LUND UNIVERSITY

Design side by side

Jönsson, Bodil; Anderberg, Peter; Brattberg, Gunilla; Breidegard, Björn; Eftring, Håkan; Enquist, Henrik; Inde, Krister; Mandre, Eve; Nordgren, Camilla; Svensk, Arne; Whitelock, Ingrid

2006

Link to publication

Citation for published version (APA):
Jönsson, B., Anderberg, P., Brattberg, G., Breidegard, B., Eftring, H., Enquist, H., Inde, K., Mandre, E., Nordgren, C., Svensk, A., & Whitelock, I. (2006). *Design side by side*. Studentlitteratur AB. http://www.certec.lth.se/doc/designsidebyside/

Total number of authors:
11

General rights
Unless other specific re-use rights are stated the following general rights apply:
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.
• Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
• You may not further distribute the material or use it for any profit-making activity or commercial gain
• You may freely distribute the URL identifying the publication in the public portal

Read more about Creative commons licenses: https://creativecommons.org/licenses/

Take down policy
If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

LUND UNIVERSITY

PO Box 117
221 00 Lund
+46 46-222 00 00

Edited by Bodil Jönsson

Design Side by Side

Translated by Eileen Deaner

Studentlitteratur

The Swedish title: Människonära design, Studentlitteratur, 2005

Copying prohibited

All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording, or any information storage and retrieval system, without permission in writing from the publisher.

The papers and inks used in this product are eco-friendly.

Art. No 32637
ISBN 91-44-01936-X
© The authors and Studentlitteratur 2006
Translated by Eileen Deaner
Cover design: Pernilla Eriksson
Photographer: Christofer Gustavsson

Printed in Denmark by Narayana Press

www.studentlitteratur.se

Printing/year 1 2 3 4 5 6 7 8 9 10 | 2010 09 08 07 06

Contents

Author presentations 9

Preface 15

Part 1 Ten perspectives

1 The hard truth about low vision: a Swedish experience 19
Krister Inde
A new period in life 20
Assistive devices – but only if you feel like it 21
Four steps on the road to recovery 22
Thinking about the future again 24
If I am good enough for myself, I'm good enough for others 24
The empathy and honesty of others: a balm for the soul 26
An inner calm and a natural exterior 27

2 The first time I saw you … 29
Henrik Enquist
… it was an August day 29
After images 33
Images in a bigger perspective 34

3 Lund doesn't exist … 39
Eve Mandre
Emil and his diagnosis 40
The clock of life ticks on 40
Emil and the reform in psychiatry 41
A digital camera enters Emil's life 42
Memory full 43

© The authors and Studentlitteratur

Emil's new clothes 45
The world is more than a potato patch 46
Who is Karlsson-on-the-roof? 47
Black leaves 47
"How do you build a house?" 48
County administrative court 49
A free man – but how did it go after that? 49

4 From the stock market to love by means of technology 51
Håkan Eftring
Details about Paul – and Paul about details 51
To sum up: my ten commandments 53

5 Stress radiation? 55
Bodil Jönsson and Ingrid Whitelock
A day in November 2000 55
Ingrid Whitelock
Three years later 60
Bodil Jönsson
Three–four years later 65
Ingrid Whitelock

6 An involuntary risk taker 69
Camilla Nordgren
Travelling companions 69
If I say "No" one more time … 70
Risk and security 71
Children 73
An involuntary risk taker 73

7 In the kingdom of the blind is the one-eyed person king? 75
Arne Svensk
So unimaginative 75
There are so many ways 76
New glasses 76
Different ways of measuring time in 77
Being able to anticipate 78
Trying to control 79

© The authors and Studentlitteratur

Design for cognitive assistance 80
Making the familiar strange 81

8 Mother Sweden's health 83
Gunilla Brattberg
The Swenson family 83
Network or net of pain 91
Rehabilitating back to life 92
Quality of life 92
Unemployment 93
Pressure from society 94
Learning to be a person 94
A different concept of rehabilitation 96
Keys to recovering health 97

9 Emma and the Minimeter 99
Björn Breidegard
A beginning: Minimeter 1 99
The continuation: Minimeter 2 101
The first big breakthrough 103
"Yes" or "No", one more time 105
The next step: Minimeter 3 106
A "Yes" means "Yes" and a "No" means "No" 108
Here comes Minimeter 4 108

10 Might and machines 109
Peter Anderberg
I'm alive 110
Upwards 111
Warming up 111
Technology for good and bad 112
More steps to freedom 113
Studying 115
Down from the mountain 115
And now what? 116
Coda 117

© The authors and Studentlitteratur

Part 2 Theory and method

11 Rehabilitation technology, design and pedagogy 121
Certec/Bodil Jönsson
The lived disability 122
Artefacts as thoughts realized 123
Actants 123
Not just gadgets 124
Technology as liberating pedagogy 126
The goal of research 128
Software as thoughts condensed 129
HMI, Human Machine Interaction and variations 131
The principal person in context with the technology 132
The interactive 133
STEP 133
The time factor 135
In praise of documentation 135
Case studies 139
The situated 141
In praise of technology 142

12 Design 145
Certec/Bodil Jönsson
The iterative 148
When the principal persons are included 151

13 More on methodological and ethical considerations 157
Certec/Bodil Jönsson
The specific and the general 157
Three indicators 157
Methods as tools for thinking and acting 159
World Health Organization background 162
Useworthiness 163
Redundancy 164
Abduction 168
More on the situated 169
Necessary but not sufficient 173
Constraints 174

 © The authors and Studentlitteratur

14 Scientific positioning 177
Certec/Bodil Jönsson
In general 178
Classical 179
Epistemology – if such is possible 180
Relation to the natural sciences 181
Statistically based science versus case studies 183
Heuristics, analysis and synthesis 183
More is different 184
Time geography 185
Grounded theory 186
Phenomenology and phenomenography 186
The need for concept formation and positioning 187

References 189

Index 199

© The authors and Studentlitteratur

Author presentations

Peter Anderberg has a master's in engineering and a technical licentiate and is in the process of obtaining his PhD. His thesis deals with the internet's significance for people with severe physical disabilities. Traces of this can be found in his chapter. The actual focus, though, is not on research but on his own joy in being able to act and experience as much as possible through technology, in spite of his own physical limitations. It has lifted both him and his wheelchair to new pinnacles, enabling him now to on high and "smell the snow" while his head is full of entirely justifiable, but at times paralyzing fears, all of which are part and parcel of what it means to have a disability.

Gunilla Brattberg has been involved in different aspects of pain treatment for more than 30 years of her professional life. She started as an anaesthesiologist, relieving the acute pain resulting from operations and accidents. She soon became interested in people with chronic pain and was in the forefront when hypnosis, acupuncture and electric stimulation were introduced to Sweden as a means of reducing pain. Over the years, Gunilla has studied how the medical profession treats pain patients and has investigated ways of actively involving patients in their own rehabilitation. For the last 10 years, her efforts have focused on working with people who suffer from emotional exhaustive syndrome (burnout) in discussion groups in her *Pain Workshop Project*. In recent years, she has led such rehabilitation groups over the internet. Gunilla is an adjunct professor at Certec.

© The authors and Studentlitteratur

Björn Breidegard has a master's in electrical engineering, a technical licentiate degree and has worked at Certec since 1998. Since he was three years old, his life has been filled with a fascination with machines and how they work – from taking them apart and repairing technical equipment to building entirely new devices from scratch. He worked for many years at the Department of Information Technology at Lund University with everything from analogue electronic design to that of complex digital systems, including large software applications. At Certec, he combines his creative technical interests with the aspiration to design in conjunction with the person for whom the technology is intended. Björn is driven by a genuine curiosity and desire to push the boundaries.

Håkan Eftring is a senior lecturer at Certec with a PhD in rehabilitation engineering. In his 1999 thesis, *The Useworthiness of Robots for People with Physical Disabilities*, he coined the term "useworthiness", which in contrast to "usability" places the focus on the person and the value or worth he or she attaches to a given technical solution. Håkan has a master's degree in engineering in machine technology. He emphasizes the significance of small details for a functioning whole. Håkan has contributed to the establishment of Certec's internet-based courses, starting in 1996. He instructs in the areas of rehabilitation engineering, design for dynamic diversity, computer aids for people with visual impairments and physical disabilities, as well as cognitive ergonomics (i.e. how products can be designed to fit the way people think).

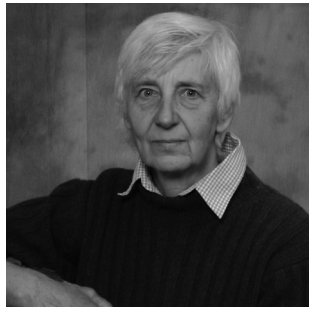
© The authors and Studentlitteratur

Henrik Enquist is a doctoral student at Certec with a background in engineering and visual arts. In both areas, he has taken an interest in how we, in different parts of society, make use of pictures and images of physical illnesses and how this affects us. In chapter 2, he provides a personal example of the difference a picture can make. Being allowed to see and visualize can be of great help to a person when it comes to concrete situations such as a foetal ultrasound examination, as well as behavioural patterns or the experience of pain. His research deals with the combination of new technology and knowledge of the cognitive and emotional characteristics of visual images. He is also examining how an individual can create and utilize his or her own pictures in areas such as rehabilitation. It is a matter of enabling people to use *pictures as tools* by means of technology.

Krister Inde has been a consultant at Certec for a number of years and is also a business development mentor, an entertaining public speaker and author of children's books. His chapter – *The hard truth about low vision: a Swedish experience* – describes what it means to be a low vision "victim" and how it affects your personality. Having low vision himself, he knows what he is talking about. As the author of the book, *See Bad, Feel Good*, he has had reason to reflect. As a developer of visual training material for children in the *See More Project* and for adults in his low vision training book, he wants to demonstrate that it is possible to improve one's residual vision, assuming that there are assistive devices, methods, empathy and others who have succeeded before.

© The authors and Studentlitteratur

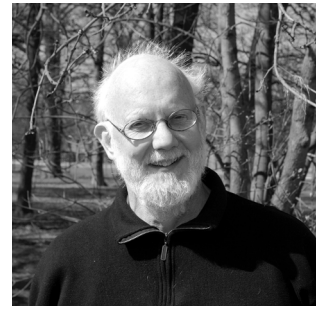
Bodil Jönsson is a professor at Certec and editor of *Design Side By Side*. From her original training as a researcher and her many active years in the field of physics, she has a strong interest in concepts and theories that assist us in seeing how things are related. In rehabilitation engineering and design she has been drawn to *concept design*, i.e. design as a process that gives shape to thoughts, and to technology as thoughts realized. When design and technology are then brought together, they govern in turn the thoughts we can think and the lives we can live. Based on these ideas, she writes in chapter 5, *Stress radiation?,* with Ingrid Whitelock, about a new disability of our times: the inability of many to tolerate stress and maintain a functioning rhythm in their lives. In part 2 of the book, *Theory and method*, she highlights the essential and underlying elements, but concretely with many examples.



Eve Mandre is a special educator who for 30 years of her professional life worked with children, young people and adults with neuropsychiatric diagnoses. Every epoch has its explanations as to why people do not function in school, at work or in social situations, and the diagnoses reflect changing theories. Thus, treatment, training and interaction with differently functioning people cannot, from Eve's point of view, solely be based on psychiatric diagnoses. In her licentiate and doctoral theses at Certec, she has attempted to find methods for reaching out to people who are in need of education as a form of treatment. Eve's method assumes that the professionals administering the treatment have to sharpen their observation skills when dealing with those who are "different" and in that encounter, devise an appropriate method.

© The authors and Studentlitteratur

Camilla Nordgren is a doctoral student at Certec with a master's in business administration. Her research area involves society's resources related to traumatic spinal injuries, and is based on her many years of experience. Her focus is on the support and services that are available. Based on her own life situation, she challenges herself and what is considered to be sensible, which you can read about in chapter 6, *An involuntary risk taker.*



Arne Svensk teaches and carries out research at Certec on issues that concern the human need for mental support in everyday situations. Cognitive design deals with designing phenomena so that they are based on aspects that most of us find easy to interpret understand and interact with. The hope is that the design itself can provide a sense of security that will enable people to want and dare to act. This kind of design process requires close co-operation with the person who is requesting mental support and of the people in his or her surroundings. It is this interaction he attempts to problematize in his contribution to the book, which deals with who it is that experiences what in the kingdom of the "blind".

Ingrid Whitelock is a journalist and producer and her chapter, *Stress radiation?,* relates how she experienced her own stress-related poor health. She chose to write about it from a before and after perspective related to the *Pacemaking* concept. In the autumn of 2005, Ingrid was one of the main contributors to a documentary film about the *Pacemaking Project* in which she participated.

© The authors and Studentlitteratur

Preface

The human sector is the one in which people work with and for other people. Since people are people, not machines, and since they follow a different logic than the mechanistic one, designing for human sector processes and products has its own distinctive features. Long-term sustainable development requires long-term sustainable people. The cutbacks of the last ten years in human sustainability, manifested by the unreasonably high numbers of people on sick leave and disability pensions as well as growing unemployment, is a strong indication of the need for fundamental changes in all areas, but perhaps more particularly in healthcare, schools and social services.

Human capital needs to be valued, nurtured, utilized and treated on its own terms. As is often the case in the human sector, the two parties who interact are the principal person (e.g. patient, client, care recipient) and the staff/relative. It is at least doubly important in these situations that the terms are humane. It is no coincidence, then, that health problems have hit those involved in the human sector hardest, a sector that has yet to clarify its logic; nor has it found or been offered a relevant design approach for products and processes. Bold design efforts in the human sector have been in such short supply that there is an almost unlimited potential for growth and renewal.

We need to develop situated research and design for everyday life in the human sector. Not least of all, its theories and methods have to be brought to the fore – many of which can also be used with great advantage outside of this field. The entire human sector has much to win from a clearer theory building, i.e. by making visible its conceptions of how things are related. Sometimes the process of doing so, in and of itself, can lead to comprehensive, positive changes.

We need to involve a wide variety of groups in order for a renewed approach to the dynamic utilization of design and technology to spread and flourish. Among them are not only undergraduate and graduate programmes in engineering and industrial design, but also educational programmes in healthcare and caregiving,

© The authors and Studentlitteratur

teacher training (particularly in the area of special education) and social work. In addition, we hope that this book will reach many other public sector employees and social service representatives on the political and administrative levels.

The starting point for most of what is written here is people with disabilities. Situations of great difficulty need to be highly prioritized, for their own sake and also because that which first appears to be "special" sooner or later comes to benefit society in general, in most cases. The book is divided into two sections. The first consists of ten diverse chapters which all show that no matter how difficult a situation may be, there is always something you can do about it. These chapters are rich in content, yet easy to read. The intention is for each author to tell his or her story, straightforward, with each chapter standing on its own. Section 2 is not as easy a read. This is where we present the theory- and method-building components to the reader that facilitate, unite and further elaborate. This section also contains a full and varied reference list.

The book has eleven authors, ten of whom work at Certec in the Department of Design Sciences at Lund University's Faculty of Engineering (if you would like to find out more about us, please access our web site at www.english.certec.lth.se/). The authors from Certec who have contributed to chapters 11–14 (in addition to those who have written individual chapters) are: Eva Flodin, Jörgen Gustafsson, Charlotte Magnusson and Kirsten Rassmus-Gröhn as well as Lone Malmborg from Malmö University, Arts and Communication.

Ingrid Whitelock, a journalist from Jönköping, Sweden, is the one author who is not affiliated with Certec. In chapter 5, she writes from the perspective of a "research person" (a term in the process of replacing "subject"). In reality, many more research persons than Ingrid have contributed to this book. They are evident in the multitude of examples that illustrate the content, and they have also been involved in the processes from which insights and knowledge have grown. We are very grateful to all of them.

I have had the privilege of editing this book, compiling part 2 on theory and method and of co-authoring *Stress radiation?* with Ingrid Whitelock.

Lund, June 2005

Bodil Jönsson

© The authors and Studentlitteratur

Part 1
Ten perspectives

1 The hard truth about low vision: a Swedish experience

Krister Inde

Leif opened his eyes that morning and realized that things were the same. He still couldn't see. Well, he could vaguely make out where he was because he knew where he had fallen asleep, but he couldn't see any details – especially not directly in front of him. He didn't have much desire to get out of bed, and he sensed the return of the sorrow and aversion to what had become his lot in life. The feeling that it is never too late to give up came over him again. What was the point of going on? What was the point of getting out of bed?

It had been over six months since the information had been thrown in his face. That skinny little eye doctor had announced in his skinny little voice that Leif's central vision had decreased to less than five percent, but that he would at least keep his peripheral vision. This was the hard truth and the major symptom of his hereditary illness.

"Thanks a lot!" he thought cynically, as if it didn't bother him and he decided not to listen to the rest of what the skinny little doctor had to say.

Now he was lying there in bed. On sick leave. Ineffective. Feeble. Lacking all the strategies he could otherwise come up with in his future plans for his company. The same company that was now withering just as fast as his own parched soul.

No desire. No eagerness. No new strategies. No happy recollections. No future.

But Leif sat up and heard how others in the house were finishing up their breakfast. He remembered that he was going to meet someone at the vision clinic that day. He had been there several times and listened to their words of kindness. They wished him well, even if they didn't appear to understand that it was all over for him.

© The authors and Studentlitteratur

Mechanically, from force of habit, he carried out his daily activities that were part of his morning ritual and got himself out the door and down on the street. He decided that his legs were going to carry him the two miles through a familiar part of town over to the other side of the river to the establishment that was his only fixed point. They had quit calling from work since he told them to manage things on their own because he was no longer interested "Do whatever you want and forget about me for a while," is what he had said to Lena, a friendly co-worker, who was left holding the receiver when he hung up on her.

A new period in life

He arrived, physically a bit stronger from the exercise. He was asked to go into a room in which there already were a number of people he would not have recognized even if he could see their faces.

After two hours, Leif was a new person. Eric, one of the people in the grey, blurred row of eight who sat there, had told how he managed the kinds of things Leif wasn't able to. Eric talked about his computer with more affection than Leif would have described his first high-school sweetheart. The computer could talk, it enlarged text and it could find words and sentences that Eric had lost track of in a document. He read books, watched films and kept a diary. He received email. It was quite overwhelming all that you could do with a computer.

But above all, Eric wasn't broken. He spoke with his entire body and a strong voice. He was alive.

The next woman was delightful. She worked with children, which helped her because they understood when she told them how things were. "And that's why it's working out well at my job at the day care centre," she said and you felt that she hadn't spoken very often in front of others. Here, though, she was comfortable, "among my own" as she expressed it.

The third person was unique. She said she had decided that she had the right to be different. She could read the way she did, with her eyes 4 cm (1½ in.) from the text and she did so wherever she was and whenever she wanted to. She was very determined. She

 © The authors and Studentlitteratur

said, "If people can admit that they are homosexual and stand for what they say, than I can admit that I have low vision and stand for it. On the coach ride here, I read a book by Håkan Nesser called Shadows and Rain (Skuggorna och regnet) [Nesser, 2004]. The trip took an hour and I was actually able to finish the 70 pages. Nobody came up to me and said that I couldn't sit there and read like that."

After listening to these three confessions, Leif got up and left. He said he was going to the men's room, and it was absolutely necessary because now there was only one person left before it was his turn.

He went to the lavatory. Stood very close to the mirror and saw his reflection and it was almost clear. He felt the damn burst. He cried uncontrollably, exhausting every nerve in his body. He cried and let the tears run down his face. His tension dissipated; he was flooded with relief and all the walls of resistance had tumbled down. He had met people who were what he didn't want to be, but at the same time were themselves. They were proud, not broken. They were sensitive, not hard and sullen like he was. They were ordinary yet extraordinary men and women; he felt a particular warmth for the woman who worked at the day care centre, a response he hadn't felt for a long time. She was genuine. Warm, soft and strong. Like his wife had been before. Like she maybe still was now, he thought as he washed his face and decided to return to the group.

There they were. People like him only they weren't fighting it. They had accepted so many things that he had rebuffed.

Assistive devices – but only if you feel like it

Strong glasses. Magnifying and talking computers. Talking scales telling everyone in the family how much you weigh.

When Leif went back into the room he realized that he had no difficulty finding his way because there was a meter-high number seven on the door. No problem seeing that! A light grey number seven on a red door.

In high school, he had had an extremely stimulating Swedish teacher, Aron Oskarsson. Leif often felt that the teacher was only

© The authors and Studentlitteratur

addressing him the entire lesson. He read everything he could get his hands on in the areas that Mr. Oskarsson spoke about, whether it was Greek drama or the literary Swedish Gothic League of the 1800s. Leif couldn't remember that Greek drama term that Mr Oskarsson used, the one that meant a sudden or unexpected turn of events or change of fortune in which all problems are resolved.

In the middle of this thought, someone said to him, "And who are you? What do you do for a living?"

Leif looked up from the table, felt the solidarity and didn't feel threatened. He said in his old voice, the one he hadn't used for a long time, "Thank you all for what you have told me. I'll share my thoughts with you another time, if that's okay, because at the moment I don't have any."

No one said anything. They all thought the same thing. He is on the road to regaining his desire to live, so let him take the time he needs.

Finally, the woman from the day care centre spoke up, "Of course. You can tell us when you're ready and able to."

On his way home, Leif remembered what that turning point was called in Greek drama: peripeteia. When everything felt hopeless in the play, God would send a messenger down from heaven who would announce that the war was over.

Perhaps the war was over now for Leif. Perhaps he could stop fighting and try to live the life he had been given, in spite of it all. In spite of the loss. They had said in the group that at least two percent of the Swedish population had low vision, and someone had to fall into that two percent, and – well – it was his lot in life to be one of them. There was nothing he could do about it.

Leif observed himself from the sidelines the next few months. He saw lots of things that did not mesh between his inner and outer existence.

Four steps on the road to recovery

There are four steps you can take to increase your chances of mastering a trauma – in Leif's case, a significant loss of vision. He had read about it, but had not understood. Now he started to, as he sat

© The authors and Studentlitteratur

there and looked at his tired body in an unobtrusive yet shinning new light.

He applied the first step when he sat down opposite his wife and said, "I'm sorry. I want to be myself again and I would like us to start talking about this for real. What do you think? Can we do that?"

She didn't respond. She just held his hand, and their tears fell together in mutual understanding.

"Yes!" she said, "You and me, kid," like she used to say before. And with that the ice was broken.

The next step in re-establishing inner harmony was to go back to the group at the vision clinic and see what those who were in the same situation had to offer. It was, he thought, like being transformed from an ugly duckling into a swan. Someone who counted because now everyone else was like him. They shared many experiences.

The third step occurred when he met an optometrist and a low vision therapist who sat opposite him and said, "We're experts at this. Trust us. We think that you are unique, but your problems are something that we know a lot about and if you want, we will be here when you need us. We can show you what to do and how to approach it." Friendly professionals.

"Thanks," Leif thought and decided to accept the offer.

The fourth step involved all the devices, the artefacts that make it easier to live, to see and to reclaim your old abilities.

Leif learned to type. It went fast because he could hear what he typed when the synthetic speech gave him immediate feedback. He could also see how the text progressed on the computer screen by magnifying it six times over. With Simon, the computer teacher, he realized that it was easier to read black text on a yellow background.

Leif sent his first email five weeks after his initial encounter with the low vision group, that time he went to the men's room and cried.

© The authors and Studentlitteratur

Thinking about the future again

Leif was back among the living. The desire to see and the desire to live came back into his life simultaneously.

Visual desire enables you to teach yourself to see in a new way. Eccentric viewing is the method that taught him to hold his gaze above the text and to move the text in front of the ugly, coke-bottle-bottom glasses. Tiresome, but still: he could make sense out of those squiggly marks called letters. He would master reading them again with the world's best optical systems. Visual desire made him want to magnify pictures and itsy-bitsy text with a video camera and transfer them to a computer screen that could reproduce pictures as large as he needed. It was visual desire that made him want to have a telescope when he went out so that he could see again at a distance, read a sign and identify objects that were transformed from black lumps into a BMW X5. Like magic!

Leif's strategic skills came to life again. He started thinking about how he could function on the job. How he would be able to see what he needed to, how he could get around, learn to read files and then compose and write answers on his own. By combining different technical solutions, he could find a system that worked.

If I am good enough for myself, I'm good enough for others

Wouldn't his customers and co-workers think that he behaved strangely when he sat there with his strong glasses and his nose so close that it looked like he was smelling his way through the text? Could he dare to reveal himself for what he was? Could he claim his right to be different, like that women in the group, and still measure up?

He had to prove it to himself.

Because of the visual impairment, he wasn't like everyone else. He had to learn to see strategically and effectively, by positioning the blurry part of his vision above the text and keeping it there by lifting and holding his gaze. He also had to practise reading faster

© The authors and Studentlitteratur

without getting a stiff neck and tired eyes. It was like starting school and learning to read all over again.

Everything he learnt made him more independent and less different.

One day when they were out practising the use of the telescope, a low-vision teacher told him his visual memory was an aid. The first time he walked along a new route, he used the telescope to identify blurry objects. The next time he walked the same stretch, he knew where he was without having to read what it said on the street signs. He knew that blue and blurry meant the Co-op store while red and yellow and blurry meant Burger King.

Before his vision loss when he went to work, he always checked to make sure he had his keys. Now he checked to make sure he had his glasses, that his telescope was in his pocket and that he could "draw" his magnifying glass as quickly as a cowboy could draw his gun in a Wild West movie.

Before he had admired the nuances in paintings and pictures at home, particularly the one of Ola Billgren that he had inherited from his aunt. It was almost entirely orange, but when you looked at it from a distance you could see the figure of a dancing woman. Ola Billgren's painting hadn't depreciated in value, but the orange nuances no longer appealed to him. Now he needed sharp contrasts like the dark stokes of the comic strip artist Ulf Lundqvist. They depict a black raven against a brownish-yellow background. The bird stood on a raised foreground and Leif could see the entire scenario from a few metres without straining. It was just as necessary to adjust his tastes in art as with everything else, he thought. But he wouldn't sell the Ole Billgren painting because his tastes had changed; it would bring pleasure to others who came to visit, especially now that they had started to re-establish contact with their old friends.

© The authors and Studentlitteratur

The empathy and honesty of others: a balm for the soul

One day as they drove past the exit to Stocksund, Leif's wife announced the name of the town. She did the driving now even when he hadn't been drinking, as he usually said a bit sarcastically, and which had become a standing joke.

"Why are you telling me where we are?" he asked.

She turned to him without taking her eyes off the road and said, "Because you can't see what it says on the road signs."

Leif smiled, slid over and whispered in her ear, "You are the best. You are my talking computer in traffic. You are my eyes and my guide in unknown territory. You are a real trooper. I love you." And he meant if for the first time in a long time.

She responded, "I'm like your own personal aid, designed just for your needs," she said and meant it. She smiled at him and because he was so close, he saw her smile, took it in and was filled with the most pleasant of feelings. It's easy to breathe when anxiety is replaced by security.

"Exactly," said Leif. "For all of my needs."

They had a good laugh and gazed at one another. She realized that he was looking directly at her again. He gazed into her eyes and she thought it was as before, even though she knew he couldn't really see her. He was doing exactly what they had said in the group: Look people in the eye even if you don't see them, because it feels better for the person you are talking to. Make eye contact even though it has no effect on your vision. It will have an effect on your contact.

It had been a while since they had laughed together. Since they had felt this close. Since they were positive to what the future had in store for them as a couple. They had stopped planning for the future and had, instead, been taking every day and every minute one at a time.

His life now meant that they had new things at home they never thought would be part of their everyday lives. Assistive devices that came in different shapes and which compensated for a negative element that had slowly crept into his personality and his surroundings. While this process was going on – the acceptance of all

© The authors and Studentlitteratur

the shapes and functions of the aids – there was a decrease in the feelings of hopelessness, anxiety and powerlessness. It corresponded in degree and occurred at the same instant as the loss was being compensated for.

An inner calm and a natural exterior

Inner and exterior harmony reigned, even though things went wrong some times. Like when he said "Hello" to the same person three times in an hour, and when he couldn't get to a customer meeting on time because no taxis were available. But worst of all was when depression set in and he was reminded of his limitations. When he could no longer manage to be the clever, patient and nose-reading user of optical devices. When he wished he would wake up from this nightmare. When he threw the car keys at the wall even though he knew that it was childish. When he didn't cry but yelled loud and angry – mostly when no one could hear – "Damn it! Is it really going to be like this for the rest of my life?"

But he let it run its course. Especially when he was home alone; then it felt good to let off steam. If he was out of town, it was worse. When the frustration took over it made him feel anxious and tired. With time, the number of such attacks subsided and one day when he was out walking in the woods with his wife he said, "It's been a long time since I've been down in the dumps, hasn't it?"

She answered quietly, warmly but firmly, "You mean that you blame your bouts of depression on the fact that you see bad? I remember you had days of self-doubt like that even before your sight went bad."

Leif said nothing, but thought so loudly that she heard. He could never come to his own conclusions about himself without her always having to explain what he was like.

Then she said, "Race you to the car!"

Leif ran like he had never run before and used all the visual memory he had to beat her. And he won. By a couple of metres.

© The authors and Studentlitteratur

2 The first time I saw you …

Henrik Enquist

A picture says more than a thousand words, as the old saying goes. But aren't there some things you simply cannot describe in words? That you have to see instead? That's how it was for my partner and me when we were expecting our first child. It wasn't until the first ultrasound examination that it became real for me that I was going to be a father, and that there was a person in my partner's womb who was going to become a part of my life and whom I would love.

I have reflected considerably on this also being the case for medical conditions in general. How would I be influenced when I could see images of what was wrong with me, images that meant something to me and that could help me understand or relate to others something about myself?

This chapter deals with my experiences as a father-to-be and how I saw my son for the first time. The big moment took place in a dreary room under rather prosaic circumstances and was in no way on my terms as a future father. What did we as anxious and expectant parents *miss out on* in this unique situation, which wasn't at all intended for us but considered to be purely a diagnostic tool? What could be gained by another, complementary way of using these and other medical images?

… it was an August day

Lennart Nilsson's photography of developing foetuses in books such as *A Child Is Born* [Nilsson, 1990] filled a great need for people to see what happens during pregnancy. His images accomplished this in a way that was dramatically different from schematic drawing or medical slides at a museum. The photographs are lyrical and

© The authors and Studentlitteratur

beautiful, which makes them easier to take in as parents-to-be. The most important emotional parameter, however, comes from the depiction of the living foetus. The biggest disadvantage is that these pictures are not depictions of one's own child. The difference between "she/he can look like this" and "she/he really does look like this," is the difference between guessing and knowing. My partner and I knew that we were expecting a particular child. We didn't know if it was a boy or a girl, but were quite sure that it would be a little person. I use the word "quite" because we sometimes joked about the child inside her being a puppy. Not because we thought it would be a dog of course, but because it was our first; the whole idea was so abstract that it could just as well have been a puppy. Based on what we saw from the outside, we had no concrete mental equivalent of what was inside. In other words, it was her stomach that grew, not the person dwelling there. We spoke about her stomach as though it were an individual, when we should really have been speaking about the child inside.

We parents-to-be would be greatly assisted in maturing into our new roles if we perceived the baby-to-be as an actual person, something other than mental projections of our hopes, dreams and fears. To this end, ultrasound pictures are a great help. They not only make the child tangible as such, but prepare us as parents for the delivery and for the responsibility we have taken for another individual. The pictures also create an emotional connection, albeit only one-directional, from us as parents to our infant in the womb even before the delivery. I particularly experienced it as becoming clear for me as the future father because I did not have the physical/biological connections to the foetus that my partner had. A myriad of thoughts rushed around in my head before I first saw the foetus: "Is it a real child there inside her and in my thoughts or is it only an 'imaginary' one? Does it really exist or is it only my imagination?"

The first ultrasound image was a revelation in and of itself. We saw something; we saw a creature that was alive and growing. Awesome! The moving images provided us with a strong sense of the reality of this foetus. Something to connect to the kicks I had felt from the outside and my partner from the inside. It was possible to distinguish parts of the body and my imagination managed to fill in what was missing. The examination, however, was over so quickly that we were hardly able to take in what we saw on the

 © The authors and Studentlitteratur

screen – our child! The joy of it all was a bit diminished by the assembly-line feeling present in the room and we were slightly disappointed but still happily dazed when we left the maternity clinic after twenty surprisingly short minutes. When we looked at the pictures later on, we thought they mostly resembled a skull. In the blurry images you saw large, empty holes where eyes were supposed to be, a wide-open mouth and a thin body, but not much else. Now, after his birth, we know of course what he really looks like; that he turned out "fine" with all the parts in the right places and without a doubt the most beautiful and intelligent child in the world. We didn't see that in the pictures we took home from the clinic, though – we saw that better without them. I'm almost embarrassed to say that we laughed at the pictures of our son. What we were actually laughing at were the bad images and what they showed. In the waiting room there was a poster documenting the development of ultrasound as a technology with examples of pictures taken with different equipment. There was an impressive, colourful 3D image with shadows, depth and high resolution. That was the kind of picture we wanted of our son. When we asked why they didn't have equipment like that, they responded that there was no reason to use that kind of new technology for the diagnostics that they were carrying out. But for us as future parents, it would have made a big difference. Better quality would have made the picture of our child more alive, more real. Better yet – 3D coloured film sequences with the sound of a beating heart would better correspond to the individual you expected to come out. A minute's worth would have been enough to provide us with an enormous amount of joy over the next months. We would have been willing to pay a lot for a film like that, and I don't think we're the only ones. Imagine being able to look at it in the comfort of your home, over and over again!

The second ultrasound examination was just as hurried as the first. I understand the pressure hospital staff are working under and the county council's limited healthcare budget. But since having a child was the biggest event of my life, I just couldn't get enough of looking at the screen. Arms and legs quickly swept by; one second our child was on his head, the next his backside filled the entire screen. That he didn't get seasick was a mystery! I was completely enthralled and tried to memorize everything I saw, while at the same time curiously trying to count fingers and toes. When I came

© The authors and Studentlitteratur

up with eight on one hand and two on the other, I gave up. It all went too fast for my untrained eyes and as an experienced photographer, I was frustrated at not being in control, not being able to compose and focus the picture. This was not a situation where special requests were welcomed. I couldn't help but think of how it is in the USA. Not because it is necessarily better there, but I imagine that if you can afford it, you can probably decide the camera angle and picture composition – you get what you pay for.

The midwife finally let us know that everything looked fine. If I didn't trust the Swedish healthcare system as much as I do, I would have been sceptical when you consider all that had to be checked in the short time it took to carry out the examination. Instead, I was impressed with the routine and experience. The pictures we could purchase (inexpensive, two small ones for 2 euros) showed a more human-like creature than the one from the first visit; a shot from an oblique angle in which his nose looked enormous (Dad's nose!) and in partial profile. It was only in the better of the two pictures that we were able to figure out where our baby's body started and ended because in the poorer one, the contours blended in with the background and half of the body was shown in cross-section. What have they done with my baby?

Because our child was below the average weight, we were offered a third ultrasound examination. We felt experienced at this point and knew what we could expect picture-wise, considering that it was only a few weeks until the due date. The measurements were carried out, and although the foetus insisted on holding one arm in front of his face, we got an idea of how much he had changed from the last visit. He had grown tremendously! The feeling that delivery time was near was so overwhelming that tears came to my eyes. Exactly at that moment, the nurse decided to take a picture of our child's feet! Time was short and she hadn't been able to move the arm even after nudging the stomach with the transducer. Not that there is anything wrong with feet, but they do not have the same emotional impact as the face, even with an arm in front of it. I felt snubbed at being treated like that. We knew it was an extra exam exclusively for checking growth, and we did have the old pictures after all. Nor would it be very long before we would see our son in the light of day, but it was insensitive and unsympathetic of the midwife not to make the extra little effort to see the situation from

 © The authors and Studentlitteratur

our perspective. Or was I just too demanding? One might think that this desire for pictures for the parents' sake is a luxury that the healthcare system can't afford. That may be the case, but the examination was going to be carried out anyway and it could just as well be recorded at the same time. If parents-to-be could then purchase the recording, there is really no difference from the pictures they can already buy, other than the format. Having willing parents share the expense can help clinics defray the cost of the expensive equipment as well.

After images

Now that our son is two years old and when I think of the many pictures I have taken of him during that time, I wonder how they affect me. Is it purely due to parental love and the fact that he is our first child that the camera has been used so much? Or is there some other reason for my need for pictures? He wasn't more than five minutes old when he saw his first camera flash and now he is as used to it as a Hollywood star. He poses and smiles most captivatingly as soon as a camera appears. Is it healthy to do what I am doing? One thing I'm sure of, I'm not alone.

These images have come to mean many different things to me. They are the instant caught on the fly, the one lost forever if not captured on film. As a picture, it remains and becomes something to gather around, something to show, to point at and to talk about. It tells something about our lives. This collection of pictures will be a part of our life history because the changes and appearances that you hardly notice in everyday life become apparent in a photo album. Pictures have been a way for me to talk about and share something important or problematic and are a way of "writing" my biography.

© The authors and Studentlitteratur

Images in a bigger perspective

Humans, disability, illness and medical images

What would this line of reasoning be like if we moved from ultrasound images of foetuses to medical imagery in healthcare on a more comprehensive level? What is the current situation with pictures of disabilities and illnesses and what could it be? It is hardly reasonable to expect that they too in the future will only be used for diagnostic purposes. The person involved also needs pictures that are both emotional and informative; pictures that provide new information and new knowledge, raise new questions and provoke other feelings. Ethically, there are also many questions about the purpose of these images, questions of control, copyright and user rights to the enormous number of medical pictures being taken.

A large and relatively unexplored number of medical images of the human body can be found in hospital archives: anatomical drawings, autopsy pictures, photographs, cytological images, videos, MRIs (Magnetic Resonance Imaging), x-rays, computer tomography, chromosome staining, histology incisions, electron microscopy, ultrasound examinations, and more. This picture material is invaluable for diagnosis and treatment but has, to a very limited extent, been used for other purposes than the purely clinical. This, in spite of the fact that medical images have an enormous psychological and emotional effect, particularly when they are used for diagnosing severe illnesses. Among these there are cases of chromosome analysis in amniocentesis, MRIs for identifying tumours, ultrasounds of foetuses, etc. This kind of diagnostics means that the images are also the basis of a normative process that divides up those who are sick from those who are healthy, normal from abnormal.

How do people with disabilities and other groups in society come in contact with these pictures? Marginally, I would assume if you take into consideration the enormous quantity of images that are generated. They are not available to the public for many reasons, but they are often not even available to the patient either, for more than a quick look. In that case it usually involves x-rays or ultrasound images, which are considered relatively easy to understand and which do not cry out for explanations or calming reassurances. The treatment of these medical pictures seems to be surrounded

 © The authors and Studentlitteratur

with what could be described as mystery and secrecy from a patient point of view. A relevant question is why and for what purpose medical images are produced. Do people with illnesses and disabilities have other wishes and needs than the doctors? And in that case, what are they?

It seems as if the technical developments in medicine do not correspond to parallel changes in attitudes about medical imagery. The cause can be difficult to determine, but that there is a connection between technology and the culture from which it arises is apparent. As the rest of society is changing in the direction of active knowledge seeking, dialogue, communication and emancipative participation, the praxis still exists in the healthcare system of a one-way flow of information with the doctor as the sender and the disabled person as the receiver. There is no true dialogue, perhaps due to language and knowledge barriers, perhaps because the importance of breaking this pattern is not apparent to doctors. Change is unavoidable in the long run, when not only medically well-educated patients but the chronically sick and other groups in the community who spend a lot of time in the healthcare system acquire knowledge from sources other than the local healthcare provider. This will result in them demanding greater access and insight into their care situation and more information about and power over their poor health. In other words, they will become enlightened, expert patients.

The enlightened human

A considerable amount of knowledge that doctors and other care providers have only marginal access to has to do with the patients' own personal experiences of their illnesses or of their life situations in general. People find information, knowledge and power individually or through patient and support organizations and this, in turn, influences their attitudes to the care they demand and receive. Disability and patient organizations have proven to be successful as pressure groups and in public relations in and outside of healthcare. The fact that people on their own, independent of the healthcare system, actively seek out knowledge and information about their conditions indicates that something is missing in what they are

© The authors and Studentlitteratur

being offered. The answers they receive do not fit the questions they ask. One explanation can be that knowledge and experience of poor health differ between care provider and care recipient. Lived knowledge and experience are basically different from acquired knowledge. This is not to be seen as a threat to clinical care, but more as a complement from the perspective of the person experiencing the poor health. This can result in a shift in the dialogue between both partners so that it is not only the ill or disabled person who has to adapt to and accept healthcare's premises and format, but that the healthcare provider is open to suggestions. It is also a matter of a mutual acknowledgment of knowledge and respect for wishes and expectations.

The discrepancy between the parties is clearly noticeable when it comes to the purpose and use of medical imagery. People are still considered to be objects in the images as well as passive receivers of information already processed by the doctor. Doctors have a monopoly on examining and interpreting medical images, which are really about the patient involved. In other areas of society, this would be considered offensive because we are usually encouraged to seek information ourselves in order to influence our own situation.

Many people with or without disabilities or illnesses have a well-developed ability to critically relate to images. This will certainly increase in the future. This is because society is based on images in many respects. By constantly being exposed to and consuming advertisement and news images – personal images, photographs as well as videos – the habits and skills have been established of producing and using pictures in a variety of situations. The different purposes of pictures influence how they are interpreted and used. The question can be posed: Why do we expect ourselves to be able to deal with these images but not the medical ones when both depict and directly affect us so very much? Can't we be counted on to cope with seeing ourselves or is there a fear that we will discover illnesses that we really do not have? Can it simply be the case that the medical establishment does not believe that people are interested?

© The authors and Studentlitteratur

Empowerment

Being able to see images of one's health condition can perhaps make the sick person feel less sick. That's not to say that a picture can cure, but it can alleviate, exactly as the majority of medical measures that are carried out. To be able to point at a picture of your illness and then talk about it with your doctor can play down the diagnosis and may even facilitate the actual recovery.

Empowerment and participation in the creation and interpretation of the image result in the person himself also participating in the healthcare efforts, but in another way. Medical language can be exact when it comes to classification, but how does the consultation with the patient involved take place, i.e. how can you convey knowledge to someone who doesn't already have knowledge? Can the dialogue be facilitated when it is based on images? They can act as the starting point for explaining diagnoses and for clarifying medical information to avoid misunderstanding, anxiety and uncertainty. Bringing a picture of your sickness home with you can also be facilitating – not only in your mind but also in your hand: you can put it on the refrigerator door or in your billfold. It can result in strengthening the band between the health you experience and that which has been diagnosed, i.e. the connection between feeling healthy and being healthy. It is also a way of avoiding the prototypical and shocking images of worse case scenarios that healthcare professionals present but that patients reject, resulting in patient denial instead of focussing on what is most important – their own health.

One question that immediately surfaces is which images should be sent home with the patient. This question should be preceded by another, namely, why images are produced in healthcare in the first place. If you proceed from the assumption that people are individuals instead of cases, the answer will be something different. Ignorance or unfamiliarity in healthcare concerning the public's desire to know more details is related to the fact that a person is often considered to be a "case". The different wishes, demands, knowledge and abilities of individuals in combination with greater influence, transforms the patient into being a subject with requirements and opinions concerning his or her own healthcare. By using images, questions are generated that require answers; this results in the

© The authors and Studentlitteratur

sender-receiver relationship being exchanged for that of searcher-feedback provider.

What is presented in this chapter follows the same line of reasoning on rights and empowerment that is behind the current right that patients have to their own medical records. To that can be added the strong emotional power of images compared to that of the text that is found in medical records. This power means that the research idea introduced here can lead to significant changes in how patients experience their good and their poor health and with that, significant changes for healthcare in general.

© The authors and Studentlitteratur

3 Lund doesn't exist …

Eve Mandre

Emil is 45 years old and at that age should have a considerable store of life memories. But in Emil's case there are few episodes that he can pick out of his past with which to establish a continuous life history. Emil lives almost entirely in the here and now and his memories, for the most part, are hidden from himself as well. He finds it difficult to spontaneously and automatically recall them. When you ask him about it he answers, "It's like I'm not able to retrieve the whole picture …" But because Emil does not have the ability to reflect over what he knows and what others may be thinking, this lack of a life history is of little concern to him. He is living *here* and he living *now,* isn't he? What happened before or what will happen in the future doesn't really bother him.

"What did you look like as a child?" you can ask Emil to try to trigger some associations.

"The way I look now, only smaller!" would be Emil's answer.

"What colour was your hair?" you might try again to get his memory going.

"Same as now," Emil answers without a thought that his head is currently shaved, providing absolutely no information about the colour of his hair, now or earlier in his life.

Is Emil "the man without a memory"? Or is it the case that he does *not want* to talk with others and tries to dismiss them in this effective manner? The fact is that Emil, due to his inadequate communication and his deficiencies in being able to evoke memories and make associations has been considered to be unwilling.

"Emil *won't,*" is what the people around him say.

"Unreachable", "Isolates himself" is what has been written in his patient records year after year. So he has been left in peace – the wishes of the patient have to be respected, don't they?

© The authors and Studentlitteratur

Emil and his diagnosis

Is Emil really "Mr. Unwilling" or can there be another way of looking at his difficulty in communicating with people? Those who have been around Emil for all of his adult life are personnel in psychiatric care. They have all wanted the best for him and believed that they were respecting him by taking him at his word. Emil's home for almost twenty years has been that of closed forensic psychiatric facilities, and as everyone else, he was placed there with a diagnosis – but he has never understood what a diagnosis is and why he should have one – he is even less aware that it is schizophrenia NOS (not otherwise specified) and that he is considered to be paranoid. Nor does Emil know that the reason he was moved from the Big Hospital to the new unit in town was because of reforms in psychiatric care. That his long stay at the Big Hospital came under the Closed Psychiatric Care Act and that he is now cared for according to the Forensic Psychiatric Care Act has absolutely no meaning for Emil. Many years ago he was sentenced for assaulting someone, but it's been so long that it no longer has any connection with his life today. Emil lives in the here and now and the past is not even something that flickers by in his internal recollections.

The clock of life ticks on

Life ticks away on the hands of the clock and clock time is very important to Emil. Minute added to minute, hour to hour and day to day and in that way Emil's life rolls along. When the clock says 7 a.m., Emil stands at the door of the nursing station to receive his medication. He takes the little pill in his hand and goes quickly into his room to avoid meeting anyone in the hall.

At exactly 10 a.m., Emil comes out of his room again to go out for his daily walk. For the first time in twenty-three years, Emil has been allowed to go out in the neighbourhood on his own. The new surroundings do not feel as secure and predictable as the park around the Big Hospital. Here there are all kinds of people, cars, a pet shop, video shop, music store and much more. Ester, his contact person, went with him the first time to help him orientate himself

 © The authors and Studentlitteratur

in all that was so unfamiliar, and to assist him in establishing a new routine. Now he follows in his own footsteps, taking the same route every day.

One day when Emil comes back from his walk, Ester is standing outside his room. She looks worried and says, "Emil, I was emptying your wastebasket and found your medicine in it. How long have you been throwing it away?"

Emil doesn't really understand the question, but answers honestly, "I've always done that."

In that instant, Ester understands that it's hardly possible for Emil to have the schizophrenia NOS with which he has been diagnosed. Why Emil so directly and honestly tells her that he has always thrown out his pills remains a mystery to Ester. A good while afterwards she finds out that because Emil's thought processes are so literal and concrete, the request, "Take your medicine," does not mean anything more to him than to take it in his hand and go. If Ester had wanted him to put it in his mouth and swallow it as well, she should have explicitly said so. Emil was only doing what he was told: "Take your medicine!"

Emil and the reform in psychiatry

When Emil left the Big Hospital to move to his new home on the smaller unit in town, he was dressed in hospital clothing. No one has been able in all these years to get him to buy his own clothes. He is used to the khaki trousers and white cotton shirt with the county council hospital emblem and that is why he wears them – nothing at all peculiar! Emil does what he is accustomed to doing and nothing else. It is the simple rule that he lives by. And it has become well established over twenty-three years in a world in which he "does not want" to do anything else. The new legislation that regulates the lives of psychiatrically disabled people is based on the patient's wishes to a considerably higher degree than the old one. It is an admirable step away from guardianship, repression and arbitrary treatment of people who have long been powerless and disadvantaged. Before the new law went into effect, there were also well-intentioned people in Emil's life who listened to his wishes. What is

© The authors and Studentlitteratur

paradoxical for Emil is that it has been these well-wishers who have created a world of isolation for him with no exit. Emil did not *want* to talk to other people – so he was left in peace. Emil did not *want* to participate in any group activities – so he didn't have to take part in any activities at all. Emil did not *want* to eat with the others – so he was allowed to eat by himself in his room. Emil did not *want* to have anything in his room – so he was allowed to live in a bare, inhospitable space.

Emil had just moved into the unit in town when I was asked to explore the possibilities of introducing educational aspects into the treatment of patients with chronic schizophrenia. The unit had many forensic psychiatric patients but also many who had been there so long that they were considered *chronic* – or with the new terminology – *psychiatrically disabled*. If Emil expressed few thoughts, a number of his co-patients in contrast had many more to articulate. Per, for example, had lived the happy student life in the 1970s, and he continued to do so now in his mind, day in and day out. He had a stream of associations and he could retrieve and mix recollections as if he were sorting a pack of cards. Suddenly, his house of cards would fall, and Per's mental images would lie there all over the place. He would then start to sort them out again – from the beginning in exactly the same way. In these lively and vivid recollections, Per lived out his days – year after year. Per and Emil – two opposites – the one had a rich inner life, continually replaying in his mind without alteration over time; the other lived in mental emptiness in which routines and habits characterized everything in his life.

A digital camera enters Emil's life

I had a digital camera with me when I visited the unit. It was to be used to make illustrated schedules and reminders for the patients who found it difficult to structure their time. During my first few days on the unit, the more social and extroverted of the patients wanted to have their pictures taken and to put them on the doors of their rooms. In order for them to get used to me being there, I took pictures of everything from the staff to the beautiful fish in the aquarium as well as what the patients requested. Every afternoon, I

 © The authors and Studentlitteratur

put the pictures on a notice board by the door. And I observed that Emil also on occasion passed by the notice board on his way to his room.

One day – at exactly 12.30 – when Emil, like clockwork, fetches the food cart at the outer door, he walks by me with the camera in my hand. He stops and makes his usual gesture when approaching people – holding his arm over his face – and wonders what kind of camera I have. He says he has never seen one like it before. He asks questions about how it works, how you can develop pictures without film, what it costs and how you take a photo with it. Suddenly, Emil has quite a few appropriate questions to ask and he is the one who has initiated contact. I show Emil how to take a photograph and hand him the camera when he is ready to go to the kitchen to work.

2.30 p.m.– as always – Emil is finished with the washing up and cleaning of the kitchen. He has also taken twelve pictures to show. He talks about the pictures on the small screen and starts to reflect on what the kitchen looks like. He wonders if he should have waited until he was finished with the washing up and cleaning before he took the pictures. It's such a mess! And then he wonders if it is possible to develop real pictures – on paper – that he can keep. I tell him that his unit does not yet have a computer and that I usually print out the photos that I take on my computer at home. I promise Emil the pictures the next morning.

Emil is waiting for me when I arrive the next day and comes out of his room even though it is not yet 10 o'clock. He is curious about the photos and has lots of comments about them. He makes sure that he can borrow the camera between 12.30 and 2.30 that afternoon so that he can photograph a clean kitchen. Then Emil leaves for his daily walk.

Memory full

One day when Emil is on his way out at 10, I ask him if he wants to take the camera along. He does. An hour later, Emil is back, displaying an unusual eagerness.

"It says 'memory full' on the camera!" he informs me.

© The authors and Studentlitteratur

That's how I know there are 59 pictures in the camera's memory. We look through them together and I promise that he will have the printed versions late in the afternoon. When I upload them to my computer, I am pleasantly surprised – Emil has chosen his subjects with great care and the images are well arranged. He has been able to pick up on brightly coloured details and unusual themes in the crowded streets.

In no time, Emil becomes my most important conversational partner on the unit. The personnel also start to see him in a different light and attempt to initiate conversations and suggest outing. Emil turns a cold shoulder to all suggestions that have to do with going to unfamiliar places.

"The world is nothing more than a potato patch!" he declares, putting his arm over his face and heading to his room.

It is apparent that Emil is unable to think about places or activities that he has no experience of. Nor is he able to imagine things that are only possible and not yet reality. That is why Emil needs his routines. That's the only way he can visualize what it is he is supposed to do. Emil does not possess the mental ability to shift his thoughts between the here-and-now and the past, tie them together with the present and come up with desires or requests for the future. That is why it is necessary for him to make associations using external pictures – he has to have cognitive tools to support thought and it appears that the digital camera can be one of them.

Emil has also understood that the photographs make a difference for him. It is December and he has seen the Christmas window displays and decorations in town. Large Christmas trees with lights are suddenly erected along the route he takes on his daily walks and something starts to come to life in Emil. He relates that he once rode through town on the Big Hospital's bus right before Christmas and he remembers that there was a beautiful Christmas tree – can I find it and photograph it for him? I can easily guess which one it is. I take a picture of it and then go to the department store nearby and take pictures of the window displays. On the way, I run into the Swedish king's state coach, which is out for its daily tour. I quickly pull out the camera and manage to get a picture.

When I return with my pictures, Emil shows an unusual eagerness. He normally doesn't show any emotions at all, always having the same facial expression and body language. Now his whole face

 © The authors and Studentlitteratur

is radiant and he laughs out loud and for a long time when he catches sight of the coachman in the coach box wearing a thick fur hat and an old-fashioned black cape with silver braids.

"It looks like he's from *Revenge of the Vampire*!" he exclaims.

When I ask Emil about the vampire's revenge, he tells me that he saw the film at the cinema, many years ago.

Emil's new clothes

Just before Christmas, Emil asks if you are allowed to take photos in a department store and explains that he would really like to see what it is like in a toy department these days. Before I carry out this assignment, I decide with Ester that we are going to start using pictures to get Emil to exchange his hospital clothes for more personal ones. On my way to the toy section, I pass through the men's department and photograph trousers, shirts and jumpers. It is these forty-eight pictures I present first to Emil when I describe my trip to the toy department. Emil examines an interesting pair of kaki-coloured trousers with large pockets on the legs. After a moment's thought, he comes to the conclusion that he has never seen a pair of trousers like this before and then asks, "What do they cost?" I find out the price, Ester takes the measurements and Emil has a new pair of trousers along with a shirt and jumper for Christmas. Ester has explained to Emil well in advance that on this unit, you are not allowed to wear hospital clothes to the Christmas party. Emil accepts this because he really wants to attend. He knows that presents will be passed out at the party and he has wished for a remote controlled car, which he saw in one of the photos from the toy department.

After Christmas, we start to see Emil wearing his own clothes more often. We also see him driving his remote controlled car. It takes two hands to operate and Emil is so busy with his driving that he forgets to put his arm in front of his face when he meets others. This gesture soon disappears. The hypotheses and speculations about Emil's habit of covering his face for others included paranoia and fear of radiation, among others. When we later ask Emil why he covered his face, he has no real answer other than, "I don't know. I'm just used to doing it."

© The authors and Studentlitteratur

The world is more than a potato patch

After Christmas, the unit's own computer and digital camera are delivered. The young male mental health assistants, who until recently thought it was difficult to talk to Emil, have now acquired a tool through which to work with him. Instead of going up to Emil and asking him if he wants to join them for an outing, they prepare him for it by showing him pictures. Using the images, they describe where they plan to go later on in the week, what you can do there and Emil knows in advance how long they expect to be away. Through these simple preparations, Emil can now form a mental representation of what exists out there in the world. He no longer claims that it is a potato patch. He is now a man who has started to add experience to experience, and his mental representations of the world are expanding. In addition, there are photographs of these new experiences after the fact, and he can look at them again and again – going over them in his memory as many times as he wants.

Even though Emil now has quite a few mental representations of the world, it is more than he can comprehend when I tell him in the spring that I'm planning to move to another Swedish city called Lund.

"I won't be able to come to visit you as often," I explain.

Emil looks at me seriously and says, "You can't move to Lund. It doesn't exist!"

Since Lund is not a part of Emil's concept of the world, and he has seen no pictorial representation of the city, it simply doesn't exist for him. Right after I move, I send him a letter and enclose photographs of the train that took me to Lund, the station, the street to my building and finally, the view over the rooftops from the windows of my flat. I write to him in the letter that, "I live on the roof, just like Karlsson," (a well-known character in a Swedish children's book).

© The authors and Studentlitteratur

Who is Karlsson-on-the-roof?

When I visit Emil in the summer, his first question is, "Who is Karlsson-on-the-roof?" I then tell him Karlsson is a man of his age who lives in a little house on a roof and is able to fly there with the help of a propeller on his back. Emil is immediately interested and wants to know more about this man with the propeller. I tell him that there is a book about Karlsson that I can send him – but there is one condition. I have a birthday the week before Emil's, and if I receive a birthday card from him, I will send him the book in return for his birthday. Emil is at first totally terrified. He doesn't know where to buy cards, what to write on them, or how to get stamps. I write down all the details so that he knows exactly how to send a birthday card to someone. Emil also wants to know which letterbox he should deposit the card in and thus is given a photograph of the letterboxes with an X under the correct one.

The day before my birthday in July, I receive a card with the exact text that I had written down for Emil. There is a stamp too and you can see that the task was meaningful because a lot of effort went into pressing the tip of the pen to form the letters. On Emil's birthday, he receives the book about Karlsson on the roof. I also promise that I will read the book to him when I come in August. Emil has explained that he doesn't especially like to read books because the letters are just people's fabrications and he doesn't want to have anything to do with them. He would rather have books with pictures.

How surprised I was that day in August when I ask Emil if we should read the book about Karlsson and he answers, "I already have!" Thus, Emil has become a reading and writing person – even if he maintains that he prefers pictures.

Black leaves

One sunny and hot August day, Emil is a bit troubled by something and I ask him what is on his mind.

"It's strange," he says, "when I look out through the window the leaves are so green. They were usually black when I was growing up."

© The authors and Studentlitteratur

This can appear to be a peculiar statement about leaves, but many of Emil's statements seem odd at first if you do not ask follow-up questions.

"Now I don't understand," I say in an attempt to get an explanation as to why leaves can be black.

Emil reflects for a while and then he replies, "I don't like sunlight so I usually sit in the shade under a tree; maybe that's why I remember them as being black – or maybe there was another kind of tree where I grew up," he tries to explain.

When Emil says that he doesn't like sunlight, it also becomes understandable where he got the habit of putting his arm over his face. An over sensitivity to light coupled with a dislike or inability to look people in the eye seem to be the probable causes of this gesture rather than fear of radiation or other paranoid fantasies.

Since Emil also tells me that he used to sit in the shade of a tree, I ask him where this tree was. He then relates that he grew up in a cottage in the country.

"How do you build a house?"

Over the next few months, I send many photographs that I have at home and we talk about them when I come to visit. On one occasion, Emil has received several pictures of my cousin's house in Estonia. In one, there is a woodpile and a water pump. Emil's thoughts go to the cottage where he grew up.

"We also had a pump and a wood stove," he relates, "I usually carried in the water and chopped the wood."

After this conversation, Emil wants to know more about how you build a house.

"Are there books on how to build houses?" he asks.

Since it is picture books he wants, I have to borrow them from the children's section of the library and the building descriptions given there are not detailed enough for his needs. He wants books that tell exactly what to do, what kind of tools you need and where you can get a hold of the planks. Emil asks a lot about different kinds of houses. His assistant on the unit helps him to get answers to his questions. He gives him brochures, books and photographs to study.

© The authors and Studentlitteratur

County administrative court

Emil was admitted to forensic psychiatry under a regulation stipulating that every six months the county administrative court has to review his case and consider the possibility of releasing him. Such hearings have occurred regularly during Emil's entire stay in psychiatric care. For all these years, it was determined that Emil was not capable of participating. Doctors and staff members have represented him instead; they considered him to be too sick and that a release was entirely out of the question. Emil still has no idea what his diagnosis is, but he has now started to realize that it is possible to live someplace other than on a hospital unit. His mental health assistant has encouraged these thoughts. It has also been explained to him what a county administrative court hearing involves and suggested that he should attend and explain to the court that he has changed.

During the hearing, Emil is asked how he would like to live if he were released and he answers with certainty that he wants to live in a cottage. He would prefer, of course, to have his cottage quite close to where he takes his daily walks. He thinks that it could be arranged. The court feels that Emil's concrete and lucid account indicates that he no longer requires forensic psychiatric care. And so he is released and is a free man after his nearly twenty-five-year-long sojourn in closed psychiatric care.

A free man – but how did it go after that?

Emil, after many years in a hospital setting, was now going to learn to live in freedom and in his own place. With the difficulties he has, it is obvious that he will be dependent on cognitive support for the rest of his life. Photographs have been one form of memory support for him. Through them he has been able to generate new thoughts and associations. The mental representations that he is unable to achieve on his own, he now gets assistance in doing from the external pictures. The dream of living in a cottage was not within the scope and resources of the system. Thus, his housing needs were solved in a more conventional manner: he was placed in a flat with

© The authors and Studentlitteratur

support. Since it is close to where he takes his daily walks, at least part of his dream has been fulfilled. He can retain one of his routines and thus feel at home in the familiar neighbourhood.

When Emil was released it became apparent that he could learn from his experiences and generalize his knowledge. He didn't know how to purchase and send a birthday card the first time. But when he succeeded and it was so well rewarded, Emil thought it would be just as profitable to send Christmas cards when they appeared in the corner store. And he was right! He received a Christmas present soon after he had mailed the Christmas card. The next Easter, Emil discovered Easter cards and so he tried his luck again. Soon thereafter he received a big Easter egg filled with sweets. This ritual is still going strong.

© The authors and Studentlitteratur

4 From the stock market to love by means of technology

Håkan Eftring

Sometimes life is like the value of stocks on the market. Not only because of the unpredictable ups and downs – or that there can be a downturn in an upturn or an upturn in a downturn, but that how I feel today depends quite a bit on what I believe about my future possibilities, in the short or long run.

Even though things are bad at the moment and have been for a while, I can still be in a good mood if I actually believe that things are getting better. They need not get better immediately; it's enough believing they will.

Details about Paul – and Paul about details

That is exactly how Paul feels at times – quite often, actually. Paul is an ordinary fellow with a physical impairment, and who doesn't have one once in a while? The difference is that Paul will always have to live with his disability, even if it can change over time.

This was a conversation he had recently when he was making a new acquaintance:

"I see that you are disabled," the new person said.

"No, I'm Paul and I have a disability. People with disabilities are people first. And don't forget it!"

"I won't forget it. What's it like for you now? Have you got used to having a disability?"

"Used to and used to. I'm always reminded of it. Let me tell you, having a disability is really impractical. And don't forget it! Many times the small, small details stop me from being able to do some-

© The authors and Studentlitteratur

thing on my own. How much fun is it to almost be able to feed yourself? To almost be able to make a mobile phone call on your own? To almost be able to change channels on the TV, or read the paper or get yourself out of the house or read your mail on your own?"

"What do you mean? Isn't there anyone who can make sure that all of those small details are fixed? Have you ever talked to an engineer?"

"Yes, once. But she said that it was impossible to do anything."

What is impossible can be made possible

"But you shouldn't listen to people who say that something is impossible. Nothing is impossible. You should ask another engineer. And don't forget it! There are lots of engineers. We should all actually take a minute to reflect on what we believe is impossible to do in our lives. Much of it can, in fact, be done. And don't forget it! It's actually rather exciting. People have used technology and tools for ages, you know, and developments are going on all the time. What was impossible to do a few years ago is suddenly possible today. Just think if you discovered some new kind of technology tomorrow that you couldn't imagine existed in your wildest dreams. Try to keep up with new trends in technology. There is a considerable amount of financial news on TV these days, but maybe there should be much more technical news instead. What do you think of that?"

Paul explained that being independent and having power over his life are two crucial elements. He would, in most cases, prefer to utilize technical solutions that he had control over and could use exactly when he wanted rather than getting help from another person. Even if it goes faster when someone helps him, he would rather do it himself in the way he thinks is best.

"Sometimes just testing a new technical aid helps me realize what it is that I actually want. That's why I think it's good to be able to try out a technical aid, even if it ends up being something I don't use. The important thing is follow up and documentation explaining why the aid wasn't any good, or, if it was used, why it was good. And don't forget it!"

© The authors and Studentlitteratur

Socially isolated? Not Paul!

"But isn't there a risk of becoming socially isolated with all that technology?" asked his physically vigorous friend.

"That's the stupidest thing I've heard!" Paul replied. "Would I be socially isolated if I could make a mobile phone call myself? If I could get out of the house to visit friends on my own? And if I could read my mail myself? Technical aids do not create social isolation. And don't forget it! If that were the case, people who are severely physically vigorous would be socially isolated – and you aren't, are you?"

"No, of course not. You're right. I'll never say that again."

"Good! Being dependent on someone else when you don't want to be is harmful. And don't forget it!"

"No, I won't – but do you also mean the opposite? That you can be dependent on someone else and choose to be so?"

"Yes. That's called love! And don't forget it!"

To sum up: my ten commandments

1 People with disabilities are people first and foremost.
2 Having a disability is impractical.
3 Having independence and control over your life is important.
4 A small detail often determines if an activity can be performed independently or not. Fix the detail!
5 Assistive technology DOES NOT create social isolation.
6 There is nothing wrong with coming up with assistive technology that no one uses. Technology has a way of bringing forth and defining the real needs. Ask what was wrong with the aid or – if used – what was right.
7 Don't say that something is impossible before you have talked to an engineer. If the first one says it won't work, get a second opinion.
8 Contemplate the things you think are impossible. A lot of them can, in reality, be solved!
9 To be unwillingly dependent on another person is harmful.
10 To be willingly dependent on another person is love.

© The authors and Studentlitteratur

5 Stress radiation?

Bodil Jönsson and Ingrid Whitelock

Could there be functional reductions that were hardly noticed in 1950 but that now cause significant problems? Are today's stress-related illnesses one such example? Are they a sign of the times? Has our modern world created a new and relative functional impairment for people who find it difficult to maintain a reasonable rhythm and pace in their lives when they are exposed to a constant bombardment of stress? It's not an impossible thought that changes in the spirit of the times, if pushed to the extreme, can generate new disabilities. And if there is no help available for pacemaking from assistive technology as an external support that enables people to maintain a reasonable rhythm and pace in life, such a disorder can lead to poor health and illness.

A day in November 2000

Ingrid Whitelock

I was looking forward to 2000. Such an even and fluid number. I liked that. It was the same feeling I had as a child when it was finally my turn to erase the blackboards at school.

I also preferred saying "two thousand" instead of "twenty hundred" because there is such a world of difference between the two of them. "Two thousand" sounds elegant and clean. "Twenty hundred", bulky and awkward, as if a piece of dough were falling out of your mouth when you pronounced it. It was the same in all dialects, with the possible exception of the news broadcasters'.

© The authors and Studentlitteratur

I, a person

I cannot, in all honesty, say that the year started off well. My divorce had just come through after a short and stormy marriage. Our daughter was just over two years old and I was working full-time plus as a commercial producer for a large TV broadcasting company. It was stressful being a middle manager at a TV station working on a sales campaign, supposedly confidential, but for which facts and rumours abounded. Poorly motivated changes washed over the production division and everyone tried to adapt. A wrenchingly nervous atmosphere prevailed in the workplace.

While all this was going on, I closed a deal on a terraced house in need of considerable renovation and immediately moved in with my daughter. Why not?

Have you ever put fuel tablets in one of those small steam engines for children? Then you know how the engine starts out, sluggishly at first but soon working itself up so that it runs like crazy, grinding away at an unbelievably high tempo before it suddenly stops after only a few revolutions. During that unholy year of 2000, I behaved as though I were propped full of fuel tablets; the wheels were spinning so fast you couldn't even see the spokes. But I didn't know that at the time.

A November morning 2000

My sense of hearing no longer sleeps. It registers each and every click. This means that I think it is time to get up every time I wake during the night. I immediately sit up and stare nervously at the clock. I always feel as though I have forgot or missed something.

I get up between 5 and 5:30 in the morning and get dressed. Then I feel more at ease and can lie back down on top of the covers for a while. I try to think of solutions for everything I have to do during the day, both at home and at work. The problem is that I lose a thought as quickly as I think it; if I don't write it down right away, it's gone forever. The feeling that I had a hold of something remains in me for a long time, but the "what" and "how" of it has disappeared. It puts me in a state of anxiety.

At 6 o'clock, I sit at the kitchen table and write down on post-it notes the things I have to remember. Even such details as the times

 © The authors and Studentlitteratur

when I usually start and finish work. Since on several occasions I have actually got my daughter and myself up and ready to go to nursery school and work on a Saturday, I always check text TV to see what day of the week it is.

For some reason, it seems simpler to make up a little breakfast tray for the two of us and take it upstairs to the bedroom. In that way I can clean up everything right away and all that is left is the tray and two cups. Then I wake my daughter and we have a peaceful and quiet time together, a moment when I feel good, when I feel as though I have in some way caught up with myself.

Several strategies

I am always able to find my way to nursery school in the morning, and I always manage to get to work on time, but in strange sorts of ways. It feels as though I lose a good portion of my consciousness when I'm behind the wheel. I suddenly find myself driving towards the city centre and come to of my own singsong voice asking, "Well, where are you going now?"

If I walk and move quickly all the time, it feels right. I neatly stick the notes that I have written on the edge of my computer screen and on my desk. Then I start to deal with things in an effective, efficient manner. The system functions well for practical and physically substantial items such as writing a script or a production order. That still works; it's still there. It's a lot worse when it comes to telephone conversations.

To be honest, I do not remember if I have made the call or not. I stare alternately at the receiver and at the notes with names and numbers, but have no memory of a conversation. This is when my creative abilities are put to the test. Writing a script is a piece of cake compared to this. So I grasp the receiver, dial the number and ask to speak to so-and-so. And then I play it by ear. Does it seem as though I have already spoken to this person today or is it as new to him as it is to me?

I dodge and shuffle with clever small talk until I feel certain and then ask, for example, to confirm what we had previously agreed upon. That is where the gaps in my memory are to be found. Of course, I don't always succeed and am sometimes exposed, but no

© The authors and Studentlitteratur

one says anything directly and no one objects when I repeatedly and resolutely explain how important it is to get it right. What I do remember, though, I am quick to add.

What are the others saying?

My bosses are never on my back because I get everything done. Being able to complete a project and file the report goes on automatic pilot. I can still do a good job of spouting ideas, if somebody else carries them out – that's something I just can't manage. Finishing things up, that is – I come, I see, I get things going … then I drop it.

The cameramen and editors are experienced fellows (I work only with men in a world dominated 90% by them) who can easily see the project through to the end with just a question or two, if I tell them I have a lot to do. My job is to make sure they meet the deadlines. But now in November, they are starting to grow tired of my perpetual excuses that I don't have the time. They are overloaded too. And they are on to me as well. I have aimlessly wandered about down in their room and passed out the same production order to the same person several times. I forget what they say a second after they have said it. And I repeat myself so often that they have started calling me "Can't-remember-a-Shitelock" (pronouncing "shit" in the northern English way by drawing out the "i" so that it rhymes with "white"). Quite original in its own way. "Whitelock Shitelock," I hum as I go up and down the spiral staircase between the two floors.

Then I miss nursery school

One evening I put my daughter to bed, read a fairy tale, turn off the light and sing a song. We both fall asleep. I wake up with a start. Damn! It's 7.30 and we've overslept. I force her to eat a little breakfast and quickly dress her; we rush out to the car in the cold November darkness. She complains the entire way that she is really tired and wants to sleep longer. I skid to a stop in front of her nursery school, but when I go to open the door, it's locked.

I am totally confused. What's the matter? I look at my watch and it is exactly 8, but it's dark inside. Then I call her father.

 © The authors and Studentlitteratur

"Do you know if nursery school is closed today?"

"Are you drunk?" he asks.

"What kind of question is that?" I snap, "It's 8 o'clock but the nursery school is closed. It's dark inside and I have to get to work!"

"It's 8 o'clock in the evening. Didn't you know that?"

Like a stuttering idiot, I lie at first for some strange reason and then just admit that I woke up confused. It's all so embarrassing. No wonder my daughter, who had only slept for 40 minutes, was so tired.

Could something be wrong?

As I drive home again, I very slowly start to suspect that things are not quite right with me. But I don't give in to those thoughts. When my daughter has fallen asleep again, I stand in front of the bathroom mirror and look at myself. That which in September started out as a cold sore and an irritating itch close to my nose has spread so that I have small sores all over. None have healed properly and my face looks like a map of Europe in different shades of pink and red. The cough that hung on after a bout of pneumonia and was supposed to clear up on its own according to the doctor is still there. I've just grown used to it. And then I'm only sleeping three, maybe four hours a night.

The anxiety starts sometime around lunch and intensifies during the afternoon, hitting a high point in the evening. When I try to fall asleep, the heart palpitations are so loud that if my ear comes in contact with any kind of material, it pounds unbearably. I take some of the sleeping pills the doctor prescribed. I'm in a sitting position, leaning up against the wall so that I will drowsily glide down when I fall asleep.

When I answer the phone at work, I no longer remember my name, or where I work. So I say, "Hello," instead with my most charming voice to try and cover up and get things going from there.

I'm late most of the time getting home. I lose my way so easily and get turned around in the roundabouts. I just drive on by instinct. Does it feel like the right direction at that moment? On a few occasion I arrive at home without my daughter and have to go back for her. Emotionally, that is absolutely the worst.

© The authors and Studentlitteratur

End of the beginning

As we approach the end of 2000, I am ready to call it "two hundred". Two weeks later I am on sick leave for an indefinite period due to exhaustive depression, or if you prefer, burnout. My life as a speeding, fuel-tablet fed steam engine finally came to an end. "I stopped pushing myself, swore off drinking, smoking and heavy eating, and in fourteen days I lost two weeks." Joe E. Lewis

Three years later

Bodil Jönsson

Pacemaking is a research programme at Certec, which is Lund University's Division of Rehabilitation Engineering Research. (See: www.english.certec.lth.se/pacemaking/.) A part of it involved a group in Jönköping, Sweden in the spring of 2004. And there, among 45 other executives and middle managers, all highly involved in stress-related ill health (their own or their co-workers) sat Ingrid. Still unable to work, still having difficulties finding her way in everyday life, tired of telling her story over and over again about how it feels, ready to find something new, something to hold on to, a platform to swing from.

Ingrid had sought out and applied to a programme that was essentially internet based and that I not only initiated and lead, but was actively involved in at every level, down to commenting on the smallest contribution made to the virtual discussion forum. I wanted to read, I wanted to know, I was and still am curious and deeply engaged in this issue. In a situation where governmental agencies, workplaces and the healthcare system were at a loss when faced with the rapid growth of stress-related ill health, my own point of departure was that you perhaps should ask the people themselves. Is it possible that we "know" much more than we think we "know"? And if we are just able to become aware of what we know, can we perhaps do something about it? The growth of stress-related poor health was actually something we were all a part of. We were all there; even those of us who were not yet on sick leave perhaps understood a lot based on our own experiences. But it was a

 © The authors and Studentlitteratur

matter of getting people to talk or write in a way that the material was freely accessible, could be structured, could be responded to and could result in change.

I developed a net-based concept with thought-provoking content, feedback, structure and interaction. The intention was to inspire people to the point that they simply couldn't resist participating. And to then have access to good feedback opportunities – to be able to show who said what and when, to be able to provide structure and context and connect people so they could continue sharing the ideas they had in common.

In other words, something quite simple and straightforward. Yet, at the same time, quite difficult. Because its success depends entirely on the participants' feeling that they are getting something out of it, and that they are improving. Many of them, like Ingrid, had been burdened with years of isolation, uncertainty as well as distrust and accumulated hope. Not surprising, then, that profound existential questions surfaced so easily.

What I brought to the programme was my own view of stress as a disability – a disturbance in a person's relationship to his or her surroundings. Disability research theories and methods were part of my basic view of things, along with a decade's worth of reflection and writing about people's relationship to time and rhythm.

The situated

It makes a big difference when people write, expressing themselves in their own terms. The design research I represent is based on being *there*, that you have to be *situated*. The solutions that arise become an interpretation of the actual problem and elucidate it in an applied form in its own language. It is based less on general words and interpretations and more on people, acting from concrete examples, being able to show one another what they mean.

At the same time, the situated isn't enough – it is a necessary but not sufficient condition. You have to be able to see action in context through the use of structures. During our spring in Jönköping, I wasn't the only one who became so well acquainted with the participants to the point that I really felt I knew them as individuals – they were also able to see each other in a way we seldom do in real

© The authors and Studentlitteratur

life. The internet is quite revealing. In many aspects, it was a sort of coaching I was putting into practice, in a form that resulted in the participants also coaching one another.

An entirely different kind of information was collected than what usually comes out of traditional, formalized studies. Individually based experiences, needs, wishes and dreams were brought to the fore. In context. In place. I structured this highly personal information so that previously unknown patterns emerged and so that discrepancies became apparent. All of the material, both in its original form and in its structured form was openly accessible to all the participants.

The situated, that which is not obviously generalizable but quite close to people, has a special function when it comes to stress. Stress-related poor health is at an all-time record high in Sweden and by far surpasses such countries as Denmark and Germany. It is also well known (but less spoken of) how the number of people on long-term sick leave in general, and due to stress in particular, varies considerably across the country. *Society* isn't one entity but many, and the community that people relate to is definitely not the global one, or the national one for the most part, but primarily the local one, on the verge of the personal one.

This is one of the reasons why it can be so difficult on a general level to get at stress-related poor health. It is not *there*, at the general level of the National Social Insurance Board or the Ministry of Health and Social Affairs: it is to be found in its context. Nor is it only connected to the individual who is experiencing it; it is a part of her in her context.

Meaning

People are always looking for meaning. If we find meaning, conditions change for the better; if we don't, and are unable to rely on one another, the opposite happens. The effects of meaning can be just as strong or even stronger than the effects of what is rational and observable.

In the human sector, the one in which people work with and for other people, professionally or voluntarily, it is particularly important that we look for the effects of the search for meaning. In the

 © The authors and Studentlitteratur

human sector it is a matter of at least two parties who are searching for meaning, and the meaning they are after isn't necessarily the same. Refusing to admit and take the existence of the search for meaning into consideration can result in a double failure in the human sector.

Relationships

While I am writing this and thinking of the Jönköping group, I realize that I did indeed really like them. And still do. I like Ingrid, of course. Very much. I smile, too, when I think of O. who explained how he had a red sticker on the edge of his computer screen: "Breathe," it says – and so he remembers to breathe. And of B. who now finally, thanks to the Pacemaking way of thinking, can explain to her ageing mother how it has come to be that we nowadays can be so tired without "doing anything". Of C. who had created his own life style and stood for it and its values. I will never forget her story of what her maternal grandfather had given her and what she herself would like to contribute. Of N. and Ch. who could relate just as dramatically as Ingrid does in this chapter about all that happened to them before "The Big Crash".

But didn't you notice that something was wrong?

The warning signals were there, loud and clear, but it was as though Ingrid, N., Ch., and many others were unable to hear, unable to see, and were instead mentally deaf and blind to all the exceedingly clear signs of overload. I have witnessed all of these stories of losing a sense of time, muttering one's name over and over in order to remember it, going round and round in the roundabouts, double vision, heart palpitations. But you must have noticed something was wrong?

"Noticed, yes. But understood, no," was the answer. And the stories are so much alike that you could put carbon paper between them. These extreme accounts are hardly situated – they are more like templates with sharp, clear edges. Body therapists relate how easily they can diagnose how sensitive or insensitive a person is to

© The authors and Studentlitteratur

signals from his or her own body. People suffering from exhaustive depression appear to have a strikingly low degree of sensitivity for overload, so strikingly low that it could be included in the actual diagnosis.

Does insensitivity also have prognostic value, i.e. has it been there from the beginning and could it have been used as a warning? Or is it acquired though learning? Stress is very much a learnt behaviour, but we can be differently predisposed to learn to be stressed.

Poor health as a healthy sign

Poor health can be seen not only as a sign of illness but also as a sign of health. At last there is a reaction! At last, things can start to change! This applies on the individual level. But it also applies on the workplace and societal levels. I would welcome systematic studies of what would be illuminated if you proceeded from the supposition of poor health as a sign of health.

How did it go in Jönköping?

The programme lasted close to six months – and in that time we came a long way. There were many who were deeply affected. Yet the "only" help we had were words and a simple but effective internet tool. It is possible to clearly differentiate three key elements:

- *Examples, examples, examples*: one of the keys was to never be allowed to express yourself in general terms but to always try to give an example of what you meant.
- *Unifying concepts*: I was the one who established the reference points, i.e. concepts under which the examples could be grouped. The concepts with their associated examples guided the participants along the path to continued improvement.
- *Conceptions of how things are related*: just as the examples need to be consolidated under concepts, so must the concepts be related to one another coherently. This helps participants put their lives back in context and give it meaning.

For people suffering from exhaustive depression, most things in their lives are out of context. Their bodies do not react coherently

 © The authors and Studentlitteratur

and they are mentally pulled in different directions. In that situation, being able to see clearly how things are related provides such a positive lift.

And it really lifted in Jönköping, then and now. Many of the participants are still in contact with me. And with one another: a third meet regularly, on their own initiative. There are many happy endings. But let's get back to Ingrid. Where did Pacemaking take her – and how did it happen?

Three–four years later

Ingrid Whitelock

Since I managed to miss the champagne party of the 1980s, it is interesting now to be part of something that is considered a trend, this time for those with burnout. That's the diagnosis I have. With unbecoming wrinkles on my forehead, I read articles in the morning and evening papers that question the degree of truth of all these people on sick leave for this reason, how to detect those who exploit the diagnosis and how shocking it is that more and more companies offer dubious treatments for stress. At the same time they publish advice on how you can avoid ending up there in ten easy steps.

But it's no party being on sick leave for burnout. For the three years prior to January 2004, I was at home for only about one and a half months. The rest of the time I completed four weeks of treatment for stress, earned a European computer driving licence, participated in a nine-month job training programme at a publishing company, an even longer one at the advertising department of a health food company, more computer training, translated material to English, attended a job-seeking course, lectured on what it is like being burnt out, and a little more computer training – among other activities. The computer courses seemed to be the Swedish equivalent to the British "cuppa tea" – used to fix just about anything.

My greatest fear was that I would live up to the image of the typical, lazy burnout patient, so I threw myself into all the measures offered. This resulted in a certain amount of wear and tear because of all the new situations, new places of work, new routines and new

© The authors and Studentlitteratur

people. Everything that happened was more of the same. I wasn't getting any better even though, propped full of medication and their side effects, I picked my way through life like a mechanical wind-up toy chicken.

I was accepted into the programme

One day a psychologist called from the Working Life Services where I was being evaluated and said something that made me cock my already sensitive ears.

"There's a project starting up in Jönköping called 'Pacemaking' that I think you could get a lot out of," she said. And that's how it came to be.

After much emailing and many phone calls, I was accepted. So, freshly showered (not something you do every day with this diagnosis), I showed up at the introduction full of expectations.

My expectations were based on what I knew about Bodil Jönsson from her books and what I had seen of her on TV. At the same time, I thought it was a topic for which it seemed impossible to forge a union between knowledgeable people from the "outside" with the needs and insights of those on the "inside". Everything I had read and heard being discussed on radio, TV and in the papers indicated that – so what could I dare hope for now?

I don't intend to try to explain how it all happened in practice, because I don't really know. I read a lot, thought a lot, gave a lot of examples and stumbled from one clarity to the next. I started to see my situation in a different light because Pacemaking gave the burnout phenomenon intellectual credibility. Suddenly, it became a worthwhile endeavour on which to expend mental energy. In the articles I read online, there were entirely new concepts, placed in enlightening contexts and with ideas I had never been even close to thinking before. There were other ways to look at things and I was filled with hope and possibility. Just think if it could be like that – and what did it mean for me?

I utilized the project on an entirely personal level, eager as I was. Great acceptance, less shame, broader views and ways of thinking and a new set of concepts made previously blurry thoughts tangible and comprehensible; it helped me to understand and forgive myself

© The authors and Studentlitteratur

and my situation. Maybe I wasn't just a weak little nobody who couldn't take the pressure. Maybe I was part of a bigger picture.

Sometimes I quietly reflected: "Why didn't I come up with this myself? Now, when I read it like this, it seems to be so obvious."

But it was a long process, no quick fix, no evening paper supplement full of advice or a monthly magazine with ten easy steps. Every assignment involved reading, and the related questions required that you reflect and in the process arrive at constructive answers; you couldn't get away with general criticism aimed at society, the workplace, the boss or mum. And you had to give examples.

The example requirement forced me to be very concrete. And I think that when you have to define a problem in that way, when you have to put it in words, explain the context, that is when you can see a solution. Feedback from Bodil was what pushed me even further, gave me new insights and made me feel that I was being heard and seen; that I was being taken seriously. I wasn't just armchair philosophizing. I was progressing and as a result, I tried to give even more.

After Pacemaking

When the group completed the project, a hallelujah atmosphere prevailed, albeit a low-key one. We were all deeply involved and already applying what we had learnt, both in the workplace and on the personal level. We felt as if we had arrived at the awareness ourselves, that we actually knew a whole lot about the problem and the solutions. Pang! Boom! It worked in reality.

Many months have passed since our Pacemaking project ended and I feel how difficult it is to describe the great change that has taken place. What was it that happened to me during those six months? How did it come to be that through Pacemaking, I actually "thought" myself to mental well-being? And that I have been able to stay healthy?

I can't tell you exactly how it happened, but it did. So it appears to be possible for those on the "outside" to understand those on the "inside"; that is really, truly important.

© The authors and Studentlitteratur

6 An involuntary risk taker

Camilla Nordgren

Reminiscing with friends at my high-school reunion, it came up that I had travelled around as a backpacker in Asia. A former classmate's reaction to my story was that she would never have dared to do so. I wondered if she meant she would never have done it if she, like I, sat in a wheelchair or if she, as a walking and standing person would never have dared. I hadn't really thought of it in those terms before. If there was anyone who shouldn't have taken that risk, it would certainly be me with my physical limitations, wouldn't it? Her spontaneous reaction got me thinking of the kinds of situations I put myself in that I assume I can manage when others, who are in full possession of all their physical faculties, choose to forgo.

Travelling companions

I was around 20 when I decided to backpack. All my friends were doing it or were going to do it and it was one of those things that everyone was talking about. I had never gone off on my own into unknown territory without having some idea of what I would encounter. I defended my own and everyone else's arguments against this rather foolhardy project by simply saying that if it didn't work out, I would manage to get home one way or the other. And return home I did – many experiences richer. Of course there were some close calls, but nothing insurmountable or too dangerous.

I never considered travelling on my own. It seemed too difficult. It was essential that my travelling companions felt secure and that I could count on them. I had only vague notions of what it would be like getting around in a wheelchair, finding accessible toilets, taking public transportation. At the same time, I had no desire to consider all the eventualities that might cause difficulties; that

© The authors and Studentlitteratur

would completely discourage us from hitting the road. The desire for adventure was stronger than the fear of difficulties. It is impossible to plan or imagine what could happen in time and space when you set off on a long trip like that. We never spoke to any great extent about what my companions thought about travelling with me, before or after the trip.

If I say "No" one more time …

The proverb, "She who travels always has something to tell," is valid for my entire social existence. By participating, being there, being seen and heard, I am included. I think in particular about my college days in Lund, when lots of time was spent partying and socializing, and when the greater portion of my social network was established. When something was going on, I always tried to find out and anticipate where we were going to be, where we were going to move on to, who was going to be there, etc. It was an obvious attempt to determine if it was going to be too much trouble, too insecure or too difficult. Essentially none of the student settings were wheelchair friendly at the time. If I thought it was going to be too hard, I declined. Every time I did so, though, I knew that it wasn't just that party I was missing out on, but all the talk about it in the days that followed when we would get together. This included new activities already planned without my knowledge. If I wasn't present where the action was, I missed it all.

I wasn't always honest as to why I decided not to go. Having to motivate my decision with excuses like poor accessibility or that there was too much running around was tedious. My friends may have figured it out themselves; we never went any further into it. Perhaps the focus of our relationship would then also have shifted to my disability and not to me as a person. Even though I knew in my mind that they were all willing to "help out", it wasn't on those terms that I wanted to join in. And in the laughing, talking and hubbub of the party, people could disappeare – even the ones that I was counting on. At the same time, I didn't want to, nor could I refuse too many times. I might no longer be included, a risk I absolutely didn't want to take. So, many times I threw caution to the wind.

© The authors and Studentlitteratur

Risk and security

When I am in adapted, familiar settings, I am secure in my actions and feel safe. I have considerable control over myself and the space I am in, and not much is left to chance. Through the years, I have learnt to judge the risks and the situations I put myself in, or am put in, as well as the people I am with then and there. I am highly aware of the equipment I have at hand, and what those around me have, on which I can depend in a crisis situation. I never go to the cinema, a nightclub, stay at a hotel or anything like that without being aware that I am choosing the activity ahead of personal and physical security. In spite of all the fine words and publications stating that the personnel are responsible for evacuating/helping customers in an emergency, it is quite evident that a person in a wheelchair is far, far down on their list of priorities.

When something unexpected and difficult to manage arises, it is clear that my margins are reduced. It is not an issue in the secure settings where I normally spend my time, but when I am exposed to an unexpected event, it becomes quite clear. Flexibility is minimal.

A couple of examples can serve as an explanation.

When boarding an airplane, it has been the routine in Sweden for the last few years that I should sit in my wheelchair right up to the door of the plane if the route is accessible. There I am transferred to a chair with wheels, which is narrow enough to roll down the aisle. Currently, at Sturup/Malmö Airport, it is the Swedish Civil Aviation Administration that performs this service. I have never really understood where I am supposed to sit in the plane. It is unclear if it depends on the airlines, the type of plane, and/or the more or less experienced or pragmatic flight attendants. On domestic flights, I am often seated by the window with the explanation that I cannot sit in an aisle seat because it will obstruct other passengers in case of an evacuation. On the days when I am up for a discussion, I question this of course. If an evacuation should be necessary, it would be of utmost importance that I be supplied with whatever equipment necessary so that I could, on my own, get to the emergency exit. I am then informed that it is the airplane personnel's responsibility to evacuate me. When I ask how this will be put into practice and why I should place my life in their hands, I am told that those are the regulations. I am never allowed to sit at an emergency exit; pre-

© The authors and Studentlitteratur

sumably with the same argument, that I would obstruct other passengers. When flying on a foreign airline with the rest of my family, we are sometimes separated. Once, I was placed in the back of the plane and my husband and son somewhere else. This was also according to "security regulations". In this case, they chose to strip me of another of my "tools", namely my reliance on those near and dear to me.

Most modern cinemas have steep inclines. Previously, the side aisles had a sloping floor. Steps and landings have replaced these. They often have one or two places for wheelchairs and that is where the cinema personnel want me to sit. If I protest loudly or meet a sympathetic staff member, I can actually choose the row I want to sit in, but it requires that I get assistance in transporting myself there because of the steps. If I move from my wheelchair to a stationary seat, the personnel want to remove my wheelchair from the aisle or theatre, with the motivation that the aisles must not be blocked in case of an evacuation. I am thus denied any possibility of getting myself out of the cinema on my own. I have even been refused a ticket because there were already two people in wheelchairs who had purchased tickets to that showing. The explanation was that the fire brigade did not allow more than two people in wheelchairs in the theatre at a time. The fire department obviously has no such regulations for other disorders such as anxiety, hysteria or heart disease, which can be triggered by stress.

Newly constructed cinemas are required by law to be accessible. This is achieved by arranging some kind of predefined wheelchair location. It doesn't appear, though, that the accessibility requirements include the emergency exits. The cinemas have installed ramps and elevators so that I can easily enter, but then put in steps at the emergency exits making it hard for me to get out.

I have encountered the same treatment and approach several times in nightclubs. The guards at the door have refused me entrance because they are unable to take responsibility for my safety.

© The authors and Studentlitteratur

Children

As long as I didn't have children, my choices only had consequences for me and possibly another adult. With two children in my life, I have to take even greater caution and more thoroughly attempt to determine how great the risk is and what we will miss if I decide to forgo the visit or event. Now, I not only have to deal with my own disappointment, but that of my children. It is easy to give in to please them for the moment, and decisions often have to be made in double quick time. I have to determine if I can put them in the position of also automatically landing further down on the list of priorities in my company. Perhaps my parental responsibilities are broadened to include teaching them at an early age to judge and act for themselves.

My children place their total trust in me. It is terribly frightening knowing that I may not be able to handle a situation and that they may be harmed. During the constant stream of news after the tsunami in Asia, our five-and-a-half-year-old son reflected on how he would have reacted if we had been there. "Mamma," he said, "I would run as fast as I could and then swim really fast and save your life." I felt it was extremely important to respond to this spontaneously expressed reflection. How much concern for my safety can I place on him?

An involuntary risk taker

For me, choosing an activity often means taking risks. Forgoing the activity doesn't only result in missing an isolated event, but the experience of it and the social interaction that is included – and those happen to be two of the things I value most in life.

© The authors and Studentlitteratur

7 In the kingdom of the blind is the one-eyed person king?

Arne Svensk

The chapter title is a slight modification of a famous saying of Jean Jacques Rousseau. At the end of the 1990s, I used it without the question mark in the courses I taught on rehabilitation engineering at Lund University's Faculty of Engineering. The point was to problematize the World Health Organization's (WHO) concept of relative disability that was current at the time. Instead of seeing people's abilities and shortcomings as static, I hoped that the students would start reflecting on issues concerning handicapping versus accessible settings.

So unimaginative

It took a few years before I realized that, if anything, the quotation expressed the opposite of what I really wanted to say. In the kingdom that blind people would build, there would be no airplanes, cars, traffic lights, motorways, houseplants, Venetian blinds, lipstick, paintings or other phenomena that require a person to see.

Instead, they would make use of smells, tastes, touch and hearing input as sources of information and navigational support. In such a society, it is not obvious that the one-eyed person would have any advantage with his sight.

One reason why it took so long for me to grasp the obvious can be that I saw before me a copy of the society I lived in, the only difference being that the people who were to inhabit it could not see.

Another explanation can be that I, like others, have a tendency to regard even the most complex phenomena as one-dimensional. We

© The authors and Studentlitteratur

come to the same conclusions as the pigs in Orwell's *Animal Farm*, namely that "Four legs are better than two," or in this case, that two eyes perceive better than one while one eye perceives better than none [Orwell, 1945]. Many pedagogues I meet often refer to Kierkegaard's well-know formulation: "In order to help someone, I certainly have to understand more than she does, but first and foremost, understand that which she understands. If I am unable to do so, it doesn't make any difference if I know more." But what does it really mean to understand *more* than she does and to know *more*? If we choose instead to discuss in terms of "differently", we avoid the "good-better" comparison trap.

There are so many ways

A man with autism whom I became acquainted with many years ago, used parts of musical compositions to express to people how he felt. Was this somehow inferior to what most people do, i.e. turning up the corners of their mouths, raising an eyebrow or sighing deeply? Probably not. Just considerably more unusual than the traditional ways of expressing feelings.

Taking things for granted hinders us not only from discovering problems but also from coming up with creative non-traditional solutions. Just the fact that almost all societal information is text-based should make us react and do something about it. New technology, after all, has created opportunities for presenting information in such a way that it is accessible even for those who are unable to read or understand language.

New glasses

If you take what are thought to be self-evident phenomena and twist and turn them, you can often see something new. Does time really have to be measured with clocks that have hands revolving around a face with numbers on it? How do you know when evening stops and night begins? How do you define with words what the

 © The authors and Studentlitteratur

difference is between dawn and dusk? How long is "a while" and how many "seconds" make a "moment"?

Time and again I realize that I have great difficulties answering my own questions. How hard would it then be for people with cognitive limitations? Many of their problems have less to do with themselves and more with how the people in their surroundings try to force them into a system of thinking that they are simply not suited for. A considerable amount of imagination and a desire to question the obvious is required in order to adapt the surroundings instead.

Different ways of measuring time in

If you start from the ground up, there are three simple astronomical ways to measure time: the earth's rotation around the sun, the moon's rotation around the earth, and the earth's rotation around its own axis, i.e. year, month and day. All other forms of time measurement are human inventions. We have created artefacts for measuring time. This human creation does not need to remain static but can be changed and simplified so that is suits many different people.

During the more than ten years I worked in special education, I participated in daily morning assemblies that ended with the teacher using a calendar to name the month, the day of the week and the date. Among the pupils there were, of course, some who after a few terms began to understand that there was a difference between "March" and "Wednesday", but others seemed just as surprised every time. The entire operation was more a form of conditioning than understanding.

But the power of ingenuity can triumph when conditioning fails. Such was the case for the man who had struggled every day to learn the days of the week during the time he spent in special education classes while growing up. Each of his teachers during those 16 years had tried without success to get him to understand "the system". Finally as an adult he found his own way of determining if it was a workday or not. Early one Saturday morning, a colleague saw how the man came dashing from his flat down to the bus stop. When he

© The authors and Studentlitteratur

got there, he stood and looked at the bus that was on its way in, but when it was about 10 meters away, he dashed back up to his flat again. The assistant was surprised at what she had seen and asked the fellow later that morning what had happened.

"What were you doing down at the bus stop at 7 this morning?" she asked curiously.

"I wanted to see the number on the bus," he answered.

After talking about it for a while, she understood that he had run down to determine if the bus number had one or two digits: On workdays it only had one, but on weekends it had two.

This man was not at all interested in the actual names of the days you worked versus the days you were free. The most important thing was that he was able, on his own, to come up with an easy and reliable means of determining which was which. You may have your own opinion about this unconventional and impractical "bus calendar", but in comparison to all the others, it was his own invention and it worked for him.

Being able to anticipate

I have met many people with developmental disabilities who spend considerable time searching for patterns that enable them to interpret and anticipate different events. At a group home, there was a young man who was usually in a good mood but every once and a while was subject to inexplicable fits of aggression. In that frame of mind, he could vent his frustration on anything or any person that got in his way. Even though I saw him every day, I was unable to discover a pattern until I mentioned it to a colleague who said, "Haven't you noticed that he gets really angry every time you take your rucksack with you when you go out?"

He had realized, in other words, that when I went out the door with my rucksack it meant that I was going to be away considerably longer than if I didn't take it with me. After further discussion, it became apparent that he was particularly clever at interpreting other patterns in the group home. He knew the staff members who stayed out a long time when they smoked because they had a lot to talk about, and those who didn't because they didn't have much in

 © The authors and Studentlitteratur

common. He utilized the subtle sounds and signs in the setting to "read" people's intentions and actions and he was also able to arranged things in such a way that they functioned as indicators of what he wanted to communicate.

Trying to control

Every morning before breakfast, he went up to the large notice board that had pictures of the assistants who where working that day, evening or night. These pictures were important for him as well as all the others who lived in the group home because they provided structure. Unfortunately, there were many staff members who forgot to tell the people who lived in the group home that they were going on holiday, taking a leave to study or for some other reason were going to be away for a long time. This was frustrating for the young people living there who looked forward every morning to seeing the photo of a certain staff member on the schedule.

To improve the information, the personnel group thus chose to design a notice board where they could post photographs of all the co-workers who were absent for different reasons. In that way, the residents could see that Martin, for example, was away but not gone forever and would come back when his leave was over. For all who really liked Martin and found security in his presence, this kind of information was consoling.

After the introduction of the on-leave notice board, it was studied as thoroughly as the one with the pictures of those who were currently working. Quite early one morning, this young man quietly and carefully left his room and went out into the kitchen. After a few moments, he disappeared back into his room with a smile on his face without waking the others. What had he done? Well, he had moved the photograph of Axel from the current work schedule to the on-leave notice board. In this way, he showed demonstratively that he did not like Axel – and did so in a way that no one could misunderstand.

© The authors and Studentlitteratur

Design for cognitive assistance

The American psychologist Donald Norman names three forms of thought support we can use when our own mental powers are not sufficient:

1 We can co-operate with other people.
2 We can exploit the information present in the environment.
3 We can develop and use tools of thought – cognitive artefacts.

People are best suited to provide certain kinds of assistance, especially in situations that require insight, flexibility, creativity and social competence. For other types of support, external cognitive artefacts may be better suited, especially in situations that require fixed initiators, inflexible patterns, stability and continuity. Everyday life involves many routine tasks that some people would rather perform with technical than with personal assistance.

Artefacts have the advantage of not disappearing as easily as people. Unfortunately, the knowledge gained by the personal assistants who work with this population is lost when they quit. With today's high staff turnover in the care giving service sector, this can have serious consequences for people with developmental disabilities. They risk, among other things, losing significant portions of their own life histories forever.

Cognitive artefacts can convey one human's experiences to another over time and space in a very tangible manner. An assistant who has had a close relationship for many years with a person with cognitive limitations has, due to a plethora of successes and failures, succeeded in developing methods and technical solutions that work for that person. In this way, the assistant has also created the conditions for future assistants to use the artefact as a means of guidance. The philosopher Bruno Latour speaks of technology as "society made durable", while Donald Norman expresses something similar when he speaks of "knowledge in the world" in contrast to "knowledge in the head".

© The authors and Studentlitteratur

Making the familiar strange

It is broadly underestimated how artefacts, the exterior courses of events, and even the entire world around signals to us and exert power over us – all the time. To understand how uniquely people with different cognitive abilities can understand this requires a good measure of curiosity and imagination; a desire not only to try and teach someone else more and more about prevailing perceptions of the world (to make the strange familiar) but to also turn, twist and re-examine that which most of us take for granted (to make the familiar strange).

One way to get at the kinds of cognitive assistance that will work in meeting a person's needs, wishes and dreams is to try to design it technically. Attempts at design force us to an intimate understanding of what the problem is, and also an intimate understanding of what is useworthy among all the possible solutions. To this is added the fact that it is much easier to customize technological support than to customize human assistance.

© The authors and Studentlitteratur

8 Mother Sweden's health

Gunilla Brattberg

If you take a cross section of Swedes and ask them how they feel, you will find that 66 percent of all adults between 18 and 84 years of age have recurring pain. Four out of ten have had considerable pain for more than 6 months, pain that can be compared with the stiffness and aches after exercising, or worse. For many of them, pain is a disability in their everyday lives. Twelve percent are so handicapped that they are in need of some form of treatment. Pain is probably the most common disability – but it is not regarded as one by society.

The Swenson family

Sofia, Sara, Sonja and Selma are from different generations in the Swenson family. Many Swedish families will see themselves in the story about the Swensons.

Childhood pain

Sofia is a nine-year-old schoolgirl. She has headaches. In her class 42 percent of the girls usually have headaches. In teenage girls, seven of ten have headaches. Six out of ten have back pain and five out of ten have both headaches and back pain. Every eighth teenage girl reports both protracted headaches and prolonged backaches. Social, psychological and emotional factors play a greater part than physical ones. If Sofia does not receive help for her headaches, there is a great risk that she will develop long-lasting pain as an adult. There is a clear correlation between the presence of back

© The authors and Studentlitteratur

pain and headaches between 8–14 years of age and the incidence of pain at 25 years of age. In addition, because Sofia is a nervous person, the connection is even more pronounced.

When Sofia started school, she was given a bus pass. She walks in the opposite direction from school to reach the bus stop. The bus ride takes more time than if she were to walk, but her friends take the bus and that's why Sofia does. Sofia, her mother and the school authorities do not take into account that movement is good for our bodies and that Sofia, through regular physical activity, could perhaps prevent chronic pain from becomes a dominating problem for her as an adult.

When her mother was pregnant with Sofia, she was called in for routine check-ups at her local prenatal clinic. When Sofia was an infant, she was called in for routine check-ups with her mother at the local infant and children's clinic. As Sofia was growing up, she was automatically reminded to come in for her vaccinations, check-ups, dental appointments and more. The local healthcare authorities sent her reminders and made sure that Sofia received the health protection and help she needed. As long as you are healthy, society takes its responsibility and sends notices in the mail when it is time to come in. We are used to this in Sweden. When you are ill, have pain and other complaints, you go on your own to the doctor's and expect to be cured.

Adult pain

Sara is Sofia's mother. She is a thirty-year-old single parent, holds down a job and runs the household. When Sara was entering the labour market, she was told that girls were quite capable of managing male jobs. It was even desirable that young women applied for traditional male positions. It usually worked out just fine. Many traditional female jobs were actually heavier than male ones.

Interest, education, training and job opportunities are often the determining factors when choosing a career. But how many consider what their bodies are able to manage? A professional athlete trains regularly and purposefully to maintain overall good condition as well as improve the muscle groups that the chosen sport requires. No athlete would ever dream of competing without training

 © The authors and Studentlitteratur

in advance. When Sara starts working on an assembly line or at a computer terminal, she is supposed to manage the physical and mental demands the work involves without previous training, sometimes at a competitive tempo to meet production quotas.

A few years pass. Sara has developed neck, shoulder and back pain. Fifty-nine percent of people in her age group suffer from pain. She finds it increasingly difficult to cope with work and goes on sick leave more often. Her co-workers are irritated and she feels like an outsider. Sara is familiar with the marketing message of the healthcare system: "You have the right to feel well," says the county council in a poster campaign. "Come to us and we will help you. If you don't receive help, you can complain to the county council's patient board." In line with these promises, Sara makes an appointment at her local clinic.

There she finds out that she is just fine. All the tests are negative. That's a good sign. She is healthy. Although it is not evident externally, Sarah does not feel well. In medical school, students learn to identify disease. They learn to differentiate sickness from health; diseases are often diagnosed with EKGs, lab reports and X-rays. They haven't all learnt that pain is a subjective experience that can appear in the absence of tissue damage. No one really knows what kind of disease or condition Sara has – if she even has one. She is prescribed painkillers in any case, is put on sick leave and files an occupational injury report. While waiting for the evaluation of her report, she is sent to or makes appointments with different doctors. In between, she visits the local social insurance office. Sara feels that no one believes she has as much pain as she says: no one takes her seriously. The specialist Sara has seen states in his sickness certificate that she is unable to work with the injury she has. The social insurance office doctor, however, who has never met Sara is of a different opinion. She should be able to manage a less demanding job. But there aren't any where Sara is employed. After two years of sick leave and sick leave pay, the social insurance office informs Sara that they are going to cut off payment because she is able to work. Sara is ineligible for unemployment benefits, though, because according to her and her doctor, she is unable to work.

Sara does not want to go on "the dole". She borrows money from friends and relatives. The tax collector comes calling. Finally, she if forced to go to the welfare office anyway. For her child's sake she

© The authors and Studentlitteratur

has to accept this help. Sara is sad, angry and humiliated. For many years she has paid taxes for the healthcare she now needs. When the policy makers then decided that sick leave and sick leave pay are to be combined with active rehabilitation, Sara is sent for occupational rehabilitation. She doesn't refuse because they may then recall the sickness benefits that were finally reinstated as a result of her appeal to the Parliamentary Ombudsman. She can't bear the thought of working, feels forsaken and burnt out in her contacts with the healthcare system and the social insurance office.

People suffering from burnout are physically tired. They sleep too little or too much and never feel as though they are rested. They also feel mentally tired. They find it hard to concentrate, forget and postpone decisions. They don't have the energy to think, read or write. To that is added social exhaustion. They can't manage to be around more than a few people; they withdraw, feel extremely lonely and even relationships with their immediate relatives become very taxing. Mental and emotional exhaustion is expressed in over sensitivity. Sara is oversensitive to the "atmospheric disturbances" she encounters when dealing with the healthcare system and the social insurance office. She starts wondering if there is any point in living. The will to survive diminishes. The exhaustive depression caused by burnout is added to her existing pain symptoms and it is no longer clear what is causing what, for Sara, for the medical professionals, or for the social insurance officers.

This is a catastrophe for Sara. Her subjective catastrophe is devoid of objective signs and of interest from the mass media. Thus, it does not receive the same attention as do the Estonia and Tsunami disasters. But for Sara, there is no difference. The tax collector, social insurance office and employment assessment institute have ripped her life to shreds. That is how she experiences it. Sara needs a break from medical treatment and rehabilitation programmes that aim for a speedy return to work. Before this can happen, she needs to be acknowledged, understood and accepted for the person she is.

People in pain are not always sick in the biomedical sense. If your problems are biomedical, you are well received, treated and, hopefully, cured. Many people praise the healthcare services for a job well done. With few exceptions, they are people with a medical diagnosis. But those who are ill, yet are considered to be healthy from a biomedical point of view, have entirely different stories to tell.

 © The authors and Studentlitteratur

They often feel affronted, disappointed and some times furious over the way they are treated. Many times there simply is no medical diagnosis for the pervasive, diffuse pain women experience.

In Sara's case, no physical cause for her pain could be found. Many others in her situation have a life filled with obligations. They have very little time to themselves. Life is full of so many "musts". What Sara wants to do has to wait. You can see at a distance how tense she is, but she does not perceive this herself. She has been operating at such a high tempo for so long that she no longer knows how it feels to relax. It would do her good to sit down and contemplate just what it is she wants out of life. Could the pain be a warning signal that things aren't right? But everyone else is able to manage, so why can't she? Sara needs help in identifying her "musts" and in reflecting on her situation. She also needs help in looking forward, in formulating goals for herself, for her family, her work and her leisure time.

Middle-age pain

Sonja is Sara's 55-year-old mother who has been in pain for many years. It started in the same way as it did for Sara. But now the pain has spread to her whole body, as she explains to the doctor, expect for the tops of her feet. She has chronic pain, meaning that it has existed for more than six months. This is not an absolute time limit, though. Pain can be considered chronic when it has gone on longer than expected after a disease or injury. The word "chronic" seems to imply "hopelessness", both for the patient and the professional treating her. Chronic pain can be treated even if it cannot always be cured, which is why the term should be replaced with "long-lasting pain". Over the years, this kind of suffering has been known by many names. Swedish doctors in the past derogatorily referred to women with this complaint as "pain, suffering and burning hags" because that is how they described their symptoms. The current healthcare system is at a loss when it comes to patients with Sonja's complaints.

On the surface, Sonja like Sara appears to be quite healthy. It doesn't cheer her up when the doctor says, "But you don't look like you're suffering." He says that because he has learnt to diagnose

© The authors and Studentlitteratur

people with acute pain. The stress reaction that follows acute, intense pain is clearly visible. A patient suffering from long-lasting pain, though, doesn't break out in a cold sweat. Pulse, blood pressure and breathing are normal. You can't deduce from this that the person's entire life situation is so negatively affected.

Half of all women in Sonja's age group have pain. Half of all men do as well, but the extensive pain that Sonja experiences is more common in women. In the population, there are just as many middle-aged men as women who suffer from pain, but more women seek medical attention, almost three times as many. Primary care doctors find it difficult to deal with these women. They get such patients off their hands for a while by referring them for tests and to specialists. Some of the patients even demand to be referred. There are many different levels: first to the local hospital, then to the county hospital. If that doesn't help, Sonja can be sent to the regional medical centre or perhaps even to a specialist in one of the bigger cities. Referrals aren't necessary to a chiropractor, naprapath, masseur and homeopath; Sonja seeks them out herself. With luck, she can be kept going around and around in the referral cycle a couple of years. But sooner or later she returns to the final stop – primary care. She is dejected, and has as much pain as when the referrals began. Everyone has given up, Sonja as well.

Fortunately, there have been fewer long referral cycles in recent years. The National Swedish Board of Health and Welfare has stated that if the primary care doctor has not been able to help improve the quality of life of the patient within three months, then she is to be referred to a pain clinic instead of specialists. This sounds good on paper, but in practice there aren't sufficient resources for all who are in need. The referral cycles have been reduced, to a large extent, because each referral is now invoiced separately. Instead, Sonja and her unlucky sisters are told, "You have to learn to live with your pain." But they almost never find out how they are to go about doing so.

People like Sonja are frustrating for healthcare professionals to deal with. They stir up feelings of inadequacy. On some days, a doctor can go home having had five such appointments. The doctor doesn't feel good about it. If it continues over a long period, he may simply burnout. In order not to succumb, he needs to feel he is capable of doing something, and how is that going to happen when

© The authors and Studentlitteratur

he doesn't have any idea how to help people like Sonja? One way is to designate her as a difficult patient. If he has dealt several such "difficult" patients in a day, he can almost feel that he has done a good job. No one is thinking that in addition to her own problems, Sonja is now being deemed responsible for the doctor's feelings of inadequacy.

Sonja has low-status pain. When she meets a new doctor, the mere sight of her medical record is enough to cause aversion. It has grown very thick through the years. Seeing it for the first time, a doctor is gripped with distaste. These feelings are often unconscious, but they are present in the consulting-room. Even if the doctor has every intention of respecting Sonja, listening to her and showing empathy in every way, she picks up on his dislike. She is on her guard and the communication is not as relaxed as planned. When Sonja goes home, she is disappointed. No one takes her seriously, no one understands her. "If only I was really sick – so that you could see it on the outside," she thinks.

People whose pain is visible have higher status in healthcare. So do people who have limited and temporary pain – and those who have treatable pain. Then the healthcare personnel feel sure of themselves. Then know what to do. Those are the kind of patients they like. Women's pain has lower status than men's. The age of the patient is also significant. The lowest person on the totem pole is the older woman with long-lasting, pervasive, diffuse pain lacking a specific diagnosis.

"I shall always be a flower girl to Professor Higgins because he treats me as a flower girl, and always will, but I know I can be a lady to you because you always treat me as a lady, and always will," explains Eliza Doolittle in *My Fair Lady*. It's called the Pygmalion effect based on the George Bernard Shaw play of the same name [Shaw, 1916]. It is also referred to as self-fulfilling prophecy. If you expect a person to be troublesome, she will be. Just imagine if it really is true that through our expectations we can influence the behaviour of others! Could it actually be the doctors and healthcare professionals who create these difficult patients?

We have all met people who energize us. After those kinds of encounters, we feel exhilarated. We have the strength to deal with something we have been avoiding for a long time. But after other kinds of encounters, we feel entirely exhausted. Some people ener-

© The authors and Studentlitteratur

gize us; others take it out of us. Not only healthcare employees suffer from burnout; even patients can from the medical treatment process. In their encounters with certain healthcare professionals they find the strength to go on, the strength they are so in need of to deal with their life situation. After others, they are dejected. Everything feels meaningless and hopeless. Sometimes both the patient and the person treating her are completely stuck.

Even if you are unable to provide any specific treatment, you can give a patient the strength to go on. One prerequisite for breaking the vicious cycle is to stop searching for new specialists and enable the patient to establish a relation with someone with the right personal chemistry instead. It can be a doctor, nurse, physiotherapist, counsellor or someone else the patient trusts. The effect thus achieved is often referred to as being "just placebo"; it really should be called "unspecified treatment effect" and is something we should strive for to a greater extent than we do today.

For Sonja to even be able to think about working again, she needs to have an employer who sees, understands, and appreciates what she does. She wants affirmation of her worth, and understanding that her work capacity is reduced even though there are no visible signs of it. She also needs assistance in clearly defining her work assignments and setting limits. That is why Sonja would like to have a long acclimatization period with frequent reviews, and once she is back on the job, she would like relief when the work accumulates or increases. Because Sonja, as a result of her illness and burnout/exhaustive depression, has become quite sensitive to stress, she needs a calm work setting. She would also like to have flexitime so that she can work more on the days she feels up to it and take it easier when she is feeling poorly. She needs to work at her own pace without her boss and co-workers thinking she doesn't measure up. Most of all, Sonja would like to have a competent boss, a real leader, someone who can create a cheerful atmosphere and team spirit on the job and set a good example.

© The authors and Studentlitteratur

Old age pain

Selma is Sonja's 80-year-old mother. Selma is depressed because her husband is suffering from dementia and because she has constant pain in her legs and back. She sleeps poorly, worrying over what her husband might do. More than half of the women in Selma's age group have long-lasting severe or pervasive pain. Selma is too old to be referred to a pain clinic; she has long since passed the upper age limit many of them set. She has to get by on painkillers. New research findings on pain treatment are pretty much out of the question for Selma. She is too old. You usually have pain when you are older and many think that pain is a natural part of ageing. Research in this area is meagre.

Network or net of pain

Sofia, Sara, Sonja and Selma belong to different generations of the Swenson family. It is no coincidence that they all suffer from pain. Pain is often handed down from one generation to the next. It is seldom genetically inherited, but there are indications that children of parents with pain have pain themselves to a greater extent than others. At least they have each other. They are part of a network in which they support and help one another as best they can. It is a well-proven fact that a social network is an asset when it comes to managing all sorts of difficulties. But it can also be a disadvantage when the network consists of people who all have problems. In addition to Sofia, Sara, Sonja and Selma there is a great-grandfather with dementia, Sonja's husband with a drinking problem, Sara's ex-husband who is a workaholic, and Sofia's brother who has just been diagnosed with diabetes. Who is going to take care of them all? Life is so tough. Just the act of living hurts. Or is it perhaps the feeling of anxiety that your life will be over before you have had the chance to do all that you wanted. Sometimes it just may be the absence of a genuine life that causes pain.

© The authors and Studentlitteratur

Rehabilitating back to life

The Swenson family is not unusual. Theirs is the picture of poor health in Sweden today. When you read the stories of Sofia, Sara, Sonja and Selma, it becomes clear how much needs to change for Mother Sweden to regain her health. What the system has to offer is most often based on the knowledge, experience and perspective of doctor's and leaders. Patients don't always recognize themselves in this world. Another way would be to start with the patient's experiences. A rehabilitation concept that sprung up from a very close co-operation with patients on long-term sick leave has been applied in the Pain Workshop since 1994.

A physiotherapist suggested that Sara look into the Pain Workshop. There she met others who had similar problems and experiences. After a couple of visits, she brought her mother Sonja along. They felt acknowledged, understood and accepted in their miserable situation. When they asked Sara what her greatest wish was, she answered without hesitation, "A better network in healthcare," and, "That the doctors and social insurance officers have greater insight." In the healthcare system, they often discuss the personalities of the patients and their inadequate social networks. Very seldom do they speak of the personalities of the care providers and their healthcare network, i.e. the co-operation between doctors, the social insurance office, the employment assessment institutes, etc. The problems are transferred to the patient instead.

Quality of life

Sara and Sonja received help in recovering their self-respect and self-confidence, which had been wiped out as a result of the insensitive and at times offensive way they had been treated. The goal was improved quality of life. Slowly they began to see the light. They were meeting others who seemed to have managed the impossible. Their self-esteem started to return, slowly but surely. Sonja took on a little task and it gave her a kick. She gradually became more active and as time went by, took on more responsibility in the Pain Workshop. After six months, both Sara and Sonja were starting

© The authors and Studentlitteratur

to come back to life, even though returning to work still was light years away. But now, Sonja had to be careful. If you can work voluntarily, you can work for pay was society's message. That she had lost her job a long time ago, and after years of sick leave and sick pay had very little chance of returning to the labour market, were not considered extenuating circumstances. The social insurance office paid no attention to the fact that Sonja was unable to find a job. They said they were "streamlining" the system. Sonja felt that she was being divided up into different pieces. They distanced themselves from the comprehensive approach that Sonja had so sincerely longed for.

Unemployment

Sara and Sonja were to be rehabilitated to unemployment. When Sara understood this, her life fell apart again. Being unemployed meant even lower status than being on sick leave. Sara was forced to change identities yet another time. She had to adapt to life as an unemployed, single mother with chronic pain and with little chance of being able to accept a job that might be offered. It was a catch-22. Sara and Sonja had paid taxes all the years they had worked for, among other things, the security of knowing they would be taken care of in case of illness or work incapacity. They understood that the state, like themselves, had poor finances and they were willing to do their part. What they couldn't understand, though, was that it would be cheaper to let them receive their allowance from the unemployment office instead of the social insurance office. Sonja asked and was told that it wasn't any less expensive, but that it was more fitting from a societal point of view. This transfer of responsibility from one government programme to another was for Sonja the ultimate proof that she had landed entirely outside of the mainstream. She was sick, not unemployed. She was bitter and she saw on TV that the situation was going to get even worse. The social insurance office had started a campaign to crack down on "health insurance fraud".

© The authors and Studentlitteratur

Pressure from society

The increase in the frequency of sick leave has been dealt with extensively in the mass media. Everyone is in agreement that something has to be done. Opinions differ, however, in how to handle the problem. Sara and Sonja feel guilty almost every time they open a newspaper. They feel they have a duty to get better. Every week, people on long-term sick leave attend the Pain Workshop. They feel pressure from their employers, from the social insurance office, from relatives, from all the demands and disturbing reports in the media. Sometimes they have a chronic pain diagnosis, sometimes burnout, sometimes chronic fatigue syndrome, sometimes exhaustive depression and sometimes no diagnosis at all. What they have in common is that they are totally worn out. Many just want to die. The Pain Workshop is the last ray of hope for some of them. Many come after years of ineffective treatments and rehabilitation. Most of them are big healthcare and prescription drug consumers. They express their despair in having fallen between the cracks. Medical rehabilitation is the job of healthcare, but in their case there is nothing more to be done medically. Occupational rehabilitation is the job of the social insurance office, but many are too ill to participate. When your entire life has fallen apart, you don't even want to hear the word "work". What you want first is to be rehabilitated back to life, but neither the authorities nor employers want to defray the cost of that kind of rehabilitation.

Learning to be a person

The Pain Workshop takes no medical responsibility. It offers clearly structured group discussions based on educational materials developed by the author. This is a crucial element so that it doesn't just end up being another place to come and complain. The participants look forward with a focus on possibilities instead of difficulties, and are helped to mourn for what they have lost, to leave their feelings of shame and guilt behind, and to set goals for the future. Surprisingly, the participants are able to lift themselves out of hopelessness and despair and start to live again. Some return to work, but many are over 55 with years of sick leave behind them, which is why a job

© The authors and Studentlitteratur

is not a realistic goal. This rehabilitation programme is beneficial nonetheless because the majority of participants reduce their healthcare and drug consumption considerably. Stockholm's Pain Workshop saves the county 2,040 euros per person/patient annually in reduced healthcare consumption, and 130 euros per person/patient annually in reduced drug costs. Most of those who regularly attend the Pain Workshop recover. Significant improvements in general health have been measured including physical, mental, social and emotional health as well as vitality and pain reduction. Sometimes it takes many months, but some participants have been able to change their attitudes to suffering after only a few visits.

When you ask the participants how their improvement came about they answer: "I have learnt how to be a person! It's like going to the university of life. Why haven't I been told this before? I have been exposed to all kinds of possibilities but there has been no pressure involved." They all agree that not placing pressure and demands is very important. For the first time in the Pain Workshop they have not felt pressured to change; as a result, they have been enabled to change of their own accord. They decide for themselves how often and how long they will participate in the Pain Workshop, and so rehabilitate themselves at their own pace. In traditional programmes, it is the social insurance office that determines the pace. Many describe how previous efforts were badly timed because they simply weren't open and ready for change. Past programmes have almost always involved full-time activities in training, therapy, discussion groups, etc. They were, however, in need of time to "land" first and to reflect over what they wanted in life.

Sara and Sonja told about their time at the Pain Workshop. "It was like lying in a comfortable cradle when I was there, and I didn't want to climb out of it right away," explained Sara. "But somewhere along the line they must have turned it upside down so that I fell out, even though I never felt the impact," Sonja added, "They somehow initiated a self-healing." Sonja also related that all of this led her to start reflecting. She and Sara gradually arrived at the choice between living in the past as a chronic pain patient or beginning to dealing with herself in the present. They chose the latter. Today you could say that they are pain masters. They still have pain even if it is not as intensive as before, but they feel good as long as they take their functional reductions into consideration.

© The authors and Studentlitteratur

A different concept of rehabilitation

The Pain Workshop started ten years ago during my time as a teacher at a pain school, paid on an hourly basis. There, I regularly met people on long-term sick leave with different sorts of suffering and pain. They were all participating in a rehabilitation programme that, in addition to medical treatment, included therapy sessions with psychiatrists, counsellors and the pain school. Many teachers participated, primarily applying a traditional transmission pedagogy approach. The conventionally structured classes had about 25 participants each. The majority were more or less dissatisfied with the rehabilitation programme in which they were forced to participate in many cases. Half of the group lay on mattresses on the floor or sat in lounge chairs. Some appeared to be sleeping, others interrupted constantly with disruptive comments on how wrong I was and how impossible everything was. I was bombarded with their anger and bitterness. When I related what I had learnt from life, there were some who began to stir and to my surprise came up at the break and asked for a copy of my notes. I also noticed that they stayed after class and discussed what I brought up. This made me decide to continue and to develop an unconventional rehabilitation concept. It includes elements from research, support groups, lectures, shared memories, Socratic dialogues, motivation-enhancement methods, consciousness-raising methods, cognitive behaviour therapy, master-apprentice, experience-based learning and self-help groups.

The road back

Most rehabilitation programmes involve elements of physical training, ergonomics, communication, etc. It is more seldom that patients are helped to reflect on themselves, their lives and their life situations. In healthcare, they seldom talk about despair, anxiety, grief, anger, fear, guilt, shame, meaninglessness, loneliness, abandonment and other natural human reactions to poor health and other problems. If you are in pain, you usually do not feel well. In certain phases you are unable to differentiate between being in pain and feeling bad. It all runs together in one big chaos. Existential dis-

© The authors and Studentlitteratur

cussions help you put this chaos in words, and once you are able to do that, it is no longer chaotic. Instead, it becomes a number of areas to work on.

Existential discussions are a way of helping a person to understand herself in her own framework and to expand and extend it. It is not a matter of understanding yourself in the light of any psychological theory. The existential discussion is a way of initiating a process in which the person examines what makes life meaningful. The goal is to find out what actually means something for you, not what should mean something. It is a matter of learning to live a meaningful life. You learn difference between having pain and feeling bad, and that it is possible to have pain and feel good. In healthcare, they concentrate on the actual pain and try to reduce it. In the Pain Workshop, we work instead on finding the level of pain that is acceptable; then it is no longer the same problem. Pain takes a backseat in your life. You can feel good even though the pain is still there.

Keys to recovering health

When it comes to prescription medication, one talks about the active substance. In the search for the active substance in rehabilitation, two components stand out: learning environment and life-related existential discussions. The environment is the prerequisite that enables these discussions to effect change. The participants have described their Pain Workshop experiences as being in an incubator or in the womb. They feel that they are seen, heard, touched and affirmed. The atmosphere is non- pressuring, full of love and care, all of which are optimal conditions for learning and reorientation in life. There are many things to choose from. It is like going to a smorgasbord and deciding for yourself what and how much you want to eat, the pace and how long you want to stay.

Participants have also described their rehabilitation process as going through a washing machine. When the cycle is over, you have a new way of thinking, of seeing a situation and of behaving. You have arrived at emotional insight, and you are alive again, even if the suffering and pain are basically unchanged. In addition, after

© The authors and Studentlitteratur

having gone through the grieving process, you have created a more stable identity that is no longer based on your job or profession and where neither pain nor suffering is a natural part. You have learnt the art of self-confirmation. In that way it becomes easier to set limits. You no longer have to agree to do whatever anyone else asks in order to satisfy your unconscious need for confirmation. You become more sustainable on the job and in life on the whole.

If you see the Pain Workshop as a bank, you also have a way of maintaining your new identity as a living human being. Those who have received help but are still unable to return to work can become volunteers and role models so as not to risk falling back into the old destructive patterns. You go to the Pain Workshop and "deposit" your energy when you feel good in order to be able to "withdraw" some when depression sets in. When you pass it on, the roots grow deeper in yourself.

More information about the Pain Workshop can be found on its website (in Swedish): http://www.varkstaden.se/.

© The authors and Studentlitteratur

9 Emma and the Minimeter

Björn Breidegard

Emma Nilsson was involved in an accident with a horse just before her ninth birthday. She sustained a severe brain injury and since then she has only been able to communicate with a few people she knows with the utmost of difficulty. She is unable to speak and her mobility is extremely limited. From the start, the parts of her body that she could best control – at least with some volition – were one of her little fingers, her head and eyebrows.

I am an electrical engineer and my greatest interest throughout life has been practical activities such as designing, repairing and modifying all sorts of technical devices. Designing technology can be sufficiently difficult. Getting it to work with people is even more difficult. And getting it to work with people with severe disabilities is downright complicated.

A beginning: Minimeter 1

Emma's parents, who had searched the world over for help, contacted Bodil Jönsson at Certec in 1998. Their wish was short and simple: "Give us a tool that will enable Emma to answer *Yes* or *No*."

I had recently been employed at Certec after many years in a career in electronic and computer system design as an instructor, and as a designer of CAD tools as well. Now it was a matter of coming up with technology for a single individual's very special needs. After taking on this task, I spent the first week getting to know Emma, her parents, personal assistants and other helpers such as her masseur, physical therapist and speech-language pathologist. I was very curious and asked many question about Emma, what she was able to do and what it was possible for her to learn. Emma, of course, couldn't

© The authors and Studentlitteratur

answer these questions herself. Unfortunately, no one else could either. Nobody knew for sure; everyone believed and hoped. When I asked if Emma understood spoken language, they all thought so but no one was certain. How well did Emma see? Did she comprehend what she saw? Could she see colours? Emma had glasses but were they the correct prescription? How close to the computer screen should she sit? Again, no one could answer with certainty.

The conclusion I came to after that first get acquainted week was that no one knew much at all – and I wasn't any wiser either. Where should I begin then? First, I had to choose a control method for Emma. I selected the movement of her little finger. This could control a computer that in turn could assist Emma in communicating. The next question was: How do you design a reliable and sensitive sensor capable of detecting the movements of her little finger? This wasn't so easy. Previous attempts with mechanical switches hadn't succeeded very well. The next big question: What would happen when Emma moved her little finger? Since nobody knew much about her interests and abilities, this wasn't particularly self-evident either.

I decided to carry out a simple experiment. Emma would be able to turn on the ceiling light in her room with a very slight movement of her little finger. My first choice was a sensor that would detect finger movements by measuring the electrical potentials generated by the muscles. This was accomplished by placing two electrodes on the skin in locations where they could detect flexing of the little finger. I borrowed a commercial EMG apparatus (a device that measures electronic muscle signals) and with some homemade electronics, I was able to get the system to work – a slight flexing of the little finger turned on the ceiling lamp for a few seconds. I tested it myself in the lab. Surprised and happy, I bent my little finger and the lamp went on, again and again.

The next step was to move all the equipment to Emma's home to let her try to turn her ceiling lamp on and off. Emma's mother, Ewa, went first. She sat in Emma's wheelchair, skin electrodes with wires taped to her right forearm, and started turning the ceiling lamp on by flexing her little finger. She did this several times and it worked perfectly. The device was so sensitive that it didn't even require an observable finger movement, or as Ewa expressed it, "Just thinking of turning on the light is enough for it to happen!"

 © The authors and Studentlitteratur

Now Emma was to be given the opportunity to influence her environment for the first time in nine years. The procedure had been tested on Emma's mother, so it was just a matter of doing the exact same thing with Emma. And sure enough, after being instructed how to turn on the ceiling lamp by bending her little finger, Emma was able to do it. She did it several times on request. But after a while, the light no longer went on. Something was wrong. We saw that Emma's little finger was moving, but the lamp wasn't reacting. What was the matter? This was extremely irritating and annoying – it had worked perfectly with Ewa. We thought that Emma was bending her finger in the same way the entire time. It turned out, however, that she was moving her finger in many different ways, not just with the muscle on which we had placed the skin electrodes. Ewa had dutifully followed the instructions to bend her little finger, but not Emma. She moved her finger the way she could. I had to re-think the sensor. But the first version of "the Minimeter", a simple steering device, was born.

The continuation: Minimeter 2

It was time to design a sensor that reacted to small finger movements in any direction. In the ELFA catalogue (several thousand pages of electronic components you can purchase[1]), I found a super sensitive magnetic field sensor for 5 euros. I spent a few days designing the electronics needed to adapt the magnetic field sensor so the computer could receive its signals. At the same time, I programmed software that would visualize the magnetic field sensor's signal as a bar graph on the computer screen. The big moment came when I connected the cable between the computer and the magnetic field sensor's electronics and could test my vision in reality. I placed a rubber thimble (the kind you use when flipping through a pile of papers with your forefinger) on my little finger with a small permanent magnet attached. It was a great success. The slightest movement of the little finger in any direction was reflected in changes on the computer screen's blue bars. It was possible to dif-

1 Available at: http://www.elfa.se/en/

© The authors and Studentlitteratur

ferentiate between direction, speed and size of the movements. The first step was complete: a perfect sensor for tiny movements of the little finger. The best thing was that the sensor was robust and did not require difficult calibrations. An extra bonus was the elimination of all the electrodes, wires and tape connected to the user, as well as not having to deal with electrical safety problems.

Feeling confident after having succeeded in solving the sensor challenge, it was time to let more things happen with computer sounds and pictures when Emma moved her little finger. What would they be? Well, that wasn't so easy to answer because no one really knew much about Emma's abilities and interests. It was just a matter of letting imagination flow freely – of coming up with as many little finger control opportunities for Emma as possible. That is what we call "broadcast sowing" at Certec – you scatter your seeds far and wide: some fall on rocky places and some fall in good soil. Then it is a matter of being observant – because a vigorous seedling can take root in the rocky places too.

A couple of yes-no control functions were designed: A downward movement of the little finger resulted in the word "Yes" appearing on the computer screen in big letters with a female voice saying "Yes" from the speakers. Correspondingly, an upward movement resulted in a "No". It was possible to count (one, two, three), to add numbers, to spell "E" as in "Emma" or to browse among scanned-in pictures from the family photo album. And, of course, to turn on the light. It was simple and inexpensive to implement all these control functions. It was just a matter of programming the computer, which is relatively quick and easy when you have mastered the art.

For a number of days in February 1999, I tested the results of the broadcast sowing with Emma. I video documented everything in order to later analyse and discover things I had missed. Emma was first instructed to turn on the light by moving her little finger. She did so several times over several days on request. The lamp lighted up for a few seconds and the computer's female voice said: "You turned on the light, Emma!" Now all the rest of us finally received confirmation: Emma could do it on command. She had understood our instructions. Then she was asked to count. "Can you count to three, Emma?" She slowly clicked forward to number three with her little finger. The computer provided her with continuous feedback: "One", "Two", "Three", on both the screen and from the speakers.

 © The authors and Studentlitteratur

"What's 4 + 2, Emma?" She clicked slowly forward to six. Sometimes she made a mistake, often one click too many. It was just as difficult for Emma to stop the movements of her little finger as it was for her to initiate them. There was no doubt that Emma understood numbers; we now had found out even more about her. When it came to letters, though, Emma did not respond to the spelling request. She either couldn't or didn't want to spell "E" as in "Emma".

Unfortunately, the yes/no control function did not work for Emma. She was unable to reliably carry out two different movements with her little finger: one for "Yes" and another for "No". If she could have managed that, we would have solved our initial assignment. It would have been a big success and we could have continued working in that direction.

The first big breakthrough

The first big breakthrough came when Emma was able to look at pictures of family and friends. I had scanned in a hundred from the family photo album that Emma could browse through at her own pace using her little-finger clicks. She was very concentrated on the computer screen when doing so. As soon as she sat at the right distance from the bright screen, she confined her eye movements to it. If there was a picture, she looked towards the centre of the screen. If there wasn't, she swept her gaze over the entire screen and stopped at the edges. This was very apparent. The most significant, obvious and gratifying results were the mouth movements Emma made when her personal images started to change on the screen. How conscious her control was (if at all conscious at this point), was impossible to say. But it was entirely and absolutely evident that she moved her mouth the whole time whenever she saw herself, her friend Sofie and other familiar faces parade past. Emma looked happy and there was no doubt that she even smiled at times. Afterwards, when her face returned to its customary melancholy expression, the contrast made her appear quite sad. We could confidently state that Emma was quite emotionally affected by the picture show because it was documented on videotape.

Here are some excerpts from her parents' diary during this time:

© The authors and Studentlitteratur

"Terese asked Emma if she would like to sit at the computer after taking her shower. Emma clearly answered, "Yes", with her eyebrows. I (Ewa) came upstairs around seven in the evening. Emma appeared to be upset, was breathing intermittently, her eyebrows were raised and her hands tense. I asked Emma if she would like to sit at the computer. She answered me clearly in the affirmative. She succeeded in turning on the light. The mood was tense. We decided to try with the pictures. Emma soon calmed down. Her hand relaxed and she seemed to have control over her finger and the pictures. She looked at them and changed them herself. Her eyes were gazing at the pictures all the time and she moved her finger at regular intervals. Sometimes she looked a bit longer at a picture. I was impressed and tremendously happy."

"The pictures interest Emma the most. She grows tired of the numbers. When we change to the pictures she brightens up."

"We started right off with the pictures. Emma calmly clicked to bring up new ones. She was in control. When we talked about the photographs, i.e. 'There you are on the winners' stand, Emma,' her gaze lingered a long time. Emma can indeed control the computer; well, sometimes at any rate."

"Emma has shown that she likes looking at holiday pictures; she paused several times at a picture in the pool where she is bathing with Kerstin and Nina."

The premise that you cannot know until you have tried is certainly applicable here. No one could have predicted that Emma's big breakthrough would come with her access to personal photographs. We purchased a digital camera for Emma; her mother and assistants were taught how to use it and to transfer pictures to the computer. I designed a new user interface for Emma so that she would be able to navigate among her pictures using her little finger. We introduced the concept of "picture books", each of which had a cover page and contained five to ten pictures with related audio comments, recorded by the assistants. Emma could choose a picture book and then page through it with her little-finger movements. A reporter from one of the Swedish newspapers, *Aftonbladet*, came to do a story on Emma in April 2000. As was always the case when reporters and photographers visited, Emma was in top form; she really wanted to show what she was capable of doing. On that occasion, we asked Emma to show us something from her diary. She let

 © The authors and Studentlitteratur

the yellow frame scan through day after day. Oh, we thought, this doesn't look good. Emma went back a few more days and then opened her diary and stopped at the first picture. It showed Emma with her assistants high up on the big wheel at the People's Amusement Park in Malmö. This is what Emma wanted to show us all, and perhaps her mother in particular – no one had yet told her of the exciting adventure.

Now it was Emma's turn to be the centre of attention. She was the one showing the pictures. She had the initiative. She showed sequences of pictures to her mother, her assistants and her friends. Even though we hadn't yet achieved a reliable "Yes" or "No", the Minimeter meant a lot for Emma, her family and friends. And if you have a computer and the Minimeter, you can connect to the internet as well. Emma was able to "click" away a picture mail to her sister who was visiting Australia. Everything seemed to be going well and the future looked bright. After a year of using the Minimeter on a daily basis, the movements of her little finger had become bigger and more precise. In addition, she had been training a separate movement in her thumb. So we placed the rubber thimble with its little permanent magnet on Emma's thumb. Everything Emma had previously been able to control with her little finger she could now control with her thumb.

"Yes" or "No", one more time

It was time to try again and see if Emma could answer "Yes" or "No" – she was able to reliably execute two independent movements now: one with her little finger and one with her thumb. One more magnetic field sensor was needed, and both the equipment and the software were prepared for this possibility. Emma demonstrated that now she was also able to slightly bend her right foot up. So, we decided that a movement of the little finger would mean "Yes" and a tilt of the foot would mean "No". Expectations were high and we started to ask Emma questions. Unfortunately, it didn't work at all. Emma simply wasn't able to utilize two different movements to answer "Yes" or "No". We then tested letting one of the movements turn on and the other turn off a light or transistor radio, but it still

© The authors and Studentlitteratur

did not work. We had considerable expert educational support during this time, but nothing seemed to help. Nor was Emma in the best shape; different medical problems disrupted her concentration and alertness.

The next step: Minimeter 3

Now it was time for an entirely new choice of technology. Computers were coming down in price and going up in power. TV cameras could be purchased for about 100 euros. So the next "Minimeter" was based entirely on equipment you could buy inexpensively in computer shops. The technical efforts were focussed instead on designing an advanced and customized software that could handle the image processing needed to decode human facial movements for control and feedback.

The new fundamental concepts for the Minimeter were:

- To decode human facial movements.
- To attribute these movements with communicative significance.
- To allow these movements to control something meaningful for the user.
- To offer the user suitable and individually adapted feedback (e.g. with pictures and sound) to facilitate control.

During the previous year, I had been in contact with several people who were in need of solutions for their special needs, and, of course, new ideas had come and gone all the time.

Up until now, three test users have tried the new Minimeter concept and contributed to its development; Emma, of course, is one of them. Over the last three years, Emma has improved her ability to turn her head to the right and left as the result of excellent physiotherapy. She is now capable of reliably giving two equally valuable signals: turning her head to the left defined as "No", and to the right as "Yes". Lack of movement does not mean "No" as it did previously, but simply no response. The interpretation of the answer is objective – determined by the computer. The feedback that facilitates control in answering "Yes" or "No" is provided by a large yel-

 © The authors and Studentlitteratur

low ball, appearing on the screen against a sky blue background. The ball tracks Emma's slightest head movement so that she can see which direction she is going. When she turns her head a little to the left (and the ball moves a little to the left), it grows redder and redder and when she has succeeded in rolling the ball all the way to the left edge of the screen, the entire screen turns red and a "No" is heard from the speakers. When she then turns her head back, the ball changes to yellow again. In the same manner, the ball grows greener and greener the more she turns to the right and finally turns entirely green and a "Yes" is heard.

Emma learnt quickly to answer "Yes" or "No". She exhibited a strong desire to answer questions – the answer was most often a "Yes" or a "No", and seldom no answer at all. It was evident that Emma could learn new things. Each time she was placed in front of the camera and computer screen, she spontaneously started to roll the ball to the left and right interchangeably. She also learnt a strategy: to more easily initiate turning her head to the right, she started to shove off with a little swing to the left.

We asked her different kinds of questions, some for which we could check the answers, some which were an expression of her wishes. One such example: "Do you want to take a break, Emma?" If Emma answered "Yes" we took a break, otherwise not. "Would you like chocolate pudding when you get home?" She answered "Yes" and received the pudding when she returned home. This question continued to conclude every training session – and she answered "Yes" every time. After a number of occasions, she unexpectedly answered "No". Some of the people in the room reacted strongly. There must be a problem with the equipment – the answer wasn't "right". Emma was asked another time and answered "No" again. At last she was asked: "Are you tired of chocolate pudding, Emma?" She answered "Yes."

© The authors and Studentlitteratur

A "Yes" means "Yes" and a "No" means "No"

Emma's yes-no control has two equally valuable movements for "Yes" and "No" and feedback, in the form of a ball that changes colour, follows Emma's slightest intentions and alerts her continually to where she is heading. She can change her mind several times before giving her final answer, and she can work entirely at her own pace.

Currently, Emma's mother and teacher are convinced that Emma, when she is in good form, can volitionally answer "Yes" and "No". Emma correctly answers common yes-no questions to which the answers are known almost all the time, questions such as: "Is your sister's name Nina?" "Do you have a brother?" When Emma chooses music, she often returns to certain songs and skips over others straight away. She almost always chooses the same brand of lollipop.

Here comes Minimeter 4

In the spring of 2005, we initiated the development of the fourth Minimeter. Over the next three years it will be improved with new technology, new ideas and more users, each with his or her own special needs.

© The authors and Studentlitteratur

10 Might and machines

Peter Anderberg

The air was cold and completely still. The sky was bright blue and the snow sparkling in the sunlight. I sat in my wheelchair, close to the edge of the mountain. Far down below was a dark blue lake with its clear, clean water. The sun was on my back and I let my gaze rest on the snow-capped mountains on the other side of the lake. The only sound that reached me was muffled and almost obliterated by the snow and grandeur.

The silence was broken now and then by a rescue team whizzing by carrying a poor, unfortunate skier on a stretcher. I clearly remember one of the rescue worker's very surprised and anxious glance when he first skied by me. It was obvious that he wondered if I was one of his previous "accidents", someone he had struggled so hard to get down the mountain who had somehow made his way back up again, just to annoy him. A wheelchair, in the snow, up on the mountaintop – it just didn't fit!

Since I had neither a plaster cast nor appeared to be in pain, but was just sitting there calmly and peacefully on my wheels, I was obviously not his medical responsibility. People who work in healthcare often find it difficult not to be needed. That is why they seldom make good personal assistants. He turned his head one last time to make sure I really didn't need his help, not even a little, and was on the verge of going right out over the edge. His colleague in front of the stretcher yelled out a warning and he returned his concentration to the task at hand. I was soon forgotten. And it was utterly quiet again.

© The authors and Studentlitteratur

I'm alive

I suddenly realized that I no longer hated snow. Just that would have been enough to make the day on the mountain something very special. But the other thing that flashed into my mind as I sat there trying to work out where the border went between California and Nevada was even more remarkable: the realization that I was alive. Not just that I was breathing, but that I was truly alive and enjoying every single second of the life I was living. The month before, I had been in Los Angeles and the month before that, I had celebrated Christmas and New Years In Mexico, and next month I was off to Hawaii and to propose to my girlfriend on Waikiki Beach and she would answer, "Yes!"

The world was no longer so terribly dangerous; it was just dangerous enough to make it interesting to live in. I had cut myself off from the world and from life for so long that now my hunger was immense; I just couldn't get enough of what it had to offer.

Just a few years earlier, I had made the choice to be a prisoner in my own home, afraid of everything. The world was black and I wasn't able to manage anything anymore. I was afraid to go out and found it hard to face up to my wheelchair because I felt little and vulnerable sitting in it. I hated the feeling of everyone staring at me. I have a neuromuscular disease called spinal muscular atrophy (SMA) that results in some of my muscles gradually weakening and wasting away. It was causing me to lose functions that I previously had taken for granted. Over the course of many long years I had lost the ability to walk and had started using a wheelchair. At great personal cost, to say the least.

At the time of my visit to the mountaintop in Heavenly, Lake Tahoe, I was an exchange student at Santa Clara University. I had left my secure home in Sweden and travelled half way around the world to California to complete my engineering studies. It had been a big leap right out into the unknown, and it was preceded by a long process of eager ambivalence and anxiety-laden expectations before I dared to take the jump. It finally became something I simply had to do. It was a question of winning or disappearing. For real.

When I sat there and breathed in that special scent of sun-warmed snow and of damp woollen mittens, I remembered that I

 © The authors and Studentlitteratur

had actually loved snow once upon a time when I was a little boy. Before snow made me freeze and fall down. Now we were hesitantly re-establishing contact.

Upwards

I had seen the snow from the village below the first day and thought how much I really wanted to see my girlfriend ski. The gondola was accessible so that I could role on with my wheelchair. This impressed me a lot. It wasn't until later that I realized it was most likely for carrying the occasional passenger on a stretcher – possible future wheelchair users like the one I had just seen the rescue team help – down the mountain.

I had gotten myself up higher than I had ever been before with a wheelchair and cable car that I could get myself into. Fantastic! I didn't even get dizzy from the height, something I usually do when other people even mention someone they know who climbs mountains.

I was no longer afraid. Not even the precipice beyond the "Experts Only" sign could strike terror into me. I was, instead, relatively secure and very satisfied that it was actually possible for me to do what I had done. I was there in the snow again. It wasn't a love affair; the snow, lying there beautifully white and restful, would still try to freeze me if I came in contact with it. But there was no longer any hate between us. And I was no longer afraid.

Warming up

Many things had fallen into place for me so that I could give up the relatively comfortable and secure life that I was leading with no fear but with a certain degree of boredom and lingering dread of the unknown. My brothers and I had taken trips through Europe in an old Toyota Hiace. I slowly began to realize that I could be away from home several days in a row and survive. With a decent mattress, the floor of a Hiace suffices as a bed, and my wheelchair actually

© The authors and Studentlitteratur

worked quite well and was not such a bad thing after all. It was comfortable to sit in and transported me to different places. I didn't know it at the time but with it, I would be able to get myself up to a mountaintop and down to the depth of a Mexican jungle.

Then and there in Europe, I was satisfied with it being able to transport me to bars and nightclubs. I could drink beer again without the fear of falling over. But I soon discovered that whiskey was better because a wheelchair is only an effective enabler in a setting adapted for its use. My two strong brothers could push the wheelchair up and down the steep hills of Biarritz and into the pubs, but the narrow, curved staircase down to the basement did not afford me the function of getting down to the only WC in the place. My renewed acquaintance with beer made me long, at that moment, for that ability.

Technology for good and bad

Technology and technical structures (e.g. architecture and other human constructions, artefacts) can function as originators, consolidators as well as demolishers of functionally disabling structures. The old building that housed the bar in Biarritz, its structure and design, were outdated and run down. No one really cared if a person in a wheelchair could use the WC or not. It just couldn't be done, could it? This resulted in my newly found lust for life losing some steam again. I had only been deceiving myself in thinking that I was a real person, when I was actually only a nobody in a wheelchair.

But this time it wouldn't let it knock me down; I was already sitting. The old engineer, problem-solver and designer in me got going instead. The experience of physical space is quite concrete and tangible when you have mobility impairment. You soon realize that almost everything has to do with how a space and its contents are organized and the attitudes behind that organization. Organization and attitude are many times a greater problem than the actual technical solution. Disablism is so pervasive and such a natural part of our everyday lives that it is often impossible to identify it by anything less than changing your focus.

© The authors and Studentlitteratur

The wheelchair in its setting constitutes a system that can afford or obstruct function. Without a wheelchair I can't go anywhere. With my regular wheelchair, I am unable to move around in the unspoiled countryside or other inaccessible settings. The solution in Biarritz was to move on to another pub or bar which was more accessible, or to stop drinking beer and start drinking whiskey instead (more alcohol per unit of liquid = fewer visits to the lavatory). Or to simply forget about France and Europe and go someplace else where there is proper legislation and a more welcoming attitude.

All solutions that mean that I, due to external factors, am forced to forgo activities that I would like to participate in limit the control I have over my life and over functions that satisfy my wishes of how I want to live my life and the person I want to be. When the restrictions and limitations are already great from the start, they are very irritating. It is even worse when they are unnecessarily compounded as a result of unwillingness, unawareness, unresponsiveness and irresponsibility.

More steps to freedom

I was tired of aiding and abetting the discrimination against me by stepping aside and withdrawing. I wanted to have solutions, life and enthusiasm. The European trips had whetted my appetite. I set off entirely on my own for the island of Tenerife off the northwest African coast. It was to the relative security of the Vintersol Rehabilitation Centre, but I made the journey alone; just me and my wheelchair.

At first, I stayed within the secure, sheltered, accessible and walled-in compound most of the time. But a good friend kept nagging me to hire a scooter – a three-wheeled motorized wheelchair – and join him out in the obscure unknown world on the other side of the walls. Or at least to Burger King to get a hold of some real food! As always then, before I had become familiar with the enabling power of technology, I was reluctantly hesitant and thought I couldn't manage driving one of those machines. The speed would certainly throw me off and I would certainly …

© The authors and Studentlitteratur

You are really ignorant before you try. My curiosity finally got the better of me about the machine and what was out there on the other side of the wall.

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, and more often after that on my own. Me and my machine. The machine that obeyed me. Just me. Up 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.

I went out in the evenings, enjoyed choosing which direction to go myself and sometimes taking dangerous and foolhardy chances that I should have avoided. But I did it because I wanted to and because I could. Because I needed to test my limits and because I needed to do a lot of things I hadn't done in a long time. It always worked out and I always made it back to Vintersol. Sometimes late at night, sometimes early in the morning. But that was OK; the old rule that you had to notify the night nurse if you were coming home late had been done away with a few years earlier. Someone thought that adults were actually capable of taking their own responsibility for when they were going to bed, even if they had a functional impairment. Imagine that!

When I returned to Tenerife a few years later, many of the fears that I had encountered the first time were a thing of the past. A new functional aid, the mobile phone, had caught on. Equipped with a black, plastic, brick-like gadget in my bag, I could call for help if anything went wrong, no matter where I was. The world had become more controllable. Fantastic!

© The authors and Studentlitteratur

Studying

My self-confidence grew with the number of machines and devices I acquired. I had a computer that I used for writing and programming. I wanted to resume my university studies, which had been cut short. I received invaluable help in doing so from one of my former teachers. She showered me with even more gadgets and machines and as time went by, I began to see what I could use them for.

I got hold of a newer, faster and better computer and it was connected to something novel called the internet. From my computer at home, I could hook up to the Faculty of Technology at Lund University. There wasn't very much to download in the beginning, though, since most of the instructors I met didn't really believe that internet and email could be used in the courses they taught. They wanted me to fax them anything I needed to send. But there were a few who understood that something revolutionary was going on, and who could consider using email even with a student. In addition, there was an entire world outside of the university where a lot of cool things were happening. I was virtually transporting myself farther and farther away from my flat.

My resumed studies went well, really well actually. And when the coming year's programme for exchange students was announced, I felt a mixture of fear and desire seep down from my brain, through my spine and into my heart. California. Santa Clara. Maybe I could …

Down from the mountain

I don't remember if I thought about my computer or the internet when I finally decided the heavenly snow in Heavenly was a bit too cold, and that the California sun was not quite warm enough at that altitude. In any case, I started to prepare myself for the descent from the mountain. One of the fellows on the rescue team stopped to talk with me on his next trip past. He told me there were a few fellows who were "sit-skiing" on the other side of the mountain. They used a kind of wheelchair that didn't roll but was mounted on

© The authors and Studentlitteratur

skis. The idea was to fling yourself down a vertical slope on such a contraption. “Great fun!” he said. “Sure, thanks,” I responded. But having just discovered that I was alive, I felt I wanted to continue living a little while longer. I still had some sense of self-preservation left. But just the right amount. I reminded myself, though, that you should never say never.

On my way down from the mountaintop, I probably should have thought of the internet anyway. For every trip I take in the physical world, I can find an abundance of information about my destination in advance on the internet. It enables. It gets me to start packing. I amassed a lot of information about Santa Clara on the net before I could even consider going there. And it was under a lemon tree in that sunny part of the world that I found all I needed to know about Heavenly and Lake Tahoe before I went there. Control, control.

And now what?

In the virtual world, I travel entirely without a problem. In the real world, many problems can be solved owing to what the virtual one can help me with. And that is what makes a man in a wheelchair brave in a new world.

What I have described here happened a number of years ago. Not so very many actually, but if measured in the era of the internet, this all took place in its stone age. I still use the internet to take the edge off my remaining and recurring doubts and fears. An email to someone enables me to ask about the width of the lift, or if I am able to get into a theatre or restaurant. And that can make all the difference. It gives me control, and not just over the width of the doors. The act of asking means that they know that I am the one who is coming, not just anybody. From the answer (information and manner) I can also determine their attitude.

© The authors and Studentlitteratur

Coda

My intention writing this chapter wasn't to just contribute a few good stories. I also wanted to have control over the index of this book so that it would contain the following words:

afford
attitude
control
disablism
enable
function
functional impairment

© The authors and Studentlitteratur

Part 2
Theory and method

11 Rehabilitation technology, design and pedagogy

Certec[1]/Bodil Jönsson

The ten chapters that you have just read are quite different from one another, but they all carry one and the same message: a disability can cause significant problems, but there is always something you can do about it. It is the *doing* that we want to highlight in this section, but now based on theory and methodology. This includes elements of design, technology and pedagogy.

Even though situations and impairments may vary tremendously, the theories, methods and approaches to the actual *doing* have much in common. Consequently, different efforts and ideas can reinforce one another. Each and every theoretical or methodological leap that we have achieved or been involved in has improved the quality of individual projects.

On three previous occasions, Certec has presented its thoughts on theory and methodology: *Certec's Core* [Jönsson, 1997][2], *Rehabilitation Engineering and Design Research – Theory and Method* [Jönsson, Anderberg, 1999][3], and *Situated Research and Design for Everyday Life* [Jönsson et al., 2004][4]. Much of what follows is derived from these three articles as well as the book, *Just Give Us the Tools* [Bauth, Jönsson, Svensk, 1995][5].

1 Chapter 11–14 authors in addition to those who have written individual chapters: Eva Flodin, Jörgen Gustafsson, Charlotte Magnusson and Kirsten Rassmus-Gröhn as well as Lone Malmborg from Malmö University, Arts and Communication, Malmö, Sweden.
2 Available at: http://www.certec.lth.se/doc/certecscore/index_t.html
3 Available at: http://www.english.certec.lth.se/theory.html
4 Available at: http://www.certec.lth.se/doc/situatedresearch
5 The original Swedish version is out of print. Both Swedish and English versions are available online, the latter at: http://www.certec.lth.se/doc/justgive/

© The authors and Studentlitteratur

We hope that you will utilize and benefit from the structure and overview that is presented as well as the comprehensive references list for continued study.

The lived disability

What rehabilitation engineering can and should affect above all is the *lived disability*. We have the same goal as medical research: to cure, alleviate and comfort. But our focus is on the principal person's *perceptions* of what is important for her and what she wants to be able to *do*. It is the doing rather than the diagnosis that is emphasized. The person is central: we begin and end the process with her and her needs, memory, preferences, personality and future dreams. It sounds so simple and obvious, but in realty, that is what poses the greatest challenge. Neither the priorities nor the exclusions are evident from the start. Just coming up with a requirements specification isn't so "just" – when it is completed, the most difficult part is over. In our experience, you are seldom able to methodically come very close to achieving this through questionnaires and interviews. In many cases, it is only in the *doing*, the acting, and the situated that you are able to succeed. There are even ideas that can only be expressed in actions, not in words [Vygotsky, 1930]. Take a look at Peter Brusén's book, *Livet en gång till (Life One More Time)*, which has many thought provoking examples [Brusén, 2005]. He suffered a spinal cord injury in an accident that left him paralyzed from the chest down. His children were unable to understand how severely injured he was before he actually returned home – that's when the magnitude of it became apparent. He also emphasizes how an understanding based on empathy requires action. On a small scale, it can be doing something about those antenna wires hanging down in front of the closet in the hospital room. On a large scale, it can be a matter of questioning what is professional in, for example, the handicap bureaucracy and case management. Johan Cullberg, in his preface to the book, hits the nail on the head when he states: "The necessary empathy based on reflection is exchanged for a protective wall of cool objectivity that is often mistaken for professionalism."

 © The authors and Studentlitteratur

Artefacts as thoughts realized

Technology can function as a language both when used as a questioning probe ("Is this what you want to be able to do? In this way?"), and when it functions as an answering probe ("Oh, is it 6 o'clock already? Then it's time for me to …"). Bruno Latour is the person who best expresses the power struggle between humans and technology [Latour, 1991]. He asserts that technology is society made durable. What has enabled our ancestors to live on in us are not only traditions, stories and memories but perhaps even more so, the long-term sustainability that we encounter everyday in buildings, products and technology, all products of human ingenuity, which in the language of technology and design are called *artefacts*.

Perhaps you have never thought that artefacts in reality are nothing more than *thoughts realized*. The ability of artefacts to make thoughts (or the lack of them) visible and robust is a characteristic that can be of special value for people with disabilities. Artefacts can act as liberating pedagogy if they liberate you from the difficulties that otherwise dominate your life (e.g. problems planning or remembering). Sometimes artefacts "only" facilitate, sometimes they provide true first-time opportunities, such as computers and internet have done and continue to do for large groups of people with different kinds of disabilities. The opposite can also occur: lack of thought resulting in artefacts that exclude. This occurs in physical planning that prevents access to people in wheelchairs, text that because of size or contrast is invisible for a person with low vision, or cognitive oversights that reduce intelligibility, particularly for those who cannot read.

Actants

Thoughts realized, i.e. concrete artefacts, can in the early stages of a design process work well as a background against which you can clearly express yourself and come up with new ideas ("That wasn't what I meant. I wanted something more like …"). Latour makes no clear distinction between humans and their technology – he calls

© The authors and Studentlitteratur

both *actants* and focusses primarily on the interplay between them [Latour, 1991], how power flows, how there is a fluctuation in who and what is taking the initiative. Agreements that were originally social in nature can become permanent in a technological form. Just consider how the introduction of the internet has accentuated the searching, inquiring nature of people – reinforced it, and made it self-evident and impossible to any longer be called into question by those with an authoritarian point of view [Jönsson, Rehman, 2000; Jönsson, 2001].

Technology can only be developed in interplay with its surrounding culture, and it needs to express values that, if not in harmony with the culture, are at least accepted by it [Castells, 2000].

Not just gadgets

Rehabilitation engineering and design are based on human needs, wishes and dreams and have as their most important goal the perceived enjoyment and benefit they bring the user and those in his or her world. The process thus begins and ends with the individual. At the same time, the method and to some extent the language 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.

The overall goal of research in rehabilitation engineering and design is that the results sooner or later benefit people with disabilities. This means continually striking a balance between quick-fix efforts for particular aids that can be ready *now*, and greater intellectual and research efforts that can pave the way for an entire arsenal of aids, sometimes built into the culture and thus so ubiquitous that they are almost invisible. Compare this with the discussion of stress in chapter 5.

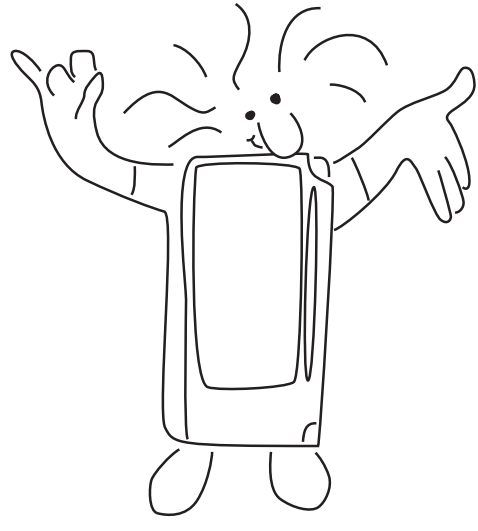
It is also important to realize that the results of research are far from always individual prototypes for production development or for improved design with active participatory assistance. Just as significant are the new insights into the needs, wishes and dreams that are revealed by means of technology and design. In other words, knowledge of person and of new methods to access such knowl-

 © The authors and Studentlitteratur

edge. The efforts may need to be of a high-tech nature, but they can just as well turn out to be low-tech or no-tech at all. After practical testing, it may be demonstrated that the problem complex needed entirely different solutions than those of technology. In other words, it is not the solution's final level of technology that is central in rehabilitation engineering, but the approach to thinking and working, which includes a systematic utilization of technology in order to better understand what the problem in question is all about.

Example

Isaac. Isaac is an example of a project that initially was exceedingly high tech. It started in 1993, long before digital cameras and GPS (Global Positioning System) were the property of the common man (or at least familiar to most people). We combined one of the first handheld computers, Newton, with a digital camera, GPS and telephony that enabled photos to be sent wirelessly. The project is still running – longitudinal in the true sense of the word [Jönsson, Philipson, Svensk, 1998; Jönsson, 2004].



Isaac with screen and pointer was personified to the point that he became a member of the group.

© The authors and Studentlitteratur

Isaac's primary lasting value is that we were using digital pictures at such an early stage that by the time general technical developments caught up, we had already established an experienced-based conceptual framework for how pictures as language could improve life in general for people with cognitive limitations. Another lasting value was the profound lessons we learnt about the design process. One of these is: You cannot know until you have tried. Another: Repeated and unexpected leaps in development can occur for cognitively limited participants when they master a new technology. By this, we do not chiefly mean that it takes time to learn (on the contrary, it often happens amazingly fast if you find the right approach from both sides), but that the horizons for needs and desires are quickly broadened and extended. When one need was satisfied, they were soon ready to move on to the next and then a new one after that. From having previously been content with predictable, calm stereotypic repetitions, new ways of formulating wishes and requests arose that neither the person involved nor those working with him were previously aware of.

Just as important in this more than a decade-long project is that the research teams and the research persons (i.e. the principal persons involved) now have a foundation of shared memories and a common set of experiences. This highly influences the interactivity as it occurs in a way that is rather unusual in a design context, where there are often new combinations of designers and users all the time and from which knowledge thus needs to be abstracted and sometimes formalized from one situation to the next. In the Isaac Project, we have been able to amass both situated and abstract knowledge in what at times has been a tacit interchange over an extended period.

Technology as liberating pedagogy

Not until there is a pre-prototype (or a mock-up, something that concretely shows the contemplated solution with the approximate weight, size and form) can the person who is the subject of the research utilize it to clearly express what she really thinks and wants. It is possible that she will find an entirely different use than the one

 © The authors and Studentlitteratur

that was assumed from the start – and that in turn will generate other ideas.

Common denominators can be discovered in a series of prototypes developed for different purposes, and these can lead to design principles and new hypotheses. Of course, the next group of users will very often need new solutions, but the knowledge acquired in one design process enables a designer to use the technology and ideas in asking more relevant questions the next time around.

It cannot be emphasized enough that solutions and conceptual approaches originally intended for disability populations can also be valuable for all people. *That which is designed for special, even extreme situations, sooner or later benefits the general public*. From the Isaac Project, ten well-proven assertions crystallized [Jönsson, Philipson, Svensk, 1998]. They have considerable significance over and above the project itself:

1 You cannot rely on needs to be formulated just because they exist. By providing a solution, technology can be a very good means (and sometimes the only) of showing that a problem exists and what it consists of.
2 You cannot know until you have tried.
3 The researcher is often controlled by his or her mental images to the extent that the end result often turns out to be amazingly like the original image. Consequently, you should attempt to make this inner picture visible as early as possible in the design process in the form of a mock-up, for example, so that others can see it too and constructively criticize it.
4 When an idea from the researcher's high-tech setting is transformed into a product in the user's no-tech environment (without even passing through a low-tech one) and finds its place there, almost anything can happen.
5 If the solution leads to the empowerment of the user, it can be a useworthy and powerful tool for change. If not, the effort will have been in vain.
6 Technology always develops more quickly than you can imagine. And then it turns out to be completely different from what you expected!
7 Empowerment and initiative are closely related. The multiplicity of personal digital photographs and their diversity proved

© The authors and Studentlitteratur

to set in motion an invisible inner process in the users that was essentially different from what pictograms' instructional methods were able to accomplish.

8 The language used in alternative communication should also be effective and in use outside of its specific environment.

9 The importance of pictures for accessing the user's past cannot be overemphasized.

10 Assistive technology (in this case digital pictures) can have far reaching consequences for the users, perhaps as a pedagogical aid that they will eventually be able to manage without, or perhaps as a compensatory device that they will need all the time. It is important that the same technology is used everywhere: at home, on holidays and breaks as well as at work.

The goal of research

"The overall goal is to gain new knowledge which will enable us to better understand the world in which we live and if possible, change it for the better. This goal should be the guiding principle for every scientist regardless of how the research is funded, or of the field and level of the research." This refreshing, strongly worded statement in the Swedish government report, *God sed i forskningen (Ethical Research Practice)* [SOU 1999:4, p. 23], indicates that research should not have to apologize for aiming to improve the human condition. On the contrary, the Commission wishes to emphasize that this is the obligation of every researcher.

In the social sciences, research that aims to bring about change during the actual research process is called *action research*. This concept originated in a paper by Kurt Lewin entitled "Action Research and Minority Problems" [Lewin, 1946]. Although it has existed for 60 years now, action research has not become firmly established. At times it has been severely criticized because the same researcher observes, influences, documents and analyses a process of change that he or she is involved in. This is, of course, very different from research that solely focusses on describing and analysing, and which has as its hallmark that the process should not be influenced by the researcher.

 © The authors and Studentlitteratur

With respect to technical and design research, there usually is no need to state the obvious: that its aim is to bring about change. In technology and design there is a strong "lean forward" approach ("What if we do it like this?"), which is something essentially different from that of pure analysis, i.e. to "lean backward" and reflect. The difference does not mean that you do not reflect and analyse in technology and design, but that reflection is more intimately associated with doing and takes place during a continuous, refining, iterative process.

All technology is *teleological*: it has a basic element of "in order to" (unlike the mechanistic "because of" of the natural sciences). Clocks for example are made *in order to* indicate time and telephones *in order* to talk with someone at a distance. In all technical development research there is at least a vague notion that the technology in question should meet some need – it may be a need for one or many individuals or an improvement or addition to existing technology, already being used (e.g. "time-saving" technology). Rehabilitation engineering is even more distinctly purpose oriented than technology in general.

There is an overlooked epistemological connection between technology and pedagogy. Both are teleological. Both require stringent structuring of reality in order to make it more understandable and manageable. Although exposing structures can be just as essential to educational activities as to technical ones, it is much easier to have a tacit structure in teaching than it is in programming, for example, where the reasoning process has to be spelt out and thus becomes accessible outside of the person's head.

Software as thoughts condensed

If an educator is able to make her educational assessment explicit, as well as the connections between assessment and the pedagogical steps then taken, education can assume the structure of software, to some extent at least. Eve Mandre's licentiate thesis is an example of this [Mandre, 1999].

The primary function of the software design process is to force the originator, in this case the educator, to expose her reasoning as

© The authors and Studentlitteratur

to what can and should be assessed and how assessment and pedagogical measures are related.

Charlotte Magnusson has gained similar experience through her research on expert systems on how rule-based relationships can be a way of extracting knowledge from experts [Magnusson, 1998]. The expert in question, the person whose knowledge is the foundation of the system, is forced to become more aware of his or her own thinking than ever before. Subsequently, once the software (e.g. educational software in the example above) has been created, it enables other people to carry out an assessment according to the input structure requested and by using the program to obtain suggestions for possible educational solutions.

This inspires substantive pedagogical discussions of an unprecedented nature – we now have access to the other person's *conceptions of how things are related*, i.e. her perceptions of how assessment and remedial measures are connected. (The phrase "conceptions of how things are related", which is much more expressive than the traditional term, "theories", was used by Torsten Hägerstrand in a letter to Bodil Jönsson in 1997.)

Think back to chapter 9 about Emma and the Minimeter. The potential was there from the beginning in the computer and in Emma Nilsson; her relatives and/or assistants and Björn Breidegard were there *together* and tested again and again. This is similar to the *Reading With Hands Project* that Björn is also working on in co-operation with experts from the fields of technology, psycholinguists, education and cognition. The goal is to design and test methods for recording, measuring and analysing tactile reading online. For the first time, it is possible to directly follow how Braille reading takes place and to compare eye movements to finger movements, in both the reading of text and when looking at pictures [Breidegard, 2007]. The blind people who have been involved as Braille-reading subjects can really be considered co-researchers or research persons themselves, because they have participated to as great an extent as any of the experts in the pedagogical discussions, which were made possible as a result of the great precision achieved in determining exactly how such reading takes place. The external technology elicited thoughts and ideas that not even the people reading Braille were previously aware of.

 © The authors and Studentlitteratur

HMI, Human Machine Interaction and variations

HMI has its origins in experimental psychology. As early as the 1970s people were talking about *usability and adaptability*. Attempts were made using *iterative prototyping*, but such efforts were difficult to combine with requirements specifications. Around 1985, *usability design* came into being (with measurable usability). Criticism grew, however, that proponents were only measuring what was easy to measure, and this resulted in 1987 in the reinvention of *participatory design*, now under the name of *contextual design*.

Good technology means the right parts are visible and that they afford the user a choice or convey the right message. For example, a button should convey the message "push me" and a knob "turn me." To be easy to use, technology needs to provide the user with confirmation that the right task or function has been executed. What if a seat belt didn't click when fastened correctly? What if a camera didn't snap when you took a picture? (Unfortunately, something absent in many digital cameras.) Another way for a technical device to confirm that it has received information can be a lamp that lights up.

The user should receive help in remembering and cognitive support from technology. It should be self-explanatory and not obviously frustrating (such as the warning text on a Swedish train – "Don't pull the emergency brake in case of fire" – without any explanation as to what you should do instead). Donald Norman [Norman, 1988] expresses this by ascertaining that people in general want to learn how to *handle tasks*, not how to handle devices. In terms of design, it is thus essential to bring the tool to the task, rather than the task to the tool [Norman, 1993]. Paul Dourish is also convinced of this as he states in the book, *Where the Action Is*, which we will return to later [Dourish, 2001].

The user should be able to come up with a good mental image of how the technology works. There should be an understandable relationship between the functions of the device and the controls used to operate it. In addition, the device needs to be robust.

Preferably, you should not be able to make a mistake when using it. And if you still end up doing so, it should not result in a catastro-

© The authors and Studentlitteratur

phe. Examples of good systems are electrical plugs that only fit in the right outlets and cars that will not allow you to lock the keys inside.

The principal person in context with the technology

That technology must be adapted to the individual and not the opposite is particularly apparent when it comes to people with disabilities. They are not always able to compensate for technology's shortcomings, as others often do and are thus able to make the system work *in spite of* deficient functionality on the part of the technology.

In other words, it is necessary to set about designing technology so that it is usable and useworthy for all, not just for technically oriented men between 18 and 30. In advanced airplanes, nuclear power plants and processing industries, it is the technology that dominates the entire setting. Here it defines what is to be done – a job needs to be completed and the technology was produced to do so. But when it comes to everyday technology and rehabilitation engineering, the situation is different. Here there is always a central person, and a human as well as technical setting to be considered. There is a big difference between developing a personal robot for the needs of someone with a physical impairment and a factory robot for industrial use [Eftring, 1999].

The significance of the environment makes it difficult, if not impossible, to test assistive technology primarily in the laboratory. In order for the final product to be useable, the central person, i.e. the person for whom it is intended, has to be part of the development process in a situated manner, in the setting in which the technology is intended to be used.

© The authors and Studentlitteratur

The interactive

In the development at the Pictorium, a day activity centre in Lund, Sweden for adults with developmental disabilities, it is difficult to differentiate which ideas have come from the researchers and which from the people who are being studied, i.e. the research persons. The development is described in *What Isaac taught us* [Jönsson, Philipson, Svensk, 1998]. Recently, it has progressed even further in the framework of the project entitled *Mobility and Learning* [Jönsson et al., 2002; Svensk, Jönsson, Malmborg, 2005].

Every previous experience, and particularly those that were realized in products or routines, can function as springboards to new kinds of communication. Implemented thoughts are also especially effective when you want to transfer knowledge to people other than the original research persons – in this regard, read *Design for Cognitive Assistance*, Arne Svensk's licentiate thesis [Svensk, 2001].

STEP

For people with cognitive limitations, it is important that the design results in the person experiencing:

Security
con**T**ext
Experience (memory)
Precision

Arne Svensk, who wrote chapter 7 ("In the kingdom of the blind is the one-eyed person king?"), developed this concept which goes by the acronym STEP. STEP can function as a checklist before and after a design process, and as a guide while it is in progress [Svensk, 2001]. Does this approach to design reinforce the "Sense of Coherence" (Antonovsky's SOC as described in *Unraveling the Mysteries of Health* [Antonovsky, 1987])? Does it improve the sense of security? Does it build on the concerned person's previous experiences? Does it have a precision that the user understands?

© The authors and Studentlitteratur

STEP for Security, conText, Experience and Precision.

Example

Precision in expressions of time. If you often say "in a while" to someone with difficulties understanding time, you are not being especially fair. "A while" can mean just about anything from a minute to an hour – or maybe something quite indefinite. People with weak cognitive contours need precision and to this end, you can actually introduce a "while-clock" that with great precision visualizes how long this particular "while" is going to be. The "while-clock" acts as a standard, something both parties can go by, a mutual agreement on how long the "while" is going to last.

The underlying principle of the STEP method is that cognitive processes and problems always exist in contexts and are distributed over people, time and artefacts. That is why they have to be studied and analysed in current, interactive situations.

© The authors and Studentlitteratur

The time factor

The time factor is often the most crucial one in determining if rehabilitation engineering efforts will be meaningful or not. It is particularly important for children that assistive technology appears at the right time. A solution that comes two years later is actually no solution at all for the child involved. This was one of the considerations behind the *See More Project*, directed at introducing assistive devices early in the lives of children with low vision so that they would increase their desire to see as well as their learning at an early age [Inde et al., 2001]. For many adults, particularly those with severe progressive disorders, time can be a crucial factor as well.

It is not just external conditions that can change during a design process causing it to draw out in time. The interests and dreams of the person involved can also change. Still, a design process shouldn't be sped up just for the sake of getting it done quickly. Sometimes, you have to accept that what is done for one research person may only actually come to benefit the next.

Sometimes it can eventually end up benefiting *all* the people involved. That is our hope for the new technological methods that easily enable us to follow the fingers of a person reading Braille [Breidegard, 2007]. This can result in improvements in the teaching of Braille that are clearly evidence-based on reading styles that have proven to be more practicable and effective. This, in turn, can affect learning to read Braille for *all* blind children.

As soon as somebody becomes a research person, his or her expectations and hopes are raised. If these are not fulfilled, it can result in disappointment and a refusal to assist again. This places a moral responsibility on the shoulders of the researcher/ designer/ rehabilitation engineer to never forget the significance of the time factor and to do their best so that the work they carry out will at least result in a little something of value for the research person initially involved.

In praise of documentation

You often hear that there is no point in documenting since you are still unable to interpret the context. The documented reality may

© The authors and Studentlitteratur

look like the following 39 postulations in the case of Per. Are all 39 points of equal importance? Are there any connections between them? Are there principal and subordinate problems? Where should you start? The result of documenting in this manner, by just making a long list, may be that you clearly demonstrate for yourself and others how incompetent you are, that you really do not understand anything at all. Read for yourself and reflect:

- Per has no friends at school or at home.
- He has hallucinations due to his migraines.
- He can become very aggressive if he doesn't get what he wants.
- He often dresses in women's clothing.
- His father physically abused both Per and his sisters.
- Per's intelligence borders on normal but he refuses to go to school.
- His biggest interest is guinea pigs, and his room is full of cages.
- He can ride the bus but refuses to do so because he fears it will bring on a migraine.
- Per lived in six different institutions before the age of 15.
- His parents would rather he didn't come home on the weekends, but Per wants to.
- Staff members are afraid of him. The women in particular want him to move out of the group home.
- Sometimes Per refuses to wash himself for a week.
- He likes all kinds of food and can eat large quantities. Currently he weighs 110 kilos.
- He ends up in psychotic-like states in which he feels hounded and humiliated.
- If demands are placed on him, that he should wash himself for example, he locks himself in his room for several days.
- Per goes in and out of his fellow residents' rooms.
- He has extensive language limitations and does not understand certain common words.
- On the weekends, Per often refuses to participate in planned excursions. As a result, the others can't either – staffing limitations make it impossible.
- Per is both tight with his money and extravagant. He can spend lots on certain gadgets, but at other times claims that he can't afford chewing gum.

© The authors and Studentlitteratur

- Per has difficulties separating migraines from nightmares. This confuses him.
- In the evenings, Per can sit and talk several hours on the telephone, resulting in enormous telephone bills that he refuses to pay.
- At times, when Per has decided he is going to do something, like go shopping, and it is not possible, he tries to get his way by threatening and aggressive behaviour.
- No one who works in the group home likes Per. He senses it.
- At times it seems that Per uses his migraine attacks to get his way, for example, in a shop.
- Per is afraid of young children because they can tease him.
- He is thoughtful when it comes to his guinea pigs and takes care of them meticulously.
- Because of his migraines, Per takes a lot of medicine, which changes his personality.
- Per's sisters have normal intelligence and are working.
- Per does not like to watch TV.
- Per's greatest interest, outside of his guinea pigs, is dance music.
- Per will agree to draw up a budget if someone helps him, but he abandons it when it suits him.
- Per thinks that he knows everything better than anyone else.
- Per demands to switch rooms with Sven so that he has space for more guinea pigs, but Sven doesn't agree. Per then threatens Sven.
- Per sometimes becomes afraid when he is told that he is making progress. He doesn't like praise.
- Per often calls off duty staff members at home to play them against other staff members who are working. It's usually about money.
- Per is not afraid to go to the dentist even when it involves a lot of work on his teeth.
- Per would never think of getting birthday presents for his friends in the group home. But if he doesn't get expensive ones himself, he gets angry.
- If there isn't an abundance of food on a given day, Per makes sure he gets as much as he wants, and leaves whatever is left to the others to share.
- If the staff draw up an agreement with Per, he makes sure they fulfil their part of the bargain. But he feels he has the right to break his promises at any time.

© The authors and Studentlitteratur

This kind of documentation is necessary but not sufficient. One has to be able to determine when Per has a migraine, even when he does not report it himself. One has to be able to deal with Per when he becomes aggressive. This requires something more than going on intuition. It means being able to discover hidden connections and situations and to consciously search for the kind of technology that can be used as support. When those who work with Per approach it this way, they do not just read through the list from top to bottom and try to deal with the individual items. Instead, they will see things differently as they start looking in terms of what they can *do*. Their thoughts will take a different turn, for example: What if we try initially to give Per a set of protest buttons he can use: one for "DON'T WANT TO," and one for "ABSOLUTELY DON'T WANT TO." Is it possible to design a migraine "meter", or something else that clearly signals when the reason for Per's aversion is that he has a severe headache? And in that case, would it help? If it is possible to design someway for Per to indicate, "I WANT TO GO OUT AND RIDE MY BIKE!" – will he do so?

These kinds of efforts can be a simple way of starting to deal with what otherwise appears to be an insurmountable list. Perhaps those working with Per will soon discover some underlying factors or that some of the initial interpretations were completely erroneous. One example can be supported by another. This is also the case when you go from person to person or from organization to organization.

Example

How one thing leads to another. A group home employee stood in the lavatory with a disabled resident and tried to get him to pull up his trousers. He was deaf, so she pointed to the trousers on the floor. No indications that he understood. She tried again to point down at the trousers. Nothing happened. She then tried pointing at the trousers and then pointing upwards. The reward was not only that he pulled up his trousers, but smiled as well, which he seldom did.

After this story was told, the supervisor related how once when she was on a group outing in the woods, she tried to get a man to step over some bushes by the side of the path and come to where she was standing. He didn't understand so she lifted one of her legs to show him how. That didn't help. She lifted her leg again. He still

 © The authors and Studentlitteratur

didn't understand. Finally she took a big step forward with her leg raised. Then he understood and immediately stepped over the bush.

The story of the trousers on the floor led to the related example of stepping over the bushes. The one experience could be linked to the other and become a simple, applicable theory: observe yourself and see how logical or illogical your message is when you try to show a person with cognitive limitations how to carry out a sequence of movements.

Case studies

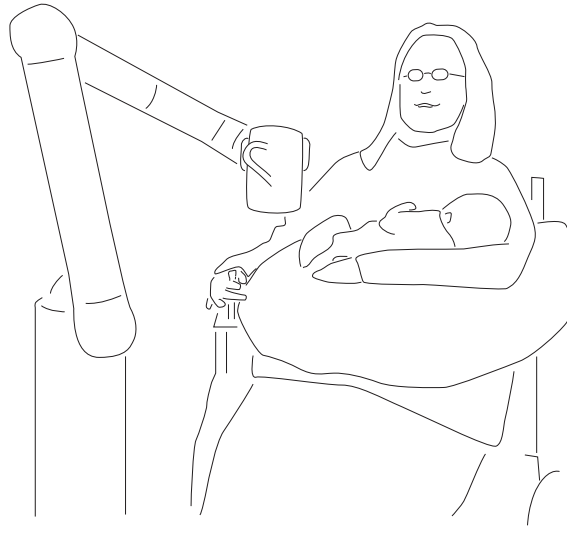
Case studies – immersing yourself in individual cases, formulating the problem and solutions, studying the effects – are something beginners as well as experienced researcher regularly devote themselves to. We contend as do others, among them the Danish social scientist Bent Flyvbjerg, that case studies are a widely underestimated research strategy. The interested reader is referred to his book, *Rationalitet og makt (Rationality and Power)* [Flyvbjerg, 1991] and above all to the brilliant Chapter 8. "Exemples magt" ("The Power of the Examples"). From Flyvbjerg we have borrowed the following outline of how cases should be selected to maximize information:

1 Look for the extreme/aberrant cases

The extreme or aberrant can act as an eye-opener – the phenomenon is often not only found in the deviating person, but he or she also helps us catch sight of it. An example of this is the in-depth interview with Eva Almberg, a person who to a certain extent accepts her disability but is in no way willing to accept one of its consequences: constant dependence on other people [Eftring, 1999].

There is an aspect of "more is different" (see chapter 14), which can be especially tangible for people with impairments: individual requests for assistance, when added together to make up a long chain, become something entirely different. The individual act of asking for help to pick up a piece of paper or to take a book down

© The authors and Studentlitteratur



Eva Almberg would rather have technology than people as actants.

from the shelf or fetch a sweet is something quite different from asking for help five or ten or fifty times. Even though it is the job of a personal assistant to assist, they are also human, and there is a difference between ordering a person to do something and doing it yourself with an assistive device. It is not just a matter of being considerate and polite to the assistant – it is even more about having to formulate in words exactly what it is you want the assistant to do instead of being able to do it yourself with technological assistance. Eva Almberg has an exceptionally strong preference for the technological over the personal – and she is able to articulate it. In that way, she is a valuable extreme case.

2 Look for maximally divergent cases

It can be advantageous to select 3 to 4 cases that diverge maximally on a given parameter. A classic example of mental support: When, in the world of physics, they wanted to show that 1 kg of material falls just as fast no matter what it consists of, it was enough to carry out the experiment with 1 kg of lead and 1 kg of feathers. Lead and

 © The authors and Studentlitteratur

feathers have such different densities that if the fall time was the same for both, it would be the same for all other materials. Once the extremes are measured, there is no reason to repeat the experiment.

3 Look for critical cases

Critical cases are those in which you can say: "If it applies to him, then it applies to everyone." Or: "If it doesn't apply to him, it won't apply to anyone."

4 Look for paradigmatic cases

This is what Flyvbjerg calls cases that found a school for the field. A scientific activity is recognized and acknowledged as good science based on similarities with one or several examples of good scientific work. A specialist field without many good case studies is a field lacking the systematic creation of models and is thus weak. Certec wants to contribute to making the field of rehabilitation engineering and design a strong specialist field, and our best way of doing so is most likely by working with more case studies which can generate models. We are particularly pleased that case studies are so well suited to being a meeting place for people with disabilities, researchers and other interested parties. This is where the generalizable and the particular can co-exist and both merit being accentuated.

We will return to case studies in chapter 14, which deals with the scientific positioning of rehabilitation engineering and design.

The situated

It is good, often best, if relevant information can be captured in the situated, where people involved live, work and act [Dourish, 2001; Hutchins, 1996]. To be able to start with the needs, wishes and dreams of the person and end with some kind of technology that enhances function for the person, you can also be in need of a little technology along the way. Technology can function as a cultural probe (see chapter 12) or even as a language. It can be used as a tool for both asking and answering [Jönsson, 1997]. Testing imaginative,

© The authors and Studentlitteratur

small artefacts early on can show if you are on the right track ("Was it something like this that you mean?"). In practice, the design of technological solutions consists of an interpretation of the underlying problems and doing so in a language that is based on technology's own means of expression.

Our emphasis is on the actual *function* and design so that life will *function* better, whether it has to do with closeness and communication, pleasure and recreation, learning, empowerment, freedom, flexibility or safety – just to name some of the aspects of a person's life. Technology can make a difference in all of these.

In praise of technology

Many people find technology fascinating and will gladly spend hours and hours on it. In rehabilitation engineering and design some special features emerge:

1 Technology is honest

People with disabilities and those around them can interact with technology instead of passively waiting for someone else to take the initiative. Design requires a kind of practical reflection. It is closely related to the situated, case studies and time geography (see chapter 14) by restricting the research to the situation in question. Technology is what it purports to be: no more, no less.

2 Technology is neutral

It is difficult, perhaps impossible, for a human being to be entirely neutral. This is particularly important to recognize when people act as representatives for others who have problems communicating or other cognitive limitations. In that situation, technology's neutrality represents a greater respect for the individual's integrity than a fellow individual, however well meaning, is able to do.

© The authors and Studentlitteratur

3 Technology is concrete

When it comes to people with cognitive limitations in particular, it is essential to have an object to refer to when you are trying to understand needs, wishes and dreams. Abstract questions or thoughts simply do not work.

4 Technology provokes

An idea, a discussion or a lecture has something fleeting about it. A technical device, on the other hand, remains and eventually forces you to take a position. Sometimes technology brings a previously hidden contradiction to light, which must be dealt with.

5 Technology surprises

In an attempt to utilize technology as a language, we have often been surprised by how the reality answers entirely different questions than the ones we asked when it was introduced.

6 Technology liberates

There are occasions in which neither the person with a disability nor anyone she deals with notices her limitations and the obstacles she is facing. It can also be the case that those in her surroundings do indeed perceive the impairment but take for granted that there is nothing they can do about it. Instead, efforts go into making living with the disability bearable. In a third case, people with disabilities experience the actual need, but no one else sees it. It is in this situation in particular that a technical measure can function as a liberating pedagogy. The absurdity of the situation is revealed. The unknown can be discovered, by twisting around what is already known and taken for granted [Mandre, Jönsson, 1996a; Mandre, Jönsson, 1996b; Mandre, 1997].

7 Technology empowers

Our experience tells us that in the entire chain from simple push-button commands to advanced computer technology, only the technology that empowers has a profound effect. Consider the following list of technological risks and possibilities:

© The authors and Studentlitteratur

Dangers	Possibilities
Technology is cold, people are warm.	Technology can contribute to human warmth surfacing and spreading from one person to another.
Disabled people risk becoming isolated if they are able to manage activities of daily living on their own with technology.	Thanks to technology, disabled people can better manage activities of daily living and seek out the contact they want to have with others on their own. See chapter 4.
New technology is not primarily intended for the people receiving social services, but is instead a way for local authorities and county councils to reduce personnel, in group homes for example.	New technology is intended for the people receiving social services. When they are able to manage a portion of what they previously needed personal assistance for, they will be able to progress further in their wishes for experience and support. It won't be cheaper for the local authorities, but they will get better quality for their money.
If you have a lot of technology for mental support in a group home, you will lose the feeling of being at home, replacing it with a small institution.	If you have a lot of technology for mental support at home, it becomes your own secure living space with opportunities to do things in private without anyone seeing, and for the right to be able to make mistakes in private.
Modern technology is so advanced that not even the staff members know how to handle it. How will a disabled person be able to?	Modern technology is so advanced that not even the staff members know how to handle it. People with disabilities will perhaps find it easier to handle.
If you start using technical aids, there is a risk you will stop training and thus not be able to achieve your optimal level.	If you start using technical aids, it is possible for people to come much further in their development than they would have otherwise.
Technology is insensitive and unreliable while people are sensitive and flexible.	Technology is an obedient tool that you can control, while people interfere and interpret.

© The authors and Studentlitteratur

12 Design

Certec/Bodil Jönsson

Design stands for usability, useworthiness, functionality and aesthetics. Part of the designer's task it to listen to how the situation "talks back" [Schön, 1983], not just during the prototype phase but also during the entire life cycle of the product including recycling. This perspective has been reinforced over the last 20 years. The anthology, *Future Interaction Design* [Pirhonen et al., 2005], does not emphasize technology per se, but rather the social, cognitive, emotional, creative and action directed dimensions in humans. These make up the foundation of interactivity and are in the process of gaining a progressively stronger hold on design.

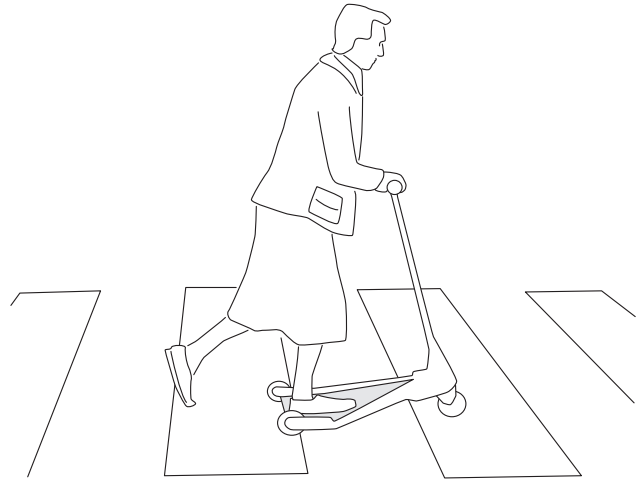
Design has a *direction*. At its core, it deals with how things *should* be, what they *should* become, rather than how they *are* [Edeholdt, 2004]. The focus is on an analysis of possibilities and future effects rather than the existing difficulties and their current effects – they can soon be a thing of the past.

"Design is such a natural human ability that almost everyone is designing most of the time – whether they are conscious of it, or not" [Nelson, Stolterman, 2003]. Design is not only a professional activity or research. It is also a common, daily-life, human activity, not least of all among people with disabilities.

Example

Design based on one's own needs. When Elisabeth Linderoth, then 84, didn't have a practical vehicle with which to go shopping, she invented the shopinette: a kick scooter with room for a shopping bag on the foot platform [*Svenska Dagbladet*, 2003]. It won a prize for its stability, space, steering and braking, which were obvious and necessary features for her.

© The authors and Studentlitteratur



A shopinette in use.

This example provides us food for thought: curiously enough, contemporary design and technical developments have so far contributed little to the area of *elderly people and design*. A research programme initiated in 2003 is now underway in that area.[1]

No matter what the purpose of the design or who is going to realize the product, user participation is crucial. It concerns finding out as much as possible about the dream, wishes and needs, not only at the start but during the production phase and later on when the product is in large-scale usage. When people have grown accustomed to an artefact, learnt all about it, and thus utilize it more consciously, other features emerge, not just for the person, not just in the product, but in the interaction between them. Obvious questions are: Is it being used as was originally "thought" (often not)? What are its effects?

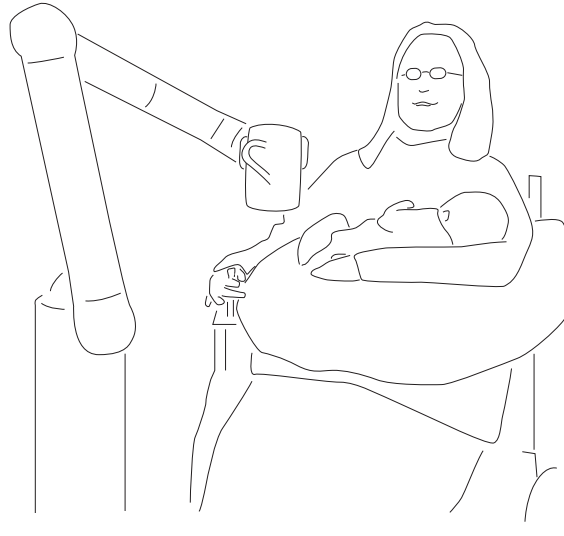
1 Information available at:
http://www.design.lth.se/aldreochdesign/elderlypeopleanddesign_screen.pdf

© The authors and Studentlitteratur

Example

Right-handedness. This is an example of a crucial aspect that did not become obvious until the assistive device was in use. If you are a wheelchair user and have some slight functional movement in your right hand, the controlling joystick is most likely mounted on the right side. Personal assistants often provide help from the right as well. If you want, in addition, to have a robot arm mounted on your wheelchair so that you can do things on your own, it would thus seem logical at first to place it on the left side. It wouldn't be in the way. But how natural is it for a right-handed person to control a device positioned on the left? Right-handedness is not in the hand, but in the brain. In the case we are thinking of, the robot arm was moved so that it would be worth using (i.e. useworthy) for the principal person involved [Eftring, 1999]. But this wasn't discovered until the robot was put into use.

Lundequist states that there are three areas of design. The first is obvious, what we usually call "design", i.e. development of the actual product. The second is production, and the third is usage [Lunde-



Eva Almberg again: It didn't become clear until after she had used the robot arm for a while that it had to work from the right because Eva "thinks right-handed".

© The authors and Studentlitteratur

quist, 1995]. Research-wise, this trinity leads to a whole battery of questions:

What qualities should the future artefact have? What is its purpose?

What kind of design is it? What methods, activities and resources are going to be used?

How do you design for actual usage, so that the product will be as self-explanatory as possible? So that maintenance and service will function? So that it can be recycled?

"Artefact" denotes what is created by humans, the tangible results of thoughts realized (implemented). The term is used not only in design, but in many other fields such as ethnology and archaeology (where it can be important to differentiate that which is humanly created from everything else that has come to be over time). It is also a medical term, but in a negative sense of the word: an "artefact" in a medical test is unwanted matter that has somehow made its way into the sample.

The iterative

Donald Schön in his book, *The Reflective Practitioner* [Schön, 1983], revealed how development sometimes best takes place through action: acting and reflecting, acting and reflecting, over and over again. Through reflection, rehabilitation engineering and design can find out quite a lot about a person based on his or her use of technology, information that otherwise would not have surfaced. Successful action presupposes open reflection – and vice versa.

Design, the act of creating, can result in a multitude of *different* special products for different purposes for one and the same group of people. Sometimes this is necessary so that afterwards, by examining the artefacts rather than the people, you are able to see what the underlying need really is. These insights enable you the next time around to better and more quickly arrive at the best possible artefacts for the people involved [Svensk, 2001]. This corresponds to healthcare's "proven experience".

 © The authors and Studentlitteratur

Example

Diffuse cognitive contours. To see the common denominator in such widely varying activities as brushing teeth, cutting grass, baking, vacuuming or telling time, you can examine the successful aids that already exist for these functions. The solutions are essentially similar to one another because they solve one and the same underlying problem: all these activities have diffuse cognitive contours for the users. *Thus, what has to be added is distinct cognitive assistive technology*. The next design process that deals with, say, a shaving aid, can as a result of this insight get right to the point: what are the diffuse cognitive contours in shaving and how can you compensate for them? This approach doesn't mean that a shaving aid can be designed without user participation in the future, but that the design process proceeds from the right direction from the start, to the benefit of the users as research persons and the actual research process [Svensk, 2001].

Example

More is different. Time measurement is an example of an area of crucial significance for people with cognitive limitations. Not being able to orient oneself in time can result in constant anxiety. If you examine the clocks that have been designed for this purpose, you see how they all have fixed points and do not require personal assistance from others. Thus, they aim to compensate for diffuse cognitive contours [Svensk, 2001].

An experienced designer has a rich supply of metaphors: "It is like …" – "seeing as," according to Schön. "Thinking from exemplars," is how Kuhn expresses it [Kuhn, 1962]. You avoid unnecessarily mystifying intuition or creativity and can instead see ideas for solutions as springing from your rich world of experiences expressed as: "It is as if …", "It's like the time when …", "How did I do it last time?", "I've had a problem very similar to this one before!"

Rittel and Webber noted that design often works with "wicked problems": problems that cannot be fully described or analysed before they are solved [Rittel, Webber, 1984]. On the contrary, they are described and analysed in the course of the design process. This is comparable to a lesson learnt from the Isaac Project: needs will not

© The authors and Studentlitteratur

necessarily be expressed just because they are there. "Technology can be a very good (and sometimes the only) means of showing that a problem exists and what it consists of."

Donald Norman's position in the field of design is indisputable. He has argued forcefully that people are *analogue*, not digital; that people are *biological*, not mechanical [Norman, 1988]. That they want to learn how to handle tasks, not technical devices, and as we have already mentioned, to bring the tool to the task, rather than the task to the tool in the design process. Donald Norman has also provided the clearest specification of a number of user requirements for IT agents. One of the most important and central in the rehabilitation context is that the user must trust the agents. Only on that condition can autonomous technology be of value for a person with a disability – otherwise it can easily provoke anxiety.

Camilla Nordgren offers many thought provoking insights into risk and risk taking in chapter 6. See also *Funktionshinder, säkerhet, osäkerhet och katastrofer* (*Disability, Security, Insecurity and Catastrophes*) [Jönsson et al., 2004].

Further discussions concerning design applied to or specific to the IT field can be found in Löwgren and Stolterman's *Design av informationsteknik (Design of Information Technology)* [Löwgren, Stolterman, 1998].

Example

Insight through user testing. In a navigation experiment in an urban setting using mobile phone technology, the designer thought the major challenge was to describe as precisely as possible different routes for Erik to get from one place to another. Due to the limitations of GPS technology, you are unable to determine exactly which direction he is facing, so that telling him he should turn left or right, or go forward or backward is meaningless, even if Erik knows the difference between left and right.

The problem and the possibilities are quite different if the concept is based on an interaction between people who know one another. Erik sends a picture and the person receiving understands that he is somewhere in the centre of town, not far from the cathedral. Erik wants to go to the city park. The receiver, who knows that Erik can find his way to the computer shop, tells him to go there.

 © The authors and Studentlitteratur

Once Erik arrives, they re-establish contact and from there it is easy because the city park is almost within sight. There is a great difference between designing for an impersonal, general co-ordination centre and for a friend-based navigation support system.

Example

Having control over your own history. At an early stage in the Isaac Project, one of the participants with cognitive limitations wanted to take a trip back to the institution where he had lived as a child [Jönsson, Philipson, Svensk, 1998]. He suddenly wanted to use his digital camera for the purpose of taking pictures of the buildings that had been significant to him once upon a time. Why was it so important now? Perhaps he no longer wanted to rely on others to tell him about his past – he wanted to have his own verification and wanted to be able to tell about it himself. When he took control over the pictures, he was no longer dependent on the memory of others, their good will or time. In this case it was one and the same concept – the digital camera and access to the multitude of digital pictures – that could also be used to document his personal history. But what was genuinely new, was that this person who had discovered the power in the pictures and in the ownership of them, was also able to transfer that to a desire to document his own history.

When the principal persons are included

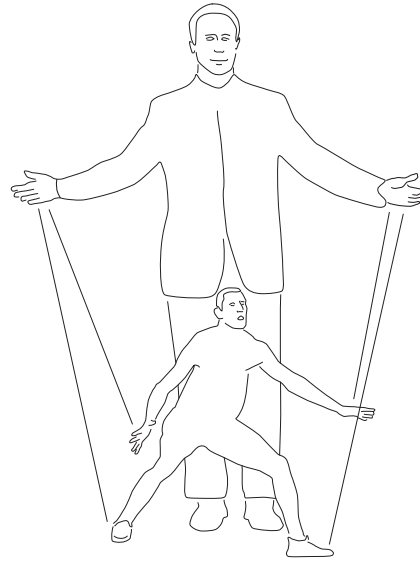
It is important that the target audience for the product is there from the start, not only for detailed functions but just as much for the product in its entirety [Kirschner, Buckingham-Shum, Carr, 2003; Plato, Jönsson, 2001].

Example

The experienced whole. For a robot researcher, it may seem obvious that a person with a physical disability would want to have a voice-controlled robot. But one of the reasons for choosing to have a robot can actually be that she *won't* have to give instructions all the time, *won't* have to talk and instead will be able to *act* and *control* it herself.

© The authors and Studentlitteratur

There are many ways of involving the user in the design process [Preece, Rogers, Sharp, 2002]. user-centred design emerged in the mid-1980s. The three main principles are: early focus on users and tasks, empirical measurements and iterative design [Gould, Lewis, 1985]. In the European Union's accessibility *UserFit Project*, methods are described to elicit what users and user groups want [Poulson, Ashby, Richardson, 1996], and descriptions can also be found in the standard literature in the areas of human-machine/human-computer interaction and human factors [Sanders, McCormick, 1992; Helander, Landauer, Prabhu, 1997]. Empirical data can be obtained by letting future hypothetical users use early simulations and prototypes, and then measuring what is wrong, how much is wrong, how long it takes to complete the task, etc. Good descriptions of such test methods can be found in the *Handbook of Usability Testing* [Rubin, 1994]. Finally, iterative design is a standard method that advocates design of early prototypes, testing, improved design, repeated testing, etc. – over and over again [Gedenryd, 1998]. A focus on *degree of usability* as a measure of when the iterative process can be considered complete can facilitate the entire technological process [Nielsen, 1993].



A shared "where-to" and "why" is essential.

© The authors and Studentlitteratur

The *participatory design approach* has its roots in a Scandinavian tradition. Originally, it was almost assumed that any involvement of the user would guarantee that the artefacts developed were meaningful [Ehn, 1988; Bødker et al., 1987 and 1993]. Over the years with increased experience has come increased humility. A shared "where-to" and "why", preferably in the form of an artefact, that unite the user and the designer are essential; otherwise the users can easily become the hostage or the alibi [Bødker, Iversen, 2002].

It is possible to differentiate four approaches when considering design in relationship to the user and usage [Bødker, Iversen, 2002]:

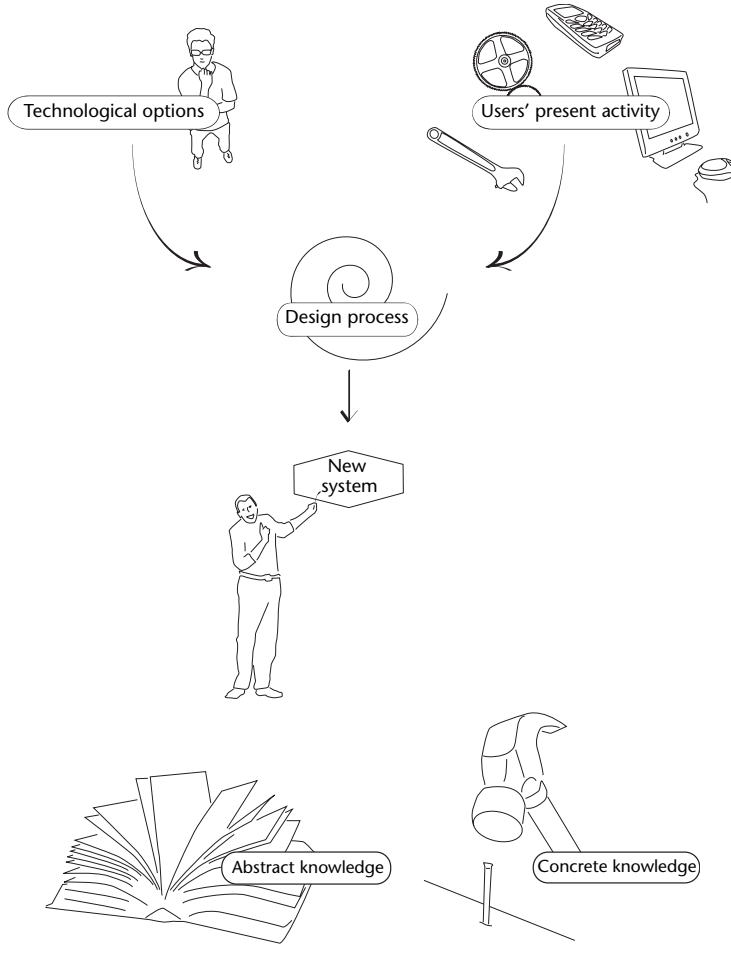
1 Design in context

Designing a computer artefact can mean that you influence the conditions for its entire usage. That is why you need to understand the contextual, the given milieu. If you interview someone, do it in context. In order to understand a situation, you have to be there in some sense, directly or indirectly [Wixon, Holtzblatt, Knox, 1990]. Many methods have been developed to do just that. Videoethnography is one of them [Suchman, Trigg, 1991]. You can also make use of cultural probes (see point 4).

But what does it really mean to "understand" a user situation? One way to consider this was presented early on [Kensing, Munk-Madsen, 1993]. These authors maintain that there are three different arenas that need to be taken into account: users' present activity, technological options and the new systems that evolve during the design process. For all three, you should make a distinction between abstract and concrete knowledge.

The user has, unquestionably, the concrete knowledge of what she is doing. But that does not necessarily mean she has the abstract knowledge which would enable her to explain how and why she does what she does and to formalize and abstract structures from concrete situations. At the same time, the designer can stand there with only an abstract description of, say, a step in the work process, without ever having carried it out himself. The risk is thus great that they talk at cross-purposes. A situated design approach prevents users with only practical experience and designers with only abstract knowledge from doing this.

© The authors and Studentlitteratur



Example

"*Aha!" experience*. When they started to use a web camera at a day activity centre for adults with cognitive limitations, it had unforeseen effects. The sound connection was not working for some reason: the two people communicating (the centre participant and the designer) from different locations could see one another and how their lips were moving, but couldn't hear a sound. The designer then telephoned the person at the day activity centre, and suddenly there they were, looking at one another on the screen with the tele-

© The authors and Studentlitteratur

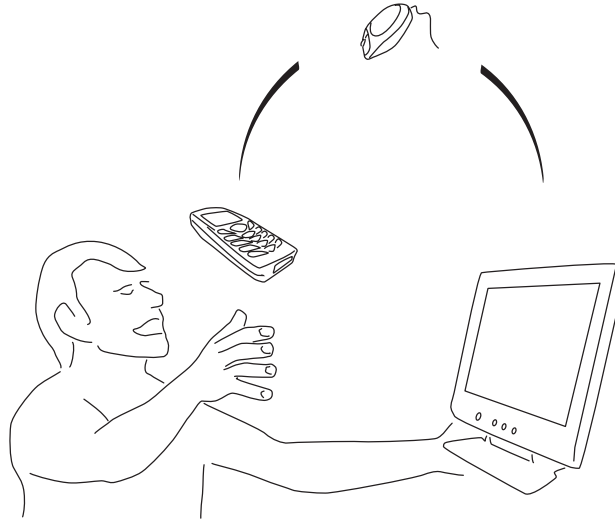
phone receivers in hand. This was a true "Aha!" experience: the receiver of the call had obviously never before been able to imagine what it was like for the person on the other end of the line when he was talking on the phone.

2 Communities of practice

Different users (and designers) have different backgrounds, different communities of practice, and that influences co-operation [Lave, Wegner, 1991; Wegner, 1998]. Each community of practice has its own identity inwardly and outwardly towards society on the whole [Lesser, Stork, 2001].

3 Experiencing future design

Users can be in need of experiencing future applications in advance in order to gain the "touch and feel" of them, and in order to stipulate their requirements. A mock-up (which provides an early model of existing parts as a unit and how it is expected to appear with, for example, the right size and weight from the start even if it is not yet functioning), different prototypes and user scenarios are



Lots of play is needed.

© The authors and Studentlitteratur

some of the standard methods [Kensing, Munk-Madsen, 1993]. Video prototypes are making their appearance where the users and designers together direct and film short "trick videos" simulating working designs [Madsen, 2002]. Another way of experiencing the future is to let the user play with early versions of the technology.

4 Cultural probes: engaging users and transcending practice

To be sure, the users' everyday life should always be the starting point. But both users and designers need to view their well-known situations and environments in new ways; they need to be challenged by new ideas to transcend well-established practices and habits. This can be accomplished through the use of *cultural probes* [Gaver et al., 1999 and 2004; Kensing, Munk-Madsen, 1991; Madsen, 1994]. They consist of items that make it easier to communicate thoughts and actions in different everyday situations. Assignments can be to: photograph the most exciting feature of your kitchen, send the postcard of the thing you long for the most, open the green envelop when you receive an SMS in the morning and answer the question inside (about the setting that you happen to be in at the moment), etc. Both the user and the designer can be informed and inspired in this way. It can be valuable to reflect on the design process before, during and after to insure that there is an x in all four of the boxes in this table:

	Inspire	**Inform**
User	X	X
Designer	X	X

Cultural probes are particularly valuable when the participants have language limitations: interviews, questionnaires or diaries simply do not work. That is when artefactual, inclusive pictures are even more in need.

© The authors and Studentlitteratur

13 More on methodological and ethical considerations

Certec/Bodil Jönsson

"Special needs are often talked about in connection with impairments. But it is not really the needs that are special. The needs are more or less the same – it is the methods, technology and theories that are special. They help ensure that the person involved can fully express his or her needs, wishes and dreams, in spite of functional reductions. If anything, it has more to do with special technology, special pedagogy, special care and special imagination than with "special needs".

The specific and the general

Special solutions almost always come to benefit people in general. Sooner or later. It was, for example, the difficult situations for children (poverty, devastation, disability) that brought about a significant change in how humans were viewed; brought about new educational approaches and new kinds of assistive technology that gradually become public property. In healthcare as well you can find innumerable examples of how interest in the special in due course also comes to benefit people in general.

In the long run, it is obvious that we cannot afford to be without knowledge of what is especially challenging, in particular because such knowledge provides us with tools that can counteract the exclusion of people.

Three indicators

Rehabilitation engineering and design methods should be subordinate to the imperative ethical demands in such research that one

© The authors and Studentlitteratur

has to proceed from the individual's wishes and viewpoints. We find support for this reasoning in three essential documents:

1 Article 27 of the United Nations' Universal Declaration of Human Rights

"Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits" [*Universal Declaration of Human Rights*, 1948].

2 Rule 13 of the United Nations' Standard Rules On the Equalization of Opportunities for Persons with Disabilities

"Information and research. States assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including obstacles that affect the lives of persons with disabilities [*UN Standard Rules*, 1993].

3 Ethical Research Practice, Official Swedish Government Report 1999:4

"Ethical issues arise throughout the entire research process, from the researcher's choice of scientific problem statement to practical application of the results of the research. Ethical questions arise when there are conflicting values …/

/… The whole research process as well as the role of the researcher must be subjected to a strict ethical analysis, primarily by the researcher himself. The ethical analysis requires good knowledge of the facts and an awareness of the values that may be gained or risk being lost. When important values are at stake it is morally responsible to say 'yes' as well as 'no' to research. Moral responsibility also means taking responsibility for not carrying out an experiment" [SOU 1999:4].

Ethical considerations are always close to the surface in rehabilitation engineering and design research [Fält, Jönsson, 1999]. The internet can bring such considerations to a head. That is why Certec developed a special web code of conduct.[1]

1 Available at: http://www.english.certec.lth.se/code.html

 © The authors and Studentlitteratur

Methods as tools for thinking and acting

Methods are tools for thinking and acting. Successful rehabilitation engineering and design research presupposes a good mental and action toolbox and the ability to select the right tools. An important step can be to divide the methods up into different compartments. It is not just a matter of choosing between low and high technology or between different kinds of design methodology. It also makes a difference if you:

- try to imitate the solution for a non-disabled person (the parrot method),
- search for a solution that can provide the same functional result but in a different form (the chameleon method), or
- develop something entirely different but which retains its fundamental characteristics, its very core (the poodle method).

Whichever method is used, it is self-evident that as far as possible, you should avoid designing special technology. The more you build on existing technology and computer applications that strive for compatibility with standard software, the greater the potential for successful utilization.

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 made up of the disabled person and her technology is capable of doing exactly what she would otherwise have been able to do without technology and she chooses exactly the same approach to problems that other people can handle without the aid of technology. For example: glasses, prostheses, corrective medication, wheelchairs, etc.

This is the most common approach in the field of rehabilitation engineering. The parrot method can be successful and, at any rate, this is often where you have to begin. Your imagination may not get you any further. But it is important to let the situation talk back and to follow up to ensure that you are solving the right problem.

© The authors and Studentlitteratur

You can sometimes avoid a dead end by defining the function you are aiming for before trying to solve the technical problem. Would it be better to try the chameleon method? Or maybe even the poodle method?

The Chameleon Method

The chameleon is a master at changing colours. This, in a figurative sense, is exactly what the chameleon method wants to do: preserve the same function but do it in an entirely different way.

Sometimes the chameleon method works in the open, sometimes surreptitiously. The task of mailing a letter is a good example. Not so long ago, all letters were tangible material objects, written on paper and sent physically. Then came electronic mail, and today the majority of letters are sent electronically. This was not something promoted in the interests of people with disabilities, but it is a good example of a development that has turned out to be a boon for them.

But during the time electronic mail was starting to catch on, a choice still had to be made. Should we put our rehabilitation engineering energies on the entire chain of activities that a physically disabled individual needs to accomplish in order to mail a letter, i.e. getting himself out of his flat, into the lift, out onto the street and to the letterbox, which was not always easily accessible? Or should we instead put our energies towards developing good computer interfaces for email? The choice was quite easy. Since it was possible to achieve the same *function* with email as with the physical letter, that was where we put our efforts. The electronic function was highly satisfactory and well adapted, something much more difficult to attain with the go-and-post-the-letter chain.

More examples: Increasingly more people are using talking books instead of reading (you seldom consider the fact that you are actually listening when you assimilate the contents of a book). Braille and synthetic speech are other examples of the chameleon method.

© The authors and Studentlitteratur

The Poodle Method

This is about getting to the heart of the matter; about finding the essence of the dream, the wish, the need. It may not always be possible to achieve what you want, even with technology. The cost may be too high or too demanding. Is it possible to find something else that *experience*- and *feeling-wise* can be just as important?

Example

When push-button sailing is no real alternative. A teenager who sails a lot is diagnosed with a degenerative muscle disease. Is it meaningful for him to try and maintain his sailing abilities by using buttons and switches to steer the boat? No. The physical and mental challenges involved are what he likes best about sailing (e.g. "How is that wave going to turn? What do I have to do to compensate for it?"). Parrot or chameleon solutions that enable push-button sailing but without these challenges are meaningless. Instead, can you find *another* activity that fulfils the same function and is equally intellectually challenging? And perhaps even one more that enables physical exertion, feels real and lets the person experience a rush of joy and exhilaration?

Example

Take care to counterbalance. A poodle way of thinking can also lead to the realization that if two parties are going to be able to cooperate as well as possible, *both* of them may be in need of aids that supports their efforts. Medical images, for example, which are essentially used in diagnosis are the domain of healthcare professionals. To achieve a meeting between the person experiencing the lived disability and the professional with the diagnostic and treatment responsibility, the former can also be in need of his or her own medical images [Enquist, 2004]. See chapter 2 as well.

Example

Revealing prejudices. The parrot, chameleon and poodle metaphors help us reveal our preconceived notions. Why is it, for example,

© The authors and Studentlitteratur

that so many believe that people with autism entirely lack empathy? The heart of the matter (i.e. the poodle) may be that people with autism sometimes *interpret* a situation quite differently from others. It may even be the case that the person simply does not understand it at all, and consequently is unable to show any empathy. But the rest of us – so-called normal people – are not being very empathetic either when we only see the situation from *our* viewpoint, and examine a person's actions and alleged lack of empathy from *our* criteria. The way to resolve this lies in figuring out what the differences in interpretations actually are, and how to go about approaching one another. This also increases the conditions for mutual empathy. Compare this with Krister Inde's explanation (chapter 1) of the need for empathy not only from the outside world but also from within oneself.

World Health Organization background

It was a big step forward when the World Health Organization (WHO) relinquished its previous disability classification system, the *International Classification of Impairment, Disability and Handicap (ICIDH)*, and came up with the *International Classification of Functioning, Disability and Health (ICF)* [WHO, 2001]. Basing the new classification system on function rather than disability – starting with the functioning rather than the non-functioning – constituted a 180 degree turnaround. This is of great significance because you always have to start from the person's abilities rather that from her inabilities for development to take place.

In addition, WHO has a diagnostic classification, the *International Statistical Classification of Diseases and Related Health Problems (ICD-10)* [WHO, 1992]. While the purpose of ICF is to classify functions and functional possibilities from the perspective of health, ICD focusses on diagnoses and illnesses. Or more to the point: "In short, ICD-10 is mainly used to classify causes of death, but ICF classifies health."[2]

2 Available at: www3.who.int/icf/beginners/bg.pdf

 © The authors and Studentlitteratur

For rehabilitation engineering and design, ICF is the best one to follow. But that is not sufficient either: it does not include social or political aspects, nor does it take into consideration the desired function of the principal person involved. It does not take much reflection, really, to realize that the entire focus in functional thinking should be on what the person wants to be able to do. Compare this with *Our Own Devices* [Tenner, 2003].

Useworthiness

In his doctoral thesis, *The Useworthiness of Robots for People with Physical Disabilities*, Håkan Eftring defined the concept as follows: "Useworthiness is the individual user's assessment of the extent to which the technology meets the user's high-priority needs" [Eftring, 1999, p. 23].

Useworthiness focusses on the importance of a product in the user's life situation, both the actual and the desired. The related concept of usability [Nielsen, 1993; Lindgaard, 1994; Löwgren, 1993; ISO, 1997] is more focussed on the user interface, i.e. the ease and efficiency with which a product can be used, and on the tasks for which the product can be used. But usability is only a limited aspect of useworthiness and says nothing about the *lived* value; just as little as does a readability index say about how worthwhile a text is to read.

Example

Cost ineffectiveness. It is well known how many assistive aids are particularly cost ineffective because they are almost never used. This is one way for the people for whom the aids are intended to register their dissatisfaction; an expensive and unnecessary one. The useworthiness perspective should be introduced much earlier in the design chain.

© The authors and Studentlitteratur

Example

Cost effective for whom? So far, health economics has not included useworthiness in its calculations. But there are efforts being made in that direction, including Camilla Nordgren's doctoral research on the economic consequences of traumatic spinal cord injury.[3] Such an injury has profound consequences for the injured person [Nordgren et al., 2003]. A long rehabilitation process follows the initial period of hospitalization. Then it is a matter of learning to live with the injury the rest of your life, which impacts your personal finances, family and community. Based on a person's situation, cost effectiveness is a balance between indirect costs, such as loss of income, and direct ones, such as healthcare and rehabilitation costs, assistive technology, sickness benefits and eventual disability pension, car adaptations, personal assistants, etc.

Redundancy

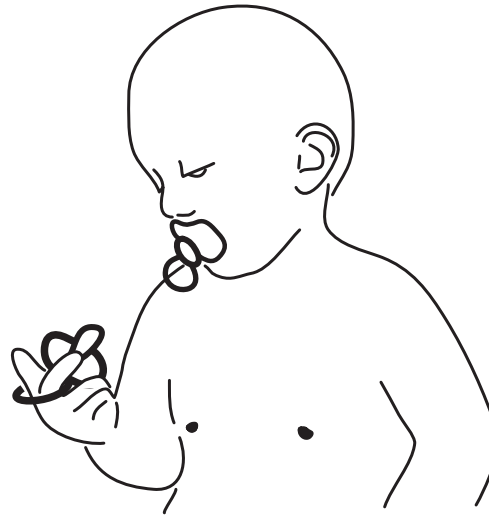
Redundant means excessive.

Excessiveness in rehabilitation engineering can be necessary, fruitful, liberating as well as unnecessary and confusing. That is one reason for discussing redundancy here. Another is that researchers in rehabilitation engineering and design often come from a variety of disciplines with a corresponding variety of attitudes towards redundancy. For example, it can be different attitudes towards redundancy that are behind a good part of the classical division between the natural sciences and the arts. C. P. Snow's first book on the subject, *The Two Cultures and the Scientific Revolution*, was published in 1959. In *The Two Cultures* [Snow, 1993] you find the original texts and a further elaboration of his thoughts.

Snow does not write about redundancy, but we do in order to call attention to how the natural sciences normally try to keep redundancy to an absolute minimum while the arts attempt to highlight what is richly individual and abundant: the joy of language, large vocabularies, and a personal tone. In the eyes of the natural sci-

3 Information available at: http://www.english.certec.lth.se/staff/camilla/

 © The authors and Studentlitteratur

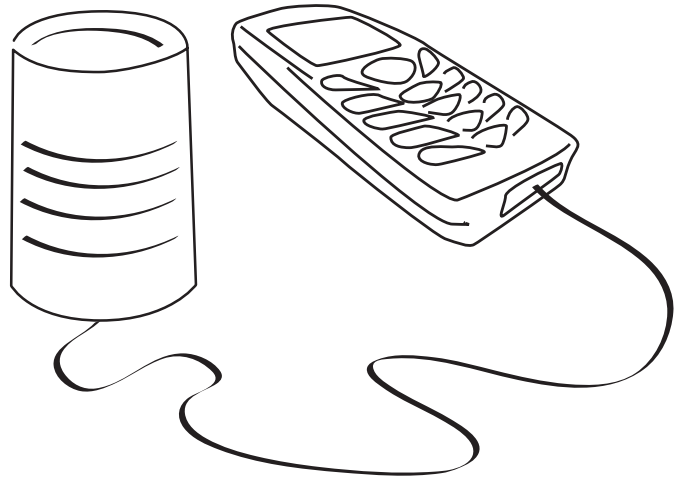


Everyday redundancy.

ences, the arts have entirely *too much* redundancy, and find it entirely too difficult to stick to the subject. Judgements can be quite different, which is exemplified with an anecdote from the world of music. Music can have a clarity that verges on austerity, but it can also abound with redundancy as in a Mozart opera. When Archduke Ferdinand of Austria complimented Mozart on his work but added the comment, "… but far too many notes," the composer replied, "Thank you, your Majesty! But not one more than necessary."

The minimalist natural sciences follow principles introduced in the 14th century when the English logician, Occam, took out his famous razor and elevated it to the principle of cutting away all the unnecessary. Such a uniform endeavour is not to be found in technology. Instead, redundancy is chosen according to the area of utilization: sometimes low for the greatest possible speed, simplicity and lowest possible cost; sometimes high to increase security, for example.

© The authors and Studentlitteratur



Redundancy in a mobile phone conversation is at the compression level.

Redundancy in the technical world

In the technical world, redundancy is systematically increased or decreased depending on what one wants to achieve. From an information theoretical point of view, it is possible to remove much in a spoken message without losing its meaning, because the human being at the other end is always looking for meaning, thus filling in the gaps. It is also possible to technically compress and then decompress a message.

At the same time, the lower the redundancy, the greater the risk for misunderstanding and error or at least the loss of that which is brilliant and subtle. An example of the use of redundancy to facilitate error detection is the control digit added to a personal identity number/social security number. In computers, there are often duplicate functions for one and the same purpose. Many times, only one is used, but if a problem arises, the other one can take over. The double brake system is another similar example.

© The authors and Studentlitteratur

Redundancy in rehabilitation engineering

Reliability is essential when the user has a functional impairment. But it should not be taken for granted that there should be a great deal of redundancy. On the contrary, low redundancy can sometimes be advantageous and correspond to strong and comforting conditioning. (If you are accustomed to a clean room smelling of lemon, changing to a product with a different odour will cause confusion.)

You need to be careful, however, so that what is best does not become the enemy of what is good, ending up with everything always having to be exactly the same. It is impossible to get individuals on the staff to become identical robots, but it does not mean that you should adjust to the weakest link in the chain of personnel. If you do that, you block opportunities for learning and change.

In many rehabilitation engineering contexts, it is beneficial to make use of as many senses as possible (e.g. using both sound and pictures). It can be advantageous to start broadly in order to later subtract functions. The more the input there is, the greater the chance the person will have of finding something she understands and that suits her.

Vygotsky writes in *Mind and Society* about the difference between chimpanzees and two-year-old children [Vygotsky, 1930]. Chimpanzees can only make use of the mental assistance that exists within view, while the child through language can also receive support from people and things that do not exist in his field of vision. But not every person can always manage that. For people with cognitive limitations and for the rest of us, if we end up in extremely stressful or conflict-filled situations, it can be difficult to utilize that which is not present in the here and now. In that context, it can be valuable to have access to technology that either takes over on its own or exercises direct conditioning.

Example

Knowing that there is help – and where. At the Pictorium Day Activity Centre in Lund, they have created a distinct and clearly demarcated area that they call the Emergency Spot where a person can go to sort out things that have to do with physical injuries, accidents and re-

© The authors and Studentlitteratur

lated problems. *That* is the place to go when something goes wrong – this far it is straightforward conditioning and is important because the centre participants don't always know themselves how they should deal with pain, for example. Once they get there, relief is on the way. On some occasions, it is enough to just go there, sit down and look through the digital pictures and artefacts to get the mental support they need. Other times, they use the digital pictures to ask someone to come and look at their injury or to gain insight into the problem.

Abduction

Induction and *deduction* are opposites. Using an *inductive* approach involves thinking in terms of a chain of *individual cases* that lead to something more general. *Deduction* goes in the opposite direction: to discuss from a theoretically general level what happens in an individual case.

Abduction is a third form which works in both directions. It also assumes that when you inductively go about registering and compiling individual cases, you always do so based on an initial conception of what you will be observing. Completely independent observations are exceptions. Abduction starts with empirical facts, as does induction, but during the ongoing process pays attention to how new patterns and hypotheses often emerge. Thus, previous theories and observations need to be reinterpreted [Alvesson, Sköldberg, 1994; Niiniluoto, 1999]. It does not mean that previous observations and old theories are "wrong". However, abduction demands that you strive to describe not only the changed view but also what characterizes the "new glasses" used for observation and analysis compared to the old ones. design using cultural probes often presupposes an abductive approach since the outcomes of such studies urge reinterpretation and reflection.

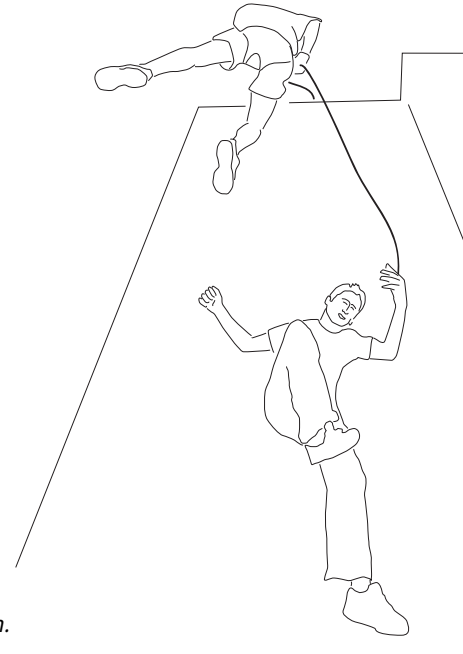
In reality, abduction is frequently used in the natural as well as the social sciences, even if it is not always recognized. Quality research often results in the discovery of other connections and through them, other facts than the ones you set out to test. Niiniluoto states that the abductive method has been a part of the

 © The authors and Studentlitteratur

everyday life of the human species [Niiniluoto, 1999]. Thus, we have had a lot of practice in seeing through "glasses", catching sight of something, which then prompts us to change "glasses", etc. Abduction allows us to change midstream – given that we do it distinctly and document it well.

More on the situated

It is not just a matter of *being there*, of being *situated*, but also of grasping the action *in its context*; not to immediately intellectualize it [Mandre, 1999 and 2002]. This is how ethnologists work as well [Jönsson, H., 2000]. The question is not really, "What *is* the situation?" rather, "What do we have to *do* in order to find out?" By acting, you can capture at an early point many of the factors that you would otherwise have missed [Suchman, 1987]. The technology itself can serve as a catalyst and can provoke reflection, answer existing questions while at the same time raising new ones [Jönsson, 1997].



Seize the events where they happen.

© The authors and Studentlitteratur

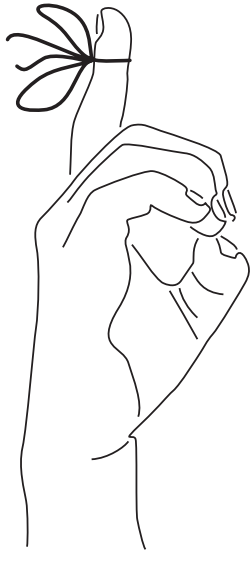
Example

Technology as a challenger/teaser. One reason for choosing to have a robot arm on your wheelchair can be that you know that just by having it there, you will come up with new ways of using it. That's the moment of triumph [Eftring, 1999].

Example

Learning potential. An "hour rule" time telling device (measures time as if it were length: one row of small lights corresponds to an hour and the lights extinguish as time passes) is more challenging than a door opener. A door opener can be used for opening doors. Period. But an hour rule can have all kinds of imagined and unimagined uses: structuring, planning, sequencing, etc.

Edwin Hutchins started to use the expression *distributed cognition* in the mid-1980s to indicate that the thinking of individuals arises out of an interaction with other people and objects. He had extensive experience in laboratory studies. That was why he could so clearly see that what happened in cockpits and on navigation bridges could not be discovered by observing individuals in a lab. Cognitive processes are so strongly influenced by cultural and so-



Important: Try to capture cognition in concrete situations.

© The authors and Studentlitteratur

cial phenomena that they neither can nor should be studied under artificial conditions. This is explored extensively in his book, *Cognition in the Wild* [Hutchins, 1996].

Example

Media as mediator. People often learn the best by meeting others with similar problems. When you can identify with someone else, you do not feel alone. If in addition you can meet others who have similar problems but who have come further – good role models – you gain hope in the possibility of achieving a good quality of life yourself. The internet is a superb meeting place for this. The discussions that arise are often more reflective than normal ones, that by definition occur in the same place and at the same time [Brattberg, 2003]. See chapter 8 as well and Brattberg [2004].

A phenomenologically based contribution in the interaction design area is Paul Dourish's book *Where the Action is: The Foundations of Embodied Interaction* [Dourish, 2001]. Dourish comes from a computer science background but contributes new perspectives to the philosophy of science and methodological approaches for interaction design. It is based on the acting person and her tools, rather than on rational and disconnected actions.

Dourish turns away from the narrow cognitive perspective and abstract representations of the world and to the situated and the embodied interaction between humans and computer systems [ibid. p. 18]. That his approach is phenomenological is clear when he states that our experience of the world is closely tied to the reality of our bodily presence in the world. The same argument holds for our social actions: A conversation between two people is dynamically constructed in response to the present action rather than being abstractly planned in advance.

Dourish clearly delineates his idea of embodiment. It should not be understood as the commonplace, physical reality that we exist separately as individuals on this earth, but that we are embodied in a world of artefacts that are constantly interacting [ibid. p. 18]. He maintains that we have to understand that interaction is closely connected to the context in which it occurs, that we need to develop sensitivity to settings and understand how interaction is embodied within these settings.

© The authors and Studentlitteratur

Example

Technology in context increases precision. A woman thought her wheelchair-mounted robot arm was too slow. But what exactly does that mean? "Too slow" can refer to speed as well as to *acceleration*. She thought it was "too slow" when she tried to fry meatballs: they slipped away when she attempted to turn them. In this case, it was the acceleration that was too low. But when she was irritated because the arm was "too slow" at pouring sugar in her teacup, it was speed she was referring to. Neither of these needed to be remedied with a stronger motor, which you could have easily concluded if you had not looked at the context. Improving the construction of the grip device technically solved these two problems.

Example

Technology as an eye-opener. During a fire drill in a group home, one of the residents explained what he would do if the alarm went off. He would wave a newspaper under the smoke detector. Why? It turned out that every time they toasted bread and the smoke detector went off, that is exactly what the staff member did.

Example

Concrete and logical situated understanding. Go back to chapter 7 by Arne Svensk and re-read the part about the man who determined if it was Saturday by checking the number on the bus.

Example

Visibility as a tool for empowerment. In the same chapter, you can also read about the man who by moving the photo of Axel from the daily schedule to the staff holiday list could show that he was not particularly fond of Axel. For the personnel, the use of pictures was primarily a way of providing information; for the resident in question, it also became a way to make a point and a wish.

© The authors and Studentlitteratur

Example

Being there without being there. At the Pictorium Day Activity Centre, there was a participant who no one thought was capable of understanding pictures. He had had many opportunities to react to them in the picture-rich setting, but had never with a facial expression revealed if he was interested or not, or if he understood anything. A homemade video was running one day, showing the participants involved in activities at the Centre. There were two short scenes in which he appeared: one in which he was doing the washing up, and another in which he was showing his wallet and keys. On both occasions, he demonstrated by gestures, mime and sounds that these scenes affected him in an entirely different way than anything else on the video. It was apparent from this that he could identify himself and his position in pictures, which had great significance for continued work.

Necessary but not sufficient

We have now, on quite a few occasions, written of the necessity of being there, where the action is. It is not just about the ability to learn and invent from the situation, but equally as much about letting everything that happens there activate and integrate *associations* from previous design work. That is how the synchronous and the asynchronous are woven together. Something new and relevant can arise when new insights *co-exist* with old ones in your head [Marton, Booth, 1997]. See chapter 3 as well, "Lund doesn't exist …"

If good assistive technology is ever to be developed for people with dementia [*Elderly People and Design*, 2003], competent designers have to be "on location", not directed by requirements specifications based on how others interpret the situation. What you see depends on previous experience and knowledge, a fact that is obvious in hermeneutics and phenomenology (see chapter 14), but is not always emphasized in technology, design and medicine.

It is not enough to just be situated, however. The situated is a necessary but not sufficient condition. "I was there and saw it with my own eyes!" does not tell the whole truth because one person never perceives the same as another; nor do they interpret it in the same way.

© The authors and Studentlitteratur

Example

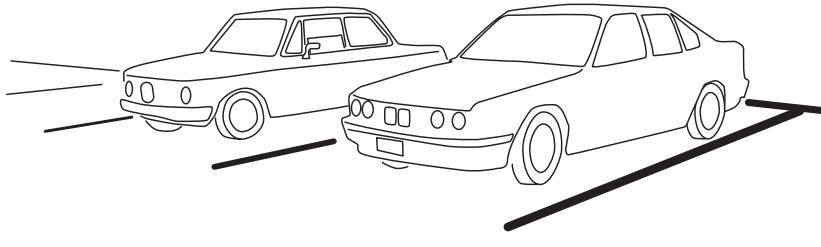
Worlds apart. A long-time psychiatric clinical department head and the chief psychiatrist saw something completely different in a patient than did a teacher who came on the scene many years later. Their disparate views of reality were not only individual, but closely related to the different spheres of knowledge they represented. In one, the patient in question was dangerous and impossible to be near for any extended period of time; in the other it was possible to be alone with her in a closed room. All three were there, worked there, had first hand information, but their conceptual frames of reference were so dissimilar that their situated information was different.

A researcher from the outside had yet another interpretation. She was trying to determine the technology that could be introduced and the more she asked and challenged, the clearer it became that it was the situation rather than the patient who was sick.

When the new technology was then introduced, the old ways of thinking gave way entirely [Mandre, Jönsson 1996a and 1996b; Mandre, 1997]; not due to the technology itself, but by revealing the impossibilities in the prevailing conceptions. The preposterous could endure as long as the speculations centred on how things "were", but collapsed under a design-centred focus on how thing could and should *be* [Edeholt, 2004].

Constraints

During our work with knowledge-based systems we have increasingly discovered the importance of constraints [Magnusson, Mandre, 2004]. It may sound negative, but in fact, they are often neces-



Constraints are good – how else would we be able to park sensibly?

© The authors and Studentlitteratur

sary and constructive. Well-selected content constraints constitute a support not only in problem solving but in creative activities as well [Gedenryd, 1998].

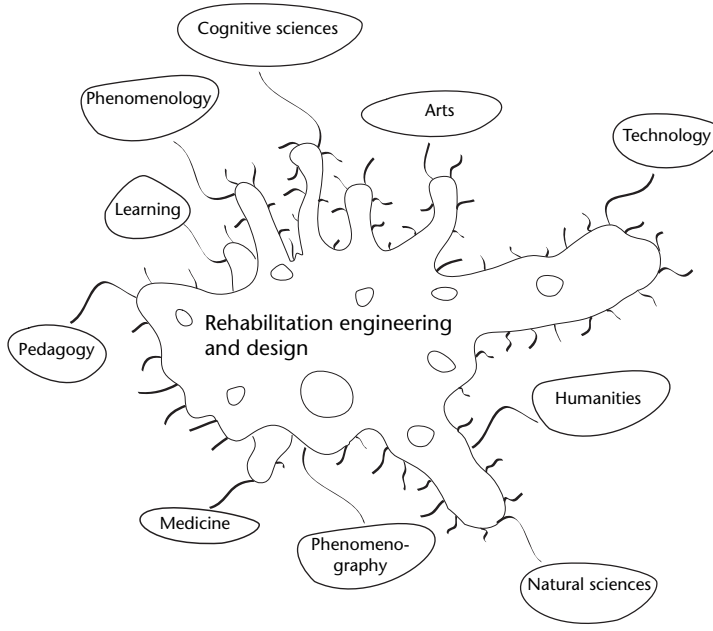
In the situated, constraints are built in automatically in the actual context. A non-situated approach may cause the designer or the researcher to be unaware of or ignore constraints in individual cases. The full complexity of reality is rarely to be found even in detailed descriptions, and constraints often will not emerge unless the design process is situated.

© The authors and Studentlitteratur

14 Scientific positioning

Certec/Bodil Jönsson

This last chapter is devoted to positioning rehabilitation engineering and design in relation to other disciplines.



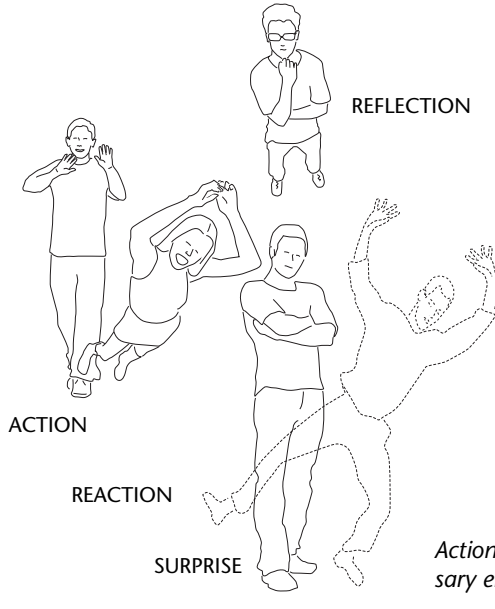
© The authors and Studentlitteratur

In general

The only research result worthy of the name is *new knowledge*. Often in a research project it is only a small portion of the results that are *original*. It is essential to identify what is new, differentiate it from the rest and relate it to the existing. This is quite a delicate task, especially in the domain of phronesis (see the next section).

The extent to which a research project results in new knowledge is impossible to predict, but one can and should structure the research so that the results are not predictable. The Swedish government report, *God sed i forskningen* (*Ethical Research Practice*), includes the following statement concerning "new knowledge": "Professor Johan Cullberg uses a criterion for good science that fits in well with the Popper's solution, the so-called surprise criterion. This criterion means that it should not be possible to predict the result of an experiment or a study. There must always be an element of surprise if the knowledge that is generated really is new" [SOU 1999:4, p. 67].

In analysing whether the emerging knowledge is new and scientific, it helps considerably if the methods involved are standard for



Action, reaction and reflection are necessary elements. So is surprise.

© The authors and Studentlitteratur

the related scientific fields. In some, one of them being phenomenology, there is no given phenomenological method [Husserl, 1901].

If you create your own method, much is required for the results to be considered credible. On the other hand, the researcher is forced to take more responsibility for the knowledge building than if he or she follows established methods. An example of this kind of research is David de León's doctoral thesis, *Artefactual Intelligence* [de León, 2003]. His two main questions were: "How can tools help organize tasks to make them cognitively easy to perform?" and "How do artefacts, and the strategies for using them, develop over time in cognitively beneficial ways?" To find the answer, de León went outside of the prevailing methods, which, in turn, required a careful accounting of the methods used – their strengths and why they were used.

Classical

Aristotle describes the following three categories:

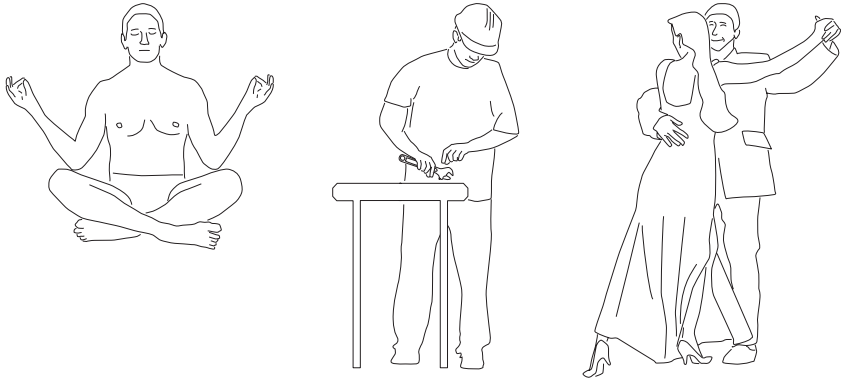
Episteme
Techne
Phronesis

A glance at these words tells us that the first two have survived and are in active use: episteme (epistemology, the theory of knowledge) and techne (technology, technique). Phronesis, however, is a word for which we have no active, contemporary equivalent. It is about values and reality, about people and their actions. See Mårten Ringbom's version of *Den Nikomachiska etiken* (*Nikomachean Ethics*) [Aristotle, 1993].

Interest in phronesis was rekindled in the 1990s, primarily in the social sciences. It was referred to now and again in the design context as well. See, for example, Pelle Ehn's preface to Löwgren and Stolterman's *Design av informationsteknik – materialet utan egenskaper* (*Design of Information Technology – The Material without Properties*) [Löwgren, Stolterman, 1998].

Martha Nussbaum explains that phronesis is needed as "an attack on the claim that all valuable things are commensurable; an argu-

© The authors and Studentlitteratur



Episteme, techne and phronesis are personified here as different individuals. It doesn't have to be that way in real life: in design and rehabilitation engineering, a researcher can possess characteristics of all three.

ment for the priority of particular judgements to universals; and a defence of emotions and imagination as essential to rational choice" [Nussbaum, 1990].

Phronesis is not scientific in the epistemological sense, since epistemology is primarily concerned with scientific knowledge that is universal, constant in time and space, context-independent and based entirely on analytical rationality. The knowledge relativism that is an integral part of phronesis is thus almost unforgivable in an epistemological approach. The connection between "techne", the reflecting knowledge of concrete action, and phronesis is better developed, however.

Epistemology – if such is possible

If something can be described with fixed concepts, generalizations and universal theories, a great deal is gained. Large areas of rehabilitation engineering and design can be dealt with within the framework of epistemology and can thus pride itself on:

- the ability to systematize and accumulate
- the ability to articulate new questions

 © The authors and Studentlitteratur

- openness and transparency even in the handling of methods and data
- the capacity to generalize on the basis of experience gained
- 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* [Nussbaum, 1990; Gillberg, 1999] must apply, i.e. we enter the domain of phronesis. Here, the ideal is the Aristotelian agent, characterized as follows by Minna Gillberg: "The Aristotelian agent is a person whom we trust to describe a complex situation with full concreteness of detail and emotional shading, missing nothing of practical relevance" [Gillberg, 1999, p. 22].

We feel that it is somewhat double-edged to bring to light an area, such as phronesis, that has been dormant since the days of Aristotle. Most of us are scientists and/or technologists and feel more at home in the concepts of those fields. The reason we include phronesis is that the epistemological and the technological alone are not able to stand for all that is relevant in rehabilitation engineering and design.

Relation to the natural sciences

Scientific knowledge in the natural sciences fulfils many of the needs of design. It is *concrete*. It derives it fundamental basis from *experimental investigations* (induction) or relates to the concrete by comparing reality with deductions from theory. There are also crucial differences: the natural sciences strive to be objective and general, while design, at least in its initial stages, prioritizes being *situated* and engaging in what is *relevant* for a person or a group.

Design's initially by situated nature makes the question of whether the results can be generalized or not something to be taken up later. But objectivity does not need to be tied to the general. You can be objective in individual cases as well without aiming to generalize the results.

© The authors and Studentlitteratur

Example

Verifiable communication. Go to chapter 9. Anyone who questions if Emma actually has intention and conscious communication will be convinced by seeing how she handles the technical interface. More can be found in Breidegard [2004].

Example

Owner of the problem. The early stages of schizophrenia and depression can be difficult to detect for the person with the condition. If in the use of an artefact, a computer keyboard for instance, distinctive features indicating the onset of a cycle can be detected in the keystrokes (rate, mistakes, pauses), this could function as an early sign and thus warn the person of the imminent onset of a cycle which in the best scenario could be avoided entirely or reduced considerably. Feedback of this sort is guaranteed to be objective but is not generally applicable: different individuals can have completely different patterns of change. But the method can be one and the same.

Example

Significance of relevant feedback. It is quite easy to ignore signals from your body. This is the case for people with exhaustive depression syndrome (also know as burnout). Simple, portable biofeedback equipment can provide an objective indication that it is time to relax. Here too, what is general and objective can be found in the method and equipment, while what is individual can be found in level settings and the effects. Is it possible to gradually re-establish contact with one's body in this way? Or does the biofeedback equipment need to remain as compensatory assistive technology?

Example

What is communicable? For some people with autism, you can't reach the person by pointing at the object in question and saying: "This is what I mean!" However, it works well in many cases to take a detour using a picture – it's as if pictures are experienced as being more real than reality itself. When a special education teacher dur-

© The authors and Studentlitteratur

ing a walk in the woods wanted to show a pupil a stone he could sit on, he didn't understand at all what she meant. When she took a picture of the stone and showed it to him on the camera's display screen and told him that was the stone he should sit on, he smiled and did so immediately [Plato, Jönsson, 2001; Jönsson, 2004]. That is also the way it happened when Thomas at the adult day activity centre was going to learn to use a yardstick – it didn't work at all to point and show him how to use it, but it worked extremely well to digitally photograph the process and explain via the photos [Jönsson, Philipson, Svensk, 1998].

Statistically based science versus case studies

A comparison of statistically based science and case studies shows that both have strengths and weaknesses. Case studies are not only pathfinders for later statistical studies [Ramachandran, Blakeslee, 1998]. They are also relevant and situated in a way that statistical studies can never be.

From the point of view of the person "living" the case study, her own changes are often the most relevant. Her perspective is "before" and "after": Did this help? Is my life better because of this?" Many individual, longitudinal and well-documented case studies can together provide a richer image than the best-planned and implemented double blind tests of subject and control groups.

Heuristics, analysis and synthesis

Heuristic reasoning is a fundamental element in rehabilitation engineering and design because interpretations of a situation and its possibilities are rarely strict and final but rather multifaceted and provisional. Heuristic elements exist in most types of problem solving, including mathematical ones [Polya, 1962 and 1990], where one must:

© The authors and Studentlitteratur

- *Understand the problem* – interpret the influencing factors, their mutual relationship how to structure one's reasoning'
- *Find the connection* between the unknown and what we already know, initially perhaps by simply exploring possible plans for finding these connections
- *Implement* the plan
- *Examine* the solution – is the result correct and reasonable? Could it have been achieved in some other way? Can it also be used for other purposes?

From the heuristic point of view, the following are special features of rehabilitation engineering and design:

- The scientist and the user are seldom the same person, and it is the user's assessment of the outcome that is the most important end result (although not the only one – the research result is the *new knowledge* that has been generated, as already mentioned).
- The number of variables is so great that the choice of analysis level will determine how the problem is solved (see the next section, "More is different").
- It isn't the situation as it *exists*, but even more so, the situation as it can *become* that is the object of the research.

More is different

More is not only more, more is also different. The article "More is different" by P. W. Anderson in *Science* [Anderson, 1972] is a key document, the inspiration of which has reached far beyond the field of the science. It conveys the message that even if reductionism – analysing complex things into simpler constituents – has often proven to be a successful scientific method, it is not obvious even in the natural sciences that it is possible to successfully proceed in the opposite direction, i.e. to constructivistically work one's way up based on the results from a lower level. Thus, given knowledge on a basic level does not in itself construct relevant complex connections at a higher level. Rather, genuinely new characteristics appear on each new level, and they need to be studied on the basis of their own complexities.

 © The authors and Studentlitteratur

In the context presented here, "more is different" means that both problems and possibilities must be studied on several different levels. A relevant analysis can require that you break the problem down into lower levels (e.g. to technically manageable ones) but that you continuously go back to the original context when you are to assess relevance and success of the results. And perhaps most important: the scientist in the field of rehabilitation engineering and design needs to form an image of the *prospective* reality, not primarily an image of how it currently is.

Time geography

No matter how much you try to focus on context, it still happens that you lose track of the situated and the real. Support for avoiding this can be found in time geography.

The creator of time geography, Torsten Hägerstrand, describes it as "mental diagrams which sort out our thinking and enable us to know the place of empirical studies in the overall picture" (in *Om tidens vidd och tingens ordning [On the Scope of Time and Order of the Artefact]* [Hägerstrand, 1991]). Time geography is thus a kind of "situational science", i.e. it is interested in situations in the true sense of the word and with that, case studies as well. In addition to the specifically geographical aspects – space and presence – case studies also involve personal, cultural and social ones.

By looking at a situation from a time geography perspective, one becomes more aware of the limitations inherent in extracting things and events from their context in order to subsequently analyse them by way of various experiments, for example. According to Hägerstrand, it is easy to miss what he calls "vicinity" relationships, i.e. the proximity and simultaneity of the elements. Vicinity relationships comprise everything in the temporal and spatial world that interacts with the phenomenon in question. A different way of expressing it in the context presented here would be: everything that affects *useworthiness*.

© The authors and Studentlitteratur

Grounded theory

Grounded theory has an almost magical aura. The task of the researcher in this context is to understand what is happening and how the players manage their roles. The researcher gains understanding through observations, conversations and interviews. Categories and theories are expected to emerge during the process of data collection, annotating, coding and sorting. It is not a matter of testing hypotheses, but as Glaser explains, to discover the theory implicit in the data [Glaser, 2003].

Grounded theory has a *lean backward* rather than a *lean forward* attitude and is thus not particularly well suited for rehabilitation engineering and design. Even here, new theories and interpretations emerge throughout the process, but they are so focussed on *future* effects and consequences that an interpretation of what already exists is not as meaningful.

It might appear that design researchers are less humble than their grounded theory counterparts. There is no doubt that the design researcher is more likely to take the obvious initiatives, at least at the start. But as the process progresses, it is the person for whom the design is intended who takes the lead, which is not always the case in the social sciences where you can gradually remove yourself from your subjects without this being directly apparent to anyone.

Phenomenology and phenomenography

Phenomenology has been around for 100 years with its two fundamental concepts: *phenomenon* and *lifeworld*. Phenomenon in this context does not stand for the occurrence itself, but for the occurrence *experienced by someone* (in our case the *lived* disability). Lifeworld is also relevant to rehabilitation engineering: it is the world we find ourselves in and take for granted and in which the phenomenon occurs. The French phenomenologist, Maurice Merleau-Ponty, speaks of *the lived body*:

"The body is the vehicle of being in the world" [Merleau-Ponty, 1962, p. 82]. "The body is the general medium for having a world" [ibid. p. 146]. Our own lived bodies are the basis for all our experiences and encounters.

 © The authors and Studentlitteratur

Phenomenology more firmly attempts to differentiate the qualitatively different ways in which we understand phenomena and the lifeworld [Marton, Booth, 1997]. These different ways of understanding can be categorized, described and logically related to one another. Phenomenography has originated with the Swedish Göteborg Pedagogues and has been used to describe different ways of understanding scientific phenomena and various ways of learning. Phenomenography is well suited in rehabilitation engineering and design to illuminate *differences* and *variations* in the way in which people experience affordances in rehabilitation engineering. See chapter 10, "Might and machines".

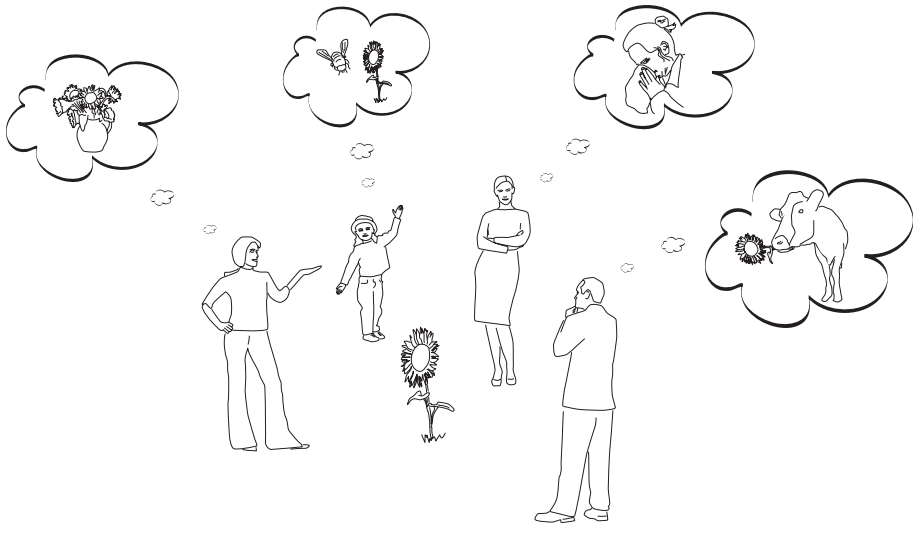
The need for concept formation and positioning

The design sciences are young and so is rehabilitation engineering. It is difficult to see any real difference between phenomenology's "phenomenon" and design's "affordance". An example of affordance is that a tree offers or affords a bird a place to build a nest, something for a child to climb, a place for an adult to seek shade, and something for the forest industry to cultivate – in other words, the phenomena are different even though the actual object can be one and the same.

The similarity between "affordance" and "phenomenon" is just one example among many that the design sciences have not made any particular attempt to find support for their theory and method formation in other sciences. Rather, concept has been added to concept, method to method and no one has yet attempted to construct a more consolidated concept formation. It is possible that the absence of such can be liberating and inspiring but in our opinion, it is, if anything, more confusing.

It would be good with a little consensus that could provide more mutual understanding. The International Organization for Standardization/International Electrotechnical Commission's (ISO/IEC) Guide 2, describes what a standard can result in: "A standard is defined as a *document* established by *consensus and approved by a recognized body*, that provides for common and repeated use, rules, guide-

© The authors and Studentlitteratur



A flower also offers different affordances.

lines and characteristics for activities or their results aimed at the achievement of the optimum degree of order *in a given context*" [ISO/IEC, 1996] (Our italics). Just think that something as dry and dull can sound so worth aiming for and attractive – for rehabilitation engineering and design as well.

© The authors and Studentlitteratur

References

Alvesson, Mats; Sköldberg, Kai 1994. *Tolkning och reflektion (Interpretation and Reflection)*. Studentlitteratur, Lund, Sweden.

Anderson, Philip W. 1972. More is different. *Science* vol. 177, nr. 4047, pp. 393–396.

Antonovsky, Aaron 1987. *Unraveling the Mystery of Health*. Jossey-Bass Publishers, San Francisco, CA, USA.

Aristotle, translation 1993. *Den Nikomachiska etiken (Nikomachean Ethics)*. Mårten Ringbom. Bokförlaget Daidalos AB, Göteborg, Sweden.

Bauth, Ruth; Jönsson, Bodil; Svensk, Arne 1995. *Ge oss bara redskapen (Just Give Us the Tools)*. Natur & Kultur, Stockholm, Sweden. Available online in English at: http://www.certec.lth.se/doc/justgive/ (May 24, 2006).

Brattberg, Gunilla 2003. *Rehabiliteringspedagogik för arbete med långtidssjukskrivna i grupp (Rehabilitation Pedagogics for Working with Groups of People on Long-term Sick Leave)*. Värkstaden, Stockholm, Sweden.

Brattberg, Gunilla 2004. *Väckarklockor (Alarmclocks)*. Värkstaden, Stockholm, Sweden.

Breidegard, Björn 2007. Enlightened: The Art of Finger Reading. *Studia Linguistica* (to be published).

Breidegard, Björn 2004. *The New Minimeter: Modern inexpensive communication technology for people with severe brain injuries*. Certec, LTH, Lund University, Lund, Sweden. Available online at: http://www.english.certec.lth.se/minimeter/index.html (May 24, 2006).

Brusén, Peter 2005. *Livet en gång till – En ryggmärgsskadad möter svensk handikappolitik (Life one more time – A person with a spinal injury's encounter with Swedish Disability Policiy)*. Égalité, Malmö, Sweden.

Bødker, Susanne; Iversen, Ole S. 2002. Staging a Professional Participatory Design Practice: Moving PD beyond the Initial Fascination of User Involvement. *Proceedings, Second Nordic Conference on*

© The authors and Studentlitteratur

Human-computer Interaction, pp. 11–18. ACM Press, New York, NY, USA. Available online at: http://doi.acm.org/10.1145/572020.572023 (May 24, 2006).

Bødker, Susanne; Grønbaek, Kaj; Kyng, Morten 1993. Cooperative Design: Techniques and Experiences from the Scandinavian Scene. In Douglas Schuler; Aki Namioka (eds.), *Participatory Design: Principles and Practices*, pp. 157–76. Lawrence Erlbaum Associates, Hillsdale, NJ, USA.

Bødker, Susanne; Ehn, Pelle; Kammersgaard, John; Kyng, Morten; Sundblad, Yngve 1987. A Utopian Experience. In Gro Bjerknes, Pelle Ehn; Morten Kyng (eds.), *Computers and Democracy: A Scandinavian Challenge*. Avebury, Aldershot, UK.

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

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

Edeholt, Håkan 2004. *Design, Innovation och andra Paradoxer – om förändring satt i system (Design, Innovation and other Paradoxes).* Doctoral thesis. Chalmers tekniska högskola. Available online at: http://webzone.k3.mah.se/k3haed (May 24, 2006).

Eftring, Håkan 1999. *The Useworthiness of Robots for People with Physical Disabilities*. Doctoral thesis. Certec, LTH, Lund University, Lund, Sweden. Available online at: http://www.english.certec.lth.se/doc/useworthiness/ (May 24, 2006).

Ehn, Pelle 1988. *Work-Oriented Design of Computer Artifacts*. Swedish Center for Working Life, Stockholm, Sweden. Almqvist & Wiksell International, Falköping, Sweden. (Also distributed by Lawrence Erlbaum Associates, Hillsdale, NJ, USA).

Elderly People and Design. 2003. Research Programme at the Dept. of Design Sciences, Faculty of Technology (LTH), Lund Universty, Lund, Sweden. Available online at: http://www.design.lth.se/aldreochdesign/english/ (May 24, 2006).

Enquist, Henrik 2004. Emotional Images in Medicine. *Abstracts of the Fourth International Conference on Design and Emotion*, Ankara, Turkey. Kurtgözu, A. (ed.), p. 22. Available online at: http://www.certec.lth.se/doc/emotionalimages/emotionalimages.pdf (May 24, 2006).

 © The authors and Studentlitteratur

Flyvbjerg, Bent 1991. *Rationalitet og makt (Rationality and Power)*. Akademisk Forlag, Copenhagen, Denmark. Available online at: http://flyvbjerg.plan.aau.dk/

Fält, Annika; Jönsson, Bodil 1999. *What is right? Everyday legal and ethical questions encountered by Certec*. Available online at: http://www.certec.lth.se/doc/whatisright/ (May 24, 2006).

Gaver, William W.; Boucher, Andrew; Pennington, Sarah; Walker, Brendan 2004. Cultural Probes and the Value of Uncertainty in *Interactions*, Sept.–Oct., pp. 53–56. ACM Press, New York, NY, USA.

Gaver, William W.; Dunne, Anthony; Pacenti, Elena 1999. Design: Cultural Probes. *Interactions*, vol. 6, no. 1, pp. 21–29. ACM Press, New York, NY, USA. Available online at: http://doi.acm.org/10.1145/291224.291235 (May 24, 2006).

Gedenryd, Henrik 1998. *How Designers Work – Making Sense of Authentic Cognitive Activities*. Doctoral thesis. Conitive Studies, Lunds Univeristy, Lund, Sweden. Available online at: http://asip.lucs.lu.se/People/Henrik.Gedenryd/HowDesignersWork/ (May 24, 2006).

Gillberg, Minna 1999. *From Green Image to Green Practice*. Doctoral thesis. Dept. of Sociology, Sociology of Law, Lund University, Lund, Sweden. Available online at: http://www.lub.lu.se/cgi-bin/show_diss.pl?db=global&fname=soc_179.html (May 24, 2006).

Glaser, Barney G. 2003. Naturalist Inquiry and Grounded Theory. *Forum: Qualitative Social Research*. Online Journal, 5 (1), Art. 7. Available online at: http://www.qualitative-research.net/fqs-texte/1-04/1-04glaser-e.htm (May 24, 2006).

Gould, John D.; Lewis, Clayton 1985. Designing for Usability: Key Principles and What Designers Think. *Communications of the ACM*, vol. 28, nr. 3, pp. 300-311. ACM Press, New York, NY, USA. Available at: http://doi.acm.org/10.1145/3166.3170, http://doi.acm.org/10.1145/3166.3170 (May 24, 2006).

Helander, Martin G.; Landauer, Thomas K.; Prabhu, Prasad V. (eds.) 1997. *Handbook of Human-Computer Interaction*, 2nd edition. Elsevier Science Inc., New York, NY, USA.

Husserl, Edmund 1901. *Logische Untersuchungen (Logical Investigations)*, Halle. Available online in German at: http://www.princeton.edu/~batke/phph/husserl/lu/ (May 24, 2006).

© The authors and Studentlitteratur

Hutchins, Edwin 1996. *Cognition in the Wild*. MIT Press, Cambridge, MA, USA.

Hägerstrand, Torsten 1991. *Om tidens vidd och tingens ordning (On the Scope of Time and Order of the Artefact)*. Texts of Torsten Hägerstrand. Byggforskningsrådet, Stockholm, Sweden.

Inde, Krister et al. 2001. *Hur mycket ser ett nyfött barn? (How Much Does a Newborn Infant See?)* Barns syn, Specialpedagogiska Institutet, Stockholm, Sweden.

ISO (International Organization for Standarization) 1997. *ISO 9241-1:1997, Ergonomic Requirements for Office Work with Visual Display Terminals (VDTs) – Part 1: General Introduction*. Geneva, Switzerland. Ordering information available online at: http://www.iso.ch/iso/en/ISOOnline.frontpage (May 24, 2006).

ISO/IEC (International Organization for Standardization/International Electrotechnical Commission) 1996. *ISO/IEC Guide 2:1996, Standardization and Related Activities – General Vocabulary*. Geneva, Switzerland. Ordering information available online at: http://www.iso.ch/iso/en/ISOOnline.frontpage (May 24, 2006).

Jönsson, Bodil 1997. *Certec's Core*. Certec, Faculty of Technology (LTH), Lund University, Lund, Sweden. Available online at: http://www.certec.lth.se/doc/certecscore/index_t.html (May 24, 2006).

Jönsson, Bodil 2001. Läraren, lärandet och informationsteknologin (Teacher, Learning and Inforamtion Technology). *Datorn i Utbildningen (Computers in Education)*, no. 5. Stockholm, Sweden. Available online in Swedish at: http://www.diu.se/nr5-01/nr5-01.asp?artikel=s6 (May 24, 2006).

Jönsson, Bodil 2004. Enabling communication: pictures as language. In Malcolm MacLachlan; Pamela Gallagher (eds.), *Enabling Technologies. Body Image and Body Function*, pp. 33–57. Churchill Livingstone, Edinburgh, UK.

Jönsson, Bodil; Anderberg, Peter 1999. *Rehabilitation Engineering and Design Research – Theory and Method*. Certec, Faculty of Technology (LTH), Lund, Sweden. Available online at: http://www.english.certec.lth.se/theory.html (May 24, 2006).

Jönsson, Bodil; Deaner, Eileen; Mandre, Eve; Nordgren, Camilla; Svensk, Arne 2004. *Funktionshinder, säkerhet, osäkerhet och katastrofer (Disability, Security, Insecurity and Catatrophes)*, Report no. 1:2004, Certec, LTH, Lund University.

 © The authors and Studentlitteratur

Jönsson, Bodil; Malmborg, Lone; Svensk, Arne; Anderberg, Peter; Brattberg, Gunilla; Breidegard, Björn; Eftring, Håkan; Enquist, Henrik; Flodin, Eva; Gustafsson, Jörgen; Magnusson, Charlotte; Mandre, Eve; Nordgren, Camilla; Rassmus-Gröhn, Kirsten 2004. *Situated Research and Design for Everyday Life*. Certec, Faculty of Technology (LTH), Lund University, Lund, Sweden. Available online at: http://www.certec.lth.se/doc/situatedresearch/situated.pdf (May 24, 2006).

Jönsson, Bodil; Philipson, Lars; Svensk, Arne 1998. *What Isaac taught us*. Certec, Faculty of Technology (LTH), Lund University, Lund, Sweden. Available online at: http://www.certec.lth.se/doc/whatisaac/excerpt.html

Jönsson, Bodil; Rehman Karin 2000. *Den obändiga söklusten (Learning by Searching)*. Brombergs Förlag. Out of print. Available online in Swedish at: http://www.certec.lth.se/dok/denobandigasoklusten/index.html (May 24, 2006).

Jönsson, Bodil; Svensk, Arne; Cuartielles, David; Malmborg, Lone; Schlaucher, Pierre 2002. *Mobility and Learning Environments: Engaging people in design of their everyday environments*. Certec, Faculty of Technology (LTH), Lund University and Malmö University, Creative Environments, Sweden. Available online at: http://www.certec.lth.se/doc/mobility1/MobilityLearningReport021215.pdf (May 24, 2006).

Jönsson, Håkan 2000. *Certecs användarforskning ur ett etnologiskt perspektiv (Certec's User Research from an Ethnologcial Perspective)*. Certec, Faculty of Technology (LTH), Lund University, Lund, Sweden. Available online in Swedish at: http://www.certec.lth.se/dok/certecsanvandarforskning/ (May 24, 2006).

Kensing, Finn; Munk-Madsen, Andreas 1991. Generating Visions: Future Workshops and Metaphorical Design. In Joan Greenbaum; Morten Kyng (eds.), *Design at Work: Cooperative Design of Computer Systems*, pp. 155–168. Lawrence Erlbaum Associates, Hillsdale, NJ, USA.

Kensing, Finn; Munk-Madsen, Andreas 1993. PD: Structure in the Toolbox. *Communications of the ACM*, vol. 36, nr. 6, pp. 78–85. ACM Press, New York, NY, USA. Available online at: http://doi.acm.org/10.1145/153571.163278 (May 24, 2006).

© The authors and Studentlitteratur

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.

Kuhn, Thomas 1962. *The Structure of Scientific Revolutions*. University of Chicago Press, Chicago, Il. USA.

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

Lave, Jean; Wenger, Etienne 1991. *Situated Learning: Legitimate Peripheral Participation*. Cambridge University Press, New York, NY, USA.

de León, David 2003. *Artefactual Intelligence: The Development and Use of Cognitively Congenial Artefacts*. Doctoral thesis. 105. Cognition Research, Lund University, Lund, Sweden.

Lesser, Eric L.; Storck, John 2001. Communities of Practice and Organizational Performance. *IBM Systems Journal*, vol. 40, no. 4. Available online at: http://www.research.ibm.com/journal/sj/404/lesser.html (May 24, 2006).

Lewin, Kurt 1946. Action Research and Minority Problems. *Journal of Social Issues* 2. pp. 34–46.

Lindgaard, Gitte 1994. *Usability Testing and System Evaluation: A guide for designing useful computer systems*. Chapman & Hall, New York, NY, USA.

Lundequist, Jerker 1995. *Design och produktutveckling. Metoder och begrepp (Design and Product Development. Methods and Concepts)*. Studentlitteratur, Lund, Sweden.

Löwgren, Jonas 1993. *Human-Computer Interaction: What every system developer should know*. Studentlitteratur, Lund, Sweden.

Löwgren, Jonas; Stolterman, Erik 1998. *Design av informationsteknik – materialet utan egenskaper (Design of Information Technology – Material without Properties)*. Studentlitteratur, Lund, Sweden.

Madsen, Kim H. 1994. A Guide to Metaphorical Design. *Communications of the ACM*, vol. 37 (12), pp. 57–62. ACM Press, New York, NY, USA.

Madsen, Kim H. 2002. *Video Prototyping. Centre for Pervasive Computing*, Århus N, Denmark. Summary available online at: www.pervasive.dk/projects/vidProt/vidProt_summary.htm (May 24, 2006).

 © The authors and Studentlitteratur

Magnusson, Charlotte 1998. *Expert Systems and Learning*. Certec, Faculty of Technology (LTH), Lund University, Lund, Sweden. Available online at: http://www.certec.lth.se/doc/expertsystems/

Magnusson, Charlotte; Mandre, Eve 2004. *The Social Simulator Project*. Report, Certec, Faculty of Technology (LTH), Lund University. Available online at: http://www.english.certec.lth.se/doc/socialsimulatorproject/socialsim.pdf. More about the project at: http://www.english.certec.lth.se/expertsystem/social_simulator.html (May 24, 2006).

Mandre, Eve; Jönsson, Bodil 1996a. *Free Freja, Part 1. Before becoming computerized*. 2:96, Certec, Faculty of Technology (LTH), Lund University, Lund, Sweden. Available online at: http://www.certec.lth.se/doc/freefreya1/index.html (May 24, 2006).

Mandre, Eve; Jönsson, Bodil 1996b. *Free Freja, Part 2. Explosive Development*. 5:96. Certec, Faculty of Technology (LTH), Lund University, Lund, Sweden. Available online at: http://www.certec.lth.se/doc/freefreya2/index.html

Mandre, Eve 1997. *Free Freja, Part 3. A year of education in the psychiatric care services*. 1:97. Certec, Faculty of Technology (LTH), Lund University, Lund, Sweden. Available online at: http://www.certec.lth.se/doc/freefreya3/index.html (May 24, 2006).

Mandre, Eve 1999. *Designing Remedial Education: Education meets psychiatry*. Licentiate thesis. Certec, Faculty of Technology (LTH), Lund University, Lund, Sweden. Available online at: http://www.certec.lth.se/doc/designingremedial/ (May 24, 2006).

Mandre, Eve 2002. *From Medication to Education: People with autism in adult psychiatry*. Doctoral thesis. Certec, Faculty of Technology (LTH), Lund University, Lund, Sweden. Available online at: http://www.certec.lth.se/doc/frommedicationto/ (May 24, 2006).

Marton, Ference; Booth, Shirley 1997. *Learning and Awareness*. Lawrence Earlbaum Associates, Hillsdale, NJ, USA.

Merleau-Ponty, Maurice 1962. *Phenomenology of Perception*. Routledge, New York, NY, USA and London, UK.

Nelson, Harold G.; Stolterman, Erik 2003. *The Design Way*. Educational Technology Publications, Englewood Cliffs, NJ, USA.

Nesser, Håkan 2004. *Skuggorna och regent*. Albert Bonniers Förlag AB, Stockholm, Sweden.

Nielsen, Jakob 1993. *Usability Engineering*. The Academic Press Inc., San Diego, CA, USA.

© The authors and Studentlitteratur

Nilsson, Lennart 1990. *A Child Is Born*, Dell Publishing, New York, NY, USA.

Niiniluoto, Iikka 1999. Defending Abduction: Philosophy of Science. Vol. 66, Supplement. *Proceedings, 1998 Biennial Meetings of the Philosophy of Science Association*. Part I: Contributed Papers. (Sep. 1999), pp. S436–S451. Available online at: http://www.umkc.edu/scistud/psa98/papers/niiniluoto.pdf (May 24, 2006).

Nordgren, Camilla; Levi, Richard; Ljunggren, Gunnar; Seiger, Åke 2003. Societal Services after Traumatic Spinal Cord Injury in Sweden. *J.Rehabil.Med.*, vol. 35, pp. 121–126.

Norman, Donald A. 1988. *The Psychology of Everyday Things*, Basic Books, New York, NY, USA.

Norman, Donald A. 1993. *Things That Make Us Smart*. Addison-Wesley, Reading, MA, USA.

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

Orwell, George 1945. *Animal Farm*. Secker and Warburg, London, UK.

Pirhonen, A.; Isomäki, H.; Roast, C.; Saariluoma P. (eds.) 2005. *Future Interaction Design*. Springer-Verlag, London, UK.

Plato, Göran; Jönsson, Bodil 2001. *Art and Science – A different convergence*. Certec, Faculty of Technology (LTH) Lund University, Lund, Sweden. Available online at: http://www.certec.lth.se/doc/artandscience/artandscience.pdf (May 24, 2006).

Polya, George 1962. *Mathematical Discovery*. John Wiley & Sons, New York, NY, USA.

Polya, George 1990. *How to solve it*. Penguin Books, New York, NY, USA.

Poulson David; Ashby, Martin; Richardson, Simon 1996. *USERfit: A practical handbook on user-centred design for Assistive Technology*. ECSC-EC-EAEC, Brussels-Luxembourg. Portions available online at: http://www.stakes.fi/include/1-4.htm (May 24, 2006).

Preece, Jennifer; Rogers, Yvonne; Sharp, Helen 2002. *Interaction Design*. John Wiley & Sons, Inc., New York, NY, USA.

Ramachandran, Vilayanur S.; Blakeslee, Sandra. 1998. *Phantoms in the Brain. Probing the Mysteries of the Human Mind*. William Morrow & Company, Inc., New York, NY, USA.

 © The authors and Studentlitteratur

Rittel, Horst W.J.; Webber, Melvin M. 1984. Planning problems are wicked problems in *Developments in Design Methodology*, N. Cross (ed.). John Wiley & Sons, New York, NY, USA, pp. 125–144.

Rubin, Jeffrey 1994. *Handbook of Usability Testing*. John Wiley & Sons, Inc., New York, NY, USA.

Sanders, Mark S.; McCormick, Ernest J. 1992. *Human Factors in Engineering and Design*. McGraw Hill International Editions.

Schön, Donald 1983. *The Reflective Practitioner. How Professionals Think in Action*. Basic Books, New York, NY, USA.

Shaw, George Bernard 1916. *Pygmalion*. Brentano, New York, NY, USA.

Snow, C. P. 1993. *The Two Cultures*. Cambridge University Press, New York, NY, USA.

SOU 1999:4 1999. *God sed i forskningen (Ethical Research Practice)*. Available online in Swedish at: http://www.regeringen.se/sb/d/108/a/23647 (May 24, 2006).

Suchman, Lucy A. 1987. *Plans and Situated Actions: The problem of human-machine communication*. Cambridge University Press, New York, NY, USA.

Suchman, Lucy A.; Trigg, Randall H. 1991. Understanding Practice: Video as a medium for reflection and design. In Joan Greenbaum and Morten Kyng (eds.), *Design at Work: Cooperative Design of Computer Systems*, pp. 65–89. Lawrence Erlbaum Associates, Hillsdale, NJ, USA.

Svensk, Arne 2001. *Design for Cognitive Assistance*. Licentiate thesis. Certec, Faculty of Technology (LTH), Lund University, Lund, Sweden. Available online at: http://www.certec.lth.se/doc/designforcognitive/designforcognitive.pdf (May 24, 2006).

Svensk, Arne; Jönsson, Bodil; Malmborg, Lone. 2005. Mobility and Learning: Engaging People in Design of their Everyday Environments. *Proceedings, International conference on inclusive design–Include*. Royal College of Art, London, UK. Available online at: http://www.hhrc.rca.ac.uk/programmes/include/2005/proceedings/index.html (May 24, 2006).

Svenska Dagbladet. 2003. Hennes uppfinning var guld värd i Paris: Elisabeth Linderot, Shoppinetten (Her invention was worth its weight in gold in Paris: Elisabeth Linderot, the Shopinette). Available online at:

© The authors and Studentlitteratur

http://www.svd.se/dynamiskt/naringsliv/did_6310306.asp (May 24, 2006).

Tenner, Edward 2003. *Our Own Devices – The Past and the Future of Body Technology*. Random House, Inc., New York, NY, USA.

UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1993. Available online at: http://www.un.org/esa/socdev/enable/dissre00.htm (May 24, 2006).

Universal Declaration of Human Rights, Article 27 1948. Available online at: http://www.un.org/Overview/rights.html (May 24, 2006).

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

Wenger, Etienne 1998. *Communities of Practice: Learning, Meaning and Identity*. Cambridge University Press, New York, NY, USA.

Wixon, Dennis; Holtzblatt, Karen; Knox, Stephen 1990. Contextual Design: An Emergent View of System Design. *Proceedings, SIGCHI Conference on Human Factors in Computing Systems: Empowering People*. Seattle, WA, USA. ACM Press, New York, NY, USA, pp. 329–336.

WHO (World Health Organization). 1992. *International Statistical Classification of Diseases and Related Health Problems (ICD-10)*, 10th revision. Geneva, Switzerland. Ordering information: http://www.who.int/whosis/icd10/ (May 24, 2006).

WHO (World Health Organization). 2001. *International Classification of Functioning, Disability and Health (ICF)*. Geneva, Switzerland. Ordering information: http://www3.who.int/icf/icftemplate.cfm (May 24, 2006).

 © The authors and Studentlitteratur

Index

abduction 168
abstract 30, 153
acceleration 172
accessibility 61, 69, 72, 75
accumulate 180
actant 124
acting 61, 122, 148, 159
action research 128
aesthetics 145
affirmation 90
afford 113, 117
affordance 187–188
aggressive 136, 138
aid 25–26, 52
airplane 71, 75
alleviate 37, 122
analysis 145, 149, 158, 183
anxiety 37, 56, 72, 149
archaeology 148
Aristotelian agent 181
artefact 23, 77, 148, 153
arts 164
assistant 79–80, 104, 140
assistive device 21, 135, 140
assistive technology 53, 128, 132, 149
associations 39, 44, 173
attitude 117
autism 76, 162, 182
autonomous 150
availability 34

back pain 83
blind 63, 130, 135
bodily presence 171
body therapists 63
Braille 130, 160
Braille reading 130
Braille teaching 135
brain injury 99
brake system 166
broadcast sowing 102
burnout 60, 65–66, 86, 182

camera 42
car adaptations 164
care provider 35–36, 92
care recipient 36
case study 139, 141–142, 183, 185
challenge 170
chameleon method 159–160
cinema 72
clock time 40
closed psychiatric care 49
Closed Psychiatric Care Act 40
coaching 62
cognitive artefact 80
cognitive assistance 80–81, 133
cognitive limitations 77, 80, 133, 149
cognitive support 49
communication 39–40, 99, 142, 156
communities of practice 155
compatibility 159
compression 166
computer 20, 43, 100, 152
computer course 65

© The authors and Studentlitteratur

computer interface 160
computer screen 23–24, 101–102, 107
concept 64, 66, 130, 180–181
concept formation 187
conceptions of how things are related 15
conditioning 77, 167
confirmation 98
consensus 187
constraints 174
context 67, 132–133, 153
context independence 181
contextual 153
contextual design 131
contrast 123
control 53, 100, 113, 151
control digit 166
cost effectiveness 164
cost ineffectiveness 163
county administrative court 49
critical case 141
cultural probe 153
cultural probes 141, 156, 168

day activity centre 133, 154, 167
deadline 58
delivery 30
dementia 173
dependent 49, 53, 139, 151, 166
design 26, 121, 188
design principles 127
design research 61, 121, 129
desire to live 24
developmental disability 78, 80, 133
diagnosis 29, 34, 40–41, 49
diffuse cognitive contour 149
digital camera 42, 44, 46, 104, 125, 151
disability 61, 83, 121
disability pension 15
disability research 61
disablism 112, 117
disorder 55, 72
distributed cognition 170
distrust 61
doctor 35, 85
documentation 135
dream 30, 62, 141, 157
driving 26

eccentric viewing 24
education 42
electrical potential 100
ELFA catalogue 101
email 20, 115–116, 160
emergency 71
emergency exit 72
emotional health 95
emotional pictures 34
empathy 26, 122, 162
empirical 152, 168, 185
empowerment 37, 127, 142–143, 172
enable 24, 55, 78, 95, 117
engineer 52–53
entirety 151
episteme 179
epistemological 129, 180
epistemology 179–180
ethical issues 158
ethnology 148
evacuation 71
evidence-based 135
exhaustive depression 60, 64, 86, 90, 94, 182
existential discussion 61, 97
experience 19, 62, 92, 144
experiment 100, 185
experimental psychology 131
expert patient 35
expert system 130

© The authors and Studentlitteratur

feedback 23, 61, 102, 106, 182
fire brigade 72
fire drill 172
flexibility 71, 80, 144
foetus 29–30, 34
Forensic Psychiatric Care Act 40
forensic psychiatry 42, 49
function 112, 117, 145, 160
functional impairment 55, 114, 117, 167
functional reduction 55, 95
future 19, 44, 155

general 157
general public 127
generalizable 62, 141
generalization 180
glasses 21, 76, 159, 168
good will 151
GPS 125, 150
grounded theory 186
group home 78, 144
Göteborg Pedagogues 187

handheld computer 125
headache 84
hearing 56
heart disease 72
hermeneutics 173
heuristics 183
high tech 125
HMI, Human Machine Interaction 131
honesty 26, 70, 142
hope 61, 66, 94, 171
human capital 15
human rights 158
human sector 15, 62
hypothesis 45, 127, 168, 186
hysteria 72

ICD-10 162
ICF 162
ICIDH 162
inclusion 70
independence 53, 114
induction 181
inform 156
information theory 166
initiative 127
initiative taking 124
inspiration 156
institution 144, 151
intelligibility 123
interaction design 171
interactivity 126, 133–134, 145
internet 60, 62, 105, 115–116
Isaac 125, 133, 149, 151
isolation 61
IT agent 150
iterative 148, 152
iterative prototyping 131

joystick 147

kindness 19
knowledge-based system 174

language limitations 156
lean backward 129, 186
lean forward 129, 186
leap 110, 121, 126
learning environment 97
liberate 143
liberating pedagogy 123, 126, 143
life history 39
life memories 39
lifeworld 186–187
lived disability 122, 161, 186
long-term sustainable development 15
long-term sustainable people 15
low vision 19, 22, 123, 135
low vision therapist 23

© The authors and Studentlitteratur

love 26, 33, 51, 53, 97, 111
low-tech 125

magnetic field sensor 101, 105
magnification 23–24
magnifying glass 25
maternity clinic 31
meaning 40, 62, 64, 97
mechanical 100, 150
medical imagery 34
medical images 29, 34, 36, 161
medical records 38
medicine 35, 41, 177
memory 122, 133
memory support 49
mental assistance 167
mental representation 46
mental support 140, 144, 168
method 119, 121, 124, 157
migraine 136, 138
Minimeter 99, 101, 106, 108
mobile phone 114, 150, 166
mock-up 126–127, 155
muscle disease 161

navigation 150
need 29, 62, 129, 141
net-based concept 61
new knowledge 34, 128, 178, 184
non-relativism 181
no-tech 125

objectivity 106, 122, 181
occupational rehabilitation 94
optometrist 23
over sensitivity 48, 86

pace 55
pacemaking 55, 60, 65, 67
pain master 95
pain school 96
Pain Workshop 92, 94–95, 98
paradigmatic case 141
paranoid 40, 45, 48
parrot method 159
participate 70
participatory design 131, 153
patient records 39
pedagogy 76, 121, 130
pension 164
peripeteia 22
peripheral vision 19
personal assistance 80, 149
personal assistant 109, 164
personal history documentation 151
personal identity number 166
phenomenography 186
phenomenology 173, 179, 186
phenomenon 186–187
photography 29, 43
phronesis 178–179, 181
physical disabilities 163
physical disability 151
physical impairment 132
physical planning 123
Pictorium 133, 167, 173
picture 33, 37, 42, 103
poodle method 159, 161
poor health 38, 55, 60, 92
positioning 187
power 35, 81, 139
pregnancy 29
prejudice 161
preparation 46
principal person 15, 122, 151, 163
priority of the particular 181
process of change 128
production 147
production phase 146
prognostic value 64
progressive disorder 135
prototype 124, 126–127, 145
proven experience 148

© The authors and Studentlitteratur

psychiatry 40
psychiatry reform 41

quality of life 88, 92
quick-fix 124

readability index 163
reading with hands 130
recycling 145
reductionism 184
redundancy 164, 166–167
reflect 52
reflection 43, 95, 122, 142
rehabilitation engineering 148, 167, 180, 188
reliance 72
requirements specification 131, 173
research goal 128
research person 16, 126, 133, 149
rhythm 55, 61
right-handedness 147
risk 53, 71, 83, 150
robot arm 147, 170, 172
robot researcher 151

scan 102
schizophrenia 40–42, 182
security 71–72, 150
See More Project 135
sensitivity 144
shopinette 145
sick leave 15, 60, 85, 93
sickness benefits 164
situated 15, 61, 169, 181
sleep 56, 59, 86, 91
sleeping pill 59
smoke detector 172
SOC 133
social insurance office 85
social sciences 128, 168, 179
social security number 166
societal information 76
society made durable 80
software 101, 105, 129
special education 77
special pedagogy 157
speed 102, 172
spinal muscular atrophy 110
standard method 152, 156
STEP 133–134
stereotype 126
stress radiation 55
surprise 143, 178
sustainability 98, 123
synthesis 183
synthetic speech 23, 160
systematize 180

take for granted 76, 143
technical solution 24, 52, 80, 112
teleological 129
telephone 154
telephone conversation 57
telescope 24
telling time 149
text-based 76
the lived body 186
thoughts condensed 129
thoughts realized 123
time 55–59, 61, 63–66
time measurement 149
toilet 69
tool 44, 72, 159, 179
transcending practice 156
traumatic spinal cord injury 164
trust 73, 90, 150
TV camera 106

ultrasound 29–31
UN Standard Rules 158
unemployment 93
universality 181
usability 131, 145, 152, 163

© The authors and Studentlitteratur

user participation 146, 149
user scenario 155
user-centred design 152
useworthiness 81, 132, 145, 163

values 63, 124, 158, 179
web camera 154
verification 151
wheelchair 69, 100, 109, 170
wheelchair user 71, 111, 147
WHO 75, 162
vicinity relationship 185
video documentation 102
video prototype 156
videoethnography 153
wish 35, 81, 113, 157
vision clinic 19, 23
visual desire 24
workplace 56, 64, 67

© The authors and Studentlitteratur