
Context for design for task-planning and task-adherence for person with developmental delay

Alysha Folst ¹, Freek ter Maat ², Jakob Trock-Jansen ³, Lieke van der Hoorn ⁴, Yvonne Jukkema ⁵

1 S2741806, a.e.folst@student.utwente.nl

2 S2819368; f.g.j.termaat@student.utwente.nl

3 S2853264 j.d.trock-jansen@student.utwente.nl

4 S2496577; l.m.vanderhoorn@student.utwente.nl

5 S2683520 y.jukkema@student.utwente.nl

* Contact person: y.jukkema@student.utwente.nl

Abstract:

The aim of this paper is to communicate the context (research) as a literature study, which serves as the basis for designing a product for Thijs, who due to his developmental delay struggles with planning and task organization. When looking at the societal trends and the changing perspectives on disability, it can be seen that there is less stigma surrounding people with a disability and that they are being treated with more respect and compassion. Assistive technologies are pieces of equipment that improve the functional capabilities of individuals with disabilities. In order to create a fitting product for the case owner, the focus will be on human-centered design. Human Centred Design is a technique to solve problems which puts real persons in the middle of the development process in order to create products or services that fit better with the audience's needs. The case owner of this project is Thijs, who has a developmental delay and a disharmonic IQ profile. A disharmonic IQ profile in Thijs' case means that he scores significantly higher on verbal intelligence than performance intelligence. Thijs' main struggles is with planning and focus. Some of his struggles are therefore related to fine motor skills. Research shows that adults with learning disabilities can benefit from electronic planning devices, if adapted to their needs and measures are taken to eliminate the negative side effects of the device. Additional research shows that students with learning disabilities were 50% more on time when using electronic personal device than physical. Several digital planners exist, however they are overcomplicated and not adapted to Thijs specific needs. During this project, participatory design or co-design will be used. This design approach involves active participation of end-users throughout the whole design process and ensures that the final product will meet their needs. Three relevant co-design projects were discussed as well as what tools and methods used could also be relevant to this project. Based on the research done until now, it was concluded that the main design challenge is to use participatory design to create a product that fits to Thijs' needs and helps him plan and structure his day.

Citation: Folst, A.; ter Maat, F.; Trock-Jansen, J.; van der Hoorn, L.; Jukkema, Y. Title. *The Designing for Specific Users Journal*. 2023, 1. <https://doi.org/10.3390/xxxxx>

Academic Editor: Jelle van Dijk

Publisher's Note: University of Twente stays neutral with regard to jurisdictional claims in published maps and institutional affiliations.



Copyright: © 2023 by the authors. Submitted for possible open access publication under the terms and conditions of the Creative Commons Attribution (CC BY) license (<http://creativecommons.org/licenses/by/4.0/>).

Keywords: disharmonic profile; developmental delay; planning; emotional regulation; participatory design.

1. Introduction

People with developmental delays often struggle with everyday circumstances such as planning, adherence to tasks and emotional regulations. How can the participatory design process help to create a product that can make their lives easier? A look was taken at the societal view on disabilities and how this perspective is slowly changing. The fields of assistive technologies and human-centered design were explored to see how such a perspiratory product can be designed. The situation or condition of the specific user, Thijs, was discussed to get to know the pains, needs and wants that would have to be accounted for in the design process. It was found that the biggest need was for a planning system. To complete the context mapping, the current market of planning systems or similar products was researched.

2. Literature Study

Societal trends and the changing perspectives on disability

The perspective of people towards a person with a disability is slowly changing, the chances of a disabled person being accepted and looked after used to be way lower than it is nowadays. This is caused by the “idea” that society had about people with special abilities which mostly used to be linked to sin or the impression of these humans being lunatics [1]. Some cultures created quite harmless beliefs about a disorder, the Babylonians thought babies born with a condition were good predictors of the future, but most environments either caused death or even more struggles like mental problems for the disabled [2]. In the 1800s having a condition was portrayed as weak and pathetic, in the 1900s eugenics were starting to become the norm but the patients with learning and mental health issues were seen as idiots, imbeciles and more. In 1935 Hitler ordered “mercy killings” and euthanized disabled people throughout the second world war. In the 1960s there was a huge improvement when a wheelchair user was one of the characters of a popular soap and when the first paralympic games were held in the United Kingdom in 2012 [3].

There is still a stigma around these people, but how they were treated throughout history is nowadays seen as shameful. The culture that has been created about the people who vary or differ a bit from the majority, causes them to be observed and labeled as disabled and as a group with special needs without acknowledgment of the oppression [2]. A social judgment is made and society acts like it matters which impacts the consequences towards disabled people and their mental well-being. However, positive changes can be observed due to more information being available and a better understanding of the conditions. Disabled are being treated with more respect and compassion which not only directly enriches their lives but also causes them to receive more help which increases their access to opportunities [1].

Introduction to Assistive Technologies

The Assistive Technology Act of 1988 states that the term “assistive technology device” means any piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities and the term “assistive technology service” means any service that directly assists an individual with a condition in the selection, acquisition, or use of an assistive technology device. Assistive technology can be described as equipment that is used to improve the capabilities of a person with special needs for activities of daily living. This technology promotes greater independence by helping people to perform these activities which they were formerly unable to accomplish without the help of a caretaker. It also aids disabled humans in need to perform tasks associated with education, work and social/ cultural life. Assistive technology is often confused with adaptive technology which is a subset of assistive technology. Adaptive technology is specifically designed for disabled people and often specifically refers to electronic and information access while assistive technology is any system or object which helps people with an impairment but can also be used by a non-disabled person. This means that any piece of equipment can be used even if it is low-tech, for example, a communication board made out of cardboard [4]. For cognitive dysfunctions, there

is existing equipment that aids the person with their attention, planning, memory, emotion recognition and management, navigation and sequencing activity. The most common services focus on memory and planning which is being proven to be very helpful and efficient [5].

Human-Centered Design

Human Centred Design is a technique to solve problems that puts real persons in the middle of the development process in order to create products or services that fit better with the audience’s needs. The goal is to keep the wants, pains and preferences of the user in mind during all of the design phases [6]. Human-centred design helps to create the best fitting product for the targeted audience. It is also said that Human Centred Design can help to bridge a gap between developing an idea until broad use by making sure that implementations are more people-centered [7]. The implication of Human Centred Design for our ‘design vision’ is really important. To make sure the best possible product for the case owner is made a lot of research has to be done to get to know the person well. The idea is to make the product as fitting as possible in the person’s life. With the gathered information and also getting back to this person for regular feedback will help the design process to make the product a good fit. In this process, the person who you design for should always be respected. Listening to the wants and needs of the person you are designing for is key in designing a good product.

Introduction to the condition of the specific user

Our specific user, Thijs, has a developmental delay and a disharmonic intelligence profile. An Intelligence profile can be subdivided into two areas of intelligence, verbal intelligence (VIQ) and performance intelligence (PIQ), together they combine into the full-scale intelligence score (FSIQ). VIQ is about knowledge, verbal reasoning and attention to verbal materials. PIQ concerns spatial intellectual abilities, spatial processing, attentiveness to details and visual-motor integration of information as well as body movement coordination [8]. We speak of a disharmonic intelligence profile when there is a noticeable difference between the scores of PIQ and VIQ. In the case of Thijs, his PIQ is the one that is the lowest. Thijs' verbal communication is good, he can participate in normal conversation. His motoric skills are less developed. He has a tricycle for example. Other difficult motoric skills are combing his hair, brushing his teeth, etc. Small movements can be difficult for him. Thijs cannot handle losing in games, mainly board or card games, cards would fly through the air when he got mad. But it is a lot better now than a few years ago. Now if he loses a game he walks away and takes some rest before entering the room with people again and he apologizes [9].

When asked about the disharmonic profile, Thijs found it hard to answer, the coach said that the troubles are with daily planning and structure. If for example in the morning he can do everything on his own also planning until something goes wrong like a roommate showering later than expected, then his planner is ruined and his day will start badly already. If one or two extra unexpected or bad things happen he feels his day is ruined or finished[9].

Thijs has a developmental delay, which causes some issues. He has trouble with focus and planning. But sometimes he can also be too focused. If he is playing a game on his phone he is too invested in the game and is unable to do other things if it’s needed. For example, if the alarm for medication would pop up he swipes it away and forgets about it. Luckily the coaches also have alarms for medication [9].

Market research on existing products

Research by Adolfsson et Al. into the “Perception of the influence of environmental factors in the use of electronic planning devices in adults with cognitive disabilities” shows that when using EPDs (electronic personal devices, which in this case would include electronic calendars, reminders, smartphones and personal digital assistants with adapted software) in these circumstances, measures must be taken to prevent or eliminate negative influences of the device. Individual users need adaption of EPDs to their specific circumstances, and the EPDs must be user-friendly,

manageable, and work in any season [10]. In Thijs' case, a scenario that involves the aforementioned negative influence would be that he ignores notifications to take his medication because he is playing a game.

Research has been done on the efficiency of using PDAs (Personal Data Assistants) to enhance the organization and memory skills of students with cognitive disabilities. Research by Gillette, Y. and Depompei, R. shows that students who received reminders via PDA (with a single daily morning reminder) were on time 50% more often than students who used a physical list or planner [11]. Thijs struggles with organization and planning of daily activities (work, family, taking medication, chores), so this research is relevant to some extent.

Thijs currently shares a rudimentary whiteboard planner with several housemates. Current products on the market which fulfill Thijs' needs to some extent are digital calendars. Techradar provides an adequate overview of the best competition on the market. Design aspects of these competing products that should be considered when designing a solution for Thijs are as follows: Outlook has intuitive design, Fantastical's desktop version is only for Mac, Business Calender 2 can be overwhelming for new users, Lightning Calender is not available as a stand alone app, and Apple Calendar has clean and smooth design [12]. These products may serve as inspiration, but are far from appropriate for this design case, as explained by the aforementioned study by Adolffsson et Al.

Co-design / Participatory Design

Participatory design or co-design is an approach that involves active participation of end-users throughout the whole design process. By involving end-users from the beginning of the process, instead of only during user testing, it is ensured that the designed product will meet their needs [14]. Since the end-users are the ones who will eventually use the designed product, user input is always useful during the design process. However, participatory design becomes even more important when designing products for people with disabilities. Their situations, wants and needs differ greatly from those of abled people and also from those of other disabled people. It is important to involve them during the design process as co-designers, since they are the experts of their experience [15]. In order to prepare for our project, research was done into other co-design studies. The found studies all include and/or focus on people with cognitive disabilities. Some examples, including relevant methods and tools, will be discussed.

The first relevant co-design project aimed to design a handweaving loom that is accessible for people with different disabilities and allows them to weave independently. The involved co-designers have disabilities ranging from cognitive to sensory. An important aspect the ideation phase was developing a task analysis of the loom. By detailing the steps necessary to operate the loom, possible barriers and constraints for the co-designers could be identified. Since our project will likely also involve adapting/re-designing existing products to cater to our case owner's needs, this is an important first step in understanding what currently causes difficulties in using a certain product. After the first prototype of the loom was made, the new design was evaluated by the co-designers. Based on this evaluation, a second iteration was made. By constantly evaluating and improving the prototype together with our case owner, we can ensure that the final product will cater to our case owner's wants and needs [16].

The second co-design study involved co-designers with intellectual disabilities and aimed to promote their independent living. During the co-design workshops, the co-designers were presented with various problems to be solved. These problems were presented as scenarios and were solved by building new objects using different materials from an ideation toolkit. This method allowed the co-designers to solve the presented problems in a playful and imaginative way. Since our case owner also has an intellectual disability, it could be very useful to have more playful co-design sessions and use different materials to come up with more creative solutions [17].

The last relevant co-design project aimed to make mobile phones more accessible for people with a cognitive disability. Remote communication can play an important role in safety, independence and keeping contact with others, but mobile phones are often difficult to use for people with a cognitive disability. The study was done together two families, who both have an adult daughter with a cognitive disability. First, the families took part in a co-design session where they made and evaluated low-fidelity paper mock-ups of the user interface of a phone that fit the abilities of the users. Using paper mock-ups is a good way to make quick and simple prototypes and could be especially useful if we are designing a planner. After the co-design session, the user interfaces were

implemented on phones and given to the users. Not only did the researchers keep track of the usage of the phone, they also got updates from the caregivers and observed the users while they were interacting with the phone during normal activities. This allowed the researchers to understand spontaneous behavior and to interpret data collected by the phone. For our project it is also important to understand how our case owner would use the designed product during normal daily use. Because of this, it is also important to let the case owner use the product for a longer time, to get updates from the caregivers on the usage and to observe the usage ourselves. This will allow us to better understand if changes need to be made [18].

4. Discussion and conclusions

For this project, a specific piece of assistive technology will be designed for Thijs who has a developmental delay and a disharmonic profile. Knowledge about how the world views disabled people, human-centered design works, existing products on the market, co-design and the theory about the condition that Thijs has, will all be taken into consideration for the final design. Thijs has problems with daily planning, structure, motoric skills, focus and mood regulations, but the thing he wanted to be helped with most was getting a structured planner for each day and therefore the design challenge is to use participatory design to create a product that fits to Thijs' needs and helps him plan and structure his day.

Author Contributions

Abstract: Alysha Folst , Keywords: Freek ter Maat, Introduction: Freek ter Maat, Societal trends and the changing perspectives on disability: Lieke van der Hoorn, Introduction to Assistive Technologies: Lieke van der Hoorn, Human Centered Design: Yvonne Jukkema, Introduction to the condition of the specific user: Freek ter Maat, Market research on Existing products: Jakob Trock-Jansen, Co-design/ Participatory Design: Alysha Folst , Discussion and conclusions: Lieke van der Hoorn, Interview: Yvonne Jukkema, Alysha Folst, Powerpoint: Lieke van der Hoorn, Presenting: Jakob Trock-Jansen, Lieke van der Hoorn, Persona: Yvonne Jukkema, Storyboard: Lieke van der Hoorn

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Acknowledgments: Assistance from several outside parties was used during the context mapping. These people were our specific user Thijs, his coach and our tutor Edsko Hekman.

References

1. Baglieri, S. et al. (2011) Assistive Technology for Individuals with Disabilities: A Review and Synthesis of the Literature, Remedial and Special Education. Hammill Institute on Disabilities. Available at: <https://journals.sagepub.com/doi/pdf/10.1177/0741932510362200> (Accessed: February 23, 2023). 229-232
2. Danermark, B. Coniavitis Gellerstedt, L. (2010) Social justice: redistribution and recognition—a non - reductionist perspective on disability, *Disability & Society*. Taylor & Francis Online. Available at: <https://www.tandfonline.com/doi/full/10.1080/09687590410001689458> (Accessed: February 23, 2023). 233-235
3. Brauner, K. (2018) Disability and Society: How Have Things Changed?, *Therapists. Welldoing*. Available at: <https://well-doing.org/article/disability-society-how-have-things-changed> (Accessed: February 23, 2023). 236-237
4. Alper, S. Raharinirina, S. (2006) Assistive Technology for Individuals with Disabilities: A Review and Synthesis of the Literature, *Journal of Special Education Technology*. University of Northern Iowa. Available at: <https://journals.sagepub.com/doi/pdf/10.1177/016264340602100204> (Accessed: February 23, 2023). 238-240
5. LoPresti, E.F. et al. (2004) Assistive technology for cognitive rehabilitation: State of the art, *Neuropsychological Rehabilitation*. Routledge. Available at : <https://www.tandfonline.com/doi/pdf/10.1080/09602010343000101> (Accessed: February 23, 2023). 241-243
6. Landry, L. (2020) What is human centered design, *online.hbs.edu*. Harvard Business School . Available at: <https://online.hbs.edu/blog/post/what-is-human-centered-design> (Accessed: February 22, 2023). 244-245
7. Kachirskaia, I., Neuwirth, E. and Mate, K.S. (2018) Human-centered design and performance improvement: Better together, *NEJM Catalyst*. Available at: <https://catalyst.nejm.org/doi/full/10.1056/CAT.18.0144> (Accessed: February 24, 2023). 246-247
8. Vermeulen, K. et al. (2022) Toddler Motor Performance and intelligence at school age in preterm born children: A longitudinal cohort study, *Early Human Development*. Elsevier. Available at: <https://www.sciencedirect.com/science/article/pii/S0378378222000123> (Accessed: February 23, 2023). 248-250
9. Personal communication with specific user and coach. 251
10. [10] Päivi Adolfsson, Helena Lindstedt, Ingvor Pettersson, Liselotte Norling Hermansson & Gunnel Janeslätt (2016) Perception of the influence of environmental factors in the use of electronic planning devices in adults with cognitive disabilities, *Disability and Rehabilitation: Assistive Technology*, 11:6, 493-500, DOI: 10.3109/17483107.2014.989418 252-254
Gillette, Y. and Depompei, R. (2008), Do PDAs enhance the organization and memory skills of students with cognitive disabilities?. *Psychol. Schs.*, 45: 665-677. <https://doi.org/10.1002/pits.20316> 255-256
11. Hanson, M., Turner, B. and Spadafora, A. (2022) Best calendar apps of 2023, *TechRadar*. TechRadar pro. Available at: <https://www.techradar.com/best/best-calendar-apps> (Accessed: February 24, 2023). 257-258
12. C. Spinuzzi, "The Methodology of Participatory Design," *Technical Communication*, vol. 52, no. 2, pp. 163–174, May 2005, Accessed: Feb. 24, 2023. [Online]. Available: <https://www.ingentaconnect.com/content/stc/tc/2005/00000052/00000002/art00005#> 259-261
13. C. Quintero, "A review: accessible technology through participatory design," *Disability and Rehabilitation: Assistive Technology*, pp. 1–7, Jul. 2020, Available at: <https://doi.org/10.1080/17483107.2020.1785564>. (Accessed: February 24, 2023) 262-263
A. Recupero, P. Marti, and S. Guercio, "Enabling inner creativity to surface: the design of an inclusive handweaving loom to promote self-reliance, autonomy and wellbeing," *Behaviour & Information Technology*, vol. 40, no. 5, pp. 497–505, Apr. 2021, Available at: <https://doi.org/10.1080/0144929x.2021.1909654>. (Accessed: February 24, 2023) 264-266
14. H. Spencer González, V. Vega Córdova, K. Exss Cid, M. Jarpa Azagra, and I. Álvarez-Aguado, "Including intellectual disability in participatory design processes: Methodological adaptations and supports," *Proceedings of the 16th Participatory Design Conference 2020 - Participation(s) Otherwise - Volume 1*, Jun. 2020, Available at: <https://doi.org/10.1145/3385010.3385023>. (Accessed: 24 February, 2023) 267-270
15. M. Dawe, "'Let me show you what i want,'" *CHI '07 Extended Abstracts on Human Factors in Computing Systems*, Apr. 2007, Available at: <https://doi.org/10.1145/1240866.1240976>. (Accessed: 24 February 2023) 271-272