FACE Disabled People, Technology and Internet

Anderberg, Peter

2006

Citation for published version (APA):
Anderberg, P. (2006). *FACE Disabled People, Technology and Internet*. [Doctoral Thesis (monograph), Certec - Rehabilitation Engineering and Design]. Certec, Lund University.

Total number of authors:
1

DOCTORIAL THESIS CERTEC, LTH NUMMER 1:2006

Peter Anderberg

FACE

Disabled People, Technology and Internet

Certec

Division of Rehabilitation Engineering Research
Department of Design Sciences
Lund University

Peter Anderberg

FACE

Disabled People, Technology and Internet

Acknowledgements

If I had dared, this section would have been entitled “Musical Intro” because nowhere else have I commented on all the music that helped me finish this thesis. However, I will stay with the more conventional “Acknowledgements”. But had I gone with the first choice, I would have played “The Long And Winding Road”, “Eight Days A Week”, “I’ve Just Seen A Face” and perhaps “Not A Second Time” to get people in the right mood for this thesis.

And then, I would have dedicated “With A Little Help From My Friends” to all my colleagues at Certec, colleagues at the Independent Living Institute, colleagues at the Swedish Knowledge Foundation’s national virtual research school, LearnIt, and all the people on Tenerife and in Sweden who have given me such invaluable support and insights during this work.

To my supervisor and very good friend, Professor Bodil Jönsson, I would have requested “Carry That Weight”, “You Know What To Do” and “Don’t Ever Change”.

To my assistant supervisor, Professor Berth Danermark, I would have played “Tell Me What You See” and “Fixing A Hole”.

To Miles Goldstick and Eileen Deaner who have helped me with my unanswered love to the English language, I would have played “The Word” and “Ob-La-Di, Ob-La-Da”. To Kate Hellqvist for capturing my thoughts and putting colour to them, “Thank You Girl”.

To my beloved wife I would have crooned “I Want You” and to my children “All My Loving” and then together with my lovely big family I would have bellowed “Strawberry Fields Forever”.

I would have finished with “Tomorrow Never Knows” and that would have been it!

Peter Anderberg
Lund, August 2006

Summary

This thesis is based on the Internet experiences of people with significant mobility/physical impairments who are proficient and experienced computer users in their computer world but have limitations in mobility that severely restrict their functioning in the physical world. The Internet *functioning* of this group is analysed by means of the factors *attitude, control* and *enabling*, with the main focus on what is achievable when all access problems such as unadapted interfaces, beginners' difficulties and the digital divide are overcome. If the virtual world is fully available but the real world is not – what are the effects on learning, self image, communities of practice, sense of coherence, power and control? What are the effects on peer-to-peer learning and co-operation? Independent living concepts and theories manifest themselves throughout the thesis, most obviously, perhaps, in the selection of issues that are studied and in the perspectives.

The theoretical background and concepts are those of disability studies, with a social model and independent living perspective, and with strong influences from rehabilitation engineering and design.

Throughout the thesis elaborations and clarifications of the possibilities of interplay and co-existence between rehabilitation engineering and design and disability studies are made. Different aspects of function design and technology are examined from an expanded view on functioning, where technology is put in an individual and social context with the **FACE** (**F**unction – **A**ttitude, **C**ontrol, **E**nabling) tool.

KEY WORDS

Rehabilitation Engineering, Functioning, Internet, Social Model, Disability Studies, Independent Living, Design, FACE

Purpose

Based on the personal actions and descriptions of people with mobility/physical disabilities, the purpose of the research presented in this thesis is to identify, describe and analyse functional opportunities on the Internet for accustomed users with considerable physical impairments. In addition, the goal is to illustrate, discuss and develop the interactive potential that exists between the field of rehabilitation engineering and design and that of disability studies.

Contents

Appendices

Introduction

The research presented in this thesis emerges from the situation for people with significant mobility/physical disabilities vis-à-vis the Internet at the beginning of the 21st century. It deals with function and power, technology, relationships and the potential for personal development.

My Own Background

"Disability is not a 'brave struggle' or 'courage in the face of adversity'… disability is an art. It's an ingenious way to live."
Neil Marcus

My ability to function physically has gradually diminished over the last 25 years as the result of a muscle disease. I have used wheelchairs for the last fifteen years, both electric and manual, and have personal assistance a good part of the day and night to help me with activities of daily living. I graduated from university with a Master's of Engineering in 1997 and was awarded a Licentiate in Engineering in 1999.

ANDREAS, LINUS & I

Andreas is seven years old and Linus is five. They love to play hide and seek with me. It starts with them running far away and with me counting slowly to 10 before I go and look for them. They usually take the path down to the brook, over the bridge and towards the waterfalls, so I have a good idea of where I should start looking. When they are hiding, they keep an eye on me so they know where I am heading. Of late, they have learnt to take the path that goes up the hill and towards the long wall, the one that resembles the Great Wall of China, and that runs from the valley floor to the top of the mountain. It is harder to find them there, but they usually give me a clue to get me on the right track. As I approach, they always sneak away and I have to chase after them to their great amusement. They love it when we race over the fields and into the woods.

When I have almost caught up to them, they usually take a leap and jump straight up in the air. When they learnt to fly like this, they realized that it was another dimension they could utilize to get away from me. The feeling of speed is glorious as we glide low over the great wall. I love to fly there with Andreas and Linus in my lap, holding on to them and cuddling them as we fall headlong towards the wall at full speed.

Sometimes I take them with me to town and we look at all the strange things and houses that are there. They ask about everything in the way that children do, and I explain as best I can all that we encounter. Sometimes we hike in Yellowstone or in a world full of snow, or run around among the ruins of ancient Greece. We have even visited Mars a number of times as well as examined the spaceship.

In other words, Andreas and Linus usually sit on my lap in the wheelchair when we explore and play in all the different environments that can be found in the 3D virtual reality universe of *Active Worlds*. I have my computer on the desk right in front of me and Andreas has his on the left, while Linus has his on the right. We sit together in the physical world and play together in the virtual one. Just me and my kids. My wife isn't there, no personal assistants, no one else but a father and his kids, running around and having fun.

I spend a lot of time with my children. We draw, build with Lego bricks, read books and lots of other things. But in many of the games and activities, I take on the role of a passive spectator. That I can play with my children in the way I have just described is because for a long time I have been using computers as well as Internet and virtual environments to compensate and eliminate the functional limitations that arise in a variety of situations.

BEING AN ENGINEER

I am an engineer and technician and have, in some sense, always been that. As long as I can remember, I have taken things apart to see how they worked and sometimes, though not as often, even succeeded in putting them back together again. As a seven year old, my paternal grandfather shared his interest in electronics with me by allowing me to unscrew and play with radios, tape recorders, transformers and such gadgets that today I would consider highly dangerous for my own children to play with. In those days, apparently, children were not as fragile.

My grandfather mentioned sometime later on that there were two types of engineers: those who liked to take apart things that already existed and those who liked to build new gadgets that worked. The best, according to grandpa, were those who had a little of both in them. I took this as a sort of reprimand because I was mostly interested in taking things apart, seeing how they worked and what they looked like inside, removing or altering something, and then screwing them back together to see if the results were something different and if they still worked. If they did not, that was just as interesting, because that meant you had found something that was important. I was quite interested in how things appeared on the surface. When I built my first electric guitar, it was not so that I could play it – I knew it would never really work – but because it was so cool and because it was beautiful. My boat was not primarily for sailing, but to alter or rebuild and because it looked so good. Functionality, to the degree it was achieved, was often a pleasant and unexpected bonus.

This kind of information may appear to be a bit odd in a thesis focused on function and functioning, but I have included it because I believe it has significance in a least two areas. Firstly, it is a characteristic that has been a part of me all my life. I love technology and electronics and I am not satisfied just knowing that it works; I really want to know how and why. I think that the appearance of objects matters enormously, and that artefacts talk strongly to me by virtue of their appearance and their context. I have carried this with me into the areas where I have explored the interaction between technology and disabled people as a central characteristic in technology and design.

Secondly, it is because on many occasions I actually think that technology that does not work is just as interesting as technology that does. This means that I have a high tolerance for error and like to repeatedly try in different ways to see if I can get something to function. I have never grown tired of a computer that does not do what I want it to, but look for other ways to solve the problem instead. I have patience with “wilful” computers and do not give up if they do not work the first one-hundred times. I try to find new ways through or around the difficulty. This is an attribute I have discovered among several of the experienced Internet users with disabilities that I have interviewed. Their Internet usage is not uncomplicated and they simply have to solve the problems that arise from time to time. But they do this because of the benefits that are waiting when a solution is found.

MY DISABILITY AND MY INTERNET EXPERIENCE

A disability is not an inherent characteristic of a person but something that is situated and contextual. A disability arises in specific situations and settings when an impairment results in a person’s inability to carry out a desired, specific action in a desired manner. “Impairment” and “disability” are both relative concepts, but they relate to different things and the one does not necessarily follow the progression of the other – not even to the extent that one increases when the other does. In my case, my impairment has increased over the last ten years, whereas my disabilities have decreased over the same period. Much if not most of my increase in function can be attributed to computers and Internet. I have worked, communicated, searched, participated, been there, played and learnt.

Originally, it was inconceivable for me to consider doing research on the disability problem complex that occupies such a great deal of my life. Gradually, I realized that it was actually my own physical impairment and my own Internet experience that provide me with unique opportunities to formulate relevant hypotheses and see the connections that would otherwise require years of research to even begin to imagine. Undoubtedly, researchers without physical impairments and without Internet experience can contribute in these contexts, but if you are going to take the individual Internet user with a disability as your starting point, it makes a considerable difference to be a member of the group yourself.

The Papers

This thesis is based on the following papers, the complete versions of which are appended. The papers are referred to as Papers I, II, III, and IV throughout the text.

All four papers deal with function and design of functioning in different ways. Two papers (I & II) discuss empowerment through the importance of involving disabled users in the design process and how to go about doing so.

The other two (III & IV) discuss the direct consequences of technology usage: they deal with the empowerment afforded through the use of Internet.

PAPER I: MAKING BOTH ENDS MEET

The purpose of this article was to launch a new conceptual design tool, FACE, in rehabilitation engineering, technology and disability studies, useful both as guidance and help for disabled people in analysing their own functional aids, and as inspiration and meta-guidelines for designers. It is non-discriminating and classification free and differs from a mere classification system such as the *International Classification of Functioning* (ICF) (WHO, 2001). The origin of the tool is twofold: experiences of my own disability, and research in rehabilitation engineering and disability studies.

The resulting FACE tool combines three different factors that influence Functioning, Attitude, Control and Enabling. This makes it possible to analyse functional assistance in a new way, taking into account more factors than mere practical or mechanistic functioning.

The paper was originally published in *Disability Studies Quarterly* (special edition on technology and disability studies), Summer 2005, Volume 25, No. 3. It is published here with the kind permission of *Disability Studies Quarterly*, Society for Disability Studies, www.dsq-sds.org.

PAPER II: ETHICS IN THE MAKING

The purpose of this article is to analyse how general ethical guidelines are challenged by situated ethics in a design context. This paper illustrates how values are present not only in what is done, but also in how it is done. Neither “the medical model” with its focus on individual impairments and interventions, nor “the social model” with its focus on social and ideological analysis can alone provide firm ground for ethical considerations with repect to the experiences of the people affected by the design.

It is the whole chain of design and technology as well as the whole chain of societal resources that are relevant for how ethics are experienced: from the initial inspiration and design decision through the design process to actual usage where human everyday life is influenced by the design results. Ethical research perspectives are discussed in the context of international codes, charters and declarations of human rights as well as in the context of situated ethics and particular desiderata, with an emphasis on the latter.

The paper was originally published in *Design Philosophy Papers*, No. 4, 2005. It is published here with the kind permission of *Design Philosophy Papers*, www.desphilosophy.com.

PAPER III: BEING THERE

This paper examines the use of the Internet as experienced by people with significant mobility/physical impairments who are accomplished computer and internet users. The study is based on interviews and focuses on computer usage in everyday action and interaction.

The results show that in many cases, the new possibilities that the computer and Internet offer have meant not only important improvements in quality of life but first time occurrences of great personal significance.

The analysis is phenomenographic, resulting in main categories and subcategories, illustrated primarily through direct quotations. The three main categories are: independence, communication and learning.

The paper was originally published in *Disability & Society*, Vol. 20, No. 7, December 2005, pp. 719–733. It is published here with the kind permission of Taylor and Francis, http://www.tandf.co.uk.

PAPER IV:
PEER ASSISTANCE WITH PERSONAL ASSISTANCE

This paper describes and analyses a community of disabled people in Sweden that uses an online forum to discuss personal assistance issues. The forum is a community of practice (CoP) that has its roots in everyday living with personal assistance. The contributions to the forum were studied over a four-and-a-half year period including a total of 2,755 postings from 146 persons. The levels of the CoP's learning system were analysed using the **FACE** tool, which examines **F**unction based on **A**ttitude, **C**ontrol and **E**nabling. The results indicate that a learning system within a CoP that makes it possible for disabled people to complement, confront and counterbalance the influences of existing learning systems, theories and methods of the professionals in the area.

The paper has been submitted for publication in *Disability & Society*, 2006.

Research persons, methods and procedures

The research that is presented here was conducted over a period of five years from 2001 to 2006. The mental process leading up to this actually started, though, around 1995 when I, as a "quite disabled" person, resumed the engineering studies that I had interrupted when I was still "quite able-bodied" but found studying too difficult due to my disabilities. Previous examples of my reflections and contributions on the potential of Internet for disabled people can be found in the following list of publications. All of them are available at http://www.certec.lth.se/publicat.asp.

Year	Author/s	Title	Type
1999	Anderberg, P.	Internet Learning for All	Licentiate thesis
1998	Anderberg, P. Falkvall, J. Jönsson, B.	Inside the Internet	Report
1998	Anderberg, P. Magnusson, C.	Learning from Learning	Article
1998	Anderberg, P. Jönsson, B.	To Make the Strange Familiar	Article
1997	Jönsson, B. Anderberg, P. Eftring, H. Falkvall, J.	IT, Disabilities, Research and the Process of Learning	Article
1996	Jönsson, B. Neveryd, H. Eftring, H. Anderberg, P.	Creating a University for Everyone	Article

Research persons

There are several disabled people who have directly contributed to my work during the five years of active research (see Table 1). In the interview study, a total of 22 people were interviewed, 8 women and 14 men, ranging in age from 25 to 60. In the forum study, 146 persons have contributed with postings. There is also a background group of a large number of other people with mobility/physical disabilities that I have met internationally over the years, particularly on Tenerife and in Sweden. I have discussed with them possibilities and problems involving Internet and technology. With a handful of them, I have discussed in-depth issues related to this thesis.

To this, as already mentioned, I can add myself as an ongoing, complementary group of one since I have been unable to avoid coming up with ideas in my daily life based on personal experiences or of personally recalling every new trend, hypothesis or connection that has arisen for the groups of research persons.

Number of research persons	Presented in	Type of study	Duration
22 persons	Being There, *Journal of Disability and Society* (Anderberg, 2005) Paper III	Phenomeno-graphic Interview study	Nov. 2002 to June 2003
7 persons	WWW. Welcoming. Wide. World. Certec Report (Anderberg, 2006b)	Case study, interviews	Nov. 2002 to June 2003
146 persons, participants in a web forum on personal assistance	Peer Assistance with Personal Assistance *Journal of Disability and Society* (Anderberg, 2006a) Paper IV	Analysis of a web forum	Oct. 2001 to March 2006

Table 1. Scope of the studies and the articles in which they are presented.

Methods and procedures

The processes and the results are described in the published articles and I do not intend to repeat that here. I would, however, like to comment on my own engineering background and its influence on the practical aspects of the research.

For the most part, I have utilized databases and my own written routines and programs to manage the large flow of data in order to find and retrieve specific information, be able to structure it and use it as mental support, and for testing different possibilities. To that can be added the disability perspective: Since my arm and neck functions do not allow for repeated movements or long shifts, one ambition has been to automate repetitive activities as much as possible and let the computer do that kind of work, thus minimizing the number of keystrokes in each task.

Study	Description of computer support
Interview studies	All the interviews were carried out in digital sound format directly on the computer to enable a simple and entirely computer-based processing of the transcriptions and text. Coded text units could be directly entered into the database using the voice recognition program, *Dragon Dictate Naturally Speaking*, in conjunction with a sound processing program the author developed for this purpose.
All texts	A program that checks references in the text against the reference list. It saves references with descriptions for quick search and retrieval. The program can be used to search for references from different authors on the Internet, download and enter them directly into the database. This means that one can avoid repeated and needless usage of regular books.
Forum studies	Self-developed programs that regularly check requested forum postings on the Internet, download and save the information in a structured manner directly in the database for further processing.
Data processing	A large variety of different and specialized programs to structure and support coding and structuring of text data.

Validity and reliability

The issues of reliability and validity are closely related to the concept of knowledge. Reliability traditionally refers to the consistency of results, i.e. if repeated measurements yield the same results. Reliability in this sense does not have a key role in this thesis because the everyday Internet conditions vary and change from day to day as do the research persons.

Validity, however, ought to be discussed. It generally answers the question of whether the studies presented in the papers actually investigate what they intended to. The concept of validity cannot stay the same from a modernist positivist stance in which the world is objectively measurable, to a post modernist stance in which truth is regarded as a social construction and knowledge a product of individual and collective negotiation. In qualitative research, validity is based on existing, extensive and open knowledge about the subject being investigated. According to Patton, “Qualitative inquiry depends, at every stage, on the skills, training, insights, and capabilities of the researcher, qualitative analysis ultimately depends on the analytical intellect and style of the analyst” (Patton, 2001, p. 433).

Kvale (1997) considers validity to be the quality of craftsmanship of the researcher. It cannot be reduced to a post research check of the results but is present in the entire research process. Validation is seen as continuously checking, questioning, and theoretically interpreting the findings. In this process, the researcher uses in-depth knowledge about the question being investigated and his skills in the various phases of research.

Kvale mentions communicative validity in which testing the validity of knowledge involves a dialogue with the persons interviewed, the general public and the scientific community. It is a necessary factor in obtaining valid knowledge about the object being studied. “Communicative validity involves testing the validity of knowledge claims in a dialogue. Valid knowledge is constituted when knowledge claims are argued in a dialogue: What is a valid observation is decided through the argumentation of the participants in a discourse” (Kvale, ibid., p. 244–245).

The third kind of validity presented by Kvale is pragmatic validity. This refers to practical testing of the knowledge claimed by the research and the researcher. The best test of validity would be if any portion of the communicated results are of any use to the interview persons, practitioners, the general public or the scientific community. Kvale quotes Patton in saying that, “The ultimate test of the credibility of an evaluation report is the response of decision makers and information users to that report” (Patton, 1980, p. 339).

Kvale sees communicative validity as including an aesthetic dimension, but pragmatic validity involves an ethical dimension. “A pragmatic concept of validity goes further than communication; it represents a stronger knowledge claim than a mere agreement through a dialogue. A pragmatic validation rests upon observations and interpretations, with a commitment to act upon the interpretations – ‘Action speaks louder than words’” (Kvale, 1997, p. 248).

The ability to generalize in qualitative research is closely related to the question of validity. Kvale suggests three types of generalization: naturalistic, statistical and analytic.

Naturalistic generalization comes from the researcher himself; it is his personal experience of the phenomena contrasted to his previous knowledge about, and experience of, similar phenomena. These are the everyday generalizations people make about the world.

Statistical generalization is formal and explicit. It is based on the notions of random sampling of a general population and formalized parameters of the confidence of the outcome.

Analytic generalizations are made from an analysis of the similarities and differences of the situation examined and the one we are interested in predicting. It differs from naturalistic generalization because it specifies and demonstrates the supportive arguments where the researcher makes it possible for others to judge the claim of generality.

In this way, an analytic generalization becomes the shared responsibility of the researcher and the reader concerning what the researcher wants to communicate. The researcher's role is to prepare and guide the reader to the results, but it is up to the reader to complete the generalization.

"Thus the chief point to be remembered with this type of research is not so much whether another position with respect to the data could be adopted (this point is granted beforehand), but whether a reader, adopting the same viewpoint as articulated by the researcher, can also see what the researcher saw, whether or not he agrees with it. That is the key criterion for qualitative research" (Giorgi in Kvale 1997, p.189).

MYSELF AS A TOOL FOR RESEARCH

My knowledge of the area covered in this thesis stems from 20 years as a computer user, 15 years as a wheelchair and personal assistance user, more than 10 years as an Internet user and rehabilitation engineering professional, and at least 5 years of higher education in social model and independent living theories. Just by living my life, this blend of experience and knowledge gives me access to several crucial insights but is also cause for caution. There is always a risk of bias influencing the result. Since Internet and other technologies have had such a large positive impact in my life, I may be tempted to present them in a more positive light than they deserve. This could be interpreted as there being a political agenda behind my research. The expertise described above can be used to paint the picture I would like the onlooker to see, rather than the picture I actually saw. This could be deliberate, but there are other unpremeditated sources of error: I could simply be too close to the subject.

It is my strong belief that no research is without bias, and this may be particularly true for qualitative research, where the researcher himself is the instrument, the measuring tool. The first step in dealing with this is to be well aware of the problem and problematize it in every phase of the research. The second is to ensure openness in sources and to provide richness in the descriptions and in analysis.

In all four papers on which this thesis is based, I have tried to ensure that my reasoning is clearly stated and that the craftsmanship validity is possible to judge. It is, however, difficult to extensively elaborate on critical and important background issues and discussions that are central to a greater understanding. I have tried to include more of this material in this thesis instead. All the papers have been through the peer-review process with subsequent corrections and clarifications. This is a form of communicative validation.

In Paper I, the FACE tool for analysing the functioning of disabled people is introduced. It arose out of my situation and knowledge of how disabled people use technology. The primary empirical data is from my own situation, but the abductive process leading up to the formulation of this tool for analysing, assessing and developing functional assistance, involves a multitude of other sources; other peoples as well as experience and writing.

The nature of this research's validity is mainly pragmatic and to some extent communicative. It is through actual testing of the FACE tool that its usefulness and validity will be determined. If people in other situations can utilize it, it will prove to have general qualities. Another test of this nature is if it is possible to generalize to other types of impairments.

In Paper II, the analytical reasoning is found in the text. It is the paper per se that the referees considered valid for the context of the online journal of *Design Philosophy Papers.*

The two empirical studies presented in Papers III and IV aim to describe the Internet functioning of disabled people. Not much is mentioned in these reports about any problems for disabled people with Internet use and the positive outcomes reported are apparent. This can be seen as an incomplete picture of disabled peoples' Internet use, but the research purpose has been to investigate the Internet functioning and the situation for people who have already solved many of the problems of disabled peoples' Internet use reported in other research. This makes it possible to generalize in a different way, to see in depth what this technology can mean for a larger group of people, if the problems are solved.

The problem with giving an incomplete account of disabled peoples' Internet use can be addressed by acknowledging that this research is only a piece of the whole picture, one aspect or angle. Others, for instance Seymour (2005), have a different research focus and different research persons and elaborate how disabled people abandon and under utilize the Internet technology. Her focus is "the self-identity of the user and to the broad dimensions of global capitalism within which the user-technology relationship is negotiated in order to explore the factors that shape decisions to adopt or to abandon technologies."

Sheldon (2004) also gives a somewhat different picture of disabled peoples' Internet and technology use. Her research participants were largely unwaged people, many of them older. She focuses on the line between technological possibilities and the dangers, and the division between those who can benefit and those who cannot.

Sapey (2000) has examined employment data from the USA and UK on the process of informationalization, and found that disabled people are more likely to be excluded from employment in the informational sector and that the current reforms of welfare may remove some of the safety net provisions that have been part of the hegemony of care established under industrialization.

The backgrounds and perspectives of the researchers differ, as well as their analyses of the study object. The object of study is constantly changing and the time lapsed between the studies can show a moving picture. Young people may have a different view than old. People who are positive towards technology and changes see things differently than people who are more hesitant. Children today live their lives in virtual worlds to a greater extent than children did only five years ago. When these children become adults, their childhood experiences will probably result in different research outcomes.

In any case, it is when many different aspects or pieces are put together that the full picture in all its complexity and changes can begin to emerge.

The interview study in Paper III was conducted with 22 persons with motor impairments who were experienced Internet users. This group enabled me to access information that would have been impossible to acquire from a random sampling of the population.

The limited length of Paper III was not enough to convey the richness of the answers of the persons interviewed. To ensure maximum exposure to this material, another report was presented, a case study with seven cases (Anderberg, 2006b).

In Paper IV, all the source material is available in uncorrupted form over the Internet in the forum studied. The interesting situation where all the material that the researcher has used is potentially available for the reader, makes the question of validation somewhat special. It is actually possible to check my analysis against the source material for anyone who is really interested. However, the ethical implications of this are not trivial. In Paper IV, I have described the measures I have taken to protect the people in the web forum from exploitation. This is my responsibility as a researcher. The possibility to check my results thus exists but is interwoven in a delicate fabric of ethical considerations, necessitating an ethical discussion before making this kind of validation possible.

Making all ends meet

Two approaches guide this research: 1) empowerment through technology, and 2) participation in and control over the design, implementation and use of technology as functional enhancement.

In this chapter, I present the theoretical background of my research and this thesis. First there is a description of relevant background in the field of rehabilitation engineering and design, focused on empowerment and user participation. This is primarily based on elaborated material from two reports: *Rehabilitation Engineering and Design Research – Theories and Methods* (Jönsson & Anderberg, 1999) and *Situated Research and Design for Everyday Life* (Jönsson & Anderberg et al., 2004).

This is followed by descriptions of basic concepts in the areas of disability studies and independent living.

Rehabilitation Engineering and Design

Rehabilitation engineering and design is a multidisciplinary subject concerning that which arises when a person and the disability she experiences in a potentially disabling setting encounters technology that is intended to minimize or eliminate the disability. Jönsson and Anderberg (1999) define rehabilitation engineering and design as follows:

> The starting point for rehabilitation engineering and design research are human needs/wishes/dreams and its most important yardstick is the enjoyment and benefit it brings to users. The process thus begins with the individual and ends with the individual. At the same time, the method, and to some extent the language, of rehabilitation engineering research is that of technology – the technical solutions and their design demonstrate how problems have been interpreted and how technical and educational possibilities can be implemented.

In rehabilitation engineering and design, the person is central and technology is used as a means for achieving the functions that the user desires. The design process includes the time after the user has started utilizing the technology. This is crucial since the design process also involves a variety of factors that are not only technological in nature. Involving the user in the entire process and focusing on such factors as independence, integrity and personal power results in the whole design process being based on the user's lived disability. There is a fundamental division between a person's impairment and the different factors in the surrounding environment that disable or cause a disability to arise.

The field of rehabilitation engineering and design has a lot in common with rehabilitation science and engineering as it was introduced in the 1997 IOM report, *Enabling America* (Brandt & Pope, 1997) and further developed in 1999 by the National Institute on Disability and Rehabilitation Research (NIDRR Long Range Plan, 1999). Katherine Seelman, director of the NIDRR, described rehabilitation science and engineering as a new disability paradigm that is both "integrative and holistic" and focuses on the whole person functioning in an environmental context. The contextual aspects of disability are central along with the focus on function in rehabilitation science and engineering. Disability studies "assure that the perspective of the group under study is reflected in the methodology and body of core knowledge. It also maintains that individuals from the group have the opportunity to participate in the development and promulgation of the methodologies and the curricula" (Seelman, 2000).

RESEARCH OBJECTIVES OF REHABILITATION ENGINEERING

The explicit objective of rehabilitation engineering research is that disabled people will benefit from the results, sooner or later. The results can consist of prototypes suitable for product development or for continuing use as they are. They can also be tools for acquiring relevant knowledge. The research results usually concern knowledge of needs, of how products should be designed, and of how the process for eliciting the needs and products should be designed. None of this can be achieved unless the researchers are there as situated actors, with design and technology as tools and with good opportunities for the people involved to provide feedback through their way of using or not using. Along the way in longitudinal projects a common memory may evolve which considerably strengthens the preconditions for interactivity.

The main objective for acquiring knowledge of the needs of a user could be to establish user requirements for developing a specific product into a commercialized one, but also to discover design principles for designing and developing other technological solutions as well. By developing prototypes in close co-operation with users up to a level where they can utilize the prototypes in real situations, it is possible to discover common patterns in user needs. These patterns may generate design principles as well as new hypotheses. Of course, different individuals often require different solutions, but with new knowledge it is in any case possible to ask more relevant questions in the design process.

In the very design process, artefacts may serve as probes to reveal new knowledge about and for the user. Technology can be considered a language: It affords a means with which to ask, to intervene, and to give feedback. Certain aspects may be better expressed through actions than through verbalization (Vygotsky, 1930). In the essay, *Technology is Society Made Durable*, Bruno Latour uses "actant" as a term comprising artefacts as well as humans. The separate actants are not as important as are the relationships between them (Latour, 1991). Artefacts transcend the will of people who might be far away in time and space. The artefacts and the technology as a whole make society sustainable, acting as implementations of agreements that originally were purely social. Since technology can only develop in dialogue with the culture and has to express values that are accepted there (Castells, 2000), it can be regarded as thoughts made visible and robust. The stability achieved through technology and artefacts is of special importance for people with disabilities. The actants should not be in charge but at hand, transcending the necessary involvement and help.

THE DESIGN PROCESS

The design of technical solutions represents in itself an interpretation of problems in a language of its own, different from the word-based analyses of observations, interviews, questionnaires, etc.

In rehabilitation engineering, technological measures influence the interaction between the person and her environment in such a way that she experiences increased function or functionality in that setting. *Function* is a product of all the lived effects of the introduced technology for the individual. Technology in and of itself is not rehabilitating but can only become so when it has such a function. This means that all technology is potentially rehabilitating, depending on the function it has for the individual who is using it. Research should continuously problematize who has power over what technology should be developed and why, as well as what problems need to be solved. It is thus important to pay attention to and describe the underlying social and cultural structures in which technology should be developed and used.
A strong emphasis on participation in the entire research process is a necessity.

In rehabilitation engineering the person should not be seen as an object that can be studied, functionally measured and treated. Neither the user's list of priorities nor the criteria for their fulfilment are accessible from the start. These are shaped through interplay with technology/ technological efforts (models, mock-ups, early prototypes), with designers and other people with similar disabilities. The critical moment in the design of assistive technology is not about the choice between high and low tech, but rather between straight-forward solutions aiming to normalize (reduce the effects of the immediate shortcomings) and attempts aiming to grasp at least parts of a situation out of at least parts of its complexity. Jönsson and Anderberg express this as follows: "… it may be appropriate to question, at the very outset, whether the solution should imitate fully the solution for a non-disabled person (the parrot method), have the same purpose but a different form (the chameleon method), or be completely different and only retain its fundamental characteristics, its very core (the poodle method)" (Jönsson & Anderberg, 1999). The parrot method is most common because it is natural to build on an established pattern of thought, technology and modus operandi. But you always have to ensure that the technology solves the right problem, and be aware of how the technology interacts with both the physical and social environments.

The Parrot Method. If it is possible to imitate, like a parrot, the way a non-disabled person would handle a certain situation, this may be the best solution (at least from a social perspective). This means that the system, consisting of the person with a disability and her technology, is capable of doing exactly what she would otherwise have been able to do without her technology: She chooses exactly the same approach to problems that other people can handle without the aid of technology. Examples are: glasses, prostheses, corrective medication.

The parrot method can be successful, and sometimes this is where one must begin. But it is important to let the situation talk back and to follow up to ensure that one has solved the right problem. You can sometimes avoid running into a dead end by defining the function you are aiming for before you begin to solve the technical problem.

The Chameleon Method. The aim might be to perform the same task as the non-disabled person is able to do, even if it is not meaningful to imitate the way in which it is carried out. Instead, like a chameleon, one tries to change the "colour" of the solution by changing technologies to achieve the same result.

Examples of chameleon solutions for people with visual impairments would be using Braille, speech synthesis or audio books instead of ordinary text (the purpose is the same as it is for sighted people: being able to take in something that has been documented). Using wheelchairs and guide dogs are other examples (the purpose is the same as for sighted people: being able to move about independently).

The Poodle Method. Like Goethe's metaphor in Faust, this is about getting to the heart of the matter; about finding the innermost part of the dream, the wish, or the need. Even with technology, it may not always be possible to do what you want to do. And even though it may be possible, it might not be worth it to make the original dream come true at any cost. Perhaps the specific activity is not the most important – another activity that yields the same feeling might serve the same purpose.

An example: A young man used to enjoy sailing very much, but after a neuromuscular disease his muscles were too weak for sailing. He liked the challenge of the sea, feeling his body working and strong, feeling his powers. So to him an automatically operated sailboat controlled simply by pushing two or three buttons was meaningless. That was not what he experienced in sailing; it had nothing to do with his need and wishes. What was the driving force for the sailing activity? Was it the physical or the intellectual challenge? Is it possible to find an activity that can be physically experienced just as much or even more so? An activity that will make the body buzz with exhaustion and joy? Perhaps there is an altogether different activity that would provide the same intellectual challenge. These are the types of activities that should be supported by rehabilitation engineering, not the original ones which, in fact, can no longer be achieved.

Originally, the parrot, chameleon and poodle methods were side effects of a communication about methods in a narrow research community at Certec. Later, the metaphorical labels began to be used in wider communities, probably due to their pedagogical and communicative strength. The manual, *Go For It*, that was produced by the EU financed EUSTAT project, Enabling Users of Assistive Technology, is a good example. The main aim of the EUSTAT project was to develop training models and educational material for persons with disabilities and elderly people in order to empower them in making informed and effective choices of assistive technology. The manual has been translated into seven European languages. In this manual, the methods described above are seen as especially advantageous to consider before starting the process of acquiring assistive technology. To have this information can help empower a potential user to control the service delivery process and to stand up against the professional knowledge of the advisors (EUSTAT, 1999).

In one way, the parrot, chameleon and poodle methods resemble both the FACE tool introduced in this thesis (see the FACE section below) and the STEP model introduced by Arne Svensk (Svensk, 2001). But while the parrot, chameleon and poodles have to stay on their metaphoric level as reminders before and after, A, C and E (Attitude, Control and Enabling) can be checked more concretely in the implementations as can Security, conText, Experience and Precision, the main concepts when designing for distributed cognition.

ENGAGING USERS IN THE DESIGN

One cornerstone of fruitful design is the necessity of involving users in the design process. This engagement requires not only users to become active in the process but also requires developers to become engaged themselves in gaining a better understanding of use contexts and situations (Kirschner et al., 2003; Plato & Jönsson, 2001).

There are many ways to involve users in a design process (Preece et al., 2002). The concept "user-centred design" emerged in the mid-1980s. According to Gould and Lewis the three main principles of user-centred design are: early focus on users and tasks, empirical measurement and iterative design (Gould & Lewis, 1985). Early focus on users and tasks incorporates various methods to examine characteristics of a user group through, for example, user mapping, task analysis, questionnaires or direct observation. These surveying methods are described in the EU accessibility project *Userfit* (Poulson et al., 1996) or standard human-computer interaction and human factors literature (e.g. Sanders & McCormick, 1992; Helander et al., 1997). Empirical measurement is the practice of letting future users use simulations and prototypes, and measuring their performance through quantitative feedback including measures of efficiency, number of errors, time to complete tasks, etc. Good descriptions of such test methods may be found in Jeffrey Rubin's *Handbook of Usability Testing* (Rubin, 1994). Iterative design is a standard component in design methods (Gedenryd, 1998) and builds on a cycle of design, testing and measurements that is repeated as often as needed, starting with early prototypes. Usability engineering (Nielsen, 1993) builds on the user-centred approach, but attempts to make the process easier to fit into an engineering perspective by focusing on the usability goals as a measure of when the iterative design process may be stopped.

PARTICIPATORY DESIGN

Participatory Design (PD) has its roots in a Scandinavian tradition and had from the very beginning a political agenda. The researchers and designers who worked with trade unions in the 1960s had a clear aim to empower workers and involve them in the introduction and design of new technology (mostly regarding information and communication technology – ICT) in the workplace. Ever since, it has kept a strong focus on the democratic and ethical perspectives of design, as well as the introduction and use of technology in the workplace, even though socio-economic conditions have gradually changed since the 1970s. (Ehn, 1993; Kensing & Blomberg, 1998; Beck 2002a; Bjerknes & Bratteteig, 1995).

Worker and user participation is, however, still a focus in PD, even though the view of the involvement of other organizational members, including management, has shifted with the spirit of time. Today, many people in the work organization "with various relations to the technology design effort are included in PD projects" (Kensing & Blomberg, 1998).

The main interest of PD is still firmly rooted in user involvement and empowerment. Howard (2004) finds the principal objective of Participatory Design to be the "empowerment of laypeople to participate deeply, and with some measure of authority, in the evolution of technological systems."

Balka (1995) sees PD as having both "political and technical features", political in that it raises questions about democracy, power and control in the workplace, and technical in that its epistemological stand is that the end product will be better if designers and end-users co-operate in the design process. Greenbaum (1993) proposes a similar division in describing three different perspectives of the need and usability of a PD approach: the political perspective , the pragmatic perspective (better with early end-user involvement) and the theoretical perspective(s): "Since systems developers and people at workplaces do not experience the same things, this limits how well they can understand each other's experiences" (Greenbaum, ibid.). Thus prototyping and situated learning are required. For both users and designers it is necessary to be "a reflective practitioner" (Schön, 1983).

Kensing and Blomberg (1998) have identified three main issues that have dominated the discourse in the PD literature: "the politics of design", "the nature of participation" and "methods, tools and techniques for carrying out design projects."

The philosophical grounds for PD make its tools and techniques, with their emphasis on the situated and the organizational context, a useful point of departure for rehabilitation engineering and design research. Bringing about empowerment through the use of technology is just as important in this context.

An unawareness of the economic, social, political and cultural causes of the origin of disabilities in rehabilitation engineering development and research can, instead, result in the consolidation of disabling structures in society.

Disability Studies

Disability studies is an interdisciplinary and multidisciplinary field that focuses on the social creation of disability and rejects medical approaches to explaining, interpreting and responding to disability. Like ethnic, women's, gay and lesbian studies, disability studies has developed from a position of engagement and activism rather than detachment (Barnes et al., 2002).

A social model understanding of disability and the disabling factors in society constitutes the ideological foundation of disability studies. The original social model of disability was formulated in the early 1980s by Mike Oliver following the Union of the Physically Impaired Against Segregation's (UPIAS, 1975) definition and separation of any causality between impairment and disability.

The social model makes a sharp distinction between adapting the individual and adapting the surrounding structures in which the individual lives. This is accomplished by differentiating the *impairment* the individual has and the *disability* that different social and physical settings create for a person with such an impairment. Disability is defined as a socially constructed oppression.

This distinction between disability and impairment is central to the social model. As a theoretical point of departure, this distinction is essential because it moves the disability from being a problem or a characteristic that is exclusively individual to being a contextual characteristic of the surrounding social and physical environment. Categorizations of people based on medical or social diagnoses are rejected.

> All disabled people experience disability as social restriction, whether those restrictions occur as a consequence of inaccessible built environments, questionable notions of intelligence and social competence, the inability of the general population to use sign language, the lack of reading material in braille or hostile public attitudes to people with non-visible disabilities (Oliver, 1990).

The social model of disability developed in the UK originally referred to a rather materialistic view of the causes of disability. In the US, a more social constructionist model was framed in line with many other civil rights movements. Today, many more models or paradigms with the social model as its origin are found in the academic research field of disability studies. The core message in most of them is, however, that societal structures should be changed to accommodate people with disabilities, not that the individuals should be changed to fit into a rigid environment and discriminating society. Disabilities are seen as a demand for justice and equality and not a question of individual shortcomings. Disability is not a characteristic of the individual but rather the discriminating situated response to an inaccessible, inflexible and unadapted environment and society. This response is directed at a wide variety of people and excludes them because of their inability to conform to a societal concept of physical and intellectual normalcy. Disabling and discriminating attitudes are routinely produced and reproduced in social, political, and cultural practices in everyday life (Oliver, 1990; Barnes et al., 2002; Barnes & Mercer, 2003; Albrecht et al., 2001).

In the Nordic countries, a relative model of disability can be said to be a version of the social model of disabilities. Exactly who is considered to be or to become disabled in this context is a question of environment and context, and the boundaries are indistinct. People can be disabled in different settings for a variety of reasons, age being a common one. That people become disabled in different environments should not be seen as an anomaly but as an element that exists in every society, defined by how it is constructed. Disability can be seen as a phenomenon that arises primarily from society's treatment of people who function differently than the societal norm.

Criticism of the social model has come from within the disability community for not taking into account the physical body in its analysis of disabling factors. It has been depicted as too unbending in its concentration on structural societal factors and criticized for "disregarding the cultural and experiential aspects of disablism" (Barnes & Mercer, 2003).

Barnes and Mercer describe three main strands of this criticism. The first is that the social model fails to recognize the physical and emotional problems that are associated with some impairments and that are disabling factors regardless of societal response. The second is that specific impairment groups are marginalized by some social model writings. The third criticism is that there is a failure to recognize that the experience of both impairment and disability can be different for different groups of disabled people (ibid.).

Both individual and social factors influence everyday life for a person with an impairment, as it does for anybody else. For example, not being able to lift and hold your child the way you would like, to take on physical challenges, to conduct your sex life the way you want are not disabilities because of lack of assistive devices or because of an unadapted society, but are the direct effects of the individual's impairment. This, however, does not mean that other restricted desired actions are not due to the lack of assistive devices or an unadapted society.

Thomas (2002) makes a distinction between disability and what she calls "impairment effects." They are, for example, that blind people are unable to drive a car safely with today's technology. This becomes a disability only if driving a car is a condition for obtaining paid employment (Barnes & Mercer, 2003).

Gabel and Peters (2004) argue that the social model emerged in resistance to the medical model and that this makes it difficult to acknowledge any benefits of the latter within the social model. Gavel and Peters acknowledge the benefits for disabled people that have come from medications and technologies that improve function. They see, however, the danger in the misapplication of the medical model to the social contexts of disability. It becomes a problem when the professional use of medical knowledge expands beyond the cure of the effects of illness, and starts taking precedence over social factors in analysing disabilities.

Influential critics, such as Tom Shakespeare and Nicholas Watson (2001), have pointed out that "the strong social model" has become too strong and that it is a "modernist theory of disability – seeking to provide an overarching meta-analysis covering all dimensions of every disabled person's experience." They see disability as sitting at the intersection of biology and society, and that the original "strong" social model over-simplifies the complex concept of disability and reduces it to a singular identity.

Most of the criticism can be perceived as legitimate, even though the orthodox social model that is being argued against is hard to find to any large extent amongst researchers today. In fact, what we see are a number of "theories that incorporate aspects of the traditional or 'strong social model', yet provide ways of theorizing disability more suited to current contexts and more responsive to emerging world trends" (Gabel & Peters, 2004).

Thomas (2004), however, suggests that the (strong) social model used in this criticism is a "simplified" and "impoverished version" of the early UPIAS social relational understanding of disability. She claims that "what has been lost is an understanding that disability only comes into play when the restrictions of activity experienced by people with impairment are socially imposed, that is, when they are wholly social in origin. Such a social relational view means that it is entirely possible to acknowledge that impairments and chronic illness directly cause some restrictions of activity. The point is that such non-socially imposed restrictions of activity do not constitute 'disability'".

Even if it is not currently possible to talk about one well defined social model, there is definitely a social model perspective. It still holds the ground breaking separation of impairment and disability that has undoubtedly yielded many political benefits and provided a theoretical starting point for research, activism and discussion. Even if this perspective needs to be improved, challenged and adapted to the changing conditions for disabled persons in a modern society, it still holds the key to having broken the strong and direct causal link between the body and the situation of disabled persons in society.

Independent Living

"To boldly go – where everyone else has gone before!"
Martin McNaughton, Dublin CIL

The independent living movement and the philosophy behind it are closely connected to the fundamental thoughts expressed in a social model perspective. They share the notion that disabilities are socially created rather than a consequence of a medical condition (Hasler, 2003). The welfare system can, through its organization, create the image of disabled people being dependent and a burden on their families and society, in need of professional interventions and assistive efforts. Independent living philosophy can be seen as a radical challenge to this conventional thinking on disability as it "combines both an ideological and practical solution to the everyday environmental and cultural problems encountered by disabled people and their families" (Barnes, 2003). Given the right tools, disabled people are the best organizers of the functional support they need in their lives.

Independent living is a philosophy, a way of looking at disability and society, and a worldwide movement of disabled people who work for self-determination, self-respect and equal opportunities (Ratzka, 2005).

A common definition of the independent living philosophy is the one stated by Frieden et al.: "Control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, making decisions that lead to self-determination, and minimizing physical or psychological dependence on others" (Frieden et al., 1979).

The focus on the individual's ability to control and make choices in his/her life together with the concept of peer-support are cornerstones in the independent living movement. This means a rejection of unnecessary professional involvement and control (Ratzka, 2003a) and that disabled people themselves are the experts when it comes to their lives. Hasler (2003) has made a compilation of definitions of independent living and found that they focus on a few key concepts, namely choice, control, freedom and equality.

Independence in this case does not refer to "doing everything by ourselves" or "living in isolation" (Ratzka, 2003c). This is an important distinction since with an increase in disability comes an increased need for help with various functions, which in some ways leads to a greater dependence on others, both individuals and society. Independence is the right to define this need and to have control over the functional assistance you need to level out the difference, as well as to demand political power to build and rebuild in a way that is more accommodating for all citizens (Oliver, 1996; Corbett, 1997; Ratzka, 2003b).

Political power through the organization of disabled people and attempts to influence public opinion in favour of civil rights for disabled people are goals for the independent living movement, as well as for the disability rights movement in general. Still the focus of independent living can seem to have an individualistic element, where the living conditions of the disabled individual are at the centre, "while the independent living movement is allied with the disability rights movement, it can be distinguished from the disability rights movement by its core concern with improving the everyday life of individuals with disabilities. The disability rights movement is focused on improving the quality of life of disabled people as a class" (Global Summit, 1999). In this respect, the independent living philosophy comes close to the basic thoughts of rehabilitation engineering and design.

Introducing Enability Studies

The context for rehabilitation measures should be the political, economical, cultural and social environment, since this influences both purposes and selections of relevant aids. But there is also a reverse dependency: the view of disabilities and disabled people is influenced by the rehabilitation measures that exist in a society. With this in mind, it is important that rehabilitation engineering and design allow the knowledge gained from disability studies to provide feedback to all forms of rehabilitation measures.

The focus on the individual, and the perceived focus on an individual fix, makes the relationship between rehabilitation engineering and (assistive) technology and disability studies, rather complicated. While some disabled people rely on individual technology to function in their daily lives (the wheelchair being a good and common example), it is common within disability studies to view technological solutions to disability with scepticism.

Technology is sometimes acknowledged for its potential to liberate disabled people, but even more so for its potential for oppression. This "double-edged nature" was described by Mike Oliver in his influential *Politics of Disablement* (1990), and it is still an issue when technology is discussed in disability studies. In an article on disability, work and disability politics in the 21st century Barnes suggests that, “While new technology, deregulation and more flexible production techniques may prove enabling to some, to others they will almost certainly mean worsening social isolation, and new and enhanced forms of exclusion” (Barnes, 2000, p. 446).

Control over, and attitudes towards technology, play an important role. In a conversation with a disabled woman about the potential of the stair-climbing wheelchair (we are both wheelchair users) she stated that she would never use such “a contraption” because she did not trust advanced technology. Further discussion, however, revealed that she had flown over the Atlantic in an airplane, and travelled in her adapted car on the motorway regularly…

The disabling structures that create disabilities influence, to the same high degree, the entire system consisting of the individual’s personal technology and physical environment. Economically, culturally, politically and socially disabling structures influence, to the same high degree, the individual’s personal technology as well as the surrounding physical structures. Oppression and discrimination of disabled people manifest themselves, to the same high degree, in these physical systems, and the interaction between these and the social structures is fundamental.

The division that is made between impairment and disability in the social model is fundamental and extremely significant because it places the disability outside of the individual. In rehabilitation engineering and design you move closer to the individual and look at the system in the space between the individual’s personal technology and the surrounding physical environment. You concentrate more on the function than on the disability and proceed from an existing function to gain access to the lived disability. To accomplish this from the perspective of the individual does not mean that the context and the structures that cause the disability can be ignored. Social model perspectives are, to a great extent, a point of departure for rehabilitation engineering and design as well.

Rehabilitation engineering defines the disabling environment as including the entire material space the person lives and moves in. It is not possible to separate the individual, his personal technology and the surrounding physical setting when your goal is to improve a function. For example, a wheelchair and the physical setting in which it is to be used must be seen as one system. It is crucial not to view them as being isolated from one another.

Technology and design can be said to mediate both function and disability. The general view of impairment in society steers the formation of the individual’s personal technology as well as the configuration of the surrounding physical environment. The reverse is also true. The formation of these systems influences the view of disability in society.

In Paper I, the example of the difference of the wheelchair space in a movie theatre being located in the aisle or in the middle of the row is given. Regardless of the technical or design solutions, whether the wheelchair space occupies the best or worst situation in a theatre sends out different attitude signals. These signals are received by all visitors to the movie theatre. The same goes for a lecture hall – if the podium is accessible with a wheelchair or not, if it is easily accessible with a permanent solution or if it is a provisional solution – all send messages about the attitude towards a lecturer in a wheelchair.

In his book, *Enabling Technology: Disabled people, work and new technology*, Roulstone (1998) uses the social barriers approach to understand the experiences of disabled people using new technology in the workplace. Roulstone uses a social model perspective to identify social barriers such as negative attitudes and perceptions about disabled people and disability against the background of new technology. This approach allows him to focus "on the broader configurations of factors that surround the experience of new technology, and in seeing the main benefit of technology in its impact on these barriers" (ibid., p.10). This is contrasted to a traditional rehabilitation approach using the individual or deficit model, seeing the introduction of new technology as "one that corrects an individual's personal shortcomings"(ibid., p.11) without problematizing the physical and social environment in which it is introduced.

Roulstone sees that it is the disabling and restrictive features of the work environment that many times constitute the problem for disabled people in the labour market, rather than lack of skills or other personal features. Disabling and excluding attitudes limit the potential of new technologies, and it is necessary to address these attitudes along with the introduction of technology in the workplace.

Even so, Roulstone concludes that the introduction and use of technology gave a majority of the people in the study control over their work situation and the possibility to actually change the attitudes of their co-workers as well as the general public, through the enabling process that was a result of the introduced technology. "For some, this enabling process reversed a lifelong conditioning which suggested that as a disabled person they were definable in terms of what they could not do" (Ibid., p.125).

To the same extent that disability studies uses social model perspectives to describe and analyse how environments, structures and attitudes disable people with impairments, Roulstone shows one can study how technology can enter these environments as function creating enablers. This can be seen as a supplement or sub-discipline to disability studies accordingly named “enabling studies” or “enability studies”.

The FACE tool

The FACE tool, developed as a conceptual design approach for the "disability ACE (Attitude, Control, Enabling)", is an attempt to create a layer system where the different factors can coexist and be given appropriate explicatory value according to their different influences on the actual experienced functioning (Paper I).

The factors are derived from and have their base in my personal experiences as a personal assistant and assistive technology user, and my professional experiences in rehabilitation engineering and design. In Paper IV, the "disability ACE" is further defined, and the layers are described with respect to the theoretical paradigms used in this thesis: rehabilitation engineering and design, independent living and disability studies.

Attitude concerns how the function is perceived, framed and socially constructed by others and by oneself in the context where it is used, i.e. to what extent is the function free from or affected by disablist and discrimination attitudes? *Attitude* is connected to the *social model perspectives.*

Control focuses the extent to which the user, the owner of the function, has the power and right to define and execute the function (its choice, development, execution and economy). *Control* aspects are closely connected to the *independent living perspectives.* It is necessary to clarify that this control must include the right to decline and refuse any use of assistive technology or function solutions that for some reason does not fit the needs of the individual user.

Enabling validates how well the constructed implementation of the design, its technology, economy, flexibility, physionomy, etc., matches the individual's wish to perform the desired actions. *Enabling* is the traditional approach in rehabilitation technology and design.

The FACE tool can be used as an abstract guideline, especially before and after a design process. To become concrete and continuously useworthy it must, however, be supplemented by examples and practical use. In the following chapters I will discuss technology and function assistance for disabled people in an argument for the need of a tool that can hold all these different levels at the same time. In order to do this the FACE tool presumes a political, ideological and normative awareness and an awareness of the difference between what is disabling and non-disabling attitudes in society. If for instance the users have no concept of the different ways of having control over one's life situation, the tool becomes rather useless as an instrument for guidance. In such cases it can still work as an instigator and awareness creator of the mere fact that there actually are other levels that influence and affect functioning.

In Paper IV, I used the FACE tool to examine how a web community of disabled people discussing their personal assistance can serve as a learning platform. It was obvious that some attitude, control and enabling aspects were more important than others. When structured out of ACE, the practical examples helped deepen the understanding of what "better personal assistance" actually means, not at a generalized consensus level but on an individualized with elaborated possibilities to pinpoint your own aspects of choice.

In Paper II, the FACE perspective is applied through the focus on the situated ethics. Control and attitude decisions in an actual design situation have obvious ethical consequences.

In Papers III and IV, the FACE perspective shows that the Internet is an arena with high functioning for groups of disabled people on both the control and attitude levels. The individual is afforded high control over his Internet functions and can experience a desired independence. He/she can control, counter or avoid negative attitudes in the online setting. The question here can be on the enabling level, where economic factors and the lack of good user interfaces can disallow a number of disabled people access to the Internet.

I would like to give two short additional examples of how the different levels of FACE can be used:

The first example is to look at the Independent Living Institute's "Taxi for All" project. The background is that it is virtually impossible for disabled people in Sweden to use public transport outside of their own municipality. No forms of taxi services are available for Swedes (or visitors from abroad) who, for example, are visiting the capital of Sweden, Stockholm. Designated "taxi service for disabled people", so-called *färdtjänst*, in specially adapted buses is available on an advance approval basis in one's own municipality. This taxi service has to be ordered about a day in advance.

The purpose of the "Taxi for All" project was to create a more "normal" alternative for public transport and taxi services for disabled people, by suggesting that all taxis should be adapted for use by disabled people as well. (For more information see the Swedish description in www.independentliving.org/taxi/index.html.)

FÄRDTJÄNST – DESIGNATED TAXI SERVICES FOR DISABLED PEOPLE

(A) The discriminating attitude that is shown by society when an entire system with special solutions for disabled people is created instead of making public transportation accessible for all consolidates disablist attitudes. Only people who are approved for the service can travel. Disabled visitors can not use public transportation in Sweden.

(C) The individual has limited control over his/her travelling, since such travel can be grouped together with other disabled persons travelling. No time guarantee is given for departure or arrival and it is impossible to travel with friends or family since the service is designated for disabled people and assistants only. The necessity to order the taxi service a day in advance makes spontaneous or unplanned travelling impossible.

(E) It has a high degree of enabling, since it is performed in specially adapted vehicles, and you can travel from door to door.

TAXI FOR ALL (ACCESSIBLE PUBLIC TAXI SERVICES)

(A) Disabled people are seen as full citizens with access to the same transportation system as all other.

(C) You can decide yourself when, where and with whom you want to travel.

(E) Depending on the adaptation of the taxis, the accessibility might be slightly lower for some disabled people than with "Designated taxi services for disabled people".

This example shows one of the strengths of the FACE method for analysis of functions. If only the Enabling factor had been considered it could have been argued that "färdtjänst" had the same or higher functioning than taxi for all. But if attitude and control factors are weighed in, taxi for all can be shown to have a higher degree of functioning.

A NEW SPORTS ARENA

The second example is another authentic case: the construction of a new sports arena in Karlskrona, Sweden in 2005. The functioning for disabled people in this arena can be seen as high, both on enabling and control levels. Door openers, elevators, big bathrooms, etc., make it possible to move around the arena independently with a wheelchair.

However, the available place for people in wheelchairs to sit is separated from the "normal" seats on a balcony with plexiglass, in the corner. This makes it impossible for a family, with both wheelchair users and walkers, to sit together, and the functioning on the attitude level is low. It would have been easy to design the gallery to allow wheelchairs next to seats and solve this problem, if only this aspect had been identified with a FACE analysis early in the design phase.

Technology, society and disabled people

The feeling of freedom and independence was enormous. With three wheels and a motor under me, I set off into the world again. First with my friend as a guide and for security, later on my own. Me and my machine. The machine that obeyed me. Just me. Up the hills and into buildings. Down the backstreets and over kerbs. Strong, quiet, obedient, without a fuss, without exhorting. No questions and no negotiations. A light push of the thumb on the throttle. An electric motor, two batteries, three wheels, a few steel rims and a few other odds and ends. I knew exactly how it worked technically. But I hadn't had a clue as to how it would work for me. ("Might and Machines", Anderberg, 2006a).

In this chapter I will discuss technology and disability and I will also try to give weight to the argument for looking at the man-technology-environment as one system, one unit of analysis. This is important both for a further understanding of the background to the FACE tool and for an understanding why the Internet has become such an outstanding technology for disabled people.

Attitudes, disabled people and technology

The following subsections discuss the question of attitudes and technology.

WHERE DOES THE PERSON END AND THE TECHNOLOGY BEGIN?

It is difficult, often meaningless to try to figure out where the person ends and the technology starts. You touch the ground and feel the pavement with your wheelchair and when you turn around, your wheelchair turns with you. You are part of a functional system consisting of your body, your wheelchair and the ground beneath you. The boundaries you have for experiencing the world go beyond the physical limitations of your skin and are determined by the system for experiencing the world in which you exist.

In his book, *Steps to an Ecology of Mind* (1972), the cybernetics pioneer Gregory Bateson illustrates this point with the example of a blind man with a walking stick.

> Where do I start? Is my mental system bounded at the handle of the stick? Is it bounded by my skin? Does it start halfway up the stick? Does it start at the tip of the stick? But these are nonsense questions. The stick is a pathway along which transforms of difference are being transmitted. The way to delineate the system is to draw the limiting line in such a way that you do not cut any of these pathways in ways which leave things inexplicable (ibid., p. 459).

Bateson's view is that the information received through the cane is directly relayed to the person's mental system and processed as any other information received, for example, by the eye or the finger:

“There are lots of message pathways outside the skin, and these and the messages which they carry must be included as a part of the mental system whenever they are relevant” (ibid., p. 458).

The image of the prosthesis as an extension of the body, and an enhancement of the bodily functions evokes many connotations and thoughts. In her book, *The War of Desire and Technology at the Close of the Mechanical Age*, Allucquere Roseanne Stone (1995) describes her feelings after attending a lecture given by the physicist, Stephen Hawking. Stone starts off listening to Hawking outside the overcrowded auditorium through the Public Audio system (PA), but decides she wants to go in and see and listen to him in person.

> Sitting, as he always does, in his wheelchair, utterly motionless, except for his fingers on the joystick of the laptop; and on the floor to one side of him is the PA system microphone, nuzzling into the Votrax’s tiny loudspeaker...Exactly where, I say to myself, is Hawking?...In an important sense, Hawking doesn’t stop being Hawking at the edge of his visible body. There is the obvious physical Hawking, vividly outlined by the way our social conditioning teaches us to see a person as a person. But a serious part of Hawking extends into the box in his lap. In mirror image, a serious part of that silicon and plastic assemblage in his lap extends into him as well...No box, no discourse...On the other hand, with the box his voice is auditory and simultaneously electric, in a radically different way from that of a person speaking into a microphone. Where does he stop? Where are his edges? (ibid., p. 4-5)

Stone sees the prosthesis in the shape of a speech synthesizer. Her fascination with how Hawking “extends” into a piece of technology and her thoughts on his vocal presence and displacement in time and space, could in one way be seen as typical for the time, at the beginning of the era of information technology. This “extension” of Hawking into the speech synthesizer is not fundamentally different from how people can be seen as extending into a computer or an email or a chat room, when using that kind of text based conversation. The limitations of the prosthesis of written communication, as well as the habit of answering email without too much time for reflection, are limiting factors that are taken for granted today. One could easily argue that it is the format of an IRL (In Real Life) lecture that creates a discrepancy between how the prosthesis in the form of an external speech synthesizer is experienced, relative to using the voice from one’s vocal cords (internal speech synthesizer). Sarah S. Jain puts it as follows:

> Questions of human-prosthesis or human-machine interfaces are central to one's active agency in a community embedded in prefigured modes of technological praxis that always already privilege certain body configurations (Jain, 1999, p. 41).

It is easier for the person using the prosthesis. It is first and foremost about function, and the desire to perform and control this function. But secondly, the function is inscribed in a system of internal and external perceptions of this technology, and the integration of technology into the self is not unproblematic (Sobchack, 1995).

Hernwall uses the concept "cyborg" when considering a human being with his or her technology as a functional unit. He sees the cyborg as a "human who incorporates technology and its affordances into her own essence to the extent that the technology becomes a self-evident prosthesis" (Hernwall, 2001; translated from Swedish by the author). Hernwall views the cyborg concept as a chance to move beyond technology's limitations and focus on the individual's opportunities and terms in the utilization of technology. He argues, with support of Haraway (1991) and Landow (1992), not to separate the human from her technology and not to evaluate the individual based on norms of technology and its limitations, but to focus on the potential gain for the individual.

The concepts of cyborg and prosthesis as metaphors with unnecessary or undesirable connotations are not unproblematic when used to describe a person's usage of technology. For the modern person, different products and artefacts as functional aids have become so natural that they already represent an extension of the human. For disabled people where technology is often necessary to perform a function, it should also be seen as a natural element. Technology can be individual and accompany the person, such as a wheelchair, hearing aid or glasses. Or it can be built into the surroundings such as ramps, door openers, hearing loops, contrastive signage, etc.

This does not make the question of where the boarders between man and technology are drawn uninteresting. But based on the expanded technological perspective applied in this thesis, the focus on the desired function means the person is central and that the technology used is problematized from the individual's wishes concerning the function.

This corresponds to hitting a nail – it is true that you hold the hammer, true that you hit with it, but it is the driving in of the nail that is in such focus that you hardly notice the hammer. Similarily, both the computer mouse and the cursor are subordinate – it is what is done and what is achieved that matters. The focus is on the action (Dourish, 2001). That is why, in most cases, it is meaningless to measure physical functions without including the use of the available technical aids. This is an area in which the ICF (International Classification of Functioning) needs to be modified (World Health Organization, 2001).

According to Claiborn, there is a "multiplicity of possibilities that go beyond any separation of human and machine. A Paralympian shot-putter, in this view, is not an individual person helped by high-tensile carbon-fibre legs, or a hybrid defined by dual constituent parts, but an athlete capable of multiple boundary-shifting performances" (Claiborn, 2005).

The quality and height of a pole-vaulter's jump is judged on what height he or she manages to clear with the pole, not without it. It is of little interest to find out how fast a race car driver is able walk or run the length of the track because it is the system made up of the driver, the car and the support team that is the relevant unit to optimize.

THE INFLUENCE OF ARTEFACTS AND TECHNOLOGY ON DISABLED PEOPLE

In 1985, you could receive a mobile telephone as a disability aid in Sweden, but today it is an obvious functional aid for almost all people. What is considered to be assistive technology versus standard technology is determined by the culture, location and point in time.

Progress often lags behind. In an interview for *Time Magazine*, the Independent Living Institute Director, Adolf Ratzka, posed the rhetorical question about the situation in Stockholm: "I cannot go by ordinary bus," he says. "Is that because I had polio 37 years ago, or because the transport authority doesn't buy buses that will work for everybody?" (*Time Magazine*, 1998-1999). Technology for adapting buses has existed for quite a while, and the only reason why so few buses are adapted are political and financial.

Science and technology studies examine how commercial, political, cultural and social values and interests steer scientific and technological developments and vice versa. One subject in the field is *Actor-Network Theory (ANT)* (Akrich & Latour, 1992; Callon, 1986; Law, 1987). In *Actor-Network Theory* all actors, human or non-human, are considered equally important for the analysis and are referred to in the same vocabulary. An example: The mobility of a wheelchair-user is dependent on a large number of factors, among them, the design of the wheelchair, the funding to buy a suitable wheelchair, the user's ability to manage and control the wheelchair, the organization and accessibility of the environment in which the wheelchair is used, etc. It is up to the person doing the analysis to find the relevant factors for the action under analysis.

It may seem radical and somewhat ethically shaky to grant objects and artefacts the same explanatory status as human beings in an actor network. But for the *Actor Network Theory* analysis, the boarder between humans and machines is not the issue, and their equity in the analysis "does not mean that we have to treat the people in our lives as machines. We don't have to deny them the rights, duties, or responsibilities that we usually accord to people. Indeed, we might use it to sharpen ethical questions about the special character of the human effect – as, for instance, in difficult cases such as life maintained by virtue of the technologies of intensive care *(*Law, 1992*)*.

Ingunn Moser and John Law (1999) have used *ANT* to elaborate on disability and ability in a series of stories about Liv, a wheelchair and personal assistance user. They find that the "links between dis/ability and subjectivity are close – which means that any study of the materialities of dis/ability is incomplete unless it also attends to the continuities and discontinuities of subjectivity" (ibid.). Liv is inscribed in an enabling network, with technological aids and personal assistants, giving her a considerable amount of agency in some of the environment she exists in, less in others.

Moser and Law see Liv as a cyborg, "in the sense, that she is irreducible to a unity, even though 'she' is also a unity" (ibid.). They make a convincing argument in showing how dis/abilities are created in networks made up of heterogeneous, material, and specific entities as described from this particular ANT perspective.

Myriam Winance (2006) has studied how persons with neuromuscular problems test their wheelchairs. With an *Actor-Network Theory* as a starting point, and also leaning towards phenomenology, she analyses the network made up of the wheelchair user, wheelchair, technical personnel, etc. The negotiation of various compromises and improvements during the trial period gradually transforms the entities involved, including the person's identity, and the relations between them.

ATTITUDES, TECHNO-FASCINATION AND TECHNO-FREAKS

There is an interesting techno-fascination in the detailed descriptions of how Liv controls her environment, making her not only a cyborg in the sense of a human in control of her human-technology unit, but also an incapable person, at the mercy of technology. What was intended as stories of enabling and control transfer, are partly transformed into pity stories with the cyborg as the incapable techno-freak.

This is a common way of portraying disabled people's use of technology in popular media (Claiborn, 2005). Jeffrey Deaver's novel hero, Lincoln Rhyme, is described as follows in the publisher's note:

> Lincoln Rhyme dazzled readers with unparalleled forensic sleuthing – all done from the confines of a wheelchair. A famed criminologist, paralyzed from the neck down, Rhyme compensates for his physical disability with his brains – and the arms and legs of his brilliant and beautiful protégée, Amelia Sachs. It is Amelia who "walks the grid" for Rhyme, acting as his eyes and ears for the famously dangerous and difficult cases (Deaver, 1998).

In spite of the frequent use of disablist language and occasional perpetuating stereotypes which are not confronted, the character of Lincoln Rhyme is an interesting one. He is inscribed in a truly fantastic and enabling actor network. He has one personal assistant attending to all his personal needs; he has access to all the technology he needs to perform his work as a forensic wizard consultant for the NYPD (New York Police Department); and he has access to a personal assistant doing his work for him in the field, to whom he is wired through the modern technology of cell phones and radio. He is in many aspects a very interesting and modern novel hero, brilliant and highly capable despite his impairment. Deaver is obviously fascinated by enabling technology and his descriptions are both detailed and interesting. But many times Deaver finds himself describing in detail incapabilities instead, for example, when he lets Rhyme fail to make an important telephone call because he is too nervous and his computer voice recognition program fails; as a result, two people die (Deaver, 1998, p. 284). In an interesting epilogue to this incident, Deaver counters the guilt ridden and self-pitying Lincoln Rhyme with another character, a woman airplane pilot. She makes the argument that modern human beings are in most cases putting their own and other's lives in the hands of the technology they use. And that technology sometimes fails in this network, and sometimes the human actor (ibid., p. 384).

ABOUT THE NEED TO DEFINE ASSISTIVE TECHNOLOGY

The US National Council on Disability has summarized the focus on the qualitative and quantitative difference in the use of technology as follows: "For Americans without disabilities, technology makes things *easier*. For Americans with disabilities, technology makes things *possible*" (Radabaugh, 1988).

Among all the definitions of assistive technology, I want to cite two. First, the US law text:

> Any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. (The US technology-related Assistance for Individuals with Disabilities Act of 1988, Section 3.1. Public Law 100-407, August 9, 1988).

Second, the international standard, ISO 9999, which defines a technical aid for disabled persons as:

> Any product, instrument, equipment or technical system used by a disabled person, especially produced or generally available, preventing, compensating, monitoring, relieving or neutralizing the impairment, disability or handicap (International Standardization Organization, 2002).

The only absolute reason to define assistive technology is the funding people with disability can receive to obtain assistive devices. If I drive my three-wheeled powered wheelchair scooter to work, is it an assistive technology device or is it a vehicle with which I go to work? When my personal assistant drives it home, because I have to go somewhere else with a car, is it still an assistive technology device? When my sons borrow the scooter to drive around the park outside the house because it is fun, does it cease to be an assistive device and become a toy?

I can not get off it and walk if I wanted to, but my personal assistants and my sons can. I, my scooter and the surrounding environment make up a functional system that is necessary for me to get to work. That is what makes it an assistive technology device for me. But if I try to go down to the beach, in the fine-grained sand, or go up two stairs, it ceases to assist me and to be assistive technology, because it does not provide any function in those settings. But does the actual wheelchair cease to be an assistive device at that moment?

Some of my assistants refuse to sit on my powered scooter when they need to take it home or anywhere else. Sitting in a wheelchair makes them feel uncomfortable, although not in a physical sense. Some of them would rather take on the complicated and risky task of walking next to it, trying to manoeuvre it from the side. One assistant who was driving it home said that he felt that everyone was staring at him, and he felt so uncomfortable that he had to stop and get off the scooter and walk around for a while so that everyone would see that he did not have an impairment. He felt that people's attitudes towards him changed considerably when he was driving the scooter. The actual device signals the disability. That is not inherent in the technology per se, however, but an aspect of the attitudes towards disabled people is transferred to the technology associated with them. Applications of technology for disabled people are often developed to meet health criteria rather than social criteria (Seelman, 2001).

Control, disabled people and technology

In the following subsections the question of control and technology is discussed.

TECHNOLOGICAL OR HUMAN PERSONAL ASSISTANCE

Personal Assistance (PA) or Personal Assistance Services (PAS) mostly refer to human personal assistance, i.e. a human being who helps out with daily chores. Following the definition of the independent living theorist, Adolf Ratzka, the word “personal” refers to the user and that the assistance is customized to the user’s individual needs. “Personal” means that the control over the assistance situation is in the hands of the user. He/she decides what activities are to be delegated, to whom and when and how the tasks are to be carried out (Ratzka, 1997). This definition does not in any way imply that personal assistance is limited to human assistance; personal assistance in the form of technological solutions should also be included, stand alone or as a complement. Such is the case in Paper I, which is included in this thesis.

There is a growing consensus that the functional needs of disabled people must be looked upon as systems rather than isolated instances. The concept of support systems was introduced by Simi Litvak and Alexander Enders in their chapter, “Support Systems: The Interface Between Individuals and Environments” in the *Disability Studies Handbook,* as a framework to study how different services work together. Support systems refer to the integration and fluidity of various supports that are necessary to serve individual needs. “Support systems bring together a full range of elements necessary to enable human beings to function in the world community and to accomplish tasks. Individuals have limited control over the environment. However humans do have control of the tools and people that enable us to live our lives” (Litvak & Enders, 2001). Just as is the case with personal assistance, support systems are “intensely and intimately individual” (ibid.) and depending on the “individual’s conceptual framework of self, role and community” (ibid.).

Support systems for disabled people, according to Litvak and Enders, are made up of three necessary components: personal assistance services (referring here to human assistance), assistive technology, and adaptive strategies. All of these are necessary for a person’s functional ability but the reliance on any of them depends on the situation and thus the importance of either type constantly changes. The independence afforded by a powered scooter may be the best solution for going shopping at the mall, but a light and simple manual wheelchair and a strong personal assistant may be the only way to get up the Great Wall of China, in the absence of a stair climbing wheelchair.

Litvak and Enders list seven factors influencing the choices or preferences for how the individual designs his/her support systems:

1. Cost of the support and the individual's ability to finance it.
2. Time required to use one support versus another.
3. Availability of the desired support in one's society and area.
4. The degree of privacy and confidentiality versus companionship that a particular support affords.
5. Maintenance and managing cost for the support.
6. Physical and mental ease of use.
7. Visibility, intrusiveness and degree of stigma attached to the support.

ASSISTIVE TECHNOLOGY AND POWER

Technology can be seen as a manifestation of economic, political, social and cultural concepts as well as individual wishes and ideas, and the question of power is embedded. The possibility of empowerment or risks of disempowerment is strongly dependent on the power relations in the system in which the technology is introduced. The perspectives of the users or the task of changing power structures "is not at the heart of technical research unless social science perspectives are integrated" (Östlund, 2005). Optimization from technological factors alone is seldom fruitful when it comes to *Assistive Technology*. Technology that is used to empower people can also be used for the construction of the image of the "disabled person".

Seelman (2001) argues that technological decision-making has been too much in the hands of professionals and experts and that disabled people are invited mostly in an advisory capacity with no real power over policy decisions. Goggin and Newell (2003) suggest that this deficiency can widen the gap between disabled and non-disabled persons, rather than diminishing it.

> The problem is that accounts of the development of digital technologies, like those of the wheelchair and cochlear implant, overwhelming view such technological systems as being inherently good and evidence of society's progress. Rarely is a broader perspective on the creation of technology taken, acknowledging how it is shaped by the role of professional

> groupings and specialized knowledges, or the politics of technological systems (ibid., p. 9).

The power relations affect the use of technology all the way down to the individual user. A friend of mine refuses to use a certain assistive device because it makes him look "stupid". Another friend discards the use of a certain technology because he does not trust it, i.e. does not have sufficient control over it.

The question of under-use, abandonment and non-use of assistive technology is a well known and discussed problem (Wessels et al., 2004). In a number of studies, Scherer has examined the complex issue of under-use and abandonment (Scherer, 2002; 1996; 2000). Scherer pinpoints the meagre user involvement in the selection of assistive technology as the single most important reason for the devices not being used.

Ratzka (2003a) further elaborates how the users of assistive technology must be strengthened as consumers rather than be considered patients. To be in good health but in need of functional assistance has nothing to do with the medical system. Ratzka concludes that the placement of assistive technology within the health care system "places us in the midst of the medical model of disability where disabled people are seen as problem bearers, where professional training is valued higher than first-hand experience, where disabled people are relegated to passive objects of professional intervention" (Ratzka, ibid.). Ratzka suggests a model where direct payments are used for the provision of assistive technology and foresees that this could turn over control of functional assistance to people with disabilities, making them take an "active role in the provision of assistive technology" instead of being only "frustrated embittered patients" subject to unwanted and unnecessary medical attention.

A way to break loose from the sometimes unwanted influence of professionals can be to share solutions with each other. Internet has hugely enhanced the prospects for do-it-yourself devices, cf http://www.atsolutions.org/ .

UNIVERSAL DESIGN – DESIGN FOR ALL

Assistive Technology has many connections to *Universal Design* (with its roots in the US) and *Design for All* (European), with its British branch *Inclusive Design.*

The concept of *Universal Design* was put forward by a group of professionals and researchers at the Centre for Universal Design at North Carolina State University. Seven principles of Universal Design are provided to guide the design of both products and environment (Connell et al., 1997). They are as follows:

1. Equitable Use. The design is useful and marketable to people with diverse abilities.
2. Flexibility in Use. The design accommodates a wide range of individual preferences and abilities.
3. Simple and Intuitive. Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
4. Perceptible Information. The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
5. Tolerance for Error. The design minimizes hazards and the adverse consequences of accidental or unintended actions.
6. Low Physical Effort. The design can be used efficiently and comfortably, and with a minimum of fatigue.
7. Size and Space for Approach and Use. Appropriate size and space is provided for approach, reach, manipulation, and use regardless of the user's body size, posture, or mobility.

The European Institute for Design and Disability (EIDD) defines *Design for All* in the Stockholm Declaration as follows:

> Design for All aims to enable all people to have equal opportunities to participate in every aspect of society. To achieve this, the built environment, everyday objects, services, culture and information – in short, everything that is designed and made by people to be used by people – must be accessible, convenient for everyone in society to use and responsive to evolving human diversity (EIDD, 2004).

Both *Universal Design* and *Design for All* are "holistic approaches that enlist ergonomics to create goods, processes, and environments accessible to all" (Seelman, 2005).

DESIGN FOR ALL AND DESIGN FOR ME

Not to be hindered by unnecessarily built in obstacles in environments and artefacts is a key factor for disabled people being able to participate fully in society, and have control over their presence there. The principles behind *Design for All*, *Universal Design* and *Inclusive Design* are extremely important for disabled people (Imrie & Hall, 2001; Aslaksen et al., 1997) and they are fairly well accepted as a desired goal in design. But to put these into practice is not without problems. No standard disabled person, with standard wishes exists, but rather a multitude of individuals with different abilities, wishes and personal standards.

The concept of *Design for Me* is introduced here to balance, complement and further *Design for All.*

From the perspective of the designer, *Design for All* means accommodating for a great number of personal solutions. Where *Design for All* is the societal, market or designer perspective, *Design for Me* holds the user perspective. The user wants his/her functions to work as smoothly as possible and to be able to have control over them.

Design for Me is already the predominant design solution when it comes to personal assistance; tailor made to fit the needs of the individual and where full personal control is seen as a prerequisite for high quality of assistance. The same argument holds for technical assistance.

Design for All and *Design for Me* aim at the same problem complex, the desired functioning of the individual, and are complementary but differ on where the main technological solution is positioned. *Design for Me* can be associated with "stand-alone AT" or "orphan technology" (Seelman, 2005) but goes much further. *Design for Me* consequently implies, but is not synonym to, a high degree of adaptation with the individual. This does not imply that adaptation with the environment is unwanted or unnecessary, quite the opposite. It merely points to the fact that higher functioning control can be achieved in a system where assistance can be more personalized, and that assistive technology with high functioning power that follows the individual makes him/her more independent of the environmental changes.

Design for Me also implies a high level of participatory design efforts with a high degree of user involvement in the shaping of the whole support system of technological and personal assistance.

In almost all cases a good *Design for All* facilitates *Design for Me. Design for Me* can also help in dealing with the *Design for All* paradox: accommodating for all possible use by all people in a certain situation is impossible. All people do not require the same kind of solutions. Sometimes the desired solutions are directly incompatible.

An example: I once had to use a bathroom at a Centre of Independent Living I was visiting. The bathroom held a number of different advanced adaptations; these were not helpful but rather in the way for me, and made the bathroom virtually unusable.

This paradox is of course a well known, but a seldom problematized (at least to any depth) fact within *Design for All* and *Universal Design* writings.

In many cases technology that has been developed for disabled people has made its way into the majority of the population (taps operated by one hand, remote control, low-floor buses, etc.)

(ICTSB Project Team, 2000). In many cases it is true that what is good for disabled persons is also good for the majority without disabilities, but it is no universal truth. Even less of a universal truth is that what is good for some disabled people is good for others.

Arguments can be raised against relying on individual technological solutions, seemingly associated with the individual model of disability, where the disability is positioned as a defect of the individual. The improvement of functioning of the individual have often been portrayed as promoting a negative, disempowered image of disabled people, rather than seeing the problem as political, social and environmental.

Along with many other disability studies, Litvak and Enders (2001) support this view:

> The more "friendliness" that can be built into the environment, the fewer specialized supports the person will need to carry along. While elevators are not likely to be installed on Everest, curb cuts on city streets and accessible buses reduce the "hostility" of the environment. Continuing to see the problem as being in the individual (the medical model), as opposed to seeing the environment or society as being disabling (the interactive or environmental model), leads to design priorities for building stair-climbing wheelchairs rather than building ramps and curb cuts.

This point of view is at first easy to argue along with. Curb cuts, ramps and accessible buses signals, no doubt, a welcoming attitude, and the lack of them can be perceived as hostility towards a person in a wheelchair. But it could also be argued that in relying on the multitude of necessary adaptations of the environment, both manmade and in nature, disabled people lose control over where and when they want to go. Instead, the sporadic and occasionally made adaptations in places decided by others determine where we are allowed to go. With individual solutions the control lies with the individual. It may be argued as well that a high degree of individual control can be a positive attitude shaping element in itself. The image of helplessness can be hard to maintain where an individual has control over the situation.

A wheelchair that can climb stairs and drive around in the countryside could prove to be a better solution than having to adapt all buildings and environments in the world; and a cell phone is a much better solution than installing stationary telephones on every street corner. The closer to the individual and the more mobile and adaptable, the better the solution often is, at least if the emphasis is on control.

Rather than seeing the difference between *Design for Me* and *Design for All* as a question of the individual vs. the environmental model of disability, it could (somewhat simplified) be seen as a question of weigthing attitude vs. control aspects of functioning.

As Litvak and Enders (ibid.) suggest, research is needed on what kind of technology disabled people desire and expect, "e.g. should there be curb cuts or curb-climbing wheelchairs?"

The question of where the line is drawn between desired use of *Design for Me* and *Design for All* must be constantly negotiated and problematized in the situations where the assistance is needed. The FACE method is designed to investigate this type of questions.

One should not allow *Design for All* to make oneself blind to the possibilities of *Design for Me.* Situated solutions (for Me!) represent in themselves one of many possible ways of adapting environments. It is not fruitful to be too dogmatic. For instance, if I could not see the blackboard at a distance, I would not demand it to be brought to me and only me; I would put on my glasses like everyone else. It is the multiple, parallel ways to perform a function that allow for *Design for Me*, and a selection from a smorgasbord is better than a dish that contains all different flavours.

The Internet is often a wonderful example of *Design for Me.* Functions can be performed in a multitude of ways and controlled and adapted according to the wishes of the user. In Papers III and IV, many examples are given as to how disabled people have been able to create solutions to desired functions by using the multitude of functions afforded to them in the virtual environments.

Assistive Internet technology

With increasingly more societal functions being moved to the Internet, an online identity is becoming more "normal". It promotes a wide variety of new opportunities, i.e. the possibilities of being a student (Amtmann & Johnson, 1998; Anderberg, 1999; Schenker & Scadden, 2002) or being a teacher (Lance, 2002; Coombs, 2000; Tobin, 2002) by using online education.

Furthermore, the ability to control your online identity by disclosing or not disclosing information about yourself, and choosing any online identity you wish, is a beneficial result of the bodiless online presence. This facilitates, increases and enhances social interaction and opens up new communication opportunities for disabled people. Bowker and Tuffin (2002) have analysed the effects of communication on online media for disabled people from the perspective of identity. They identified a "choice to disclose" repertoire that was organized around three key resources: relevance, anonymity and normality. In an online setting with text-based communication, individuals can control how others perceive them, by disclosing or not disclosing information about themselves. In addition, an individual can choose any identity he/she wishes, thus "assimilating into 'normal' culture" and thereby positioning this identity within a subjectivity removed from impairment. This provides disabled people access to a social context they would not normally have, as well as "time-off" from the disabling perceptions of others.

In a similar study, Seymour and Lupton (2004) examined online communication for disabled people. They found social and communication benefits, but were concerned that these opportunities were not fully exploited by disabled people as a group. "In providing the technological means to participate, cyberspace must be used by disabled people to construct satisfactory avenues of fulfilment for themselves and effective new forms of political activity. Techno-sociality and virtual participation promise new avenues for personal fulfilment and political action, and point to new ways of being and having a body" (Seymour & Lupton, 2004).

In a study of disabled Internet users in China, Huang and Gou found that involvement in online activities could generate higher levels of social capital for the users (Huang & Guo, 2005).

The visual anonymity associated with online interaction offers disabled people the potential to participate in social interaction beyond the stigma of a disabled identity. This is evident in the qualified deception repertoire where participants deliberately construct themselves and situations in ways which have no reality beyond the online context, yet are entirely justified because they protect disabled people from stereotyped judgements (Bowker & Tuffin, 2003).

The opportunity for autonomous skill acquisition and presentation is one of the most powerful functions that computers and the Internet have to offer. Improvement of spatial functions and skills in children by using computerized games (Akhutina et al., 2003) and virtual reality environments (Wilson et al., 1997; 1998) are examples. Studies with disabled children have shown that certain skills learnt with and via the computer can result in a number of social gains, including play and communication with peers and parents. Just as important as the creation of a system where skill acquisition is possible, is the potential to present these skills and to be able to excel in certain areas (Lindenstrand & Brodin, 2004; Lindenstrand & Brodin, 2003).

The Internet is a comparatively fast and easy-to-use source of information for disabled people. The ease in publishing online lets disability information and culture flourish there on many different levels (Thoreau, 2006; Goggin & Newell, 2003). Especially interesting is the possibility for disabled people to access and control information, e.g. peer-to-peer information and contrasting views of mainstream, non-disabled and professional information sources. Thoreau carried out a qualitative study of representations of disability by disabled people on *Ouch*, a BBC-owned web magazine produced largely by disabled people. Thoreau found that the discourse on the website produced quite a different picture than that offered by the mainstream traditional media. It offered a disability-centred, experience-based, active, and positive picture of disabled people, within which they were represented as the majority, while non-disabled people were seen as an "other" (Thoreau, 2006).

In a study of 200 Centres of Independent Living in the US, a great variety of information was found online that promotes "consumer management over services, peer exchange, disability resources in local communities, advocacy, employment, and current information" (Ritchie & Blanck, 2003).

The possibility of expanding the geographical area for finding interesting contacts among other disabled people is a function available in virtual environments. This improves knowledge transfer between disabled people and can provide positive role models and expanding career choices (Burgstahler & Doyle, 2005). Disabled people can find it difficult to find specialized information appropriate to them regarding health care. The Internet can be used to provide disabled women with this kind of specialized information about reproductive health, for example (Pendergrass et al., 2001).

The Internet is a "unique tool for people with disabilities and others to engage directly in advocacy and social change activities" (Blasiotti et al., 2001). Transfer of information over the Internet can counterbalance and complement the information that flows from the professional world to people with disabilities. An arena where peer-to-peer learning is made possible can have a number of positive consequences in efforts to create political and ideological awareness. In mainstream politics, Internet provides opportunities for being included and participating in democratic processes by using different tools of e-government (Stienstra & Troschuk, 2005).

The potential of computers and the Internet for disabled people is undisputed for the most part, even though present-day practice fails to fulfil this potential in a number of ways and for many. Critics have pointed out the dangers of building a new and inaccessible environment on the Internet. Goggin and Newell argue that the Internet holds great opportunities for disabled people, but is in danger of becoming a new arena for the social creation of disability. Developments ignore disabled people and assume non-disabled patterns, thereby creating a system where disability increases rather than decreases (Goggin & Newell, 2003).

The term "digital divide" has been coined to point out the differences in Internet access that stem from social, economic and educational barriers in a discriminating society. The grim reality is that disabled people, to a great extent, are on the have-not side of the digital divide. Stephen Kaye found that those who are disabled have considerably less access to both computers and Internet connections than non-disabled individuals (Kaye, 2000).

A Chinese study found a large reduction of social barriers for disabled people in that country who were Internet users, with a significantly improved frequency and quality of social interaction. But these are a minority and unrepresentative of the vast majority of disabled people in China. Disabled people with access are privileged and generally have a high level of education, relatively high levels of socio-economic support, and access to computer equipment and Internet services (Guo et al., 2005).

Criticism of the use of the term digital divide for being too "mechanistic-binary" in the sense that one is either "info-rich" or "info-poor" based on the mere availability of technology, has been put forward by Chaudry and Shipp. They have examined the barriers to information access faced by visually disabled people and propose a new paradigm, "information inequity", that would consider the economic, political, cultural and educational as well as the technological aspects of marginalization (Chaudry & Shipp, 2005). All these aspects are intertwined in one another and are hard to separate. However, the actual user interface adaptations and the accessibility of online material are on a special level. People with different impairments experience different problems; without proper technological adaptations, portions of the online arena remain inaccessible for many, even when an Internet connection is available. Disabled users of the Internet who have sensory impairments or learning difficulties may find themselves excluded from online information sources due to an inaccessible web format. Still, these shortcomings must be analysed, keeping in mind that old information technologies, such as the printed press, "created enormous quantities of inaccessible information" (Coombs, 2000) for people who are blind or have low vision.

You can either be optimistic about the possibilities of technology and the market economy to solve these problems (Tusler, 2005) or take on a more negative approach to these mechanisms (Seymour, 2005). Either way, Internet developments must be closely watched and principles of universal design enforced at the earliest possible stages of IT research and development. Incorporating accessibility from the beginning is the only workable strategy (Seelman, 2000).

The question of development of new technologies or services can be seen as an invasion of the private lives of the users. This is interesting from an ethical point of view (Rauhala, 2003). Technology that supports independent living and/or health care in the home can easily be used for surveillance and control. The question of who is in control over the ICT that is used and developed must always be problematized.

Conclusions

"I put all my things in a pile in the middle of the floor. That way I know where they are."

"But Mu, you have so many things," said Mamma Mu, "That's certainly a big pile, isn't it?"

"You're right about that," said Crow, "Big, bigger and biggest. And bigger than biggest. That's how big it is."

"Oh, no," said Mamma Mu. "Is it that big? But how will you be able to find what's at the bottom?"

"No problem! I put everything on top." (from *Mamma Mu Cleans*, by Jujja & Tomas Wieslander, 1997)

The Handbook of Disability Studies is impressive in its content and size. If it is on the table in front of me, I can browse through it, but I can not manage to put it back; nor am I able to take it out when I need it. It is the same for most books now, particularly if they are at the bottom of a pile. And it is not just books; most of what I need seems to be at the bottom of a pile or out of reach for some other reason.

That is not the case with my computer and Internet, though. Everything there is in a great big pile too, but it is all on top. I quickly find the books or articles I need and just as quickly can find the sections I am looking for. I read everything I am able to on the computer without a problem. Unfortunately, the selection of older texts is still meagre. I do not understand people who say they have to have a hard copy of a book in order to read it, or have to use an old typewriter with a ribbon or a goose quill in order to write. Books are beautiful on the shelf, but quite useless for me. But if it best suits someone else to read a traditional book, I think that they should be able to do so. The greater the number of solutions for the function of reading, the better it is for even more people. Digital books, talking books, hard cover, paperbacks; all make the contents of the book accessible for as many people as possible. Above all, it makes the text accessible for me, in the way *I* want it and in the combinations that suit *me* best on any given occasion. It can be designed for me.

Disabled people will always live in a predominantly "able-bodied" world, where the practices related to living with a disability are rarely visible. The Internet provides opportunities for increasing contacts and building personal networks, as well as increased visibility for the disabled individual, both inwards (to our own group) and outwards (to people who do not normally meet disabled people). Peer support and role modelling can more easily become available to a larger number of people. Possibilities of independence, learning and communication are afforded the disabled persons who make their way to the online environments. Still a tendency to view the online environments and contacts as a second best solution, or an impoverished substitute to physical environments and "real" human contact, can be found in many texts. This is not, however, a very fruitful standpoint. Apart from the obvious fact that far from all people find the online setting second best to the physical under all circumstances anyway, it is also possible to do a simple current state analysis. There is actually an enormous number of inaccessible buildings and environments, discriminating attitudes and structures in the world, and there is no way that they will go away in any near future, regardless of the policies today. Even with the most progressive politics, fully enlightened by a social model understanding, disabled people will continue to be discriminated against in the coming years. The Internet actually exists here and now, it is what we have and what can give us relief here and today. The functioning described and analysed in this thesis shows that the opportunities afforded by computers and the Internet have resulted in not only improvements, but also in first time occurrences of great personal magnitude, where functions previously unavailable or impossible became readily available.

Needless to say, the possibilities to network and learn online must also be used for increased political and ideological strength, a strength that can be used in the physical world as well. This is because the different systems are complementary, in that everyone should be allowed to have their mixture of online and physical environments according to their personal wishes. And it should always be kept in mind that for some people, the physical contact possibilities are so limited that it is really not an option; the development of a virtual arena is the only one possible. It is important that it is allowed to develop and grow as an arena of its own, and not constantly be compared to the more "real" physical contact space. The improvement of Internet and other technologies, as well as our understanding of how people can control and interact with the technological systems they occupy and use is extremely important for the possibilities of disabled people to improve our lives.

I find it difficult to accept that the field of disability studies often seeks to leave out the whole area of rehabilitation and assistive technology and place disability studies "as a socio-political-cultural examination of disability", distanced from "the interventionist approaches that characterize the traditional study of disability" (Linton, 1998). If instead, studies of the use of technology by, and its consequences for, disabled people were at the heart of disability studies, it would have at least two key consequencies:

1) Some of the modern rehabilitation engineering research of today tries to approach disability studies, with a more holistic view on disabled people. But the theory building and analysis in rehabilitation engineering and design could no doubt benefit from a greater interest in its epistemology from theorists within disability studies. Who decides what a wheelchair should look like, and why are

there so few models and types? Who has the power to decide what research should be performed in rehabilitation engineering? How is disabled peoples' self image affected by the technological systems one uses and dwells in every day, and how can this be changed? These are some of the questions where rehabilitation engineering research could benefit from the insights and analyses from disability studies.

2) Disability studies could broaden its area of implementation. The successful lean-backward analysis of functional barriers and shortcomings of society and technology is not sufficient for guiding the implementation of empowering and enabling technology. There is a need for a lean forward-analysis, as well, which utilizes the possibilites of technology both as probes and solutions. The outcome of such situated, user oriented "enabling", or " enability studies" is by no means foreseeable but could yield insights into the needs, wishes and dreams of users on a level more concrete than other methods.

This research is a small step in highlighting and extracting key aspects of the relevant features at the intersection of disability studies and rehabilitation engineering and design. FACE can be considered an early representative of future tools for analysis of assistive technology in its widest context, tools which emanate from both technology and sociology.

The functions and environments described in this thesis are not exclusive to disabled people and they have few distinctive or identifiably unique solutions. In the virtual world, the functional impairment is left unremediated, and the functionally creative effect that arises is a consequence of the technology's ability to enable full participation in a variety of arenas without the usual limitations of the body. Accordingly, this is where the rehabilitation disciplines' individual functional enhancement and the social model's requirement for change in the environment come together – it becomes an arena accessible for all.

Populärvetenskaplig sammanfattning på svenska

Denna avhandling baserar sig på de erfarenheter av Internet som ett antal människor med betydande kroppsliga funktionsnedsättningar gjort. Personerna i studierna är erfarna och duktiga dator- och Internetanvändare och har få eller inga funktionshinder i dator och online världen, men däremot stora funktionshinder i den fysiska världen. Deras *functioning,* förmåga att fungera, på Internet analyseras i denna avhandling med hjälp av faktorerna *attitude* (attityd), *control* (kontroll) och *enabling* (möjliggörande) för att utröna vad som är möjligt när alla nybörjarproblem och alla dåligt anpassade gränssnitt redan är avklarade. Om den virtuella världen är fullt tillgänglig men den fysiska inte är det – vilka blir då effekterna på självbild, lärande, lärande gemenskaper, känsla för sammanhang, makt och kontroll? Vilka är effekterna av *peer-to-peer* lärande och samarbete? *Independent living*, dess begrepp och teorier, går som en röd tråd genom avhandlingen. Mest uppenbart är detta kanske genom valet av studier och perspektiv. Den teoretiska bakgrunden och de begrepp som används kommer från d*isability studies* utifrån ett *social model* och *indepdendent living* perspektiv samt från rehabiliteringsteknik och design. Just möjligheterna till samspel och ömsesidig utveckling mellan rehabiliteringsteknik och design å ena sidan och å den andra disability studies är ett centralt tema. Olika aspekter på design och teknik för funktion behandlas med hjälp av FACE-verktyget (Functioning- Attitude, Control, Enabling) ur ett utökat funktionsperspektiv, både individuellt och socialt.

SYFTE

Med sin grund i rörelsehindrade personers handlingar och beskrivningar av sitt Internetanvändande är syftet med denna avhandling att identifiera, beskriva och analysera de funktionsmöjligheter som Internet erbjuder.

Dessutom är målet att illustrera, diskutera och ge förslag på utveckling av den potential till samspel och ömsesidig utveckling som finns mellan rehabiliteringsteknik och design på ena sidan och disability studies på den andra.

BAKGRUND

Sedan ca 30 år tillbaka har jag gradvis fått en ökande funktionsnedsättning pga en muskelsjukdom. De senaste femton åren har jag använt rullstol, både elektrisk och manuell. Jag har personlig assistans en stor del av dygnet för att få hjälp med praktiska göromål i den fysiska miljön. Jag utexaminerades som civilingenjör 1997 och avlade teknologie licentiatexamen år 1999.

ANDREAS, LINUS & JAG

Andreas är sju år och Linus är fem. De älskar att leka kurragömma med mig. Det brukar börja med att de springer iväg långt bort och jag väntar en stund innan jag följer efter. De brukar ta vägen ner mot bäcken, över bron och bort mot vattenfallet, så jag vet ungefär var jag skall leta. När de har gömt sig brukar de hålla ett öga på mig så de vet var jag tar vägen. På senare tid har de lärt sig att ta vägen uppför kullen och bort mot den långa muren, den som liknar kinesiska muren, och som går hela vägen nerifrån dalen och upp mot bergen. Där är de svårare att hitta, men de brukar alltid låta mig få ana var de finns så att det inte tar mig för lång tid att komma på rätt spår. När jag börjar närma mig brukar de alltid smita iväg och jag får jaga efter dem igen till deras stora förnöjelse. De tycker också att det är roligt när vi far fram över ängarna och in i skogen.

När jag nästan fått fatt på någon av dem så brukar de ta ett skutt och hoppa rakt upp i luften. Sedan de lärde sig att flyga så har de insett att det är ett bra sätt att utnyttja ytterligare en dimension för att komma undan. Det är en härlig känsla med farten när vi far fram ganska lågt över kinesiska muren. Jag älskar att flyga fram där med Andreas och Linus i knäet, hålla om dem och gosa lite med dem när de är upptagna av att störta ner för den kinesiska muren i full fart.

Ibland tar jag med dem ner till stan och så tittar vi på alla konstiga saker och hus som finns där. De frågar om allt på barns vis och jag förklarar så gott jag kan alla de konstiga saker vi stöter på. Ibland fotvandrar vi omkring i Yellowstone eller i snövärlden, eller springer runt bland ruinerna i det gamla Grekland. Vi har faktiskt varit på Mars några gånger också och tittat på rymdskeppen.

Andreas och Linus brukar alltså sitta i mitt knä i rullstolen när vi utforskar och leker i Active Worlds alla olika världar. Jag har min dator på skrivbordet rakt framför mig och Andreas har den datorn som står på bänken till vänster, Linus har den till höger. Vi sitter tillsammans i den fysiska världen och leker med varandra i den virtuella. Det är bara jag och mina barn, min fru är inte med, inga personliga assistenter, ingen annan utan bara en pappa och hans barn som springer runt och busar.

Jag umgås ganska mycket med mina barn, vi ritar, bygger lego, läser böcker och en massa annat. Men i många lekar och aktiviteter får jag ta rollen av relativt passiv åskådare. Att jag kan leka med mina barn på det sätt som jag beskrivit ovan, beror på att jag sedan lång tid tillbaka använder mig av datorn, internet och de virtuella miljöerna för att kompensera och eliminera de funktionshinder som uppstår i olika situationer.

REHABILITERINGSTEKNIK OCH DESIGN

Rehabiliteringsteknik och design är ett tvärvetenskapligt ämne som omfattar det som uppkommer då en människa och de funktionshinder hon upplever i en eventuellt funktionshindrande miljö möter teknik som är ägnad åt att minska eller eliminera detta funktionshinder.

Rehabiliteringsteknik och design har människan i centrum och använder tekniken som ett medel för att uppnå de funktioner som användaren av tekniken önskar. Designprocessen omfattar även tiden efter att användaren börjat använda tekniken. Detta är centralt eftersom designprocessen då kommer att omfatta en mängd faktorer som inte är bara tekniska till sin natur. Att involvera användaren i hela processen samt att fokusera på faktorer som oberoende, integritet och egenmakt gör att hela designprocessen måste vara grundad i användarens levda funktionshinder. Det krävs ett medvetande om den grundläggande skillnaden mellan en människas funktionsnedsättning å ena sidan och de olika faktorer i den omgivande miljön som i sig kan ge funktionshinder eller förhindra att de uppstår.

DISABILITY STUDIES

Den ideologiska grundstenen i Disability Studies utgörs av *the social model.* Den ursprungliga *social model of disability* blev formulerad på tidigt 80-tal av Mike Oliver, med utgångspunkt i *the Union of the Physically Impaired Against Segregation (UPIAS)* (1975) och dess definition och separation av funktionsnedsättning och funktionshinder (*impairment and disability*). *The social model* gör en skarp skillnad mellan att anpassa individen och att anpassa de omgivande strukturer i vilken individen vistas. Detta görs genom att man skiljer på den funktionsnedsättning som finns hos individen (impairment) och det funktionshinder (disability, disablement) som olika sociala och fysiska miljöer skapar för en människa med en sådan funktionsnedsättning.

Detta flyttar funktionshindret från att vara ett problem eller en egenskap hos den enskilde till att vara en kontextuell egenskap hos miljön. Funktionshinder definieras som ett socialt konstruerat förtryck.

INDEPENDENT LIVING

Independent living rörelsen och filosofin bakom den är starkt knuten till de grundläggande tankarna som uttrycks genom *the social model* perspektivet. Funktionshinder ses som socialt konstruerade snarare än som en konsekvens av ett medicinskt tillstånd.

Välfärdssystemet kan genom sin organisation skapa bilden av funktionshindrade människor som en börda för sin familj och samhället och att professionell hjälp och assistans är överordnad egna preferenser och upplevelser.

Independent living filosofin är en radikal utmaning av detta tänkande, då man ser funktionshindrade människor själva som de verkliga experterna och de bästa organisatörerna av den funktions assistans man behöver i sina liv. De grundläggande begreppen inom independent living kan sägas vara valmöjligheter, kontroll, frihet och jämlikhet.

ARTIKLARNA

Denna avhandling är en sammanläggningsavhandling och har fyra artiklar som bärande element. Här nedan presenteras artiklarna i korta sammandrag.

ARTIKEL I: MAKING BOTH ENDS MEET

Syftet med denna artikel är att föra fram ett nytt begreppsmässigt designverktyg, FACE, användbart både som vägledning och hjälp för funktionshindrade människor att analysera sin egen funktions assistans, samt som inspiration och begreppsmässiga riktlinjer för designers och forskare inom rehabiliteringsteknik och disability studies. FACE är icke-diskriminerande och fritt från klassifikationer av människor och skiljer sig på så sätt från ett klassificerande system som WHO:s *Klassifikation av funktionstillstånd, funktionshinder och hälsa* (ICF), (WHO, 2001).

Ursprunget till FACE är tvåfaldigt: mina egna erfarenheter av funktionshinder och assistans samt min forskning inom rehabiliteringsteknik och design och disability studies.

FACE verktyget kombinerar tre olika faktorer som påverkar den upplevda funktionen: *attitude* (attityd), *control* (kontroll) och *enabling* (möjliggörande). Detta gör det möjligt att analysera och beskriva funktions assistans på ett nytt sätt genom att fler parametrar än de medicinska, tekniska, ekonomiska och samhälleliga tillskrivs ett förklaringsvärde. Artikeln publicerades ursprungligen i *Disability Studies Quarterly* (special edition on technology and disability studies), Summer 2005, Volume 25, No. 3.

ARTIKEL II: ETHICS IN THE MAKING

Syftet med denna artikel är att analysera hur generella etiska riktlinjer utmanas av en situerad etik i ett designsammanhang. Denna artikel illustrerar hur värderingar är närvarande inte bara i vad som görs utan även i hur det görs. Vare sig ”the medical model” med sin inriktning på individuella funktionsnedsättningar och insatser eller ”the social model” med sin inriktning på ideologisk och politisk analys ger i sig tillräckligt fast mark för etiska ställningstaganden med hänsyn till den berördas upplevelser. Det är i stället hela kedjan av design och teknik respektive hela kedjan av samhällsresurser i sitt använda sammanhang som är det relevanta för det upplevt etiska: från den inledande inspirationen och designbesluten, genom hela designprocessen till det faktiska användandet där mänskligt vardagsliv påverkas av resultaten. Etiska forskningsperspektiv diskuteras både utifrån internationella koder och deklarationer om mänskliga rättigheter och utifrån situerad etik i sammanhang med särskilda önskemål och behov.

Artikeln publicerades ursprungligen i *Design Philosophy Papers*, no 4, 2005.

ARTIKEL III: BEING THERE

Syftet med denna artikel är att utforska Internet användandet så som det upplevdes av människor med betydande rörelsehinder som även är erfarna och kompetenta dator- och Internetanvändare. Studien baserar sig på intervjuer och fokuserar på datoranvändning i vardagslivet, både professionellt och på fritiden.

Resultaten visar att i många fall ger de nya möjligheter som datorn och Internet erbjuder inte bara viktiga förbättringar av livskvalitén utan leder också till helt nya funktioner med viktiga personliga konsekvenser som följd.

Analysen är fenomenografisk och har resulterat i kategorier och subkategorier, som illustreras av citat från intervjuerna. De tre huvudsakliga kategorierna är: *independence* (oberoende), *communication* (kommunikation) och *learning* (lärande).

Artikeln publicerades ursprungligen i *Disability & Society*, Vol. 20, No. 7, December 2005, pp. 719–733.

ARTIKEL IV:
PEER ASSISTANCE WITH PERSONAL ASSISTANCE

Syftet med denna artikel är att beskriva och analysera ett online forum som används av en grupp funktionshindrade människor för att diskutera personlig assistans. Forumet är en *community of practice (CoP)* med sin grund i praktiken att leva med personlig assistans. En *community of practice* är en social gemenskap i vilken praktik, identitet, lärande och meningsskapande kan integreras. Inläggen i forumet studerades under en period av fyra och ett halvt år och bestod av 2755 inlägg från 146 personer. De olika nivåerna av lärandesystemet i CoP analyserades med hjälp av FACE verktyget (se ovan).

Resultaten indikerar att det lärandesystem som uppstår i gemenskapen gör det möjligt för funktionshindrade människor att komplettera, konfrontera och bilda motvikt mot det professionella lärandet på området, dess system, teorier och metoder.

Denna artikel har inlämnats för publicering i *Disability & Society.*

SLUTSATSER

"– Jag la alla mina saker i en hög mitt på golvet. Då vet jag var jag har dom.
– Men mu, du har så mycket saker, sa Mamma Mu. Det blev väl en väldigt stor hög?
– Jajamensan, sa Kråkan. Stor, större och störst. Och större än störst. Så stor blev den.
– Oj då, sa Mamma Mu. Blev den så stor? Men hur ska du kunna hitta det som är underst?
– Jag la allting överst."
(Mamma Mu städar, Jujja & Tomas Wieslander, 1997)

The Handbook of Disability Studies är en imponerande bok både till innehåll och till yttre form. Om den ligger framför mig så kan jag bläddra i den, men jag orkar inte lyfta undan den och kan inte heller ta fram den när jag behöver den. Så är det för övrigt med de flesta böcker numera, speciellt om de har hamnat i den nedre delen av en hög. Inte bara böcker förresten, det mesta jag behöver tycks ligga underst i en hög eller på något annat ställe utom räckhåll.

Fast inte i min dator och inte på internet. Där ligger allt i en stor hög och allt ligger överst. Jag hittar snabbt de böcker eller artiklar jag behöver och jag hittar snabbt de stycken jag söker i böckerna. Jag läser allt jag kan på datorn utan problem, tyvärr är fortfarande utbudet av framförallt äldre texter ganska magert. Jag har ingen större förståelse för människor som säger att de måste ha en pappersbok att hålla i för att kunna läsa och en gammal skrivmaskin med färgband eller gåspenna för att kunna skriva olika texter. Böcker är vackra i bokhyllan men oanvändbara för mig. Men om det av olika anledningar passar någon annan att läsa en pappersbok, så tycker jag att de skall få göra det. Ju fler olika lösningar på funktionen att läsa en text som finns, desto bättre för desto fler. Digitala böcker, talböcker, textböcker, ja, ju fler kanaler och format, desto tillgängligare för fler personer.

Om *Disability studies* i större utsträckning intresserade sig för funktionshindrade människors teknik och teknikanvändning skulle deras kunskap befrukta rehabiliteringsteknik och design – och vice versa. Internet är här ett specialfall av stort intresse eftersom det ger ökade möjligheter till kontakter och personliga nätverk och samtidigt synlighet, både inom intressegemenskapen och ut mot samhället i övrigt. *Peer support* och möjligheten att själv vara förebild och hitta andra ökar. Så gör också oberoende, lärande och kommunikation. Därför bör inte *online* miljöer och kontakter ses som en andrahands lösning, en lite sämre lösning än den fysiska världens och den 'riktiga'mänskliga kontakt som finns där. I själva verket är tillgängligheten och möjligheterna på Internet överlägsna vad otillgängliga byggnader och trafiksystem och rigida sociala strukturer erbjuder. Dessa avarter kommer inte att kunna byggas bort inom en rimlig tid även om politiken skulle ändras och bli mer progressiv på detta område. Internet däremot är redan ett existerande alternativ för många funktioner och kan dessutom användas som utmaning gentemot den fysiska miljön.

References

Akhutina, T.V., Foreman, N., Krichevets, A., Matikka, L., Narhi, V., Pylaeva, N., & Vahakuopus, J. (2003) Improving spatial functions in children with cerebral palsy using computerised and traditional game-tasks. *Disability and Rehabilitation*, vol. 25, no. 24, 1361-–1371.

Akrich, M., & Latour, B. (1992) A Summary of a Convenient Vocabulary for the Semiotics of Human and Nonhuman Assemblies. In: W. E. Bijker & J. Law (Eds.), *Shaping Technology/Building Society: Studies in Socio-Technical Change* (pp. 259-264). Cambridge, MA, USA.: MIT Press.

Albrecht, G.L., Seelman, K.D., & Bury, M. (Eds.) (2001) *Handbook of disability studies.* Thousand Oaks, California, USA: SAGE Publications.

Amtmann, D. & Johnson, K.L. (1998) Increasing access to higher education through the use of the internet. *Technology and Disability*, 8, 133-140.

Anderberg, P. (1999) *Internet learning for all: on initial efforts to achieve satisfactory study opportunities for disabled people.* Licentiate thesis. Lund, Sweden: Certec, Lund University. English summary available online at: http://www.certec.lth.se/doc/internetlearningforall/ (accessed 9 Aug 2006).

Anderberg, P. (2006a) Might and Machines. In: B. Jönsson (Ed.) *Design Side by Side.* Lund, Sweden: Studentlitteratur. Available online in the autumn of 2006 at: http://www.certec.lth.se/doc/designsidebyside/ .

Anderberg, P. (2006b) *WWW.Welcoming.Wide.World.* Lund, Sweden: Certec, LTH, Lund University. Available online at: http://www.certec.lth.se/doc/welcomingwideworld/ (accessed 9 Aug. 2006).

Aslaksen, F., Bergh, S., Bringa, O., & Heggem, E. (1997) *Universal Design Planning and Design for All.* Olso, Norway: The Norwegian State Council on Disability. Available online at: http://www.independentliving.org/docs1/nscd1997.pdf (accessed 9 Aug. 2006).

Balka, E. (1995) Political Frameworks for System Design: Participatory Design in Non-Profit Women's Organizations in Canada and the United States. In: J. Gaertner & I. Wagner, (Eds.) *Workshop Proceedings: Political Frameworks of System Design from a Cross-Cultural Perspective.* Aarhus, Denmark. Available online at: http://www.sfu.ca/~ebalka/aarhus.htm (accessed 9 Aug. 2006).

Barnes, C. (2000) A Working Social Model? Disability, Work and Disability Politics in the 21st Century, *Critical Social Policy*, 20(4), 441-457.

Barnes, C. (2003) Independent Living, Politics and Implications. In the English version of J. V. G. Alonso, *El Movimiento de Vida Independiente, Experiencias Internacionales.* Internet publication URL: http://www.independentliving.org/docs6/barnes2003.html .

Barnes, C., & Mercer, G. (2003) *Disability.* Cambridge, UK: Polity.

Barnes, C., Barton, L., & Oliver, M. (2002) Introduction. In: C. Barnes, L. Barton, & M. Oliver (Eds.), *Disability studies today*. Cambridge, UK: Polity.

Bateson, G. (1972) *Steps to an ecology of mind: A revolutionary approach to man's understanding of himself.* New York, NY, USA: Ballantine.

Beck, E.E. (2002a) P for Political: Participation is Not Enough. *Scandinavian Journal of Information Systems*, summer.

Bjerknes, G., & Bratteteig, T. (1995) User Participation and Democracy. A Discussion of Scandinavian Research on System Development. *Scandinavian Journal of Information Systems*, vol. 7, no. 1, April, pp. 73-98.

Blasiotti, E., Westbrook, J., & Kobayashi, I. (2001) Disability studies and electronic networking. In: G. Albrecht, K. Seelman, & M. Bury (Eds.), *Handbook of Disability Studies* (pp. 327-347). Thousand Oaks, CA: Sage.

Bowker, N., & Tuffin, K. (2002) Disability discourses for online identities. *Disability & Society*, 17 (3), 327-344.

Bowker, N., & Tuffin, K. (2003) Dicing with deception: People with disabilities' strategies for managing safety and identity online. *Journal of Computer Mediated Communication*, 8 (2). Available online at: http://jcmc.indiana.edu/vol8/issue2/bowker.html (accessed 9 Aug. 2006).

Brandt, E.N., & Pope, A.M. (Eds.) (1997) *Enabling America: Assessing the Role of Rehabilitation Science and Engineering*, Institute of Medicine. Washington, DC, USA: National Academy Press.

Burgstahler, S., & Doyle, A. (2005) Gender Differences in Computer-Mediated Communication Among Adolescents with Disabilities: A Case Study. *Disability Studies Quarterly*, 25(2).

Callon, M. (1986) Some Elements of a Sociology of Translation: Domestication of the Scallops and of the Fishermen of St. Brieuc Bay. In: J. Law (Ed.), *Power, Action, and Belief: A New Sociology of Knowledge?* (pp. 196-229), London, UK: Routledge & Kegan Paul.

Castells, M. (2000) The Information Age: Economy, Society, and Culture. 1st volume (of 3), *The Rise of the Network Society* (1996, revised edition 2000). Oxford, UK and Malden, MA, USA: Blackwell Publishers.

Chaudry, V., & Shipp, T. (2005) Rethinking the Digital Divide in relation to Visual Disability in India and the United States: Towards a Paradigm of "Information Inequity". *Disability Studies Quarterly*, 25(2).

Claiborn, L.B. (2005) Ditching Dualisms: Education Professionals View the Future of Technology and Disabilities. *Disability Studies Quarterly*, 25(3).

Connell B. R., Jones, M., Mace, R., Mueller, J., Mullick, A., Ostroff, E., Sanford, J., Steinfeld, E., Story, M., & Vanderheiden, G. (1997) *The Principles of Universal Design* (Version 2.0 -4/1/97). Retrieved April 16, 2006 from http://www.design.ncsu.edu/cud/newweb/ about_ud/ udprinciples.htm

Coombs, N. (2000) *Assistive technology in third level and distance education.* Available online at: http://www.rit.edu/~nrcgsh/arts/dublin.htm (accessed 9 Aug. 2006).

Corbett, J. (1997) Independent, proud and special: celebrating our differences. In: L. Barton and M. Oliver (Eds.), *Disability studies: past present and future.* Leeds: The Disability Press. Retrieved 13 June 2004 from http://www.leeds.ac.uk/disabilitystudies/archiveuk/corbett/chapter6.pdf

Deaver, J. (1998) *The Coffin Dancer.* NJ, USA: Simon & Schuster.

Dourish, P. (2001) *Where the Action Is. The Foundations of Embodied Interaction.* Cambridge, MA, USA: MIT Press.

Ehn, P. (1993) Scandinavian Design: On Participation and Skill. In: D. Schuler, & A. Namioka, (Eds.), *Participatory Design. Principles and Practices.* Mahwah, NJ, USA: Lawrence Erlbaum.

EIDD (The European Institute for Design and Disability) (2004) *The Stockholm Declaration.* Available online at: http://www.design-for-all.org/images/stockholm_declaration.doc (accessed 9 Aug. 2006).

EUSTAT (1999) *GO FOR IT! A Manual for Users of Assistive Technology.* EUROPEAN COMMISSION DG XIII Telematics Applications Programme Disabled and Elderly Sector Deliverable D05.4 Project DE 3402.

Frieden, L., Richards, L., Cole, J. and Bailey, D. (1979) *ILRU Sourcebook: Technical Assistance Manual on Independent Living.* Houston,TX, USA: ILRU.

Gabel, S., & Peters, S. (2004) Presage of a paradigm shift? Beyond the social model of disability toward a resistance theory of disability. *Disability and Society,* 19 (6), 571-596.

Gedenryd, H. (1998) *How Designers Work – Making Sense of Authentic Cognitive Activities.* Doctoral thesis. Cognitive Studies, no. 75. Lund, Sweden: Lund University.

Global Summit (1999) An International Summit Conference on Independent Living September 21-25, *Analysis of the International Independent Living Timeline.* Washington, DC, USA. Available online at: http://www.ilru.org/html/projects/international/4-analysis_of_the_timeline.htm (accessed 9 Aug. 2006).

Goggin, G., & Newell, C. (2003) *Digital Disability: The Social Construction of Disability in New Media.* Lanham, MD, USA: Rowman & Littlefield.

Gould, J.D. & Lewis, C. (1985) *Designing for Usability: Key Principles and What Designers Think.* Communications of the ACM, vol. 28, issue 3, pp. 300-311. New York, NY, USA: ACM Press. Available online at: http://doi.acm.org/10.1145/3166.3170 (accessed 9 Aug. 2006).

Greenbaum, J. (1993) *PD: A personal statement*, Communications of the ACM (CACM), Special Issue on Participatory Design, 36(6), p.47. New York, NY, USA: ACM Press. Available online at: http://doi.acm.org/10.1145/153571.214816 (accessed 9 Aug. 2006).

Guo, B., Bricout, J.C., & Huang, J. (2005) A common open space or a digital divide? A social model perspective on the online disability community in China. *Disability and Society*, 20(1), 49-66.

Hasler, F. (2003) *Philosophy of Independent Living*. In the English version of J. V. G. Alonso, *El Movimiento de Vida Independiente, Experiencias Internacionales*. Internet publication URL: http://www.independentliving.org/docs6/hasler2003.html (accessed 9 Aug. 2006).

Haraway, D. (1991) A Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late Twentieth Century. In: D. Haraway, *Simians, Cyborgs and Women: The Reinvention of Nature*. New York, USA: Routledge.

Helander, M. G., Landauer, T. K., & Prabhu, P. V. (Eds.) (1997) *Handbook of Human-Computer Interaction*, 2nd Edition. New York, NY, USA: Elsevier Science Inc.

Hernwall, P. (2001) *Barns digitala rum. Berättelser om e-post, chatt & Internet*. Stockholm, Sweden: Pedagogiska institutionen, Stockholms universitet.

Howard, J. (2004) Toward Participatory Ecological Design of Technological Systems. *Design Issues*, 20(3).

Huang, J. & Guo, B. (2005) Building social capital: a study of the online disability community. *Disability Studies Quarterly*, 2005, 25(2).

ICTSB Project Team (2000) *Design for All*. Final Report 15.05.2000. Available online at: http://www.ictsb.org/Activities/Documents/ICTSB%20Main%20Report%20.pdf (accessed 9 Aug. 2006).

Imrie R., & Hall, P. (2001) *Inclusive Design, Designing and Developing Accessible Environments*. London, UK/New York, USA: Spon Press.

International Standardization Organization (2002), ISO 9999:2002, *Technical Aids for Persons with Disabilities – Classification and Terminology*, Central Secretariat, Geneva Switzerland, http://www.iso.ch/iso/en/ISOOnline.frontpage (accessed 9 Aug. 2006).

Jain, S. (1999) The Prosthetic Imagination: Enabling and Disabling the Prosthesis Trope. *Science, Technology, & Human Values*, 24(1), 31-54.

Jönsson, B., & Anderberg, P. (1999) *Rehabilitation engineering and design research-theory and method*. Lund, Sweden: Certec, LTH, Lund University. Available online at: http://www.english.certec.lth.se/theory.html (accessed 9 Aug. 2006).

Jönsson, B., Malmborg, L., Svensk, A., Anderberg, P., et al. (2004) *Situated Research and Design for Everyday Life*. Lund, Sweden: Lund University, LTH, Certec. Available online at: http://www.english.certec.lth.se/doc/situatedresearch/ (accessed 9 Aug. 2006).

Kaye, H. S. (2000) Computer and internet use among disabled people. *Disability Statistics Report* (13), Washington, DC, USA: Dept. of Education, National Institute on Disability and Rehabilitation Research.

Kensing, F. & Blomberg, J. (1998) Participatory Design: Issues and Concerns, *Computer Supported Cooperative Work*, 7:3-4, 167-185.

Kirschner, Paul A., Buckingham-Shum, Simon J., Carr, Chad S. (2003) *Visualizing Argumentation. Software Tools for Collaborative and Educational Sense-Making.* Springer-Verlag, London, UK.

Kvale, S. (1997) *Den kvalitativa forskningsintervjun* (The qualitative research interview), Lund, Sweden: Studentlitteratur.

Lance, G.D. (2002) Distance learning and disability: a view from the instructor's side of the virtual lectern. *Journal of Information Technology and Disability*, 8, 1. Available online at: http://www.rit.edu/~easi/itd/itdv08n1/lance.htm (accessed 9 Aug. 2006).

Landow, G.P. (1992) *Hypertext. The convergence of contemporary critical theory and technology.* Baltimore, MD, USA & London, UK: John Hopkins University Press.

Latour, B. (1991) Technology is Society Made Durable. In: J. Law (Ed.) *A Sociology of Monsters. Essays on Power, Technology and Domination* (Sociological Review Monograph) New York, USA and London, UK: Routledge, pp.103-131.

Law, J. (1992) *Notes on the Theory of the Actor Network: Ordering, Strategy and Heterogeneity.* Lnacaster, UK: Centre for Science Studies, Lancaster University.

Law, J. (1987) Technology and Heterogeneous Engineering: the Case of the Portugese Expansion. In: W. E. Bijker, T. P. Hughes & T. Pinch (Eds.), *The Social Construction of Technical Systems: New Directions in the Sociology and History of Technology.* Cambridge, MA, USA: MIT Press, pp. 111-134.

Lindenstrand, P. & Brodin, J. (2003) Are computers the solution to support development in children in need of special support? *Technology and Disability*, 16, 137-145.

Lindstrand, P. & Brodin, J. (2004) Parents and children view ICT. *Technology and Disability,* 16, 179-183.

Linton, S. (1998) Disability Studies/Not Disability Studies. *Disability & Society*, 13(4), 525-540.

Litvak, S., & Enders, A. (2001) The interface between individuals and environments. In: G.L. Albrecht, & K.D. Seelman (Eds.), *Handbook of disability studies.* Thousand Oaks, CA, USA: Sage.

Moser, I. & Law, J. (1999) Good passages, bad passages. In: J. Law, & J. Hassard (Eds.), *Actor Network Theory and After.* Oxford, UK: The Sociological Review and Blackwell, pp. 196-219.

NIDRR (National Institute on Disability and Rehabilitation Research) (1999) *NIDRR's Long Range Plan – Technology for Access and Function Research.* Washington, DC, USA: US Dept. of Education.

Nielsen, J. (1993) *Usability Engineering.* San Diego, CA, USA: The Academic Press Inc.

Oliver, M. (1990) *The politics of disablement.* London: Macmillan Education.

Oliver, M. (1996) Defining impairment and disability. In: Barnes, C. & Mercer, G. (Eds.) *Exploring the divide: illness and disability*. Leeds, UK: The Disability Press.

Patton, M.Q. (2001) *Qualitative evaluation and research methods*, 3rd Edition. Thousands Oak, CA, USA: Sage.

Pendergrass, S., Nosek, M.A., & Holcomb, D.J. (2001) Design and Evaluation of an Internet Site to Educate Women with Disabilities on Reproductive Health Care. *Sexuality and Disability*, 19(1).

Plato, G. & Jönsson, B. (2001) *Art and Science – A different convergence*. Lund, Sweden: Certec, LTH, Lund University. Available online at: http://www.certec.lth.se/doc/artandscience/artandscience.pdf (accessed 9 Aug. 2006).

Poulson, D., Ashby, M., & Richardson, S. (1996) *USERfit: A practical handbook on user-centred design for Assistive Technology*. (May 2, 2004) ECSC-EC-EAEC, Brussels-Luxembourg.

Preece, J., Rogers, Y., & Sharp, H. (2002) *Interaction Design*. New York, NY, USA: John Wiley & Sons, Inc.

Radabaugh, M. P. (1988) In: *Study on the financing of assistive technology devices and services for individuals with disabilities: A report to the President and the Congress of the United States*, March 4, 1993, p. 1. Washington, DC, USA: National Council on Disability.

Ratzka, A. (1997) *Towards and operational definition of personal assistance*. Stockholm, Sweden: Independent Living Institute. Available online at: http://www.independentliving.org/toolsforpower/tools15.html (accessed 9 Aug. 2006).

Ratzka, A. (2003a*) From patient to customer: Direct payments for assistive technology for disabled people's self-determination*. Stockholm, Sweden: Independent Living Institute. Available online at: http://www.independentliving.org/docs6/ratzka200308b.html (accessed 9 Aug. 2006).

Ratzka, A. (2003b) *Independent living in Sweden*. Stockholm, Sweden: Independent Living Institute. Available online at: http://www.independentliving.org/docs6/ratzka200302b.html (accessed 9 Aug. 2006).

Ratzka, A. (2003c) *What is independent living/a personal definition*. Stockholm, Sweden: Independent Living Institute. Available online at: http://www.independentliving.org/def.html (accessed 9 Aug. 2006).

Ratzka, A. (2005) Independent Living Empowers People with Disabilities. In: *Development Outreach*. World Bank. July 2005. Reprinted from http://www1.worldbank.org/devoutreach/article.asp?id=317. Available online at: http://www.independentliving.org/docs7/ratzka200507.html (accessed 9 Aug. 2006).

Rauhala, M. & Topo, P. (2003) Independent living, technology and ethics. *Technology and Disability*, 15, 205-214.

Ritchie, H. & Blank, P. (2003) The promise of the Internet for disability: a study of on-line services and website accessibility at centers for independent living, *Behavioural Sciences and the Law*, 21, 5-26.

Roulstone, A. (1998) Enabling technology: Disabled people, work and new techno!ogy. Buckingham, UK: Open University Press.

Rubin, J. (1994) *Handbook of Usability Testing*. New York, NY, USA: John Wiley & Sons, Inc.

Sanders, M.S. & McCormick, E.J. (1992) *Human Factors in Engineering and Design*. Columbus, OH, USA: McGraw Hill International Editions.

Sapey, B. (2000) Disablement in the informational age. *Disability & Society*, 15(4), 619-636.

Scherer, M.J. (1996) The impact of assistive technology on the lives of people with disabilities. In: D.B. Gray, L.A. Quatrano, & M.L. Lieberman (Eds.) *Designing and Using Assistive Technology: The Human Perspective*. Baltimore, MD, USA: Paul H. Brookes Publishing Co.

Scherer, M.J. (2000) *Living in the State of Stuck: How Assistive Technology Impacts the Lives of People with Disabilities*, 3rd Edition. Cambridge, MA, USA: Brookline Books.

Scherer, M.J. (2002) The change in emphasis from people to person: introduction to the special issue on assistive technology. *Disability and Rehabilitation*, 24(1).

Schenker, K. & Scadden, L. (2002) The Design Of Accessible Distance Education Environments That Use Collaborative Learning. *Journal of Information Technology and Disability*, 8, 1. Available online at: http://www.rit.edu/~easi/itd/itdv08n1/scadden.htm (accessed 9 Aug. 2006).

Shakespeare, T., & Watson, N. (2001) The social model of disability: An outdated ideology? In: S. Barnartt & B. Altman (Eds.), *Exploring theories and expanding methodologies: Where we are and where we need to go*. Oxford, UK: Elsevier Science Ltd., p. 9-28.

Schön, D.A. (1983) *The Reflective Practitioner, How Professionals Think in Action*. Aldershot, UK: Ashgate Arena.

Seelman, K.D. (2005) Universal Design and Orphan Technology: Do We Need Both? *Disability Studies Quarterly*, 25(3).

Seelman, K.D. (2000) Rehabilitation Science. *Technology & Disability*, 12(2/3), 77.

Seelman, K.D. (2001) Science and technology policy: Is disability a missing factor? In: G.L. Albrecht, K.D.Seelman, & M. Bury (Eds.), *Handbook of disability studies*. Thousand Oaks, CA, USA: Sage, pp. 663-92.

Seymour, W., & Lupton, D. (2004) Holding the line online: exploring wired relationships for disabled people. *Disability & Society*, 19(4), 291-305.

Seymour, W. (2005) ICTs and disability: Exploring the human dimensions of technological engagement. *Technology and Disability,* 17, 195-204.

Sheldon, A. (2004) Changing technology. In: J. Swain, S. French, C. Barnes,& C. Thomas (Eds.) *Disabling Barriers, Enabling Environments.* London, UK: Sage.

Sobchack, V. (1995) Beating the meat/surviving the text, or how to get out of the century alive. In: M. Featherstone & R. Burrows (Eds.) *Cyberspace/cyberbodies/cyberpunk: Cultures of technological embodiment.* London, UK: Sage, pp. 205-214.

Stienstra, D., & Troschuk, L. (2005) Engaging Citizens with Disabilities in eDemocracy. *Disability Studies Quarterly*, 25(2).

Stone, R.A. (1995) *The war of desire and technology at the close of the mechanical age.* Cambridge, MA, USA: MIT Press.

Svensk, A. (2001) *Design for Cognitive Assistance.* Licentiate thesis. Lund, Sweden: Certec, LTH, Lund University. Available online at: http://www.english.certec.lth.se/doc/designforcognitive/ (accessed 9 Aug. 2006).

Thomas, C. (2002) Disability theory: key ideas, issues and thinkers. In: C. Barnes, L. Barton & M. Oliver (Eds.), *Disability Studies Today.* Cambridge: Polity.

Thomas, C. (2004) How is disability understood? An examination of sociological approaches. *Disability & Society*, 19(6), 569-583.

Thoreau, E. (2006) Ouch!: An examination of the self-representation of disabled people on the Internet. *Journal of Computer-Mediated Communication*, 11(2), article 3. Available online at: http://jcmc.indiana.edu/vol11/issue2/thoreau.html (accessed 9 Aug. 2006).

Tobin, T.J. (2002) Issues In Preparing Visually Disabled Instructors To Teach Online: A Case Study. *Journal of Information Technology and Disability*, 8, 1.

Tusler, A. (2005) How to Make Technology Work: A Study of Best Practices in United States Electronic and Information Technology Companies. *Disability Studies Quarterly*, 25(2).

UPIAS (Union of the Physically Impaired Against Segregation) (1975) *Fundamental Principles of Disability.* London: Union of Physically Impaired Against Segregation. Available online at: www.leeds.ac.uk/disabilitystudies/archiveuk/UPIAS/fundamental principles.pdf (accessed 9 Aug. 2006).

Wessels, R., Dijcks, B., Soede, M., Gelderblom, G.J., & De Witte, L. (2004) Non-use of provided assistive technology devices, a literature overview. *Technology and Disability,* 15, 231-238.

Wieslander, J. & Wieslander J. (1997) *Mamma Mu städar (Mamma Mu Cleans)* Stockholm, Sweden: Natur och kultur.

Wilson, P.N., Foreman, N., & Stanton, D. (1997) Virtual reality, disability and rehabilitation. *Disability and Rehabilitation*, 19, 213-220.

Wilson, P.N., Foreman N., & Stanton, D. (1998) Virtual reality, disability and rehabilitation: A rejoinder. *Disability and Rehabilitation*, 20.

Winance, M. (2006) Trying Out the Wheelchair. *Science, Technology , & Human Values*, 31(1), 52-72.

WHO (World Health Organization). (2001) *International Classification of Functioning, Disability and Health* (ICF). Geneva, Switzerland: World Health Organization.

Vygotsky, L.S. (1930) *Mind in Society*. Cambridge, MA, USA: Harvard University Press, 1930.

Östlund, B. (2005) Social science research on technology and the elderly – does it exist? *Science Studies,* 17 (2), 45-63.

Appendices

I Making Both Ends Meet

Disability Studies Quarterly
Summer 2005, Volume 25, No. 3
<www.dsq-sds.org>

Back to Table of Contents

Making both ends meet

Peter Anderberg*
Certec, Division of Rehabilitation Engineering Research
Department of Design Sciences
Lund University, Sweden
E-mail: peter@anderberg.net

Abstract

The purpose of this article is to launch a new conceptual design tool in rehabilitation engineering, technology, and Disability Studies, useful both as guidance and help for people with disabilities in analyzing their own functional aids, and as inspiration and meta-guidelines for designers. It is non-discriminating and classification-free and differs from a mere classification system like the International Classification of Functioning (ICF). The origin of the tool is twofold: experiences of my own disability and of research in rehabilitation engineering.

Keywords: rehabilitation engineering, technology, disability, design, function

A. Introduction

Neither the medical nor the social model of disability is satisfactory for rehabilitation engineering and design. The medical model oversimplifies disability as an individual characteristic and directs attention towards individual adjustments and means. The social model, on the other hand, directs attention towards ideological and political analysis, not towards practical everyday solutions for experienced functioning.

Such an experienced functioning demands at least as thorough ideological considerations as do political analyses. The absence of an appropriate conceptual design model for rehabilitation engineering is a considerable hindrance for better functioning and better design of rehabilitation tools.

1. The Medical Model

The medical model, also called the deficit or individual model, has held and still holds a firm grip on society's current conception of disability. This perception of disability places the problem with the individual and sees disability as a direct consequence of an impairment. However, there is a strong ideological opposition to the medicalization of disability in most disability organizations around the world (Basnett, 2001). Medicalization of disability meaning that the disability is seen as a direct consequence of the impairment and the medical condition of the body. People with disabilities view the medicalization of their everyday lives as a form of social oppression (Johnson & Woll, 2003). The professional use of medical knowledge has, in the case of people with impairments, expanded beyond the cure of the effects of illness. Batavia (1999) describes how this point of view considers people with disabilities "paternalistically as dependent patients rather than as self-directed individuals fully capable of autonomy." Far too many people in health care and society who make decisions of uttermost importance for individuals (on such issues as functional assistance, for instance) have adopted the medical view of disabilities and consider clinical measuring, questioning, numbering and classifying to be the only yardsticks of choice. Almost all access to assistive or rehabilitative aids presupposes and calls for this kind of medical and "too-close" classification in the assessment and determination of various benefits (Oliver, 1990); it lacks a focus on the actual functions desired by the individual (Turner, 2001). It is alienating rather than supportive to the individual to be faced with a clinical analysis, a professional language of description and a lack of considerate interest for the functions most relevant in her/his own context.

2. The Social Model

People with disabilities are generally more inclined to adopt the social model approach. The Social Model of disability was formulated in the early 1980s, following the Union of the Physically Impaired Against Segregation (UPIAS) (1975) definition and separation of impairment and disability. The social model of disability originally referred to a rather materialistic view of the causes of disability, but has since been used in a number of contexts referring to the social creation of disability. Pfeiffer makes a distinction between the more materialistic U.K. social model and the social constructionist U.S. model based on Goffman's "differentness" (Pfeiffer, 2002a & 2002b). Many more models or paradigms that can be said to originate from, or be versions of, the original social model are found in the academic research field of Disability Studies. The core message in most of them is that societal structures should be changed to accommodate people with disabilities, not individuals that should be changed to fit into a rigid environment and society. Disability is not a characteristic of the individual but rather the situated response to an inaccessible, inflexible and unadapted environment and society. This response is directed to a wide variety of people and excludes them because of their inability to conform to a societal concept of body normalcy. Disabling and discriminating attitudes are routinely produced and reproduced in social, political, and cultural practices in everyday life (Oliver, 1990; Barnes, Oliver & Barton, 2002; Barnes & Mercer, 2003; Albrecht, Seelman, & Bury, 2001).

Criticism of the social model has come from within the disability community. It has been criticized for not taking into account the physical body in its analysis of disabling factors. It has been depicted as too unbending in its concentration on structural societal factors and criticized for "disregarding the cultural and experiential aspects of disablism" (Barnes & Mercer, 2003). Barnes and Mercer describe three main strands of this criticism. The first is that the social model fails to recognize the physical and emotional problems that are associated with some impairments and that are disabling factors regardless of societal response. The second is that specific impairment groups are marginalized by some social model writings. The third criticism is that there is a failure to recognize that the experience of both impairment and disability can be very different for different groups of disabled people (Barnes & Mercer, 2003).

Much of this criticism can at first be seen as well-founded on the grounds that both individual and social factors influence everyday life for a person with an impairment. Still, the social model perspective, with its separation of impairment and disability, has undoubtedly yielded many political benefits and given a theoretical starting point for research, activism, and discussion. Furthermore, the body is not left out. Even one of the most "fundamentalist" social model advocates, Michael Oliver, acknowledges that:

> This denial of the pain of impairment has not, in reality been a denial at all. Rather it has been a pragmatic attempt to identify and address issues that can be changed through collective action rather than medical or professional treatment (Oliver, 1996).

Still the influence of the social model has been limited and hindered by its stand-alone stance in relation to the fields of medicine, rehabilitation, and technology.

3. The Integrated Model and ICF

The integrated model of disability is an attempt to merge, or at least bring together, the medical and social perspectives (Seelman, 2003). This model allows for people with disabilities to have a number of different roles "including citizen and patient, among many others" (Seelman, 2003).

One of the operationalizations Seelman (2004) sees of the integrative model is the World Health Organization's "International Classification of Functioning, Disability and Health" (ICF) (World Health Organization, 2001). ICF is probably the most well known existing framework used for analyzing the functioning of people with disabilities. The ICF has shifted, or at least broadened, the focus from its predecessor, ICIDH-1 (World Health Organization, 1980), which was strongly criticized by representatives of disability organizations (Pfeiffer, 1998; Hurst, 2000).

ICIDH-1 presented a predominantly medical and individual model for explaining disability, whereas ICF has sought to include environmental factors as well, along with activities and participation. The introduction of environmental and social response variables is a big step forward and very important, since ICF will be used by many health professionals and policy makers. The hope is that functionality shall not be assessed on its own, but be "qualified in relation to all other dimensions" (Hurst, 2003). But mixing these two paradigms does not come without problems. ICF still remains an instrument for measuring and classifying individuals on the level of impairment (Pfeiffer, 2000).

This also makes its use in an "integrative model" somewhat inappropriate or at least complicated both from an individual or social model perspective. Seelman (2003) finds that researchers should "be challenged to identify the relationships among the components" in ICF. This may be a good approach, but the relationships hardly lend themselves to description in numbered classification systems, since disability is a "complicated, multidimensional concept" (Altman, 2001). Measuring and classifying disability is fundamentally problematic with a risk for negative consequences, such as discrimination and labeling, as a result (Albrecht, 2002). The risk of creating a "we and they" that further widens the gap between professionals and people with disabilities is apparent. Barile finds that the classification in ICF "still centers the locus of the 'problem' in the individual's body," and that "the individualistic ascription of the 'victim approach' and the pathology are camouflaged but are still present" (Barile, 2003).

Rachel Hurst has pointed to the following problem with "too-close" classification:

> There is no other group of individuals who have been subjected to this analysis of individual characteristics. Women and Indigenous people as discreet groups have been analyzed, but only in relation to their social, cultural and economic status. An in-depth classification of their individual characteristics has never been seen as necessary as an analysis of their status or for the provision of services or the implementation of policies to implement rights. (Hurst, 2000)

It can be noted that one aim of ICF is to provide a tool for international comparability of health information and in this respect; it may be successful. The aim of this article is not in any way to try to disprove the usability of ICF as a tool in some areas, but simply to make the observation that its method for classifying, measuring and numbering individuals is detrimental to its being used together with a social model perspective.

4. Technology as a Mediator

Not only societal and medical efforts need thoughtful models as a basis for their implementation. The same is true for rehabilitation engineering and design and their unquestionable potential to reduce function hindrances, to empower and enable.

The perspectives of Bruno Latour deserve to be illuminated. According to Latour (1991), technology is what makes a society durable. Technology and artifacts play an important role in how our predecessors continue to actively influence us and also how we influence each other. Nothing rules the future as recklessly as an infrastructure of old ideas. That is why it is primarily through changes in the way we think that the future is affected (Jönsson, B., 2001).

Technology and its artifacts (man-made constructions and objects) also exert an influence on the individual, both on how her/his thoughts are shaped and what she/he can and will do (and of course what she/he does not think or do). Håkan Jönsson sees artifacts as being imprinted with the goals, visions, and thoughts of their constructors. Artifacts are thus no neutral carriers of information (Jönsson, H., 2005). They affect how we relate to things and people around us, and how we learn about and perceive the world in which we live. From a socio-cultural perspective, we learn and develop by using cognitive resources that are incorporated in the artifacts as information, procedures and routines. Our way of thinking is guided and colored by the intellectual and physical tools we use (Säljö, 2000).

Technology and design can thus be seen as mediators of disability and can be used to create new and to consolidate old, disabling structures. But they also hold the power to break down existing disabling structures and create new function supports. Without a wheelchair I would not get anywhere, but my standard wheelchair does not give me much function in unspoiled nature or in an unadapted environment. Goggin and Newell give the example of how the wheelchair can be "theoretically regarded as an aid to mobility," but is an effective enabler only in a system where the environment is adapted to wheelchair use. They also write: "Without the necessary pavement, curbs, ramps, and funding of so-called access, the wheelchair as a system has different meanings and effects" (Goggin & Newell, 2003).

The wheelchair together with the environment is a system that can support or hinder function. From this starting point it is necessary for people with disabilities to problematize and influence the entire system of individual-oriented and individual-dependent technology in the space that exists between the individual and the environment. The body and the various technical artifacts around us make up a system that enables or disables us to perform desired actions. Freund makes the following comment:

> Space is also important because of the way its organization constructs bodies and offers bodily possibilities and constraints. The body is not simply a culturally constructed representation nor is it physically shaped like clay by social force, but it is experienced and 'lived-in' differently in various socio-material environments and material cultures (e.g., technologies) (Freund, 2001).

There is a difference if the wheelchair space in a movie theatre is located outside in the aisle or in the middle of the row. Regardless of the technical or design solutions, whether the wheelchair space occupies the best or worst situation in a theatre sends out different attitude signals. It is also important to note that these signals are received by all visitors to the movie theatre. The same goes for a lecture hall — if the podium is accessible with a wheelchair or not, if it is easily accessible with a permanent solution or if it is a provisional solution — all send messages about the attitude towards a lecturer in a wheelchair.

Technology is never just technology, the physical artifact. Technology is a manifestation of economical, political, social, and cultural concepts and individual wishes and ideas. For a designer or engineer or purchaser to be unaware of this can be potentially dangerous. Also, a naïve belief that all technology is always for the better can be dangerous, especially for those extremely dependent on technological functioning.

This is why problematization of technology, its consequences, use and meaning is so important for Disability Studies. The "Guidelines for Disability Studies" published by The Society for Disability Studies (SDS, 2004) fails to directly acknowledge the importance of technology for the field. This is unfortunate, because technology and design are too important to be left only to the technicians and designers; it cannot be seen as being separate from other instances of the culture we live in. Technology and functional aids belong in the heart of Disability Studies.

B. My contribution: the FACE tool

Ten years of work in the field of rehabilitation engineering research with a focus on the lived disability have resulted in me developing "function" as a concept. Function is the main concept describing the outer course of events in the life of a human being (getting out of bed, going to the bathroom, taking a shower, getting dressed, having breakfast, reading the newspaper, taking the children to school, going to work, going to a meeting, reading and writing documents, learning, meeting people, being left alone, being a father, being a husband, going to a cinema, etc.). Function is analyzed by using three different factors: Attitude, Control, and Enabling.

1. Function

Most functions are possible to split up into a finite number of smaller functions. However, appropriate caution should be exercised so as not to use a more detailed level of description than is suited to the purpose of the person involved in the context of the function.

Functions are situated in a context, as are hindrances to functions. Functions are located in the space between the individual and his/her surrounding. Functions exist in concrete and well-defined situations but are not a property of the individual. Individuals neither can nor shall be classified with the function concept. Thomas (2002) makes a distinction between disability and what she calls "impairment effects." Impairment effects are, for example, that blind people (with today's technology) are unable to drive a car safely or that someone like me in a wheelchair cannot play ice hockey for my local ice hockey team. This becomes a disability only if driving a car to work is a condition for obtaining paid employment, for instance (Barnes & Mercer, 2003), or if I wanted to try to pursue a carrier as a professional ice hockey player. According to the definition of function in this article, functions deal with the effects of impairment in order to reduce disabilities. The interest is in identifying and analyzing the situations where an impairment can lead to a disability and discovering how technology can affect this situation.

It is the function, as experienced by the individual in the environment in which technology has been introduced that is the measure of the function. Functions are thus assessed by how well they correspond to the desired action from the perspective of the individual and not relative to a preconceived norm. It is by long chains of functions that a day and a life are built. From the technological perspective used in this article, it is important to take the concept of function away from a mere mechanistic perspective and put it into a larger context with more variables.

A focus on functions could bring together the situated and relative perspective on disabilities found in the social model with the more individual and absolute perspective found in rehabilitation and rehabilitation engineering.

Sometimes there is a need to problematize space and to discuss functions from an environmental perspective rather than from an individual perspective. For example, to make sure a building is as accessible for as many people as possible, it can be of interest to discuss functions from a number of hypothetical cases. For each and every one of these cases a number of functions are enabled. Together these constitute the function opportunities of the environment. Affordance, according to Gibson (1979), is the relationship between a potential user and the physical artifacts in the environment affording possible actions in that environment. Function affordances are the potential functions available in any given environment.

An important factor to establish is that it is the person involved in the function, referred to as the owner of the function, who decides what a good function is. This is referred to as "ownership of the function."

There is a concept in the ICF called "functioning." This is not to be mistaken for the environmental and situated concept of function described above. Functioning in the ICF is defined as "an umbrella term for body functions, structures, activities, and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors." Body functions in the ICF definition are the "physiological functions of body systems (including psychological functions)."

The important difference is that function, as described in this article, never refers to bodily functions, but only to the realization of a desired action. Function cannot be assessed as an absolute measure, but only relative to the desired action, and situated in a context with appropriate function support. Functioning in the ICF includes body functions and structures; function as described here is firmly placed in the space between.

2. Function Support

An important concept to understand when discussing function is the concept of function support. Function support refers to what is needed to perform a function. It can refer to technology or to a person and it is made up of those requirements necessary to perform a function according to the wishes of the function owner. Function support always corresponds to a given function, but a function does not necessarily have dedicated function supports.

Function support consists of two main categories: technological and human. These two can be combined in a number of ways for the execution of a function. Human function support refers to when **another person** is a part of the execution. All other supports are classified as technological function supports, including the use of one's own body to perform a function. The difference between using human or technological function support is that the former has a will of its own. This can be a very concrete and tangible problem, something well known to all users of personal assistance. Technology has no will of its own, but is an extension of the user's will. In principle (and in this context) there is no difference between using a wrench or the hand to fasten a screw nut, but having an assistant do it does constitute a difference. There is no difference between walking and driving your own wheelchair, but if your personal assistant (PA) pushes your wheelchair it constitutes a difference, in terms of attitude, control, and enabling. One's own body is, in this context, considered to be more similar to the use of technical aids, as it is an extension of individual will.

It is an inevitable fact that the use of human function support in the form of personal assistance, for example, will constitute a filter to the world around, amplifying or reducing. Still, the use of human function support is often an unsurpassable system for enabling a function, since the possibilities for adjustment and adaptation to the environment are very high. One big problem with human function support is the loss of control. In a system with technological function support there is a high level of control, but normally it is less flexible, and thus has a lower enabling capacity.

The use of function support as a concept is to ensure that the function is looked upon as situated.

3. The disability "ACE"

Functions and function support can be analyzed by using the disability "ACE". It is made up of three different aspects of independence and disability eliminating/creating factors: enabling, control, and attitude. Each of the factors represents a different level of looking at functional assistance. Each level has its basis in my extensive experience as both researcher and developer in rehabilitation technology and as a user of functional aids.

Starting from the bottom, *enabling* is the traditional approach in rehabilitation technology. This concerns how the function supports are actually constructed and implemented, i.e. the technological solution. This is of course the basic level. The second factor is *control*, and this concerns the extent to which the user, the owner of the function, has the power and right to define and execute the function. This is the individual level. The top factor is *attitude;* this is the social response level. This concerns how the function is perceived by others and by oneself in the context where the function is used.

The ACE Assessment criteria
Attitude: To what extent is the function and the design of the function supports free from disablist and discriminating attitudes?
Control: To what extent does the individual have control of the development or choice of function support in the function?
To what extent does the individual have control of the execution of the function?
To what extent does the individual have control of the economy in the function?
Enabling: How well does the function correspond to the action desired by the individual?
To what extent is the desired function possible to perform
(e.g., technology, economy, flexibility, etc.)?

The acronym FACE is made up of the first letters in the words "function, attitude, control" and "enabling." However, it also has a second meaning: the individual in need of function enhancement cannot be reduced to a series of numbers in a classification, but is an equal partner and truly the owner of the function, a face not a number.

The assessment is normative in the sense that a good function is one that gives an individual power over, or ownership of, the function and that strives to optimize the function according to the given criteria in accordance with the desired function of the individual.

A particular function can have different function supports depending on the extent of a person's impairment, interests, or wishes etc. Inversely, different function supports display a different FACE, so that the function support is more or less in accordance with the desired function. A disability results when a function support is missing, insufficient, or inadequate in a FACE analysis.

C. From Conceptual Design to Design of Artifacts and Infrastructure

Rehabilitation technology and engineering is the attempt to influence and affect with technology the interplay between a person and her/his environment in such a way that the person experiences an increase in functioning or functionality in this environment. Function is the product of all the experienced effects that the introduced technology has on the individual. Technology in itself is not rehabilitating but can be if it is used in such a function. This also means that all technology can be potentially rehabilitating, depending on the function it has for the individual who is using it.

Sometimes it can be hard to exactly realize a function according to a person's wishes. Functions like riding a rollercoaster or playing ice hockey may be impossible to realize because the physiology of a particular individual simply will not allow any enabling function supports. At this point it may be helpful to question, at the very outset, whether a solution should imitate fully the solution for a non-disabled person (the parrot method), have the same purpose but a different form (the chameleon method), or be completely different and only retain its fundamental characteristics, its very core (the poodle method) (Jönsson & Anderberg, 1999).

For example, in the case of the rollercoaster or ice hockey, what is the driving force? Is it a desire for an intellectual or physical challenge? Perhaps playing ice hockey on a computer is a better way to fulfill the wish for a challenge. Perhaps there is an altogether different activity that could provide the same challenge as a rollercoaster. Using the FACE tool can assist in finding the right function support.

with disabilities. Retrieved November 22, 2004, from www.ilru.org/mgdcare/batavia.html.

Freund, P. (2001). Bodies, disability and spaces: The social model and disabling spatial organisations. *Disability and Society, 16*(5), 689-706.

Gibson, J.J. (1979). *The ecological approach to visual perception*. Boston: Houghton Mifflin.

Goggin, G., & Newell, C. (2003). *Digital disability: The social construction of disability in new media*. Boulder CO: Rowman & Littlefield.

Hurst, R. (2000). To revise or not to revise. *Disability and Society, 15*(7)*,* 1083-1088*.*

—. (2003). The international disability rights movement and the ICF. *Disability & Rehabilitation*, *25,* 11-12, 572-576.

Johnson, J. L., & Woll, J. (2003). A national disgrace: health disparities encountered by persons with disabilities. *Disability Studies Quarterly, 23,* 1, 61-74*.*

Jönsson, B., & Anderberg, P. (1999). *Rehabilitation engineering and design research-theory and method*. Lund, Sweden: Lund University, LTH, Certec. Retrieved November 22, 2004, from www.english.certec.lth.se/theory.html

Jönsson, B. (2001). *Unwinding the clock*. New York: Harcourt.

Jönsson, H. (2005). Kondenserad mjölk [*Condensed milk*], Doctoral dissertation (to be published). Lund, Sweden: Lund University, Department of European Ethnology.

Latour, B. (1991). Technology is society made durable. In J. Law (Ed.), *A sociology of monsters: Essays on power, technology and domination* (pp.103-131). London: Routledge.

Oliver, M. (1990). *The politics of disablement.* London: Macmillan.

Oliver, M. (1996). Defining impairment and disability. In Barnes, C. & Mercer, G. (Eds.), *Exploring the divide: Illness and disability*. Leeds: The Disability Press. Retrieved November 22, 2004, from www.leeds.ac.uk/disability-studies/archiveuk/Oliver/exploring%20divide%20ch3.pdf.

Pfeiffer, D. (2000). The devil is in the details: the ICIHD2 and the disability movement. *Disability and Society, 15*(7),1079-1082.

—. (1998). The ICIDH and need for its revision. *Disability and Society, 13*(4), 503-523*.*

—. (2002a). The philosophical foundations of disability studies. *Disability Studies Quarterly*, *22*(2), 3-23*.* Retrieved November 22, 2004, from www.dsq-sds.org/_articles_pdf/2002/Spring/dsq_2002_Spring_02.pdf

—. (2002b). A comment on the social model(s). *Disability Studies Quarterly*, *22*(4)*.* Retrieved November 22, 2004, from www.dsq-sds.org/_articles_pdf/2002/Fall/dsq_2002_Fall_24.pdf

Seelman, K. D. (2003). *Trends in rehabilitation and disability: transition from a medical model to an integrative model.* National Rehabilitation Conference Keynote. Tokorozawa, Japan: National Center for Persons with Disabilities. Retrieved November 22, 2004, from www.disabilityworld.org/01-03_04/access/rehabtrends1.shtml.

Seelman, K.D. (2004). Disability studies in education of public health and health professionals: Can it work for all involved? *Disability Studies Quarterly, 24*(4)*.* Retrieved November 22, 2004, from www.dsq-sds.org/_articles_html/2004/fall/dsq_fall04_seelman.html.

The Society for Disability Studies (SDS). (2004). *Guidelines for disability studies*. Retrieved November 22, 2004, from http://www.uic.edu/orgs/sds/Guidelines%20for%20DS%20Program.doc

Rehabilitation technology and engineering research must always begin and end with the individual. It is the function as it is experienced by the individual that is the measure and yardstick. It should, as well, always problematize who has the power over what technology should be developed and why, and what the problems are that need solving. To identify and place the ownership of a function means that the priority for defining is given to the person who is affected by the problem. Using FACE assures that all aspects of a function, not just the practical or technological, are evaluated and that invasion of privacy is avoided, since no body measurements are required.

The context in which rehabilitation technology and design practices are developed must be seen in the light of their cultural and social environment. The prevailing view of disability and people with disabilities affects how, which and why certain technology and function aids are developed and supported. There is also an inverse relationship: The view of disability and people with disabilities is also affected by the technology and function aids that are available and used by people with disabilities in the society. Using FACE assures that these attitudinal aspects are considered when designing functional aids.

Conclusion

Social model perspectives are needed in rehabilitating science and engineering, fundamental for control and self-determination for people with disabilities. They can be included without compromising the political benefits of the social model perspective if the focus is directed towards the space betweer the individual and his/her surroundings and towards the functional need and wishes rather than the mere functioning of the individual. The ability of FACE to eliminate the alienation of too-close methods of classifying is ready to be proven in use and in examples, and to be tested against the possibilities of the medical language when the goal is to achieve best possible function assistance, be it personal or technological.

*Note on the author

Peter Anderberg currently works at the Institute of Independent Living in Stockholm, Sweden. He holds a MSEE and conducts research as a Ph.D. candidate in the field of Rehabilitation Engineering at Certec, Lund University, Sweden. His main research interest is how technology can enhance function and how power relationships and distribution affect and are affected by, disabled people's use of technology. The research is conducted from the perspective of a social model of disability. Anderberg has been a wheelchair and personal assistance user since the early 1990s.

References

Albrecht, G. (2002). American pragmatism, sociology and the development of disability studies. In C. Barnes, M. Oliver & L. Barton (Eds.), *Disability studies today* (pp.18-37). Cambridge: Polity.

Albrecht, G.L., Seelman, K.D., & Bury, M. (Eds.). (2001). *Handbook of disability studies*. Thousand Oaks CA: Sage.

Altman, B. M. (2001). Disability definitions, models, classification, schemes and application. In G.L. Albrecht, K.D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 97-122). Thousand Oaks, London: Sage Publications.

Barile, M. (2003). Globalization and ICF eugenics: historical coincidence or connection? The more things change the more they stay the same. *Disability Studies Quarterly, 23*(2), 203-223. Retrieved November 22, 2004, from www.dsq-sds.org/_articles_html/2003/Spring/dsq_2003_Spring_18.html.

Barnes, C., Barton, L., & Oliver, M. (Eds.). (2002). *Disability studies today*. Cambridge: Polity.

Barnes, C., & Mercer, G. (2003). *Disability*. Cambridge: Polity.

Basnett, I. (2001). Health care professionals and their attitudes toward decisions affecting disabled people. In G.L. Albrecht, K.D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (p.p. 450-467). Thousand Oaks CA & London: Sage.

Batavia, A.I. (1999). *The role of independent living centers in meeting the health care needs of people*

Säljö, R. (2000). *Lärande i praktiken: Ett sociokulturellt perspektiv* [*Learning in practice. A sociocultural perspective*]. Stockholm: Prisma.

Thomas, C. (2002). Disability theory. In C. Barnes, L. Barton, & M. Oliver (Eds.), *Disability Studies Today* (pp. 1-17). Cambridge: Polity.

Turner, B.S. (2001). Disability and the sociology of the body. In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 252—266). Thousand Oaks CA and London: Sage.

Union of the Physically Impaired Against Segregation. (1975). *Fundamental Principles of Disability*. London: Union of Physically Impaired Against Segregation. Retrieved November 22, 2004, from www.leeds.ac.uk/disability-studies/archiveuk/UPIAS/fundamental principles.pdf

World Health Organization. (2001). *International Classification of Functioning, Disability and Health.* Geneva: World Health Organization.

World Health Organization. (1980) *International Classification of Impairments, Disabilities and Handicaps — A manual relating to the consequences of disease*. Geneva: World Health Organization.

II Ethics in the making

From *Design Philosophy Papers* no 4, 2005 www.desphilosophy.com

ethics in the making

Bodil Jönsson, Peter Anderberg, Eva Flodin, Lone Malmborg, Camilla Nordgren & Arne Svensk

Applied ethics in research is no longer regarded as a concern exclusive to the medical field. Exemplars in ethics from other fields such as design are, however, meagre, as are relevant practical and design applied guidelines. The more ethically grounded a given area of research is, the greater the chance it can contribute to long-term, meaningful breakthroughs in knowledge. An improved *ethics in design* can enable a critical questioning that in turn leads to entirely new research questions.

The mere involvement of human subjects and the application of safety provisions in design research do not guarantee it will meet ethical considerations, best practices or standards. The entire complex interaction with users offers intriguing possibilities and risks, or can result in mediocrity in areas such as: preparation and implementation that is worth the research person's time; respect for users' contributions; dignified treatment; feedback in an iterative and interactive process with mutual information and inspiration; and products and processes that are truly influenced by the users. This reasoning applies to all, but with special distinction to people who are disabled and elderly. Starting with specific needs as opposed to more general ones (the latter of which result in the necessity for more abstract specifications for the multitudes) can, above and beyond the ethical dimension, also result in increased innovation and effectiveness for society on the whole. Proceeding from the particular to the general is of considerable value, for ethical reasons as well as for sheer effectiveness.

Involving persons with a variety of disabilities in product development helps to ensure innovative and useworthy products.[1] One of many prerequisites for ethically sound user involvement is that all participants are aware of the interference taking place in an iterative design process.

An elaboration of ethical aspects in design can be valuable for different stakeholders (user organisations, NGOs and the design community) and, of course, for the relevance of resulting products and processes. A more considerate ethical approach could have substantial economical value due to the higher relevance of the results. There has been a considerable increase in the ethical expectations placed on businesses and professions in recent years. Scores of organisations have reacted by developing ethical codes of conduct and professional guidelines to explicitly state their values and principles.[2] Moreover, the drafting of a code of ethics can be seen as an indication of professionalism in an emerging profession.[3]

Ethical guidelines versus situated ethics

Traditionally, medical research and clinically practicing professionals have been in the vanguard of creating ethical guidelines, with other research fields involving human subjects and human well-being close behind. Today, the medical disciplines are also front runners in combining their work on general ethical principles (autonomy, justice, and beneficence, for instance) with research on situated ethics, which is less mechanistic and closer to the context of real people in actual situations and work practices.

Situatedness urges different approaches for different disciplines. The engineering and design sciences, having safety, accessibility and 'universal design' of artefacts and the built environment on their agenda, cannot lean towards medical exemplars. They need to develop their own. An initial difficulty is that the existing key ethical principles, however 'universal' they appear to be, originate from medicine. The spirit of the *Nuremberg Code*, the *Helsinki Declaration* and *The European Convention* (with its explanatory report) is not particularly vitalised in design, to say the least.[4], [5], [6] The reason is obvious: none of them have been formulated based on experiences from design of civil products for everyday life. Nonetheless, ethical aspects are definitely present in test usages as well as in the influence of the resulting technology in later, everyday use.3 Ethical design perspectives can also be deduced from *The Charter of Fundamental Rights of the EU* ('the right to freedom of expression and information'), [7] the *Convention on the Rights of the Child*, [8] and from *Citizens Rights and New Technologies: A European Challenge* in which the European Group on Ethics in Science and Technologies (EGE) stresses the two basic concepts of *dignity* and *freedom*.[9] Accessibility and 'design for all' are such fundamental perspectives that they should not be treated separately. They have societal implications for education, information and participation in social and political processes. *The Principles of Universal Design*, with the approach that environments, services and products should be designed for use by as many people as possible regardless of situation or ability, is an example of this perspective.[10]

Creating common guidelines for rehabilitation design is a challenge, as is the possibility of working the other way round: to open up for a mainly *situated ethics,* based on the spirit of existing codes and declarations rather than being deduced from them. The core of situated design ethics is made up of means and methods that (using the main declarations as guidance) reveal the most important ethical aspects in a given situation, elaborate these, document the thoughts, their implementations and outcomes and make them openly available with the goal of yielding exemplars and inspiring a vital and on-going discussion.

Exemplar 1: You have to have options to make a choice

Hanna was born with a nerve-muscle disease that severely restricts her mobility. At 1½ years of age, she received her first standing support device in order to exercise her muscles and put pressure on her skeleton. In the process of standing, however, she discovered that there was a lot to see from this upright vantage point. Objects in other parts of the room caught her attention. Without the support of her mother's arms she was suddenly on her own in the world. She wanted to come closer to the objects that she could see at the edge of her upright horizon. Her mother had to move the stationary supporter to the thing that attracted Hanna's attention. 'There! There!' she said and pointed. She quickly focused on something else and wanted to move on to it and then the next object and the next. Her mother soon realised that this was not so much about Hanna's wish to interact with different objects: what she actually was after was the enjoyable feeling of moving around in an upright position. This resulted in the construction of a motorised standing support device that offered Hanna the opportunity to move around in an upright position on her own.

One such device after the other has seen the light of day and enabled Hanna, now a young adult, to gain the identity of a standing – not a sitting – person, including all the existential, physical and practical effects and side effects involved. One such side effect (that was foreseen) is that Hanna will never master the ability to sit – she will remain a standing or a lying person for the rest of her life. The critical moment is to be found in her early childhood when the people in her surroundings were open-minded enough to start questioning whether a future position as a seated person would be right for Hanna with her 'stand-up' ambitions.[11], [12]

This exemplar might serve as a revelation: what are the ethics (if any) behind the dominating 'wheel-chair-for-all' attitude that in no way questions the underlying assumption that somebody who cannot stand up and walk on her own has to live her life primarily as a seated person? In design terms: what are the ethical issues involved in not offering motorised standing supports as an option for mobility injured people? It is easy to understand that an aid in the best of cases does not only fulfil the function it is meant to (to stand up in the example of Hanna); it can also reshape the person's existence and existential terms (Hanna achieved an autonomous, upright mobility). This aspect should be involved in future body technology.[13]

In design, the focus might be on 'that-which-ought-to-be' (*desiderata*) versus 'that-which-is' (description and explanation).[14] The concept of *desiderata* is an inclusive whole of aesthetics, ethics and reason. *Desiderata* is about what we intend the world to be, which is more or less the voice of design. The greater the difference between the designer's and the user's worlds of concepts, the greater is the need for a user-adjoining and situated design process. You need to immerse yourself in concrete experiences – not only base your understanding on abstract ones. You need to accept and acknowledge the existence of different communities of practice.[15] You need to accept desire as an initiator of change. You need to allow disturbances and not only inform and be informed, but also inspire and be inspired. Designers may be informed and inspired by the users, at the same time as the users are informed and inspired by the designers. Utilising this two-way information and inspiration in both groups to its full extent has profound ethical implications, while at the same time making the process more efficient and situated. Cf. the framework by Kensing and Munk-Madsen.[16]

Cultural probes

Among situated design methods, cultural probes have a special position and they have developed in two primary directions: the inspirational and informational. The pioneer version of cultural probes belongs to the first direction. It was developed at the Royal College of Art, Computer Related Design by Bill Gaver and focuses on novel forms of self-reporting by participants on details of their everyday lives. These are then taken up to inspire the design process. The group of academic and artistic members were working on redesigning three community sites in Norway, Holland and Italy. The idea behind these probes was to provoke inspirational responses from elderly people living at the sites.[17], [18], [19]

The informational direction of cultural probes developed out of the design research community oriented towards use of ethnographical methods in the design process. Pioneers in this usage of cultural probes have been members of the Cooperative Systems Engineering Group, Computing Department, Lancaster University in the UK, which has extensive experience in the use of ethnography in design.[20]

We believe that the "friction" contained in the probe's design also works as a way of inspiring users to create new use situations and to look at their environment in a new way – with new glasses.

In interactive design processes involving people with extensive language limitations, questionnaires and interviews are extremely blunt instruments for capturing people's dreams, needs or aversions. Cultural probes are many times preferable in this context because they do not require specific prerequisite knowledge or language abilities. We introduced a number of probes in a day activity centre for people with cognitive and communicative limitations. The reactions to these cultural probes have both inspired and surprised us.[21]

Example: Cultural probes as a source of inspiration

One probe was a web camera for communication. During the initial connection, the sound disappeared so the researcher and day activity centre participant could only see one another on their respective computer screens moving their lips. The researcher quickly telephoned the person at the day activity centre (the phones were next to the computers) and on the screen the two of them could see each other sitting there holding the telephone receivers to their ears and talking. From the facial expression of the person at the centre, it was obvious that this was a true “Aha!” experience. It took a while before the researcher realised that the surprise was because this was the first time the person in question had actually seen what it was like for the person at the other end of the line. Since then, the two take turns phoning one another even though the sound works on the computer because the feedback the user receives from using the telephone and from seeing the person he is talking to doing the same, provides him with more clues to the mystery of telephoning.

Design ethics and the human sector

> To smash the little atom,
> All mankind was intent.
> Now every day,
> The atom may
> Return the compliment.
>
> Max Born, Physicist, Nobel Prize Winner, 1882-1970

State-of-the-art in design ethics has been well elaborated in another issue of *Design Philosophy Papers*, particularly in the articles by Donahue and Fry.[22], [23] Addressing ethics makes it possible to discuss what design does, what it contributes and what designers may affect in their work. As Tonkinwise puts it, ethics has always been associated with human-to-human relations.[24] But, according to Latour, artefacts are society and culture made sustainable.[25] Products, artefacts, built environments and communication are also ‘actants’ themselves and therefore enter the ethical domain not only as neutral means used by humans in their relations to other humans. Using an analogy from physics, Bruno Latour finds in designed activities what he labels ‘the missing masses’, which is to say that if we only take into account what we currently understand by ‘sociality’, our cultures should have long since collapsed into irretrievable immorality. The ‘missing masses’ names an ethical force hidden beyond what we now call ‘the social’, and the force is in the things per se. Things are acculturating or ethos-generating and a vital part of any ethos with a future.

In the *human sector* people work with and for other people. In addition to healthcare, schools and social services, this sector comprises people-to-people operations in business, the rest of society and the large, informal sector/economy in which people help people because they are relatives or friends. Awareness of the role of artefacts and design of new artefacts requires design processes that proceed from the *logic of the human sector*, not the technical one as is the case in the electronic, manufacturing and forest industries. With another approach to humans in design, the opportunities for real participation of people with disabilities increase, as do their opportunities to make decisions on their own.

The design of a new technology can have a strong impact on the human sector and help improve it.

Exemplar 2: Being there

The following excerpts from Peter Anderberg’s study elaborate how people who have significant mobility/physical impairments *and* who are accustomed to using computers experience the internet:

For the individual, the bodiless presence on the internet has many advantages. Why waste energy trying to convince your banking establishment to rebuild its entrance, when internet banking is so much easier? Why risk the danger of being dragged up the stairs to the local pub when it is so much easier to go to an online forum for company, where you do not have to worry about physical safety, accessible restrooms or deal with the attitudes of others? This ease and convenience, however, can easily lead to self-imposed restrictions, where what is experienced as choice becomes a restraint instead. The choice is very understandable on the individual level, but for the political endeavours of disabled people as a group, the picture becomes somewhat more complicated. The invisibility of the body can undermine the understanding of how disability is created in society, and be used against the community of disabled people. Why should a university adapt its buildings when most classes are available as online and distance studies?

> There was a sense that the world was moving in their direction, with increasingly more societal functions being moved to the internet. An online identity is becoming a more ‘normal’ one for all. If everybody else finds their information or does their banking over the internet, *being there* is the most important. [[26]]

This exemplar not only illustrates the influence of design and technology on human individuals and groups/mankind as a whole but also pinpoints some reflections with special significance for the human sector. If a successful innovation system is to be achieved in the human sector, it should be based on how people live and act rather than how machines function. A methodology can be initiated that deals not so much with ‘running faster’ but with ‘running differently’ and with a clear sense of purpose.[14]

Design science in relation to other sciences

Our intention here is not to elaborate this relationship generally but restrict ourselves to perspectives from the field of disabilities and the natural sciences. By doing so we hope to add new dimensions to the ethical discourse.

Human needs, wishes and dreams are the starting points for design research in rehabilitation engineering. The design of technical solutions represents in itself an interpretation of problems in a language of its own, different from the word-based analyses of observations, interviews, questionnaires and the like.

A design process in a disability context has to start with the person, end with the person and interact with her throughout the process if the results are to have any success. The situated is a necessary but not sufficient condition. It is a matter of understanding the action in its context and having previous scientific knowledge and considerable, solid experience in order to see the structures and possibilities and from that, propose solutions. The solutions that grow out of the situated processes represent in themselves an interpretation of the actual problem and illuminate them in an implemented form and in their own ‘languages’, based less on words and interpretation and more on that we humans, in action, can show one another what we mean. This was already pinpointed and analysed by Vygotsky in the 1930s.[27] Paul Dourish discerns similar perspectives from a phenomenological interactive design perspective.[28]

Exemplar 3: Pictures as a language

Sometimes virtual reality can be experienced as more real than actual reality. This can only be revealed through artefacts. For some people with autism, communication with other people isn’t sufficient, not even that which includes pointing at the real object. It may require a detour by means of artefacts so that the concrete can be made real for the person involved. During an outing in the woods, a special education teacher placed her hand on a stone at the same time as she asked a pupil with autism to sit on it. The pupil did not seem to understand at all what she meant. She then took a photo of the stone with a digital camera and showed the display screen to the pupil while at the same time asking him to sit down on the stone. He did so immediately.[29]

Case studies compared to statistically based studies

Case studies should not be considered merely pathfinders for later statistically based studies.[30] They have significant advantages that cannot be found in statistical studies and vice versa. The field of rehabilitation engineering and design is based largely on case studies. This is not only because of the difficulties in finding enough subjects in the same ‘category’; it is also (mainly) connected to the situated: it is the human being in her environment together with those around her that is the focal point. To pretend that one’s own everyday environment can be replaced by a laboratory environment without considerably influencing usability tests is not only naïve but unethical in its approach.

Exemplar 4:

When designing a friendly restroom for elderly or disabled persons, interactions with the future users play an important role. To replace authentic users with young people loaded with weights and knee-joint movement restrictors reveals a misunderstanding of the situation as well as an absence of respect. Our experience tells us that research persons from the actual groups are happy to commit their time, share experiences and take part in testing. But it is pointless not to take into account outside influencing factors such as how much sleep the person got the night before, time of the day, season, increased or decreased weight, temperature, etc. Average percentages in usability tests that disregard the influences of these factors are misleading and of much less importance than relevant situated descriptions of individual cases and processes out of which later important patterns of needs and wishes can be detected.

Most often, the design of doors, locks, alarms, toilet seats, lighting, etc. are carried out separately. For the target groups, the margins are so small that a failure in one can result in a failure of all that follows – it is the entire chain of artefacts and the complete process that ought to be tested. The key question is whether the research person is satisfied with the situation and can carry out the desired activity without too great an effort even if one of the tasks negatively affects what follows.

Design and action research versus phenomenology and grounded theory

In rehabilitation engineering and design, the researcher is supposed to lean forward rather than lean backward, to be a practitioner but a reflective one.[31] Although seldom mentioned or brought up to a conscious level, technology and design involve action research. Action research is sometimes considered questionable in social sciences. There is a fear that the researcher might be involved to such a degree that he or she is no longer 'objective', and that the situation is so biased that it can no longer be scientifically studied. However, *not* being an action researcher in rehabilitation engineering and design, *not* aiming to improve situations, solve problems, strengthen capabilities, enable functioning – at least in the long run – is unethical in the context discussed here.

The quality criteria of design in a disability context are linked to interaction with the user, through cultural probes, sketches, mock-ups, prototypes, material or immaterial artefacts; and observing and intervening in actual usage. It is possible to use emerging technology early in the design phase to reveal new knowledge about the user. Of course, a process of this kind influences the persons involved, but that is not to be considered a drawback. On the contrary, it is a built-in part of the process and a cornerstone of the research. It is part of the aim of the iterative design process. Including the user with the designer and researcher in the design process is 'a goal, not a foul.'

Let's take a look at two of the fundamental concepts in phenomenology: *phenomenon* and *lifeworld*. Phenomenon in this context does not stand for the occurrence in and of itself, but for the occurrence experienced by someone. The word 'phenomenon' means 'that which shows itself' and it is implicit in the definition that there is someone to whom it is shown. Our focus on the experienced person – the individual with the disability – thus becomes obvious from a phenomenological perspective. It is the phenomenon as it appears to her that we want to call attention to; how she experiences her world and the special conditions that we, if we understand them, can help to improve and enhance with an assistive aid. 'We want to go back to the things themselves,' says Edmund Husserl, phenomenology's founder, in his 1901 publication *Logische Untersuchungen*.[32]

The *lifeworld*, the lived world, is the other indispensable concept and is strongly associated with that of phenomenon. The lifeworld is the world we already find ourselves in, are familiar with and take for granted. It is pre-reflexive and pre-scientific and it both influences us and is influenced by us. We exist in this world with our bodies, which, in the philosophy of the French phenomenologist Maurice Merleau-Ponty, is an integrated whole that he calls 'the lived body'. 'The body is the vehicle of being in the world'. 'The body is the general medium for having a world'.[33]

Phenomenology's desire to allow phenomena, the things that appear, to be the controlling factors, in our opinion is close to Norman's affordance, a concept that surfaced 80 years later.[34] A significant difference is that phenomenology does not just indicate the phenomena, the individual things and how they emerge, but also the lifeworld as the point of departure. Affordance is a concept that originally was used in psychology to describe how objects, people, situations and so forth, offer or afford opportunities for possible interactions to an observer. It is these offerings in the first place that we perceive when we are confronted with phenomena.

The designer in a rehabilitation context has quite a different task than a researcher in a grounded theory context, where the task is mainly to understand what is happening and how the players manage their roles. The researcher gains understanding through observations, conversations and interviews. Data collection, note taking, coding and sorting are all part of the work before writing; categories and theories are supposed to emerge during the process. Grounded theory is distinguished in that it is explicitly emergent and does not test hypotheses. The aim, as Glaser explains, is to discover the theory implicit in the data.[35]

Design versus the medical or social model

Of course, there are many models in disability sciences, but none that is satisfactory for design. *The medical model* oversimplifies disability as an individual characteristic and directs awareness towards individual adjustments and means. *The social model*, on the other hand, directs awareness towards ideological and political analysis, not towards practical everyday solutions for experienced functioning. In 'Making both ends meet', Peter Anderberg introduces what might be the beginning of a relevant model, *FACE,* in which Function is analysed from three different factors: Attitude, Control and Enabling.[36] One of the advantages with the FACE model is that it necessitates the consideration of ethical aspects.

Design science and natural sciences

Regardless of theoretical or methodological standpoint, the only research result worthy of the name is new knowledge. Accordingly, in a research project it is seldom the entire process or the project results as such that are the actual research results; the new knowledge generated in the project often constitutes a rather minor portion. But it is essential to identify and define this knowledge and relate it to what already exists. This is quite a delicate task. It helps considerably if the methods involved are standard for the related scientific fields. However, this is not always possible. The phenomenology of Husserl's time as well as grounded theory and to some extent abduction mean that the phenomenon that is the object of investigation can and should be the controlling one.32 The disadvantages with inventing your own methods are manifest – much is required for the results to be considered credible. At the same time, the advantages are also manifest: it is through them that you achieve proximity to the reality being investigated. The researcher is forced to take more responsibility for the knowledge building than if he or she follows established methods.

Large areas of rehabilitation engineering and design can be dealt with within the framework of epistemology and can thus pride itself on:

- its ability to systematise and accumulate
- its ability to articulate new questions
- its openness and transparency even in its handling of methods and data
- its capacity to generalise on the basis of experience gained
- its openness to other perspectives which may make the results look different

In all these instances, epistemology strives for universality, context-independence and non-relativism. This is advantageous – *provided that it is possible and relevant*. If not, the priority of the particular must apply.[37]

To sum up

In rehabilitation engineering and design, there is a need for concrete experiences, acknowledgement of different communities of practice, acceptance of desire as an initiator of change, and an openness for the value of two-way inspiration and information. This all implies an ethics that is dual: operationally situated but with its exemplars continuously questioned and examined in the spirit of international ethical codes, charters and declarations. Induction, deduction, and abduction in between the generalised ethical level and the situated one would vitalise ethics in the design research community. The processes can be strongly facilitated if the confusion and overlaps of design concepts could be replaced by more standardised and agreed-upon core concepts.

Bodil Jönsson is Professor of Rehabilitation Engineering in the Department of Design Sciences at Lund University, Sweden. A physicist and educator, she focuses on the benefits of new technological and educational concepts for people with disabilities. Peter Anderberg, Eva Flodin, Camilla Nordgren and Arne Svensk are doctoral candidates at the same Department with the following research areas respectively: IT, learning and disabilities; spinal muscle atrophy; economic consequences of traumatic spinal injury; design of cognitive assistance. Lone Malmborg is Associate Professor in Arts & Communication at Malmö University, Sweden and the Royal College of Art, London. Her interests include embodied interaction, augmented spaces and artefacts, interaction design and virtual reality environments as well as computer supported collaborative learning and working.

---

[1] Håkan Eftring 'The Useworthiness of Robots for People with Physical Disabilities' Doctoral thesis, Lund, Sweden: Certec, LTH, Lund University, 1999. Available at: http://www.english.certec.lth.se/doc/useworthiness/useworthiness.pdf

[2] Online Ethics Center for Engineering and Science, Ohio, USA: Case Western Reserve University, 2004. Available at: http://onlineethics.org/

[3] Marjo Rauhala and Päivi Topo 'Independent living, technology and ethics' *Technology and Disability* no 15, 2003, pp. 205-214.

[4] *Nuremberg Code* Washington, D.C., USA, 1949-1953. Available at: www.ushmm.org/research/doctors/Nuremberg_Code.htm

[5] *Helsinki Declaration* Helsinki, Finland: 18th World Medical Assembly, June 1964, amended 1975, 1983, 1989. Available at: http://onlineethics.org/reseth/helsinki.html

[6] *The European Convention 2003*. Available at: http://european-convention.eu.int/

[7] *The Charter of Fundamental Rights of the European Union* Nice, France, Dec. 2000. Available at: http://www.europarl.eu.int/charter/default_en.htm

[8] *Convention on the Rights of the Child* UNICEF, 2002. Available at: www.unicef.org/crc/crc.htm

[9] *Citizens Rights and New Technologies: A European Challenge* Brussels, May, 2000. Available at: http://europa.eu.int/comm/european_group_ethics/docs/prodi_en.pdf

[10] Bettye R. Connell, Mike Jones, Ron Mace, Jim Mueller, Abir Mullick, Elaine Ostroff, Jon Sanford, Ed Steinfeld, Molly Story, and Gregg Vanderheiden *The Principles of Universal Design* NC, USA: NC State University, The Center for Universal Design, Version 2.0, 1997. Available at: http://www.design.ncsu.edu/cud/univ_design/principles/udprinciples.htm

[11] Eva Flodin 'Assistenter i min livsvärld (Assistents in my lifeworld)' Praktiskt-Pedagogiska Problem (Practical-Pedagogical Problems) Halmstad, Sweden: Halmstad University, no 12, 2000.

[12] Eva Flodin 'Jakten på Instinktivspelaren' (Hunt for the Instinctive Player) Master thesis, Halmstad, Sweden: Halmstad University, 2000.

[13] Edward Tenner *Our Own Devices – The Past and the Future of Body Technology* New York: Random House, 2003.

[14] Håkan Edeholt Design Innovation och andra Paradoxer – förändring satt i system (Design, Innovation and other Paradoxes) Doctoral thesis, Göteborg, Sweden: Chalmers University of Technology, 2004. Available at: http://webzone.k3.mah.se/k3haed/

[15] Jean Lave and Etienne Wenger *Situated Learning: Legitimate Peripheral Participation* New York, USA: Cambridge University Press, 1991.

[16] Finn Kensing and Andreas Munk-Madsen 'PD: structure in the Toolbox' Communication of the ACM vol 36, issue 6, New York, USA: ACM Press, 1993, pp. 78-85. Available at: http://doi.acm.org/10.1145/15371.163278

[17] William Gaver, Anthony Dunne, and Elena Pacenti 'Design: Cultural Probes' *Interactions* vol 6, no 1, 1999, pp.21-29.

[18] William Gaver, Anthony Dunne, and Elena Pacenti 'Projected Realities: Conceptual Design for Cultural Effect' Proc. of CHI '99 ACM Press, 1999, pp. 600-608.

[19] Hilary Hutchinson, Wendy Mackay, Bosse Westerlund, Benjamin Bederson, Allison Druin, Catherine Plaisant, Michel Beaudouin-Lafon, Stéphane Conversy, Helen Evans, Heiko Hansen, Nicolas Roussel, Björn Eiderbäck, Sinna Lindquist, and Yngve Sundblad 'Technology Probes: Inspiring Design for and with Families' in Proc. of CHI '03 ACM Press, 2003, pp. 17-24. Available at: http://insitu.lri.fr/~roussel/publications/CHI03.pdf

[20] Cooperative Systems Engineering Group, Computing Dept., Lancaster University,UK. Available at: http://www.comp.lancs.ac.uk/computing/research/cseg/index.html

[21] Bodil Jönsson, Arne Svensk, David Cuartielles, Lone Malmborg and Pierre Schlaucher *Mobility and learning environments: engaging people in design of their everyday environments* Lund, Sweden: Certec, LTH, Lund University and Malmö University, Creative Environments, 2002. Available online: http://www.certec.lth.se/doc/mobility1/MobilityLearningReport021215.pdf

[22] Sean Donahue 'Discipline Specific Ethics' Design Philosophy Papers no 2, 2004.

[23] Tony Fry 'Design Ethics as Futuring' *Design Philosophy Papers* no 2, 2004.

[24] Cameron Tonkinwise 'Ethics by Design, or the Ethos of Things' *Design Philosophy Papers*, no 2, 2004.

[25] Bruno Latour 'Technology is Society Made Durable' in J. Law (ed) *A Sociology of Monsters. Essays on Power, Technology and Domination* (Sociological Review Monograph) New York and London: Routledge, 1991, pp.103-131.

[26] Peter Anderberg 'Being there' *Disability and Society* vol 20, no 7, 2005, pp. 721-735.

[27] Lev S. Vygotsky *Mind in Society* Cambridge, MA, USA: Harvard University Press, 1930.

[28] Paul Dourish *Where the Action Is. The Foundations of Embodied Interaction* Cambridge, MA, USA: MIT Press, 2001.

[29] Bodil Jönsson 'Enabling communication: pictures as language' in Malcolm MacLachlan and Pamela Gallagher (eds) *Enabling Technologies. Body Image and Body Function* Edinburgh, UK: Churchill Livingstone, 2004, pp. 33-57.

[30] Vilayanur S. Ramachandran and Sandra Blakeslee *Phantoms in the Brain. Probing the Mysteries of the Human Mind* New York: William Morrow & Company, 1998.

[31] Donald Schön *The Reflective Practitioner. How Professionals Think in Action* New York: Basic Books, 1983.

[32] Edmund Husserl *Logische Untersuchungen (Logical Investigations) vol II*, 1901, p.7. Available online in German at: http://www.princeton.edu/~batke/phph/husserl/lu/

[33] Maurice Merleau-Ponty *Phenomenology of Perception* New York and London: Routledge, 1962, pp. 82 and 146.

[34] Donald Norman *The Psychology of Everyday Things* New York: Basic Books, 1988.

[35] Barney G. Glaser 'Naturalist Inquiry and Grounded Theory' *Forum: Qualitative Social Research* Jan., 2004. On-line Journal, vol 5, no 1, art 7. Available at: http://www.qualitative-research.net/fqs-texte/1-04/1-04glaser-e.htm

[36] Peter Anderberg 'Making both ends meet' *Disability Studies Quarterly* vol 25, no 3, 2005.

[37] Martha Nussbaum *Love's Knowledge. Essays on Philosophy and Literature* Oxford, UK: Oxford University Press, 1990.

III Being There

Disability & Society
Vol. 20, No. 7, December 2005, pp. 719–733

Being there

Peter Anderberg* and Bodil Jönsson
University of Lund, Sweden

This paper examines the use of the Internet as experienced by people with significant mobility/physical impairments who are accustomed to using computers. The study is based on interviews and focuses on computer usage in everyday action and interaction. In many cases, the possibilities that the computer and Internet offer have meant not only important improvements in quality of life, but first-time occurrences of great personal significance. The analysis is phenomenographic, resulting in main categories and subcategories, illustrated primarily through direct quotations. The three main categories are independence, communication, and learning.

Introduction

Computers and the Internet have changed and improved the functioning of many people in a variety of areas. The potential of computers and the Internet for disabled people is undisputed for the most part, even though present-day practice fails to fulfil this potential in a number of ways and for many. Still, groups of disabled people have gained relatively more than have their non-disabled counterparts who do not need to adjust their bodies to the rigid structures of an inaccessible, inflexible and rejecting physical environment. In digitalised environments, structures can be adjusted to suit the individual (Amtmann & Johnson, 1998; Anderberg, 1999; Lance, 2002), and for many disabled people there have been not only improvements, but also first-time occurrences of great significance. Examples of these are being able to do their banking and to communicate with others in private, without having to rely on family members and personal assistants.

Critics have pointed out the dangers of building a new and inaccessible environment on the Internet. Goggin and Newell argue that the Internet today is in danger of becoming a new arena for the social creation of disability. Developments ignore disabled people and assume non-disabled patterns, thereby creating a system where disability increases rather than decreases (Goggin & Newell, 2002). Disabled users of

---

*Corresponding author. Certec, Division of Rehabilitation Engineering Research, Department of Design Sciences, PO Box 118, S-221 00 Lund, Sweden. Email: peter@anderberg.net. Web: http//www.anderberg.net

ISSN 0968-7599 (print)/ISSN 1360-0508 (online)/05/070719–15

DOI: 10.1080/09687590500335733

the Internet who have sensory impairments or learning difficulties may find themselves excluded from online information sources due to an inaccessible web format. Still, these shortcomings must be analysed keeping in mind that old information technologies, such as the printed press, 'created enormous quantities of inaccessible information' (Coombs, 2000) for people who are blind or have low vision.

Michailakis (2001) has studied the impact of Information and Communication Technologies (ICTs) on the opportunities for disabled people in the labour market. He concludes that, 'ICTs must be regarded as a variable dependent by the economic, social and cultural order. Its effects on disabled persons' employment opportunities are not independent by the power relations at a given time' (p. 477).

Technology is never just technology, the physical artifact. Technology is a manifestation of economical, political, social and cultural concepts as well as individual wishes and ideas. It can be empowering or disempowering, depending on the system in which it is introduced (Anderberg, 2005).

Bowker and Tuffin (2002) have analysed the effects of communication on online media for disabled people from the perspective of identity. They identified a 'choice to disclose' repertoire. In an online setting with text-based communication, individuals can control how others perceive them, by disclosing or not disclosing information about themselves. In addition, an individual can choose any identity they wish and thus 'assimilating into "normal" culture'. This provides disabled people access to a social context they would not normally have and 'time-off' from the disabling perceptions of others.

In another study, Seymour and Lupton (2004) examined online communication for disabled people. They identified and described how the online medium offers disabled people the opportunity to manage relationships and contacts. The importance of being able to control one's 'online image' and the choice of disclosure were also identified in this study, as were the attendant positive consequences for the individual.

The possibilities provided by an online bodiless identity and the ability to reach beyond time and space limitations do not just apply to the increased social activity that results from facilitated communications and contacts. There are several other areas and effects that can be studied. The Independent Living Movement has helped to develop the concepts of autonomy and independence for disabled people. Ratzka defines independence as having access to 'the same choices and control in our everyday lives' as everyone else has. Furthermore, exclusions from the definition of independent living are equally important. It does not mean 'to do everything by ourselves' or 'to live in isolation' (Ratzka, 2003). This is an important distinction since the more limited a person is by an impairment the more help he or she requires, which leads to a greater dependence on other individuals and society. The right to define this need and to control the functional assistance required to even out the difference is the true basis of independence (Ratzka, 1993; Oliver, 1996; Corbett, 1997).

Reindal describes a discourse where the notion of independence is examined in light of the difference between a professional's definition and one embraced by disabled people. While the professional measurement of independence concerns the level of performance of everyday and self-care activities, disabled people's notion of independence has more to do with control and choice over the 'when and how' of obtaining assistance (Reindal, 1999). Corbett describes how the striving or necessity to do everything on your own, like 'normal' people, inhibits rather than enhances quality of life when too much time is spent on daily chores. There is a high price to pay for this 'normality' (Corbett, 1997). For some disabled people this is not even an option, since the need for personal or technical assistance is total.

If a person needs to use another person to perform a task or a function, an undesired filter can be imposed between the assistance user and the desired function. This happens even if the assistance user is in control of how and when the task is carried out. Technological solutions often have the added value of offering the user direct control. Being able to do everyday tasks on one's own is not to be underestimated. Finding a platform where one is unhindered by an uncooperative body, where body in general is less of an issue, can lead to an increased sense of independence for the individual. Grimaldi and Goette (1999, p. 272) concluded in a questionnaire study that the 'increase in the number of internet services used positively influences the perceived level of independence among individuals with physical disabilities'.

The computer and Internet usage described is dependent on at least two important access factors. The first concerns Internet and computer availability. This is referred to as the 'digital divide': the differences in Internet access that stem from social, economic and educational barriers in a discriminating society. The grim reality is that disabled people, to a great extent, are on the have-not side of the digital divide (Kaye, 2000; Goggin & Newell, 2002; Keane & Macht, 2002).

The second factor concerns user interface adaptations and the accessibility of online material. People with different impairments experience different problems; without proper technical adaptations, portions of the online arena remain inaccessible for many, even when an Internet connection is available.

Neither the digital divide nor user interfaces are addressed in this paper. The aim is to draw attention to and elaborate on what can be achieved when a wide variety of obstacles are overcome. The focus is on how people with mobility impairments experience and use the Internet as a tool for enhancing their functional abilities.

Participants

This article describes the everyday action and interaction with computers by people with significant mobility impairments. A purposeful selection of a sample of participants was required to find people already experienced in using the Internet, both at work and privately (Patton, 1990; Miles & Huberman, 1994).

Contact with the majority of the participants was established through the Swedish Internet Centre in Tenerife, Spain. The Centre provides computer workstations for work, study and leisure for Swedish citizens with disabilities who are receiving rehabilitation services. Close to 200 people with mobility impairments who visited the Centre were contacted and asked about their use of the Internet. Those who fitted the profile were asked to participate in a longer interview. Fifteen persons were selected in this way and all of them agreed to participate. Four people whom I already knew fitted the profile were contacted, and an additional three were suggested by other participants.

A total of 22 people were interviewed, eight women and 14 men, ranging in age from 25 to 60. Pseudonyms have been used to ensure anonymity. All of the informants have mobility impairments and all are experienced in using computers and the Internet in their everyday work and for personal purposes. Nineteen of them require personal assistance (PA) from seven to 24 hours a day.

The participants do not constitute a statistical representation of Internet users with disabilities, but rather a specially selected group of users. This made it possible to collect reflections and answers based on extensive and rather specialised experience; it eliminated the effects of inexperience and poor adaptations of the user interface.

Procedures

Participants were invited to take part in a face-to-face interview or an online interview conducted via MSN (Microsoft Network) Messenger. Fifteen of the informants chose a face-to-face interview and the remaining seven the MSN Messenger option. In the latter group, four of the informants had spoken language impairments as well, and three preferred Messenger because of geographical distance. Procedures of informed consent and confidentiality were followed. Participants could withdraw from the study at any stage and were not obliged to answer any questions. All participants were informed of the aim of the study and how the results were to be used.

The interviews were what Kvale (1997) calls 'semi-structured'. This means that an interviewer follows an interview plan without prepared questions, instead using general areas of interest in which to ask questions. This allows participants to speak freely about their interests while the interviewer further pursues interesting discussion points without losing focus on other important areas. The interviewer is able to return to the core interest of the interview.

The face-to-face interviews were transcribed with the aim of keeping the content intact rather than giving an exact reproduction of the spoken language. Kvale suggests that the style and exactness of a transcription should be guided by the intentions (for whom and for what) of the transcription (Kvale, 1997). In this case, a certain amount of rephrasing and condensing has been done, without changing or corrupting the meaning of what was originally said.

For the online interviews, the original interview protocol was only changed with regard to errors of spelling, grammar and typing. Identifying information was either removed or substantially altered to protect participant anonymity. Pseudonyms were also used.

Validity

In qualitative research, content validity is based on an existing, extensive and open knowledge about the subject under study. My knowledge of the area stems from 20 years as a computer user, 15 years as a wheelchair and personal assistance user, more than 10 years as an Internet user and at least five years of higher education in the area of social model and independent living theories. The basis of these theories is that disability is situated and relative, which has greatly influenced and guided my work (Oliver, 1996; Albrecht, 2002; Barnes *et al.*, 2002; Thomas, 2002; Barnes & Mercer, 2003; Ratzka, 2003). This blend of experience and knowledge is the most important keystone of my career as a researcher in the field of rehabilitation engineering.

As to the degree to which it is possible to generalise the results presented in this study, it should be noted that the group under study is a privileged one, as all participants have full access to computers and the Internet. All of the participants are Swedish and having a disability in Sweden is in many ways different from having one in other parts of the world. Social and cultural differences affect the results of the data. But to some extent, the Internet is an international arena and people who are fairly fluent in languages can reach beyond the boundaries of their own country and access people and information resources abroad. The focus of this study is on how disabled people use computers and the Internet, and as such, its results are also valid for a larger group of people, including both current as well as future computer and Internet users with disabilities.

Categories

In the pre-coding phase, the interviews were listened to, transcribed and read several times in order to grasp the material. The systematic search for categories was guided by the research question using a 'comparative pattern analysis' (Patton, 1990). Categorising involved organising coded data units into categories identified as having similar characteristics using content coding (Miles & Huberman, 1994). An MSSQL database was used to facilitate this phase. The constant comparative coding resulted in a number of subcategories that were further grouped into three categories. The aim of the categorisation was to find the different ways in which people with mobility impairments experience their use of the Internet. This is standard procedure in phenomenographic research. Marton and Pang (1999) write that, 'In phenomenography, the object of research is variation in ways of experiencing a phenomenon'. The object here is the variation in the use of the Internet as perceived by experienced computer users who have mobility impairments.

Responses to the interview questions fell into the three main categories of independence, communication and learning. These categories represent the primary variation of ways in which disabled people experience their use of the Internet.

First category: independence

Avoiding being controlled

Adam uses personal assistance (PA) on a 24-hour basis. The online arenas available offer him the opportunity to handle many functions in his life without unwanted control or supervision by people around him. He feels a boost in his integrity now that he can write to others in private and manage his finances without any one else knowing how much money is left in his account.:

> Before I had my computer the PAs knew everything I did. I couldn't write a word without them knowing it. It was very annoying and frustrating.

Avoiding friction

Beatrice uses personal assistance on a 24-hour basis. She is totally dependent on her PAs in the physical environment, and she feels that this closeness at many times creates friction. She is also affected if a PA has a hangover or is in a bad mood for any reason. The computer provides access to online arenas and becomes a neutral place in which she can function:

> I can enter that world and shut out the PAs. They can help me to the bathroom but I don't need to socialise with somebody who is in a bad mood.

Avoiding human filters

Beatrice feels that her PA gets in her way when she meets people. The computer frees her from being dependent on a PA by opening up new arenas for contact that she is able to control without the presence of a PA:

> They are always with me when I am out, so even if I send them away people think we are out together. At work my colleagues freak out when the PAs have to sit in another room. But it feels good not to have them know everything I do. They come too close otherwise.

In a physical environment Beatrice needs her PA to be around and this constitutes an unwanted presence, a filter in many contacts. In chat rooms and other online contacts, Beatrice can meet and get to know other people independent of her PAs.

Avoiding negotiation

Charles uses personal assistance on a 24-hour basis. Even if the PAs normally do what Charles asks, it is the repetitive and 'serial' asking he does not like. Situations where his PAs suggest an alternative to what he wants them to do irritate him considerably. Charles feels that the direct control of functions offered by an online computer provides him with a negotiation-free zone and adds to his independence:

> When you are such a high quad as I am, you are always dependent on others, on their benevolence, willingness or unwillingness. But now I don't need to negotiate about which channel I want to listen to; I can read what I want or look at or communicate with whom I want. It is a freedom I never had before.

Being independent of the physical environment

An easily recognised advantage of a digitalised environment is that moving your body around is not necessary for the performance of various functions. A person can have

> I would never have gone otherwise. Talking to people on the telephone just doesn't work. And you can't trust what they say either.

Another way to experience the world is to surf on the Internet. Web cameras, pictures and printed descriptions enable you to see and learn about places that you may not be physically able to travel to.

> I found one of those virtual reality things where you could travel around up in Machu Pichu. It was awesome! (Ivan)

Getting information immediately

The Internet provides an opportunity to broaden and intensify your thought processes by providing immediate access to a range of facts and opinions. Previously unavailable or difficult-to-access information is now close at hand for everyone, including people with mobility impairments. You can get immediate answers to questions and spontaneously follow the thought patterns of others.

> It gives me an enormous freedom too. There are a lot of things I just couldn't do before. I've never been able to take a book off the shelf and page through it. (Charles)

Getting more information

The power relationships between disabled people and the professionals they have to deal with are seldom, if ever, on an equal basis or to the advantage of the former. Being well-informed can reduce this inequality to some extent. Current, correct and multiple sources of information can provide an advantage and ensure proper treatment.

John, who is a relatively young Parkinson's patient, was not pleased with how the healthcare system was treating him. He started to look for more information and also found people in situations similar to his own:

> John: I was advised to e-mail a person who had the same problem as I had and after a while I felt an enormous confidence in him. He saw that my medication was wrong and suggested changing it.
>
> Interviewer: Was he a doctor?
>
> John: No, but he is very competent when it comes to medicine; he knows much more than my doctors. And he has Parkinson's as well so he knows much more about the person behind the disease. My doctor accepted his advice eventually.

Being good at something

For people with mobility impairments, it is difficult to find areas in which to excel, to test one's limits, and to experience skill improvement. Karl has muscular dystrophy, resulting in weak limbs. He plays computer and online games for recreation. He finds that this is one area where he has the satisfaction of improving at something:

> Playing games offers me a lot. All these games require a certain amount of motor activity and alertness. You need to be perceptive and quick otherwise you drive off the track or if

> you play hockey, you get beaten badly. There is a kind of training or practice in the midst of all the fun. You simply need to be alert. You have to make quick decisions and everything moves fast in the games. Everything else in my life is very slow.
>
> Whenever I start with a new game, I think there must be something wrong with it because I am so bad. But then I discover that I get better and better and finally I master it.

Comparing oneself with others

Another aspect of seeking challenges in virtual arenas is being able to compare oneself with others and taking part on equal terms in games and challenges:

> And it is important when you are disabled like I am to see that you can assert yourself. I have played online games against people without disabilities and we are on the same level. In real life, there are no games in which I could play against someone without getting really beaten. (Karl)

Karl describes a situation where his disability disappears when the playground is virtual. When he is playing a game it is 'for real' and no less challenging than it would be in real life. It gives him the opportunity to vent and channel feelings that otherwise would be suppressed or expressed in other forms:

> Karl: When you are sitting there, it's for real; you are entirely in to it. It's as if you were sitting in a car or really playing hockey and you can tackle, which you can't do in real life. You can even tackle so you get a penalty and that is really a boost for your confidence, that you can be …
> Interviewer: … a bit bad?
> Karl: Yeah, exactly. You don't always have to be nice and apologise and be careful with your fragile body.

Creating

Karl makes a distinction between recreation (playing games) and work (creating music). He has always composed and played music. When his decreasing muscular strength made it impossible for him to play instruments, he transferred these functions to the computer. He uses something called a 'band-in-box' where he can program different styles and also download music files from the Internet. This enables him to continue his creative work:

> That is what is fantastic. You do not have to stop playing or creating music just because your arms grow weaker and you lose some of your functional abilities. There are things today that enable you to play music as long as you can tell the computer what to do.

Becoming visible

The Internet provides an opportunity to present oneself and one's life to a large number of people, and by so doing, maintain full control over the image that is presented. Dora has a homepage where she introduces herself in pictures and text. She feels this lets her provide a contrasting and more accurate picture of a person with an impairment than is commonly available:

a variety of arenas available to them in the comfort of their own home, where the physical environment is adapted. Dora uses personal assistance on a 24-hour basis and has a lot of trouble transporting herself, regardless of the accessibility of the environment, because she easily gets tired and cold. Dora found herself absorbed by the ease of the digital environments and for a while she was spending almost all her time there:

> Everything is available to you in your own home. It's so easy. Not having to leave your home when it's winter and cold, not having to move yourself physically!

Eric works at a computer helpdesk for a big company and accesses computers remotely. Due to the physically inaccessible environment at his office, he is not able to get around in his wheelchair to do his job locally at every workstation. Being able to access all the client computers remotely, he works in the same way as his colleagues.

Another effect of independence from the physical environment is the enhanced opportunity to change an inappropriate environment. Fredric, who has rheumatoid arthritis, leaves Sweden during the winter months to live in a warmer climate. Even though he is away, he can still participate in the same online arenas, making the transition much easier.

Being independent of an external pace

The asynchronous nature of the Internet makes it possible to live certain aspects of one's life at a personally determined pace or rhythm. Gloria has multiple sclerosis and her problems vary over time. She needs to change her work pace and rhythm accordingly.

> I have a computer at home where everything looks exactly the same as on my work computer and is connected to the company server. I decide myself how I organise my day, and thanks to that, I can work full-time.

Second category: learning

Accessing information about the world

A problem for people with mobility impairments is that many places in their community are inaccessible; asking for this information from people who do not have accessibility difficulties can be misleading. Dora always uses the Internet to check in advance:

> When I go to a museum, new restaurant or cinema, I always check the Internet to find out if I can get in with a wheelchair and if it is otherwise accessible. If you don't find anything, you can always send an email.

For longer journeys it is even more important to get accurate information about the physical environment of the destination. Without it, some people would not dare to go. Harry used the Internet to examine a resort he wanted to visit:

> When you look in newspapers, for example, disabled people are either heroes or objects of pity. I am neither, and I want people to see that.

Third category: communication

Meeting as equals

When people first meet in a text-based, digital environment, there are no visual disability indicators available; an impairment does not become a hampering factor. Ivan uses personal assistance on a 24-hour basis. He prefers that first-time meetings take place in a text-based environment:

> If I come to a meeting and must be carried up the stairs, then the others immediately have an unconscious, negative impression of me. Or at least a condescending impression. It doesn't matter what they think or what they say. And even if they really don't care, I do. On the Internet that doesn't happen. There, I'm like everybody else.

Choosing what to disclose

The choice of disclosure is a strong function in a text-based, digital environment. Beatrice has chosen not to tell the people she meets on the Internet about her disability. She utilises the fact that she can create an online identity that does not include her disability. She talks about how nice it is to be 'normal' for a while, to be 'one of the crowd' and to 'take time off' from the disabling perceptions of others.

She is not anonymous in the chat rooms she uses in the sense that nobody knows who she is, but she has reconstructed her identity leaving out certain components, that is, her impairment and its consequences. In her online identity, she has a lot of friends who only know her on the Internet, and she makes a clear distinction between her Internet identity and who she is IRL (in real life). She feels that she is revealing different aspects of her identity, but she is always herself, only without her disability. Since she has no wish to meet her Internet friends in real life, she does not feel there is a problem with having separate identities.

> Interviewer: Do you ever tell anybody in your chat rooms that you have a disability?
> Beatrice: No.
> Interviewer. Why not?
> Beatrice. Because I don't want to meet anyone in person. I only want to relax and chat for a while.
> Interviewer. And not 'be disabled'?
> Beatrice. Yes.
> Interviewer. Do you like that?
> Beatrice. Yes. It's unbelievably nice. To be normal for a while.
> Interviewer. Aren't you normal otherwise?
> Beatrice: No, not in the eyes of others. They only see an invalid. Most of them anyway; there are always exceptions.
> Interviewer: Over the Internet nobody can see your disability?
> Beatrice. No, you're just one in the crowd, just like anyone.

Defusing a disability

The bodiless environment of the Internet provides not only the choice to disclose; it also provides an arena where a person can open up and discuss disabilities. Since there is no disability present, the discussion becomes only indirectly and abstractly connected to a person.

Lars thinks it positive that people he meets in digital environments dare to ask things they would not in 'real life'. For him, it is an opportunity to refute prejudices and misconceptions. It is also easier to answer these kinds of question over the Internet. Lars feels that it does not come 'so close' when he talks about these things over the Net:

> Lars: When you tell people after a while, you almost always encounter curiosity.
> Interviewer: Yes, it's interesting. People seem to ask more when they meet you on the Internet.
> Lars: Yes, so it is. There's a big difference compared to meeting people IRL. It's easier to answer as well. It doesn't come so close.

Building a special social network

The opportunity for increasing the geographical area for making contact with other disabled people is another function the digital environment provides. It is not necessarily so that a person wants to socialise with other people who have a similar disability, but if a person wishes to do so, the selection is usually limited. Digital environments provide arenas where you can make contact with people with similar experiences, and increase the number of people available for social encounters.

For John it was important to find people who shared experiences and problems that were difficult for the uninitiated to understand:

> I had no one around me to compare notes with. In January I found a webpage for people with the same illness I have, and I wrote a couple of lines about who I was and that I needed to get in contact with people in a similar situation. The same day I got an answer and within a week I had a couple of answers. I am very close to some of them now.

Ivan gives a slightly different description:

> IRL I don't feel like hanging out with other disabled people. They mostly complain and whine about everything. The local disability organisation is only for seniors. On the Internet I find disabled people who are more enterprising and that can be fun. There you can choose and you don't have to be packed together with a lot of other people just because they are in wheelchairs, but with whom you have nothing in common otherwise.

Discussion

In the interviews, people told stories from different angles about how they have taken control over a number of functions, and thus (re)gained control over important areas in their lives. In many cases, it meant physical relief, and tasks that were arduous or impossible in the physical world were easily performed when moved to a digital environment. It did not so much change the conditions for the body: a person who needed help in the bathroom still needed that help. But the more dependent a person is on others in the physical world, the more the access to uncontrolled and unsupervised areas of activity results in a sense of independence. The more activities available online, the more independence the individual is afforded.

Relative independence from the physical body also provides a certain independence regarding time and place, which can have many positive effects as described in the interviews. The same elements exist for people with and without disabilities. The essential difference is that for people with impairments, it may be the only way to perform a function single-handedly, in full control, acting on equal terms.

The direct control of functions is a prerequisite for the myriad learning, expressive and creative opportunities afforded in digital environments. Anyone who has ever tried to get another person to do something exactly the way s/he wants knows that it is hard, to say the least. A compromise would be to allow things to be done in another way, or not to do them at all. If a person wants to compose and play music, however, doing it through somebody else is hardly an option. That is why being able to create and play music on his computer is so great for Karl. If he could not do it himself, he would not do it at all. Having only secondary control of functions makes skill acquisition difficult as well. The knowledge of 'the hand' is neither established, challenged nor increased if it does not itself act, control and receive feedback directly. Technology – in this case computers and the Internet – is a neutral and impersonal tool enabling direct control of a function and removing unwanted filters.

That a person has a bodiless manifestation on the internet also makes it difficult to identify an impairment unless it is actively disclosed (Bowker & Tuffin, 2002). To the persons in this study the ability to control their online image has been a source of many new positive outcomes.

Ratzka talks about 'global incompetence' meaning that 'an environmental incompetence affects other aspects of one's personality with the result that a disability limited to one aspect of a person is associated with global incompetence in all areas' (Ratzka, n.d.). If no visual clues are available, and the asynchronous nature of the Internet makes the time spent on various tasks unimportant, ICTs thus constitute a levelling ground with no inherent inequality for people with mobility/physical impairments; they thereby enhance interaction with others.

Some argue, as Goggin and Newell (2002) do, that other inabilities or disabilities will emerge on the Internet, and this is most certainly true. However, with proper user interface adaptations none of these will be directly connected to a body's mobility or sensory impairment. The disabilities that arise are to a large extent secondary and indirect, and stem from social, economical and educational differences for disabled people in a society that discriminates. This includes under-representation in higher education, low available income, and so on. The inability of being there, on the Internet, is a much bigger problem than unadapted information sources.

For the individual, the bodiless presence on the Internet has many advantages. Why waste energy trying to convince your banking establishment to rebuild its entrance, when Internet banking is so much easier? Why risk the danger of being dragged up the stairs to the local pub when it is so much easier to go to an online forum for company, where you do not have to worry about physical safety, accessible restrooms or deal with the attitudes of others? This ease and convenience, however, can easily lead to self-imposed restrictions, where what is experienced as choice becomes a restraint instead. The choice is understandable on the individual level, but for the political endeavours of disabled people as a group, the picture becomes somewhat more complicated. The invisibility of the body can undermine the understanding of how disability is created in society, and be used against the community of disabled people. Why should a university adapt its buildings when most classes are available as online and distance studies?

This is an important issue, and one that most of the people interviewed had reflected on. None of them, however, worried too much about it for themselves. They saw the online environment as a place to perform rather distinct functions that were otherwise unavailable or very difficult for them. The independence, learning and communication opportunities afforded online were not seen as being problematic but more as tools in a toolbox.

According to Castells (1996), one can look at the Internet as a 'culture of real virtuality', in this case meaning the existence of a diversified and hypertext based network culture. The online presence in this network is free from bodily, social and cultural constraints. The texts, games, online communities and fiction become the data of our experience and a new form of reality is created. Miller and Slater (2000), however, argue against what they see as Castells' division of the virtual and real, and suggest that the online and offline worlds are continuous and integrated, sharing the same experiential base. In the material presented in this paper, both these ways of looking at the Internet are relevant to disabled people.

There was an obvious flow of experience between the online and physical environment. Lars expressed how much easier it had become to meet new people IRL when they had met online first. Being able to 'defuse' the disability image in the other person and getting to know somebody without his body getting in the way, made him much more confident. Many of the persons interviewed gave the same picture: improved social skills and work relations, a boost in confidence, new relationships and more. Competence in the online world very obviously spilled over IRL.

For some individuals, it was also obvious that the choice had never been there, and may never be in the physical environment, regardless of adaptation. For them, the online world was the important thing. There was a sense that the world was moving in their direction, with increasingly more societal functions being moved to the Internet. An online identity is becoming a more 'normal' one for all. If everybody else finds their information or does their banking over the Internet, *being there* is most important.

It is hard to believe that the persons interviewed will let themselves be silenced or confined to the online world. Rather, their increased activity and knowledge and the ability to form social networks will be an additional tool in the political struggle for a more equal and discrimination-free society.

Conclusion

It is important that the life-changing positive effects described in this paper should not remain invisible, hidden behind prejudice and bias, initial implementation problems, lack of proper technical aids or just sweeping generalisations on the failure of computer use for disabled people. By describing the lives of people who are already there, taking full advantage of the online independence, learning and communications opportunities, an overall picture emerges of how computers and the Internet can have an even greater impact on the lives of people with mobility/physical impairments than many of the initial predictions foresaw.

References

Albrecht, G. (2002) American pragmatism and disability studies, in: C. Barnes, L. Barton & M. Oliver (Eds) *Disability studies today* (Cambridge, Polity).

Amtmann, D. & Johnson, K. L. (1998) Increasing access to higher education through the use of the internet, *Technology and Disability,* 8, 133–140.

Anderberg, P. (1999) *Internet learning for all: on initial efforts to achieve satisfactory study opportunities for disabled people.* Licentiate thesis (Lund, Certec, Lund University). Available online at: http://www.certec.lth.se/doc/internetlearningforall/ (accessed 28 March 2005).

Anderberg, P. (2005) Making both ends meet, *Disability Studies Quarterly,* 25(3).

Barnes, C. & Mercer, G. (2003) *Disability* (Cambridge, Polity).

Barnes, C., Barton, L. & Oliver, M. (2002) Introduction, in: C. Barnes, L. Barton & M. Oliver (Eds) *Disability studies today* (Cambridge, Polity).

Bowker, N. & Tuffin, K. (2002) Disability discourses for online identities, *Disability & Society,* 17(3), 327–344.

Castells, M. (1996) The culture of real virtuality, in: *The rise of the network society* (Malden/Oxford, Blackwell).

Coombs, N. (2000) *Assistive technology in third level and distance education.* Available online at: http://www.rit.edu/~nrcgsh/arts/dublin.htm (accessed 18 November 2004).

Corbett, J. (1997) Independent, proud and special: celebrating our differences, in: L. Barton & M. Oliver (Eds) *Disability studies: past present and future* (Leeds, The Disability Press). Available online at: http://www.leeds.ac.uk/disabilitystudies/archiveuk/corbett/chapter6.pdf (accessed 13 June 2004).

Goggin, G. & Newell, C. (2002) *Digital disability: the social construction of disability in new media* (Lanham, MA, Rowman & Littlefield).

Grimaldi, C. & Goette, T. (1999) The internet and the independence of individuals with disabilities, *Internet Research: Electronic Networking Applications and Policy,* 9(4), 272–280.

Kaye, H. S. (2000) *Computer and internet use among disabled people* (Disability Statistics Report 13) (Washington, DC, US Department of Education, National Institute on Disability and Rehabilitation Research).

Keane, C. & Macht, J. (2002) Universal access to CAP sites for disabled people, in: *B.C. identification of barriers, solutions and next steps* (Neil Squire Foundation). Available online at: http://www.neilsquire.ca/cap_finalreport.pdf (accessed 22 July 2004).

Kvale, S. (1997) *Den kvalitativa forskningsintervjun* [*The qualitative research interview*] (Lund, Studentlitteratur).

Lance, G. D. (2002) Distance learning and disability: a view from the instructor's side of the virtual lectern, *Journal of Information Technology and Disability,* 8(1). Available online at: http://www.rit.edu/~easi/itd/itdv08n1/lance.htm (accessed 12 August 2004).

Marton, F. & Pang, M. (1999) Two faces of variation, paper presented at the *8th European Conference for Learning and Instruction*, Gothenburg, Sweden, 24–28 August.

Michailakis, D. (2001) Information and communication technologies and the opportunities of disabled persons in the Swedish labour market, *Disability & Society*, 16(4), 477–500.

Miles, M. B. & Huberman, A. M. (1994) *Qualitative data analysis: an expanded sourcebook* (2nd edn) (Thousand Oaks, CA, Sage).

Miller, D. & Slater, D. (2000) *The internet: an ethnographic approach* (Oxford and New York, Berg).

Oliver, M. (1996). Defining impairment and disability, in: C. Barnes & Mercer, G. (Eds) *Exploring the divide: illness and disability* (Leeds, The Disability Press). Available online at: http://www.leeds.ac.uk/disability-studies/archiveuk/Oliver/exploring%20divide%20ch3.pdf (accessed 22 November 2004).

Patton, M. Q. (1990) *Qualitative evaluation and research methods* (2nd edn) (Newbury Park, CA, Sage).

Ratzka, A. (n.d.) *Micro vs. macro planning.* Available online at: http://www.independentliving.org/docs5/micro_macro.html (accessed 24 September 2004).

Ratzka, A. (1993) *Personal assistance and disability pride.* Available online at: http://www.independentliving.org/docs4/pride93.html (accessed 24 September 2004).

Ratzka, A. (2003) *What is independent living/a personal definition.* Available online at: http://www.independentliving.org/def.html (accessed 24 September 2004).

Reindal, M. (1999) Independence, dependence, interdependence: some reflections on the subject and personal autonomy, *Disability & Society,* 14(3), 353–367.

Seymour, W. & Lupton, D. (2004) Holding the line online: exploring wired relationships for disabled people, *Disability & Society,* 19(4), 291–305.

Thomas, C. (2002) Disability theory: key ideas, issues and thinkers, in: C. Barnes, L. Barton & M. Oliver (Eds) *Disability studies today* (Cambridge, Polity).

IV Peer Assistance for Personal Assistance

Peer Assistance for Personal Assistance

Analysis of online discussions about personal assistance
from a Swedish web forum for disabled people

PETER ANDERBERG*

Lund University Sweden

Abstract

This paper describes and analyses a community of disabled people in Sweden that use an online forum to discuss personal assistance issues. The forum is a community of practice (CoP) that has its roots in everyday living with personal assistance. The contributions to the forum were studied over a four-and-a-half-year period including a total of 2,755 postings from 146 persons. The levels of the CoP's learning system were analysed using the FACE tool, which examines **F**unction based on **A**ttitude, **C**ontrol and **E**nabling. The results indicate that a learning system was established within the CoP that made it possible for disabled people to complement, confront and counterbalance the influences of existing learning systems, theories and methods of professionals in the area of personal assistance.

Keywords: Internet, Web community, Community of Practice, Learning systems, Personal assistance, Peer-to-peer

---

* Certec, Division of Rehabilitation Engineering Research, Department of
Design Sciences, Lund University, P.O. Box 118, S-221 00 Lund, Sweden. Email: peter@anderberg.net. Web: http// www.anderberg.net

Introduction

The Internet offers a number of excellent opportunities for the creation of learning systems and communities of practice for disabled people. This paper examines the submissions made to a Swedish online discussion group on personal assistance over a four-year period. The purpose is to see how the peer-to-peer learning in the group allows discussion of a variety of interesting subjects on a number of different levels.

First, the context of the discussion forum is described by providing background information on disabled peoples' use of Internet and personal assistance in Sweden. Wenger's concept of community of practice is introduced along with the idea of treating disabled peoples' knowledge of personal assistance as the equivalent of 'professional' knowledge. The FACE tool for the analysis of technological and human personal assistance is presented. Thereafter, the discussions in the forum are presented and analysed.

Background

Mobility Impairments and the Internet

The Internet has provided disabled people with a set of new tools for participation and personal development in a wide variety of areas and practices. Access to areas of learning, entertainment and expression, as well communication and collaboration, has increased the possibilities for taking an independent and direct part in society. The more functions and activities that become available online, the more independence individuals can achieve. The direct control of functions is seen as a prerequisite for the myriad learning, expressive and creative opportunities afforded in digital environments (Anderberg & Jönsson, 2005).

With increasingly more societal functions being moved to the Internet, an online identity is becoming more 'normal'. The possibility of controlling your online identity by disclosing or not disclosing information about yourself, and being able to choose any online identity you wish, is a result of the bodiless online presence. This facilitates, increases and enhances social interaction, opening up new communication opportunities for disabled people (Bowker & Tuffin, 2002; Seymour & Lupton, 2004; Guo, Bricout & Huang, 2005; Huang & Guo, 2005).

In recent years, there has been a significant increase in information and information sources available on the Internet, including more services such as banking and booking travel. Particularly interesting is the opportunity for disabled people to access and control information, e.g. peer-to-peer information and contrasting views of mainstream, non-disabled and professional information sources. In a study of 200 Centres of Independent Living in the US, a great variety of information was found online that promotes 'consumer management over services, peer exchange, disability resources in local communities, advocacy, employment, and current information' (Ritchie & Blanck, 2003).

Virtual environments enable disabled people to expand their geographical area for finding interesting contacts among others in a similar situation. This improves knowledge transfer between disabled people. The Internet can counterbalance and complement the information that flows from the professional world to people with disabilities. An arena where peer-to-peer learning occurs can have positive consequences in efforts to create political and ideological awareness. The Internet is a ‘unique tool for people with disabilities and others to engage directly in advocacy and social change activities’ (Blasiotti, Westbrook & Kobayashi, 2001).

It must, however, be noted that present-day Internet practice fails to fulfil this potential in many ways and for many disabled people, mainly through lack of access to the Internet or to areas of information made unavailable there.

Personal Assistance in Sweden

The forum examined in this study discusses personal assistance in Sweden for people with significant mobility/physical impairments. Such assistance is considered a right and is financed as direct payments, allowing the users to employ personal assistants (PAs). The relevant legislation went into effect in 1994. You are eligible for this service if you require personal assistance for basic needs (e.g. personal hygiene, dressing and undressing, eating, and communicating with others) for an average of 20 hours or more a week. In December 2004, about 7,400 people with significant mobility/physical impairments were granted assistance allowances in the form of direct payments (Fkassan, 2005). See Nikku (2005) for an overview of the research and a bibliography in the area of personal assistance.

The form of direct payments used in Sweden was inspired by the independent living movement philosophy, where choice and control are central issues (Ratzka, 1997; Ratzka 2003; Berg, 2003). The 1994 legislation gave many disabled people control and ‘could be viewed as constituting a paradigm shift from former communitarian type services to autonomous rights’ (Berg, ibid).

The money received allows for full coverage of assessed needs including assistance at work, household chores and parenting, together with full coverage of administrative costs. Furthermore, there is an absence of means tests, i.e. your income, property or other personal means do not affect the amount you receive for personal assistance.

The law enables assistance users to freely use their direct payments to purchase services from any provider. Local government, private companies, co-operatives, or for the individual user to be the employer him/herself, are available choices.

Communities of Practice (CoP)

Identity and Learning in Communities of Practice

Lave and Wenger (1991) coined the term ‘communities of practice’ with reference to a social grouping with a joint interest in learning, transferring skills, and practices. It can be seen as the context in which a process of learning in a domain of collective interest takes place. The concept of CoP is developed in subsequent publications by Wenger and is, essentially, a social entity recognised as such by its members who are bound together in a sense of joint enterprise that emerges from a mutual understanding of a problem or issue, and a desire and commitment to solve it. Wenger currently provides the following definition on his website: ‘Communities of practice are groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly’ (Wenger, undated).

Wenger further describes the three elements that constitute a CoP: the domain, community and practice. The domain is the joint area of interest, the internal and external delimitations of this shared interest, knowledge and expertise of the group. The community is built up by the relationships that develop in the group when sharing learning experiences and activities related to the domain. The practice is essential to the community, since it provides the shared context, history and experiences that constitute the realm in which the community learns.

A CoP is not static, but a continuous and developing project continually renegotiated by its current members, as the experience and identities of the individual members change. Wenger (2000) sees communities of practice as the 'basic building blocks of a social learning system because they are the social "containers" of the competences that make up such a system.'

The model of social learning developed by Wenger (1998; 2000; 2005) deals primarily with the dualism between learning systems and identity. Learning systems provide the contexts in which the learning and formation of an individual's identity take place.

One definition of learning used by Wenger is 'the tension between socially-defined competence and personal experience,' where the community in which competence is sought determines its definition. The competence held in high regard in one community may not have any significance in another. This is why it is essential for disabled people to build communities, cultures and learning systems of their own based on the shared practices involved in living with a disability; a very special practice, with a specialised knowledge base.

Individuals can belong to several different communities or learning systems and one's identity is shaped by participation in them. According to Wenger, knowledge and skills are subsumed under identity, where the identity of the individual is understood as constructed from participation in these multiple contexts and learning systems. Identity is a mosaic of learning experiences, constantly changing by participation in a multitude of communities.

A CoP Devoted to Personal Assistance

From a socio-cultural perspective on learning, the way we experience reality is a product of a socio-cultural process where all knowledge is mediated in these processes and situated in practice (Wenger 1998; Säljö, 2000; Lave & Wenger, 1991). Living with a disability is a very special practice or subculture in which information creation and knowledge transfer can be difficult since there are professionals who feel they have the right to interpret knowledge in the area, and thus claim control and power over the subsequent construction of knowledge and its interpretation. This is the reason why peer support and role modelling have always been at the heart of the independent living philosophy.

Personal assistants and professionals, such as social insurance office administrators, medical personal and occupational therapists (OTs), do not share the same practice or learning system as disabled persons. Administrating the necessary help for someone to go to the toilet, just seeing how someone is helped to go to the toilet, helping someone go to the toilet or being helped to go to the toilet are not the same practices. The situation is understood and experienced in different ways because meaning is negotiated 'with the full range of resources within the scope of our identity' (Wenger, 2005). The way professionals understand the situation belongs to separate learning systems and different communities of practice, drawn from educational, experiential and professional standards. This knowledge could be valuable and should by no means be ignored; in many cases it is necessary but not sufficient to fully serve the purposes of disabled people.

Reindal describes a discourse where the notion of independence is examined in light of the difference between a professional’s definition and one embraced by disabled people. While the professional measurement of independence concerns the level of performance of everyday and self-care activities, disabled people’s notion of independence has more to do with control and choice over the ‘when and how’ of obtaining assistance (Reindal, 1999).

Still, the dominant and controlling views in society of personal assistance practices are that of the professionals. To counter this, it is important for the assistance users themselves not only to problematise and discuss practical problems and solutions, but also the political and ideological aspects of personal assistance related to practical day-to-day situations. The understanding of theories and concepts from disability studies and independent living theorists is increased by relating them directly to the everyday practice of personal assistance. Knowledge based on the practice of personal assistance from the user perspective ought to be developed and refined iteratively in learning systems controlled and developed by disabled people themselves, in order to gain more control over how legislation and practice are shaped.

Selection and Data Gathering

In this study, data was gathered over a period of four-and-a-half years from a forum in a web community for disabled people. The community was initiated and is run by disabled people. I contacted and met the site managers and stated my interest, explaining my research proposal, and that I planned to publish the results. The response was positive and appreciative.

Since I have followed the discussions in the forum regularly for over four years, I have a good understanding of the material. The forum is open to anyone who wishes to participate, and lurking (covert observation) is an option. All discussions are conducted online and are available after registration. The ethics of covert observation can be discussed from a number of perspectives. Risks of exploitation and invasion of privacy are addressed in a number of articles, as are the potential benefits of using web-based material (Berry, 2004; Bowker & Tuffin, 2004; Brownlow & O’Dell, 2002; Eysenbach & Till, 2001; Mann & Stewart, 2000).

The first ethical concern is the risk of exploitation. Since I am ‘one of them,’ living with a disability and personal assistance myself, the research is conducted from a peer perspective, with all the possible implications of misuse of the material easily understandable to me. I have been an interested member of the community, but have refrained from actively participating in the discussions as they were the subjects of my research. This alone does not assure non-exploitation. I have made every attempt to treat the material in a way that eliminates any possibility for harming the forum participants.

Invasion of privacy is another important ethical issue. No individuals are described in the text, and the material cannot be traced back to any individuals. Direct quotations have been avoided to protect the integrity of the participants and to make identification impossible by searching the Internet for the quotations used. In those few cases where quotations have been used, they have been shortened and altered, but in a way that has preserved the essential meaning.

FACE Analysis

A **FACE** analysis (**F**unction based on **A**ttitude, **C**ontrol, **E**nabling) was carried out. I developed this conceptual design approach by using the ‘disability ACE’ including its three aspects of independence and disability eliminating/creating factors (Anderberg, 2005). These aspects can be seen as an attempt to integrate important perspectives on functioning into one concept. These factors are derived from and have their base in my personal and professional experiences as a rehabilitation engineering professional and personal assistance user.

Enabling is the traditional approach in rehabilitation technology. It concerns how the function and function supports are actually constructed and implemented, i.e. the technological or practical solution. How well does the function match the action desired by the individual and is possible to perform?

Control concerns the extent to which the user, the owner of the function, has the power and right to define and execute the function, i.e. to what extent does the individual have control of the choice, development, execution and economy of the function? This is at the individual level and could be seen as the independent living perspective.

Attitude is at the social response level. This concerns how the function is perceived, framed and socially constructed by others and by oneself in the context where it is used, i.e. to what extent is the function free from or affected by disablist and discrimination attitudes? This could be seen as the social model perspective.

The FACE expanded view on functions and functioning makes it possible to consider and analyse more than just the practical solution of functional assistance. Each of the factors represents a different aspect of functional assistance. ‘The assessment is normative in the sense that a good function is one that gives an individual power over the function and that strives to optimise the function according to the given criteria in accordance with the desired function of the individual’ (Anderberg, 2005).

Function is the main concept describing the outer course of events in the life of a human being (getting out of bed, going to the toilet, taking a shower, getting dressed, having breakfast, reading the newspaper, taking the children to school, going to work, going to a meeting, reading and writing, learning, meeting people, being left alone, being a father, being a husband, going to a cinema, etc.). Functions are situated in a context, as are hindrances to functions. Functions are located in the space between the individual and his/her surroundings. It is the function experienced by the individual in the environment in which assistance has been introduced that is the measure, not generalised usability standards. Functions are thus assessed by how well they correspond to the desired action from the perspective of the individual and not relative to a preconceived norm.

An important concept to understand when discussing function is that of function support, which refers to what is needed to perform a function according to the wishes of the function owner. There are two main categories of function support: technological and human. They can be combined in a number of ways for the execution of a function. In human function support, another person is a part of the execution. All other supports are classified as technological, including the use of one’s own body to perform a function.

A FACE analysis was carried out to see the extent to which enabling, control and attitude are expressed and manifested in the discussions in the online forum. The importance of discussing practical problems and solutions, as well as the political and ideological aspects of personal assistance grounded in everyday practice, is seen as a prerequisite for a learning system that can challenge and counterbalance the learning systems of professionals.

Results

The Quantitative Flow in the Community

The personal assistance forum analysed is one of 19 forums on a website for people with disabilities. A total of 2,755 postings in 297 threads posted between 18 October 2001 and 31 March 2006 were examined. A total of 146 persons participated in the discussion forum by submitting postings. No data is available on how many people participated indirectly as readers only.

FACE Analysis of the Discussion

	Postings	**% of Postings**
Attitude	614	22.3 %
Control	523	19.0 %
Enabling	778	28.2 %
Info	76	2.8 %
Social & Other	764	27.7 %
Total	**2,755**	**100.0 %**

The table above shows the number postings in the forum sorted by category. Categorising involved organising and constant comparing of coded data units into categories identified as having similar characteristics using content coding from the given categories: Attitude, Control, Enabling, Info and Social & Other.

What follows is a brief description of the contents of the threads and sub-categories (denoted by the letters A to D) of each of the three categories analysed.

Attitude. The participants vary in the depth of their understanding of the structures and attitudes that create disabilities. The discussions often analysed and illustrated different political and ideological positions and standpoints in the area of disabilities, many times based on practical personal assistance situations.

A. *Participants' experience of the attitudes of PAs towards their jobs and the participants as work leaders.*

These discussions dealt with how the PAs, by talk and action, reveal their attitudes towards personal assistance recipients and to disabled people in general.
Ex. How do health care school training programmes provide future personal assistants with the wrong focus for their job assignments? Do PAs feel intimidated by the fact that their 'care recipient' is also their employer?

B. *Participants' experience of the attitudes of PAs and others towards the personal assistance legislation and personal assistance in general.*

These discussions dealt with the participant's feelings of how the phenomena of personal assistance and practice are treated in different contexts, discussions and public debate.
Ex. When personal assistance is felt to be questioned by the government or in media, the arguments for and against are discussed and analysed.

C. *Participants' experience of attitudes manifested through use of language.*

This concerns how the use of language creates, illustrates and confirms attitudes towards disabled people, and how self-image and self-discrimination correspond with the labels used.
Ex. Does it make any difference what a personal assistant and work leader are called? Are you a care recipient, a user or a boss? Does the vocabulary used matter?

Control. This concerns the freedom of the participants as work leaders to decide in practice and have control over their lives, and how this collides with the possibility for PAs to exert control over their working conditions. It could be described as dealing with the boundaries between the work leader and PA in the very close and almost intimate relationship created in personal assistance. How much can one party control the other and who has to accommodate to whom, and in what situations? There is a perceived conflict between the work leaders' wish to control their everyday situations and the wish of PAs for normal working conditions.

A. *Control over time.*

Ex. Scheduling, including holidays, the order in which activities are carried out, and whether the PAs' breaks and quitting time take precedence over the activities of the work leader.

B. *Control of the realm.*

Questions concerning who has control over everyday activities.
Ex. Who decides how to clean, how to cook, etc. Can you send the PA out for a walk when you want to be alone with your boyfriend?

C. *Internal control over the PA – work leader system.*

Questions concerning the power relationship in the social interaction between the work leader and the PA.
Ex. Can you, or should you be friends with your PA and can you have friends as PAs without compromising either the work or the friendship? What are the problems and advantages of having relatives as PAs? How does one deal with PAs who are unpleasant or in a bad mood when you need to be close to them and are dependent on their help in many situations?

D. *External control over the PA – work leader system.*

Ex. What are the consequences of outsiders viewing the work leader and the assistant as a unit? How should the assistant behave in contexts where other people are present? Can PAs dress however they want when they are working? Can they talk to the work leader's friends and contacts, and what can they talk about? How can you control the kind of information that originates from your home and your personal life? How strict should the confidentiality rule be and why is it so important?

Enabling. To a great extent this level concerns ‘how’ questions. This is where practical advice and experiences are exchanged, and where it is possible to ask others how they solve problems and get practical help.

A. *Employer responsibility – finances and administration.*

Questions regarding the formal responsibility as an employer.
Ex. How to pay fees, taxes, wages, and so on. How does one construct a good schedule? What expenses are reasonable for the employer to cover? What assistance should the PAs provide? What can and are PAs permitted to be used for?

B. *Employer responsibility – human relations.*

Questions regarding what can be called coaching or management.
Ex. How in practice can PAs be given a creative and fun work environment without compromising the right to shape your own day? What should be done if an assistant is very good at one thing and the others grow envious because she will not let them perform the activity, e.g. travelling? How do you deal with PAs who are late, or have too many sick days? How much appreciation or criticism should you give your PAs, and how should you go about it? How do you handle the shift from a work relationship to friendship or love?

C. *Employer responsibility – employment.*

How do you find and hire good and suitable PAs?
Ex. What qualities do you look for? How do you conduct an interview? How do you fire someone when it does not work out?

D. *Formal organisation and legislation concerning personal assistance.*

What are the practical and legal steps necessary to receive personal assistance?
Ex. What are the advantages and drawbacks of different forms of personal assistance solutions (e.g. co-operative, municipal, private, and taking on the role of employer)?

Info, Social and Other
Info refers to links to relevant information about PA. *Social and Other* are postings that include small talk and things that are not directly related to PA. These three categories have not been subject to further analysis, but are considered to be important for the social relationships in the community..

Discussion

Disabled people live in a predominantly ‘able-bodied’ world, where the practices related to living with a disability are rarely visible. The Internet provides opportunities for increasing contacts and building personal networks, as well as increased visibility for the disabled individual, both inwards (to our own group) and outwards (to people who do not normally meet disabled people). Peer support and role modelling can more easily available to a larger number of people. In the web-based community examined here, it is obvious that the possibilities to create and maintain a learning system of this kind could not exist in the same way without the Internet.

Anderberg and Jönsson identified (2005) three main functions of the Internet for people with mobility impairments: independence, communication and learning. All three were found to be strong functions for the participants in the online forum examined.

Independence – being able to participate in this kind of discussion without the PAs is, of course, very important. Since the discussions in many cases deal with the PAs, their involvement would no doubt be hampering.

Communication – the ability to reach a larger number and a larger selection of plausible discussion partners is also necessary to create a community of practice like this. Being able to find suitable discussion partners independent of geographic location is a strong function. Anonymity and control of one's identity can also be a prerequisite for participation in sensitive discussions. Anonymity in this context does not mean that no one knows who the participant is. One could build a strong identity in the forum, but it may not necessarily be linked to a physical person. The choice of disclosure is a strong function in this context.

Learning – a very strong and direct learning situation in the practice of living with personal assistance with elements of both peer-to-peer and scaffolding is created when one's own practice is confronted and contrasted by others. This kind of forum also allows considerable LPP (legitimate peripheral participation). Newcomers and others who feel unable to express themselves, gain access to old and new discussions and arguments that lead them to the core of this community of practice.

In the web community examined, several work leaders discussed questions concerning personal assistance, from their individual and common practices and experiences. The three elements of a CoP, the domain, community and practice, in the sense defined by Wenger are all found in this community, providing the participants with ample learning opportunities.

The FACE tool, used to analyse the CoP learning system, evaluated functional assistance. One assumption was that the basis for constructing knowledge in the area of personal assistance needs to be problematised on a higher level. In order to appropriately enable good functional assistance, one must be aware of the higher levels of control and attitude. This is consistent with the reflective practitioner described by Schön where critical reflection on practice establishes the knowledge base necessary to improve it (Schön, 1983).

A great number of discussions dealt with practical issues, such as those categorised under enabling in how to employ good personal assistants. The answers were often stated in the form of practical, hands-on advice on how to write an employment advertisement or conduct an interview, as well as different strategies on how to select the applicants. In the process, the participants also reveal their ideals of a good PA. This often paves the way for in-depth discussions on the essence of personal assistance – what it should and could be.

A discussion about the moral responsibility for the actions taken in the functional system of work leader/PA is a good example. It started with a posting about the information that would be good to have about a company or a co-operative that you wanted to engage to provide personal assistance, and ended in a discussion of who is morally responsible for the actions desired by the work leader and performed by the PA. The hypothetical question used was: “What would happen if the work leader wanted to use illegal drugs?”

> The PA is our arms and legs. Period! If I want to use drugs, that's my business. The assistant can be moralistic in his time off.
>
> The assistant isn’t my moral watchdog. What if you have six different assistants? You would have to live your life according to six different moral codes depending on which one was on duty.

This point of view, the ideological or PA-as-a-right view, is often represented in the discussions. It contains the notion of the PA as a tool for the work leader to live his life with full control, and that any restrictions or reductions in this control are unacceptable. This notion is often contrasted by a more pragmatic or PA-as-a-negotiation view, where the control over the situation, or the outcome, is seen as a negotiation between the different standpoints of the work leader and the assistant.

> A PA has to have the right to refuse to meddle with drugs. Otherwise he can be nailed for complicity.

In many cases this contrasting of the desired versus the possible control over one’s life is necessary to reach a balance between the two. As the discussions swing between ideological statements and practical examples and advice, a reflected understanding of personal assistance is chiselled out. For newcomers, this peer support may be essential to make the personal assistance work properly.

> Question: How do those of you who need a lot of assistance manage to have a ‘private life’ and integrity? It feels like I am being constantly watched or followed by someone and am unable ‘to do anything on my own’. I may not even be perceived as an individual. Help!
>
> Answer 1: You can send your assistant away for a while with a mobile phone, which will give you and the person you are out with a little space. It’s also important that you teach your PA to stay in the background when you meet somebody. They are there to help you, nothing else. You can also have an assistant room at home with a TV where they can be when you don’t need help with anything. Good luck!
>
> Answer 2: At the same time, I understand your feelings. I haven’t always felt that my assistance has worked out as well as it is doing now. Set clear boundaries, even if it might seem that you are being “mean”. Keep in mind that it is your life but only their job!

Many discussions started like this, with a practical question that in the course of the postings ended up showing how the practical problem had its roots in, or at least is affected by, aspects of attitude or control. One such question was if the work leader had the right to tell PAs how to dress.

> I have a PA who dresses very badly. To what extent can I interfere with his choice of clothing? The PA represents his work leader after all.

This posting was followed by a number of answers. Many people found it unacceptable to interfere with the integrity of the assistant by requiring a certain dress code. But many of the objections were made with reservations. It was felt that the PA in principle could decide what clothes to wear, but it was also assumed that the PA should dress according to the situation.

> I also have a PA who dresses a bit badly, but I don't really care. He has his style and I have mine. However, if I'm going to do something special, like go to a nice restaurant, I would really like my PAs to dress appropriately.

Quite a few examples were given of situations were either the PA or the work leader had experienced embarrassment or awkwardness when a PA was inappropriately dressed. Some people found that others in the discussion were far too lenient.

> I'm often surprised by how many people don't realise that being a personal assistant is a job! It is nothing you do now and then to be nice. When you are at work you wear clothes that are appropriate for the work you do.

The discussion was widened to include how the PA should generally behave when accompanying the work leader in different social settings, and how this directly affected the quality of the assistance.

Another discussion thread about professional confidentiality was also obviously polarised from the beginning. Some people believed that you do not need to be too strict, while others have quite a different view and demand absolute professional confidentiality. Many examples, thoughts and arguments were given from the participants' lives, lending them considerable credence.

> I have a PA who thinks she has to discuss her work situation with her family when she has a rough day. I feel that respect for professional confidentiality is extremely important and I have absolutely no wish to be the subject of discussion during the assistant's family dinner. An assistant who applied for a job (she was 32) actually asked me how firmly I felt about professional confidentiality since her mother wanted to know what she did at her work and she wanted to be able to discuss this with her mother.

The questions about clothing and professional confidentiality were shown through the discussion to have their roots in the potential to control the outer and inner limits of one's identity when living with personal assistance. It could also be expressed as the possibility and right for the work leader to define the boundaries between her/himself and the PA, and to make this division visible for people on the outside. In addition, the discussion brought to light that the heart of the problem is that this involves another human being (the PA) and his or her integrity.

Discussions about how words and language are used to convey and consolidate discriminating attitudes showed how both control and enabling are affected by such attitudes. An example is the lengthy and recurrent discussions in the forum about how people applying for PA jobs expressed themselves, thus exposing their attitudes towards their future employers.

> As I have written before, I'm recruiting a new PA. There are a lot of things that I think about and am unsure of. For example, almost everyone writes that they want to 'help me,' 'support me,' 'give me psychological support,' 'are looking forward to caring for me,' 'have a deep sympathy for my suffering' and so on.
>
> I had a telephone interview the other day with a girl who had written a lovely letter of introduction. But when I spoke to her it was her feeling to be needed, to be supportive and helpful that was the thing for her. That this was NOT what I needed was very strange to her – she had difficulties understanding that it was 'me' on the other end of line. To help and to put up with us, despite 'the difficult physical and psychological demands' as one of the

> applicants wrote, really got to me when I was reading all the applications. I get so tired of how people look down on me, on us.

These postings yielded more examples of how the perceptions of others can disable people and how important it is to be aware that the quality of the assistance can depend on the assistant’s perception of what personal assistance is. The medical model, the care perspective, found with many assistants is not only irritating but can be perceived as oppressive behaviour, affecting the quality of the personal assistance from the perspective of the work leader. For some participants this idea was new and they were introduced to a new way of looking at themselves and their personal assistance.

The forum discussed the necessity of dealing with these attitudes and how to go about doing so. This again led back to practical advice on how to avoid hiring people with these attitudes, by asking specific questions at the job interview, by avoiding all applicants with formal health care training and that the work leaders themselves should train their PAs. Without it being openly expressed, it means in practice, that a professional standard for PAs grounded in the work leaders’ definitions of the practice, is gradually being formulated. The reflected and discussed practice creates a strong learning system. Newcomers who start out with enabling questions become gradually aware of how issues of control affect this practice and how the attitudes in society at large affect the whole complex of personal assistance.

The work leader and PA share the situation and in one way have a common learning system. Their practice is different, however, and they experience the situation with the identity they have in this practice. It is critical for the discussions in this learning community that it is the practice and the identities of the assistance users themselves that is the standard.

Conclusion

Being able to understand and deal with issues regarding control of and attitudes towards personal assistance and similar situations requires considerable knowledge gained through practical experience. The forum examined in this paper is a place for reflection on personal assistance that can provide a foundation for a development of deeper understanding and knowledge about the practice of living with personal assistance. The multitude of examples and opinions that are discussed, reflected and sometimes agreed upon, serve as templates for new discussions and for improvement of personal assistance practice in the participants’ daily life. Example by example, the different points of views that exist when people with a variety of needs, interests and concepts discuss their common practice, is negotiated and developed. This way a knowledge base is established in the form of examples and reflected practice.

When disabled people engage in learning systems that are separate from the learning systems of the professionals (personal assistants, OTs, nurses, physicians, etc.), the added aspects of attitude and control are as frequent as is the mere enabling. This illustrates how the experienced disability involves other aspects than the diagnosed and treated one. Thus, living with a disability requires different learning systems and knowledge to evolve, and development of theories and methods that are grounded in the reflected practice of the users themselves.

References

Anderberg, P. (2005) Making both ends meet. *Disability Studies Quarterly*, 25(3), ISSN 1041-5718.

Anderberg, P. & Jönsson, B. (2005) Being there. *Disability and Society*, 20(7).

Berg, S. (2003) *Personal assistance in Sweden* (Stockholm: Independent Living Institute).

Berry, D. M. (2004) Internet research: privacy, ethics and alienation: an open source approach. *Internet Research: Electronic Networking Applications and Policy*, 14(4), 323-332.

Blasiotti, E. L., Westbrook, J. D. & Kobayashi, I. K. (2001) Disability studies and electronic networking, in: G. L. Albrecht, K. D. Seelman & M. Bury (Eds) *Handbook of disability studies* (Thousand Oaks, CA: Sage Publications).

Bowker, N. & Tuffin, K. (2002) Disability discourses for online identities. *Disability & Society*, 17, 327–344.

Bowker, N. & Tuffin, K. (2004) Using the online medium for discursive research about people with disabilities. *Social Science Computer Review*, 22(2), 228-241.

Brownlow, C. & O'Dell, L. (2002) Ethical issues for qualitative research in on-line communities. *Disability & Society*, 17(6) 685-694.

Eysenbach, G. & Till, J. E. (2001) Ethical issues in qualitative research on Internet communities. *British Medical Journal*, 323, 1103-1105.

Fkassa (2005) Assistansersättning. Available online at: http://statistik.forsakringskassan.se/rfv/html/lass_12_2_2004.html (accessed 4 April 2006).

Guo, B., Bricout, J.C. & Huang, J. (2005) A common open space or a digital divide? A social model perspective on the online disability community in China. *Disability and Society*, 20(1), 49-66.

Huang, J. & Guo, B. (2005) Building social capital: a study of the online disability community. *Disability Studies Quarterly*, 2005, 25(2).

Lave. J. & Wenger, E. (1991) *Situated learning: legitimate peripheral participation* (Cambridge: Cambridge University Press).

Mann, C. & Stewart, F. (2000) *Internet communication and qualitative research. A handbook for researching online* (Thousand Oaks, CA: Sage).

Nikku, N. (2005) Personlig assistans – En inventering av forskningsläget. Socialstyrelsen. http://www.socialstyrelsen.se/Publicerat/2005/8824/2005-123-27.htm (accessed 4 April 2006).

Ratzka, A. (1997) *Towards and operational definition of personal assistance* (Stockholm: Independent Living Institute). Available online at: http://www.independentliving.org/toolsforpower/tools15.html (accessed 4 April 2006).

Ratzka, A. (2003) *Independent living in Sweden*. Internet publication available online at: www.independentliving.org/docs6/ratzka200302b.html (accessed 4 April 2006).

Reindal, M. (1999) Independence, dependence, interdependence: some reflections on the subject and personal autonomy, *Disability & Society*, 14(3), pp. 353–367.

Ritchie, H. & Blank, P. (2003) The promise of the Internet for disability: a study of on-line services and website accessibility at centers for independent living, *Behavioural Sciences and the Law*, 21, 5-26.

Schön, D. (1983) *The reflective practitioner. How professionals think in action* (Hampshire: Ashgate).

Seymour, W. & Lupton, D. (2004) Holding the line online: exploring wired relationships for disabled people, *Disability & Society*, 19(4), 291-305.

Säljö, R. (2000). *Lärande i praktiken. Ett sociokulturellt perspektiv [Learning in practice. A sociocultural perspective].* (Stockholm: Prisma).

Wenger, E. (Undated) Communities of practice – a brief introduction. Available online at: http://www.ewenger.com/theory/communities_of_practice_intro_WRD.doc. (accessed 4 April 2006).

Wenger, E. (1998) *Communities of practice: learning, meaning, and identity* (Cambridge, UK: Cambridge University Press).

Wenger, E. (2000) Communities of practice and social learning systems. *Organization*, 7(2), 225-246.

Wenger, E. (2005) *Learning for a small planet – a research agenda*. Available from the author.

This thesis is based on the Internet experiences of people with significant mobility/physical impairments who are proficient and experienced computer users in their computer world but have limitations in mobility that severely restrict their functioning in the physical world. The Internet functioning of this group is analysed by means of the factors attitude, control and enabling, with the main focus on what is achievable when all access problems such as unadapted interfaces, beginners' difficulties and the digital divide are overcome. If the virtual world is fully available but the real world is not – what are the effects on learning, self image, communities of practice, sense of coherence, power and control? What are the effects on peer-to-peer learning and co-operation? Independent living concepts and theories manifest themselves throughout the thesis, most obviously, perhaps, in the selection of issues that are studied and in the perspectives.

The theoretical background and concepts are those of disability studies, with a social model and independent living perspective, but with strong influences from rehabilitation engineering and design.

Throughout the thesis elaborations and clarifications of the possibilities of interplay and co-existence between rehabilitation engineering and design and disability studies are made. Different aspects of function design and technology are examined from an expanded view on functioning, where technology is put in an individual and social context with the FACE (Function – Attitude, Control, Enabling) tool.

Certec
Division of Rehabilitation
Engineering Research
Department of Design Sciences
Lund University

✉
Certec, LTH
Box 118
SE 221 00 Lund
Sweden

🚶 🚚
Ingvar Kamprad Design Center
Sölvegatan 26
SE 223 62 Lund
Sweden

☎ 046 222 46 95
📠 046 222 44 31
✉ certec@certec.lth.se
🌐 www.certec.lth.se

Knowledge Foundation

This research was financed by The Knowledge Foundation (KK-stiftelsen)

DOCTORIAL THESIS   CERTEC, LTH NUMBER 1:2006
URN: ISBN 10 91-628-6936-1
ISBN 13 978-91-628-6936-6
AUGUST 2006

Peter Anderberg

FACE

Disabled People, Technology and Internet

Printed by JUST NU-Tryck 2006.   Illustration: Kate Hellqvist http://www.kategallery.com