

Designing a co-design toolkit to support caregivers and the personal support network in tailoring technologies for users with Profound Intellectual and Multiple Disabilities

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Public summary

This assignment entails improving the possibility to design for people with Profound Intellectual and Multiple Disabilities by using people from their formal and informal network. This is done by designing a co-design toolkit which will enable the people from these networks to redesign an existing product themselves by creating small alterations to- and tailoring of the product.

De Hoge school Arnhem en Nijmegen (HAN) is developing the Helpende Hand method. This method is meant to include the experience and knowledge of family, caregivers and personal support network in the care for people with Profound Intellectual and Multiple Disabilities (PIMD). Currently a lot of that knowledge is not being used. (*Helpende Hand: Werk beter samen in de zorg met hulp van persoonlijke zorgtechnologie*, n.d.)

A person with Profound Intellectual and Multiple Disabilities or PIMD, has multiple severe disabilities. These disabilities are both mentally and physically. The characteristics and symptoms of someone with PIMD can differ tremendously per person. (VGN et al., n.d.) Because of these handicaps people with PIMD are unable to take care of themselves and can only communicate minimally. Designing products for a target group consisting of people with PIMD is therefore challenging. The user is unable to express their experience of a product.

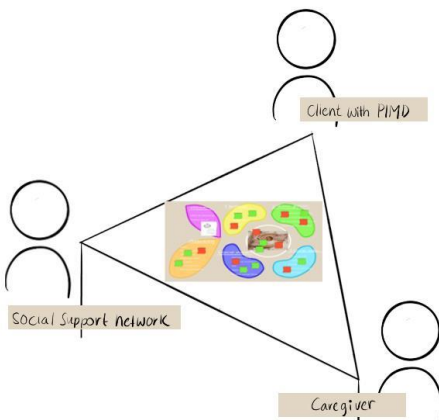
The target group of people with PIMD has been neglected for a long time and there are only limited products developed for these people. (Lyle, 2021) The products that are available are designed for a wider target group, for example a combination of severely disabled people and elderly with dementia. Because this target group is broad and the symptoms for PIMD differ per person, products lack a connection to the abilities and interests of users with PIMD. In this assignment the focus lays on products owned and used by care facilities for disabled people. Products that have been bought for clients with PIMD end up limitedly used or not used at all. Tailoring these products will be beneficial to the care provided by care facilities and the quality of life for people with PIMD.

People as close to clients with PIMD as family, friends and caregivers have a lot of knowledge about their needs and wishes. (Kruithof et al., 2020) Adding this practical knowledge to literature research will result in a better ability to design products specifically for people with PIMD.

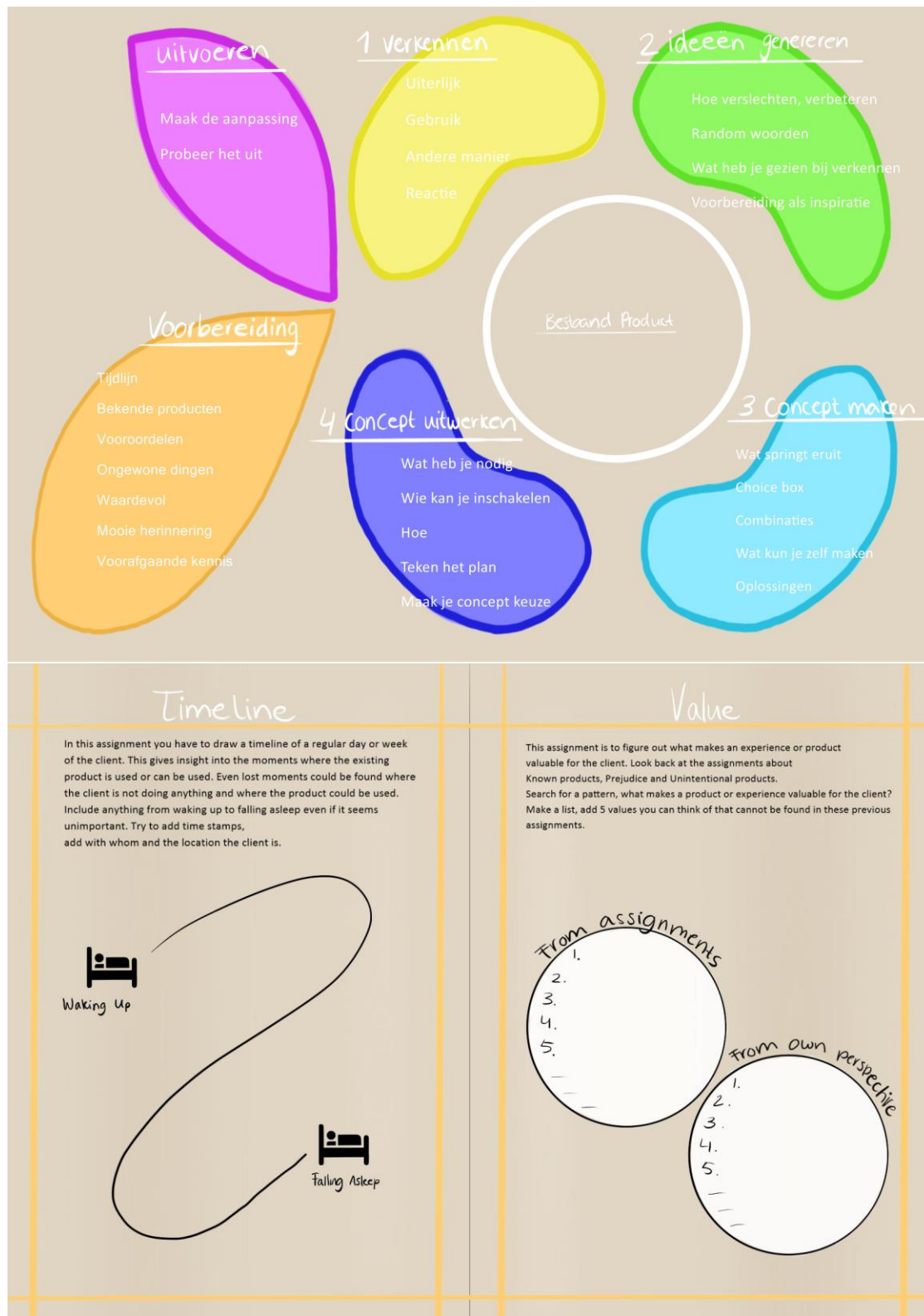
The main research question for this project is: *How can the knowledge of caregivers and a personal support network be used in the process of tailoring technology to the needs of users with Profound Intellectual and Multiple Disabilities using a co-design toolkit?*

In order to answer this question two different approaches were used; first literary research was conducted to create a base for the co-design toolkit. Second an iterative process was started to further develop and design this toolkit. This was done during co-design sessions with a designer, the caregiver of the client, someone from the social support network of the client and the client themselves. These co-design sessions were conducted at a care facility in Enschede.

The co-design sessions led to a better understanding of people with PIMD, their environment and the people in their network.



The toolkit went through two iterations and then the final version was created. The final product consists of a poster visualizing the steps with accompanying assignment cards and book. Executing all these assignments will result in the design of an alteration for an existing product. (The final poster is written in Dutch because the care facility and all the participants are Dutch.)



During these co-design sessions it was hard to include the caregiver in the session. The caregiver could not be missed in the care facility. Furthermore, some questions about the need

for these specified adaptations arose. It became clear that the value of such a product is not just the approval of one client. Every client within the care facility should be able to enjoy the product. Another question is about the ability to interpret communication signals. Is it truly possible for other people to correctly interpret the opinions of a client with PIMD?

People from the formal and informal network of clients have the most knowledge when it comes to the behavior of their person with PIMD. They are not able to interpret signals perfectly, but they are more capable than any other. While using the toolkit the mother of the client was able to design an addition to an existing product. This addition elicited a positive response from the client. This shows the final toolkit can be used to support the design process of tailoring existing products to the needs of a user with PIMD. However further development and research is needed to eradicate any of the discussion points.

References

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