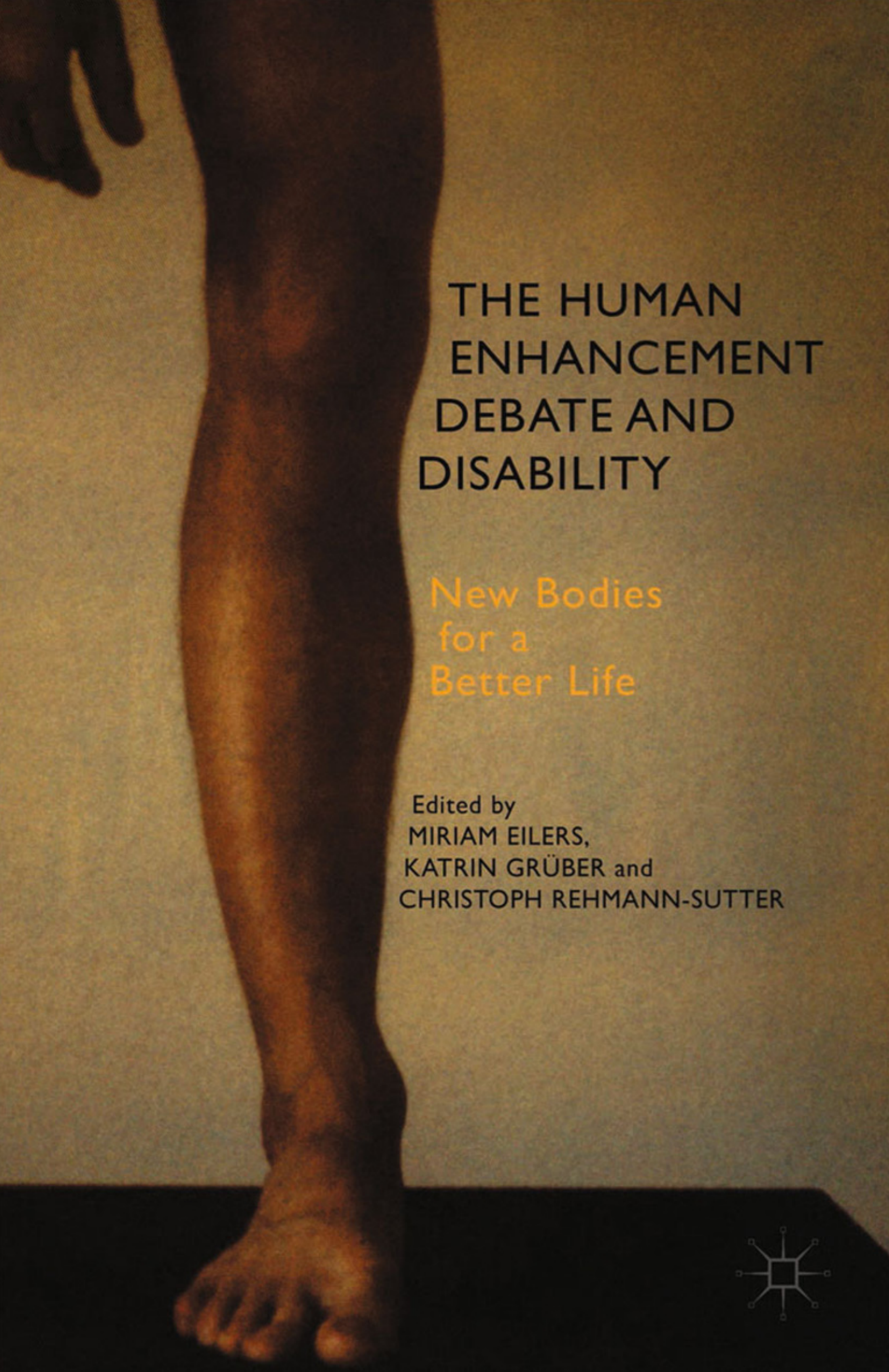

THE HUMAN ENHANCEMENT DEBATE AND DISABILITY

New Bodies for a Better Life

Edited by
MIRIAM EILERS,
KATRIN GRÜBER and
CHRISTOPH REHMANN-SUTTER

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Foreword: Five Thoughts About Enhancement

There is no single disability response to the enhancement debate

When faced with the difficulties of disability, the traditional answer has been medicalization. If only these difficult conditions could be cured or prevented, goes the argument, those poor benighted souls would be better off. I support medical research, and public health, and rehabilitation, and all the other clinical interventions which can improve health. But medicalization is not the full answer, and is often not the most appropriate and cost-effective answer, and sometimes is entirely the wrong answer.

The whole thrust of the disability rights movement over nearly 50 years has been to broaden our understanding of the disability question, and to show that the answers are also civil rights, barrier removal, inclusion in mainstream services, independent living, self-advocacy, and many other ways of accommodating difference. Medicine has its place, but alone it cannot solve the problem of disability, and sometimes can even make things worse.

This is why so many disability activists and disability scholars are so skeptical about the promise of enhancement technologies, be they genetic or pharmacological, surgical or prosthetic. Enhancement sounds very individualistic, it sounds very expensive – and hence unlikely to be available to all – and it sounds like it misplaces the disability problem.

However, this skepticism is not the only response to enhancement from the disability community. There are also those who say, from their position of difference, that we should embrace the prosthetic promise. If you are yourself abnormal in your embodiment, if you are used to surgical reshaping and orthotic or prosthetic or assistive technology solutions – wheelchairs and communication devices – not to mention having to pop pills every day to compensate and remedy and tweak, then it becomes much easier to envisage a different, wider, deeper, and more extensive engagement with enhancement. And when your whole society is relying on technological tweaks and boosts, then your own ventilator or anti-psychotic drugs or power chair perhaps becomes less noticeable, more acceptable.

Start with an adequate understanding of disability

In my view, disability is the outcome of an interaction between the individual and a health condition, and the wider physical and social environment. This approach is compatible with both the World Health Organization International Classification of Functioning, Disability and Health, and the Convention on the Rights of Persons with Disabilities. Further, I believe that disability cannot be reduced either to a simple biomedical issue, or conversely to a purely social issue – whether the latter is conceived in terms of barriers and oppression, or in terms of social constructionism. Disability starts with bodies, and some of the disadvantage which disabled people experience derives from the decrements in functioning which flow from their health condition. But disability does not end with bodies because social arrangements, cultural representations, and public attitudes create additional burdens which make life with disability more difficult. So disability, on average, means having a harder life, because of the disadvantages which flow from the interaction of these less-than-usually-functional bodies and these discriminatory or neglectful societies. For me, there is little benefit in being relativist about disability. Disability may not be a tragedy, but neither is it just a neutral difference: disability, as I have argued elsewhere, is perhaps best conceived of as a predicament (Shakespeare 2013).

The lived experience of disability challenges the quest for perfection

Despite the objective difficulties that confront disabled people – coping with a malfunctioning and possibly deteriorating body, and enduring the barriers and discriminations of an unwelcoming society – for most people, life with disability is quite tolerable. Evidence suggests that the subjective quality of life is rather high, certainly higher than non-disabled people imagine (Albrecht and Devlieger 1999; Amundson 2005). Health does not determine happiness, in most cases, although persistent pain, whether mental or physical, is hard to live with. Life with disability, in general, is entirely livable.

This last point is an important correlative to the more lurid exponents of enhancement, with the insatiable quest for stronger, fitter, faster, longer. Contra the perfectionist, it suggests that according to empirical evidence, less does not necessarily mean worse, and that perhaps more may not equate to better. The well-evidenced success of disabled people in leading good and full lives, notwithstanding their impairments and their experience of exclusion, provides evidence that a happy life does not require particular attributes. It may even be, although it is harder to cite proof, that being faced with obstacles and difficulties contributes to a more well-balanced and harmonious outlook. People can put things into proportion, they can see what is most important, perhaps they give up ceaseless striving and accept their situation. This has lessons for those who pursue the transhumanist chimera, but it seems unlikely that this will be acknowledged.

Enhancement is about phantoms

I write this preface from Geneva, where Mary Shelley's *Frankenstein* came into being, the city of CERN and other cutting-edge science, the city of the historical League of Nations and the modern World Health Organization and many other visions of a better world, from Calvin onwards. This is a city of reality, but also of fantasy.

We are poised on the cusp of a future where we are promised transformations in human embodiment every bit as profound as the transformations in science, manufacturing, communications, travel, and understanding which emerged in the last century. None of us know whether this is sober prediction or science fiction. But I have a strong suspicion that the enhancement debate is about phantoms, about our secret hopes and fears and psychic troubles. We fear death, we daydream about physical and mental prowess, we want the very best for our children. These are normal human emotions, and it is hard to imagine that they will ever change. But these are not our only phantoms: we also dream of control and domination and superiority, fantasies which are more dangerous and more exclusive.

The future is out of reach

When it comes to envisaging futures, fantasies are not a reliable guide. We need grounded, balanced, and immediate understandings. Disability research can offer us this correlative. In the *World Report on Disability*, to which I contributed, there is data about access to health and rehabilitation which shows how uneven the distribution of actually existing therapies and technologies is. Only 5–15 percent of disabled people worldwide have access to the assistive devices they need – and this refers to simple gadgets such as hearing aids, wheelchairs, crutches, and artificial limbs. According to the World Bank, two billion people in the world lack access to electricity. In the context of low and middle income countries, the solution is not the iBot, the futuristic power chair which lifts the owner to make eye contact, and enables them to negotiate stairs and other obstacles (cost $25,000). The solution is the Motivation basic wheelchair (cost $200). Rather than Oscar Pistorius' $13,000 state-of-the-art Icelandic blades, the option for an amputee in Sierra Leone or Haiti is more likely to be the Jaipur foot (cost less than $30). In this real world of seven billion human beings, people with epilepsy do not get the anti-convulsive drugs they require, people with depression lack access to proven treatments, and there is a lack of simple painkillers in many settings.

None of this means that enhancement technologies are intrinsically immoral or mistaken. But from the point of view of justice, it is clear that technologies have to be evaluated in terms of their potential for widening or narrowing inequality. Computers and space travel were pioneered at about the same time, and both challenged expectations and showed human ingenuity at its best. Computers are now cheap and ubiquitous, and it is hard to imagine life without them. Conversely, despite the best efforts of Richard Branson, even rich individuals are still not taking their vacation on the moon. Which is the better analogy for a particular enhancement technology?

Standards and expectations change, and sometimes technology does 'trickle down' from the elites to the masses. Mobile phones are a high-tech device which started as a pretentious luxury. But now, cheap and simple handsets have liberated farmers and fishers and traders in Africa, and brought the benefits of knowledge and communications to billions of people. Many enhancement technologies, I would argue, are unlikely to be similarly liberating.

It is an honor to be asked to introduce this wide-ranging collection of papers. Different disciplines are relevant to the topic of disability and the body. Disability studies has an important and valid contribution to make to the question of enhancement, and the voice of disabled people should be heard just as much here, as it is in other theoretical or policy debates. This book promotes the inclusive conversation and grounded analysis that this often exclusive and abstract topic lacks, and I welcome this sober and balanced contribution to an often over-heated field.

Tom Shakespeare
World Health Organization

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Tom Shakespeare has researched and taught at the Universities of Cambridge, Sunderland, Leeds, and Newcastle. His books include *The Sexual Politics of Disability* (1996) and *Disability Rights and Wrongs* (2006). He is currently a technical officer in the Department of Violence and Injury Prevention and Disability at the World Health Organization, where he is one of the editors and authors of the *World Report on Disability*.

1

Refocusing the Enhancement Debate

Christoph Rehmann-Sutter, Miriam Eilers, and Katrin Grüber

Superhumans (and the monsters in their shadow) have populated cultural imagery since the times of Mary Wollstonecraft Shelley and her Frankenstein. In Shelley's novel, the purpose of enhancement is improvement – 'what glory would attend the discovery, if I could banish disease from the human frame, and render man invulnerable to any but a violent death!' (Shelley 1993, p. 23) – but the results prove disastrous for those directly affected. The power to alter the human condition for the better by constructing better-abled bodies cannot be reduced to a simple matter of good or evil, but is itself deeply ambivalent. It may appear to be an irresistible, sometimes even morally tempting power, seemingly in the pursuit of good, but such a pursuit is also rife with hubris and produces many parallel disadvantages. This ambivalence is captured in the narratives of cultural imagery, where the beauties and the beasts, the heroes and the monsters, frequently appear as closely related, even as two personae of one and the same individual, one lurking just beneath the other.

The significance of enhancement, both in fiction and in reality, has not remained the same since Shelley's times, when the old experimental superhumans represented fictive attempts to conquer the roots of disease, evil, or death. To capture the intricacies of enhancement thinking and cyborg technologies, we can distinguish between different directions of 'improving' (see discussions in Hauskeller 2013): becoming smarter, making humans morally better, making them feel better, making them 'truly human', living longer, looking better, getting stronger, or compensating for natural frailty. We can also distinguish between currently possible interventions on the one hand – such as cosmetic augmentation of body shape, smart prostheses such as artificial limbs, mechanical exoskeletons, or implanted hearing aids – and more theoretical and futuristic ideas on the other – such as elimination of aging and death, deep genetic redesign of human bodies to something that is beyond human, or intelligent electronic brain implants to improve mental performance.

The debates about 'transhumanism' and future developments in enhancement are most frequently staged as a set of abstract moral questions (see Savulescu and Bostrom 2009), often referring to imaginary futuristic scenarios of what might be possible 'if and then' (Nordmann 2007, 31ff.). This discourse, as many of those who contribute to it themselves have complained, lacks concreteness. We believe that the perspective of disability will contribute towards substantiating the enhancement debate.

Disability studies

Even though the question seems to be an obvious one, it has rarely been raised in academic bioethics debates on enhancement biotechnologies: how does enhancement relate to disability? At first glance, the relationship might seem simple: enhancement is the gain of function, disability is the loss of function. One relates to something above normal functioning and the other below, like mirror images with the level of normality as their axis of reflection. A closer look, however, reveals a tremendously rich and complex relationship, whose exploration proves fruitful in discovering what enhancement is really about.

Disability studies, an interdisciplinary field of anthropological, social, philosophical, and political research, have shown that the common view of non-disabled people of disability as a loss of function is both far too narrow and far too discriminatory. If we see disability as implying a life of missed possibilities and opportunities, as a 'harmed condition' (Harris 1993, 180) or a 'physical or mental condition we have a strong rational preference not to be in,' (Ibid.) as John Harris has described it, (see Chapter 9, this volume) we are adopting the general perspective that has been described as the 'medical model' of disability: 'From the medical point of view, people are disabled when they are less functionally proficient than is commonplace for humans, and when their dysfunction is associated with a biological anomaly' (Satz and Silvers 2000, p. 173). Medicine, accordingly, aims to reduce, preferably to cure, such dysfunction. According to disability studies, operating within the medical model of disability disregards crucial contextual factors, and sometimes, rather than easing the physical or mental impairments of those classified as disabled, actually creates further problems.

The founding credo of disability studies has been the 'social model' of disability, which shifts the attention away from the physical or mental impairment to the living conditions and societal situation in which an impairment becomes a disability and manifests itself as a problem. The approach started as a 'materialist' one in the sense that it looks for the social causes of all harmful or negative aspects of disability. A disadvantage of this approach is that it tends to overlook the effects of impairment on the individual experience of disability and therefore cannot really explore the differences between different impairment groups.

The most recent versions of the social model of disability consider that the experience of disability is a composite of factors that emerge within a wide context. However, there are also intrinsic factors, such as the type and severity of impairment, the attitude of the person towards this impairment, and her or his personal characteristics and possibilities. Furthermore, there are extrinsic factors, such as the attitudes and reactions of others, the presence of a supporting or disabling environment, and further cultural, social, and economic issues. Proponents of the social model approach in disability studies have experienced some difficulties acknowledging this ambivalence in taking into account the condition of the body while also working on the grounds that well-being depends on social circumstances and society's capacity to recognize all of the specific needs of people with variant bodies beyond simply the internal/external condition of the body (Shakespeare 2006, pp. 29ff.; Williams 2001). In one consensus perspective, disability can be viewed as 'a dynamic interaction between health conditions and contextual factors, both personal and environmental' (World Health Organization and The World Bank 2011, p. 4).

The social model approach indicates that medical improvements do not always have a positive effect on people with a disability; rather, their effects may be multiple and as dependent on social and cultural factors as the disability itself. It considers the limitations of the assumptions made by those with 'normal' bodies of what life is (including notions of a 'good life') for people with variant embodiment and of the biopolitics of human difference. This way of thinking is sensitive to the social conditions necessary for leading a good life, including the importance of variant bodies (Blume 2012; Scully 2008; Shakespeare 2006; Vehmas 2012). The perspective of disability studies might also be necessary, therefore, to bring the enhancement debate onto more reliable ground.

Tom Shakespeare (2013), in capturing the state of current research in disability studies, distinguishes different directions or approaches to disability. Apart from the 'materialist' approach there is a direction called the 'cultural' approach, in the sense that it looks for the social and cultural construction of the dichotomies that underlie the experience of disability and normality. Disability itself becomes a social construct that needs to be deconstructed, using the analytical instruments of poststructuralism or critical cultural studies. Another direction that also tries to meet this difficulty can be called the 'realist' approach (or better, 'critical realist' or 'post-social-model'), in the sense that it is primarily interested in the empirical investigation of the life conditions and the needs of differently impaired and disabled people in different places, countries, and situations. We believe that all of these different approaches to disability might have something to contribute with regard to the topics discussed in this book. The chapters will draw in different ways on the concepts from these three approaches to disability, as well as on existing knowledge about the phenomena and social processes of disability.

Our working hypothesis is that connecting the two fields of enhancement bioethics and disability studies brings both forward and infuses each with a new set of questions. Just as the enhancement debate lacks the perspective of disability, disability studies lack the question of enhancement and technology development. The contributors to this volume have thus investigated the intimate, ambiguous, and in many ways significant relationship between good lives and (better) bodies, and the role that enhancement technologies could and should play in this relationship. It is an interdisciplinary book that combines philosophical, anthropological, and sociological disciplines with cultural studies. It aims to invite more grounded discussions about enhancement, which set aside the counterproductive and reductive division between dis- and plus-ability research.

The authors assembled in this book do not all share the same approach to disability, but they are all skeptical about the medical model of disability and about biomedical practices that reduce the experience of people with disabilities to their impairments. We acknowledge the importance of medical progress for disabled people, but this in no way excludes the possibility of skepticism regarding the medical model in terms of explaining disability. Medical-technical developments in many fields have improved the lives of people with a disability, and many experience severe problems if they do not have access to the health care system (Grüber 2012; WHO and WB 2011). The medical and ethical issues connected to strategies to find appropriate solutions for the problems that people with disabilities face are, however, not the topic of our book. Rather, the central issues in this volume are questions around the concepts of normality and normativity, which contribute both to the enhancement debate and to disability studies.

Where does the idea of normality, which is crucial for the therapy–enhancement distinction, come from? How relevant is the concept of normality? What is the hidden normativity within the concept of normality? And what kind of normality is relevant? Is it

- the statistically average functionality in all species members;
- species-typical normality (whatever the word 'typical' means here – for example, an ideal, as in the sociological term 'ideal-typical', or a necessary minimum just fit for survival of the species); or
- an individually experienced state of accustomed embodiment?

It is important to look deeper into these concepts in order to obtain a clearer picture of the possibilities of enhancement.

The biopolitics of a debate

There are several reasons why the enhancement debate excludes the perspective of disability and disability studies. For one, the perspective of disabled people is generally underrepresented in the various debates within bioethics (Scully 2008). Another concrete reason might be the widely shared assumption that enhancement is conceptually distinct from repair, therapy, or prosthetics. This distinction is defended by referring to the idea of normality: enhancement is what brings the human body beyond normal functioning, whereas repair and therapy bring it back to normal. In this sense, prostheses or disability aids should imitate a normal embodied function, replacing the natural limb or sense with an artificial device. Even though they may enhance the shape and function of an individual's impaired body, they are therefore not enhancements.

The ethical issues of medically assisting persons with disabilities in their lives or the ethics of medically eliminating disabilities are separate from those ethical issues that surround interventions that go 'beyond therapy' (President's Council 2003). This framing of biotechnology as having the potential to repair or enhance is the standard 'order of things'. It implies – like all order – politics (Foucault 1974). If it is taken for granted, disability marks the space underneath the table at which 'normals' take their seat. Normality is, moreover, constructed as a dividing zone, from which some forms of embodiment deviate – either towards the negative or the positive.

The discourse on the social and ethical implications of human enhancement technologies focuses on the issue of moral permissibility. Is it morally permissible to enhance in a specific way? Or are enhancing interventions intrinsically wrong; should they be banned by law? The objects of controversy are frequently hypothetical endeavors, such as advanced germ-line technologies for creating new generations of children with a longer health span, creating increased 'moral strength' or additional senses through the use of imaginary nano-bio-cogno devices to be implanted into the brain, or even the idea of switching human life forms to a digital form of existence through uploading minds onto computers. In a moral and also regulatory perspective, the main question of interest here is: should somebody who has the desire or interest to do such things be allowed to do them or not? This is a difficult question, for the simple reason that we do not know enough in order to address it properly; this is why enhancement is a challenge that calls for 'postconventional' ideas (Shildrick 2005). Enhancement is, insofar as it puts the question of the *conditio humana* at stake, not only a futuristic discourse. It also points to the present, since it is already modifying the current academic and public dialogue about the body, as well as taking ethics to the past. How, therefore, can concepts from modernity fit postmodern (such as enhancement) discussions (Shildrick 2005, pp. 3–4.)?

How can ethics – which far too often takes 'what it means to be human' for granted and has a strong tendency to rely on modern templates when imagining new (future) knowledge (Ibid.) – take a stance on enhancement? One answer would be to admit the unfamiliarity of the consequences of such knowledge and pursue the link between enhancement and disability, as both an example of thought and a training of thinking. In this sense, our book contributes towards reconfiguring the ethical framework of the enhancement debate.

Michael Hauskeller pulls attention in a slightly different direction when he observes that enhancement, in a strict logical sense, is rather impossible: 'we lack any clear idea of what it would actually consist in without being aware of that lack' (Hauskeller 2013, p. 186). The lack of awareness of this lack of insight is dangerous because it is not recognized. The enhancement projects we are talking about are planned within an instrumental rationality. Such instrumental rationality, however, has its limits, because it is not clear whether the improvement (according to whatever scale) will be a real betterment overall for the persons affected and for their social relationships, or whether it will be at least ambivalent, or possibly even prove to be harmful. What seems to be good in certain respects might be bad in others. What is clear is that enhancement would, in a certain respect, imply 'more than good': we should demand an improvement of the human condition or human well-being.

What would the relevant understandings of 'morality' and 'the good' be in order to decide upon such questions? On what grounds could someone be denied access to enhancement technologies (if available), and on what grounds could the application of such technologies be ethically legitimized?

It would of course be better to begin to explore this murky terrain of upcoming biotechnology early and assess its potential effects well before the fact, that is, upstream in the flow of biotechnological innovation. However, it is not so clear how to frame the ethical questions at this point, when many things are still so vague and hypothetical (Rehmann-Sutter and Scully 2010). Even though some scientists and scholars do argue that at least some enhancement developments are already quite realistic, or will be soon, it would still be early enough in terms of such developments to say 'no' if necessary. What is perhaps more important is that there is still room to understand and frame such developments in appropriate ways, since the technological and therapeutic imperatives have not yet been reshaped and the persuading 'normative power of facticity' ('use them because they are available and others use them too!') is not yet overwhelming.

A phantom?

With good reason, many of the visions discussed in the enhancement discourse can be seen as unrealistic or purely hypothetical. In a review article, pharmaco-psychologist Boris Quednow (2010) called the discussion on cognitive enhancement drugs a 'phantom debate' because it assumes that a technology 'that will probably never materialize' (Quednow 2010, p. 156) is in fact realistic. He states: 'The assumption that, in the near future, we will have access to compounds that are not only effective cognitive enhancers, but also safe and well tolerated and therefore suitable to be taken by everybody' (p. 154) is unlikely to be true. The same could be said about other enhancement visions. Gregory Stock's 'genetic molecule' that one could 'safely add to an embryo and thereby give your future child extra decades of healthy life' (Stock 2002, p. 78) is intentionally kept vague. Molecular biologists are careful not to overstate the progress of genomics (Lander 2011), as we are currently far from seeing realistic genetic augmentation, and perhaps never will arrive at those radical enhancements that transhumanists ponder over.

This gap between what is dreamed of, feared, and debated and what is actually possible means that we need to reflect on the phenomenon of enhancement and its associated debates, to view it as a cultural phenomenon. The discipline of science and technology studies can contribute here, as it enables us to see technologies not as a given but as contingent and contextual. Through this lens, we can take a closer look at the consequences, at the 'decisions, the trade-offs, the evidences and their interpretation within certain political strategies' (Blume 2012, p. 352). Such an approach allows for the possibility to actually shape the developments and technologies, instead of simply observing and documenting them.

As pointed out above, the enhancement debate has two sides: one which focuses on the applications already in practice, and the other which reflects on future visions. By drawing attention to this distinction, and to the experiences with enhancing biotechnologies that are already available, we hope to counteract a tendency in the debate to stay on a (sometimes astoundingly) high level of abstraction and generality regarding the question of duties, aims, permissibility, and the illicit. Even if unrealistic, such visions can be seen, as for instance Peter Wehling (2011) has suggested, from a Foucauldian perspective on biopower, as one part of a larger biopolitical process of technification. Such visions have the potential, if realized, to dramatically change the climate in the public sphere; for example, by discursively constructing the 'natural' human body as 'imperfect' compared to those that are enhanced. The debate might be based on unrealistic plans or expectations, but it may nonetheless have a real effect on what people see as the limits of the human condition. Furthermore, it has the potential to delimit moral perception. Even taking into account the sometimes exaggerated leaps in technology that enhancement proponents assume, the debate and its framing still prepare people to see the human body and its basic structures as a legitimate object of (at least reasonable) biotechnological improvements; whatever 'reasonable' means in any given time and place.

We, the editors and authors of this book, do not want to fall into such assumptive traps, nor do we intend to set them. One advantage of adopting such a cautious attitude is that it helps in terms of being wary of the common conclusion that we are morally obligated to use genetic technologies to produce 'the best children possible' and to 'improve ourselves' (Savulescu and Kahane 2009; Sparrow 2011). Such an obligation seems to be derived from moral principles of beneficence and autonomy, meaning from our duty to promote the well-being of children without reducing their freedom of choice. This value-driven approach is based on questionable assumptions. Firstly, it assumes that if something is an enhancement of the human body, in certain respects it will indeed promote the well-being of those who live with this kind of body. To equate enhancement (of a desired function or feature) with a higher state of well-being in this way is unlikely to be true, since in some cases (such as muscle strength or longevity), this function is dependent on other conditions in order to be a contribution to well-being, and in other cases (such as memory), the function must be well balanced with an opposite (such as the capacity to forget). Secondly, it assumes that we know enough about future humans' life plans to be in the position to decide about the necessary conditions for their well-being. If only of these assumptions questionable, the conclusion that we have a moral obligation to enhance our children because we have an obligation to improve their well-being is called into question.

From visions to real life

One reason why the enhancement debate is abstract might be the unavoidable lack of evidence with regard to the contextualized real life impacts of futuristic biomedical if-and-then scenarios (Nordmann 2007). When we enlarge the focus and concentrate on the 'now', we can detect some medical interventions and devices that could, depending on the concept of normality one is using, also be viewed as enhancement technologies: for instance, cochlear implants and high-tech prostheses. There is no sharp line between restoration and enhancement because the device never provides a one-to-one replacement of a lost body part, and the selectively added functional abilities can rarely be measured against the ones that were replaced. Experiences of the real life impact and socio-political implications of medical devices are available and, to an extent, systematically studied. These experiences are, however, frequently expatriated from the bioethical enhancement debate because, according to the dominant view, prostheses 'restore' but do not 'enhance'. But what is seen as 'just restoring' versus 'enhancing' depends on the definition of the measurement that defines these concepts; namely, the concept of 'normality'. For people who live with certain disabilities or chronic illnesses, their 'normal' is different from the generally assumed 'normal' that is proposed by medicine, or from the 'normal' that is seen by population biologists or public health