# Context mapping study of a co-design with a wheelchair user

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**Abstract:** This document focuses on multiple different topics about disabilities and how to design for and with disabled individuals. First, the societal trends around general disabilities are discussed. This is the overview of policies and perceptions of people towards disabilities. After which an introduction is given to assistive technologies. This part goes in-depth about technology abandonment and the assessment of these technologies. Subsequently, human-centred design is touched upon, this is a design approach on how design should first focus on the users wants and needs before starting to design a product. Following the theoretical research, the disability of the participant, perinatal asphyxia, is researched. Next, it is discussed what co-design is and how it can be useful in product design. The rest of the paper is focused on the participant themselves and situations they experience. Concluding, it was found that wheelchair users still run into avoidable problems daily and the design challenge reads; to improve the well-being of the participant by addressing and focusing on issues that Jan is experiencing in his daily life.

**Keywords:** co-design 1; wheelchair 2; disability 3; health 4

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## 1. Introduction

The purpose of this academic research paper is to dive into the complex reality of a wheelchair user. Together with a participant, who is a wheelchair user himself, two semi-structured interviews have been conducted to learn about their daily life and struggles that come with being in a wheelchair. On the basis of the interview results this research delves into topics such as: current views on disabilities, co-designing with a participant and the struggles of the participant.

## 2. Literature Study

The collaborative information gathered research is presented below.

### *2.1. Societal trends and changing perspective on disability*

The definition of health evolved rapidly in recent years, this caused a change in the view on disabilities. More people get educated on the challenges of physical and mental disabilities. According to Heerkens et al. (2017) adjustments have been made from 2001 onwards that reformed negative wording presented by ICF into more realistic and contextual phrasing. It changes the definition of health from "The absence of disease." to "Resilience and ability to deal with the illness and to integrate it into one's life.". This evolution is being considered as "the ability to adapt and to self-manage in the face of social, physical, and emotional challenges".

Additionally, according to Escorpizo and Bemis-Dougherty article in 2015, starting from 2001 application of ICF found in research papers and clinical papers gets more often

applied towards resource allocation and prevention and wellness of the diseases. Rather than curing it, showing the shift in how professionals and people regard the disability topic. This finding implies that rather than to "fix" something about disabled people, the general population now tries to take into consideration their perspective and adjust the accessibility of products to make sure and accommodate those with disabilities.

However, in recent years there is increased amount laws and policies being implemented into the construction and product developments which is representative of growing disabled -people recognition and adjustments. Some of the Key disability initiatives of EU include the European accessibility act, regulations on the rights of passengers with reduced mobility in main modes of transport, and EU directive 2016/2102 of website accessibility (European Commission, nd). With every year, the voices of disabled people are getting louder and heard, they make themselves increasingly more visible, and in 2021 European Union presented European Disability Strategy 2021-2030 (Mabita, 2022). This plan shows how rights of disabled people will be advanced in a span of 10 years. These initiatives are aimed to raise the awareness and to provide the financial and social support to disabled people, among other points.

More attention in design community is being paid to the inclusivity and comfortability of the product to those who have certain bodily limitations. For example, in United Kingdom the common spaces such as retail shops must include wheelchair access according to Disability discrimination act of 1995. This is done to "ensure that the wheelchair users can access all public buildings in the same way as the average person who doesn't suffer from mobility issues"(Go Access, 2014). The wheelchair designs are now being made in large variety as well and are often personally tailored for the specific user. In general, the range of the special tools and devices is getting larger and larger with every year.

However, despite all the good intentions and efforts that are set to push these trends forward they are still mostly unavailable for average person. Even though most countries now have some accessibility standards there is still a big issue of architectural barriers (Mafatlane, 2014). For instance, even though the shop might have a ramp the wheelchair user physically cannot turn around in their wheelchair to pass between the shelves or the heigh of the counter or shelves is too high for them to reach. In addition to that, even though the market for disabled people is growing because of the prices that are being charged for this kind of products very small range of population can afford it. As a result, instead, they often adapt existing products applying clever affordances that designers or people without disabilities often miss.

### *2.2 Introduction to Assistive Technologies*

Assistive technologies (AT's) are a subset of health technology which consist of all the knowledge and skills needed to create assistive products as defined by the World Health Organization (WHO Press, 2017). Furthermore, they state that assistive products improve or maintain the independence and functioning of an impaired individual. These products are used to improve someone's well-being or prevent injuries and secondary health conditions. There are many types of AT's for different disabilities. This report is within the context of a wheelchair user. Wheelchairs also fall into the category of AT's. One effective way to create these AT's is with the co-design methodology. This method "can be used as a set of iterative techniques and approaches that puts users at its heart, working from their perspectives, and engaging latent perceptions and emotional responses." (De Couvreur & Goossens, 2011, p.113). This research also gives an example of such a co-design case. One participant in a wheelchair could not grip an ice-cream stick. During a co-design session a ring prototype with a small clip was developed which was

used and liked very much by the participant. The solution was based on observed patterns in terms of performance, identity and convenience aspects.

Technology abandonment is a big issue in assistive technologies. Around 29.3% of all AT's were completely abandoned (Philips & Zhao, 1993). This could lead to decreases in functional abilities, freedom, and independence in disabled people. The study (Kaplan et al., 1966) show that a lot of patients that do not necessarily need a wheelchair still prefer to use it because other solutions including orthotic braces were too complex to use. However, according to reports by Philips & Zhoa (1993) wheelchairs are still the most abandoned devices. To prevent this issue the AT's should have a certain quality insurance. This can be done using the matching person and technology (MPT) as described by (Scherer & Craddock, 2002). The MPT assessment process is personal and collaborative and uses simple questions as an interview guide. Users of the MPT measures have reported high satisfaction with the usefulness of the ATD.

There are several different factors to the abandonment of the assistive technologies. Those include the initial purpose of the assistive product, location, life situation and perceived importance of the product Especially strong correlation is found to be between the amount of the different AT that are being used simultaneously by one user which would also intertwine with the strongly with the type of the AT. It is noticed that "the chances to use increase for groups of users who received up to three products and then start diminishing for those who received four devices or more" (Suagawara, 2018).

### *2.3 Human centred design*

**"Human centred design is a philosophy, not a precise set of methods, but one that assumes that innovation should start by getting close to users and observing their activities."**

*Donald A. Norman, co-founder of Nielsen Norman group (2010)*

The human-centred approach to design has origins from a diverse type of fields, however Professor John E. Arnold (1913-1963), an American professor in mechanical engineering, promoted a holistic, human-centred design approach to engineering already in the 1950s (Arnold, 1956/2016). This approach was implemented with the Stanford Graduate Program in Product Design and is seen as the foundation of Human-centred design in product design.

This design project is concentrated on the wants and needs of one person, to create a product or service that perfectly fits with the participant of the project. Therefore, it is important to gather as much information as necessary about the participant to find the correct parameters to create requirements for the final product. This means that this design should be human centred, the goal of human centred design is to create products or services that match users' practices, needs and preferences (Steen, 2011). That definition means that the people who experience a certain problem should at first be fully understood throughout, before any solution is found (DC Design, 2017).

When focusing on the participant we will keep our participant central in the design process, keeping them constantly updated and informed about the steps that are taken. The participant has suffered congenital brain injury during their birth and has therefore been in a wheelchair for his entire life and lives in a 24-hour care building facility. This can make the human-centred design process difficult since the participant is not within close range of the designers. Therefore, a well-defined plan needs to be constructed to maintain the goals of the human-centred design process.

*2.4 Theoretical introduction to the disability of your user.*

The participant has perinatal asphyxia. Perinatal asphyxia is a lack of blood flow or gas exchange to or from the fetes in the period immediately before, during, or after the birth process. This can result in profound systemic and neurologic sequelae due decreased oxygen flow to an infant during the peripartum period. The peripartum period is the last month of gestation and the first few weeks after delivery (Gilliam-Krakauer & Gowen Jr, 2017). Perinatal asphyxia consists of two phases. There is placental (prenatal) and pulmonary (immediate post-natal) phase.

An estimation is done on how many children are born having perinatal asphyxia. According to a study (van Handel et al. 2007) the range of children with perinatal asphyxia is 1 to 8 per 1000 live births. This wide range can be attributed to problems with detecting perinatal asphyxia.

When diving a little bit deeper into perinatal asphyxia, it can be found that in less developed countries the major cause of death and disability is perinatal asphyxia. The pattern of risk factors, nature of sequalae and the options/priorities for interventions are different from further developed countries. Nearly 4 million newborns suffer from asphyxia, from those 4 million at least 800.000 children die, and the rest suffer from physical or/and mental disability. The higher rate in less developed countries results from less informed people about timing and events that can affect healthy birth (Costello & Manandhar, 1994).

Mothers and fathers participating in a birth where perinatal asphyxia takes place, experience strong trauma. They need a lot more psychological support and help during the first year of raising the child. Furthermore, fathers with a child that has perinatal asphyxia have larger rates of PTSD than fathers of a healthy child. During this research it is found that it is harder as a parent to bond with a child with perinatal asphyxia which may lead to lack of parental support and presence in a child's life. This may cause in variety of social and mental problems the child may be facing later in life (Horsch, et al., 2017).

Very little is said about the in-depth consequences of the asphyxia aside from the fact that it is a second cause of neuro-disability worldwide (Locci et al, 2020). It is hard to prevent and it can significantly affect human life via long-term complications (Bustamante et al, 2003). Such include not only mild brain damage and seizures but also motor deficits that can onset later in life and that our co-designer displays. Because of how often this brain-damaging problem occurs in newborns, its research is highly encouraged in the medical field. However, the aftermath of parental asphyxia is treated in most cases as separated disabilities as the level of the damage depends on the severity of the case. It means, that for our design we must focus on a specific case of our participant as it might be different from all other cases. Prenatal asphyxia affected his ability to control his legs. As such, he needs to use wheelchair constantly to be able to move around. This limits his ability to access certain heights and areas.

What the designers must also consider is the fact that prenatal asphyxia is known to also affect mental abilities and brain functions as even short period of lack of oxygen still harms the brain. Therefore, our co-designer might also have slight deviancy in terms of mental capacities. For instance, during the interview he mentioned that he avoids using products or systems with a lot of choices as it makes him feel confused. For the project it means that it is necessary to limit the variety of functions that are included in the product but it might also have other implication that should be taken into account.

*2.5 Co-design*

Co-design is the practice of designing a product alongside one or more stakeholders, also known as participants. This way of designing highlights the importance of the stakeholders' needs and the usability of the product throughout the design process. It is particularly handy when creating a product that needs to fulfil and be tailored to an individual's needs, as these can be quite different from those of most people. The following few paragraphs will examine some co-design situations that could offer insights into the upcoming project.

Zooming in to the project, the participant is an adult male with congenital brain injury. This injury from birth has made it impossible for him to walk or even stand on his own. Henni et al. (2022) have shown that people with motor impairments ask for rehabilitation gaming systems to replace repetitive exercises when talking about digital health solutions. Moreover, games like this should be affordable and space-efficient for the users. This could be something for the group to explore further in case the design focuses on issues like these.

Another noteworthy insight comes from an article about the participatory design of a wheelchair convoy system. Sharma et al. (2008) state that physical models and prototypes are more effective in co-design than visuals because participants could interact with them. Although physical products take more time to make than drawings, they could be very useful when meeting the participant for assessing the product.

Furthermore, Hussain et al. (2012) have found that members of a design team should observe and reflect on what they have learned throughout the process of co-designing so they can make adequate decisions regarding the design. This learning process revolves around reasoning why and when participants are involved in the design process as well as in what ways the research is acquired. For a project about a specific user with specific disabilities, it is important to keep improving the research methods so the participant will be better understood.

## 3. Engaging with the practice

Four interviews were conducted with the co-designer to determine his desires and preferences in regards of the visuals of the product, its interface, and the purpose. All the interviews were semi-structured and were conducted in real life in the setting of the participant's home. This setting was purposefully chosen with the intention to observe the participant's surrounding. This would help the team to determine what kind of style, colors, technologies, and other small details to be able to confirm them later with more in-detail questions.

The topics that were explored during the interviews included:

- In-person introduction with mention of the hobbies and activities
- Routine of the participant
- Kinds of difficulties or problems that he might encounter
- How he performs certain activities
- Ideas discussion
- Style preferences (with collages in different styles presented to the participant)
- Product details exploration

During the discussion the participant presented himself as an optimistic and social person. He mentioned that he does not encounter many problems in his daily life. Those that he does encounter, however, are often connected to the interior and exterior of certain building such as shops and transport such as trains and the lack of convenience that he

suffers from. However, those were the only negative points that he mentioned on his own. As such, the team had to investigate further via additional questions to determine his favorite or desired activities and how he performs them or why he cannot perform them anymore.

Via the interviews, valuable insights were gained. First and foremost, it was discovered that he really loves to listen to music however the only device he can use for it is his Personal Computer at his home. He mentioned that it makes him wish he could listen to it when he is in the care center. The reason for him to not use such devices as smartphone or the IPad was also discovered. The participant has mentioned that the text, buttons and icons of the most smartphones are too small and complex for him. The interviews also gave us important insight in his preferred aesthetics which included colors and shapes.

For the third interview the team made a low-fidelity prototype to test different outlines of the interface, font type, font size and the size of buttons/icons. From this interview it was determined what interface sizes must be avoided in the design as well as their preferred shape and position.

## 4. Discussion and conclusions

After meeting the participant, some valuable insights were gathered. These findings discuss the overall conditions the design must be adjusted and made for as well as the specifics of Jan's lifestyle. Following from the research as well as the interview, although the society tries to adapt and to include people with disabilities, certain activities may still be difficult for them. This includes usual day-to-day routine and common hobbies and sports. As such the design challenge aims to improve the well-being of the participant by addressing and focusing on issues that Jan is experiencing in his daily life. The current and future direction for design and further research will discuss Jan's hobbies and interests, such as interactive sports games and listening to music. The aim is to make the chosen activity more accessible, and thus enjoyable, for him. It is important to include Jan's perspective and perceptions into the further work as the collaborative design will allow to create the product which is tailored for his needs and wishes.

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