CONTEXT MAPPING FOR CO-DESIGN AND EDS

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In this paper the context for which will be designed is shown. The product will be designed for a specific user with Ehlers-Danlos Syndrome while being in close contact to fit the design with their needs. The design challenge is: "How can we design a product that allows for people with EDS to enjoy painting and drawing while avoiding unnecessary harm?".

In this paper the name and other personal details of the co-designers have been altered to protect their privacy, informed consent was obtained from all subjects involved in the study.

1. Ehlers-Danlos Syndrome.

Ehlers-Danlos Syndrome (EDS) is a collective term for clinical and genetic binding tissue disorder of which there are 13 different types documented at this time. These can be classified according to their symptoms and genetic characteristics (Janssen Rahabilitation Medicine & Consultancy;).
Most of the types share overlap with other types and they are sometimes only identifiable through identification of DNA on molecular level when this overlap is evenly distributed which is likely to occur (Fransiska Malfait, 2017).

1.1 Symptoms

1.1.1 Main symptoms

The three main general symptoms are hypermobility, instability, and dislocation. The term joint hypermobility is used when one or more joints have the ability to move beyond normal boundaries. When this hypermobility leads to instability in the joints, complaints might arise. Joint instability can then lead to dislocation of and damage to the joints and nearby connective and soft tissues (Janssen Rahabilitation Medicine & Consultancy;).

1.1.2. Skeletal and muscular symptoms*:*

Symptoms of the skeleton and muscles may include trauma to tissues such as muscle, tendons and joints and degenerative harm to the skeleton, this can lead to people with EDS having trouble holding things or exerting force on the related joints (Janssen Rahabilitation Medicine & Consultancy;).

1.1.3. General/systematic symptoms:

Tissues such as blood vessels, skin, mucous membranes, and connective tissue won't heal properly. Also, the involvement of the nervous system in preventing harm malfunctions (Janssen Rahabilitation Medicine & Consultancy;).

1.1.4. Chronic pain:

The experience with and intensity of pain varies, so does the way to treat it. Ergotherapy, physiotherapy, or manual therapy are available; therapy could also help with accepting and dealing with the constant pain (M.A. Griffioen, 2021). There is currently no cure for the underlying binding tissue issue; therefore, medical guidance, correction and prevention of the consequences are suggested (Janssen Rahabilitation Medicine & Consultancy;). When considering the need of any invasive surgery it is very important to keep the possible risks of EDS in mind. Reluctance is suggested especially for non-essential surgery (M.A. Griffioen, 2021).

2. Perspectives on disability

2.1 Changes in perspectives

Originally people with disabilities were very dependent on people around them. They simply could not participate in society on their own. In the United States, around 1970's this changed due to the Independent Center Living Movement, in which a new realization arose which stated that to be free one must take control of their own life (Bryan, 2010).

Disabilities used to be viewed as if there was only one set of symptoms and treatment plan for a disability (Munyi, 2012). To live more independently, countless research was done on anatomy and

the fundamental cause of a disability resulting in broader knowledge and treatment. Along with this knowledge came a better understanding and sympathy for people suffering from disabilities and prejudices disappeared (Bryan, 2010). Over time, disabled people were not seen as a group but received more personal views and attention. A view of understanding that every person and each situation is unique and has its unique and specific needs (Munyi, 2012).

The understanding and acceptance towards people with a disability resulted in the comprehension that a disability does not necessarily mean that someone is unable to participate in society. On the contrary, they might need some adaptation but nowadays the aim is to create the best possible integration and participation into society with the assistance of all kinds of technologies that have been and are being developed. The role of technology as a part of daily care is growing since it can bring empowerment to someone with a disability. Given the change in the social views on disabilities and syndromes, the aim is to make everything that is accessible to the public, accessible to the ones with a disability, the extreme users; making it possible for them to participate in society.

3. Participation and empowerment

According to the Oxford English Dictionary, participation is the action or fact of having or forming part of something; the sharing of something (Oxford University Press., 2022). Participation can be seen as the chance to live a “normal” life. Having the right to study, see a doctor, work, and even go to a restaurant or store. All these things that seem so normal for people without a disability, can be a big challenge for those with one. By making the “normal” things possible for someone with a disability they are empowered to live their life. This empowerment means that they get the power and authority to do something on their own, to claim their rights, control their own lives and reach their potential. Empowerment can be divided into five types: social, educational, economic, political, and psychological (Mandal, 2013).

4. Target user

The scope of this societal perspective is also applicable to people who have the third type of Ehlers-Danlos Syndrome, like our participant Anne. Since Anne can do limited activities daily, she does not require someone to watch over her at all times. Her syndrome does not yet limit her to aids such as a wheelchair. So, the outside world currently only notices her syndrome through the braces that she is wearing. She can even perform some extremer activities such as driving a car or making the bed. The only two things limiting her in these activities are her energy levels that depletes rapidly and her bones and joints that hurt or could dislocate.

5. Assistive Technologies.

What are assistive technologies? What are ideas and theories and concepts behind it that may help?

Assistive technologies are products or designs that suit as a supplement to aid the user in pursuing a normal lifestyle when they are unable to do so on their own. In short, it enhances working, learning and daily living for people with disabilities. Assistive technologies come in an abundance of forms, and shapes; sometimes supporting the user, or completely substituting for the disabled part of the user. This leads to empowering the target user to do tasks on their own.

Figure 1 – back support for walking upright (Amazon)

In order to apply assistive technology in the right manner, it is of great importance that the technology is tailormade for the target user. Additionally, the technology should also be well understood by the user, and it must fulfil the task that it is designed to perform. The user should greatly benefit from this assistive technology to make it successful.

5.1 Successful assistive technologies

ATs exist for many different applications and can be seen everywhere in daily life. Examples of these are ATs that aid with walking or standing upright (Figure 1). For EDS and similar disabilities many assistive technologies are already available on the market. When looking at Anne's hobby, different ATs exist that help her with certain actions in a different way. The ATs that apply to Anne's situation do not have to limit themselves to just painting alone, as there are also tools out on the market that allow for both painting and writing in the same product (Figure 2) (Lancioni, 2013).

Figure 2 - writing aid (Online Ergonomics)

5.2 abandonment

If assistive technologies happen to be too expensive to maintain or if they fail to fulfil their function, technology abandonment occurs. This is the phase that can be identified in a development cycle where an AT gets dispersed for certain reasons. To counteract this, assistive technology can be redesigned or made specifically for the user to better fit the product or design to their life. This process is what technology appropriation encompasses. The adaptation of assistive technology is a process that also falls under this term.

6. Human-centered Design.

Human-centered design is a method of designing that puts the users first in the process and keeps them connected throughout the entire design process. It is designed from the perspective of the user, keeping their limitations, constraints, and desires in mind. A reason for HCD to be implemented is to create a better working design by having the end-user involved (Wal, 2019).

6.1 Concerns

As stated by the article (Norman, 2005), there is a big risk by focusing on one person in a group. HDC will likely improve the design for them but at the cost of functionality for others. Therefore, you should reconsider during the design process whether your design is still functional for others and will still be functional in the nearby future. Thus, the second risk is that by focusing on one group and one problem you could focus too much on the present without thinking about functionality in the future.

6.2 The process

An HDC process usually starts with the users; co-designing and close collaboration with the users are important. Starting with the first phase, defining the problem; here the foundational research for the project will be done. The second phase of the process is ideating; coming up with daring designs is encouraged at this part of the designing process. After the ideation, the best ideas should be selected, and the prototyping and testing phase can begin. Within this phase, the concept can be worked out further and can be tested on functionality accordingly. The last step is to translate the final design into a final product. In this phase you finalise your product for the market and refine your business model (invision).

7. Co-design / Participatory Design.

Participatory design, which is often called co-design or co-operative design, is about challenging the imbalance of power held by individuals, who perform important decisions about others' lives, livelihoods and bodies. Co-design is about designing with, not for (Beyond Stickynotes, n.d.).
Participatory design is a relatively new approach to designing products, which has its roots in 1970 in a work of Kristen Nygaard and Olav-Tarje Bergo with the Norwegian Iron and Metal Union (Cipan, 2019).
It is attempting to actively involve all stakeholders e.g., employees, partners, customers, citizens, end

users in the design process to help ensure the result meets their needs and is usable. The term is used in a variety of fields as software design, urban design, architecture, landscape architecture, product design, sustainability, graphic design, planning, and even medicine as a way of developing environments that are more responsive and appropriate to their inhabitants' and users' cultural, emotional, spiritual and practical needs (Val Mitchell, 2016).

A co-design approach provides opportunities for people to meet and work together on a collective vision. This builds new social capital and strengthens existing networks. When people know one another better, they tend to be more tolerant, trustful, and capable of making change collectively.

Moreover, the Participatory design approach is essential for the process of the current project which is in fact designing a product for a specific user. It is truly important to focus on Anne's needs and desires and by meeting regularly a good connection between the group members and her will be maintained in order to reach the common outcome.

8. Persona

Anne (Figure 3) is a forty-year-old woman living together with her husband. She suffers from EDS, short for Ehlers-Danlos Syndrome. Anne must go about her day wearing braces around her arms to keep her fingers from bending independently or her wrists overstretching too much. In addition, special gooseneck rings ensure that her fingers bend in the right way.
These jewels are required, as Anne's joints tend to bend and stretch way beyond what other people would be able to achieve. Due to EDS, her connective tissue is far weaker than other people's tissue.

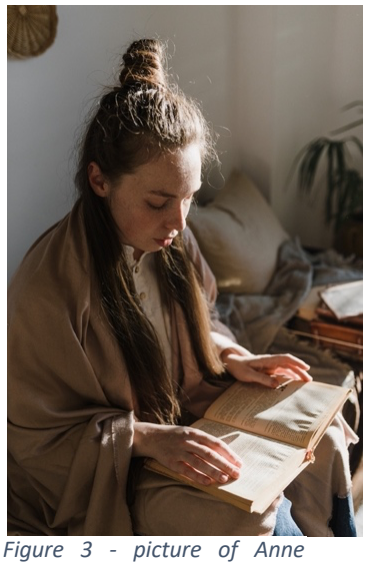

Figure 3 - picture of Anne (pseudo photo) (Krasnikova)

On a normal day she starts with a bit of reading. She's unable to work due to her syndrome, so she stays at home while her husband works. After reading, she walks the dog on a balance bike, she rests for half an hour and then starts with either making the bed or vacuuming the hallways. When her husband returns from work, he walks the dog for the second time and makes dinner. Due to her limited energy, she makes a maximum of one appointment each day.

Since her connective tissue is not strong enough to go through the motions of the day like anyone else, she made her schedule to allow her to enjoy her hobbies at her personal pace. Once day a week she reserves to go painting. She's able to drive there herself as she drives an automatic car, but because of pain, she alternates between getting picked up by her friend or driving herself.

When painting, Anne takes off the braces on her left arm so that she can perform the delicate movements that the painting requires. The brush strokes she produces with the left arm, and the unused brushes are held in the right hand. This hurts her fingers a lot (Figure 6).
Finally, Anne really likes the styles Steampunk and the Fifties and hopes these can be included in the design of the product. Collages of these styles can be found on the next page (Figure 4 & Figure 5).

9. Discussion and Conclusion

Overall, the independent care and research for different disabilities has improved over the years, with product design tending to the needs of specific user with methods such as human-centered design. The people with disabilities who these products are designed for and tuned to will be able to participate in things they would normally not be able to, which in turn allows them to feel empowered. For our participant, Anne, and for other users like her that would imply they would be able to paint comfortably without having to take their braces off, which would allow them to protect themselves from the degenerative effects of her EDS.

Figure 4 - collage - steampunk

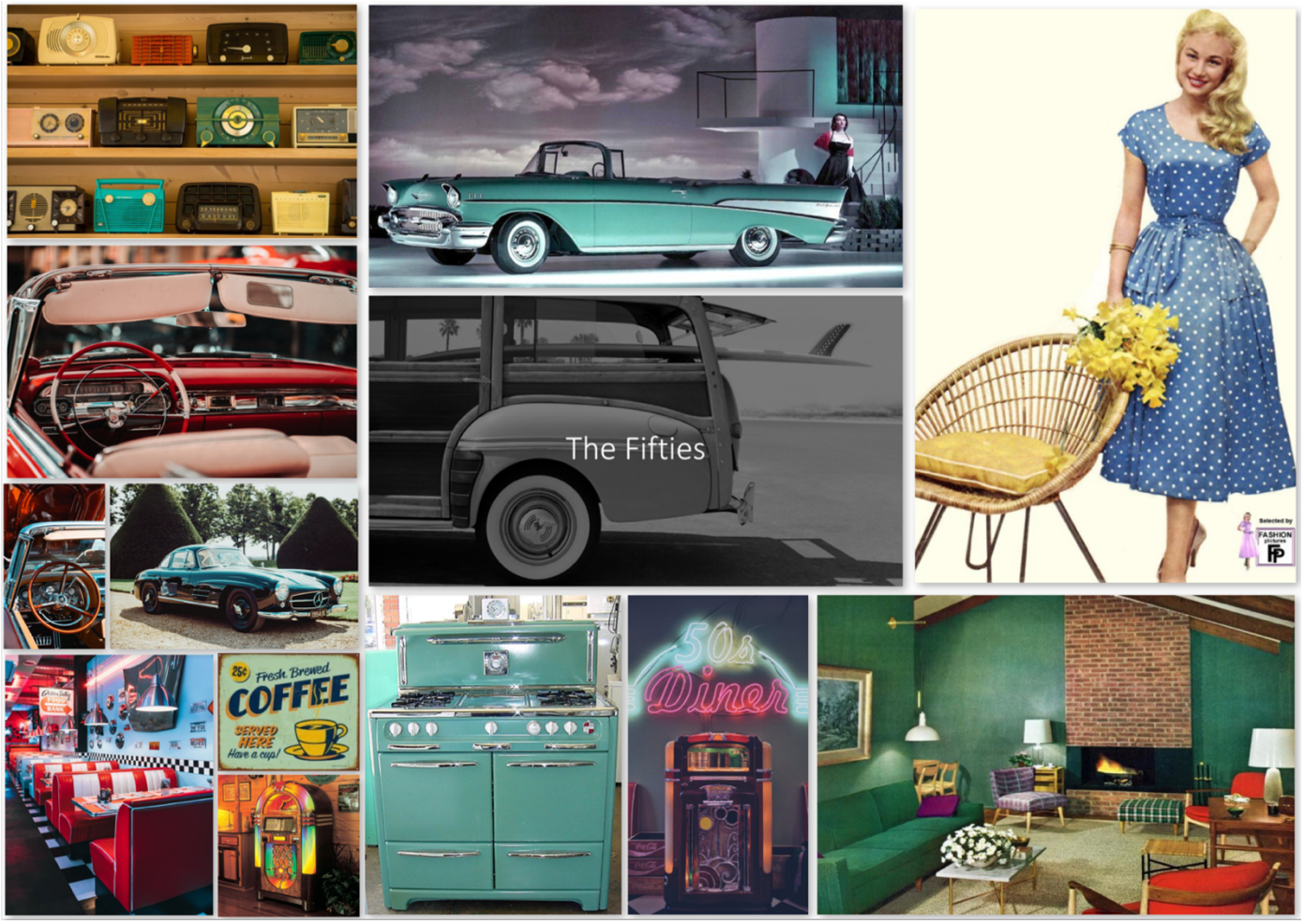

Figure 5 - collage - the fifties

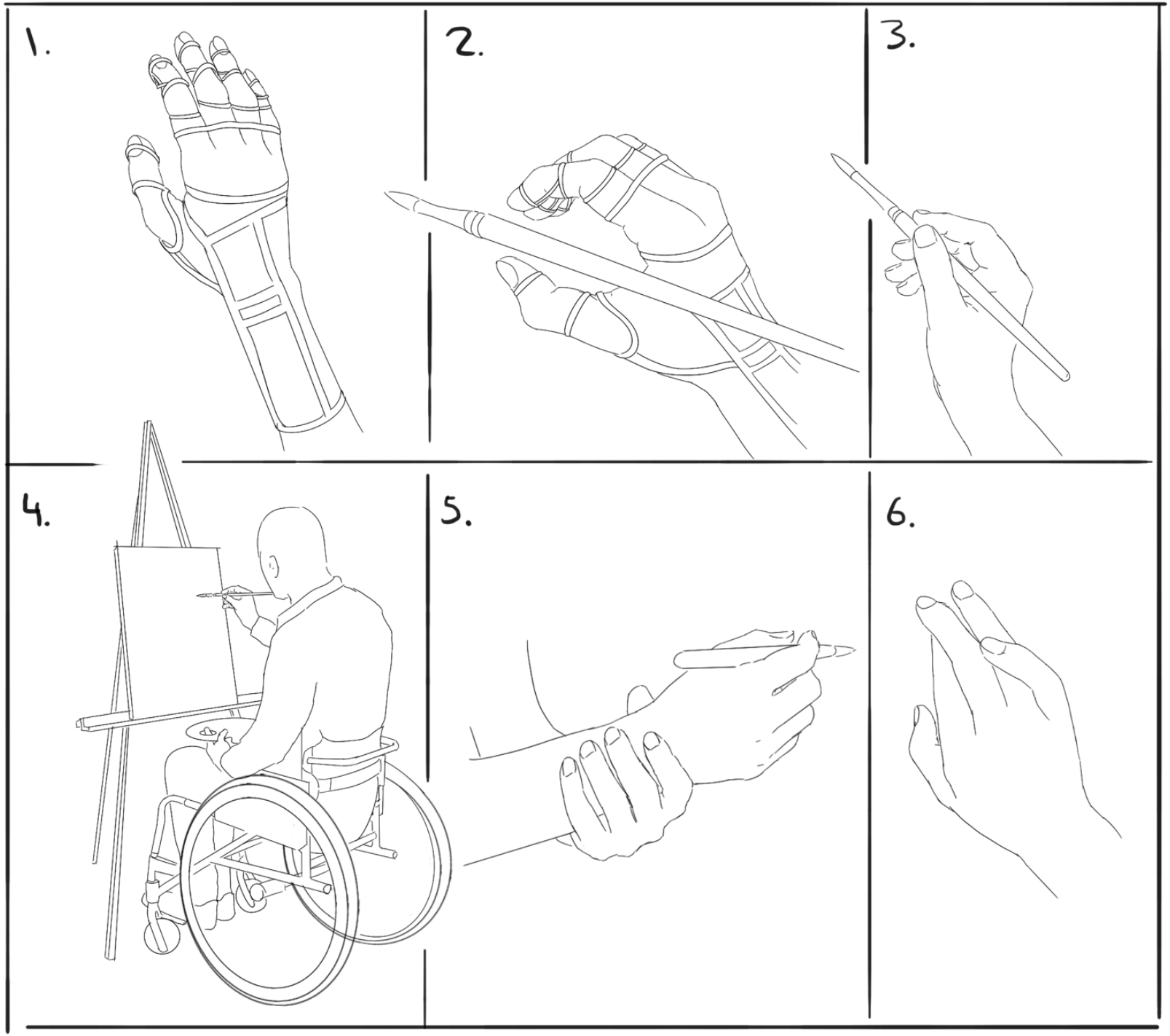

Figure 6 - Visual Storyboard for EDS

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