Co-design in context to cerebral palsy

Matthias Heindl[1], Feike Knol[2], Dongmin Lee[3], Madeline van der Linden[4], Arsenii Myronyk[5], Jasmijn Poorts[6], José Rosenfeld Eluani[7]

[1] Affiliation 1; m.m.heindl@student.utwente.nl
[2] Affiliation 2; f.k.knol@student.utwente.nl
[3] Affiliation 3; D.lee@student.utwente.nl
[4] Affiliation 4; m.l.vanderlinden@student.utwente.nl
[5] Affiliation 5; a.myronyk@student.utwente.nl
[6] Affiliation 6; J.s.c.poorts@student.utwente.nl
[7] Affiliation 7; j.rosenfeldeluani@student.utwente.nl

Abstract: This context mapping study provides an insight on a co-design process with someone with cerebral palsy. Information will be provided on methods used in designing assistive technologies as well as the development of a design process using human-centred design and co-design. To understand the design challenge details will be provided on cerebral palsy and societies view on disabilities. Finally, the report concludes with a more detailed representation of the co-design participant using persona and storyboards.

Keywords: co-design, cerebral palsy, disability, assistive technology, human centred design

1. Introduction

The goal of the project 'Designing for specific users' is to design a product for a user with a disability. In this case, the participant has a form of cerebral palsy. Cerebral palsy is a disability caused by a developmental defect during the early stages of life that affect the motor cortex of the brain. There are many types and therefore cerebral palsy affects people in different ways and to different extents. In this specific case, the participant has certain issues. These issues include difficulty with speech and uncontrollable spasms, which are mainly in the arms. The participant uses assistive technology, such as an electric wheelchair. The project challenge in this specific case is to design a product that will aid the participant when giving public speeches, such that he is more understandable to the public and that his face, in particular his mouth, is not covered by his arms and hands. It is important to use co-design when designing products for specific users. Co-designing a product is to design a product while working closely with the user. Co-design is a core element of this project and has many advantages. All further information on the disability and co-design is discussed in this paper based on our particular participant.

2. Literature Study

2.1 Theoretical introduction to the disability of your user

Cerebral palsy is a condition that arises during the development of the brain during childhood, caused by abnormal development or damage to the brain.[1] The disability affects the part of the brain that allows a child to control their muscles, resulting in reduced muscle function, with severity varying from weakness in certain limbs to a complete lack of controlled movement. The

term cerebral palsy covers a number of disorders, and there are several types of cerebral palsy. Cerebral palsy is presently not curable.

Types of cerebral palsy:

- *Spastic diplegia/disparesis*
- *Spastic hemiplegia/hemiparesis*
- *Spastic quadriplegia/quadriparesis*
- *Mixed cerebral palsy*
- *Dyskinetic cerebral palsy*
- *Ataxic cerebral palsy*

Abnormal brain development or brain damage resulting in cerebral palsy can occur at various stages, including prior to birth, during birth, and up to early childhood. A diagnosis can typically be made in the first two years of a child's life, but in some cases it may take longer to make a diagnosis, especially when symptoms are mild.

Cerebral palsy can be the result of genetical factors, in which cases it is not preventable. Nevertheless, there are numerous steps that can be taken to reduce developmental problems such as CP, most of which revolve around ensuring a healthy pregnancy. [1], [2], [3]

The most common symptoms of cerebral palsy are:

- *Being floppy or stiff*
- *Exaggerated reflexes*
- *Muscle weakness*
- *Lack of muscle coordination*
- *There are uncontrolled body movements*
- *There are problems with balance and coordination*
- *There are problems with swallowing, sucking, eating*
- *The person uses one side of the body to reach for things*
- *There is a delay in learning to speak*

2.2 Within society

Society has shifted its belief that disability is a disease and that people just need help to cure or treat it. Nowadays, these "patients" are seen as citizens, having the same rights and skills. In an inclusive society, there are no special facilities for people with disabilities. Special facilities usually mean that people with disabilities have to be assisted by someone. True inclusion means that all buildings and facilities are accessible to everyone and people with disabilities can use them independently. [4]

In 2021, over two million people with a disability lived in the Netherlands, this includes people with limited hearing or sight, as well as those with physical and mental disabilities.[5] Some of these people need lifelong care and supervision. These problems stop being individual medical situations and became community orientated. The transformation of the social structure, from a contemptuous attitude towards disabled people to the vision of equity and inclusion, empowers people with limited abilities to participate in the community as active and influential members, contributing to the daily activities of our society.

2.3 Human Centred Design

Human-centred design (HCD) describes a design process in which users are considered at all steps of the design process. In this case, 'user' should be interpreted to mean not just the primary user, but all humans that interact with the product. Taking these users into consideration can involve a number of participatory research methods that help to understand the users and the context in which they use products[6]. HCD ideally allows designers to create a product that is more suited to the target group's needs, making it almost inevitable when designing for a specific user.

Human-centered design should not be understood, in the context of co-design, as designing a product based on an idea that the user already has in mind, because this prevents a broad design process that considers problems or solutions that the users had not thought about when they came up with the idea.

In terms of design ethics, HCD is a double-edged sword, because the participatory nature may create increased expectations for a product that might be perceived as specifically tailored and therefore magnitudes better than existing products. Therefore, expectation management is absolutely essential from the very start of the design process.

Another ethical consideration is that a product could create a dependency. For instance, a product aimed to help with a certain motor function could end up having a negative effect when the user does not have the product available to them, at which point the motor function without the product may be reduced due to a lack of practice. Potential risks such as these show that long-term effects of the use of a product should also be kept in mind throughout the design process.

2.4 Co-design

Co-designing is designing together with your user(s) to better include their perspective, experience and better define their needs. [8] By constantly testing with and talking to the user(s) the end product will be better implemented and meet the expectations. The user(s) have to be involved during all phases of the design process to help make the best design decisions for the end product.

Codesigning started in Scandinavia around 1970. There was a lack of involvement of primary users in major decision implementation/ development for new products, architecture, healthcare etc. The focus with co-design was now more on personal experience instead of firm-view, which created a new value to products/services[7].

Co-design is now a common practice all over the world and is used when the design challenge is very complex to understand. It is useful to use co-design to involve your end-user and get feedback before major design decisions. They will know better what you are designing for (the design

challenge), whether the design is usable for them (prototyping) and if they would indeed use it (market expectations). Great insight can be given that designers might overlook because it is a whole other perspective. In a way, co-design is always useful. Getting the opinion of your end-user and stakeholders is very valuable, however, when the group you are designing for is very large it might not be the best way to go. User testing and survey might be better to get a bigger feedback group later in the design process.

To get some inspiration research was done on other co-designs. One research[8] was found on people with speech disorders ordering in restaurants. The methods used in this co-design, for creating a better environment in restaurants, was to sit together with the stakeholders (catering staff, speech experts, person with speech disorder and friends/ family of them). They actively got involved in finding the solution to the problem(s) by tools like listening to personal stories and brainstorms. This method and tools could be used in designing our product as well by listening to personal stories of the participant and brainstorming together with stakeholders like caregiver, participant, and audience.

Another research[9] was found on people with aphasia speaking in groups. This relates to the participant's problem of being understandable in front of a group. In the research, it was concluded that two tools for participation worked very well: floor transfer (getting the opportunity to talk) and question-answer series (sequences of yes/no type questions). The method used to come to these conclusions was communication analysis. This might be a good method for the project as well to find out when and why the participant is inaudible. Also, the conclusion might be something to inform the audience about or in a way signal them.

Next to observing, it is also useful to look at assistive technologies that already exist. One app, Make Me Speak, was created in co-design with a person with cerebral palsy to communicate. [10] Analysing the steps taken in developing this app could provide valuable insight for this project.

2.5 Assistive technologies

Assistive technologies are products, equipment, and systems that enhance learning, and daily living for persons with disabilities. [11] So for example a wheelchair is a form of AT, it is a product that helps a person with a disability in their daily life. There are much more examples of Ats, like hearing aids to help people hear, or something like closed captioning during movies to help people with hearing problems to also enjoy the tv. [12]

2.5.1 What are ideas and theories and concepts behind it that may help design successful ATs?

> *The major goal of AT is to develop a solution that will solve a problem for the person with a disability. Therefore it is really important to listen to the co-designer and really find out what this person wants. And this begins with building a healthy collaboration between the designers and the co-designer, this is key to achieve this goal. Let the co-designer test things out, let them experience and give feedback. Researchers found out that co-designers are more likely to stick with an assistive technology if they feel they are actively participating in the creation of that technology. [13]*

2.5.2 Examples that relate (even just in a broad sense) to project.

- *Microphone with speaker*

- *To make the co-designer speech louder.*

- *Megaphone*

  - *To make the co-designer speech louder.*

- *Arm constrains*

  - *To restrict the arms of the co-designer (voluntarily), so they will not block his speech (hand in front of mouth)*

2.5.3 Research and discuss the term 'technology abandonment' and technology 'appropriation'.

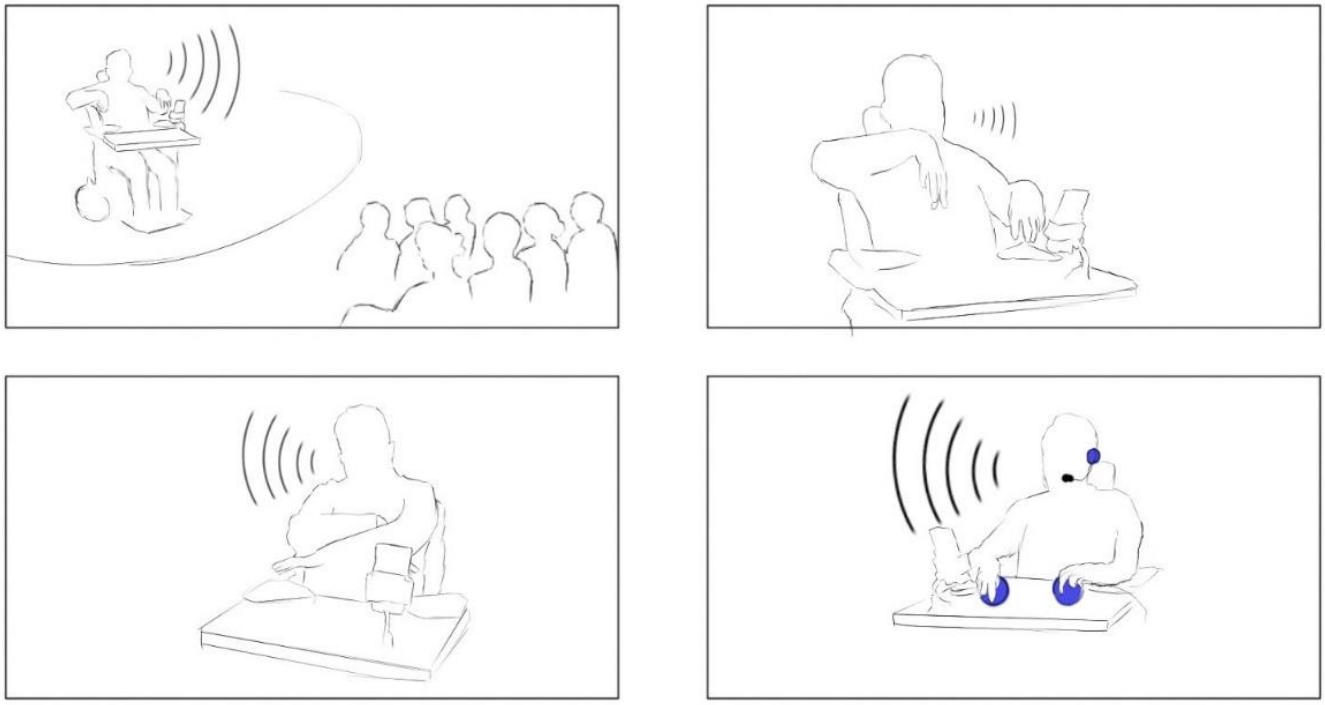
Assistive technology abandonment rates are very high and is a serious problem. For example studies have reports abandonment rates of 78% for hearing aids. [14] [15]

These abandonment rates have various different reasons. For example if the product has an improper fit this could lead the product being not comfortable for long-term use. And if this is the case for, for example people with hearing aid, the product will be abandoned. Even if it meets the co-designers needs. [16] *Changes in needs of users can also lead to abandonment of the ATs. These changes can be permanent, like worsening of sight or temporary like an increase in tremor with Parkinson.*

There are also discussions about the appropriation of ATs. Who is responsible for the ATs and who will facilitate these. Luckily often they will be facilitated by a school, by an insurance company or by the state, but this is not definite and should still be considered during the design process.

3. Engaging with the practice

3.1 Story board



3.2 Persona

4. Discussion and conclusions

The information in this study will be essential in an effective co-design process. It should allow the group to maximise its understanding of the disability, the group's responsibilities, the task at hand, and the steps and tools required to achieve a successful end product. The findings should be referred to periodically during the process, in order to ensure that the process remains focused.

With all the above background knowledge in mind, having a better understanding of the challenges faced by our participant, we decide to proceed with our main design challenge: To make our participant's speech more audible without creating any discomfort.

References

1. What is Cerebral Palsy. Centers for Disease Control and Prevention. (2021, November 30). Retrieved March 4, 2022, from https://www.cdc.gov/
2. Cerebral palsy. healthdirect. (2020, October). Retrieved March 4, 2022, from https://www.healthdirect.gov.au/cerebral-palsy
3. Cerebral palsy. Mayo Foundation for Medical Education and Research. (2021, September 1). Mayo Clinic. Retrieved March 4, 2022, from https://www.mayoclinic.org/diseases-conditions/cerebral-palsy/symptoms-causes/syc-20353999
4. *Shifting beliefs about disability.* (2016). Retrieved from: https://www.odi.govt.nz/home/about-disability/shifting/
5. Nwanazia, C. (2021). *How inclusive is the Netherlands for people living with disabilities?* Retrieved from: https://dutchreview.com/expat/how-inclusive-is-the-netherlands-for-people-living-with-disabilities/#:~:text=An%20estimated%20two%20million%20people,in%20political%20and%20administrative%20functions .
6. D. Townson. "The seven tenets of human-centred design." Design Council. https://www.designcouncil.org.uk/news-opinion/seven-tenets-human-centred-design [accessed Mar. 03 2022] .
7. Wikipedia Contributors, "Participatory design," *Wikipedia*, Sep. 23, 2019. https://en.wikipedia.org/wiki/Participatory_design. [accessed Feb. 17 2022] .
8. C. Carroll *et al.*, "Social participation for people with communication disability in coffee shops and restaurants is a human right," *International Journal of Speech-Language Pathology*, vol. 20, no. 1, pp. 59–62, Dec. 2017, doi: 10.1080/17549507.2018.1397748. [accessed Feb. 16 2022]
9. B. Archer, J. H. Azios, N. Gulick, and J. Tetnowski, "Facilitating participation in conversation groups for aphasia," *Aphasiology*, pp. 1–19, Oct. 2020, doi: 10.1080/02687038.2020.1812030. [accessed Mar. 01 2022].
10. N. Zamin, "Make Me Speak: A Mobile App for Children with Cerebral Palsy," *International Journal of Advanced Trends in Computer Science and Engineering*, vol. 8, no. 1.4, pp. 368–373, Sep. 2019, doi: 10.30534/ijatcse/2019/5681.42019. [accessed Mar. 01 2022].
11. Assistive Technology Industry Association. 2022. *What is AT? - Assistive Technology Industry Association*. [online] Available at: <https://www.atia.org/home/at-resources/what-is-at/> [Accessed 4 March 2022].
12. https://www.nichd.nih.gov/. 2022. *What are some types of assistive devices and how are they used?*. [online] Available at: <https://www.nichd.nih.gov/health/topics/rehabtech/conditioninfo/device> [Accessed 4 March 2022].
13. Phillips, B. and Zhao, H. Predictors of assistive technology abandonment. *Assistive Technology 5*, 1 (1993), 36–45.
14. Martin, B., Mccormack, L.: Issues surrounding assistive technology use and abandonment in an emerging technological culture. In: Bühler, C., Knops, H. (eds.) 5th European Conference for the Advancement of Assistive Technology (AAATE 1999). IOS Press, Düsseldorf, Germany, p. 852 (1999) Google Scholar
15. Scherer, M.J.: Living in the State of Stuck: How Technology Impacts the Lives of People with Disabilities, 2nd edn. Brookline Books, Cambridge (1996) Google Scholar
16. 2022. [online] Available at: <https://link.springer.com/chapter/10.1007/978-3-319-94274-2_77> [Accessed 4 March 2022].