
Implications of the social model of disability for co-designing assistive technology

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Abstract:

Co-Designing a product with a disabled person requires mutual respect. In order to understand and respect the situation that is designed for, a context mapping study was conducted.

In contrast to the medical model of disability, the social model of disability does not immediately evaluate an impairment of a disabled person as negative but acknowledges that they might evaluate it neutrally or even positive. Its approach for tackling problems that disabled people face everyday is therefore not fixing their bodies, but rather fixing a society that was designed without impairments in mind.

Assistive technology is designed to aid disabled people in all sorts of activities. An assistive technology that is designed according to the social model of disability encourages the user to do an activity their own way, rather than trying to adapt their bodies to normal societal standards. Assistive technologies come in different categories.

In order to design an appropriate AT, a human centered design approach is useful, since it values understanding the user and designing technology catered specifically to them, resulting in less error prone, more intuitive products that the user does not have to adapt to.

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A subtopic of human centered design is co-design. Here, a designer works with a client to develop the product in a very close relationship. Especially when working with a disabled person, it is important to keep the relationship human, respectful and level in terms of hierarchy. This ensures a productive environment to create in, in which both parties feel seen. The goal of designing with and for the co-designer is to always be kept at high priority.

The case owner that is present in the case this paper is preparing for is Alex (name changed), who is a former breast cancer patient. Treatment has left her with fatigue, limited movement possibilities and sensitive areas due to amputation. She also suffers from bad eyesight. Her solace in life is art, which she does in an art studio for disabled people. Since her life converges in painting, because she does not have the energy to do much more, she asked the design team to design something that aided her in that activity. Context mapping activities confirmed that this is likely the area in her life where an assistive technology can have the most impact. It also pointed out that the actual painting (not preparation or cleaning fe.) is the area Alex most requires assistance.

Finally, the product should respect Alex by embracing and supporting her way of painting, allowing her to comfortably sustain the activity longer and improve the experience, by enabling her to do movements she is unable to do right now.

Keywords: Assistive Technology; Co-Design; Respect

1. Introduction

Designing a product for a specific disabled person poses challenges for a designer that would not occur when designing for a non-impaired person.

As Sara Goering mentions in her paper about the role of disability in society (2015), disability is commonly viewed by the able-bodied population as a “problem in a person’s body”, with the utmost relief for a disabled person being the fix of said problem. By contrast, disabled people often feel that negative experiences in daily life does not stem from their body, but rather society’s reaction to, and ignorance of it. Goering attributes this to the popularity of the medical model of disability and offers a different concept, the social model of disability, as a different way to treat disability. In contrast to the medical model, which is often concerned with fixing a disability, the social model distinguishes between disability and impairment. An impairment, which is defined as a “lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body” (Goering, 2015) does not yet contain an evaluation, thus acknowledging the personal assessment of a disabled person’s impairment, which might not be negative.

As a designer who is developing a product that is supposed to aid a disabled person in their daily life, this view on disability should be considered. On first thought, it is very tempting to think of the product to-be-developed as a fix of the divergence of a disabled person’s body from the norm, whilst it should rather be considered as a way to eradicate cases in which the environment a disabled person is living in was designed without them in mind.

This way of thinking becomes increasingly important when applying a human centered design approach on product development, which relies on close collaboration with users. It is obvious that this collaboration relies on mutual respect between the designers and participants. Thus, a problem definition that goes beyond “fixing” a participant’s body and dives deeper into the obstacles that the environment and society pose to a disabled person, is essential for an effective and successful design process.

This paper approaches that problem by conducting a context mapping study, a part of the human centered design process, to map out the context that is designed for whilst working with a disabled person, as part of Module 7 – Design for a Specific User, Bachelor Industrial Design Engineering, University of Twente.

The paper is going to start with a literature study about human centered design and its various methods, as well as a deeper dive into disability and the specific impairment of the case owner. Afterwards, the application of human centered design is going to be justified and the implications and context of working with the case owner is going to be laid out.

2. Literature Study

2.1. Why human centered design is important when designing for a disabled person

Human centered design (also called Human factors engineering) is a design approach that works towards developing technology that is adapted to a human, rather than requiring a human to adapt (Lee et al., 2017). It has been shown that it results in more usable, faster to learn and less error prone products (Norman, 2005). Activities within Human centered design focus on gaining an extensive understanding of the user and their problems and applying this theory to develop a product catered to the findings. A distinction is to be made between Human centered design and Activity centered design. In big

parts, both methods share common ideas, but in contrast to HCD, activity centered design focuses on the tasks to be accomplished by a user and develops a tool according to that, potentially requiring users to adapt to the tool. It is said that ACD may result in less intuitive products, which do however appeal to a bigger target group, by not focusing as much on individual users (Norman, 2005).

As stated in the introduction, the distinction between impairment and disability is important in the respectful treatment of disabled people. An impairment may not be evaluated negatively and as such does not need a fix. Moreover, the attempt to “fix” something that does not need to be fixed, may result in negative emotions, essentially creating the problem and not solving anything.

This distinction alone justifies the application of HCD whilst designing for a disabled person, since it highlights the importance of gaining a deeper understanding of the user. It is also important to see what speaks against HCD. In his article from 2005, Norman mentions that human centered design often results in products that are too catered to their users, which decreases applicability to a bigger target group. He states that humans could be expected and are of capability to adapt to a product.

Looking at problems disabled people face on a day-to-day basis, these often stem from products being designed without them in mind (not because their bodies lack any feature). Also, many disabled people just cannot adapt to a product designed for a non-impaired body. Lastly, since the product this context mapping study is made for, is meant to be used by one person only, it does not need to be applicable to a bigger audience. All of this highlights that ACD is not applicable and the criticism brought up against HCD (although potentially valid in other cases) to not apply to this particular case.

2.2. An introduction to assistive technologies

The World Health Organization defines Assistive Devices as “products that maintain or improve an individual’s functioning and independence, thereby promoting their well-being”. Further, Assistive Devices are supposed to help impaired users to perform tasks that they’re struggling with because of their impairment. It’s important to define the difference between an assistive device that aims to adapt the user in a way where they can exist like an unimpaired person and an assistive device that supports the user in their own way of life. The ‘National Network of Americans with Disabilities Act’ explains that it’s vital to refer to the person first and the disability second, labeling a person can be disrespectful and dehumanizing. This approach is called Person-First Language, and is applicable to Assistive Devices too. This also means that Assistive Devices often have to be designed and fitted specifically for the individual user, making them expensive both in terms of design and manufacture.

Assistive devices for impaired people usually split into two categories:

First, there are aids that are designed to help the user communicate, either with other people or with devices. The second category of aids are interaction aids. Those are devices that are designed to help or allow the user to perform certain movements or interaction, often by countering the effects of gravity or providing stabilization.

The WHO explains that hearing aids and spectacles are common examples of communication aids. Another common aid for communication is the ‘switch access’, a technology which allows the user to interact with computers or other electronic devices. This is done with just a simple switch. The realization of this switch is dependent on the condition of the user, there are for example simple hardware switches meant to be pressed

with the finger, switches meant to be pressed with the chin, and even switches that are activated by blowing onto them. Further there are voice inputs, which can also be used to communicate with a computer. Lastly there are Brain Computer interfaces, which come with a significant overhead and aren't very reliable, however they can allow a severely impaired person to communicate (at all) with other people or computers.

Devices like wheelchairs or crutches belong to the movement aids category. Longatelli et al confirm that assistive devices can compensate for muscle weakness and help the user to perform daily activities. The Armon Ayora is one example, it is an exoskeleton arm that supports the user's lower arm and allows for an extended range of motion and less fatigue. Hartman et al further discuss how assistive devices can support a user with an impaired shoulder/hand.

2.3. Approaches for Co-Design

2.3.1 General guidelines

When using the method of Co-Design to create a new tailor-made product or service, there are a couple of pointers and key principles to give thought to in advance and keep in mind during the entire process of codesigning.

When working with people it is important to enhance mindful awareness (Moll et al., 2020) Thoughts, sensations, perceptions, and emotions need to be handled with care as in any interpersonal relationship.

As a designer, it is crucial to be able to take other perspectives, improvise and be willing to be transformed during the Co-Design process (Moll et al., 2020)

Possibly one of the most essential principles is understanding the position of power and privilege in a Designer-User Co-Production.

To successfully cultivate the most useful ideas, one must aim to keep the power hierarchy between the process coordinators and the end users as horizontal as possible.

Only then do the ideas of the Co-Designing parties receive the space they need to develop into useful solutions. It is not unusual for Designers to overestimate their understanding of the user's perspective, therefore compassion and humility are paramount prerequisites for any Co-Design process. (Steen et al., 2011)

„Codesign has been described as both a philosophy and a method that includes authentic and equitable collaboration between stakeholders in projects that are emergent, flexible and iterative.“ (Moll et al., 2020)

In order to create fertile grounds for ideas to flourish, the Design process coordinators should provide low-fidelity prototyping tools such as drawing material, clay, and Lego which might evoke insights and ideas that transcend what people might put into words.

Asking the subject for a clear image of what outcome is not desirable is possibly a good starting point for the Co-Design process.

This avoids ideating in the wrong direction and makes the design process more efficient.

2.3.2 Three Approaches to Co-Design as found in (Steen et al., 2011)	194
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1. <i>Step Back Approach</i>	196
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This approach initiates the Co-production process with an extensive survey to form an idea of the perspective of the co-designer(s).	198
The next step is the wall-flower style observation of the user's experience. Documentation can be in form of video recording, audio recording, notes, and pictures.	199
Finally, the validity of the findings is verified by the user and either confirmed or corrected.	200
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This approach allows us to obtain an untainted image of the user experience. It avoids a big part of biases that could be introduced by the designer's own perception.	202
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2. <i>Facilitator Approach</i>	209
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With this approach, the Co-Design supervisor is involved in the creation process as someone who stimulates the co-designer's creativity and helps them materialize ideas.	211
The Designer needs to facilitate the use of prototyping tools and help visualize and realize ideas that are verbalized by the co-designing party.	212
It is also the task of the designer to present the co-designing party with examples of existing solutions and the possibilities of today's technology. This might unlock new ideas and help the co-designer to think outside of their area of understanding.	213
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3. <i>Immersion Approach</i>	221
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The first step in this approach is similar to the first approach that was presented.	223
The Co-Design supervisor begins by analyzing, observing, and measuring the user's environment, behavior, and experience.	224
The second step is where this approach differs from the first. With the collected data The Designer tries to simulate the observed circumstances to immerse him/herself into an identical user scenario.	225
It is important that the Designer remains open and empathic to the subject's perspective on things, and tries to recreate a user experience through the co-designers eyes.	226
The third step is to take a step back and analyze the immersive experience. If it is not close enough to the original point of view and experience, improve the simulation and repeat.	227
After the designer created an immersive simulation of the observed and described experience he can begin finding ideas for an improvement or a product.	228
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2.4 Theoretical background to specific condition	238
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"Cancer treatment for AYA (adolescent/young adult) patients typically involves the combination of chemotherapy, surgery and radiation for a period of one to two year." (Soliman and Agresta, 2008)	240
The case person for this project has described difficulties moving their arms. Upon talking to her, she described their fight with breast cancer that lasted two and a half years in	241
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the past. The operation to remove the tumor was what led to their disability. They experienced an amputation of the right breast which led to an expander being placed inside her body. Her body would not accept the expander which led to an infection and a wound that would not close. After removing the expander, the wound did close, but the case person never felt the same again. "Long-term affects vary depending on the age of initial diagnosis and treatment." (Soliman and Agresta, 2008). The case person was treated for cancer 1 year after starting to experience symptoms.

She had a job in the cleaning business in which making certain movements became really hard. The chronic fatigue became made any physical activity exhausting, and her legs would not work after walking for a certain amount of time which made her unable to work without frequent breaks. After receiving the diagnosis for breast cancer she came to the lowest point of her life both physically and mentally. Her body would not work anymore, and she could only stay at home or be in the hospital and rest. This led to depression.

"Other studies have shown an increased risk of depression in survivors that is attributed to the chronic sequelae (e.g., Pain, disfigurement) that affects quality of life." (Soliman and Agresta, 2008) After the cancer was removed from the body, the case person started doing treatments to regain control over her extremities. She had to find a new passion in life to focus on. She could not work anymore because of her condition. She still has pain all over the body. She always feels as if she has bruised ribs. Her arms can only make certain movements (raising her right arm is so strenuous that she cannot execute the movement twice in a row without significantly losing range of motion with every repetition); when her arm is up in the air, she can't make a clockwise movement. Due to her constrained mobility, she is forced to move counterclockwise to continue where she left off.). She can't stand for a long time and must rest many times a day. Also, because she is still undergoing treatment, she must visit the hospital for half of the days of the week.

Finding a new passion in life was the only way to escape the emotional burden of the new circumstances. In her younger years, she loved to paint and draw. This activity restored hope to find her way back to a meaningful life. She found an art studio close to home where she could spend half of the days of the week focusing on her creations and feeling happy again. Said art studio is a place where coaches help people with disabilities to find purpose again through art. Receiving access to these facilities requires a government permission. In view of the fact that her condition is chronic, our case person will benefit from a life long permission to use this place happy place. She still struggles with her disability in the art studio because of her limited range of motion in the right arm. As she does nothing more than resting and visiting hospitals in her time outside of the art studio, the project we want to focus on is creating a product which would make her daily life at the art studio a bit better.

3. Practical Context Mapping

In addition to the theoretical work, some more applied context mapping activities were done.

First, the observations and applied user research results were organized on different level in an affinity diagram. Orange post-its represent overarching areas of a problem, pink post-its problems, blue post-its sub problems and yellow post-its specific observations. Work on the clustering started from the bottom up, working from observations to problems.

Before clustering, it already became clear that the general direction of design was going to be something that supported Alex in painting, which was her favorite activity. She described that she had trouble painting and it was the only thing she found happiness in. Besides that, she does not really have energy to do anything else.

The areas of problems whilst painting boiled down to:

- Fatigue
- Limited range of motion
- No comfortable posture
- Limited movement abilities
- Bad eyesight

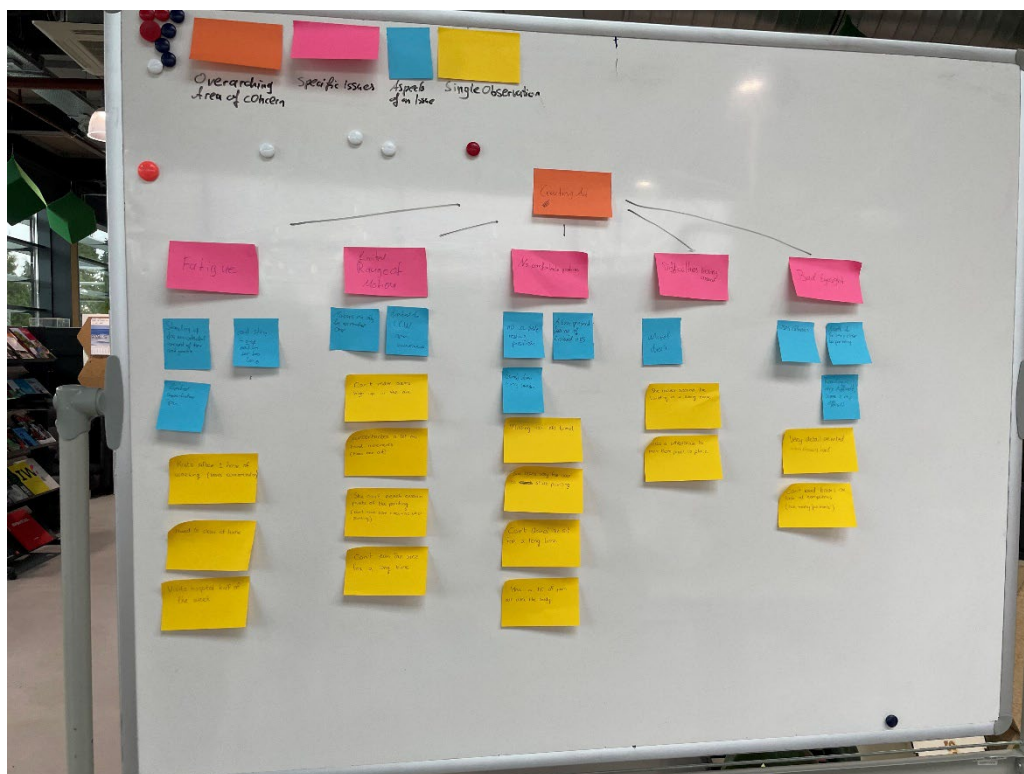


Figure 1. Affinity Diagram on a whiteboard

From the background information in the interviews, a stakeholder map with all important persons that a product for the case owner may concern was also drawn up.

With this information, a persona visualization about Alex was created, which acts as the main stakeholder in the design process.

Persona



Alex - she/her
60 years old
Former Breast Cancer Patient

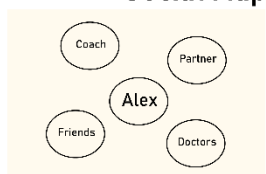
Difficulties:

- Fatigue
- Limited movement possibilities
- Finding a comfortable position
- Bad eyesight
- Moving around
- Depression

Interests



Social Map



Weekly Schedule



Figure 2. Persona of case owner

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Finally, with the observations during the interview and the information provided by the case owner, a user journey map for the process of painting was created.

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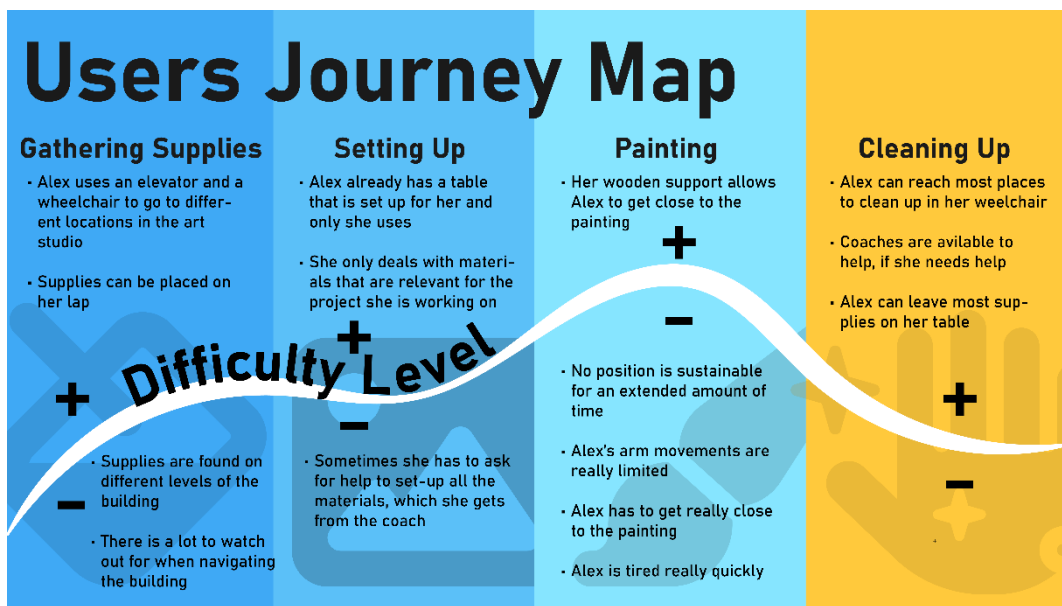


Figure 3. User Journey Map of Alex painting

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This really emphasized that the area of concern for the design was the painting process itself, since this was an area where Alex couldn't rely on help from the outside, but really needed the autonomy to paint. It also became clear, that this was the most difficult part of the activity of painting for her.

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Photos and illustrations from the case owners place of work at the art studio were used as a basis for this step.

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Environment

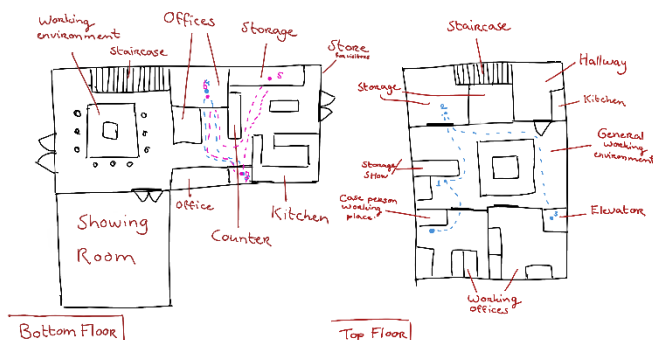


Figure 4. Overview of the environment

4. Discussion and conclusions

Whilst writing this paper, its own importance for a design process involving disabled people became apparent.

Whilst researching assistive technology, a prominent player stated their product was “essential for basic human interaction, like shaking hands or participating in social life” (Memory Protocol). This statement can be seen as an application of the medical view of disability: A person’s impairment is to be compensated (fixed) by a device, to participate in activities that were clearly designed for non-impaired people (eg. “shaking hands”).

Modern research shows that the medical model of disability is often not applicable to how disabled people actually view their impairment. A product that is respectfully designed for non-able-bodied people should therefore take into account not to try to “normalize” their bodies, but rather support them in their ways of performing actions.

Applied to the specific case that this paper is written alongside with that means, that the objective behind designing a product that allows Alex to paint like an able-bodied person. Her own way of painting has evolved as part of her disabilities. As an example, her bad eyesight meant she had to get close to a painting to see it properly, which might have enabled her to become the detail-oriented painter she is. The goal should therefore be to design a product that embraces and supports this way of painting.

The final design vision is: “Design a product that helps Alex during the activity of painting. The product should adapt the environment Alex is working into her impaired body. Particular areas of concern are allowing her to find a comfortable position where she can get close to a painting, extending the amount of time she can paint at a time and allowing her to easily reach all parts of a painting.”.

Respectfully Co-Designing a product with the case owner requires great care in communication and planning of the design process, that goes beyond acknowledging the social model of disability. Alex’s disability has caused her great depression and changed her

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life in many ways. Although we as designers are essentially working for her, it is important to keep in mind that she grants us a lot of intimate insight into her life which requires a large amount of respect and trust.

In the Co-Design process it is important to acknowledge the power-dynamic the process brings with it and reflect on it. The goal of designing with and for the case owner should remain the highest priority. Methods that show Alex respect and comfort her are important to apply, like co-designing with art supplies (fe. whilst painting).

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Research was done jointly.

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