

Figure 1. The Embodied perspective rejects the Cartesian splits between mind and body, and between (inner) self and (outer) world, revealing instead our *embodied being-in-the-world*. Details in text.

Designing for Embodied Empowerment of people with an Autistic Spectrum Disorder

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Abstract

Taking an *embodied perspective*, we report on the design of two interactive products aimed at *empowering* people with an Autistic Spectrum Disorder in coping with challenges of everyday life. Our Research-through-Design study combined theory with hands-on co-design work and in situ user observation, in close collaboration with clients and their professional caretakers, constructing experienceable prototypes as tangible anchors for reflection. Reflection resulted in guiding principles addressing the design potential of designing for *Embodied Empowerment*, centering on the client's *embodied-being-in-the-world*.

Author key-words

Embodiment, Situatedness, Autism, Empowerment, Assistive Technology, Research-through-Design.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous).

Introduction

Along with reforms in health care, promoting client empowerment [8] and seeking cost-reduction at the same time, various kinds of Assistive Technology (AT) have been proposed [3] to help people with Autistic Spectrum Disorder (ASD) in coping with the challenges of everyday life. In practice, however, relatively few

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ATs are truly successfully appropriated [15]. As Gitlin et al, observe:

"[AT] may be viewed positively, ... to regain independent performance, or negatively, as a symbol of lost function and abilities. [AT] modifies the way an activity is performed either by altering the ... environment or by serving as an extension of a person's body. The individual may therefore need to adjust...by relinquishing previously valued and preferred ways of carrying out basic living tasks." [10, p. 43].

Reasoning along with Gitlin *et al*, we investigate how an *Embodied perspective* [20,7] may guide designing successfully appropriated AT to empower people with an ASD in daily life activities.

The Embodied perspective

Figure 1 illustrates how the Embodied perspective, 'opens up' the classical Cartesian divides between 'mind' and 'body', and between 'self' and the 'outside world' [12,14] to reveal a conceptual space centered on a person's *embodied being-in-the-world*. [4,5,6,20]

Embodied theory hinges on the observation that people are always already interacting with the world [4], from which routines and skills emerge that help us deal with circumstances in practical ways [6]. By forming action-perception couplings [4], we perceive our world in terms of affordances for action [9]. This goes hand in hand with *social coordination*, situated in *practices*, whereby people together make sense of what is going on as a participatory achievement [7]. Importantly, embodied skills and social coordination are both sustained by artifacts, tools, and ad hoc appropriated objects [13], which together form our *lifeworld* [1].

Our starting hunch in the cases presented below was that an embodied perspective could help to design AT that builds on a client's personally evolved embodied practices [5], thereby promoting his empowerment, instead of *replacing* practices with externally imposed instructions and methods. In the remainder of this paper we specify these ideas by means of reflecting on insights from two one-year lasting, participatory Research-through-Design cases: MYDAY and M-Power. In both cases, several design iterations produced intermediary prototypes that could be evaluated at the level of actual experience in the real use-context. Using the design process as our guide, we iteratively integrated Embodied theory with 1) ethnographical observations, 2) user feedback, and 3) specific design ideas and problems [12].

Case 1: MYDAY

We designed for- and with Rob, a 31 year-old male with Asperger's (not his real name, IQ above average) who lives in a supported living facility. After initiating a domestic activity, say, doing the dishes, or answering mail, Rob is easily distracted by recurring worries, or is drawn towards 'irrelevant' details. As a result, tasks often remain unfinished, leading to frustration and a sense of personal failure. In response to this challenge we designed MYDAY: a ubiquitous, interactive light system that helps in structuring daily activities (Figure 2). It consists of a set of wireless multicolored led-lights in Rob's own, existing lamp-bodies, together with a central station called the beacon (top figure). Using MYDAY, Rob plans self-chosen activities for the coming days via Google Calendar on his PC. He assigns to each activity a time-window, a physical location and a color. When an activity is due, both beacon and the lamp in the associated location (centre and bottom figure) light



Figure 2. MYDAY. Second prototype with Rob (top), use scenario (centre) and final prototype (bottom)



Figure 3. M-Power. Screen interface (top), use scenario (centre) and fully working prototype (bottom)

up in the selected color, for the set time. This cues Rob's attention to start the associated task and keep focused. Once time is up, the next activity will 'light up', with the beacon as a point of reference. Interaction with the beacon allows postponing, skipping or declare a task finished.

Case 2: M-Power

For and with eight adolescents (12-15 years) visiting day care, suffering from both autism and a mild intellectual disability (IQ < 85), we designed a tool that stimulates initiating and perpetuating social conversation. Although these clients are aware of social conventions (making eye contact, responding when being asked something, etc), they prefer solitary activities and do not spontaneously make conversation. Makeshift interventions, such as 'social skills training' and a necklace with cards holding tips for dealing with particular social situations, were not very successful since they departed from clients' disabilities rather than their capabilities. Hence, social interaction became a very artificial activity. The final design, called M-Power, (see Figure 3) consisted of a smart watch (ZGPAX S82 Android Bar Phone) application that fosters practicing social skills in realistic situations, on a moment that clients choose themselves. Information in clients' digital profiles are used to display sentences that help to start conversation. Lighting up and turning black of each clients' watch manages *turn-taking*. After initial guidance, clients are expected to continue their conversation without using the app. A clients' profile content is updated by the caretaker, during individual coaching sessions with the client. The use of the M-Power also serves as input to reflect on social skills

training during these coaching sessions. In a next iteration, the system should enable the clients to enter topics/ questions themselves.

Discussion

By reflecting on cases from theory we were able to formulate principles that guide designing for Embodied Empowerment (see Figure 4). We discuss each in turn.

1. *Beyond informing: highlighting affordances*
Rob's apartment is full with 'habituated objects' [2], whose spatial arrangements have meaning for Rob in relation to his routines. Instead of sending notifications, MYDAY literally highlights areas in the apartment to foreground task-relevant action-affordances [5,9,18].
2. *Beyond reminding: developing situated habits.*
Regarding M-Power, highlighting for perception means providing cues right in actual real-world conversations instead of educational settings. Rather than detached, rote learning of phrases, these cues help to perceive conversation opportunities in actual situations, developing a *situated conversation habit* [1,2,6].
3. *Beyond instructing: cues for (reflection on) action.*
Rob showed aversion towards a planning schedule, made by his caretaker. Instead, MYDAY does not *instruct* so much as providing attention to action *opportunities* [19]. Likewise, while M-power does initially instruct users what to say, this functions as a conversation *starter* only, *to get the conversation going*. Even acts like planning the calendar, or collaboratively filling the client's profile are more than just filling a database with content: the activity itself invites *reflection-on-action*, as in Schön [17].

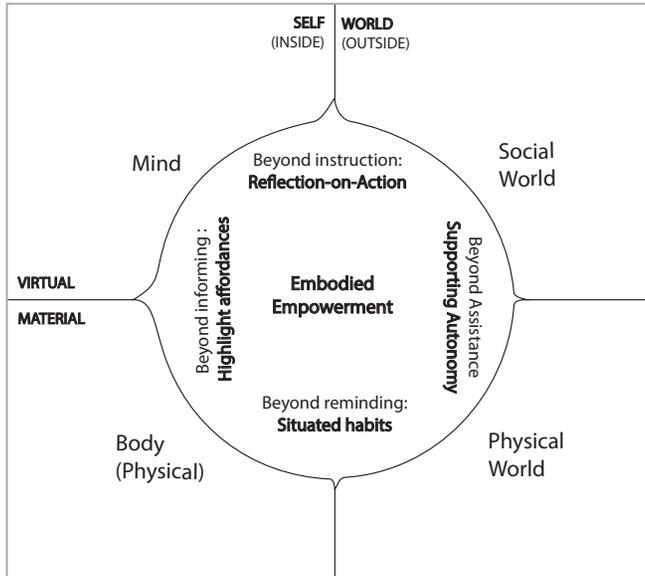


Figure 4. Our vision of Designing for Embodied Empowerment: utilizing affordances, situated habits, reflection-on-action and supporting personal autonomy. Details in text.

4. Beyond assisting: autonomy through use.

Embodied interaction is not only a way to deal skillfully with the world: embodied use of artifacts is also a way to express ourselves, and take position in relation to others [6,7,18]. We noticed how Rob started to contrast 'his lamp' with the caretaker's planning schedule, using it to assume a more autonomous position in coordinating with the caretaker. M-Power contributed to the client's autonomy in multiple ways: It empowered clients to maintain a conversation for 15

minutes that they would not otherwise have had. One client even stopped stuttering because he felt more secure about himself. The way artifacts become extensions of ourselves [6,12,16] may also explain why designs induce stigmatized experiences, as with the 'un-cool' early wearable concepts of M-Power.

Embodied Empowerment

In [21] a distinction is made between two kinds of Empowerment: 1) the situation where the client does not need external care, that is, when (s)he is self-sufficient, and 2) the situation in which the client experiences autonomy in living his/her own life. Embodied Empowerment, as we see it, strongly favors the latter interpretation. To see why, consider the extreme case where AT simply *replaces* the caretaker, still instructing, informing and controlling the life of the client as before. Superficially we may be satisfied: the

client is now able to get on the bus, pay his bills, etc, by him/herself. In reality, the client is still dependent on others – the dependency is one by proxy, managed by a device. This may indeed reduce costs. But it also raises a question that goes to the heart of designing for Embodied Empowerment: how can we design products that allow people, *through using technology, to be their own autonomous selves*? Philosophers have argued how this is true for craftsmen, such as when the carpenter expresses his identity through his skilled dealings with the hammer [6][12]. Can we create a similar relation for clients and assistive devices? With MYDAY and M-Power we have taken some first exploratory steps into this direction.

Embodied tool versus situated practice

Finally we discuss one of the main differences between the cases concerning the practical feasibility of embodied design. For M-Power focus was on seamless integration with the clients' current, situated practice, which is why we rejected more exotic wearable designs in favor of a rather conventional 'smartwatch'. By contrast, MYDAY was a more radical attempt to design for deep, core aspects of human embodiment. Where M-Power was only modestly 'embodied' in its design, for MYDAY it remains to be seen if the product will truly be practical in use, or in the end be experienced as 'too weird' to be more than an interesting experiment. We thus see a tension arising between the desire to incorporate fundamental aspects of embodied action, and the equal desire to fit in with existing situated practices, where these existing practices happen to be strongly dominated, at least in the present age, by virtual data and screen-based technologies. How to sensibly navigate the fine line here is something we hope to explore further in the near future.

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Dr. Fenne Verhoeven is senior researcher at Utrecht University of Applied Sciences. Her research focus is on developing co-design methods and tools, in particular in projects of designing products and services in health-care. She has done Some of her co-design work involves, e.g., children with cancer and children with Autistic Spectrum Disorder. Fenne's research spans both the fuzzy front-end as well as in the final evaluation phases of technology design projects.

In this workshop we would like to receive feedback on our theoretical framework from researchers with experience with designing for people with ASD, with the aim to sharpen our framework, especially with regard of this specific target group, and iterate it towards making it more usable and relevant for designers and researchers in their own projects. Also we hope to discuss our co-design research methods and wish to learn from other people's methodologies regarding what works and what doesn't – and why - in researching and designing for with people with autism.