# Design for Participation and Inclusion will Follow.

## Disabled People and the Digital Society.

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# Abstract

Digitalization is rapidly taking over all aspects of society, but still there are parts of the population who have to struggle for access to, and to be able to use, the digital resources. Design processes and outcomes in the form of artefacts, that takes accessibility into account, is key to participation. This gives the designer a central role in providing for a more equal participation of all, in the digital society. The work in this thesis contributes to a better understanding of the prerequisites for participation in the digital society, and in the design processes to accomplish this, by presenting research done together with three communities: people with cognitive impairments, people with mental health issues and homeless people.

The overall question has been **How can participation in the digital society be understood?** We have investigated the nature of difficulties or enabling factors for people with impairments, people with mental health issues and homeless people, when using the internet. We have also investigated possible digital divides within the groups, and how they can be explained.

Ontologically, the work is based on an assumption that knowledge is to be found in a dialectic interplay between the material world and how we interpret what is going on in this world. The underlying epistemological assumption is that data has to be empiric, and critically interpreted in dialogue between members of the communities, which are being researched, and other stakeholders. This work draws on the idea of emancipation and that research can be liberating.

The work also takes on a pragmatic stance. We have used adapted versions of Emancipatory Participatory Research, and of Participatory and Value Sensitive Design, thus making them accessible to people with cognitive impairments, people with mental health issues or homeless people. We have tested and adapted methods for sampling of rare populations, to enhance the quality of quantitative studies of how people with impairments and people with mental health issues have access to, and are using, the internet.

In our research, we have found fourteen prerequisites, all of which need to be in place to provide for participation. To promote participation, we need a toolbox of methods and accessible tools. Finally, to analyse what is

going on we need an analytical model which allows for analysis on multiple levels and from multiple perspectives.

As a result, I here propose, define and position a framework for researching and understanding participation in the digital society, based on three parts: Guidelines, Ethics and Statistics. Guidelines can be understood as the theories, the regulations, the standards, etc. that inform our thinking. Ethics guide us in the right direction. Statistics make progress or lack of progress visible.

The conclusion is: if we plan for participation - by improved statistic survey sampling methods, a participatory approach to collaborative research and in using research methods in an accessible and emancipatory way – inclusion will follow.

# Sammanfattning

Digitaliseringen tar snabbt över alla aspekter av samhället, men det finns fortfarande delar av befolkningen som måste kämpa för att få tillgång till och kunna använda de digitala resurserna. Designprocesser och resultat i form av artefakter, som tar hänsyn till tillgängligheten, är nyckeln till deltagande. Detta ger designern en central roll i att skapa ett mer jämlikt deltagande av alla, i det digitala samhället. Arbetet i denna avhandling bidrar till en bättre förståelse för förutsättningarna för deltagande i det digitala samhället, och i designprocesserna för att åstadkomma detta, genom att presentera forskning som görs tillsammans med tre grupper: personer med kognitiva funktionsnedsättningar, personer med psykiska hälsoproblem och hemlösa.

Den övergripande frågan har varit hur kan deltagandet i det digitala samhället förstås? Vi har undersökt vilken typ av svårigheter eller faktorer som gör det möjligt för personer med funktionsnedsättningar och/eller psykiska hälsoproblem och hemlösa att använda Internet. Vi har också undersökt möjliga digitala klyftor inom grupperna och hur de kan förklaras.

Ontologiskt är arbetet baserat på ett antagande att kunskap finns i ett dialektiskt samspel mellan den materiella världen och hur vi tolkar vad som händer i denna värld. Det bakomliggande epistemologiska antagandet är att forskningsdata måste vara empirisk, och kritiskt tolkas i dialog mellan medlemmar av gemenskaperna som utforskas, och andra intressenter. Detta arbete bygger på idén om frigörelse och att forskning kan vara befriande.

Arbetet har också en pragmatisk hållning. Vi har använt anpassade versioner av Emancipatory Participatory Research, och av Participatory and Value Sensitive Design, vilket gör dem tillgängliga för personer med kognitiva funktionsnedsättningar och/eller psykiska problem eller hemlösa. Vi har testat och anpassat metoder för sampling av sällsynta populationer, för att förbättra kvaliteten på kvantitativa studier av hur personer med funktionsnedsättningar och psykiska hälsoproblem har tillgång till, och använder, Internet.

I vår forskning har vi funnit fjorton förutsättningar, som alla måste vara på plats för att kunna delta. För att främja deltagandet behöver vi en verktygslåda med metoder och tillgängliga verktyg. Slutligen, för att

analysera vad som pågår behöver vi en analytisk modell som möjliggör analys på flera nivåer och från flera olika perspektiv.

Som ett resultat av detta föreslår, definierar och positionera jag här en ram för forskning och förståelse av deltagandet i det digitala samhället, baserat på tre delar: riktlinjer, etik och statistik. Riktlinjer kan förstås som teorier, förordningar, standarder, etc. som informerar vårt tänkande. Etik vägleder oss i rätt riktning. Statistik gör framsteg eller bristande framsteg synliga.

Slutsatsen är: om vi planerar för deltagande - genom förbättrade samplings-metoder för statistiska undersökningar, ett deltagande förhållningssätt till forskningssamverkan och genom att använda forskningsmetoder på ett tillgängligt och emanciperande sätt - kommer som ett resultat inkludering att följa.

# Preamble and Acknowledgements

Digitalization penetrates almost every aspect of human life. I like to think about it as a frontier where we can find people and phenomena not yet digitalised or partially digitalised. I use the metaphor of a frontier because frontiers have borders over which you can travel back and forth. You can either be outside the digital society, at the border or within it.

By spending time in the frontier landscapes, I have met some of the people who live there. People who can tell how it is to cross the border and tell what prevents or enables the border crossing. In this landscape you can find Hussein and Nicholas, super-skilled digital wizards – from time to time cut out of the digital society due to lack of money. You can meet Mike who struggles with reading and the prejudice from those who are able to read. You can find Camilla or Berit who lost their language and struggle to get it back, or Uno, who gave all his money away "*in a moment of madness when I thought I was about to die, but I survived, ha-ha-ha*". Or Kristina who recently started to enjoy the internet as a middle-aged woman, because previously, teachers and staff thought she was not able to learn how it works. I cannot name them all but everyone who struggles to participate in the digital society has a story to tell. If we want to know the prerequisites for participation in the digital society, we should listen carefully to what they have to say.

## Acknowledgements

Finally, I want to thank Bodil Jönsson, not as supervisor this time but for being the one initially igniting all this, years ago, by saying "Stefan, you are doing research, you just don't know it".



Figure 1: The Begripsam Group. From upper left: Charles Löfblad, Sonia Gunnarsdotter, Louise Tengstrand, Max Bullerjahn, Anita Hildén, Cecilia Olsson, Viktor Lundqvist, Hans Hammarlund, Tommy Hagström, Annika Johansson, Michael Wallón, Kerstin Ivarson Ahlstrand, Stefan Johansson, Simon Sjöholm, Hussein Mohammed Ali, Karin Forsell, Peder Johansson. Sitting from the left: Melvin Löfblad, Anette Green, Joakim Uppsäll Sjögren, Frida Lundin, Camilla Lucchesi Jingåker, Malin Lucchesi. Missing: Laleh Zarei, Malin Nilsson, Inger Rålenius och Tomas Karlsson. Photo: Mia Larsdotter.

Stefan Johansson
Nysjö Fäbod, November 2019

# Terminology

Before reading further, I hope you could take some time to reflect on the terminology used in the thesis. The terms used, or not used, form a clear distinction for my thinking. The terms used are not self-evident. Often other terms could have been used, not as synonyms, but rather representing subtle – but important - differences. I have, however, not used the terms consistently throughout the years. If you read my papers in chronological order you might notice a shift in my use of terminology. I look upon this as a maturing process, as a thinking progress. This is still an ongoing process.

### Accessibility

There are several definitions of accessibility. They have shifted over time. I use the definition presented by the International Organization for Standardization, ISO 26800 defined 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 [1]"*

I regard accessibility as situated. It happens here and now, situated in time and place. We can plan for accessibility, but true accessibility is to be found where the action is. This view is heavily influenced by the work of Per-Olof Hedvall in the Activity Diamond [2] where he presents an enhanced model for accessibility.

### Design and Designers

I define design/designers in a very broad sense. In this thesis I use the terms ´design/designers´ to represent anyone involved in thinking, planning, shaping and developing artefacts, such as products, systems and services. Depending on the type of design, designers can have many competences and titles. Jeffrey Bardzell [3] has a description of the characteristics of a designer:

> *"design professionals require a cultivated ability to read socio-cultural signs and trends; a creative and reasoned ability to explore alternative futures; a verbal ability to articulate these activities; a receptiveness to alternative framings and a willingness to explore highly variable alternative directions; and above all a personal identity or*

*coherence that holds all of these moving parts together
through a given process" (Section 21.10.1)*

## Digitalization

Digitalization is the process that transforms how societies and humans interact and communicate by using information technology. It is a rapid process and gradually digitalization becomes present in all parts of our lives. We are all affected by this transformation. Even those of us not directly using digital tools face the consequences of digitalization. It is relevant to talk about people being citizens in a digital society, and Sweden is among the most digitalised countries in the world.

## Disability, Impairment and Diagnosis

This thesis focuses on people with impairments, homeless people and people with mental health issues. I sometimes describe those people as **disabled**, in the meaning that they have been disabled by someone or something. They are not disabled in every context, *per se*. They become disabled when they face situations, services, products, practices and policies not accessible for them. I avoid framing those people as "having a disability". They might have impairments or difficulties of some kind and even when facing accessible environments some of those impairments or difficulties might still be seen as **predicaments** [4], to use the words of Tom Shakespeare, or **impairment effects** in the words of Carol Thomas [5], thus making things harder to do.

An accessible society does not contain any disabled people but will contain people with impairments and difficulties. Impairment is a natural part of human diversity, which should be regarded as a normal thing to consider in any design process, if the design has something to do with humans. **Disability is a mismatch** - an indication of something being wrong between human diversity and how we construct society [6]. Things we do, as a society, or the way we think, can be either disabling or enabling. **Disablement,** as the process of creating disability, can either be explained as an outcome of a pathological process [7] or as an outcome of the organisation of the society [8]. I most often search for societal phenomena to explain why people with impairments become disabled.

**Disablism**, explained by Carol Thomas [5] as; "the social imposition of avoidable restrictions" on people with impairments, can help us understand why disability exists even when we know how to avoid it.

**Ableism**, as the assumption that everyone is able-bodied and that an able body is superior to an impaired body, is explained by Fiona Kumari Campbell [9] as "a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human". Disablement, disablism and ableism operate on both conscious and un-conscious levels, and able-bodied people often find it hard to understand when they enact them.

I use the terms **impairments, issues** and **difficulties** to relate to **problems in functionality** that people might have. Humans are diverse, also in how we function. Diversity in functionality needs to be understood by designers. This **diversity** can be communicated to designers as design challenges. Detailed understanding of an impairment or difficulty can provide the precision and understanding designers need, to solve design problem.

I sometimes use specific diagnostic language to target a specific population to communicate results in a way that can be used by and related to society. For me, diagnostic language is more useful for communication while impairments and difficulties are more useful for understanding. Diagnostic terminology does not promote the same precision as can be achieved when focusing on specific functionality, impairments or specific difficulties.

**Inclusion and Participation**
I see inclusion as an outcome. When people participate in activities, they are included. It is often said that disabled people should 'become more included' in the digital society. By saying that, we establish a power relation. Someone (the disabled person) is supposed to become more included (most often by a non-disabled person or by some undefined force). In this perspective, the disabled person is passive and must be included by someone else, who is already a participant in the digital society. From my point of view anyone becomes included by actively taking part. Participation and activity result in inclusion.

## Homelessness

There are different definitions of homelessness. I use the one from the Swedish National Board of Health and Welfare where homelessness can be one of four situations: 1. Acute homelessness; 2. Living in a shelter or an institution; 3. Get accommodation by the Social Service in special apartments; 4. Staying at places without a contract or on contracts shorter than three months.

It is justified to engage homeless people in research related to accessibility since many homeless people have cognitive or mental health issues. A society that works well for people who are, or are at risk of becoming, homeless, would have to be a cognitively accessible society.

Many homeless people are in a pendulum-situation at the border of digitalization, moving back and forth. There is much to learn in co-operating with homeless people. Also, the interaction between homeless people and Social Service Administrations is still not digitalised. In Sweden it is increasingly difficult to find practices not affected by digitalization, but here we have one to study.

## Mental Health Issues

I use the term mental health issues to frame people with a wide range of diagnoses and difficulties that can be related to internal mental processes in their brains. I am aware of other definitions. Although it has problems, I have decided to use 'mental health issues'.

## Rare Populations

There is no exact definition on when a population becomes rare. A limit often used is when the group of interest is smaller than ten percent of the general population [10]. If "people with impairments" is regarded as one group, this group is above the ten percent threshold and can be handled with standard statistical procedures on how to survey populations. However, - if we deconstruct the concept of people with impairments and acknowledge that this is not a homogenous group, we will get groups related to diagnoses or impairments which are below ten percent (some far below one percent). Then standard statistical procedures no longer are sufficient, and we need to apply methods on how to survey rare populations.

**Scaffolding**

I have borrowed the term scaffolding from the field of education[1] but also from the construction industry[2]. In education it is explained as a "*method that enables a student to solve a problem, carry out a task, or achieve a goal through a gradual shedding of outside assistance*". From the construction perspective scaffolding is "*a temporary structure on the outside of a building, made of wooden planks and metal poles, used by workmen while building, repairing, or cleaning the building*". The idea is to provide the optimal structure, arrangement and preparation, so that people can direct their energy to actively taking part in the meeting.

**Universal Design**

I use the United Nations'-definition [11]:

> *"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)*

**User Experience**

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"* [12]

**Usability**

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 [13]."*

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[1] Universal Design for Learning have more reading on scaffolding: http://udlguidelines.cast.org/engagement/self-regulation/coping-skills-strategies/coping-skills-strategies

[2] https://www.lexico.com/en/definition/scaffolding

# 1. Introduction

Digitalization has not reached all of us equally. It is unevenly distributed and participation and non-participation in the digital society are complex phenomena. My contribution to the understanding of participation has been to work closely with some of the people often described as excluded or at risk of being excluded, by exploring and aiming to understand the prerequisites for participation.

## 1.1 Objective and Research Questions

The objective for this thesis has been to discuss: **How can participation in the digital society be understood?** This is a very broad topic, so to narrow it down, I will present the work done together with three communities, populated by people who have personal experiences of the border between participation and non-participation:

**1) People with impairments of a cognitive nature**

**2) People with mental health issues**

**3) Homeless people**

There are three basic hypotheses for the thesis. They are based on earlier experiences, the study of literature and discussions with other people interested in the subject:

**1)** A key to participation is design. Design is a useful tool for expanding the space available for participation in the digital society.

**2)** The likelihood that design will emancipate and empower participation, is higher if those in need of such design are taking part in the design process.

**3)** Most people want to be part of the digital society, but there are barriers preventing some from entering to the extent that they want.

**The research questions used in the thesis are:**

**RQ1**:    What is the nature of difficulties people with impairments, people with mental health issues and homeless people face, when using, the internet?

**RQ2**:    What enables people with impairments, people with mental health issues and homeless people, to connect to or use the internet?

**RQ3**:    Are there digital divides between people with impairments, people with mental health issues and homeless people, compared to the rest of the population? And if so, how can those be explained?

**RQ4**:    Are there digital divides in-between groups of people with impairments, people with mental health issues and homeless people? And if so, how can those be explained?

**RQ5**:    What special considerations, methods and tools are needed when surveying participation in the digital society among people with impairments, people with mental health issues and homeless people?

**RQ6**:    How could people with impairments, people with mental health issues and homeless people be included in, and contribute to, the design process on equal terms with other stakeholders?

## 1.2 Papers Included in the Thesis

**I. Cognitive Accessibility for Mentally Disabled Persons**
Stefan Johansson, Jan Gulliksen & Ann Lantz. 2015. In Human-Computer Interaction–INTERACT 2015 (pp. 418-435). Springer International Publishing. Peer reviewed. (Acceptance level 31%).

To write this paper I worked together with people from RSMH (Swedish National Association for Social and Mental Health), and my colleague Tommy Hagström.  We wanted to explore whether the society is digitally accessible for people with mental health issues and how those persons coped with their situation related to this. Basically, we wanted to explore if there was a digital divide between the citizens in general and the citizens with mental health issues and if reported problems could be related to cognitive accessibility. The results show that a digital divide was present. The results indicate that the special needs this group might have are often not identified in wider surveys on the citizens' use of the internet, digital services and use of different technical devices. Several of the participants described this as of being left outside and not fully participate in a society where digital presence is considered a prerequisite for a full citizenship.

My role as Principal Investigator was to facilitate discussions. Tommy had the role of observer and Jonas Andersson arranged the sessions in collaboration with local RSMH-representatives. In total, we met over 100 members of RSMH, from all over Sweden. It was in this project we first put together a reference group. We planned to meet three times, but we are still meeting many years after ending of the project. Many ideas on activities and methods stem from this co-operation. I had the main responsibility for writing the paper. Jan Gulliksen and Ann Lantz contributed to the overall writing and to refining the arguments.

**II. User Participation When Users have Mental and Cognitive Disabilities**
Stefan Johansson, Jan Gulliksen, and Ann Lantz. 2015. In Proceedings of the 17th International ACM SIGACCESS Conference on Computers & Accessibility (pp. 69-76). ACM. Peer reviewed. (Acceptance level 25%).

This paper presents the methods used in paper I. The paper describes how we worked closely together with persons who had mental health issues and cognitive impairments, in order to test and develop methods

for participation in assessments and in processes for developing products and services based on Information and Communication Technology (ICT). More than 100 persons with mental health issues and cognitive impairments participated in the study (people with diagnoses such as depression, anxiety disorder, bipolar disorder, and schizophrenia). To explore the conditions for a more equal and fair participation, we elaborated with and developed a set of methods, tools and approaches which are cost effective and can be incorporated in existing design processes. The result also showed that the quality of the analysis increases if the collaborative approach is extended to also embrace the analysis of data. I had the main responsibility for writing the paper. Jan Gulliksen and Ann Lantz contributed to the overall writing and to refining the arguments.

### III. Can Mainstream Smart Technology Support Homeless People Leaving Homelessness?
Stefan Johansson and Jan Gulliksen. Submitted to ACM Transactions on Computer Human Interaction ToCHI.

This paper presents the results of a project using an action research methodology to create a user-informed practice on how to introduce and use smart technology as a supporting tool for homeless people about to leave homelessness. Homeless people, practitioners, accessibility experts and researchers, collaborated to develop, test and refine a new practice, where homeless people use smart technology in the process to re-establish themselves in society.

The new practice challenge homeless people to reflect on how they, with the use of digital tools, can be more pro-active and improve their management of crucial activities. The practice challenges traditional methods and calls for the social services to reflect on skills, attitudes and prejudice. Furthermore, it challenges practices, policy and regulations within the Social Service Administration.

The paper presents and reflects on the process from initial qualitative research, through pilot testing and implementation activities up to the presentation of a handbook of implementations. The paper also presents outcomes of interventions with smart technology conducted during the pilot and implementation phase. 88% of the participating, 41 homeless

people reported functional improvements, and 35% of those, reported them as life-changing improvements.

The conclusion is that smart mainstream technology is simple enough to be providing assistance and that many homeless people are ready to use smart technology while the Social Service is not equally ready. We added to earlier research that smart watches and smart pens can be important tools. By focusing on the number of meetings homeless people face, we contributed with new information on the situation for homeless people in the process of leaving homelessness.

I had the main responsibility for writing the paper. Jan Gulliksen contributed to the overall writing and to refining the arguments.

## IV. Disability Digital Divide: - The Use of the Internet, Smartphones, Computers and Tablets Among People with Disabilities in Sweden

Stefan Johansson, Jan Gulliksen, and Catharina Gustavsson. Paper submitted to the Universal Access in the Information Society (UAIS).

Although Sweden is one of the most digitalised countries and the Swedish population's use of the internet is among the most studied in the world, little is known about how "Swedes with impairments" use the internet.

The purpose of this study was to describe use of and perceived difficulties in use of the internet among people with impairments, and to explore digital divides in-between and within disability groups and in comparison to the general population.

What initiated this work was that the Begripsam group started to realise that there must be something wrong with the official statistics on the use of the internet. The national statistics presented did not make sense to us and we started to discuss how to do our own survey.

A cross-sectional survey targeting the same issues as other nationwide surveys but adapted for people with impairments. Participants were recruited from May to October 2017 by adaptive snowball sampling. The survey comprised questions on access to and use of devices, and use of and perceived difficulties in use of internet

771 people responded to the survey, representing 35 diagnoses/ impairments. Larger proportions of people with autism, ADHD and bipolar disorder reported using internet than other disability groups.

Women with autism used the internet more than any other disability group, and women with aphasia used the internet the least. People with impairments related to language and understanding reported more difficulties using internet than other disability groups. Larger proportions of participants than the general Swedish population, reported not feeling digitally included. In many but not all disability groups larger proportions of men than women reported not feeling digitally included.

Our findings show that there are differences in digital inclusion between sub-groups of diagnoses/impairments. Thus, disability digital divides are preferably investigated by sub-grouping impairments, rather than studied as one homogeneous group.

 I had the main responsibility for writing the paper. Catharina Gustavsson was in charge of the description of method and data analysis and for the sharpening of arguments. Jan Gulliksen contributed to the overall writing.

**V. Survey methods that enhance participation among people with impairments**
Stefan Johansson, Jan Gulliksen, and Catharina Gustavsson. In manuscript.

This paper gives a deeper presentation of the methods used for the survey, as presented in paper IV. Rare populations, such as people with impairments or with mental health issues, have been poorly represented in surveys. Research has shown that common probability sampling methods for the recruitment of participants to surveys often fail to include people with impairments even when they are in the target population. Also, that using one single option for "disability status" as proxy for all conditions that can contribute to a disability, prevents disaggregation into disability sub-groups.

The purpose of this study was to investigate the feasibility of an adaptive snowball sampling method for the recruitment of participants with impairments, collection of data  in a survey entailing thoroughly elaborated questions in regard to accessibility, and to describe effects on response rates and on the representativeness for the entire population with impairments.

A mirroring-survey concept was used to compare a nationwide survey on the use of the internet, which applied a probability-sampling method, with a modified survey applying adaptive snowball sampling of people with impairments. Questions from the mirrored survey were elaborated on to increase accessibility for the targeted respondents. Multiple channels for data collection were being used: questionnaire online or printed on paper, and telephone or face-to-face interview.

In total 771 persons participated, representing all the 35 targeted populations. A majority responded by the online questionnaire and 57 responded by interviews. Missing response to single questions was 2.5–6%.

With the adaptive snowball sampling method, it was feasible to reach people with a wide range of diagnoses and impairments. A modified survey targeting accessibility issues was feasible to enable participation by all target populations. The mirroring-survey concept and adaptive sampling methods are suggested favourable to achieve representation of people with impairments in surveys. I had the main responsibility for writing the paper. Catharina Gustavsson was in charge of the description of methods and data analysis. Jan Gulliksen contributed to the overall writing and to refining the arguments.

## 1.3 Activities for Societal Changes Related to the Thesis

In parallel with the research activities presented in this thesis, it has been possible to apply theories, methods and ideas on real life activities. Some of those are important to present to the reader of the thesis in order to understand the dialectic interplay between theory and practice. It is also a vital part of the methodology used. These activities provide an opportunity to discuss the interplay between research and the work on changing and transforming the society. The activities included in the thesis are Begripsam (1.3.1), The DigiJag Project (1.3.2), How to Find Rare Populations (1.3.3), The Understandable Text Project (1.3.4), Participatory and emancipatory activities together with HSO Skåne (1.3.5), and ISO 21801-1 Cognitive Accessibility -- Part 1: General guidelines (1.3.6)

The relationship between the process of societal change and the process of producing new knowledge is presented in figure 2. The model presents three processes of change; societal, personal and scientific. In Action

Research these processes are parallel and intertwined. Visioning/ imagining corresponds with Hypothesising/Theorizing. This include plans for research as well as for societal change. There is planning for both societal change and research projects. In a societal context there is a job to be done and this corresponds with the data collection in a research process. While the researcher contributes with the analysis, society is changing its current practice. The result will be new knowledge for the scientific community and a reformed society.
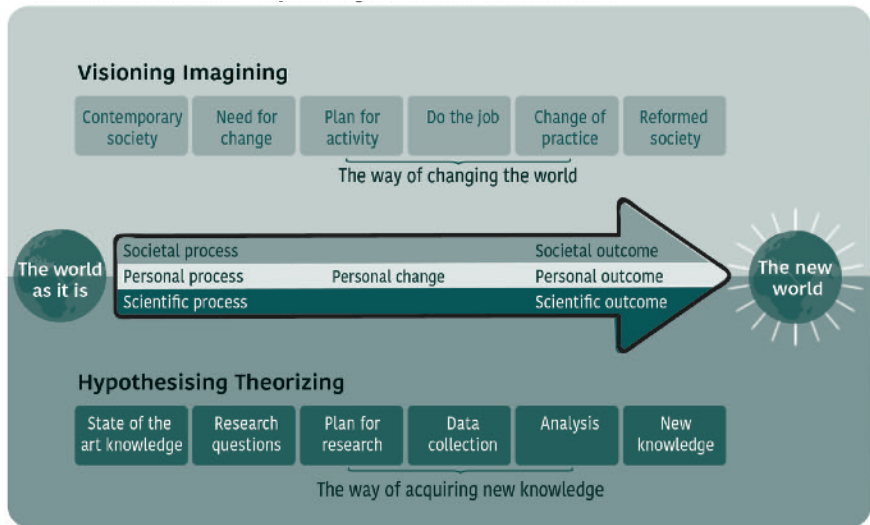


Figure 2. The Model for Participatory Action Research. Societal change, personal change and the acquisition of new knowledge are equally important. Illustration: Carina Söe-Knudsen, based on an idea from the author.

### 1.3.1 Begripsam

Begripsam started as a project and has transformed into both a member organisation and a company in the intersection between research, consultancy and activism. It is my workplace outside of academia. We have an agenda for societal change. We believe that we can contribute to this change by working close to the design community, by doing research and by consultancy. It is Begripsam who has funded the research on internet usage, presented in papers IV and V, together with the Post and Telecom Authority and the Swedish Consumers Agency.

We work with prioritised areas, decided by the members, first presented by Begripsam chair, Joakim Uppsäll Sjögren, at a conference in May 2016[3]. The target areas include Bank services, Money handling, Ticket vending machines, Audio Books, Social Insurance and Social Service, Employment, Psychiatric care and Health care, and Traffic information.

Our work is theoretically grounded, and we often organise activities drawing on action research methodology. We work in the spirit of conviviality and are guided by our seven guidelines:

1. Use participatory and democratic methods whenever possible
2. Take action! Do something!
3. Collaboration is better than conflict
4. Use nudges and gentle provocation to move unwilling counterparts
5. Take the lead, be the inviting, not the invitee
6. Reflect!
7. Do it again, better this time!

Conviviality was introduced to the Begripsam group by Bodil Jönsson[4]. The term was coined by Ivan Illich [14] in the 1970s and elaborated by Beskow et al. [15]. They describe conviviality as:

- An energetic 'here and now' process, which demands attention and care to keep going
- Trust and communicative openness. Low needs for defence and secrecy.

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[3] A video from the event can be found at http://www.fungerandemedier.se/begripsams-topplistor-pass-3. (in Swedish only)

[4] http://bodiljonsson.se/blog/okategoriserade/10-konvivialitet

- The fellow human being is created in conversation.
- To fully accept The Other as a unique individual, and by this approach as the foundation, create a common space for communication between My Self and The Other.
- Closely related to safety and love, but also, to feelings of being close, warmth, having consensus.

### 1.3.2 The DigiJag-project

This project allows us to apply many of the methods, approaches and thinking that have been developed during the work with this thesis. I work in this project together with a group of adult people with moderate intellectual difficulties. Some of them can read, some cannot or can read a small number of words. Learning sometimes takes a long time and many digital artefacts can be really difficult to use. This group of people have participated in the ground-breaking "Adjusted IT Course" at Mora Folk High School under the leadership of Kerstin Gatu and IT coach Micke Kjellberg[5]. We are now developing a Learning Platform[6] together with designers and accessibility experts. The project shows that people with moderate intellectual difficulties have the capacity to participate in the digital society and also to participate in and heavily influence on, the design process.

### 1.3.3 How to find rare populations

The methods presented in paper V have been used and further elaborated in different settings. We have developed methods to complement traditional surveys using randomised probability-samplings. Such surveys usually have difficulties finding enough respondents with impairments. We call this a mirroring method, as we start out with the same questions as the traditional survey, but then adapt questions, sampling methods and sampling procedures to make the survey more accessible to respondents with impairments. We have used this method to explore:

- E-health among impaired people in Region Skåne [In Swedish: Skåningar med funktionsnedsättning och e-hälsa] [16]

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[5] www.sikta.nu (in Swedish only).

[6] http://digijag.se (in Swedish only).

- Swedes with impairments and the internet 2019 (a new round of the same survey presented in paper IV)
- Public transport and Accessibility
- Dyscalculia in the Workplace

### 1.3.4 The Understandable Text project

One of the results presented in paper IV is how people with difficulties related to language and learning, struggle the most with the internet. Participants with reading difficulties, together with representatives from The Swedish Dyslexia Organization, The Autism and Asperger Association, The Swedish Aphasia Organization, and The Swedish National Association for People with Intellectual Disability, used the methods, initiated in the work presented in paper II and III, to find 19 important guidelines which facilitate readability and understandability for digital as well as printed text[7].

### 1.3.5 ISO 21801-1 Cognitive Accessibility -- Part 1: General guidelines

The standard was approved by ISO in 2019 and this has been a parallel work to the thesis. I am the main author of the text and members of the Begripsam group have been heavily engaged in the work. Committee members, national committees and ultimately member countries have commented and eventually voted in favour of accepting the document. The standard presents guidelines for designers on how to design with respect to people having cognitive impairments. Scope, Content and Introduction is presented in Annex B. In parallel with producing a text for the standard, we have also challenged the ISO process on how to work with standardisation. The current process is not accessible for people with cognitive impairments.

## 1.4 My Position as a Researcher

As a reader of this thesis I hope that you can appreciate that my agenda is declared and open to be discussed and also criticised. I have the privileged position of being a white, middle-aged man living in a very rich and prosperous corner of the world (Sweden). I have the privileged position of belonging to the 1.3 % of the people in that country who get to

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[7] www.begripligtext.se (in Swedish mostly, but some videos have English subtitles).

obtain a doctoral degree[8]. I have decided to use this position to promote social change towards an accessible and universally designed world, in this case the digital society. I work on this mission together with people with impairments, people with mental health issues and homeless people.

My view on my research is that it has to critically reflect on phenomena in the world, and try not only to describe them, but to, with Danermark's words "*discover the underlying structures that generate empirically observed outcomes*" [17]. I shift between what Jeffrey and Shaowen Bardzell [18] describes as a humanistic grounded Human Computer Interaction with a focus on expanding our thinking, and a social science orientated Human Computer Interaction, where research is structured around replicable settings and reported by the presentation of hypotheses, methods and findings. Multiple perspectives, layers and approaches are needed to build understanding of participation in the digital society. There is no single model or no single perspective, and nor is there any single method that can alone explain this complicated matter.

My inquiry can be described as mostly of an interpretative nature, and the results are best judged as trustworthy or not, by the people and communities with whom I collaborate. I like the way philosopher Charles Taylor [19] argues. He said, that it is the puzzling things that are the starting point of all interpretation, as an:

> "*attempt to make clear, to make sense of an object of study. This object must, therefore, be a text, or a text-analogue, which in some way is confused, incomplete, cloudy, seemingly contradictory in one way or another, unclear. The interpretation aims to bring to light an underlying coherence or sense.*" (p1).

From the tradition of pragmatism, I find support in the idea that if you want to change something, just start to change it. As Cherryholmes [20] put it, pragmatism:

> "*seeks to clarify meanings and looks to consequences. For pragmatists, values and visions of human action and interaction precede a search for descriptions, theories, explanations, and narratives. Pragmatic research is driven by anticipated consequences. Pragmatic choices about what*

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[8] https://www.ekonomifakta.se/fakta/utbildning-och-forskning/utbildningsniva/forskarutbildade-i-sverige/ (Swedish only).

*to research and how to go about it are conditioned by
where we want to go in the broadest of senses. Values,
aesthetics, politics, and social and normative preferences
are integral to pragmatic research, its interpretation and
utilization" (p13).*

Ethics, as in the moral principles that should guide one's activities, is an
important part of the work presented in this thesis. A panel at CHI 2001
[21] discussed ethics in a Human Computer Interaction perspective and
found that:

*"Ethical issues permeate our profession, but there are
relatively few public discussions of these issues, perhaps
because they are uncomfortable for many
practitioners." (p1).*

The panel called for "*a collection of case studies illustrating the ethical
concerns other HCI professionals have been struggling with*". Typically,
the discussion in the panel was about how to protect and uphold the
integrity of the users in research. The way of protecting users is to
anonymise them. In Participatory Action Research, participants become
co-researchers and that is why I mention the names of people involved.
Otherwise, their contribution to the research would pass unnoticed.

## 1.5 Theoretical Foundation for the Thesis

Participation in the digital society by people with impairments, or with
mental health issues and homeless people is a complex phenomenon. I
believe that an interdisciplinary theoretical approach is needed to
understand this phenomenon. Although it can be very fruitful to focus on
single factors, there is no single factor to be found that can explain why
people with impairments, people with mental health issues and homeless
people participate or do not participate in the digital society. Danermark
[17] explains the characteristics of interdisciplinary research:

*"… the point of departure is most often an empirical
phenomenon. The task is to find the mechanisms that
produce the actual phenomenon and to understand the
interplay between them and how they shape the
outcome" (p5).*

The mechanisms "*have the power to produce events*" in a "*generative
process*", although "*counteracting mechanisms*" can prevent the
occurrence of an event. Danermark argues that the outcome of a

mechanism is determined contextually. The task for a researcher is to "*discover the underlying structures that generate empirically observed outcomes rather than describing empirical patterns*". By shifting focus between levels, it becomes possible to see the emergence of "*something qualitatively new… that cannot be explained by mechanisms working at another level*".

Theories used in research on Human Computer Interaction, often draw upon an array of theories from other research fields, thus being interdisciplinary by nature. The theoretical foundation and rationale for the thesis is:

- Theories on how disability and oppression is created, and how emancipation might be achieved
- Theories on artefacts, humans and activities and how those can be embedded in practices and form participation
- Theories on design

# 2. Background

## 2.1 Participation, Activity and Practice

The starting point for this thesis is **participation**. It is by participation that we become **included**. Participation is embedded in **activities** and activities are embedded in **practices.**

There are different forms of participation represented in this thesis; Participation in the digital society, participation in research processes, participation in design processes and participation in the Begripsam group.

There is a wide range of uses of the term 'participation' and a unified definition does not exist. The International Classification of Functioning, Disability and Health (ICF) explains participation as involvement in a life situation [22] Carpentier [23] uses Democratic Theory to analyse participation and argues that (p170-172):

- *The key defining element of participation is power*
- *Participation is always situated in particular processes and localities, and involves specific actors.*
- *The concept of participation is contingent and in itself part of the power struggles in society*
- *Participation is not to be seen as part of the democratic-populist fantasy, which is based on the replacement of hierarchical difference by total equality.*
- *Participation is invitational.*
- *Participation is not the same as access or interaction.*

Access and interaction are, however, important prerequisites for the possibility of participation, but Carpentier argues that they cannot be equated with participation.

I regard participation and non-participation as two separate phenomena, even though it is tempting to see them as dichotomous extremes of the same continuum. I think we can learn more about participation in the digital society from people who are at the border of participation or already participants, than from people who are not participating at all. Conversely, I think it is possible to learn something about why people do not participate, in the study of participation.

Participation can be discussed, and also measured, in terms of people's sense of belonging or sense of being included. The annual survey "Swedes and the internet" [24] uses a question about how included in the digital society respondents feel. It is used to determine exclusion and inclusion. This is not exactly the same as participation and non-participation, since people can feel excluded although they do use the internet to some extent.

Participation can be restricted, and a well-known metaphor is to describe restrictions as barriers [8]. Accessibility is a key concept to provide for participation, and is regarded as so important that the United Nations issued a general comment [25] on Article 9 Accessibility in the Convention on the Rights of Persons with Disabilities, CRPD [11]. The first sentence in the general comment states: "*Accessibility is a precondition for persons with disabilities to live independently and participate fully and equally in society*".

Participation in society is done by citizens. In many cases people with impairments are reduced from full citizenship to 'clients' or 'consumers' or sometimes as objects at an institution, deprived of the capacity to be a subject, responsible for their own actions. Sépulchre [26] argues that citizenship for disabled people is complicated and full of contradictions.

> *"disabled people cannot take their citizenship rights for granted but have to fight for their rights". That, on the other hand, is "an indication of one's ability to act as full citizen". (p196).*

Sépulchre points to the social division of dis/ability as a reason for structural inequalities, and to tensions in the promise of equality and full participation for everyone in a *"context of scarce resources"*.  On a European level, efforts have been made to define rules for how "users with disabilities" should be given equal opportunities to participate in research and development processes. One attempt to create a *"reference model for participation of users with disabilities, and a set of criteria for the assessment of user participation"* was the FORTUNE project, within the EC Telematics Applications Programme. [27]. Seven principles were identified (p88):

- *Co-operation is based on the idea of partnership*
- *Users are members or representatives of an organisation of end-users*
- *Users receive payments on the same basis as all others*
- *All project materials, communications and premises are made accessible to the users*
- *Every partner has to provide qualified staff members to the project*
- *The project plan contains appropriate workpackages and tasks for user participation*
- *Users are partners from the very beginning of a project*

In this model, participation is also representation, since participants are required to have a connection to an organisation within the disability movement and thus do not only represent themselves.

### 2.1.1 Participation in Research

Oliver coined the term **Emancipatory Disability Research**, 1992, to describe a shift within Disability Research, into drawing on disabled people's experiences beyond impairment and into a study of the disabling organisation and construction of society [28]. Barnes [29], [30] presents the emancipatory research agenda as:

> *"disabled people and their organisations, rather than professional academics and researchers, should have control of the research process. Also, that this control should include both funding and the research agenda" (p3).*

Barnes argued for a dialogue between researchers and disabled people, and that researchers should *"put their knowledge and skills at the disposal of disabled people"*. This is very similar to Freire's notion *"To the oppressed and to those who suffer with them and fight at their side"* [31] where Freire calls for solidarity and co-operation with oppressed people, who are struggling for emancipation.

Even if total control almost never is the case, can Emancipatory Disability Research be seen as a model, and Barnes presents the core principles in this model as:

- **Accountability**, to the disabled community.
- The role of the **social model of disability**, to find solutions in the transformation of society and not to focus on the impaired body.
- The question of objectivity
- The choice of **methodology**, using an array of qualitative and quantitative methods,
- The **role of experience in the research proces**s, to use disabled people's experiences within a social context.
- **Research outcomes**, to disseminate widely in various ways throughout the disabled community.

For an introduction to the critique, from disabled people, of the research within "*an oppressive theoretical paradigm and within an oppressive set of social relations*", and also an introduction to principles for emancipatory research, see Stone and Priestley [32].

As for objectivity, Barnes argues that all sociological judgements are coloured by personal experience and that medical or academic perspectives cannot be regarded as more or less biased than 'social model' or activist perspectives;

> "*Nonetheless, all social scientists, and particularly those who endorse a politically sensitive or minority group perspective, are vulnerable to accusations of bias. In response, all researchers can do is make our position clear at the outset. This means stating clearly our ontological and epistemological positions and ensuring that our choice of research methodology and data collection strategies are logical, rigorous and open to scrutiny.*" (p7).

Oliver and Zarb argues that it often "*makes more sense to talk about doing 'participatory' rather than 'emancipatory' research*" [33]. The difference lies in power and control and Oliver and Zarb presents a set of questions that can be used to distinguish between the two:

> "*Who controls what the research will be about and how it will be carried out? How far have we come in involving disabled people in the research process? What opportunities exist for disabled people to criticise the research and influence future directions? What happens to the products of the research?* (p. 128).

**Relevance** is a key factor in Emancipatory Disability Research. According to Barton [34], research should be "*transformative, relevant to and significant in the lives of disabled people*". Barton highlights the importance of researchers being "*self-aware to their own values, priorities and processes of interpretation*". **Reflection** is key to this process, as is **critical analysis** of the general research process and an openness for how to organise research theoretically and methodologically.

### 2.1.2 Folkbildning – Non-formal Adult Education

*Folkbildning* has been used in Sweden as a social force for change since the beginning of the 20th century. It is based on voluntary and democratic participation. The study circle has a central role in *Folkbildning* [35] and it is characterised [36, p. 201] by:

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*

Typically, people gather to gain knowledge of a specific topic, several times during a period of weeks or months. Some circles can go on for several years. A study circle leader facilitates the process. RSMH, The Association for Social and Mental Health, a partner in the study presented in paper I and II, has a long tradition of working with adult education methods, and I, myself, have for several years worked at the ABF (Arbetarnas Bildningsförbund) – the largest adult education organisation in Sweden.

### 2.1.3 Activity

Participation is closely related to activity. To understand activity, it can be necessary to apply both detailed and holistic perspectives. A frequently used theoretical basis for this is the 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 by, among others, Leontiev and Engeström [37]. Engeström's description of

an activity system [38] is often used in Human Computer Interaction. Hedvall elaborated this description to an Activity Diamond (Figure 3), and added accessibility perspective to an activity system, with the activity system as the unit of analysis [2]. The Activity Diamond describes how an individual achieves an outcome by mobilising different resources (humans, artefacts, environment) in performing some kind of activity.
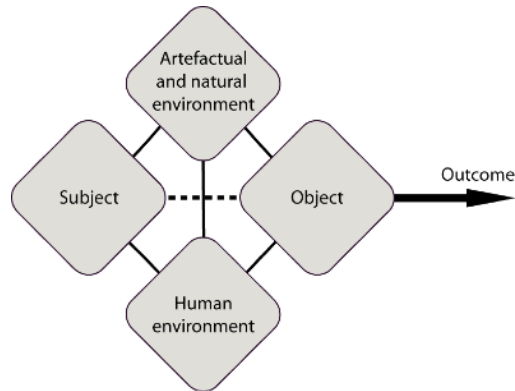


Figure 3. Hedvall's Activity Diamond. Illustration: Per-Olof Hedvall.

### 2.1.4 Practice

Studies of practices offer a possibility to shift focus away from individuals performing activities to the practice; a unit of analysis containing multiple individuals and bundles of activities. Early forms of practice theory were established in the 1970-80s by, among others, Giddens [39] and Bourdieu [40]. The focus was on actors and structures. Later on this was considered too limited, as material objects, infrastructures and products should also have a place within practice theory [41]. Reckwitz [42] and Schatzki [43] vitalised and renewed the field by proposing widely recognised definitions and by moving away from the individual as the unit of analysis. Reckwitz's definition of a practice is widely used:

> "a routinized type of behavior which consists of several elements, interconnected to one another: forms of bodily activities, forms of mental activities, 'things' and their use, a background knowledge in the form of understanding, know-how, states of emotion and motivational knowledge. A practice – a way of cooking, of consuming, of working, of investigating, of taking care of oneself or of others, etc. – forms so to speak a 'block' whose existence necessarily

*depends on the existence and specific inter- connectedness
of these elements, and which cannot be reduced to any one
of these single elements. Likewise, a practice represents a
pattern which can be filled out by a multitude of single and
often unique actions reproducing the practice". (p 250)*

Reckwitz describes how an individual can be seen as a carrier of a practice
and a carrier of certain qualities or "*conventionalized 'mental'
activities*" (understanding, knowing how, desiring). Schatzki was
interested in "*how things come about and is perpetuated*". Schatzki also
described practices as "*arrays of activity*". Later on, this was
conceptualised to argue that practices can be described as assemblages of
materials, competences and meanings, often being presented as stuff,
skills and images [41]. Feldman and Orlikowski [44] describe stability
and change as different outcomes of the same dynamic. Warde [45] notes
that practices: "*consist of both doings and sayings, suggesting that
analysis must be concerned with both practical activity and its
representations*". Shove [46] describes how a practice can be hard to
change, since stronger paradigms such as economy and psychology seem
to dominate over practice.

## 2.2 Participatory Action Research

The purpose of Action Research is to **collect and analyse data** in order
to **take action** and to **change something**. Greenwood and Levin [47]
describe Action Research as: "*A set of collaborative ways of conducting
social research that simultaneously satisfies rigorous scientific
requirements and promotes democratic social change*". Greenwood and
Levin place the origin of Action Research within the tradition of American
Pragmatism, and especially the work of John Dewey, who (in their
description) "*believed that all humans are scientists, that thought must
not be separated from action, that the diversity of human communities
is one of their most powerful features*" and who "*laid out an action
approach to science as a form of human inquiry*".

Action Research becomes 'participatory' by emphasising that research is
done **together** with, and not 'on', participants, that it **supports
empowerment,** and that it **combines action and reflection** in an
iterative cycle [48]. Frauenberger et al. [49] describes Action Research
and Participatory Design as having "*obvious parallels*", a
"*shared ideological heritage*" and "*accountability and rigour delivered*

*through debate, critique and reflection*". One other similarity is that both "*sees knowledge generation as a dialogic process that is mediated by values and strongly situated*". **Trustworthiness** is key in Action Research, and Frauenberger et al. argues that rigour in Action Research stems from trustworthiness rather than from validity or reliability.

Balcazar et al. [50] trace the roots of Participatory Action Research by referencing Selener [51], who claimed that pioneering researchers were "dissatisfied with the traditional positivistic research methodology, which looked at people solely as subjects of study, depriving them of any input in the research process other than responding to the researchers questions". Balcazar et al. states that disabled people can be regarded as co-researchers and benefit from Participatory Action Research by (p1):

- *The active role individuals with disabilities play in defining, analyzing and solving identified problems*

- *The opportunities for more accurate and authentic analysis of people with disabilities in social reality.*

- *The resulting awareness among people with disabilities about their own resources and strengths*

- *The opportunities for improving the quality of life of people with disabilities.*

According to Balcazar et al., consequences of Participatory Action Research can include raised awareness and better understanding among all participants on issues related to disability, and that participants point out the shortcomings of both the research and the researchers. They also claim that "*It is important that from the outset, participating agencies realize that they will be criticized by participants and will need to handle the criticism appropriately*".

Participatory research often takes several years. An important step for the researcher is to develop a working relationship with community members and organisations. Suarez et al. [52] found that "community entrance" is especially important for project planning and building trust between researchers and participants.

## 2.3 Models of Disability

Disability is a complex and multi-facetted concept [53], [54]. Over time, in different contexts and for different purposes, alternative terms and alternative definitions have been used. The purpose is to describe people who do not function within the norm of how humans are supposed to (as defined by people within the norm). Terms, such as "the handicapped" or "invalids" have been found to be obsolete, but still persist [55] and contribute to the stigmatisation of persons who function outside of the norm. New terminology can also be seen as stigmatising. In Sweden some people[9] advocate for "funktionsvariation" (functional variation) to supersede "funktionsnedsättning" (impairment) even though the latter has just been recognised as the correct term to use [56]. The argument is that "variation" can be seen as less stigmatising than "impairment". The re-positioning and re-definition of terms is an ongoing process and can be understood through the perspective of stigma [57], [58]. As long as terms get negative connotations, there will be a launch of new terms.

Models of disability have surpassed each other, and it is tempting to put them on a timeline, indicating some kind of progression in how people consider disability and disabled people's participation in society. Even if that is the case, we can still find echoes of every model in contemporary policy, and some models exist in parallel. Charity, and the segregation of disabled people, characterise the models of disability in the 19th and well into the 20th century [59]. People deviating from the norm were often separated from the rest of society and placed in institutions. The notion was that they needed to be protected, since they were considered vulnerable, not capable of taking care of themselves [60]. A strong influence of control characterised this way of thinking. Institutions were often placed far away from the rest of society. The segregation started already in early age, in special schools e.g. for deaf or blind children. Disability and impairments were often described as tragedies. Since institutions were regarded as the best solution, little attention was devoted to an accessible society at large. Infrastructure and buildings are long lasting constructions, thus we still suffer from inaccessible environments dating from this period [61].

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[9] An argumentation against: https://www.dagenssamhalle.se/debatt/nonsensord-goer-mig-inte-mindre-funktionshindrad-26237 and a reply arguing in favour of 'funktionsvariation': https://www.dagenssamhalle.se/debatt/funktionsvariation-ett-begrepp-som-passar-oss-26317

A so-called Medical Model of Disability[10] focuses on diagnoses, and how to cure or rehabilitate, the impaired body [62]. It is described as a model by people criticising what they think is a too strong a focus on medical conditions. In this model, or approach, the focus is on the individual person [63]. Disability is considered an observable deviation from biomedical norms of structure or function as direct results of a disease, trauma or other health conditions [64]. The Medical Model is strongly normative and driven by professionals, especially within the fields of medicine and social work, who 'know what the best is' for an impaired person [65], [66]. It is still a widely practiced approach and a significant amount of contemporary research is based on this model (See for example [67]–[69]. Many scholars within the field of health research would probably argue that they work within the tradition of a Biopsychosocial model [70] rather than a pure medical model. This model acknowledges that factors of importance for human functioning ought to be studied within the relationship between biological, psychological, and social dimensions.

Charity and medical approaches co-existed for a long time and dominated the view on disability well into the 1970s. During this time, in the United Kingdom, Finkelstein and others [71], [72] questioned the current models and developed a radical social relational view on disability, later defined by Oliver as the Social Model of Disability [73]. In this model disability was introduced as an outcome of an oppressive process. The result was exclusion, not because of impairments but due to inaccessible environments. Disabled people were described as oppressed and discriminated against by a competitive society [74], [75]. The organisation UPIAS [76] captured this view in the famous statement:

> *"in our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society"*

Accordingly, since the exclusion is a result of how society is organised and as it could have been organised without causing isolation or exclusion, society thus exercises oppression on the excluded population.

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[10] This is only described as a model by critics. A medical approach or a medical perspective would perhaps be a fairer label.

Finkelstein and others argued for a radical societal change as the path towards, and a tool for, emancipation [77]. The Social Model focuses on a shift towards removing obstacles and barriers that create difficulties [78], and away from a focus on functional limitations, but it does not deny the values of individual interventions [79]. The basic idea is to provide the possibility for humans to live a good life with their persisting impairments. If correctly designed, society will not stop anyone from achieving their full potential.

A different argumentation, inspired by the social rights movement, was developed in the United States, were disability came to be regarded as a minority-group phenomenon [80]. Both the UK and the US models originate in a critique of society, and of traditional research, from disabled activists. A similar critique can be found in Sweden. In 1968, von Ekensteen published the renowned book "På Folkhemmets bakgård" (In the Backyard of the People's Home [81]) and co-founded the activist group Anti-Handikapp, in Lund, Sweden. The 'People's Home' (Folkhemmet) is a strong metaphor for the Swedish welfare state. von Ekensteen and Anti-Handikapp heavily criticised how people with impairments were being treated by the welfare state.

Both the minority-group perspective [80] and the strict focus on society in the Social Model have been criticised, among others, by Scotch and Shriner who argued that human variation and diversity need to be acknowledged and that impairment actually does affect the outcome [82], [83]. Anastasiou and Kauffman [84] heavily criticised the Social Model for ignoring biological facts. They argued that no single-dimensional explanation can be used to understand disability:

> *"…what is needed is a unified and multidimensional understanding of disabilities, clarifying the relationship among the biological and cultural, individual and social, psychological and behavioural, intrinsic and external factors affecting the lives of people without eliminating one of these levels of analysis. (p.454)*

Thomas [5] argues for a deeper understanding of the relationship between disability and impairment and focuses her own research on what she calls **disablism**. Disablism is "*the social imposition of avoidable restrictions*" upon people with impairments. If we know how to make something accessible and still don't do it, that is disablism. This is closely

related to the kind of oppression found in racism, sexism, ageism and homophobia. For Thomas it is important to understand how disablism comes into being. Thomas also recognises the impaired body as important, and presents "***impairment effects***" [85] as a way to acknowledge the impaired body and still be able to prioritise studies of how society is constructed.

Bickenbach et al. argued that universalism would be a more useful approach than a civil rights/minority group approach [80]. This formed the Diversity Model of Disability and later a Human Rights Model of Disability [86]. The human rights perspective evolved from the early activism and civil rights movement, over to diversity and universalism. The most prominent manifestation of this model is the United Nations' Convention on the Rights for People with Disabilities (CRPD) [11] . The CRPD, from 2006, is connected to the general concept of human rights as presented in 1948 by the United Nations Universal Declaration of Human Rights. With a human rights-centred approach follow the need for legislation, often related to accessibility and/or anti-discrimination. The starting point, in the 1980s, was the built environment. An important event from this perspective was the adoption of the Americans With Disabilities Act (ADA) in 1990[11]. In 2018, the member states of the European Union implemented the Web Accessibility Directive [87] into national legislation and in 2019, the European Union decided on the Accessibility Act [88], focusing on services blending accessibility in artefacts, with digital accessibility.

Alongside with the British social model and the US civil rights model, there is a third influential model called the Relational model or the Gap model. This model stems from professional work within the Nordic countries and is often described as the Scandinavian Relational model [89], [90]. It originates in the late 1960s and 1970's when discussions about social inclusion and de-institutionalisation emerged in the Nordic countries [91]. It is a model developed by professionals rather than activists, and by that, it does not share its origins with activism, materialism or the struggle for social rights. Rather, it draws on a strong Scandinavian model of a welfare state, taking care of its citizens. Goodley [92] describes this model as "influenced by the principles of

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[11] An introduction to ADA can be found at https://adata.org/factsheet/ADA-overview

normalisation" and with a "leadership often being found within the academy". According to Goodley there are three main characteristics for the Scandinavian Relational Model:

- disability is a person-environment mismatch
- disability is situational or contextual
- disability is relative

This can be described as a biopsychosocial model or a psychosocial model, depending on how much attention is given to impairment. See for example Danermark [93] and Grue [94] for a deeper presentation of the Scandinavian relational model.

Several attempts have been made to bridge and synthesise different models of disability. Shakespeare [34] objects to the Social Model and argues that even if we remove all obstacles and barriers, there will still remain disabling factors in many impairments, that will cause difficulties. Thus, according to Shakespeare, the polarisation between the social and the medical model has gone too far. In Disability Rights and Wrongs Revisited [4] Shakespeare offers 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)*

The World Health Organisation, WHO, has a widely used and cited definition [95], of what is sometimes termed as the biopsychosocial model of disability [80]:

> *"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."*

Both Shakespeare and WHO attempt to bridge opposing models of disability together. The shift in focus from individual to societal factors was, according to Shakespeare and others [96], necessary. It provided tools for creating better lives, but other perspectives including medical ones, are also valid.

Shakespeare advocates a 'Critical Realist' approach where he claims it is wrong 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 or levels. Instead of reductionism, he argues for holism and points out the following perspectives, (drawing on the work of Bhaskar and Danermark [97]:

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

Bhaskar and Danermark describes the Critical Realist perspective as **laminated** by "*several different layers of reality"* and Danermark emphasises the **anti-reductive** ontology[17].

Shakespeare also differentiates between **external factors**, (such as poverty, war, upbringing, culture, accessible or inaccessible environments, support systems, repression) and **internal factors** (the nature and severity of attitudes towards one's own disability, and personal ability, quality and personality).

The International Classification of Functioning, Disability and Health (ICF) [22] published by the WHO, is intended to integrate the medical model with the social model of disability (Figure 4). Disability and Functioning are described as umbrella terms, one being the mirror of the other. The focus is on activity and it is possible to arrive at activity from different perspectives. Medical scholars can target on health conditions or

bodily functions, psychologists can target on personal behaviour, and social scholars can target on phenomena in the society or environment. Action researchers or activists can target on participation. All perspectives can potentially bring better lives for people with impairments (and actually for everyone, since ICF cover all humans, even though it is rarely used to analyse for example how Usain Bolt can run 100 meters very fast).
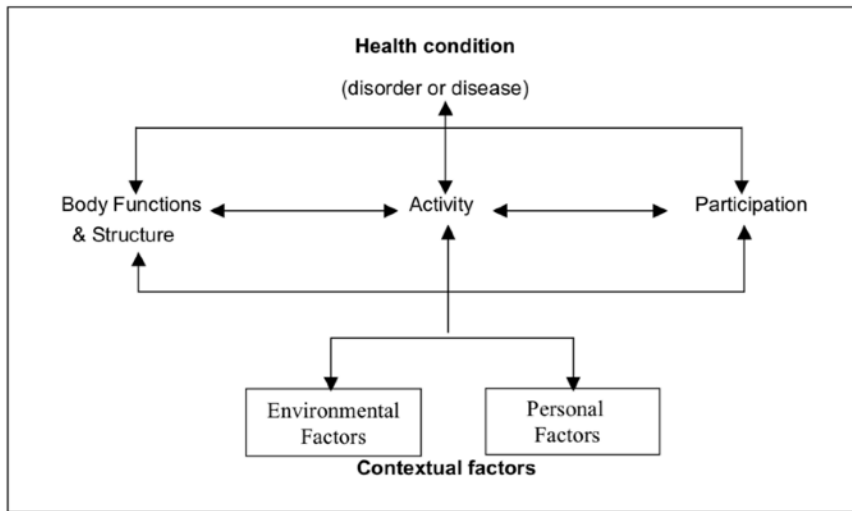


Figure 4. ICF model of Functioning, Disability and Health. Illustration: WHO [98].

Frauenberger [99] develops how a Critical Realist Approach can allow for a more holistic view, where it is possible to go further than the medical model's focus on a need to rehabilitate the impaired body and the social model's focus on a need to eliminate, or prevent, barriers in society. Frauenberger claims that a more holistic approach will change the way we look at technology, including assistive technology:

> *"Can technologies work across the multiple layers that all together shape the disabled experience? Can it consider the physical, the biological, the psychological, the psychosocial and emotional, the socio-economic, the cultural and the normative at the same time in meaningful ways? Can it be non-reductionist?" (p89)*

Mitra [100] introduces a capability approach to disability, based on ideas brought from the field of Economics. The original capability approach is developed by Sen [101] and elaborated by Nussbaum [102], [103]. Mitra argues that this approach, applied as a model of disability, can be used to: *"explain how disability may result from three types of factors: the individual's personal characteristics, the individual's resources, and the individual's environment"*. What distinguishes this model from others is that it brings resources into the picture. This might help in explaining the standard of living of people with impairments. It might also explain disability as such. Alongside with an impairment, a lack of resources might lead to a deprivation of capability or function – a disability:

> *"... impairments limit the earning capacity and put constraints on the spending patterns of a person, and thus constitute an economic burden at the individual and household level and may lead to a disability at the capability or functioning level. The economic environment influences the practical opportunities, in terms of employment or self-sufficiency, that persons with impairments have, as well as the costs of achieving given functionings. Understanding the economic burden and the economic environment of disability is part of understanding disability" (p242)*

Mitra argues that the Capability approach, by differentiating the problem to the **capability level** and the **functioning level**, provides new tools for understanding disability.

These capabilities are, in accordance with Nussbaum's theory, more generally applicable than the Western-oriented human rights in the CRPD.

## 2.4 Accessibility

Accessibility can be seen as a solution to the challenges and demands presented by the disability rights movement and scholars within the field of Disability Studies. Accessibility studies often have individuals performing an activity as their central unit of analysis. See for example the requirements for e-identity solutions [104], and voting systems [105]. Whether something is described as accessible or inaccessible depends on an individual's ability to take some kind of action. This typically involves a user performing a task in interaction with a device and an interface.

Hence, for example, a web page or a form can be regarded as accessible or inaccessible depending on the outcome of this interaction.

A conventional accessibility study often relates to heuristic guidelines [106], checklists and standards. The well-established standard for web accessibility, WCAG 2.1 [107] has for example 79 checkpoints that have to be tested for every component or function in a web site or a web service. Other domains, such as the built environment, museum exhibitions[12], software[13] etc. have similar and often detailed instructions. My experience after almost 30 years in the field of accessibility, is that even after careful and meticulous compliance to the rules; some users with some impairments will still claim that they are excluded due to inaccessibility. The answer from accessibility researchers and the standardisation community then is to go deeper in to understanding activity, and the (impaired) body and to provide more checkpoints. My own work on ISO 21801-1 [108] is an example of that approach

Another strong tradition in research on accessibility is to focus on the societal level. In those cases, the focus shifts from personal activities to policies, rules and regulations, often on a global level. Examples of this tradition include Ellcessor [109] and  D'Aubin [110] who both take a human-rights or high-level perspective on accessibility. Ellcessor analyses web-accessibility from a policy perspective and D'Aubin uses a rights-based approach to argue that "*improved legislation, regulation, policy, and programs are required to remove the barriers to ICT experienced by people with disabilities*". According to Ellcessor: "*the online public sphere must be examined in terms of its fundamental exclusions*". The solution thus lies in variation. By the separation of content from its presentation, it should be possible to cater for individual adaptations, covering needs that cannot be specified in detail in standards.

### 2.4.1 Access as a Human Right – CRPD and Corporate Responsibility
Accessibility is a key principle in The United Nations' Convention on the Rights of Persons with Disabilities (CRPD) [11]. It is by making society accessible for all, we can assure people with impairments equity and the same living conditions as anyone else. The CRPD was established in 2006

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[12] https://www.si.edu/Accessibility/SGAED

[13] https://docs.microsoft.com/sv-se/windows/uwp/accessibility/designing-inclusive-software

and is now incorporated in policy and legislation in many parts of the world. Accessibility, and the work for increased accessibility, are described as prerequisites for those rights to be realised in practice in Article 9 [25]:

> *"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 rights 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).*

Most legislative accessibility obligations are directed towards states. The CRPD targets national states as being responsible for providing for accessibility. Pathakji [111] argues that also large corporations should be legally responsible for the execution of Disability Rights. In an interconnected global village, state borders are no longer the only relevant borders, and states cannot act individually to provide digital accessibility. Digital accessibility is an issue on a global scale. Single states have little or no power over e.g. Facebook, Google or any other global business. Pathakji argues that "*effective realization of human rights cannot be guaranteed unless corporations' are also taken onboard*" and introduces "*a regulatory space*" by presenting **the Interconnected Pentagon Model:**

- **International Organisations**: Conventions, Treaty, Declaration, Multilateral and Bilateral Agreements, Universal standards.
- **States**: National Policy, legislation, Taxation, enforcement mechanism.
- **Market**: public procurement, certification.
- **Community**: policy inputs, audits.
- **Corporations**: CSR, Industry Codes, social reporting.

### 2.4.2 Web Accessibility

As soon as the internet started to grow, it also became of interest to recognise who could use it or not. As in the case of the built environment, it became clear that if special considerations were not undertaken, people with impairments would face a risk of being excluded. This is my personal entry point into the field of disability and accessibility. As a newly graduated information manager I produced information for people participating in adult education (study circles and cultural programs). As soon as it became possible to create digital material I did so, but when I did, representatives from different disability communities approached me and explained that their members were unable to access the information. Together we started to try to understand what we could do to make the information more accessible. We produced, tested, reflected and re-produced, a structure and a model that I have remained faithful to since 1996.

The dominant guidance on how to create web accessibility can be found at the W3Cs Web Accessibility Initiative, WAI [112], promoting a three-pillar model for web accessibility: Content (Web Content Accessibility Guidelines, WCAG [107]), Authoring Tools, ATAG [113], and User Agents [114]. This material has become highly normative and the work is driven by conformance evaluations, often with the help of checklists.

Disabled people are not a homogenous group. The demands on an accessible interface will differ depending on the type of impairment. Broadly we have seen four main categories of access issues; those related to vision, to hearing, to physical mobility, and to cognition. A fifth category may be added, issues related to emotion. Flexible interfaces and adaptation strategies might be useful to comply with (really or seemingly) inconsistent requirements. Gajos and his colleagues argue that interfaces that automatically adapt to the device's or the user's needs could make the web more inclusive (see for example [115] and [116]). Their research taps into an approach to digital accessibility where the idea is to use e.g. machine learning or situational and momentary adaptations that could provide for an accessibility 'here and now', which compliance with guidelines cannot achieve. They point to the fact that this kind of approach, which they call Personalised Dynamic Accessibility [117], is also very useful for the adaption of mobile interfaces and situational barriers.

Accessibility on the web is often closely related to Assistive Technology. In situations where a direct access to web content is not possible, Assistive Technology works as a bridging technology between the user and the web interface. The most prominent example is screen reader technology used by blind people or people with low vision. WCAG 2.1 would not be effective as a standard if it could not rely on screen reader technology. The use of Assistive Technology can also add an extra need for competence [118]. It is not enough to know how the internet works, the combination of web interface, browser and assistive technology demands an array of extra knowledge from the user and, in addition, this often compromises mainstream support structures. People delivering technical support are often not aware of how Assistive Technology works in combination with mainstream equipment. On top of that, World Health Organization (WHO) estimates that, globally, only one out of ten persons who could benefit from Assistive Technology, have access to such technology [119].

### 2.4.3 To Measure Accessibility

There are multiple research papers noting that a studied artefact has accessibility shortcomings (see for example [120], [121]), but little research is found on why designers/developers have failed and on how they perceive working with accessibility requirements. Crabb et al. [122] report from a series of workshops with designers/developers and students and conclude that "*an effort must be made to promote learning resources in accessibility implementation and not accessibility assessment*". It is often too difficult to implement accessibility during an ongoing process even when there is awareness that accessibility is an important quality. One way of lowering the barriers for developers, to adapt to accessible techniques, might be to build-in accessible features in pre-made code libraries. One such example is Bootstrap [123].

Content producers are a significant source of accessibility errors. People who produce text, pictures, audio and video content are often not educated in accessibility and WCAG offer little support for the production of accessible content. The lesser known ATAG is supposed to provide that kind of support, but so far only a small body of research has been directed towards ATAG. One example is Pascual et al. [124] who addressed content production by creating an editing tool that "*focused on the empathy between the content author and his final users*". The tool

abandoned the traditional, technology-related, methods for communicating accessibility errors, in favour of information *"presented in a way that is closer to their own language and their own knowledge, and that links them to the impact they have on other people."* An empathy-creation strategy can also be found behind the development of tools, which are simulating impairments. The rationale of this is that a deeper understanding, based on personal, simulated, experience of issues related to impairment will result in a stronger and more emotional commitment to cater for accessibility[14]. A contemporary trend is design teams, who are creating Empathy Labs[15].

Baily and Gkatzidou [125] discuss how web accessibility could be adopted from an organisational viewpoint, based on both regulatory requirements and business needs to reach "accessibility maturity". It is a well-known problem, that the responsibility to address accessibility, often relies on one or a few persons, and is neither integrated in management systems or systems for quality, nor in ordinary processes. Baily and Gkatzidou argue that much can be learned from how User Experience (UX) professionals have achieved a central role *"at the heart of the development process"*. Accessibility, usability and user experience should be regarded as *"interdependent quality attributes of a product"*. They propose a six-step maturity model, very similar to, but with fewer steps than, the more general Community Readiness model [126]. They present a model for accessibility divided into technical, operational and psychological aspects. Another critique of WCAG is that it is more applicable to developed countries than to developing countries, and that the narrow focus on technology as the (only) tool for inclusion might prevent other approaches [73], [127]. A global digital accessibility policy is still far away [128]. A similar critique has been presented by Cooper et al. [129], who argue that *"technical accessibility guidelines are only one part of a wider strategy to encourage organisations to use the web to deliver inclusive services"* and that accessibility should be regarded as a process *"built into the everyday practices across the full web product life-cycle from*

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[14] See for example Funkify, https://www.funkify.org

[15] For an example, take a look at the UK Governments Empathy Lab https://gds.blog.gov.uk/2018/06/20/creating-the-uk-governments-accessibility-empathy-lab/. You might notice that there is no device for cognitive accessibility. The Lab is constructed for sensory impairments.

*conception and specification through development to delivery and maintenance.*"

Conformance claims (that is, to conform to Web Content Accessibility Guidelines, WCAG 2.1, AA) are at the heart of the new legislation for all member states within the European Union [87]. Only a few of the guidelines in WCAG 2.1 are automatically testable. The rest need human supervision and human judgement to be evaluated. Brajnik et al. [130] focused on the human testability part of WCAG and the distinction between Reliably Human Testable and Not Reliably Testable. To be considered reliably testable, it should be estimated that at least 80% of knowledgeable human evaluators would agree on the conclusion. Brajnik et al. recruited both experienced and novice evaluators and put this to a test. They concluded that in most cases neither experienced nor novice evaluators reached the 80% limit. Experienced evaluators were accurate 76% of the time and novices 66%. Experienced evaluators reported 26-35% false positives and missed 26-35% of true problems. They concluded that "*conformance claims made even by experienced evaluators can lead to disputes…*". Involving WCAG-experts could be a way of improving reliability as well as providing more specific guidance. Not even pooling of two experienced evaluators was enough to reach the 80% mark. Brajnik et al. argues for "*pluralistic reviews where evaluators have a chance to interact and negotiate what they believe are success criteria violations*". Time taken for novice evaluators was three times longer and with lower validity, making it hard to argue for engaging novices in conformance evaluation. Similar results are presented by Yesilada et al. [131] who found that expertise matters. Trained evaluators perform significantly better when evaluating web accessibility.

Pluralistic review methods, proposed by Brajnik et al, could be User Testing, Subjective Assessments, Barrier Walkthrough or Screening Techniques. For a presentation of each method, see Brajnik [132]. Lepistö and Ovaska [133] concludes that several combined methods need to be used for usability evaluation with people with cognitive impairments. Methods such as 'Think aloud' did not work well. Instead they combined informal walkthrough, classroom observations and interviews.

The issue of testability is the reason why many justified requirements related to the domain of cognitive accessibility are rejected from entering the WCAG-guidelines. It is not that there is a disagreement on the

justification of specific user needs and on specific requirements. The problem is that there are no approved methods on how to evaluate them. For example, Seeman and others made a formal objection [134] to how W3C claimed that cognitive accessibility was covered in WCAG 2.0 [135]. In a letter, re-published as a web page [136], a response from W3C stated that some cognitive requirements could not be included since they were 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 2.0 guidelines did contain support for persons with cognitive impairments. To address the problems related to cognition, the W3C has established a "Cognitive and Learning Disabilities Accessibility Task Force" [137]. A summary of current knowledge has been submitted by the Task Force [138]. The ongoing work on cognition is presented on the web page Cognitive Accessibility at W3C [139]. Current work from W3C indicates a shift in the attitude towards testability. The Silver Task Force[16] works with the successor of WCAG [140] and admits that "*In addition to the current true/false success criteria, other ways of measuring (for example, rubrics, sliding scale, task-completion, user research with people with disabilities, and more) can be used where appropriate so that more needs of people with disabilities can be included". (3.1).*

This highlights the conflict and tension between guidelines aiming to sensitise designers towards a more accessible outcome, during the planning and development stages, and using the same guidelines, prescriptively claim conformance. A sensitising process does not require repeatable and well-defined methods for testing conformance. In such a process, the aim is to change or enhance the way designers think about design and to expand their imagination about what it is to be human and the wide range of characteristics that are significant for human beings. As soon as conformance to a specific claim becomes important, it is a complex task to apply a correct evaluation method [132], [141], [142]

### 2.4.4 Cognitive Web Accessibility

The absence of guidelines in the area of cognition cannot only be related to a lack of test methods, there is also a knowledge gap. Issues related to for example vision, design wise, can be narrowed down to a relatively

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[16] https://www.w3.org/WAI/GL/task-forces/silver/wiki/Main_Page#What_is_Silver.3F

limited number of design problems; people cannot see at all, have low or blurred vision, or cannot perceive e.g. colour. Issues related to cognition span over a much wider range of specific functions. [143].

The WHO's International Classification on Functioning, Disability and Health (ICF) [144] provides a systematic presentation of possible issues within the cognitive domain (and other), that designers might have to relate to in order to develop cognitively accessible artefacts. ICF specifies seven global and eleven specific cognitive functions. Those can often be divided into further sub-categories. Relevant areas for this thesis are:

**Global functions related to:**
- Consciousness
- Orientation, Intellect
- Psychosocial
- Temperament and personality
- Energy and drive

**Specific cognitive functions related to:**
- Attention
- Memory
- Psychomotor
- Emotional (feelings and affections)
- Perceptual (recognise and interpret sensory stimuli)
- Thought
- Complex goal-directed behaviour
- Decision-making
- Abstract thinking
- Planning
- Start and stop tasks
- Mental flexibility
- Undertake complex tasks
- Undertake boring tasks
- Language (reading, writing, using signs, symbols)
- Calculation
- Sequencing and coordinating complex actions
- Awareness of one's identity, body and position in space and time
- Time management
- Handling stress

- Communicating (receiving and producing nonverbal and verbal communication)
- Acquiring skills

Issues related to cognition do not always originate from an impairment. See for example how stress can affect cognitive functioning [145].

Guidance on how to build cognitively accessible web sites has been provided in a number of papers. The starting point for this kind of research can be found around the years of 2004-2005, with some early notes already made by Nielsen in 1996 [146]. In 2005, Lewis summarized how Human Computer Interaction could improve the living conditions for people with cognitive impairments [147] and argued that the current ignorance on cognitive user needs could be improved by people with cognitive impairments being involved in user testing. At that time  Small et al. published a paper where they concluded that people with cognitive impairments could not successfully navigate WCAG-compliant web sites [148].

In a review on "web usability" for people with cognitive impairments, between 2002 and 2011, Jiménez et al. only found 10 empirical studies. A conclusion was, that even if a web site complied with WCAG, this did not ensure that it was usable for people with cognitive impairments. The European Union funded the WWAAC-project around 2005, focusing on people who need augmented and alternative communication, AAC, (mostly by using symbol-based languages).  Poulson and Nicolle [149] presented the result of this work and concluded that although there is some limited general guidance in WCAG:

> *"there is no comprehensive source of information about the design of WWW pages for people with learning or communication difficulties, and even less information on designing sites to facilitate access by symbol users." (p52)*

In 2007, Friedman and Bryen published a set of guidelines for cognitive accessibility on the web, synthesised from twenty design guidelines (many from disability-organisations and disabled people advocates) found in a review, resulting in 86 recommendations. Based on the frequency of occurrence in different guidelines they could conclude that there was strong agreement on for example "*Use pictures, icons and symbols along with text*", "*Use clear and simple text*", "*Consistent*

*navigation and design on every page",* and *"Use headings, titles and prompts".*

In 2015 Hu and Heidi Feng studied difficulties within navigation, and searching to find information, for people with cognitive impairments. They compared searches which required navigation in broad structures with navigation in deep structures. Their conclusion was:

> *"Participants frequently visited incorrect categories in both the deep structure and the broad structure conditions. However, it was more difficult to recover from incorrect categories on the lower-level pages in the broad structure than in the deep structure. Under the search engine condition, failed tasks were mainly caused by difficulty in selecting the correct link from the returned list, misspellings, and difficulty in generating appropriate search keywords."*

Narrowing down the scope, researchers sometimes focus on specific diagnoses rather than the whole cognitive domain. Britto and Pizzolato [150] have focus on users with autism, and synthesised findings from 17 works published between 2005 and 2015.  The result is a proposed set of guidelines, organised around ten categories and 28 guidelines. According to their findings, the most important category is "Visual and textual vocabulary". In that category we can find guidelines such as; "*Use a simple visual and textual language, avoid jargons, spelling errors, metaphors, abbreviations and acronyms, using terms, expressions, names and symbols familiar to users' context*" or "*Be succinct, avoid writing long paragraphs and use markups that facilitate the reading flow such as lists and heading titles*". Harrysson et al. [151] studied how a group of people with intellectual impairments managed to navigate and search the internet, and found that many of the basic features did work well (forward, back, up, down, scroll), but typing a correct URL, or typing specific text in search boxes, were found to be very difficult.

### 2.4.5 Standardisation and Web Accessibility
Accessibility on the internet and also to devices to access the internet, draws heavily on standards [152]. One of the earliest attempts of presenting a specific guideline (and a document that arguably set the standard for the structure of such documents) was provided by Vanderheiden at Trace Research and Development Centre in 1995 [153].

Trace was also responsible for the Unified Web Site Accessibility Guidelines, where about 40 different early sources on how to make the web accessible were presented in a unified document. Version 8 of this document was published in January 1998 [154] and this was the version, transferred to the W3C-consortium, that later formed the first version of the Web Content Accessibility Guidelines, WCAG [155].

The European Committee for Standardization (CEN) defines a standard as a "*technical document designed to be used as a rule, guideline or definition. It is a consensus-built, repeatable way of doing something*" [156]. The idea is to bring all interested parties together in order for all parties to benefit from standardisation. Parties can, for example, be manufacturers, consumers and regulators. Benefits can for example be safety, quality, and lower costs. Products, as well as services or processes can be standardised.

People from disability organisations have been engaged in standardisation for a long time. The main argument is that if the needs of disabled people are implemented as requirements or guidelines in a standard, it is more likely that those needs will be met in a product, service or process. The voice of consumers (or users, or citizens) can be weak in a standardisation process where other parties have stronger financial power to send representatives. There is a European collaboration between non-profit consumer organisations through ANEC[17], with a strong commitment to Universal Design [157]. The Swedish Disability Federation[18] is engaged in standardisation and on the European level, European Disability Forum (EDF)[19] represents disabled peoples voice in standardisation. The Swedish Standards Consumers & Workers Council (SKA-rådet)[20] can provide funds for the costs of participants in standardisation projects and international meetings, as representatives of consumer, workers, disability, environmental and other non-profit organisations. But this does not cover the costs for working with text production, reading and commenting proposals, internal meetings etc. This pose a major barrier to participation for disability organisations. Another barrier is that the standardisation

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[17] https://anec.eu

[18] https://funktionsratt.se/om-oss/in-english/

[19] http://www.edf-feph.org

[20] http://skaradet.se

process as such can be considered inaccessible for people with impairments.

Standards can be used to harmonise a market. For example, EN 301 549 - Accessibility requirements suitable for public procurement of ICT [158] is a way of creating a common market for the European Union, where all procured Information and Communication Technology must comply to accessibility requirements.

Standards central for this thesis are:

- Web Content Accessibility Guidelines, WCAG 2.1 [107]

- ISO 21801-1 Cognitive accessibility -- Part 1: General guidelines [159]

- EN 17161:2019 'Design for All - Accessibility following a Design for All approach in products, goods and services - Extending the range of users [160]

Standards can become even more important when they are connected with legislation. This is a matter of fact for WCAG 2.1. When the European Union decided on the Web Accessibility Directive, level AA in WCAG became the legal minimum level of accessibility for public web sites in all member states [161].

A critique of a guideline, or standardisation, approach is that it ignores the context and the situation. A guideline or standard aims at forecasting accessibility and can be used for planning and regulation. Hedvall, however, emphasises the situatedness of accessibility [162]. According to Hedvall there is a tension between plans, and what is happening here and now (Figure 5).
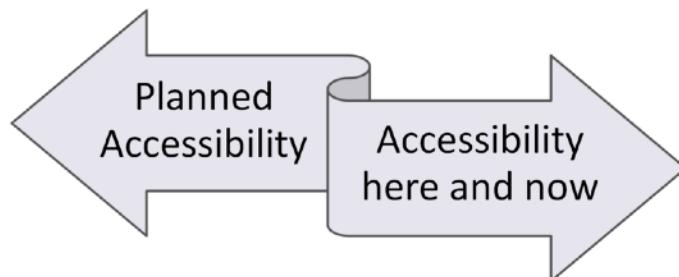


Figure 5: Hedvall's illustration of the tension between plans for accessibility and the actual accessibility in a specific situation.

Also Kelly et al. argues that accessibility standards should be more "context aware"[21]. Cooper et al. argues that standards should put people and processes first and not technical aspects [129].

## 2.5 Humans and Artefacts

### 2.5.1 Human Diversity

This thesis argues for an understanding of **humans as very diverse**. We come in **many shapes and sizes**. Our bodies and minds can function very differently. Researchers and designers, even when claiming that their work is 'user-centred', might have a too narrow an idea of what a human body and mind can be like. They base their research or design on what is considered to be 'normal people'. Garland-Thomson [163] coined the term "normate" to describe a 'normal' person as a sort of 'template-human'. A normate is a privileged and de-stigmatised body, a generalisation of a human. Garland-Thomson also defined the 'misfit' [164] as: *"A misfit occurs when the environment does not sustain the shape and function of the body that enters it"*. To this picture, I have added the "nearly normate", as a way of describing how it is often possible to accept small deviations from the norm, for example in a design process. Using normates as templates for design will end in the exclusion of people outside the norm.

### 2.5.2 Artefacts as Non-Humans

There would be no Human Computer Interaction without artefacts. Take the artefacts away and we are discussing Human Interaction. Take the interaction away and the use of an artefact becomes impossible. Artefacts need to be used by someone in some kind of meaningful context. In this thesis I have studied artefacts as the **end result of a design process,** as **provisional objects** (sketches, mock-ups prototypes) forecasting a possible future, as **objects people use in activities** or as **objects embedded in practices**.

With artefacts comes a possibility to discuss **Context**, **Trust**, **Experience** and **Precision**, to sketch out the scene set up by Svensk [165]. With artefacts also comes a possibility to discuss **Affordances**, which can be real or perceived, and **Constraints**, which can be of a logical or cultural nature, to sketch out the scene set up by Norman [166].

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[21]  http://www.ariadne.ac.uk/issue71/kelly-et-al

An affordance can be understood as an artefacts ability to in itself explain how it should be used. Conventions evolve much like a practice evolves. It takes time for them to be adopted and they are slow to go away.

With artefacts also comes a possibility to discuss **Agency** [167]**.** Agency can be understood as the capability or power to be the source and originator of acts [168]. Most scholars agree on humans having agency but argue over whether non-humans can have it. Scholars who agree on non-humans having agency might disagree on how to describe such agency; is it symmetrical, intertwined or entangled? [44].

## 2.6 Design

Design is the core procedure of transforming ideas into products, systems or services. Behind design we can find **designers**. Designers are engaged in design through a **design process**. The emphasis on what design is supposed to deliver, has changed over time from an early focus on ergonomics, to usability, and on to experiences - an evolution often described as three waves, in the literature of Human Computer Interaction, HCI [169]–[171]. To have influence on the design process, it is considered essential to be in the process and it is those who participate early in the design process who can have the most influence on it [172].

The way designers "do design", how they think and how they work, is represented by a huge body of knowledge. It will only be briefly presented in this thesis. An introduction to the relationship between design and Human Computer Interaction can be found in a paper by Kuutti [173].

According to Kuutti, a traditional designer is supposed to "*solve the problem arising from a design brief: how the needed functionality can be produced smartly by using the available materials and production technologies*" and "*this must happen within the limits given by potential production volumes and costs of production, distribution, and marketing.*" As a clear distinction from scientific processes where the same data and the same methodology will lead to reproduceable results, Kuutti claims that "*it is assumed that a design brief interpreted by two designers will lead to two different designs*". However, designers are also engaged in collecting data and doing user research, and they may draw on previous experiences. Data is often derived from a combination of sources. Statistics, previous research, background information, and evaluations of similar design or previous versions of a design, are often

combined with interviews, focus groups, workshops and other methods for getting information from important stakeholders.

Society tries to exercise influence over the design process by educating designers, implementing requirements in procurement [158], standardisation [174], guidelines [175], and, ultimately, legislation, as in the European Web Accessibility Directive [87].

### 2.6.1 Universal Design

Universal Design, UD was first coined by the architecture Mace in 1985 [176]. Universal Design discourse goes beyond accessibility in the sense that it addresses all kinds of diversity. One strong argument in favour of Universal Design, is that focusing only on disabled people can enforce stigma [57], [58]. By addressing more than the needs of disabled people's, it should be possible to argue that common (economic) sense justifies a design, usable for the widest range of users. The concept of Universal Design [177] stems from Barrier free design and there are similar related concepts, such as Inclusive Design [178], Universal accessibility [179], User Sensitive Inclusive design [180], Accessible Design, Universal Access and Design for All. For an extensive presentation of those concepts and also a problematisation of having too many concepts and even different definitions of the same terms; see Person et al. [181]. See also Person et al. for a historical presentation of how thinking about accessibility has evolved and how important legislation (primarily within an US and European perspective) has evolved alongside with policy development within the United Nations and World Health Organization.

The approaches of universal design where primarily a response to shortcomings in the built environment and a result of the collaboration between disability rights activists and professionals (with Mace representing both perspectives in one person). Proponents of the social model of disability presented disability as a social construction and Universal Design scholars claimed to be presenting a way of designing a society for all.

Early initiatives to transfer Universal Design argumentation into the field of Human Computer Interaction (HCI) can be found in  "User Interfaces for All - Concepts, Methods, and Tools" in 2001, where Universal Design rhetoric was introduced by Stephanidis [182]:

> *"The underlying vision of user interfaces for all is to offer an approach for developing computational environments that cater to the broadest possible range of human abilities, skills, requirements, and preferences. Consequently, user interfaces for all should not be conceived as an effort to advance a single solution for everybody, but rather, as a new perspective on HCI that alleviates the obstacles pertaining to universal access in the information society" (p34).*

Stephanidis establishes a clear connection between Universal Design and "user interfaces for all/universal access":

> *The roots of user interfaces for all can be traced in the notions of universal access and design for all. The term design for all (or universal design-the terms are used interchangeably) is not new. It is well known in several engineering disciplines, such as, for example, civil engineering and architecture, with many applications in interior design, building and road construction, and so on (p34).*

Hamraie [183] argues that Universal Design can be criticised for being too informed by the ideology of ability rather than signalling that it is accepting disability [183]. If Universal Design focuses on making disability disappear by design, it at the same time is at risk of taking a standpoint where being able is more preferable than being disabled. This is generally known as ableism. Hamraie argues that part of the contemporary Universal Design argumentation, echoes the rhetoric of eugenics, and aims to assimilate disabled people rather than to facilitate and design for a world where disabled people can live and be accepted as they are. Architects Lifchez and Winslow explain this as different views on how to define good design, and argue for *"more humane concepts of what makes for good design"*. They describe a tension between accessibility and good design, that sometimes is expressed by designers:

> *"a disabled person may have a point of view about the design that challenges what the designers would consider good design. Many designers have, in fact, expressed a certain fear that pressure to accommodate disabled people will jeopardize good design and weaken the design vocabulary"* [26, p150].

When launching the concept of Universal Design, Mace stated that
accessibility is a requirement for good design and in a later work [185]
Mace and Lusher widened the scope to cover a broad range of human
beings:

> *"Instead of responding only to the minimum demands of*
> *laws which require a few special features for disabled*
> *people, it is possible to design most manufactured items and*
> *building elements to be usable by a broad range of human*
> *beings including children, elderly people, people with*
> *disabilities, and people of different sizes. This concept is*
> *called universal design".*

By both foregrounding disability and at the same time, with the concept
of Universal Design, creating an alliance between disabled people and
other marginalised groups, Mace and Lusher framed design as a way to
transform society in line with arguments from the civil rights movements
of the 1960s and 70s.

Hamraie argue that this early alliance between activism and design later
has been compromised by Universal Design moving away from accessible
design. According to Hamraie, this can be noticed, for example, in a shift
in Universal Design rhetoric. Instead of directly addressing people with
impairments as a targeted group Universal Design now says "users" or
"all users" and in general presents itself as a disability-neutral marketing
concept rather than a radical call for the transformation of society by
more accessible design.

One example of a clear distinction between Accessibility and Universal
Design can be found in a handbook of Universal Design for the city of
New York from 2003 [186]:

> *"Accessibility is a civil rights issue focused on eliminating*
> *discrimination against one minority group. In contrast,*
> *universal design is a market driven concept. Rather than*
> *responding to legal mandates, it reflects the realities of*
> *contemporary societies with their diverse populations.*
> *Instead of a focus on one minority group, universal design*
> *is an inclusive approach that benefits the entire*
> *population." (p7).*

This is, in the words of Hamraie, "- a framing that explicitly divorces
Universal Design from the politicised work of disabled designers and

activists, as well as from the notion of disability as a marginalised identity".

The adoptation of Universal Design within the design community has been slow. Choi et al. evaluated what they call Universal Design Resources, (UDRs) [187]. Such a resource can for example be a standard or a set of heuristic guidelines. They found that these were rarely ever presented aligning with a designer's perspective or with "design psychology" in mind. For example, designers seem to welcome relevant information, but not in a prescriptive way. The same group of researchers presented a set of principles and heuristics on how to best organise guidance for designers who want to support Universal Design in their design practice. This guidance is organised around three principles:

1.  Address the pertinent product design aspects

2.  Support the design process and design psychology

3.  Design the document effectively

A contemporary vital branch of Universal Design is Universal Design for Learning (UDL) [175] The generic seven principles of Universal Design [188] have been elaborated into an educational context and there seems to be evidence of its effectiveness [189]. Some efforts to link Universal Design with the concept of Sustainability have been made, for example a proposed framework linking principles from the respective fields [190]. Lid [89] considers Universal Design to be most useful at macro and meso level, while Usability and Accessibility is more useful at a micro level.

### 2.6.2 Human Centred Design Approaches

Knowledge about the users is central in most contemporary design approaches. The process of bringing the user to the centre and move away from what was described as technology centred approaches, happened at the same period as architects and others started to argue for Universal Design in the built environment. Norman and Draper elaborated the concept of Human Centred Design [191]. Central to this thinking is the presence of the users and the user's needs throughout the design process. The user is often not represented in person. A common procedure is that the designer collects data on user needs and preferences, transforming the result into requirements.  Whether accessibility is represented in those requirements is down to the skills of the designer, what kind of

users the designer have met, and whether other (for example legal) requirements contribute to a focus on accessibility.

The usability paradigm, with its focus on completion of task, efficacy and productivity, is very strong in Human Computer Interaction. Typically, usability addresses the need of time to learn, the speed of performance, rate of user errors, retention over time, and the subjective satisfaction. Part of its success could be explained  by the fact that usability "*supported interface design in a way that was both powerful in making design issues tractable, and also practical in the sense that teams of virtually any size or budget could deploy*" [18].

The Usability paradigm was followed by the User Experience (UX) paradigm [192]. The perception of the interplay with technology has become more important. Even rather mundane technologies, such as a form for submitting information, can attract the attention of experts on user experience. User experience moves attention from instrumental and task-oriented issues to intrinsic and non-instrumental needs, such as beauty or trust [193]. The difference between Human Centred Design and UX was explained by a group of researchers and practitioners, who tried to bring some clarity to the concept by publishing a white paper:

> "*While traditional usability factors were largely related to performance and smooth interaction, new UX factors relate to affect, interpretation and meaning. Some UX factors, such as social and aesthetic aspects, are likely to be very different in character from the traditional concerns" (p11).*

In this perspective, experiences are interpretations and not as easily measured as usability.

### 2.6.3 Participatory Design
Human-centred design approaches place the user in the centre, but the user seldom have a strong voice or a say in the design process. Users are often merely informants and might be engaged in test activities. The tradition of Participatory Design is an attempt not only to have the user in the centre, but to design together with the user. Björgvinsson et al. [194] describes the background as "*Participatory Design started from the simple standpoint that those affected by a design should have a say in the design process*". Therefore "*controversy rather than consensus should be expected around an emerging object of design*". Theories on

**Participatory Design** is thought to have originated in Scandinavian attempts in the 1960s/70s to democratise the workplace, a shift from management-orientated to user-orientated development of systems. The intention was to give 'resource weak' groups (the workers and their trade unions) more influence, legitimise them as stakeholders, and include them in processes aiming for consensus with other stakeholders. This is also named **Cooperative Design**. For an extensive description of its history and main characteristics, see Lindquist's thesis "Perspective on Cooperative Design [195].

It was the Scandinavian tradition that initiated the methodology we today often take for granted, involving users very early in the design process, low-tech prototyping, and early design sessions with users [196]. Participatory Design have inspired later design approaches. One example is **Design Thinking[22],** that Björgvinsson et al. describes as "*sounds like good old Participatory Design, although we have to admit it has a better articulated and more appealing rhetoric*". Björgvinsson et al. can also see similarities between Participatory Design and **Social Innovation[23].** They describe Social innovations as "*products or services just like any innovation, but they can also be a principle, an idea, a piece of legislation, a social movement, an intervention, or some combination of them*".

A useful definition of Participatory Design is presented by Robertson and Simonsen in the introduction of the Routledge International Handbook of Participatory Design [197]:

> "*a process of investigating, understanding, reflecting upon, establishing, developing, and supporting mutual learning between multiple participants in collective 'reflection-in-action'. The participants typically undertake the two principal roles of users and designers where the designers strive to learn the realities of the users' situation while the users strive to articulate their desired aims and learn appropriate technological means to obtain them*" (p2).

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[22] As an example of Design Thinking rhetoric, see https://www.ideou.com/blogs/inspiration/what-is-design-thinking

[23] Definitions on Social Innovation, presented by the Social Innovation Academy: http://www.socialinnovationacademy.eu/8-popular-social-innovation-definitions/

As a result of this definition, the user becomes a participant rather than an informant. Users are regarded as experts in their own domains. Halskov and Hansen [198] have identified 5 characteristics for participation in a design process (p89);

- People who are affected by a decision should have an opportunity to influence it.
- People play critical roles in design by being experts at their own lives.
- The use situation is the fundamental starting point for the design process.
- Methods are means for users to gain influence in design processes.
- The goal of participation is to design alternatives, improving quality of life.

### 2.6.4 Values and Value Tensions in Design

A design process has to deal with stakeholders and stakeholder perspectives, and often also consider indirect stakeholders. A design process has to relate to legislation and regulations. Designers are sometimes being influenced by current trends and rhetoric[24], and designers also sometimes take notice of what other designers might think of their design and aim to build their own brand as designers. Stakeholders in a design process represents different, and sometimes conflicting, perspectives. Stakeholders have power, but power is unevenly distributed (Figure 6). All participants in a design process might come with a set of assumptions and a-priori beliefs, into the process.

**Value Sensitive Design** is a method to bring values and value tensions to the surface in a design process. Stakeholders and indirect stakeholders bring different values to a design process, alongside with preferences and wishes. It is important, to be able to distinguish between values and preferences. A Value Sensitive Design methodology typically consists of three parts: a Conceptual, an Empirical and a Technical inquiry. It is possible to start from any of these three investigations. [199], [200]. A proactive nature is also typical for Value Sensitive Design, in the sense that it can be applied to any design process, The method takes a wide

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[24] Designers are sensitive to trends and as an example, see the trends for 2019, presented as "the last call for web designers to make their mark on the decade": https://99designs.es/blog/trends/web-design-trends-2019/.

range of human values into consideration, it is interactive in its nature, and finally, it "*builds from the psychological proposition that certain values are universally held, although how such values play out in a particular culture at a particular point in time can vary considerably*" [201].
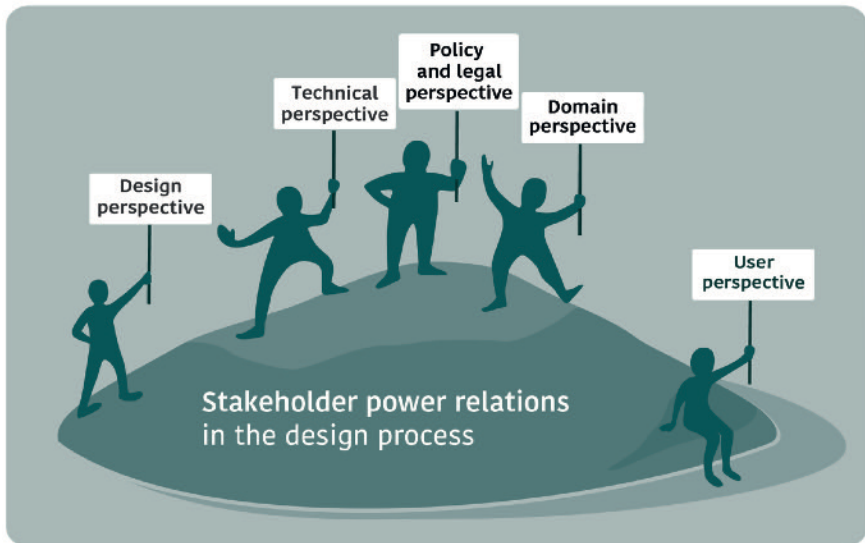


Figure 6: Stakeholder power relations in the design process, indicating that Design perspective and User perspective have a weaker voice than Technical perspective, Policy and legal perspective, and Domain perspective. Illustration: Carina Söe-Knudsen, based on an idea from the author.

Manders-Huits [202] describes Value Sensitive Design as the "*prime candidate for implementing moral values in design*", but criticises the method on several points. She argues that there is no clear methodology for how to identify stakeholders and a lack of a "*complimentary or explicit ethical theory for dealing with value trade-offs*". She proposes the term "Value Conscious Design" and argues that an ethical theory must complement the method. By drawing on this critique, Jacobs and Huldtgren argues, that Value Sensitive Design needs a methodology for "*distinguishing genuine moral values from mere stakeholders-preferences and runs the risk of attending to a set of values that is unprincipled or unbounded*" [203]. They argue for a "*mid-level ethical theory to fulfil this role*" and that the characteristics for such a theory

should be Explanatory power, Justificatory power and Simplicity and practicability.

Boring and Muller [199] discusses whether Value Sensitive Design (VSD) "*is a method that can be applied in principle to any set of values, vs. VSD as the methodological instantiation of a particular set of values*" and calls for a stronger voice of participants in the interpreting and reporting of the results. They refer to the tradition of Participatory Design and suggests that experiences from that field could improve Value Sensitive Design methodology. They also want the researcher's own values, background and relationship to the participants, to be more visible.

## 2.7 The Internet – a Human Right?

One of the first authors who recognised an emancipatory potential in technology was Otlet, from Belgium [204]. His writings in the 1920s, about the "Radiated Library", contains an, almost prophetic, vision of how people could use networks to send messages, share files, socialise, learn etc, that foresees, what are now known as hyperlinks. Several other thinkers have imagined things that they at the moment did not have the technology for to actually build at the time. Science fiction writers and other visionaries have predicted or argued for what eventually took place. Among other intellectuals, have, for example, the science fiction author Wells [205] (who wrote about a "world brain") and Goldberg [206] (who invented a mechanical search engine), been working on ideas of a networking world as a peace-keeping project. Otlet tried to create a catalogue of all published information in the world, a network of museums and cultural institutions. Other science fiction writers, such as van Vougt and Asimov, have, like Wells, included imagined forms of connected networks, in their writings. Bush [207] published a famous paper in 1945 about extending human intellect by making collective knowledge, as a peace-keeping project.

However, it was not until the 1980s and 1990s that technology had advanced to a point where the suggested solutions were possible to construct. Building the internet according to principles of accessibility was emphasised by prominent key players from the very beginning. Berners-Lee, described as the inventor of the internet, stated: "*The power of the Web is in its universality. Access by everyone regardless of*

*disability is an essential aspect"* [208]. Initiatives were taken to secure that accessibility would be included. The most powerful, the Web Accessibility Initiative, WAI was launched in 1997 [209] and at this event Berners-Lee said: *"The W3C is committed to removing accessibility barriers for all people with disabilities - including the deaf, blind, physically challenged, and cognitive or visually impaired. We plan to work aggressively with government, industry, and community leaders to establish and attain Web accessibility goals."* The first version of Web Content Accessibility guidelines, WCAG 1.0 was launched in 1999 [155].

In "The Struggle for Web eQuality by Persons with Cognitive Disabilities" [210], Blanck illustrated the barriers still existing for people with cognitive impairments. To justify why people with cognitive impairments have the right to be able to use the internet, he argues; "*Inclusion and active participation has always been the remedy to segregation, and they are the principles set out in disability rights laws for equal opportunity, independent living, and economic self-sufficiency*". (p30). Those rights are manifested for example in the 2013 Declaration of the Rights of People with Cognitive Disabilities to Technology and Information Access [211]. Blanck is not the only scholar connecting the internet with fundamental human rights. It has been debated whether the internet is a fundamental right in itself, or if it should be seen as an enabler of such rights. Wicker and Santoso [212] argues that "*access to the Internet is directly tied to a set of human capabilities that are considered fundamental to a life worth living*". In their view, the internet should be regarded as so important that "*the government should implement a regulatory policy that recognizes Internet access as a human right*". There are strong arguments for regarding access to the internet as a human right worthy of protection by the United Nations and engagement from states. Mathiesen [213] present those arguments in a "philosophical defence" and concludes:

> "*While access to the Internet is not a "primary" right, it can be derived from the primary right to communicate. Furthermore, since the right to communicate is a linchpin right that empowers people to exercise their rights and fulfil their responsibilities, states have an obligation to see to it that people have access to Internet technology" (p20).*

## 2.8 Digital Divides

As soon as the internet took off, researchers started to examine what people were doing with it, what kind of people connected to the internet as well as what characterised people who did not use the internet. The US-based researchers Di Maggio, Hargittai, Celeste, Shafer, and Dobransky [214]–[216] and van Deursen and van Dijk in  Europe [217], [218] have studied the development of internet use over a long period, investigating digital divides. Sweden has, since the year 2000, had an ongoing longitudinal survey with yearly reports; The Swedes and the Internet [219]. The government agency SCB also presents statistics on internet usage on a regular basis [220].

From an early focus on access to the internet, usage and frequency in use have become more important and in later years competence and skills have emerged as phenomena to study [221]. Consequences of this research are, that many early on noticeable gaps have now been closed, or are about to be closed, and that a majority of the population have rapidly integrated the use of the internet in their activities, covering almost all aspects of life. But there is also a consistency in the fact that, even in highly digitalised countries, there is still a substantial minority of people who are not participating in, or who only have a very weak connection to, the digital society.

There is no strong evidence that the internet is an egalitarian force. The same societal divides, as were noticed before, seem to remain in place even after the digitalization. People with low education, low income, unemployed people, old people and people with poor health, face a higher risk of being excluded from the internet [222]. Impairment, though, seems to be an overlooked factor. Eurostat is the EU-organisation for collecting data on internet usage, for all member states, and the gathered data do not cover impairments or disability.

A problem all researchers have to consider, is how to reach the disabled populations. The standard procedure for sampling a population, randomised probability samplings, needs large sampling sizes to find enough people with impairments, since people with impairments belong to so called rare populations [223]. Sampling sizes for above mentioned Swedish surveys is about 3000 Swedes and attempts have been made to "bolt on" a question, thus, in the end of a survey, to ask the participants if they have an impairment. The small number of disabled people,

randomly found within such a sample, is not enough to provide reliable information about how people with impairments use the internet. Also, since many groups are very small some diagnoses and impairments will always end up within the margin of error (see paper IV for a table on the prevalence of relevant diagnoses). The conclusion is that researchers cannot separate different impairments, and thus they have to report all impaired people as being one group, as if this was a homogenous group.

Another crucial problem is that surveys and sampling methods can be inaccessible. Disabled people might want to take part in a survey but are unable to do so due to barriers within the chosen survey methods. A barrier could be that if telephone is used for interviews, people who cannot or do not want to use a telephone will be excluded from the sample.

# 3. Method, Data Collection and Data Analysis

The methodological cornerstones for this thesis are **data collection by participation in processes for change**, **analysis of data in a co-operative interpretative practice**, and **triangulation**. The choice of methods has been guided by the methods' potential to deliver a useful result, their emancipatory or participatory power, and whether or not they are ethically sound.

The triangulation process is based on **analysis of empirical data** (Paper I-IV in the introduction), **studies of literature**, **activities in society** (Presented as activities A-F in the introduction), and **trustworthiness of** the methods and outcomes, **as perceived by** the communities of people with impairments, people with mental health issues and homeless people.

The gathering of empirical data has been of a both qualitative and quantitative nature, and the specific research questions have determined the type of data needed.

## 3.1 Methodological Approach

A starting point has been to find an existing method, described in literature, and to use it. When needed, methods have been adapted to be accessible for all people participating. Adaptation of methods to be accessible can mean either adapting the method as such or the arrangement in which the method is embedded. Adaptations have mainly been made from the perspective of cognitive accessibility. The idea was to develop new methods only if no previous methods were to be found.

A description of the methods and tools can be found in Annex A.

We have found most of the methods for the work presented in this thesis within the tradition of Participatory Action Research, Emancipatory Disability Research, Folkbildning, Participatory Design and Value Sensitive Design.

An important methodological starting point has been that the issue, the problem that should be solved by research, originates from real life experiences described by people with impairments, people with mental health issues or homeless people. We have used inventorial methods to

compile potential issues to work with, and then by methods for prioritising, rank the importance of these issues. The final decisions on what to start with have been guided by;

- A top-down approach – starting with the issue prioritised by the most people.
- An impact approach – picking something on the list for which we think we have the tools, ideas, connections and partners, to deliver a credible result.
- A relay approach – we pick an issue close to something we have already worked with, expanding from the known, to the unknown.
- Do something. To take any action is probably better than doing nothing at all.

Characteristics for most activities have been that they:

- Move from problematising, to deepening understanding and then on to the construction of ideas that could describe a possible future.
- Return to the topic several times. It is by reflection, feedback and the maturity of thoughts that a solid standpoint is created.
- Apply different perspectives when looking at the same thing, moving in and looking out from different directions.
- Apply different materials (text, video, audio, eye tracking, illustrations, sketches, mock-ups, prototypes or to build usable software) to cater for imagination, innovation, reflection and analysis.
- Deconstruct highly abstract concepts by dividing them into simple questions and then reconstruct the abstract concept, and our understanding of it[25].
- Use of metaphorically strong objects (Toppling counterforce, cards that are red-orange-green, red dots, arrows, gamification rhetoric).
- Provocative objects, nudging and gentle provocations.
- Sketches, mock-ups and prototypes.

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[25] This idea was first expressed by Anna Hildingsson. I was complaining that I could not make sense of survey data from people with intellectual impairments. Did they use the internet or not? Then Anna said, "Well, you know for us with intellectual issues "internet" is not an easy word… But YouTube is internet, right" Me: "uhu". Anna: "And Google is internet? And Facebook"? Me: "Yeah…" Anna: So why don't you ask about that and then figure out if we are using the internet? We concluded that we probably needed to ask four simple questions and if the answer was yes on any of those the person was an internet user.

The most often used collaborative method has been to work in groups, in sessions of about 1,5 to 2,5 hours with short pauses. It has been allowed for individuals to break away and work alone. A common method has been to start with all participants (often between 10-60 people) and introduce a topic/issue/dilemma/task. After that we split into smaller groups and work with the matter. Every group documents their work and a session ends with all groups gathering, discussing each other's results and findings. Post-it notes, mind maps or drawings have been used to support the analysis of group results and findings.

### 3.1.1 Text as a Methodological Issue

An overall methodological issue has been how to deal with a research tradition of turning all kinds of data into text, thus using the text as the unit of analysis. Many people with cognitive impairments, people with mental health issues and homeless people cannot, or do not want to, work with large blocks of texts. We have complemented text by using visualisations and metaphors and discussed texts, rather than read texts. For some, text first becomes useful if it is converted into speech, while for others, text is always problematic. Intermediators [224] have been used to support people struggling with text. Through the support of intermediators they can get the text read out load, get difficult words and concepts explained, or be helped in the handling of abstract stuff through given examples etc.

## 3.2 Qualitative Data

Rich and multiple sources of data form the basis for the work presented in this thesis. Documentation by different modalities (video, audio, photos, illustrations and texts) have been used, along with fieldnotes and data from questionnaires. Both quantitative and qualitative data have been gathered.

Many of our sessions have been recorded on video[26]. On www.begripligtext.se (Activity 1.3.4) you can find almost 100 blog posts about 'understandable text', and a lot of video material[27]. Sessions from

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[26] An assemblage of 50 of the most important video recordings from Begripsam's first three years, can be found on http://www.fungerandemedier.se/begripsam. Videos are in Swedish only.

[27] Video recordings from the Begriplig Text (Activity 1.3.4) project can be found on https://www.begripligtext.se/textmakthavare-moter-lasare. Here you can find 4 video-summaries with captions in English, Italian and Swedish.

all activities, regardless of project, are either audio recorded or documented in written reports. Many of those projects use the three-step method we call "Three evenings about…" indicating that we penetrate the same topic at least three times in a reflective practice that ends with a proposal of how to improve current situation.

Since many participants find both reading and listening to reports to be problematic, we often try to visualise important issues through illustrations, summarising long discussions or descriptions, capturing the essence of the phenomena. The examples below are two early sketches explaining how ISO-Standardisation works. They basically give the same information (Figure 7 and 8).
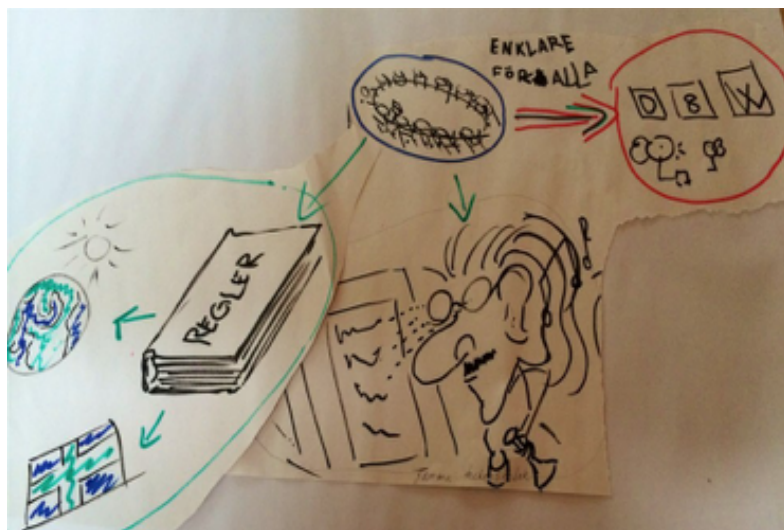


Figure 7. Illustration of how a global standardisation process could end up with better design of web pages globally and in Sweden. The circle above the head is the process. The red circle is a checklist. When this works, the result will be happy days for people using web pages, illustrated with a man spotting the improvements, ready to trumpet out this message all over the world.  Swedish text: Regler = Rules, Enklare för alla = Easier for all. Illustration of a group discussion with Begripsam members.

*Figure 8.Illustration of how the same standardisation process, as described in Figure 7, is perceived by another group of Begripsam members. This group applied a mind-map approach to describe the process.*

At one point, we introduced the Begripsam group to a method of qualitative content text analysis (Project 1.3.1), but the first attempt turned out to be a frustrating experience for many of the participants. To convert other types of material into text, is for some participants to move away from a content that is accessible. These participants may be better at finding themes and patterns by reflecting orally on what they have seen or heard, rather than on what has been written.

Recordings with eye-tracker technology have been used in several projects, to make us aware of what is going on when people are trying to solve a task on a screen. A typical example is presented in the picture below (Figure 10). Heatmaps, number of eye fixations, length of fixation and order of fixations are techniques used to analyse the interface. By heat maps, several results can be merged together to identify problematic objects in a design.

Figure 9: Example from an eye-tracker test in cooperation with designers from The Swedish Tax Agency.

### 3.2.1 Accessible Data Collection Methods

Data collection methods need to be accessible. In qualitative data collection, this means that people must have the possibility to provide multiple means for contributing with data. This requires a flexibility in the study design and when planning a data collection strategy. We have often applied a main strategy that works for most of the participants and then allowed for variations for those who could not conform with the main strategy. As an example: When we worked with the ISO 21801-1 standard most of us produced an edited text, but a small group created a prototype instead. They chose to design a ticket vending machine to test if the guidelines presented as text could be applicable when designing a ticket vending machine In other situations people made drawings, or recordings instead of producing texts. If the main strategy was to work in groups, people have still been allowed to break away from groups and work individually.

In quantitative data collection we have used different ways of participating in surveys. The base is an online survey and it is complemented by the possibility to answer on paper, to receive a Word-file, and to be interviewed. For some groups we have complemented by using sign-language speaking interviewers, intermediators, enhanced text comprehension with symbols. We have also used venue and activity samplings by visiting events where we knew that many people with

impairments and people with mental health issues could be expected to visit.

The main strategy for penetrating deep into different disability communities have been a snowballing strategy, assuming that people with impairments and people with mental health issues know of other people in similar situations. Since we are well known in most of the participating communities, we have been allowed to tap into already established information and distribution channels, allowing for a deep penetration into rare populations. It has become clear, that in communities where we are lesser known we also will get fewer participants

## 3.3 Quantitative Data

The data collection method (described in paper V) allows us to collect quantitative data from a large number of people. To complement the quantitative data, all surveys also contained open-answer questions and as a result of this, we have a rich source of written comments from over 2.800 participants in our surveys. We have undertaken 5 major data collection activities. Every survey contains at least some questions about participation in the digital society and some are totally dedicated to this subject. So far have the statistic conclusions been only descriptive. However, for the 2019 survey on internet usage, we will have the capacity to do more advanced statistical analyses. Open-ended answers are for now used to analyse specific topics but are at the same time a rich source for future analysis. For the presentation of this thesis, open ended answers have been used to analyse feelings of exclusion in the digital society, and for the work on a framework for participation. We are a bit overwhelmed by the vast number of participants in our surveys, since from literature we have learned that it is considered difficult to recruit people with impairments to take part in surveys, usually resulting in small sample sizes.

To get the snowball rolling, and to keep it going, we have applied information strategies that could be described as pulses. Periods of intensive information activities is typically followed by an increased inflow of answers. When the inflow declines, we have launched another information campaign. By closely monitoring answer ratios for each group we can see in which communities the information strategy is working and where further outreach efforts are needed.

## 3.4 Accessible Data Analysis Procedures

The process of analysing data needs to be accessible. The general idea of having people with impairments, people with mental illness or homeless people  participating as co-researcher would otherwise fail.

All data analysis takes time but for the analysis process to be accessible, time for reflection is important. The analysis process has most often been orally driven. That is, we discuss what is in the data, and we repeat those discussions several times. To support the discussion, we have used text, video, audio, photos and illustrations. Since analysing data, especially data of a qualitative nature, is a very abstract process, means to support participation in analysis procedures are extra important for people with cognitive impairments. To summarise complex phenomena in the form of pictures and to use intermediators, are two ways of support more people to take part in the analysis.

The end result of an analytical process might thus be a picture instead of a text. The example below (Figure 10) is from the work presented in paper III. Simple sketches would replace long text entries in the journal system. All of Hussein's problems were documented in his journal, but he never read the text.

Figure 10. An Activity System made by Stefan and Hussein to describe how technical assistance from artefacts could help break the dependence on staff at the shelter for homeless. We started with the preferred outcomes to the right. Then we moved backwards towards Hussein, reflecting on what kind of devices and applications could "do the job". Today Hussein teaches others how to do this, at a company working with assistive technology. This is a back-casting method.

# 4. Results

## 4.1 Analytical Tools

The work has resulted in three analytical tools: a Central Analytical Model, a presentation of Prerequisites for Participation in the Digital Society and Toppling Counterforces.

### 4.1.1 Begripsam's Central Analytical Model

We have developed and used a central analytical model to facilitate a high-level analysis of the data (Figure 11). At the core of the model is the **central unit of analysis**. For analysing data presented in the thesis the unit of analysis has shifted between "cognitive accessibility", "artefacts" (for example smartphones) and "homelessness". The central analytical model presented in the thesis is influenced by Entwistle et al. [225].

The different levels on the left in the model allow for analysing the roles played by Society, Practices, Activities and the Individual, in relation to the central unit of analysis. Infrastructure and artefacts, on the right in the model, represent the built environment and the devices that we use to participate in the digital society.
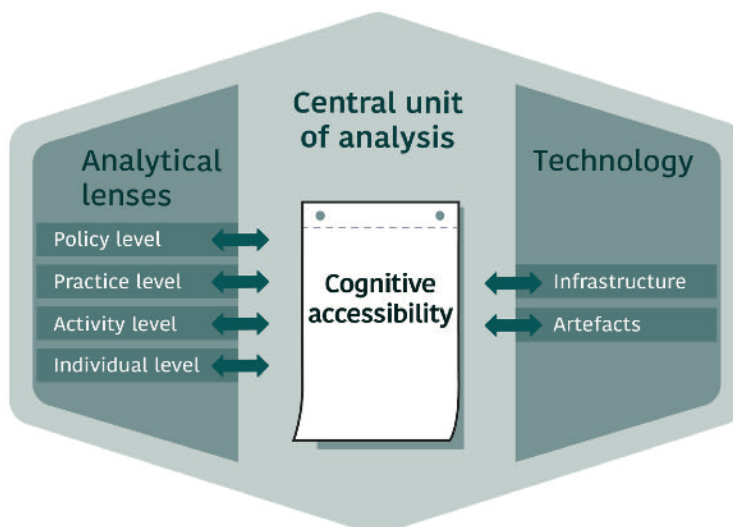


Figure 11: The Begripsam Analytical Model. Cognitive Accessibility is the central unit of analysis in this example. Illustration: Carina Söe-Knudsen, based on an idea from the author.

This analytical model can be used to understand on which level a problem or a solution is located. The model can also be used to plan interventions and activities. These can include small-scale activities as well as full scale research or projects. The model is also used to inform collaborating partners.

An important insight is that by starting with what is going on in the intersection between individuals using an artefact for a specific activity, we can identify flaws in practices, legislation or policy. This also allows for a critique of society or practice to be grounded in real life experiences.

Some examples of when this model has been useful for the interpretation of our data, are:

- It is the education system for people with intellectual impairments that does not prepare many students to participate in the digital society, not the impairment itself and not a lack of appropriate tools (Paper IV and V). This digital exclusion is maintained by the system of special housing and daily activity centres. All three institutions are under governmental control. Activities in project 1.3.2 present pedagogical tools and methods, that should be used in the school system.

- It is the law that states that homeless people have to receive calls for meetings by postal letters, to a post box that many of them do not have (Paper III). In the same paper, we can present support for, that both homeless people and the digital tools that they could use for cognitive support, are ready, but the Administration of Social Service is not ready to change its practices.

- People with mental health issues (Paper I and II) do not find the principles of universal design useful to analyse smartphones. In our model such principles are placed at the societal level. This analysis led to the construction of the metaphor of **Toppling Counterforces**.

- When trying to understand differences in participation in the digital society such as the differences between women and men, or the differences within the same group or between groups, we could not find the explanation in this model (Paper IV and V). Results pointed to all levels at the same time. This led to the development of a model for **prerequisites for participation** in the digital society.

### 4.1.2 Prerequisites for Digital Participation

When trying to understand the data, indicating that people with the same diagnoses, impairments, or mental health issues or the same situation of homelessness, relate very different to the digital society, we could not find any comprehensive, already existing, explanation in literature. We learned from literature, and saw also in our data, that a complex mix of factors seemed to be at play. These factors were often intertwined and entangled in each other. In literature we find that scholars might have detected some of those factors. There is for example some knowledge on which skills disabled people need in order to participate (Paper IV) and a large body of knowledge of general accessibility. There is, however, not that much knowledge about cognitive accessibility.

This led us to the attempt of presenting a holistic picture of known factors, either derived from literature or from our own data. The result is a model describing prerequisites for participation in the digital society (Figure 12).
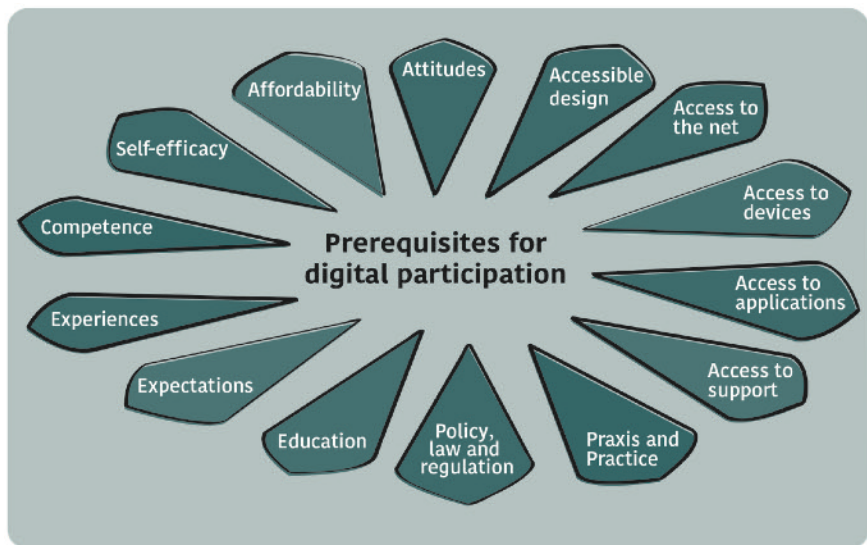


Figure 12. Prerequisites for Digital Participation. Participation in the digital society depends on; Affordability, Access to the net, Access to devices, Access to applications, Access to support, Praxis and practice, Policy, law and regulation, Education, Expectations, Experiences, Competence, Self-efficacy, and Attitudes. Illustration: Carina Söe-Knudsen, based on an idea from the author.

This model presents an opportunity to look at data from other perspectives than those offered by the central analytical model, but the two models relate to each other. For example, we could not find any homeless people using assistive technology as cognitive support (Paper I), even when they clearly needed it and sometimes even when they understood that society might provide those tools for free. To get that support, however, they needed to shift from interacting with the local municipality to the regional level. They did not know how to do this and how to conform to the different set of rules. Many of the homeless people did not view themselves as capable of conduct the application process, and of describing their problems.

The model of prerequisites allows for the telling of stories, and to piece things together, while at the same time deconstructing what doesn't work, both on individual and more generalised levels. It allows us to see that even if we focus a lot on accessible design, it is only a part of what has to be done to cater for participation.

Deconstruction of complex phenomena can also be done using Hedvall's Activity Diamond in an adapted way. We have not changed this model, but we have found that it is sometimes useful to "run it backwards". If we start with an **intended outcome,** instead of regarding the outcome as a result, it is possible to discuss the mix of human and technical assistance a person needs to 'get there' – thus, a sort of back-casting.

### 4.1.3 An analytical Tool for Identifying Toppling Counterforces in Design

The third analytical tool that has been developed, is a tool to analyse flaws in design (with design broadly defined).
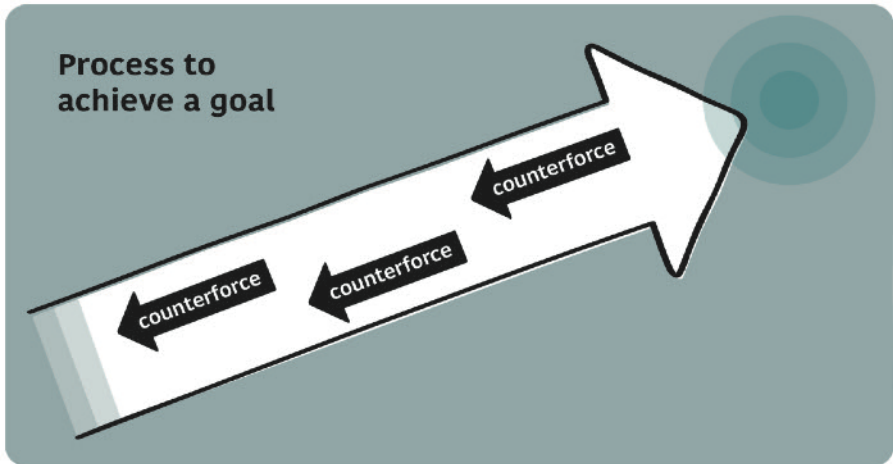


Figure 13: Toppling counterforces. Illustration: Carina Söe-Knudsen, based on an idea from the author.

Toppling Counterforces (Figure 13) is a powerful metaphor that was first introduced in paper I and II and in my licentiate thesis [224]. A Toppling Counterforce is a contribution that is **counterproductive in relation to the overall purpose** of the design. It can be **unintentional** or **intentional**. By identifying Toppling Counterforces, it becomes possible to visualise and discuss phenomena that cause 'predicaments' or barriers.

The search for "arrows pointing in the wrong direction" can be done both as a group activity and individually. This is a powerful metaphor, since most people intuitively seem to have a feeling of something not helpful, going on in the design. With the metaphor explained, they are provided with a tool to put words to, or draw a picture of, the problem. The problem is moved from an unconscious to a conscious level, and thus it becomes possible to intellectually relate to and discuss it with others.

As an example from papers I and III, homeless people and people with mental health issues have been discussing the potential toppling counterforces in the process of homeless people getting a home. When we added piece by piece, we could finally present a picture that revealed an array of problems (Figure 14).
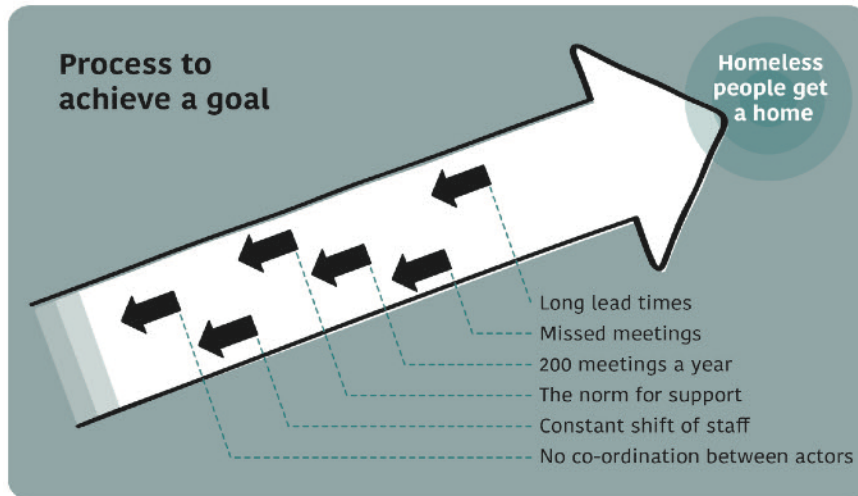
Figure 14: Toppling Counterforces in the process of homeless people get a home with help of the Social Service Administration. Summary from a series of workshops and interviews with homeless people and people with mental health issues. Illustration: Carina Söe-Knudsen, based on an idea from the author.

## 4.2 Begripsam's Ethical Framework

This section presents a compilation of ethical dilemmas we have encountered and transformed into recommendations, suggesting a framework for participatory practices. The result is compiled from work presented in papers I, III and IV and projects A, B, D and E, and from engagement in many design processes. An outline of an ethical framework was presented by Mia Larsdotter and Stefan Johansson at the Nordic Network on Disability Research (NNDR) conference in May 2019. In the Begripsam group we try to adhere to this ethical framework, in our research and member activities.

**Act in the spirit of conviviality!** Unless you have a good reason for why a conflict would be better, use a friendly approach to make people change. Develop tools for conviviality.

**Act in the spirit of solidarity.** We are all fellow beings. We are in this together. We can always do something to help each other. Act in solidarity and do not pity. Avoid charity, but if someone is giving you a lot of money

for a good cause, consider accepting it (and refer to the point about pragmatism).

**Be pragmatic about it!** Take the steps forward which are possible at the moment. Don't be afraid to try. Don't be afraid of mistakes or breakdowns. Just do it better next time.

**Cater for citizenship and democracy.** Go in directions that will enhance participation in society and be as democratic as you can.

**Don't design for diagnoses!** Diagnoses are for medical research and interventions. In such domains, diagnoses provide precision. When doing design, it is the understanding of impairments that provides precision. If people for example struggle with memory, the medical reason why is not that important.

**Don't be surprised when people have needs according to their difficulties.** Why send letters to a homeless person? Why start a new medical exam on deafness if a deaf person says his assistive device is broken? Why not just give the person a new device? Why blame a mentally ill person for not attending a meeting, why not contact the person and see how they are doing? Why demand that people with writing difficulties describe these problems in their own words, by writing a text? (All of the examples above are true stories.)

**Don't patronise, don't treat people as vulnerable.** Think about participants with impairments or mental health issues and homeless people as equals, as co-operating partners or as co-researchers. It is another thing that some of them might need special arrangements to make things work.

**Emancipation and power relations.** Go in directions that help people to take control over their own lives. Go in directions that give people power. Think about how to liberate people from oppression. Be aware of when you are imposing power and think about what could be oppressive in a design or a design process.

**Enable - Avoid being disabling and ableist.** Go in directions that support people to grow or to just to be as they are. Think about the beauty of diversity. Think about the design challenges of designing something that everyone can use and enjoy. Do not only design for 'normal people'.

**Moral or law?** Do the right thing, whatever the law states.

**Think Participation and Activity and Inclusion will follow.** Cater for people to be able to take part. We take part by acting. With activity comes inclusion. Think about inclusion, as an outcome not a beginning.

**Think twice, it's alright.** Feedback is good. Reflection is good.

**Save the world – but be sustainable and accessible at the same time.** Have respect for, that also in a sustainable society there will be people with impairments, people with mental health issues, though hopefully no homeless people (but as long as there are, you have to think about them too).

**Special solutions or mainstream?** Go for the mainstream as often as you can. Mainstream solutions can avoid stigma, are often cheaper and probably easier to maintain over time. Only go for solutions specially designed for certain groups, if you can justify why this will be better. Also think about special solutions as provisional solutions – as a way to inform the mainstream about a possible future. Many products and services have started out as special solutions and then found their way into the mainstream[28].

**Use guiding stars!** The space for ethical mistakes becomes smaller if you let yourself be guided by powerful ethical guiding stars. A guiding star can be the UN Convention on the Rights of Persons with Disabilities, CRPD; Universal Design; ISO 21801-1; heuristic guidelines; this list of ethical considerations… It is a good thing to have something to fall back on, to support your thinking.

## 4.3 Artefacts in Real Life and as Objects for Reflection
The concept of artefacts has been studied to see how well they **support participation** in the digital society, as **tools for interventions,** in order to **study effects in real life situations,** and to **reflect, discuss and propose possible future scenarios**.

### 4.3.1 Artefacts as support for participation
The work in papers I, III and IV and the work in projects A and B reveals that mainstream artefacts such as smartphones, smart watches, smart

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[28]  I especially like the story of how the spellchecker travelled from an assistive tool for one person to something no writing human can live without [262].

pens, digital calendars and an array of apps and software can be used as assistive devices in their own right. The point where people start to need specially designed assistive technology seems to have moved in direction of where mainstream artefacts more often "are doing the job". One explanation is that what is now an inbuilt function in a mainstream artefact was previously a stand-alone assistive artefact. A noticeable problem, however, is that many people use mainstream artefacts "directly out of the box", even when there are possibilities to adjust them according to preferences and needs. The adaptation is often regarded as difficult.

Take the artefact away, and there will be no participation. The Swedish Internet Foundation argues that access to two devices is needed to achieve full participation - one mobile device for when we are out and about, and one device with a larger screen, at home. Some people report that they cannot afford internet subscriptions or to buy devices, or that their devices are too old to really be of use.

Artefacts as Tools for Interventions to Study Real Life Situations

The work in paper III basically started out with the idea of giving homeless people access to the devices they wanted, and to see together what happened then. We knew about the low level of digital interaction between clients and social service staff from our work presented in paper I, and the reference group from RSMH pointed out this as a problem. This intervention spiralled on into several co-operations with both homeless people and the Social Service Administration.

Many important insights come from analytical processes where an artefact has been the centre of analysis, often combined with the placing of the artefact within an activity system or a practice. As for an example, from paper III, we could identify differences in calendar practice when we shifted between paper calendars and digital calendars as the central unit of analysis. Paper calendars create problems that digital calendars can solve. One central finding is how digital calendars lower tension between staff and clients, at the shelter for homeless people. Digital calendars can use digital tools as reminders, and they can keep on reminding in a neutral tone. Paper calendars demands staff to carry out reminders and staff get irritated if reminders do not work. Staff often forget to give reminders. Many participants attended more meetings, using digital calendars and digital reminders, than when using paper calendars.

A reason that people with mental health issues often end up in debt to the psychiatric health services is that the service first sends out invitations to an appointment by postal letters, and then send invoices, charging money for the missed appointment, by postal letters, not realising that one frequent effect of mental health problems is that people panic in front of postal letters and do not open them. A digital notification seems to be more neutral.

Having artefacts as the unit of analysis can provide important insights, especially if combined with interventions in real life situations.

### 4.3.2 Artefacts as Tools for Reflection, Discussion and to Propose Possible Futures

The work in paper II and activities A, B, D and E relies heavily on artefacts. The future can be a very abstract concept to talk about, and it can be difficult to discuss alternative future scenarios. When the Swedish Consumers Board visited the Begripsam group and started a session by saying: "We are going to build a new web site, please tell us what is important for you", there was one very long minute of silence. Then Frida said "eeh... I don't think you can ask about that in this way...". A discussion about something that does not yet exist needs to be accompanied by things that do exist. Sketches, mock-ups or prototypes, but also oral briefs, recordings of eye-tracker sessions or different walk-through methods, can all present something tangible enough to spark the discussion. Without tangible support, many people will find discussions about the future, as being too abstract.

An adapted version of Future Workshops [226] is the most common tool for intervention used when we collaborate with designers, discussing which problems there are and how they should be solved. Provisional artefacts are at the core of this work. We use for example a presentation (a brief) from the collaborating partner, or perhaps some sketches to get the discussions going. We document with mock-ups, visualisations, etc.

Another very common tool for reflection is to evaluate an existing artefact, often a web site or page, an e-service application, an app or a piece of software. The idea is to gain insights for future improvements. As for example, in Activity 1.3.1, a communication robot was being used at the Nordiska Museet in Stockholm, to evaluate how useful it could be for people who could not take part in guided tours on site. By testing the

robot with guides in a real museum setting we could reflect on pros and cons, proposing how the existing robot could be used in interaction with guides and online or onsite visitors, and also propose some improvements in the design.

## 4.4 Prerequisites for Participation in the Digital Society

The model showing the 14 prerequisites (Figure 12) has been described in the beginning of this chapter. In this section I will present the 14 factors in greater detail.

**1. Access to the web:** This is perhaps the most obvious prerequisite for participation in the digital society. People need to at least be able to find free Wi-Fi. Many have several access points; at home and in the workplace are the most common. Some people have an on/off access to internet, depending on if they can afford to refill their subscription or not. Many of the homeless people in paper III are cut off of web access in the end of the month, until they have money coming in.

**2. Access to devices**: We need at least one device to access the internet, and many Swedes now have several devices [227]. A noticeable finding is that many people with impairments, and also their support organisations, have to settle for old devices (Paper I). It is also quite common that people with impairments who join workshops or participate in activities, use broken devices, held together with tape or with broken screens. What we can see in our data is that if a person needs to prioritise between devices, it is the smartphone that takes the number one position.

For people with impairments, access to devices also can be a question of access to assistive devices. This adds an extra layer of complexity. Mainstream devices and assistive devices need to be compatible and support each other, but that is not always the case.

A critical moment is when a device needs to be replaced by another. To move all the data from one device to another can prove impossible. It is common that people lose data (for example contacts, pictures, notes), lose the ability to identify themselves, lose applications, or lose their specific adaptations when applications return to default mode.

For access, there needs to be infrastructure and electricity. Some of the homeless people report a problem to find somewhere to recharge their

phones. The people at Brukarföreningen[29] have a set of chargers. People can drop in, have a chat and charge their phone. A problem is that newer smartphones need to be recharged more often than older mobile phones.

**3. Access to applications**: By 'applications' I mean all the resources at our disposal. A set of applications comes with the operating system of the device, while others have to be downloaded and installed. Some are free and some come at a cost. Free applications often mean that users have to put up with commercials (a very distracting feature for people with attention-related problems) or lower functionality. Access to applications is unevenly distributed for many reasons. One has to know what applications there are and how they can be of use. One has to be able to afford to buy the applications.

**4. Access to support**: For people with impairments, 'support' does not mean just any support. Support needs to be presented in accessible ways. Support staff might need specific knowledge about accessibility and assistive technology, and sometimes knowledge of the impairment. They need to know how mainstream and assistive technology can interact. For most people, support (informal or formal) is something they can get at work. There is always someone who can help, and there are no strict borders between support for personal use or support for the good of work-efficacy. If we have no job, we often also lack a support network.

**5. Practice and praxis**: Practice and praxis can cause problems for participation by:

- A resistance to change even when a change in practice/praxis would promote participation in the digital society

- A change in practice/praxis lead to new problems with participation

- Activities embedded in the practice/praxis become digitalised, but the practice/praxis remains the same as before

A resistance to the change of a practice could for example be noticed in the case of the Social Service Administration (Paper III). Digital interaction between staff and clients could have improved the participation in the digital society.

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[29] https://www.brukarforeningarna.se/stockholm/#aktuellt

An ongoing and fast transformation in Sweden is the rise of cashless stores and restaurants. Digital payment technology is replacing cash payment at high speed. In these cases, practices change so rapidly that some people are left behind.

A common critique from members of the Begripsam group is that an old paper-form have been replaced by a digitalised exact copy, without taking advantage of the potential simplifications that could have been made, for example by importing already known information into the digital form.

**6. Policy, law and regulation** have to provide for participation and to protect against discrimination. Some groups might need extra resources to be allocated. A wide spectrum of political areas is involved (School and adult education, Work, Social and Health, Infrastructure, Finance). We have found problems connected to obsolete legislation, including how we support poor people, how we organise special schools, how we divide responsibility for assistive technology, how standards only protect people with some impairments, how labour market and social insurance systems produce outsiders, how prejudice and patronising views can be institutionalised through regulation, etc. These kinds of top-down prerequisites trickle down through the system and prevent organisations and people from doing the right thing and taking the right action.

**7. Education:** To keep up with the pace of digitalization is a lifelong learning project. Knowledge quickly becomes obsolete, and new knowledge is constantly required. Regardless of situation in life, people need to educate themselves, either to enter into the digital society or to stay there.

An extra need of education can be found among those who use assistive technology. With access to such technology, often follows a substantial need of instruction, something that many people report as missing.

**8. Expectations:** If you are brought up in an environment expecting you to be a 'digital citizen', it is likely that you end up being one. What we can see in our data, is that in special schools, special housing and daily activity centres, people with intellectual impairments often are met by low expectations. From interviews and discussions, we learn that parents sometimes, in order to protect their children, restrict their use of the internet, and these restrictions can still be in force when the child becomes an adult.

**9. Experiences**: The more we participate, the more we are able to transfer our knowledge into new areas and new situations, intuitively knowing how to solve problems, etc. Drawing on earlier positive experiences we reconfirm our ability to master the internet. The richer your use of digital resources, the more likely it is that you find the digital society useful, fun, and important.

**10. Competence:** Participation requires a set of skills. This set of skills are not fixed. The skills required fluctuate over time and depend on how one wants to participate and what one wants or need to do. Competence is more than skills. I would like to describe it as a combination of skills and the ability to understand which skills are needed and where to find support, and to realise what you need to do and whom you should connect with to solve a problem.

A specific kind of competence is to know how devices and applications could be adapted as to better support your needs, and how to combine features in mainstream technology with assistive technology to maximise the utility of your tools. There is often an unrealised potential in how your tools could be set up to fully support you.

A specific problem is that people with impairments can be heavily dependent on another person's competence. Designers, support staff, manufacturers, innovators, parents, and friends, are only a few of those who may need to be competent.

**11. Self-efficacy:** Can we see ourselves as successful users of digital tools? Or do we look at ourselves as someone who probably will fail? The way we perceive our ability is a strong internal prerequisite. The intrinsic psychology around participation seems to be complicated for some people and to be no problem at all for others. When people argue that "this is not for me" or "I am not interested", it could be an indication of low self-efficacy.

**12. Attitudes:** Our own and others' attitudes towards technology, towards change and towards ourselves can be enabling or disabling. Attitudes can be internalised and become out of reach for reflection. As an example, it is common that people not using the internet say, "I am not interested". That might be true. However, behind such statement there can be fear, shame, stress or other phenomena explaining a negative

attitude towards using the internet. It is important to critically examine our attitudes towards participation.

**13. Affordability**: The total cost of being a digital citizen can be higher than some of us might be able to afford. People with impairments often have very low incomes, and they may live with low incomes as a lifelong circumstance. With low income you have to prioritise. Maslow's pyramid of needs is at play here. If you cannot properly feed and shelter yourself, you might let the internet and the smartphone go. All of the homeless people who I have met have had a mobile phone. Only a few of them have had a smartphone. Low income is a strong predictor of digital exclusion.

**14. Accessible design**: Even when other prerequisites are fulfilled, an inaccessible interface might prevent the use. This makes accessible interfaces a key prerequisite. All other efforts will be in vain if the interface is inaccessible.

## 4.5 A Step Forward for Design Practice and Design Thinking

The thesis presents both practical and theoretical contributions to the field of design. It contributes to design practice by:

* Presenting a standard on cognitive accessibility, with guidelines and checklists

* Presenting tools and methods for collaboration between designers and people with impairments, people with mental health issues and homeless people.

It contributes to Design Thinking by:

* Presenting arguments, to support designing for all humans

* Presenting arguments for, that design should be emancipatory, and ethically grounded.

* Presenting arguments for, that design is a tool for transformation of society, and that neither designers nor technology are neutral.

### 4.5.1 Contribution to Design Practice
**Guidelines for Cognitive Accessibility - The ISO standard 21801-1**
The standard (Activity 1.3.5 and presented in Annex B) consists of 9 areas and 57 guidelines and is applicable for all kind of systems and services. The purpose is to complement other guidelines, for example those covering sensory issues. The standard is a result of accumulation of requirements proposed by scholars over a long period of time. The requirements have been edited by national work groups and an international committee, with me as the main editor and Begripsam as an editorial board. It is the first of its kind within the ISO system, and being within that system also means that there are mechanisms for future revisions.

### 4.5.2 Methods and Tools for Collaboration
The work presented in the thesis includes an evaluation of the usefulness of earlier methods for collaboration, found in literature. Some methods have been found to be useful as they are. In some cases we have made adaptations of earlier methods and in some cases, we have developed new methods (though in a sense all methods can be viewed as adaptations of earlier ones).

From earlier literature we have learned that there is no clear evidence on how to engage (especially) people with cognitive impairments in design processes. Papers I, III and V and activities A, B, C, D, E and F have all contributed to the evaluation and develop a set of tools and methods. This work is presented as a **Toolbox for Participation in the Design Process**, see Appendix A. The appendix is divided in:

- A table with short presentations of the methods we have used

- A table with short presentations of the tools we have used

- A list of advice on how to provide a scaffolding structure, that activities should be embedded in, to be cognitively more accessible

**One finding is that many established tools and methods do work**. It is often not the tools or methods, in themselves, that need adaptation, to become accessible. Rather, it is the arrangement around the tools or methods that needs adaptation. One arching issue in relation to participation is energy consumption. When we have deconstructed a session, many of the activities have been described as being draining of

energy, and only a few as being recovering energy. A familiar structure and a well-planned arrangement of the activity allow for a creative flow and high-quality material to emerge from the activities within the arrangement.

### 4.5.3 Contribution to Design Thinking
The thesis (and the work presented in papers and activities) aims to sensitive designers to be more careful and thoughtful in how to collaborate with disabled people in the design process and describes the nature of such collaboration. It especially points at things to consider when collaborating with people with cognitive impairments, people with mental health issues and homeless people, but also highlights how rewarding such collaboration can be for the overall result of the design.

It also sensitises designers to be more careful and thoughtful about whether their design will uphold oppression or be a means for liberation. It draws attention to the fact that both intentional and unintentional decisions and standpoints have the potential to either create barriers or to provide enabling structures. It provides analytical models and tools which can be used to go in the right direction and to avoid disabling and ableist design. It argues that the design outcome will be better if it is guided by an ethical framework, and proposes one to start with. It argues that designers should deal with the question of morality and take a standpoint. It calls for all designers to have a conscious approach to these matters.

## 4.6 A Deeper Understanding of the Disability Digital Divide
The thesis provides contributions to the understanding of the disability related digital divide. It also contributes to a wider understanding of how rare populations should be handled in statistics. It provides a framework for how to survey rare populations. The contributions of the thesis can be found in papers IV and V and activities C and E.

The work has resulted in three major reports (on internet use, devices and assistive technology) and over 50 special reports (all in Swedish)[30]. Additional reports have been delivered to disability organisations and government agencies. I was invited to the Swedish Parliament, together with two other Begripsam members, Michael and Cecilia, to present our

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[30] http://www.begripsam.se/internet/rapporter/

results. Several members of the parliament have in debates referred to our data[31].

### 4.6.1 Impairment Alone Cannot Explain the Disability Related Divide

The survey on internet use reached people with diagnoses and impairments from 35 groups (presented in paper IV). We have collected enough data to report results from 28 groups. The questionnaire was proposed by the Begripsam group and adjusted in minor parts by me and one researcher outside the group, and in consultation with experts on statistics. It was tested by all members in the Begripsam group before being launched.

I recommend reading the papers and the reports or browsing the open access dataset from paper IV at http://internet.begripsam.se. Currently much of the material is in Swedish. We are working on providing at least some in English, since we have not found any other data of this kind.

The results of the survey present a complex picture. In some cases, people with impairments use the internet more, compared to the general Swedish population. The most significant example is having a blog. Seven percent of the Swedish population had a blog at the time of the survey. Among women with some form of autism, 32 percent reported having a blog, and a majority of the groups had a level of blogging above that of the general population. However, in general, people with impairments report less internet use than the Swedish population, in some cases very much less. A short summary of the main findings:

**Impairment alone, cannot explain digital exclusion**: In every group we can find a large proportion of people who feel they are included in the digital society. In every group we can find people who do not feel that they are included in the digital society. There seem to be other factors more significant than impairment, for explaining a digital exclusion.

**"People with impairments/disabilities" cannot be the unit of analysis**: People with impairments are not a homogenous group. Data from paper IV rather suggests that people with diagnoses / impairments

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[31] Two videos are published from this event: Stefan presenting the survey; https://youtu.be/f-cOpNmclZw and Michael, with some help from Cecilia, talking about accessible web pages; https://youtu.be/FBlL0UbKu0w

are among the most heterogenous group that we can find. Every one of the reported 28 groups are different from each other in one or more ways.

**Language and intellectual capacity matter the most**: It was people with impairments related to language and to intellectual capacity who reported the most severe difficulties using the internet. People who were blind or with low vision managed better to use the internet, while the best at managing the internet, in this survey, were people with some form of autism.

**Barriers have been reported from people within all categories**, including Cognition, Affection, Mobility, Hearing, and Vision; there are no groups that report full accessibility.

**The barriers people report is of a wide spectrum**, ranging from accessing the internet or specific content, to navigation/finding content, understanding content or understanding how to use a specific resource or device. Many reports that they need more skills, that they need assistive devices and also that they need more technical support.

### 4.6.2 How to Handle Rare Populations in Statistics?
We deconstructed "disabled people" into 35 "impairment groups", providing answering options in the questionnaire, for both diagnoses and impairments. The main argument for this is that "People with impairments" does not constitute a homogenous group. Instead people in this group represent a wide variety, to the extent that it could be the most heterogenous group that can be found, still considered to be a 'group'. Since the same methods are used for a large proportion of official Swedish statistics, the critique of how to survey people with impairments goes far beyond the surveying of internet usage. If counted as one group, "disabled people" are well above the ten percent mark, below which groups in a population are regarded as rare. Rare populations need to be surveyed differently, especially if they are not found as distinguished in registers available for sampling procedures.

**Summary of issues identified with traditional methods used for surveying how people with impairments use the internet**

1. Since diagnosis groups and impairment groups can be small, all people with any diagnosis or any impairment will probably be counted in as one group, 'disabled people'.

2. In many cases a whole group can be found within the statistical margin of error. For numbers on prevalence, see paper IV.

3. Reporting on the level "People with impairments" results in differences between and within groups being averaged out. Having irrelevant diagnoses or impairments in the sample, will further bias the result.

4. Any diagnosis or impairment could be in the sample. Even those not relevant for an internet perspective survey.

5. Disability or impairment is not a variable that can be distinguished in the registers from which samples are retrieved. The occurrence of disability within the sample therefore becomes coincidental.

6. "Disability status" can only be detected by 'bolted-on' questions as a part of data collection, and not as a part of the preparation of the sample.

7. Survey constructions often have questions and answering options that are perceived as inaccessible by some people with impairments.

8. The methods of data collection are often perceived as inaccessible by some people with impairments.

### 4.6.3 A Framework on how to Survey Rare Populations

A result from working with the methods presented in paper V and activities C and E is a proposed framework on how to survey rare populations.

**A proposed framework on how to survey rare populations.**

1.  Co-operate with the rare population on what questions are relevant to ask

2.  Co-operate with the rare population on how to formulate questions and answering options

3.  Test questionnaires and analyse how they work, together with the rare population.

4.  Co-operate with the rare population on how to find members of the population. Become credible to the rare population by visiting and engaging in activities that are important for them. Build trust by showing a long-term interest in issues that are important to the population.

5.  Use a multi-channel distribution strategy for communication of your survey. Conform to accessibility requirements from the rare population.

6.  Use a multi-channel strategy for participation in the survey. Between 3-6 options should be the minimum. Conform to accessibility requirements from the rare population.

7.  Co-operate with representatives of the rare population in the analysis of data, and in discussions on the representativeness of the collected data.

8.  Disseminate results widely to the rare populations. Participate in as many activities as you can to spread and discuss the results.

## 4.7 A Framework for Participation in the Digital Society

Pieced together, I would propose that a contribution of this thesis could be a framework to help to understand participation in the digital society for people with cognitive impairments, people with mental health issues and for homeless people. This framework consists of:

- The Central Analytical Model
- The Prerequisites for Participation
- The Ethical Framework
- The ISO 21801 Guideline on Cognitive Accessibility
- The Toolbox for Participation in the Design Process
- The Framework on how to Survey Rare Populations
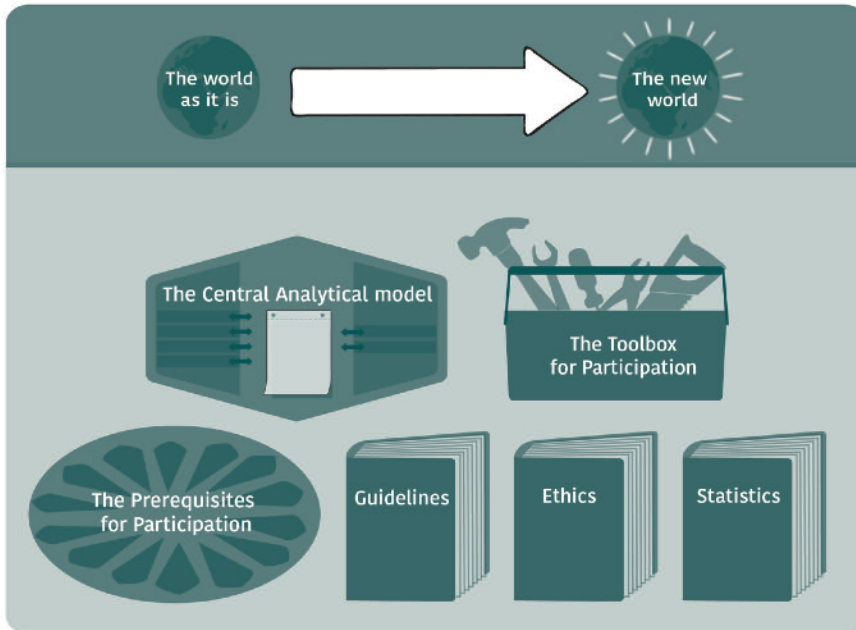


Figure 15. The Framework for Participation in the Digital Society. The framework consists of Guidelines, Ethics, Statistics, a Toolbox, the Central Analytical Model, and the Prerequisites for Participation. Illustration: Carina Söe-Knudsen, based on an idea from the author.

# 5. Discussion

## 5.1 Analytical Models

The three models, **The Central Analytical Model**, **Prerequisites for Digital Participatio**n and **Toppling Counterforces in Design,** can be seen as tools to shift between levels and perspectives. They are needed in order to handle the complexity that comes with an aspiration to understand how people with impairments, people with mental health issues and homeless people can participate or not participate in the digital society.

I believe I have presented that impairments, mental health issues and homelessness are not the main causing factors in themselves, for potential participation or non-participation. It seems possible to be an active and engaged participant, belonging to either one of the surveyed 35 groups (Paper IV, Activity 1.3.3). The reasons why some struggle to participate and some do not participate at all must be searched for outside of impairments, mental health issues and homelessness. When turning away from the individual, we can use the Central Analytical model to identify whether it is the activity, the practice, the society (with its laws, rules and regulations) or infrastructure and artefacts, that cause problems and makes some people have to struggle for participation. This model is inspired by the work done by Entwistle et al. [225] and informed by theories on practices presented by Reckwitz [42] and Schatzki [43]. To look at practices as potential roots for accessibility problems is not that common in accessibility research. Most accessibility researchers focus on the intersections between individuals, activities and artefacts, or with a high-level approach target e.g. CRPD compliance, legislative matters, etc. By bringing practice theory into the model, I think we get a complementary perspective, targeting middle-range accessibility problems.

It is possible to use the model for Prerequisites for Participation to understand why individuals (or groups of individuals) struggle with participation. We have identified 14 prerequisites for digital participation. If society wants the remaining population to become digitally active, it has to acknowledge the complicated matter of bringing those people over the border of participation. If individuals see an enhanced participation in the digital society as a tool for liberation, they might use the model to

identify what needs to be done for them to be able to take part on a larger scale. People with the same profile of needs could join in together in collaboration. In such a struggle it has been found useful to apply this metaphor of Toppling Counterforces, for people to identify flaws in a design, on any level indicated in the central analytical model, with the assistance of this tool. Still today, when I meet some of the participants from the work presented in paper III, people say; "Hey, Stefan, I think I have found one of those backward pointing arrows". This is liberating, as we can put the blame where it belongs by looking away from ourselves and outwards at society.

## 5.2 An Ethical Framework

Critical reflection on ethics can help designers take the right standpoint. In Bruno Latour's words: "*By expanding design so that it is relevant everywhere, designers take up the mantle of morality as well*" [228]. An ethical framework can be reduced to one question: What is the right thing to do now? But to arrive to an answer to that question, we need guidance. Flaws, or ableist and disabling design might originate in unsolved, or incorrectly solved, ethical dilemmas. Conscious or unconscious ethical decisions and standpoints can pose major implications both in the design process and in its results. Ethical arguments are embedded in artefacts. We have now seen the first robots making decisions on who will get support from the Social Service. This is only the beginning. Humans and the machines we build need to be guided by ethical frameworks.

In a time where accessibility is in a juridification process, I think it is important to remind ourselves that not everything we should do can be inscribed in legislation. This juridification process can be exemplified by e.g. the European Web Accessibility Directive [87], the American with Disabilities Act[229], or the expanding number of accessibility related court cases and negotiations which are being settled outside of the court[32].

Latour points to the moral obligations in design. In the following section I will discuss some ethical implications. These have emerged and increasingly called for my attention as my work has progressed; at first

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[32]  Examples on court cases, see http://karlgroves.github.io/a11y-lawsuits/lawsuits.html) and negotiations to settle outside court, see https://www.lflegal.com/negotiations/).

perhaps as something 'nagging or itching', which much later takes on the form of an ethical dilemma.

**Dilemma 1: Participation or Inclusion?**

The nature of inclusion is that someone who is already included must invite the not-yet-included, for this person to become included. People outside have to be included by people inside. This is a paternalistic approach, and there is a problematic power relation between the inviter and the invitee. It is difficult for people outside to include themselves. This is why I find "arguments for inclusion" problematic. The one who should be included is passive and has to wait to be included. Control over the inclusion process is therefore out of reach for the one who should be included.

In this way, inclusion is a process. I propose that we should instead see inclusion as an outcome of participation. Anyone can take action and by taking action we can take part. Participation is a more emancipatory process than inclusion. We should plan and act for participation, and then inclusion will follow.

**Dilemma 2: Oppression or Liberation?**

Many people with impairments experience themselves as being disabled by the society they live in and the nature of a disabling process can be described as oppressive. Paolo Freire describes the dialogical interplay between oppressors and the oppressed:

> *Reality which becomes oppressive results in the contradistinction of men as oppressors and oppressed. The latter, whose task it is to struggle for their liberation together with those who want to show true solidarity must acquire a critical awareness of oppression through the praxis of this struggle. One of the gravest obstacles to the achievement of liberation is that oppressive reality absorbs those within it and thereby acts to submerge human beings' consciousness. Functionally, oppression is domesticating. To no longer be prey to its force, one must emerge from it and turn upon it. This can be done only by means of the praxis: reflection and action upon the world in order to transform it.* [106, p51]

Designers and design should be liberators, not oppressors, and this can be done by recognising the widest range of human diversity.

**Dilemma 3: Solidarity or Charity**

Solidarity operates both on a personal and societal level. Solidarity acknowledges that all of us need support from others to fulfil our full potential as human beings and that we have a right to be provided with that support. Charity-based approaches often operate on a personal/ activity level, and they are rarely challenging for the existing power relations, while solidarity sometimes does lead to such challenges. With charity-oriented approaches comes the notion of impairment as a tragedy. When planning activities or analysing how people with impairments are provided with resources, it might be useful to consider whether solidarity or charity is at play and how that affects people.

**Dilemma 4: Design as a Moral Imperative or should we just Follow the Law?**

Jacobs [203] argues that design sensitive to values, needs ethical guidance. I agree. The design process is pushed forward by decisions. There are often some right things to do and some wrong things to do. Any decision can be directed in the right direction, by the guidance of an ethical framework. Universal Design or CRPD can be used as ethical frameworks. Nussbaum's capability approach [102], [103] can also be used as ethical guidance, as well as ISO 21 801 [159], or the Ethical framework proposed in this thesis.

Morally, we should strive to maximise the number of people who are able to participate in the digital society, whatever the law says. However, contemporary trends reveal the weakness in moral arguments. Since people, corporations and states are not doing the right thing, we have seen a shift towards legal regulation. Now we have to be accessible, because it is the law.

The "juridification" processes have not passed unnoticed. Söder [230] draws attention to the fact that  "*Juridical thinking and rules of law tend to be applied to areas that traditionally have been regulated by ethics*". 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 the risks of having rights on paper but not in reality.

### Dilemma 5: Discriminated by Law

Web accessibility for public web sites, services and applications is now regulated by law within the European Union. The way to conform to the new legislation is to conform to the standard WCAG 2.1 level AA. At first this might seem like a good idea. We have a law and even an instrument to measure conformance. The problem is that there are many important accessibility requirements that are outside the scope of WCAG 2.1 level AA[33]. The law specifies a minimum level of accessibility. Many organisations will set that minimum level as their target.

The idea in Universal Design and in the definition of Accessibility, *to reach the widest range of characteristics and capabilities to achieve a specified goal in a specified context of use*. This is now in danger of being compromised by jurisprudence. As long as requirements for cognitive accessibility are not implemented in WCAG, people with cognitive impairments are not protected by the law on web accessibility.

### Dilemma 6: Perceptions of incapability

Not long ago, disabled people could be labelled invalid (without value). Vocabulary has changed, but an echo of this approach can be traced when people with impairments or mental health issues or homeless people are treated as incapable, often in a patronising way. To get support from society, people in those groups often have to present themselves as incapable. It is this incapability that is the key to support, and the gatekeeping restrictions on such systems force people to generally describe themselves as incapable.

Perceptions of incapability can be internalised. In the work presented in paper III, we could see that a reason for not trying out smart technology such as smartphones, smart watches etc was the inability to see oneself as a successful user of such technology.

### Dilemma 7: Who is vulnerable and why?

People with impairments, people with mental health issues and homeless people are often being labelled as vulnerable and in need of protection. To label general groups as vulnerable stem from the medical or charity/tragedy models of disability.

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[33] To be correct: The law refers to EN 301 549 V1.1.2, who in turn refers to WCAG 2.1 AA.

If there is vulnerability it is, in my view, a social construction. Socially constructed vulnerability needs to be discussed in public. When a person feels unjustly treated by society, any representative of that society can hide behind the argument that they will not (or even cannot) discuss the specific person and the specific case in public. The argument for doing so is that they protect the person, but people must have the right to be their own examples when they want to discuss their situation in public.

We can all be vulnerable; it is part of being human. But, more or less automatically assuming that certain groups, by default, are vulnerable, that is wrong. Why disability, *per se*, is regarded as vulnerability has a lot to do with the notion of stigma [57]. But it also has to do with practice. We have for a long time gotten used to seeing those people as vulnerable. Some of them are. Most of them are not more or less vulnerable than anyone else.

### Dilemma 8: Good Research Practice makes People with Impairments Invisible

The WMA Declaration of Helsinki [231] is based on the importance of confidentiality, and on the researcher taking measures to protect the integrity of **research subjects**.

Every precaution must be taken to protect the privacy of the research subjects and the confidentiality of their personal information, and to minimise the impact of the study on their physical, mental and social integrity. The WMA declaration is rooted in a medical setting, but since this code of ethics is applied to almost any research involving humans it has two often-neglected drawbacks:

- It makes the contributions from impaired people anonymised in research. The credit for findings, immaterial property rights, goes to the researcher, not necessarily the person who made the actual contribution. There is a risk that the real contributor goes down in history without a name, for the sake of protecting that person.

- It poses major concerns when working with Participatory Action Research and in Participatory Design, where people are not "research subjects". In Participatory Action Research, participants choose to join the team by their free will, to become co-researchers. Participatory Design has a similar view of participants. This is also the idea behind Folkbildning and in Freire's work on liberation of oppressed groups.

The idea that participants should have to go to someone else to ask for permission to form such groups, and that they must be allowed by someone else to work together, is a violation of the fundamental principles that lie behind Participatory Action Research and Folkbildning.

## 5.3 Artefacts

We cannot 'be digital' without artefacts. Bruno Latour [228] regards humans and artefacts as actors, both with agency: "*when humanists accuse people of "treating humans like objects", they are thoroughly unaware that they are treating objects unfairly*". It has been very fruitful in our analyses, to place a specific artefact as the central unit of analysis. The design of artefacts in activity 1.3.2 shows that people with mild and moderate intellectual impairments are capable of complex interaction with technology, but also that special schools do not prepare and train those people to be digitally integrated in mainstream society.

Interventions with artefacts (paper III) exposed serious flaws in policy and how society treats homeless people. When we introduced smart technology to homeless people, all activities evolved with artefacts in the centre. Participants could pick any device they wanted from an assemblage of mainstream, potentially assistive, devices. We introduced devices and then took a step back to see how people made use of them. We discussed their experiences on a regular basis. If they wanted, they could get support. If they wanted, we could introduce some ideas on what they could do with an artefact. Many of the homeless people described the artefacts as tools for personal change and for change in how they were perceived by others.

The relationship between the artefact and the person using it, and what lies in the space in between, can be noticed for example when Eva (Paper III) described her relation to the egg-shaped phone. It is obvious that this artefact was doing something with Eva that extended far beyond the practical purpose of making phone calls. Also, when Leif, in the same paper, re-connects with the music of his youth, by creating a playlist using Hussein's Spotify family account, there is something going on between the abstract artefact-as-an-interface and Leif's daily functioning. The playlist somehow triggers small changes in how Leif takes care of himself. However, it is not always positive stories. An old and deprecated artefact

might tell its unwilling users that they "*have to settle with the computers that staff at the municipality office have dumped as useless*" and make people "*feel like the losers we are*". Quotes are from people we met in paper I. They had received the computers as gifts, but those were so old that they could not be used for paying bills.

Artefacts are concrete, visual and tangible. These are qualities that many people with cognitive impairments need, to get in touch with the more abstract and hidden qualities embedded within the artefact, within the activity, the practice or in policy. Many of the shortcomings in practices carried out by the Social Service Administration (Paper III) became visible through the use of artefacts. Artefacts can be used to bring up a tacit acceptance, or the unspoken, to the surface. Bourdieu uses the term "habitus" to explain how unconscious norms and rules are at play to form a practice. In order to challenge a practice the unconscious has to be brought to a conscious level. Wilk [232] explains this as:

> "*Social rules, predispositions, common sense and even embodied feelings can all change when they are brought out of the habitus, into the daily world of speech, debate, manipulation, and argument*" (p 10).

Artefacts can be used to challenge status quo and to reveal prejudices, norms and unspoken rules. By being tangible, artefacts can bring this process to a level of abstraction, that is cognitively accessible for many people. To return to an artefact now and then, allows for a critical reflection on what we are doing with technology and what technology is doing with us. This can be seen as a response to Winograd and Flores [233] who argued that we need to understand what the devices do and not only how they operate:

> "*In order to understand the phenomenon surrounding new technology, we must open the question of design - the interaction between understanding and creation. In speaking here of design, we are not restricting our concern to the methodology of conscious design. We address the broader question on how a society engenders inventions whose existence in turn alters that society.*" (p 4-5).

## 5.4 Prerequisites for Participation in the Digital Society

The prerequisites are a compilation of requisites gathered from literature and from the work presented in papers and projects. The list of prerequisites is an attempt to visualise the complexity in participation. Each of the requisites is intertwined and intertangled with several others. To deconstruct and reconfigure participation makes it possible both to apply a high-level holistic view and to dig deep into one specific requisite. I regard the 14 items on the list as temporary. Items can potentially be merged, removed or added. If society wants more people to be digitally included, it is important to very specifically target the requisites that pose barriers. The profile of disabling barriers seems to be very heterogenous (Figure 16). It does not follow the borders of disability, impairments, mental health issues or homelessness. In every targeted group in paper IV and V, we could see people both included and excluded. Their reasons for non-participation seem to be constituted by a very personal mix of unfulfilled prerequisites.
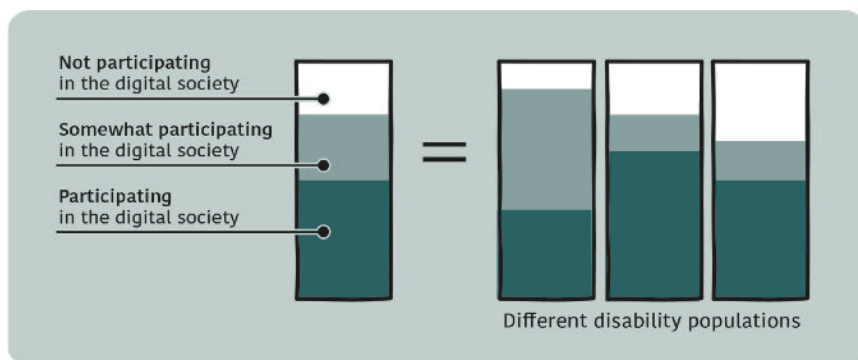


Figure 16. Visualisation of how participation in disability populations differs. The proportion of participation differ in every group. Impairment alone cannot explain the differences. Illustration: Carina Söe-Knudsen, based on an idea from the author.

## 5.5 Design and Design Processes

Designs are not value neutral and value trade-offs are a part of the design process. Not articulated values, can cause problems both in the design process and with the end result. Non-articulated values might be the reason that ableist or disabling values survive through the design process and "explode" when the end result is launched for use. Non-articulated values can often be found 'lurking around' in the background of a toppling counterforce. Values cause tensions, and by exposing values early in the design process it is more likely that the tensions can be managed. It is easier to identify value tensions if relevant stakeholders are represented in the design process.

The transformative nature of design has been discussed by Latour [228], who regards design as a "*clear substitute for revolution and modernization*". He argues that design is always actually a matter of re-design. There is always:

> "*something that exists first as a given, as an issue, as a problem. Design is a task that follows to make that something more lively, more commercial, more usable, more user's friendly, more acceptable, more sustainable, and so on*". (p5)

According to Latour, designing something "*allows us to raise not only the semiotic question of meaning but also the normative question of good and bad design*". With this statement, Latour brings attention to the moral imperative of designers' possibility to give design a direction. It can be either good or bad, or in the perspective of this thesis, it can be accessible or inaccessible. Latour also describe design as an interpretative exercise: "*Design lends itself to interpretation; it is made to be interpreted in the language of signs*".

### 5.5.1 Toppling Counterforces

The metaphor of toppling counterforces (Figure 13) has been useful to visualise phenomena on different levels. At first, we only used the metaphor to discuss flaws in the individuals' use of artefacts.

We then realised that toppling counterforces can be found on all levels in the analytical model. Policy, law and regulation can be carriers of toppling counterforces. Practices can be carriers of toppling counterforces. We can even find toppling counterforces in the way we think. People can

internalise a picture of themselves, as not being successful in the use of technology.

Toppling counterforces can be used as a tool to identify oppression. According to Freire, we become so used to being oppressed that it demands hard work to realise that we are oppressed. Thomas from paper III received over 200 invitations from approximately 25 different organisations (healthcare, social workers etc.) per year, calling him to attend meetings. He felt bad about occasionally missing some meetings. When we reflected on this matter, we could notice that:

- It would have been easier if he had received digital calendar invitations.
- Staff invited colleagues to the same meeting by sending them digital calendar invitations
- Staff argued that the law did not allow them to send digital meeting invitations to clients.

In the words of another Thomas [5], this is "*the social imposition of avoidable restrictions*". By realising that we are being oppressed we can shift focus from ourselves to society, and call for change.

### 5.5.2 Design vs Universal Design
In the 1980s, designers started to develop theories and methods on how to put humans and human needs at the centre of the design process. At about the same time, the dominant model of disability shifted from a medical perspective to a social perspective. Disability rights activists and scholars started to describe disability as socially constructed. Full participation for disabled people was framed as a human right, and the implication for design was that it should be universal. Society needed to be transformed so that it would become accessible for all. It needed to be re-designed, and new design needed to be accessible from the start.

The slow adoption of Universal Design in Human Computer Interaction can possibly be explained by the fact that this community is occupied with the concept of User Centred Design. Those two concepts have never really met. The paradigm of User Centred Design has been more powerful than Universal Design and represents a major shift in how designers are supposed to think and act. Compared to Universal Design it has resulted in a useful methodology. A huge body of research have been allocated to

develop, criticise and elaborate methods for User Centred Design. Designers are trained in and know how to do User Centred Design.

Some Universal Design advocates seem to have abandoned the artefact as focal point. Instead they present Universal Design as a process [234]. This shift also represents a shift from Universal Design operating at a micro level to a meso-level, and when connected to the CRPD, it shifts further to a macro-level phenomenon [89], [90]. It becomes a top-down approach. To be useful at the point where design decisions are being made, designers need micro-level guidance, or precision.

Applying Universal Design principles, who stem from the built environment, for digital interfaces, can prove difficult[34]. As a part of our design sessions (Paper I) we evaluated smartphones according to the seven principles. This was not fruitful, and participants either had difficulties understanding or criticised the principles. For example, they criticised "low physical effort". In the perspective of a lot of people being physically inactive, it is not obvious that low physical effort is a universal design quality. On the other hand, "low cognitive load" was identified by the participants to perhaps be a missing universal design principle.

### 5.5.3 Design Qualities and Design Challenges

Visualising bad design as toppling counterforces can create common ground for laypersons and experts to discuss and explore what is good and bad in a design. People with impairments, people with mental health issues or homeless people are often good at identifying design flaws. With a trained group, such as the people in the Begripsam group, we evaluate interfaces in 2-hour sessions and the result is often a rich material for designers to contemplate. Together in the group we have concluded that:

- Bad design is visible, tangible, and itching

- Good design is invisible, it just works

- The foundation of good design is to avoid using bad design

There seem to be an infinite number of ways of doing good design, as long as you avoid bad design. These conclusions might sound trivial, but the

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[34] An example of an ambitious attempt to bridge the principles to design practice can be found at https://www.interaction-design.org/literature/article/learn-to-create-accessible-websites-with-the-principles-of-universal-design. It is also an example of how difficult this is in reality.

distinction between design that contributes to the fulfilment of a goal and design that works against that goal is at the core of a discussion about design qualities. Designers should bring a set of qualities into the design. The Universal Design rhetoric could make its way into mainstream design processes by being presented as design qualities, formulated as challenges.

Designers are trained to handle challenges. A design brief is in a way a challenge. Finding clever and elegant solutions on messy problems is a challenge. Satisfying a client with high ambitions and low budget is a challenge. To represent the design craft in an environment only focusing on profit, is a challenge. To talk about human diversity as a challenge would be using the language of designers. To discuss a wider scope as a challenge might open the way for a more inclusive approach. To nudge or present a gentle provocation of designers' perception of what can be designed is to challenge the designers. Ticking boxes on a list to conform to accessibility or universal design principles is not a challenge. As soon as there is a prescriptive element, it becomes harder to get the attention of designers.

### 5.5.4 Design for Normal People

When Putnam et al. [236] investigated how User Experience and Human Computer Interaction professionals considered accessibility, they found that a clear majority (83%) answered that accessibility is important or very important. However, further analysis showed that in practice only 23% could be regarded as giving it a high priority, and the focus was almost only directed towards visual impairments. Many professionals also indicated that how accessibility was taken into consideration, was out of their control, and that trade-offs were made against budget, time and company/client needs.

Most designers want their design to be used and approved by the widest range of their target population. However, when evaluating design, it is often easy to identify features in the design that exclude people within the target population. People with impairments often report this experience. They are clearly within the target population but are nevertheless outside the range of users. The outcome of a design prevents them from acting as a part of the target population they belong to. This is bad for citizenship. It is bad for business. It is bad for the relationship between design and any target population.

To acknowledge human diversity is often easy as a principle, but in practice it is common to instinctively fall back into what unconsciously is considered to be normal. This relapse also allows for ableism. We assume that everyone is able-bodied and that an able body is superior to an impaired body.

People belonging to the part of the target population at risk of being excluded from the design outcome are often also excluded from the design process. It might therefore go unnoticed that exclusionary forces are at play. Both literature and our own experience have identified the designer's conception of normality as critical. The mistake often made is to equate the target population with "normal people", as if the target population cannot contain diverse people[35].

Even when designers are aware of diversity, almost every designer takes a direction of thought starting with normal people, expanding into territories of 'not-so-normal' people and almost never arrives at people far away from the norm. Restraints in time or budget (or both) foster designer arguments like "we need to pick the lowest hanging fruits" or to deliver a "Minimum Viable Product". The mental model at play is the belief that normal people always represent a vast majority of the users and that there have to be design trade-offs when including 'not-so-normal' people. This perception of normality has been challenged by Garland-Thomson with her concept of 'normates' [163]:

> *"Normate, then, is the constructed identity of those who, by way of the bodily configuration and cultural capital they assume, can step into a position of authority and wield the power it grants them. If one attempts to define the normate position by peeling away all the marked traits within the social order at this historical moment, what emerges is a very narrowly defined profile that describes only a minority of actual people" (p8).*

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[35] See for example https://www.sciencedirect.com/science/article/pii/S2214845014000143 discussing 'normal people' within the field of economics; "Behavioral finance is finance with normal people in it, people like you and me. Standard finance, in contrast, is finance with rational people in it. Normal people are not irrational. Indeed, we are mostly intelligent and usually 'normal-smart.' But sometimes we are 'normal-stupid,'…"
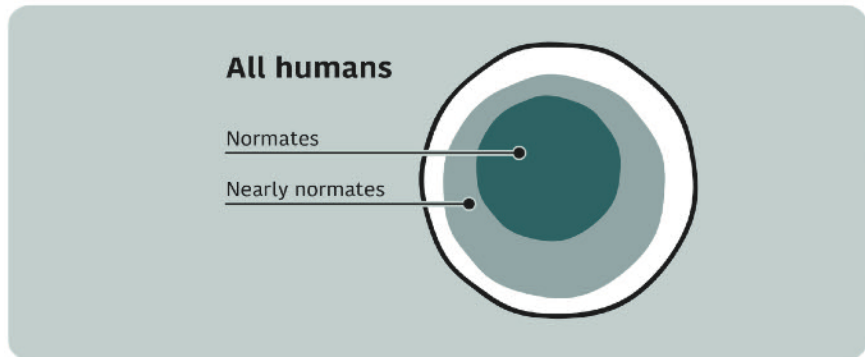
Figure 17: The direction of thought in Universal Design is to start with all humans. The direction of thought in most design processes is to start with the normates and sometimes expand into the nearly normates. Illustration: Carina Söe-Knudsen, based on an idea from the author.

I have added the 'nearly normates' to describe how many designers are willing to expand from designing for normates and to accept a small deviation from the norm by adding people who are 'almost normal' (Figure 17). I have also added nearly normates to be able to discuss the direction of thought. The idea of starting with all humans (the Universal Design perspective) can be described as having an 'extreme' user perspective. When designers start with understanding the prerequisites for those with the highest demands, there will be no design trade-offs in approaching the nearly normates and the normates. Moving in the other direction will result in multiple trade-offs, since the first design is done with a minority in mind. As Garland-Thomson argues, 'normal people' are a minority.

### 5.5.5 Participation in Design – a Slow Progress

As Larsdotter [237] notices, it has been seen as an imperative for a long time that disabled people should participate in research: "*research overviews and evaluations repeatedly argue for the importance of participation of disabled people. This request has been recurrent and more or less intact in its form for over 20 years. My question is why this request has not been fulfilled or altered in its form*". The same question can be asked regarding participation in design. The Universal Design movement has been arguing for disabled people's participation in design for a long time. Research practice and design practice have been slow to

adapt to these requests. The answer from the design community has sometimes been to invite people with impairments to user testing, and sometimes to engage people with impairments in workshops. People with impairments are still regarded more as containers of data than members of the design process. Few shifts in power relations can be noticed. The obvious reason is that the design community does not want to change. They welcome opportunities to be better informed but want to remain in control of the analysis and of the decisions.

When designers are opening up to more collaborative approaches, they seem to hesitate, due to a lack of knowledge and awareness of methods. Dirks [238] claim that there is no "*methodological sound basis*" for how to integrate people with cognitive impairments in research teams. The work presented in this thesis is an indication that deeper participation is possible. This work aligns with Laitano's [239] argument that a participatory agenda gives opportunities for "*sharing expertise, sharing power and inspiring change in the accessible design agenda*". Laitano argues for giving more power to people with impairments or others who know about their situation: "*to prioritize the voices that come from the experience of stakeholders over the voices that are based on the accessibility standards*", and by referencing Björgvinsson [240] that controversies should be transformed into creative opportunities. She also finds it important to take care of the non-technological outcomes of Participatory Design projects, such as "*new knowledge, new competencies and new stakeholders' networks*". To bring the expertise of lived experiences into the process, will reveal otherwise hidden power relations, and perhaps present alternative ways for problem-solving. It can, for example, challenge the risk of 'technology positivism' or "*assuming that a technology can be a universal solution, which can satisfy any subject with a certain disability*" [239]

There are two strong motives for placing the user at the centre of a design process; democracy and money. The Scandinavian participatory design tradition originates in democracy, while the American user-centred design tradition is about how to help companies earn more money. Both traditions actually use the same or quite similar tools, but for different purposes. Designers have successfully built a rhetoric around design as a business case, claiming that it is possible to maximise profit by gaining more knowledge about users, hence it makes sense to allocate resources

for hiring of design teams. There is no strong design rhetoric on using design for democratic purposes. Instead, the business rhetoric has expanded to government and public spheres.

### 5.5.6 Tools and Methods

There is a request from earlier research to develop tools and methods to make it possible to include people with impairments in research and design. Authors including Brajnik et al [132] and Lepistö and Ovaska [133], call for a combination of methods to evaluate cognitive accessibility. They mention user testing, subjective assessments, barrier walkthrough, screening techniques, classroom observations and interviews. Dirks [238] argues that, due to the complexity and heterogeneity of the group, the only way to address the needs of people with cognitive impairments is to include them in the design process by using some kind of participatory method. However, "*the challenges of working together with people with cognitive impairments must be anticipated and understood, and there must be solutions to the emerging problems*". According to Dirks, people with cognitive impairments might have problems with skills (such as understanding, reading, abstractions, generalisations, following different perspectives) that are "*relevant for a successful work in research teams*". Dirk claims that there are currently no "*methodologically sound basis for working in research teams with team members with cognitive impairment*".

Kusunoki and Sarcevic [241] discuss the paradox that, at the same time as design paradigms has shifted several times (described as waves by Bödker [170]), the methods for evaluation of design have not shifted, thus they are still rooted in usability testing and "*evaluation is typically a vaguely defined process*". They argue that evaluation should be "*planned, implemented, and reported with rigor, and at the same time, carefully woven into the system design process*". They come to a similar conclusion that we have done in the Begripsam group, that: "*Evaluation is more about how to carefully integrate selected methods into the system design process than just what methods to select*".

We have tested and evaluated methods and tools, and the selection of which one to use is a fundamental part of the planning of projects, events and activities. As a result, we can add some insights and experiences to the earlier calls for more knowledge on this matter. One really important insight is the importance of a distinction between scaffolding for the use

of a method/tool and the actual use of the method/tool. I entered this work with the belief that new methods and tools were always what was needed, since scholars claimed the old ones did not work. My current understanding is that it was probably the preparation, the scaffolding and the mediating that did not work. The arrangement around the participation was inaccessible rather than the method/tool itself. We have learned that close attention to details in the arrangement allows for successful use of a method or tool. This attention starts when a participating person leaves home and ends when this person returns home after the participation. We frame this as a discussion about "saving energy". The less energy spent on details outside the activity, the more energy is left to allocate to the activity. This is for example the reason why we work together with our 'Chef Ursula' Food is a major issue for many participants and for many "a meal" and "a break" is energy consuming, even though it is supposed to be recovering. Having someone preparing our meals takes away the concerns about food. Arranging sessions in familiar places and working with a clear structure are other examples. We plan for highly routinised procedures, framed as 'scaffolding', to cater for a maximum of interaction and engagement in the activity.

Often, old methods and tools need to be slightly adapted, because they were not developed with accessibility in mind. One common example is that when old methods could use an arrangement of individual work, we often find group activities work better. The priority given by old methods of observation over discussion, is often changed so that discussion becomes more important than observation. Old methods often used a one-session approach, while we often return to the same topic with the same participants multiple times.

### 5.5.7 Focus on Practice
Social Practice Theory is most widely used in contexts such as; **sustainability** [225], [242], **climate change**[243], [244] and **consumption** [45], [245], and there are some attempts to use it in **policy and governance** at low and high levels in society [246], [247]. Social practices have also been used as the unit of analysis in **design** [248]–[250]. I propose that theories on social practice can be a significant contributor to the understanding of accessibility. Most studies on accessibility are located in the intersection between individuals and

activities. By studying practices, it becomes possible to focus on the practice and de-focus from the individual/activity level.

Reckwitz's definition of a practice [42] and later descriptions of "boundary objects" [225] and the work by Schatzki [43] make it possible to define what constitutes a practice. It becomes thus possible to analyse whether this practice could be regarded as accessible (for whom and in what situations). Hargreaves et al. [244] brings tension and power into the picture. Groups can have more or less power, and therefore more or less difficult to advocate for a change of practice. Power structures often seem more focused on maintaining, stabilising and reproducing practices (protecting the status quo) than changing them. Hargreaves et al. also describe that links and elements of the existing practice (or bundles of practices) have to be challenged (or problematised) and broken down, before being replaced. This can create a space that enables possibilities to question current practices, and further to disassemble and reconfigure practice.

A practice survives by recruiting individuals who act within the boundaries of its domain. A new practice has to convince carriers of the old practice to abandon it. Practices are hard to change, and we need to disturb them or challenge them if we want them to change (or go away). They rarely ever change by themselves, and carriers of a practice can fiercely defend the old regime, even when arguments for change are compelling.

## 5.6 Cognitive Accessibility
When I started my research project in 2013 it was only a limited body of research targeting cognitive accessibility. That body is slowly growing, both with very specialised work targeting one issue at a time (or sometimes one diagnosis at a time) and more general work covering several cognitive domains simultaneously. The latter is really important, since results in Paper A show that most people with cognitive impairments report having more than one problem at the same time (with some reporting more than 10 and up to 17 issues). There are different ways of categorising cognitive impairments, and these are often more adequate for a medical perspective. From a designer's point of view a specific diagnosis is not as relevant as specific impairments. In a strategy for designers, it might be more appropriate to target specific

functions (such as attention, memory, maintaining focus on a task, etc.). This view is supported by Bohman and Andersson [251] who argue that "*there is not a direct link between the diagnoses and the actions the developer must take to accommodate people with these diagnoses*".

### 5.6.1 There is no Theory on Accessible Experience

Accessibility and Usability have a strong dialogical relationship, where accessibility reminds designers of the fact, that "specified users" also means users with the widest range of capabilities [142]. But so far, User Experience has no dialogical counterpart who is advocating human diversity. Human Computer Interaction in general has moved on to cover perceived experiences and emotions in wider and wider domains (social platforms, games, virtual and augmented reality, etc.) and in more and more aspects of life. But there is no discussion on accessible experiences, or on how emotion and cognitive impairment or mental health issues interact.

### 5.6.2 The Epistemological Divide in Accessibility

An important insight is, that a deconstruction of how we know whether something is accessible reveals that people engaged in the field of accessibility, align their work with two very different epistemological views. The dominant view so far is that we can know whether something is accessible by testing it with methods, ending up with claims of approved/not approved (or true or false if you like). This is the epistemological tradition from Medicine and Natural sciences. Truth is a matter of objectivity. Repeatable experiments or tests will always end with the same result. Cognitive accessibility can be better understood as an interpretative phenomenon, closely related to the epistemological tradition in Humanities. Truth is a matter of subjectivity. Something can be more or less accessible. Something can be accessible in one context and inaccessible in another. The same test arrangements will not end with the same result, since people interpret things differently, so there is no 'final truth' to be found. The true-false scale is replaced by a more-less scale.

This epistemological divide cuts across the accessibility community, and the best example is how difficult it is to implement cognitive accessibility in Web Content Accessibility Guidelines (WCAG). A true-false epistemological stance is applicable to technical constructions. A more-

less epistemological stance is applicable to design. To combine those
different views in a single standard, such as WCAG, has so not succeeded.
I would argue to abandon this road and instead clearly separate them.
WCAG is very useful for explaining how we should technically construct
web pages, but it is not very useful for how to design them. Designers are
better informed by standards such as ISO 21801-1. This is in line with the
separation of building standards and architecture, that we can find in the
built environment.

When accessibility is regulated in law, the law should recognise that some
accessibility claims should be judged on the 'true-false' scale while other
needs to be interpreted according to a 'more-less' scale. The European
Union Web Accessibility Directive basically makes WCAG 2.1 level AA the
law in all EU member states. Only minor cognitive issues are covered in
WCAG 2.1 AA. Hence, people with cognitive impairments are poorly
protected by the law.

ISO 21801 could provide an authoritative complement to WCAG. It could
be regarded as a second pillar of an accessibility framework and be
regarded in law as equally important. Conformance can be discussed in a
conversation between users with cognitive impairments and other
stakeholders in a perspective of reasonable accommodations.

### 5.6.3 The issue of Measurement

Cognitive Accessibility is not as straightforward as, for example,
accessibility for the visually impaired. Issues related to vision can often be
solved by technical constructions and technical constructions are often
measurable. To take a simple example: Is there a h1-tag for a heading or
not? If there is, the heading is considered accessible and it is an easy thing
to measure. But: Should there be a heading at all? Should there be
another one? Can I make sense of how the heading is formulated? Can I
get the same sense of the heading as the author intended? All those
questions are located in the cognitive domain. None is measurable in the
way that WCAG and W3C postulate. The way we have solved this problem
in Begripsam is that we discuss those issues and communicate our
thoughts to, in this example, the content creator, often with the content
creator present in the room. The process is about sensitising and
accommodating for reasonable improvements.

Moving back to the h1-tag example once again: There is only one correct way of constructing a main heading. If the h1-tag is correctly implemented, the problem is solved. There are potentially many ways of formulating a heading that would be approved by people testing it. There are probably even more ways of formulating a heading that people would not approve of. A tool can crawl all pages for h1-tags and report conformance. The simple rule is that every page should have at least one h1-tag. However, when you have discussed the formulation of a heading on a specific page and either approved it or not, you have to look at the next page, and the next page... This simple example of headings shows the fundamental differences between different types of accessibility needs and how to measure them.

### 5.6.4 The Issue of Privileging Text

WCAG positions text above all other types of content. Every form of non-text content is obliged to have an alternative text description. There is no obligation on text content to be provided with an alternative image or video. From the results in paper IV and the work in many projects, we can see that some people would place video content above text, and some would say it is equally important. They do not agree that accessibility is present as soon as there is text.

Even though Sweden is a country of high literacy, there are 25 percent of the Swedish adult population who struggle with text comprehension, and among those we can find 15 percent with severe problems handling text [252]. One of the main findings presented in paper IV is how difficulties related to text and language are a barrier for using the internet. Already in the earliest sets of guidelines presented in the beginning of the 21st century, there was a clear consensus among disability organisations, experts and users on the importance of presenting written text in an accessible way (see for example Friedman and Bryen [253] or Britto and Pizzolato [150]). Although WCAG privileges text, it is weak on literacy. The level of reading difficulty in a text is only covered by one very general guideline (3.1.5) on level AAA[36]. This level is outside the scope of the EU Web Accessibility Directive.

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[36] https://www.w3.org/TR/WCAG21/#readable

### 5.6.5 The Danger with Tools and Methods Aiming to Create Empathy

Tools and activities to create empathy are sometimes used as a substitute for interacting with real people with real impairments, mental health issues or homelessness. The idea is to "walk in someone else's shoes", and by doing so gaining a better understanding. We sometimes work with such tools, but it is important to be aware of the power relations at play. The one who is supposed to receive empathy is subordinated the one who is supposed to give empathy.

Contemporary design methods emphasise empathy. For example, in Design Thinking and other human centred design approaches, empathy is often presented as the first stage in a design process. For example, the Interaction Design Foundation explains; "*In the empathise stage, your goal, as a designer, is to gain an empathic understanding of the people you're designing for and the problem you are trying to solve[37]*". Note that the phrase "the people you're designing for" implies that there are no people with impairments in the design process, and no real co-operation between designers and people with impairments.

Human Centre Design pioneer, Norman, critiques this turn in Human Centered Design[38] by arguing: "The idea is that, essentially, you're in a person's head and understand how they feel and what they think. In my opinion that's impossible". Norman argues that: "Instead we must really focus on the activities that people are trying to carry out. We must also understand people's capabilities and their points of view and how to support them. That requires us to understand the wide variety of abilities that people have".

My experience is that empathy-oriented design methods generalise too much based on their data. There is rarely enough time and money in the design process to empathise with the widest range of people. If people with impairments are at all engaged, one or two often represent the whole population of people with impairments. One central idea with the work in Begripsam is that members do not represent only a specific impairment. We represent a collective knowledge of lived experience of being disabled by design, but also a collective knowledge of possible ways of doing

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[37] https://www.interaction-design.org/literature/article/design-thinking-getting-started-with-empathy. I chose this example since I find it representative of how designers are instructed to think about empathy.

[38] https://theblog.adobe.com/why-i-dont-believe-in-empathic-design-don-norman/

enabling design. We do not believe that designers are able to just 'collect the data' from our collective knowledge, and move on to do an enabling design on their own.

### 5.6.6 Predictable Mistakes should be an Accepted Reason for Doing Wrong

People with cognitive impairments should be expected to make mistakes when interacting with technology, even when reasonable design measures have been undertaken. This is arguably what Thomas describes as an 'impairment effect'.[85],

It is, for example, predictable that people with some impairments will miss deadlines, upload the wrong paper, or struggle to gather required information and to fill in long forms. It is predictable that some people cannot describe their problems in their own words. All of the examples above have been found mandatory for people to provide when interacting with the Social Insurance Agency. They have to provide the information to get the financial support they need and have a right to, according to their diagnoses. Support is rejected if people fail to provide this information. People report many severe consequences when acting in line with a given diagnosis (data from the survey presented in paper IV and from many projects). They act as can be predicted by the diagnosis or impairment, but society does not accept that behaviour, even when people apply for support provisions that they have the right to receive due to their diagnosis.

### 5.6.7 The Security Perspective Compromising Accessibility

There is a strong tension between Accessibility and Security, with the security perspective having the power to compromise accessibility. The security perspective often fails to acknowledge the widest range of human diversity. To give some examples: If accessibility and security were balanced as equally important, we would not have to deal with CAPTCHAs, identifying road signs on blurry pictures or remembering passwords like gaaah%%%#9WTF.

A common security strategy is to adopt a one-security-solution-fits-all strategy. A very naïve security assumption is that people will adapt to poor security design, for example that we will use and remember a large number of different and very complicated passwords without having them noted in some kind of document.

A particular problem in the digital society is personal identification. This problem has been brought up over and over again (from participants in paper I and III) and in answers and comments from survey-participants (paper IV). The technology for electronic identification is inaccessible for or considered too complicated by many. As digitalization moves along, it is increasingly important to be able to identify oneself as an online citizen.

## 5.7 Disability Digital Divide

There is a thin body of quantitative data on disabled people's participation in the digital society. Most research is qualitative in nature and based on small numbers of participants. Other researchers have called for more quantitative data on this.[215], [254].

The existing paradigm on how to research the Swedish population's use of the internet is to utilise randomised probability samplings. Many impairment-groups are so small that the general group can be within the statistical margin of errors. Quantitative research related to small proportions of the population cannot follow this standard procedure. The main problems are that sampling sizes are too small and that presence of impairment is by coincidence since impairment is not a factor when establishing the sample. To be able to tell anything, people with impairments are aggregated into one group, and this thesis present arguments why that is wrong. We have used methods on how to survey rare populations to be able to present quantitative data for 35 disability groups (Paper IV and V). There is no fixed proportion at which a population becomes rare, but many scholars use the ten percent limit. Populations under ten percent of the general population should be considered rare [223].

This critique of how statistical data on people with impairments are gathered, is one of the main contributions made by this thesis, to the research on disability matters. Michael, one of the members of the Begripsam group, once said (when reflecting on participation in surveys) *"my education doesn't count"*. He claimed that society does not value his education and asked us to take any survey from Statistics Sweden to check it out. He was right. One percent of Swedish students [255] attend special schools for students with intellectual impairments (särskolan). Take any survey covering the Swedish population. Among the list of types

of education, you will not find the alternative 'Särskola'. You have to tick "Other", and then write 'Särskola'. This is an example of how the creation of "otherness" works [256]. One percent is within the statistical margin of error. Michael and many others live their life in that margin.

The process of critiquing existing surveys was sparked by the national railway company (SJ) arguing it would not be a big problem to close down manual ticket selling offices at railroad stations[39]. They referred to Statistics Sweden [220], which stated that only one percent of the population found the internet difficult to use, and therefore people could buy their tickets online. People within the disability movement felt this could not be right. According to their experience the problem had to be more significant. The Begripsam group started to investigate this issue. We designed our own survey, offered several ways to participate, and used many different channels for penetrating the targeted groups. We could show that, when using accessible survey methods, the number of people having difficulties using the internet was underestimated [257].

The methodology around recruiting people with specific impairments, introduced in paper V, has been elaborated further and fine-tuned in other projects. We can now get around 1000 respondents to participate in any survey. Our concept of mirroring population-based surveys makes it possible to compare phenomena in the general population with different disability groups (diagnoses or impairments). Our strategy is **not to include** people with impairments in surveys based on methods where disability-presence is based on coincidence. Instead we take the same survey, adapting it so it becomes accessible, and target impairment groups drawing on methods for sampling rare populations.

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[39] https://www.svd.se/regeringen-kan-sanka-kraven-pa-sj [Swedish only]

### 5.7.1 To be Able to Shift when Technology Shifts

Technology changes rapidly. It is not a durable strategy to "freeze" the use of devices and interfaces at a certain point and then stay there, as we can do for example with an old car. We cannot keep using Word Perfect, or Mosaic, or Hamsterpaj even if we want to. We can try to freeze (like Peder in the Begripsam group), but eventually we have to move on (also Peder).

I am old enough to have witnessed some problematic shifts:

- When text-based bulletin board systems were superseded by graphical interfaces, many people in the deaf-blind internet community could no longer communicate online.

- When audio books on tape were superseded by Compact Discs, it could be noted that the new technology solved every problem with the old one. Still many users hung on to the old technology for as long as they could.

- When the Mobile BankID application stopped supporting "old" operating systems, many people in the RSMH-organisation could no longer use equipment at their local support centres for paying their bills.

- A common experience reported by many is that when mainstream technology shifts, the assistive technology does not, or lags behind for a long time. The complicated interplay between devices, mainstream software, assistive devices and assistive software is so delicate that when it works, people do not want to disturb that order by introducing anything new.

There is a scepticism among many towards having to transfer over to new technology. The period of transferring from one technology to another is cumbersome, and for some can be a reason to stop being active online or to have an unintended pause. It can also be expensive. We can see groups in our data who cannot afford to "keep the pace" and people who are worried that they could slip away from the digital society due to lack of resources. Technology transfer [259], Technology Readiness and Digital Readiness are often discussed on an organisational level, but the discussion is also relevant on an individual level. Leung [260] found that almost half of the Australian population might struggle with staying 'digital', if issues related to affordance, functional literacy and digital skills are taken into account. Leung argues that this is not a minority

problem and concludes that "*availability does not guarantee uptake, nor does it ensure access*" and that government must take action so that people using old technology will not be discriminated against.

A return to the artefact can in this case be to question why we are supposed to change them so frequently. When will we see more sustainable business models, making it possible to upgrade parts when they get old? What should we do to support people who cannot afford to renew their devices at a pace that aligns with the mainstream pace?

### 5.7.2 Who should Protect the Right to Use the Internet?

As Pathakji [111] argues, access to the internet should be considered a human right  and this is defended in a strong argumentation by Mathiesen [213]. But as Pathakji argues, states cannot protect those rights alone. Pathakji argues that large corporations are more important than states in this matter[40]. Corporations act on a global scale and we use their devices and services on a daily basis. If some of them consider accessibility in their design, it can have a far deeper impact than activities at the national level. The problem, according to Pathakji, is that corporations have no strong legal obligation to take their products in this direction. They can reverse the process if they like and abandon technology that is important for people. Corporations have to be bound to stronger commitments to complement commitments on state level.

## 5.8 A Framework for Participation in the Digital Society

The passage from non-participation to participation seems to be very individually framed. We need to understand the unique combination of prerequisites that has to be addressed. We can probably not find "one-size-fits-all" solutions, but people with similar needs can probably form groups and work together.

Without deeper reflection, the response to digital exclusion, is almost always more education. This, however, is only one of many prerequisites. Many of the homeless people in my study, do not need more skills. It was not a lack of skills that kept them excluded.

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[40] Think about how smart technology is rapidly leading Sweden towards a cash-free society. Only 13% of their latest payment was made with cash; [263].

A very large group, about 5 percent of the Swedish population, is partially participating in the digital society [24]. To take further steps we might need to focus on self-efficacy and create situations where the use of the internet would be emancipatory, liberating, joyful or solve an annoying problem. People with impairments often have low income, in many cases very low income. To live in poverty may be more disabling than having an impairment. Having both an impairment and being poor probably means having higher barriers to digital participation. There are well-known factors relevant for participation:

- Demographic factors: age and gender.
- **Geographic factors**: living in rural areas or cities, poor areas or rich areas.
- **Socio-economic factors**: class, education, occupation, income.

To those factors we should add **impairment**, or maybe **Body and mind related factors**. Such factors seem to play a role but cannot, as a single factor, explain participation or non-participation. To the background factors that we already know about, I would like to propose to add **loneliness**. Being isolated, having small or no networks to interact with, or having no or very few friends and relatives seems to play a role also in relation to participation in the digital society. There is an echo of loneliness in many comments. Discussions in workshops and interviews sometimes tap into a reflection on loneliness.

# 6. Conclusions

I have placed my inquiry in a landscape of frontiers, to be able to see how participation in the digital society works for people with impairments or mental health issues and for homeless people. The basic assumption was that it is together with those who struggle back and forth over the borders of a digital society, we can learn the most about participation.

There is no single factor explaining participation, and no single theory or method to be used. The inquiries have to be operating on several levels and must be studied from different perspectives. They must be moving back and forth from external to high-level societal phenomena, to how we carry out our practices and activities, and into our bodies and minds. Different perspectives are needed, and a set of theories and methods have to be used in order to make sense out of what is going on.

The so called Scandinavian relational paradigm, or the Gap model, holds a strong position within Swedish Disability Research. It is almost an imperative that disability is to be found, and studied, in a mismatch between an individual with impairments and the 'environment'. In my work though, I find that the relational model cannot on its own fully explain disabled participation in the digital society. We can see that there are impairment effects in play, so, impairment clearly matters to some extent. However, our findings point to that a major explanation of disablement in this context is to be found, and studied, outside of the concept of impairment. Social stratification and how society have been organised seems to be crucial for the understanding of participation, but also a person's emotional approach and perceptions of self as well as a more general 'peoples' perception of the other' – especially perception of the 'other's' impaired body and capabilities. Thomas [85], argues, and I agree, that disability should be studied in the same line as gender, race, sexuality, age and social class as a: *"key dimension of global social divisions and inequity that can be approached from a multiplicity of analytical directions, using a rich mix of theoretical perspectives, methodologies and research techniques" (p210).*

Disablement, as in the process of creating disability, can either be explained as an outcome of a pathological process or as an outcome of the organisation of the society. I most often search for societal phenomena to

explain why people with impairments become disabled. If we know how to make something accessible and still don't do it, then it is disablism.

Researchers and practitioners are often somewhat naïve about how their work affect people with impairments or with mental health issues and homeless people. Disablism, oppression, and patronising attitudes are often in play, often unconsciously, as a background noise. We need to deliberately bring attention to this noise by visualising it, debating it, and reflecting upon it. And we need to do this together with the people concerned.

As my work has progressed, I have come to realise the importance of being ethically grounded. To be ethically clear is equally as important as to be ontologically and epistemologically clear. As a researcher, I have a privileged position, and it matters how I use this position.

When this work started, we found literature stating that there are no reliable methods for how to do to include people with cognitive impairments in research or design processes. One of the most important results of this work is that we now can present some methods we consider do work. Surprisingly, it is many of the 'old methods' that actually do work. It is often the arrangement, the embedding of the method, what I in the thesis call 'scaffolding', which needs to be adjusted, rather than the method in itself. The mirror-survey concept, and the adaptive sampling methods presented, are suggested as favourable to achieve representation of people with impairments in surveys – and consequently, in statistics.

## 6.1 Trustworthiness and Representativeness

An important quality in Emancipatory and Participatory Action Research, is Trustworthiness and Accountability. The community you are serving for, as a researcher, needs to recognise the field of inquiry as important, and the result as relevant. They do not have to agree on all the results, but it is important that the results can be recognised as relevant and used in the process of change. The process of change operates on three levels; Personal, Societal and Scientifically.

Action Research is strongly situated, and whether a result can be generalised or not, is up for debate. A form of generalisation is the potential of Transferability and Replicability of a research project. Transferability addresses the question of whether this research could be

used within other domains, with other groups, in other parts of the world etc. Replicability addresses the question of whether the same population could gather again and do research on participation, using our settings. I think there is potential for replicability in the work we have done. I cannot say so much about the transfer potential, as that has to be discussed with people belonging to other communities.

At this point, we should also discuss Representativeness. Are the people, participating in this research, representative of all people with impairments, with mental health issues or homeless people? Since those people are not identified in any usable registers, the characteristics for representatives have to be pieced together relying on a range of sources, where I found the organisations and communities these people belong to, as the most credible sources. I have recruited research participants with the assistance of a large number of organisations and with the help from many people.

We should also discuss my own potential biases. As for the prevention of the effects of a bias I am open with my agenda and I declare with whom I collaborate and to whom I direct my solidarity. I have tried my best to accomplish rigour in my research and to present methods, data and results as fair as I can.

There is still a lot more work to be done towards a digital society that includes all its citizens as active participants. With this thesis I would like to say that I am suggesting a way forward. The methods we have used in this research, and adapted according to our needs, are not new, but thoroughly tested and renewed, and this work has been firmly grounded in the participants' lived experience of exclusion.

My final word will be, that we should design for participation, and inclusion will follow.

# References

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

[2]     P. O. Hedvall, The Activity Diamond: Modeling an Enhanced Accessibility. Certec, 2009.

[3]     J. Bardzell, "Commentary on: Shusterman, Richard (2014): Somaesthetics," in *The Encyclopedia of Human-Computer Interaction*, Aarhus, Denmark: The Interaction Design Foundation, 2012.

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

[5]     C. Thomas, "Disability and impairment," in *Disabling Barriers, Enabling Environments*, 3rd ed., J. Swain, S. French, C. Barnes, and C. Thomas, Eds. Sage, 2014, pp. 9–17.

[6]     K. Holmes, Mismatch: How Inclusion Shapes Design. MIT Press, 2018.

[7]     L. M. Verbrugge and A. M. Jette, "The disablement process," *Soc. Sci. Med.*, vol. 38, no. 1, pp. 1–14, 1994.

[8]     J. Swain, S. French, C. Barnes, and C. Thomas, Eds., *Disabling Barriers - Enabling Environments*, 3rd ed. Sage, 2014.

[9]     F. K. Campbell, "Refusing Able(ness ): A Preliminary Conversation about Ableism," *J. Media Cult.*, vol. 11, no. 3, 2008.

[10]    S. R. Porter, "Rare Populations," in *Encyclopedia of Survey Research Methods*, P. J. Lavrakas, Ed. Thousand Oaks: Sage Publications, Inc., 2011, pp. 690–691.

[11]    United Nations, "Convention on the rights of persons with disabilities," 2006.

[12]    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].

[13]    International Organization for Standardization, "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].

[14]    I. Illich, *Tools for Conviviality*, Reprinted. Marion Boyars Publishers Ltd, 1973.

[15]     A. P. Beskow, J. Beskow, and M. T. Miró, Kognitiv psykoterapi och medvetenhetsutveckling: om att leva i konvivialitet. Center för kognitiv psykoterapi och utbildning, 2001.

[16]     S. Johansson and R. Hansen, "E-health among Disabled people in Region Skåne [In Swedish:Skåningar med funktionsnedsättning och e-hälsa]," Malmö, 2018.

[17]     B. Danermark, "Interdisciplinary Research and Critical Realism The Example of Disability Research," *Alethia*, vol. 5, no. 1, pp. 56–64, 2002.

[18]     J. Bardzell and S. Bardzell, *Humanistic HCI*. Morgan & Claypool Publishers, 2015.

[19]     C. Taylor, "Interpretation and the Sciences of Man," *Rev. Metaphys.*, vol. 25, no. 1, pp. 3–51, 1971.

[20]     C. H. Cherryholmes, "Notes on Pragmatism and Scientific Realism," *Educ. Res.*, vol. 21, no. 6, pp. 13–17, 1992.

[21]     R. Molich, B. Laurel, C. Snyder, W. Quesenbery, and C. E. Wilson, "Ethics in HCI," *CHI '01 Ext. Abstr. Hum. factors Comput. Syst. - CHI '01*, p. 217, 2001.

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

[23]     N. Carpentier, "The concept of participation. If they have access and interact, do they really participate?," *Commun. Manag. Q.*, vol. 21, no. 13, pp. 13–36, 2011.

[24]     The Internet Foundation in Sweden (IIS), "The Swedes and the internet 2018," 2018. [Online]. Available: https://2018.svenskarnaochinternet.se/the-swedes-and-the-internet-2018-summary/. [Accessed: 19-Jan-2019].

[25]     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. 2014, p. 14.

[26]     M. Sépulchre, "This is not citizenship. Analysing the claims of disability activists in Sweden," Uppsala University, 2019.

[27]     C. Bühler, "Empowered participation of users with disabilities in R&D projects," *Int. J. Hum. Comput. Stud.*, vol. 55, no. 4, pp. 645–659, 2001.

[28]     M. Oliver, "Changing the Social Relations of Research Production?," *Disabil. Handicap Soc.*, vol. 7, no. 2, pp. 101–114, 1992.

[29]     C. Barnes, "'Emancipatory disability research': project or process?," *J. Res. Spec. Educ. Needs*, vol. 2, no. 1, 2004.

[30] C. Barnes, "What a difference a decade makes: Reflections on doing 'emancipatory' disability research," *Overcoming Disabling Barriers 18 Years Disabil. Soc.*, vol. 7599, pp. 346–361, 2006.

[31] P. Freire, *Pedagogy of the Oppressed*, 50th Anniv. New York, USA: Bloomsbury Academics.

[32] E. Stone and M. Priestley, "Parasites , Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers," *Br. J. Sociol.*, vol. 47, no. 4, pp. 699–716, 1996.

[33] G. Zarb, "On the Road to Damascus: First Steps towards Changing the Relations of Disability Research Production," *Disabil. Handicap Soc.*, vol. 7, no. 2, pp. 125–138, 1992.

[34] L. Barton, "Emancipatory research and disabled people: some observations and questions," *Educ. Rev.*, vol. 57, no. 3, pp. 317–327, 2005.

[35] 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.

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

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

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

[39] A. Giddens, The Constitution of Society: Outline of the Theory of Structuration. 1984.

[40] P. Bourdieu, "Outline of a Theory of Practice," *Cambridge Univ. Press*, 1977.

[41] E. Shove, M. Pantzar, and M. Watson, The Dynamics of Social Practice - Everyday life and how it changes. London: Sage Publication Ltd, 2012.

[42] A. Reckwitz, "Toward a theory of social practices: A development in culturalist theorizing," *Eur. J. Soc. Theory*, vol. 5, no. 2, pp. 243–263, 2002.

[43] T. R.Schatzki, "Introduction - Practice theory," in *The Practice Turn in Contemporary Theory*, T. R. Schatzki, K. K. Cetina, and E. von Savigny, Eds. Routledge Taylor & Francis Group, 2003.

[44]    M. S. Feldman and W. J. Orlikowski, "Theorizing Practice and Practicing Theory," *Organ. Sci.*, vol. 22, pp. 1240–1253, 2011.

[45]    A. Warde, "Consumption and Theories of Practice," *J. Consum. Cult.*, vol. 5, no. 2, pp. 131–153, 2005.

[46]    E. Shove, "Beyond the ABC: Climate change policy and theories of social change," *Environ. Plan. A*, vol. 42, no. 6, pp. 1273–1285, 2010.

[47]    D. J. Greenwood and M. Levin, Introduction to action research: Social research for social change. SAGE publications, 2006.

[48]    M. Tanabe, E. Pearce, and S. K. Krause, "'Nothing about us, without us': Conducting participatory action research among and with persons with disabilities in humanitarian settings," *Action Res.*, vol. 16, no. 3, pp. 280–298, 2018.

[49]    C. Frauenberger, J. Good, G. Fitzpatrick, and O. S. Iversen, "In pursuit of rigour and accountability in participatory design," *Int. J. Hum. Comput. Stud.*, vol. 74, pp. 93–106, 2015.

[50]    F. E. Balcazar, C. B. Keys, D. L. Kaplan, and Y. Suarez-Balcazar, "Participatory Action Research and People with Disabilities: Principles and Challenges," *Can. J. Rehabil.*, vol. 12, pp. 105–112, 1998.

[51]    D. Selener, *Participatory action research and social change.* Cornell Participatory Action research Network, Cornell University, 1997.

[52]    Y. Suarez-Balcazar, F. E. Balcazar, and C. B. Keys, "A self-help guide for community needs assessment and action planning," 1997.

[53]    M. Oliver, Understanding Disability, From Theory to Practice. London: Macmillan, 1996.

[54]    T. Siebers, *Disability theory*. University of Michigan Press, 2008.

[55]    "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].

[56]    Socialstyrelsen, "The National Board of Health and Welfare - Term Bank [In Swedish: Socialstyrelsens Termbank]," 2019. [Online]. Available: http://termbank.socialstyrelsen.se/?TermId=794&SrcLang=sv. [Accessed: 20-Apr-2019].

[57]    E. Goffman, Stigma: notes on the management of spoiled identity. Simon and Schuster, 2009.

[58]    J. Stuber, I. Meyer, and B. Link, "Stigma, prejudice, discrimination and health," *Soc. Sci. Med.*, vol. 67, no. 3, pp. 351–357, 2008.

[59]    D. L. Braddock and S. L. Parish., "An Institutional History of Disability," in *Handbook of Disability Studies*, 2nd ed., G. L. Albrecht, K. D. Seelman, and M. Bury, Eds. Thousand Oaks: Sage Publications, 2001.

[60]    W. Wolfensberger, "The Origin And Nature Of Our Institutional Models," *Changing Patterns in Residential Services for the Mentally Retarded*, 1969. [Online]. Available: http://www.disabilitymuseum.org/dhm/lib/detail.html?id=1909&page=all. [Accessed: 15-Apr-2019].

[61]    R. Imrie and M. Kumar, "Focusing on Disability and Access in the Built Environment," *Disabil. Soc.*, vol. 13, no. 3, pp. 357–374, 1998.

[62]    A. Llewellyn and K. Hogan, "The Use and Abuse of Models of Disability," *Disabil. Soc.*, vol. 15, no. 1, pp. 157–165, 2000.

[63]    M. Johnston, "Models of disability," *Physiother. Theory Pract.*, vol. 12, no. 3, pp. 131–141, 1996.

[64]    C. Boorse, "On the Distinction between Disease and Illness," *Philos. Public Aff.*, vol. 5, no. 1, pp. 49–68, 1975.

[65]    M. Oliver, "Theories of disability in health practice and research," *BMJ*, vol. 317, pp. 1446–1449, 1998.

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

[67]    I. Lourida *et al.*, "Association of Lifestyle and Genetic Risk With Incidence of Dementia," *JAMA*, Jul. 2019.

[68]    A. L. Komaroff, "Advances in Understanding the Pathophysiology of Chronic Fatigue Syndrome," *JAMA*, Jul. 2019.

[69]    D. Alnæs *et al.*, "Brain Heterogeneity in Schizophrenia and Its Association With Polygenic Risk," *JAMA Psychiatry*, vol. 76, no. 7, pp. 739–748, Jul. 2019.

[70]    R. Epstein, F. Borrell-Carrio, and A. Suchman, "The Biopsychosocial Model 25 Years Later: Principles, Practice, and Scientific Inquiry," *Ann. Fam. Med.*, vol. 2, no. 6, pp. 576–582, 2004.

[71]    V. Finkelstein, "The commonality of disability," in *Disabling barriers, enabling environments*, Swain, Finkelstein, French, and Oliver, Eds. Sage, 1993.

[72]    V. Finkelstein, "A Personal Journey Into Disability Politics." Leeds University Centre for Disability Studies, Leeds, pp. 1–15, 2001.

[73]    B. Kelly, S. Lewthwaite, and D. Sloan, "Developing countries; developing experiences," *Proc. 2010 Int. Cross Discip. Conf. Web Access. - W4A '10*, p. 1, 2010.

[74]    M. Oliver, "Social Policy and Disability : Some Theoretical Issues," *Disabil. Handicap Soc.*, vol. 1, no. 1, pp. 5–17, 1986.

[75]    P. Abberley, "The Concept of Oppression and the Development of a Social Theory of Disability," *Disabil. Handicap Soc.*, vol. 2, no. 1, pp. 5–19, 1987.

[76]    UPIAS, "Fundamental Principles of Disability, Union of the Physically Impaired Against Segregation." London, 1976.

[77]    V. Finkelstein, "The social model of disability repossessed." Manchester Coalition of Disabled People, pp. 1–5, 2001.

[78]    M. Oliver, B. Sapey, and P. Thomas, *Social work with disabled people*. Palgrave Macmillan, 1983.

[79]    C. Barnes, "Understanding the Social Model of Disability: Past, present and future," in *Routledge handbook of disability studies*, Routledge, 2013, pp. 26–43.

[80]    J. E. Bickenbach, S. Chatterji, and E. M. Badley, "Models of disablement , universalism and the international classification of impairments , disabilities and handicaps," *Soc. Sci. Med.*, vol. 48, pp. 1173–1187, 1999.

[81]    W. Ekensteen, På Folkhemmets bakgård [In English: At the People's Home Backyard]. Verdandi debatt, Prisma, 1968.

[82]    R. Scotch and K. Schriner, "Disability as Human Variation: Implications for Policy," *Ann. AAPSS*, vol. 549, 1997.

[83]    K. Schriner and R. Scotch, "Disability and Institutional Change. A Human Variation Perspective on Overcoming Oppression," *J. Disabil. Policy Stud.*, vol. 12, no. 2, pp. 100–106, 2001.

[84]    D. Anastasiou and J. M. Kauffman, "The social model of disability: Dichotomy between impairment and disability," *J. Med. Philos. (United Kingdom)*, vol. 38, no. 4, pp. 441–459, 2013.

[85]    C. Thomas, "Theorising disability and chronic illness: Where next for perspectives in medical sociology," *Soc. Theory Heal.*, vol. 10, no. 3, pp. 209–228, 2012.

[86]    G. Quinn, T. Degener, A. Bruce, C. Burke, P. Kenna, and S. Quinlivan, Human Rights and Disability The current use and future potential of United Nations human rights instruments in the context of disability. United Nations, 2002.

[87]    European Union, "EU Web Accessibility Directive," *Official Journal of the European Union*, 2018. [Online]. Available: https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX%3A32016L2102.

[88]    European Commission, "Proposal for a European Accessibility Act," 2019. [Online]. Available: https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM:2015:0615:FIN. [Accessed: 15-May-2019].

[89]    I. M. Lid, "Developing the theoretical content in Universal Design," *Scand. J. Disabil. Res.*, vol. 15, no. 3, pp. 203–215, 2013.

[90]    I. M. Lid, "Universal Design and disability an interdisciplinary perspective," *Disabil. Rehabil. ISSN*, vol. 8288, 2014.

[91]    B. Nirje, "The Normalization Principle and Its Human Management Implications," *SRV-VRS Int. Soc. Role Valorization J.*, vol. 1, no. 2, pp. 19–23, 1994.

[92]    D. Godley, Disability studies: An interdisciplinary introduction. Sage, 2016.

[93]    B. Danermark, Sociologiska perspektiv på funktionshinder och handikapp. Lund: Studentlitteratur, 2005.

[94]    J. Grue, *Disability and Discourse Analysis*. Farnham, England: Ashgate Publishing Company, 2015.

[95]    "WHO - Disabilities." [Online]. Available: http://www.who.int/topics/disabilities/en/. [Accessed: 30-Sep-2019].

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

[97]    R. Bhaskar and B. Danermark, "Metatheory, interdisciplinarity and disability research: A critical realist perspective," *Scand. J. Disabil. Res.*, vol. 8, no. 4, pp. 278–297, 2006.

[98]    WHO, "How to use ICF - A Practical Manual (draft)," 2013.

[99]    C. Frauenberger, "Disability and Technology A Critical Realist Perspective," in *ASSETS'15*, 2015, pp. 89–96.

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

[101]   D. Gasper, "Policy Arena: Sen's Capability Approach and Nussbaums's Capabilities Ethic," *J. Int. Dev.*, vol. 9, no. 2, pp. 281–302, 1997.

[102]   M. Nussbaum, "Capabilities as Fundamental Entitlements: Sen and Social Justice," *Fem. Econ.*, vol. 9, no. 2–3, pp. 33–59, 2003.

[103]   M. C. Nussbaum, "Social Justice and Universalism: In Defense of an Aristotelian Account of Human Functioning," *Mod. Philol.*, vol. 90, pp. 46–73, 1993.

[104]   T. Schulz and L. Fritsch, "Accessibility and Inclusion Requirements for
        Future e-Identity Solutions," in *ICCHP 2014, Part I, LNCS 8547*, 2014, pp.
        316–323.

[105]   D. Castro and W. Quesenberyl, "Innovations for Accessible Elections,"
        2013.

[106]   S. Carmien and A. G. Manzanares, "Elders using smartphones - A set of
        research based heuristic guidelines for designers," *Lect. Notes Comput.
        Sci. (including Subser. Lect. Notes Artif. Intell. Lect. Notes
        Bioinformatics)*, vol. 8514 LNCS, no. PART 2, pp. 26–37, 2014.

[107]   W3C, "WCAG, Web Content Accessibility Guidelines 2.1," 2017. [Online].
        Available: https://www.w3.org/TR/WCAG21/. [Accessed: 02-Jan-2019].

[108]   I. O. for Standardization, "ISO/TC 173 Assistive Products." [Online].
        Available: http://www.iso.org/iso/
        iso_technical_committee%3Fcommid%3D53782. [Accessed: 24-
        Jan-2016].

[109]   E. Ellcessor, "Bridging Disability Divides - A critical history of web content
        accessibility through 2001," *Information, Commun. Soc.*, vol. 13, no. 3,
        pp. 289–308, 2010.

[110]   A. D'Aubin, "Working for Barrier Removal in the ICT Area: Creating a
        More Accessible and Inclusive Canada," *Inf. Soc.*, vol. 23, no. 3, pp. 193–
        201, 2007.

[111]   N. Pathakji, Corporations and Disability Rights: Bridging the Digital
        Divide. Oxford University Press, 2018.

[112]   W. A. I. W3C, "Making the Web Accessible," 2019. [Online]. Available:
        https://www.w3.org/WAI/. [Accessed: 25-Jul-2019].

[113]   W3C, "Authoring Tool Accessibility Guidelines (ATAG)
        Overview." [Online]. Available: https://www.w3.org/WAI/intro/atag.php.
        [Accessed: 30-Sep-2019].

[114]   W3C, "User Agent Accessibility Guidelines (UAAG) Overview," 2016.
        [Online]. Available: https://www.w3.org/WAI/intro/uaag.php. [Accessed:
        13-Aug-2016].

[115]   J. O. Wobbrock, S. K. Kane, K. . Gajos, S. Harada, and J. Froelich,
        "Ability-Based Design: Concept, Principles and Examples," *ACM Trans.
        Access. Comput.*, vol. 3, no. 3, pp. 1–27, 2011.

[116]   K. Z. Gajos, J. O. Wobbrock, and D. S. Weld, "Improving the Performance
        of Motor-Impaired Users with," in *CHI 2008, April 5-10, 2008, Florence,
        Italy*, 2008, pp. 1257–1266.

[117]   K. . Gajos, A. Hurst, and L. Findlater, "Personalized Dynamic Accessibility," *Interactions*, vol. XIX.2, 2012.

[118]   British Assistive Technology Association, "ASSISTIVE TECHNOLOGY IN THE WORKPLACE Towards a more inclusive working environment," 2013.

[119]   World Health Organization, "Global priority research agenda for improving access to high-quality affordable assistive technology," Geneva, 2017.

[120]   W. Harpe, J. Kingsbury, and J. Hassell, "Accessibility study of BBCi: Problems faced by users with disabilities," 2003.

[121]   S. May, "A web accessibility assessment on the Texas public school system," *Univers. Access Inf. Soc. Int. J.*, p. 18, 2009.

[122]   M. Crabb, M. Armstrong, M. Heron, H. Reid, and A. Wilson, "Understanding Current Knowledge and Areas for Future Support," in *CHIConference on Human Factors in Computing Systems Proceedings (CHI 2019), May 4–9, 2019, Glasgow, Scotland UK*, 2019.

[123]   "Bootstrap." [Online]. Available: https://getbootstrap.com. [Accessed: 25-Jul-2019].

[124]   A. Pascual, M. Ribera, and T. Granollers, "Empathic communication of accessibility barriers in Web," in *W4A2015 Technical Paper, May 18-20*, 2015.

[125]   C. Bailey and V. Gkatzidou, "Considerations for Implementing a Holistic Organisational Approach to Accessibility System Concepts," in *W4A 2017, April 02 – 04, 2017, Perth, Western Australia, Australia*, 2017.

[126]   R. W. Edwards, P. Jumper-Thurman, B. A. Plesred, E. R. Oetting, and L. Swanson, "Community readiness: Research to practice," *J. Community Psychol.*, vol. 28, no. 3, pp. 291–307, 2000.

[127]   B. Kelly, S. Lewthwaite, and D. Sloan, "Developing countries; developing experiences: approaches to accessibility for the Real World," *Eprints-journal*, vol. 1805992, 2010.

[128]   D. Sloan and S. Horton, "Global Considerations in Creating an Organizational Web Accessibility Policy," in *W4A '14, April 07 - 09 2014*, 2014, no. January.

[129]   M. Cooper, D. Sloan, B. Kelly, and S. Lewthwaite, "A Challenge to Web Accessibility Metrics and Guidelines: Putting People and Processes First," in *W4A 2012: 9th International Cross-Disciplinary Conference on Web Accessibility, 2012-04-16 - 2012-04-18, Lyon*, 2012.

[130]    G. Brajnik, Y. Yesilada, and S. Harper, "Is Accessibility Conformance an Elusive Property? A Study of Validity and Reliability of WCAG 2 .0," *ACM Trans. Access. Comput.*, vol. 4, no. 2, 2012.

[131]    Y. Yesilada, G. Brajnik, and S. Harper, "How Much Does Expertise Matter? A Barrier Walkthrough Study with Experts and Non-Experts," in *ASSETS'09, October 25-28*, 2009, pp. 203–210.

[132]    G. Brajnik, "Beyond Conformance: The Role of Accessibility Evaluation Methods," in Web Information Systems Engineering – WISE 2008 Workshops. WISE 2008. Lecture Notes in Computer Science, vol 5176., 2008, pp. 63–80.

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

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

[135]    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].

[136]    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].

[137]    W3C, "Cognitive and Learning Disabilities Accessibility Task Force (Coga TF) of the AG WG and APA WG." [Online]. Available: http://www.w3.org/WAI/PF/cognitive-a11y-tf/. [Accessed: 30-Sep-2019].

[138]    L. Seeman and M. Cooper, "Cognitive Accessibility User Research," 2015. [Online]. Available: https://www.w3.org/TR/coga-user-research/. [Accessed: 26-Jul-2019].

[139]    W3C, "Cognitive Accessibility at W3C," 2019. [Online]. Available: https://www.w3.org/WAI/cognitive/#cognitive-accessibility-work-at-w3c. [Accessed: 26-Jul-2019].

[140]    W3C, "Requirements for Silver Draft - Community Group Report 11 June 2019," 2019. [Online]. Available: https://w3c.github.io/silver/requirements/index.html#multiple-ways-to-measure. [Accessed: 15-Aug-2019].

[141]    S. Abou-Zahra, "Web Accessibility Evaluation," in *Web Accessibility*, S. Harper and Y.Yesilada, Eds. Springer-Verlag London, 2008.

[142]    H. Petrie and N. Bevan, "The evaluation of accessibility, usability and user experience," in *The Universal Access Handbook*, C. Stephanidis, Ed. CRC Press, 2009.

[143]   E. Jokisuu, P. Langdon, and P. J. Clarkson, "Modelling cognitive impairment to improve universal access," in *Universal Access in HCI, Part II*, vol. 6766 LNCS, C. Stephanidis, Ed. Springer-Verlag Berlin Heidelberg, 2011, pp. 42–50.

[144]   J. E. Bickenbach, Assistive Technology and the International Classification of Functioning, Disability, and Health. John Wiley & Sons, Inc, 2008.

[145]   M. A. Staal, "Stress, Cognition, and Human Performance: A Literature Review and Conceptual Framework," Moffett Field, California, 2004.

[146]   J. Nielsen, "Accessible Design for Users With Disabilities," 1996. [Online]. Available: https://www.nngroup.com/articles/accessible-design-for-users-with-disabilities/. [Accessed: 26-Jul-2019].

[147]   C. Lewis, "HCI for people with cognitive disabilities," *ACM SIGACCESS Access. Comput.*, no. 83, pp. 12–17, 2005.

[148]   J. Small, P. Schallau, K. Brown, and R. Appleyard, "Web Accessibility for People with Cognitive Disabilities," in *CHI 2005*, 2005, pp. 1793–1796.

[149]   D. Poulson and C. Nicolle, "Making the internet accessible for people with cognitive and communication impairments," *Univers. Access Inf. Soc.*, vol. 3, no. 1, pp. 48–56, 2004.

[150]   T. C. P. Britto and E. B. Pizzolato, "Towards Web Accessibility Guidelines for People With Autism Spectrum Disorder," no. January, pp. 138–144, 2016.

[151]   B. Harrysson, A. Svensk, and G. I. Johansson, "How people with developmental disabilities navigate the Internet," *Br. J. Spec. Educ.*, vol. 31, no. 3, pp. 138–142, 2004.

[152]   M. Cooper, "Web Accessibility Guidelines for the 2020s," in *W4A'16, April 11 - 13, 2016*, 2016, pp. 3–6.

[153]   G. Vanderheiden, "Design of HTML (Mosaic) Pages to Increase their Accessibility to Users with Disabilities Strategies for Today and Tomorrow (1995)," *Trace R& D Center, University of Wisconsin - Madison*, 1995. [Online]. Available: https://trace.umd.edu/publications/design-html-mosaic-pages-increase-their-accessibility-users-disabilities-strategies. [Accessed: 15-Jul-2019].

[154]   G. Vanderheiden and W. Chisholm, "Central Reference Document - Version 8 Unified Web Site Accessibility Guidelines," 1998. [Online]. Available: https://trace.umd.edu/publications/central-reference-document-version-8-unified-web-site-accessibility-guidelines. [Accessed: 15-Jul-2019].

[155]   W3C, "Web Content Accessibility Guidelines 1.0," 1999. [Online].
        Available: https://www.w3.org/TR/WAI-WEBCONTENT/. [Accessed: 15-
        Aug-2019].

[156]   The European Committee for Standardization, "What is a Standard?,"
        2019. [Online]. Available: https://www.cen.eu/work/ENdev/whatisEN/
        Pages/default.aspx. [Accessed: 15-Jul-2019].

[157]   Anec, "Updated ANEC Policy Statement on Design for All," 2007.

[158]   ETSI, EN 301 549 - V2.1.2 - Accessibility requirements for ICT products
        and services, vol. 2. ETSI, 2018, pp. 1–152.

[159]   ISO/TC173, ISO 21801-1 Cognitive accessibility -- Part 1: General
        guidelines. 2019.

[160]   CEN/CLC/JTC 12, EN 17161:2019 'Design for All - Accessibility following
        a Design for All approach in products, goods and services - Extending the
        range of users. 2019.

[161]   "DIRECTIVE (EU) 2016/2102 OF THE EUROPEAN PARLIAMENT AND
        OF THE COUNCIL of 26 October 2016 on the accessibility of the
        websites and mobile applications of public sector bodies," *Off. J. Eur.
        Union*, 2018.

[162]   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.

[163]   R. Garland-Thomson, Extraordinary Bodies: Figuring Physical Disability
        in American Culture and Literature. Columbia University Press, 1996.

[164]   R. Garland-Thomson, "Misfits: A Feminist Materialist Disability Concept,"
        *Hypatia vol.*, vol. 26, no. 3, 2011.

[165]   A. Svensk, "Vad är det som sitter i väggarna? Om att utforma miljöer och
        ting som stöd för tanken," 2005.

[166]   D. A. Norman, "Affordance, conventions, and design," *Interactions*, vol. 6,
        no. 3, pp. 38–43, 1999.

[167]   S. B. Ortner, Anthropology and social theory: Culture, power, and the
        acting subject. Duke University Press, 2006.

[168]   S. Ortner, "Thick resistance: Death and the cultural construction of
        agency in Himalaya mountaineering," in *The fate of 'culture': Geertz and
        beyond*, S. Ortner, Ed. 1999.

[169]   S. Harrison, D. Tatar, and P. Sengers, "The three paradigms of HCI," *Alt.
        Chi. Sess. SIGCHI …*, pp. 1–18, 2007.

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

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

[172]   PwC Australia, "The Benefit of Designing for Everyone," 2019.

[173]   K. Kuutti, "HCI and design : uncomfortable bedfellows ?," in *(Re)searching the Digital Bauhaus*, Binder, Löwgren, and Malmborg, Eds. London: Springer, 2009, pp. 43–59.

[174]   International Organization for Standardization, ISO/TS 20282-2 Usability of consumer products and products for public use — Part 2: Summative test method, vol. 2013. 2013.

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

[176]   R. L. Mace, "Universal Design: Barrier-Free Environments for Everyone," *Des. West*, vol. 33, no. 1, pp. 147–152, 1985.

[177]   M. F. Story, J. L. Mueller, and R. L. Mace, The Universal Design File: Designing for People of All Ages and Abilities. The Center for Universal Design, NC State University, 1998.

[178]   P. John Clarkson and R. Coleman, "History of inclusive design in the UK," *Appl. Ergon.*, vol. 46, no. PB, pp. 235–247, 2015.

[179]   J. Abascal, S. D. J. Barbosa, C. Nicolle, and P. Zaphiris, "Rethinking universal accessibility: a broader approach considering the digital gap," *Univers. Access Inf. Soc.*, vol. 15, no. 2, pp. 179–182, 2016.

[180]   A. F. Newell, P. Gregor, M. Morgan, G. Pullin, and C. Macaulay, "User-Sensitive Inclusive Design," *Univers. Access Inf. Soc.*, vol. 10, no. 3, pp. 235–243, 2011.

[181]   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.

[182]   C. Stephanidis, User Interfaces for All - Concepts, Methods, and Tools. Taylor & Francis, 2001.

[183]   A. Hamraie, "Universal Design and the Problem of 'Post-Disability' Ideology," *Des. Cult.*, vol. 8, no. 3, pp. 285–309, 2016.

[184]   R. Lifchez and B. Winslow, Design for Independent Living: The Environment and Physically Disabled People. Berkeley, CA: University of California Press. Linton, 1982.

[185]   R. Lusher and R. L. Mace, "Design for Physical and Mental Disabilities,"
        in *Encyclopedia of Architecture: Design Engineering and Construction*,
        Wilkes and Packard, Eds. New York: John Wiley and Sons, 1989.

[186]   D. Levine and E. Steinfeld, *The NYC Guidebook to Accessibility and
        Universal Design*. New York: Center for Inclusive Design and
        Environmental Access, 2003.

[187]   Y. S. Choi, J. S. Yi, C. M. Law, and J. A. Jacko, "Are 'universal design
        resources' designed for designers?," p. 87, 2007.

[188]   M. F. Story, "Maximizing usability: the principles of universal design,"
        *Assist. Technol.*, vol. 10, no. 1, pp. 4–12, 1998.

[189]   S. Seok, B. DaCosta, and R. Hodges, "A Systematic Review of
        Empirically Based Universal Design for Learning: Implementation and
        Effectiveness of Universal Design in Education for Students with and
        without Disabilities at the Postsecondary Level," *Open J. Soc. Sci.*, vol.
        06, no. 05, pp. 171–189, 2018.

[190]   M. Mustaquim and T. Nyström, "Designing Sustainable IT System – From
        the Perspective of Universal Design Principles," in Universal Access in
        Human-Computer Interaction. Design Methods, Tools, and Interaction
        Techniques for eInclusion. UAHCI 2013. Lecture Notes in Computer
        Science, vol 8009, 2013.

[191]   D. A. Norman and S. . Draper, User Centered System Design. New
        Perspectives on Human-Computer Interaction. Erlbaum Associates Inc,
        1986.

[192]   H. Petrie and O. Kheir, "The Relationship between Accessibility and
        Usability of Websites," in *CHI 2007, April 28–May 3.*, 2007, pp. 397–406.

[193]   M. Hassenzahl and N. Tractinsky, "User experience - A research agenda,"
        *Behav. Inf. Technol.*, vol. 25, no. 2, pp. 91–97, 2006.

[194]   Erling Bjögvinsson, P. Ehn, and P.-A. Hillgren, "Design things and design
        thinking: Contemporary participatory design challenges," *Des. Issues*, vol.
        28, no. 3, pp. 101–116, 2000.

[195]   S. Lindquist, "Perspective on Cooperative Design," KTH; Stockholms
        Universitet, 2007.

[196]   S. Bødker and Y. Sundblad, "Usability and interaction design – new
        challenges for the Scandinavian tradition," *Behav. Inf. Technol.*, vol. 27,
        no. 4, pp. 293–300, 2008.

[197]   Toni Robertson and J. Simonsen, "Participatory Design," in *Routledge
        International Handbook of Participatory Design*, Routledge., 2012.

[198]    K. Halskov and N. B. Hansen, "The diversity of participatory design research practice," *J. Hum. Comput. Stud.*, vol. 74, pp. 81–92, 2015.

[199]    A. Borning and M. Muller, "Next steps for Value Sensitive Design," *Conf. Hum. Factors Comput. Syst. - Proc.*, pp. 1125–1134, 2012.

[200]    B. Friedman and P. Kahn, "Value sensitive design: Theory and methods," *Univ. Washingt. Tech.*, no. December, pp. 1–8, 2002.

[201]    B. Friedman, P. H. Kahn Jr., and A. Borning, "Value Sensitive Design and Information Systems," in *The Handbook of Information and Computer Ethics*, K. E. Himma and H. T. Tavani, Eds. John Wiley & Sons, Inc., 2008, pp. 1–27.

[202]    N. Manders-Huits, "What Values in Design? The Challenge of Incorporating Moral Values into Design," *Sci. Eng. Ethics*, vol. 17, no. 2, pp. 271–287, 2011.

[203]    N. Jacobs and A. Huldtgren, "Why value sensitive design needs ethical commitments," *Ethics Inf. Technol.*, vol. 0, no. 0, pp. 1–4, 2018.

[204]    A. Wright, Cataloging the world: Paul Otlet and the birth of the information age. Oxford University Press, 2014.

[205]    H. G. Wells, "World brain," *Encycl. Française*, 1937.

[206]    M. K. Buckland, Emanuel Goldberg and his knowledge machine. Greenwood Publishing Group, 2006.

[207]    V. Bush, "As we may think," *Atl. Mon.*, vol. 176, no. 1, pp. 101–108, 1945.

[208]    W3C, "Accessibility," 2018. [Online]. Available: https://www.w3.org/standards/webdesign/accessibility.

[209]    World Wide Web Consortium (W3C), "World Wide Web Consortium (W3C) Launches International Web Accessibility Initiative," 1997. [Online]. Available: https://www.w3.org/Press/WAI-Launch.html. [Accessed: 05-Jan-2019].

[210]    P. Blanck, "The Struggle for Web eQuality by Persons with Cognitive Disabilities," *Behav. Sci. Law*, no. 32, pp. 4–32, 2014.

[211]    The Coleman Institute, "The Rights of People with Cognitive Disabilities to Technology and Information Access," 2013. [Online]. Available: https://www.colemaninstitute.org/technology-and-information-access/. [Accessed: 27-Jul-2019].

[212]    S. B. Wicker and S. M. Santoso, "Access to the Internet Is a Human Right," *Commun. ACM*, vol. 56, no. 6, pp. 43–46, 2013.

[213]  K. Mathiesen, "The Human Right to Internet Access: A Philosophical Defense," *Int. Rev. Inf. Ethics Vol.*, vol. 18, no. 12, pp. 9–22, 2012.

[214]  E. Hargittai, "An update on survey measures of web-oriented digital literacy," *Soc. Sci. Comput. Rev.*, vol. 27, no. 1, pp. 130–137, 2009.

[215]  K. Dobransky and E. Hargittai, "Unrealized potential: Exploring the digital disability divide," *Poetics*, vol. 58, pp. 18–28, 2016.

[216]  P. Di Maggio, E. Hargittai, C. Celeste, and S. Shafer, "From Unequal Access to Differentiated Use : A Literature Review and Agenda for Research on Digital Inequality," in *Social Inequality*, K. Neckerman, Ed. New York: Russell Sage Foundation, 2004, pp. 355–400.

[217]  A. J. van Deursen and J. A. van Dijk, "The digital divide shifts to differences in usage," *New Media Soc.*, vol. 16, no. 3, pp. 507–526, 2014.

[218]  A. J. A. M. van Deursen and J. A. G. M. van Dijk, "Internet skill levels increase, but gaps widen: a longitudinal cross-sectional analysis (2010–2013) among the Dutch population," *Inf. Commun. Soc.*, vol. 18, no. 7, pp. 782–797, 2015.

[219]  O. Findahl, "Svenskarna och Internet 2016," 2016.

[220]  Statistics Sweden (SCB), "ICT usage in households," *Use of computers and the internet by private persons 2016*, 2016. [Online]. Available: https://www.scb.se/Statistik/_Publikationer/ LE0108_2016A01_BR_00_IT01BR1601.pdf. [Accessed: 05-Jan-2019].

[221]  A. Scheerder, A. van Deursen, and J. van Dijk, "Determinants of Internet skills, use and outcomes. A systematic review of the second- and third-level digital divide," *Telemat. Informatics*, vol. 34, no. 8, pp. 1607–1624, 2017.

[222]  E. Hargittai and Y. P. Hsieh, *Digital Inequality*. 2013.

[223]  G. Kalton and D. W. Anderson, "Sampling Rare Populations," *J. R. Stat. Soc.*, vol. 149, no. 1, pp. 65–82, 1986.

[224]  S. Johansson, "Towards a framework to understand mental and cognitive accessibility in a digital context," KTH Royal Institute of Technology, 2016.

[225]  J. M. Entwistle, M. K. Rasmussen, N. Verdezoto, R. S. Brewer, and M. S. Andersen, "Beyond the Individual: The Contextual Wheel of Practice as a Research Framework for Sustainable HCI," *Proc. 33rd Annu. ACM Conf. Hum. Factors Comput. Syst. - CHI '15*, pp. 1125–1134, 2015.

[226]  K. Halskov and P. Dalsgård, "Inspiration card workshops," Proc. Conf. Des. Interact. Syst. Process. Pract. Methods, Tech. DIS, vol. 2006, pp. 2–11, 2006.

[227]   The internet Foundation in Sweden (IIS), "Swedes and the Internet 2018 [In Swedish: Svenskarna och internet 2018]," 2018. [Online]. Available: https://2018.svenskarnaochinternet.se. [Accessed: 05-Sep-2019].

[228]   B. Latour, "A Cautious Prometheus? A Few Steps Toward a Philosophy of Design (with Special Attention to Peter Sloterdijk)," in *Networks of Design", Annual International Conference of the Design History Society, University College Falmouth*, 2008, pp. 2–10.

[229]   The U.S. Department of Justice, "Americans with Disabilities Act (ADA)," 1990. [Online]. Available: https://www.ada.gov. [Accessed: 30-Sep-2019].

[230]   M. Söder, "Tensions, perspectives and themes in disability studies," *Scand. J. Disabil. Res.*, vol. 11, no. 2, pp. 67–81, 2009.

[231]   The World Medical Association, "WMA DECLARATION OF HELSINKI – ETHICAL PRINCIPLES FOR MEDICAL RESEARCH INVOLVING HUMAN SUBJECTS," 2019. [Online]. Available: https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/. [Accessed: 30-Jul-2019].

[232]   R. Wilk, "Consumption , human needs , and global environmental change," *Glob. Environ. Chang.*, vol. 12, pp. 5–13, 2002.

[233]   T. Winograd and F. Flores, Understanding Computers and Cognition: A New Foundation for Design. Intellect Books, 1986.

[234]   D. Grogan and R. Ruzik, "Walking the Walk: Universal Design on the Web," *J. Spec. Educ. Technol.*, vol. 15, no. 3, pp. 45–49, 2000.

[235]   A. Svensk, "Design of Cognitive Assistance [In Swedish: Design av kognitiv assistans]," 2001.

[236]   C. Putnam, K. Wozniak, M. J. Zefeldt, J. Cheng, M. Caputo, and C. Duffield, "How Do Professionals Who Create Computing Technologies Consider Accessibility?," in *ASSETS'12, October 22–24*, 2012, pp. 87–94.

[237]   M. Larsdotter, "Discursive (dis) orders of Disability Research A Critical Discourse Analysis of 'participation in research' in Swedish Disability Research articles and overviews," Halmstad University, 2018.

[238]   Susanne Dirks, "Empowering Instead of Hindering – Challenges in Participatory Development of Cognitively Accessible Software," in 13th International Conference, UAHCI 2019 Held as Part of the 21st HCI International Conference, HCII 2019 Orlando, FL, USA, July 26–31, 2019, Proceedings, Part I, 2019.

[239]   M. I. Laitano, "Developing a Participatory Approach to Accessible Design," *Int. J. Sociotechnology Knowl. Dev.*, vol. 9, no. 4, pp. 1–11, 2017.

[240]   E. Björgvinsson, P. Ehn, and P. A. Hillgren, "Participatory design and 'democratizing innovation,'" *ACM Int. Conf. Proceeding Ser.*, no. Ehn 1988, pp. 41–50, 2010.

[241]   D. Kusunoki and A. Sarcevic, "Applying participatory design theory to designing evaluation methods," *Proc. 2012 ACM Annu. Conf. Ext. Abstr. Hum. Factors Comput. Syst. Ext. Abstr. - CHI EA '12*, p. 1895, 2012.

[242]   H. Hasselqvist, M. Hesselgren, and C. Bogdan, "Challenging the Car Norm: Opportunities for ICT to Support Sustainable Transportation Practices," *Proc. 2016 CHI Conf. Hum. Factors Comput. Syst. - CHI '16*, pp. 1300–1311, 2016.

[243]   T. Kurz, B. Gardner, B. Verplanken, and C. Abraham, "Habitual behaviors or patterns of practice? Explaining and changing repetitive climate-relevant actions," *Wiley Interdiscip. Rev. Clim. Chang.*, vol. 6, no. 1, pp. 113–128, 2015.

[244]   T. Hargreaves, "Practice-ing behaviour change: Applying social practice theory to pro-environmental behaviour change," *J. Consum. Cult.*, vol. 11, no. 1, pp. 79–99, 2011.

[245]   E. Ganglbauer, G. Fitzpatrick, and R. Comber, "Negotiating food waste," *ACM Trans. Comput. Interact.*, vol. 20, no. 2, pp. 1–25, 2013.

[246]   J. A. Raelin, "Imagine there are no leaders: Reframing leadership as collaborative agency," *Leadership*, vol. 0, no. 0, pp. 1–28, 2014.

[247]   E. Shove and G. Walker, "Governing transitions in the sustainability of everyday life," *Res. Policy*, vol. 39, no. 4, pp. 471–476, 2010.

[248]   J. Pierce, Y. Strengers, P. Sengers, and S. Bødker, "Introduction to the special issue on practice-oriented approaches to sustainable HCI," *ACM Trans. Comput. Interact.*, vol. 20, no. 4, pp. 1–8, 2013.

[249]   L. Kuijer, A. de Jong, and D. van Eijk, "Practices as a Unit of Design : An Exploration of Theoretical Guidelines in a Study on Bathing," *ACM Trans. Comput. Interact.*, vol. 20, no. 4, p. 22, 2013.

[250]   B. Latour, "Teknik är samhället som gjorts hållbart." 1990.

[251]   P. R. Bohman and S. Anderson, "A conceptual framework for accessibility tools to benefit users with cognitive disabilities," no. May, p. 85, 2005.

[252]   OECD, "Literacy in the Information Age - Final Report of the International Adult Literacy Survey," 2000.

[253]    M. G. Friedman and D. N. Bryen, "Web accessibility design recommendations for people with cognitive disabilities," *Technol. Disabil. ·*, vol. 19, no. 4, pp. 205–212, 2007.

[254]    F. Scholz, B. Yalcin, and M. Priestley, "Internet access for disabled people: Understanding socio-relational factors in Europe," *Cyberpsychology J. Psychosoc. Res. Cybersp.*, vol. 11, no. 1, 2017.

[255]    Skolverket, "More students in schools for students with learning disabilities 2017/18 [In Swedish: Fler elever i grundsärskolan läsåret 2017/18]," 2018. [Online]. Available: https://www.skolverket.se/ skolutveckling/statistik/arkiverade-statistiknyheter/statistik/2018-03-22-fler-elever-i-grundsarskolan-lasaret-2017-18. [Accessed: 27-Mar-2019].

[256]    N. Murdick, P. Shore, M. M. Chittooran, and B. Gartin, "Cross-Cultural Comparison of the Concept of 'Otherness' and Its Impact on Persons with Disabilities," *Educ. Train. Dev. Disabil.*, vol. 39, no. 4, pp. 310–316, 2004.

[257]    S. Johansson, C. Gustavsson, and K. I. Ahlstrand, "Swedes with impairments and the internet [In Swedish: Svenskarna med funktionsnedsättning och internet]," Stockholm, Sweden, 2017.

[258]    K. Dobransky and E. Hargittai, "The disability divide in internet access and use," *Inf. Commun. Soc.*, vol. 9, no. 3, pp. 313–334, 2006.

[259]    B. Bozeman, "Technology transfer and public policy : a review of research and theory," *Res. Policy*, vol. 29, pp. 627–655, 2000.

[260]    L. Leung and C. Cheng, "e-Health/m-Health Adoption and Lifestyle Improvements: Exploring the Roles of Technology Readiness, the Expectation-Confirmation Model, and Health-Related Information Activities," in 14th International Telecommunications Society (ITS) Asia-Pacific Regional Conference: "Mapping ICT into Transformation for the Next Information Society", Kyoto, Japan, 24-27 June, 2017, International Telecommunications Society (ITS), Kyoto, 2017.

[261]    C. Miserandino, "The Spoon Theory," 2003.

[262]    L. Rello, M. Ballesteros, and J. P. Bigham, "A Spellchecker for Dyslexia," in ASSETS 2015: The 17th International ACM SIGACCESS Conference of Computers and Accessibility., 2015, pp. 39–47.

[263]    Riksbanken, "Payment patterns in Sweden 2018," 2019.

# Appendix A

Table 1: Presentation of methods used in the work presented in the thesis.

| Method | Description |
| --- | --- |
| Back casting and Forecasting | In a Back-casting exercise we start in the future and work our way closer and closer to the situation of today. A Forecasting exercise starts today and then we try to predict how the future can be and how to get there. |
| Barrier walkthrough | Group activity to identify problems in an existing design or in a proposed design (at a minimum presented as sketches). Adapted version of formats from Participatory design and other walkthrough methods. |
| Brainstorming | Semi-organized way to display a lot of options in a short period of time. Works better if people work in pairs or groups rather than alone. |
| Design session | Group activity to propose a design. Mock-up, sketches etc. are used to visualise ideas. This activity is often carried out in a joint activity with designers and/or product owners. |
| Fake user test | A method that borrows the attributes of a user test. We work in groups and perform tasks, but the result is not so important. The most important is to be sensitized on enabling and disabling features in the design. This activity is often carried out in a joint activity with designers and/or product owners. Sometimes the session or a consecutive session shift to a discussion on how to redesign or solve the identified problems. |
| Future workshop | Workshop to propose possible future artefacts or revisions of existing artefacts. Adapted version of format from Participatory design. |
| Gamification rhetoric | Boss fights, levels, onboarding are rhetorical examples that can be used to visualise personal challenges |
| Prioritizing exercise | Method to sample issues to work with and then make a prioritized list in order of importance. Can also be used in adapted form to support people with intellectual impairments when making decisions, choosing between a large number of options. |
| Nudging and Gentle Provocations | Methods to carefully push someone in the right direction, without causing conflict. |
| Stakeholder workshop Value Tension Workshop | Workshops to identify direct and indirect stakeholders and then to identify tensions between stakeholders and values. From Value Sensitive Design. |
| Three evenings about… | Three-step model. Starts with complaining and problematizing the current situation. Continues with participants taking votes and prioritize the most important issues. End with proposals, prototypes etc. to describe possible solutions. Draws on Study Circles. |
| Visualisations | Often illustrations, sometimes photos or videos. Used to summarize long/complex discussions or to make something clear. Substitutes for written accounts. |

Table 2 Presentation of tools used in the work presented in the thesis.

| Tool | Description |
|------|-------------|
| Activity system | Can start with an activity and end with an outcome or in reverse, start with the outcome and move back. Draw on Hedvall's Activity Diamond |
| Contact Map | A mapping of all formal and informal instances of support a person have related to impairment, mental health issue or homelessness. |
| Energy Barometer | A board-game like tool to measure accumulated cognitive workload. Development paused due to lack of funding. Draws on the Spoon Theory [261]. |
| CompairCompare | Online tool for A/B-testing of propositions and to present participants' preferences in a ranked order. A and B stands for alternatives that can be ranked and we have ranked up to 20 items. |
| Data viewing | Online data presentation tool with accessible diagrams. See http://internet.begripsam.se as an example. |
| Eye tracker recording and analysis | Individual recordings, heatmaps and gaze plots used for sensitizing, analysing and visualizing |
| Green – Orange - Red | Visual tool to take a vote. Green means something is OK. Red is disapproved. Orange is in between, some improvements are needed. |
| Intermediators and Intermediating artefacts | Intermediators: People who facilitate and help people who need extra support to participate. Intermediating artefacts: Things that helps a collaborative process going. |
| Provisional proposals for possible futures | Illustrations, sketches, mock-ups, prototypes. We have made no adaptations; ordinary techniques often work. |
| ISO 21801 Checklist and Deck of Cards | Checklist for cognitive accessibility. Tool to use for design sessions, workshops and seminars. Each card presents a guideline and has a QR code to access more information. Ongoing activity. |
| Provocative object | Since abstract thinking and open questions can be difficult as starting points, it can be useful to spark a discussion with a provocative object, e.g. a simple sketch, a web page, a statement. |
| Stop card | When a participant wants to discuss formal arrangements, thinks that the pace is too fast, etc. it is OK to play the stop card. |
| Toppling counterforces | Metaphor to identify a contribution to a design that is counterproductive in relation to the overall purpose of the design. |

Table 3. A set of advice compiled from a large number of session-evaluations:

| Nr | Description |
| --- | --- |
| 1 | A session starts with the information about the session. |
| 2 | The second phase of a session is travelling to the session. Many people have issues related to transportation, only some of which relate to the physical environment. Some people always travel with another person as support. Some need to be picked up at the train station, airport etc. Some need to know that they can easily get in contact with a support person if they need to. Some need an app (or several) to support transportation. Delays or trouble related to transportation have the potential to ruin participation in a session. |
| 3 | Wayfinding support can be needed inside a seemingly familiar building or between the building and the hotel – even if it is the same hotel every time. |
| 4 | A single session to deal with an issue is rarely participatory. Traditional user testing often means a person participates only once. This reduces people to informants. One-time events create stress and a pressure to say as much as possible in a small amount of time. There is often no way to provide a second thought. It is often the second or third thoughts that deliver the real insights. Multiple session arrangement with time for feedback and reflection in between are often preferable. |
| 5 | Scaffold sessions (create a supporting structure) with close attention to structure, environment, organization and people. The more carefully planned a session is, the more tolerance there is for the errors and mistakes that inevitably will happen. |
| 6 | Meals and snacks need careful consideration. Many people have issues related to food. Begripsam have hired our own chef, Ursula, to fix our menus and meals. Close attention to food, snacks and meal situations provide more energy for the activities on the agenda. Meals also have a potential to build trust and friendship. |
| 7 | Have a clear structure and keep to the time schedule to minimize energy consumption. |
| 8 | Breaks are for recovery, but to be that way they need to be structured. The nature of many pauses is that they are unstructured in a way that some people might find energy consuming rather than recovering. |
| 9 | Think about how discussions should be organized. Some people need to speak out as soon as they think about something. Others prefer an organised structure for taking turns in talking. Think about people who are silent and provide opportunities for them to speak but with no pressure. Think about other means of contributing than talking, that could be more empowering for people who are not that comfortable with talking. |
| 10 | There is a delicate balance between: not interrupting or filling in words when someone tries to formulate something and liberating a person who has got stuck in the middle of a thought, by proposing some words. |
| 11 | Another delicate matter is the balance between letting people talk freely and "This is clearly a detour from today's issue and should be stopped" or "We have already discussed this and there seems to be no new arguments, so we must move on". |
| 12 | A session ends when people are safely back home. |
| 13 | Be convivial! It helps with handling the mistakes that will inevitably happen. |

# Appendix B
ISO/PRF 21801-1 Cognitive accessibility — Part 1: General guidelines