debates lead to the fact that the consideration of well-being takes place on different levels, that is to say the ontological, the evaluative and the epistemic level. In order for it to be applicable, an adequate approach needs to take account of these various levels.

3. *An adequate concept of well-being has a variable breadth which is not limited to health-related aspects:* the above depicted findings concerning the breadth of the concept of well-being illustrate the fact that some debates require the application of a comparatively narrow approach to well-being whereas others, such as the enhancement debate, are in need of a broad conception which is

not limited to health-related issues. If the concept of well-being is to function in the various debates it needs to be adaptable with regard to its breadth.

4. *An adequate concept incorporates the restoration, protection and promotion of well-being:* on account of the content of the various debates the restoration, protection as well as the promotion of well-being are involved within biomedical ethics. Hence, an adequate concept of well-being needs to be sufficiently extensive so that it incorporates all three dimensions.

Obviously, these four requirements merely provide a tentative and rough suggestion and are in need of further examination and elaboration. Generally speaking, the results show that the various issues within biomedical ethics in which well-being comes into play demand the character of well-being to have a great flexibility and to be comprehensive. In the various contexts alternative dimensions are of relevance. At this point it seems possible to state that, on the basis of these tentative criteria of adequacy, neither of the three alternative unitary theories depicted in chapter 2, namely hedonism, desire fulfilment theories and objective list theory, is sufficient for the field of biomedical ethics. This is due to the fact that they are inflexible and too narrow, above all, with regard to the criterion that an adequate concept needs to encompass subjective as well as objective dimensions of well-being. Furthermore, they confuse the three alternative levels concerning the subjective/objective distinction. However, it can be said that each theory provides an important perspective which deserves attention within a comprehensive approach to well-being appropriate for the field of biomedical ethics.

The question of what can be considered an adequate comprehensive approach to well-being in the field of biomedical ethics is indeed challenging and needs to be approached from various angles, for example from the perspective of ethical theory or taking into consideration the fruits of empirical research on well-being. The context of biomedical ethics, which has been dealt with in this book, constitutes just one of these angles. Hence, it can be maintained that rethinking well-being for its application in biomedical ethics is an ongoing and also vital endeavour.

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Rethinking Well-being in Biomedical Ethics

Barbara Stroop

The notion of well-being accompanies us on a daily basis right from the beginning of life through to its end. As a matter of course we base the decisions that we make on whether or not our alternative options will promote our well-being or the well-being of others. Yet there appears to be not the slightest suggestion of agreement as to what *well-being* actually is.

One area in which this poses a significant problem is the field of biomedical ethics since this is obviously in need of an operational concept with regard to the notion of well-being and urgently requires a common language. *Rethinking Well-being in Biomedical Ethics* sets out to undertake this task of developing a common language by establishing a critical analysis of the role which well-being currently plays in biomedical ethics. The book takes the reader on a journey through four major fields of discussion representing the various stages in life: debates concerning the beginning of life, that is to say prenatal testing and selection, discussions in the intermediate phase of life such as the deliberations on enhancement, the allocation of scarce goods representing critical states in life and finally those dealing with the end of life namely cases of assistance in dying and foregoing life-sustaining treatment. It thereby provides a vivid illustration of the presence and meaning of well-being in each field of discussion.

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