The power of making; co-design with Profound Intellectual and Multiple Disabled individuals and their support network.

Caretaking facilities for people with disabilities often have a range of different assistive technologies (AT) available to use with their clients. They see the value of assistive technologies, but the amount of use these technologies receive is lower than desired. Especially the group of individuals with Profound Intellectual and Multiple Disabilities (PIMD) does not use these assistive technologies. Individuals with PIMD have neuromotor dysfunctions next to profound intellectual disabilities, which means they are often wheelchair-bound and are entirely dependent on the support of their informal network and professional caretakers for all aspects of their daily life.

This motivated the Hogeschool Arnhem Nijmegen to start a project called the “Helpende Hand”. The key idea behind the project is to try and adjust existing assistive technologies to fit the individual user needs of PIMD clients. The focus is specifically on the co-creation of a method with PIMD clients and their professional and informal support network. This method, in the form of a toolkit, should describe how healthcare professionals together with the informal network and PIMD client can improve the implementation and adjustment of assistive technologies within the care practice to facilitate a better and more personalized healthcare offer.

This thesis reports on a subproject of the “Helpende Hand”. The aim of this design and research project is twofold. Firstly, a case study is carried out in which concepts are developed and prototyped in a co-design process to ultimately improve the quality of life of a specific person with PIMD. Secondly, insights about the ‘Power of making’ in design and the role of making in a co-design process are provided to aid the development of the “Helpende Hand” method.

In the case study, five co-design sessions were organized with the informal and professional support network of the PIMD individual to develop concepts that allow the PIMD individual to entertain themselves independently in the wheelchair. A general design thinking approach was used and ‘making’ was adopted as a central aspect in this co-design process. The first two co-design sessions focused on acquiring empathy for the PIMD individual and getting to know the co-designers. A design challenge was formulated, and after two rounds of ideation sessions, three concepts were realized and prototyped (*Figure 1*). These prototypes, focusing on a sensory experience for the PIMD individual were tested and evaluated. The evaluation and early testing of the prototypes were positive. These results indicate that the artifacts have the potential to improve the quality of life of the PIMD individual. However, long-term testing with the prototypes and the PIMD individual is needed to reach a definitive conclusion. For other assistive technologies, it took years and lots of repetition for the PIMD individual to start using them.

Parallel to the case study, autoethnographic research was conducted to reflect on personal experiences of ‘making’ in a co-design process. During the co-design case study, multiple ways of ‘making’ were used. It was concluded that ‘making’ has value in the early stages of the co-design process as it enhances creativity, communication, and decision-making, it provides inspiration, and allows for early validation of principles and mechanisms in the design process.

Figure 1: The three prototypes of the concepts.