

## ENABLING TECHNOLOGIES

Between the needs for assistance and acceptance

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# Table of Contents

Summary .....	0
1 Introduction.....	1
1.1 Content.....	1
1.2 Methods .....	4
2 Enabling technologies.....	6
3 Disability and technologies.....	10
3.1 Individual model .....	11
3.2 Social model .....	12
3.3 Cultural model.....	14
4 Philosophy of Technology .....	17
5 Ethical implications of enabling technologies .....	22
5.1 Stigmatization and discrimination.....	22
5.2 Therapeutic technologies .....	23
5.3 Restoring technologies .....	24
5.4 Compensatory technologies.....	25
5.5 Assistive technologies .....	25
5.6 Universal technologies .....	27
6 Ethics of Enabling Technologies .....	28
6.1 Capability approach and disability .....	28
6.2 The ethical desirability of enabling technologies.....	33
7 Case Study .....	41
8 Conclusion .....	47
References.....	50
Annex I: Interview .....	i
Annex II: Consent Form .....	iii

## Summary

Enabling technologies are defined as technologies that alleviate the impact of a disability. This alleviation can happen in many ways, which are reflected in five categories of enabling technologies. Despite their usefulness for disabled people's participation in society, some enabling technologies aim at 'fixing' disabled people or stigmatize and discriminate against them. Many disabled people would like to be accepted as they are instead of 'fixed' with technology. This need for acceptance constitutes a problem when its implications contradict a need for assistance. The resulting dilemma will be called dilemma of assistance and acceptance. Despite its relevance, the dilemma has not been sufficiently considered in the literature and constitutes a severe gap in the research on enabling technologies. The thesis answers the question *How can enabling technologies overcome the dilemma of assistance and acceptance?* in two parts; the dilemma's identification and steps towards resolving it.

The dilemma of assistance and acceptance will be explained by taking recourse to disability studies and philosophy of technology. Different models of disability will be evaluated regarding their preference for different categories of enabling technologies. The cultural model will be established as the suitable conception of disability for this thesis, as it demands the analysis of social segregation processes that technologies can contribute to. Following this incentive, the five categories of enabling technologies are checked for their liability to violate the need for acceptance via reinforcing contested views on disability, stigmatization, or discrimination. These results will be evaluated with the capability approach, which demands that disabled people are capable of participating in society. It will be concluded that those enabling technologies that stigmatize or discriminate against their user are violating the ethical norms of the capability approach. Building on the criteria developed from the capability approach, the five categories of enabling technologies can be analysed for their ethical desirability.

Universal technologies will be established as the best solution for the dilemma of assistance and acceptance. Because they do not allow for the perception of a difference in their use, they contribute to a more inclusive society. Assistive technologies, which often can be replaced by universal technologies, establish user differences where none are necessary and were evaluated as potentially discriminatory. Therapeutic and restoring technologies will be identified as reinforcing contested views on disability. Compensatory technologies potentially offer more choices than therapeutic technologies, but are used individually and can lead to stigmatization and discrimination. These results were applied to a case study of a hand orthosis developed for people with Duchenne muscular dystrophy. The case study was deemed ethically acceptable based on the capability approach under certain conditions.

In sum, the research question can be answered as follows: The dilemma of assistance and acceptance arises when enabling technologies reinforce contested views on disability, stigmatize, or discriminate against disabled people. Following the guidelines for inclusive design informed by the capability approach can minimize violations of the need for acceptance. The only way to completely avoid them, however, is cultural change. Enabling technologies can support this cultural change by reinforcing positive views on disability.

# 1 Introduction

## 1.1 Content

In his 2013 book *Invasive Technification*, Gernot Böhme describes three phases of the relation between individual and society. First, in the early modern period, the individual's membership of the social environment was determined by his position in the state – being a nobleman, a clerk, or a commoner. Second, in the 18<sup>th</sup> and 19<sup>th</sup> century, it was defined by the free-market economy, being a participant in the exchange of labour. Finally, today, there is an additional factor; the individual's role in the system of technological infrastructure (Böhme, 2012, p. 111). Social integration, he explains, demands technological integration.

An obvious case for the third relation is the social integration of physically disabled people. The connection to technological integration is especially evident because disabled people often need more technologies than others to fully participate in society. These additional technologies are called *enabling technologies*, of which reading devices, TV captions, and wheelchairs are mere examples. Given the crucial role such technologies play in possibly improving one's well-being and social integration, it seems surprising that enabling technologies are not always embraced by members of the disabled community (Hansson, 2007, p. 264). For example, some deaf people reject the use of cochlear implants (Hansson, 2007, p. 259; Lupton & Seymour, 2000, p. 1853). This rejection does not happen for generally common reasons, i.e. a technology that is too complicated to use, too expensive or too unsightly. Instead, the rejection is motivated by a desire to be accepted: Many disabled people do not want to be 'fixed' with technologies but would like to be accepted as they are. This need for acceptance makes enabling technologies ambiguous: On the one hand, they are needed for assistance to participate in society and on the other hand, some are rejected because they violate the need for acceptance. In this thesis, this dilemma shall be introduced as the dilemma of assistance and acceptance.

The need to be accepted has not received much attention from philosophy and ethics of technology (Gibson, Upshur, Young, & McKeever, 2007, p. 8; Lupton & Seymour, 2000, p. 1851). Although the topics of disability and technology have been connected (e.g. Hansson, 2007; Roulstone, 2016), as well as the topics of disability and ethics (e.g. Leach Scully, 2012; Nussbaum, 2006), an analysis of enabling technologies and the dilemma of assistance and acceptance is missing so far. A likely reason for this research gap is that several disciplines must be consulted for meaningful results. To understand the dilemma of

assistance and acceptance, different models of disability must be understood in their connection with technology. It has been argued that neither disability studies nor philosophy is sufficient to understand disability (Vehmas, Kristiansen, & Shakespeare, 2008, p. 1). Disability studies provide empirical research to understand disability as a social phenomenon but lack the philosophical depth to adequately describe the complex processes at play. Philosophy (of technology) can provide this depth but usually falls short of considering the realities of people with disabilities. After connections between disability studies, philosophy, and technology have been made, political philosophy is needed to form normative ideas about enabling technologies. Finally, these ideas must be tested for feasibility with insights from engineering sciences. Hence, disability studies, philosophy of technology, political philosophy, and engineering sciences must contribute to an adequate understanding of the dilemma of assistance and acceptance. Filling this research gap can provide a better understanding of disability, of the role of enabling technologies in society, and ideas for the improvement of enabling technologies. Since the inclusion of disabled people is a matter of social justice, the topic has a not only a high theoretical but also societal relevance.

Following the previous considerations, this thesis asks: *How can enabling technologies overcome the dilemma of assistance and acceptance?* The question will be answered in two parts. Chapters 2-5 answer the question: How does the dilemma arise and which social and technological processes are at play? Chapters 5-7 turn to the application of these results: What is the ethical acceptability of enabling technologies and how can it be improved? The following paragraph sketches the thesis' structure in more detail.

First, to build a basis for the argument, the definition and categorization of enabling technologies by Hansson (2007) will be explained and criticized (2). The analysis of different models of disability is necessary for an adequate understanding of the rejection of certain enabling technologies. The individual, social, and cultural model do not only frame disability differently, but also suggest different strategies, that, in turn, promote the use of distinct enabling technologies. For instance, the individual model promotes individual adjustments to the body, while the social model asks for social adjustments and accessibility (Anderberg, 2005). The cultural model of disability will be identified as most helpful in the context of this thesis because of its theoretical accuracy and its possible connections to philosophy of technology (3).

Following the cultural model of disability, technologies must be included in the

analysis of disability because they are a crucial part of culture. Philosophy of technology can explain how technologies shape views on disability. With the application of mediation theory (Verbeek, 2005), it is possible to understand the different categories of enabling technologies not only as neutral results of the different models but as value-laden artefacts that shape the perception of disability and the actions of disabled people. As they are actively mediating human perceptions and actions, they express and reinforce (contested) models of and views on disability (4).

More concretely, this result will be applied to the five categories of enabling technologies. Technologies that restore body functions imply that disabled people are not 'sufficiently normal' and need 'fixing'. Other technologies are exclusively used by disabled people and can lead to stigmatization and discrimination of disabled people. Therefore, the design and use of enabling technologies become morally relevant (5).

The capability approach will provide the normative basis to evaluate the different technologies' ethical acceptability. It captures the dilemma of assistance and acceptance and provides approaches to the ethically justifiable design of enabling technologies. Together with principles for anti-discriminatory and inclusive design, design principles for enabling technologies will be developed (6). Finally, the case study of a compensatory technology will be used to test the theoretical findings and, in turn, will be evaluated with the previously developed conditions (7).

In following the previously explained structure, there are also certain points that the thesis will not address. First, it will solely focus on *physical* disabilities, not mental disabilities or diseases. This focus was chosen because the participation in society of physically disabled people is especially dependent on the use of enabling technologies. Mental disabilities pose different questions of autonomy and responsibility that are beyond the scope of this thesis. Diseases will be addressed only insofar as they result in physical disabilities, e.g. the inability to walk. Throughout the thesis, the general term 'disabled people' refers to physically disabled people, unless indicated otherwise.

Moreover, the thesis will not deal with the general enabling nature of most technologies. 'Enabling Technology' has also been defined as 'Equipment and/or methodology that [...] provides the means to generate giant leaps in performance and capabilities of the user' (BusinessDictionary, 2017). This definition addresses influential technologies that facilitated major changes in industry, e.g. the internet 'enabling' smaller

firms to compete on the market. In the literal sense of the word, most technologies could be interpreted as 'enabling', simply because they 'enable' their users to do something. Stairs enable to reach other floors, a kettle to boil water, a pen to write, etc. At the same time, there are also many disabling technologies preventing their users from doing things – speed bumps prevent from speeding, fences prevent accessing, train station barriers from boarding the train without a ticket. However, these properties do not make the respective technologies 'enabling' or 'disabling' in the sense that they are used in this thesis. These terms are exclusively reserved for the context of disabilities. The crucial difference is that the kettle allows any user to boil water and not just a certain user group while enabling technologies enable only disabled people. At the same time, stairs do not enable disabled people. In the thesis, the term enabling technology will only refer to technologies used to alleviate the effect of a disability.

Finally, some enabling technologies have the potential to not only enable, but enhance their users. Enhancement, the improvement of body functions beyond 'normal' human capacities, will not be covered in this thesis. The most-discussed case of such an enabling technology are the prostheses of runner Oscar Pistorius. They not only enable him to walk and run, but were also discussed to giving him an unfair advantage over able-bodied contestants (Burkett, McNamee, & Potthast, 2011, p. 645). Since many enabling technologies could potentially lead to an enhancement of not only disabled people (e.g. brain implants leading to cognitive enhancement, eye lenses providing better than average eyesight, colour sensors for blind people making them perceive colours out of the average colour spectrum), this potential cannot be the crucial factor to explain why some enabling technologies are stigmatizing and their use is rejected. The enhancement debate, interesting as it is, does not contribute to answering the research question.

## 1.2 Methods

This thesis aims at conducting empirically-informed philosophy. The largest part draws on the literature study in the fields of disability studies, philosophy of technology, and political philosophy. However, philosophical research on the topic of disability has been accused of missing the reality of disabled people (Vehmas et al., 2008, p. 1). Although this point has not been made about disability studies, there is almost no literature in disability studies explicitly scrutinizing enabling technologies. To avoid such unawareness, this thesis uses a case study.

The respective enabling technology, a hand orthosis for people with Duchenne

muscular dystrophy (DMD), is being developed in the *Flexension Symbionics project* in the department of biomedical engineering at the University of Twente. A collaboration with the responsible PhD student, Ir. Kostas Nizamis, was initiated and he became an official external advisor to the master thesis project. Nizamis was visited in his laboratory and accompanied to the Dutch Duchenne Parent Project Congress on May 20<sup>th</sup>, 2017, in The Hague. This visit enabled contact with people with DMD. The presentations gave an impression of their everyday lives, needs and goals. Together with additional reading material like blogs and articles, this background information ensured an understanding of the perspective of disabled people.

For the engineering perspective, an interview with Nizamis has been conducted and field notes were taken, which were later approved by him (K. Nizamis, personal communication, September 1, 2017)<sup>1</sup>. For this interview, an approval by the faculty's ethics committee was granted. This interview serves three purposes. First, it investigates the engineer's assumptions about people with DMD and disability. Second, it offers insights into different possibilities of constructing an enabling technology and the principles guiding the construction. Third, it makes possible an evaluation of the participatory features in the construction process. These insights provide enough information to evaluate the hand orthosis with the developed criteria for enabling technologies.

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<sup>1</sup> In line with the APA guidelines, the conducted interview is not listed in the reference list, as it does not constitute recoverable data. However, the field notes and the consent form are provided in the annexes. It will be further cited in-text as 'Nizamis, 2007'.



## 2 Enabling technologies

- ➔ This chapter presents Hansson's (2007) definition and categorization of enabling technologies, which is criticised and improved. The developed categories serve the purpose of clearly defining the subject of research.

Before the notion of *enabling technologies*<sup>2</sup> can be defined, it should be clarified what the term *technologies* refers to in this thesis. Due to the unsolved, on-going discussion in philosophy of technology about the definition of technology (Reydon, 2017, p. 21), no clear-cut definition will be provided. Roughly, technology is understood as the techniques and skills that relate to its artefacts, 'man-made constructions and objects' (Anderberg, 2005, p. 7). Such artefacts are not only high-tech gadgets like smartphones or electron microscopes but also low-tech devices and built environments. This understanding covers examples such as reading glasses, toolboxes, a city, a building, or a bathroom, and by its scope, demonstrates technology's omnipresence and importance.

Subsequently, also enabling technologies could be low- and high tech, in the form of gadgets, medical procedures, or the built environment. As mentioned in the introduction, enabling technologies have been defined as technologies which 'alleviate the impact of disease or disability' (Hansson, 2007, p. 258). Thus, enabling technologies are exclusively directed at the user group of disabled people<sup>3</sup>. This definition covers many technologies, e.g. wheelchairs, tactile paving, captions for people with hearing loss, or accessible versions of text online. These examples vary in their design and use: While some technologies are mostly owned and used by only some individuals (e.g. wheelchair, walking cane, glasses)<sup>4</sup>, others are owned by authorities and used in public spaces (e.g. tactile paving, ramps, accessible text). Some are produced by specialized manufacturers and used privately (e.g. special skiing equipment for paraplegic people), and some are so common that they are not even perceived as enabling technologies (e.g. subtitles for movies). To better describe the differences between enabling technologies, Hansson (2007) has proposed four categories of enabling technologies, depending on the distribution of their impact between individual and

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<sup>2</sup> Throughout this thesis, technology will be referred to in plural: 'technologies'. This accounts for the insights from the empirical turn in philosophy of technology; according to which there is no 'technology' in general, but several technological artefacts that must be studied separately.

<sup>3</sup> As explained in the note to the introduction, this thesis will not address the topic of disease.

<sup>4</sup> These technologies are sometimes also owned by institutions or public places, e.g. many airports own wheelchairs. Although it is possible to rent wheelchairs, many wheelchair users prefer their own, because they can make individual adjustments more easily.

society: Therapeutic, compensatory, assistive and universal technologies. Although all are designed to 'enable' their users, they do so differently.

### **Therapeutic technologies**

restore a biological function. When a function is missing or lost, a therapeutic technology restores it permanently. After the use of such a technology, the user is not dependent on other resources. For example, eye surgery is addressing the missing body function of full sight, which is permanent after the surgery, and almost no additional treatment is needed. For this procedure, only the individual, the doctors, and the insurance company might be involved; it is a matter dealt with in private. Another example often mentioned in connection to therapeutic technologies are cochlear implants. Technically, they do not restore hearing because hearing with a cochlear implant works differently than the biological hearing, so the result is not a fully restored body function. Yet, hearing does take place and more importantly, cochlear implants are permanent. Hence, this thesis will address cochlear implants as therapeutic technologies despite the slight ambiguity of their categorization.

### **Compensatory technologies**

replace a biological function with a new function of a general nature. For instance, a lost visual function can be replaced with the function of touch provided by a walking cane. Compensatory technologies enable their users not by restoring the body, but by providing new abilities. The body function is only replaced while the compensatory technology is present and working. Many examples can be named, e.g. wheelchairs, eyeglasses, hearing aids, walking canes, or adult diapers.

### **Assistive technologies**

provide assistance in particular situations. For instance, remote controls for doors only help wheelchair users when they want to open a door and not in every aspect of their lives. The focus lies not on the missing body function, but on the task whose performance is enabled. Further examples are plates that cannot slide off the table, reading machines, knives that require less strength, etc. These devices enable their users to perform tasks that able-bodied people can perform with technologies that do not have extra features.

**Universal technologies**

are intended for general use (i.e. not only use by disabled people). Although designed with disabled people as users in mind, they are not exclusively made for them. The results are technologies that are usable by everyone, even without the extra features of assistive technologies. The difference between assistive and universal technology lies in these extra features and in the usability by disabled people only or by all people. The latter is determined by the concrete example and its context. Hansson explains this difference with the example of a ramp: While a ramp in front of a building, usable by everyone, is a universal technology, a ramp at a side entrance, marked with a wheelchair symbol, is an assistive technology (Hansson, 2007, p. 259).

Although these categories clarify the differences in enabling technologies, two shortcomings shall be noted and respective improvements suggested. First, the category of compensatory technologies is, as mentioned, very broad. It contains, e.g., both glasses and walking canes, although these technologies do not work in the same way. Glasses restore the vision of a short- or far-sighted person to an extent that the person can almost see like a person with average eyesight; contact lenses to an even greater extent. In contrast, a cane does not restore eyesight but compensates the visual impairment with the function of touch. Both technologies are clearly not therapeutic or assistive technologies, as they are neither permanent solutions nor focus on a specific task. Subsequently, a new category is proposed that accounts for the glasses' non-permanent restoration of a body function. These technologies could be called restoring technologies, the 're' indicating the use of the same body function, but not a permanent change of the body as given with therapeutic technologies. Glasses would then be categorized as restoring while walking canes would be compensating technologies in the original sense of the word.

Second, Hansson's distinction between the categories seems to rest on different grounds. While the first three are about the way in which a body function is restored or replaced, the fourth seems to be about the designer's intentions. This would be problematic for an analysis of the dilemma of assistance and acceptance because many technologies are stigmatizing or discriminatory although the designer did not have any intention for them to be. The designer's intentions are no suitable measurement for the stigmatizing or discriminatory effects technologies can have. The difference between assistive and universal technologies can better be described by their results; i.e. the use by disabled people or by all

people. Subsequently, it is not so much the intention of the designer but the potential attractivity for and usability by all people that decides whether a technology is assistive or universal. That implies that not all assistive technologies can be universal. There are some technologies that are so specialized that they are not interesting to able-bodied people, e.g. reading machines.

Because there are distinct categories of enabling technologies, the same goal can be achieved with different technologies. This possibility can be demonstrated with the example of a person with hearing loss who wants to enjoy a movie. The person could use therapeutic technologies, such as a cochlear implant, or restoring technologies, such as hearing aids, to permanently or temporarily restore the biological function of hearing. Another possibility would be to use assistive technologies, such as subtitles on television. Subtitles for people with hearing loss are called captions and do not only cover what is spoken but also descriptions of other sounds. These captions were traditionally an option in an accessibility centre of televisions, where they can be understood as assistive technology. Nowadays, subtitles are easily available in streaming services such as Netflix or Amazon Prime, where often the subtitles in the original language conform to captions. As these captions are a standard function and not only available for people with hearing loss, they can be understood as a universal technology. They do not only help people with hearing impairments but also people who want to talk, do not want to disturb their neighbours or want to eat something crispy.

Although these technologies seem to do the same supposedly good thing – enable the person with hearing loss to understand the movie, *the way in which they do it* can be of ethical significance. In the movie example, persons with hearing loss might not want to watch the movie alone. The technology they use to understand the movie influences how they are perceived by other persons. Using a cochlear implant or hearing aid, the persons could listen to speech and music, but as the devices are not invisible, they would also be recognized as persons with hearing loss. Using captions, the persons would not hear speech and music but would use the same technology as everyone else in the room. At the same time, the persons would have to ask for subtitles if the rest of the audience does not activate subtitles themselves, while the use of hearing aid would be solely in the persons' own responsibility. These differences hint at the meaning enabling technologies can have for the understanding of a disability, stigmatization or inclusive societies.

### 3 Disability and technologies

- This chapter presents three different models of disability; the individual, social, and cultural model of disability. After they are discussed and their relation to enabling technologies is analysed, the cultural model is established as the appropriate model of disability for this thesis.

Aside from enabling technologies, the second important concept to understand for this thesis is the one of disability. In the last chapter, enabling technologies were defined to ‘alleviate the effect of a disability’ (Hansson, 2007, p. 258). The two definitions are linked to each other: What is meant by an enabling technology could differ depending on the definition of disability.

In a literal sense, a disability means a restriction – a disabled person is not *able* to do something because someone or something prevents her from doing so. Like any restriction of possibilities, disability is mostly negatively connoted (Albrecht & Devlieger, 1999, p. 978). However, whether disability constitutes a problem and where this problem is located, varies with the definition. As several authors have pointed out, disability is a term that is nearly impossible to define (Mitra, 2016, p. 236; Wasserman, Asch, Blustein, & Putnam, 2016b, p. 2), for two reasons: First, the self-perception of some disabled people might differ from their perception by others. For instance, many people in the Deaf community do not comprehend their deafness as a disability (Roulstone, 2016, p. 95). This self-perception reveals that there is a difference between people identifying as disabled and people being ‘objectively’ categorized as disabled. Second, disabled people are a very heterogeneous group, including mentally and physically disabled people as well as temporarily or permanently disabled people.<sup>5</sup> Despite these difficulties, two features stand out in the definitions used by the WHO and UN:

‘(i) a physical or mental characteristic labeled or perceived as an impairment or dysfunction [...] and (ii) some personal or social limitation associated with that impairment’ (Wasserman et al., 2016b).

Following this definition, it is estimated that around 10% of the world population are disabled (Leach Scully, 2012, p. 1). Although such statistics should be cautiously evaluated, this number rejects the common misconception that there are only a few disabled people

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<sup>5</sup> In addition to the difficulties in the definition of disability, the politically correct use of the word is debated in the disabled community and the academic discourse. In this thesis, it was chosen to use the term ‘disabled people’ or ‘disabled person’ instead of ‘people or person with disability’, because this formulation, suggested by British disability activists, highlights that disabled people are a group of people with political interests and that disability can be a part of identity that is not shameful (Brown, 2016).

and that disability is a minor issue. The two features, a dysfunction and a social limitation, are taken up by different models of disability. In the literature, abstractions about disability are not summarized in *definitions* or *theories*, but in *models* of disability. The use of the term *models* makes clear that the respective conceptions are not backed up by data collection, but are merely an abstract system for explaining phenomena (Llewellyn & Hogan, 2000, p. 157; Roulstone, 2016, p. 49). Therefore, they are not meant to be ‘true’ depictions of reality but are merely representations supposed to generate explanations (Llewellyn & Hogan, 2000, p. 157). Although there are many, two models stand out through their clarity and relevance in the public and academic discourse: the individual and the social model of disability. It is important to notice that these models are no neutral observations but conceptions that evolved in an academic and political discourse.

### 3.1 Individual model

The *individual model* understands disability as an individual problem which can be identified and, ideally, fixed (Llewellyn & Hogan, 2000, p. 158). Also called the medical model, it locates the disability entirely in the body of a disabled person and focuses on the medical restoration of missing body functions (Wasserman et al., 2016b). This notion of disability is also employed by Hansson (2007), who defines disability as ‘an impairment of a bodily or mental function’ (p. 257). Narratives are often given a negative spin and frame disabled people as deserving pity or as experiencing a personal tragedy. On a more positive account, there is the picture of the ‘supercrips’, managing everyday life ‘despite’ their disability (Shew Heflin, 2017). Disabled people often get praised for otherwise ordinary accomplishments, because they are expected to perform less well in general (Goffmann, 1986, p. 26). Both perspectives emphasise disability as something different from ‘normal’. Although the individual model describes the predominant understanding of disability until the 1980s, it has only been named when the social model was developed in contrast to it. The medical profession has not actively built this idea of disability, which is why it has been suggested that the individual model might not be a model at all (Roulstone, 2016, p. 49). Although the necessary theoretical reflection did not happen until the emergence of the social model, it did happen later. The ideas expressed in the individual or medical model are, even if only retrospectively, very clear and will in this thesis be further summarized with the term ‘individual model’.

Due to its individual character, the individual model asks for technologies that restore

body functions or at least supports disabled people individually (Leach Scully, 2012, p. 2). Being the predominant conception of disability until the emergence of disability studies, it shaped how enabling technologies were built and used. Research on technology and disability largely focused on rehabilitation and occupational therapy: 'Much of this work then was about producing more comfortable, impairment-focused technologies of mobility, posture and gait and ultimately as great an approximation to 'normalised function' as possible' (Roulstone, 2016, p. 88). The more negative the account of disability, the more positive the account of technology – technology could 'save' disabled people by freeing, compensating or augmenting body functions (Roulstone, 2016, p. 91) and thereby end or improve an unwanted condition. After World War II, a state-push in the United States made technologies the symbol for taking care of war veterans, especially the wheelchair (Roulstone, 2016, p. 91). The role in the recovery of patients did not only serve humanistic and symbolic purposes, but also the re-integration of disabled people into the workforce. Enabling technology, especially prostheses, are an expression of the apportionment of work procedures. Clearly defined work tasks made it possible to identify necessary body functions and respective technologies to adjust bodies that were not able to work. These technologies also had a reverse effect: because of their existence, the identification of deficits in bodies became much clearer. The focus on deficits and respective technologies did not allow for the discussion of the patients' choices and independence, much less the politics of technology (Roulstone, 2016, p. 91).

The disregard of disabled people's choices is part of the heavy criticism the individual model received when disability studies emerged. Instead of autonomous persons, the individual model frames disabled people as dependent patients (Anderberg, 2005, p. 2). Disabled people reject pity partly because they, unlike generally assumed, experience a widely good quality of life (Albrecht & Devlieger, 1999, p. 977). Furthermore, the individual model has been criticised for promoting a questionable notion of 'normal' bodies; a 'standard' that should be restored through therapeutic means.

### 3.2 Social model

The development of the *social model* of disability was initiated in the 1960s by disabled people's growing frustration with the individual model (Leach Scully, 2012, p. 2; Vehmas et al., 2008, p. 2). The social model distinguishes between *impairment*, describing a missing or lost body function, and *disability*, describing the social effects of this impairment (Leach

Scully, 2012, p. 2). In the individual model, any disability would directly stem from an impairment; the terms could be used interchangeably. The new distinction allows considering that a lost or missing body function does not necessarily lead to a disability. Being short-sighted, for instance, can be understood as an impairment, but since there is almost no stigma or disadvantage due to glasses and eye lenses, short-sighted people are not considered disabled. In contrast, the missing body function of walking is an impairment and the absence of accessible buildings constitutes the disability. The disability is not located in the body of a disabled person, but in the social conditions that turn an impairment into a disadvantage (Leach Scully, 2012, p. 2). In principle, every missing body function could merely be an impairment if only society would adapt accordingly.

The social model, just as the individual one, understands disability as a problem that needs to be fixed, but by different means (Waldschmidt, 2005, p. 23). The solution lies not in individual treatment but in the reduction of structural discrimination: While the individual model pursues the eradication of disability by restoring body functions, the social model does so by demanding accessibility.

Although the social model is generally perceived as being more advanced than the individual one, it has been criticized as well (e.g. Harris, 2000). An important problem lies in its understanding of impairment. In contrast to disability, an impairment is a biological and medical fact that can be diagnosed in terms of functioning and non-functioning. Yet it has been argued that the social model unjustifiably separates body and culture and thus neglects the sociology of the body in its analysis of impairments (Anderberg, 2005, p. 4; Hughes & Paterson, 1997, p. 326). The social model inaccurately presents the body as static, lacking a history (Gibson et al., 2007, p. 10). Impairments are not objective facts but shaped by social processes. Bodies as subjects to power and change (Hughes & Paterson, 1997, p. 326). Furthermore, it can be asked to what extent disability should be understood as a problem. Both individual and social model problematize disability and try to solve the problem (Smith, 2008, p. 17), although disability could also be understood in neutral terms.

Coming back to enabling technologies, it can be observed that Hansson (2007) calls any impairment a *disability*, and distinguishes it from a *handicap*<sup>6</sup>, which refers to ‘the presence of obstacles that people with disability are subject to in society’ (p. 257). To avoid

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<sup>6</sup> The term ‘handicap’ will not be used in this thesis, as it has been said to reinforce negative stereotypes about disabled people and is considered offensive (English Oxford Living Dictionaries, 2017b).



further confusion, the terms will be used as introduced by the social model, as those form a standard in disability studies. Although Hansson's clarification suggests that he is concerned with the alleviation of effects of (what the social model calls) an impairment, he further explains that while therapeutic technologies address impairments, non-universal enabling technologies address disabilities. However, the social model clearly problematizes disability and not impairment and would focus on enabling technologies tackling disabilities, not impairments. Subsequently, technologies need to support the changes in the social environment of disabled people and not change disabled people's bodies (Anderberg, 2005, p. 3). Following this thought, therapeutic and restoring technologies are less important than assistive and universal technologies, especially in public spaces. Yet, there are disabled people who express a desire for therapeutic and restoring technologies. The social model fails to account for the desire for individually used enabling technologies. This failure can be traced back to the social model's disregard of the body. If there is nothing physical about a disability, how is technology, which is often attached to the body or working with it, supposed to alleviate the effect of a disability? Both models have been criticised for their non-applicability to enabling technologies. As Ervin Anderberg points out:

‘The medical model oversimplifies disability as an individual characteristic and directs attention towards individual adjustments and means. The social model, on the other hand, directs attention towards ideological and political analysis, not towards practical everyday solutions for experienced functioning.’  
(Anderberg, 2005, p. 1)

In sum, neither the medical nor the social model seem suitable to provide a basis for technological analysis.

### 3.3 Cultural model

The *cultural model* of disability seeks to address the previous criticisms by understanding disability as socially and culturally constructed. The relevance of culture's role for disability was admitted by disability scholars as early as 1994: ‘Disability is a complex process, which involves a number of causal components. Within this, the role of culture and meaning is crucial, autonomous and inescapable’ (Shakespeare, 1994, p. 289). Although the cultural model is not yet established in the literature to the extent that the individual and social models are, many attempts have been made to understand disability from a cultural perspective. These attempts have been collected by German disability studies scholar Anne Waldschmidt and condensed into her version of the cultural model of disability.

Her approach consists of four main ideas. First, neither impairment nor disability should be called categories that cause discrimination. Instead, they are classifiers whose meaning is entirely dependent on the social and cultural circumstances. 'In short, the cultural model considers disability not as a given entity or fact but describes it as a discourse or as a process, experience, situation, or event' (Waldschmidt, 2017, p. 24). Second, disability is only attributed if bodily differences, relevant in a cultural context, are distinguished. Third, disability and ability are connected to institutional practices that lead to the construction of normality and deviance. Fourth, by analysing cultural processes, not only disabled people but also the able-bodied majority become subject to research. This wider focus allows asking deeper questions about the construction of normality and deviance, health and functioning (Waldschmidt, 2017, p. 25). In sum, the cultural model 'investigates how practices of (de-)normalization result in the social category we have come to call "disability"' (Waldschmidt, 2017, p. 24). It is not meant as a replacement but as a supplement for the social model of disability (Waldschmidt, 2017, p. 23). As such, it supports the decrease of structural discrimination advocated by the social model but adds the plea for cultural change, in which able-bodied and disabled people are respected and culturally represented.

With these four ideas, Waldschmidt avoids the main criticisms of the social model of disability. Most importantly, impairments are not seen as natural facts, but as socially and culturally constructed, while at the same time, grounded in a perceivable difference. This understanding of impairment as a classifier avoids the social model's criticism: The sociology of the body is not merely considered but a crucial part of the analysis. At the same time, an impairment is not entirely socially constructed, but grounded in what has been called a 'brute fact' (Vehmas & Mäkelä, 2008, p. 47). Drawing from Searle's distinction between brute and institutional facts, Vehmas and Mäkelä (2008) argue that impairments are based on brute facts, such as an extra chromosome or a spinal cord injury, but only in a socio-cultural context, they become impairments, such as trisomy 21 or paraplegia (p. 48). Thereby, the cultural model considers the social and cultural construction of an impairment without neglecting the role of the body.

Moreover, the cultural model does not understand disability as a problem in need of solution but as a phenomenon in need of analysis. By allowing disability to be ambiguous, it avoids understanding it as a purely negative classifier. Understanding disability as part of

pride and identity also has been recently initiated by disability activists in social media using the hashtag #saytheword (Brown, 2016).

Despite its advantages, the cultural model of disability faces problems. The definition of disability is not only important in the academic discourse but has an impact on the lives of disabled people (Mitra, 2016, p. 236). The cultural model understands disability as a classifier dependent on socio-cultural conditions and explicitly dissolves the boundaries between able-bodied and disabled people. Once the distinction between able-bodied and disabled people gets blurred, it is more complicated to objectively identify disabled people for the purpose of supplying government support (Hammel et al., 2008, p. 1446). The problem is that a 'label' of disability might be theoretically inaccurate but needed for political practice. This problem is shared with any 'experience model' of disability, which focuses on the subjective experience of getting or being disabled. Even if people do not feel disabled, they might have impairments that make them need assistance and government support.

Notwithstanding, the cultural model offers a valuable approach to avoid the oversimplifications of the individual and social model. In addition to its theoretical accuracy, the cultural model will be used in this thesis for its compatibility with philosophy of technology. Waldschmidt (2017) stresses the usefulness of a broad conception of culture as social practice and analytical category. In doing so, she explicitly mentions the importance of material culture: Her understanding 'denotes the totality of "things" created and employed by a particular people or a society, be they material or immaterial' (Waldschmidt, 2017, p. 24). As part of material culture, technologies become an important part of any cultural analysis of disability. Enabling technologies, due to their crucial role for participation, should receive special attention.

## 4 Philosophy of Technology

- This chapter explains why technologies should play a role in the analysis of cultural processes and how technologies can reinforce political ideas. Mediation theory and extended body theory demonstrate how technologies shape human-world relations and different user experiences.

Following the cultural model of disability, an analysis of disability must research the social and cultural processes that lead to the distinction between disabled and able-bodied people. In this chapter, it will be argued that the role of technology is crucial for such cultural processes and scrutinize how it is possible that technologies contribute to them.

Philosophy of technology and science and technology studies have shown that technology cannot be understood as mere neutral tools (Anderberg, 2005, p. 9; Gibson et al., 2007, p. 14). A prominent school in contemporary philosophy of technology is postphenomenology, from which mediation theory has emerged (Verbeek, 2005, p. 101). Mediation theory is popular because it avoids two main criticisms of classical philosophy of technology: It allows for the analysis of particular technologies from a user perspective, but it also asks important philosophical questions about the existential and hermeneutic meaning of technology. These advantages make mediation theory eligible to explain why certain enabling technologies have different meanings than others, and how far they can influence views on disability.

Coming from the postphenomenological school, mediation theory takes a user perspective to analyse the users' relation to the world. This human-world relation is shaped by technology, as technologies mediate the users' perceptions and actions. This role makes technologies not neutral intermediaries but active mediators (Verbeek, 2005, p. 114). As technologies actively shape experiences and actions and are omnipresent in most societies, they play a crucial role in human self-understanding, ethics, and politics. For enabling technologies, that means that they mediate the human-world relations of their users (and non-users). They can shape disabled people's experiences and actions, their self-understanding and relevant views in ethics and politics. Building on the work of Don Ihde, Verbeek (2005) identifies four forms of mediation.

### **Embodiment relations**

describe situations in which technologies become embodied with their users. In these relations, humans perceive reality through technologies that become transparent.

Subsequently, humans do not perceive the technology itself. Ihde's own examples are enabling technologies: He names hearing aids, glasses and contact lenses, which he calls sensory technologies. They withdraw from attention but are still detachable (Ihde, 2008, p. 400).

### **Hermeneutic relations**

Humans can also perceive the world via technology that must first be interpreted. In such a *hermeneutic relation*, the human perceives the technological artefact which represents the world. Unlike in an embodiment relation, the technology cannot withdraw from attention, because it first must be interpreted. For example, braille signs need to be felt and interpreted for their users to understand their meaning.<sup>7</sup>

### **Alterity relations**

In *alterity relations*, humans actively engage with a technology. In this case, the technology emerges as a quasi-other that the human not only needs to interpret but needs to engage with. For example, a care-robot can respond to human actions, becoming a quasi-other. It is not merely embodied or interpreted for perception, it is actively engaged with.

### **Background relations**

Fourth, technologies can withdraw completely from human perception without being embodied. In *background relations*, technology constitutes the environment that shapes human-world relations in, e.g., public spaces. Not only artefacts in use but also their mere presence shape human-world relations. Background relations are especially important for enabling technologies in public spaces. Assistive and universal technologies, e.g. an access ramp, are not only important while being used, but also while merely being present.

In addition to the four relations described by Ihde, Verbeek argues that there are configurations of humans and technologies that are even more intimate than described by an embodiment relation. In cases such as implants for, e.g., deep brain stimulation, these

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<sup>7</sup> Another hermeneutic technology from the disability context is the ultrasound monitor. The pictures represent the reality in a mother's womb and must be interpreted to know something about this reality. The ultrasound technology has implications in the context of disability since it allows for the screening of dysfunctions and, eventually, subsequent abortion. Because of this 'preventive' role used for diagnostics only, the ultrasound is not an enabling technology. Together with other technologies like pre-implantation diagnostics and in-vitro fertilization, it falls out of the focus of this thesis.

technologies merge with the human being into a new being. These intimate relations are called *cyborg relations* (Verbeek, 2015).

Given that there are at least five relations, the question arises of how to determine which relation particular technologies are in. To some extent, the materiality limits the possibilities – fully functioning glasses do not need interaction and will be rather in embodiment than in alterity relations. However, glasses could be used for different purposes. They can be used to correct a visual impairment, but they can also be used in art projects, as part of a costume, to ignite a fire, etc. Hence, technologies could be used for many purposes and are not definable by their use. This observation is accounted for by the concept of *multi-stability*. Technology can be understood as what it is used for, but it remains undetermined what it ‘really’ is. Multi-stability is, therefore, the theoretical foundation for what was observed by Hansson: That the category of some enabling technologies only depends on their use and social factors, and that specific goals can be technologically realized differently by a range of artefacts. If the use of technologies can vary, so can the human-world relation they shape.

For example, a compensatory technology would probably evoke embodiment or alterity relations, e.g. a walking cane or braille signs. In contrast, universal technologies might withdraw from attention and could be categorized as background relation technologies, e.g. an accessible entrance. In the second chapter, it was hinted at the different effects of using hearing aids or captions to watch TV as a user with a hearing impairment. With the insights from this chapter, this analysis can be made more precise. A hearing aid, being a restoring technology, is in an embodiment relation with the user and the world. It is transparent, withdraws from attention and enables the user to experience the movie almost like the user’s peers whose hearing is not impaired. Captions, however, can here be assumed as universal technologies, and are in a hermeneutic relation. They need to be read and understood – interpreted – for them to say something about reality, even if this reality is on screen. The user experience in both cases differs because the hearing aids withdraw from attention and enable the user to listen, while the captions are clearly visible and need interpretation. The human-world relation and the category of enabling technologies are shaping the user experience. This effect is increased if other people are taken into account. To continue the example, the person with the hearing impairment might feel separated from or closer to her fellow TV watchers depending on whether she uses the

same technology and has a similar experience to theirs.

So far, it has been discussed how technology mediates the perception and action of an individual. Additionally, a technology might also shape the perceptions and actions of a third person. In the case of embodiment relations, this intersubjective perspective is addressed by the extended body theory (Feenberg, 2003). Feenberg explains his theory with a well-known example in the phenomenology of perception; a blind person's walking cane (Merleau-Ponty, 1945/1962, p. 165). Following mediation theory, this cane is in an embodiment relation with the user and the world. Following Feenberg, this mediation of the user's experience leads to the cane becoming a part of the user's body; an extended body. This extended body is not only relevant for the user's perception of the world, but also for the perception of the user by others: A walking cane reveals the user as a person with a disability. The extended body is then not only a body that acts through technological mediation, but also a body that signifies itself through that mediation (Feenberg, 2003). Back to the TV example, this intersubjective aspect is crucial to the user experience. The user acceptance of enabling technologies will depend on not only the self-experience of disabled people but also on the interactions with other people mediated by the technology.

While the interpretation of technology as an active mediator has made it possible to explain different human-world relations, it has not yet been explained how values or worldviews can be embodied by technology. The form of mediation results not only from the use of the artefact but also from the designer's intentions. These intentions are expressed by technological artefacts via a materialized intentionality, a prescribing role (Verbeek, 2006). Many technologies are made for a certain purpose. A typical example is the speed bump, which prescribes drivers to slow down. As illustrated by, e.g., Rosenberger (2014), design can be used to prevent certain actions. His examples are public park benches, which have armrests that disallow homeless people to use the benches as sleeping places. In this case, the design is used to drive the homeless away; the materialized intentionality is the unwillingness to have homeless people in public spaces. These results from philosophy of technology can be made fruitful for the context of enabling technologies.

Materialized intentionality explains how the designer's intentions can take effect in the world via technology. In the third chapter, it was demonstrated how different models of disability demand distinct categories of enabling technologies. Now it was analysed that different categories can express political views, which means that they can, in turn, reinforce

models of disability. Coming back to the TV example, hearing aids would reinforce the individual model's idea that disability is a private matter and should be 'fixed' individually, while captions would reinforce the social model's idea that disabled people should be accepted and that a focus should lie on accessibility.

In the third chapter, it was also established that the cultural model of disability asks for the analysis of social processes leading to the categorization of people. With the insights from this chapter, it can now be explained why technologies must be a crucial part of this analysis: '[B]odies and technologies are intimately intertwined in the production of disabilities and social exclusion or inclusion' (Gibson et al., 2007, p. 18). In sum, enabling technologies are not neutral. As mediators, they shape disabled people's experiences and actions; they can even mediate views on disability by others (Anderberg, 2005, p. 8). In this mediating role lies their potential to violate the need for acceptance. Enabling technologies can reinforce obsolete views on disability and their use can stigmatize and/ or discriminate their users. These violations might seem minor, but constitute yet 'another small moment in a system of separate and unequal accommodation and access', as Wittkower (2016) describes the exclusionary effect of white band-aids (p. 3). Although this context is not the one of disability, he stresses the discriminatory effects of small exclusions from every-day situations, which can also be applied to the disability context.



## 5 Ethical implications of enabling technologies

- This chapter explores the ethical implications of different categories of enabling technologies. Based on definitions of stigmatization and discrimination, they will be analysed in their potential to violate the need for acceptance.

### 5.1 Stigmatization and discrimination

After the crucial role of technologies for the reinforcement of models of disability has been established, this chapter turns towards a more specific analysis of different categories of enabling technologies and their ethical implications. It will be analysed to what extent they violate the need for acceptance by reinforcing the contested views on disability from the individual model or by stigmatizing and discriminating against disabled people.

To explain how technologies might contribute to the stigmatization of disabled people, it must be clarified what the terms *stigma* and *stigmatization* refer to. An older, but still very up-to-date definition was developed by Erving Goffmann (1986):

‘While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind — in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap.’ (p.12)

In this quote, a stigma is defined as an attribute that makes a person seem different and ‘less than others’. In the case of disabilities, this attribute can be a missing body function, somewhat harshly referred to by Goffmann as ‘abominations of the body - the various physical deformities’ (Goffmann, 1986, p. 14). A missing leg, or a very low height, let a person be perceived as different and ‘less’, and, thereby, constitute a stigma. Due to their relational definition, stigmas occur in social interactions. Like Goffmann’s, most definitions consist in the recognition of a difference and a devaluation (Bos et al., 2013, p. 1, 2013). Because of the devaluation, a stigma is, by definition, negatively connoted. Subsequently, one can distinguish between a neutral difference and a negative stigma.

Whether a difference constitutes a stigma is dependent on the cultural context. In Western societies, a stoma is certainly more stigmatized than blindness. As the cultural model of disability suggests, these differences in the perception of attributes are crucial for understanding disability. Perception, as the fourth chapter demonstrated, is mediated by technology. Hence, an attribute cannot only be a non-conformable body or body

movements, it can also be the use of technologies, e.g. enabling technologies. In the negative case of a stigma, there might be a stigma attached to the body, but there can also be a stigma attached to the use of a technology. A person with missing legs might be stigmatized because of her body (primary stigmatization), but she might first be stigmatized because of the use of a wheelchair (secondary stigmatization). Especially if disabilities are not clearly visible, the technology is perceived first. For example, a hearing impairment is not necessarily visible, unless the person uses hearing aids. Similarly, wheelchairs can be perceived before the person and her body. In these cases, like Feenberg (2003) described, the technology reveals the user as disabled. Therefore, enabling technologies can contribute to social processes of stigmatization (Gibson et al., 2007, p. 15).

Stigmatization often gets confused with the term discrimination. While stigmatization refers to the perception of persons as different and less than others because of certain attributes, discrimination refers to concrete disadvantages. Stigmatization means to be perceived differently, while discrimination means to be treated differently. First, there is a difference in perception, then there is a difference in treatment. This treatment can be neutrally or negatively connoted: *Discrimination between* simply means to treat some people differently than others, while *discrimination against* implies an unfair treatment (English Oxford Living Dictionaries, 2017a). These distinctions have implications for the ethical acceptability: discrimination between different user groups might be necessary and justifiable while discrimination against people is problematic.

In the following sections, it will be explained how the categories of enabling technologies might allow for stigmatization, discrimination or reinforcement of obsolete views on disability. The analysis of inherent features of the categories will be illustrated with examples.

## 5.2 Therapeutic technologies

Therapeutic technologies are defined as technologies which restore a body function permanently. As explained before, they are in line with the individual model of disability, which has been heavily criticized by the disabled community. These technologies devalue disabled bodies and understand them as in need of ‘fixing’. The intention to make disabled people fulfil ‘normal’ standards materializes in the technology, as explained in the fourth chapter. Subsequently, therapeutic technologies by definition violate the need for acceptance. A well-discussed example is the cochlear implant for deaf people whose use has

often been denied for this exact reason. Members of the Deaf community have argued that deafness is not a medical condition, but rather identity, culture, and community (Häyry, 2008, p. 158). Therapeutic technologies can contribute to static ideas about 'standards of normality' and a narrower spectrum of accepted bodies.

Due to the permanent character of therapeutic technologies, the choice for or against them presents itself only once; before their implementation. The finality of this choice makes therapeutic technologies especially problematic for the use on children. They are not capable of making the choice themselves but must live with it eventually forever. For both children and adults, the choice is often influenced by medical professionals but must be made individually. This individual choice and their individual use make therapeutic technologies reinforce the view of disability as a solely individual problem, distracting from the political dimension of disability (Lupton & Seymour, 2000, p. 1853). By confining the matter to the private context, matters of social justice are ignored.

### 5.3 Restoring technologies

Following their definition, restoring technologies can be interpreted as non-permanent therapeutic technologies. Thus, restoring technologies also ask disabled people to change themselves to conform to 'normal standards'. Following their temporality, they are likely more visible than therapeutic technologies, because they are, e.g., not implanted. Due to their higher chance of visibility, restoring technologies, such as glasses or hearing aids, can constitute a stigma. In such a possible stigma, for example, the preference for eye lenses instead of glasses is rooted. This preference can stem from the discrimination against users of glasses, e.g. in high schools.

The invisibility of enabling technologies is related to the idea of 'passing' (Goffmann, 1986, p. 93). In an environment where disabled people need to be 'fixed' to count as human beings deserving support and respect, people who are for any reason not able to be 'fixed' need to 'pass as normal' to receive the same respect. The alternative would be a disvalued attribute; a stigma in Goffmann's (1986) sense. While therapeutic technologies can allow for passing perfectly, restoring technologies, due to their increased visibility, do not. They can be relatively discrete, such as hearing aids, but their use is mostly visible. Compared to therapeutic technologies, restoring technologies offer more frequent choices regarding their use.

#### 5.4 Compensatory technologies

Compensatory technologies replace a body function with another general function. As they do not restore a body function, they do not run the risk of ‘fixing’ disabled people. Users can decide whether they want to use them every day; they are not permanent. Compensatory technologies can be customized and account for the fact that disabled people are not a heterogeneous group and often have highly individual needs. For example, wheelchairs have possibilities to individually adjust position, height, etc., and allow for the addition of assistive technologies. Due to their specialization, compensatory technologies are crucial for disabled people’s participation in society. Mobility for paraplegic people can only be achieved with wheelchairs. Compensatory technologies can be interpreted as equalizing the differences between disabled and able-bodied people for the common use of other technologies. For instance, a wheelchair equalized its user and an able-bodied person, so they can both use an elevator. Their acceptance of disabled bodies, their permission of choice, and their necessity form compelling arguments in favour of compensatory technologies.

Yet, they are often individually used, e.g. wheelchairs and walking canes. By letting the individual adapt and not the environment, compensatory technologies could contribute to the reinforcement of the individual model of disability. Because they do not aim at fixing people, this contribution is smaller than with therapeutic and restoring technologies. A bigger problem of compensatory technologies is their potential for stigmatization and discrimination. Since they are used by disabled people only, their use constitutes a perceivable difference. A wheelchair or walking cane is firmly connected to disability and can emphasize the otherness of disabled people. Finally, compensatory technologies are not sufficient for their user’s participation in society. Without the necessary additional adjustments like lower curbs, elevators, etc., the wheelchair cannot enable its user at all (Anderberg, 2005, p. 8).

These considerations make compensatory technologies difficult to evaluate. On the one hand, they are necessary and accepting, and on the other hand, they can easily contribute to stigmatization and discrimination. Hence, the dilemma of assistance and acceptance becomes especially evident with compensatory technologies.

#### 5.5 Assistive technologies

Assistive technologies are designed for specific purposes and tasks. They do not attempt to fix disabled people and they offer choices. However, just like compensatory technologies,

they are exclusively used by disabled people. Their use is a perceivable difference to other people, which is why they can contribute to stigmatization and discrimination as well. The functions they enable might be as crucial for participation, but in contrast to compensatory technologies, their design could be – depending on the concrete technology – more inclusive. A more inclusive design would allow more people to use the technology and its use would not make the user perceived as disabled.

This effect can be illustrated with Hansson's (2007) ramp example. A ramp in the back of a building, with a wheelchair sign, would be an assistive technology. This ramp prescribes the action of entering a building *as a wheelchair user*. The division of user groups for front and back entrances shows that wheelchair users and able-bodied persons are not the same. Following Goffmann's (1986) definition, the mere use of the door makes the wheelchair user different; and can put a stigma on him. Of course, the wheelchair user would have been revealing himself as disabled with his body or with the use of his wheelchair alone. As described in the beginning of chapter 5, a missing leg can constitute a primary stigma, and the use of a wheelchair a second. But the use of the back door emphasizes his otherness (Gibson et al., 2007, p. 15), which could be called tertiary stigmatization. Other people might notice the backdoor ramp's existence but will refrain from using it for reasons of convenience. The use of the back door does constitute a tertiary stigma, as the use of an inconvenient door is, in Goffmann's words, 'less desirable' (Goffmann, 1986, p. 11).

In addition to the difference in perception, wheelchair users have expressed discomfort with the use of back entrances, particularly in neighbourhoods with higher crime rates (Doucette, 2017). This practical disadvantage is a discrimination of disabled people through technology that is supposed to enable them. The back-door ramp, which contributes to stigmatization and discrimination, could be replaced with a front-door ramp, the more inclusive option that was previously mentioned.

However, not all assistive technologies can be made universal. While everybody has an interest in accessing public buildings and can use a front-door ramp for it, other assistive technologies are not interesting to able-bodied people, e.g. reading machines. These irreplaceable technologies share the same ethical implications as compensatory technologies: necessary, yet possibly stigmatizing.

## 5.6 Universal technologies

Universal technologies are often used in public spaces and are, as has been described in chapter 3.2, in line with the social model of disability. They do not attempt to fix disabled people. More importantly, they are designed to be used by everybody. Subsequently, their use does not constitute a difference between able-bodied and disabled people. They do not provide the first condition for stigmatization or discrimination and avoid violating the need for acceptance by definition.

Continuing with the ramp example, a front-door ramp can be identified as a universal technology. This ramp would be a technology that enables both wheelchair users and people with strollers or delivery people with handcarts to enter a building. It is also usable by everyone who does not have unusual circumstances requiring a ramp. This ramp mediates and prescribes the action of simply entering a building – as a person, not as a member of a certain user group. In sum, the position of the ramp makes a difference (Anderberg, 2005, p. 9).

Universal technologies are not confined to public spaces and use. For instance, the company Eone produces haptic watches that are very useful for people with visual impairments but are advertised as innovative watches attractive to everyone, instead of ‘watches for the blind’ (Eone, 2017). Likewise, the usability of everyday devices by disabled people could be improved.

## 6 Ethics of Enabling Technologies

- This chapter provides the ethical argument against the violation of the need for acceptance. Based on the capability approach, the ethical desirability of different enabling technologies is evaluated.

### 6.1 Capability approach and disability

The previous chapters have offered a detailed analysis explaining which power enabling technologies have over the perception of disability and how they can violate the need for acceptance. However, it has been argued that a descriptive analysis of disability is not sufficient in general: ‘The proper response to the disadvantages associated with disability depends not only on causal attributions but also on moral judgments about responsibility, respect, justice.’ (Wasserman et al., 2016b). While the social and cultural model of disability connect their analyses to a social and cultural agenda, their demands are usually not grounded in more elaborate ethical theories. The normative basis for such demands will be developed in this chapter.

The capability approach, most prominently developed by Martha Nussbaum<sup>8</sup> and Amartya Sen, is a prominent approach to well-being, development and justice (Robeyns, 2016, p. 2). Unlike other approaches for ethical evaluation, it does not focus on subjective well-being, but on ‘the moral significance of individuals’ capability of achieving the kind of lives they have reason to value’ (Wells, 2017, p. 1). In doing so, the capability approach does not only describe subjective well-being (e.g. in form of happiness) or the availability of material means, but it provides the normative basis to assess people’s capabilities of achieving their lives objectively. This focus contains two main claims: first, that there is a moral significance to the freedom to achieve well-being; and second, that this freedom must be understood in terms of capabilities (Robeyns, 2016, p. 1). How to achieve well-being is an individual choice, but the different options must be available. In demanding such availability, the capability approach is not descriptive, but inherently normative (Robeyns, 2016, p. 3). For assessing a society’s social justice, it asks ‘What is each person able to do and to be?’ (Nussbaum, 2011, p. 18). The answers to this question are capabilities, meaning actual opportunities to choose and to act (Nussbaum, 2011, p. 20; Robeyns, 2016, p. 1). De jure possibilities cannot be called a capability, only de facto opportunities. Two notions of

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<sup>8</sup> This chapter focuses on Nussbaum’s theory because it, through its list of central capabilities and explicit problematization of stigmatization and discrimination, is especially well-applicable to the disability context. It thereby avoids the formulated criticism of Sen’s approach to not specify capabilities (Clark, 2006, p. 6).

capabilities are specified: *Internal capabilities* refer to the characteristics of a person, such as skills, traits, bodily states, etc. They are not fixed, but can be trained, learned and are subject to change (Nussbaum, 2011, p. 21). Together with the social, political and economic situation of the individual, they constitute a *combined capability* (Nussbaum, 2011, p. 22). This combined capability can be further distinguished from a *functioning*, which refers to the realization of a capability (Nussbaum, 2011, p. 25). ‘The distinction between functionings and capabilities is between the realized and the effectively possible, in other words, between achievements, on the one hand, and freedoms or valuable opportunities from which one can choose, on the other.’ (Robeyns, 2016, p. 4). These terms can be explained with the example of a wheelchair user who wants to vote in a political election:

- Internal capability: The ability to critically think and understand the political system;
- Social/political/economic context: Accessible polling station, democratic state, money to reach the polling station or possibility of postal voting;
- Combined capability: The actual opportunity to vote in the election;
- Functioning: Going to vote.

According to Nussbaum, the combined capabilities are the ones that measure social justice (Nussbaum, 2011, p. 25). The provision of such is any government’s responsibility, while the choice of their realization into a functioning is made freely and individually. In the example, it would be the government’s task to ensure that the wheelchair user has the combined capability, the actual opportunity, to vote in the election – otherwise, it inflicts social injustice. To avoid social injustice, it must be clear which capabilities are relevant enough to be secured by the government. This unclarity constitutes one of the major points of criticism for the capability approach (Robeyns, 2016, p. 11).

For identifying capabilities that can justifiably be demanded, Nussbaum makes use of the notion of human dignity. Specifically, she argues for ten capabilities that are required for a dignified life (Nussbaum, 2011, p. 33; Oosterlaken, 2012, p. 223). They are ‘(1) Life; (2) Bodily health; (3) Bodily integrity; (4) Senses, imagination and thought; (5) Emotions; (6) Practical reason; (7) Affiliation; (8) Other species; (9) Play; and (10) Political and material control over one’s environment’ (Clark, 2006, p. 6). These ten central capabilities should be secured by the government for all citizens ‘at least on a threshold level’ (Nussbaum, 2011, p. 33). The focus on a threshold leaves room for interpretation: Nussbaum clarifies that the list of central capabilities is a suggestion and that the threshold level must be defined in each



nation (Nussbaum, 2011, p. 41). Not providing such a threshold results in *capability failure*, which is morally problematic (Nussbaum, 2011, p. 19). The previously described situation, in which a wheelchair user might not be able to vote because of inaccessible polling stations, constitutes such a capability failure.

Negotiation is necessary for cases in which central capabilities contradict each other. Regardless of the choice that is made, the choice for one capability over the other always violates one capability. Because all capabilities are essential, such choices are called 'tragic choices' by Nussbaum. However, she suggests that there are situations in which a clear preference is possible, even if the choice still violates the other capability. The capabilities of *affiliation* (7) and *practical reason* (6) are preferred over others for their pervasive role for the other capabilities (Nussbaum, 2011, p. 37). Affiliation describes social interaction, but also self-respect and non-humiliation. As part of non-humiliation, non-discrimination is mentioned.

The capability approach will be applied in this thesis for two reasons. First, it captures one of the most central goals expressed by the disabled community; full participation in society (Hammel et al., 2008, p. 1445). Nussbaum includes several forms of it in her list of ten central capabilities (Burchardt, 2004, p. 740), e.g. the ability to change locations freely (3), an adequate education (4), play (9), and the ability to participate in political life (10) (Nussbaum, 2011, p. 34). 'To fully participate in society' will henceforth be treated as a central capability, and the capability approach can serve as the normative basis to demand this capability.

The second reason to use the capability approach is that it has been proven valuable in the disability context (e.g. Burchardt, 2004, p. 736; Mitra, 2016, p. 236; Robeyns, 2016, p. 7). This success can be ascribed to the reflection of the importance of human diversity:

'[H]uman diversity is one of the main reasons to focus on human capabilities, instead of on the distribution of resources; the capability approach recognizes that, due to human diversity, access to a resource does not always translate in an expansion of human capabilities' (Oosterlaken, 2012, p. 224).

Following the capability approach, not resources but capabilities are the crucial conditions for the well-being of citizens. In the case of disabled people, this analysis becomes especially evident. For example, a wheelchair user and prospective student might receive resources to cover the tuition fee and housing costs. However, if the study buildings are not accessible, the wheelchair user will not have the combined capability to study, although he has the

resources. The simple allocation of resources does not consider that people and their bodies differ. The focus on the capability to receive education, meaning the real possibility to study, frames the situation differently: the wheelchair user does not have the capability to participate in university classes and is a victim of social injustice.

The previous argument is hard to make with most other theories of social justice. Rawlsian approaches focus on procedures and have been criticized for understanding disabled people as ineligible to form a social contract. Outcome-oriented theories have been criticised for excluding disabled people as well; and it has been argued for outcomes that consider disabled people's special needs (Wasserman, Asch, Blustein, & Putnam, 2016a, p. 12). Although such theories of social justice could be adapted to allow for the allocation of more resources to disabled people, these theories would focus on welfare. Following the social model of disability, disabled people are not in need of welfare, but in need of accessibility. A focus on individual welfare makes these theories fall back into the individual model of disability. The applicability of the capability approach to the disability context is also reflected in the use of its language in United Nations policies, e.g. *the United Nations Convention on the Rights of Persons with Disabilities* (Harnacke, 2013, p. 769). The usefulness of the capability approach is acknowledged by Hansson (2007), although he focuses on Amartya Sen's theory and not Nussbaum's (p. 263).

Applied to the disability context, the capability approach provides the possibility to demand that disabled people should have the capability to participate in society. To ensure this capability, it does not only demand the allocation of resources to individuals but highlights the importance of public infrastructure (Nussbaum, 2006, p. 321). Technology is an essential part of transportation and enabling technologies are crucial for the mobility of disabled people. Hence, the capability approach supports enabling technologies and would, in general, approve their development. Based on the capability approach, disabled people could demand enabling technologies for achieving the capability of participation.

If society does not provide the capability of participation and a capability failure emerges, society can be blamed for contributing to social justice. It can be the result of people not knowing about the needs of disabled people or of people deliberately ignoring those needs. In both cases, this failure is one of society, not the individual, as the state is responsible for providing the central capabilities. This focus on the state's responsibility resembles the social model of disability's focus on the social adaptations to alleviate disabling

effects. In both theories, the state is responsible for an individuals' capability to participate in society, not the individuals themselves. The social model and the capability approach have also been linked in the literature (e.g. Burchardt, 2004). Their compatibility suggests that the capability approach would rather embrace enabling technologies advocated for by the social model instead of by the individual one. Additionally, the capability approach, by its focus on individual freedom, highlights the importance of choice and dignity. Disabled people can decide themselves which capabilities they want to realize. The capability approach does not claim that disabled people *must* participate in society, it only says that disabled people should *have the capability* to participate if they want to. In sum, the closeness of social model and capability approach, as well as its focus on individual freedom, speak for the rejection of the individual model's perception of disabled people as non-autonomous patients, incapable of decision-making. The reinforcement of the individual model of disability, as the first possibility to violate the need for acceptance, can thereby be judged ethically problematic with the capability approach.

The focus on the government's responsibility also points at a prominent criticism of Nussbaum's approach. She rather vaguely refers to 'state', 'society' and 'government' as institutions responsible for providing capabilities. It remains unclear which players are responsible for which actions in realizing capabilities (Robeyns, 2016, p. 15). Especially in the context of enabling technologies, other institutions, i.e. industry and insurance companies, are part of a more complex network that could realize capabilities. This weakness of the capability approach makes it more complicated to demand the ethically correct development of enabling technologies from certain actors. It does not, however, concern the evaluation of certain technologies as violating the need for acceptance.

Concerning the other possibilities of violating said need, the capability approach clearly condemns stigmatization and discrimination. Nussbaum states that her approach is 'concerned with *entrenched social injustice and inequality*, especially capability failures that are the result of discrimination or marginalization' (Nussbaum, 2011, p. 19). Discrimination is rejected by the capability approach as a capability failure, which in turn identifies as social injustice. As mentioned before, non-discrimination is explicitly mentioned as a specification of the eighth central capability; affiliation (Nussbaum, 2011, p. 34). Marginalization, i.e. the different treatment and denial of social participation of certain groups, can be interpreted as the result of discrimination against a certain group, such as disabled people.

Overall, the capability approach supports the need for acceptance and goes against its three possible violations: reinforcement of obsolete views on disability, stigmatization and discrimination against disabled people. Together with the insights from the previous chapters, the following argument can be made:

Premise 1: The capability approach is suitable to approach ethical issues in the disability context. (as argued for in chapter 6.1)

Premise 2: The capability approach condemns obsolete views on disability, stigmatization, and discrimination against disabled people. (as explained in chapter 6.1)

Premise 3: Some enabling technologies reinforce obsolete views on disability and/or contribute to the stigmatization and discrimination against disabled people. (as explained in chapter 4 and 5)

**Conclusion:** Some enabling technologies are violating the ethical norms of the capability approach.

The capability approach captures perfectly the dilemma of assistance and acceptance: Enabling technologies are morally justified to support the capability to participate in society, but they are problematic when they violate the need for acceptance. All three forms of such violation, the reinforcement of obsolete views on disability, stigmatization, and discrimination against disabled people, are deemed problematic by Nussbaum's capability approach. The preference of the central capability of affiliation in cases of tragic choices, including non-discrimination, suggests that for a dignified life, the need for acceptance might be more important than the need for assistance.

## 6.2 The ethical desirability of enabling technologies

How can stigmatization and discrimination be avoided? Following the insights from chapter 5, both begin with the perception of a difference. Although the capability approach's focus on dignity condemns stigmatization and discrimination, it does not give many clues on how to counter it. A finer-grained analysis is possible with the work of pragmatist philosopher Richard Rorty. Just like the capability approach, he stresses the importance of human diversity (Huang, 2009, p. 84). He introduces the notions of 'morally relevant' and 'morally irrelevant' differences. Although differences are to be embraced, they should be considered morally irrelevant in most cases. For example, in court, the defendant's gender or race

should not play a role for the degree of penalty. In fact, situations in which gender, race or religion should play a role are an exemption. Likewise, being disabled or able-bodied should be irrelevant for the capability to participate in society.

According to Rorty, highlighting commonalities can help to overcome prejudice and foster acceptance. For example, most people, non-regarding their cultural background, religion or appearance, care for their families, are hurt by humiliation and have similar reactions to medicine (Huang, 2009, p. 84). Another similarity could be the need of a certain technology, e.g. an access ramp. The use of such a universal technology would, as described before, unite delivery people, injured people, people with strollers, and wheelchair users. Because universal technologies are usable by everyone, their use does not add to the visibility of the disability. Therefore, they are the only enabling technologies that do not run the risk of secondary stigmatization and discrimination. As they also have been associated with the social model of disability, they meet the need for acceptance. Considering their role in the participation of society, they can be judged ethically demandable by the capability approach. Hansson (2007) also prefers universal technologies over compensatory and assistive technologies for their inclusive character (p. 260). The moral acceptability of universal technologies has implications for assistive technologies. They should, if possible and as demonstrated in the ramp example, be replaced by universal technologies. Ramps in front entrances and haptic watches are a good start, but many other assistive technologies could be designed in a 'more universal' way.

Unfortunately, at least three problems arise with universal technologies. First, they are out of individual control. Users are dependent on architects and designers to build their product in a way that makes it usable for everyone (Hansson, 2007, p. 260). Second, as stated before, universal technologies on their own are not sufficient for enabling disabled people to participate in society because there is a need for individualized technology. Third, not all technologies can be designed to be usable by everybody; what is enabling for some might be disabling for others. Curbs, for instance, help people using a walking cane but are an obstacle for wheelchair users (Bösl, 2009, p. 330). For these three reasons, not all enabling technologies can be universal. If it was possible to design all enabling technologies as universal ones, the dilemma of assistance and acceptance would not arise.

The question remains how therapeutic, restoring, compensatory and assistive technology can avoid violating the need for acceptance. However, as a concrete result for

universal technologies, it can be stated that it is important that they are made compatible with more individual technologies, e.g. elevators or busses with wheelchairs. As observed before, many technologies cannot function on their own, but only in a network of compatible technologies. For an optimal result, designers should not only think about diverse bodies but also about the other technologies that people might use a new technology with.

The importance of universal design has also been recognized by policy-makers and designers. For instance, the UK project CAGE, the government's advisor on architecture, urban design and public space, gives five principles of inclusive design. These principles include 'Inclusive design places people at the heart of the design process' and 'Inclusive design provides buildings and environments that are convenient and enjoyable to use for everyone' (Fletcher, 2006). The first principle refers to a participatory design process and reflects the previous observation that the priority should be to involve disabled people in the design process. The second principle shows that universal technologies are deemed best for inclusive design. A third principle explains what to do in the case of the third problem previously identified with universal technologies: 'Inclusive design offers choice where a single design solution cannot accommodate all users' (Fletcher, 2006). In sum, CAGE deems participation, universal design and provision of choice most important for inclusive design.

Although the capability approach judges all non-universal enabling technologies as ambiguous, it points at an important insight for the development and use of enabling technologies which has also been emphasized by CAGE; the importance of choice. As analysed in chapter 6.1, the capability approach considers people's individual preferences. Depending on the individual character and situation of disabled people, e.g. whether they have been disabled from birth or since an accident, their opinion about enabling technologies might vary substantially, even from day to day. Allowing for choices and, thereby, understanding disabled people as autonomous persons, should play an important role in the development of enabling technologies. However, not all choices are meaningful and relevant and must be protected by the capability approach. The choice between red and blue walking canes is not very meaningful. Meanwhile, choices that relate to stigmatizing or discriminating effects are certainly relevant.

As analysed in the fifth chapter, therapeutic technologies do not offer more than one choice. If disabled people receive the capability to participate via therapeutic technologies,

the government, being responsible for providing capabilities, does not treat disabled people as autonomous people having a choice, but as dependent people who have no choice but one. That is not to say that some disabled people would not very much welcome the government support with the purchase of therapeutic technologies and that they should not receive such support for the sake of their capability to participate. However, to avoid falling back into the medical model, the government support should not focus on such technologies and medical staff should be taught to carefully communicate different options without devaluing a disabled person's body. This recommendation clearly opposes the opinion of Hansson, who prioritizes the use of therapeutic technologies (Hansson, 2007, p. 259).

Restoring, compensatory and assistive technologies are better insofar as they allow for more choices than therapeutic technologies. Disabled people can choose whether they want to use them every day – whether, in case this choice is applicable to the individual situation, they want to 'pass as normal' or display their non-conformable body. Ideally, this choice also presents itself not only in the question of whether to use the technology but also in the way of using it. By giving these choices, it is ensured that disabled people are addressed as autonomous persons. Yet, even with these choices, the technologies could still contribute to discrimination and stigmatization, which will be discussed in the next paragraphs in that order.

To properly analyse the possible discrimination against disabled people by technology, it is useful to return to Rorty's work. In some contexts, a disability should be a morally irrelevant difference, but in other situations, it becomes morally relevant. For, e.g., receiving government support, the differences of disabled people must be emphasized, but for accessing a building, the disability should be irrelevant. It is important to notice that in both cases, the neutral term 'difference' is used. If disabled people are treated differently, it should only happen because their difference is morally relevant in that context. That ensures that there is a mere *discrimination between* able-bodied and disabled people, but no *discrimination against* them. This ensures ethical acceptability based on the capability approach.

So when does discrimination between become discrimination against? In the context of disability, Wittkower (2016) proposes three conditions to identify discrimination (against): 'The difference [in treatment]

- is not merely in ease of access, but in access itself;

- does not reflect a difference in user demographics that requires distinct provision of service to distinct demographics;
- cannot be accommodated through multiple equivalent providers of service' (p.1).

These conditions constitute a threshold after which discrimination becomes discrimination against, although the social context must be considered as well (Wittkower, 2016, p. 3). Examples of technologies that clearly discriminate against disabled people are narrow doorways, revolving doors, signs without Braille, etc. Revolving doors, for example, as a sole access to a building, would deny access to wheelchair users (1). Using a wheelchair does not constitute a difference that necessarily requires distinct provision of service (2); on the contrary, for entering a building, it constitutes a morally insignificant difference following the capability approach. Finally, the access to the building cannot be provided through multiple equivalent providers, because there is only one access available, namely the revolving doors (3). Hence, the revolving doors fulfil all three of Wittkower's conditions and can be judged as discriminating against disabled people. However, a revolving door is not an enabling technology, because it is not supposed to alleviate the effect of a disability. The example was used for its clarity, but how can Wittkower's principles be applied to enabling technologies? The first condition, a difference in access and not ease of access, does not apply to enabling technologies in general. They cannot exclude someone from access because that is against their nature of providing access to a function. Similarly, the third condition, the accommodation through multiple equivalent providers of service, does not apply either, because the accommodation, which would have been denied by the revolving doors, is again provided by enabling technologies by definition. Applicable to enabling technologies is the second condition. Enabling technologies are discriminating against disabled people when they make unnecessary distinctions between user groups. This result is in line with the analysis from chapter 5.4: most assistive technologies run the risk of discriminating against their users when they could also be universal. In the context of these assistive technologies, the difference between able-bodied and disabled people should be morally irrelevant.

Although neither Wittkower nor Nussbaum gives an explicit definition of discrimination, their terms' contexts suggest that they both refer to *discrimination against* as introduced in chapter 5. Following Nussbaum and Wittkower, the revolving door is clearly discriminating against disabled people and, hence, morally problematic. Even if there was



another extra door for wheelchair users, as often provided in public spaces nowadays, it can be doubted whether this 'extra' door would constitute an 'equivalent provider of service'. As analysed in chapter 5.4, this difference would at least contribute to stigmatization, and is, subsequently, not equivalent. As explained in chapter 5.5, these problems apply to most assistive technologies.

With restoring and compensatory technologies, things are different. As Wittkower (2016) stresses, technological design cannot possibly accommodate every user. In contrast to assistive technologies, restoring and compensatory technologies cannot be made universal because they are being designed for disabled people with very individual needs. In that, they fulfil Wittkower's second condition, but they are more likely to stigmatize disabled people.

If stigmatization should be avoided, the obvious conclusion from the insights of the fifth chapter would be the need of a cultural change. Following that, a stigmatization could be a mere difference and a discrimination could be a neutral discrimination between users with diverse needs. This cultural change can be supported by the right technologies. If technologies are showing a body difference in a non-pejorative way, the common use of such technologies can lead to the acceptance of such differences and to respective cultural change. 'Invisibility is overrated' has been named a design principle for assistive technology (Hendren, 2014). More accessible places, more visibility, lead to more social acceptance of disabled people. This approach stands in sharp contrast to the idea of making disability disappear with technology, as expressed with therapeutic technologies. As Taylor (2010) summarizes, physical access leads to social access. For example, children's prostheses have been designed by their users in a participatory approach. The children were enthusiastic about colourful designs that evoke interest and awe in their peers rather than pity or disconcertment (Jinman, 2015). In these cases, the social context does not allow for the stigmatization of such technologies; the technology indicates a mere difference.

It can be objected that cultural change cannot be obtained by a 'technological fix'. Resolving issues with technology instead of processing and solving them via public debate and cultural change has been problematized in other contexts. For instance, it has been doubted whether tackling climate change with geo-engineering instead of social changes does justice to the responsibility towards future generations (Committee on Geoengineering Climate, 2015; Gardiner, 2010). Similarly, it could be argued that the use of enabling

technologies and the subsequent presumably successful participation in society of disabled people distract from deeper sociological issues that lead to a devaluation of differences in the first place. However, the fourth chapter has demonstrated that culture and technology are deeply intertwined, as technologies mediate human actions and perceptions. Thus, technological and cultural change are not separate but connected. Any effort to evoke a cultural change can, therefore, be supported by technology without the technological changes constituting a technological fix. Hence, the objection against using enabling technologies to induce cultural change is not tenable.

Although technologies that present a disability in a positive way are helpful to bring about cultural change, these technologies do not offer much choice to their users. Until the aspired cultural change has happened, the use of such technologies would put disabled people in a constant position as fighters for justice; their suffering would be necessary to bring about the desired cultural change. Constantly taking this position would be too much to ask of disabled people. Before cultural change happens, what can be done against the stigmatization of disabled people? A good design would need to give a choice between 'passing' and demonstrating a disability – if not in the same device, then at least in the choice between two devices that are used temporarily. Choices are possible in three situations – first, whether to use the technology at all (e.g. hearing aids), second, whether to use the technology to 'pass' or to generate attention (e.g. a colourful design or a discrete one), and third, when to use it as one or the other (customized, changeable design options for one pair of hearing aids). In sum, the following principles can be deduced from the previous analysis:

- If possible, enabling technologies should be universal.
- Universal technologies should be made compatible with restoring, compensatory, and assistive technologies.
- If enabling technologies cannot be universal, they should allow as many meaningful choices as possible for their users.
  - Users should be able to decide whether to use the technology more than once.
  - Users should be able to decide whether he wants inconspicuous or eye-catching design and he should be able to make this decision more than once.

- In general, enabling technologies should not express shame, but pride and dignity.

Enabling technologies with designs that do not reflect these principles contribute to stigmatization and can be judged, based on the capability approach, as ethically problematic. Besides these principles for design, recommendations can be made for the procedures of such design processes. Based on the CABE principles and the capability approach, it can be recommended that engineers and designers should involve disabled people in the development of enabling technologies. How often and in which way they should be involved are questions of participatory design and responsible research and innovation (RRI). For example, a diverse developer team can help to put weight on different perspectives (Wittkower, 2016, p. 7). However, it is highlighted in the literature that avoiding any discriminatory effect is almost impossible to achieve. Yet, this impossibility does not weaken the imperative to follow the presented guidelines, but rather stresses the importance to try.

## 7 Case Study

- This chapter presents the case study about a compensatory technology. The theoretical findings of chapter 4-6 are applied to the case study to test their compatibility. The case study is evaluated with the ethical principles developed in chapter 6.

Chapter 5 demonstrated that the dilemma of assistance and acceptance is especially evident in compensatory technologies. For a better understanding of compensatory technologies and for a road towards the application of the ethical findings from chapter 6, the on-going development of a particular compensatory technology was observed. This technology is a hand orthosis for people with Duchenne muscular dystrophy (DMD) which is developed at the biomedical engineering department at the University of Twente. DMD is a ‘genetic disorder characterized by progressive muscle degeneration and weakness’ (Muscular Dystrophy Association, 2017). The disease affects mostly boys and the symptoms begin in the age between 3 and 5. Starting with muscle weakness, many boys use a wheelchair by the age of 10. ‘These weaknesses lead to difficulty in rising from the floor, climbing stairs, maintaining balance and raising the arms’ (Muscular Dystrophy Association, 2017). Due to advances in medicine, life expectancy increased from teenage years to men in their 30s and 40s. Aside from the previously mentioned wheelchair, boys or men with DMD use several other technologies, such as ventilators, hand splints, heart and lung support, and computer-assisted rehabilitation programs (Nizamis, 2017).

DMD has received some attention in the literature. In interviews with ten men with DMD, Gibson et al. (2007) asked the interviewees about their relation to the technologies they are using. Talking about their wheelchairs, two participants expressed the feeling that they are used to them, and that the wheelchairs became part of them (Gibson et al., 2007, p. 13). This feeling relates to the previous observations made in chapter 4; the wheelchair as a compensatory technology is in an embodiment relation with the user and the world. The technology does not only withdraw from attention, it almost becomes part of the body – the extended body – and, thereby, becomes part of the user’s identity. One participant explained that he felt uncomfortable if others would sit in his wheelchair without permission (Gibson et al., 2007, p. 16). Just like a biological body part, the wheelchair seems to be ‘owned’ by its user and part of his personal space. Not only the material, also its use seems to be constitutive of the participants’ identities: participants expressed no intention to abstain from using their wheelchairs even if they could walk again (Gibson et al., 2007,

p. 13).

Nonetheless, the opinion about the wheelchairs is not exclusively positive; for example, the participants reported having difficulties in dating people, because potential partners would 'see the wheelchair first, before the person' (Gibson et al., 2007, p. 15). Here, the intersubjective aspect of technology is addressed. Because the wheelchair makes the potential partners perceive the men with DMD as unsuitable partners, there is not only a difference, but a devaluation to be observed, so the wheelchair can be interpreted as a stigma in Goffmann's (1986) sense. 'The techno-body-subject is perceived as a negatively coded whole and rejected because of the stigma attached to impaired bodies and assistive technologies' (Gibson et al., 2007, p. 16). What Gibson et al. call 'techno-body-subject' is the same as what has been described in chapter 4: Technology in an embodiment relation does not only mediate human-world relations, it also shapes the subject itself. Because of the technology and attached stigma, the study participants changed their self-perception; they 'knew their place' within social order. This self-perception has affected their character: all participants described themselves as 'shy', partly because of negative experiences in their childhoods (Gibson et al., 2007, p. 15). The use of certain technology and the stigma attached to it had an effect not only on human-world relations but also on the subject as described by Verbeek (2006). In sum, the experiences described in the interviews are in line with the theoretical framework from chapter 4.

After the theoretical compatibility has been ensured, it can now be asked how the Twente case study relates to the findings of chapter 5 and 6. In a semi-structured interview with Nizamis, the construction and design process of the hand orthosis was discussed. With this information, it can be evaluated whether the technology would stigmatize or discriminate people with DMD, based on Nussbaum, Wittkower (2016) and Rorty. The hand orthosis is supposed to support and extend the hand function of people with DMD. It uses signals from the arm muscle for supporting the movements so that people with DMD can grasp and hold objects. People with DMD usually have intact nerve cells to feel a touch, but the muscle strength is not sufficient to hold objects. With the envisaged hand orthosis, people with DMD could grasp objects, not with a robot arm attached to their wheelchair, but with their own hands, feeling what they grasp. Additionally, the technology helps to extend the hand function: If the technology is used before the hand function is lost, it can help to preserve it (Nizamis, 2017).

The idea to design a hand orthosis was derived from a previous research project, which focused on arm support. This so-called *Flexension A-Gear project* was user-driven, i.e. financed by the Dutch Duchenne parent project. Boys with Duchenne expressed the desire for better arm function, of which the hand function is a logical consequence (K. Nizamis, 2017). The new hand orthosis would be made compatible with the existing arm support. Throughout the project, people with DMD are involved in various research stages (Nizamis, 2017). Their interests are taken into account insofar as the hand orthosis is very light (only 150g, which is the lowest weight in the literature) and built as low-tech as possible. Developed this way, the hand orthosis is comfortable to wear and easier to repair. Comfort and independence are values that are explicitly named by Nizamis (2017). As guidelines for his research, Nizamis names ‘the three C’s of prosthesis design: control, comfort, and cosmesis’, developed by Plettenburg (1998). Control and comfort are secured by weight and maintenance. Cosmesis, the preservation and restoration of bodily beauty, is not a technical question, but one of aesthetics and design, which will be addressed later.

From Nizamis’ explanations, it can be derived that the hand orthosis is in an embodiment relation with its user. It is attached to the arm and its functions are to support the hand as well as reaching and grabbing. No interaction or interpretation is needed. The type of human-world relation is important because it reveals the technology’s possible significance for the self-understanding of its user. Technologies in embodiment relations are, as described by Feenberg (2003), part of an extended body.

The presented case study was chosen because compensatory technologies are difficult to evaluate. In the following paragraphs, it will be investigated whether the hand orthosis runs the risk of violating the need for acceptance. The first possibility to do so is the reinforcement of the individual model of disability. Compensatory technologies are not doing that insofar as they do not attempt to ‘fix’ disabled people. They also allow for multiple choices to use them, addressing disabled people as autonomous persons. Moreover, the hand orthosis was asked for by people with DMD. This reversed relation of supply and demand shows that the people with DMD have the power to request technologies. It stands in contrast to governments and medical companies imposing their technologies on disabled people, such as happening in the individual model. Overall, it seems that the hand orthosis does not reinforce the individual model of disability.

Whether it can contribute to discrimination can be, as demonstrated in chapter 6.2,

tested with Wittkower's (2016) principle. As explained by Nizamis, the technology is specifically designed for people with finger deformities. Other hand orthoses do not work with the finger deformities, which results in the need for specialized technology. Because it addresses a special need, the hand orthosis does 'reflect a difference in user demographics that requires distinct provision of service to distinct demographics' and does not violate Wittkower's principle. Thus, the analysis comes to the somewhat unsurprising result that the hand orthosis is not discriminating against people with DMD.

More complicated is the analysis for possible stigmatization. As a compensatory technology, the hand orthosis is used only by people with DMD. Its use constitutes a difference, which could lead to a stigma; depending on the cultural context. This potential stigma cannot be avoided by design because it is possible for every compensatory technology. However, the capability approach's focus on individual choices and dignity provides the means to identify better and worse options.

As a compensatory technology, the hand orthosis is non-permanent and offers the choice to use it more than once. The second meaningful choice demanded in chapter 6.2 is the choice for inconspicuous or noticeable design. Although Nizamis has only minor influence on the design, he has clear ideas about the message behind it: In his opinion, the hand orthosis should stand for strength and independence. He wants to build an attractive gadget that users can be proud of. Its design should not aim for 'passing' and express shame, but for an affirmative message (Nizamis, 2017). If users like their hand orthoses and are proud of them, they will show their friends, which will eventually lead to acceptance. As an example, he mentions the evolvement of the public's perception of tooth braces. Strictly speaking, braces are prostheses as well, although they are not publicly perceived as such. Because the manufacturers made them more attractive via customization and colourful design, there is almost no stigma attached to their use anymore (Nizamis, 2017).

This opinion is very much in line with the analysis in chapter 5 and 6.2. Since stigmatization depends on the cultural context, a change in the cultural context will reduce stigmatization. Technologies can support such change via their mediating role, as demonstrated in chapters 4 to 6. Affirmatively designed technologies would shape the perception of disabled people more positively. As Nizamis imagines, such technologies can evoke interest and acceptance instead of stigmatization. Such an affirmative design would be part of cosmesis – an aesthetic value that leads to the attractive gadget Nizamis has in

mind. About the desired outcome, Nizamis says: 'There is no point in people looking like a machine - people will think that you are a machine'. This quote supports the point made about the power of technology for the perception by others and can be directly connected to mediation theory and extended body theory. The technology shapes the perception of a disabled person as either machine-like or human-like. Nizamis' envisaged design would centre the human, but not hide the technology at the same time (Nizamis, 2017).

The expressed clear preference against inconspicuous design is in line with the cultural model of disability and opposes the contested individual model. However, the choice for such 'proud' design rules out the possibility for 'passing', taking this choice away from people with DMD. As explained in chapter 6.2, it cannot be expected of disabled people to suffer from stigmatization because a cultural change needs to be induced. Opting for 'passing' would reduce such stigmatization because a difference would be less visible. In this sense, the hand orthosis does not meet the criterion for meaningful choices. Yet, it can be questioned what level of 'passing' would even be possible in the case of the hand orthosis; the technology would be clearly visible in any case. Additionally, the user groups of the hand orthosis must be considered. Nizamis explains that most users are boys and teenagers and have presented themselves to him as enthusiastic about technology (Nizamis, 2017). An affirmative design fits their preferences.

The final design will be decided by the company which will be in charge of manufacturing the hand orthoses. Although the design cannot be anticipated, the previous project that the hand orthosis is building on was marketed with a choice of colours (Nizamis, 2017). Such choice, despite not being morally relevant on first glance, shows that people with DMD are customers like everybody else, who have different taste and like to choose from different options. A similar choice would be desirable for the hand orthosis. This choice could also take up the problem of 'passing' or highlighting DMD, as the simple difference between colours, e.g. a simple black design or a colourful one, can already have a big effect on its perception.

In sum, the hand orthosis:

1. is compatible with other technologies, such as the arm support;
2. considers user interests;
3. mediates pride and dignity instead of shame;
4. addresses specific user demographics that necessitate specialized technology;



5. offers the choice to use or not to use;
6. does not offer the choice to 'pass' or to highlight;
7. might offer the choice of different design options.

As evident from the list, the hand orthosis meets most requirements for enabling technologies postulated in chapter 6.2. The only exception is point 6, which is neglectable given the target group, their expectations and the expected choices provided via design options. In sum, the development of the hand orthosis can be approved, under said conditions, with the capability approach.

## 8 Conclusion

This thesis addressed a gap in the research on enabling technologies by asking *How can enabling technologies overcome the dilemma of assistance and acceptance?* The question can be answered in two steps. First, to overcome the dilemma, its origin must be identified. The dilemma of assistance and acceptance arises when enabling technologies reinforce contested views on disability, stigmatize, or discriminate against disabled people. Second, solutions for the dilemma must be found. Following the guidelines for inclusive design informed by the capability approach, enabling technologies can minimize their violation of the need for acceptance. The only way to completely avoid the dilemma of assistance and acceptance is cultural change. Cultural change would convert stigmata into mere differences, and discrimination against disabled people into mere discrimination between disabled people and able-bodied people. With the need for acceptance secured, the dilemma of assistance and acceptance would be solved. Enabling technologies can support this cultural change by reinforcing positive views on disability.

The guidelines can also be applied to the development of technologies in general. Not only enabling technologies, but all technologies should avoid violating the disabled people's need to be accepted. Wittkower's (2016) principles have been developed to be applied to all sorts of designs. The moral difference between most enabling technologies and technologies in general is that enabling technologies are always aiming for the morally justified goal of participation in society, even if they violate the need for acceptance. Non-enabling technologies might serve other values than assistance, which, due to different relevance, can lead to dilemmas or not. Therefore, their ethical acceptability must be researched individually in further investigations. The criteria developed in chapter 6.2 can still give useful ideas about what to consider for including disabled people in design considerations. In addition to that, the thesis focused only on physically disabled people, although many problems, e.g. problems of accessibility, are equally relevant for mentally disabled people. Further research can reveal whether the results can be transferred to this context.

Besides these results regarding the dilemma of assistance and acceptance, the thesis also offers insights regarding the applied theories. It was demonstrated that the cultural model of disability, mediation theory, and the capability approach provide the adequate terms to identify and analyse the dilemma of assistance and acceptance. The cultural model

of disability and mediation theory demand the analysis of material culture from a user perspective. A common criticism of mediation theory is that it lacks normativity: after a postphenomenological analysis, it is often unclear how to react to the possible ethical implications of different human-world relations that technologies evoke. At this point, the capability approach adds value to mediation theory because it provides the normative basis to specify such ethical implications and their ethical analysis. The capability approach is also compatible with the social and cultural model of disability, arguing for the capability of participation. However, only three models of disability have been presented. There are more models of disability in the literature whose analysis might bring forward more helpful suggestions for the engagement with enabling technologies. Furthermore, the capability approach, despite its success in policy, has received criticism, e.g. for its concept of freedom and for neglecting interpersonal relationships. More work on the capability approach and disability studies can help to decide whether these criticisms are challenging the useful connection between the two disciplines.

It can be asked to what extent other normative theories would have led to other outcomes. Other theories might assign different degrees of relevance to the needs for assistance and acceptance, so that the dilemma might not arise. The quality of results also depends on the explanatory power of the applied theory for ethics and justice. For instance, resource egalitarianism, even if it is concerned with internal and external resources, is exclusively concerned with the allocation of resources, e.g. to individually buy enabling technologies. Next to such a perspective not prioritizing universal technologies, it would also not necessarily recognize the need for acceptance. In contrast, the need to be treated as an autonomous person and the importance of choice would be covered by Kantian deontology, which, in turn, does not explicitly consider the allocation of resources to disabled people. More research into different ethical theories and theories of justice and their take on the dilemma of assistance and acceptance might reveal new strategies for dealing with the dilemma.

Finally, the thesis is a fine example of the usefulness of empirical information for philosophy. In general, the connection with a case study was very helpful to understand different perspectives. First, the perspective of people with DMD was easier to understand after visiting the Duchenne Congress in The Hague, where people with DMD and their parents explained their daily routine, as well as their hopes for the future. Their focus did

not lie on the therapy of DMD, but on increasing the quality of life with DMD. Although these insights are not part of reproducible research and not explicitly referenced in the thesis, they have been valuable to understand the need for acceptance. For further background information and a general impression of the disability perspective, many blogs and newspaper articles were consulted. More direct research with people with DMD could have deepened the understanding of their perspective, not to mention research with people with other disabilities. As explained in chapter 1.2, this thesis does not aim at representative social science research, but at conducting empirically informed philosophy. For confirming the theoretical insights, more empirical research is needed.

Second, the perspective of engineers was experienced through several talks with Nizamis, including the evaluated interview. This perspective ensured an understanding of the technological limitations of enabling technologies as well as the cooperation with people with disabilities. The selected case study needs to be evaluated further, following the different steps in its production and measuring its success afterwards. Not only the developing engineer but also users, designers and manufacturers need to be consulted. Although interviews with other engineers would have enhanced their significance, the results have been very useful to evaluate assumptions made about the needs of disabled people.

Despite these limitations, the offered insights provide a substantial start for solving the dilemma of assistance and acceptance, for the analysis of the interplay of disability studies, ethics of technology, and engineering; as well as for the improvement of enabling technologies. In doing so, it constitutes a fertile ground for exciting further research, like the analysis of disability through the lens of technology.

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## Annex I: Interview

Interview with Konstantinos Nizamis September 1st, 2017

### 1. Which enabling technologies are used by people with DMD?

It depends on the progress of the disease. In sum, people with Duchenne use a splint, crutches, a simple wheelchair, a high-tech wheelchair, hand splints while sleeping, a ventilator, heart and lung support. They usually make no use of exoskeleton, but they have an external manipulator controlled by a joystick attached to their wheelchair. Sometimes they also use AFO's.

### 2. How did Kostas come up with the idea of making a hand orthosis?

There are two answers to that. First, the idea grew naturally out of previous research. The so-called Flexextension A-Gear project aimed to support the arm function of people with DMD. This project was very much driven by the users; the arm function is one of the most commonly expressed wishes of people with DMD. Hence, the Dutch Duchenne Parent Project initiated the Flexextension A-Gear project in 2012. After the project came to an end and a product was developed, the next logical step was to look at hand movements. It is not very useful to move your arm if you cannot move your fingers. People with Duchenne can only move their fingers only a little bit; their motion is very restricted. The hand orthosis can replace the robot arm currently attached to the wheelchair. The device is not only for end-use but also for rehabilitation. If boys use them at an early stage when they still have finger function, this function can be kept later and the deformation can be slowed down. The problem is motivation: How to tell someone to use something before he has a problem?

The second answer is a more general one. The main motivator for this research was the fact that through medication, people with DMD are now living not only until their early 20s but into their 30s and 40s. Until their early 20s, the quality of life was relatively good, because the progress of the disease was only rapid at the end. Now, there are extra 10-20 years in which the quality of life is not very good without technology.

### 3. Which role do the people with DMD play in the development and design process?

The whole development process is very user-inspired. There were focus groups at least once per year, at the Duchenne congress day. 500 people have Duchenne in the Netherlands. Many boys are very enthusiastic about the research and want to help and try new technologies. Sometimes, some boys join the user committee meetings, where all stakeholders meet twice a year. The Duchenne parent project can ask questions at any time. As it is a PhD project, they cannot officially have power over the design, but they take people with Duchenne very seriously. Sometimes, what they want is not realistic from an engineering perspective. It is also important not to promise too much.

### 4. Which different possibilities are there to develop such an orthosis and why did Kostas choose for this option?

He decided to build the orthosis as low-tech as possible, for two reasons. First, the field of hand orthotics is relatively new and there are not many resources and expertise that could lead to a high-tech orthosis in four years. More importantly, there is a high rejection rate for high-tech devices. He has not encountered any people with Duchenne who rejected technology, but it is known from the literature. These devices are nice from an engineering point of view, but they are rejected by the potential users because they are too complicated. For his own project, his goal is that the use is as easy as a new phone – maybe you need a week to get used to it, but then it's part of your daily life.

The idea of a hand orthosis is not new, but the previously built ones are not very good for people with DMD. These new ones specifically target people with finger deformities. Hence, they are very specialized and might not be used by other people. However, they are better for people with DMD exactly because they address their condition. Comfort and safety are most important: the orthosis is light-weight (only 150g, lowest in literature), it is adjustable to the shape of the fingers, and easy to take on and off. He did not go for high-tech, but for practical solutions. Engineers can do many nice things, but they do not make sense if they do not look at their users, and with people with DMD, there is a difficulty in the intention detection. Even if the fingers were perfect, we would not have enough signals to control these perfect fingers, because the signal-maker, the amplifier, the muscle, is not working. In sum, the quality of the product is so high because it addresses a highly specific target group.

5. Who will design the orthosis and to what extent can Kostas influence the design?

The design is mostly done by his colleagues, but he can give suggestions. Usually, these technologies are as inconspicuous as possible. However, Kostas does not go for passing, he wants to have a very attractive gadget that the user can be proud of and wants to show off. This technology gives strength and independence, so there should be no reason to be ashamed of it. Hiding just enforces the shame. We should be proud of this technology, we should show it, and eventually, people will like it as well. However, the actual design is the job of the company who will produce it and their marketing department. In the arm project, they have a customary design, so the people with DMD can choose different design options, like the colour.

He refers to the three C's of prosthesis design: control, comfort and cosmesis (Plettenburg, 1998). Many prostheses have been used for decades and are not perceived as such anymore, e.g. tooth braces. Designers started to put colours and other customizable features on them; instead of hiding them, the designers tried to make them attractive to their customers. There is no point in people looking like a machine - people will think that you are a machine. If people really like their technologies and go to their friends, being proud of it, that will lead to acceptance.

6. Why does Kostas avoid the term 'patient' when talking about people with DMD?

They do not suffer from sickness, they do not have the flu. They do not want to be defined as a 'patient' but define themselves as people in a special condition. Some don't mind, but the term can be stigmatizing. And if they are not calling themselves patients, why should he?

7. Are people with DMD disabled and why/ why not?

DMD is progressive. At some point, they are disabled, but until the age of 5, they are not different from other children. They are slowly losing function. And after a certain point, they are disabled – maybe at 30 when they are fully paralyzed. But he does not see them as disabled because they can still do a lot of things. Although they depend on other people, many people with Duchenne have studied and work on the design of enabling technologies themselves. And the hand orthosis is supposed to make them more independent. The overall goal for the researchers is an improvement in quality of life, for which independence is a strong ingredient.

## Annex II: Consent Form


## Informed Consent for standard research

'I hereby declare that I have been informed in a manner which is clear to me about the nature and method of the research. My questions have been answered to my satisfaction. I agree of my own free will to participate in this research. I reserve the right to withdraw this consent without the need to give any reason and I am aware that I may withdraw from the experiment at any time. If my research results are to be used in scientific publications or made public in any other manner, then they will be made completely anonymous. My personal data will not be disclosed to third parties without my expressed permission. If I request further information about the research, now or in the future, I may contact

Alexandra Kapeller, [a.kapeller@student.utwente.nl](mailto:a.kapeller@student.utwente.nl) or  
her supervisor Michael Nagenborg, [m.h.nagenborg@utwente.nl](mailto:m.h.nagenborg@utwente.nl).


If you have any complaints about this research, please direct them to the secretary of the Ethics Committee of the Faculty of Behavioural Sciences at the University of Twente, Drs. L. Kamphuis-Blikman P.O. Box 217, 7500 AE Enschede (NL), telephone: +31 (0)53 489 3399; email: [L.j.m.blikman@utwente.nl](mailto:L.j.m.blikman@utwente.nl)).

Signed in duplicate:

Kostas Nizamis 

Name subject      Signature

'I have provided explanatory notes about the research. I declare myself willing to answer to the best of my ability any questions which may still arise about the research.'

Alexandra Kapeller 

Name researcher      Signature