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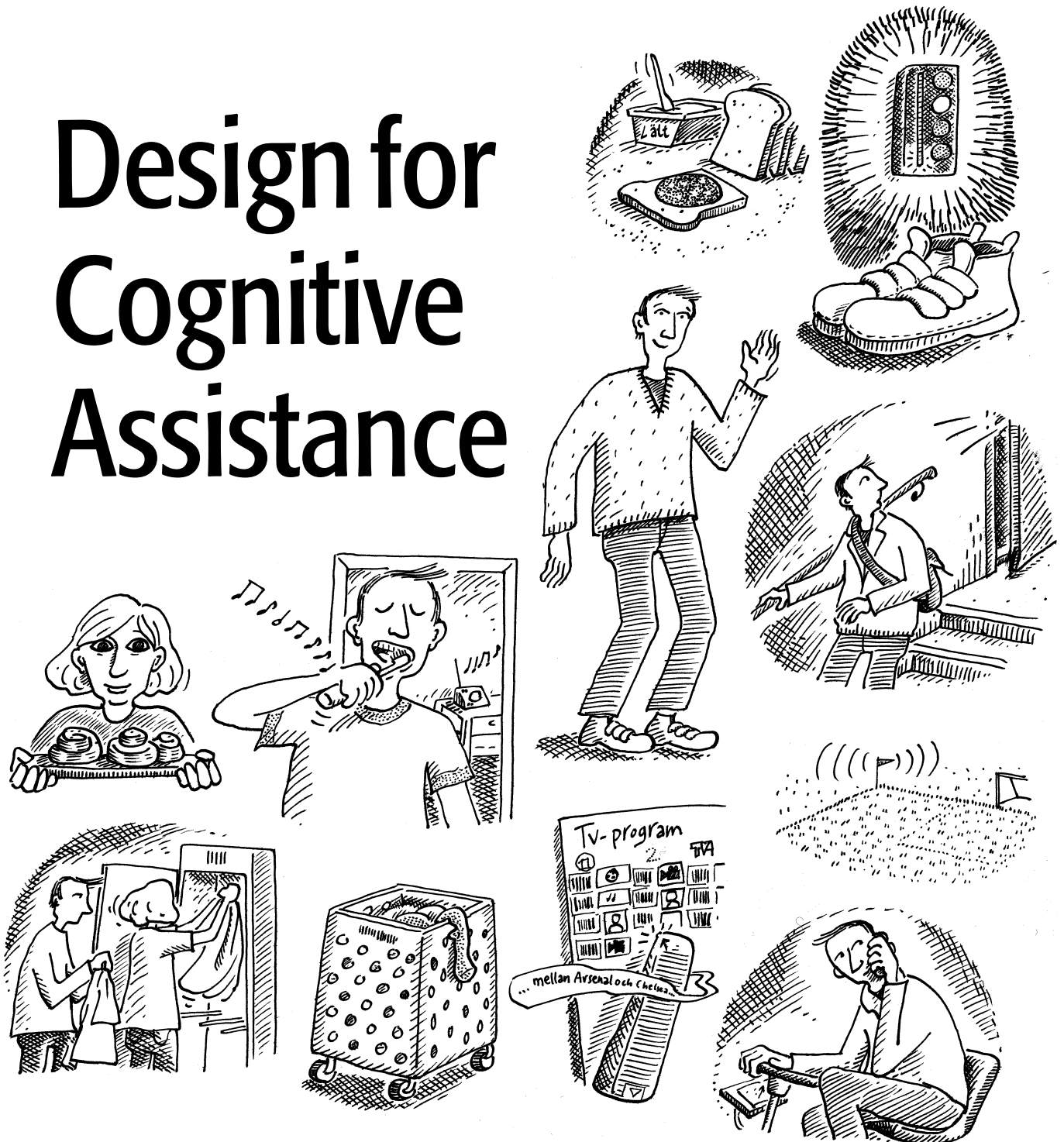
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LICENTIATE THESIS CERTEC, LTH NUMBER 1:2001

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# Design for Cognitive Assistance



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Arne Svensk

# Design for Cognitive Assistance



## Preface

Like the Swedish novelist Fritiof Nilsson, known as “the Pirate”, I have the habit of putting off until tomorrow what I should have done today. Sometimes this is simply due to laziness and lack of resolve, but most often because of an irresistible curiosity that continually leads me astray. Choosing inlines instead of deadlines has always felt natural to me and that is why no one is more surprised than myself that this thesis is finally completed (with the possible exception of my advisor).

It is not the thesis I had in mind, nor is it the one I had wished I could have written. Instead, it ended up like this, luckily enough, because it deals with exactly the issues that are important to me. It has to do with the commonplace, everyday problems that we all run into and that we eventually learn to live with. But if obstacles are stacked one on top of the other, they require so much energy and effort that there is none left for all the fun things that you would like to do. Charles Bukowski expresses a similar train of thought in the poem *The Shoelace* (1971):

*it's not the large things that  
send a man to the  
madhouse ...  
no, it's the continuing series of small tragedies  
that send a man to the  
madhouse...  
not the death of his love  
but a shoelace that snaps  
with no time left...*

What luck, then, that there are people who help you up when you stumble and then tie your shoelace in a double knot. In the special education schools and group homes where I have worked in, I have had the benefit of having such friends and I would like to start by thanking all of you.

There are many here at Certec who have supported me and one of them is Simon Nyman who gave me good advice and cleared away the thicket from the cyber trails. Gun Andersson along with Kirsten Rasmus-Gröhn redirected me when I got lost and Henrik Daneilsson made use of both whip and carrot to get me to keep on going. I would also like to thank my wise and sensible advisor, Professor Bodil Jönsson, who realized early on that sensible shoes with Velcro straps were needed if I was to stand on my own two feet.

I would also like to extend a big thanks to Göran Plato, Stig Nilsson, Thomas Åkesson, Stig Möller and Anette Hartlow at The Pictorium; Vibe Björfors and Mona Ekelin at Fågelskolan; Agneta

Dyberg-Ek and Gertrud Widell at Georgshillskolan and Inga Richard-Olsson because you shared your experiences with me and because you still are so filled with enthusiasm for what you are doing. That is how you have inspired me and others.

I would like to conclude by thanking my family, Kerstin, Elin and Anton for all their support.

## Summary

In Sweden over the last twenty years, many people with developmental disabilities have chosen to move into their own apartments with different levels of assistance. For most of them, it has resulted in increased personal responsibility for household chores and daily routines. Some have managed without any problems, while others have had considerable difficulties. To help them in difficult situations, society has arranged for *personal assistance* and research has been carried out on these efforts as well. However, attempts to implement *technological assistance* have been marginal, and research in this area and on its effects is almost non-existent. This thesis will show that design for cognitive assistance should also include technological efforts.

The starting point is found in the problems that arise when a fictional character by the name of Henrick Person has one of those days when almost everything goes wrong. By using a story format, I try to illustrate some of the typical difficulties a person with cognitive limitations needs to overcome in everyday living. The story will also show how an event that would be considered a trivial setback in most cases, can, under the wrong circumstances, develop in a way that finally pushes a person to the verge of losing control over the situation.

I use this unlucky day to show that making use of relatively simple means can give a person like Henrick Person the cognitive assistance he needs to manage many daily living situations on his own. As background information, I will describe portions of a specific design process that were used to reach the goal. It has much in common with many other design processes but also has its own distinctive features. For an artifact or phenomenon to be accessible to a person with cognitive disabilities, it should support the person's awareness of security, context, experience/memory and precision.

The STEP method, its name a combination of letters from the words Security, conText, Experience and Precision, is the specific contribution this thesis has to make to general design science. The STEP method is intended as support for the people whom the work primarily concerns and the world around them. A

STEP  
Security  
conText  
Experience/memory  
Precision

fundamental idea is that cognitive processes are distributed over people, time and artifacts and as a result should also be studied in actual interactive situations.

Distributed cognition as a design process model increases the scope of design for cognitive assistance and thereby also increases the opportunities of finding solutions that correspond to the person's needs, wishes and dreams. As this report will demonstrate, the people who assist a person with developmental disabilities play a key role in the design process, and consequently the way in which their involvement and knowledge can be put to use is also discussed.

## Purpose

The purpose of this thesis is threefold:

1. To discuss issues that concern the design of assistance based on a model of distributed cognition.
2. To present a method that offers support in the analysis of a variety of cognitive obstacles that people with developmental disabilities meet in daily living.
3. To demonstrate concretely how specific design criteria can provide support in design for cognitive assistance based on the person's own wishes.

### KEYWORDS

Design, distributed cognition, ethnography, cognitive artifact, cognitive assistance, personal assistance, technological assistance, cognitive limitations, developmental disabilities, cognitive disabilities.





# Contents

Preface 3

Summary 4

Purpose 5

## 1. Introduction 9

1.1 Background 9

1.2 Change in my view of assistance 10

1.3 Design, generally and specifically 12

1.4 Thesis organization 12

1.5 Documentation 13

1.6 Articles, books and conference contributions 14

1.7 Research and development projects 16

## 2. Henrick Person's terrible Tuesday 19

## 3. Henrick Person's wonderful Wednesday 25

## 4. HP and cognitive ethnography 29

4.1 Qualitative research methods 31

4.2 Fieldwork 31

4.3 Participatory observation 32

4.4 Dialogues and interviews 33

4.5 Field notes 33

4.6 Ethnographic reporting 34

4.7 Cognitive ethnography 34

## 5. HP and cognitive design 39

5.1 Cognitive design for people  
with cognitive limitations 39

5.2 Cognitive design specifically for HP 41

5.3 HP and general design criteria 47

## 6. The role of distributed cognition 53

6.1 Some things are not negotiable 57

6.2 Parrots, chameleons and poodles 58

6.3 Design for different numbers 59

6.4 Significance of support persons in the design process 61

## 7. Results and conclusions 65

Appendix

*Examples of projects and design ideas 68*

Design for creating precision 68

Design for creating context 70

Design for supporting memory 72

Design for creating security 73

Idea design 74

References 75

Literature 78



# 1. Introduction

The primary focus of this thesis is on the design of technological assistance. By its nature, though, it also deals with the interaction between people and technology. My intention is to shed light on the following questions:

- Are there critical elements in connection with design for cognitive assistance?
- What distinguishes this design process from others?
- Are there any qualitative differences between cognitive assistance provided by people versus that provided by technology?
- What role do support persons play in a design process in which the client finds it difficult to formulate his or her needs and wishes?
- Can a model of distributed cognition facilitate the needs analysis and design process?

## 1.1 Background

My interest in cognitive assistance stems from twenty years of work in services for the disabled in Lund, Sweden, as a caregiver, teaching assistant, personal assistant, health sciences teacher and group home supervisor. For many years I was also a part-time union representative for the staff of nursing homes, group homes, day activity centers and special education schools in Skåne, the southernmost province of Sweden.

These are the experiences that I now utilize retrospectively as the foundation material for this research. During the last ten years at Certec I have maintained and expanded my network in the areas of disability care and special education and in so doing have continually received new, primary material. Additional material has been obtained from the IT-based courses offered by Certec for working professionals. Through documented dialogues in these courses, I have been able to acquaint myself with thoughts and information that would have otherwise been difficult to access. These dialogues have often dealt with ideas and partially formulated thoughts that for a variety of reasons can be difficult to

express in everyday work situations in the care of people with disabilities.

My clinical experience is extensive—altogether I have been in close contact in my work with over one hundred people with developmental disabilities. I have had professional contact with ten of them for between five and ten years. I am still in touch on a regular basis with some of the people I first met in the early 70s and they usually offer me their views on developments in disability care when we meet. At the same time, no claims can be made that this research is a “clinical study”. Rather, it is through my work that I have really *gotten to know* the people I am describing.

Ethnologists use the expression “go native” when a researcher’s involvement results in him identifying with those he is studying. But just going native is not sufficient; one needs to reflect upon what has been experienced. Arnstberg (1997) explains it as follows: “A piling up of information is not enough. It is, instead, the author’s analytical interest that determines the value of the written ethnography, entirely irrespective of if that interest is particularly apparent in the report or not.”

Research of this nature requires both distance and proximity. My years at Certec have provided me with the chance to distance myself and come closer, distance myself again and come closer again. This process has enabled me to bring to a conscious level possible design processes and also to be able to participate in design research as a “reflective practitioner” (Schön, 1999).

## 1.2 Change in my view of assistance

1990 was the first time I came in contact with adults with developmental disabilities who had chosen to live on their own, had jobs on the open labor market, and participated in leisure activities of their own choice. After a while in that context, I encountered a phenomenon I had never noticed before in my work with children and youth for whom activities most often were carried out collectively with a considerable amount of personal assistance. By being in a structured environment that left little room for error, the cognitive limitations that people had and the effects thereof were seldom manifested.

The situation was entirely different for adults who were expected to manage a variety of activities on their own. There were some who neither ate prepared food nor drank coffee on the weekends that they were unable to get personal assistance. There were those who went to work in summer cloths on cold, windy winter mornings. It often happened that I received a call from a person who wanted help in finding out if he was running a temperature. My view of assistance definitely changed thanks to

the woman who rushed in to my office one morning and demanded that I fire the night staff in her apartment building and see to it that the supervisors at work were reprimanded.

After my conversation with the woman, it was apparent that from her point of view the demands to fire and scold personnel were logical. She had woken up as usual, got out of bed and fixed breakfast while the night staff was still sleeping. When she arrived at work, there was nobody there. Since she had, from her way of seeing things, gone through her regular morning routine at the usual pace, it was natural to lay the blame for what had happened on the personnel. That she had actually gone to work in the middle of the night because she couldn't tell time was not a part of her concept of the world.

This event made me realize that it is not enough to treat a problem with more of the same "medicine" (e.g., higher staff ratios, more training in telling time). Entirely different measures were required, the most importance of which was to find a way of representing time that she could interpret. Certec contributed to the solution by developing a prototype of a 24-hour clock that measured time in length. This technical solution, in and of itself, was an important milestone. But the most significant, lasting effect for me was a leap in thought: to go from only thinking in terms of human assistance to begin thinking in terms of technical assistance as well.

What surprises me in hindsight is that in spite of my own interest in technology, I had not been able to change course much earlier. I had certainly had the opportunity ever since 1973 when the first pupils moved out of a large institution in Lund into smaller residential facilities. At the large institution, four to six children and youths shared one room and had no privacy. When the new legislation made it possible to move into more personal living arrangements, each pupil would be able to emerge as the unique person he or she was. Those of us who worked in the first smaller residential facilities, however, did not take full advantage of this opportunity, and that had repercussions for how assistance was structured.

It was not until the mid 1970s when I started working in a special education school that I had access to tools that made my work fun and meaningful. Ten years later, the same tools were no longer of use in group homes for adults. They wanted to live, work and enjoy their spare time on their own terms, and cautiously started demanding to live like everyone else. Unfortunately, neither the civil rights legislation, individual assistance nor the best intentions were enough to fulfill even the most modest of their wishes or dreams in a practical, everyday plan.

### 1.3 Design, generally and specifically

There are considerably more similarities than differences between the general and specific design process. That which is distinguishing is based on the special difficulties that people with cognitive limitations can have in communicating their needs, wishes and dreams. Special knowledge and insight are required of the support persons/designer to get the process going and for the results to be what Efring (1999) characterizes as *useworthy*.

Another characteristic of the specific design process is that it occurs in everyday interactive situations between a few people. The results of the process are often intangible and focused on only one person.

I hope, of course, that this thesis can contribute to providing support persons with methods and mental models that can be used in their daily work. I have been inspired in my research by well-known researchers such as Edwin Hutchins and Donald Norman and have applied their ideas on *distributed cognition* in the context of care services for the disabled. Distributed cognition means that the individual is part of a mental process along with other people and artifacts. Hutchins and Norman also emphasize that thinking does not originate in a vacuum but is strongly influenced by cultural and social factors (Norman 1988, Hutchins 1996).

### 1.4 Thesis organization

The introduction is followed by the story of Henrick Person's terrible Tuesday, which the reader should keep in mind while reading the rest of the thesis. Henrick Person, HP, unlike the other people and situations I describe—is a fictional character. Nothing about him or his terrible day, though, is improbable. I then describe another scenario, Henrick Person's wonderful Wednesday, which is not particularly improbable either. The rest of the thesis deals with theoretical and methodological descriptions and discussions as well as illustrating the need for a STEP method (Security, conText, Experience and Precision).

This thesis stands or falls on my ability to make a credible argument for the transition from a terrible Tuesday to a wonderful Wednesday being the result of the type of design process that I describe. I am well aware that presenting my results in this manner goes against established conventions in a research context. But I am willing to take that risk because I am not primarily out to analyze the parts but instead to illustrate and reflect over the whole concept. Consequently, the credibility, relevance and originality (both in a research context and for those people directly effected) should be looked for in the entirety of what is presented.

## 1.5 Documentation

There is relatively little documentation on the design of technological assistance for people with cognitive limitations. One reason may be that in most cases, the technical solutions produced for a given person in a given environment are one of a kind. The need to document the everyday design processes has, for some reason, not been deemed as important for those involved in the process or for outsiders. Here are examples of literature that deal with technological assistance:

- Applications of Artificial Intelligence to the Needs of Persons with Cognitive Impairments (Vanderheider & Cross, 1992)
- Assistive Technology For Cognitive Disability (Granlund et al., 1995)
- Begåvningshjälpmedel (Cognitive Aids) (Handikappinstitutet [The Swedish Handicap Institute], 1995)
- Ett kassaregister för intellektuellt funktionshindrade: utveckling och utformning av ett användargränssnitt (A Cash Register for the Intellectually Disabled People: Development and Design of a User Interface) (Frid, 1998)
- USERfit. A Practical Handbook on User-centered Design for Assistive Technology (USERfit, 1996)

Considerably more common is the attention directed towards the significance of special education and personal assistance, of which the following books are examples:

- Vägval och växande. Förhållningssätt, kunskap och specialpedagogik för yrkesverksamma hjälpare (Career Choice and Growth. Attitudes, Knowledge and Special Education for Professional Caregivers) (Danielsson & Liljeroth, 1996)
- De hjälper oss till rätta. Normaliseringsarbete, och människor med psykisk utveckling störning (They Help Us Get it Right. Normalization Efforts and People with Developmental Disabilities) (Mallander, 1999)
- Liv & kvalitet i omsorg og paedagogik (Life and Quality in Caregiving and Education) (Holm et al., 1994)
- Från observation till specialpedagogisk design. Pedagogikens möte med psykiatri (Designing Remedial Education. Education meets Psychiatry) (Mandre, 1999)  
[www.english.certec.lth.se/doc/designingremedial/](http://www.english.certec.lth.se/doc/designingremedial/)



## 1.6 Articles, books and conference contributions

### SCIENTIFIC ARTICLES AND CONFERENCE CONTRIBUTIONS

**Magnusson, C. and Svensk, A.**

*A research method using technology as a language for describing the needs both of people with intellectual disabilities and people with brain injuries.*

European Conference on the Advancement of Rehabilitation Technology (Proceedings of ECART 2), 1993.

**Magnusson, C.; Larsson, J. and Svensk, A.**

*Svarne, an Expert System to be used in the Care of the Mentally Retarded (II).*

Proceedings of ECART 3, European Conference of the Advancement of Rehabilitation Technology, p 198, 1995.

[www.english.certec.lth.se/doc/svarne2/](http://www.english.certec.lth.se/doc/svarne2/)

**Magnusson, C.; Svensk, A. and Harrysson, B.**

*The Svarne Project—a New Tool to be used in the Care of People with Cognitive Impairments.*

Proceedings of the 10th World Congress, International Association for the Scientific Study of Intellectual Disabilities, Session 275, 1996.

**Jönsson, B. and Svensk, A.**

*Isaac—A Personal Digital Assistant for the Differently Abled*

The European Context for Assistive Technology, Proceedings of the 2nd TIDE Congress, pp 356–361, 1995.

[www.english.certec.lth.se/doc/isaaca/](http://www.english.certec.lth.se/doc/isaaca/)

**Svensk, A.**

*Empathic Modeling (The Sober Version)*

Advancement of Assistive Technology, Proceedings, pp 432–435, IOS Press, 1997.

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Conference Report. p 287–290. Magnus Tideman (ed.).

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*(Re)habiliteringsteknisk forskning [(Re)habilitation Technology Research]* Socialmedicinsk tidskrift häfte (Social Medicine Journal Booklet) 6–7 pp 224–230, 1995.  
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**Svensk, A.**  
*Omsorg inför lyckta dörrar? Tankar om ett närmare samarbete mellan omsorgspersonal och tekniker (Care Services Behind Closed Doors? Thoughts on Closer Cooperation between Caregiving Personnel and Engineers).*  
Brobygget. Kunskapsutveckling och partcipatorisk forskning. Proceedings från Andra nordiska symposiet om forskning och praxis i socialt arbete s 249-252. Institutionen för social omsorg. Hälsa och samhälle. Malmö högskola, 1999. (Building Bridges. Development and Participatory Research. Proceedings from the Second Nordic Symposium on Research and Practice in Social Work, pp 249-252. Social Care Program, Department of Health and Society, Malmö University, 1999)  
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**Svensk, A. and Jönsson, B.**  
*Technology and Differently Abled People*  
Natur och Kultur, 1994.  
[www.english.certec.lth.se/doc/technologyand/](http://www.english.certec.lth.se/doc/technologyand/)

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*Just Give Us the Tools*  
Natur och Kultur, 1995.  
[www.english.certec.lth.se/doc/justgive/](http://www.english.certec.lth.se/doc/justgive/)

**Jönsson, B.; Philipson, L. and Svensk, A.**  
*What Isaac Taught Us*  
Certec, 1998.  
[www.english.certec.lth.se/doc/whatisaac/](http://www.english.certec.lth.se/doc/whatisaac/)

**Jönsson, B. and Svensk, A.**  
*In Users in Action. Stories of users and telematics in everyday life*  
Karlsson, Marianne and Östlund, Britt (eds.)  
Kommunikationsforskningsberedningen. KFB Report 1999.

## INTERNAL REPORTS

**Jönsson, B. and Svensk, A.**

*Teknikutveckling för förståndshandikappade (Technical Development for Developmentally Disabled People)*

Certec, Lund Institute of Technology, Nr 2:1992

**Magnusson, C. and Svensk, A.**

*Expertsystemet Svarne- beslutsstöd vid våldssituationer (The Svarne Expert System—decision-making support in aggressive situations)*

Certec, Lund Institute of Technology, Nr 2:1993

**Magnusson, C. and Svensk, A.**

*Kunskap på burk, SVARNE projektet och dess utveckling (Canned Knowledge: The SVARNE Project and its development)*

Certec, Lund Institute of Technology, Nr 3:1997

[www.english.certec.lth.se/dok/kunskappa/](http://www.english.certec.lth.se/dok/kunskappa/)

## 1.7 Research and development projects

What follows is a short summary of the five extensive R & D projects in which I have participated.

### PUST

*(Psykisk Udviklingshaemmede, Støtte og Teknologi) (Developmental Disabilities, Support and Technology) 1992–1997*

PUST was a Nordic project with the purpose of promoting the development of technological aids for adults with developmental disabilities. The idea was to study and evaluate the possibilities of using AI technology to develop decision support that these people could use in everyday decision-making situations. The project resulted in an electronic calendar, *My Plan*, with which a person can, for example, plan a week in advance on his own. The calendar also offers suggestions for different activities if the user so needs.

### TASC

*Telematics Applications Supporting Cognition, 1997–2000*

*Fourth Framework Programme of European Community Activities in the Field of Research and Technological Development. Telematics Applications Programme. Disabled and Elderly.*

*Project Number DE 3214(DE).*

[www.tascsupport.com](http://www.tascsupport.com)

TASC was a further development of the PUST project focusing on people with mild dementia, acquired brain injuries and developmental disabilities. The goal was to develop advanced computer aids based on user requests that could support people

who had reduced cognitive abilities in the home, at work and in other social situations.

## **SVARNE**

*Ett beslutsstöd in samband med våld och aggressions (Decision support system for aggressive behaviour).*

1993–1997. [www.english.certec.lth.se/svarne](http://www.english.certec.lth.se/svarne)

The development of the expert system SVARNE aimed to make use of the tacit knowledge the staff have concerning violence and aggression. Staff members from group homes, day activity centers and special education facilities in Skåne, the southernmost province in Sweden, worked together to come up with a computer program that was tested in ten different facilities to see if it could be used as an analysis instrument and decision-making support when encountering violent behavior. In addition to the program, a computer network was established, SvarNet, which the testers could use to communicate with one another. We also developed an educational kit on violence and aggressions in which literature, lectures, games, documentation and a video dramatizing violent events were included.

## **THE ISAAC PROJECT AND ITS CONTINUATION 1993–ONGOING**

[www.english.certec.lth.se/isaac/](http://www.english.certec.lth.se/isaac/)

The idea behind the Isaac project was to give people with cognitive limitations a tool that could help them cross cognitive thresholds in the community. With the help of Isaac, a further development of the Newton hand-held computer, we established conditions that allowed developmentally disabled people to plan, make phone calls, ask for help, find out where they were, take pictures and send them from a distance, all on their own. The trials demonstrated that being able to communicate through digital photos was the function of greatest significance for the users. The concept has since been further developed in special education classes, group homes and particularly at The Pictorium Day Activity Center in Lund, Sweden, which is the facility that has come the farthest in this area.

[www.tryckolera.certec.lth.se/](http://www.tryckolera.certec.lth.se/)

## **IT VILLAGE 1997–FF**

[www.certec.lth.se/itbyn/feb00/lattnet.html](http://www.certec.lth.se/itbyn/feb00/lattnet.html)

The IT Village is a cooperative project between Certec and the Development Board in Skåne. The aim of the project is to make regional information available to people with disabilities via the Internet. The IT Village will also make it possible for a person to get in touch with friends, play games, listen to music, look at

pictures and send information. The IT Village has gradually come to focus on people with cognitive limitations who have difficulties reading. Content and design have grown out of cooperation with staff in group homes, special education facilities, and day activity centers in southern Sweden. Björn Harrysson, who initiated the project, is responsible for testing the different prototypes that are being developed. Over the last few years, he has tested interfaces with cognitively impaired people in order to make the IT Village even more accessible.

## 2. Henrick Person's terrible Tuesday

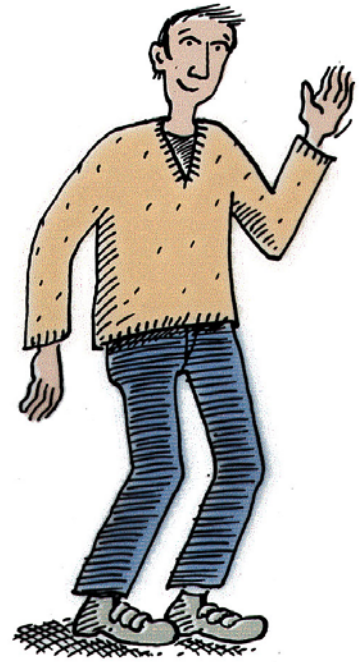
*In this chapter I will describe one day in the life of a fictional character, Henrick Person. The description of HP is based on a longitudinal study (20-30 years) of what are to a great extent real problems for real people with cognitive limitations.*

Henrick Person suddenly wakes up to the ringing of the telephone. He answers and on the other end he hears his work supervisor, Eskil Lindberg, who is irritated and wonders if he knows what time it is. Henrick looks at the clock and sees that the hands are pointing in another direction than they usually do when he gets up. But he doesn't really know what that means, because he has never understood telling time. "You've overslept!" says Eskil, sounding even angrier. Henrick understands that he has to hurry up and get to work and so he jumps in the shower. As usual, the water is icy cold, but that's better than when it's too hot, so Henrick leaves the mixer tap where it is.

He washes his face, but when he grabs the shampoo bottle it's empty. Henrick doesn't know how much to use, so sometimes he goes through a bottle in three days. The staff think that it's entirely too expensive and they tell him time and again that he has to use less shampoo. But Henrick has trouble getting the amounts right when he uses bottles or tubes.

He dries off and starts to brush his teeth. The dentist has said that if he doesn't do it properly, he won't have any teeth left. "Properly?" he thinks. He brushes his upper teeth a few times and does the same with the lower ones and thinks that his mouth smells good. "That's properly done," he thinks.

He gets dressed in the clothes a staff member has laid out on a chair and then goes to the kitchen to make breakfast. He takes out the butter, bread and a knife and starts to cut. The bread slices come out really thick on one end and too thin on the other. Why does cutting have to be so difficult? When he goes to spread the butter, it's so hard that the bread breaks up into small pieces. He puts the cheese and sausage on the crumbs anyway and starts making coffee. He guesses at the amount of water he puts in the glass coffeepot and then measures the coffee. Three spoonfuls usually is just right but today the coffee ends up the consistency of



asphalt. How strange! He drinks the coffee, but being in more of a hurry than usual, he burns his tongue.

Just then he remembers that last night one of the staff members said he had to water the plants and this upsets him. Eskil said that he should hurry, but at the same time he promised he would water the plants, and a promise is a promise. Watering the plants is difficult because Henrick never knows when to stop. So suddenly, water starts dripping onto the floor from the hibiscus and the begonia. “Gotta wipe it up!” Henrick thinks. But where are the rags? He takes the dishcloth from the kitchen, but for every trip he makes between the living room and the kitchen, the floor gets wetter and wetter. “I’ll have to do it this evening when I come home, otherwise I’ll never get to work,” Henrik thinks.

He puts on his jacket and cap and tries to tie his shoes, but that never turns out right. Now he’s really in a hurry, so he grabs his bag and runs to the bus stop. No bus! Typical! He suddenly remembers that he forgot to turn off the coffeemaker and the staff members have said how dangerous that is. He rushes back to his apartment but trips on his shoelaces and falls headlong to the ground. His hands are bleeding and he is frightened. When he gets back to his apartment, the door is wide open, but the important thing now is to wash his hands, so he runs into the bathroom and rinses off the blood. He needs an adhesive bandage, but where are they? He’s never put a bandage on by himself. It takes a while for him to find the first aid kit in a kitchen cupboard. There are pictures of bandages on a package, so Henrick guesses that he’s right. But instead he finds a lot of small pieces of paper. “That’s strange!” Henrick thinks, but to be sure he picks up one of the pieces of paper and can feel that there is something inside of it. He rips it open and to his delight he sees that it’s a bandage.

He tries to put it on, but it keeps falling off because there is plastic where it should be sticky. Now his hands are all bloody again as well as the kitchen table, so he washes off in the kitchen sink and starts looking for the bandages that the staff usually use. Unfortunately, he finds none, and now he feels that he has to have help. He decides to call the nurse, but how does he get a hold of her? He looks at the telephone numbers that the staff have written next to the phone, but since he can’t read, he doesn’t know which one is for the nurse. He calls his mother instead, but there is no answer so she has probably gone to work. What to do now?

He tries to call the emergency number (90 000) but doesn’t know how many zeros there are, so after a while he gives up. Hadn’t they changed it, by the way, to another with ones in it? He tries to speed dial the apartment office, but gets the answering machine that tells him to leave a message after the beep. He waits and waits and then says in desperation, “I’m bleeding!” and hangs

up. He goes to the kitchen counter and takes some paper towels that he winds around his hand and that seems to stop the bleeding a bit.

Now he suddenly feels tired and sad. He sits down on a kitchen chair and says quietly to himself, "I don't want it to be this way." The kitchen floor is red with blood as is the counter. He hears the water dripping from the potted plants and now the phone is ringing again. It's Eskil wondering where he is. Eskil says that he has to hurry if he wants to get to the football field before lunch. Eskil doesn't sound at all happy and Henrick tries to tell him about the hibiscus and the blood and the nurse, but it's all too confusing so he just promises to come on the next bus.

He heads for the bus stop one more time and notices how people are looking at the bloody paper towels around his hands. When the bus comes and Henrick gets on, he realizes he has left his bag with the bus pass at home. Thank heavens the bus driver is a decent fellow who recognizes Henrick and lets him ride anyway.

When he gets to work, Eskil is at first really angry, but when he sees Henrick's hands he changes his tone and shows in different ways that he feels sorry for Henrick. He helps Henrick to wash his hands and puts on four big bandages. All at once everything feels better and Henrick is ready to start working. Eskil tells him that he is to cut the grass on the football field, which is one of Henrick's favorite things to do. He gets on the lawn mower and calmly drives the short distance to the football field. While cutting the grass for the next few hours, he thinks about all that happened that morning.

Eskil calls him on his mobile phone at noon and says that it's time for lunch. Henrik drives carefully back to the shed with the mower. He washes up and goes into the lunchroom and sits down next to Lena and Mats as usual. Today they are having stuffed cabbage rolls, gravy, cranberries and potatoes, one of Henrick's favorite dishes. But the potatoes are hard to peel, as usual, so there isn't much left when he finishes.

Mats and Lena tell Henrick about the bowling tournament they will be attending on the weekend. Eskil suddenly appears at the table, all red in the face. He tells them that the caretaker at the football field has called and said that Henrick has to come back and mow the field again because he missed too many patches. The division four team will be playing against Åkarp in the finals on Sunday and if Henrick doesn't shape up, he will lose the job. They will find someone else who can cut the grass properly.

Henrick starts to cry, because it's the best job he has ever had, and if he loses it he won't be able to keep his job with the city. "What are patches anyway?" he asks and Eskil tells him that they are areas of grass that Henrik forgot to cut.



“Can’t you see where the grass is standing up higher than the rest?” asks Eskil, and Henrik has to admit that he can’t. Eskil tells Mats to go with Henrik and show him the spots he has missed and what he should do so as not to make the mistake again.

At four o’clock Henrick leaves work and he broods despairingly over this thing with the patches. He has to find a way to cut the grass more evenly than he has obviously been doing. But how? That’s the thing he can’t really figure out.

When he gets home, he stretches out on the couch and turns on the TV. Because he can’t read the program listings, he usually changes back and forth between channels to make sure he isn’t missing an important football game or the sportscast. Cable TV was installed a few weeks ago so he now has even more channels to keep track of. At the same time, there are a lot more sports programs to watch so it’s worth the trouble.

All of a sudden he remembers that he has to buy a new bus pass. He looks in his wallet but only finds coins and he knows he needs bills for the bus pass. What should he do? He calls the office and Lena answers. She’s worried because she heard someone talking about blood on the answering machine and wonders if it was Henrick who called. He tells her that it’s over now and wonders if Lena can help him with the money for the buss pass. She promises to do so.

When Lena comes, they sit down and go through the May budget. What does he need to buy and how much money does he have? Henrick doesn’t understand a thing. He can’t distinguish between the bills even if they don’t look the same. That you sometimes need an orange bill with a little girl on it and sometimes a blue with an old lady is beyond him. Why does it have to be so complicated? He usually just gives his wallet to the checkout girl and she takes what’s needed. But sometimes he’s afraid they are cheating him because he never has money left to buy CDs. Lena explains and explains and tells him he has to shape up otherwise he won’t have enough money for the bus pass and will have to walk to work, and he doesn’t want to do that, does he? Lena tries every possible way to get Henrick to understand money. She divides it up in envelopes for the rent, the bus pass, food and sweets, but it doesn’t help.

Sometimes Henrik gets really angry at Lena when he doesn’t have enough money for what he wants to do. He yells at her and says that she is the one who is taking his money when he isn’t home. Henrick’s mother has, a little accusingly, intimated the same thing on a few occasions and Lena would rather not have to deal with his money. But what would happen then?

He receives a few orange bills and one blue one and goes to the bus station to buy his monthly pass. He gets some gold-colored

coins back in change and he likes those best because he can use them to buy candy.

When he returns home, Lena tells him that the coffeemaker was on all day and that it looks like a tornado struck in his apartment. Henrick promises to clean up, but first he has to get something to eat. Lena takes out the boiled sausage and mashed potato powder and promises to come back later that evening.

Henrick slices the sausage and for some reason it's easier than cutting bread. He takes out the frying pan and turns on the electric burner. Now he's not really sure which dial he should turn, but he takes a chance on the one furthest out. He puts a dab of butter in the pan and waits for it to melt, but when it doesn't he moves the pan to the next burner and then the butter starts sizzling. He puts the sausage in the pan and moves it around. When it starts to smell as it should, he removes the pan and puts the pot of water on to boil. He pours the potato powder in and stirs but it doesn't thicken. It ends up the consistency of white sauce. After a while Henrick gives up and pours the sauce onto his plate and places the sausage on top. The sausage tastes good anyway and the potatoes are edible even though he has to use a spoon.

Although Henrick has difficulty with the days of the week, he has a hunch that it's laundry day, so he hurries up to find all the clothes that look like they've been worn. And since there is blood on the shirt he's wearing, he takes that too, even though he had planned to wear it tomorrow.

He stuffs the clothes in the washing machine and turns the dial apparently at random. He's failed so many times, but this time he's made up his mind that it will work out. He turns one of the dials so that the black dot that looks like a balloon is at the top and the other dial he sets with the partially worn-away number at the bottom. That's how the staff usually set it, so he can't be wrong, can he? But there's something wrong because it doesn't sound like it should but is completely quiet. Water! He forgot to turn on the water tap and when he does that, it sounds like it should. Great! Won't Lena be surprised when she discovers that he did something right for once!

While the washing machine is running he can listen to some music and wipe up the floor, but the telephone rings and he answers. It's his mother. He tells her all about his terrible day and she wonders if he really can live on his own or if he should move into a group home so that he can get more help. He's totally against the idea because he felt the personnel were always watching him when he lived like that before.

The conversation is a long one, and when his mother hangs up, Lena returns and Henrick tells her that he's doing the wash and asks Lena to help him with the dryer. They go out into the kitchen

and take out the laundry and Henrick sees that the white shirt is no longer white but pink. Even his underwear has turned pink. Lena looks at the temperature and realizes that he has washed the clothes at 90 degrees centigrade again. She tries calmly and patiently to tell him that sheets and towels can be washed at 90, while underwear and shirt should be washed at 60 and shows him the numbers on the dial. As usual, Henrick doesn't understand what she's talking about. Degrees, programs, colored garments, delicate fabrics, dosages. . . . He gets so tired of all the strange words.

They hang up the laundry together and after that, Lena wipes up the floor while Henrick watches the sports news that Lena had fortunately reminded him of. Lena sets out a new shirt and says, "Good night. See you in the morning."

Henrick continues watching TV, hoping that there will be more sports. But tonight there are mostly foreign films, and he doesn't like those at all since he's unable to read the subtitles.

Henrick finds it very difficult to decide when he should go to bed because he can't tell time. He usually listens to the upstairs neighbor and when he hears him shower, it means it's time for bed.

But sometimes the neighbor isn't at home and sometimes he doesn't take a shower. Henrick has ended up sitting in front of the TV half the night some evenings. Why are clocks so incomprehensible and why can't you count on the neighbors nowadays?

When Henrick has gone to bed, he lies awake a long time and thinks about the events of the day. It's those patches of grass that trouble him the most because he will probably never get such a good job again. Tomorrow morning he's going to turn over a new leaf. It's going to be a day without missed patches, pink underwear, leaking hibiscuses and annoying staff members.

# 3. Henrick Person's wonderful Wednesday

*In this chapter, I will show how a similar day in the fictitious life of Henrick Person can turn out if he is offered a better combination of technology and personal assistance. A discussion of many of the details will be taken up in the following chapters. But it is already worth mentioning how much shorter this chapter is than the last one; about half as long, because Henrick no longer has as many cognitive shortcomings, nor do they have as many negative consequences. The entire picture has changed just as much as the details.*

*Just as in the last chapter, the fictitious story is based on actual events and/or possibilities that will later be related to theories and methods.*

Henrick wakes up to the sound of country music on his clock/cassette radio. He jumps out of bed because on country-music day he usually cuts the football field grass and he just loves doing that. He goes to the shower stall and when he closes the door the water comes on automatically at just the right temperature. He soaps up and then empties the contents of a portion-sized packet of shampoo on his hair and washes it. Then he dries off and starts brushing his teeth. The electric toothbrush plays a little tune while he brushes and when it's over he replaces the toothbrush.

He goes back in the bedroom and fetches his clothes from the white compartment in his closet and gets dressed. After that he goes to the kitchen to fix breakfast. He spreads low-fat margarine on pre-sliced bread and then some marmalade. Then he pushes the small-cup button on the automatic coffeemaker because he likes espresso.

After breakfast he goes to the livingroom to check and see if there is water left in the clay cones that water the plants. The red cone is almost empty so he fills it with fresh water up to the top.

He puts on his jacket and cap and the new shoes with Velcro straps. There are two lights shinning on the hour ruler so he has plenty of time to get to the bus. But Henrick likes to talk to his friends at the bus stop so he decides to leave anyway. When he has gone a few steps from the door he hears the signal that reminds

him that he left the door open. He goes back and locks the door and continues on his way to the bus stop. He is able to talk with his friends a few minutes before the bus arrives. He takes out his bus pass, which is fastened with a rubber band to his inside pocket and he sits down in the front of the bus.

When he gets to work, Eskil, his boss meets him and tells him today is the big day. Henrick reacts with surprise, but Eskil explains that the football club has purchased a new lawn mower that will make it easier for Henrick to cut the grass. They have installed small transmitters on the corner flags in the field that relay information to a screen on the lawn mower showing Henrick where he is to cut.

Eskil accompanies Henrick to the football field and shows him what appears on the screen when the grass is not cut and when it is. Henrick is given some trial runs and after an hour he understands quite well how it works. Then Eskil returns to the office.

It goes a little slower than usual because Henrick's not used to looking at a screen and driving at the same time. When he has just a few rows left, Eskil calls him on the mobile phone and tells him it's time for lunch. Henrick says that he'll just finish up before coming in and Eskil promises to keep his food warm. Henrick washes up when he gets to the office and sits down next to Lena and Mats as usual. Today they are having stuffed cabbage rolls, gravy, cranberries and potatoes, one of Hendrick's favorite dishes especially when the potatoes are already peeled. They talk about the bowling tournament in which Lena and Mats are participating the coming weekend.

When all the lights except one have gone out on the Certec 24-hour clock, Henrick goes to the bus and on the ride home he talks with his friends about the new lawn mower that shows him where to cut.

When he gets home, he turns on the TV and finds out what's going to be on that evening using his bar code scanner on the program listing. Most of it consists of boring soap operas, but there is a football game between Arsenal and Chelsea on channel 1, the synthetic voice tells him. He clicks on the scanner so that the TV knows what program he wants to watch so that it will turn it on at the correct time.



Suddenly he remembers that it's county-music day and that's when he's supposed to buy a new bus pass. He goes down to the bus station and asks for one, after which he draws his cash card through the scanner. He walks back to his apartment and just as he comes in the door, Lena calls from the office and wonders if he needs any help that evening. Henrick replies that she certainly can come up and have a cup of coffee and chat a bit during the game, but he has to do the laundry first and fix some supper.

Lena wonders what he is going to have and Henrick tells her that he is going to warm up a pizza in the microwave. He takes it out of the freezer, puts it in the microwave and pushes the blue button for frozen food. The microwave signals when the pizza is done; he takes it out and starts eating.

Then he puts his plate, glass and cutlery in the dishwasher, but it is only half full so he doesn't turn it on.

Since it's county-music day, it's time to do the laundry. He takes the clothes out of the red hamper and places the scanner over the bar code on the side of the hamper before he puts the clothes in the washing machine and closes the door. He waits until he hears that the water is running and the washing cycle has started, but when he hears the telephone he leaves what he is doing to answer it. It's his mother who wants to know how he is doing and he talks with her a long time about the fantastic new lawn mower even though his mother doesn't really understand how it works. When their conversation is over, Lena rings the doorbell. She has sweet rolls with her. Henrick pushes the espresso button on the coffeemaker for himself and the one for a small cup of regular coffee for Lena because she has trouble sleeping if the coffee is too strong.

They go into the livingroom and the game has evidently started. Henrick hadn't heard the TV signal when he was turning on the washing machine. The sweet rolls are delicious and Henrick tells about the highlight of his day, the new lawn mower. Lena asks if he needs help with depositing more money in his cash card accounts, but Henrick has already checked them with his scanner and there is a lot left on all but his candy cash card. Two dots, though, should be enough for a few more days, he thinks.

Before Lena leaves, she helps him hang up his wash because Henrick thinks it's difficult to fit it all in his small drying cupboard.

When the game is over, the last light has gone out on his evening clock so Henrick understands that it's time for bed. After he has gone to bed, he lies awake a long time and thinks about the new lawn mower. He can hardly wait until the next country-music day when he will be able to drive it again.

# 4. HP and cognitive ethnography

There are three reasons why I have chosen to base this thesis on the imaginary character of Henrick Person instead of on any of the many people I have followed over the years or in the variety of jobs I have had. The reasons have to do with: 1. ethics, 2. credibility and 3. increased opportunities to use cultural analysis.

## HP AND ETHICS

I am not sure if any of the people I know would like to be described as unfavorably as Henrick, even though many would recognize themselves in his shortcomings. Neither does it feel right for me to reveal in detail, events and conditions that have been related to me in confidence. Consequently, I have chosen to create a hypothetical figure as a means of anonymously writing about people I know.

You may wonder if this is not just an evasive tactic. Is it ethically defensible to write a thesis about a hypothetical person with characteristics borrowed from real people who might recognize themselves but still not want to admit it? I believe so, because the potential recognition of problems and obstacles that I illustrate would depend on their universality and not on them being tied to any given individual. In addition, this thesis can ethically be credited with having a clearly expressed twofold purpose, namely, to show *that* problems can be remediated and *how* this can be accomplished.

## HP AND CREDIBILITY

The second reason to base this study on HP is that by making use of this story and the remedial measures suggested, I am better able to illustrate what I have learned in twenty years of work in the field of disability care and ten years at Certec. It deals with the issue of being *credible*. Ely (1993) writes the following about achieving credibility:

The word sounds good. Who can have anything against Lincoln and Guba's (1985) declaration that in order for a researcher to increase the chances of carrying out credible research—that which the people who are being studied as well as those who will read the report can believe in—they have to:



- Have been active in the field a long time
- Carry out extensive, sustained observations
- Triangulate; search for negative cases
- Determine the adequacy of references
- Discuss their work with colleagues at the same level
- Check the results with the people who have been studied.

However, it is the implementation of these acts that establishes credibility. It is not easy and tidy.

No, the road to HP and his terrible Tuesday and after that, his wonderful Wednesday has been neither easy nor tidy for me. But now I can combine a number of longitudinal studies with design theories and ethnographic methods and in that way clarify the relationships that have been difficult or at times impossible to understand in a more traditional research context.

## HP AND CULTURAL ANALYSIS

By focusing on Henrick Person, I can, to a great extent, make use of cultural analytical methods. I utilize *perspectivizing* (calling into question the ingrained and the obvious), *contrasting* (trying to understand what is un-acceptable, dis-honest, in-conceivable in the culture I am studying). When it comes to *dramatization*, I have chosen through the HP story to elucidate certain phenomena that would otherwise be difficult to capture. Just saying that someone cannot tell time or is unable to tie his shoes may seem to be relatively insignificant if you do not show the effects this can have when misfortune strikes. Dramatization makes it possible to follow events over time in order to see how they develop and how they influence one another. Another advantage with dramatization is that all elements can be removed that distract the reader and which do not enhance the explanatory value.

Something that I continually return to is the *active search for similarities and differences* because I believe it has significance for one's view of assistance. I may go a bit too far in my eagerness to find similarities between my own shortcomings and those of the cognitively limited person; but at the same time, it is necessary because so many others have focused on showing the differences.

This thesis is based on spending time naturally over a long period with the people being studied and is essentially based on qualitative methods that are quite similar to those used by ethnologists and anthropologists in their research. In order to show the similarities as well as the differences in approaches, I will first present an account of what three experts in the field consider to be characteristic of qualitative research followed by a description of my approach.

## 4.1 Qualitative research methods

Ely's (1993) attempt to find common denominators in a number of qualitative research methods resulted in the following six characteristics:

1. Events can only be correctly understood if they are observed in context. Consequently, qualitative researchers carry out in-depth studies in environments and contexts.
2. The context of the study or investigation is natural, not constructed. Nothing is predetermined or given.
3. Qualitative researchers want the people being studied to speak for themselves in such a way that their perspectives will be evident from their words and actions. Consequently, qualitative research is an interactive process in which the persons being studied teach the researcher about their lives.
4. Qualitative researchers regard the experience in its entirety and not as separate variables. The goal of qualitative research is to perceive experience as a unit.
5. Qualitative methods are ones that agree with the assertions listed above. There is no single, universal method.
6. For many qualitative researchers, the process gives rise to a reappraisal of what is being studied.

When I compare these characteristics with those of my own approach, I see that there is considerable agreement.

## 4.2 Fieldwork

Since long-term presence was a prerequisite for this thesis, I would like to present an account of how two ethnologists view fieldwork.

Arnstberg (1997) writes:

You carry out fieldwork in a place where people live their lives. You can go there to observe the participants, to transcribe or interview, or mix dialogue and interaction—which is the most common . . . Participant observation is the preferable method when it is applicable . . .

What a fieldworker acquires by doing his job is *competence in interpretation* in regards to the behavior that groups of people exhibit. Any final and definitive knowledge is, however, impossible since all forms of life are in a constant state of change. Interpretations can vary in quality, of course, in regards to those who are the object of interest.

Håkan Jönsson (2000), who has examined Certec's user research from an ethnological perspective, writes:

In order to *enter into* a different life, you must, to some degree, also try to *live* it. This is based on the insight that you can hardly expect to acquire complete knowledge of a culture if you have not experienced it with all your senses. Reality cannot just be *observed* at a distance; close contact is required to experience how it *smells, tastes, feels* and *sounds* as well.

In these descriptions, competence in interpretation is a central concept for me since it actually says something about the time that is required to learn about another culture. The more foreign the culture is to the researcher, the longer it should take to reasonably acquire the necessary competence to interpret its most subtle manifestations. A person who comes to a group residence from the outside can certainly discover and expose patterns and phenomena that none of those involved are aware of. On the other hand, the same researcher has little chance of calling attention to such phenomena that have taken the people involved many years of learning to see and interpret.

### 4.3 Participatory observation

Margot Ely (1993) describes participatory observation as follows:

Classic participatory observation . . . always involves looking and listening . . . and observation and questioning are interwoven—and part of the listening and questioning can approach or be the same as intensive interviewing. Inversely, intensive interviewing can embrace repeated and extended contact between the researcher and the informants, sometimes over several years, but largely a reciprocal commitment in the private lives of the people involved. This is often viewed as being the distinguishing characteristic of participatory observation.

Ely (1993) points out that there are no shortcuts, but sees long-term observation as a prerequisite for overcoming the effects of misinformation, for example. The long-term commitment requirement may explain why there are proportionately so few researchers in the area, among them, Sundet (1997), Liljeroth (1976), Mallander (1992), Mandre (1999) and Färm (1991).

Since the role of the participatory observer has been a prerequisite for writing this thesis, Ely's description is one of the ties that bind me to the qualitative research method. It also is a confirmation that questions can be developed while the research is in progress and that they can be as simple as:

- What is he doing?
- What do you think she meant by that?

- What are they going to do?
- Why did she do that?

It is exactly these kinds of question that I, along with all the other support persons, ask ourselves on a daily basis in our interactions with people with cognitive limitations.

## 4.4 Dialogues and interviews

Both of the stories about HP are based on a multitude of dialogues and interactions with people who have developmental disabilities. I have, however, on only a few occasions carried out the kind of formal interviews and participatory observations that Arnstberg (1997) discusses as methods for getting closer to the people I wanted to study:

It is *dialogue*, which takes place on fairly equal terms, as well as *interaction*, that are what ethnologists usually devote themselves to when they *say* they are carrying out participatory observation. Accordingly, we have the following four methods, of which the two middle ones are probably the most common:

Interviews  
Dialogue  
Interaction  
Participatory observation  
....

From my perspective, ethnologists would gain from adopting the two concepts of dialogue and interaction . . . : in part because they are “more honest” than the other two when you consider how ethnologists usually carry out fieldwork. I have never felt right about calling fourteen days of interaction participatory observation.

## 4.5 Field notes

Håkan Jönsson (2000) describes field notes in the following manner:

Everything is recorded in *field notes*, from interviews to dialogues, descriptions of the setting, smells, tastes and feelings that are experienced during the fieldwork. Because you are dealing with a cultural concept that to a large extent comprises the *human being's entire life situation*, even apparently uninteresting events and objects can be of interest.

He also describes how a very detailed description, tight ethnography, makes it possible to go back and make new interpretations. I have to admit that it has never been of immediate interest or even felt particularly important to describe the color of

the wallpaper or the odor in the hall. On the other hand, a tight cognitive ethnography that in great detail accounts for a person's actions in a cognitive process would be considerably more tempting to carry out. According to Hutchins (1998), these kind of ethnographic studies under real circumstances are rare; personally, I think that Eve Mandre (1999) has shown how one can proceed.

## 4.6 Ethnographic reporting

Arnstberg (1997):

Ethnography is a common term for ethnologists and anthropologists. It is closely associated with fieldwork. Only after carrying out fieldwork is a researcher able to author an ethnographic report or write ethnographically, not otherwise . . . .

An ethnographic report should be sufficiently empirical to give the reader a strong feeling of being there, as well as being ethnographically authoritative. Not just anybody should be able to claim that things are different from what is stated in the ethnographic report. At the same time, it has to be sufficiently analytical to be of interest. A piling up of information is not enough. It is, instead, the author's analytic interest that determines the value of the written ethnography, irrespective of if that interest is particularly apparent in the report or not . . . .

The fieldwork report should, in my opinion, be written as a *presentation* of experiences, material and interpretations. This means that you start out with a rather clear idea of what you want to say, whereupon you do so as clearly and concisely as possible. The aim, of course, is that many readers will benefit from the text.

## 4.7 Cognitive ethnography

I attempt in this thesis to carry out the type of ethnographic reporting described by Arnstberg, but with a focus on cognitive processes.

For more than ten years I had my office in a group home. In addition to the customary administrative duties, I also participated in the daily activities that were scheduled in the residence. If you eat breakfast every weekday morning for ten years with a group of people, you notice after a while the slightest deviation from the pattern. Ingrid Liljeroth and Lennart Danielsson (1996) write the following about these everyday situations:

There is a tendency among people who work as practitioners to underestimate their own experiences on the job. What others relate—particularly people with high status—is considered to be more important. We have noticed that the day-to-day, recurring situations are thought to be insignificant, commonplace and trivial. It is, however, these recurrent situations, which on the surface appear to be commonplace and trivial, that are of

particular interest on the job. The more often a situation recurs, the more useful it is when you analyze the work being done. Seldom recurring situations that have a strong impact can, of course, be significant but can never have the in-depth effect of the analysis of commonplace situations.

I personally have never experienced these daily recurring situations as commonplace or trivial. Even if things were calm on one level, there could be greater drama on other levels. I agree with Liljeroth and Danielsson's assertion that what appears to be routine, repetitive events presents the opportunity to observe what is otherwise difficult to pin down in situations that arise incidentally. To characterize what happens at breakfast as static is a misrepresentation of what is really going on. To be sure, there are certain attributes that are always represented, but their relations to one another are constantly changing. The size of the group, its composition and the placement of individuals at the table is seldom the same, which makes it possible to observe the effects of different constellations of people. There are also other variables worth noticing, for example, who has to wait, how long and why. Who refuses to sit next to whom, and who chooses to always sit in the same place. It is even more interesting to study different attempts to make contact and what happens as a result. What actually happened when the boy who always sits quietly suddenly one morning started talking nonstop to the young trainee? Why was everyone so aggressive one day and so happy and cheerful the next?

I am not sure that even my closest colleagues had the same opportunity as I to perceive the nuances in the complicated interaction around the breakfast table because they participated sporadically.

On the other hand, there were many activities that I seldom participated in that were routine for my colleagues. I had to ask my co-workers what happened during evening, night and weekend activities, and on those occasions in which I did participate, I could see that things that occurred that were apparent for them went right by me.

That we shared our experiences also made it possible to follow the development of cognitive processes over time, even though each of us only observed parts of the process. Many times this transfer of knowledge was a prerequisite for being able to interpret behaviors that at first glance seemed inexplicable. That a person who is always lively in the morning refuses to get out of bed one day is explained when the night staff member reports that his new medication appears to disturb his sleep. It turns out that the girl

who does not want to go on the evening walk was scared by a dog the last time she was out. The list of examples can go on and on.

Observations, which occurred sporadically but under circumstances that were relatively similar, could also be of great value in answering specific questions. Courses, doctor visits and outings are examples of activities that observers could use as the basis for finding signs of progress over time.

It is, of course, a part of the professional's job to be observant and to reflect in order to be able to make judgments and decisions about measures to be taken. But there are always things that the staff does not notice or perhaps does not even have the opportunity to find out; that is when I have had considerable help from friends of people who are in need of support. Even people with extensive cognitive limitations clearly notice when something is not right and try in different ways to convey that information to someone in their surroundings whom they believe can be of help.

In contrast to the everyday observations are things which occur quite seldom but which are so dramatic that they leave an indelible impression (Bauth, 1995).

## FEEDBACK

A great advantage with being present in people's everyday lives is that you continually receive feedback on the measures you have taken or, just as importantly, neglected to take. It can, of course, be difficult in real-life situations to sort out which factors influence what, but if the circumstances are favorable, you can at least get an indication of what direction to take.

It is also possible to set up a situation so that you come much closer to the kinds of conditions that prevail in controlled laboratory experiments. The advantage of doing so in the home setting is that the subjects' daily routines are not disturbed, which makes it easier to discover causal connections.

Some measures provided instantaneous feedback while others did not produce results until days, weeks or months afterwards. Still it was often possible to track connections because we knew what we should be observing.

The opportunity to continuously be able to test hypotheses and have them confirmed or rejected has been very significant in my acquisition of knowledge. There has been a considerable difference in what I have learned through interaction with people in my surroundings and that which I have acquired in more round about ways.

## DIALOGUES AND INTERACTION

My interactions with people with cognitive limitations have, in most cases, occurred quite naturally in everyday situations such as

food preparation, games and other leisure activities. The dialogues have been natural elements in these activities and anyone has been able to initiate them. Still, I do not claim that the dialogues took place on equal terms because I, as a staff member, am in a position of authority in relation to my partners in dialogue. An important precondition for the dialogues has been that I have the necessary understanding to be able to associate with events and feelings that the cognitively limited person has chosen to express but for various reasons has difficulty verbalizing. In order to ask a question, there needs to be a feeling of trust and security in the interaction but you also have to know how the questions should be formulated so that the person will be able to answer.

When it comes to people who have considerable difficulties in interaction and communication, such as those with autism, many years of close contact can be a prerequisite for a serious dialogue to at all take place. That the dialogues take place in their home settings has considerable significance because it makes it possible to refer to people and objects in the surroundings. This has meant that the dialogues did not lose momentum or come to a halt, which can easily happen in settings that do not provide any cognitive support.

Carrying on dialogues through a spokesperson can be a means of gaining access, but conflicts of interest can exist which make some topics hard or even impossible to discuss.

## MY DOCUMENTATION

When it comes to field notes, there are a great many differences between the ethnologist's approach and mine. I was, for various reasons, not particularly interested in describing the events and environments in as detailed a manner as ethnologists do. Instead, I focused on cognitive processes and other aspects that were relevant to the tasks I wanted to solve.

Most of what my colleagues and I observed was not put down in writing. But that does not mean that it was not preserved in some way. I committed a large number of observations to memory because I had learned that they could be of use at any time. This was not a particularly good method, but in the situation I was in, it suited the purpose and was manageable, which was good enough. When, however, it concerned observations that were surprising, that deviated from the pattern or offered new perspectives, my co-workers and I tried to immediately write down what we had observed in the report books that were always on the table. It was a matter, in general, of a few lines of text that were not always so well formulated. But these texts were around for a while and could be used as puzzle pieces on other occasions.



None of these notes remain. At the end of each month, all the material was burned so that the notes could not be used in the future in a way that might harm the person who was described. Before the papers were burnt, each contact person went through the month's notes to see which observations were significant enough to save. The monthly summaries also contained reflections, suggested measures and question that the contact persons had. All the employees read, reacted and acted according to what was written in the summaries. It was also the case that the staff member who was most involved would read and comment and even correct things that he or she thought were misleading. The monthly summaries, daily notes and mental images were then used as the basis for the weekly advisory sessions the team had with a psychologist.

My impression is that important observations were treated with respect and that they all and all, over a longer period, influenced, altered and improved a variety of habilitation efforts. It was also the case that potentially valuable observations were never used because we did not understand how important they were.

It was when I started to work at Certec that I had a reason and opportunity to compile, analyze and systematize these experiences and data that I had gathered during my time in care services for the disabled. What I have been most interested in has been *everyday events*, because they help explain many other phenomena. During the past ten years, relatives, staff and people with developmental disabilities have related a great many reports to me that have complemented my own experiences in certain areas and provided me with entirely new perspectives in others.

# 5. HP and cognitive design

*If the previous chapter primarily explains how I know so much about HP and about his terrible Tuesday, this chapter deals extensively with how I implemented the design process that is the basis of the transformation to his wonderful Wednesday.*

I believe it is neither possible nor desirable to establish general hierarchical systems for cognitive design, because so much is dependent on the situation. At the same time, it is obvious that all problems are not on the same level or have the same importance for Henrick or his surroundings. This means that you need to set up strategies for prioritizing apparent problems and procedures for discovering the hidden ones.

## 5.1 Cognitive design for people with cognitive limitations

Design does not only result in form and function—it also results in *experiences*. For people with cognitive limitations it is important that a phenomenon offers an experience of:

- Security
- ConText
- Experience/memory
- Precision

These four points, and the combination of the underlined letters to form the acronym “STEP”, indicate the structure of the chapter to come. The prioritization of different experiences can vary from person to person, which is why they should be weighed differently in individual design processes.

STEP can work as a mnemonic rule in many situations, not just in the design of artifacts. It can thus provide support when buying merchandise—how does this product satisfy the need for a feeling of security, of context, of related experiences of precision? STEP can also be used in the design of personal cognitive assistance, in the choice of work assignments and leisure activities and for the overall design of the physical surroundings. If HP, the staff that work with him and friends, based on cognitive design situations

can agree on what his fundamental needs for experience are, the effects can then be transferred to other areas.

The concepts in STEP should not be considered as static but exchangeable depending on the experiences that are important for the particular individual. A prerequisite for a support person to be able to make use of the concepts in a design process is, of course, that she has such a close relationship to the individual in question that she can picture the individual's experiences in different situations.

Experiences are, naturally, difficult to put down in words but I will make an attempt to briefly describe what I mean.

## **SECURITY**

If a person does not feel that she can depend on people or technology, she will end up spending energy building a safety net instead of getting involved in activities and social interaction.

Being able to anticipate what is going to happen, to see continuity and structure are some of the concepts I associate with security.

## **CONTEXT**

By "context" I mean that the person has to be able to create an image of how different phenomena are connected. It can involve causal connections, how a part is related to the whole or how events in a chain are related to a process. If you do not have a good sense of context, it can be difficult to understand what is meaningful in carrying out an action or step.

## **EXPERIENCE/MEMORY**

People who find it difficult to picture people, objects and phenomena that are not present in the here and now need concrete clues in order to make connections to previous experiences.

Phenomena that stimulate recognition are preferable to those that require associations or active remembering. Artifacts and environments should be designed in such a way that they can work as extra reminders if the individual should be in need of that.

## **PRECISION**

Experiencing precision is often an important prerequisite for a person with cognitive limitations to be able to carry out an activity independently. Activities requiring different types of judgments do not offer that experience. For the user to experience precision, the phenomenon should have cognitive contours which, simply put, means that it is possible, in a relatively unambiguous manner, to illustrate it through pictures, gestures or words.

## 5.2 Cognitive design specifically for HP

Henrick Person has obvious difficulties in certain areas. He finds it hard to make judgments, for example. This can be seen in connection with showering, brushing his teeth, making a sandwich, peeling potatoes, cutting the grass and laundering his clothes. His memory can fail him when he is going to make a phone call, remember his bag and bus pass, lock the door and turn off the coffeemaker. His difficulties in seeing cause-effect relationships are exhibited in his attempts to use clocks, bandages, call the nurse and prepare a budget. He finds it hard to make decisions under pressure, which results in him hesitating between watering the plants and rushing off to work. An overall problem is that he cannot read and has difficulties with numbers.

But everything is not hopeless, not even on the most terrible of Tuesdays. Henrick displays time and again that he has the ability to use information from his surroundings to assist him in making decisions and judgments. He figures out which burner is hot; when the edge of the bandage does not stick, he uses paper towels instead. He identifies the fixed settings on the washing machine's dial and uses the sound from the upstairs apartment to orient himself in time. He is curious and wants to try new things like cable TV, even if he cannot fully master all the steps, and he asks others for help when he cannot manage on his own.

The question is, what is to be done with this knowledge about his abilities and shortcomings? Are all of Henrick's problems equally important to solve or should some be prioritized? Are there some that need to be solved immediately while others can wait? Should we solve the problems in a certain order because they are interdependent? Can we utilize knowledge about Henrick's abilities when trying to solve these problems?

I will now present my approach to analyzing Henrick's most obvious shortcomings and also motivate my suggestions for cognitive assistance.

As I previously explained, I do not think it is either appropriate or even possible to compile a checklist that specifies the order in which common, day-to-day problems should be solved in general.

When it comes to an individual however, you need some points of reference in the design process and for Henrick, I have decided upon the following:

- He likes living on his own and wants to continue doing so in his present apartment.
- He wants to take responsibility for certain activities and also wants to be able to decide when and how they are to be carried out.

- He would like to have access to personal assistance when he needs it; otherwise, he would like to try and manage things independently as much as possible.

I will bear these three wishes in mind during the entire design process in order to orientate myself and to prioritize. When it comes to concrete measures, I base them on my knowledge of Henrick's cognitive abilities and make use of the four STEP concepts, Security, ConText, Experience/memory and Precision, as a guiding instrument. Since I cannot see how to go about reducing Henrick's anxiety over having to make decisions, it is a topic that we will continue to discuss. We were able to solve it for this Tuesday, but it will certainly arise again in other forms and situations.

Even though it is not always evident from these brief descriptions, Henrick and I discuss, co-operate and re-prioritize during the entire processes so that the cognitive assistance will be designed the way he wants it.

#### **STEP** *Stove*

Since there is an obvious risk that Henrick will forget to turn off the stove when he leaves the building, I choose to start with this problem because the consequences could be very serious.

There are a good many measures that you can take to make stoves safer such as timers, overheating protection and motion detectors. But I choose another way. Henrick does not just have a problem with turning off the stove, but with preparing food on it as well. No matter what safety measures you take, there is always the risk that things will start burning. Henrick finds it particularly difficult to decide under pressure, so it is uncertain he would do the right thing in the event of a fire. His inability to dial the emergency number is an additional drawback. I recommend that Henrick should get a microwave that he can use to warm up and defrost ready-cooked meals and to boil water.

#### **STEP** *Telephone*

Henrick needs a telephone that is easier to use, not only for reaching emergency numbers, but for calling friends and acquaintances too. Many telephones on the market have a speed dialing function and large keys on which pictures can be fastened. This should solve the problem at present. Henrick might also need a telephone that has an order-of-priority function for emergencies so that he would be certain that his call would be forwarded if the first number was busy.

*Mowing the lawn*

It is clear that Henrick's thoughts continually circle around how he is going to satisfactorily manage to carry out his lawn-moving job. Since this job assignment is so significant for his self-esteem, I give it very high priority. He has no problem running the power lawn mower mechanically. The difficulties lie in determining which surfaces have been cut and which have not. I do not think it is particularly meaningful to try and train Henrick to locate the patches he has missed, since it is very difficult to define exactly how the surface of cut grass differs from the uncut, even under ideal conditions. If it is raining or windy, it can be even more difficult to perceive the differences.

Seeing that the task of judging grass length is altogether too difficult, we have to try and find other ways of avoiding uncut patches. The job would probably not be as stimulating for Henrick if he had to have a personal assistant help him all the time, so that solution is out. If we could find a way to get Henrick to follow a straight line with the lawn mover, however, he could probably avoid missing patches. One way of doing this would be to mow along the short side of the field and see to it that new sight lines were drawn up while mowing. This could be accomplished by attaching a funnel to a hopper full of colored powder on a brace that sticks out from the law mower.

Each time Henrick comes to the long side of the field, he turns the brace 180 degrees and then he simply follows the line he made on the last turn. If he has enough overlap, there is very little chance of him missing patches with this method, which does not require any advanced judgments on his part. With modern technology it is possible to further simplify the process. By attaching transmitters to the corner posts and a receiver to the lawn mower, Henrick can see information on a display screen showing him where to steer in order to keep a straight course, as well as providing a graphic representation of which surfaces he has mowed and those he has not.

*Measuring time*

That Tuesday morning got off to a bad start. Henrick usually wakes up to an alarm clock allowing him enough time to get ready for work. But sometimes his morning activities take longer than expected, something that Henrick has difficulty compensating for and which results in him being late.

Ordinary analogue and digital clocks are hard for him to decipher, particularly when it has to do with measuring time intervals. Henrick needs a clock that represents time in a more concrete manner and there are a number from which to choose.

With the help of a *quarter-hour clock*, he can see how many 15-minute intervals are left until the bus departs. On Certec's *24-hour clock*, he can see for himself, or Lena can mark the point in time, when he should leave for the bus stop. If he presses the red button on his *hour ruler* when the alarm clock wakes him up, he can continually check to see how much time he has left.

He can also use these three clocks to get to bed on time or to the post office before it closes or whenever he needs to orient himself in time. So that Henrick knows which day of the week it is the moment he wakes up, he has been given a tape recorder that works like an alarm clock: it identifies the day of the week by playing different pieces of music.

### **STEP** *TV programs*

Lena and Henrick come up with the following solution for Henrick to see the TV programs he wants to watch: She cuts out the bar code from the TV magazine in order to preprogram the video. Then she pastes the bar code under a picture of the programs she knows Henrick usually watches and arranges the pictures on a weekly schedule so that he knows which days they are on. Henrick only needs to move the bar code scanner over the picture in order for the program to come on at the right time.

### **STEP** *Money*

Henrick's ability to handle his money is also an important issue for Lena, because is a continual source of disagreement between them. Henrick does not understand the value of money and it is hard for him to make it last.

The results of Lena's attempts to train Henrick to manage his money have been less than desirable. He simply does not understand the system, more than knowing that he has to hand over money to get what he wants. When you ask Henrick whether it is more important for him to learn more about money or to do something with it, Henrick, like the rest of us, is most interested in the act of buying. He is not really very interested in how it works. One way to get around the money management problem is to have an account that automatically pays all his fixed expenses such as rent, bus pass, cable TV, and makes transfers to a savings account for bigger expenses in the future. Henrick would like the money that is left to be at his disposal to use in ways that he deems appropriate.

What is needed is to find a way of representing money that Henrick can understand. I recommend a cash card because it gives Henrick a clear picture of what he wants to know, namely, how much money he has access to at the moment. What he needs is a scanner that displays his assets in a way that he can interpret. You

could, for example, select items that he buys often and that he can easily put in context such as CDs, potato chips or magazines. Another way would be to represent his weekly or monthly assets with a number of dots in a row. Each purchase results in one or more dots disappearing and when all the dots are gone, he cannot buy anything else. It is facilitating for Henrick to have more than one cash card because he then finds it easier to have control over and determine how much he has. Lena still needs to help Henrick divide his monthly salary up among the different cards, and she does this by representing his salary as long strips of paper of different lengths. They illustrate Henrick's priorities among the various purchasing categories. The advantage here is that she only needs to do it once a month; Henrick can then manage the responsibility for his own purchases.

### *Laundry*

Henrick's problems with doing the laundry mainly concern all the decisions he has to make. Above all, he has to determine the color of the garment and then the temperature at which it should be laundered or if it needs to be washed by hand.

He has to determine if the color will run and in that case, which other garments he should wash it with. Much of this can be solved through labeling and by careful selection when purchasing clothing. Lena helps Henrick to label his newly acquired garments with symbols that represent the temperature and color so that Henrick only needs to compare them to the corresponding symbols on the hampers. Everything that he cannot manage to sort, he puts aside for Lena to help him with later. When he sets the temperature on the washing machine, all he needs to do is compare the symbols on the hamper with the ones on the temperature dial.

Another solution is that Lena helps him attach the bar codes to his clothing and the hampers so that by using the bar code scanner he can sort the garments into the correct hampers. By scanning in the hamper code, he can then set the washing machine at the right temperature and cycle. The advantage with this solution is that the garments in the shops will most likely have already been supplied with bar coded labels which tell how they should be laundered. This would make it possible for Henrick to manage the laundry process from beginning to end on his own.

### *Breakfast*

The purchase of the microwave solved most of the food preparation problems but not those involved in making coffee and a sandwich for breakfast. Henrick is uncertain of how much coffee and water he should use and he sometimes forgets to turn off the coffeemaker when he leaves for work. A timer that turns the

## **STEP**

## **STEP**



machine off after 20 minutes in combination with fixed coffee and water measurements would be an acceptable solution, but I choose instead to get him an automatic coffee dispenser because he will not have to worry about the right amount when he has guests.

There is still the problem of the sandwich to solve. Henrick finds it difficult to cut the bread and the question is if he really needs to do so. With the wide variety of presliced bread that you can purchase today, I am sure that Henrick will accept one as an alternative. The crumbling of the bread when he spreads it with butter can be avoided if he exchanges the butter for a margarine spread that softens up quickly at room temp.

**STEP** *The shower*

Henrick's problem with the shower is due to his difficulties in determining where the temperature control handle should be set. Most of the modern ones have a set position that adjusts to a comfortable water temperature after a few seconds and this is a solution that he certainly would have accepted. Still, I recommend a shower that instantaneously provides a comfortably warm stream of water when he closes the door to the shower cabin.

**STEP** *The outer door*

When Henrick is in a hurry, he often forgets to close the outer door. One way to solve this problem would be to install a door closer. Instead, I recommend an electronic door guard that reminds him that the door is open, since this solution also reminds him indirectly to lock the door.

**STEP** *Bag and bus pass*

One of the surest ways to remember to take the bag is to always put it in a place that he will see on his way out. If the bag is hung on the same hook as his jacket, or placed in front of his shoes, it would help him to remember it, even if he is in a hurry. The bus card should be attached with a rubber band to his jacket so that he never needs to think about if he has it or not.

**STEP** *Adhesive bandages*

Henrick would probably not find it so difficult to put on an adhesive bandage in a normal situation. For safety's sake, though, he should have the bandages in a dispenser mounted on the wall because they are ready to apply as soon as you pull them out.

**STEP** *Miscellaneous*

There are many explanations for Henrick's inability to take care of his dental hygiene. One it that he does not really understand what

he is supposed to do with the toothbrush. And even if he did, he would probably still not have the ability to follow through to completion. This has to do with his inability to interpret expressions such as “properly”, “carefully” and “clean”. He also finds it difficult to know how long he should brush. My suggestion is that he should exchange his manual toothbrush for an electric one, since it is considerably more effective in cleaning teeth. There are electric toothbrushes that play a melody to tell the user how long he should brush. If Henrick uses the red tablets he gets from the dentist, he will more easily be able to discover the spots he has missed (Sucking on a tablet coats his teeth in red. His job is to brush the red away). The solution is not all encompassing and needs to be supplemented with fluoride tablets and regular visits to the dental hygienist and dentist.

Washing your hair and watering the plants both involve getting the amount right; you have to make a judgment of how much you need to use. When it comes to shampoo, there are small, disposable packages that Henrick can use instead of large bottles. He can water the plants by using ceramic cones that are pushed down into the pots and from which the water can slowly trickle out for a number of days. All he has to do is fill the cone with water when it is empty. Watering the plants directly in the pot requires a more advanced judgment ability than this.

Shoes with laces should immediately be exchanged for a pair with Velcro® fasteners.

He can also tell when it is bedtime by labeling one of the lamps on the Certec clock with a picture of a bed or some other symbol.

In conclusion, when I look through this list of miscellaneous items, I see how totally dominated it is by technological assistance that adds *precision* in action.

### 5.3 HP and general design criteria

Of course, it is not just my STEP method that has been valuable in the design of HP’s technological assistance. I have benefited from cognitive design in general, which also deals with designing artifacts to make them understandable to the user. Donald Norman (1988) uses the expression “knowledge in the world”, which offers a good description of the main guiding principle when it comes to cognitive design. If knowledge is visible, it facilitates the user’s understanding of how the artifact functions and how it can be handled.

What follows is an attempt to summarize some design principles that several researchers mention, even if they do not always express them in the same manner (Winograd, 1999; Nielsen, 1993; Hutchins, 1995; Norman, 1988, 1995, 1996).

### *Affordance*

The object provides clear clues as to how it is meant to be used.

### *Visibility*

You should make all the information visible that the user needs in order to handle the artifact.

### *Mapping*

It should be possible to make a connection between the actions and their outcomes, between the controls and their effects and between the system's status and what is visible.

### *Feedback*

The user's actions will be confirmed so unequivocally that he has no doubt that the system has registered them.

### *A good mental model*

The system should be so transparent that it is possible for the user to come up with his own internal image of the construction and how it works.

### *Recognizable*

It is facilitating for the user if the choice of alternative actions is based on recognition instead of reflection.

### *Error reducing*

The system should be designed so that the user has few chances of making mistakes. If a mistake occurs in spite of this, the system should be able to compensated for it or guide the user onto the right track again.

### *Standardization*

It is facilitating for the user if the symbols and functions she has learned in a situation are used in a similar fashion in other situations.

### *Reminding*

The system can assist the user in remembering.

### *Provides guidance*

## **CONTEXT-GENERATING DESIGN**

People without cognitive limitations often take it for granted that everyone else has the same pre-understanding that they do when it comes to everyday technology. This causes problems for people with developmental disabilities. For a variety of reasons, they may

be missing the pieces of the puzzle that are necessary to make understanding possible. If you have never seen an electrician installing wiring, it can be difficult to understand how the flip of a switch allows light to flood into the room. The person who cannot read will, of course, have great difficulties understanding the connection between the package expiration date and his ground beef going bad.

If you base what you are doing from the start on the assumption that people's prerequisite understanding can vary considerably, there is a chance that you will succeed in creating a design that will compensate for this. Norman mentions mapping as a means of supporting understanding. An example of this is the positioning of elevator buttons. Since all elevators move vertically, the buttons should naturally be placed in that direction too, with the bottom floor as the lowest button. Other kinds of mapping can be established out of convention. Since red in our society is connected with danger, it is natural to choose that color if you want to *caution* someone, while green should be used to show that something is allowed or good. To then choose red price tags for products that are low priced is a prime example of mapping that a person with developmental disabilities can find difficult to interpret in the way it is intended. Shops that use green price tags guide their customers much better.

Receiving feedback is important in all functional aspects of design. One of particular importance concerns the difficulty or ease the user has in imagining how the artifact works. The person who uses a telephone that gives no pressure feedback to the finger when pushing the buttons can find out if the number is registered by listening afterwards to the signal in the receiver or by looking at the number on the display. A person with cognitive limitations may need confirmation that she is right after each number she has pushed.

If several functions are integrated into one unit, it often complicates the causal relationships. A button that is used for a given purpose in one context can, in another, have an entirely different function, resulting in uncertainty. Clock radios are good examples of technology that people with developmental disabilities find difficult to deal with because the functions often are difficult to keep separate.

## SECURITY-GENERATING DESIGN

Most people take it for granted that a product should be reliable. My experience, though, is that the tolerance level for certain types of errors is surprisingly high. It might be because we blame ourselves for them or because they do not really have any significant effect on the product's functionality. People with

cognitive limitations have a considerably lower tolerance level and for them it can be a matter of all or nothing. A door that can be unlocked ninety-nine times but not the hundredth can cause such trauma that the person does not dare go out again after a certain time of day for fear of not being able to get back in. Another person would have taken the mishap in stride and found another way of getting in, but this requires a flexibility that many people with cognitive limitations lack. They simply cannot reorganize their mental processes, especially when they are in such vulnerable situations.

There are areas in which the consequences of the assistive technology's unreliability are so negative that others in the person's surroundings would not accept him using it without special protective measures. At the start of the Isaac project, there was great interest in the GPS system that was going to help a person if he got lost or for other reasons needed to be located. If the person, due to this navigational equipment dared to venture out into unknown territory, he would have to be able to depend on an extremely high level of reliability in those situations in which he needed assistance (Svensk, 1994).

## **EXPERIENCE-RELATED DESIGN THAT PROVIDES MEMORY SUPPORT**

According to Donald Norman (1988), we use approximately 20,000 objects in our everyday life. Norman finds it is unreasonable to expect people to carry around the mental manuals needed for using all of these artifacts.

One should therefore be able to require of good design that it reduces the user's memory load. This is especially important when the purpose is to make life easier for people with considerable memory problems. If a chain of actions is long, the risk is great that that the actor will forget to perform one of the steps.

Artifacts should thus be designed so that they contain few steps or so that they guide the user through the process; in this way, he or she does not need to keep the entire sequence in mind. Many people with developmental disabilities find it easy to recognize patterns they have seen. For this reason, it is advantageous if usage can be built on recognition instead of on reflection and free associations.

People who under normal circumstances manage to perform a given action can fail entirely under pressure. The designer should bear this in mind when he designs artifacts that can be used in stressful situations.

In the case of fire, you have a few minutes at the most to take the steps you have practiced in less dramatic situations. No matter what your cognitive abilities, this is a difficult task. Two students

participating in one of Certec's project-based courses focused on this and constructed a talking smoke detector that in the event of a fire would give the person in the emergency situation *voice* instructions on how to get to the emergency exit. When the batteries needed to be changed, the smoke detector gave an oral reminder instead of emitting a auditory signal that could easily be misinterpreted.

People who have difficulties thinking of things that are not in the here and now often need clues to be reminded of what they should do or to remember things that have happened before. Artifacts in the room or spatial arrangements can facilitate this mental process. A person who forgets to take her keys with her to work can hang them on the same hook as her coat to be sure to remember them. The person who does not sense when he is thirsty may need a tangible reminder to drink in the form of a pitcher with water on the dinner table. Kitchen cupboards without doors or ones with transparent ones also facilitate calling attention to the drinking glasses that are inside. Individual packages containing the correct dose of medication are an excellent external memory device because they make it possible to check if the person has taken his pills or not.

Digital picture have proven to be invaluable as memory support. At The Pictorium, a day activity center in Lund, Sweden, the participants have made use of digital pictures in order to be able to tell others and themselves about an outing they have been on or to remind themselves of certain details. Sometimes it is necessary that the person himself is in the photograph to initiate the memory processes. See the report, *What Isaac Taught Us* (Jönsson, 1998).

## PRECISION-CREATING DESIGN, COGNITIVE CONTOURS

An artifact or phenomenon has cognitive contours if the user or the instructor can physically indicate or in words express what he means with precision. Information technology's definition of information as *reduction in uncertainty* expresses quite well what we should be striving for.

A bakery is an operation where developmentally disabled people have a great need for clear-cut instructions. Many of the steps in the baking process are difficult to define. How warm should the water be so that the yeast will rise? One person says "warm to the touch", another says "lukewarm" and a third says that it should be "tepid". But these are rather vague concepts and therefore difficult to make concrete for people with cognitive difficulties. "Medium warm oven", "season to taste", "a pinch of salt" and "beat until fluffy" are example of other expressions that

are often used in a bakery and that are hard to put a finger on. One way of getting around these fuzzy concepts is to make sure that the units of measurement have clear cognitive contours, i.e., that they are relatively unambiguous.

This can be done by using *set scales* of different types or by making sure that the measuring instrument's results are easy to interpret. If you make use of a measuring spoon, you do not have to deal with terms such as "a pinch". A thermometer that displays green when the yeast water is at the right temperature solves the problem with "tepid" and "lukewarm". A dough cutter shows the exact amount of dough needed so the cinnamon rolls will be uniform in size.

But the problems with sliding scales and diffuse job assignments can be found at places of work other than bakeries. They hinder many people with developmental disabilities from getting a job. How do you explain to a person with developmental disabilities how a dirty floor differs from a clean one or a well-done steak from a rare one? Many of the requests that have come to Certec over the past few years have dealt with job assignments that lack cognitive contours. In the home, they often deal with getting the amounts right.

When it comes to technological artifacts, there are some that should be avoided because they are difficult to handle. This includes such things as continuous (versus discreet) dials on stoves, washing machines and other electrical devices. Artifacts that require judgments of time, space and reason are in general also unsuitable to use since you never can prepare yourself for all conceivable situations.

Sometimes a person's shortcomings are due to the inability of others in the surrounding to express themselves clearly rather than because the activities themselves are diffuse or hard to define. It is possible, for example, to specify time and place precisely using different types of landmarks, but unfortunately we are often careless in this respect and say, "I'll meet you at the cinema tonight," instead of, "I'll meet you on the steps outside of the cinema tonight at 7 p.m."

# 6. The role of distributed cognition

The use of ready-sliced bread and electric toothbrushes to solve basic problems has become standard procedures in most group homes. On the other hand, it is unusual that a person has access to an advanced automatic coffee dispenser in his or her apartment, and I do not know anyone who has a washing machine with a bar code scanner. However, it is not primarily these particular solutions that I want to focus on in this thesis, but rather to supply the reader with a mental framework for reflecting on the whole. This can be found in general in cognitive design, in my STEP method and in the more underlying assumption that cognition does not need to be tied to the individual but can be distributed in the environment as well as in the technology.

I became interested in distributed cognition long before I knew that such a concept existed. It started with the successful and failed attempts at cognitive assistance in different group homes. It became apparent that good technological assistance could compensate for deficiencies in human assistance and vice versa. It also demonstrated that it was possible to set up well-functioning cognitive assistance even if all the parts did not work optimally. There was, in other words, a reason to start looking at the whole instead of at the parts.

An essential aspect of the bigger picture involves the time aspects of distributed cognition. Probably the most important is that the *results* of cognitive cooperation can be preserved and recycled time and time again.

Edwin Hutchins started to use the concept *distributed cognition* in the middle of the 1980s to indicate that the thinking of individuals arises out of an interaction with other people and objects. Hutchins has studied cognitive processes in the cockpits of airplanes and on the navigation bridges of navy ships. He demonstrated that the final result of the actors' cognitive cooperation could not be derived from any single actor but was the product of their interaction with one another. But Hutchins goes even further than that when he attempts to explain cognitive processes. Thinking is so dependent on cultural and social phenomena that it cannot be studied under artificial conditions in



a laboratory but only in real situations, which is apparent from the title of his most well-known book, *Cognition in the Wild*.

I have adopted this view of cognition for several reasons. One is that the model is easy to apply to cognitive cooperation between a person with cognitive limitations and his technological and personal forms of assistance. The knowledge that cognitive processes can also be distributed over time is significant in analyzing different actors' contributions to an activity. Let me turn to Dennett, Norman and once more to Hutchins for support.

Dennett (1996):

Our brains are modestly larger than the brains of our nearest relatives (although not larger than the brains of some dolphins and whales), but this is almost certainly not the source of our greater intelligence. The primary source, I want to suggest, is our habit of *off-loading* as much as possible of our cognitive tasks into the environment itself—extruding our minds (that is, our mental projects and activities) into the surrounding world, where a host of peripheral devices we construct can store, process, and re-represent our meanings, streamlining, enhancing, and protecting the processes of transformation that *are* our thinking. This widespread practice of off-loading releases us from the limitations of our animal brains . . . .

We keep “pointers” and “indices” in our brains and leave as much of the actual data as we can in the external world, in our address books, libraries, notebooks, computers—and, indeed, in our circle of friends and associates. A human mind is not only not limited to the brain but would be rather severely disabled if these external tools were removed—at least as disabled as the near-sighted are when their eyeglasses are taken away.

Hutchins (1996):

This heavy interaction of internal and external structure suggests that the boundary between inside and outside, or between individual and context, should be softened. The apparent necessity of drawing such a boundary is in part a side effect of the attempt to deal with the individual as an isolated unit of cognitive analysis without first locating the individual in a culturally constructed world . . . . These boundaries can always be drawn in later, but they should not be the most important thing.

Donald Norman (1996):

The power of the unaided mind is highly overrated. Without external aids, memory, thought, and reasoning are all constrained. But human intelligence is highly flexible and adaptive, superb at inventing procedures and objects that overcome its own limits. The real powers come from devising external aids that enhance cognitive abilities. How have we increased memory, thought, and reasoning? By the invention of

external aids: It is things that make us smart. Some assistance comes through cooperative social behavior; some arises through exploitation of the information present in the environment; and some comes through the development of tools of thought—cognitive artifacts—that complement abilities and strengthen mental powers.

## COGNITIVE ARTIFACTS

Artifacts usually are defined as objects created by people but many include intangible phenomena as well. I use this extended definition because I do not see the point in making a distinction between mnemonic devices in the form of a string around the finger and a memorized phrase or jingle.

When Hutchins (1996) uses the term “mediating artifact” he means, in contrast to many others, not something that stands between the person and the task but sees it instead as one of the many elements that are brought into coordination to perform the task. Hutchins sees language, cultural knowledge, mental models, arithmetical and logical rules as examples of mediating structures but also such everyday phenomena as traffic lights and the layout of supermarkets.

Mediating structures can, according to Hutchins, be embodied in artifacts but also in ideas and systems of social interaction or in all of these at the same time.

Both Hutchins and Norman are in agreement that cognitive artifacts do not make people smarter but alter the activity so that it can be carried out in a different, often less abstract manner.

Norman (1996) expresses it as follows:

The *personal* point of view:  
Artifacts change the task

The *system* point of view:  
The person+the artifact are smarter than either alone.

Norman points out that you cannot just purchase a cognitive artifact and then assume that the person using it will automatically manage a task better. Cognitive artifacts cost in other ways since they often require that a person learns something new which can take some time; one example of this is learning to read and write. By studying artifacts and their usage, you can, according to Norman, gain knowledge of people’s cognitive abilities and this is a method that I also use in my research.

I share Norman’s opinion that cognitive artifacts in general require that the user acquires knowledge of how they are to be used. This is certainly an explanation as to why cognitive aids do not always provide the support or the compensation the user had hoped for.

Many aids for telling time, for example, require both knowledge and long-term commitment from others in the environment if the person with a developmental disability is to be able to plan and prepare on his own for a variety of activities. The support person's job is to collect and arrange information in such a way that it is accessible to and can be relied on by the user. My experience from a number of group homes is that it requires involvement and patience from the surroundings for the user to feel certain that the information that has been provided is correct.

## PEOPLE OR ARTIFACTS?

Norman (1998) makes the following interesting comparison between how people and machines view one another's strengths and weaknesses.

The machine-centered view:

<b>People are:</b>	<b>Machines are:</b>
Vague	Precise
Disorganized	Orderly
Distractible	Undistractible
Emotional	Unemotional
Illogical	Logical

The human-centered view:

<b>People are:</b>	<b>Machines are:</b>
Creative	Unoriginal
Compliant	Rigid
Attentive to change	Insensitive to change
Resourceful	Unimaginative

*Comments:* Based on Norman's lists, it is not difficult to ascertain which activities people neither should, nor with difficulty can, be replaced by artifacts. In most contexts which demand that a person quickly sees discrepancies and alterations, and based on these comes up with alternative solutions, people are still considerably more reliable than machines. One example of an everyday activity that requires this type of flexibility is cooking. No matter how closely you follow a recipe, there is no way of avoiding unexpected events that require you to momentarily deviate from the original plan. Accidents and fires are more dramatic examples of situations in which flexibility and the ability to reorient come to the fore. When it involves complex everyday phenomena, which can quickly change and which require snap judgments and

decisions, it is hard to imagine that anything other than a person would be able to manage the cognitive support that is required.

But much of what happens in everyday life is a matter of routines and relatively predictable events and, according to Norman's machine-centered view, artifacts should be able to function extremely well because they are noted for being precise, orderly, undistractable, unemotional and logical.

From experience, and based on the many conversations I have had with personnel in group homes, I have identified such everyday phenomena that people with developmental disabilities receive help from other people in managing, but that could just as well or better be supported by cognitive artifacts. When it comes to reminders, time measurements and planning, an artifact can provide support with an accuracy and structure that few people can manage.

One of the most central issues concerning cognitive assistance involves accessibility, which Norman (1998) does not take up in his comparisons. It is in this regard that artifacts have the greatest merits because they are there when the user needs them, something she cannot always take for granted when it comes to human assistance. Some users prefer technological assistance because they do not consider it a threat to their personal integrity.

## 6.1 Some things are not negotiable

If, from the beginning of a design process, the people in the setting consider the individual's expressed and unexpressed needs and wishes as negotiable, it will be tempting to choose the type of assistance that one already has mastered and that, to a somewhat acceptable degree, fulfills the needs. Or else to simply say, unfortunately, that HP *cannot* live on his own and that he *cannot* be allowed to continue cutting the grass. If, on the other hand, one sees at least some of the expressed needs as absolute and binding, one is forced to go outside of the well-worn paths and in so doing increase the chances of finding solutions that will come closer to satisfying the person's wishes. Such an approach also sets the stage for unexpected insights into one's own strengths and weaknesses as well as those of the person in question.

As I see it, we would gain tremendously from studying how and when all the different actors make their contributions to a given mental process, instead of only focusing on the person with the developmental disability. It will be easier for the support person who is clear about his or her role in a joint mental process to find a way of changing it. To view thinking as distributed can also contribute to the support person gaining a more nuanced picture of his or her own significance for the central person. Instead of

seeing cognitive assistance as something that only people can provide, the field becomes open for forms of assistance that take into account all the actors' strengths in different areas.

There is an important difference between the mental processes that Hutchins (1996) has studied in airplanes and on ships and what I describe in this thesis. It has to do with the division of labor. The relationship between a person with developmental disabilities and her personal assistance is not the same as that which exists between a navigator and the captain in the cockpit. The support person is expected to be the one who has the overall responsibility for processes and events moving in the direction they are supposed to. This means that even in cases where there is agreement as to how the responsibility for the mental process is to be divided up, the support person still has to constantly have an overview of how things are going and be prepared to step in and put things right if something unpredictable happens.

## 6.2 Parrots, chameleons and poodles

The critical moment in the design of everyday cognitive assistance is not about the choice between advanced and “homemade” technology but instead is about the choice between the *known* and the *unknown*. Jönsson and Anderberg (1999) express it as follows:

It may be functional to question, at the very outset, whether the solution should *imitate* fully the solution for a non-handicapped person (the parrot method), have *the same purpose but a different form* (the chameleon method), or be *completely different* and only retain its fundamental feature, the very core (the poodle method).

In the story of Henrick Person's terrible Tuesday, it is quite apparent that he lacks fixed points in time. Through the years, I have been involved in a great number of solutions in this area, and almost all of them are based on the parrot method. “They” are going to have it the same way as “we” do, only a little adjusted. There are calendars in which the text and numbers have been replaced with colors and symbols. There are ordinary analogue clocks where the second and minute hands have been removed and the face divided in to sectors with different colors, etc. The music clock, which provides Henrick with information about what day of the week it is, has, on the other hand, more of the chameleon about it because it represents time in another way than the traditional. Most solutions I have suggested are based on the chameleon method, and there are few that clearly approach the core, poodle method. That is where the microwave oven belongs as well as some of the solutions that concentrate on cognitive contours.

These solutions can appear to be deceptively chameleonic in nature, but let us stop and examine them a little closer. The story about Henrick Person demonstrates quite clearly that he finds phenomena that are diffuse by nature to be difficult because they place demands on his ability to make judgments. It is not certain that extensive training will help him in making better judgments. When it comes to sliding scales, we could profit a great deal more from putting our *efforts into the design and development of the artifact* instead of investing them in training the user. It is important that the artifact in and of itself has cognitive contours, that is, characteristics and functions that can be precisely specified in different ways. What is possibly even more important is that the different steps in the actual process can be defined in a tangible manner. That is why it is often better to start with an analysis of the process because *the cognitive difficulties that may be revealed in this process can indicate that entirely different tools are needed than the ones that were thought from the beginning.*

That the parrot method is so common in connection with cognitive assistance is not so strange. It is more natural to build on an established, working technology than to take the big step that is needed to change tracks. Another explanation can be related to the way in which the analysis is carried out. The publication *Begåvningshjälpmedel (Cognitive Aids)* (1997) offers the following description:

Of all the cognitive aids that exist today, most can be classified as situational in nature. The development of situational aids is built on an analysis of the different steps that are included in a given situation. Based on a judgment of what is considered to be a desirable result in a certain situation, it is divided up into the steps the person has to manage in order to reach that result. These steps are then analyzed according to the types of cognitive resources that are needed to carry them out.

But by relating the analysis to the steps that are involved in the current activity right from the start, you run the risk of not being open to equally valuable alternatives. If during the on-going analysis it then proves to be the case that only two of the twenty-five steps place cognitive demands that are too high, it would be more worthwhile to solve those instead of going back to square one to find other solutions.

### 6.3 Design for different numbers

It is not a satisfactory situation that people with developmental disabilities and their caregivers always need to be the ones adapting everyday objects. It would be ideal if the producers and manufacturers would take responsibility and design their products

in such a way that they were accessible even for people with cognitive limitations. This is really built into the concept “design for all”.

In my opinion, developments are also going in that direction even though many maintain the opposite. To be sure, many everyday items are still unsuitably designed, but you mustn't forget that you can often find alternative products that have been designed with children, the elderly, people with cognitive limitations and the technically-disinterested general consumer in mind. If when purchasing, you take the time to analyze the demands that household appliances and other articles for the home place on the user's cognitive abilities, you can avoid the worst pitfalls and in so doing save time and energy for many years to come.

### **DESIGN FOR A FEW**

There are products that not even the most idealistic entrepreneur is prepared to invest in because the presumptive buyers are so few that it would prove to be unprofitable. I have personally, on several occasions, failed to get state-owned and private companies interested in innovations despite documented demand. That some prototypes have made it all the way to production has been due to the right circumstances and close personal contacts with the developer and manufacturer. An example of this can be found in the documentation of the specially designed urinal bottle for women who are confined to bed (Jönsson and Knall, 1999).

In order to stratify the need for cognitive artifacts intended for a relatively small target group, I see no other possibility than society taking on the responsibility. This responsibility will not be fully accepted as long as it is placed on established social service providers.

### **DESIGN FOR ONE**

Even if you should optimally succeed on the levels of *design for all* and *design for a few*, the greater part of the work will still be on the individual level. That design of cognitive assistance takes place at this level and often against the clock is something you just have to accept, if you want the individual's needs and wishes to be the determining ones. That is not to say that efforts should not be made to try and eliminate some of the emergency measures. I have previously explained why the story of Henrick Person's wonderful Wednesday is considerably shorter than the one about his terrible Tuesday. I would like to point out here that the cognitive assistance HP receives in one situation establishes the conditions for him to better succeed in the next, because he avoids working under pressure and can concentrate on one task at a time. It is in

this context that I see a great advantage with technological assistance because it lays a foundation that exists over time in a way that is different from most personal assistance.

Technological assistance is also a way to document experiences and make it possible for a support person to find out how her predecessor approached a given situation and in that way not have to start all over again. “It’s in the walls,” is an expression that is often used in Swedish when people recognize that they have a small chance of influencing the situation. When I consider the fantastic development that has taken place in the area of digital pictures, the phrase, “It’s *on* the walls,” summarizes both the individual’s opportunities to influence his or her life situation and the possibilities of those in his or her surroundings to gradually acquaint themselves with and build on what has been.



## 6.4 Significance of support persons in the design process

It has been explained time and again in this thesis the central role played by the people involved with the person who has cognitive limitations. Without their active participation in the design process, the person in question would not receive the assistance he or she requests. But even if you wished it were the case, you cannot always count on a support person acting in the best interest of the people they care for. In group living arrangements there are times when conflicts arise because the individual’s wishes infringe upon the support staff’s freedom or result in extra work for them. In most cases, the support personnel usually are the winners. Instead of pretending that these conflicts do not exist or considering them as unfortunate misunderstandings, I think that there is much to be gained from accepting the on-going presence of what Bruno Latour (1998) calls *antiprograms*. Latour makes use of a hotel manager’s statement to the hotel guests to, “illustrate what I believe to be the right focus for discovering the point where technology enters into the human collective.” The hotel manager’s problem is that the guests, for different reasons, do not return their keys to the reception desk when they leave the hotel, which Latour designates as an antiprogram. The manager tries a variety of ways to get the guests to accept his program by placing demands, oral requests, signs to remind the customers and finally by adding a heavy weight to the keys. Latour uses the concept *statement* for “whatever is thrown, sent or delegated by a herald . . . Sometimes it refers to a word, sometimes a sentence, sometimes an object, sometimes a mechanism and sometimes an institution.” He writes: “This small example illustrates the ‘first principle’ of every study of a scientific or technological innovation: a statement is in



the hands of others.” By placing weights on the keys, the manager finally gets the majority of guests to abandon their antiprogram, but they are not following the original program of “turing in your keys to the reception desk” but a new one that involves getting rid of a cumbersome object that fits uncomfortably in their pockets or purses. Latour points out something significant, namely, that there are statements that can reduce antiprograms but that they also carry a cost.

I think that Latour’s theories can help shed light on support persons’ actions in relation to the introduction of technological assistance. Cognitive artifacts that make humans less dependent on personal assistance can, at the same time, make the support persons more dependent on others for maintaining the technology. If you are aware that a certain design of cognitive assistance will not be accepted with open arms, you also have the opportunity to take the necessary measures to ensure that the suggestion is more positively received.

One step in this direction can be to not just place demands on support persons or caregivers but to offer them something in return. If you like to work with people it does not automatically mean that you will also have the ability or intention to participate in all the steps in a design process that aims to provide a person with cognitive assistance. It might be enough to let the support person report his or her observations of different shortcomings and leave it to others to analyze the material and come back with suggested solutions. Being able to find out how other support persons handled similar situations would also increase motivation and creativity, as would technical support and the cognitive assistance of expert systems (Magnusson, 1997).

There is a tendency to paint the life situation for developmentally disabled people black or white. Instead of describing how it really is, one often presents a picture of how it should be without clearly indicating that it is a dream scenario. In these idealized descriptions, not a word about personnel turnover can be found, all have adequate training, are motivated, keep their promises and always have the cognitively limited person’s best in mind.

It is very seldom like that in reality. I am of the opinion that everyone has a lot more to gain by starting from reality instead of the going by the book. Even if we should do all we can to improve the situation, we have to accept the fact that there are personal assistants who tire of their work and look for other assignments, forget important agreements and who do not have very good judgment. Realizing that even those who assist people with developmental disabilities have their own weaknesses makes it

possible to take steps that minimize the consequences for those affected.

The answer to the question involving the choice of artifacts or people is that they are both necessary. The natural thing is for people to concentrate on tasks that require creativity, flexibility and sensitivity; artifacts are for tasks that, based on experience, we know people find difficult to carry out on a reliable basis. The boundary between the two is by no means clear-cut—the largest area may just be the overlapping one. Inside this, we can and should be very careful to make sure that as much control and power of initiative as possible is transferred to those affected. The advantage with discussing forms of support from the perspective of distributed cognition is that you avoid ending up in the “either-or” trap and can, instead, focus on what can be done to find optimal solutions.



# 7. Results and conclusions

I would like to bring this thesis to a close by highlighting the most important results and conclusions of the research.

## RESULTS

- It is possible and constructive to make use of fiction to illustrate experiences, phenomena and design ideas that are difficult to express in any other way.
- General design criteria and mental models of distributed cognition are applicable in design processes that aim to provide cognitive assistance to people with developmental disabilities.
- General methods and theories need to be supplemented. My contribution is the STEP Method that is used to steer the design process in a direction that responds to individual needs but also provides mental support in relation to the design of cognitive assistance.
- Artifacts that are intended for use by people with developmental disabilities should be designed so that they have clear cognitive contours, provide memory support, make the cause-effect relationship visible and are particularly reliable.

## CONCLUSIONS

An organization that is primarily based on human assistance is vulnerable in many ways. The trust and security that has taken years to build up can quickly erode if key people disappear or the competence of a personnel team is reduced. The person who is dependent on others for reminders and to repeat for her what she has done is especially hard hit when support persons disappear. She is unable to keep her life history going on her own. My experience is that there are great deficiencies in this area because no one is assigned the personal responsibility of preserving and further conveying what is significant for a cognitively limited person's identity. Not even under the best of circumstances can life histories be preserved and allowed to live on in a personnel collective, even less so when the staff turnover is high.

An important condition for cognitive assistance on the terms of the intended person is, therefore, that the people in her proximity stay around long enough to be able to discover her unexpressed needs. Taking steps to insure such staff continuity should, of course, be a very high priority. But even if we could succeed in that, for preventive reasons, we should be sure that the experiences of the support persons are utilized in such a way that they can benefit others. It is in this connection that I see one of the greatest benefits of technological assistance. The biggest difference between Henrick Person's terrible Tuesday and wonderful Wednesday is that because of his cognitive artifacts, he can carry out certain everyday activities on his own. But the artifacts in and of themselves can also be seen as tools that preserve and further convey important information. The physical changes that Lena implemented have been preceded by many years' observation, reflection and trial-and-error until they have evolved into their final forms. Even when Lena is not present, her substitute can access in a tangible manner the knowledge and experiences that are behind the changes of different artifacts.

Simply by going around the apartment, the substitute can gain access to her predecessor's thoughts and in that way also indirectly gain insight into how Henrick thinks and acts. But artifacts are more than bearers of information; they also steer the design of the assistance. Even small changes in the setting can render some forms of assistance impossible, while other are enhanced. Photographs are one of the most effective ways to reduce vulnerability when key people quit. That other people are the only ones who carry my recollections creates dependency and leads to uncertainty. If I, with the help of photographs, can build up my own external memory bank, I no longer have to be as reliant on other people when I want to relive particular events or feelings. Photographs are also an excellent aid when a person wants to plan, envision something or remember. In interactive situations, photographs can be a means for people with cognitive limitations to take the initiative and express their preferences.

#### **FROM MY RESEARCH IT FOLLOWS THAT:**

- A prerequisite for cognitive assistance based on the terms of the person for whom it is intended is the supplementation of personal assistance with technological.
- People's vulnerability is reduced if the community they are a part of is stable. It is possible to reduce vulnerability through:
  - Continuity in personal assistance
  - Technological assistance

- Better documentation in the form of cognitive ethnographies, life histories and photographs.
- The construction of technological assistance requires original thinking on many levels simultaneously.
- Research on the effects of technological assistance can contribute to this process.

## *Appendix*

### *Examples of projects and design ideas*

What is presented here is a compilation of some of the cognitive artifacts that were developed by student in our project-based courses. My role in the projects has been that of idea collector, conveyor, provider and/or advisor, and which role I play in each case is evident in the accompanying description. There are also examples of my own development work and design ideas that are used in courses and lectures.

More detailed descriptions of the projects can be found in Efrting (1994) and Rasmus (1996), combined at the following site in Swedish:

[www.english.certec.lth.se/dok/projektarbeten/index\\_9195.html](http://www.english.certec.lth.se/dok/projektarbeten/index_9195.html)

#### **Design for creating precision**

##### **DOUGH CUTTER 1**



A bakery at a day activity center in Lund, Sweden, had difficulties producing cinnamon rolls and other buns of uniform size. The supervisor was unable to verbally explain for the bakers exactly where they were to slice the length of rolled dough. Johan Severson's idea was to come up with fixed points that the bakers could use, showing them where to cut. He accomplished this by attaching short prongs every few centimeters along the edge of a plastic ruler. The ruler was first dipped in water and then in cinnamon, the water making the cinnamon adhere to the prongs. The baker then pressed the ruler into the dough so that it would leave a cinnamon imprint at even intervals. The supervisor could then refer to these marks to instruct the bakers exactly where they were to cut the dough: "Cut where it is reddish brown," or, "Cut where you see the cinnamon."

##### **DOUGH CUTTER 2**



The project proposal came from the Sofia Day Activity Center in Lund, Sweden. They requested a tool that would make it easier for the bakers to cut pastry dough in uniform pieces. Irenne Turcu's solution was a rolling pastry cutter with sharp blades attached to a handle. The baker rolled the cutter over the dough and the blades cut pieces at even intervals.

##### **CAKE CUTTER**

The Sofia Day Activity Center bakery also produced brownies and problems arose when they were to be cut into pieces of uniform size. Maria Wittrup made use of a rectangular sheet of Plexiglas

with slots that could be placed over the brownie pan. The baker first moved the knife along the slots to cut the cake in one direction and then turned the sheet 90 degrees and cut in the other direction. The sheet of Plexiglas had a supporting frame resulting in a perfect fit in both directions.

### **MEASURING TOOL**

The Sofia Day Activity Center bakery expressed a need for a measuring tool that people with developmental disabilities and low vision could use when baking. The measuring tool was to be used primarily with flour and other dry ingredients. Kristina Gramh added eight balls to an existing measuring tool with a crank to make it clear for the user how many times she had turned the handle.

### **TOILET PAPER HOLDER**

People with developmental disabilities can find it difficult to judge how much toilet paper they should use because there are not any clear indicators on the roll of toilet paper. Jonny Winberg solved part of the problem with a device that allows the user to only pull a limited amount of paper at a time from the toilet roll holder.



### **MEASURING IN THE HOME**

Anette Lilja and Anna Jonasson, in cooperation with Birgitta Månsson-Ekelund who works at a group home, made an inventory of different problems with dosages and measurements in the home. In their report they listed products that do not require advanced judgments by the users.

[www.english.certec.lth.se/dok/projektarbeten/fk\\_vt99/dosering/](http://www.english.certec.lth.se/dok/projektarbeten/fk_vt99/dosering/)

### **OUTDOOR THERMOMETER**

The problem with thermometers is that they are difficult to read since they often consist of a column of fluid that continuously moves up and down. When it come to outdoor thermometers, you would also like to connect reading them with making the right clothing selection for the weather. Patrik Wählin and Anders Wahlström developed a clothing advisor that in addition to temperature also measures humidity and wind velocity. From that, a picture is presented which illustrates what kind of clothing would be suitable.

[www.english.certec.lth.se/dok/projektarbeten/akspecial\\_fritid.html#klader](http://www.english.certec.lth.se/dok/projektarbeten/akspecial_fritid.html#klader)

### **BODY THERMEOMETER**

The problem with a thermometer for finding out if you are running a temperature concerns both the continuous design of the





scale and the interpretation of the results. Melker Danielson and Peter Appelgren developed a prototype of a thermometer in which the scale is replaced by three pictures and three lights. When the user sees the green light and the picture of a happy, leaping person, he knows that he is healthy; the yellow light in combination with a person in bed means that the user is feverish/ill; the red light and a picture of an ambulance means a very high temperature/call the doctor.

## MICROWAVE

Microwaves often have dials for time and power which makes them difficult for people with cognitive limitations to use. That is why I used an ordinary microwave that had buttons for all functions except heat or defrost. When tested at a group home, it proved to be the case that a person who previously had never been able to prepare food on his own managed it quite well with this simplified version, which in addition could sense if the food was ready and indicate this with a bell signal.

## TIMER

Most timers make use of a dial to set the time, which is difficult for many. I received help from a company in developing a timer for a coffeemaker with a button instead of a dial. When the person pushes the button, the coffeemaker is turned on for twenty minutes. Testing in a group home in Lund, Sweden, demonstrated that the function was very easy to understand.

## Design for creating context

### CASH REGISTER



The request for a cash register came from a day activity center in Lund that sold the handicrafts they produced at an open-air market in the center of town. Some of the salespersons did not know how to make change and so there was a need for a simple cash register. Karin Svensson, who attended the 1991 project course, chose to represent the value of money as a measurement of length.

A five-kronor coin was equal to a three-centimeter-long black piece of wood; a 50-kronor bill was 30 centimeters long and yellow. Price tags in the form of different lengths of wood were attached to the products and when the customer paid, the price tag and the piece of wood corresponding to the value of the customer's bill were set side by side in two trays in the cash register. The difference in length then showed how much a customer would receive in change. If the salesperson was unable to tell the difference, he could, with the help of one or more pieces of

wood, make sure the rows were equal in length and in that way had a measurement of how much the customer should get in change.  
[www.english.certec.lth.se/dok/projektarbeten/akspecial\\_inkop.html](http://www.english.certec.lth.se/dok/projektarbeten/akspecial_inkop.html)

## BUDGET GUIDE

People with developmental disabilities say themselves and through their representatives that they would like an instrument for drawing up a weekly or monthly budget. I took the simplified cash register and made it into a budget guide. The lengths of the pieces of wood were now proportional to a variety of ordinary expenses. A person who smoked had, for example, a number of pieces of wood with pictures of the cigarette brand that he usually purchased. A long piece of wood corresponding to his salary was placed in a compartment and the compartment next to it was filled with the pieces of wood with pictures representing the value of cigarettes, CDs, bus rides, the cinema, etc. The user's task was to make sure that the sum of his expenses in pieces of wood was equal in length or shorter than those representing his salary.

## CASH CARD

The origin of this idea was a conversation with a parent of a young man with cognitive limitations. The son did not dare to go into a store and shop because he did not understand coins and bills. His mother wondered if I had any ideas. Because the conversation took place the same day that cash cards were introduced in Lund, Sweden, it was natural to consider them as a possible solution. The advantage with a cash card compared to bills and coins is that it is possible to choose a form of representation that suits the user. A card scanner at home can display on its screen pictures of goods or products that the person can relate to or, by presenting simple symbols, show how much of the person's salary is left.  
[www.english.certec.lth.se/dok/projektarbeten/akspecial\\_inkop.html](http://www.english.certec.lth.se/dok/projektarbeten/akspecial_inkop.html)



## GAMES

A neglected area involves games for adults with developmental disabilities. The games that are available often have rules that are difficult to understand, which means that many people cannot play them without personal assistance. Annette Hansson and Kirsten Rasmus took a game that already had well defined rules, simplified and improved it so that people with cognitive limitations could play it on their own.  
[www.english.certec.lth.se/dok/projektarbeten/AKspecial\\_fritid.html](http://www.english.certec.lth.se/dok/projektarbeten/AKspecial_fritid.html)





## MUSIC

A man at a day activity center in Lund, Sweden, was very interested in music but tape recorders were too complicated for him to handle. Yvonne Bie, an occupational therapist, suggested that we develop a tape recorder that only had one button. Per Andersson took a tape recorder that had been designed for blind people and simplified it so that people with cognitive limitations could use it on their own.

[www.english.certec.lth.se/dok/projektarbeten/akspecial\\_fritid.html#band](http://www.english.certec.lth.se/dok/projektarbeten/akspecial_fritid.html#band)

## EXERCISE

Lund's day activity center had an exercise bike but the functions were difficult to understand which negatively effected the users' motivation. Fredrik Sörenson chose to represent speed with different colored light-emitting diodes which proved to be considerably easier to understand.

## Design for supporting memory

### SIMPLIFIED REMOTE CONTROL



People with developmental disabilities who like to watch television have considerable problems with standard remote controls. There are too many buttons to keep track of and many times they have to be pushed in a particular sequence to get to the right channel. I wanted a remote control that had only one button. Per Andersson almost succeeded in achieving that goal. Pressing the big green button turns on the TV and if you continue to push, it goes through the channels until you come back to the starting point. When you push the red button, it turns off the TV. Per is now commercially producing the remote control on a small scale. He is also developing remote controls for video and CD players based on the same concept.

### THE TALKING SMOKE DETECTOR

After many failed fire drills with conventional smoke detectors, I suspected that the people who lived in their own apartments would have great difficulties remembering the fire exits if and when a fire actually started. I presented the project idea of a talking smoke detector that would provide the necessary instructions. Sören Adamsson and Michael Spångberg developed a prototype that replaced the repetitive alarm with a spoken message recorded in a calm voice by someone close to the person involved.

[www.english.certec.lth.se/doc/thecertectalking/](http://www.english.certec.lth.se/doc/thecertectalking/)

## POCKET MEMORY

In a toy store I found a small, easy and inexpensive digital tape recorder that could be used for shopping lists, lists of things to do, and to save spoken messages on the telephone, for example. You pushed one button to record a message and you pushed the other to play the message back as many times as you wanted. A woman has placed the device outside the door to her apartment in order to let her son know where she is when he comes home from school.

## Design for creating security

Several of the projects I have mentioned could also fit under this heading, such as the talking smoke detector and the pocket memory. Similarly, the time aids could be placed under several of the previous headings, but I have chosen to place them here since the ability to orient one's self in time is for many a prerequisite for feeling secure.

## AIDS FOR TELLING TIME

Almost all of the aids that I have developed for telling time, share in common the provision of different types of reference points. Certec's 24-hour clock displays that evening has gone over to night when the last lamp on the evening clock goes out. A picture of food on the day portion of the clock clearly tells how much time is left until lunch.

I got the idea for an "hour ruler" when a young man with autism did not want to go on an outing for fear of missing a sports program on TV the same day. Jonas Falkvall made a rough draft and Jonas Lagerström built a prototype that he further developed into a commercial product.

The hour ruler helps a person measure how much time is left of a given activity or how much longer he or she has to wait for something to happen. As the result of user request, the hour ruler is now produced in three different versions with expanded time frames.

## MAKING THE FAMILIAR STRANGE

I have in different ways attempted to illustrate the difficulties people with cognitive limitations can have with conventional clocks, since it can otherwise be difficult for those in the person's surroundings to provide the assistance needed.

One such hypothetical experiment is the Blue Clock, which consists of a glass container into which a blue-colored liquid continuously drops. By using TV program listings and time schedules in different shades of blue, I have attempted to illustrate



for support persons and others how it would feel to not be able to understand the system.

The Flower Clock that Charlotte Magnusson constructed based on my request is a further development of the Blue Clock and it shows time in the form of a pattern that is constantly changing. I have used it in our distance courses since it is available on the Internet. [www.certec.lth.se/technical/java/jclock/](http://www.certec.lth.se/technical/java/jclock/)

To further emphasize the importance of reference points, I have developed prototypes of clocks that measure time using sound, color, shape, scent, music, rhythm and flavor. I hope that this will make it easier for staff and relatives to find a way of representing time that the person involved can decipher.

## **Idea design**

Behind almost all the prototypes that have been developed in our project-based courses there is a customer who is close to a person with cognitive limitations. The prototypes that have been of such quality that they can be used have been given to the customer when the course was over. But regardless of the quality, all the prototypes have been used in the courses, in external lectures and in connection with exhibitions to tangibly demonstrate potential solutions for relatives and other support persons. My experience is that I get a better response when I have a cognitive artifact to show and that it is the idea more than the actual form that people internalize.

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