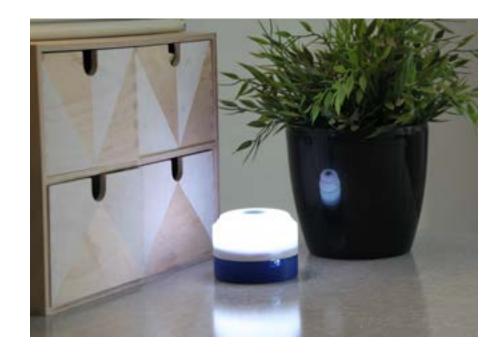


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Method& Critique Frictions and Shifts in RTD



Empowering Young Adults on the Autistic Spectrum: Reframing Assistive Technology Through Design

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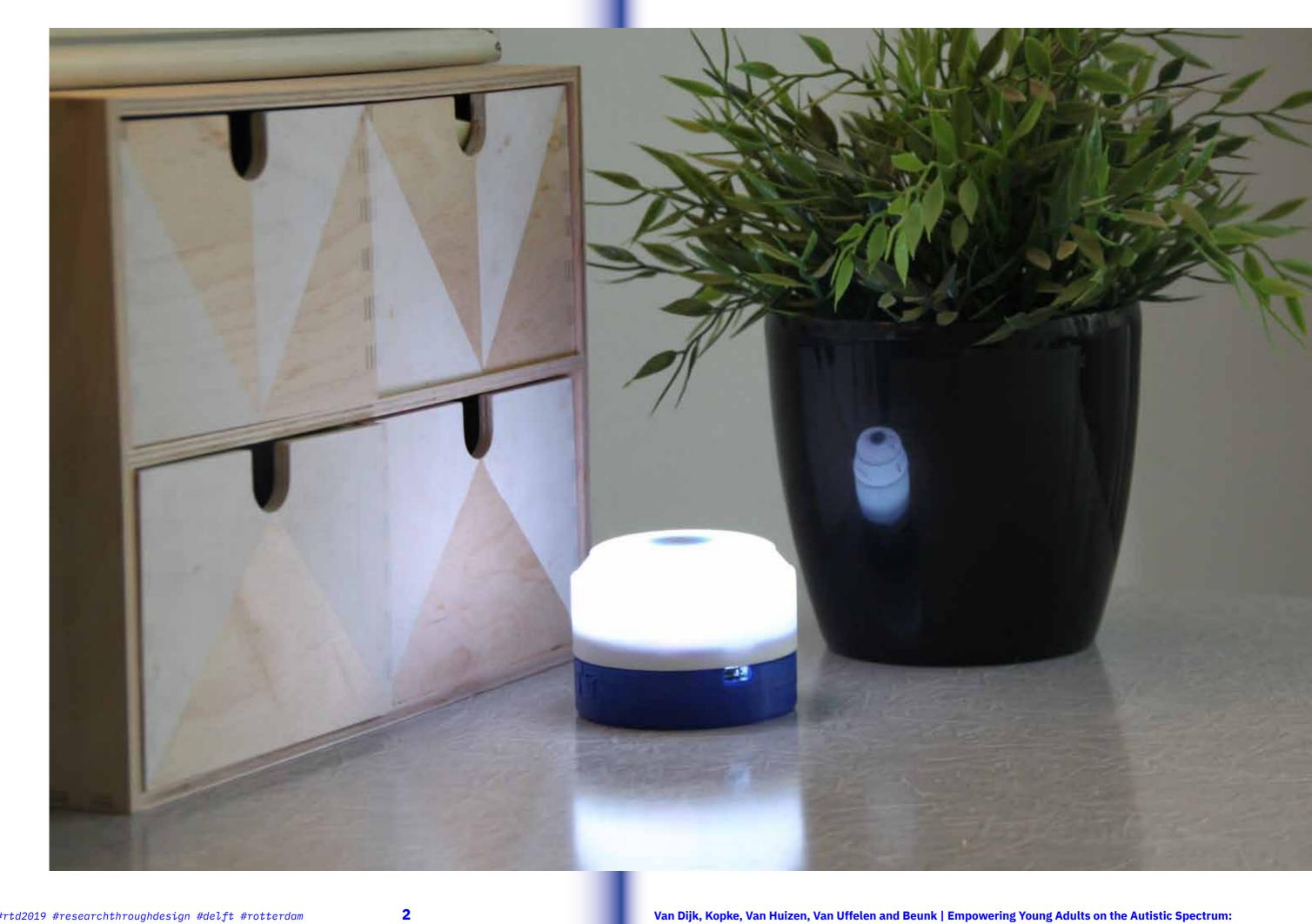
designed to 'empower' people with cognitive and social challenges. But what does it mean to say technology empowers? In a four-year participatory Research-through-Design project we addressed this question. Eleven autistic young adults participated in designing MyDayLight: an IoT system supporting self-management of domestic activities. Contextual inquiry, co-design, design reflection, prototype deployment and embodied interaction theory were woven together in an iterative reflective process. This allowed us to critically address certain background assumptions that typically underly common understanding of assistive technologies. We present three reframings of our evolving concept of 'empowering technology': 1) From 'planned reminder' to 'situated attention grabber' 2) From 'supporting action' to 'scaffolds for developing your own supportive routines' 4) From 'assistive product', to 'co-design tool in a larger transformational process'. In contrast to empowerment as 'self-sufficiency', MyDayLight embodies a developmental-experiential interpretation of empowerment. It helps users experiment with reconfiguring their own environment, reflect on their experiences and gradually develop more grip on life. The design artifacts enabled young adults on the spectrum and their care-givers to share, questionand reframe implicitly held understandings and to imagine and explore new ways for assistive technology

to play an empowering role in a person's life-world.

Abstract: Increasingly, assistive technologies are

Keywords: empowerment; autism; assistive technology; ubiquitous computing; tangible interaction; domestic technology







Introduction

Over the past decade *empowerment* has become a popular notion in Dutch health care practices (Boumans et al., 2012; Rappaport, 1987; Vernon and Qureshi, 2000). Increasingly, empowerment is an explicit goal in the care provided to people with cognitive and social challenges, as for example in daily care for young adults on the autistic spectrum (Magnee and Teunisse, 2015). In traditional practice, professionals would determine what care should be provided and the receivers of care would in effect adopt a relatively passive role. Using empowerment as a driving concept, the current trend is for receivers of care to manage as much as possible their own daily lives and to have a strong voice in co-determining the amount of supplementary care needed, and even what form this care should take (Rappaport, 1987). In pactice, the term empowerment is associated with ethical as well as economical aspects. Ethically, the argument is that people should be enabled to have control over their own lives to the highest extent possible. Receiving care should not mean to become objectified as a 'disorder', surrendered into the hands of the professional. Policy makers at the same time tend to focus more on the economical aspect. Decreasing budgets, less available skilled professionals, and increasing numbers of people in need of care push organizations and government into searching for alternative care arragnements that demand less time of the professional.

Assistive technologies have been proposed as enabling people to become empowered in managing their own lives (Peeters et al., 2013). But what does it mean to say technology empowers? A superficial interpretation would perhaps see technology as straightforwardly replacing human care. But would that mean a person is truly 'empowered'? According to (Vernon and Qureshi, 2000) empowerment refers not just to being able to do tasks without human support: empowerment is about having the feeling of being in control, of experiencing grip on ones' life and having an actual say in what goes there (Vernon and Qureshi, 2000). This warrants careful analysis of the ways in which a particular piece of assistive technology would mediate the actions and experiences of a person in daily life. Such mediation depends on the specific ways in which assistive technologies are designed (Shinohara and Wobbrock, 2011). A simple replacement of human care with a technology may actually do more harm than good. We propose that to design empowering technologies means to take explicitly into account the question of what the new role of the human care professional will have, seen as one actor within a wider network of person, assistive technology, and other people and things that form a person's lifeworld (Dijk and Hummels, 2017; Shinohara and Wobbrock, 2011)

In order to investigate these issues, we engaged in a four-year running co-design study, working in close collaboration with various stakeholders. Our case study focuses on young adults on the autistic spectrum, who are in the process of growing towards more independence in daily live. Before we turn to the design case we give a brief overview of the target group and their situation.

Approximately 1% of the (world's) population is diagnosed with autism. Only a minority of adults lives and works independently, which means this group produces a significant societal burden. At the same time many autistic individuals are motivated, intelligent and creative people who could contribute significantly to society, provided they

would receive the right support that would enable to manage daily life, not drop out of school, and cope with typical work situations (Magnee and Teunisse, 2015). Autism has been characterized as a disturbance in central coherence: the capacity to integrate a multitude of sensorial input into a meaningful whole (Happé and Frith, 2006). Amongst other things, this produces information overload, impaired executive functioning and may easily cause anxiety and stress. Autism is a multi-faceted heterogeneous spectrum, with diverse manifestations. Individual characteristics play out in unpredictable ways, possibly subject to context factors (Frauenberger, 2015). Younger children on the spectrum typically learn to cope with the complexities of daily life by means of applying reliable, predictable routines, which are often strongly supported by their parents (Schaaf et al., 2011). Moving towards independence in adulthood means adapting to new situations (e.g. living by oneself in a new home), developing new sorts of routines, being able to deal more readily with unexpected events and most of all, to manage daily life with less immediate support from one's parents. Yet it may be hard to break old habits and move into new roles and responsibilities, especially if one does not (yet) know how to develop new ones.

One of the promising recent developments concerns technologies designed to support people with autism in daily life (Fletcher-Watson, 2014; Magnee and Teunisse, 2015). Given the diversity of specific cognitive and social challenges and sensory needs across individuals, it seems impossible to create 'one-size fits all' solutions. Yet most technologies target assumed generic traits characterizing the 'autistic disorder', ignoring individual interests

and talents and context. This may contribute to the fact that many assistive technologies are abandoned in practice (Francis et al, 2005). We believe autistic people should have a say in what sort of technologies they think would help them in daily life (Milton, 2014). Our investigation thus centers on what it means for technology to empower young autistic adults in their everyday lives. What could such empowering technology look like, and what would be its role within the larger constellation a person and their social and physical lifeworld? In what follows we first describe our approach, the structure of the project and the people involved. We then report on our findings over the three main phases of the project. In the discussion we speculate about the wider implications for health care practices and reflect on the role of the prototype in our research process.

Project description and methods

The project ran between 2014 and 2018 in close collaboration with Dutch healthcare organizations Philadelphia Care and Siza. It consisted of series of smaller projects summarized here in three phases.

In phase 1 (12 months, 2014) we worked with Max (Age 25, Asperger) and Bert (Age 40, Asperger), both in a assisted living arrangement. We also worked with their three supervisors, and, in a final evaluation meeting, with Max's parents. We conducted contextual interviews and co-designed the very first concept. We built a prototype of one central 'beacon' connected to six Philips Hue lights in fixed sockets connected to Google Calendar (Fig. 7a), tested for one week in Max' home (Fig. 2a)

In phase 2 (6 months, 2016) we worked with Lucas (age 24, Autism and mild intellectual impairment) and Tim (age 27, ADHD and autism traits) both in residential 24-hour care, as well as with their two supervisors and one parent. Two co-design sessions with each participant led to the second concept: a system of Wireless led-units, a graphical tablet interface called the REFLECTOR and user feedback in the form of selecting a colour on the units. We evaluated this concept using a Wizard of Oz prototype with three other young adults on the spectrum who were otherwise not involved in the project (Zoë, Age 21, PDD-NOS, Assisted Living; Minc, Age 21, PDD-NOS, Assisted Living; Theo, Age 22, Asperger, living situation unknown).

Building up to **phase 3** (6 months, 2018) we built a working prototype of seven wireless lamps and one graphical interface on a laptop (interfacing to Google Calendar data in the background). We brought the prototype to Shena (19, ASC, on the brink of moving to her own apartment) and Toby (22, ASC, living independently with external coaching) and had a contextual interview with them about their living situation and about the possible value of the product in it. Subsequently we undertook two one-week prototype deployments with Gary (Age 24, ASC, in Assisted Living) and with Adam (Age 21, ASC, living with parents). During the one week testing we co-designed and immediately implemented personalized improvements, which were then evaluated again by the user in their home. Finally we had several evaluation sessions during this process with Toby's coach and with Gary's daily supervisor.

Apart from concept design, interaction design and prototyping, each design iteration included contextual interviews (Holzblatt and and Jones, 1993), co-design activities and evaluations. Co-design







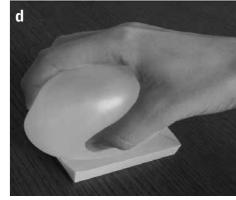


Figure 2a. Use evaluation Phase 1, installing prototype in Max' home. 2b. Phase 2 cardboard mockup. 2c. Co-design with Lucas and supervisor (Phase 2). 2d. One of various prototypes to co-design interaction styles (Phase 2).

took place at the home of the autistic person, often together with a professional, and consisted in collaboratively exploring ideas on: product, functionalities, interface, detailed features and personalization options. To scaffold imagination and communication, we used cards with inspiration photos, basic tinker materials, early mock-ups and visual storyboards, together with 'black box' props, i.e. 'magic things' that could take on any function envisioned to be useful within the scenario (Iacucci et al., 2000; Frauenberger, 2015; Sleeswijk Visser et al., 2007; Van Dijk et al., 2016; See Figures 2a-d and 3). In evaluation sessions with stakeholders we would first talk concretely about the prototype design, and then move into more general reflections about the topic of empowerment and technology assistance. Each phase also included a general reflection in which the design team weaved together insights from the contextual inquiry and co-design, the design decisions made, the evaluation outcomes of of prototypes and embodied interaction theory (van Dijk, 2018).

Insights

We now describe our main insights, summarized for each phase. The subtitles below (chosen in hindsight) reflect how we came to see the core empowering role of technology in that phase..

Phase 1: Distributed and Situated.

The first phase lasted for a year and contained six iterations. We only have space to describe the major insights (But see Van Dijk et al, 2016). In initial conversations with care professionals the problem was defined as how to persuade people to use a calendar and plan their day. Professionals told us their clients wanted to do things, but often didn't not manage to actually do them. They also wanted existing 'work schedules' to be integrated, and suggested to give rewards. At the same time, they also suggested options for personalization and that the client should 'be in control'. Through the many contextual interviews with Max we developed a slightly different view on the challenge. Max recounted how he could easily get stuck in one activity and then had difficulties moving on to the next. But he was also frustrated about the 'work schedule' pinned to his corkboard. He stated he 'needed it' but also 'hated it'. He did not wanted 'to be treated like a child'. Max explicitly did not want an 'App' on his phone, because attending to the screen would mean 'even more distracting information' and 'not having his hands free'. Max had many idiosyncratic routines involving objects in his home. For example, his cupboard, given to him by his grandmother, had a strong personal significance and in it, and the many seemingly unrelated items in it always needed to be in their proper places.

While his professionals were open to the idea of empowerment, their ideas seemed to focus on control: a tool that would help a person do things 'in the right way'. Moreover ideas focused on cognitive messages on a screen. Yet as both Max and his care-givers told us, understanding what to do was not the problem. Providing more information in the midst of action would distract rather than help. Inspired by embodied and distributed cognition theory (Van Dijk, 2018) we decided to start from the fact that the local environment of Max was personally significant for Max. We envisioned a system that would not replace this world of situated local meanings with a 'work schedule' or 'reward system', but instead build on it. We wanted to help Max use his own world to his advantage. This lead to the first version of MyDayLight. It is a system of one central lamp and a number of



Figure 3. Co-design interaction toolkit used in Phase 2 with Tim and Lucas.

controllable Philips Hue lights, placed in fixed (self-selected) positions in the apartment. Using Google Calendar, Max programs the lamps to 'high-light' certain things at certain times, which gives a subtle hint to start on a certain task. What these things are is up to Max. We saw the lights as distributed attention grabbers in the environment. The natural affordance structure of that environment would then invite the planned activity.

Interestingly, over the course of the project, Max also started to think about the organization of his apartment in a more general sense. For example, while selecting places for his lamps, he came up with the idea to create a 'relaxation corner', to help him remind to take his rest. This way in which the system started to support reflecting on ones' routines and personal environment became the theme of the second phase.

Phase 2: Adaptive and reflective

In the second phase we engaged in co-design sessions with Lucas and Tim (Table 2). Acting out various situations with stakeholders helped us to emphasize with the client and the supervisor. One of the main insights out of these sessions is that Lucas and Tim would sometimes linger in a certain 'mood' depending on something that went wrong earlier on the day. Even if overall the day went well, this mood overshad-

owed otherwise positive experiences. In one session, Lucas' mother and caretaker took great effort to convince Lucas that things had been fine that day, while Lucas in response insisted things were 'all terrible'. Lucas said his mother was being 'sarcastic', while his mother insisted she wasn't. Lucas and his mother both had a very different perspective on the situation. In relation to this, a recurring theme was the need to celebrate success, and not just focus on the experience of failure. In phase 1 we had been hesitant to design explicit 'rewards' into the system, as they would mean to install success criteria from an outsider perspective. But now we saw a role for enabling users to give themselves a reward, or in other words, to make positive experiences more explicit. At one point Tim gave himself a tap on the shoulder, which we took as an apt metaphor of what the system could do.

Over the course of phase 2 we replaced the fixed lamps with wirelessly connected, handsized led-units (prototype running on Arduino mini, led-ring, rotary encoder and ESP wifi module, Figure 5). We added a graphical interface for a tablet (Figure 6). As in a regular calendar, one may plan activities to do next day (and repeating each day). One then couples this activity to a led-unit. One places the unit at a convenient place in the living space. The unit gradually lights up when the task is due. When one has finished the activity, pressing the unit will turn it off. As the lights are wireless, one may play around with their locations, with the number of units, what tasks to assign,

then doing. Following Lucy Suchman's theory of situated action (Suchman, 1987) we added the possibility grabbing a new light unit on the fly and activate it to mark an 'improvised' activity. In the graphical interface, the new unit will appear as a new object, which can then later be named and turned into a proper, repeating task, if one so wishes. Taken together, the system now allows for experimenting, reflecting on experiences and gradually developing new routines. Finally, we implemented the possibility of marking positive or negative emotional states by turning the units top into a colour. This 'self-report' of one's current mood is displayed on the graphical interface a a coloured

and their timing. Initially, focus

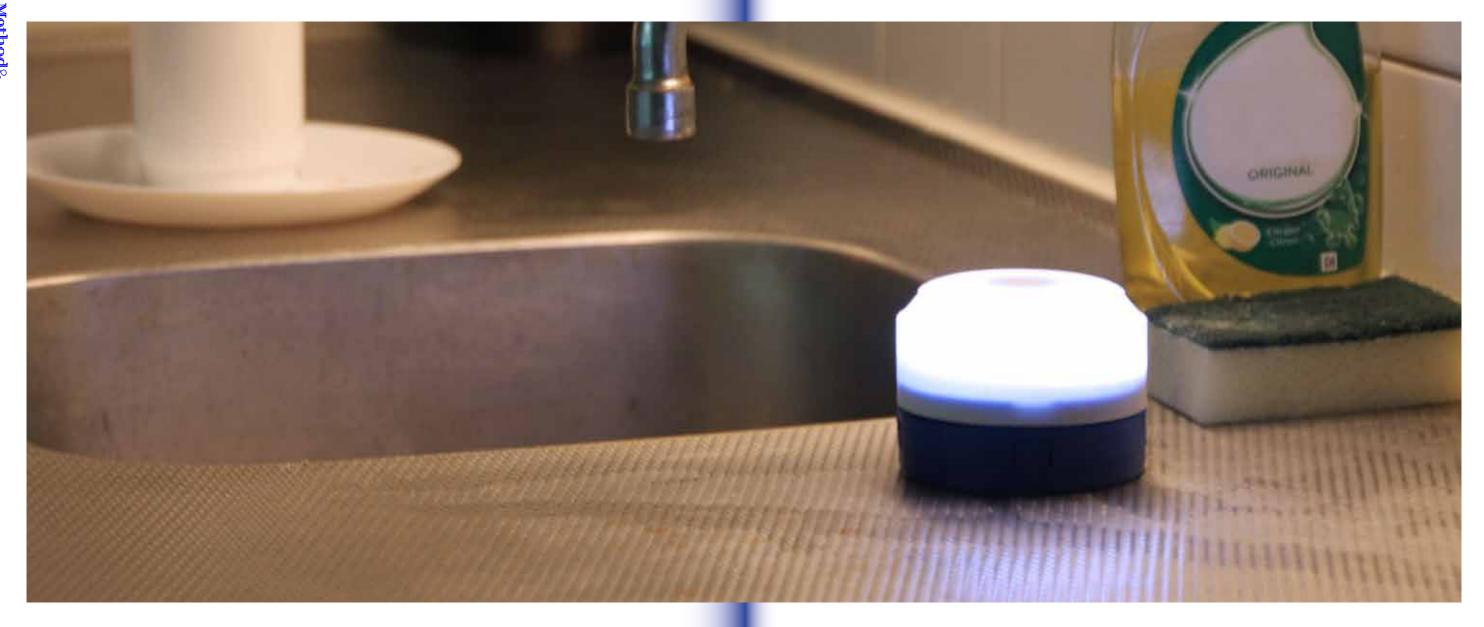
had been on first planning, and





< Figure 4a: One of the MyDay-Light lamps, placed by Max on his cupboard next to items that had special significance for him. 4b. A MyDayLight led strip placed in the open kitchen.

6



dot (Figure 6). This information can later be used to reflect on the day, possibly together with a care-giver, to gain insight into ones' moods and to scaffold shared understandings between person and care-giver.

Reflecting on phase 2 we saw the light units still to be guiding action in the here-and-now, while the graphical interface functions in 'offline' moments, when one looks back on past experiences. We renamed the calendar 'REFLECTOR' to emphasize that planning tasks is an aspect of learning from past experiences. The design was evaluated with three participants not earlier involved in the project using roleplay and mockups embedded

with LittleBits elements (Figure 2b). One result was that the design seemed still too rigid, as each individual person may have their own particular preferences for types of system feedback. Also, the risk was voiced that a user may 'outgrow' the design with development. We envisioned how a system could evolve with the user, providing feedback about the sorts of tasks and situations that are challenging in any particular phase of development towards independent adulthood. For this, a highly personalized and adaptive system seemed to be needed. This, then, became the theme for our final phase.

Phase 3: Personalized and Transformative

In the final phase we tested out a fully working prototype with seven light units and a graphical REFLECTOR interface (Figure 5, 6a, 7c) with Garv and Adam (Table 2). Both used the lamps for several days, after which we discussed possible adjustments, implemented these and live enacted the new system together. We now discuss the main results.

Gary lives at a supervised, sheltered accommodation, does his own groceries and cooking. On weekends he visits his parents. Working with Gary was challenging, if only because he often did not show up for appointments. Gary used the system to remind

him to leave his house on time and doing the laundry (Figure 8). In the evaluation session Gary wished to make the system more persuasive, for example by adding sound. In response, we built in a limited number of sounds (Figure 6b)

Next, we took the system to Adam. Adam lives with his parents and attends college. Adam told us he often keeps planning activities until he has no more leisure time. He is also often so immersed in an activity (hyperfocus) that he forgets everything else. His mother supports him with scheduling and taking time to rest. Adam appreciated the trigger is not a smartphone notification. In the latter case he would just start doing something else on his phone and forget his tasks. Adam believed the sound feedback could scare him when badly-timed, but may also be necessary to grab his attention during hyperfocus. Adam suggested users could record different sounds for each lamp. The personalisation idea triggered other suggestions: change the obtrusiveness of the sound, volume, duration, and changing the dynamics of the lights.

In the expert evaluations the need for personalization was confirmed. One professional suggested to have 'live updates' from the system so as to monitor the user. The autistic participants stated not to want

Figure 5. MyDayLight wireless led body, the final prototype that ended Phase 2. The body contains a led ring, an ESP wifi module, Arduino controller and a rotary encoder. The lamp can be pushed on top (on / off) or turned 180 degrees (changing the colour on a full spectrum) Changing colour is automatically sent to the main computer where it appears as colored dots in the graphical interface.

'someone else looking into their business'. This conversation illustrates how talking about a prototype in a design context enables stakeholders to explore an abstract notion such as empowerment by making it very concrete: is the supervisor allowed to look into your data, yes or no (or under what specific conditions)?

Looking back on phase 3 we see examples of a process by which each individual person could themselves finalize their own personal system, based on a more generic starting platform. However, participants also told us that providing all available options at once would cause information overload. We therefore envisioned a structured process of exploring and experimenting, not unlike the co-design activities we had conducted, that could be carried out by care professionals as part of daily practice.

In the final prototype we implemented three sliders to change what tune is being played, the duration and its volume, as well as a recording button. To illustrate how such a system could be used in a personal learning process, consider the final evaluation with Gary. At first he did not see use for the recording button (which was Adam's idea). Later on the conversation turned to Gary's alarm clock. Gary then became enthusiastic about having that tune in the system. With the recording button we could try this immediately. Afer that, Gary and his care-giver talked about Gary not wanting too many options but also needing the right sort of cues to activate him. In other words, thinking about the prototype helped Gary and his care-giver to reflect on what would empower Gary. One professional explicitly reflected after the project that co-design process is already 'an intervention'.

Conceptual reframing

Our concept of 'empowering technology' developed throughout the project through a number of reframings, summarized here:

1. From planned, cognitive reminders to integrating attention cues into the personal and situated lifeworld

Instead of explicitly instructing people what to do, the traditional idea of a calendar with tasks turned into a set of situated 'attention grabbers' that 'reorient our attention' (Suchman, 1987) in such a way as to naturally afford the desired action. The

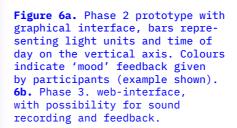
meaning grasped by the user is not a message encoded in the light signal, meaning is found 'in the whole situation', that is, in the way the world at that moment 'shows up' (Merleau-Ponty, 1962). Many technologies are designed to communicate information from a health-care professional *to* the user. Our system is of the user and for the user. One may incorporate the expertise and advice of others, but this social 'scaffolding' is secondary to a person's own, ideosyncratic routines. This means the lights function not just to present a a situated form of communication of meanings - they are meant to enable a situated form of production of meaning, that is, to help people perceive their own familiar world in new ways that are more fruitful to the kinds of activities they wish to be able to do.

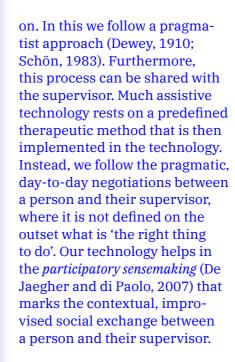
2. From tech-support for desired behaviors, to providing reflection scaffolds with which one may organize ones' own supportive routines.

At first we focused on affording desired actions by highlighting relevant elements in the environment. We then came to see that the system also affords the gradual rearrangement of that environment such that it becomes even more supportive. As a part of this we saw how using the tool - thinking about where to put the lights, and to what purpose, and so on, would help trigger a reflective process through which a person learns about the ways in which routines and the environment interact and how this may lead to desired or undesired outcomes - for that person. Using the affective feedback and the REFLECTOR interface a person can step back for a moment and 'make sense' of what is going

< Figure 6. Evaluating a mock-up with Gary

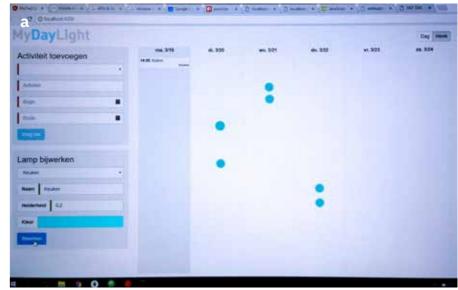
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3) From 'designing a product', to designing a 'co-design process and tools to scaffold a broader transformational process by which one develops of a self-empowering life-world.

Similar to the work of (Hurst and Tobias, 2011) we finally came to see our project not as one design solution but rather as a starting point by which each individual person could adapt the system to their own needs. Changing your own environment such that it better suits your routines aligns with what David Kirsh termed 'epistemic actions': re-organize the world such that it works better for you (Kirsh, 2010). Here we see an important role for the





care professional, who can play the part of a co-design facilitator, supporting a person in moving from the enormous set of possibilities towards one personal solution, and helping to reflect on experimenting with earlier versions and adapting the device in response. We also found that having working prototypes tremendously helped in allowing for the co-design process to be grounded in actual, tangible use experiences rather than situated in a more abstract 'creative space' or design studio. However, building dedicated working prototypes for each project costs time and effort. This final line of thought only emerged at the end of the project. In our future work we intend to develop this further, for example in thinking about how co-design may become part of a supervisor's basic competencies and to see whether and how generic 'toolkits' could be used to kick-start the process.

General reflection

In this study we investigated what it means to design 'empowering' technologies for young adults on the autistic spectrum. When is a technology truly empowering? Through the design of MyDayLight we showed how the question of empowerment is not a practical question of enabing a person to 'do things on their own' – it concerns a deeper, experiential and developmental question, concerning the











Figure 7a. Demonstration prototype ending Phase 1. 7b. Demonstrtion prototype ending phase 2. 7c. Current prototype with seven light bodies and a web-interface as used in Phase 3.

sorts of technology interaction that would mediate ways for people to gradually increase their grip on the world. Vernon and Qureshi (2000) make the distinction between 'self-suffiency' and (true) empowerment. Many technologies are focused on self-sufficiency, in other words: how to make sure the dishes get done. Empowering technology as we came to see it should help generate the experience of agency: technology contributing to the feeling of having a grip on your life. Technology should work in such as way as to foster the experience of doing things you intended, you initiated, and of doing them in the way that you feel is right. In some sense, interacting with such technologies becomes a way of expressing ones' identity. Or to put it in Merleau-Ponty's terms, doing grounds our 'being-in-the-world' (Merleau-Ponty, 1962; Van Dijk, 2018). This is why MyDayLight became a flexible system that first hooks on to the existing lifeworld, then triggers reflection on action, and then can be used to adapt both routines and environment. It does not define what 'a task' is, let alone when and how it should be executed. It 'highlights' moments in the flow of action that later on may become a task, for you, in your life.

We came to see how the difference between autonomy and dependence depends in practice on the details of the enacted relation between a person and their environing world, both social and physical. This became clear as we started to conceptualize MyDayLight as mediates this enacted relation (Verbeek, 2000).

Another aspect that surfaced concerned the relation between lived experience and institutional structure. Institutional care is laid down in procedures, methods, diagnostic criteria and the like. Technologies are typically lined up with such institutional processes and structures. While important to ensure a level of quality and coordinate work, institutionalisation may also lead to an objectification of the person (Baxter, 1987). What we observed over the years is that it is in the experiential, one-to-one relational work between professionals and autistic people that empowerment is realized. Rather than implementing institutional policy, MyDayLight therefore also serves to show what technology can do for the improvised, one-to-one, day to day social relational work, without thereby turning such work into a formalized structure.

We like to emphasize once more how the present project was never an interaction design project aimed at developing an assistive tool. Its purpose was to foster conceptual reframing, based on reflecting on co-created designs. We had many discussions with health professionals and technologists during this four-year project. Upon confrontation with our prototypes, a typical suggestion for design improvements would be to make it more explicit and easier for clients to understand 'the task to be performed'. The power of our RTD process consisted in not turning this feedback into a design requirement, but to see it first as an expression of a particular way of understanding the situation. At the same time, many autistic participants asked both for 'more structure' and for 'more freedom'. This dilemma hinted at another way of understanding. Professionals, in turn, then assumed that the call for 'more structure' meant more explicit instruction and more planning of tasks. Our evolving concepts and prototypes enabled to talk with stakeholders about these understandings. With prototypes in hand we discussed what we actually mean by 'structure' and 'task' and what it means to 'support' daily activities using technology.

The tangiblity of the prototypes was very important in this respect. We experienced our evolving artifact not unlike a pinball, bouncing back and forth between the responses of the various participants involved, including ourselves. At each confrontation between people and the evolving artifact (Stappers & Giaccardi, 2017), the artifact took something from the encounter, gradually morphing into its final form. But with the change of the design, so did the participants' understanding. By interacting with the artifact (in its various iterations) and talking concretely about its form and behavior, participants and designers were implicitly rethinking their own 'unquestioned assumptions' about what empowering technology really means to them.

In the future, we want to strengthen this process of reflecting with artifacts even more and develop ways to more explicitly harvest the insights that come out of it, not only for design, but specifically for participants to make new sense of their own practices. This, then is our final reframing: MyDay-Light not just as an example of an empowering product, but as a 'reflective scaffold' - a tangible artifact that enables reflective practices, through which adults on the spectrum, their care-givers, and significant others, can come to new understandings on what they see as empowering, and what would be needed to support it.

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Figure 8. MyDayLight in use: Gary put one of the lamps on his laundry (Phase 3).

