Designing for Embodied Empowerment of people with an Autistic Spectrum Disorder (Workshop paper for Autism and...

Conference Paper · May 2016

CITATIONS
0

READS
35

2 authors, including:

Jelle van Dijk
University of Twente
22 PUBLICATIONS **134** CITATIONS

SEE PROFILE

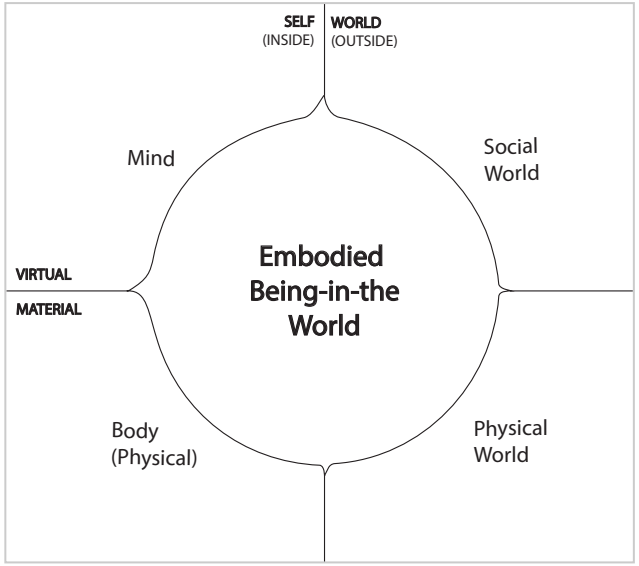

Figure 1. The Embodied perspective rejects the Cartesian splits between mind (virtual) and body (physical), and between (inner) self and (outer) world; revealing instead our *embodied being-in-the-world*. Details in text.

Designing for Embodied Empowerment of people with an Autistic Spectrum Disorder

Jelle van Dijk
University of Twente
Enschede, the Netherlands
jelle.vandijk@utwente.nl

Fenne Verhoeven
Utrecht University of Applied Sciences
Utrecht, the Netherlands
fenne.verhoeven@hu.nl

Paper accepted to the Autism and Technology: Beyond Assistance & Interventions Workshop held May 7th at CHI 2016 in San Jose, California, USA.

Abstract
Taking an *embodied perspective,* we designed two interactive products to *empower* people with an Autistic Spectrum Disorder in coping with the challenges of everyday life. Our Research-through-Design combined theory and hands-on co-design, involving clients and professional caretakers. Reflecting on several experienceable prototypes resulted in guiding principles for designing for *Embodied Empowerment,* all going beyond classical conceptions of Assistive Technology.

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 everyday challenges. In practice, relatively few ATs are successfully appropriated [14]. Gitlin et al state:

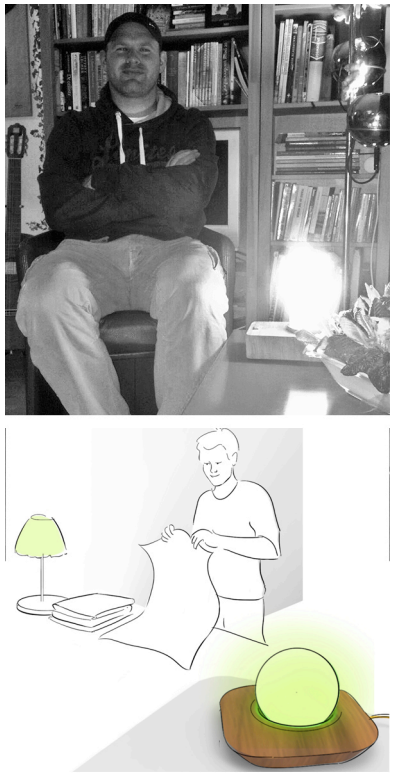

Figure 2. MYDAY. Second prototype with Max (top), use scenario (centre) and final prototype (bottom)

"[AT] may be viewed positively, … to regain independent performance, or negatively, as a symbol of lost … 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 …need to adjust … by relinquishing previously …preferred [routines]" [9, p. 43].

Reasoning along with Gitlin, we investigate how an *Embodied perspective* [19,7] may guide the design of AT that will be successfully appropriated and empower people with an ASD in everyday 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' [13,15] to reveal a conceptual space centered on a person's *embodied being-in-the-world*. [4,5,6,13,19]

Embodied theory notes how people are always already interacting with the world [4,6], from which routines and skills emerge that help us deal with situations in practical ways [6]. By forming action-perception couplings [4] we perceive our world as affordances for action [19]. This goes hand in hand with *social coordination*, situated in *practices* [18], where people together make sense as a participatory achievement [7]. Both embodied skills and social coordination are sustained by artifacts, tools, and ad hoc appropriated objects [2,12], part of what forms our *lifeworld* [1].

Our initial motivation was based on a hunch that an embodied perspective could help to design AT that would build on people's embodied practices [5], which would enhance empowerment, instead of *replacing* practices with externally imposed methods. In the remainder of this paper we elaborate this hunch by reflecting on two one-year lasting, participatory Research-through-Design cases: MYDAY and M-Power. In both studies several design iterations produced intermediary prototypes, 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 observation, 2) user feedback and 3) specific design issues [10].

Case 1: MYDAY

We designed for- and with Max, a 31 year-old male with Asperger's (not his real name, IQ above average) who lives in a supported living facility. During daily activities Max is easily distracted by recurring worries, or drawn towards 'irrelevant' details. As a result, tasks 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 Max's own, lamp-bodies and a central station called the beacon (Fig. 2, top). Using MYDAY, Max plans self-chosen activities 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 (Fig 2, centre) light up in the selected color, for the set time. This cues Max's attention to start the associated task and keep focused on it. 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.

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

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

Figure 4 maps the following main insights from the iterative reflection on our cases:

1. Beyond informing: highlighting affordances
Max's apartment is full with 'habituated objects' [2], whose spatial arrangements have meaning for Max in relation to his routines. Instead of sending notifications, MYDAY literally highlights areas in the apartment to foreground task-relevant action-affordances [5,19,17].

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 [1,2,5,6,18]*.

3. Beyond instructing: cues for (reflection on) action.
MYDAY does not *instruct* so much as providing attention to action *opportunities [19]*. While M-power does initially instruct users what to say, this functions as a conversation *starter*, *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 [16].

4. Beyond assisting: autonomy through use.
Embodied use of artifacts means to express ourselves, and take position in relation to others [6,7,17]. We noticed how Max started to contrast 'his lamp' with the caretaker's planning schedule, using it to assume a more autonomous position. M-Power contributed to the client's autonomy by enabling them to maintain a conversation: one client even stopped stuttering because he felt more secure about himself.

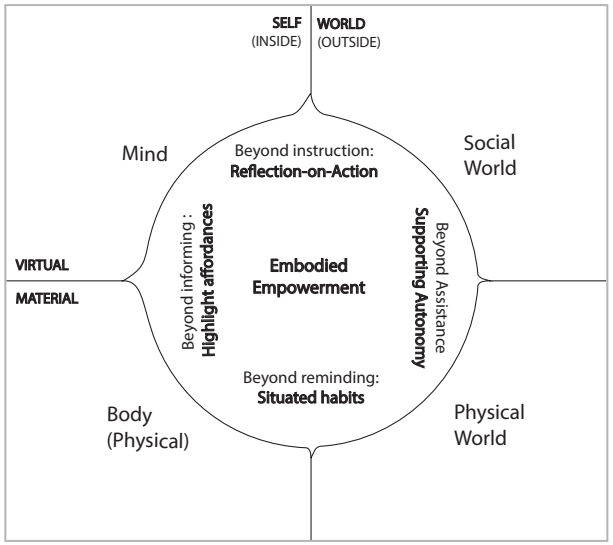

Figure 4. Our vision of Designing for Embodied Empowerment: utilizing affordances, situated habits, reflection-on-action and supporting personal autonomy. Details in text.

Embodied Empowerment

Through designing, we asked what it means to support *Embodied Empowerment*: i.e. how people, through using technology, can be *most fully themselves* [15]. Philosophers describe how e.g. the carpenter expresses his identity through his skilled hammering [6][11]. Can we create something similar for clients with AT? MYDAY and M-Power are our first explorations in this direction. Reflecting on the cases, we distinguish between empowerment as self-sufficiency, i.e., technology that helps to perform activities independently of others, and empowerment as *autonomy* [20]. In the first case, we may argue, one is still essentially dependent on others – by proxy, as it were, managed by a device. In contrast, the central aspects of embodiment: sensorimotor skills and social coordination [19] support the second form of empowerment: technology that enables a person to develop individual skills, and to socially take up position in relation to others. In general phenomenological spirit this means to not solve some objective problem but to rather to promote ones' *embodied being-in-the-world*.

The question is to what extent our first attempts can said to be *empowering* in the manner just described. The most important challenge we see is how to deal with existing practices. Traditionally, participatory design puts people's practices at the centre stage [10] and this is seen as a way to connect to the situatedness of human action [18]. In M-Power, we wanted a tool that clients would actually want to use in real life and so we stayed close to existing practices. This however meant partially to give up on theoretically informed directions. From a skills perspective, we initially explored new forms of wearable gesture interactions, but these were rejected by the children, in favor of a 'smartwatch' (which they found 'cool'). And though we would have wanted a tool that helps children to make conversation 'in their own way' - therapists framed the tool mainly as a digital version of *their* therapeutic methods. In giving priority to these 'demands from practice', the tool became a GUI-based training tool rather than a radically embodied way for children to take up a skilled*, autonomous position viz a viz their* therapists. MYDAY, on the other hand, remained conceptually close to the embodied vision, but may be less easily appropriated 'in practice', as it contains quite unfamiliar interactive forms. Also, we actually sometimes ignored the stakeholders' interest in the digital interface, in favor of exploring embodied interactions. The lamp did help Max in making his perspective explicit in relation to the wishes of his caretaker and parents. But Max is (already) a verbally strong, intelligent adult. Our present challenge is to transfer this empowering effect to situations with less symmetrical client-caretaker relations, as in M-Power.

Acknowledgements

We would like to thank Philadelphia Care Foundation, all participating end-users, their care-givers and involved family members, as well as all involved students for their valuable contributions to this research. This project is partly funded by a RAAK-SIA 'Publiek' grant:"Powertools" (2016-2018).

Dr. Jelle van Dijk is assistant professor at University of Twente, researching Embodied theories in the design of mixed physical-digital systems, focused on designing for disabilities in the cognitive-social domain. Jelle combines participatory design with research-through-design in an iterative form of inquiry in which theory and practice are mutually informing.

Dr. Fenne Verhoeven is senior researcher at Utrecht University of Applied Sciences developing co-design methods and tools, in particular in projects of designing products and services in health-care. Her 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.

In this workshop we would like to receive feedback on our theoretical framework from researchers with expertise in designing for people with ASD. Our aim is iterate towards a more usable and relevant framework for designers and researchers that wish to design for 'empowerment as autonomy' and seek new forms of interactive technology as an extension of our embodied being-in-the-world.

References

1. Philip Agre and Ian Horswill. 1997. Lifeworld analysis. *J. of Artificial Intelligence Research*, 6: 111-145.
2. Margot Brereton. 2013. Habituated objects: everyday tangibles that foster the independent living of an elderly woman. Interactions 20(4): 20-24
3. Stefan Parry Carmien and Gerhard Fischer. 2008. Design, adoption, and assessment of a socio-technical environment supporting independence for persons with cognitive disabilities. Proc of CHI '08. ACM, New York, NY, USA, 597-606. http://doi.acm.org/10.1145/1357054.1357151
4. Andy Clark. 1997. Being there: Putting brain, body, and world together again. Cambridge (MA): MIT
5. Paul Dourish. 2001. Where the action is: The foundations of embodied interaction. Cambridge (MA): MIT.
6. Hubert L. Dreyfus. 1991. Being-in-the-world: A commentary on Heidegger's Being and Time, Division I. Cambridge (MA): MIT
7. Caroline Hummels and Jelle van Dijk, J. (2015). Seven Principles to Design for Embodied Sensemaking. In *Proceedings of the Ninth International Conference on Tangible, Embedded, and Embodied Interaction* (pp. 21-28). ACM.
8. Daniel B. Fisher. 1994. Health care reform based on an empowerment model of recovery by people with psychiatric disabilities. Psychiatric Services 45(9): 913-915.
9. Laura N. Gitlin, 1995. Why older people accept or reject assistive technology. Generations 19(1): 41-46.
10. Mark Hartswood, Rob Procter, Roger Slack, Alex Voss, Monika Büscher, Mark Rouncefield and Philippe Rouchy, 2008. Co-realization: Toward a principled synthesis of ethnomethodology and participatory design. Scandinavian Journal of Information Systems, 14(2), 9-30
11. Martin Heidegger. 1927. Sein und Zeit. Tübingen: Max Niemayer Verlag
12. Edwin Hutchins, 1995. Cognition in the Wild. Cambridge (MA): MIT press
13. Maurice Merleau-Ponty. 1962. Phenomenology of Perception. New York: Routledge & K. Paul
14. Betsy Phillips, and Hongxin Zhao. 1993. Predictors of assistive technology abandonment. Assistive Technology 5(1): 36-45
15. Kai Riemer, and Robert B. Johnston. 2014. Rethinking the place of the artefact in IS using Heidegger's analysis of equipment. European Journal of Information Systems 23(3): 273-288
16. Donald A. Schön. 1983. The reflective practitioner: How professionals think in action. Basic books
17. John R. Stewart, Olivier Gapenne, and Ezequiel A. Di Paolo. 2010. Enaction: Toward a new paradigm for cognitive science. MIT Press, 2010
18. Lucy A. Suchman, 1987. Plans and situated actions: the problem of human-machine communication, Cambridge university press
19. Jelle van Dijk, Remko van der Lugt, and Caroline Hummels. 2014. Beyond distributed representation: embodied cognition design supporting socio-sensorimotor couplings. In Proc of TEI '14. ACM, New York, NY, USA, 181-188. http://doi.acm.org/10.1145/2540930.2540934
20. Ayesha Vernon and Hazel Qureshi, (2000). Community care and independence: self-sufficiency or empowerment? Critical Social Policy, 20(2), 255-276.