Mapping the Context for Co-Designing with a Mild Intellectual Impaired Person Lotte Lammers¹, Milo Storm², Lelie van

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Abstract: This article addresses the context mapping of a co-design related project involving a mild intellectually impaired person. Over the past few decades, societal views on disability have drastically changed. Assistive technology can contribute to the inclusion of people that are usually overlooked by society. In this project the co-designer has a mild intellectual impairment, meaning basic tasks and chores can be performed autonomously. However, some assistance with finances and communicating is called for. In order to develop a product optimized for the envisioned user, Human-Centred Design will be used to identify the core problems, needs and preferences of the target group, and keeping those in mind during the design process. To properly include the codesigner in the design process, a proposal will be done to include co-design activities in the design process. The findings of this article will contribute to a smooth sailing co-design process with the co-designer.

Keywords: Context mapping; Co-Design; Intellectually Impaired; Human-Centered Design.

1. Introduction

This study is meant as a familiarisation with subjects such as societal trends and the changing perspectives on disability, assistive technologies, HCD, minor intellectual impairments and co-design. Furthermore, the context of a person with the impairment will be analysed. The purpose of these studies is to develop a better understanding of the co-design participant and create a foundation for a design vision and later on, the product development.

2. Societal Trends and the Changing Perspectives on Disability

Over the past few decades, societal views on disability have drastically changed. In the second half of the twentieth century, disabled people were often viewed as pathetic and defective. Disabled people were removed from the rest of society by representing them as threats to the norm. By only talking about disabled people instead of with them, power was being kept away from them. Intellectually impaired people were not taken seriously: by viewing them as 'creatures' who only needed care and could not fend for themselves, they were being belittled.

However, over time a shift in perspective happened. Current views on disability are about empowerment: giving disabled people control of their own lives by offering solutions and aid that supports this. Intellectually impaired people should be taken seriously and have their own voice. They should be able to participate in society: be considered part of it and have access to the same opportunities.

This is where assistive technology can step in: it can empower disabled people to actually participate and reach their goals. Assistive technology can bridge the gap between 1) simply saying disabled people should be respected and included, and 2) actually enabling them to do what they want and have the same opportunities.

3. Introduction to Assistive Technologies

"Assistive technology (AT) is any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities" (What is AT?, z.d.). AT is available in all sorts of shapes and sizes since each product is suitable for a specific target group in the disorder spectrum. To design successful ATs, it is important to know what the needs of the primary users are and, therefore, should be co-designed with the end-users. As first-hand users, they can help inspire the designer to find the necessary solutions (Alfaro Arias et al., 2020).

Even though ATs are very important for people with disabilities to live a normal life, a lot of ATs get abandoned. This phenomenon, called technology abandonment, is mainly caused by not serving the needs of the user anymore (Petrie et al., 2018).

Lots of products used for other things than they were designed for, this is also the case for ATs. This phenomenon is called technology appropriation. Appropriation is desirable since it allows the users to be able to meet their needs better. But designing for appropriation is hard, however, there are some guidelines to help designs become more suitable for appropriation (McKnight, 2013).

4. Human-Centred Design

In Human Centred Design (HCD) the focus is on the end-user, identifying the core problems, needs and preferences of the target group, and keeping those in mind during the design process, in order to develop a product optimized for the envisioned users (DC Design, 2017).

Human-Centred Design can be approached in different ways. The one that will be explained here is the IDEO approach, which consists of 6 phases (User Testing, 2018). In this project, these different phases can be used as guidelines for the co-designing process. During the design process, it is most important to keep track of and stay open to the ideas, expectations and wishes of the co-designer and end-user in all phases.

The first phase is all about understanding the end-user. Ideas will be generated in the second phase. The generated ideas will be turned into prototypes using rapid prototyping in the third phase and will be tested with the envisioned users in the fourth phase. The fifth phase consists of iterating on the ideas, using feedback from the prototypes, and further developing the concepts by repeating the previous steps. Once a final design has been chosen, the sixth and final phase is reached. This phase is about bringing the developed solution into the world and finalizing the design process. For most processes the development does not stop here as new technologies, changes in society or other aspects mean the "final" product is never fully finished. To redesign or update the design, one can start at phase 1 again and go through the different stages over and over again.

5. Theoretical introduction to the impairment

Our co-designer is diagnosed with a mild intellectual impairment. This impairment can vary strongly in severity and occurrence. A person who is diagnosed with a mild intellectual impairment lags behind in conceptual development and social and daily living skills compared to people of the same age. However, they can learn practical life skills, which allows them to function in everyday life with minimal levels of support (National Academies of Sciences, Engineering, and Medicine et al., 2015, pp. 1–3).

This is also the case for our co-designer. She is able to function independently in practical situations like, for instance, cooking, cleaning her apartment, doing the laundry and the groceries. She only needs help with the finances.

The main issue for our co-designer is expressing her mood, stress, anxiety and thoughts, which are typical symptoms of her impairment. Coping with the mood, stress and anxiety is difficult, as well as finding a solution to feel better

6. Co-design

Co-design is an act of collective creativity applied over a whole design process (Sanders & Stappers, 2008). It is based on the knowledge that people know best what they want from a design because they are situated in the environment the product will be used. During co-design, designers work together with non trained people in design, in a design process. The term co-design is used to describe many methods that can be applied to the design process in different stages.

6.1 Where did it come from?

Co-design goes all the way back to the 1970s when it was called participatory design. In Scandinavia, they came up with the Collective Resource Approach, to gain value from industrially produced products by asking input from people that are impacted by the final product. At the same time in England, a book made up of papers called Design Participation was published (Sanders & Stappers, 2008). The used methods for co-design originate from marketing and business, where the value of a product is important to make sure the customers are satisfied with the product.

6.2 Why and when is it useful to do it?

The design process starts with a fuzzy front end and is followed by a regular design process. The fuzzy front end refers to the broad explorations when the end product is not known yet. "The co-design activities typically aim at searching new potential directions and producing design ideas and solutions" (Mattelmäki & Sleeswijk Visser, 2011). Co-design is useful for idea generation, throughout the process feedback from the co-designer is very valuable (Friedrich, 2013).

6.3 Comparable projects

We looked at some interesting examples of co-design that have some properties in common with our project. An example is "Lessons from expert focus groups on how to better support adults with mild intellectual Disabilities to engage in co-design" (Gibson et al., 2020). This paper is most useful to us since it gives insights into working with people that have intellectual disabilities. Some of the findings are that it is useful to use multiple modalities, as storyboarding, interviewing, prototyping, etc. To make everything as clear as possible, concrete examples and visualization like (online) sticky notes can add great value. Do watch out for the confirmation bias since people with intellectual disabilities can be sensitive to this.

Another paper on "Co-design process of a smartphone app to help people with down syndrome manage their nutritional habits" (Lazar et al., 2018, p. 74), gives a better look at how to work with apps. As we see it now, this could be a possible solution for our co-designer. It is interesting to see how they first looked into how the target group currently handles apps and define success to build further on this. They use a lot of storyboarding and subject-related exercises. Though our target group does not cope with down syndrome, this could still be applicable for people with an intellectual disability.

Our last research paper, "User expectations of robots in public spaces: A co-design methodology" (Tian et al., 2020), dives more into the online working of co-design, which is useful because we need to do all the co-designing online. They use different online tools to replace physical activities with digital ones. They use the same kind of approach as the other two papers, first look at what is already known and work this out with co-design tools like for example scenario writing. This could be interesting for us as well.

7. Discussion and Conclusion

Our co-designer has trouble informing her supervisors when she is experiencing any mental problems. There is a lack of a proper communication and feedback system. The overall vision is to design a product/service to improve the quality of life of our codesigner. The main design value that will be kept in mind during the design process is human-centred design. Consequently, our main goal is solving the problems of the codesigner, while making sure she feels heard and included during the design process. For the actual design process, the following things will be kept in mind. Firstly, the design needs to be tailored to the target group. Secondly, the process of communicating with the co-designer and using different co-design methods should be clear and upfront. In addition to that, the co-design methods should not only use text but also include visual methods. As a result of this, our main design challenge is to design a product or system that helps our co-designer to communicate her stress and mood. To understand our codesigner and design a product that really suits her preferences and needs we will make use of some co-design activities. Among other visual assignments, we will ask our codesigner to make a collage, to keep a diary and we will propose and discuss different scenarios and solutions.

Author Contributions:

Societal Trends and the Changing Perspectives on Disability, E.J.; Introduction to Assistive Technologies, S.S.; Human-Centred Design, L. E.; Theoretical introduction to the impairment, M.S. and L. L; Co-Design, J.S. and J.R.; Discussion and Conclusion, J.R. and S.S. All authors have read and agreed to the published version of the manuscript.

Informed consent statement:

Informed consent was obtained from all subjects involved in the study

8. Engaging with the practice

The methods that have been used so far are interviews and diaries. For the interviews, a questionnaire had been sent in advance, so the participant had the opportunity to already start thinking about the topics in advance. A large advantage of interviews is that a large amount of information can be gathered in a short amount of time. Possible drawbacks of the interviews are that the co-designer is not completely honest or does not know how to articulate her thoughts or opinions. The major advantage of the diary is that it is a relatively low-effort way of getting to know the daily activities and habits. A drawback is that the amount of data can be limited since there is no possibility to directly ask for clarification. This is why the interviews are a good complementary method.

8.1 Person

Wendy Smit is a 35-year-old woman. She is diagnosed with a mild intellectual impairment. She lives in Almelo in a 24-hour residential facility in her own apartment, where a caretaker can help when needed. On Thursdays, she has daytime activities at team JOY and another company on Tuesdays and Fridays. She likes diamond painting, walking and cycling. Her boyfriend is Kevin de Jong, he is 33 years old and lives in Oldenzaal. She hopes to live together with her boyfriend in the future. In her daily life, she experiences difficulties with expressing her feelings, stress, anxiety and thoughts. Currently, Wendy fills in a mood tracker about how she feels at a certain moment. But with this system, she doesn't feel heard.

8.2 Context

Wendy lives in a modern small apartment in a 24-hour residential facility, this means that there is always someone present in case something happens. The caregivers who work in the facility come by at least once a day to talk with Wendy and discuss the mood tracker if necessary. Her apartment consists of a bedroom, a bathroom, a living room with a kitchen around the corner and a hallway. Every Tuesday and Friday Wendy has daytime activities when she is there, there is also a specific caregiver for her to help her with all struggles and goals she wishes to achieve.

8.3 Activity

Wendy currently uses a mood tracker on paper to fill in how she feels at a certain moment. Her stress occurs due to a variety of different circumstances. She uses the colour green, orange and red. Every colour resembles a different mood. And every mood has a different solution to make her feel better. A disadvantage to this is, that when Wendy fills in the mood tracker with the colour red, her caretakers don't get a notification right away. She doesn't feel heard at a time when she needs it the most. So, it would be convenient for Wendy to use a product where she can track her mood and a notification gets sent to her caretakers, so they can be there for her.

8.4 Storyboard

This storyboard displays what is happening in the head of the client when she is feeling stressed, and how she tries to handle this stress. It also displays a mood tracker and how it is used, as well as the role of the caretaker in this problem.

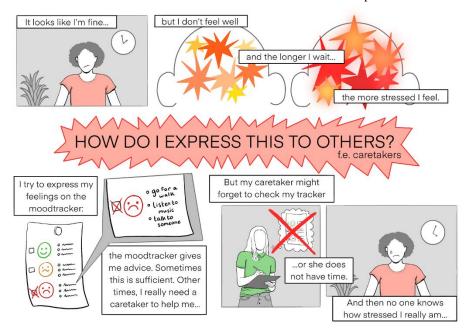


Figure 1: Story Board

8.5 Persona

This persona provides a representation of the client and gives insight into different aspects of her personality and life. This semi-fictive persona can be used as a tool during design and sharing the outcomes, while protecting the client.



Goals & Motivations

In the future Wendy wants to become more independent so that she can move in with her boyfriend. They want to live in an apartment outside of the 24-hour facility, with only ambulant help every once in a while.

Thoughts & Challenges

Wendy loves cycling, walking and diamond painting, it clears her mind and keeps her in a good mood. She also gets a lot of energy from her boyfriend, supporting her actions and beliefs. Only when her mood worsens because of certain thoughts or external frustrations, she has problems with communicating these feelings.

Frustrations

Wendy thinks it is quite hard to communicate her stress proper ly. She sometimes feels not heard by her caregivers, which can result in rather emotional blow-outs. Besides that the neighbours in her facility can work on her nerves, resulting in more stress.

Usage of Current Technology

Wendy is currently using a thermometer on paper to indicate her feelings. She can indicate her feelings by showing which co lour of the thermometer she feels like. If she feels good or even happy, she will indicate she is in the green part of the thermometer. If she is anxious or even sad or angry, she will indicate she is in the orange or red part of the thermometer respectively. For each category of moods, a corresponding quote helps her maintain that good mood or get back into it from a worse mood.

Wendy's Story

* I currently live in Oldenzael, in a facility in which I am 24/7 under the supervision of my caregivers. I have my own apartment in which I can spend time on my own. I do my own groceries and laundry, but every once in a while the caregivers check in on me.

My personal assistant Linda helps me on Tuesdays and Fridays. On the other weekdays, I go to daycare for activities for team JOY and another company.

At the moment I have a boyfriend who supports me with my hobbies and beliefs. He lives in another city, but I hope to live together with him soon. I often take my bike when I go visit him.

I struggle with how I feel when I feel sad or anxious, I do not know how to tell this to my supervisors. At the moment I can show my feelings using a thermometer with the colours green, orange and red. These colours belong to the feelings happy, anxious, sad or angry. The only problem is that my supervisors do not always have the time to look at the thermometer. Sometimes they do not even have time to speak to me, so my mood becomes worse. I wish I had a faster and easier way to show how I feel. Maybe I could then live together with my boyfriend and be helped by my supervisors from a distance.

Figure 2: Persona

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