1. Context mapping: Co-designing with a person that has Autism Spectrum Disorder

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1. Introduction

This literature study discusses a more in-depth view of Autism Spectrum Disorder, as well as assistive technologies for this disability. It also concerns explanation and research about co-design, the origin, and the importance of this process. This research helped in guiding the project group through the process of this project, making decisions and draw conclusions.

2. Literature Study

2.1 Social trends and the changing perspectives on disability

Society has all kinds of norms and values, standards with the goal of creating an optimal and pleasant environment. From the day you were born, you learn these social rules. These rules are aimed at the ´average´ person living in society (Autisme in onze samenleving). For people with autism, these social rules are often not as self-evident. Non-autistic people sometimes view people with autism as child-like or find interaction difficult. Negative prejudices are often quickly made. These can lead to social exclusion or isolation. As of today, only one-third of people with autism take part in community social activities (Sarris, 2015).

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In the last ten years efforts have been made to reduce the stigma around autism. More autism awareness is raised through autism awareness training, programs, or school interventions. Also, the stereotypical view of for example the typical white autistic boy is being removed. The autistic community has a big diversity in ethnicity, gender, race and sexuality (Houting, 2021). The positive aspects of people with autism are getting more recognition as well. The spreading awareness of is beneficial for the whole society, which encourages more research and support for people with autism and their associates.

2.2 Assistive technologies

2.2.1 Introduction to assistive technologies.

Assistive technologies (AT) can be any item, software, or product that helps the user to perform certain activities even when the user has certain disabilities. ATs exist to help people with any kind of disability. Depending on the disability of the user, a more high-tech or low-tech AT is needed. Usually, when a choice must be made, it is done with professionals and consultants that are experienced in the field. In this case, the team consists of a group of students and a tutor that will guide them. They are all co-designing and working together in trying to make the best fitting AT ((ATIA), 2022).

To ensure that assistive technologies work, the project group has to work together with the participant, as well as that it is designed to make them as affordable and accessible as possible for a larger audience ((ATIA), 2022).

For this project, assistive technologies are exactly those things that the group needs to think of, design, and try to make for the co-designing partner. The co-designing partner gave 4 main situations that need assistive technology and, in the end, the group needs to co-design together with the end-user to make something that the "customer" will be able to use.

The problem that is going to be worked on is that the co-designing partner feels the need to write many of their thoughts down, and this creates a mess of papers everywhere in their house. For this, assistive technology needs to be designed that can help them be more organized, as well as manage what is important and what can be thrown away after some time. For this, a constraint is given that must not be bigger than A3 format since it needs to be portable for whenever they leave the house.

2.2.2 Technology abandonment

If the AT is something that the user is not comfortable using because it does not fit, or does not perform well, for long-term use, it might be better to abandon it even though the product performs well the task that is meant to do. (Petrie, H., Carmien, S., Lewis, A. (2018))

2.2.3 Technology appropriation

Appropriation is when the user of this AT also uses the product in their daily life and becomes part of this, as well as being part of their life in a social, economic, and political aspect.

2.3 Human Centered Design

2.3.1 User centered design versus human centered design

The technique of user centered design is focused on the usability goals, user experience, surroundings, and tasks of the person. For human centered design is it very important to run several tests on the product. The needs, preferences, and experiences of the user are the main point of focus to achieve a useful, user-friendly product with a high level of satisfaction for the user.

The process of human centered design is similar to user centered design. However, there are some differences. The human centered design method is based on a problem-solving principle. There is a problem for which a social solution must be found. First, the problem must be found. Therefore, a deeper understanding of the life, needs, and wants of the users are necessary. Clear observations must be made about the problem in its environment. For the further development of the design method, brainstorming can be done. After the brainstorming phase, solutions need to be carried out. These solutions will be improved in the last phased of the process and a final solution will be delivered. To optimize the satisfaction of the users, several tests need to be performed.

The results of the two design methods will have a lot in common, both want to achieve a more suitable and relevant product for their users.

2.3.2 Co-design

The process of human centered design is, as expected, taking place together with the users. This is important because this process is used to design, for example for people with special needs, so a deeper

understanding of life situations is needed. Therefore, the design process of 'co-design' can be used. Often, the users can explain their needs and co-designing will give the optimal solution for a problem of the individual.

2.4 Autism Spectrum Disorder

2.4.1 Theoretical introduction to the autism spectrum disorder

Autism spectrum disorder or ASD (autism spectrum disorder) is a general term for a group of complex disorders of brain development. These disorders are characterized in varying degrees by difficulties in social interaction, verbal and nonverbal communication, and repetitive behaviors. ASD includes autistic disorder, Rhett syndrome, childhood disintegrative disorder, pervasive developmental disorder or PDD-nos, and Asperger's syndrome.

2.4.2 Why are there different diagnosis included in the ASD spectrum?

A diagnostic manual for all these autism subtypes was published. (DSM-5, 2013) all the disorders were merged into one diagnosis of ASD spectrum disorder.

Therefore, there is a wide range of abilities with the diagnosis of ASD. Everyone is unique in terms of intellectual disabilities, difficulties in motor coordination, attention, and physical health issues. Many of those on the autism spectrum have exceptional abilities in visual, musical, and academic skills. About 40% have average to above-average intellectual abilities. Many people on the spectrum take deserved pride in their distinctive abilities and atypical ways of viewing the world while others with autism have significant disabilities. About 25% of individuals with ASD are nonverbal but can learn to communicate using other means. One of the most important things to communicate with those who have ASD is to learn the early signs of autism and become familiar with the typical developmental milestones.

2.5 Co-Design

2.5.1 What is co design?

Co-design is a process where you design with the participant, not for the participant. So co-operation is the main part of co-design. It uses creative and participatory methods. There is no specific method that can be used for every participant you are designing for. It differs from person to person. It is important to ensure that the results meet the needs of the participant.

There are different principles which are important in the co-design process. Share power, prioritice relationships, use participatory methods and build capability are four often used examples. This is about discussing at the same level, building trust, learning from each other, and sharing your ideas. There are different phases in the co-design process. These phases can be seen in figure 1 (McKercher, 2020).

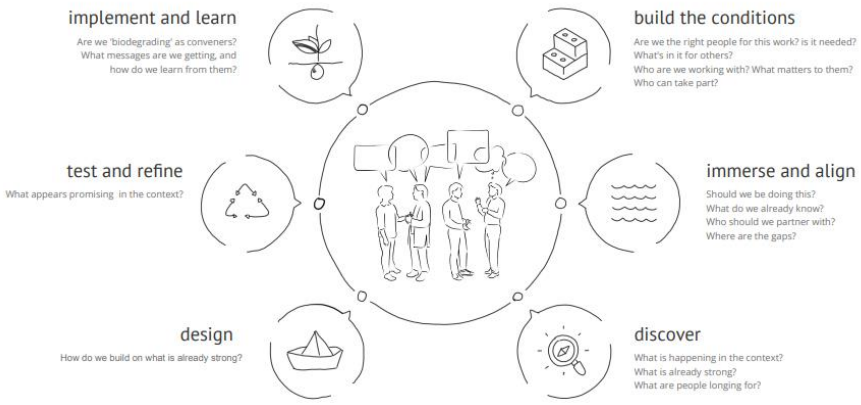

Figure 1: phases in co-design 114

2.5.2 Where did co-design come from? 115

Cooperative design methods oriented in Scandinavia in the 1970s and 1980s (Natematias, 2011). 116
During this time there was a movement of digitalization of work practices. An example is the huge 117
development in computer software. The labor unions in Scandinavia were strong, they had a lot of power 118
and influence. Their thoughts were that the workers should have a strong voice in what this computer 119
software should look like. Also, there were a lot of people who were unemployed in human centered related 120
jobs. These people started working in computer software as well, but with their human oriented minds. 121
This together started a new movement, where there was a lot of interest in what the user thinks of certain 122
designs. This was the start of co-designing. 123

2.5.2 Why and when is co-design useful to do? 124

The purpose of co-design is to discover unique perspective through working together with the 125
participant and to include user and stakeholder opinions in key decisions (Good Things Foundation, 2021). 126
This is especially important in this project, because this is designing a product for a specific person. You 127
cannot meet their needs if you do not discuss what they need. That is why it is important to involve the 128
participant in all the decisions that are made. You want to make sure you can empathize with the participant, 129
so you understand better what the needs of the end user are. 130

2.5.3 Academic papers about co-design 131

The first academic paper that describes a co-design project is one about improving healthcare through 132
the use of co-design (Boyd et al.,2012). They had a specific co-design approach which incorporate six main 133
phases. These phases are: engage, plan, explore, develop, decide and change. These phases are a good 134
guideline for the project. This starts with understanding the problem and listening to the participant. 135
Accordingly, working with the participant and coming up with ideas about the goals of the improvement 136
and how to go about doing it. Next those ideas will be turned into specific improvements and be chosen 137
what improvements to make and how to make them. Finally those improvement ideas will be turned into 138
action. 139

This co-design project uses different tools to get the interaction with the patients. They used patient 140
journey mapping, which is a summary of services experiences patients have over time. Furthermore they 141
did and experienced-based survey and they had co-design workshops. Journey mapping could be a helpful 142
tool for the project as well. This way a good overview of how the co-design feels for the participant per 143
stage can be made. 144

The second academic paper is about co-design with users who have autism spectrum disorders 145
(Francis et al., 2009). This study sought some initial co-design guidelines for the inclusion of people with 146
autism in the design process of ICT. They use the Delphi Method. This method is described as '' a method 147
for the systematic solicitation and collation of judgements on a particular topic through a set of carefully 148
designed sequential questionnaires interspersed with summarized information and feedback of opinion 149
derived from earlier responses'' (Delbecq et al, 1975, p 127). A group of individuals are likely to make 150

more accurate prediction than if they are working alone and face-to face meetings are prone bias through the impact of influential members, cited by Lang (1994, p 127). This face-to-face meetings with the participant are important in the process as well. This contributes to the communication clarity and prevents communication mistakes.

The third paper is called community Led co-design of a social networking platform with adolescents with Autism Spectrum Disorder (Zhu et al., 2021). In this paper three phases of co-design are described. In the problematizing phase group discussion, sketching and dot-voting to frame requirements and priorities requirements are used. In the solutioning phase, the design team uses sketches and prototypes along with group discussion to generate design artifacts. In the experiencing phase, the design team uses methods like storyboarding, comparison matrices and reflection to test, review and document perceptions. In figure 2 iterative methods for each phase can be seen.

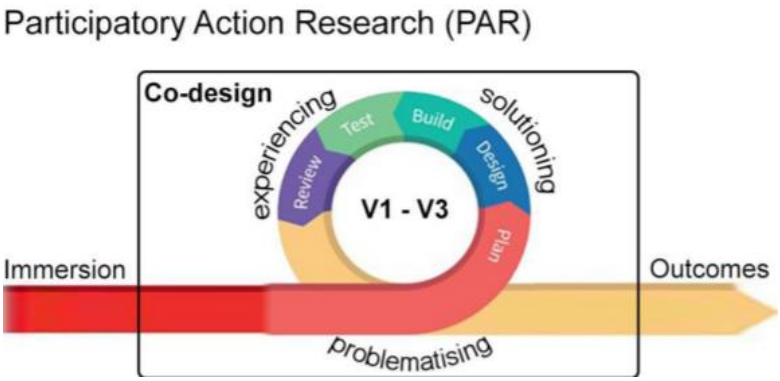

Figure 2: Iterative methods

These phases are a good guideline for the project. Especially the reviewing phase is not something that should be forgotten. Is the participant still satisfied in every decision that is made? Are their requirements met? Those are questions that should not be forgotten during the process.

3.1 resource gathering

To gather information from the participant two interviews were done. During this interview, the co-designer was asked certain questions beneficial for the research. An observation has also taken place. Two members of the group went to the house of the participant to assess the living situation and write down the nessacery observations. Throughout all of this, the consent of the participant was taken into account. The co-designer has received and signed a letter of agreement for the research.

4. Discussion and conclusions

Through the research, certain design challenges have come up that can be worked on in the future. These design challenges were the following;

- Finding a way for the user to organize notes in the right way for the user.
- Remind the user to think about their posture when they are deep in thoughts
- Make fiepen controllable for the user.
- Make social interactions understandable for the user.

The chosen challenge is the organization of the notes. The user has indicated that this is their biggest challenge they face. Through co-design, this challenge can be tackled by creating solutions and discussing said solutions with the user.

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Human centered design; Abby Keus, Introduction to assistive technologies; Edward de Smalen Sanchez, Societal trends and the changing perspective on disabilities; Yael Easton, Theorical introduction to the autism spectrum disorder; Sofia de Gruijter Eguiluz, What is co-design; Britt van Slooten, Introduction, storyboard and persona, final edit; Lara Oosting, Discussion, conclusion and format paper; Johan Lagemaat

Informed Consent Statement:

Written informed consent has been obtained from the patient(s) to publish this paper.

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