Towards a framework to understand mental and cognitive accessibility in a digital context

STEFAN JOHANSSON

Licentiate Thesis No. 02, 2016
KTH Royal Institute of Technology
School of Computer Science and Communication
Media Technology and Interaction Design
SE-100 44 Stockholm, Sweden

TRITA-CSC-A-2016:02.
ISSN-1653-5723
ISRN-KTH/CSC/A-2016:02-SE

Akademisk avhandling som med tillstånd av KTH i Stockholm framlägges till offentlig granskning för avläggande av teknologie licentiatexamen onsdagen den 16 mars kl. 10:00 i sal F3, KTH, Lindstedtsvägen 26, Stockholm.

List of appended papers

Article I
User participation when users have mental and cognitive disabilities

Article II
Cognitive accessibility for mentally disabled persons

Article III
Manuscript: Accessibility to electronic communication for people with cognitive disabilities: a review of grey literature

Content

List of appended papers **5**
Article I 5
Article II 5
Article III 5

Towards a framework to understand mental and cognitive accessibility in a digital context **9**

Preface **9**
Funka Nu and my colleagues 10
Nothing about us without us - acknowledgements 11
The perception of our human rights and our personal responsibility 11

Introduction **13**
Purpose and justification 13
Research Questions 14

Articles **15**

Accessibility **16**
The relationship between accessibility, usability and user experience 18
What is mental and cognitive accessibility? 19

Theoretical framework and methodology **20**
Democratic and change-oriented methods 21
Participatory action research 21
Folkbildning – Non-formal Adult Education 22
Activity Theory 22
Design that takes human values into account 23
The setting of the study 24

The digital society and how it is designed **26**
Human-computer interaction, HCI 27

Design Challenges....28
Assistive Technology....29

Impairment and disability....30
Disability Research....31
Diagnoses and functions....35

Contributions....36
Weak connection to the digital society....38
The mobile phone is a highly valued asset....39
Design can create disability....39
Study circles as methods for participation....42

Discussion....44
A framework for understanding mental and cognitive accessibility requirements in a digital context....44
The need of accessible experiences and blended accessibility in the post-digital world....52

Conclusions - The forthcoming dissertation work....54
Did I answer my research questions?....54

References....57

Towards a framework to understand mental and cognitive accessibility in a digital context

Preface

Almost 30 years ago, when I as a newly educated information manager was drawn into the information society and the digitalization of information production and information presentation, no one told me how different we humans can be when it comes to managing information and communicating. Or how different we can be when it comes to using various technical devices, or to understand the interaction between people and technology.

I am sometimes asked why I am interested in ”accessible information” and how it can be that I basically devoted my professional life to it. Many wer that I have a ”family member who is disabled” as an explanation to my driving force. But it is not. We all probably have relatives or friends who have one or more impairments. Most of us have an impairment of our own, or we will have some in the future, but this is not the basis of my interest.

My motivation can basically be explained with professional pride. During my training at Brunnsviks Folkhögskola (a Swedish folk high school) no one told me about people’s different capacities to handle information. My first job after graduation was in the Swedish labour movement. I soon became Communications Manager at ABF [1]. Many organizations within the Swedish disability movement are members of ABF and when I designed smart information- and marketing campaigns I realized they did not work for everyone. For a while it felt like, whatever I did, something always went wrong:

”But if you make videocassettes our members cannot hear it/see it…”

”But there is a lot of text in the catalogue and this is not good for our dyslectic members. You should produce videocassettes! ”

”Why did you not have Swedish text in your Swedish Television advertising?”

”Our demand is that advertising should be in Braille.”

So I began to find out what you should and what you could do. At the time, it requested many separate productions and versions for creating accessible information. Then the Internet came as a liberator! Suddenly it was possible to distribute the different versions and sometimes

Funka Nu and my colleagues

It is not possible to write this thesis without relate to the work of the company Funka [2]. I am one of the founders and have worked in the company since the start in 2000. Before that, I worked in the Swedish disability movement and in 1997, we identified the need for specialized expertise in the area of digital accessibility. We were two persons who started in the context of a non-profit organization and then became four when the company Funka was founded and today we are almost 40 people. Through the years, people with diverse competencies have been involved building the skills that currently exist in the company. We are engaged as global experts on accessibility. We work with the European commission, standardization organizations in the United States and in Europe. National governments, multinational companies and all sorts of organizations engage us. We cooperate closely with organizations within the disability movement and human rights organizations and we have a deep collaboration with research institutions and standardization bodies and operate our own research projects. We have always worked with innovation. We have always employed and always collaborated with persons with impairments.

Nothing about us without us - acknowledgements

Besides a slight tinnitus from a rock concert 1982 [3] I had no impairment. To gain further understanding I had to establish cooperation with persons who knew - people with profound knowledge about disabilities and how society works. Three early partners, inspirers and provocateurs were Åse Rambrink, Mikael Holmgren and Hans Hammarlund all at the Swedish Handicap Institute. Stig Ohlsson from the Association of the Swedish Deafblind, Pelle Kölhed the National Association for Traffic and Polio and Torbjörn Lundgren at the Dyslexia Association has influenced my way of thinking about accessibility, not to mention Stefan Pelc, we have worked with these issues for 20 years now. More recently, Anders Olauson, Tommy Hagström, Jonas Andersson and Mia Larsdotter have shared experiences and knowledge

that have influenced my way of thinking.

I also want to thank Jan Gulliksen, Ann Lantz, Per-Olof Hedvall and Bodil Jönsson – my supervisors who have patiently guided me into scientific thinking and scientific writing. A special thanks to Bodil, who started this process and have kept me on track with spiritual dinners and friendly reminders of what is the essence of this – the production of knowledge.

I cannot mention everyone I worked with by name, but you are many and to me it is necessary to carry out this research trip - this journey of discovery - along with people who themselves know how it is. We learn from each other and we discover together.

This text is in its final form in English. Many of the people I work with cannot read English. Therefore, the text was originally written in Swedish and is available in Swedish for those who prefer reading or listening to Swedish.

A special thanks to Post och Telestyrelsen, who financed “Pilot study on accessibility of electronic communications for persons with mental disabilities” and the review of grey literature. And a deep thank to Louise Tengstrand for all hard work with organization, documentation and support.

The perception of our human rights and our personal responsibility

30-40 years ago we did not discuss accessibility in the way we do today. When I was a little boy and moved into a newly built apartment building, there were no elevators. It was only three floors and we were not supposed to stay there when we got old. As elderly we were supposed to move away and live at specific residential homes. Today, my parents’ generation is like prisoners at the second or third floor. They still live at the same apartments but they cannot climb stairs any more. We who were children grew up and moved away. The special residential homes are gone. We changed our minds about how old people should live. Now we are supposed to live in ordinary apartments, but when old people cannot climb stairs, relatives or society needs to organize home care service with someone carrying all the things old persons need for daily life. An elevator had solved the problem. But we did not think in that way in the 1960’s and -70’s. There was no requirement to install elevators. The persons who lived in the houses were also expected to be able to climb stairs. If we had been ”thinking accessible” the cost of an elevator divided into 40 years of use had not been high. I give you this example to illustrate two things:

- Accessibility requires long-term thinking. The structures and systems we create can have long life cycles. Difficulties that are built into these structures and systems can be difficult or expensive to change once they are in place.
- Accessibility creates space for flexibility. Since we do not know how society will change in the future, accessibility principles provide us with margins that might help us manage changes.

I like to see accessibility as part of society's infrastructure and a part of a more sustainable society. Accessibility makes things easier, both for individuals and for society.

"Accessibility thinking" has emerged gradually. It is when persons with disabilities are recognized human rights it becomes relevant to consider accessibility. There are parallels between the struggles women, homo-bi-trans and queer people or ethnic minorities go through and the rights of persons with disabilities. They are all part of an overall process of change, manifested in the UN declarations on human rights [4]. Those rights are clarified in respect of persons with disabilities in the UN Convention on the Rights of Persons with Disabilities [5].

We live in the midst of an ongoing digitalization. The question is, what mistakes we make and have made? Will we, like with the built environment have reasons to regret a too short-term thinking? A quick and radical social change offers both opportunities and threats. The digitalization and the technology behind it are not neutral. It can be used to reduce or increase inequality. It can be used to create new barriers or to enable better lives for all of us. The outcome is exceedingly a matter of personal responsibility - yours and mine - and about our ability to "think accessible".

Introduction

Digitalization is one of the fastest social changes humanity has gone through. It may not yet have so much changed what we do, but rather how we do what we have always done. I use the definition on digitalization made by the Swedish Digitalization Commission [6]

> *“Societal digitalization – the social and human-revolving process that gradually becomes increasingly difficult to distinguish at all from any part of life. This means that individuals and organizations can communicate and exchange information with other people, organizations and their environment in new ways. Digitalization and the use of ICT-based solutions can help to increase the accessibility and efficiency of both the business and public administration.*

Having impairment is often connected with as a risk of exclusion and alienation. When we examine how we communicate, obtain information, learn, work, play, socialize and love, there is still no society on earth where we can say that impairments does not matter. Persons with impairments do not have the same opportunity to reach their full potential in all areas of life [7]

This digitalization has in many ways contributed to greater inclusion but access to the digital community is not evenly distributed in the population, and we can see that groups of citizens do not feel involved in the transition to a digitalized society, or are not involved as much as they would actually like. Gregg Vanderheiden predicts that what we today regard as accessibility problems can be solved within a 30 year period, but he also says:

> *"However, the consequences of not being able to effectively use technology in 2050 have grown from disadvantageous to devastating. People who cannot use ICT are unable to access education, commerce, travel, health, safety, community, family, etc." [8, p. 491].*

Purpose and justification

Although there are policy-decisions, standards, guidelines and legislation designed to ensure inclusion for everyone, the outcome is determined by each design and development process. If the result is good or bad depends heavily on persons directly involved and in their ability to implement these intentions.

The purpose of this thesis is to discuss how designers and developers to a greater extent can be able to take account of accessibility requirements for people with mental and cognitive impairments. The discussion is based on the study “Pilot study on accessibility of electronic communications for persons with mental disabilities”, literature reviews and my experience from almost 25 years of work in the field.

I use the terms "design" and "design processes" and "developers" and "development" in the text. I use those terms in a very broad perspective, covering all competences that are involved and all the activities that occur from idea to a finished product or service ready to be used by its intended users.

The design and development processes I primarily want to highlight are those that produce digital products and services in what we call the mainstream. Mainstream is the society in which we act as citizens have rights and duties, and where we should be able to realize our dreams, wishes and needs, where we find friends, family, education, livelihood and meaningfulness in the activities and the tasks we perform.

Research Questions

My research area can be described as very wide. I look at the whole society and all kinds of disabilities that can be described as mental or cognitive.

My overall research questions are:

- How does digital inclusion work for people with mental and cognitive disabilities?
- What are the benefits and what are the obstacles created by digitalization?
- How can designers and developers better understand how to create digital products and services accessible to people with mental and cognitive disabilities?

Based on this broad approach and the overall research questions I have formulated questions that are more specific:

- How do computers, tablets, smart phones and other ICT-devices work for people with mental and cognitive disabilities?
- How does the Internet and various functions and services available through the Internet work for people with mental and cognitive disabilities?

Based on the answers to those questions, it has been possible to set focus on the design and development processes, and then ask the question:

- What do designers and developers need to know to better understand how to include the needs of people with mental and cognitive disabilities in their regular design and development processes?

Articles

The thesis is based on three scientific articles. Article I and II are the result of the project ”Pilot study on accessibility of electronic communications for persons with mental disabilities”. The project was a collaboration between KTH, Funka and RSMH (Association for Social and Mental Health [9]. The aim was to examine how the digital society works for people with mental illness. We met with over 100 people in different parts of Sweden. These people had in varying degrees both mental and cognitive difficulties.

The study had a broad approach. The participants at the various activities we undertook was asked to describe the obstacles they face in their everyday lives and also prioritize which of all these obstacles was most important to discuss and understand deeper. We did not go straight to digital issues. Instead the digitalization was regarded as an underlying factor, and as much as we could see the presence of a digital society, we could also see the absence of the same. The study also used and developed methods that make it easier for people with mental and cognitive disabilities to become more involved in research projects.

The literature review examined non-scientific yet high quality material, so-called grey literature in the field of electronic communication for people with cognitive disabilities. In this context it is also important to mention the corresponding review of scientific material [10].

The articles included in the thesis are:

I, Johansson, S., Gulliksen, J., & Lantz, A. (2015). Cognitive Accessibility for Mentally Disabled Persons. In Human-Computer Interaction–INTERACT 2015 (pp. 418-435). Springer International Publishing. Peer reviewed, acceptance level of 31%.

II, Johansson, S., Gulliksen, J., & Lantz, A. (2015, October). User Participation When Users have Mental and Cognitive Disabilities. In Proceedings of the 17th International ACM SIGACCESS Conference on Computers & Accessibility (pp. 69-76). ACM. Peer reviewed, acceptance level of 23%

III, Accessibility to electronic communication for people with cognitive Disabilities: A Review of grey literature

Manuscripts submitted to the Springer Journal Universal Access in the Information Society

Author: Ann Lantz, Johan Borg, Stefan Johansson, Anita Hilden, and Jan Gulliksen

Requests to reprint the publications in the thesis have been sought from the publishers.

Accessibility

The ambitions of creating an accessible society have evolved gradually over the last few decades. This acceptance is associated with the changing perception of disability. The UN Convention on the Rights of Persons with Disabilities was established in 2006 and is now incorporated in policy and legislation in many parts of the world. Accessibility and work for increased accessibility is described as a prerequisite for those rights to be realized in practice [11]:

”The Convention on the Rights of Persons with Disabilities includes accessibility as one of its key Underlying Principles - a vital precondition for the effective and equal enjoyment of civil, political, economic, social and cultural righ ts by persons with Disabilities. Accessibility should be viewed not only in the context of equality and non-discrimination, but overpriced as a way of investing in society and as an integral part of the sustainable development agenda ”(Chapter 1.4, page 2).

With the change in approach also followed a realization that existing environments, products and services often were inaccessible and needed to be adapted. Adaptations in retrospect may face several difficulties and might turn out costly. The European Union has addressed this problem and in 2014 introduced a standard EN 301 549 [12] to ensure proper accessibility requirements set directly on procurement.

In different technological areas, there are detailed standards and guidelines describing the requirements for accessibility. A central standard for web accessibility is ISO / IEC 40500: 2012 also known as WCAG 2.0 [13]. Hedvall [14] describes how he believes that accessibility occurs in the moment and the situation, that it is situated. Each individual in each specific situation determines what is truly accessible. With this approach, we cannot say that something that meets the requirements of a standard or follow certain guidelines is accessible. What we can say is that something that complies with such requirements

is more likely to be perceived as accessible and therefore usable by people with various disabilities.

Hedvall's view on accessibility as something personal and situated highlights a conflict between personal and societal views on accessibility. On a societal level, there is often a heed to use standards or requirements to determine a (minimum) level in order to decide what is regarded as accessible. This level is often connected to policy and legislation. For example is WCAG 2.0 level AA the level demanded for web interfaces in EN 301 549.

For a person something is more or less accessible. For society, accessibility is a set of requirements often divided into levels. When conforming to a specified level or a specified number of checkpoints, then it is regarded that accessibility is at hand. Persons with needs outside the societal scope will find solutions inaccessible that is regarded as accessible by the society.

Making accessibility into something measureable relates the area of accessibility to other areas, for example sustainability, using similar ways to describe what should be done and what are acceptable levels. Making accessibility measurable also calls for methods on how to measure. One example is the SMART 2014-0061 -project funded by the European Commission and led by Funka [15], aiming to validate the monitoring methodologies for verifying compliance with national provisions on web-accessibility and present a recommended monitoring methodology for the proposal for a Directive on the accessibility of public sector bodies' websites.

For persons with mental and cognitive disabilities it seems that present standards have shortcomings. For example Seeman and others made a formal objection on how W3C [16] claimed that cognitive accessibility was covered in WCAG 2.0 [17]. In a letter re-published as a web page [18] a response from W3C pointed out that one reason, why some cognitive requirements could not be included is that they are not testable. If there is no reliable way to verify conformance, requirements cannot be included in the guidelines. In the same letter, W3C also claimed that current guidelines do contain support for persons with cognitive disabilities. To address the problems the W3C, has established a "Cognitive and Learning Disabilities Accessibility Task Force" [19]. ETSI, who standardizes telecommunications equipment, has a work in progress with a focus on cognition [20] and RESNA, who is a US standards organization, is currently developing a standard for testing ICT products from a cognitive

perspective [21]. A regulatory framework that has incorporated a cognitive perspective is UDL, Universal Design for Learning Guidelines, Version 2.0 [22].

I am personally involved in ISO/TC/173/WG 10, currently working with a General Guideline for Cognitive Accessibility [23].

Three main issues with incorporation means for cognitive accessibility in standards are:

1. To find and describe the problem
2. To convert problem descriptions into requirements
3. To describe a method on how to test for verifying conformance

The relationship between accessibility, usability and user experience

For people with disabilities the premise is that if something should work, it needs to be perceived as accessible and usable. In many modern design solutions some form of positive user experiences also is regarded as important. Accessibility, usability and user experience are intertwined and sometimes overlapping. Where usability addresses “specified users” accessibility clarifies that those users need to be seen in a perspective of the widest range of capabilities. If the widest ranges of capabilities are neglected, some of the specified users might find barriers related to accessibility problems. Users’ impairment can demand alternatives on how to achieve the intended user experience.

Accessibility is defined by the International Organization for Standardization (ISO) as:

“Extent to which products, systems, services, environments and facilities can be used by people from a population with the widest range of characteristics and capabilities to achieve a specified goal in a specified context of use [24]“

Usability is defined by the International Organization for Standardization (ISO) as:

“Extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use [23].”

User experience is defined by the International Organization for Standardization (ISO) as:

”A person’s perceptions and responses that result from the use or anticipated use of a product, system or service” [25]

What is mental and cognitive accessibility?

There is no accepted single definition of mental accessibility or cognitive accessibility. In the area of human-computer interaction, there are different ways to deal with the term cognitive accessibility. It is relatively common that the term is used without a definition [26], or that instead of a clear definition one pinpoints the term by using examples [10], or by relating to a specific diagnosis [27] or with something that closely resembles a circular definition [28]. Jiménez et al [29] conducted an analysis of the research on web usability for people with cognitive disabilities during the period 2002 to 2011, without defining what they mean by the term ”web usability for people with cognitive disability”. They have chosen the word ”usability” before ”accessibility” but do not explain why.

Jokisuu, Langdon and Clarkson [30] presents a model where the cognitive impairments are described in a way that will make it easier for designers to make everyday products and services more accessible to persons with cognitive disabilities. They connect medical and diagnostic related conditions with the typical impairments in cognitive functions that those conditions might entail.

The term “mental accessibility” is unusual. In a digital context, few researchers seem to connect mental issues with accessibility.

The thesis is related to persons who have cognitive and mental disabilities. There are different definitions of ”cognitive” and ”mentally”. Natur & Kulturs psychology dictionary [31] defines the term ”cognitive impairment” as:

”Reduced cognitive function. By illness or injury reduced level of cognitive ability, which means disruption or weakening in the ability to perceive, learn, draw conclusions and remember.”

The same dictionary gives three different definitions of the term ”cognitive” and two different definitions of the term ”cognition”.

Different scientific domains may require different definitions. For example, there may be a need for much greater precision when medical and psychological research relate to these concepts than in human-computer interaction.

My definitions, used in this thesis are as follows:

Cognitive/ Cognition: an umbrella term for how our brain manages attention, judgement, evaluation, calculation, memory, time, language, thinking, problem solving, planning, prioritization, selection, or to refrain irrelevant and unwanted behaviour. With a brief description; to take in, process, and then use the information.

A **cognitive impairment** occurs when an ability in any of these areas are so reduced that it seriously affects how an individual functions in daily life. A **cognitive disability** occurs when factors in the environment contains barriers preventing persons with cognitive impairments from participation and activity. **Cognitive accessibility** is the extent to which products, systems, services, environments and facilities can be used by people from a population with the widest range of cognitive characteristics and capabilities to achieve a specified goal in a specified context of use

Mental: an umbrella term for the reaction patterns that create difficulties caused by mental disorders, regardless of what diagnosis or condition that causes this disorder. Mental disorders affect cognition, emotion and motivation.

A **mental impairment** occurs when a person's ability to function in everyday life is seriously reduced due to effects caused by the mental disorder. A **mental disability** occurs when factors in the environment contains barriers preventing persons with mental impairments from participation and activity. **Mental accessibility** is the extent to which products, systems, services, environments and facilities can be used by people from a population with the widest range of mental characteristics and capabilities to achieve a specified goal in a specified context of use.

Theoretical framework and methodology

There are several possible ways to carry out research leading to answers to my research questions. The fact that there is a lack of related research has strongly influenced the design of my research [10] (se also article III, the review of grey literature). Also the supposed presence of tacit knowledge and the existence of knowledge outside the sciences [32] and the process described by Focault as the "insurrection of subjugated knowledges" [33], has influenced the research approach and the research design.

Much of the work needs to be done "in the wild" together with people who themselves have experienced mental and cognitive disabilities and that has contributed to the design of my research as well as my clearly expressed interest in research that leads to change. With this in mind I have used exploratory, collaborative and action-oriented approaches based on qualitative and inductive research methods.

I want to influence design and development processes in HCI, Human Computer Interaction. I want to describe the enabling potentials and

disabling barriers in design, using collaborative approaches working together with persons having cognitive and mental impairments. At this point of my research I am more interested in the phenomena's in themselves rather than how prevalent they are.

Democratic and change-oriented methods

The study (Article I and II) combined scientific research methods and methods used in Swedish Folkbildning [34], a non-formal adult educational system. By nature, the chosen methods are alike and have common characteristics. The methods are considered to be democratic, egalitarian and seek some form of improved life conditions through increased knowledge and through the activities carried out.

Participatory action research

The study is based on Participatory Action Research which is better described as a way of approaching research than as a separate research method [35]. The core idea is a respect for people's knowledge and their ability to both understand and manage complex issues in their everyday lives. This also includes respect for the complex situation people often find themselves in, and an understanding of how a range of factors influences how something is or how something works. Participants in this type of research are considered co-researchers and as researchers, it is our duty to contribute our knowledge and our resources, gain understanding, greater knowledge and change.

What also characterizes this research is that the participants are active and makes informed decisions throughout the process and the stated objective is to change (improve) something through the activities undertaken [36]. Many researchers in Participatory Action Research is inspired by Lewin, who also was the one who coined the actual concept [37].

Folkbildning – Non-formal Adult Education

Folkbildning has been used as a social force for change by among others the Temperance movement and the Labour movement. It is based on a voluntary and democratic participation. The study circle has a central role in Folkbildning [38]. Larsson describes study circles as characterized by [39, p. 201]

1. Equal participation
2. Horizontal relations
3. Deliberations
4. Knowledge that informs standpoints
5. The recognition of diverse identities
6. Internal democratic decision-making
7. Action to form Society

The basic characteristics in study circles have been reused in the design of the research. RSMH, The Association for Social and Mental Health, which was a partner in the study, has a long tradition of working with adult education methods, and I have for several years worked in the ABF – the largest adult education organization in Sweden.

In Scandinavia, the concept of study circles has been further developed to research circles as a way for researchers and practitioners to work together to produce knowledge and gain deeper understanding [40].

Activity Theory

The field of HCI studies how humans use a system, with the help of some kind of interface. The interaction takes part not in a vacuum but in a context. What actually happens needs to be understood in the specific context and a number of different actors, activities, and internal and external processes can influence the outcome. To understand, activities needs to be described in both detailed and holistic perspectives and the perspectives might shift. A frequently used theoretical basis for doing this is called Activity Theory, or Cultural-Historical Activity Theory (CHAT). It originated in the Russian psychologist Vygotsky's work and has been further developed in several stages [41]. In HCI, Engeström's description of an activity system [42] is often used and his description has been evolved with an accessibility perspective by Hedvall, who in the "Activity Diamond" [14] uses Activity Theory in a context of accessibility.

Design that takes human values into account

A way to understand why users of ICT-devices, systems or interfaces value them as "good", "bad", "simple" or "difficult" is to analyse the hidden values embedded in the design. Participatory Design [43] and Value Sensitive Design [44] can be used as theoretical models for discussions on user participation in design processes and for discussions on how humanistic values can be included in the design process.

In both Participatory Design and in Value Sensitive Design it is considered important that values should influence the process from the very beginning and throughout the whole process. Both focus on users as key stakeholders but Value Sensitive Design also focuses on indirect stakeholders. Individuals who are not direct users but in some way affected by the use.

Participatory Design focus on bringing democratic values into the design process and thereby assures users and stakeholders if not decisive influence, then at least strong influence, by being allowed to participate. Participatory Design initially had a strong connection to work but have come to be broadened to other areas [45].

Value Sensitive Design has a broader approach and acknowledges a range of values with a particular focus on moral values, conventions, and personal preferences. A distinction is made between the term usability and whether a useful artefact also is ethically and morally right.

Participatory Design thinking has influenced the design of the study while Value Sensitive Design has been used to analyse and discuss the issues the participants highlighted as important. We have also used the UN-definition of what is “universally designed [5]:

“Universal design” means the design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed (Article 2 Definitions)

Participatory methods and the recognition of values in design are ways to ensuring both direct and indirect stakeholders influence over the research agenda, the process in itself and in the overall intention to produce universally designed products and services.

The setting of the study

We have elaborated the method of study circles. In the study over 100 persons (aged 15-75) with mental impairments participated. Activities were performed in major cities, smaller towns and rural areas. In each place a group of participants met either at least three times with a week in between (three hours per session) or at a single whole day. The participants have various diagnoses such as bipolar disorder, depression, schizophrenia, panic disorder or other mental disorders. They have had their problems for a long time. In addition to different kind of mental problems, most of the participants could also describe a number of different types of cognitive difficulties. Participants were members in an organization for persons with mental problems, called RSMH. The study went on between October 2013 and February 2014.

RSMH informed about the project and recruitment can be described as a snowball sampling. Participants could be included if they were regularly attending RSMH-activities but not if they were in an active psychotic period. They should have had their mental problems for more than a year. The recruitment process was mostly conducted orally by telephone or by personal meetings. The written material we produced came to be used mostly to inform the official representatives from RSMH, but when they got the grasp of the project they turned to oral information combined with some complementary e-mailing and text messaging. The main message to the potential participant was that we would like to discuss accessibility issues, things that made life difficult if you have a mental impairment and especially accessibility issues connected with the digital society. As researchers, we kept a low profile up to the first meeting. This was a matter of trust. If a researcher, unknown to potential participants, would make contact, it is likely that many would have declined an invitation to participate. RSMH were considered the most credible actor.

Several of the participants in the study said they had difficulties with time management. The problems may involve planning time in order for you to be on time for an appointment or to be aware that the meeting time is approaching and then bring yourself to get going. Several participants also had difficulties remembering or recalling appointments.

To counteract dropouts caused by issues with time management or short-term memory problems, we worked intensely before every meeting to contact participants to remind them of the upcoming meeting. We used e-mail, telephone and SMS-messages. We soon found that it also was common that participants reminded each other in semi-

spontaneous contact chains. This was not an official activity but not entirely spontaneous either. As this is troublesome for so many, there is a tradition within RSMH to help each other. In some cases one participant passed by another participant's residence to pick him or her up.

We offered to send reminders by postal mail but no one wanted to use that option.

We had no dropouts. The persons who started the set of three meetings also fulfilled them. Some could miss one meeting due to appointments with a doctor or someone else, but that did not lead to a dropout.

Data was collected by two persons taking notes during each sessions complemented by the circle leader. Discussions were organized in themes and those themes were used when analysing data, se Figure 1.

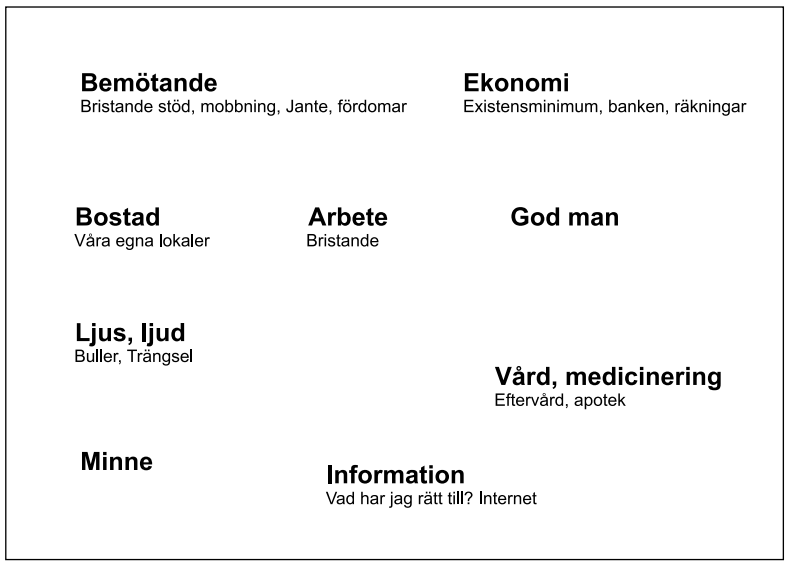

Figure 1. Example of themes: Prejudices/treatment, Economy, Accommodation, Work, Trustee, Care and medication, Information, Light and sound, Memory.

Themes, notes and discussions was also used to create visualizations. Visualizations was then refined and developed in new versions as ways to further analyse the collected data. One way to deepen the understanding was to create layers of visualizations, see Figure 2

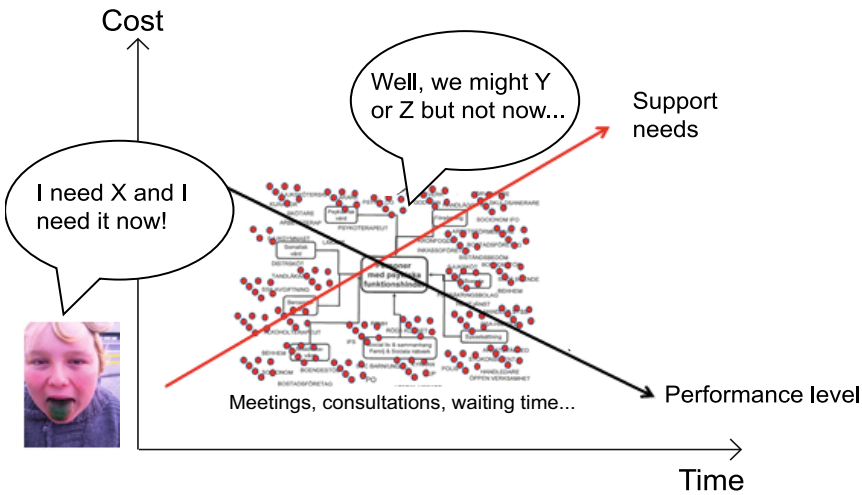

Figure 2. Example of how visualizations were used to analyse complex conditions. This visualization consists of several layers of previous visualizations. Laid together it describes how care and support systems let people down.

Digitalization or the lack of digitalization was an underlying theme in all discussions. When having the prioritized themes we could discuss how digitalization affected that theme. In the final analyses I have used my long experience from the field to relate the findings in the study to how ordinary design processes work and how they could be developed to better comply to requirements and needs.

The digital society and how it is designed

McLuhan [46] was one of the first to describe how society was changed by media, communication and information. In this change ”information” becomes increasingly important. The basic premise of this change is technological. We had, according to McLuhan’s description gradually acquired the technology we needed to reshape society. The change began with analogue technology. The major transformation went hand in hand with digitalization. With digital technology the potential of processing information, to communicate and interact have significantly changed.

In 2006, Dobransky and H argittai [47] presented statistics on digital divides and noted that there seemed to be a digital divide. According to the World Report on Disability [7] from 2011 the divides are still present. For example the report states that:

"People with disabilities have significantly lower rates of information and communication technology use than non-disabled people, and in some cases they may be unable to access even basic products and services such as telephones, television, and the Internet"(p.10)

Human-computer interaction, HCI

Human-computer interaction, HCI, is a relatively young field of research. A common description is that HCI has evolved in three waves [48] or progressed through several paradigm shifts [49].

In the first wave, the focus was on policies, practices and tests. The second wave focused more on humans [50] and how groups of people worked with different systems, often from a workplace perspective. In the third wave, technology has come to encompass all possible aspects and situations in life. Different kinds of experiences are seen as important. Bødker describes [51] how each of these steps have brought different methods and theories to the field of human-computer interaction. Hedvall [52] describes how accessibility meets the waves in HCI, calling for "accessibility 2.0" to meet the third wave of HCI.

General and special human-computer interaction

The technology itself and the interaction between people and technology evolve and change rapidly. The limit of what is possible to accomplish moves constantly. The development have created opportunities for people with disabilities but the generally used theories, models and tools of HCI will not in themselves and not automatically take into account people's diverse abilities. In general terms HCI talks about "users" or "stakeholders", then it is up to the actual design process to define who belongs to these groups. There might be a risk that the vide diversity within every group of intended users is neglected by general theories, methods and tools and as a result of that shortcoming some users end up facing difficulties due to inaccessible solutions.

There are efforts to develop support for the HCI-community to better take into account the special conditions that may apply to people with various disabilities [53]. Persson [54], [55] presents an overview of different design concepts including both how to handle the needs people with disabilities may have and how to include disabled persons themselves in design processes. The terms presented by Persson are similar and focuses on the universal – on design solutions that work for, if not all, then at least as many persons as possible.

Design Challenges

The technological development enables us to shape a more accessible future society. In this context, designers and developers face several challenges:

- Technology holds the potential to reduce, remove or hide impairments and as a consequence help people to be judged by what they do and not for who they are or how they look.
- Technology creates opportunities to convert or transform information or communication so that all parties can manage information and communicate according to their own individual preferences and needs.
- Technology used wrongly can create an overwhelming cognitive load. A recently published Swedish report [56] describes problems with digital work environment. Problems are described as leading to inefficiency, loss in production and might cause health problem related to stress and cognitive load. A strong contributing factor is poorly designed IT-systems.
- The aging population and increased cognitive demands that emerges with aging will affect all aspects of society and new assistive technological areas will possibly provide knowledge useful in mainstream design. Ambient Assisted Living, AAL [57] and ”Welfare Technology” [58] are examples of such areas.
- Cloud computing opens new possibilities and might for example be used to store personal cognitive profiles that can be used by a wide range of services.
- Mainstream technology such as sensors, 3D-printing, augmented reality has a potential of supporting people with disabilities.

A way for designers and developers to understand impairment and disability is to regard it as a “predicament”. Shakespeare [59] uses the term ”The predicament of impairment”:

> *“To call something a predicament is to understand it as a difficulty, and as a challenge that we want to minimize but which we cannot ultimately avoid” (p 86)”*

To experiment with difficulties and challenges are familiar concepts in all design and development processes. The instructions and guidelines that exist on how to consider the demands of a more universal and inclusive design do not always give the desired support [60]. There is therefore a need to describe how ordinary design processes better incorporate aspects that result in higher levels of accessibility.

Assistive Technology

Some of what we see as everyday functions embedded in everyday objects has started as special solutions to solve specific problems for people with severe impairments. For example; techniques converting text to speech or speech recognition in order to control our devices have been used for a long time in assistive technology. Now, we can see those functions finding their way in to ordinary consumer products.

Researchers in rehabilitation technology and researchers focusing on accessibility have a long history of exploring opportunities created by digitalization [61], [62]. In order to extract new knowledge they turn to the most extreme and atypical cases and work with persons with profound problems in order to solve what in the beginning are personal problems but often end up with solutions that might work for many of us. Some of their findings eventually end up in ordinary consumer products and services.

The pioneering project Isaac [63] in the 1990s provided people with learning disabilities with technology that we today can find in our smartphones. The technology was used to find out if it was possible to expand the persons own living space and help them become more independent.

All technology can in a sense be described as “assistive” but in the field of disability and accessibility some products and services are labelled assistive. Assistive technology, according to this definition, is products and services that specifically provide support for persons with disabilities. A classic assistive device is a Sock Aid, to help pulling up socks for persons with poor mobility. Anyone who does not find it difficult to pull up socks would never use such a device. The distinction between “device” and “assistive device” is clear. When it comes to ICT-products and services the line between what is a consumer technology and what is an assistive technology is more blurred. All participants in the study (Article I and II) had a mobile phone and they described it as an important object that assisted them with their cognitive shortcomings. But a mobile phone in itself is not defined as assistive technology in the system that provides persons with disabilities with assistive technology.

In parts of the world, including Sweden, there are systems to provide persons with disabilities with assistive technologies and assistive devices. To maintain the system it is important to define products and services that are approved. Often those products and services are offered for free, for low-cost or as a part of an insurance solution. The categorization

of products and services becomes important for bureaucratic and administrative reasons. Studies in Sweden have shown that people with mental and cognitive disabilities rarely receive that kind of support [64], [65].

A further reason for defining certain products and services as assistive technology is connected to production conditions. Products and services may require specific production support when the development costs can be high and the intended user group is small or cannot afford to buy expensive products or services. The Swedish authority National Post and Telecom Agency [66] has a liability to produce IT- and telecom services for persons with disabilities if the market itself does not provide accessible services.

Not all development of cognitive support has had focus on disabilities. Gillespie, Best and O'Neill [67] describe how individuals with high cognitive capacity began to use "Assistive Technology for cognition". Notebooks, diaries, pens and paper, calculators, alarm clocks, recipes and manuals are such examples. They argue that technology is expanding human capabilities and that technology can be described as a direct extension of the human body. In the literature they find clear evidence that cognitive aids can reduce difficulties linked to focusing, calculating, emotions, planning, managing time and remembering.

One example of a high-performing individual solving a personal shortcoming is the computer pioneer Les Ernest [68]. He is regarded as the person who developed the first spellchecker. Today we can find spellchecking functions available in almost all text input fields. According to Ernest the need of developing the function could be explained by "his rotten spelling":

> *"In order to cope with a personal shortcoming, I developed the first spelling checker in 1966. I didn't think that was much of an invention and was rather surprised when many other organizations later took copies.[69]"*

Impairment and disability

Today we distinguish between impairment that we may have as individuals and disability, as something created by the environment. But what we consider to be impairment and what constitutes a disability varies over time and is defined by a complex interplay between many factors.

The distinction has not always been clear. Earlier an individual

could be regarded as “the handicapped “or “invalid”. Such negative connotations persist [70] and contributes to the stigmatization of persons with disabilities.

In Disability Right and Wrongs Revisited [59] Tom Shakespeare defines a holistic definition of disability:

> *”Impairment is a necessary but not sufficient factor in the complex interplay of issues that result in disability” (p.75)*
>
> *”I define disability as the outcome of the interaction between individual and contextual factors, which includes impairment, personality, individual attitudes, environment, policy and culture” (p. 76)*

WHO has a definition that is widely used and cited [71]. It is not as nuanced as the one Shakespeare uses:

> *”Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.*
>
> *Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires intervention to remove environmental and social barriers.”*

Disability Research

The research area that examines the conditions in society for persons with disabilities is called Disability Research. The description of “the social model of disability” is an early contribution from Disability Research [59]. The social model has had a major influence on how we come to distinguish between impairment and disability. The social model emerged as a critique on what is called the medical model. In the medical model focus was on how to rehabilitate the impaired body of the disabled person. The social model has focused on removing obstacles and reducing the barriers that create difficulties. The basic idea is to provide possibilities for humans to live a good life regardless of impairments.

Correctly designed, society will not stop any of us to achieve our full potential. Shakespeare [34] objects and argues that even if we remove all obstacles and barriers, there still remains disabling factors in many impairments that will cause difficulties and, according to him, this polarization between the social and the medical model has gone too far.

Shifting focus from individual to social and societal factors were, according to Shakespeare and others [72], necessary. It provided tools to create better lives, but other perspectives, also medical, are valid.

Shakespeare advocates a ”Critical Realist Approach” where he claims it is wrong to try to reduce the question of disability to something that can be explained in a single model. He argues that the issue is multifaceted and must be viewed from multiple perspectives and multiple layers. Instead of reductionism he calls for holism and points out the following perspectives:

- Psychiatric
- Biological
- Psychosocial and emotional
- Socio-economic
- Cultural
- Normative

Shakespeare also differentiates between external factors, such as poverty, war, upbringing, culture, accessible or inaccessible environments, support systems, repression and internal factors of disability, the nature and severity of your attitudes towards our own disability, personal abilities, qualities and personality.

Frauenberger [73] develops further how a Critical Realist Approach can lead to a more holistic approach. In such approach it would be possible to recognize more than the medical model needs to rehabilitate the human body and the social model needs to eliminate barriers in society. Frauenberger claims that a more holistic approach will change the way we see technology and assistive technology.

Tensions in Disability Research

Söder [74] calls for a stronger critical approach to how Disability Research borrows influences from other research fields and areas of society. He presents fields that he describes as having tensions or contains conflicts in Disability Research; Theory and Political Action, Impairment and Disability and Juridification.

In Theory and Political Action, he draws attention to the intertwining

relationship and interaction between research and political activism, which has been a major driving force, but from a scientific perspective could lead to an uncritical attitude. He highlights a critique of the research as being both ”under-theorized” and ”under-methodologized”.

In the field of Impairment and Disability, Söder concludes that even if most researchers claim that they want to do research on disability they often end up researching impairments.

Söder also problematizes what he calls ”juridification” and with that he means that:

> *”Juridical thinking and rules of law tend to be applied to areas that traditionally have been regulated by ethics” (p.77)*

According to Söder there are risks associated with moving from assessments on an ethical / moral scale to regulation by the law. Laws often resolve conflicts in a highly simplified manner. He also sees risks of having rights on paper but not in reality.

In Söder’s critique of juridification we can find an example in web accessibility. The globally recognized guideline WCAG 2.0 [13] now becomes ”law” within the European Union as the way to fulfil the requirements of the legislation on procurement [12] will be to meet WCAG 2.0, level AA. People who will benefit from other accessibility measures, such as those located at the level of AAA, may not get the right to it, even if they take the matter to court. For designers and developers this kind of law might create incentives to only go as far as level AA even when further actions are both needed and easily accomplished.

One way to also include financial resources in what can lead to disability is The Capability Approach [75]. According to this, a lack of access to resources creates disability.

Branfield [76] has formulated what she believes is the impossibility of integrating people without own disabilities in the disability movement:

> *”The disability movement is our movement, where our voices and our actions determine the changes and redefinitions that we want. ‘Non-disabled’ people, no matter how ‘sincere’, ‘sympathetic’ or whatever, are always in the position of being ‘non-disabled’ people and all that this carries with it – domination, oppression and appropriation. In short, all the disability movement is challenging. ‘Non-disabled’ people, their values, their policies, their culture, are the objects of the analysis of our subordination. We are the subjects – its driving force, its shapers and its initiators. ‘Non-disabled’ people are not where*

we are and can never be. This is the political impossibility of their relation to the disability movement." (p. 143-144)

Similar arguments are provided by Brisenden and Drake [77], [78] with the addition of people who do not have disabilities can participate as long as they do not present themselves as spokespersons for persons with disabilities. A critique of this approach is that there are persons, whose disabilities prevent them from representing themselves, making them dependent on others to advocate for their interests

Inclusion and integration

Policies, legislation and research often have the ambition to include persons with disabilities in the society. The concept of inclusion is often used without a definition. Article 19 of the UN Universal Declaration of Human Rights of Persons with Disabilities declares the right to inclusion in society, without explaining what inclusion actually is.
The authors of a review covering research about inclusion in the Swedish school system describes how the concepts of inclusion and integration can be said to point to different approaches in how an individual can become involved in the school [79]. They argue that inclusion is about adapting the school while integration is about adapting the student. In both cases, the goal is that all students should be able to participate in the school.
In a study examining what characterizes a good integration of people with disabilities, van de Ven et al, [80] found three important areas; individual factors, social factors and factors in support system. van de Ven and his group described inclusion as:

1. Functioning in an ordinary way without getting special attention or being singled out as a result of disability.
2. Mixing with others and not being ignored in friendship and networks.
3. Taking part in and contributing to society whether through paid work or volunteering.
4. Trying to realize ones potential, which may need help from others.
5. Being director of one's life

In a design perspective, the term inclusive design [53], [55] are used to discuss principles in design that will make it possible for everyone to benefit from the outcome of a design process.

Diagnoses and functions

Studies and research projects that aim to create greater participation in the digital society often has diagnose as a starting point. An interesting example is the Poseidon project [81] whose purpose is to create digital resources properly functioning for persons with Downs Syndrome. But if the result will be good for persons with Downs Syndrome it can also be good for persons with learning difficulties or difficulties with time management, impairments connected to Downs Syndrome but also to other diagnoses.

The literature presented in Article III, and also a previous literature study [10] shows that research results relatively often are not easy to understand. It is hard to tell if persons with the targeted diagnose really benefit from an intervention. Some seem to do, others do not. A large variation is often found between individuals who have the same diagnosis. Most of the papers described are focusing on one or more diagnoses an present results related to participants' diagnoses.

An alternative to focus on diagnosis is to focus on functioning and on impairment. In the cognitive area functions as memory, concentration, attention, calculation and planning might be impaired and create difficulties for an individual, regardless of diagnose.

In the final declaration from the conference "State of the Science on the Cloud, accessibility and future" in 2014 [8], world-leading researchers in the field of accessibility questioned the focus on diagnosis. Their conclusion is that accessibility problems can be more easily managed if the focus shifts from a diagnostic perspective to a functional perspective:

> *"Individuals with different types and severity of disabilities often use similar access features. Situational disabilities (individuals without disabilities who are in limiting situations – like noisy environments) also benefit from function-based access features. As a result, access research that focuses on functions provided would be more informative and effective than research based on diagnose of beneficiaries" (p. 492)*

ICF

An example of a theoretical framework that set function before diagnose is ICF, International Classification of Functioning, Disability and Health [82]. ICF is intended to be an integration between the medical model and the social model of disability. Focus is on function and activity.

In ICF impairment arises from health conditions and might result in activity limitation or participation restrictions and create a disability. Functioning is the opposite. When functioning, body functions, structures, activities and participation, are not limited. Disability and Functioning are described as umbrella terms, one being the mirror of the other [75, p. 4].

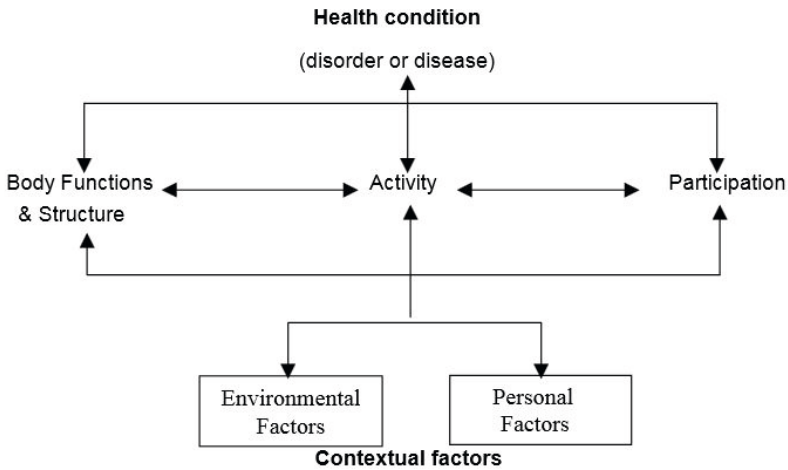

Figure 3. ICF model of Functioning, Disability and Health. Illustration: WHO [83].

The classification in ICF is most often used in medical clinical research [84], but there are also examples when ICF is used in other contexts. The classifications of impairments, activities and participation may serve as support for designers and developers to better understand the needs and demands embedded in a disability [67], [85].

Contributions

Although digitalization has a simplifying potential the participants in the study also describes how the rapid digitalization creates difficulties. Even products and services presented as easy to use might still be too difficult. There are many examples where the technology is not usable enough. Several persons describe a digital divide that is widening rather than closing.

To be a part of the digital society requires access to computers, tablets, smart phones, broadband, apps, and software and digital services. Access

to all this requires financial resources, skills, and that you are a part of an ecosystem where you can get tips and help when something goes wrong or get information about new and even better solutions as they are introduced on the market.

The digitalization of the society is a rapid process that leaves some citizens behind. It also seems to leave vital areas behind. The study described in paper I and paper II has revealed an absence of digitalization. Most important is that health care and social services do not use ICT-solutions when interacting with the participants.
The participant in the study pointed out the following areas as important to analyse in a digital perspective:

- Health care, social support and societal organizations and structures established to help them with their mental problems, also including their own and other member driven organizations.
- Information and communication, handling content, using devices and services
- Work, workplaces and processes and activities leading towards work or better possibilities to stay in the work force. Support systems when unemployed
- Architecture, furnishing, design and layout of physical environment. Including such as noises and lightning
- Design of devices and interfaces, including issues related to usability, accessibility and user experience
- Home and accommodation, places to live or places to stay for periods of time
- Economy, including handling money, credit cards, take control over spending
- Public transport system, tickets, ticket vending machines
- When discussing digitalization related to those areas problems can be divides into:
- Technology and the digital society is absent or rudimentary represented
- The possibility to test and learn how to use technology is not at hand
- Products and services have accessibility related problems

Weak connection to the digital society

The participants describe a weak connection to the digital society. Their participation is depending on whether they have the economic means to participate, if they have access to the equipment needed or if they have knowledge of a particular product or service. One such example is that the vast majority has an e-mail address but in periods they will not have accessed their e-mail because they do not have the necessary equipment or do not have access to the network. Several participants report that they usually take the opportunity to read e-mail when visiting friends, or when they are at public places where they can borrow a computer for a while.

They describe that it is difficult to exploit the existing advantages. Most persons would like to have a stronger connection, to know more and do more. They face a society shifting more and more information and services to the net. ”You can do it online” is changing to ”You must do it online.” Participants describe how several commercial and government services slides over to the net and sometimes there are no alternatives or the net is the most affordable and time saving option. The consequences of having a weak connection to the digital world are becoming more serious as important functions withdraw from the physical world.

The absence of digitalization can be a more significant problem than digitalization

A recurring problem for many of the participants in the study is that they do not naturally come into contact with or are educated in using information and communication technology through work, studies or people who are in their network. They therefore find it difficult to try something new or learn what is available on the market. In this study, for example, the intention was to discuss the participants’ experiences of tablets, but few had tested a tablet. It was the same thing with apps.

A paradox is that the institutions that the society has built for protection and support for people with mental illness very little has digitalized its activity in parts related to information and communication between caring and supporting structures and the individuals who are in need of this care and support. It might seem good, considering the group’s weak connection to the digital world but the persons in the study ask for communication via mobile phones. They want calls for appointments and reminders directly into a digital calendar or by SMS. They want to store information, take notes or record memos.

Participants describe situations where they are supposed to take part

of a large number of meetings and remember what have been said and what they are supposed to do according to decisions made during those meetings. This is a paper and oral procedure today. Calls for meetings are sent on paper and information at the meeting is given orally, giving weak support for time management and weak support on how to remember vital information.

The mobile phone is a highly valued asset

All participants in the study have a mobile phone. Very few have experience of using tablets while more have experience of using a PC. Very few have experience in using apps.

For many, the mobile phone is the link to the digital society. The phone is a carrier of important contacts and vital information. The phone is often the only channel of contact during periods of homelessness or when staying on institutions. Many of the participants in the study are using older mobile phones and if so telephone calls and text messages are the most frequent means of communication. Older models rarely handle e-mail or net-based communication.

If the phone is capable of using the internet, the use is often sporadically. The connection to the net is usually by prepaid cards or temporarily filled pots. When out of money, the person also is disconnected from the net until next time he or she can afford to pay for more time on the net. The persons presence on the net can be described as an “on and off” situation. Some have learned to locate and connect to free Wi-Fi so they go on and off between the free spots they can find.

Most participants strongly reject telephone system presenting options requiring them to press buttons to get access to services or systems playing music when waiting for service. Another problem is fixed time slots for incoming calls. Flat rates for communication are regarded as an important enabler.

The persons describe the mobile phone as a key personal device. Some describe it in loving terms.

Design can create disability

The participants in the study often describe technology that is both smart and not smart at the same time. The difficulties can often be related to poor design or lack of understanding of user needs. A recurring description is that when persons use something, do something, or participate in something with the overall intention to achieve a wanted

outcome there are embedded counterforces working in opposite direction. This is illustrated in Figure 4

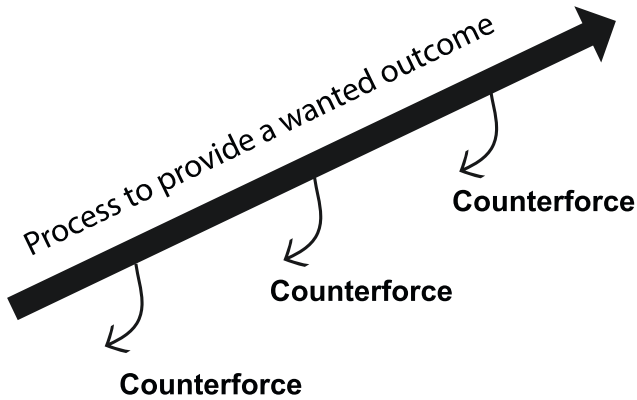

Figure 4. An activity with a positive intention can in itself have embedded counterforces, working in the opposite direction..

Some examples from the study:

- Psychiatric clinics send calls for appointments by postal letters to persons with mental impairments preventing them from opening letters. Nor the clinics systems or legislation is designed to send digital calls for appointments.
- The mobile phone is a vital tool for storage of contacts and information but everyone has experienced losing both contacts and information when changing subscription or changing telephone.
- To make an appointment to various health care services in Sweden can be done via a digital service but many of the persons in the study, which has many health care visits, says they do not want or are not able to use login functions.
- A design of a web page with objects that had sharp angles was considered as threatening.

One area of problems seems to be what could be described as ”seams” between different functions. One technical feature can work well as a standalone function, but when used in connection with another function problem arises. Functions in mobile phones or functions collaborating with downloaded apps are described having this problems as well as different kind of services on the web.

Another area of problems is details or moments that hinders or destroys

interaction. The participants describe them as divided in two categories. Some creates an immediate halt in the interaction, while others contribute to a situation when the user's energy is finally consumed, resulting in a stop or failure.
According to the participants, sign in functions are examples of immediate halts. Many of them do not use the solutions on the web that require sign in. As soon as they identify a sign in object the interaction halts, as illustrated in Figure 5.

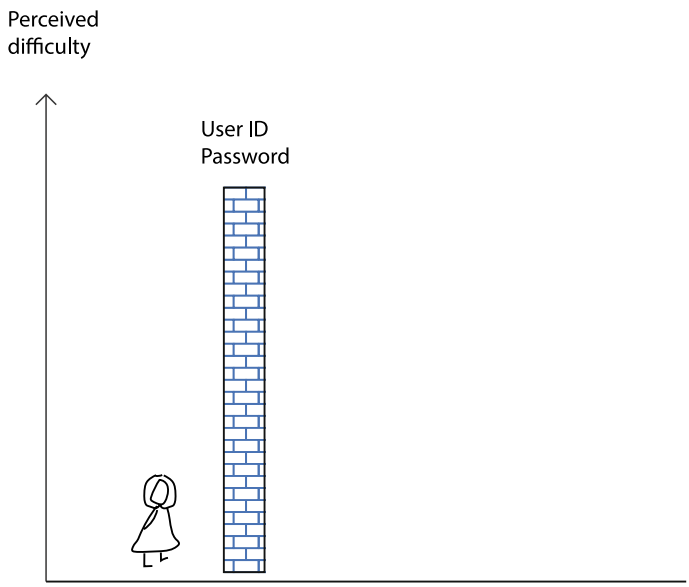

Figure 5. A detail has a perceived difficulty that will halt the interaction. In the illustration a sign in function that requires user id and password results in a total stop of interaction.

In other examples the participants describe how a number of smaller difficulties together eventually end up with a halt or a total failure. They describe the situations in terms as "energy runs out", as illustrated in Figure 6.

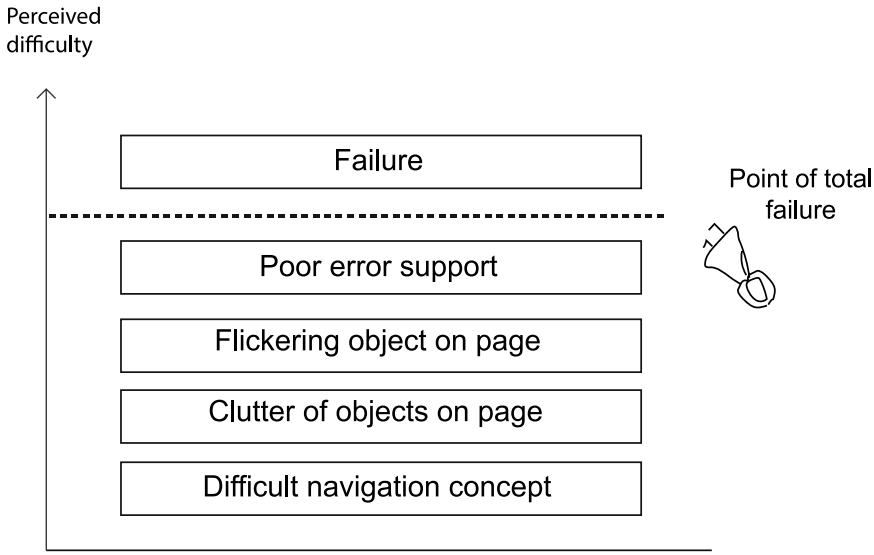

Figure 6. Several independent or dependent variables affect the result of a wanted outcome. In the example different details of a web page are interplaying negatively, resulting in a failure.

Important design issues pointed out by the users are:

- Unwanted movements or flickering
- Cluttered design
- Evil design (when design is used to persuade or trick you to do something)
- Functions and services with login
- Lack of logic and consequence in concept and design
- Lack of trustworthiness

Study circles as methods for participation

To draw on study circles and use the settings developed during the study gained further knowledge and insights on how to collaborate with persons who experience mental and cognitive disabilities. Several participants described how they on a regular basis decline to take part in surveys or studies or described difficulties and shortcomings when trying.

To divide the participation into several sessions with time to reflection in between seems to provide more information than meeting once even if the overall amount of time is the same. To visualise results worked better than writing minutes and to discuss visualizations repeatedly was

also an important part of analysing collected data. When more complex user experiences or user requirements are on the agenda more than one meeting should be the default setup for enabling users to be introduced to the overall purpose and to enable a deeper level of participation. The quality of the data improves up to a point where a further session will not provide substantial new knowledge

The prioritising exercises worked both as a way of creating themes to discuss and themes for sorting and analysing data collected. The democratic approach gave the participants opportunities to point out the subjects to discuss.

The methods for recruitment are developed by RSMH and worked well. Central positioned staff in RSMH used local contacts and local contacts used what can be described as a snowball sampling method. It made it possible to recruit a relative large group of participants on a short time. Staff also participated throughout the project. We formalized this role and called it Intermediators and a part of that role is to remind persons of the nest meeting or help if someone needs help during a session or with travelling home.

We learned that details such as meals, rooms, furnishing can be of great importance for feelings of trust an safety.

Discussion

The concept of accessibility is difficult to understand. A paradox about accessibility is that it is easier to detect when absent. It is therefore easier to detect the in-accessible than the accessible. As long as the interaction with an interface is working, few users contemplate over the interaction process in itself. The focus is on performing the desired activity. The (in) accessibility becomes visible when the interaction for some reason malfunctions.

Within the framework of the thesis, I have tried to describe the background factors that affect mental and cognitive accessibility. I have described how the participants in the study, describe their situation. I have used these results as well as my experience from many years of involvement in the development of accessible digital products and services in order to draw conclusions. In addition to the background understanding that earlier sections of the dissertation can contribute, in this section, I want to describe what may constitute a framework to better understand mental and cognitive accessibility in a digital context.

A framework for understanding mental and cognitive accessibility requirements in a digital context

The ultimate objective for most design and development processes is to deliver something that provides a specific intended outcome, something that works. Adding accessibility to those processes is to open up a perspective of inclusion. As many users as possible should be able to use that “something” and take advantage of that specific outcome. This calls for attention to human abilities to function, perform and take part in activities. In an HCI perspective, it calls for attention on the technology’s potential for inclusion.

To allow the widest range of users the widest access to the digital society we need to know how to design for all humans. In many design processes within HCI persons with disabilities are either out of focus (when designing mainstream products and services) or the focus (when designing assistive technology). Often accessibility problems are a result of ignorance an unintended outcomes of decisions taken during the design process.

The following section presents a proposed framework for the design and development processes to be able to meet accessibility requirements for persons with mental and cognitive disabilities.

Understanding the nature of the disability

Mental and cognitive disabilities may be difficult to understand. They are invisible and often manifest themselves in a way that might cause other persons to moralize and express the opinion that problems could be solved by “pull yourself together” or that others have a hard time understanding why something that they regard as easy can be so difficult. Mental and cognitive disabilities may also occur in such a way that they create anxiety and uncertainty in surrounding populations. Another complexity is that impairments might vary over time, vary depending on context or change, as a person grows older.

To understand this type of disability certain factors might need to be clarified:

- An individual person often has several impairments.
- Any impairment has its own degree of difficulty.
- Difficulties may differ from mild to very severe.
- Impairments might in combination create new and different problems than each impairment in itself.
- Over time, impairments may be permanent, increasing or decreasing.
- Impairments might be inherent or acquired, which means that they either have been a natural part of childhood and growing up, or something you had to face after having an illness or an accident.
- Impairment may occur in episodes or relapses, and vary over short or long cycles.
- Context can affect the severity of the impairment.
- Time in itself affects and changes the difficulties impairment can create and also strategies for coping with the difficulties.

Making things work, but in the wrong way - to understand the political dimension

Even with good intentions, a successful design and development process might result in criticism and rejection from persons with disabilities. Critique can be presented even when the result is a highly useful product or service. It is possible to produce a technically valid product or service that in the same time is regarded as invalid in terms of disability rights and wrongs. The product or service might (often unintentionally) be a carrier of embedded negative values.

Some participants in the study regard captcha-functions as an example of a stigmatizing feature. A captcha is used to distinguish humans from robots. By reading blurred and contorted letters and numbers and then

entering them in an input field, it is possible to positively identify the user as a human. However, not all humans can use a captcha. The captcha function is not universally designed. If you cannot read the blurred and contorted letters and numbers you are supposed to click on a “disability icon”, illustrated in Figure 7.

Figure 7. Persons who cannot read the blurred and contorted letters are supposed to click on a “disability-icon” and identify themselves as humans. Technically this works but the solution is regarded as stigmatizing.

Either technology or design is neutral. Intentionally or unintentionally both has a potential of exclusion or inclusion. Important values can be distributed and reproduced by technology and by design. To do things that work well is sometimes just not good enough.

Design for diversity – create margins

The abilities we have as humans vary. It is important to consider how different we are as information and communications partners, how different we are as technology users and how different we are in our understanding of interfaces.

The participants in the study often described situations where someone else decides how communication should take place. In situations when they prefer information in digital formats, someone else decided that they should get postal letters. With today’s technology, it should be possible for both information and communication processes to take place according to individual preferences.

As individuals we are different in how we use technology and for what we want to use technology. We also differ in how much we know and how quickly we can learn how technology and interfaces work. These

differences are often underestimated, which means that margins on who can use the product or service are narrowed down.

A main task for designers and developers who want to create solutions that can be used by as many users as possible is to aim at large margins. If we succeed in building in large margins in a design solution the result might be that users with small margins in some respect still might be able to use the solution. When we, in a design context, use terms as ”flexibility,” ”tolerance for error,” or ”equal opportunities for use” we actually talk about creating wide enough margins for a user who personally has small or no margins at all.

An example of margins is when we use technology to choose between reading a text, listening to the text, convert the text to Braille or translate text into different languages. It creates margins compared to when the same text are only on paper. The participants in the study describe another example: When they get information about meetings through postal letters they often miss some meetings. When they get the same information as SMS or calendar items, they can use reminder-functions, gps-functions and contact-functions to communicate and the risk of missing a meeting will be reduced. In the example above persons with time management impairments benefit from wider margins and those margins can be achieved simply by providing information in different formats. The impairment will in this situation not result in a disability. With too narrow margins something did not work (see Figure 5 and Figure 6). With wide enough margins a major problem can be transformed and described as “lumps and bumps” along the way, as illustrated in Figure 8.

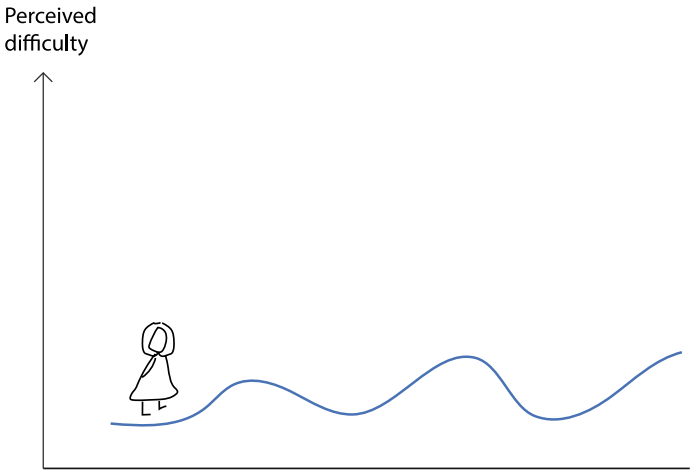

Figure 8. With wide enough margins in the design, major impairments do not have to result in disabilities. Large tolerance in design compensates for small margins in functioning

A designer of a mainstream product or service cannot affect the users' impairment directly. Indirectly the design solution has a potential to resolve many of the predicaments caused by the impairment. The better understanding of those predicaments the more persons will be able to use the product or service. It is relatively easy to influence the design solution and relatively difficult to influence a person's impairment.

An individual's ability to use the outcome of a design process and the border when a problem becomes a disability can be affected by design. In every design process there is a potential design impact where design can make the solution either more or less accessible, resulting in more or less disabled users. Se Figure 9

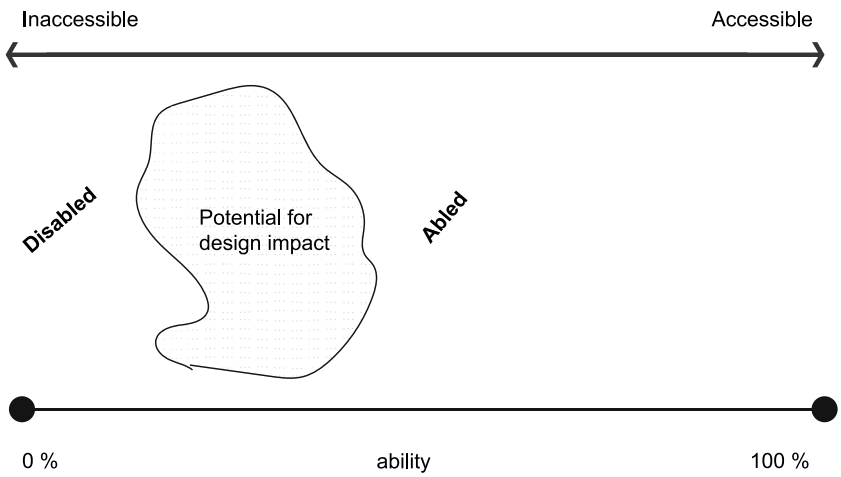

Figure 9. An individual's ability to use the outcome of the design process, the border when something becomes a disability and how those factors are related to accessibility. There is an impact-potential in design to move the border for disability in either direction. Longitudinal changes in a person's ability or in the environment will also change the border for disability.

Design for the extreme user

In many design processes, it is often the average or representative of a whole group that is the focus. When dealing with user needs it is not the extremes that will be described and dealt with, rather a combination of the target group's average shared needs. The needs the designer chooses to respond to are those who will benefit the supposed ”normal user”.

Here, the very definition of usability might guide the designer's thinking in a wrong direction. Usability is defined as “Extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use” [23]. When considering the intended users, the typical or average users often will be chosen as representatives, in the belief that it will be the best result if focusing on them. Persons with mental and cognitive disabilities are often not in that selection (and no persons with other impairments either).

With this design approach, users can be placed on a normal distribution curve. Half of all users will in varying degrees experience the solution as easy to use. The other half will experience the solution to varying degrees difficult, illustrated in Figure 10.

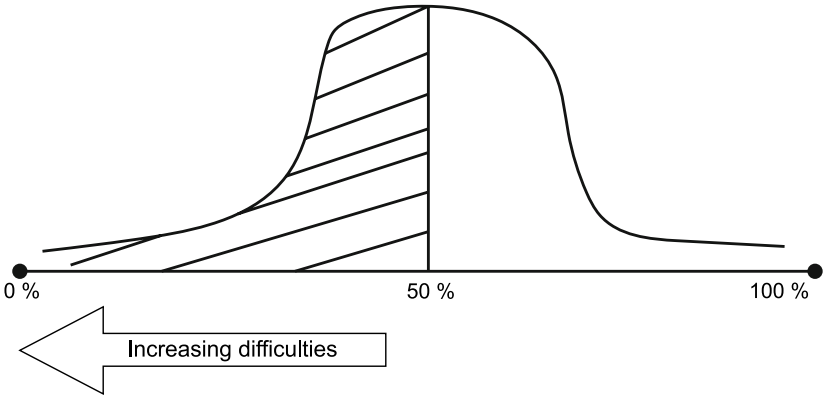

Figure 10. in a design approach for ”normal users”, half of the user population will find the solution as varying degrees of difficult.

The problem with this approach is that if we balance the level of difficulties according to preferences from average users, users below average will find the use increasingly more difficult the longer distance there is between their needs and the average users' needs. A design process shifting the balance point to the left in the normal distribution curve will result in more users finding the solution easy to use, as illustrated in Figure 11.

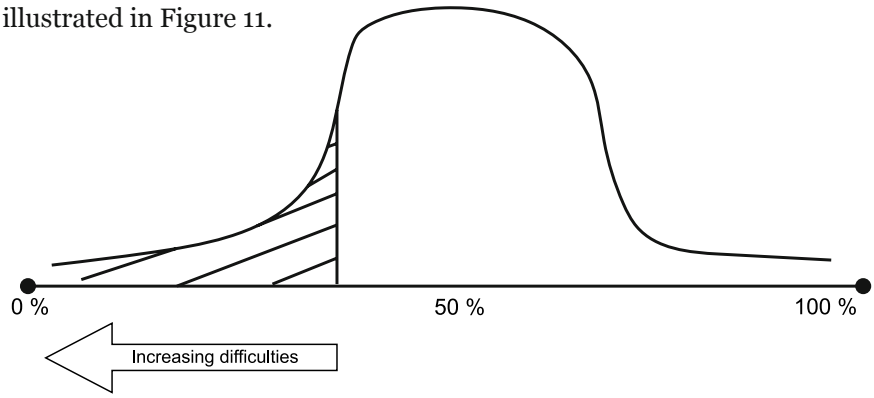

Figure 11. By focusing on users with higher needs than the average user the number of users finding the interface difficult to use will decrease.

Focusing on extreme user and extreme user situations has a potential to deliver a more usable result than focusing on typical or average user.

Design to minimize impairment effects – avoid diagnose-thinking

It may seem like a good idea to base a design on diagnoses, but within the mental and cognitive area, there are many hundreds of diagnoses where mental and cognitive impairments are included. Many diagnoses consist of a very small number of people, the so called rare diseases [86]. We cannot possibly build mainstream products and services adapted to all diagnoses and we cannot expect that designers and developers should know about the design implication for every single diagnosis.
The word diagnose relates to precision and clarity. ”Glaucoma” is a relatively precise diagnosis that describes a type of vision loss. Diabetes type II, or Measles are other examples of relatively precise diagnoses. We are accustomed to think of diagnoses in that way and it derives from a medical model of thought. In clinical treatment, the diagnosis is often a prerequisite for proper treatment. With proper diagnosis, it becomes possible to perform accurate and evidence-based interventions. From a design perspective, there is poor accuracy in diagnoses. Common diagnoses in the mental and cognitive spectrum, like depression, bipolarity, autism, ADHD etc. are not conclusive to guide designers and developers on how to think. Impairment is more accurate for a designer. When understanding the predicaments of impairments it is possible to design and develop products and services that work for the widest range of users.

If diagnoses are many, impairments are relatively few. ICF provides a classification that might help designers understand predicaments and problems emanating from impairment. The participants in the study describe difficulties related to:

- Sustaining attention
- Shifting attention
- Short-term memory
- Organization and planning
- Time management
- Problem-solving
- Experience of time
- Undertaking a complex
- Completing multiple tasks
- Handling stress

All categories above can be found in the ICF classification. There are very likely other categories in ICF that may be relevant from a design

perspective, but the total number should be manageable. The terms used in ICF are close to terms normally discussed in a design process. In that way ICF might help designers understand what all humans might find troublesome and by that providing enabling rather than disabling features and functions resulting in more universally designed products and services.

Take responsibility for the details as well as the big picture

From a cognitive perspective it is not enough that most parts of a product or a service is usable. If a small detail is too difficult or a section too complex it might endanger the whole intended outcome. Participants in the study describe this as something goes wrong and then they cannot continue. The result is that a single design problem results in a total failure.

In other cases it is not a single detail that is the problem. It is rather a sequence of problems stacked together that eventually result in an ”energy runs out-situation” as one participant described it. When this happens there is no other alternative than to rest and try to solve the task again later. From a design perspective it can be complicated to understand what happened. The most recently implemented action may indeed have been the point of failure but the more severe design failures might have occurred earlier in the sequence.

The responsibility for the designer is to be meticulous with details, designing to avoid situations that create total halts and seek minimal ”energy leaks” by taking responsibility for the big picture.

The need of accessible experiences and blended accessibility in the post-digital world

Design is mirrored in Universal Design to describe the qualities needed to design for all humans. Usability is mirrored in Accessibility to describe the qualities needed for all humans to successfully use something. But there is no mirror for user experience (UX). There is no AX. But accessible experiences should be regarded as equally important to mirror.

Affective and emotional aspects are important for persons with mental and cognitive impairments and disabling factors can often be found in factors related to (bad) experiences. Motivation, engagement, anticipations, challenges, trust, and reduction of anxiety are examples of values more related to user experience than to usability. There is a future need on focusing on accessible experiences.

In societies where the net is ”everywhere” and where ”all of us” are connected and where people and technology becomes increasingly integrated, it is important to provide accessibility from a holistic perspective. The digital and non-digital will be more and more intertwined, probably to a point when it becomes irrelevant to regard them as separate entities. The intended activity, the intended action or the intended result should be regarded as more or less accessible as a whole, rather than looking at each component and interface separately.

In a post-digital world, it does not make sense to distinguish between digital and non-digital or between technology and people. What will make sense and probably be more and more important is to be a member of an accessible digital ecosystem – an environment where you have access to devices, technology, knowledge, inspiration, news, support and contact with other users, both with and without the same predicaments as your own.

Conclusions - The forthcoming dissertation work

The knowledge base is thin when it comes to cognitive accessibility in a digital context and even thinner when it comes to mental accessibility. The knowledge we have often come from rehabilitation, assistive technology and from special solutions - excluded from mainstream activities, products and services - provided to persons with disabilities.

The persons who participated in the study describes situations where:

- Design and development processes often fail to meet the need for cognitive simplicity.
- Many in themselves relatively simple functions, processes and activities can, used together create new and unknown difficulties.
- Support processes malfunction.
- Knowledge of user requirements is missing or does not reach out to the people and the processes where this knowledge would be useful.

The people also describes that they are never involved in the design- and development processes, and that the knowledge and experience they possess is not being utilized.

There is a need for a transfer of knowledge from the areas that produce knowledge today (rehabilitation, assistive technology, special solutions) to the mainstream. There is a need to explore and describe the knowledge and experience persons with mental and cognitive disabilities possesses. There is a need to work closely with persons who have mental and cognitive disabilities directly in mainstream-solutions in order to improve the digital society. Methods seem to be further developed on how to do this cooperation, in research, in innovation and in ordinary societal processes.

Did I answer my research questions?

My research questions were:

1. How does digital inclusion work for people with mental and cognitive disabilities?

2. What are the benefits and what are the obstacles created by digitalization?

3. How can designers and developers better understand how to create digital products and services accessible to people with mental and cognitive disabilities?

4. How do computers, tablets, smart phones and other ICT-devices

work for people with mental and cognitive disabilities?

5. How does the Internet and various functions and services available through the Internet work for people with mental and cognitive disabilities?

6. What do designers and developers need to know to better understand how to include the needs of people with mental and cognitive disabilities in their regular design and development processes?

Further work needs to give more specific and detailed descriptions on benefits and obstacles and on how devices and interfaces work. A digital divide is present and many persons with mental and cognitive impairments experience disability caused by shortcomings in design and caused by problems keeping abreast of the fast development and fast introduction of new technologies and new devices. For example we have nothing to report on tablets or apps for smartphones. That is an important finding in itself and one of the most important findings is the absence of digital devices and solutions in areas described as vital by the participants. If not fully answered, I think the work presented expands our understanding of how the digital society works for persons experiencing mental and cognitive disabilities and our understanding of what designers could do to meet the needs from persons with mental and cognitive impairments.

One of my own personal experiences during this work is how much easier it is to describe disabling factors and how hard it can be to really grasp what it is that is enabling. When something works it is not easy to extract exactly what are the enabling components. I think there could be more in the material or that we could have focused more on that in the discussions. All involved in the discussions fast went in to a “problem oriented mood” and I think that in the future I need to pay more attention on how to balance disabling and enabling factors. Maybe my background as a consultant matters. Identifying problems is what clients pay for.

A question always at hand is how solid my conclusions are. Can the data collected and the analyses be trusted? On that point I feel confident. If someone else discusses digtalization in a society like Sweden with participants like the persons in the study I think the overall picture would be the same.

When I started the work I thought I knew and could explain what impairment is and what disability is and the differences between them, and at some level I could. But the most satisfying result on a personal

level is a deeper understanding of the complexity and respect for the multi-folded, multi-facetted, intertwined and holistic approaches needed for deeper understanding.

The forthcoming work

The work presented in this thesis has created a platform for a work on a doctoral thesis in this field. Several ongoing projects intends to provide a more detailed picture of what actually constitutes mental and cognitive accessibility and provide a deeper understanding of the mechanisms that contribute either too high or low cognitive accessibility. These projects also work with the development of methods for user involvement and methods for user influence in design processes. Thera is a need to further examine:

- Mental and cognitive disabilities in relation to the digital context. What is it in more detail that creates difficulties and what is it that brings simplicity?
- Design processes and how ordinary design processes can be influenced by the ideas of universal design, accessible design, and rehabilitation engineering and assistive technologies.
- How standards, guidelines, heuristic principles and classifications can be used to distribute knowledge about mental and cognitive accessibility.

How people who themselves have mental and cognitive disabilities can be a part of and have influence over design processes that to a large extent affect their lives.

References

[1] "ABF, Arbetarnas Bildningsförbund." [Online]. Available: www.abf.se. [Accessed: 03-Feb-2016].

[2] "Funka Nu AB." [Online]. Available: www.funka.com. [Accessed: 03-Feb-2016].

[3] "Ulf Lundell, turneschema 1982." [Online]. Available: http://www.alltomuffe.se/turne/host1982.php#turneschema.

[4] "Universal Declaration of Human Rights," 1948.

[5] United Nations, Convention on the rights of persons with disabilities, vol. 2515. 2006, p. 37.

[6] "The Swedish Digtalization Comission." [Online]. Available: https://digitaliseringskommissionen.se/in-english/. [Accessed: 24-Jan-2016].

[7] World Health Organization, "World Report on Disability," 2011.

[8] A. Chourasia, D. Nordstrom, and G. Vanderheiden, "State of the science on the Cloud, accessibility, and the future," Univers. Access Inf. Soc., pp. 1–13, 2014.

[9] "RSMH, Riksförbundet för Social och Mental Hälsa." [Online]. Available: www.rsmh.se. [Accessed: 03-Feb-2016].

[10] J. Borg, A. Lantz, and J. Gulliksen, "Accessibility to electronic communication for people with cognitive disabilities: a systematic search and review of empirical evidence," Univers. Access Inf. Soc., 2014.

[11] Committee on the Rights of Persons with Disabilities, "General Comment no. 2 (2014) on Article 9: Accessibility - CRPD/C/GC/2," vol. 03313, no. May 22, p. 14, 2014.

[12] ETSI, "En 301 549 - Accessibility requirements suitable for public procurement of ICT," 2014.

[13] "Web Content Accessibility Guidelines (WCAG) 2.0." [Online]. Available: http://www.w3.org/TR/WCAG20/. [Accessed: 03-Feb-2016].

[14] P. Hedvall, The Activity Diamond Modeling an Enhanced Accessibility. Certec, 2009.

[15] "SMART 2014-0061," 2016. [Online]. Available: http://monitor-wa.eu/. [Accessed: 24-Jan-2016].

[16] "W3C, World Wide Web Consortium." [Online]. Available: https://www.w3.org/. [Accessed: 24-Jan-2016].

[17] L. Seeman, "Formal Objection to WCAG 2.0," W3C Mailing list, 2006. [Online]. Available: http://lists.w3.org/Archives/Public/public-comments-wcag20/2006Jun/0118.html. [Accessed: 24-Jan-2016].

[18] J. Clark, "Letter of invitation re cognitive language and learning aspects of WCAG 2.0," 2016. [Online]. Available: http://joeclark.org/access/webaccess/WCAG/cognitive/message061122.html. [Accessed: 24-Jan-2016].

[19] "Cognitive and Learning Disabilities Accessibility Task Force." [Online]. Available: http://www.w3.org/WAI/PF/cognitive-a11y-tf/. [Accessed: 03-Feb-2016].

[20] "ETSI, STF 488. Recommendations to allow people with cognitive disabilities to

exploit the potential of mobile technologies." [Online]. Available: https://portal.etsi.org/STFs/STF_HomePages/STF488/STF488.asp. [Accessed: 03-Feb-2016].

[21] "RESNA, Cognitive Accessibility." [Online]. Available: http://www.resna.org/standards/cognitive-technologies-ct/cognitive-accessibility-ca. [Accessed: 03-Feb-2016].

[22] "UDL Guidelines—Version 2.0." [Online]. Available: http://www.udlcenter.org/aboutudl/udlguidelines. [Accessed: 03-Feb-2016].

[23] "ISO 9241-11:1998. Ergonomic requirements for office work with visual display terminals (VDTs) -- Part 11: Guidance on usability." [Online]. Available: http://www.iso.org/iso/home/store/catalogue_tc/catalogue_detail.htm?csnumber=16883. [Accessed: 03-Feb-2016].

[24] International Organization for Standardization, ISO 26800 Ergonomics - General approach, principles and concepts. 2011, p. 26.

[25] I. International Organization for Standardization, "ISO 9241-210:2010 Ergonomics of human-system interaction -- Part 210: Human-centred design for interactive systems." [Online]. Available: http://www.iso.org/iso/catalogue_detail.htm?csnumber=52075. [Accessed: 24-Jan-2016].

[26] S. Carmien, R. Depaula, A. Gorman, and A. Kintsch, "Increasing workplace independence for people with cognitive disabilities by leveraging distributed cognition among caregivers and clients," Comput. Support. Coop. Work, vol. 13, no. 5–6, pp. 443–470, 2004.

[27] N. Alm, A. Astell, M. Ellis, R. Dye, G. Gowans, and J. Campbell, "A cognitive prosthesis and communication support for people with dementia," Neuropsychol. Rehabil., vol. 14, no. 1–2, pp. 117–134, Mar. 2004.

[28] A. Lepistö and S. Ovaska, "Usability evaluation involving participants with cognitive disabilities," in NordiCHI '04, 2004, pp. 305–308.

[29] E. Jiménez, S. Márquez, F. Moreno, J. Coret, and F. Alcantud, "Analysis of research on web usability for people with cognitive disability from 2002 to 2011," Proc. 13th Int. Conf. Interacción Pers. - INTERACCION '12, pp. 1–2, 2012.

[30] E. Jokisuu, P. Langdon, and P. J. Clarkson, "Modelling cognitive impairment to improve universal access," Univers. Access HCI, vol. 6766 LNCS, pp. 42–50, 2011.

[31] "Psykologiguiden." [Online]. Available: www.psykologiguiden.se/psykologilexikon. [Accessed: 03-Feb-2016].

[32] V. Galis, "Enacting disability: how can science and technology studies inform disability studies?," Disabil. Soc., vol. 26, no. 7, pp. 825–838, 2011.

[33] M. Focault, "Society must be defended: Lectures at the Collége de France 1975–1976." ed. M. Bertani and A. Fontana, New York: Picador, 2003.

[34] Folkbildningsrådet, "Folkbildning in Sweden," 2008.

[35] M. Brydon-Miller, D. Greenwood, and P. Maguire, "Why action research?," Action Res., vol. 1, no. 1, 2003.

[36] C. Macdonald, "Understanding Participatory Action Research : a Qualitative Research Methodology Option," Can. Jorunal Action Res., vol. 13, no. 2, pp. 34–50, 2012.

[37] K. Lewin, “Action research and minority problems,” J Soc. Issues, no. 2(4), pp. 34–46, 1946.

[38] S. Larsson and H. Nordvall, “Study Circles in Sweden An Overview with a Bibliography of International Literature,” Stud. Adult, Pop. High. Educ., vol. 5, p. 47, 2010.

[39] S. Larsson, “Seven aspects of democracy as related to study circles,” Int. J. Lifelong Educ., vol. 20, no. 3, pp. 199–217, 2001.

[40] K. Rönnerman and P. Salo, Lost in Practice: Transforming Nordic Educational Action Research. 2014.

[41] L. C. Yamagata-Lynch, “Understanding Cultural Historical Activity Theory,” in Activity Systems Analysis Methods: Understanding Complex Learning Environments, 2010, pp. 13–25.

[42] Y. Engeström, “Expansive Learning at Work: Toward an activity theoretical reconceptualization,” J. Educ. Work, vol. 14, no. 1, pp. 133–156, 2001.

[43] P. Ehn, “Work-Oriented design of computer artifacts,” 1988.

[44] B. Friedman, P. H. Kahn Jr., and A. Borning, “Value Sensitive Design and Information Systems,” in Human-Computer Interaction and Management Information Systems: Foundations, 2008, pp. 1–27.

[45] E. Björgvinsson, P. Ehn, and P.-A. Hillgren, “Agonistic participatory design: working with marginalised social movements,” CoDesign Int. J. CoCreation Des. Arts ISSN, vol. 8, no. 2–3, pp. 127–144, 2012.

[46] M. McLuhan, Understanding Media - The extension of Man. The MIT Press, 1994.

[47] K. Dobransky and E. Hargittai, “The disability divide in internet access and use,” Information, Commun. Soc., vol. 9, no. 3, pp. 313–334, 2006.

[48] S. Bødker, “When second wave HCI meets third wave challenges,” 4th Nord. Conf. Human-Computer Interact. ..., no. October, pp. 14–18, 2006.

[49] S. Harrison, D. Tatar, and P. Sengers, “The Three Paradigms of HCI,” in Proc. of CHI 2007, 2007.

[50] L. J. Bannon, “From human factors to human actors: the role of psychology and human-computer interaction studies in system design,” in Design at work.: Cooperative Design of Computer Systems, Hillsdale: Lawrence Erlbaum Associates, 1986, pp. 25–44.

[51] S. Bødker, “Third-Wave HCI , 10 Years Later — Participation and Sharing,” Interactions, vol. 22, no. 5, pp. 24–31, 2015.

[52] P. O. Hedvall, “Towards the era of mixed reality: Accessibility meets three waves of HCI,” Lect. Notes Comput. Sci. (including Subser. Lect. Notes Artif. Intell. Lect. Notes Bioinformatics), vol. 5889 LNCS, pp. 264–278, 2009.

[53] J. Abascal and C. Nicolle, “Moving towards inclusive design guidelines for socially and ethically aware HCI,” Interact. Comput., vol. 17, no. 5, pp. 484–505, 2005.

[54] H. Persson, “Persons with functional difficulties as resources in ICT design processes,” KTH, 2008.

[55] H. Persson, H. Åhman, A. A. Yngling, and J. Gulliksen, “Universal design, inclusive design, accessible design, design for all: different concepts-one goal? On the concept of accessibility-historical, methodological and philosophical aspects,” Univers. Access Inf. Soc., p. 22, 2014.

[56] J. Gulliksen, A. Lantz, Å. Walldius, B. Sandblad, and C. Åborg, “Digital arbetsmiljö,” 2015.

[57] N. Garcia and J. Rodrigues, Ambient Assisted Living. CRC Press, 2015.

[58] “Välfärdsteknologi inom äldreomsorgen : Nordiska erfarenheter,” 2013.

[59] T. Shakespeare, Disability rights and wrongs revisited, Second. Routledge, 2013.

[60] C. M. Law, J. S. Yi, Y. S. Choi, and J. a. Jacko, “A systematic examination of universal design resources: part 1, heuristic evaluation,” Univers. Access Inf. Soc., vol. 7, pp. 31–54, Oct. 2008.

[61] J. Jönsson and B. Magnusson, “Handi - en väg till självständighet och delaktighet,” 2008.

[62] B. Jönsson and P. Anderberg, “(Re) habiliteringsteknologi och design-dess teorier och metoder,” Lund, 1999.

[63] B. Jönsson and A. Svensk, “Isaac-A personal digital assistant for the differently abled,” in 2nd TIDE Congress, pp 356-361, Paris, France, April 1995, 1995.

[64] P. Folkesson and T. Karlsson, “Tillgängligheten till kognitiva hjälpmedel för personer med psykisk funktionsnedsättning En fallstudie och brukarundersökning i Värmland,” 2010.

[65] Hjälpmedelsinstitutet and J. Adolfsson, “Kognitiva hjälpmedel,” 2012.

[66] “PTS, National Post and Telecom Agency.” [Online]. Available: www.pts.se. [Accessed: 03-Feb-2016].

[67] A. Gillespie, C. Best, and B. O’Neill, “Cognitive function and assistive technology for cognition: a systematic review.,” J. Int. Neuropsychol. Soc., vol. 18, no. 1, pp. 1–19, Jan. 2012.

[68] D. Spicer, “Oral History of Lester D . ‘ Les ’ Earnest Interviewed by :,” 2013.

[69] “Testimony on Software Patents by Les Earnest.” [Online]. Available: http://groups.csail.mit.edu/mac/projects/lpf/Patents/les.html. [Accessed: 03-Feb-2016].

[70] “Wikipedia - List of disability-related terms with negative connotations.” [Online]. Available: https://en.wikipedia.org/wiki/List_of_disability-related_terms_with_negative_connotations. [Accessed: 03-Feb-2016].

[71] “WHO - Disabilities.” [Online]. Available: http://www.who.int/topics/disabilities/en/. [Accessed: 03-Feb-2016].

[72] L. Crow, “Renewing The Social Model Of Disability,” Coalit. News; Gt. Manchester Coalit. Disabl. People, no. July, p. 7, 1992.

[73] C. Frauenberger, “Disability and Technology A Critical Realist Perspective,” in ASSETS’15, 2015, pp. 89–96.

[74] M. Söder, “Tensions, perspectives and themes in disability studies,” Scand. J. Disabil.

Res., vol. 11, no. 2, pp. 67–81, 2009.

[75] S. Mitra, “The Capability Approach and Disability,” J. Disabil. Policy Stud., vol. 16, no. 4, pp. 236–247, 2006.

[76] F. Branfield, “What Are You Doing Here? ‘Non-disabled’ people and the disability movement: A response to Robert F. Drake,” Disabil. Soc., vol. 13, no. 1, pp. 143–144, 1998.

[77] S. Brisenden, “Independent Living and the Medical Model of Disability,” Disabil. Handicap Soc., vol. 1, no. No 2, pp. 173–178, 1986.

[78] R. F. Drake, “What Am I Doing Here? ‘Non-disabled’ people and the Disability Movement,” Disabil. Soc., vol. 12, no. 4, pp. 643–645, 1997.

[79] K. Göransson, C. Nilholm, and K. Karlsson, “Inclusive education in Sweden? A critical analysis,” Int. J. Incl. Educ., vol. 15, no. 5, pp. 541–555, 2011.

[80] L. van de Ven, M. Post, L. de Witte, and W. van den Heuvel, “It takes two to tango: the integration of people with disabilities into society,” Disabil. Soc., vol. 20, no. 3, pp. 311–329, 2005.

[81] “Poseidon - PersOnalized Smart Environments.” [Online]. Available: http://www.poseidon-project.org/. [Accessed: 03-Feb-2016].

[82] “WHO - International Classification of Functioning, Disability and Health (ICF).” [Online]. Available: http://www.who.int/classifications/icf/en/. [Accessed: 03-Feb-2016].

[83] WHO, “How to use ICF - A Practical Manual (draft),” 2013.

[84] M. Cerniauskaite, R. Quintas, C. Boldt, A. Raggi, A. Cieza, J. E. Bickenbach, and M. Leonardi, “Systematic literature review on ICF from 2001 to 2009: its use, implementation and operationalisation.,” Disabil. Rehabil., vol. 33, no. 4, pp. 281–309, 2011.

[85] M. J. Scherer, S. Federici, L. Tiberio, M. Pigliautile, F. Corradi, and F. Meloni, “ICF Core Set for Matching Older Adults with Dementia and Technology,” Ageing Int., pp. 414–440, 2010.

[86] “Rarelink - A Nordic link collection and contact service for rare diseases.” [Online]. Available: http://rarelink.org/. [Accessed: 03-Feb-2016].