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# Cognitive accessibility for mentally disabled persons

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**Abstract.** The emergence of various digital channels, the development of different devices and the change in the way we communicate and carry out various types of services have quickly grown and continues to grow. This may offer both new opportunities for inclusion and risks for creating new barriers in the society. In a recent study we have explored the questions: Is the society digitally accessible for persons with mental disabilities? How do persons with mental disabilities cope with their situation? What are the benefits and obstacles they face? Based on the answers to these questions we wanted to explore if there is a digital divide between the citizens in general and the citizens with mental disabilities. And if so; what is the nature of this divide? Methods used in the study were Participatory action research oriented with data collection via research circles. In total over 100 persons participated. The results show that a digital divide is present. Persons with mental disabilities differ from citizens in general in how they have access to digital resources. The result also indicates that services and systems on a societal scale do not deliver the expected efficiency when it comes to supporting citizens with mental disabilities. And finally the results indicate that the special needs this group might have are often not identified in wider surveys on the citizen's use of Internet, digital services and use of different technical devices. Several of the participants describe this as being left outside and not fully participate in a society where digital presence is considered a prerequisite for a full citizenship.

**Keywords:** Mental disability, mental problems, cognitive accessibility, digital society, inclusion

## 1 Introduction

The ambition to fully include persons with disabilities in the society is manifested in the UN-declaration of human rights and in international and national legislation. The ambition is to include persons with different kinds of disabilities in all aspects of life. The example presented in this paper is located in Sweden, a country with high ambitions in this field.

In the study described in this paper we have explored the questions: Is the society digitally accessible for persons with mental disabilities? It is likely that the fast development of devices, services and techniques open up opportunities for a better life but it is also likely that different kind of obstacles may occur. So, is the digital society

accessible for persons with mental disabilities provided they live in a highly developed welfare state? What are the digital needs of people with mental disabilities in the society? How do persons with mental disabilities cope with this situation? - What are the benefits and obstacles they face? Based on the answers to these questions we wanted to explore if there is a digital divide between citizens in general and citizens with mental disabilities. And if so; what is the nature of this divide?

## 1.1 Mental health problems

Mental health is defined by WHO as “a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community”. Furthermore WHO defines a mental disorder in the following way: “*Mental disorders comprise a broad range of problems, with different symptoms. However, they are generally characterized by some combination of abnormal thoughts, emotions, behavior and relationships with others*” [1]. Mental problems are by WHO pointed out as global problems [2].

The absence of mental health is described in different ways. In this text we use the terms mental problems or mental disability and by that we include any kind of mental problem that are disabling a person in the everyday life.

The National Institute of Mental Health (NIMH) publish statistics<sup>1</sup> on mental health in the United States saying that 26.2 % of the US population experience some form of mental disorder each year and 46.4 % will experience a mental problem in their lifetime. Of all US adults 4.1 % are estimated to have serious mental problems.

Persons with mental disabilities are often described as at risk from being excluded from the mainstream society. In the public debate this group is often described as “vulnerable” or “socio-economic weak”. It is known that a long period of mental problems increase the risk of being unemployed and of dying earlier than the average population [3, 4].

The empirical study presented in this paper is based on cases from Sweden and we will therefore present some data concerning mental problems among Swedish citizens.

## 1.2 Background on the case of mental health problems in Sweden

As an example of a state with a highly developed society with a comprehensive public welfare, we have decided to look at the case of Sweden. According to the OECD<sup>2</sup>, the Swedish tax-to-GDP ratio was 44.3 % in 2012. The highest rate in the world is in Denmark, 48.0 and the U.S rate is 24.3

Sweden has a relatively large geographic area (449 964 km<sup>2</sup>) with a relatively small population (9.7 million in 2014).

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<sup>1</sup> <http://www.nimh.nih.gov/Statistics/index.shtml>

<sup>2</sup> <http://www.oecd.org/ctp/tax-policy/revenue-statistics-ratio-change-previous-year.htm>

Sweden is a highly digitized country. A very large proportion of the population is using the Internet and has access to fast broadband<sup>3</sup>. Broadband coverage is high even in remote parts of the country<sup>4</sup>. Commercial and public services have quickly built up a digital presence. In most cases the digital presence is added to traditional channels for information and communication, but there are also examples where access to the net is the only, or a much cheaper, way to perform certain services.

A few examples:

- 67 % of Swedes' income declarations 2014 are done digitally<sup>5</sup>
- Application for a place at upper secondary school must be done via the Internet<sup>6</sup>
- 62 % of Sweden's municipalities communicate with citizens through social media (2014)<sup>7</sup>
- The majority of Swedish banks will no longer handle cash. They push for the clients to use cards<sup>8</sup>

In Sweden it is The National Board of Health and Welfare (Socialstyrelsen)<sup>9</sup> or the Public Health Agency of Sweden (Folkhälsomyndigheten)<sup>10</sup> who publishes statistics on mental health. In surveys 20-40 % of the population state that they suffer from mental problems and 5-10 % is estimated having so severe problems that they need treatment but only 3-4 % is in an active treatment.

The Swedish government has assigned The Swedish Post and Telecom Authority (PTS)<sup>11</sup> to monitor if any problems emerge, especially for persons with disabilities. As a part of this monitoring effort, we have been commissioned to carry out a study on "Electronic communication for persons with mental disabilities".

PTS has also given us a mandate to carry out two literature studies "Accessibility to electronic communication for people with cognitive disabilities: a systematic search and review of empirical evidence" [5] and "Accessibility to electronic communication for people with cognitive disabilities: a review of grey literature" [6]. Both studies display great gaps of knowledge in this field.

### 1.3 Digital society

In this paper we use the term digital society to cover the broad and diverse use of technical devices, services and technologies that has changed the way we communicate and interact with both persons and systems. This development has come to in-

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<sup>3</sup> <http://en.soi2014.se/>

<sup>4</sup> <http://bredbandskartan.pts.se/>

<sup>5</sup> [www.skatteverket.se](http://www.skatteverket.se)

<sup>6</sup> [www.gyantagningen.se](http://www.gyantagningen.se)

<sup>7</sup> [www.skl.se](http://www.skl.se)

<sup>8</sup> <http://www.dn.se/ekonomi/kontanterna-forsvinner-fran-bankerna/>

<sup>9</sup> <http://www.socialstyrelsen.se/psykiskhalsa>

<sup>10</sup> <http://www.folkhalsomyndigheten.se/about-folkhalsomyndigheten-the-public-health-agency-of-sweden/>

<sup>11</sup> [www.pts.se](http://www.pts.se)

clude both how we interact with friends and acquaintances as well as businesses and government agencies. This is an ongoing process and the changes have occurred over a short period of time. All societies are subject to these changes but differ in how far progress has gone. In a specific society it is likely that there are differences between how different citizens and groups of citizens embrace this development.

In this study we have explored how persons with mental disabilities in a highly developed society with a comprehensive public welfare cope with this situation. The overall question is if the society can be described as digitally accessible for persons with mental disabilities.

## **2 Method**

The overall research approach follows the tradition of Action Research [7] More specifically the method is heavily influenced by the tradition of Participatory Design [8, 9.] or the more Scandinavian version of Cooperative Design [10, 11] and we have therefore used an adapted form of Participatory Action Research [12]. We have in the past seen many problems to actually manage to work well with user participation [13] and the traditional methods for user participation are not sufficient when users have mental problems. In this project we have explored and developed methods adapted to perform better for persons with mental problems. This work is presented in a paper called “User participation when users have mental and cognitive disabilities” (manuscript) [14].

We have used a concept called study circles [15]. Study circles have a long tradition in the Nordic countries. A study circle is a group of adults that meet and discuss a specific topic. It is done by free will and in a democratic way. There is no teacher; instead a study circle has a leader who facilitates the discussions.

The concept of study circles has been further developed to so called research circles as a way for researchers and practitioners to work together to produce knowledge and gain deeper understanding [16]. The practitioners formulate problems and try to resolve them. The basic idea is that researchers and practitioners meet and learn about each other’s knowledge and experiences. In a structured process this will lead to actions, reflection and to new knowledge.

### **2.1 Basic study setting**

In the study over 100 persons (aged 15-75) with a mental disability participated. Activities have been implemented in major cities, smaller towns and rural areas. The participants have various diagnoses such as bipolar disorder, depression, schizophrenia, panic disorder or other mental disorders. They have had their problems for a long time. In addition to different kind of mental problems most of the participants can also describe a number of different types of cognitive difficulties. Participants are members in an organization for persons with mental problems, called RSMH.

The study went on between October 2013 and February 2014.

Groups of 8-12 persons were formed and each group met at least three times with at least one week in between each meeting. A meeting lasted for three hours. Every meeting was documented with text and important discussions and important findings were documented with illustrations, so called Mock-up Visualizations [14].

In three cities we arranged half-day activities as a onetime occasion. The activity lasted for 4-5 hours. Having only one opportunity to discuss created a lot of frustration among participants. So in comparison; the three time approach was considered far better.

For most of the participants accessibility was equivalent with thresholds in the physical environment. So each set of meetings started with a short presentation on the topic "What is accessibility in the perspective of mental disabilities".

This was followed by a session where the participant could prioritize what to discuss during the rest of the meetings. The initial question was "What is it in your life that creates the biggest obstacles? Initially, there was no connection to the digital society. This connection was made later in the process. During 10-15 minutes the participants individually was asked to write down issues on post-it notes. Notes with similar issues were grouped together and in the next phase each participant was given 5 points. They were asked to use the points to prioritize what they wanted to discuss. They could go "all in" and place all five on one single item or they could spread them. By using this procedure silent participants can have as much influence on what to discuss as more talkative participants. In each group there were some participants who initially were silent and a few that remained silent almost to the end of the third session. The result was a prioritized list of topics. We went back to the list of topics during the whole process to check that prioritized issues were discussed but sometimes new topics emerged.

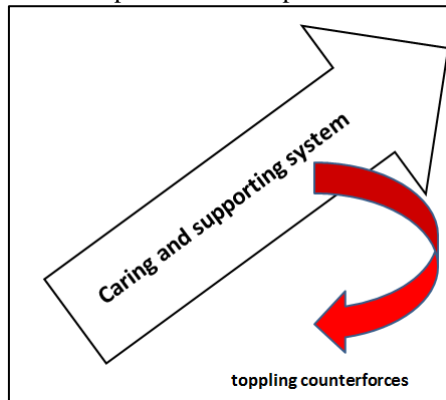
Initially the study circle leader has no influence at all on what to discuss. The researcher's role is to act as the circle leader. Later in the process the researcher connects the discussion with questions about electronic communication, design and accessibility.

### **3 Analysis**

During each session two assistants were present with the task of taking notes. The researcher and a coordinator from RSMH also took notes and all notes were consolidated into minutes. The minutes were distributed by mail or by post to all participants with a call for comments. Some discussions were visualized with so called MockUp Visualizations [14]. The visualizations were made by the researcher.

Minutes, Post-it notes and other material produced during different sessions was organized into groups of related subjects; How I am treated, Economy, Health Care and Medication, Work, Information, Housing, Light and sound, Memory and Assistance. In next step the material was analyzed and organized into different subjects such as Mobile phone, Internet, Computer, Online services. Participants were included also in analyzing the collected material mainly by discussing the MockUp Visualizations.

One example of a MockUp is shown below:



**Fig. 1.** This picture was produced to visualize that in every caring and supporting system, invented to help, there are counterforces that work in another direction. For example; a good system can be damaged by forcing the user to fill in too complex forms or use too complex web services. This picture has become a powerful tool to pinpoint counterproductive elements in systems, organizations and services.

## 4 Results

Mental disabilities often lead to a variety of cognitive difficulties [17]. When facing different kinds of practical problems it is often fruitful to analyze them as cognitive accessibility problems.

Participants in this study describe problems with: execution abilities, memory, concentration and focus. They also describe how persistent mental problems gradually affect such as: self-confidence, self-esteem, trust and security.

The cognitive difficulties the participants describe can often be linked to ICF, International Classification on Functioning, Disability and Health<sup>12</sup> in the following areas (numbers indicate the code of the ICF system):

- Sustaining attention, b1400
- Shifting Attention, b1401
- Short-term memory, b1440
- Organization and planning, b1641
- Time management, b1642
- Problem-solving, b1646
- Experience of Time, b1802
- Undertaking a complex task, d2101
- Completing multiple tasks, d2201
- Handling stress, d2401

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<sup>12</sup> <http://www.who.int/classifications/icf/en/>

The picture emerging from the stories told by the participants is that they face a number of accessibility problems but it is also possible to see that digital devices and digital services can play very important roles in the everyday life for a mentally disabled person.

#### **4.1 *Mobile phones – a hub and a lifeline***

Every participant in the study had a mobile phone. They described their mobile phone as a hub and a precious commodity. Many of the participants use the mobile phone just as a phone. They used it to talk and to send text messages. Some used it for surfing on the Internet and for e-mail but talking and texting is the most common use. For many the mobile phone works as a center for communication with friends, caregivers, authorities and colleagues (for the minority that had a work). The majority did not have a regular phone and many did not have a computer of their own.

A reason for not surfing and using e-mail was that many had old mobile phones or new cheap models that could not be classified as smartphones. In comparison to Swedes in general persons with mental disabilities seems to have less access to smartphones. 65 % of the Swedes use a smart phone and when discussing this with the participants they described a situation where a majority of them can't afford buying a smartphone.

Some of the older models could use e-mail but only a few of the participants knew how to configure this to work. Many of the participants are trying to use different features they have in their mobile phone. The most common seems to be some kind of notes. They also sometimes use the clock to get reminders of important things to do. Even if there is a calendar function and often other functions in the phone, there are few persons who use them. They seem to be too cognitively difficult to use and participants describe that it is a too big step to start using a feature even if you would benefit a lot from using it in the long run.

Only a small group of the participants have any experience of the more advanced features that can be found in smartphones. As a consequence they have not tested apps that could be used as cognitive support. Some participants have heard about apps for time managing, task planning, feedback and reminders on the market. They have also heard about apps for cognitive behavioral therapy and information management. Many participants call for opportunities to test and learn more.

#### **Text messages as a personal archive**

Many participants described that incoming text-messages works as an archive. It is much easier to search among those messages in a phone than trying to find a letter that was delivered by the postal service. Several participants described difficulties with postal messages. They often get lost and it happens that they do not open letters at all. Many described that they wanted more electronic communication with caregivers, government agencies and other important contacts. Over time many persons stored large number of messages in their phones and it becomes difficult to find in-



formation and sometimes they have experienced insufficient room for storage. Participants lack simple ways to save and move text messages.

### **Important information gets lost**

Almost all participants had experienced losing important information when changing mobile phone, upgrading their phone or upgrading or changing a subscription. Several participants describe this as a huge calamity. Stored contacts, stored SMS-messages and notes turned out to be the most troublesome information to lose. *"You get those questions whether you want to save to SIM-card or the phone, but it always ends up with me losing important stuff. I do not know how to do"*, one person said.

### **Flat rate for mobile phone calls**

Having a flat rate is one of the most important measures to achieve increased accessibility to the society for a mentally disabled person. A person in the study expressed it this way: *"The biggest accessibility-thing that happened to us with mental disabilities is flat rates for mobile phones."* As the mobile phone is central for persons with mental disabilities a low or predictable cost for subscriptions and calls is very important. When these costs vary it creates uncertainty and insecurity. Either *"How high will the bill be?"* or *"How long can I talk before the prepaid card is empty?"* A flat rate eliminates those concerns.

### **Flat rate for mobile surfing**

It is a large group in this study who do not surf with their phone. Their mobile phone cannot handle it, or they have no subscription. Among the persons who surf via the mobile phone cost control is very important and they are looking for low cost or flat rate subscriptions. It is however very difficult to predict the actual cost of a subscription and comparing different subscriptions is considered very difficult.

### *Let's talk you through the night*

An example where flat rate makes a truly vital difference is when persons with mental disabilities help each other through the night. Most suicide attempts are done during the night, especially when night turns to dawn. And almost everyone in the study could tell of friends committing suicide. Spontaneously organized groups are formed where persons with mental problems help each other and establish phone connections with a friend on the brink of committing suicide. It works like a relay and different persons take turns on speaking to the person at risk. As one participant said *"Nowadays you don't need to think about the cost, thanks to flat rate. It was really frustrating when you ran out of money and you had to hook up leaving a desperate friend all alone in the middle of the night. Some friends did not make it"*.

### **Parallel mobile phone subscriptions**

Several of the people we met during the study have experienced having parallel mobile phone subscriptions. Without really understanding, they have signed up for a

new subscription that also means that they will continue to pay on an old one. It also happens that they pay for Internet surf although they use phones with no Internet capability.

This seems to be the result of aggressive marketing in combination with poor impulse control and difficulties in understanding information about subscriptions..

#### **4.2 Postal address and letters is not the safest way to get in touch**

Handling officers in the health and social care and other authorities usually just recognize your formally registered address as a contact point and they are forced to do so due to legislation. If the authority wants to provide you with information or a call for action from you they will send a letter to the address where you are registered. The participants describe several problems connected with addresses and letters.

The most common problem is that a person simply does not open letters; to open a letter is associated with great discomfort and anxiety. Other problems are that persons for various reasons choose not to live at the address they stated, are homeless or voluntarily or forcibly admitted to a mental health care institution.

Participants in the study told us that you very well know that you should do something about received letters, but the ability is simply not there. Rather the knowledge of what needs to be done builds more anxiety and worries.

#### **4.3 When a person is institutionalized for care contact channels are broken**

People with severe mental disabilities can be hospitalized for periods of time. This may be both through free will and through force. During this period the mobile phone often is the only channel for communication alongside with personal visits from friends or relatives. Several of the persons in the study testify that they or others have got into difficulties because letters sent to their home address is not re-distributed to the clinic and you have to organize that someone drops by your home and collect the mail. Psychiatric clinics do not seem to have clear procedures for how this issue should be dealt with.

It is the clinic who decides whether you should be allowed to use a phone or not. Participants describe restrictions in phone usage is a common disciplinary tool. They regard it as a major assault being deprived of their phone and without it they have no channels of communication open.

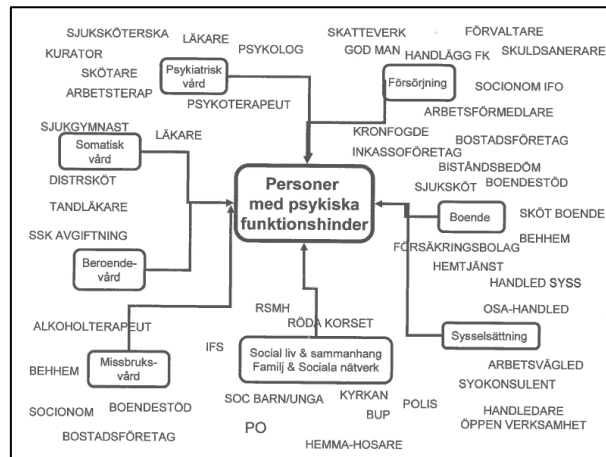
#### **4.4 Meetings with caregivers and other authorities**

The study shows that there are significant problems related to meetings. Persons with mental disabilities may be called to a large number of meetings. In some cases, there are over 100 meetings a year. There are various actors who call for such meetings. Often they represent different county and municipality organizations, but sometimes also a government agency. Also private actors invite to meetings.

Many participants describe this as a major problem. You are supposed to manage all this by your own and remembering calls, remembering what is being discussed and

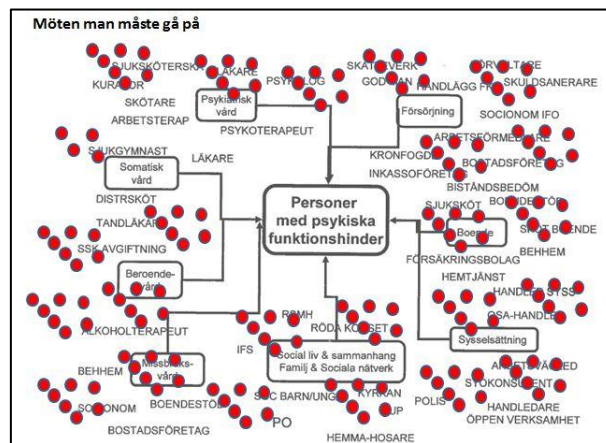
remembering to carry out different tasks between meetings is described as troublesome.

One of the participants drew the picture below. It shows different organizations you may have contact with.



**Fig. 2.** The person with mental problems is represented by the box in the middle. The boxes that are connected to this person represent different types of societal actors. Every word around these squares represents an organization/person that the person has contacts with.

Taking this one step further we discussed how many meetings it can be under a specific period of time. Schematically, it can be described as follows:



**Fig. 3.** Each dot represents a meeting. Different actors often do not coordinate their activities. It can easily be up to 100 meetings a year.

### The consequence of missing a meeting

In many cases, if you miss an appointment, you will be billed with a penalty. The various organizations have rules for how a cancellation should be done. If a person is absent or cancels too late a cancellation fee will be charged. So do many psychiatric clinics in Sweden. The purpose of this is to discipline patients so that they do attend at meetings.

Several persons in the study have testified that invoices sent from the county council psychiatric clinics eventually lead to payment defaults. It seems to happen like this: Periodically you feel so bad that you simply cannot attend at meetings. Depression, anxiety, or other conditions make it impossible to take off for the meeting, and also impossible to cancel in time. The county council's computer system records this as a case for a cancellation fee and sends an invoice by letter. As mentioned earlier it is common that letter remains unopened and this will eventually end up with a payment default.

Participants point out that they find it difficult to understand why the clinic that is supposed to support them put them into trouble when acting precisely as expected from a person with a mental and cognitive disorder. The participants want both calls for meetings and documentation to be handled in digital channels. They also call for online connections between home and clinic.

#### **4.5 Computers**

According to the participants many persons with mental disabilities do not have access to a computer at home. But many also do not have a work so they do not get access to computers through their work either. If they do have access to computers, the computers are often old with poor performance and frequent malfunction and with software that are no longer supported or functioning well.

Several of the participants in the study inform us that public authorities nowadays require modern computers and software to manage their services online. An actual recent example is the Swedish national agency for unemployed. Participants in our study have been told that they are expected to log in daily to report on their level of job-seeking activity. One participant in our study reported that she on a daily basis must log in and apply for jobs and report these activities in the system. At the same time as she was engaged by the same agency in work practices with a company. She informed the agency that she did not have access to a computer at home. She finds it problematic to do these tasks at her work practice, since she is anxious to show that she is able to follow the rules and do a good job. Consequently, they suggest her to come to the agency office to enter the information. But to do that, she would have to leave the work place during working time. She felt caught in a trap.

##### *Computers at the local RSMH associations*

As a member in RSMH you can often use computers and occasionally also get help with for example paying bills or sending e-mails at their local meeting places. These computers are often very old with frequent malfunction.

The recent development trend with simplification of computers and software has not yet reached the target audience for our study. Many of the participants report on

losing important information due to frequent computers breakdowns. Having important data "in the cloud" and thereby protect it from disappearing is not yet a common solution.

#### *Accessing computers in public libraries*

A smaller group of participants visit libraries where they can use public computers for free that often work well but have a variety of restrictions that can cause trouble.

Often there are time limits on how long a person can use a library computer. The rule exists to provide access to as many people as possible. But this creates stress.

The computers are often located in open areas where groups of people sit together and use them. There may be both advantages and disadvantages from this. For some users, it creates a sense of security, for others it is a concern. If you use the library's computer to pay bills, for example, you may not want to be completely open and transparent with this information. There may also be privacy issues relating to people "looking over ones shoulder".

## **4.6 Tablets**

In the study, we intended to discuss the participant's experiences of using tablets. None of the participants in the study has had their own tablet. Some had occasionally tried one, but in general the experience of tablets among the participants was marginal. According to the national survey<sup>13</sup> "The Swedes and the Internet 2014", 45 % of the population sometimes uses a tablet and 25 % use a tablet on a daily basis.

## **4.7 The Internet and web accessibility**

Every person in the study uses Internet to some degree. Several persons could describe difficulties with the use of web pages. Most troublesome are pages with:

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

The participants were not aware of the existence of a standard for web accessibility [18]. They did not connect problems they experience using web pages with poor accessibility rather they regarded the difficulties as personal shortcomings. Many expressed a lack of confidence in their own abilities to understand and use resources on the web. In some cases the self-esteem was affected by repeated failures. It is common that persons with mental disabilities call for help from friends or relatives to carry out tasks online. Some described this as an invasion of privacy but they really could not see any alternative. One example is paying bills online, since online bank-

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<sup>13</sup> <http://en.soi2014.se/>

ing is considered difficult. Other example where help often is needed is buying tickets or online shopping.

#### **Public and commercial services online**

The participants have little experience of using online services provided by municipalities, counties and state. An increasing amount of services has gone online the last years but they are not commonly used by the participants.

Many of the participants have bought tickets online and some have tested online shopping but when asked about preferences a majority says they rather would do this by interacting with a person rather than a machine. Some participants argue that many probably would change opinion if they were given the opportunity to learn more and to try and test devices and services.

#### **Captcha, eID and other login methods**

According to the participants in the study there is no really good way to "prove who you are" on the Internet. Most persons in the study did not use eID. Overall, there are severe problems with login procedures. Several participants seem to directly avoid any solutions that require login. Many of the participants in the study talked about the difficulties to manage passwords and other codes. Many also specifically mentioned CAPTCHA (acronym for Completely Automated Public Turing test to tell Computers and Humans Apart) as an obstacle that they cannot manage to pass. CAPTCHA was even described as "evil design" by one person.

#### **4.8 Direct Debit (Autogiro)**

Many of the participants in the study tell us that the direct debit is a very important function. It is an example of a function which compensates for periods of problems with undertaking complex tasks or problems with planning. Bills registered for direct debt is automatically paid every month.

Persons, who have lived with their mental problems for a long time, often advice newcomers to arrange for direct debt as soon as possible. You can get that help from the society, but often first after that you got a payment default.

#### **4.9 Fixed time slots, telephone queues and automatic responses**

A majority of the participants are strongly opposed to what we might call modern PBX (Private Branch Exchange) technology. Several participants said that they hang up immediately if they hear an automated voice that begins urge to "press 1 if you ...". They are not even listening to the options.

Systems with music played during periods of waiting are regarded as disturbing by many and totally inaccessible by some. For some, music, recurring information from an automated voice and waiting is so disturbing that they lose the reason why they initially called.

Another problem is fixed time slots for incoming calls. Some participants gave almost the same story: If you start every day with medication the medicine can as a side effect make it impossible for you to make telephone calls for a period of time. This means you cannot call someone in the morning and if someone only answers on fixed hours at that period you basically cannot phone them. Waiting in telephone queues is also described as very problematic.

#### **4.10 Little use of assistive tools**

In the study, there were several participants who probably would have found various IT-based assistive devices very useful. No one had access to any such tools. One of the participants had tried to get support for a memory supporting aid called Comai but it was rejected. The solution was considered too expensive for her needs. Previous studies have also shown that persons with mental disabilities find it very difficult to get assistive tools [19].

## **5 Discussion**

Since the dawn of the “information society” in the 1990s there has been an interest in exploring who is included and who is excluded from using the emerging new devices and the new services. The use of computers and the use of the Internet were of particular interest. It soon became clear that age, level of education, work presence, and level of income is key factors in this dynamic and rather complex context [20]. Disability is another, sometimes forgotten, factor. Early studies on how persons with disabilities used the Internet or had access to computers revealed a “digital gap” [21, 22]. An important question was if this gap would close or widen over time? Was it a question of late adopters who lagged behind but soon would keep up with the rest of the population or was it a question of a more permanent exclusion?

The early studies included persons with vision and hearing impairment, limitations in mobility and sometimes reading and writing difficulties. Gradually persons with dyslexia, attention disorders, autism spectrum disorders and learning difficulties have been included in digital accessibility research but it is still hard to find studies exploring how accessible the digital society is for those groups and it is still harder to find anything about persons with mental disabilities.

What we can see is that in any given point in time when someone ask the question “Is there a digital divide between people with disabilities and people without disabilities the answer is “yes”. Key factors for this exclusion seems to be fewer opportunities to get in contact with new technology, lack of competence and low incomes. Often a person with a disability reports a significant desire to increase their use of, what for the time of the study is regarded as, modern technology [23]. This indicates that being outside the digital society is not a self-selected choice, rather a consequence of poor accessibility.

Our study shows a similar pattern. We have focused on persons with mental disabilities since little is known about how this group copes with today’s digital society.

We started out by asking the questions: Is the society digitally accessible for persons with mental disabilities? How do persons with mental disabilities cope with this situation? What are the benefits and obstacles they face? Based on the answers to these questions we wanted to discuss if there is a digital divide between the citizens in general and the citizens with mental disabilities.

We have explored a broad range of devices, services and situations and the conclusion is that a digital divide clearly exists. The society is not digitally accessible for persons with mental disabilities. The participants in this study can describe numerous situations supporting this conclusion. Most of the problems the users face are of a cognitive nature. It is difficult to learn, understand, remember and recall how devices and interfaces work.

Having said that, they can also describe numbers of situations where modern technology work in their favor, especially the mobile phone and the decreasing costs for communication for both telephone calls and for using mobile Internet connections. For many participants their mobile phone is a highly valued property. The consequences of losing it or lose information stored in it can be disastrous.

### **5.1 Weak digital support in caregiving processes**

When facing mental problems and the consequences thereof a person gets in contact with a number of actors; health and care services, social care services, enforcement and police authorities, special housing services etc. The communication between individuals and those actors do not make use of modern tools for communication. Information is delivered on paper by traditional postal service; the disabled person is often supposed to remember and accurately retell oral information given by one instance when visiting another, making the quality of information heavily depending on the disabled person's own capability to remember, recall and retell the information.

A specific caregiver acts as they are the only one in contact with the person with a mental disability. They seem unaware of the problems the large amount of meetings creates. There is little coordination between different operators so a person can get calls for several meetings during a short period of time, even the same day. Better and coordinated booking systems, better communication and exchange of information would create major opportunities for improvement in this field.

It seems that many times the development of IT support for specific caregiving situations is optimized from the caregiver's perspective and from the singular situation it is supposed to support, not taking a holistic perspective from the person seeking treatment or support.

### **5.2 Low experience of using modern technology**

A majority of the participants use old mobile phones and old computers. Besides the hassles that the use of older systems brings, it also means that most of the participants do not know the potential of modern technology. As an example, there is a variety of software and apps that could serve to support people with mental and cognitive disabilities, but these do not work on the older equipment that they are using.



Smartphones and tablets have a potential to improve the access to different kinds of services and to make it easier to communicate and to be integrated in the digital society. The participants in our study describe a wish to be more included in the society and an increased digital presence is considered important. They call for activities where they can learn more and try devices and applications that could help them in different aspects of life.

### **5.3 Future research**

As the research needs in this field and the knowledge gap is so big we intend to pursue more research with this user category. In a project in cooperation with the social service in Stockholm, starting early 2015, we will explore and test how modern technology can be used to improve the communication between homeless persons with mental disabilities and the social care services.

The knowledge on how persons with mental problems experience the web needs to be deepened but the results so far indicates that standards such as the web content accessibility guidelines (WCAG) [16] do not fully support the needs of persons with mental disabilities.

## **6 Conclusions**

Increasing the cognitive accessibility for persons with mental disabilities is a very important challenge. When we survey the field we find very few published scientific studies to support the development of ICT for this group.

In short, we want to point out the following points as the most important discoveries we have made

- The important role of the mobile phone
- The importance of flat rates, both for phone and internet
- The low use and experience of smartphones and tablets
- The use of old, decommissioned, computers and old software
- The low use of public and commercial services online
- The reluctance to use login functions
- The problems with protecting important information in mobile phones
- The lack of connection between IT-systems used by caregivers and the personal devices used by persons with mental disabilities
- The struggle to keep up with the introduction of new digital devices and digital services as they emerge
- The great interest to acquire further training and competence to better cope with the digital society

Working with users with mental and cognitive disabilities does not only give us insights into their lives and needs, but we also learn a lot about ourselves, our prejudice and lacking knowledge about this group and their needs. We strongly believe that

research into cognitive and mental accessibility needs to expand, and the knowledge gained may not only be used to improve the design of ICT support for this group, but improve the accessibility and usability for all users. Some of our findings needs to be addressed to social science or other research fields. What can be done in the field of HCI then? At this stage we can see a number of interesting issues:

- Making the complicated and complex more intuitive , easy and cost effective
- Making the consequences of errors and mistakes less ominous
- Design for trust, self-esteem and self confidence
- Design login and identification techniques accepted by all users
- Better communication between social- and health care systems/staffs and the personal devices used
- Implementation of assistive technology features into standard devices and services

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## References

1. WHO, "Mental Health Action Plan 2013-2020", [http://www.who.int/mental\\_health/publications/action\\_plan/en/](http://www.who.int/mental_health/publications/action_plan/en/)
2. WHO, "Mental Health Action Plan", [http://www.who.int/mental\\_health/action\\_plan\\_2013/en/](http://www.who.int/mental_health/action_plan_2013/en/). 2013
3. OECD, "Making Mental Health Count,", <http://www.oecd.org/els/health-systems/Focus-on-Health-Making-Mental-Health-Count.pdf>. 2014
4. OECD, "Factsheet Highlights from OECD 's Mental Health and Work Review,", <http://www.oecd.org/els/soc/49227189.pdf>. 2011
5. Borg, Johan, Ann Lantz, and Jan Gulliksen. "Accessibility to electronic communication for people with cognitive disabilities: a systematic search and review of empirical evidence." *Universal Access in the Information Society* (2014): 1-16.
6. Lantz, Ann., Johan Borg., Stefan Johansson, Anita Hildén, and Jan Gulliksen. (Submitted). Accessibility to electronic communication for people with cognitive disabilities: a review of grey literature. Unpublished manuscript
7. Lewin, Kurt. Action research and minority problems. *Journal of social issues*, 2(4), 34-46. 1946.
8. Schuler, Douglas, and Aki Namioka. Participatory design: Principles and practices. L. Erlbaum Associates Inc., 1993.
9. Muller, Michael J. "Participatory design: the third space in HCI." *Human-computer interaction: Development process* 4235 (2003).
10. Kyng, Morten, and Joan Greenbaum. *Design at work: Cooperative design of computer systems*. Lawrence Erlbaum Associates, Incorporated, 1991.

11. Ehn, Pelle. Work-oriented design of computer artifacts. Vol. 78. Stockholm: Arbetslivscentrum. 1988.
12. Whyte, William Foote Ed. Participatory action research. Sage Publications, Inc. 1991
13. Gulliksen, Jan, Ann Lantz, and Inger Boivie. User centered design in practice-problems and possibilities. Sweden: Royal Institute of Technology 315. 1999.
14. Johansson, Stefan, Jan Gulliksen and Ann Lantz. User participation when users have mental and cognitive disabilities (manuscript).Sweden. Royal Institute of Technology
15. Larsson, Staffan. Seven aspects of democracy as related to study circles. *International Journal of Lifelong Education*, 20(3), 199-217. 2001
16. Rönnerman, Karin, and Anette Olin. Research Circles. In *Lost in Practice* (pp. 95-112). SensePublishers.2014
17. McGurk, Susan, Mueser, Kim and Pascaris, Alysia. "Cognitive training and supported employment for persons with severe mental illness: one-year results from a randomized controlled trial." *Schizophr. Bull.*, vol. 31, no. 4, pp. 898-909, Oct. 2005
18. ISO/IEC 40500:2012. Information technology -- W3C Web Content Accessibility Guidelines (WCAG) 2.0. 2012.
19. Adolfsson, Jeanette. "Kognitiva hjälpmedel Nationell uppföljning av hjälpmedelsförsörjningen för personer med kognitiva funktionsnedsättningar" (Assistive aids for persons with cognitive disabilities. Only available in Swedish) 2012.
20. Van Dijk, Jan, & Hacker, Kenneth. The digital divide as a complex and dynamic phenomenon. *The information society*, 19(4), 315-326. 2003
21. Kaye, H. Stephen. Computer and Internet Use Among People with Disabilities. Disability Statistics Report (13). Washington DC: U.S. Department of Education, National Institute on Disability and Rehabilitation Research. 2000.
22. Dobransky, Kerry, & Eszter Hargittai. The disability divide in Internet access and use. *Information, Communication & Society*, 9(3), 313-334. 2006.
23. Ennis, Liam, Rose, D., Denis, M., Pandit, N., & Wykes, T. Can't surf, won't surf: The digital divide in mental health. *Journal of Mental Health*, 21(4), 395-403. 2012.