NON-EXCLUDING DESIGN

How to design things for inclusion, or non-exclusion

LARS OESTREICHER
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Preface

This book has a long history, and to finally put it together is the last part of a long journey into disability studies and design thinking. I have for a long time had a great interest in the design of supportive, assistive and facilitating tools for people with different kinds of impairments. A personal interest appeared fairly recently from two different sources. One being a personal relation with a person who was using a wheel chair, which gave me a shocking insight in all the preconceptions and the bad treatment disabled people meet in their contact with other people and with society (there are of course good examples too). The second being the problems I encountered myself after have a stress-related exhaustion syndrome (burned out). I was on a full-time sick leave for about one year, and still suffer from cognitive impairments concerning memory, focusing and language problems. During...
the process of rehabilitation I have found the need for acceptance and understanding to be very large, especially in terms of how I look upon myself.

I am now working full time as a teacher in Human-Computer Interaction, and have started to work with Design issues in this field, and the problem area of design for people with special needs as a specifically important aspect in the design field.

When I finally decided to give a course on *Universal Design and Evaluation* at the HCI unit at the IT-department at Uppsala University, I had big difficulties finding a suitable course book. So, for the first course instance I gathered material and articles that I found, and that I thought could support my lectures. My students on the first course instance have also provided some material for this book. This is a book that has emanated from a course given at Uppsala University. As all books that stem from courses, this has of course been shaped according to the general course structure of this particular course. However, I have tried to actively reshape the book in order to make it a real textbook, rather than a course based book. I hope that you will find this book informative and useful also without the course.

In making it a textbook, rather than a research article, I have also included personal opinions in the text, using examples and ideas that come from my experience of both research and teaching. This, I hope will be a positive feature, in that I think you will find many thought provoking examples in the various chapters of the book. It might also be part of making this a political statement regarding the importance of looking to the situation for people with special needs.

I also want to thank my students of the first course for providing me with thoughts and discussions during the course, and thus making the book both possible and better. Some of you have even contributed to the content of the book, through assignments and reflections on the course content.
1. Introduction

What thoughts are flowing through your head when you see someone sitting in a wheel chair, or someone walking with a white cane? Is this person in any way “special”, or is it just anybody? My guess is that your answer to these questions will be different, in case you have an impairment yourself. It is difficult to understand what an impairment implies to the individual, and even worse is that it is difficult to understand how to make the situation better for a person who has an impairment and who has become disabled by it.

In this book we deal with complicated issues in many societies, namely the way that we design artefacts, architecture, and even social structures, in a way that runs the risk of excluding groups of people. This problem is big everywhere in the world, and raises different challenges in different parts of the world and in different cultures and societies. The content of this book has been selected to provide a wide overview over the problem of designing a society that tries to include everybody on an equal basis. This approach is often also named as “Universal Design”. The perfect inclusive society is a society where everybody has the same possibilities (see Error! Reference source not found.). Most people should be able to do most things in an inclusive society, and any differences in ability should not relate to any personal property.

So, what is non-excluding design in the context of, then? There are in this case several possibilities to make a non-excluding design. One possible way might be to redesign the staircase in the picture so that it becomes accessible in a wheel chair. This is today often done by adding ramps or lifts to the staircase. However, this might cause some problems, for example with cultural and architectural interests, so another and maybe more flexible solution might be to design of a device that will allow you to get up these stairs in a (semi-) comfortable way. This solution would make the person less dependent on the environment and its adaptation, but on the other hand, also requires the solution to be repeated for every individual who wants to go up this particular staircase (and any other).

There are individual solutions, such as stair climbing wheel chairs. However, the design of these machines raise several other issues that are
important to consider in this context, such as trust, safety and control issues. We will get back to discussions about these things in later chapters. In the same way we will also discuss the roles of the designer in these cases, and how we should think in order to start making the world more accessible.

There are several variations on the name “Universal Design”, such as “Inclusive Design” or “Design for All”. They all imply the same basic thought that we should design for including people in the larger context, rather than engage in special solutions for certain groups of people. If we still try to make some kind of distinction, we might end up with the following set of definitions:

- Design for all - Design for all potential users. This means that we have to consider each and every person who may want to use the artefact. This is essentially the European term for the American term *Universal Design*. 

In a non-excluding society, an active leisure time should be possible for everyone, regardless of the preconditions. The wheel chair in the picture is a Permobil Trax, which has been designed for better riding experiences outside of the city streets. (Photo: L. Oestreicher)
Non-Excluding Design

- Inclusive Design - Design to include as many users as possible. This does away with the requirement of including everybody but still aiming for as large a user group as possible.
- Barrier-free Design - Using design to overcome or remove barriers in the environment or as caused by the society.
- Universal Design - Design for a universal usage, i.e., design for all potential and possible users. In my perspective Universal Design and Design for all has the same aims. Universal Design is essentially the American term for a field that is in termed Inclusive Design or Design for All in Europe.

Which general term to choose is in my opinion irrelevant (but see chapter for a longer discussion on this topic), as long as we know what the intention is behind the design task that we address. All terms contribute to the general understanding of what we need to do, i.e., design with consideration and reflection. Design decisions have to be made and motivated, consequences have to be considered and, if negative, hopefully avoided. There are a few steps that have to be included in the design, in order to strive for this, namely, observation, acceptance, understanding and perception of possibilities. These steps are important in most design activities, but especially so, when we consider design of assistive technology and the general environment from a non-excluding point of view.

In this book the term Non-excluding Design; will be used to emphasize the design process towards a more inclusive society, where the explicit goal of the final design is to exclude as few people as possible from using the final product or environment. The main reason for thinking about non-exclusion rather than inclusion is that it is necessary to recognize that all design decisions have both good and bad consequences; consequences that we will have to consider in order to make a better design. See more about the concept of

![Figure 1-1. A staircase leading to the Moorish Castle at Sintra, Portugal. (Photo: Lars Oestreicher)](image-url)
non-exclusion in chapter 2 where I will go through the processes involved in greater detail, and we will also have a more thorough discussion of the topics involved later in the book.

1.1 How to use this book

Who is this book intended for? It would be great if it were possible to answer that question with a: “Of course it is for everybody!” And indeed, it would be good if really everyone would find something interesting to read in this book, since that would be very a step towards the goal of making the society more accessible to everybody. Some of the students on the course that gave rise to this book actually thought that everybody should take the course (and then of course, read the book, as well). Still, It is probably not reasonable to expect that kind of audience. Instead it would probably be fair to say that anyone who has an serious interest in the problems involved in designing assistive or facilitating technology could read it.

One of my favourite quotes about teaching is (probably) stemming from a desert country although there may be many versions of it. My version of it is: “You can lead a camel to the water, but you cannot force it to drink”. This book is built upon this line of thinking. The book will show you to some of the ways where it is possible to find a different perspective, but it cannot force you to use the new knowledge. The examples may instead lure

Figure 1-2. Sometimes universal design is not what we may think, such as coming up with new concepts. Sometimes universal design is already there in the original design. Drawing by the Iranian artist Mahmood Azadnia, used with kind permission.
you into thinking of appropriate ways of implementing the knowledge that is provided.

*I once had a student who came back to me after some five ten years after he was a student of mine. Upon meeting me, he exclaimed: “You have destroyed my life”. Admittedly, I was a little taken aback, and I asked him what he meant. “Well”, he said, “I can’t see a door handle or a water faucet without thinking about you!”*

Fortunately, I understood what he meant by his statement, since it didn’t feel that good to have destroyed someone’s life. On the other hand, I knew that this definitely was an effect of my teaching during that course, since they are my favourite examples of (mis-)designed objects.

I think that this way of teaching, provoking the reader of a text (or the viewer of a slide) to start a thought process using different perspectives on the knowledge presented, is a very strong way of luring people into learning something. I often use illustrations or quotes to bring home a certain point, such as in Figure 1-2. That picture is both beautiful and (in my mind) thought provoking, and my interpretation of that is (you may have another): “We don’t always have to provide special or adapted solutions, when the normal tools work.” We are often providing special solutions for people with impairments. But many times, it is unnecessary, since it often only requires a small redesign of the standard solution in order to fit many kinds of impairments, as well as most people in general.

So, for instance, are toilets for disabled people quite good also for people without wheel chairs. So why should we create two different kinds? The more spacious toilets, with extra controls are very usable for all people, and the emergency call buttons, would actually be quite good to have in all the toilets, since it is easy to slip on a wet floor. We still keep making two different kinds of toilets. But why? Of course there is an issue of increased costs. One toilet designed for the disabled takes up the space for two (small) standard toilets. And maybe this is really a cost we may have to sacrifice for the gain in not stigmatising a smaller group of people. However, a different take on this problem is to start thinking about the baseline cost. What if we set the spacious toilet for the disabled as the default design for a standard toilet. Then the cost of a spacious toilet for a person in a wheel chair is not larger than the cost for a normal toilet. And in the floor plan, then the number of large toilets might be just the same as the number of small toilets. Regulations can be made to support non-exclusion.

This line of reasoning is one way of avoiding (or reducing) stigmatisation (see more about stigmatisation in chapter 9). That thought is the water I can point to. I as a teacher can only point to the water, and even the ripples that
run over the surface, but the drinking and absorbing has to be left to the reader. And hopefully, this book has pointed you in the direction of tasty water, and maybe there are some nutrients in it as well.

I want my learners to really consider and remember the more general, overall picture, rather than focus on all the small details.\footnote{Especially now, that we have all the detailed information on the Internet, just a few mouse-clicks away. The understanding of the information, however, is most of the time not possible to Google, but has to be gained.} that they will forget very quickly after finishing the course. This means that I am very interested in pedagogic methods that will support learning in different ways.

Especially, I encourage giving an extra thought about the small coloured (grey?) boxes in the text. They contain small “considerations” and “did-you-think-about-this” ideas that are worth some extra thinking. Also, there are some explicit exercises included, such as the Reflections (see section 1.5) and larger exercises that encourage you to consider a certain question each time. I use reflections as an important part of my teaching. A reflection is a more philosophical very short (2-400 word) “essay” on a certain topic given by me. I usually describe them at each lecture, and the students are required to hand them in afterwards. There are no true or false reflections; the main idea is that they should support the student in thinking about problems that are slightly more intricate in connection with the lecture. I hope that you will find the reflections that I have added at the end of the chapters in this book useful even if you are not a student in the field but just have found this to be interesting reading. Note that the reflections are not (primarily) written to be tests of your knowledge, but important learning element, since they are intended to encourage some additional thinking about the topic.

Finally, it is impossible to provide a “how-to-design-this” type of advice in this field, for at least two major reasons. First, the design of tools for people with special needs is to a large extent an individual feat. No solution is (should be) good for all individuals. Second, the number of different impairments and possible solutions is simply too large to be able to fit into a book. For both of these problems, the solution is to learn (and teach) how to use the tool available for this process: non-excluding design thinking. From this book I hope to be able to provide you with the understanding you need to continue the process of imaginative and sensitive design thinking that I consider to be the base of non-excluding design.

Thus, the examples in the text are exactly that, examples. What you as a reader should focus on, is the general approach and the general reasoning that comes to live in the text. So, my hope is that this book will provide the
reader with some new lines of thought about the problem of designing artefacts, so that the inventions that result will decrease the gap between people (especially when impairments are considered).

1.2 Experience, Knowledge and Awareness

Let me also provide you with a final note on the usage of the knowledge in this book. It is always tempting to think that you understand something after reading a book like this. Often people say that they know how it is. They have seen or experienced situations where people with impairments have encountered difficulties in the society. But this is not the case. If you don’t have an impairment it is not possible to understand what it is like. I, despite having written this book, am sure about that I do not know how it is myself. I have a personal experience of one of the problems described in this book, namely memory exhaustion, but I don’t know what it is like being blind or having a paralysis. Still I have tried to write a book like this, since I think it is needed, but it is not written in order to make you understand what it really is like to have an impairment. Rather I hope that it will make it easier for you to be aware of a new perspective on the world.

The intention with writing this book is to raise the awareness of some of the problems and challenges that face people with impairments today. It is also intended to provide a designer with an insight that is useful during the process of designing for impairments. However, if you feel as if you have understood the problem completely, then the book has been either too well written or not written well enough. It is quite impossible to understand the situation for a person with an impairment, unless you have the same impairment yourself. You might be lucky enough to get a glimpse of the person’s perspective, but it is not a question about knowing what it is like.

Just to make a simple example of the difficulties we have: If you are not dependent on a wheelchair, you might still have a possibility of testing what it is like to run a wheelchair (over cobble stones, for example, cf. figure 12.3). You can always try out how it feels to rely on the combination of a white cane, your memory of the environment and your ears. You can try it, you can even test what it is like for a few hours, but (!) you can always rise from the wheelchair when it gets too difficult, and you can open your eyes if you lose orientation. This is impossible for a person who has the impairment for real. And this makes much of the whole difference. Being dependent on the technology, rather than just testing it, is a very important differentiating factor. This is something that cannot be purported through a book.

However, after reading this you will still have some knowledge about what needs to be done, if we want to include all people in the society. We need to
test the surfaces for accessibility with wheel chairs and for blind people. We might know that cobble stones might not be the best surface when you are using a rollator, cause the wheels will most likely get stuck between the stones, or at least give the user a good shake on the way. This awareness of the problems will lead a long way on the road to non-excluding design, but definitely not all the way. We still need to find out what the real user’s want!

1.3 Empathy, Sympathy, Pity and Awareness

In my perspective, one of the most dangerous emotions is the pity. To pity someone is also most of the time not a useful action. People don’t want to be pitied, they most of the time want to be understood. And understanding, of course, does not have anything to do with many of the emotions that we may show towards other people. To show pity, and even sometimes sympathy if it is done in the wrong way might just make people feel less valuable (Shapiro, 1994, p. 12). We might even show some misdirected sympathy, and work towards the wrong goals since we think we know what a person with a certain kind of impairment needs in order to be happy (cf. page 114).

But what about sympathy, then? Where does sympathy find its place? It’s a difficult matter. I think that sympathy might be part of what drives me to write this book, and hopefully part of the reason for you to read it. Sympathy as a word, actually has two different major meanings, one being that of expressing "feelings of pity and sorrow for someone”, and the other a more abstract notion of sharing an “understanding between people; common feeling”, “support in the form of shared feelings or opinions”, and “agreement with or approval of an opinion or aim; a favorable attitude” And I think that this latter meaning is the one that most appropriately describes the role of sympathy in the area of disability research. By encouraging this perspective of being in sympathy with the idea of inclusive design, it might be possible to actually reach even the long-term goal, as described in later chapters. By creating a sympathetic society, it might in the end be possible to share most of the contents among all the citizens, without any problems of exclusion, since by then people will be aware of that impairments also are a normal part of the society.

1.4 Book structure

It is always difficult to write a book in a completely sequential manner, and keeping the red thread throughout the structure is often somewhat difficult. Apart from that, what might seem a logic order to me as a writer might not be that for you as a reader, and in that case I apologise for not seeing it the proper way.
However, I have at least tried to structure the chapters after some logical order, and also sectioned the book into three different parts, one about impairments and disabilities, one about the effects of the impairments, and finally a perspective towards the future, as well as some kind of concluding remarks.

I have also tried to provide cross-references throughout the book, and a detailed index at the end of the book. There is a glossary in the book as well, where it is possible to find some of the more important concepts described in a terse but hopefully clarifying and accessible way.

### 1.5 Reflections

You might now want to pause the reading for a moment and ponder the following issue before proceeding to the next chapter:

1. *Reflection:* What picture can you see inside yourself when you hear the words “Impairment”, “Disability”, and “Paralysis” etc.? Which are my own “preconceptions” about a person with certain impairment?
2. *Reflection:* How can we avoid thinking in terms of *them* and *us*?
3. *Reflection:* Consider the message in Figure 1-2. What is the message now again? Can you think of any real world example that can be applied to the message in the figure?
Part I

Disabilities and their effects

The Outlier
(drawing by the author)
2. Non-Excluding Design

In this book the term “non-excluding design” will be used rather than any of the other terms that were mentioned in the previous chapter. As already stated, this is to focus more on the process of designing to minimise exclusion. The terms are of course more or less just labels, and they are given certain intentions that might or might not fit with the original meaning of the word. Thus if you prefer to use “Universal design” or “Inclusive design” instead, that is perfectly OK, as long as you know what you attach to the label.

2.1 Universal Design

Before looking at the idea of non-excluding design, it might be good idea to look at the established areas of universal (Inclusive) design. What are the ideas behind the universal design approach? How can we establish a solid process of universal design? And why should we do it, to start with? Will it not make things more difficult to use for other people if everything is designed for everyone. Surprisingly, non-excluding design will make it easier to use for most. In some places the solutions for people with impairments have been so popular that we could hardly imagine life without them. One such item is a very common tool in the homes: the remote control for TVs, Hi-Fi equipment, etc. They were initially made for people who had difficulties moving. Today many electronic devices cannot even be used without a remote control. It has been incorporated in our lives.

Sometimes an addition to traditional means will be “over-used” (at least in the opinion of the people responsible for the solution). In Sweden you may sometimes find a small note over the door-opening button, saying “Keep the button pressed for five seconds”. The reason is that the button (and the automatic door-opener) should only be used by the people who are in need of using it thus implying that a person with a wheelchair or rollator (wheeled walker) whereas the time to wait for the doors to open, whereas most people don’t have that time, and will therefore use the regular door. In this case there is a constraint imposed on the alternative in order to segregate the people. The question is WHY? Why should we constrain a solution that is perfectly good for almost everybody if there is no real reason

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2 I will in the remaining part of the book stick to “Universal design” as a common term for Universal design, Inclusive Design, and Design for all although the term Universal Design is mostly used in USA.
for it? I have heard people referring to the wear and tear of the mechanism, which will break down if everybody uses them. But then, I withhold that the mechanism is faulty and of bad quality. It should not break down from usage.

What this discussion boils down to is that many solutions for inclusion and/or non-exclusion will benefit most (if not all) users of an artefact, and in many cases people tend to prefer the “special” solution to the standard. People tend to like using ramps, rather than stairs, e.g., and while everybody can use a smooth ramp, there are some problems using the staircases for some groups. Making away with the staircases would actually solve the problem with accessibility, without producing new problems for other groups of people. In some cases it is even difficult to see the solution for people with special needs as a positive asset for everybody. (cf. Error! Reference source not found.)

Figure 2-1. An inclusive, universal design will in most cases benefit all users, by providing alternatives. It still needs to be recognised. (Used with kind permission from Michael Giangreco)
2.1.1 Observation

One of the most important steps is concerned with observing. In Human-Computer Interaction (HCI) we often talk about observing the users, and this is considered to be an important part of getting a design right. However, in the context of people with special needs, the observation becomes both more crucial, and more difficult, since we need to understand the needs from an individual perspective. How can we find all the small and big things that are difficult for someone with a certain disability (or combinations of several different disabilities)?

The first part is to participate in a context where a person is using available technology in their everyday life. Many times we can see things that are just a little bit more difficult than they have to be. From these observations we may then draw some conclusions regarding new or improved designs for the intended activity.

Today observation has become much simpler than before. Most people have a mobile phone that includes a camera, and nowadays many cameras even have an option of recording HD movies. For designers, the digital camera has become a revolution, in terms of supporting the design observations. Many of the pictures here are taken with a small simple digital camera or the...
camera in the mobile phone. You can observe and record many good and bad design examples, and use the pictures as illustrative material, when creating new designs.

Observation is often about seeing things that we normally tend to overlook. It is quite common that we walk around without seeing the things around us. And then, when we see something we forget to document it, and then it is forgotten. A picture taken as one of those time snapshots is displayed in Figure 2-2.

2.1.2 Testing

Of course, observation does not necessarily have to be a passive activity. We can also observe by trying things out ourselves, and attempt to find problematic situations where the artefact is not suitably designed. One risk with testing is that we might fool ourselves that after having tested a certain tool or situation, we know how it is. That is almost never so. We may have tested it, and maybe even received some insight into what it might be like, but it is far from knowing.

Many times we may make initial tests of designs with very simple methods. Sometimes it is difficult to get access to a wheelchair for testing environments. Then we might use a pram as a replacement. By loading it with a stack of books at the end to cause some imbalance, we might check if it is possible to pass a doorstep or other barrier in the context. If we can use a small trolley, we can check whether it is possible to access with a manual wheelchair.

It is also important to test the inclines (ramps for wheelchairs) and other designs for accessibility without support. To haul yourself up an incline requires a large effort and might be very cumbersome if the incline is too steep or too long (or both).

2.1.3 Acceptance

One of the most important steps is concerned with accepting. This means that it is important to accept the individuals we are working with. Accepting that someone has an impairment and that this impairment is part of this individual is a crucial part of designing for this impairment. Accepting implies respecting the individual, and working with that person as a normal informer.

There is also another view on acceptance, namely the contextual acceptance. It is important to realize that universal design does not start with the individual, but rather with society. As long as an impairment is an indication of something that is unusual, non-normal or deviating, universal design is
not possible. Part of the universal design paradigm is therefore connected to increasing the awareness, and acceptance among people in the society.

It is primarily society that tends to make impairments into disabilities. Preconceptions and difficulties in seeing alternative perspectives lends a bad side to how disabled people are treated in the society. Sometimes people may only see (and be jealous of) what they could be considering to be the benefits of being disabled, such as having dedicated parking places (see Figure 2.3) or having a personal assistant performing all the small duties in the home. The problems imposed by the disability are, on the other hand, of course completely obvious to the person who is fighting them every day.

2.1.4 Understanding

One of the most important steps is concerned with observing. Understanding can be achieved in many ways. By observing people in everyday situations we may gain some understanding of the problems at hand. Simply by trying out how a wheel chair behaves on a cobble stone street (cf. Figure 2.4), we may gain some insight into what we might want to avoid when planning the streets of a city. To the making of an accessible city, understanding is essential. If we do not try to understand what barriers we can find on the streets or in the
architecture of a city, then it will be very difficult to change or design its feature so that it will be non-excluding.

However, once again it is important to realize that we should never believe that we (as designers) know what it is like, just because we have tried something for 15 minutes (or even an hour). As long as we ourselves have full mobility, we may never understand what it is like to not be able to move, without assistive technology. We may gain some rudimentary insights, and that may be sufficient, as long as we don’t think that we know “what it is like”.

2.2 Possibilities

One of the most important steps is concerned with observing. In Human-Computer Interaction (HCI) observation of users is posed as one important part of the gathering of requirements the users will have on the final software. Non-excluding design is to a large extent a matter of seeing possibilities, instead of problems. A problem is a negative definition of a current state. A possibility is a constructive view on the state of things, and on the things we need to change. We are often very quick to regard something as a problem, and by this, failing to see that the situation contains new possibilities, thus running the risk of a very conservative attitude.

It should not be surprising that one of the more difficult skills needed for a designer is this ability to see the possibilities rather than the problems. Furthermore, the possibilities have to be accompanied by imagination, and framed by a strong common sense. New possibilities have to be argued and dissected into their smallest parts, in order to find the possible disadvantages with the new ideas.

But, it might be a relevant question to ask whether there really are possibilities inherent in an impairment? Essentially, I would be tempted to answer yes to that question. Of course there might be cases where it is really difficult to see anything positive in the situation. In most cases, however, the individual has compensatory skills that might be of good use, or there are fields of activity where the impairment will not be a negative load on the individual. Finding these positive instances, and building on them is an important part of the Universal Designer’s task.
2.3 The principles of Universal Design

One good starting point looking into Non-excluding design is the seven principles of universal design that were developed at the Centre for Universal Design between 1994 and 1997. The guidelines are pretty simple, although they also house several interesting design issues (Story, 2011):

1. Equitable Use
2. Flexibility in Use
3. Simple and Intuitive Use
4. Perceptible Information
5. Tolerance for Error
6. Low Physical Effort
7. Size and Space for Approach and Use

As you can see some of these principles are similar and/or related to the usability principles that were listed by Jacob Nielsen (Nielsen, 1994). This should not be surprising, since a design that claims to be universal should of course be built upon human properties and what we know about human users. Universal Design has added to the usability measures and provided the principles listed above. But what is in the guidelines? We will in the following go through each of the guidelines and expand a little on the concepts that are included in the guidelines.

2.3.1 Equitable use

The principle of equitable use essentially means that the product is usable for all (potential) users, as well as accessible and available to all people. It should also be designed to look good for the people using it. It can be summarised as the following set of rules:

The design is useful and marketable to people with diverse abilities.

- Provide the same means of use for each user: identical when possible, equivalent when not.
- Avoid segregating and stigmatising any users.
- Make provisions for privacy, security, and safety equally available to all users.
- Make the design appealing to all users.

The design for equitable use should be made to be both useful, and possible to sell or provide to people with diverse abilities. One problem is to define the concept of usefulness. What do we mean by having a useful artefact?
The term "useful" means in some way that it adds value when being used. But "adding value" is a highly subjective measure. How can we understand it in terms of something that is measurable?

How can we avoid stigmatizing the users? Well, that is what chapter 9 is mostly about. The factors that tend to cause stigmatisation and what we can do about it. Currently, we can conclude that there are two major parts to avoiding stigmatization, namely good (and appealing) design, and change of attitude in society. Both of these are important to approach.

Another aspect on equitability is such a simple thing as floor space. A person with more severe impairments will most likely already have a number of devices in his or her home. This means that any new item that is to be added as support will have to defend its place in the home (or work space). Any new artefact has to be worthy of use\(^3\). Among the

2.3.2 **Flexibility in Use**

The second principle, *flexibility in use* encourages the design of artefacts to look at multitude, rather than singularity. What it means is that it should provide for as many different ways of using something as possible. When we add a new (different?) dimension of interaction, we should not take away the old way, but rather enhance the interaction so that it seamlessly incorporates both dimensions in the same product.

The design accommodates a wide range of individual preferences and abilities

- Provide choice in methods and modes of use
- Accommodate right- and left-handed access and use
- Facilitate the user’s accuracy and precision
- Provide adaptability to the user’s pace

A design should allow for use by people with a wide range of individual choices, and varying abilities. One very simple example is to provide a design that is possible to use for both left- and right-handed people. Although left-handedness is not normally considered to be an impairment, it still causes a large number of problems for the person.

\(^3\) The term "useworthy" was coined in a PH.D. Thesis by Håkan Eftring ([Eftring, 1999](#)). This concept includes the amount of space an artefact takes up. If a tool is too big, too clumsy or awkward, or just feels like “yet another machine” it is highly likely that the person will not use it.
One simple example of when this problem occurs, for a left-handed person, is in the use of scissors. The scissors can be left- or right-handed, depending on which way the two cutting parts meet. If they meet the wrong way, the pressure from the fingers will press the edges apart, rather than together, making it difficult to cut certain materials. Most scissors are of course made for right-handed people, but there are left-handed scissors to buy in the market.

A similar example is the current trend of making asymmetric cameras. With the development of the electronic cameras, there are no practical reasons to have a symmetric design any more. Thus a modern camera is impossible to hold with the left hand, since the objective is too close to the side on the left hand side.4

In general it is possible to say that most items that are asymmetric will need to have a mirrored counterpart, in order to work for both types of handedness. Asymmetric designs might be made from aesthetic principles, but raises many problems for people who are left-handed or ambidextrous.

2.3.3 Simple and Intuitive Use

Use of the design is easy to understand, regardless of the user’s experience, knowledge, language skills, or current concentration level.

- Eliminate unnecessary complexity.
- Be consistent with user expectations and intuition.
- Accommodate a wide range of literacy and language skills.
- Arrange information consistent with its importance.
- Provide effective prompting and feedback during and after task completion.

Artefacts should be designed to be simple to understand and use by a multitude of users. The use of the design should be easy to recognise and handle and should provide the user with a good feedback. The use of the artefact should not be dependent on the individual’s experience or background, language skills or education level.

In interface design this also includes simple change of interface language, and the inclusion of Braille display when possible. Also multilingual interfaces or symbolic interfaces should be considered in the design.

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4 I am very grateful to my students Monica Kumar and Yasir Bilal for this very good example of inflexible design.
2.3.4 Perceptible Information

The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's perceptual abilities.

- Use different modes (pictorial, verbal, tactile) for redundant presentation of relevant information.
- Maximise "legibility" of essential information.
- Differentiate elements in ways that can be described (i.e., make it easy to give instructions or directions).
- Provide compatibility with a variety of techniques or devices used by people with sensory limitations.

Information should be provided by means that are effective and easy to perceive, regardless of the conditions surrounding the communication or but the individual's sensory abilities. Information should be provided in several modes, to allow for the best perception by the person. The necessary information should be legible and clear, and easy to interpret. For example, it is often better to use dials than digital displays for values, since the dials can be read even by people with visual impairments, albeit with some imprecision.

Components should use visual and tactile distinction in order to be easy to distinguish, and also to describe, in case of giving instructions. In and output should be designed with a flexibility of devices in mind, so that people with various sensory limitations can use them.

2.3.5 Tolerance for Error

The design minimises hazards and the adverse consequences if accidental or unintended actions.

- Arrange elements to minimise hazards and errors; most used elements, most accessible; hazardous element eliminated.
- Provide warnings of hazards and errors.
- Provide fail-safe features.
- Discourage unconscious action in tasks that require vigilance.

To minimise hazard and error is very important in terms of self-image. To be afraid of making something hazardous or erroneous is a very delimiting feeling which will greatly reduce the activity of a person. The hazard might not only affect the user, but also the surroundings. As an example, we could recall that an electric wheel chair weighs around 250 kg including the user. If this vehicle runs over the feet of someone else this might cause injuries to
the feet or at least damage to shoes and/or walls. If it were possible to avoid doing this by accident this would be a very positive feature for an electric wheel chair. However, the problem is to implement the avoidance without taking the control away from the user of the wheel chair.

One important factor that comes into this context is the issue about the conflict that can reside between the issue of safety and freedom. People without direct impairments can always choose to do dangerous things. This is in many cases not the case for people with impairments. Assistive technology is heavily directed by safety regulations, which may come into direct conflict with the needs of a person.

Standard wheel chairs are equipped with

2.3.6 Low Physical Effort

The design can be used efficiently and comfortably and with a minimum of fatigue.

- Allow user to maintain a neutral body position.
- Use reasonable operating forces.
- Minimise repetitive actions
- Minimise sustained physical effort.

It is well known that repetitive use of the same controls will cause damage to joints and tendons in the limbs. If an action requires much physical effort this will also exclude people who have weak muscles, or bad muscle control. If the equipment forces a user to take on a special position in order to use it, then this will also put added stress on the body.

In this context, it should also be mentioned that this does not mean that every user has the same “neutral body position”. Depending on physical condition the setting for a neutral (comfortable) body position has to be flexible and adjustable, for example, in order to fit people with muscle or nervous disorders. Position of eyes and limbs is also different for different people, and might need adjustments.

2.3.7 Size and Space for Approach and Use

Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user’s body size, posture, or mobility.

- Provide a clear line of sight to important elements for any seated or standing user.
- Make reach to all components comfortable for any seated or standing user.
• Accommodate variations in hand and grip use.
• Provide adequate space for the use of assistive devices or personal assistance.

It is important that we consider that people may have different sizes, not only in terms of clothing and hat sizes. Height is a crucial factor in many everyday situations. If a person sits in a wheel chair, the person will have a view on the world that is situated at a height of approximately 85-90 centimetres. This means that a normal desk counter in a shop, most of the time will be above the person’s eyes. If the credit card reader is placed on the desk, a person in a wheel chair will most likely not be able to use it. Also, he or she will not see anything placed on the desk.

This might also be the situation for a person who is shorter than normal\(^5\). If you are shorter than average, there are many situations that become difficult, and many activities become difficult to perform. Also tall people may have problems that are caused by bad design. Controls that are placed too low, or work places (kitchen stoves, work benches, for example) may cause reaching problems, as well as medical conditions.

One interesting example where both short and tall people have similar problems is in certain kind of ATM machines. The security screen that protects the display is so thick that the buttons on the side have to be seen at the exact straight angles, since otherwise the buttons will be aligned to the wrong text on the display. This phenomenon is the same; regardless whether you are too short or too tall.

Finally, overweight is also a bodily condition on size that may cause problems for a person. This is actually not really covered in the guidelines above. However, a large body size is severely delimiting in many situations. Seats in planes, cinemas and theatres, are many times not possible to use for people who are too big. Apart from the obvious exposure, the condition severely limits the possibilities for people who are overweight\(^6\).

We might even add a new guideline under the principle category of Size and Space for Approach and use: Allow for all body sizes, and make elements accessible regardless of body type.

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\(^5\) What is considered to be "short" often differs with the culture and geographical setting.
\(^6\) Severe cases of overweight are considered to suffer from an impairment. Contrary to preconceptions, people who are overweight are very often not completely responsible for their condition [if at all]. Overweight can be caused by medical conditions, and by genetic predispositions.
2.4 Emergency situations

Even though an artefact or architectural structure may be well designed for normal situation usage, this doesn't mean that it will work when there is an emergency. Most rooms have emergency exits, in the form of windows, for example, but only the single door, which is accessible for a person in a wheel chair. So what would happen if there would be a fire in the corridor outside of the room? How can a person with crutches or in a wheel chair be evacuated through the windows? And how will a blind person find the emergency exits?

Whenever there is a staircase we usually advocate the use of lifts in order to increase accessibility. Every apartment house in Sweden higher than three stories is required to have a lift as a complement to the stairs. But there are no requirements on providing alternative emergency escapes for people who cannot use staircases (cf. Figure 2-5). A colleague of mine even referred to a sign on an elevator that stated: “In case of fire, don’t use the elevator, unless you are using a wheel chair:”

We clearly do not have the same requirements for evacuability (there isn’t such a word, but there really should be one). The matter of emergency situations are often not considered, neither in universal design situations, nor in the design of assistive or supportive technology.

2.5 Reflections
1. **Reflection:** Try to think if some solution to the problem with elevators, in case of fires. How can people with different impairments be evacuated safely in an emergency?

2. **Reflection:** Consider the statement on the elevator sign in Figure 2-5. What is the idea purported by that statement? Why are some people excluded from using the elevator and others not?

3. **Reflection:** If we change it to the wording as in the example given by my colleague, what is the change in the meaning? Is it a better idea?

4. **Reflection:** Is it possible to design a pair of scissors that can be used just as well with the left as with the right hand? And what about knifes? Are they also left- and right-handed?

Figure 2-5. Every elevator has a sign that warns you not to use the lift in an emergency. So, how are you to get down if you are dependent on it? (Drawing used with kind permission by Garrick Tremain, New Zealand)
3. History and Politics of Impairments and Disability

Impairments have always been a part of the society, either as hidden or as visible parts. Even in the prehistoric man there are traces of impairments that will have affected peoples lives, and also signs that the tribe did look after their people when they had been mutilated by accidents or diseases (often in terms of scarring that has been healed, although the wound would have been very disabling for the individual in the meantime.

However, the role of people with impairments has been very varying over time, and the current society is even creating new impairments, which makes it very important to also look to the historic and the political perspectives on impairments.

3.1 A Historical Perspective

Although this book is not primarily about disability and impairment research, it is necessary to have some of the historic background. Impairments have been around as long as humans have been an active species on the earth. Activity implies a risk of accidents, and breaking a leg or an arm in early history was not always as (relatively) small accidents as they are today with our medical science. Many of the prehistoric cases suffered much from these accidents, provided that they survived the actual accident. Bluntly put, nature often sorted out many of the individuals that had impairments at that time. However, even in early history (pre-history) there is evidence that the human social groups supported the impaired individuals as far as they could at that time. This has been further developed during the history of civilization, where today people are saved that would inevitably have died in earlier times. However, sometimes this new possibility for survival is given at the cost of some impairments that will be a hindrance for the individual.\(^7\) (Braddock & Parish, n.d.)

People with impairments have always been stigmatized in some way through- out history. Being "outcast" was a pretty normal condition for people who were different from the mainstream population. In some cases the impairment was, however, also seen as a positive sign [from the God(s)]. In those cases they were consulted for advice or providing healing powers,

\(^7\) A very informative timeline of disability can be found at...
sometimes becoming "the old witch" or the "the old man" of the village. Often feared but sometimes also revered. (Hassenzahl, 2012; Scheer & Groce, 1988).

With the forming of cities, the “odd” people, (i.e., people with cognitive or perceptual impairments, or people who had bodily distortions, such as hump- backs, heavy limping etc.) were, if they were physically able to work, taken out for simple and often degrading work, such as street cleaners, undertaker assistants, or similar tasks that nobody else wanted to do. This was especially the case with people who had some cognitive impairment.

With this short historical perspective, it is interesting to see the growth of the various organizations that gather people with various impairments into opinion-shaping movements, and how disability issues have been brought into governmental contexts. It is, however, quite disappointing to see how slowly the process of acceptance is progressing over time. There are several examples even in our time of how people with impairments are being discredited, stigmatized or even hidden from the public eye. Having an impairment is still in many cases a matter of being degraded to a second (or even third) class of people in society. (Barnes, Oliver, & Barton, 2002)

3.2 Disability Politics

The politics of disability has slowly moved from being focused on how to take “care” about the people with impairments in the end of 19th- and the beginning of the 20th centuries. At that time it was in Europe mostly regarded as a problem how to store the old, poor and disabled people. Most of the time these were regarded as lesser citizens (unless, of course, if they were of high social status).

As late as during the Second World War, Adolf Hitler ordered the process of "Mercy killing" of people that were sick and disabled. They were mentioned as being "life unworthy of life". It is also noteworthy that this group of people, who were killed before and during the World War II, is almost never mentioned in connection with the mass extinction of Jews, homosexuals and communists. Even in special memorial events, people with impairments are often not invited. It is clearly evident that people with impairments are still neglected in this dark part of history.

War veterans in the US army are one of the groups that have been especially noted during ceremonies. Still, however, they are more or neglected in the remaining parts of society. There is currently an ongoing movement among the veterans to gain a better position in the society. Poverty and social exclusion still takes the better of the people with impairments from the war.
Even though we consider this to be “enlightened times”, still today people with more advanced impairments have a large disadvantage when applying for work positions, a fact that also renders them financially disabled. One might wonder why sitting in a wheelchair would make anyone unfit for a clerical office duty?

In recent years, however, society has started to recognize people with impairments as a political force, through the establishment of different organizations for the different kinds of impairments. These organizations have eventually become influential (at least to some degree) forces in society. Since 1970, there have been many regulatory changes that promote the rights of people with impairments, albeit some of these rights tend to stay on paper, rather than being implemented.

### 3.3 International Aspects on Impairments

The situation for people with different kinds of impairments is vastly different in different countries. We have to recognize that the situation in Europe is different from the situation in mid-Africa. This is due to a large number of circumstances, not least cultural and economical. This means that much of the discussions in this book has to be applied in a more abstract sense, since in some countries the development described is not (yet?) possible. However, sad as this might seem, there is also a small good side, in that in the cases where the society desires to allow for people with impairments, they might not walk into all the mistakes that have already been made elsewhere. In Sweden we would call this “comforting a Tiger’s heart”, meaning that this is really negligible in the large perspective. But hopefully also a small change to the better is a change, and a first step towards a universal world.

### 3.4 Interesting Reads

### 3.5 Reflections

1. *Reflection:* How can we avoid doing “the same mistake” over and over again?
2. *Reflection:* Do you think that it will be possible to have a society where disabling environmental factors are more or less extinct?
3. **Reflection:** How long time would you think it would take to change the attitudes within the society?
4. Disabilities and impairments

We often talk about disabilities or impairments, sometimes even without thinking about the intention in the words. Rather, we are more or less taking the definitions for granted. When do we have an impairment, rather than a minor deficiency? When is a condition differentiating enough to be described as an impairment? And what is the difference between impairment, disability and handicap?8

The kind and severity of different impairments is of course a central aspect of non-excluding design. Although we have a tendency to categorize the world, this can lead to dangerous effects in the case of impairments. A person with an impairment may or may not behave as another person with a similar impairment. Difficulties and obstacles may look different to different people, regardless of the kind and type of impairment. This chapter will also give a brief (too brief, in my opinion) overview over different kinds of impairments and also discuss other properties of the impairments, such as severity and how it influences life and possibilities. First let us consider a few different categories of impairments, that influence individuals’ activities in different ways. The categorizations in this chapter are rough and not very precise, but this is the intention with the description. If we start going into details here, we might be caught in an excessive categorization which will unnecessarily make a more complex picture, which will not be useful for the current mission of making good design.

4.1 Terminology

The word disability is often used as an umbrella term, covering impairments, activity limitations and participation restrictions, where,

- an impairment constitutes a problem in body function or structure,
- an activity limitation is a difficulty encountered by an individual in executing a task or action, and

8 In Sweden the term handicap has been discarded as unsuitable. However, I still consider the need for the term as a name for the indirect implications of the disability that are brought about by the context, for example, by the society. Cf. later in this chapter.
• a participation restriction is a problem experienced by an individual in executing a task or action.

Note that a disability is not necessarily due to illness or accidents. There are disabilities that are inborn properties of the individual that have been classified as disabling factors by society, such as body size. Being very short, very tall or obese are disabling conditions in certain situations, but do not stem from any particular diseases, syndromes or accidents.9

In the strategic plan for people with disabilities from the Norwegian government there is a quote that pretty well describes the term disability: Disability is “a mismatch between the person’s capabilities and the functional demands of the environment” as quoted from Tossebro (2000). This shows quite clearly what constitutes a disability. With this understanding, disability becomes a relatively complex phenomenon that is not only inherent to an individual and his/her function, but also includes limitations in possibilities, participation possibilities and the general acceptance of the society and other individuals. So the impairment is the actual property of the individual, and the disability is more or less the direct problems that are caused as a result. We will therefore use the term impairment when we talk about the bodily functions, and disability when we talk about the effects of the impairments in various contexts. It is quite easy to remember when the word “disability” is written “dis-ability”, i.e. a lack of an ability to do something. This is quite different from the meaning of “impairment”.

The term handicap should not be used in this context, due to its derogating meaning. It might still be used to express the disablement caused by environments or equipment. Being handicapped by the new construction of a ramp purports the idea that a disability is induced by poor design thinking.

One final point on terminology, regards how to refer to a person with an impairment. Even though the disability becomes part of the person, in a way that might be difficult to understand for people who are not disabled (Shapiro, 1994), it is not really suitable to refer to people as “the disabled person”, or, when we talk about people with certain impairments (Shakespeare, 1996). This is especially important when we talk about specific impairments, since the degree of disability is very different between individuals, situations and other factors. A person who suffers from

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9 The body size can of course be caused by medical or genetic defects, in which case they are often noted from a very early stage on. For example dwarfpism is caused by a deficiency in the pituitary gland.
tetraplegia will not be noticed as disabled, if he or she is working for example within telephone support. None of the customers who talk to him or her in the phone will have any reason to think of the person in the telephone as being disabled.

According to Shakespeare (ibid.) it also inappropriate to refer to people as “disabled”. The group of people who are impaired is not necessarily homogenous, but contains a large number of individuals with varying abilities and needs. The risk of grouping people under this kin of label as being similar, having similar needs etc. is too large.

4.2 Impairment categories

Essentially we can make a rough distinction between three major types of disability (although there may be all kinds of combinations within an individual), namely physical, perceptual and cognitive impairments. It is always a risky business to do a categorization, since there is always a tendency to regard the boundaries as strict and clear. This is of course even more dangerous when we work in the area of disabilities, but I will take the risk nevertheless, since it will be easier to discuss the design of personal assistive technology from the perspective of a certain category of impairments rather than as a general idea that includes all types of impairments at the same time.

Furthermore, it is important to recognize that impairments and the effect they cause are highly individual, and even the same impairment will not affect different people in the same way. Depending on personal interests, physical stamina and many other factors, a certain factor will be more or less influential. Still, the categorization above can still constitute an initial checklist for an individual design process.

4.3 Impairment visibility

One important distinction from the perspective of stigmatization and self-image construction is the issue of impairment visibility.

A Invisible impairment, whether it is visible in terms of physical bodily signs (e.g., weak limbs, limping) or in terms of visible assistive technology (such as canes, wheel chairs or crutches), always tends to be stigmatizing to some degree. We can see that the person "needs help" and that he or she is not like other people. A visible impairment is often counterproductive, reducing the person to a victim (victimization), and may affect people's attitude towards the person.
An invisible impairment, such as most cognitive impairments, heavy allergies or impairments that only have hidden signs (bodily pain, blind people wearing sunglasses, hearing problems, etc.) does not imply any immediate stigmatization, and only captures peoples interest when the impairment shows itself actively (for example, when a person doesn’t react to being addressed by spoken questions). On the other hand, the impairment can be difficult to respect (since people do not know that it exists) and it can also be a cause of many misunderstandings.

Many people suffering from such problems as migraines or cognitive problems after stress related syndromes and strokes relate that their problems are not accepted as real. It is not possible to see that they have an impairment that severely influences their lives under certain conditions.

Some impairments that in their extreme cases are visible through the use of assistive technology, will in their milder versions become invisible. A typical example of this is when a person has a severe visual deficiency, but can still see with the help of strong glasses. In case of losing the glasses this person is not recognizable physically as having an impairment. He or she will still be strongly disabled in most situations.

4.4 Impairment severity

Regardless of whether we have a physical, perceptual or cognitive impairment, the severity of this impairment can be graded according to a scale, based on how the impairment influences the individual’s life. There are Informally four different levels of severity: None, Mild, Moderate and Severe.

4.4.1 None

How strange as it may sound a person classified as having no impairment may still have an impairment. This level of impairment indicates that the person has no impairment at all or an impairment, which is so mild that it, does not affect the ability to lead a normal life. Examples of such impairments would be shortsighted people wearing glasses, or a person with mild allergies. Still, a mild impairment can still cause discomfort or problems in the everyday life, e.g., when the glasses break, or when a change from cold to warm temperature cause the glasses to fog.

4.4.2 Mild

The mild impairment classification covers those who can perform basic life management functions and use the normal ways of transportation and
communication. They do not require assistive equipment for their daily functions and the condition can be managed by medication. Such impairments include learning disabilities and hearing and sight impaired people.

4.4.3 Moderate

A moderate impairment is a condition that is stable and not progressive. It will generally not get worse. The person can perform the basic life management techniques with some assistance. The person might require home modifications, transport aids and communication aids. Disabilities that might fall into this category include mild cerebral palsy, paraplegia, spina bifida, fully sight/hearing impaired, higher learning disabilities and mental retardation.

4.4.4 Severe

A severe impairment is a condition when the person needs assistance with or having functions performed for them. Progressive, degenerative and terminal conditions fall into this category. The person will need significant home adaptions and medical care. Special adaptations for transport and communication might be required. Such conditions include quadriplegia/tetraplegia and cystic fibrosis, although it is a case-by-case basis how much the person can do for herself.

4.5 Effects of an impairment

An impairment interacts with the individual’s abilities and possibilities to engage in activities. In the International Classification of Functioning, Disability and Health we can find the picture seen in Figure 4-1. Central in the figure is the activity of the individual, and its interaction with the health condition. Impairments affect the ability to do things, and the level of activity affects the impairment to some extent, but also the health conditions. Similarly the impairment affects the body functions and the body structure, for example by hindering the training necessary to keep the body in good shape.

Impairments also affect the individual’s ability to participate both in individual and social activities. Finally, the body function, the activity level and the participation is heavily affected by contextual factors such as the physical environment and the personal, social factors that occur in the life of the person.
This interaction between all these factors is very important to understand. There is a tendency to see an impairment only as a single factor that causes a disability. It is instead only a small part of the story since the impairment and the person's apperception of it is highly interacting with many other factors, which in turn has a much larger effect on the possibilities that are available for the individual.

4.6 Disabilities induced by society

Disability is not an absolute, but rather a very context sensitive property. The same person with the same impairment can be completely disabled in one context, and completely able in another. Using a wheel chair is not a disabling factor for most office work, for example. A visual impairment might not be a disability for a person doing most of his or her work over the phone. You cannot hear that a person cannot see.

However, in many cases society directly induces disabilities, for example, by building houses with traditional doorsteps, yards, and streets using curb stones and other hindering architectural artifacts. The disability may seem to be caused by the impairment, but is rather due to an inability to foresee these kinds of problems. When we think about physical exclusion, it is most of the time a design issue to remove this exclusion. By lowering doorsteps, and curbstones we remove many unnecessary barriers in the surroundings.
Non-Excluding Design

Still, physical exclusion is much more than these obvious barriers. Physical exclusion also comes through everyday obstacles, such as heavy doors, steep slopes and other features of the landscape.

Other barriers, that are even more difficult to spot are perceptual barriers, such as spoken message systems, e.g., at airports or train stations, visual maps or orientation schemes. There can also be more physical obstacles that are placed directly in the walking paths, not barricading the path, but still constituting dangers to people with visual impairments, such as flower pots, street signs and other similar objects. All in all, there are many small things that are part of how we build our cities and other environments. If these barriers are built into the planning, then the disabilities are constructed, rather than existing from natural causes. One goal of universal design is, not to remove, but to avoid constructing these barriers in the first hand.

4.6.1 Curbs and Cobble Stone Pavements

What is the reason for having curbs on the streets? The curb can be regarded partially as a historical construction, made in order to reserve a part of a street for pedestrians, when traffic became more and more dense (cf. Figure 4-2). It still serves an important role in many cases in separating people on foot and people in cars from each other. There have been experiments with curb-less streets, i.e. streets where the curb and the street are level with each other. However, in some places the curbs became parking places for cars, which was not the intention of the change.

It is necessary to find a better way to separate traffic on wheels and pedestrians, at least if we are to remove the curbs or at least make it easier to access the pedestrian part of the street. On the other hand, it seems to be necessary to have some kind of physical delimitation between street and curb. One simple initial solution could be to have spaces at regular (or non-regular) spaces where there are level exits from the curb. These exits should also be clearly marked in order to not cause problems for people who have reduced eyesight.

Another aesthetic addition is the use of cobblestones. Cobblestones are very popular surfaces in walking areas, indicating that this is not intended for

Figure 4-2. This is a pedestrian crossing from the Roman times, here from an excavation in Pompeii
cars to drive on. They might also provide the area with a slightly more old-fashioned look, which is of course nice to have in an old city center. The reason why we have started to use asphalt instead of cobble stones for the streets and roads becomes clear if we drive an older car a bit too fast on a cobble stone area. The whole car vibrates in resonance with the stone surface. Thus, most streets for cars don’t use cobblestones.

So what is good with cobblestones? Why use them at all? Disregarding the aesthetic aspects mentioned above, there are also practical issues. The rain will not cause puddles on cobblestones (at least in theory), they are longer lasting than asphalt and they actually provide a resistance for speed driving by cars.

4.6.2 Dyslexia and Dyscalculia

The effects of dyslexia and dyscalculia were discussed in some detail in previous sections.

One of the more interesting types of disabilities that have been explicitly created by society is the cognitive disabilities relating to the skill of reading and performing mathematics. Dyscalculia and Dyslexia both are effects of the requirements put on the individual by society. In early history, it was not a big problem if you could not read, since the number of occasions where information was available only in written form was very limited. People were not expected to be able to read in any greater number. Thus, dyslexia was not a problem at that time. If you did not have the ability to read, then you chose a work where you did not have to use texts.

Today the situation is completely different. You are in many countries more or less required to be able to read, since you have to get updated on regulations and laws. In Sweden, e.g., you are by law required to know all of your duties. Not knowing about a legal rule is not an excuse for breaking it. You could of course have someone tell you all the rules (and rights) you have to follow, but in reality we have to read the information in order to access it. With increasing complexity in the society, also the requirement of being able to read increases.
In the same manner the requirement of being able to do mathematics is also fairly new. In the later years it becomes more and more a requirement to be able to different kinds of calculations in the society, from the home budget, with loans and mortgages to the yearly declaration of income. Also cost estimations and other everyday calculations are difficult for people with dyscalculia. And this also goes into school. Today it is difficult in many countries to leave school without having had your math skills being tested. This means that a person who has dyscalculia cannot avoid being sorted out already in school.

4.6.3 Bad Visual Cues

A common cause of exclusion is using smaller sizes of expressions than is necessary. So, for example, are many signs and texts made to be very small. Many things around us are designed to be seen by people with normal eyesight (and sometimes even smaller than that). The sad thing about that is that there is often not due to lack of space, but for lack of afterthought. If we think again, it is obvious that the larger we make a sign, a clock face, or text, the more people can read it without any problem.

Sometimes there are several factors that work together to exclude people. Such a combination of factors can be seen in Figure 4-3 when we have a combination of small coloured symbols that are also strangely shaped. This makes the design difficult to understand if you have a bad eyesight. The effect has been simulated in the picture on the right side, where the coloured arrows are only very faintly visible in the picture, and definitely not as arrows. In fact, the location of the arrows (when you can’t see them clearly) indicates that the handle should be turned the "wrong" way.
This problem is to some extent even fun in a sad way, since it only occurs to people when they are not wearing their glasses. The handle, however, is located in the shower area of the large bathhouse in Uppsala. When do people take off their glasses? Certainly many do not like to take a shower and wash their hair with the glasses, i.e., exactly in the situation where you are supposed to use the handle. Maybe this could have been foreseen by some non-excluding reasoning?

4.7 Reflections

1. **Reflection**: How can we remove the curbs from the street, without running the risk of mixing the different categories in a dangerous way?

2. **Reflection**: Is the situation shown in Figure 4-3 only an accessibility problem, or is it possible to see it from a different perspective?
5. Physical impairments

A physical impairment limits the use of limbs or motor abilities. This could also include less direct bodily functions such as sleep. Both having difficulties sleeping and insomnia can severely influence a person’s life, and can be caused by malfunctions in the physical mechanisms that direct the sleeping behaviour. However, in most cases a physical impairment affects body and limbs, in such a way that the individual’s movements are hindered or impossible.

Within this group it is possible to distinguish between different types of impairments dependent on the cause of the problem. In the list below I have tried to incorporate some examples of impairments and their causes in order to be able to find a possible structure:

1. Paralysis – Due to accidents or diseases (for example meningitis) – Inborn syndromes
2. Amputation – due to accidents or diseases (for example, as a secondary effect of diabetes)
3. Neural diseases, such as Multiple Sclerosis (MS), Amyotrophic Lateral Sclerosis (ALS) and similar diseases.\(^\text{10}\)
4. Muscle dystrophy
5. Parkinson’s disease
6. Rheumatic diseases

All these conditions will affect an individual’s physical possibilities to move, either body or limbs in different ways. A common factor is that they affect either the nervous system or the muscular system in various ways.

5.1 Paralysis

Paralysis is a very wide term for a large number of conditions. There are several different categories, depending for example on such things as the location of the cause of the damage in the case that the cause is a result of a damaged part of the spine, for example. But there are many other causes,

\(^{10}\) Some of the neural diseases may also affect the perceptual and cognitive abilities, but the main effect is on the physical system.
such as a stroke, a neural disease. All these may result in a partial or complete paralysis of the limbs and body. In the most extreme cases also the facial muscles are affected in case of brain damage or severe neural diseases.

### 5.1.1 Paralysis affecting the Limbs

There are two basic categories of paralysis that are based on the location of a spine damage. Paraplegia is damage to the lower part of the abdomen, and results in a disability to move the legs. The arms are still more or less functional, and allow the person to be more self-sufficient. Paraplegia is often the result of severe car accidents, and falls (unless the neck is also affected by the accident).

Quadriplegia on the other hand, includes a paralysis of both legs and arms or hands. This is often a result of damage in the neck (for example, from diving accidents), and the level of the damage also affects the related problems, such as respiratory problems that might be a result.

These conditions can be of varying severity, depending on the degree and location of the damage in the cord. If the spine is not completely severed by the damage, there might be both motor control and sensory perception, although with disturbances. It is also important to realize that even if the spine has been severed somewhere, the reflex nerve system might still be working, and reacting to stimuli.

### 5.2 Neural diseases

Neural diseases affect the nervous system, and the way that signals are conducted over the neural network in the body. The intricate network of nerves has constituted a fascination with artists and researchers over time. There are essentially two separate systems of nerves in the body, the nerves controlling active, voluntarily movable muscles all over the body, and the system of nerve cells that act autonomously and independently (mostly). Different neural diseases affect different nervous systems as well.

\[ \text{\footnotesize (2)} \text{Here we talk about physical damage in general, and not necessarily about the effects a neural disease. A disease can also result in damage to the spine, causing all the problems described in this chapter.} \]
There are a large number of different neural diseases, and here it will only be possible to describe a small selection of those. The selected diseases also represent some typical characteristics of the problems, which might be important to recognize when working with people having these types of problems.

5.2.1 Multiple Sclerosis

Multiple sclerosis (MS) belongs to the type of diseases that are characterized as auto immune, in that the disease is caused by the body’s own immune system. The cause of the disease is unknown, although the mechanisms are relatively well known. The disease may take on many forms and can progress in different ways. New symptoms may occur either in discrete (the relapsing forms), or as slowly accumulating over time (the progressive forms). Between the attacks, the symptoms may disappear completely (at least in the early stages). However, there is an increasing occurrence of permanent neurological damage, as the disease progresses.

MS is a disease, which affects the central nervous system and especially the ability of the nerve cells to communicate with each other. Nerve cells communicate by sending electrical signals called action potentials down long fibers called axons, which are contained within an insulating substance called myelin. In MS, the body’s own immune system attacks and damages the myelin, and as the myelin is lost, the axons can no longer effectively conduct signals along the spine or within the white matter of the brain.

MS is usually starting to appear in young adults, and is more common in women, than in men. There is no known cure, but treatments may return function after an attack, prevent new attacks, and also prevent some kinds of disability.

A person with MS may suffer from many neurological symptoms and signs. Examples of such signs are loss of sensations, muscle weakness, and difficulties in moving, coordination and balance, as well as problems in
speech. Some people also have perceptual symptoms, such as visual problems, seeing phosphenes. Furthermore, MS can affect the cognitive system, causing cognitive impairments, emotional instability (for example, depression or unstable mood), as well as a general fatigue. It is still listed under physical impairments, since most of the symptoms and signs are physical to their nature.

5.2.2 Amyotrophic Lateral Sclerosis

Amyotrophic lateral sclerosis\(^3\) (ALS) is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body.

As motor neurons degenerate, they can no longer send impulses to the muscle fibers that normally result in muscle movement. Early symptoms of ALS often include increasing muscle weakness, especially involving the arms and legs, speech, swallowing or breathing. When muscles no longer receive the messages from the motor neurons that they require to function, the muscles begin to atrophy (become smaller). Limbs begin to look "thinner" as muscle tissue atrophies.

The progressive degeneration of the motor neurons in ALS eventually lead to their death. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, patients in the later stages of the disease may become totally paralyzed.

There is no cure or treatment today that can halt or reverse the progress of the disease, but there are significant devices and therapies that can manage the symptoms of ALS and help people maintain as much independence as possible and prolong survival. ALS is a quite variable disease; no two people will have the same development or experiences from the disease. There are also medically documented cases of people in whom ALS burns out, stops progressing or progresses at a very slow rate.

5.3 Disability caused by Pain

Some physical impairments are indicated primarily by pain, either locally, such as in the case of migraines, which is located only to the head, or more unspecified as pain that is located in various places in the body, such as in the case of fibromyalgia, which is characterized by chronic widespread pain and a heightened sensitivity to pressure on the body. Both these conditions
are often subject to disbelief regarding the severity of the pain, but are in both cases clearly disabling.

5.4 Reflections
6. Cognitive Impairments

People with mental disabilities are some of the most neglected people in the world. In many communities, mental disability is not considered a real medical condition, but viewed as a weakness of character or as a punishment for immoral behaviour. Even when people with mental disabilities are recognised as having a medical condition, the treatment they receive is often less than humane.

*Human rights violations against people with mental disabilities occur in communities throughout the world in mental health institutions, hospitals, and in the wider community. (WHO 2012)*

As noted in this quote from the World Health Organisation, the situation of the people with cognitive disorders is very difficult, and there are many (negative) preconceptions about the cognitive disorder spectrum. Much of the disability comes from the stigmatisation of the individuals due to their inability to conform to the social rules and norms of society.

This very heterogeneous category consists of all of the different cognitive impairments and thus becomes a very large group. It covers a very wide spectrum of phenomena, from memory problems, to problems of reasoning and of specialised cognitive functions such as dyslexia and dyscalculia. It is of course impossible to cover all different aspects of all cognitive disabilities, but we will try to find a reasonable sample of properties that will count into this category. The intention of this chapter is not to provide a covering description of all the possible diagnoses, but rather to give a sample overview of the various implications that the different impairments give. Thus, stroke and stress-related exhaustion syndromes may have similar effects on the life of the affected individual, although they have completely different physical or medical causes.

We will also not go into the purely psychic disorders such as paranoia, mano-depressiveness or schizophrenia, etc., since they are not essentially publicly visible, although it is clear that they will also affect the person's life and thus will be disabling. This category of cognitive disorders will be addressed briefly in the final discussion of this chapter.

But before we go into the different kinds of cognitive impairments, we will quickly go through the most basic of the cognitive abilities in the human.
6.1 Cognitive Abilities

Human cognition is a very advanced process, and sometimes it seems like a wonder that the brain should work at all. The cognitive mechanisms are in many cases surprisingly robust and reliable. Even a larger damage to the brain, such as a tumor or a stroke, can leave the brain in a good working condition although some of the cognitive skills have been affected. The following (true) story can describe this in a quite vivid manner.

I once met a man who had had a stroke. When he woke up again at the hospital, he had no language at all. He could not speak the words he was thinking. After some time the language came back, very slowly, but to begin with only the bad and offensive language. The stroke had affected his speech area, to such an extent that he was unable to express anything legible. He went into therapy, and I was surprised to hear him talk after a little more than a year. You could not hear that he had been without words a year earlier. Correction; you could hear it from that he avoided certain words by circumscribing them. Those were the words he could still not remember.

This poor man had a second stroke some years later. This time he had a paralysis to the left side of his body. He could not walk, and had very weak muscles in the arms. This man was a very strong man in mind, so he went to therapy training again. After some time, he had regained enough control over his leg that he could use crutches to walk around again. Slowly, but he could!

The third stroke (yes, he had a third one) affected his spatial skills. He could not orient himself any more. He did not recognise any surroundings or make any spatial planning. Standing in any previously familiar surrounding, he could not make out which way to go. But he still had the same spirit and personality, and once he said to his wife: “Haven’t I made life easy for you? Now, when you get tired of me and want to get rid of me, you only have to lead me outside our house and then go back in. I won’t find my way back home...” And then he gave one of his admirable laughs and limped to the sofa.

When they X-rayed his head, they found that there were three areas, each the size of a golf ball, that were “dead” in his brain. But despite this, he still could think, talk and look at life with a sense of humour.

This example shows the strength of the brain capacity. Even with large parts of the brain not working a human can still function. Of course this person
was lucky, in the sense that the areas of the brain that were affected were not the most crucial ones, but areas that control skills without which we are still able to live. Even a single small damage in a crucial part of the brain can be immediately fatal or cause permanent paralysis. But still it is amazing to realise the redundancy that resides in our central nervous system.

6.2 Attention and Focus

The ability to pay attention and focus on a limited number of tasks is often not thought of as a cognitive ability. However, the human brain is normally very efficient in filtering out certain kinds of stimuli and keeping the line of thought under control. The filtering of the brain is also selective and allows us to focus on things, while still being (subconsciously) aware of things in the surrounding situation, such as alarm signals and other attention markers. The most important attention marker is normally the individual’s name, which penetrates most other noises.

The processes needed to keep focus and direct attention are very complex and are also crucial in some kinds of cognitive impairments, where it seems that the filtering function works differently. We will get back to this when we describe the different cognitive impairments later in this chapter.

6.3 Memory

There are many kinds of memory in a human. We normally think of memory as being able to remember a piece of knowledge, and to repeat that knowledge after some time. We also sometimes think of the problem of keeping a list of groceries in mind, during the trip from home to the shopping mall. The former is often referred to as long-term memory, and the latter as short-term memory (or working memory). The full mechanism for using the memory is of course not known, but we have several models for the way human memory works, including the mechanisms behind learning and the normal forgetting. Forgetting is a normal process in the human brain, and it is only when the forgetting becomes an unusually large hindrance in the way of life, that we will consider it an impairment. Apart from the dichotomy described above, there are also several other ways of categorising human memory, according to how it is stored and used.

6.3.1 Semantic memory

The most common notion of memory is the type called semantic memory. This is the memory that contains all the facts that makes up the general knowledge that has been collected throughout the individual’s life. This
includes facts of the type that “1+1= 2”, “Leif Eriksson discovered North America” and “The Italian word for artichoke is Carciofi”. Thus the semantic memory involves language and conceptual definitions.

The semantic memory is the base for all cognitive activities. Without concepts and facts there are big difficulties to survive in the world. It is also sometimes discussed as being holographic, meaning that the brain stores parts of the same memories in several physical places, which is indicated by the process of recovery after severe strokes, where the recovery of memories is often quite good. Also aphasia cases often have a good progress. From having no language left at all, the individual often recovers large parts of the language after some time. In some cases the person also develops a strategy that involves circumscribing words that he or she cannot retrieve. This is often not perceptible, unless you are very observant of the manner of speaking.

6.3.2 Episodic memory

The term episodic memory refers to the personal experiences of events, as connected to certain times and places. These are complex memories, mixtures of many sensory memories that are grouped together into episodes. Episodic memories are probably special to the human race, and seem to have been the last form of memory to develop. Evolutionary, it also seems to be the memory that has been least consolidated, and which is very susceptible to brain damages. It also seems to be the memory that is most affected by normal ageing.

The episodic memory is normally a very strong memory mechanism, and can also induce episodic learning, which causes a change in the behaviour of the person. An episodic memory (for example from being bitten by a dog) may infer a fear of dogs that will in turn automatically change the attitude towards dogs. Emotional reactions tend to strengthen the episodic memories, possibly due to increased association strength.

6.3.3 Procedural memory

Learning to perform physical or automated skills is much different from learning facts. Many times knowledge that has been learned by doing is much more difficult to access, and is part of what we often call tacit knowledge. Among such things are driving a car, riding a bicycle, tying a shoelace or reading. We have big difficulties explaining how to do it, even when we are experts on doing it. Many times the procedural memories are referred to as “I have it in my spine” meaning that it is almost a reflex, and that there is no conscious mental effort involved in remembering the procedure. A typical example is the report of car drivers who find themselves
parking at work on the first day of the vacation. They have followed the well-known procedure of driving to work, and performed it safely, but unconsciously.

Procedural memory is also a very stable form of memory. Even after long pauses, the skill remains largely intact, and may be revived with short or no practice. On the backside is that the procedural memory is difficult to unlearn, which shows quite clearly when we have change passwords or PIN codes. It is difficult to remember to use a new password, rather than the old, well proceduralised one.12

6.3.4 Implicit memory

Implicit memories are of the same type as procedural memories, but are even more subconscious. It results in a behaviour change caused the individual's prior experience, but the person has no conscious recollection of that prior experience. An example could be that a person changes his or her attitude towards dogs in general, after having been bitten or scared by a certain dog. If this event has happened early on in life, even the scary experience might be forgotten.

Implicit memories are often connected to emotional experiences, which make them especially strong and long-lived.

6.3.5 Prospective memory

Prospective memory is a part of our memory processes that is crucial and naturally closely connected to the human's ability to plan in advance. It affects future episodes, such as keeping appointments, returning books to a library, or paying the bills in time.

6.4 Higher-Level Cognitive Functions

The ability to learn and remember knowledge is a basic ability for the human intelligence. However, just as important is the ability of using the knowledge actively. The higher-level cognitive functions allow the individual to make use of the learned knowledge, as well as synthesize new knowledge from old (for example through reasoning). When the higher-level functions fail, this often affects a person severely, since the society is more and more dependent on a person’s possibility to use the higher-level reasoning. Just as

12 Some people even report that they don’t know the PIN code or password, unless they key it in on the keyboard. They have proceduralised the physical action, and during this process "forgotten" the actual numbers.
disabilities due dyslexia and dyscalculia are to a large extent caused by the development of the society, some of the higher-level cognitive impairments also result in a disability through a lack of understanding of situational information.

6.4.1.1 Reasoning and problem solving

One of the most important human skills is the higher cognitive skills such as reasoning and problem solving.

6.4.1.2 Spatial orientation

6.5 Dementia

To start with, it is necessary to realise that having a bad memory, at least to some extent, is a “normal” state in a human. Forgetting can even be seen as a basic effect of most cognitive memory models. In older people (above 65) memory may deteriorate. However, when the deterioration is faster than the “normal” rate, it is considered to be a case of “dementia”. One of the major causes of memory problems is the Alzheimers disease, which often has a very rapid development.

*Dementia* is not a single disease, but a non-specific syndrome, in that it covers a larger set of signs and symptoms. The condition consists of a serious loss of cognitive ability *in a previously unimpaired person*, beyond what might be expected from normal ageing.

The condition may be static, normally as a result of a brain injury, in which case a part of the brain, responsible for the memory functions has been destroyed. It can also be progressive, which results in a long-term decline, which can be caused by damage or some disease in the body. Dementia is far more common in the geriatric population (See also the chapter on Design for Elderly) Despite this it can still occur before the age of 65, in which case it is termed "early onset dementia".

The affected areas of cognition in a diagnose of dementia are memory, attention, language, and problem solving. The condition needs to be present for at least 6 months in order to be diagnosed. The alternative term for a cognitive dysfunction that has been seen only over shorter times, in particular less than weeks, is termed *delirium*.

As in all types of general cognitive dysfunction, higher mental functions are affected first in the process. This means that the more advanced skills will
be the first to disappear or cease to function. In some cases the person is also aware of the progress of the syndrome.

### 6.6 Dyslectics and Dyscalculia

Dyslectics and Dyscalculia are impairments that have been misunderstood for quite some time. People have been considered stupid just because they are not able to read or count. Even worse is that this has affected their self-esteem and their image of themselves. Since these impairments will affect a person severely in school, it is very important that it is detected as early as possible, in order not to be stigmatizing (see more about stigmatization in chapter 9). However, this is a defect that in most cases has nothing to do with intelligence. The problem is more a cognitive skill that is missing. This skill deals with detection of structures and shapes in perceived information. It might have been placed in the chapter on Perceptual impairments, but it is more of an information perception problem, than a problem with the actual perceptual organs.

#### 6.6.1 Dyslexia

*Dyslexia* is an impairment that may cause a person to have problems both reading and writing texts. It is important to realize that this impairment is not connected to the general level of intelligence, but is primarily a problem of interpreting the perceived information. It is also noteworthy that this impairment is merely instigated by the development of the society, since it is now expected by everyone to be able to read and write.

There is also a version of reading problems that appears after an accident, called *Alexia*. Alexia (also called *acquired dyslexia*) occurs when damage to the brain causes a patient to lose the ability to read. It is also called word blindness, text blindness or visual aphasia.

Those who suffer from "alexia" and "dyslexia" can have similar difficulties, however, “alexia” refers to an acquired reading disability, where reading ability had previously been developed, usually occurring in adulthood conditions, while “dyslexia” refers to developmental reading disability.

#### 6.7 Dyscalculia

*Dyscalculia* is a close relative to dyslexia, but primarily concerns the ability to use numbers rather than read. However, it may also affect the spatial abilities, such as the ability to read maps. It is also an impairment that has become a disability by the development of society, since the ability to make simple arithmetic calculations has become more and more important.
Since the impairment is invisible, it might be very difficult to diagnose. Often the person who has dyscalculia defines him- or herself to be stupid, rather than having an impairment. Thus it is very important to apply the proper means in order to support the person in the situations where it is necessary to handle numbers. Some signs that indicate the existence of a dyscalculia are:

- difficulties learning the four basic calculation methods
- is slow in calculating numbers
- has difficulties remembering numbers
- switches the digits in a number, e.g., 5638 becomes 5368.
- has difficulties making estimations of numbers and amounts
- has difficulties learning to use the clock. This also applies to analog clocks
- has a bad awareness of time and the time slots
- has difficulties managing money, and the personal budget
- has orientation problems, may confuse left and right
- has spatial problems, difficulties finding the way on a map
- has problems in planning and organizing
- has difficulties understanding and reading tables, e.g., train tables and schedules.

As can be seen the dyscalculia can also cause social stigmatization, since it may have social consequences such as bad economy and difficulties in handling planning and organization of activities. Being overly optimistic about time is also a problem that affects the social acceptance.

6.8 Autistic spectrum disorder

Autism is a large spectrum of cognitive disorders, which in the future will also cover the special case of Asperger’s syndrome. Autism is a disorder that mostly affects the social ability of the person. Among the abilities that are affected are the ability to interact socially according to social norms and rules, the ability to communicate, and the ability to see “the other person’s view”.

Autistic disorders are often detected very early in life, as early as at the age of three. It is also often combined with other syndromes, which makes it a very complex type of disorder.

The Asperger syndrome has been treated as a separate disorder, but will in the future classifications be categorized as a special variation of the Autism Spectrum Disorder. It adds some additional problems to the autistic
spectrum, such as lack of empathy (also towards the self), lack of social skill, and in some cases also with planning and organisation. It is often appearing as social problems, and/or self-damaging behaviour (cutting and self-mutilation, especially in younger females).

6.9 Attention-Deficit/Hyperactivity Disorder (ADHD/ADD)

Attention-Deficit/Hyperactivity Disorder (ADHD) is signified by two special cognitive problems either separate or in combination:

- The person may have difficulties in focusing and keeping the focus over time.
- The person may be hyperactive, and highly driven by impulses (split attention)

If a person is both Impulse driven and has difficulties in focusing but lacks the hyperactivity, it is diagnosed as Attention-Deficit Disorder (ADD). It has been discussed whether the ADHD diagnose should be separated into two different disorders, the ADD, and the hyperactivity disorder. In this way that which today is named ADHD, will be diagnosed as a combined disorder, rather than a specific, on its own.

6.10 Down Syndrome

*Down Syndrome* is a genetic syndrome, which is caused by the cells having an additional chromosome. It is a syndrome that is highly individual, and ranges from mild to more severe. The syndrome is signified by cognitive, physical and medical characteristics. The intellectual impairment ranges from mild to moderate (!). Some sensory impairments are often apparent, such as mild to moderate hearing loss, and long or short sightedness. There are clear physical features, such as a flat facial profile, small nose, an upward slant to the eyes, short stature and a single deep crease across the centre of the palm.

With the syndrome, there are also some severe medical conditions that accompany the cognitive impairments. So, for example, are people with the Down syndrome suffering from a higher risk of heart and breathing problems. The life span is generically shorter than the average life span. Beyond the age of 40 years, adults with the Down Syndrome are at a greater risk of developing Alzheimer’s disease, a common form of dementia (see above).
6.11 Stroke

A stroke is a physical damage in the brain, most often caused by a hemorrhage, or a blood clot shutting of the blood flow through part of the brain. A stroke is a sudden disruption of the brain's functions. The problems have to last more than 24 hours, and may also be the cause of death. In case that the person survives, many brain functions may be disrupted, both perceptual and cognitive. Sometimes it is difficult to imagine that the brain still works after such large damages that can be the result from a stroke. The effects from a stroke vary depending on the location of the damage, but common problems are fatigue, visual problems (parts of the visual field disappear), aphasia and other linguistic problems, as well as paralysis.

The effects of a stroke often diminish with time, partly due to that the brain heals and new neural paths are created to, and partly because the person finds new ways of circumventing the cognitive problems. Still, a stroke leaves its marks, both in the cognitive, perceptual and motor capabilities, as well as (and which is often forgotten) emotionally. Surviving a stroke is equivalent to having been very close to death, which may cause emotional chocks in the person. These emotional parts may also interact with the depression coming from the loss of ability, which may interact with the creation of the self-image “after the stroke”.

Rehabilitation is very important after a stroke. The brain is plastic, in the sense that it allows itself to be reshaped to some extent in order to recapture the lost abilities. However, the rehabilitation process needs a large amount of effort. Training devices might be designed to improve the cognitive functions during rehabilitation, and much of the old skills will still not be retrieved in the end.

6.12 Stress-related Exhaustion Syndrome

The stress-related exhaustion syndrome\(^\text{13}\) is an illness that has been under dispute for some time. It is the result of a combined long term, high stress, and low control situation. This could be a situation at work where people, who are often highly motivated, try too hard to keep up the pace in order to

\(^{13}\) Popular names on this syndrome are "being burned out" or "having run into the wall", expressing the feeling that a person with this syndrome has. The two expressions are somewhat unfortunate, in that they signify some permanence in the situation, whereas a stress-related exhaustion syndrome does heal to some extent with time.
reach deadline after deadline, resulting in a cognitive (and often also physical) collapse. The full breakout of the syndrome is often not the first sign, but there has been stress-related warnings, such as memory lapses, stuttering and minor cognitive mistakes.

After the breakout of a Stress-related Exhaustion Syndrome the person is often dominated by a tremendous fatigue. Some people sleep more than 15 hours a day for a longer period of time. This fatigue is a recurring part of the impairment that results. The remaining symptoms are among others:

- extraordinary fatigue, that will not be relieved by sleeping
- memory problems, mostly affecting short term, and very short term memory
- speech problems, stuttering, or even missing words, sometimes reminding of a mild aphasia
- problem in focusing, especially apparent when reading
- problems handling stressful situations

The types of problems are reminiscent of the problems that may appear after a stroke (see previous section). It is not clear, however, whether there is any actual physical damage from a Stress-related Exhaustion Syndrome, or whether this is a purely psychological illness.

Many of these symptoms are receding with time, but most people confirm that they have changed after the outbreak of the syndrome. They have to adjust to their new properties. Many times there might be a remaining sadness of lost skills within the person. The impairment may be especially difficult to adjust to, since it is an invisible impairment, which means that the people in the surroundings will not immediately recognize the impairment. Thus, the forgetfulness after such a condition is often a source of irritation to colleagues and family members, since they cannot see any difference in the person.

### 6.13 Reflections

1. **Reflection:** Is it proper to put all cognitive disabilities in one group, like in this chapter? Explain why or why not this would be the case. Remember that there may not be a simple answer to this reflection.

2. **Reflection:** Why do cognitive disabilities often make people feeling less comfortable than physical disabilities? Is it possible to avoid this additional stigmatization?

3. **Reflection:** Why would you think the symptoms from a stroke and from a Stress-related Exhaustion Syndrome appear to be the same?
Non-Excluding Design
7. Perceptual Impairments

Perceptual impairments are often thought of as equal to being blind or deaf. However, there are many other possible impairments included in this category, including combinations of impairments in the perceptual systems. Among the types that we are going to discuss in this chapter are the following categories:

- Visual - Seeing
- Auditory - Hearing
- Olfactory - Smelling
- Tactile - Feeling, skin contact
- Combinations of the above

7.1 Visual impairments

When visual impairments are discussed, it is often only in terms of being blind. Other impairments are many times not considered. However, since vision is the most prominent of the human senses, even smaller reductions in eye sight might have big influences on the capabilities of a person. There are many other visual impairments, and we will look into a few of them.

Since the visual system is not limited just to the eye and its function, but also to the rear parts of the brain, there may be several places where an impairment may be located. The most evident would of course still be a damage to the eye, either in the eyeball, or
in the sensory nerves, or the receptors, the staves and the cones. The eye in a human being is both delicate and complex and there are many places where it can be damaged (see Figure 7-1). To understand the different possible visual impairments, it might be necessary to describe the function of the eye in some detail. The numbers within parentheses refer to the numbers in the figure.

The light enters through the front of the eye. The cornea (5) protects the anterior chamber (6) and the iris (3) with the pupil opening (4). If the cornea becomes damaged (from external violence), this may cause distortions in the image (apart from the pain from the damage). The lens (9) itself may be clouded and not allow the light to get through. In the eye there is a large globe of Vitreous humour (10), which also may become clouded. At the back of the eye is the light (and colour) sensitive area, the retina (18) with the fovea (11). The fovea resides in the centre of the field of vision and it contains mostly cones, and is the area of the eye, which has the best colour sensitivity (but the worst light sensitivity, which is easy to observe on a dark night). In many of these places blood clots may also hinder the light from entering the eye.

To one side of the rear part of the eye is the exit of the optical nerve (13) which is responsible for the transport of the signals from the eye to the visual cortex of the brain. If the pressure of the liquids in the eye gets too high, this might put so much pressure on the optical nerve, that the nerve itself might be damaged after some time. This damage is partial and irreversible.
A second source of problems is the connection between the eye and the brain, through the optical nerve. Apart from the damage to the nerve caused by the eye pressure, the nerve can also be affected by Multiple Sclerosis (MS) and similar diseases. Although the cause is nervous, this is still regarded as a perceptual impairment.

And finally there is the place where the actual “seeing” occurs, the brain, and especially the visual cortex, which is located in the rear part of the brain. A severe blow to the back of the head might create such damage in the visual cortex of the brain (see Figure 7-3), that partial or complete blindness will be the result. In some cases this damage might heal, but many times the damage is irreversible as well.

Many times the first signs of brain tumours show up as visual phenomena,
individual due to the fantastic ability of the brain to compensate for strange phenomena in the visual field.

7.1.1 Blindness

Blindness is essentially a condition of a total lack of visual perception. This condition can be due to either physiological or neurological factors. Various scales have been developed to describe the extent of vision loss and define blindness. Total blindness is the complete lack of form and visual light perception and is clinically recorded as "NLP", an abbreviation for "no light perception." However, blindness is also often used to describe any severe visual impairment with residual vision. For example, those who are described as having only light perception have only the ability to tell light from dark and possibly the general direction of a stronger light source.

In order to determine which people may need special assistance because of their visual disabilities, various governmental jurisdictions have formulated more complex definitions referred to as legal blindness.[2] In some
countries, *legal blindness* is defined as acuity (vision) of 6/60 or less in the better eye with best correction possible.

This means that a legally blind individual would have to stand 6.1 meters away from a certain object to see it with corrective lenses with the same degree of clarity as a normally sighted person could from 61 meters. In many areas, people with average acuity who nonetheless have a visual field of less than 20 degrees (the norm being 180 degrees) are also classified as being legally blind. Approximately ten percent of those deemed legally blind, by any measure, have no vision at all. The rest have some vision, from light perception alone to relatively good acuity. Low vision is sometimes used to describe visual acuities from 3/25 to 6/60.

By the 10th Revision of the WHO International Statistical Classification of Diseases, Injuries and Causes of Death (*ICD-10 Version: 2010, n.d.*), low vision is defined as visual acuity of less than 6/18, but equal to or better than 6/60, or a corresponding visual field loss to less than 20 degrees, both of these in the better eye with best possible correction. Blindness is defined as visual acuity of less than 6/120, or corresponding visual field loss to less than 10 degrees, all in the better eye with best possible correction.

Blind people with undamaged eyes may still register light non-visually for the purpose of circadian entrainment to the 24-hour light/dark cycle. Light signals for this purpose travel through the retinohypothalamic tract and are not affected by optic nerve damage beyond where the retinohypothalamic tract exits.

### 7.1.2 Colour blindness

In the eye there are two types of light sensitive cells: *cones* and *rods*. The cones are sensitive to different colours, but require more light than the other type, the rods. The rods, on the other hand are very sensitive to light but can not react to colours. In this way they complement each other in the visual perception. The names are based on their actual shapes when seen in a microscope. The rods are also not as exact in seeing details as the cones, in that they are connected several to the same optic nerve, whereas the cones are connected to one optic nerve each.

The cones are of three types, sensitive to the three base colours: Red, Blue and Green. In the fovea there is a maximum concentration of cones, and almost no rods at all. In the periphery, on the other hand, there are only

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14 The strange figures come from the original measures, which were given in feet.
15 A rod may react to a single photon (light particle).
rods, and no cones at all. This means that in the fovea, we have almost no night vision, since the night light is too dark to activate the cones. Likewise, in daylight, we cannot perceive colours in our peripheral field of vision. This might of course seem odd, in that we know that we can see colours on the sides. However, that is a visual illusion, caused by the visual cortex filling in the colours in the picture, even though we don’t perceive them.

The cones can be damaged by a genetic defect in the X-chromosome. The damage affects how they react to a specific colour. Thus, people can be completely colour blind, or suffering from problems of distinguishing between red and green, and a few other combinations. Since the genetic defect is in the X-chromosome, it is mainly males who are suffering from colour blindness. Women have two X-chromosomes, and it is very unlikely that the genetic defect will exist in both X-chromosomes. Women are therefore carriers of the defect, whereas men are suffering from the effects.

In Figure 7-4 there are three examples from the Ishihara Colour Blindness test. Basically the test consists of numbers or shapes that have been coloured in such a way that they will merge with the background under the certain conditions that are caused by various types of colour blindness. The colouring is even more intricate than what can be anticipated from the beginning. For example, in the first circle a person who is completely colour blind will not see anything but a large number of dots. Most people with normal sight will instead see the number six. In the middle circle a person who can’t see red colours will see the number six, whereas a person who can’t see green colours will see the number two. People with normal colour vision will see the number 26. In the right circle a person who is unable to

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16 In Sweden we have a saying that “At night all cats are grey”, meaning that it is impossible to see any other colour than grey (on a cat) when light is low.
see red and green will see the number three, while people with normal colour vision will see the number eight. If the three figures are examined carefully it is possible for a person with normal colour vision to actually see the small changes in colouring that will cause these effects.

In many cases colour blindness will not affect the life of a person very much. The problem occurs mostly when signal colours are used in interfaces and in other situations where the colour has a significant meaning. However, traffic lights, for example, constitute no problems for a person who is colour blind, since there is redundant information in the positioning of the lights.

Lights that only change but stay in the same position, however, are not possible to discern if you are colour blind. The trend of using LED-indicators that only change colour (for example between red and green) is one such place where this impairment might cause some problems. My grandfather, who was unable to differentiate between red and green coloured objects gave me another such example: He could not go strawberry picking in the field, since he did not see the difference between ripe and unripe berries, and therefore came home with many green (!) berries in his basket.

Colour blindness may also cause a social disability, in that it becomes difficult to dress according to what is socially acceptable. To a colour blind person it might be perfectly OK to dress up in bright red and orange, because the perception of these colours is dependent on the saturation and brightness of the colours rather than the actual colours fitting together. Before learning the social rules, people who are colour-blind can easily utter funny comments, such as: "The red dots in the vanilla ice cream, are they the vanilla?"[17].

### 7.2 Auditory impairments

Just as with the visual impairments, there is a tendency to regard auditory impairments as equivalent to being deaf. However, there are several other kinds of impairments that are incorporated in this area.

### 7.3 Combined perceptual impairments

For visually impaired people hearing becomes an important sense, and to a person with hearing difficulties the vision becomes more important.

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[17] Thanks go to my dear cousin Gary, who is completely colourblind, and also told me about the dressing problems.
However, it is not unusual that both vision and hearing are both affected by an impairment. People who are deaf-blind have a very limited channel for the sensory impressions. Thus they need special tools for their support. Since both vision and hearing are reduced, the person is more or less isolated from the most important senses for a human being.

7.4 Reflections

1. **Reflection**: In which cases might it be very important to be able to see colours? And what can we do to not exclude people who are colour-blind?

2. **Reflection**: Try to walk in a silent room towards a wall from five meters away. Can you hear the wall “coming towards you”? Repeat this experiment with your eyes closed (be sure to not bump into the wall). Can you hear the coming towards you this time?

3. **Reflection**: Listen to some music for a few minutes, first with the eyes open and then the same music with your eyes closed. Does the music sound different? If it does, try to explain where the difference resides.
8. Socially induced disabilities

There are some types of impairments that are less recognized, since they don’t cause an instant non-ability to do something, but primarily affect people on a social level. The disabling effects from these impairments show mainly in terms of social stigmatization, although there might also be effects that cause a physical disability, for example, as in the case of overweight below. Harassments and avoidance are the most prominent features for this kind of impairments. There are several impairments that belong to this category, and in this book we will only look at a few examples.

8.1 Stuttering

Stuttering (stammering) is a speech disorder that primarily has social consequences for the person. Stuttering is a condition where the flow of speech is involuntarily disrupted by repetitions of words or syllables and in some cases even single sounds. Sometimes the stuttering can also consist of hesitations before speech that are longer than considered normal. Stuttering is primarily a developmental disorder, but can also be acquired as a result of neurological events, for example head injuries, tumours etc.

So far, no single cause of stuttering has been found. Research suggests that instead there might be multiple factors to the disorder. There is some evidence that suggest a genetic basis for stuttering, although it is clear that the genetic predisposition interacts with environmental factors that will increase the likelihood that it will occur.

The primary disability for a person with a stutter is that they have difficulties participating in normal conversations, since they take longer to finish their comments. When interrupted, stuttering may also increase. Apart from this inability, there is also a large risk for a person with a stutter to be a victim of mobbing.

8.2 Phobia

The matter of phobia is big enough to be covered in a complete book in itself, and here we will only look at phobia from the general perspective. A phobia is an extreme form of anxiety that constitutes a persistent fear of an object or situation. Just being slightly afraid is not enough to classify an anxiety as a phobia. The anxiety has to be disproportional to the cause, and is often also considered (by other observers) as irrational and exaggerated.
There is a large number of specific phobias and social phobias that are encompassed by the term phobia. Specific phobias are based on nouns such as the very common *arachnophobia* (fear of spiders) and *acrophobia* (fear of heights). Social phobias are more based on fear for certain social situations such as public appearances or being in crowded areas.

One special case of phobia is *agoraphobia*, which is a generalized fear of leaving a safe area, such as the home, or the neighbourhood. This type of phobia can also be extended to special phobias, such as fear of open spaces or of contamination (fear of germs).

Phobias vary in severity among individuals. Some individuals can simply avoid the subject of their fear and suffer relatively mild anxiety over that fear. Others suffer full-fledged panic attacks with all the associated disabling symptoms. Most individuals understand that they are suffering from an irrational fear, but they are powerless to override their initial panic reaction.

That a phobia can be extremely disabling for the person can be exemplified by describing the situation for a person with fear of germs. A person with this kind of phobia will never feel clean enough, thus washing themselves continuously all the time. Some people report that they have to wash their hands from ten to twenty times, every time they have touched something that they don’t experience as “clean”. In some cases this cleaning behaviour goes out of hand, and the person will not leave the “safe area” in the home. The extreme washing of hands may also cause skin problems, allergies and other medical side effects.

### 8.3 Overweight

Overweight is often not considered to be an impairment, in that there is a general “understanding” of that people who are very overweight have themselves to blame. Even if this had been true, overweight would still be a disabling condition. Now, overweight can have many causes, and many of them are purely medical. However, the condition itself causes both social and physical disability.

On the physical level, the size of the body hinders a person in many cases. Chairs (including wheel chairs) are too small to allow a person to sit well, and in some cases may even be too week. Being overweight on a plane, for example, very often causes strange situations, since you may not fit into a standard flight chair. On an even more serious level, stretchers and ambulance equipment may not be designed to carry large weights, which
means that you cannot even be picked up by an ambulance, in case of an emergency.

Even so, the major problem for a person who is overweight is not the physical body size, but rather the social attitude towards people who are overweight. In books and movies, people who are overweight are often displayed as having problems, or being outright disgusting people (cf. Vernon and Dudley Dursley, who are both described very typically, as being “fat” (and stupid) people in literature. On the internet, there are also many pictures of extremely overweight people that are intended as being funny, where the overweight is a large part of the fun in the situation. Many people with overweight are also victims of mobbing in schools and at workplaces.

8.4 Left-handedness

Approximately 10% of the world population is left-handed, or ambidextrous\(^\text{18}\). Being left-handed is normally not considered to be an impairment, but it is definitely a deviation from normality, which does have some consequences, not least from a social perspective.

8.5 Reflections

1. **Reflection:** How can the social implications of these types of impairments be avoided or diminished?
2. **Reflection:**

\(^{18}\) Ambidextrous means without preference (for which hand to use).
9. Stigmatization

In this chapter we will discuss the issue about the perception of a person with a deviance, as defined in relation to a perceived normality. In older times the term “stigma” was used to denote a distinguishing mark, often in the form of a burn or a tattoo, that was used to distinguish a certain (derogatory) subgroup of the population, such as slaves, or prisoners. The term "stigma" thus denotes a negative distinguishing mark on a person. This has been transferred into disability research as a term for the derogatory attitude displayed towards people with certain distinguishing features, such as impairments, or race. The modern concept of stigma was thoroughly explored by Erving Goffman (Goffman 1963) in his book “Stigma: Notes On The Management of Spoiled Identity”.

Among other things, he stated that "Stigma...is a process by which the reaction of others spoils normal identity". In this way we cannot avoid the stigmatizing factors, since they are often closely connected to the environment or "social culture". One example of this is the statue of Allison Lapper that can be seen in Figure 9-1, which was placed at Trafalgar Square in London, and immediately caused a large upheaval among people. That a person, who is suffering from

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Figure 9-1. This statue of Alison Lapper, naked, pregnant and with short or no limbs, caused a great disturbance when it was placed on Trafalgar Square, in London (Photo: Wikimedia Commons)

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Footnote: The word has its origin in the old Greek word for “to prick”, which is “stig”. In order to be able to distinguish a slave, which was a valuable property, and have him or her returned, the slaves were tattooed with a pointed instrument. The resulting mark was a “stigma” (Falk, 2001).
phocomelia, should be displayed naked, and pregnant like this, was a shocking experience to many people. The statue and the discussions it caused clearly shows that there quite simply are still things that are not all right to show in public. The symptoms of the disease were clearly stigmatising.

Therefore, one of the more difficult issues to come to terms with is the issue of *stigmatisation*. So what is stigmatisation? And how does it affect people? To give an idea of what it might be, consider the following example situation:

*Imagine that you are walking in the shopping mall. It is a nice day and you are happy. Suddenly you realize that everybody is looking at you, and smiling. After a little while you start feeling a bit disturbed by all people looking at you. You can even feel that they are looking at you from behind your back. It is getting creepy, what is wrong? Then you realize that you have a long strip of toilet paper that has got stuck in your pants hanging down as a tail.*

Now, for you this is a situation that is easy to correct. You just remove the piece of paper hanging down, and continue your errand in the shop. If you have a visible impairment, however, it is not as easy. The staring is one of the stigmatising factors that a person with visible impairments is bound to attract. People are staring, either out of curiosity, or even worse, out of pity.

But stigmatisation does not only appear as a result of personal characteristics, or actions. It may also be a result from how you are treated in various situations. If you want to go to the cinema or theatre, you may often encounter the icon in Figure 9-2. People in wheel chairs can't use the standard entrance, but regardless of how kindly we ask them to go to the alternative elevator, the person will most likely feel stigmatised by just being included in the main group of visitors.

You may of course think that it may not be the end of the world, if you had to use a different entrance than other people. The problem is not the separate entrance by itself, but the attitude that it reflects, and also the exclusion from the other people. Most people will be able to stroll to the theatre hall, chatting about the expectations and thoughts about the movie,
but you will have to go on your own, missing out of the atmosphere and the emotional context, that everybody else can be part of. Maybe it wouldn't be so bad, if it happened once, but this happens all the time, over and over again. And this is when it is starting to be a stigmatising factor. This is also the time when it starts affecting the self image of the individual.

A second type of stigmatisation is when the impairment is associated with the wrong things. In Figure 9-3 we can see a sign from a door to a toilet. It clearly states that you can use this toilet only if you have an impairment that forces you to use a wheel chair, or if you are a baby. Anyone else is excluded, which may be as intended. However, the baby is a helpless creature, and the person with the impairment, is quickly associated into the class of helpless individuals, who need help for almost anything.

These examples might seem to be on the edge to being ridiculous. But this is because you see these examples one or two times. However, if you are constantly exposed to examples like this, where your person is over and over regarded as deviant and not included, the problem becomes much more grave. Every time you see a sign like these, there is an underlying intention that you as a person is not like everyone else, which of course is something you already know, but you don’t need anyone else telling you about it, (Shakespeare, 2004; Susman, 1994)

### 9.1 Exposure

One aspect of the stigmatisation is the involuntary exposure that many people with impairments suffer. By sitting in a wheel chair, you are an exposed subject per se. There are several places where the impairment will cause access or usage problems, and where this leads to extra exposure. Consider a few example cases:

- Lifting a wheel chair over a flight of stairs.
- Getting money from an ATM machine while being blind.
- Going around in a shop with a wheel chair or using a white cane, if the shop has too narrow passages.
Each of these cases poses a different type of exposure with different consequences for the individual:

**9.1.1 Lifting a wheel chair**

Being lifted (or dragged) up a flight of stairs is a common situation for a person who is in a wheel chair. Many buildings have not been adapted for accessibility, and in many places a staircase is the only way to access a certain area. There is often not a problem of getting volunteers to help in lifting, since it is a fairly obvious problem situation. So, that is a piece of cake, or?

Probably not, when seen from an outsiders perspective, since we normally only see a technical problem: the wheel chair has to be transported to the top of the staircase. And most people know that they are capable of lifting pretty heavy loads. However, this is not the perspective of the user in the wheel chair. He or she is more concerned about all kinds of other issues: Are they strong enough? What happens if they stumble on the way? And the problem of exposure added to that: "Now they can all see me being carried, like a useless package". This is the issue of exposure. I know that I am in a wheel chair, and now all this hassle makes everybody look at me as well. People often seem to forget that in most cases the person who is sitting in the wheel chair has been in that situation for a long time. This is part of their life. (French & Swain, 2009)

**9.1.2 Getting money from an ATM**

ATM machines will in many countries soon be the only way to get cash in hands. Banks are withdrawing their office card readers, and will not provide you with cash in many places. Thus we will all be in need of using an ATM machine. This in itself is a discriminating factor, for example for blind people, or people in wheel chairs, where the accessibility is often very low.

To get money from an ATM machine you need to enter your card in a slot, a PIN code on the keyboard, and the amount of money also on the keyboard. If have an impaired vision, this means that you have to find all these controls, and you might even need to use auditory output to know how much money is left on the account.

**9.1.3 A shop with narrow passages**

The layout of a shop is often not made for access with a wheel chair or who is visually impaired. The narrow passages causes problem for someone who is using an electric wheel chair. Turning around the corners may not always
be easy, if the passages are too narrow and winding. In such case it will be necessary to turn and reverse, while blocking the passage, and being the object of the stares of all the people in the shop.

This is clearly a problem of conflicting interests. The shop owner wants to maximize the display area and attract customers to shop. In some places even crowdedness is thought to show the popularity of the shop. A person who has some kind of impairment will find the shop difficult to navigate either physically (with a wheel chair) or perceptually (with impaired vision).

9.2 Exposure through facilitating tools

In many cases this exposure is increased by constructions in society. By having to use certain additional tools it quickly becomes obvious that the person is not a "normal" person. The exposure is in some cases further increased by the (in many cases institutional) design of the tools. In the following a few examples that show in which ways an assistive device can cause an extra factor of stigmatization (together with other disadvantages of the solutions).

9.2.1 Staircase lift

The staircase lift (see Figure 9-4) is one of those aids, that we more or less start to take for granted. However, it is also in many cases made in such a way that it will expose the user of the lift for an extensive period of time. It moves very slowly up or down the stairs and the person sits fully exposed to the stares of people around. The speed is of course reduced for safety reasons, but this severely increases the amount of exposure. The person in

Figure 9-4. If you have to use a lift to access a room, this often means that you are exposed during the travel. Sitting in a cage for everyone to see. (Photo L. Oestreicher)
the lift is very obviously less able than the people rushing up the stairs. And everybody can see it. This is a stigmatization through exposure.

9.2.2 Object (key) finders

There are many commercial solutions to the problem of finding the keys. Key finder However, they are almost all based on an active receiver/sender technology, which requires batteries and a relatively big casing. This means that the object finder is difficult to attach to other types of objects, such as glasses or mobile phones, where a dangling receiver will be inconvenient.

Furthermore, the object finders most of the time do their tasks by actively responding to the user pressing a key on a remote control, by emitting a beeping sound, and sometimes also flashing a bright LED-indicator. This means that you have to make a sound, when you have misplaced something, e.g., in the office or in a library. Although people might not react so much to noise in the library any more, these places are by default pretty silent, and a will not go undetected by the people in the surroundings. Even worse is that the sender has to be within a certain range of the receiver. So, you have to know roughly where you have misplaced your thing. Even in a small flat, you might be out (Susman 1994) of range when you press the button.

Finally, the active receiver will use batteries, and as most people who have misplaced their mobile phone sometime, know, it is when the batteries have run dry that you have misplaced it, and want to find it. With all the available technology, one might think that there would be a passive solution. But so far there are few passive solutions available in the market.

9.2.3 Bed with inclining mattresses

In Sweden there are certain support possibilities, if you have special needs. One such possibility is to get a bed that allows you to sit up (which might be good, for example, if you have problems with your lungs). The problem is that as a free supportive tool you will only get the bed shown in to the left in Figure 9-5. The bed is made in chromed steel and wood, and can only be delivered in one design and colour. Nobody can be mistaken about the institutional look of the bed especially not when it is compared to the standard model, that is sold in most warehouses. There is even a handle hanging down in order to allow for a person to use the arms to get out the bed in an easier way. This is delivered regardless whether the person wants it or not.

The design of the bed is clearly stigmatizing. Who would want to have that bed in the bedroom, making it look like a part of a hospital ward? Adding to the problem is that the bed cannot be had in a double-bed version, and the
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bed itself has a weight limitation of about 130 kg. This essentially means that a person, who needs an institutional bed, is assumed to be single, and obviously also assumed not to have any sexual interest (indeed, a very common preconception is that people with some kind of impairment are not sexually active).

9.3 Deviation vs. Normality
The word “deviant” is often referring to a negative aspect, which is regarded as non-normal. The word is a marker of a distinction between something that is considered to be “Normal” on the one hand, and the deviant individual on the other. It is often considered evident that 1) there is something that can be referred to as being normal, 2) a deviation from the normal is not desired. Neither of these statements can be said to have any bearing on the concept "truth".

Lennard Davis (Davis, 2006) discusses the issue of normalcy from a historical perspective, and one of his conclusions is that the idea of normalcy is an invention that came about in the nineteenth century. To be normal, and to strive for some kind of "feeling normal is, thus, a fairly new concept. Of course the increasing population makes every deviation smaller on a relative scale, thus reinforcing the “Normality” as being the property of a “majority” of the people on earth.
However, we still have to keep in mind that “normality” can only be defined in relative terms. Something has to be normal in comparison to something else. This constitutes an important understanding of the problem around normality. Who is to decide what is normal or not, or even within which limits something can be considered to be normal (see Figure 9-6 where the distribution follows the Bell curve normal distribution)? In this model, everything between the delimiting borders is considered normal, whereas the parts that are at the ends of the curve belong to the non-normal. However, where to draw the line is not something that is fixed and established once and for all, but rather something that may change both with time and changing attitudes (cf. figure \ref{normality2}). This means that what might at one time consider to be normal can be regarded as non-normal after some time, if the society has a development trend towards a more streamlined population.

In some cases we may accept some deviance, and only dismiss the more extreme deviations, marked “abnormal” in Figure 9-8. Then it might still be acceptable to be deviant, as long as we keep within the extreme borders. It is still not good to be deviant, and it is of course still good to be normal. The people who belong to the extreme cases of deviance are often at high risk of being regarded as “outsiders”. They are often also highly stigmatised by society, and encounter large barriers against being re-included in society.
In this perspective the goal of universal design is to be able to regard everybody as belonging to the “normal” part of the population (see Figure 9-9).

In this final situation we would be so used to deviance, that it would be considered “Normal” to be “Deviant”. To be different would be part of humanity, and it would then not raise any concern when we encounter other people that are not like us. Essentially it would be more or less impossible to be unlike us, in the general sense, since it would be normal to be different (Hosking, Waller, & Clarkson, 2010). Regardless whether we will reach anywhere close to this goal or not, this is at least something which we should strive for. When we consider this goal we can also see that there are several factors that need to be addressed in order to proceed the right way.

Some of the more important factors we need to address and in the longer perspective try to change are (see Figure 9-10):
• **Understanding** - It is important that we understand the causes and the effects of impairments on the situation of the individual (Jacoby 1994). By understanding the implications we may have a better possibility to prevent bad design solutions.

• **Acceptance** - Accepting that there are people who have special needs is a crucial part of adapting the society to the idea of universal design. Without the acceptance, there will not be any will to change the situation.

• **Involvement** - To achieve accessibility in society requires involvement. People need to get involved in the design of artefacts in order to get things changed.

• **Design** - Through design it is possible to change both acceptance and understanding of people in society, and take several steps towards the normality of all people in the society.

Although the goal of achieving a universal normality is utopic, it is still necessary to strive for the unreachable in order to get a short way on the road. There is a saying: *It is necessary to aim for the stars, in order to climb over the rooftops.* This is very much the case in terms of establishing some kind of increased normality.

### 9.4 Self-esteem

Self-esteem is a reflection of a person's overall evaluation or appraisal of his or her own worth. The estimation of self is a difficult thing, but it encompasses the person’s beliefs (for example, "I am good", or "I am..."
useless") and also a spectrum of emotions such as triumph, despair, pride and shame.

Every person makes his or her own evaluation of him- or herself. To appreciate ones self is more or less a necessity, in order not to get depressed. However, lack of external appreciation will of course have destructive effects also on a person’s self-esteem. This is not only something that involves other people, but also an effect of physical barriers, or of social conventions that can be displayed through physical design.

In the self-esteem there is also a factor of perceived stigmatisation. Having an impairment has a potential of creating a feeling of being stigmatised, even if the people around the person does not give any such indications (Jacoby 1994). The self-appreciation that comes with having an impairment does add a potential risk of feeling stigmatised, due to the condition, or to the supportive tools that are needed.

9.5 Self Image

The issue of how people perceive themselves is an interesting aspect of the stigmatisation debate. Puide (Puide, 2009) made an interesting interview study with three people having acquired impairments regarding how they perceived themselves. The study, which was only built upon deep interviews with three people, indicates that the self-image develops over time. She identified four stages in the development: the medical stage, the social stage, the autonomous stage and the queer stage. Throughout the development, the perception of themselves and their relation to the surroundings changed drastically in all the interviews, even though not all the people had entered the final stage of acceptance.

9.6 Reflections

When we talk about Stigmatisation, it may be interesting to consider how stigmatisation appears. You may therefore try to think through the following question:

1. **Reflection**: How is it possible to use design in order to:
   - Minimize stigmatisation?
   - Broaden the “normality” area?

2. **Reflection**: How can we achieve a perspective on normality, such that we minimise the number of people, being regarded as deviant?

3. **Reflection**: Recently, a Swedish politician claimed that it was bad that the Swedish TV Corporation did not have any employed person in a
wheel chair, appearing on the screen. Was this a good or bad discussion?

4. **Reflection:** Is there a difference in how the self-image influences a person, between an acquired and an inborn impairment? Think about how people think about what is normal and what is not.
10. Environment, Assistive, Supportive and Facilitating Technology

There are several aspects that affect the degree of disability caused to an individual by an impairment. In universal design we mostly address the way the environment is designed in order to exclude or (preferably) include people with certain types of impairments.

10.1 Environments or Tools?

The design of the environment to avoid disabling factors in the society and the environment also constitutes a large part of supporting people with different impairments. Reducing the number of barriers in the society is one of the key factors to minimizing disability. As we shall see, the removal of barriers in the environment is often beneficial for all people, regardless of impairment or not. Using proper surface materials for walkways, removing stairs and doorsteps, and reducing the noise level in busy environments, are a few examples of environment adaptations that benefit most people and not only people with impairments.\(^{20}\) Having too smooth and slippery materials is also not beneficial for wheel chairs, since it will be difficult to get a grip in order to get up even small slopes. Universal design of the environment is thus closely related to good design, quite simply.

By adding information for certain groups to the environment we can also add to the general information for everyone, as for example, when we use an internationally adopted system for guiding people with visual impairments. The patterns on the floor (in relief) shown in Figure 10-1 are used to indicate suitable and safe paths for people who have difficulties seeing, or who are completely blind. The pattern is rough enough to allow a person wearing shoes or boots with thick soles to feel the path. Still it does not discomfort people who don’t need it. It actually provides people with the most important paths to follow. If there is such a path in the floor, it most likely leads to some place important. I was actually guided to the ticket machines that were well hidden, by using the pattern in the figure.

\(^{20}\) A surface area that is designed for good use with wheel chairs, is in most cases also perfect for people using inlines, or people with pushcarts for children.
One problem with this adaptation is, however, that the rills constitute perfect traps for small wheels. Inline skaters and trolley pushers might get the wheels caught in the rills. As may, of course, also people in wheel chairs. This is why it is very important to make the rills stand out from the floor colour. Still, the benefits are considered to be bigger than the drawbacks.

A second problem appears when people in common are not aware of the system. If they just regard these lines as decorations, they might place objects on the path, which of course makes the path anything but safe for a blind person. In my hometown there are paths that lead to the bus stops. I have so far almost never seen a bus stop at the end points of these paths.

However, just adapting the environment will not make every person abled. We will also have to consider different kinds of personal supportive tools for a person with an impairment. In many cases we are pretty familiar with these kinds of tools, such as wheel chairs, white canes, hearing aids etc. At least we imagine that we are familiar with these items, but in reality we only see the tip of the iceberg concerning these aids. Running around in a wheel chair might almost seem to be fun, especially when you see someone who is proficient in using such a tool. As with most tools it is difficult to understand the difficulty, until you try it out yourself. That a normal wheel chair is very unstable is a fact that many people are not aware of, and that most self-propelling wheel-chair users don’t use the stabilising support wheels is less well known.\footnote{In fact, many people who are used to their own wheel chairs feel discomforted if they have to use another, and even more so, if the support wheels are still attached. This means that they cannot use the wheel chair to its full capacity, and are thus more disabled than usual.}
Similarly, it is difficult to understand how difficult it is to use a hearing support device. All hearing support devices have similar problems, even though the filtering techniques have gradually become better and better. The main problem is that the human ear (and auditory perception) is very selective. All sounds do not protrude with the same strength. This is especially noticeable in what we call the *cocktail party effect*. The example is given that you are on a party, where people are talking all around you, and maybe even some music is playing. Despite this noise there is most of the time no problem understanding the person you are talking to. There are many factors\(^{22}\) that influence this, but one part of the problem can be understood if we try to record for example a speech during a party. Most of the speakers voice is drenched by background noises in the recording, whereas the person sitting in the area can hear the speech much more clearly. The person with the hearing aid hears the sounds as they are reflected in the recording.

That these technologies make life easier is often anticipated, but we fail to understand that there are big disadvantages with using them as well. Some people may wonder whether it is more important, within non-excluding design, to adapt the environment or to develop good personal tools for the individual users. It is a tricky question, since the obvious answer in many people’s eyes probably would be “*both*”. But the trickiness comes from that there are several situations where there is an explicit choice. For example, should we remove stairs as much as possible, and then accept that there are some places where stairs are inevitable, and thus run the risk that some people are excluded, or should we develop better technology that will allow people to climb stairs (with wheel chairs) and thus remove the need for ramps in general?

To answer that question we need to consider the consequences, and I have made a small comparison for this example:

*Adapting the environment* — Does not require the individual to have any specially designed assistive technology.

- Needs to be done everywhere, wherever it is possible. (−)
- Will benefit many other groups of people. (+)
- Will still exclude people from some places or activities. (−)
- Expensive for society, if this should be applied everywhere. (−)

\(^{22}\) For example, lip reading and other body expressions add largely to the interpretation possibilities.
Creating better tools — Does not require that every environment is adapted to allow for accessibility.

- Makes sure that the individual can handle every situation. (+)
- Still excluding for people who don’t have access to the better tools. (-)
- Might produce technology that should not be needed. (-)
- Expensive for each individual. (-)

A combination: Better tools and Adapted environments — Puts a requirement on the individual to use advanced tools for access and on the environment to allow for accessibility wherever possible.

- Most places will be accessible, either through individual solutions or through general adaptation. (+)
- Environment still needs to be adapted as much as possible. (+)
- The better (more expensive) tools may not be available for everyone. (-)
- Difficult balance, when it comes to responsibility. Who is to blame if some space is not accessible? (-)

This is of course a very square way of looking at this problem, but we can see that the problem essentially boils down to a matter of responsibility. Whenever we get better tools, there could be a tendency to relax the requirements on the environment. On the other hand, if we adapt the environment wherever possible, the remaining barriers might become even stronger, since we fail to develop (or market) more advanced personal tools.

A second observation is that regardless of how many restrictions and regulations that are enforced, there are always implementations that disregard the regulations. This is often because of the lack of consequences for the organization or company that fails to implement accessibility guidelines in their products or designs. Regulations may be covering, but if there are almost no consequences from breaking them, the enforcement will not take place. This means that a fully adapted environment requires enforcement by law. Thus it is important to also look at the Personal support that is available.

10.2 Personal Technology

We will take a closer look at the tools that are designed to support a person with an impairment. This is often referred to under the general term assistive technology, but I have chosen to divide the different kinds of tools for
personal use into three categories: assistive technology, supportive technology and facilitating technology. This is mainly because I think that different technology can have different roles for a person with a certain impairment.

10.2.1 Assistive Technology

Assistive technology is primarily intended to assist a person in the minimal requirements for living a daily life. This includes many of the traditional tools for impaired people, such as a standard wheelchair, braille screens, hearing equipment and similar artefacts. The assistive technology is basically the equipment that is needed for a person with an impairment to live a relatively normal life, but with many restrictions. With assistive technology, a person might still need a personal assistant to do more advanced tasks, such as cleaning, washing up or shopping.

Also computers can be assistive technology, for example for a person who has a visual impairment. A text reader + a speech synthesis interface might allow a blind person to read a newspaper in the same manner as everybody else. People with muscle tremors can use de-sensitized joysticks and mice that only react to the overall movements, while filtering out the small shaking movements.

10.2.2 Supportive Technology

Supportive technology takes the daily life to the next level, in that it supports more than the minimum requirements for a daily life. With supportive technology a person may lead a life, which is close to normal. Here we have automatic car ramps and door openers that will allow for a person to manage more complex tasks on his or her own. While assistive technology might make it possible for a person in a wheelchair to have a better quality of life, supportive technology allows her to make her own coffee, or do the laundry, things that may be performed by other people in the surroundings, but which provides a more independent form of life.

In an interview in my thesis (Oestreicher 2009) one of the informants, when asked about his possible need for a service robot, said “It would be great to be able to serve my girlfriend a glass of wine, without having to involve a personal assistant. Actually, why not have the robot help me cook, and just send the personal assistant home for the evening”. In this case the technology would support him in arranging for a romantic evening, something that is difficult when you are dependent on having a personal assistant around during the whole day.

The difference between assistive and supportive technology is not completely clear. The distinction lies foremost in how advanced activities
the person can perform using the technology. A wheel chair is definitely an assistive technology, whereas a wine-serving automaton would be more of a supportive tool.

10.2.3 Facilitating Technology

Facilitating technology is the most advanced stage in Personal technology. This would include technology that allows the individual to perform things that are not normally for everyone. To this category we would count sit-skis and bi-skis, which facilitate for people with paraplegia to go skiing downhill in (almost) the same manner as anyone else. This technology has been developed specially to facilitate a certain activity.

To the same group we would count automatic four-wheelers and the action-track chair described previously. These types of vehicles can facilitate a life with a more vivid outdoor activity. The vehicles widen the scope of transporting from simple asphalt roads to more advanced surfaces, thus making it easier and more comfortable to get around, than with an ordinary wheel chair or other similar assistive tools.

10.3 Reflections

1. **Reflection:** Who should be responsible for the accessibility, the architect or the designer of assistive technology?
2. **Reflection:** Consider various situations where people can be excluded from a context by an impairment or by some other bodily property. How many can you think of?
3. **Reflection:** Can there be situations where it is unavoidable to exclude people?
4. **Reflection:** How can we design better emergency exits for various types of impairments? How can we provide alternative escape routes instead of lifts?
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11. Guide and Service Dogs and Service Robots

This chapter might seem a bit strange, initially, but the connection between Guide dogs and Service Robots will hopefully become clear after this chapter. Guide dogs are a well-known support for blind people, but there are also other types of helping dogs around. Service or Mobility dogs have been around since 1979 and are now an institutionalised part of rehabilitation.

11.1 Guide and Service Dogs

The use of guide dogs is not a new feature. Guide dogs have been around for many years, and most people today (at least should) know that you should not disturb a dog in a white harness, or a dog that is following a person with a white cane. In both these situations the dog is hard at work, "telling" its owner about the situation around it. This work requires a hard focussing from the dog, and care should be taken not to disturb him or her. The dog has been trained to give certain signals when they approach obstacles or other difficult situations in the pathway.

There is an additional kind of service dog, namely the signal dog that has been trained to react to signals around the owner, or in some cases to a changed condition in the owner. For a person with diabetes, the signal dog can, for example, react to the slightly changed odour of the person when he or she is running into a dangerous condition. In those cases the dog is
trained to take appropriate action. The right behaviour is of course dependent on the owner and his or her condition as well.

11.2 Service Robots

Currently there is plenty of on-going research in the area of Intelligent service robots (ISR). The term is sometimes criticised as stressing the intelligence, and sometimes the term Autonomous Service Robots, or just Personal Service Robots are used. The term service robot in this respect means a robot that is supposed to serve as extra limbs for the user. In cases where the user has some kind of impairment, the robot needs to have additional properties, such as reliability and a large amount of security.

In a previous project at the Royal Institute of Technology in Stockholm, the usefulness and usability of service was investigated. The robots in this project were not very advanced, and had limited functionality (see figure

11.3 Reflections

1. Reflection: What are the delimitations in using a service robot as a support for a person with an impairment?
2. Reflection: For what kind of tasks would a service robot be of best use?
3. Reflection: What are the main benefits from using service dogs? Any disadvantages that you can see?
12. Some Good Examples of Universal Design

There are two ways we can use previous design as inspirational sources. Either as examples of bad design, or design that has failed in some way, or as examples of good design solutions, that can be used to inspire design in other areas. In the previous chapter we encountered some bad examples, and in this chapter we will take a look at some examples that are fairly successful designs for people with impairments of different kinds. We will go through the examples and discuss the useful properties as inspiring ideas.

The good examples that are shown in this section can be seen in two ways. First, they are good examples of that it is possible to design things in a way that supports people. Second, and maybe more importantly, they show that it is possible to generalize the examples (see the reflections in this chapter). The same goes for the bad examples.

12.1 Keys

Nowadays many cars have electronic locks on the doors. With a single push of a button all the locks of the car closes and the car blinks twice to signal to the user that the doors are locked. Or... was it one blink for locked and two for open? It was one of them. But how can I know, when I am 20 meters away from the car? Only way to know afterwards is to go up to the car and look. But then I could just as well have locked it with the key in the key hole.

Some car keys have just one button for locking and unlocking. Click once and the car locks, click again and the car unlocks. Simple, you only have one single button to remember. No risk for confusion. Or? Do you remember if you unlocked or locked the car, since they involve the same action to perform? Remembering that there is one blink for unlocked and two for being locked, is not always easy, especially not in times of stress.

So, why not have two buttons, that are distinguished by spatial arrangement. Side by side, or above and under each other. That is an improvement, since we can distinguish them from each other by position. But we can still confuse the two keys: Was it left to close, and right to open, or vice versa? Again, they can be redesigned once more into the final version which is shown in Figure 12-1. Here they have been moved into an asymmetric shape. They are no longer similar or symmetric. One of the buttons has also been made slightly convex, and the other concave. Now they are easy to
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distinguish from each other, and they have been given distinct shapes so that they will be more difficult to confuse.

Are the given shapes arbitrary? They might seem so, and we may not know the intentions of the designer in this case. However, there are some things that might have been designed into this set of keys. The button used to open the car is placed closer to the lock part of the key, which means that they can be associated to the opening of the car. Furthermore the convex button is easier to press by mistake (it is protruding from the surface), and has been assigned to the "lock" function. This means that an accidental press will lock the car, rather than unlock it. This means that when we put the keys in a pocket or handbag after locking, the risk of accidentally unlocking the car is reduced. The unlock (recessed) button also fits better with the shape of the thumb, which makes it easier to find in case of an emergency, for example, if you are being assaulted by wind animals, or similar.

This design makes it much easier to use the locking mechanism, avoiding the problem of a "dual-state - similar appearance" situation. By making the design asymmetric the risk of confusion becomes lower than with a symmetric arrangement/design. Furthermore, the shaping of the buttons also makes the proper selection easier, and may also avoid a mistake that can be relatively severe.

In general, we may often use touch to distinguish between choices. By adding structure and different patterns it is often possible to make otherwise similar products distinct. This skill of touching/sensing is very important to take to a larger scale.

\[\text{Figure 12-1. A car key that has been designed to offer as much support for the user as possible. (Photo: L. Oestreicher)}\]

\[\text{23 Sometimes we may not even be able to explain the difference in feel. For example, when we have used a glove for some time, and then mistake our glove for someone else’s. As soon as we put the glove on, it just feels “wrong” to the inside touch. When asked “wrong” in what way, people are often unable to explain the difference in feeling.}\]
Another observation is that symmetry might in some cases make the distinction between two controls more difficult. This was described by Donald Norman in his book the Psychology of Everyday Things (Norman 1988). (This is a brilliant book, by the way). In his example he shows two levers on the control board for a nuclear power plant. The engineers have made the levers look the same, causing the operators to confuse them. The remedy was a simple. The operators took two distinct looking levers from the local pub and put them on the two levers at the control board. The similarity and symmetry was removed and the risk of confusion was drastically lowered.

Comment: It is interesting that we use these kinds of locks for car doors, whereas the keys to apartments still require us to put small objects into small holes. This is sometimes difficult for people even when they do not have any significant impairments. Opening a lock with frozen hands might be difficult enough even if you are not normally shaking. So why are electronic locks so popular in cars that cost less than 10% of the cost of a small house, whereas the house still depends on very old technology?

12.2 The blinking key hole

In a common joke a person who is returning from a party, a little drunk, tries to unlock his door. Since he has had a little too much to drink he has some problems coordinating eyes and hand in order to get the key into the keyhole. Then he exclaims: “Stop blinking!”. Although this is a joke, the situation could easily be transferred into a situation where the person is subject to trembling muscles, or people with a vision impairment. Even if we don’t use electronic keys in the apartments, there could be other less expensive solutions.

The problem is that the keyhole is a very small target, which requires precise muscle movement. Thus, one interesting solution could include some constraining factor that would decrease the need for precision in the action.

12.3 Dispenser for Toilet Paper

A simple thing as tearing off a piece of toilet paper can sometimes be difficult for someone who can only use one arm or who has weak muscles in the arm. This is especially true for the type where the roll of paper hangs loosely on the peg, and when you pull, the roll does not give enough friction. The result can be a long line of paper rolling onto the floor. Other solutions include various types of friction systems that cause the paper to
break to early at the perforations (or elsewhere as well). Invariably, just tearing off a sufficient length of toilet paper becomes too difficult, considering the simplicity of the task itself. This is of course not a disaster, but in many cases it becomes such a nuisance that one would think that someone would devise a clever holder, that would do away with all these problems.

I just recently came across a brilliant design for this purpose (see Figure 12-2). At first I just thought that it was a nice and elegant design, with some intriguing patterns decorating the lower rim of the holder. But when I examined it a bit more closely, I found that the design was even cleverer than I originally thought. The decorations were actually functional (!). The design was so interesting that I just had to take a picture of it (which once again points out the importance for a designer of bringing a camera along all the time.

In the picture you can see that there are two parts to the functional design: the L-shape of the edge, and the edge, shaped in what looks like an old-fashioned jigsaw teeth pattern. The L-shaped part provides an edge against which it is possible to lead the pattern. A straight edge will not catch the paper well enough. The teeth complement the L-shape in providing a rough edge that will "grasp" the paper and catch on the perforations. All this means that even a slow movement will be enough to rip of a piece of pattern, while it is still not necessary to use friction to keep the roll from unrolling.

The design is easy to use for a very large part of the population. It does not matter whether the person is strong and quick or slow and weak. As long as you have the
power necessary to rip a toilet paper you will benefit from the design. Although we are talking about a design for a large number of people including people with muscle impairments, the design is still modern, sleek and streamlined. This example clearly shows that also a universal design can be aesthetically appealing. It does not have to look institutional. It is even possible to imagine a wooden version of this construction in a summer house lavatory, so it doesn’t have to be made in a brushed metal look.

12.4 Floor Numbers

Why not make things more clear than the absolute minimum necessary? By upsizing there is a large benefit, and practically no disadvantages (more than possibly in terms of economy). Larger font sizes will support many people. This is true even in physical environments (see, for instance Figure 12-3). By providing large numbers for the current floor level we make it easier for anyone to see which floor he or she is currently on, which might be very important, for example in case of panic in the possible event of a fire.

Here we can also see a very nice example of an even better inclusion. The floor number, written in Braille, has been added to the number, almost like a small decoration, but which is very obvious for the person who knows how to read it. Once again, extending the group of included people, while not excluding anyone.

12.5 Kitchen Design

Sometimes we might feel that a non-excluding design will have to look boring (but see the previous two examples). However, there are also some examples of that it is possible to really design assistive technology so that it becomes something that you would like to have in every kitchen. A good example of this is the kitchen series by Snaidero, where they have really made an effort in combining universal thinking and aesthetic design (see Figure 12-4).
As can be seen in the figures, the aesthetic design is inspired from the Italian design school, whereas the basic universal design principle is reachability. All the important places are placed within reach of a person sitting in a wheel chair. The work space is also possible to lower and raise according to need, which makes it just as easy to use if you are standing up. Thus the design is not made special for a certain category of people, but rather has been designed to fit as many people as possible.
13. Some Bad Design Examples

Many times when we try to solve a problem we get so intent on making a good solution that we tend to see the solution as an alternative, rather than as a complement to the existing solution. The good thing is that in many cases we do not need to remove anything, in order to provide a better (universal) solution to new groups of users. Still, we can often see this as a comment within critics of universal design: “We can’t make one design that works for all people!” . This is probably true, but that is not the recommended way to proceed. Rather we should provide several possibilities to access a place, or to interact with a certain device, etc. It is all about diversity of solutions, rather than too-general attempts at solving the problem for all.

Let us look into a few examples to see how this pitfall may appear. The first case actually comes from the same source as the good example in Figure 12-2.

13.1 Toilet space

When I looked at the toilet paper dispenser in Figure 12-2, a second observation was actually concerning the design of the rest of the lavatory, where this holder was located. It was a toilet designed to be used by all, with extra arrangements for people with wheel chairs (see Figure 13-1). It was a nice open space, but when I had stopped looking at the nice dispenser, I was struck by something else (see figure \ref{toilet}). The dispenser for towels is located in the corner, behind the char, and so high up that it will probably be difficult to reach for someone who is in a wheel chair. Also the wastebasket for paper towels is located very high up. Furthermore, the wash basin was not possible to adjust in height, which also makes it difficult to reach if you are in a wheel chair.
This second observation of the design mistakes actually makes you wonder whether the design of the dispenser for toilet paper really is intentional. Still the design of the dispenser is definitely a successful one.

### 13.2 Door openers

If a door is heavy to open, someone who is using crutches, is sitting in a wheel chair, or just has weak muscles, will need some support, in order to use the door. The normal solution is to use a door opener, i.e. a push bar that starts a small motor that opens the doors automatically. This solution has more or less become a standard instalment in many buildings. It should be obvious that this solution is non-excluding. All people may use both solutions, and some people may prefer one way to another.

It is interesting to note that some instalments have altered the concurrent usage possibilities so that it is necessary to press the press bar for at a minimum three to five seconds, in order for the automatic door opener to react. This means that after some time this door opener will only be used by those that have an explicit need for the support. Most people will not use it, since it takes too long. In this way, the solution has been altered so that it is only directed at a certain group of people. Essentially this means that this solution, once again, discriminates one group of people from the rest. The solution, in all its simplicity, has a stigmatizing factor: "Those that need door openers".

A second problem with this solution is also that the person in the wheel chair will have to come to a standstill before the door opens. The two most energy-consuming activities in a wheel chair are the starting and stopping of a movement. By the

![Figure 13-2. Sometimes a ramp may not be the best alternative to stairs. But it is often easy to spot the problem of using a ramp. The difficult part is to find a solution. How can we provide access to places, such as the leaning tower of Pisa instead? (Drawing by Olivia Hössjé Oestreicher)](image)
construction of the delayed door opening mechanism, the person is forced to stop the momentum, and then restore it once the door is open.

13.3 Stairs and ramps

When we need to bridge a difference in physical levels, it is natural to think of using stairs (see Figure 1-1). However, a staircase is not the best solution for many types of impairments. Both people who are using wheel chairs, and people with vision problems may have difficulties accessing areas where the only entry point is via a set of stairs. One obvious solution is to use a ramp. And also here the ramp will complement the stairs, if we design them properly.

If we have a long staircase, we might run into problems. We might build a long access way alongside the stairs, but this solution is a bit difficult, since a person in a manual wheel chair will then have a long uphill to roll. If climbing a steep set of stairs is cumbersome, then so is definitely trying to roll a wheel chair uphill by hand (see, for example the slightly humoristic Figure 13-2). So we might need to think in different ways in order to make the best solution to this problem. And of course, there might not even be a simple solution. But that is why we need to think about the problem at all.

The problem becomes even more serious when we start to consider emergency situations (cf. section 2.4). How are we to design alternatives, that are usable also in emergency situations? (Cf. also Figure 2-5). In some places, elevators have been constructed also for emergency situations, but often the elevators are not to be used in case of emergencies.

13.4 Reflections

1. Reflection: Consider the good examples in this chapter. Can these solutions be applied in other contexts? How, and why could it contribute in the situation you suggest?
2. Reflection: Can you see any problems with the solution using Braille, as shown in Figure 12-3)?
3. Reflection: Consider the bad examples in this chapter. How can we use the examples to learn for future design?
4. Reflection: How would you suggest solving the problem of using a staircase, when a ramp will not be a practical arrangement? In your reflection, you should consider the discussion on stigmatisation and exposure in chapter 9.
14. Pitfalls in Non-Excluding Design

When we start thinking in terms of designing for larger groups of people, we run an obvious risk of falling into traps, just because we don’t understand the solutions or fail to see the consequences. There are several ways in which we can fail when we try to design the artefacts. One of the more dangerous failures stems from a too strong belief in technology. (Norman 1988) We might be so inspired by the technological possibilities that we fail to see the relevance (or rather the lack of relevance) for the individual with our brilliant solution.

Sometimes it is easy to see the obvious solution to a problem. The technical solution is staring us in the eye. However, it is also very easy to fall into the trap of making a solution while considering neither the actual need, nor the consequences of the application of the solution in various contexts. Sometimes there is even a risk of making solutions to non-problems, i.e. problems that seem to be problems to most people, but which are in fact not a (or rather the) problem for the person who has the impairment. Many times people will overcome problems on the way, and then they will see new needs, which may not be possible to solve as easily. A few examples may explain this type of pitfalls a bit better.

14.1 Watering Plants

The first case of technological traps is taken from an investigation I made in my Ph.D. thesis (Oestreicher, 2009). I was interviewing a person with muscle dystrophy about the needs from a service robot to use at home or in the work space. During the interview, she told me that she was very interested in pot plants care. Her home was a pure greenhouse. I commented on that it must be a lot of work to water all the plants. And she admitted to that it was especially difficult to do the watering, since she had big difficulties carrying the water around in the flat. After some talking about the usefulness of having a robot in the home, I suggested to design a flower-pot-watering robot, that could go around and water the flowers she had in the flat. She refused completely, to my utter surprise since I thought it would be a perfect task for the robot.
When we discussed the suggestion in more detail it turned out that she enjoyed watering her flowers, some of which were almost collector’s items, and she would not let any robot handle the watering of those plants for her. But, and this is in my opinion, the interesting part of the story. She wanted the robot to follow her and carry the water. Carrying the water was the task she had problems with, not the watering itself. So the redesigned solution that was suggested in the end was a robot with a water tank, and a slouch with a faucet, that was light enough for her to carry. The robot would follow her through the flat and support her in doing the task, rather than, as in my first suggestion, replace her in doing it for her.

In afterthought, this might seem to be very obvious, but in the situation of technical hubris, it is easy to get caught in thinking about what technology can do, rather than what we need the technology to do for us. There are many innovations that have been technology-driven, where the need and the proper design of the functionality have been pushed aside by the technological challenges.

14.2 Ultrasound cane

The use of a traditional white or “Hoover cane” by people with impaired eyesight serves different purposes in one. On wikipedia four different types of this assistive tool are listed (Wikipedia 2011):
• Long cane: This “traditional” white cane, also known as a “Hoover cane”, after Dr. Richard Hoover, is designed primarily as a mobility tool used to detect objects in the path of a user. Cane length depends upon the height of a user, and traditionally extends from the floor to the user’s sternum. Some people favour the use of much longer canes.

• “Kiddie” cane: This version works in the same way as an adult’s long cane, but is designed for use by children.

• Identification cane (“Symbol Cane” in British English): The ID cane is used primarily to alert others as to the bearer’s visual impairment. It is often lighter and shorter than the long cane, and has no practical use as a mobility tool.

• Support cane: The white support cane is designed primarily to offer physical stability to a visually impaired user. By virtue of its colour, the cane also works as a means of identification. This tool has very limited potential as a mobility device.

• Mobility canes: are often made from aluminium, graphite-reinforced plastic or other fibre-reinforced plastic, and can come with a wide variety of tips depending upon user preference.

It is most often used to feel the immediate surrounding and avoiding obstacles while walking. It is also a sign to the surrounding people that this person does have a visual impairment. The cane as a mobility tool is probably quite old, and has maybe been used for centuries, but the white cane was invented by James Biggs, who became blind after an accident and thought that a stick that was painted white would be easier to see in the traffic.

The cane has more or less become the signifying sign of a blind person, for good and for bad. It is clearly a stigmatising factor, since it is really sorting out a certain group of people based on ability. However, it also provides people with a clue on how to meet the person in a proper way. This latter role of the cane (which is intentional) is an important factor, when we try to develop new devices that will replace the cane.
One such suggested solution implied replacing the white cane by a handle containing some ultrasound sonars that would translate the perceived image with a sound field where the person could distinguish the features in front of him/her by interpreting the sound. The cane would, according to the developer, be less difficult to handle, and be more precise in the positioning of objects. This of course sounded like a good idea.

However, when the idea is examined in more detail, it appears that there are several problems with the proposed solution. The first is that the signal feature of the cane will be reduced by the reduction of the cane size. This might not be such a big problem, since there are already the ID canes, which has the symbol value, but is not used as the longer cane. Still, it is a reminder of the external property of the cane, not only as a mobility tool.

Second, and maybe most importantly, when we change the way the cane will be used, we will also change several of the general properties. The standard cane uses the people’s tactile senses as a complement to the remaining senses (primarily the hearing and the tactile feeling of wind and temperature). In the proposed solution the cane would use sound for the information sent to the person. So, rather than to add a sense, we are overloading one of the most important senses that a blind or highly visually impaired person has remaining.

It is a vital observation that hearing to a blind person is not only used for communication purposes, but also to a large extent for navigation. Hearing provides directions to sounds, for navigation, and also may be used to avoid bumping into larger objects, by the sense of echo effects. The sounds made by walking will be reflected more and more when you approach a wall (this can easily be tested by walking towards a wall with your eyes closed). Both these ways of using hearing will be affected (negatively) by adding the sound field from the ultra sound sensors.

One further question that needs to be asked in this context is why we should change a tool that works to a completely new invention. Is that something that people with visual impairments want to have, or could we regard the problem and the solutions to it in a different way? Is there a real need, or is this an invented need by the designers (cf. the Saviour syndrome on page \pageref{SaviourSyndrome}).

14.3 Ramps

When we want to make a flight of stairs more accessible, it is close at hand to build a ramp on one side. This can be done very elegantly, using the same
material as in the staircase. In Figure 14-3 we can see an example of a ramp that has been designed to fit in well with the old building. The ramp is also not too steep and has ample space for access with a wheelchair. In other words, with a superficial look, it seems to be very well designed.

And indeed, so it seems until we look a bit closer on the surface of the ramp (see to the right in the picture). Here we can now see that the surface is covered with cobble stones. This is, however, most certainly not a suitable material for manual wheelchairs. Getting up this ramp quickly becomes a shaky, and very tiresome experience, and it is even very likely that you will need some help getting all the way up to the door. The irony in this construction is that all around the entrance, the surface is pure asphalt, which is smooth and nice for most vehicles. Only the ramp is covered with the cobblestones – exactly the ramp that is to be used by wheelchairs, rollators and trolleys.

The cobblestone surface is also causing a secondary problem which becomes imminent during winter time in the northern part of the world. Snow is in itself a delimiting factor when you are using a standard manual wheelchair. The smaller front wheels do not cope with even small amounts of snow. Scraping the uneven surface of the cobble stones becomes very difficult, and much snow will be left on the ramp in wintertime. This means that it will be even more difficult to use the ramp in bad winter weather conditions.24

How can we know whether a ramp is too steep or not? The security regulations in Sweden state that a ramp may not be steeper than a slope of 1:12. Thus a level difference of 35 cm requires a ramp length of 4.20 meters.

24 The same problem may occur from a badly swept surface in the fall time, when leaves will be falling on the surface and may interfere with the wheels as well
This design was a well-intended attempt, but an attempt that failed in the end, due to some quirky thinking.

A second issue with ramps is shown in Figure 14-4. Here we can see how they have rebuilt the entrance to a Pharmacy. This store used to be a bank, but when the new shop moved in they now realised the need to make the entrance accessible to people with rollators and wheelchairs (it is difficult to understand why they did not realize this need before). So they built half the stair into a ramp, with a suitable inclination. My immediate question when I saw this solution was: Who needs the stairs? If the ramp is well built, why couldn’t all use it? Now the solution makes the entrance very narrow for both populations (compare also with Figure 2-1 on page 14).

It has been shown that in the case of moderate inclinations on ramps, people seem to feel more at ease using the ramp than the stairs. Also, when there is only the ramp, there is no risk for stigmatisation or exposure. Everybody is using the same solution, and nobody will actually be excluded from the entrance.

Now why does this happen? My guess is that it is an over-generalisation. We want to include people, and then we forget that an including solution can actually be used by everybody, and not only by the people that are addressed by the solution. This might be because we have a tendency to think of non-excluding design solutions as adding possibilities, whereas it might in some cases actually be the better solution.

14.4 Some Concluding Thoughts on the Pitfalls

The designers who have made such “bad” design as in the items described in this chapter are not bad designers. Clearly, it is quite evident that it is easy to fall into the trap of designing things that seem good solutions, but in reality will not work. Then how can we avoid doing this? The first thing to realise, once again is that we as designers or developers are not supposed to be some kind of all-knowing saviours. If we think that we know what it is like having a certain impairment, without having it for real, it is easy to come
to false conclusions. If we do not know what it is like to run a wheel chair over a small bump in the road or up a too steep ramp, we might still devise some non-working solutions to problems (or even to non-problems), such as a long and winding ramp, that none will manage to roll a wheel chair up along.

It is important to remember that we are often in very sensitive situation. In the case of inborn impairments, we will actually suggest to change someone’s “natural state”. This is tantamount to saying: “your way is not good, ours is much better”. We have difficulties seeing that an impairment can be the normal state to someone, since we would of course miss all the things that the impairment hinders. Likewise, the person who has the impairment may have difficulties seeing the advantages in an unasked for solution. it may add complexity to something that already works, albeit not perfectly. And why should we change something that works, when there are other, more important, issues that need to be addressed before this.

In the case of acquired impairments they are instead an abnormal situation to the person who is affected, regardless whether it is from a sudden accident, or from a more prolonged and slow cause, such as diseases or aging. The situation is new and unusual, and there might even be a feeling forced to use the new solutions that are proposed. They don’t want to be in the situation, and there might be both an active resistance and an apathy that grows from the new situation. The feeling of being non-normal is great, and this might add to possible depression and (self-selected) social isolation. In these cases the people in many cases have one single question to ask: “How can I get normal again?” And the sad truth that has to be handled is that many of them cannot.

In those cases when the progress is slow, there is a tendency to resist accepting the fact. There is always a point of acceptance, where the individual is forced by the symptoms and effects to admit that he or she is not the same person as they once were. But the thought that often remains for a long time is that “I don’t want to accept that I have an impairment!”. In this case the solutions that are proposed might not be accepted since they don’t want the technological solution, but they want the medical progress to speed up.

14.5 Reflections

1. Reflection: For each of the pitfalls in this chapter, consider how it would be possible to avoid falling in the trap.

2. Reflection: Can you think of any other solution to using sensors on a white cane?
3. **Reflection:** Can you think of any reason why the stairs in Figure 14-4 would be needed also when the ramp is there?
15. Design for elderly

This is a chapter on *Design for Elderly*, despite that I do not admit to the soundness of the grouping of people over a certain age together into a homogenous group with similar requirements. Of course we can see that the probability of having a certain impairment becomes higher with increasing age (Langdon & Thimbleby, 2010), but there are also perfectly healthy people of age 90+.

One problem is that by grouping people into categories (such as "elderly") runs the risk of providing a ground for applying misconceptions about the group. It is easy to fall into the trap of thinking that "old people are..." and then applying all kinds of stigmatizing features to the person belonging to that group. This is clearly problematic and could even be a destructive perspective.

It is also a common situation that people in a country tend to get older and older by time (and by increased standard of living). An aging society also puts larger requirements on old people to manage on their own at higher and higher ages. This means that people will need better means for self-management in their homes, and for this some technological advancement is also needed. This is also a reason for why this chapter is necessary, despite the doubts about age as a common factor for reasoning around impairments.

15.1 Age

The first problem in talking about “elderly” people is of course where to draw the line? At what age do people grow old? And how long are they still young? The primary question here is probably how we will construct the definition of age. What do we mean by the group “Elderly”? The real age is very dependent on the individual, and there are some people who are still very vivid and active even at the age of one hundred years. Furthermore, in many countries the expected life span is still increasing, which in some way can be interpreted as people growing older at an increasingly later age.\(^{25}\)

\(^{25}\) This could maybe be regarded as a slightly strange sentence, but in many cases people today both look and feel younger at 70 than many did at 60 as little as fifteen to twenty years ago.
Medical care and supportive technology also contributes to a change in the definition of age, and politicians are even considering to raising the retirement age, since people are young for a longer part of the time. It is in this context, however, important to note that this is highly different in different countries and even parts of the world. However, the trend is that with increasing standard, the life span grows, and people tend to be relatively young later in life. Aging is also one of the factors that people may have difficulties in accepting, since being old is in many contexts not appreciated by society. Retirement is by many people regarded as “being rendered useless”.

Age can also be stigmatizing in itself, especially in social circumstances. Preconceptions about old people will affect how we think about that group in terms of disabilities. This can be especially so, in case that the physical age and the perceived age don’t coincide. Having an old woman dancing to some modern music in the streets is immediately attracting the attention of people with cameras or mobile phones. But also the expected characteristics from a person at a certain perceived age can be stigmatizing for the person. If a young man or woman is being polite and offers the bus seat to someone who does not feel old, then this might be a very negative experience for the person at hand.

In the beginning of aging, people are often reluctant to use assistive tools since they tend to stress the degree of impairment in the individual’s perception of him/herself. The tool is regarded as a stigmatizing symbol. As such, it will annotate the individual with a stigma of age, such as immobility (rollator), or hearing difficulties (hearing aids). There are of course already attributes that can add to the categorization, such as hats, handbags, scarves,
etc. This is well investigated by theatres and painters, who often use these attributes in order to classify the person as "old" in a theatre play or a movie.

The physical age is not the only factor in aging. We could easily imagine at least four different age perspectives when we start talking about age:

- Physical age - The actual age as measured in number of eclipses by earth around the sun
- Medical age - The age of the body, which may be lower than the physical age in a trained body, and higher than the physical age in a body that has several medical conditions.
- Age of mind - The age of the mind-set, a person can be more "childish" than another at the same age; some people start acting as grown-ups already in early puberty.
- Perceived age - The age group with which the person identifies him- or herself.

This classification is not based on any scientific research, but it is easy to see that the aging is a multidimensional experience in people. There are people who perceive themselves as much younger than they are in physical years, whereas in some people the association is closer with older people. So, if any of these "ages" come into conflict with each other, there is a potential risk of a lower self-esteem or bad social appearance as a result of this clash.
Thus, from this introduction it should be clear that it would be difficult to regard the “Elderly” population as anything like a homogenous group. So, how can we even say that we can consider designing for elderly. To answer this question it is necessary to think a bit further about age, and what signifies age in an individual. An elderly person has a body that has been through a long process of tear and wear, and with growing age there is a larger possibility that this process has affected the body, and induced some of the possible deficiencies that we consider to be impairments. This essentially means that in order to design for elderly people, we have to design for a multitude of attributes, but not all of them need to be fulfilled for an old person.

Thus in the Design for elderly context we will have to consider a large number of possible impairments to develop over time. Each of these possible impairments will have consequences for the design of artefacts. We will go through some of the most important impairments, and see how they influence the design.

Figure 15-3. A rollator can often be an extra sign of being old. The aid makes the person look old, although as in this case, it might be a physical health problem that causes this man to need a support. In the carriage is an oxygen pump, to support his breathing. (Photo: L. Oestreicher).
15.2 Labelling

Sociologists use a term called *labelling* for the phenomenon that occurs in this situation (Falk, 2001). There is a group of people who attach a label to the group of people considered as being “old”. Attached to the label are several properties, such as being incompetent, having learning difficulties and bad memory. Other properties that are connected to the label are being in a general state of mental decline, and of course lack of sexual interest or ability. In this case it is not the person in himself that is attributed but as part of a labelled group. Much of this labelling is done after some perception of visual properties, e.g. the use of a cane for walking, or as in Figure 15-3, the use of a rollator. Just using this kind of tools will in many people cause an unconscious labelling as being old, regardless of the actual age.

The impact of the labelling is often very large and this adds to the effects of the stigmatization. A person who is labelled “old” will in many cases get the feeling in him- or herself as being discarded by people. There are several of the organizations for elderly people who try to destigmatise or even delabel the group of elderly by launching the picture of active elderly people. In the longer run, as we see more and more elderly people who are active in the streets the labelling will most likely shift upwards in age. Those who used to be old are not that old any more.

15.3 Design Factors

In this section we will look through some possible impairments and see how they will affect the design. The examples will be selected to illustrate the principles, rather than being a complete coverage of all possible conditions. There are some types of impairments that can be more frequent in the older generations, such as stroke, heart attacks etc. Several medical conditions also tend to increase in frequency with age, such as diabetes, incontinencia, and problems with the circulatory systems. In the following sections we will take a closer look at some of the more common problems that occur, and a little bit on how we can use design to alleviate the problems.

15.3.1 Cognitive Problems

15.3.1.1 Dementia

15.3.1.2 Aphasia

Aphasia is an impairment that often comes as a result of a stroke or other brain damage. It is not a single disease, but appear in several variations.
Some people experience a total lack of communication possibilities. Other people discover that the only words that remain that they can express are swear words, and sexually explicit terms. Many times the aphasia decreases after some time, and the individual recovers more and more words in his or her language.

15.3.2 Perceptual Problems

15.3.3 Physical Problems

15.3.4 Medical Problems

15.4 Reflections
16. Gender-specific issues

How can gender be an issue of excluding design? Having a gender should not be regarded as having an impairment, of course, so why include a chapter about gender in this book? The simple answer is that people can still be excluded by properties that relate to the gender. The most well known issue is that of colour-blindness (cf. section 7.1.2), since this impairment is basically appearing in males. Thus using green-red controls will disallow a male person to perceive the difference, more often than a female. The water tap in Figure 4-3 is a typical example of when the colour-blindness could cause problems. Apart from the colour coding there is no way to determine which arrow represents the hot or the cold water. There are no symbols at all to help.

But there are several other, less obvious issues that can be distinctive between male and female users. Bodily properties, such as arm length, size of fingers, etc. show a co-variation with gender, although there are of course inter-individual variations that are larger than the general variation. But that body sizes vary means that if we don’t design for varying bodily forms, we run the risk of excluding people that are outside of the “normality”, and in this we risk excluding a larger number people from a certain gender.

16.1 Disabled women

From a less evident perspective, the social norms in society are to a large extent exaggerated in the distinction between abled/disabled. The tendency to regard people with disability as lesser-knowing, childlike, helpless and victimised becomes even greater for women. It is difficult for women with impairments to match up with the feministic ideals, of independence and strength, if you are dependent on other people. In many cases an impaired woman is also deprived of their female identities as child bearers and parents. A disabled woman is perceived to be needy, dependent and passive by the surrounding people, properties that are stereotypically attributed to “feminine” roles. (Sheldon, Alison 2004)

Other problematic issues are the relation between the right to abortion, and the view on impairments. This primarily ethic question, becomes very concrete in terms of impairments for women. The right to have an abortion (where it exists) lies normally only within the woman’s domain. Thus it is the disabled woman that has to decide on the genetic risks and the personal freedom. The fertile man has less choices in this area, but is still faced with
the same general issue, whether a child might be inheriting the impairment (if it is inherited) or not, and in the former case, whether it should be born, or aborted.

16.2 Disabled men

Men with impairments tend to face the same problem as women with impairments, but turned around. The “child-like” appearance of an impaired person as mention in the previous section has a deprecating effect on the masculine role model. In a world where the traditional ideals might be changing, this could also be a passing phenomenon, but more likely, this situation will continue to be a problem for both men and women, but for completely different reasons.

Impaired men are also in many cases relieved of their sexual ability. For many men with neurological damage in the spine, the sexual ability diminishes or disappears with the increasing degree of impairment. This does not mean that the sexual needs disappear. People with impairments are often not considered to have an active sex life, but once again from different perspectives regarding whether the person is male or female. (Robertson, 2004)

16.3 Reflections

1. Reflection: Try to give an honest reflection on how you look at impaired women and men. Do you see them in the same way? If not, what differences do you recognize?

2. Reflection: What kind of impairments do you think have the largest effect on the problem with gender roles and disability?
Non-Excluding Design
17. How to achieve non-excluding design

The word “Design” means to create something, either physically or virtually (in terms of software artefacts, for example). This shaping of something is based basically on three background factors: Knowledge, experience and intuition.

Knowledge about the need, the possibilities and the constraints in the design situation plays a crucial role in the design process. Without the knowledge, the design of supportive and assistive technology becomes very difficult. Likewise, without any experience of working with people with different kinds of impairments, design is also likely to become difficult. But knowledge and experience is not everything. Just as important is the intuition, in terms of some *fingerspitzengefühl*. To feel in advance how a design works is a very valuable skill in the design process.

The shaping is not only of the physical or visual appearance, but also of the underlying ideas, and of the functionality. The functionality is quite naturally central to the design. Without a good functionality there is little chance of acceptance, even if the external design is attractive.

There are two major parts to non-excluding design. First, we want to increase the normality span for people by designing things to be attractive and tempting to use. The problem is to understand how we can redesign an environment to incorporate a normality span that is as large as possible. Much of this work lies in changing the attitudes and the environment. Second, we want to minimise the stigmatisation factor, by design, trying to achieve a design that suggests everyday use.

17.1 Observe

One of the most important parts of the work with non-excluding design is to *observe*. What should we observe? Previous (good and bad) solutions (which we can transfer into new areas) can provide ample inspiration for new designs. It is a very good idea to bring a camera (most mobile phones today contain a sufficiently good camera, in order to take pictures of interesting design solutions) whenever we go around in the world. Just taking a simple picture of some artefact or situation will be of good use in the future design situations. Observing design solutions and useful ideas is a very strong actor in creativity.
In chapters 12, 13 and 14 we can see several examples of both good and bad design solutions. But just observing them are not enough, we also need to understand the important factors in the design. What is the new thought that we can get from a certain example? The next step is to understand the bug in the general thinking for this solution? So in Figure 14-3 we might discover from testing that there is a problem using cobble stones. That is possibly an indication of the best solution for this single example. But the general lesson to be learned is slightly wider in its scope. There are many different aspects on the design of a good support for a certain impairment, and the solution that is finally chosen has to be evaluated before it is to be regarded as finished.

17.2 Analyse

As shown in the previous section, the need for analysis is large even before a certain design is implemented. This is an essential part of the process of Non-excluding design. In many cases it is clearly possible to discover an erroneous design decision by doing a general analysis of the ideas and not least, the effects of their implementation. If the final users are involved early on the process, they may contribute with much valuable information about the artefact, even before it has left the sketch board. Many seemingly good inventions should have been stopped early on in the development process, since the ideas would have been discarded already at the sketch stage, had they only been discussed with people that have real impairments, and who have a good insight in the life of a person with an impairment.

An analysis of the design solution in the non-excluding design paradigm is to a large extent focused on the effects a certain design solution has on the general functionality. What are the consequences from a certain design decision, and how are we going to weigh the different consequences from each other? The analysis phase is in many cases not trivial, but needs a thorough evaluation of the design space.

17.3 Implement

17.4 Evaluate

Whenever a new artefact or service is designed and implemented there is a need to make sure that it really does what the users expect it to do. An
evaluation will, if it is properly administered, at least sort out the worst usability and accessibility problems. There are a number of methods available for the analysis, and which one to use is dependent on several factors, such as the situation of use, the artefact, and the intended target user group. There is no one-for-all solution that solves all the problems that are possible. In the case in Figure 14-3 it is fairly obvious that the solution has not been evaluated by any real users. Any person who is using a wheelchair for some time knows by heart that cobble stones don’t do the job. Smooth surfaces are necessary in order to make the travel comfortable.

The evaluation needs to be done from a large number of aspects, through the usability, functionality and satisfaction points of view. Within the area of assistive technology, other factors, such as safety, reliability and security will be especially important to test. Many devices used by people with impairments play crucial roles in their lives, and they need to be able to trust these devices. A power cut in the batteries, or broken hearing aids will cause severe problems if there is an emergency situation.

17.5 User Experience (UX)

Apart from the actual usability issues that are tested during the evaluation phase, there is also a separate issue of determining how the individual experiences the solution. Among the important parts to test are the feeling of stigmatisation, and whether the artefact contributes to the feeling of being exposed for others to see. Within the HCI community there is an area called User Experience “User Experience”. It starts from the idea that usability should take the user’s appreciation of the system into the evaluation. This is already addressed in the usability measure “Satisfaction”, but it not addressed in a sufficient manner. The issue of User Experience Design and Evaluation will be addressed in much more detail in chapter 20. In the current chapter it is only mentioned as one of the important parts.

17.6 User (Individual) Centred Design

Normally User Centred Design means that the users (or representatives of the user group) are involved in the whole design process. This is supposed to lead to better designed systems, since the users can influence the design not only by evaluating the product, but also by actively participating also in the earlier moments of the design process.

The assumption in user centred design is that a close cooperation with the intended user(s) is a necessary prerequisite for achieving a correct design of a system, be it digital or physical.
17.7 Reflections
Non-Excluding Design
18. Ethical aspects of Universal Design

Apart from the general discussions on disability as we have seen here in the previous chapter, there is a different issue, that is very important, namely the ethics that is involved in disability research and the design of assistive and supportive technology. But what is ethics? A standard Philosophical Dictionary, for example, states that: \textit{ethics is...}

...a set of standards by which a particular group or community decides to regulate its behaviour to distinguish what is legitimate or acceptable in pursuit of their aims from what is not” \textit{(Flew, 1979)}

In a more general sense ethics can be described as a philosophy of morality, which rules what we consider to be \textit{good} or human behaviour. There are no fixed rules of ethics. For example, it is considered to be good ethical behaviour to save someone else’s life, even at the risk of losing your own.
Other examples of good ethical behaviour is to treat other people well, and not strive for the own person’s maximum gain. In general ethical behaviour is doing a lot more than just conforming to the legal constraints.

If there is a difficulty defining ethical behaviour, the problem is even larger with unethical behaviour in a more general sense, since ethics is not necessarily connected with legal aspects of human activities. Something, which is perfectly legal in a juridical perspective, might still be highly immoral in a more human-centred perspective. This is a common discussion in economics, where people might make a large amount of money doing business that is not following the ethical thinking, although there are no legal means to stop the activities.

Thus, ethics is in many people’s opinion probably more connected to philosophical than to legal reasoning. This is also evident in the insight that there are in many cases no exact solutions to ethical problems. The proper standpoint is to a large extent dependent on the person’s background, culturally, socially and (sometimes) theologically. Ethics is therefore a topic that must be understood, rather than learnt in terms of knowledge.

Can a society be ethical or non-ethical (or even unethical)? Since ethics is dependent on the culture, this also becomes a very difficult question, since it presumes that there is some general, universal definition of ethical behaviour. We can as humans agree on that it is unethical to kill someone, something, which most people would possibly agree to. However, there are many countries that still use capital punishment. Are those societies unethical? And what does the society consider itself?

18.1 Ethics in Research

Ethics is a fundamental ingredient in most research that is being conducted (research ethics). The ethical considerations are there to protect the subjects, and to ensure good research, by ruling out unethical behaviour, both in terms of experimental honesty, and in terms of subject safety. We cannot make any experiments that run a risk of harming the subjects. There are numerous examples from earlier on, when psychological and medical experiments were performed that were hazardous to the subjects, and which may have caused bad aftereffects in the subjects.

In disability research (and in designing technology for people with special needs) the question about ethics becomes even more important. The field is concerned with issues that can be very sensitive to a person with an impairment. Suppose for example that you interview someone with an injury in the lower abdomen. This probably means that he or she does not
have any possibility to move the legs, which might be your immediate cause of problematic situations. However, you might not know about that this person has a problem with the intestines, causing him or her to have an ostomy surgery, which has several problematic issues connected. He or she might also have an injury that affects the sexual functions, which might quickly put the interview in a very sensitive state. The important issue is as always to be aware of this, and to make sure that the person feels good talking about it.

18.1.1 General Ethics Guidelines

The most important ethical considerations can be expressed through a set of guidelines. The guidelines need to be interpreted and applied to the individual situations.

- Respect for the human rights, dignity, equality and diversity of all those involved in the research process
- Advancement of social justice for people with disabilities within the wider community
- Promotion of the well-being of those participating, involved in or affected by the research process
- Avoidance of harm to those involved in the research process or to the wider community
- Facilitation of the participation of people with disabilities in research and research dissemination, including those for whom obstacles might make such participation difficult without additional support
- Maintenance of the highest professional, legal and ethical standards and competencies
- Comprehension and fulfilment of relevant legal responsibilities

In general the guidelines express the equal value of all people and the need to respect the individual, and his or her integrity and privacy. It is very easy as a researcher to become so involved in the research issues, that he or she forgets that the people under investigation are people, at the same time as being subjects of study. It is very easy to fall into the trap of thinking in terms of "we" and "them", especially when we think about people with impairments. This grouping is very "natural" in some sense. Gathering into tribes, villages, counties, and countries has been an ongoing process in the development of the human civilisation. And with this grouping follows of course an inside and an outside perspective. The "we"-factor provided a comforting feeling in the people. The "them"-factor constituted a common enemy that would unite the local group.
However, the grouping has of course become destructive in the modern society. It is the base for the immigration problem (the lack of assimilation), the conflict between youth and grownups, the equality problem between women and men and, most importantly for us, the separation of "people with impairments" and "us normals". It seems that it is almost unavoidable to have these kinds of separation between groups, and that it lies within human nature.

Also the actual selection of informants for our investigations becomes slightly problematic, if we stop to think about it more principally. Who do we want to use as informants? Naturally, we look for people who are affected by the impairment we are interested in. But this means that we are adopting a perspective that relies on the impairment, rather than the person that is affected by the impairment. The people that we use as informants will be characterised by the impairment: "Wheel chair users" or "Blind people". There is a big risk that we see the people as research objects, rather than real people with feelings and thoughts of their own. Even by testing the subjects, we imply that there is a difference between "them" and "us". We are observing "others", which might become a discomforting feeling in the subjects.

Finally there is also the issue of why we are performing the research and/or development. I have sometimes stated that there is a risk of falling into the trap of "being the saviour". This is a patronising attitude that I consider to be unethical. A researcher or developer is not there to save anyone from his or her fate. This saviour syndrome is of course difficult to avoid in some cases, but nevertheless the problem should be acknowledged by anyone who is engaging in the design of assistive or supportive tools.

Other core principles spelled out in Article 3 of the UN Convention and central to the ethical evaluation of research include:

- Equality
- Full and effective participation and inclusion in society
- Respect for difference
- Accessibility

Some examples of applying these principles in a research context are, for example:

- Involving people with disabilities in an appropriate way in informing or shaping the research process respects them as active participants in the research and not as passive objects of research.
18.2 Integrity and Personal space

An impairment is always intimately connected to the individual. This means that we are always in danger of invading the personal space with our investigations. By querying the person about all aspects of his or her life (in order to be able to understand the situation of usage for the artefact) we have to intrude in the personal aspects of the impairment. This will in most cases also affect the integrity of the subject.

In this perspective, it becomes even more crucial to adhere to the ethical considerations, and make sure that we treat an informant with all the respect that is possible to use. In many cases this implies taking the perspective of the informant. It also means to prepare in advance for the interview situation. Many impairments are more complex than expected from outside. For example, when a person has a spinal injury, this may not only cause paralysis in the legs, but may also affect the circulatory systems, and the bodily functions, including sexual ability. Thus, the topic of sexual problems might be a more central question, than the lack of limbs, which is a problem that the person has already conquered with training. We may not get the answer that we expect from the interview.

If we are not prepared for this it might cause uncomfortable situations during an interview, when we get an unexpected answer. In the situation of a surprise we may as interviewers be caught unaware and then by mistake ask questions that penetrate the personal space without intending to. It might of course be completely acceptable by the interviewee, but this must be dealt with in a well-planned and intentional interview.

But there are other aspects to the issues of privacy, integrity and respecting the personal space. Just by selecting someone as subject of an investigation, we are entering the problem area of showing respect for a person’s integrity. What do we mean by privacy and integrity? Essentially it means to respect the informant’s personal limits, and to regard the person as an individual, with human rights. Respecting the personal space can be difficult in many cases, but it is often a matter of sound thinking.
Non-Excluding Design

18.3 Non-excluding Design and Ethics

Does the idea of non-exclusion embrace an ethical perspective? It is tempting to answer yes to this question. In its pure form non-exclusion aims at the similar treatment and possibilities for all people, regardless of abilities and backgrounds. This is a very constructive and humane aim, and as such it can be said to be a positive.

18.4 Social Aspects of Stigma

One of the disabling factors is the public exposure that is a result of the impairment. The supportive tools and the different visible parts of an impairment (limps, ticks, skin abrasions etc.) all contribute to the stigmatisation of a person. If someone is deviant in some visible way, this is immediately a stigmatising exposure that will also affect the individual. The stigmatising factors are also described as stigmatising symbols. Goffman refers to three types of attitude altering symbols (Goffman, 1963).

Stigmatizing symbols – A stigmatisation symbol is a sign for a negative deviation. Through a stigma symbol, the individual is classified into a depreciated category of people.

Prestige Symbols – A prestige symbol is instead a symbol that identifies the person with a higher status, honour or some other prestigious claim. Examples of such signs are club signs, or in some cases wedding rings. Sometimes the prestige symbols serve both purposes, as when the symbol signifies both positive and negative aspects.
Disidentifiers – A disidentifier is a sign that tends to break up a coherent (negative) picture in a positive direction (as desired by the person). The disidentifier itself does not claim the more positive status, but casts a doubt on the value of the existing classification of the person.

We can either see these factors as constant, and something only to be observed and obeyed. If this path is chosen, the only way to change the stigma on an impaired person is to change the view on the stigmatising factors. This means a cultural adjustment by making the stigmatising symbol a "normal" part of society. This process can be seen in places where there are adapted apartments for groups of people with impairments. People tend to care less and less about people in wheel chairs and electric scooters, since they are seen everyday.

It is on the other hand possible to use disidentifiers in a more constructive ways, now in the case of impairments. Changing attitudes from scratch is very difficult, since there is a large cultural/social inertia. Attitudes in a society, normally changes very slowly. Disidentifiers may then be a way to actively speed up this process. So how can we attribute people with impairments with positive signs, in such a way that it can (in a longer perspective) change how people regard the people with impairments?

There are probably many ways to go, but it is possible that one way is to use design. Many times objects are designed with only a functional aspect in mind (see the pictures in the chapter on exposure). This is especially true of much of the assistive and supportive technology that is being produced. Many products are only available in institutional colours, such as grey, darker grey and black. There are exceptions, and this is in my opinion a good trend.

18.5 Reflections

1. **Reflection:** How can we avoid the risk of regarding the informants as research objects, rather than people with certain properties?
2. **Reflection:** How can we avoid the “saviour” syndrome when we work with disability issues?
3. **Reflection:** How can we ensure *ethical thinking* in Disability Research and Universal Design? And what should that ethical thinking be?
19. Disability and Computers

Although the problem of accessibility is a general problem in society, and the technological world at large, it seemed to be appropriate to add a special chapter on Computers and Disability after some extra considerations. There are essentially three reasons for this:

- The original course was given to computer science students, who really wanted to know more about the connection between these two. Initially I didn’t want to stress computers more than other technology, but I realized that their suggestions were really relevant, so in the end I decided to add a book chapter.
- Computers have some special properties that make them both supporting tools and great barriers. We can see them as saviours or as culprits depending on how we design them and how we put them to use. More about this will be apparent later in this chapter.
- I am a computer scientist from start and I think that it is very important for all people working with information technology, to be aware of this problem area.

Computers have made a late impact on society in general, many times making things easier and even new things possible. The expansion of new areas such as social media, and entertainment computing has changed life in many ways. It has also affected the lives of people with many kinds of impairments. Many people who have been socially isolated have found new ways of communication that have provided a new type of freedom.

In many cases computer-controlled replacements can be easier to use than mechanical tools. By adding some supportive software it becomes easier to drive an electric wheel chair through narrow doors, for example.

However, the computerised society has also caused many problems to certain groups of people who cannot use computers. In these cases the computer itself has become a disabling factor.

19.1 Computers as disabling force
Although this might not always seem like an impairment, some people have big difficulties coping with computers and their software. Most people still manage to use the computers to handle the tasks they need done. However, some people do have problems handle the advanced technology. Being a computer illiterate becomes more and more difficult in the society of today. There are essentially two aspects that become prominent. Complexity and Memorability or the need for good memory. Both these are connected to the cognitive abilities within the human. In these two cases, it is clear that the computer has made life more difficult, when you are suffering from cognitive impairments (cf. also chapter 6).

19.1.1 Complexity

In Figure 19-1 you can see a common situation in many homes. When you come as a guest, and need to turn on the TV (or any other Hi-Fi equipment) you are often faced with a multitude of remote controls that you need (or don’t need) to use in order to achieve the task. The introduction of the computer in more and more places has often introduced complexity into places where it was not present earlier.

This is a common problem even when you are not suffering from an impairment. However, when you have problems with reasoning or problem solving, or even memory problems (see below) this becomes even more difficult. There are stories that relate to how people don’t.

One other example where the complexity becomes even more of a problem is in the area of supportive technology, where also electric wheel chairs become more and more complex, as the technology moves forward. Now

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20 In the picture there is one remote that does not belong. That remote is quite spectacular in itself in that it is used to control a GPS unit for cars. It is difficult to understand why you would need to have a remote control to a device that you have to be close, in order to see what is on the screen. Can you see which of the remotes belongs to the GPS unit?
there are wheelchair that allow a person without the use of his or her legs can still stand up. This mechanism has been used mostly for muscle training, stretching muscles that cannot be moved on purpose. However, the stand-up wheel chairs also allows a user to stand up to use equipment that is difficult to reach, such as ATM machines. This is not a simple process, since there are many security tools that need to be involved. Straps need to be fastened and the seat has to be put in the proper position. The problem is that all manoeuvering of the chair has to be done in a sequence, and is continuously controlled by the user. A simple standing up from seated position may take as much as 4-5 minutes. So, it becomes impractical to “stand up” in order to get money from the ATM. This is even more so, since the wheelchair cannot be moved in standing position. So, if you happen to stop short of reach, you have to sit down, move forward and then stand up again. All in all, the stand-up mechanism will probably not be considered to be useworthy, and thus not used for the purpose that was intended.

The user interface just controls the movements, but does not support the user in doing the work in a smooth and practical way. In this situation it is the functionality needed to stand up that is too complex, and the interface becomes complex on a detail level, but too simple in terms of the needed activity.

19.1.2 Memory requirements

When the computer was introduced, it was supposed to support humans in the difficult tasks. However, it is clear that computers in many cases have made some tasks more difficult, for example by requiring that people remember meaningless information more and more often. A clear example of this is the constant use of passwords and PIN codes.

In figure XXX we can see the “memory flower” that is taken directly from a wallet. Each of these cards needs a separate PIN code in order to identify you as the appropriate owner of the card. In most cases you receive the code, and cannot change it. If you lose your card, you are issued a new code, without any possibility to change it to your own preferences.

The same problems are clearly visible in many offices, where the user has a large number of passwords to remember. PIN codes are not especially complex, but the requirements for a strong password, is essentially that it is
not possible to remember it. The result of this is that people tend to write down both PIN codes and passwords, since they do not remember them. Some solutions involve the “password vault” solution, where all different passwords are stored in a keychain locally on the main computer. This is a workable solution, but what happens if you lose the main password?

19.2 Using Computers

Using computers is for many something that is as common as eating and reading, and it is sometimes difficult to understand that there are a large number (actually a majority) of people to whom it is not an available facility. There are many people who live under such circumstances that they cannot afford buying a computer or where the needed infrastructure is not available. That is also an accessibility issue, although not primarily connected to impairments (although, of course, the people with impairments who are living under these conditions are also very unlikely to be able to have computers).

Many of the universal access discussions concerning computers are connected to accessibility to the screen image, for example through the W3C consortium, which is a very strong promoter of web accessibility. Their set of guidelines has become the standard requirements of many official organisation and government web sites. Most of these guidelines deal with the visual aspects on computer use.

19.3 Computers as Supportive/Facilitating Tools

19.4 Accessibility on the web

Interface design, and especially the design of web interfaces has been a very important part of the accessibility research within the computer science discipline. There are a large number of books that deal with the W3C Consortium

The US

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27 Some admins even require you to change your passwords every three months, keeping track of the passwords you have already used.
19.5 Reflections

1. *Reflection*: Are there any simpler (i.e. easier for the user) solution to the problem of identification than using passwords and PIN-codes? In that case, why are they not used?

2. *Reflection*: Why is the power of computers not used more to reduce the complexity of a tool rather than actually making it more complex to use?
20. Evaluation of Universal Design

Every design project needs to be evaluated. Without evaluation there is no possibility that we can know whether a certain design is correct or not. But how can we evaluate both the practical usefulness and the user’s appreciation of the solution? And in the case of a mismatch, how can we solve this in the best possible way?

20.1 Good enough?

Questions like the ones in the beginning of this chapter have been around in most design sciences, including the design of software systems. The qualitative evaluation is most of the time made according to the requirements specifications that have been made in the initial phases of the project. The (software) engineers are then responsible for the specifications are sufficient and limited enough. A system that will be used to manage the pay-outs for a big company should therefore have a requirement which assumes that the system will be able to handle at least 2-3 times\(^2\) the current number of employees, in order to cope with a future expansion of the number of employees in the company.

Regardless of the topic of evaluation, a designer will always have to consider throwing away the design (or in the best case, modifying it) in case the evaluation turns out in the wrong direction. A design that does not satisfy the expectations of the intended target user group will not be accepted by the end users, despite that it may be both functional and designed according “to the book”. So, we have the phrase “satisfy the expectations” as a guiding rule. But what does it mean? Without any additional interpretation, it means that if the users have low expectations, it is easier to make a good product.

People who have an impairment, often consider themselves to be in a position of dependency by default. So, any technical equipment that solves a problem for them will be appreciated (if it provides the solution to a need). If you are initially not able to do something, and then you are introduced to some artefact that enables you to do this, then you might consider the change in ability to be a wonder, even if the supportive/facilitating tool is only rudimentary. In such a case we can often accept a tool that is only “good enough”. The tool might be much improved if some effort is put into

\(^2\) Normally, the base requirement is set to at least ten times or more of the expected need, in order to achieve sufficient safety margins.
it, but it is often left at an approximation, since “the users are satisfied with it”. But one of the key messages in this book is that “Good enough is not good enough”.

But what is it that we are measuring? In the next section we will have a quick look through the field of usability, and in a later section we will also look into some of the more difficult to measure areas, such as satisfaction and user experience.

20.2 Usability Evaluation

During evaluation time, the system is tested against the specified requirements. If any of the requirements are not met, the system needs to be adjusted, until the requirements are met. Also usability requirements have been specified, and are used to evaluate the usability aspects of a system. Usability is a property of the overall system: it is the quality of use in a context. According to the ISO 9241, part 11, usability is: the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use. This usability definition is one of the widely used definitions that is used by practitioners in HCI. The usability evaluation can be made according to a large number of criteria, such as the basic usability criteria:

Effectiveness – the accuracy and completeness with which users achieve specified goals;

Efficiency – the resources expended in relation to the accuracy and completeness with which users achieve goals; and

Satisfaction – the comfort and acceptability of use

Note that effectiveness does not have to be an absolute measure, checking the exact amount of time it takes to perform a certain activity. Perceived efficiency is in many cases more important to measure. Perceived effectiveness means the user feels whether he or she is effective or not. In a simplified version this can be stated as that it is important that the user does not have to wait for the computer, but that the computer might well wait for user decisions. Being actively doing something feels more efficient than waiting for the computer to do something, even if the latter takes less time on the clock.

Other common attributes that have been discussed as having a large influence on the notion of usability, although they are not included in the ISO definition are:
**Flexibility** – the extent to which the system can accommodate changes desired by the user beyond those first specified;

**Learnability** – the time and effort required to reach a specified level of use performance with the system (also known as ease of learning);

**Memorability** – the time and effort required to return to a specified level of use performance after a specified period away from the system; and

**Safety** – aspects of the system related to protecting the user from dangerous conditions and undesirable situations.

The broad view of usability as stated above, is in the ISO standard referred to as *quality of use* since it signifies the user’s general experience of using the system. Although a very important concept, usability is not given a very precise generally applicable definition, as it is related to the users, their goals and the contexts of use that are given by the intended usage.

However, there is still the problem of the “ability”-part of “use-ability”. Is it good enough to be usable, or is there anything more than usability, that will affect the user’s willingness to use it? Is “usable” the same thing as “good”? Usability is of course measurable, but how can we measure the “goodness”? What do we really mean by the term “good”?

We might state that “good” corresponds to a positive experience in the user, regardless whether it is a physical condition or a mental feeling inside. The former aspect is more of a physiological good, and even a "goodness" that can be measured by physiological means. The latter, on the other hand is definitely a more subjective measure that will have to be evaluated according to other methods. It could be the good feeling that comes during and after the use of a product, which leaves the user in a good mood afterwards. It could also be a reduction of stress or anger. Is this a sufficient measure to complement the ordinary notion of usability? Let us at least use this as a base definition that we can work from.

### 20.3 User Experience Measures

A further question is then how to measure the positive or negative experience one gets from a system? One of the most interesting statements about usability was made by prof. Ken Eason, when he stated that: “*the indicator of usability is whether the system is being used.*” Although it may seem to be a fairly useless definition, it still holds notions of that there are parts of usability that are not possible to measure directly in a standard way. If
people don’t like the system, it will not be used, regardless of how good we may think it is.

How to measure and interpret the degree of satisfaction a system gives to its users has already proven to be a difficult issue within traditional usability evaluation methods. Then how to measure all other aspects of subjective user experiences is obviously not easy.

Is it, for example, possible to measure how much a certain device adds to the feeling of stigmatisation, or of exposure? Such aspects have not been included in the various methods for usability design, and if it would be possible to measure this, it might make it possible to avoid many fairly obvious mistakes in the design of assistive and supportive tools.

One relatively new branch of evaluation has focused more on the experience of the user from using the product, rather than the properties of the product itself. The basic idea is to establish a design perspective that is centred along the general idea of how the individuals experience the final product. This has been launched under several different labels, for example User Experience Design (Hassenzahl & Traktinsky, 2006), Affective Design (Van Gorp & Adams, 2012), etc. However, central to all these fields is the notion of (individual) experience. But what do we mean by experience and how can we measure it?

According to ISO 9241-210 User Experience is a person’s perceptions and responses that result from the use or anticipated use of a product, system or service, and it includes all the users’ emotions, beliefs, preferences, perceptions, physical and psychological responses, behaviours and accomplishments that occur before, during and after use.

This definition becomes far wider than the usability definition listed in previous section. It also addresses such aspects of product design as branding and marketing as trademark. For example, the car manufacturer Volvo did make a large effort in creating a feeling of safety and reliability and accepted a related negative feeling of being a slightly boring car. Mercedes, on the other hand has branded itself to provide a feeling of luxury, together with a type of quality more associated with solid design. This can be felt through subtle signals, such as the designed (!) sound from the closing of a

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20 The term “experience” (Hassenzahl and Traktinsky 2006) has in HCI contexts often been used to denote the background that a user has and the degree of experience, e.g. from using computers. In this chapter it is the notion of experience as in (the emotional) experiencing of a phenomenon that is intended.
door in the car. Most companies feature some User Experience factors in the company brand.

User experience design is a larger concept than User interface, and follows the general idea from Interaction Design by removing the focus from the literal user interface, and focusing on the design of the interaction that in turn generates the (positive) experience.

**Interface Quality ➔ Interaction Quality ➔ User Experience Quality**

In this way the term user experience design covers a large spectrum of areas, from marketing and branding to visual design and usability. For this book it is also appropriate to add the experiences of *stigmatisation* and *exposure* to the previous ones. These are not explicitly mentioned in the ISO definition of user experience design. It is tempting to add the word “Universal” in front of the term User Experience Design.

The user experience is to a high degree context dependent. The actual experience is based on such phenomena as fashion, habits, technology advancement, culture and time frame. What looks very modern and technological today might feel very out-dated and even insecure after a number of years. We only have to think about the development within the car manufacturing area, where this can be clearly seen.

Sometimes it is stated that affective design is more focused on the human emotions, in that the systems are designed to address, evoke, relate to, avoid, or influence the user’s emotions. This relates more to the discussions on stigmatisation and exposure that have been presented earlier. Stigmatisation is to a large extent a matter of emotion. It might not be a true stigmatisation, albeit the person feels stigmatised. The same goes for exposure.

So how can we measure and evaluate user experience? There are many different dimensions along which it is possible to evaluate a user experience, depending on what kind of information we need, the number of subjects available, and the manner in which they are available.

1. Goal:
   1.1. Summative (Scoring)
   1.2. Formative (Suggesting areas and means for improvement)
2. Approach:
   2.1. Objective investigation
   2.2. Subjective investigation (we are aware of the subjectivity)
3. Experiment setup:
   3.1. Laboratory settings
   3.2. Field research
4. Data:
   4.1. Quantitative data collection
   4.2. Qualitative data collection
5. Granularity:
   5.1. Momentary Recollection
   5.2. Episodic recollection
   5.3. Overall recollection

Among the traditional methods used for gathering data there is of course also some candidates, such as interviews, questionnaires, observations, focus group studies, etc.

Here is a short example of how different questions can provide different perspectives on the user experience from a software system.

- Utility: Are the functions in the system useful and fit the purpose?
- Usability: Is it easy and efficient to get things done with the system?
- Aesthetics: Is the system visually attractive? Does it feel pleasurable in hand?
- Identification: Can I identify myself with the product?
- Exposure: Do I look good when using it?
- Stimulation: Does the system give me inspiration? Or “wow!” experiences?
- Value: Is the system important to me? What is its value for me? ²⁰

20.4 Reflections

1. Reflection: What is the difference between User Experience Evaluation and Usability Evaluation?
2. Reflection: How is it possible to fit User Xperience evaluation into a Universal Design context?

²⁰ In Universal design contexts, the question could also be rephrased as: Is the system important enough to me to warrant its place in my space? This is close to the issue of useworthiness, see footnote on page 20.
21. Future Perspectives

We now live in the twentieth century, and although we have a long way still to go, we have also come quite a long way on the path to inclusion. But how are we to proceed in order to build a non-excluding society in the future? It is close at hand to think that the most important issue is the idea of designing the technology in a proper way. That is of course important, and not to be underestimated.

However, as shown in previous chapters there is also the issue of inclusion, and the avoidance of stigmatisation. Part of this problem can be solved by improved design, with combined functional and aesthetic efforts (cf. the wheelchair in Figure 21-1) but it is probably just as important to address the issue of deviance in itself. Impairments are, and will probably for quite some time be a distinguishing factor in the society. A hope is that all kinds of impairments will eventually be regarded as we currently view short-sightedness, i.e. something which is more or less normal, and which does not impose any extra additional disabilities than the discomforts caused by the impairment itself. In fact, the use of glasses has even become a fashion.

Figure 21-1. It is possible to make even assistive technology with an aesthetic design. The Electroscooter is designed by Patrick Leyendecker, industrial designer at the University of Pforzheim, Germany. The image is used with kind permission of Patrick.
detail, where people sometimes use the frames with non-optic glass in them, just for aesthetics.

But there are, in my opinion two different parts to the future, one more short, covering the five to ten years to come, and a longer perspective, that looks into the far future of the society. I will try to discuss these two aspects in this chapter, and maybe in the end sketch a slightly utopic version of the society. The text in this chapter is reflecting my own personal view on where the design for non-exclusion needs to go, and might be more of a political statement, than something which is based on a scientific perspective.

21.1 The Close Future

In the close future, it is necessary to deal with the practical inclusion and non-exclusion of people with impairments. Nobody should be excluded from the society due to his or her personal properties. As we have seen this might in some cases be very difficult, but if we managed to get to the moon and back, we should be able to figure out more down to earth problems, such as a way to make a safe fire exit for parents with prams or people in wheelchairs in those cases where we can’t use the elevators.

Improved design can improve the self-image of the people using it. By adding aesthetic variations and choices, it becomes possible for people to select assistive technology that fits their personality to a higher degree. Through a better functional design it is possible for a person to better avoid critical situations, where they feel exposed and “in the way”. To some extent we have addressed these issues in previous chapters (especially in the chapter on Environment, Assistive, Supportive and Facilitating Technology on page 87), and we will focus somewhat more on the other aspects in this chapter.

21.2 The Longer Perspective

The other aspect, deviance, is more difficult to address, in that it involves a social inertia. It is difficult to change attitudes within large groups of people, especially when the environment encourages the preconceptions by providing additional disabling barriers. The larger the group, the more difficult is it normally to change the attitudes of the group (i.e. affect the culture).

People with impairments have for a long time been hidden by society. People with physical and cognitive impairments were simply not accepted as part of society. Unfortunately this is still true in some countries and
cultures. Furthermore, the Institutionalisation of people with impairments is a tragic part of our history, especially such as it can be seen in the classic movie, "One flew over the cuckoo’s nest" with Jack Nicholson. Once inside you don’t get out. You are permanently stigmatized as having a cognitive disorder. And the preconceptions about people with cognitive impairments are very difficult to counteract.

But also physical impairments will signal a deviance, and cause a stigmatization. In the long run I consider that a great challenge is to approach the problem of minimizing the unwanted exposure for people with different kinds of impairments.

One of the challenges in non-excluding design is to change the image of people with impairments. People with impairments are today given a certain image from how they are portrayed in photographs, adverts and not least in how we talk about them (or rather, in which contexts that they appear). (Pullin, 2009; Taylor, 2008)

21.3 Utopia?

We often have a tendency to prescribe to others how things should be. Many utopic visions describe a world without problems, and where people are able and healthy. But is that really a utopic world, when we try to achieve a society completely without impairments? At first glance this may seem like a good suggestion, but when we discuss this from a more considerate perspective there arise a large number of ethical considerations.

First, if we consider a world completely without impairments to be the best of alternatives; how do we then regards people who still have impairments. This would in fact be the same thing the situation in Figure 9-7, where the mainstreaming of what is “normal” causes lesser acceptance of deviance. This is not really a desirable development, since it runs the risk of moving more people away from being normal.

Second, there are already discussions about abortion due to the detection of impairments. This does already cause the cessation of the births of children with Down’s syndrome, and several other major impairments. This could even be a path towards the genetic modelling of “perfect” humans (whatever that be). From an ethical standpoint this is clearly a very difficult development, since on the other hand, the possibilities to save prematurely born children are increasing, and with this the natural selection of strong children. All in all, this development, in the end points to an attitude, where some individuals are less valued than others. Being accepted is to be without impairments.
But then, what is the alternative? Forcing people to bear children is probably not a viable way to proceed. Instead, the development should be directed towards a strive to make every life a qualitative life by providing the necessary tools and supportive means that will allow people to be equal parts of the society. Through the facilitation of a rich live for all people, we may include more and more people into the “Normality” of the spectrum, and thus lower the need felt to “remove” all unwanted individuals from the society.

In this perspective I would suggest another interpretation of a utopic society, namely, where all people have the same possibilities as far as is practically possible. First, the society needs to incorporate the concept of non-excluding design in its basic planning mechanisms. Environments, technology needs to be designed with accessibility as the fundamental construction principle.

21.4 Reflections

1. Reflection: How much is possible to achieve only by design? What are problems that cannot be changed merely by redesigning the artifact?

2. Reflection: How far towards the “utopic” society do you think it is possible to get? What is possible, and what is not?
22. Concluding Remarks

The end is near. Not of the world, hopefully, but of this book. This is the final chapter, and all that remains is the strange stuff that always comes after the book. This chapter has been named "Conclusion". But it is difficult to make a conclusion of a complete book, even if we use a whole chapter about it. But hopefully you have found some refreshing water to drink in this book, and of course, I hope that you have really quenched some of your thirst for knowledge in this area. However, you are presumably still neither an expert nor an all-knowing guru in the field. This book is a starting point for further studies, and maybe also for the gathering of the necessary experience to do good design, good non-excluding design.

You might wonder why I would start a chapter by putting a mathematical equation\(^{31}\) at the beginning of the final chapter? Well, I guess I will have to blame it on my technical background. I have a basic education in computer science, and maybe it should appear somewhere at least. But there is a more real reason in that I think it is one of the most beautiful examples on what I would call a joint harmony. And essentially you don’t even have to understand the mathematics in order to see the beauty, if you allow yourself just to look at the equation a little closer. I will explain why I think this is beautiful even from a human perspective. In the equation there are five numbers, which are all fundamentally different from each other:

- \(\pi\) is a basic number that appears just about everywhere in mathematics, but maybe most importantly in definitions of perfect circles, i.e. within the area of geometry. It is also a transcendental number, which essentially means that the decimals will go on forever, and there is no (visible) pattern in the number either, so it is impossible to calculate the exact value.
- \(e\) is the base of the natural logarithm, which is also one of the fundamental numbers in mathematics, i.e. within the area of mathematical analysis. It is also a transcendental number.
- \(i\) is an imaginary number, essentially a number that does not exist (but of course it does). It is defined as \(\sqrt{-1}\) and was for a long time

\[e^{\pi i} + 1 = 0\]

Euler’s identity

\(^{31}\) The equation is called Euler's identity, after the mathematician Leonard Euler, who had many ideas that concerned the number \(e\), the natural logarithm, and many other important mathematical findings.
regarded as a number that would make no sense. It is very important as a part of applied mathematics, and is a so-called complex number.

- 1 is the simplest number there is. It is also the basic building block in any mathematic system, i.e. within the area of arithmetic. Everything starts with 1.

- 0 is actually … nothing at all (!). The concept of nothing is quite difficult to understand, which is why the number “0” is a relatively late addition to mathematics. The number “1” seems to be simpler to understand than the number “0.”

So, we have one transcendent, fundamental number, raised to the power of another transcendent, very fundamental number times a number that does not exist. To this we add the simplest number there is, and end up with … NOTHING. This is really a marvellous combination of strange numbers. And the great thing is that all these numbers are not only able to co-operate. They are all necessary; even the simplest number possible is needed. This is to me a very important thought; we need every part, from the most complex to the simplest, in order to get a good balance. No item is useless or unnecessary. They all belong.

And exactly this is one of the central thoughts that underlie my ambition to teach this subject, and to write this book. We are all needed in order to create a human world. We have to work together, just as the numbers in the equation do, in order to build a non-excluding society. We cannot work as isolated units. We are a society that consists of individuals, and all individuals are different. But all are needed! Only that way lays the good path forward. It is not the broad and well-prepared road that leads onwards, but a smaller but, in the long run, also probably a more beautiful road that takes small winds now and then, showing us both traps and shortcuts to a better society. Thus, designing proper tools is a very important process. But equally important, at least as far as I believe is that we start on the way of changing society and the public opinion towards impairments and disabilities. Only that way can the non-exclusion exist as a natural part of the society structure.

So what is my personal advice for continuing on this path towards a non-excluding society? Well, there are essentially a number of things that I consider important in this area of research and development.

First, we have to start with ourselves. By considering our own preconceptions and ideas we might filter out those ideas that are driving us in the wrong directions. It is not possible to avoid having preconceptions. Even the most open-minded person will probably find him- or herself
having preconceived ideas about other people or groups of people. The crucial point is what we make of them.

If we accept that we have the preconceived ideas that we do have, then we are free to act according to our conscience. We can choose to fight or ignore the preconceptions, or we can just as easily decide to just give in to having them (which of course is not a good strategy).

Who is different?
Who is normal?
Are you?
Am I?

Why should we care?
As long as we are humans, that should be enough!
Apart from the preconceptions we have ourselves, I think it is also important to look at how it is possible to change the large number of preconceptions in the society. The preconceptions are very harsh on the people who are the subjects, and the misunderstandings will cause a large amount of problems in society, unless we start working in more accepting, non-excluding manner with the design and shaping of the future. How can we support this?

In my mind, it is important to be visible, but not only as a representative for the disabled, but also providing good examples of acceptance and inclusion. By pointing out solutions, and showing that multitude is better than solitude, also when it comes to disabilities.

So, which road do you want to take? The broad smooth road forward which continues to foster situations such as in Figure 22.2 or the winding narrow road that leads to the beautiful countryside, where we all can enjoy life as it was meant to be?

22.1 Reflections

1. **Reflection:** Did you understand the mathematic formula in the beginning of this chapter? What was your feeling when you saw it? Could you imagine that this would have any other application in terms of accessibility?
Bibliography


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Appendices
Appendix I  Exercises

The exercises are slightly larger than the small reflections in each chapter. The intention is to try to anchor some of the ideas in this book into small projects. This allows you to reiterate the information within your head, and through this get a deeper knowledge about the field.

Some of the exercises are also made so that you can make a difference by pointing out the important findings that you will undoubtedly make. One of the assignments for this course was essentially what is presented in the first section of this chapter, namely to find some badly designed artefact in the surroundings. All students came up with very interesting findings, that could well have made it into the strategic city planning document. There is definitely a need for universal design evaluation.

I.1  Bad Design: Observe - Describe - Analyse

This exercise is intended to increase the awareness of where Design for All, Universal, and/or Inclusive Design has not been implemented, or not performed as it should.

I.1.1  Description

Go to some public place, a shopping mall, the train station, or similar. Your task is to find a major, preferably non-obvious, problem for a person who has some kind of impairment. Alternatively, you can look for a solution that has major positive implications for a person with some kind of impairment.

Make a “report” in which you should provide a sensible discussion on the cause of the problem, the reason why it is there (and why the problem has not been removed). Also try to describe a relevant way of avoiding this problem, or suggest a design some supportive tool for the person with the impairment.

The reason for you to actually make a report is that you will have to formulate the problem more precisely, and in this process think through the implications of the problem in more detail. You might also want to suggest improvements to the detected problem, and then a report is a good persuasion tool.
I.1.2 Comment

To a more complex problem it might seem difficult to find a solution. However, it might be that there are alternatives that are less obvious. Such solutions often need to be boosted by creative exercises and alternative thinking, which is not always easy to master.

I.2 Good Design: Observe - Describe - Analyse

This exercise is intended to increase the awareness of successful designs, where someone has considered a large number of individual users. It also addresses the issue of advantages and disadvantages in design solutions.

I.1.3 Description

Go to some public place, a shopping mall, the train station, or similar. Your task is to look for a solution to an accessibility problem that has major positive implications for a person with some kind of impairment.

Make a “report” in which you should provide an analysis of the problem and its solution, such as the generality of the solution, the estimated costs for implementing the solution as a general strategy, and possible disadvantages for other groups of people. If there are any such possibilities you may also consider whether the solution could be improved further.

I.1.4 Comment

It is important to recognize that even "brilliant" solutions may have negative consequences. There are few solutions that have only positive implications (although there are some examples of this).

I.3 Design for Elderly

This exercise is intended to give an insight into the problem of designing for old people. Designing for old people is in some way the essence of Universal Design, since the group of elderly people has the only common factor that the probability of having a certain impairment is higher within this group than in the general population.

I.1.5 Description

Discuss how to design a flat in a home for Elderly people, so that it can support an old person from an early stage to a late age (with possible
impairments). You should not only consider the immediate adjustments that directly concern the impairment but also more general consequences, such as facilities for communication and other support functions.

Make a report with a proposal, which incorporates as many aspects of the problems that you can think of. The various details should be clearly motivated. The report should be somewhere between 5 - 10 pages long (the exact number of pages is of course of lesser importance than the content).

I.1.6 Comment

The general idea is not to find a large number of aspects per se, but rather to see the overall picture created by these aspects together. It is therefore more important to understand the interaction or interference between the problems than a large number of disparate problems.
Appendix II  Glossary

Alexia – Alexia is acquired dyslexia, occurring, for example, after a head injury or a stroke. It is also called “Word blindness”, “Text blindness” or ”Visual aphasia”...........................

Assistive Technology – A technology that is developed in order to assist a person with an impairment in their daily life. It can be many different artifacts, such as a wheel chair, hoover cane, forceps with a long handle, etc.

Design – A process in which an artifact is being created or shaped. ........ 1

Disability – A disability occurs when an impairment has an excluding effect on a person. An impairment is related to the individual, whereas a disability is related to the context. ................................................................. 31

Handicap – the term “handicap” is obsolete and should not be used. .... 31

Hoover cane – The classical white cane, which was invented by Dr. Richard Hoover, as a tool for people with visual impairments, to allow them to orient themselves in the environment. The cane else serves as a signal to people around that the person has a visual impairment.

ICF – International Classification of Functioning, Disability and Health. The ICF is WHO’s framework for measuring health and disability at both individual and population levels. ..............................................

Impairment – Impairment is a bodily property of a person that has some negative implication on the individual’s life. An impairment is related to the individual, whereas a disability is related to the context. ...................... 31

Non-excluding design – A view on design that sets out to exclude as few people as possible. In this approach it is recognized that a design always has good and bad consequences, which have to be included in the considerations................................................................. 13

Paraplegia – Paraplegia is a condition with a partial or total inability to use the legs, but where the arms are not affected. This condition is the result of an injury or illness. A related term is quadriplegia where all four limbs are affected by the damage. ................................................................. 35
Phocomelia: Phocomelia is an abnormality of development in which the upper part of an arm or leg is missing so the hands or feet are attached to the body like stumps; rare condition that results from taking thalidomide during pregnancy.

Phosphenes: A sensation of light caused by excitation of the retina by mechanical or electrical means rather than by light, as when the eyeballs are pressed through closed lids.

Quadriplegia: Quadriplegia (or tetraplegia) is a condition that normally results from a spine injury in the neck, e.g., after diving accidents, or horse riding accidents. A quadriplegic condition means that all four limbs are affected by the damage. A related term is paraplegia, which means a condition that only affects the legs, but not the arms.

Section 508: The section in the United States Rehabilitation Act, where it is explicitly stated that all the US government websites should be accessible to everyone, in spite of individual handicaps (sic!). (Cunningham 2012)

Spina bifida: (Latin: “split spine”) is a developmental congenital disorder caused by the incomplete closing of the embryonic neural tube. Some vertebrae overlying the spinal cord are not fully formed and remain unfused and open. If the opening is large enough, this allows a portion of the spinal cord to protrude through the opening in the bones. There may or may not be a fluid-filled sac surrounding the spinal cord.

Visual acuity: A person’s visual acuity is an indication of the clarity or clearness of one’s vision. It is a measurement of how well a person sees. The word acuity comes from the Latin acuitas, which means sharpness. The reason that the number 6 is used in visual acuity measurements is because the standard length of an eye exam room (that is, the distance from the patient to the acuity chart) is about 6 meters.
Non-Excluding Design
Appendix III  Comments on some Reflections

In this chapter I have put together my personal view on some of the reflections in the book. Not all reflections are about knowledge, and some are not providing any direct answers, but might enhance your thinking by adding some additional thoughts. I make no claim for this being anything like the truth, but merely my own reflections on the topics. I hope you enjoy them anyway.

I.1 Section 1.5 Introduction

Reflection: What picture can you see inside yourself when you hear the words “Impairment”, “Disability”, and “Paralysis” etc.? Which are my own “preconceptions” about a person with certain impairment?

Are the pictures you get mainly positive or negative? Why do you think this is the case? Can you distinguish the "concept" from the person affected? Are there any feelings of pity?

Reflection: Consider the message in Figure 1-2. What is the message now again? Can you think of any real world example that can be applied to the message in the figure?

Why would you make a swing chair in the shape of a wheel chair? Could it also be a good thing, for example, in making the wheel chair a more normal artefact among children, thus widening the scope of normality (see also section 9.3 about deviations).

I.2 Section 2.5 Non-Excluding Design

Reflection: Is it possible to design a pair of scissors that can be used just as well with the left as with the right hand? And what about knives? Are they also left- and right-handed?

The difficulty with scissors is that it is an asymmetric design to start with. The legs of the scissors have to cross and this is very difficult to circumvent. The only way is to make a construction that is so sturdy as not to bend when pressure is applied, but this is still not more than half the solution, because the design of the handles is also often asymmetric, in order to give a better grip (for the right hand).
Knives (especially kitchen knives) may also be left- or right-handed in the way that the knife-edge is sharpened in a slightly different manner on the right and the left side. This is in order for the knife to “push” the thinner slice away from the main part. There is a certain type of knife that is called “ham- and salmon-knife” which is used to cut very thin slices. The edge of this knife is very sharp and symmetrically cut, so that the edge will not push itself into the meat (and thus make uneven slices).

Reflection: Consider the statement on the elevator sign in Figure 2-5. What is the idea purported by that statement? Why are some people excluded from using the elevator and others not?

Apparently, there has not been any consideration about people who are unable to use stairs in the same way as agile people. This of course also goes for parents with prams, old people using rollators etc. The main idea is that they have been forgotten, or that they are expendable.

Reflection: If we change it to the wording as in the example given by my colleague, what is the change in the meaning? Is it a better idea?

Why should elevators be avoided in case of fire? Is this problem different for people in wheel chairs than for people who can walk?

I.3 Section 3.5 History and Politics of Disability

Reflection: How can we avoid doing “the same mistake” over and over again?

How are we regulating other aspects of society? Traffic rules? Could we build the knowledge into similar rules when it comes to impairments? Consider the issue of using Design Patterns.

I.4 Section 4.7 Disabilities and Impairments

Reflection: Is the situation shown in Figure 4-3 only an accessibility problem, or is it possible to see it from a different perspective?

The labelling on the tap is definitely bad also from a general point of view. The indicators are very small, and are also contradictory in the general sense. What does the icon in the middle of the tap signify? Does it do a god job?
I.5 Section 6.13 Cognitive Impairments

**Reflection:** Why do cognitive disabilities often make people feeling less comfortable than physical disabilities? Is it possible to avoid this additional stigmatization?

*First, imagine what it would feel like to not have one of your arms. Then close your eyes and imagine what it would be like not being able to see.*

*Now imagine that you cannot understand how to reach something in a high cupboard, or that you always forget the names of or don’t recognize your children/parents when you see them. How did you feel about those experiments? Which one was most difficult to imagine? Could that be a clue to the problem?*

I.6 Section 7.3 Perceptual impairments

**Reflection:** In which cases might it be very important to be able to see colours? And what can we do to not exclude people who are colour-blind?

*In which situations is it necessary (crucial) to be able to see colours? Are there any situations where it is not possible to aid a person who is colour-blind?*

I.7 Section 9.6 Stigmatisation

**Reflection:** How can we achieve a perspective on normality, such that we minimise the number of people, being regarded as deviant?

*The first problem has to do with the definition of normality. Maybe one way to proceed is to try to increase the visibility of people with impairment in the society. By seeing more people who are "deviant", these will become part of the normalcy, thus widening the scope of normality further.*

*Also, through good design, we might make it more attractive for people to use their supportive tools publicly without feeling stigmatized. This will also make the "deviance" more normal. This has been the case when people were more or less dismissed from mental institutions, to live under normal conditions. Even though this caused many problems for*
the individuals, they started to be seen around, thus being more and more accepted.

**Reflection:** Recently, a Swedish politician claimed that it was bad that the Swedish TV Corporation did not have any employed person in a wheelchair, appearing on the screen. Was this a good or bad discussion?

*It might at first sight seem to be a good thing to say for a politician, who wants to make a popular statement. There are, however, several less obvious issues in connection with this that need to be discussed:*

1. **Is the impairment a "requirement" for the reporter, or is he or she selected due to work skill?** The issue of using quotas to achieve a more equal balance between groups is very difficult, per se, and especially so in cases like this, where an impairment becomes a “demanded skill” for employment.

2. **Why should we see the wheelchair in the TV?** Most news anchors, for instance already sit behind a table. Have you seen the legs of the news anchors (or reporters, for that part) that are on the TV today?

3. **Is a visible impairment "better" than an invisible one?** One very good reporter, who actually reacted to the comment by the politicians, wrote that she has been very active in these issues, during her 25 years as reporter, but that she has never made a thing of having a hearing impairment. So the politician was wrong, there are people with impairments on TV. (Actually it turned out that one of the program leaders, for a series of children’s programs, *is* using a wheelchair, so she was even wrong in that respect.).

*The issue of visibility and using quotas is a difficult issue, and it is very easy to fall in the trap of being politically correct without thinking in advance. Believing that you understand a situation might sometimes even be worse than admitting that you do not, and acting from a more humble perspective.*

**Reflection:** Is there a difference in how the self-image influences a person, between an acquired and an inborn impairment? Think about how people think about what is normal and what is not.

*Might a person with an inborn impairment consider his or her condition as the normality? What about such issues such as pride, sadness and*
feelings of devastation? Will they be different depending on whether the impairment is inborn or acquired?

I.8 Section 13.4 Good and Bad Design Examples

Reflection: Can you see any problems with the solution using Braille, as shown in Figure 12-3)?

How will a person who is blind know where to find the Braille-text? How are we to inform him or her about it? More generally phrased: How can we help a blind person to find the information he or she needs to use a certain artefact or architectural structure? Presenting information in different ways is good, as long as it is possible to find it.

How could we support a blind person in finding this information? Using sound? What are the consequences?

I.9 Section 18.5 Ethical Aspects on Universal Design

Reflection: How can we avoid the “saviour” syndrome when we work with disability issues?

What is the problem with the "saviour syndrome"? Might it not be a question about attitudes towards the informants? We might still do good thinks for people with impairments, as long as this does not involve any pitying or feeling sorry for. Or are there other things that can be problematic?

Reflection: How can we ensure ethical thinking in Disability Research and Universal Design? And what should that ethical thinking be?

Whose ethics are we talking about? Could there be several ethics that are involved in this problem. Maybe the universal design thinking itself is an ethic perspective. If so, what does it say?

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33 It is always important to actively consider all possible consequences when new design suggestions are made. If we do not criticise the solutions we suggest, it is quite likely that new problems are introduced (maybe also for new categories of people).
I.10 Section 20.4 User Experience Evaluation

Reflection: What is the difference between User Experience Evaluation and Usability Evaluation?

Which is the bigger concept? Does UX incorporate UE or vice versa?

I.11 Section 21.4 Future Perspectives

Reflection: How far towards the “utopic” society do you think it is possible to get? What is possible, and what is not?

This is a tricky question. What would it really mean to have the kind of society that is described in section 21.3? How much would cost, and how long time would it take? Are there some things that are extra difficult to manage?

I.12 Section 22.1 Concluding remarks

Reflection: Did you understand the mathematic formula in the beginning of this chapter? What was your feeling when you saw it? Could you imagine that this would have any other application in terms of accessibility?

Mathematics is also a language. If you don’t understand the mathematics, you are automatically excluded from the group of people who do understand it. If you are skilled in mathematics, you have the possibility to be included, since you don’t have to learn the language in order to understand. Inclusion and exclusion are so many different things, and it is very easy to forget groups if you take the skills for granted.
Appendix IV Subject and Author Index

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