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DESIGN YOUR LIFE

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Autism and Technology London

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Philadelphia health-care
The POWERTOOLS project



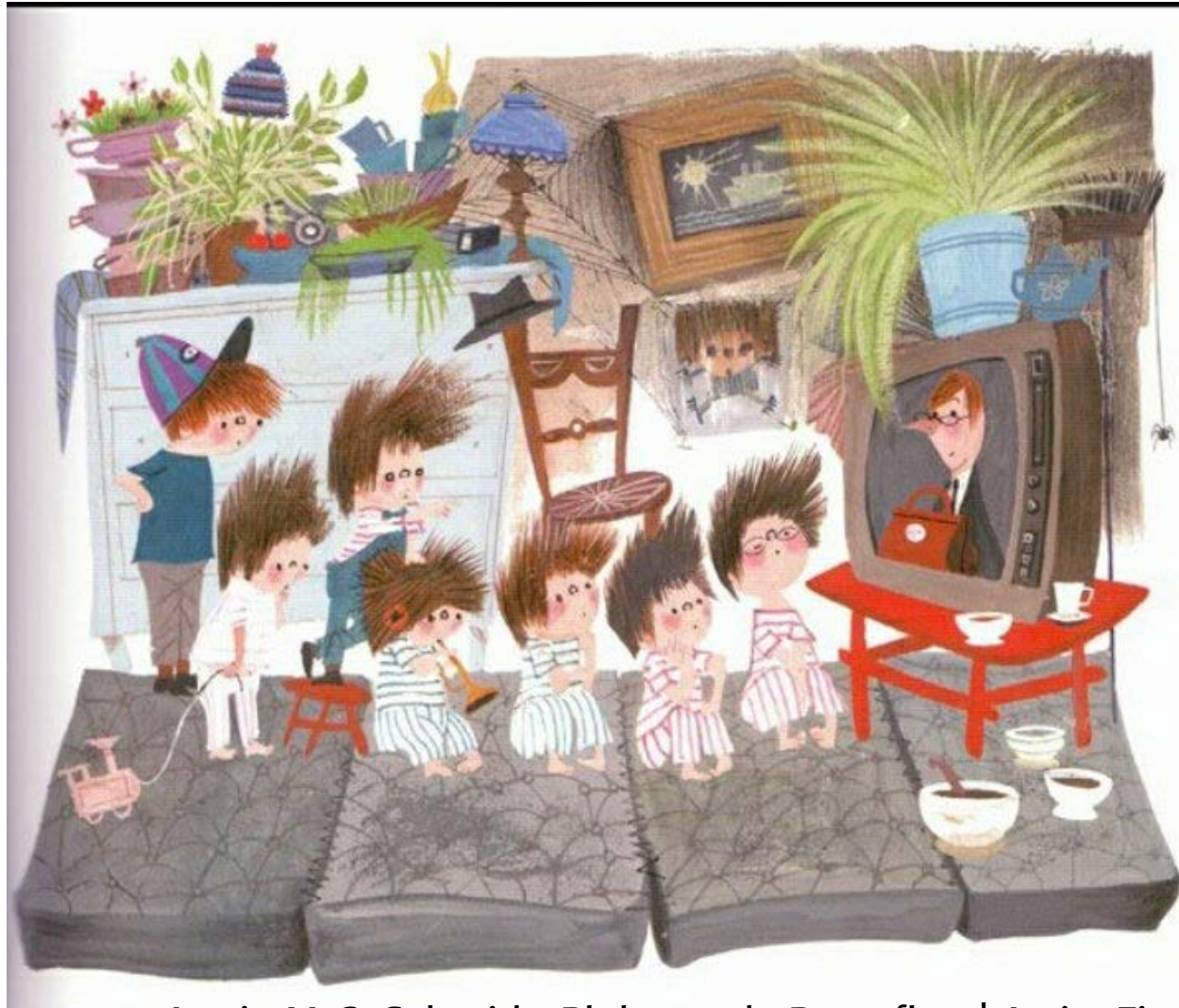
jelle van dijk 

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I do research on embodied
empowerment design @utwente |
embodied theory | designing support for
autism | drawing comics

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Change the world such that it fits to who you are



Annie M.G. Schmidt: Pluk van de Petteflet. | Artist Fiep Westendorp

‘Masking’ is sometimes unavoidable, but should never be the goal of a design



Summary

- In this talk I will present a number of critical co-design research studies. These studies figure new concepts for interactive technologies, designed to support young autistic adults in living independently. Based on these case studies, I wish to argue for rejecting some conventional ideas of technology as instructing, as training or as ‘persuading’ people to perform in desirable, normative ways. Instead, I argue for a new type of interactive technology designed to become an adaptive reflective scaffold. With such scaffolds young adults on the spectrum may develop their own supportive lifeworlds. I discuss some of the implications of this conceptual reframing both for care practices as well as for assistive technology design.

Disclaimers

- **No hard evidence** of anything will be presented in this talk
- The title ‘design your life’ is **highly misleading**: life cannot be designed, it should be ‘lived’
- The products presented in this talk **cannot be bought in any store**
- **I am not even a real designer**

Design, technology, and autism



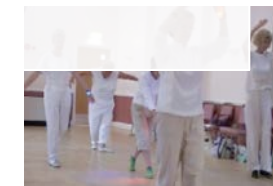
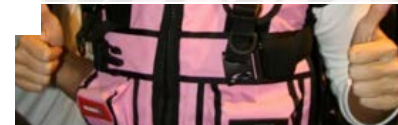
(Autism Glass Project, Haber et al 2016)

Quiz for visiting the [#INSAR2018](#) tech demo and keynote: Reflect on each device:

- ▶ Who designed this?
- ▶ What problem does it solve?
- ▶ Is that a real problem?
- ▶ Whose problem is this (really)?
- ▶ product or measurement tool?



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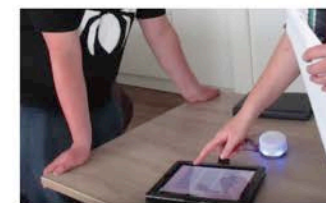
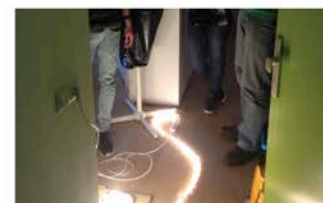
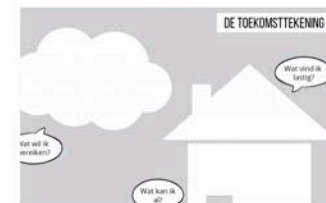
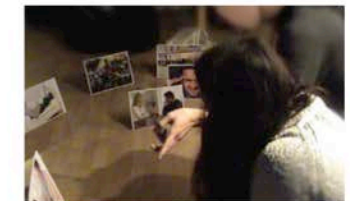
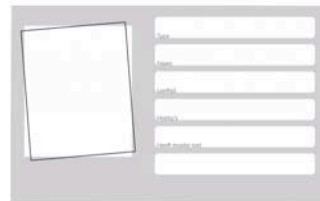
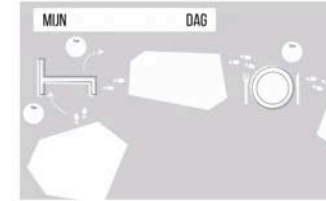
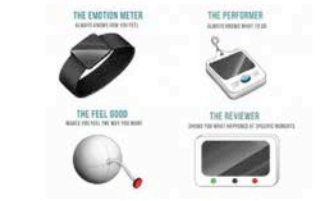
Research through Design

- Using the process, methods and tools of design to ‘research’.
- Working with all relevant stakeholders. (Especially “end-users”).
- What do we research?
- Questioning normative frames/implicit assumptions underlying current practices in health-care and assistive technology.

On the role of design (as we do it)

- Not just answering the question, but asking what the question really is
- “Reframing” implicit assumptions and ‘ways of looking’.
- Empowering users in the process, give them a voice.
- Learning by doing
- Bringing perspectives together, creating shared understanding
- Making things tangible and concrete: some-*thing* to talk about
- What ‘could be the case’, instead of ‘what is the case’

Co-design

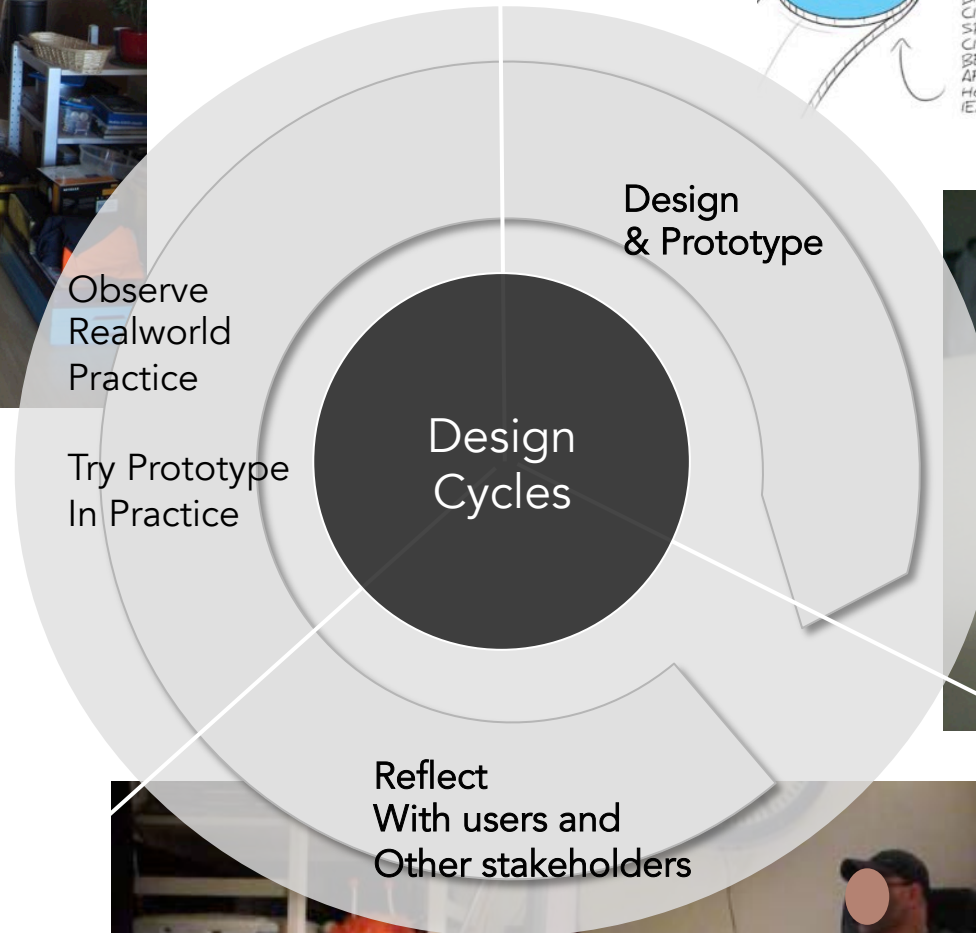


Powertools
Project
[http://www.
powertoolkit.nl](http://www.powertoolkit.nl)

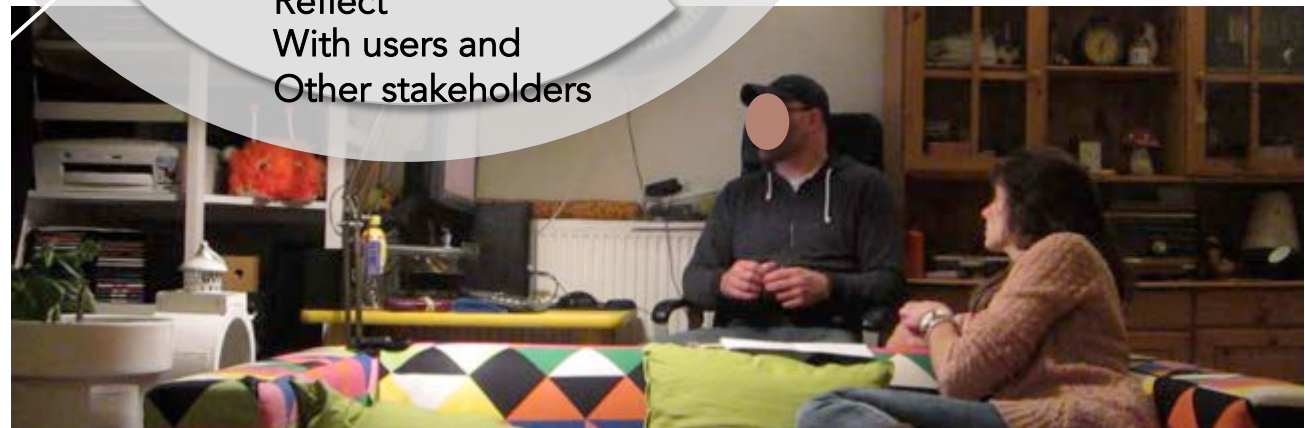
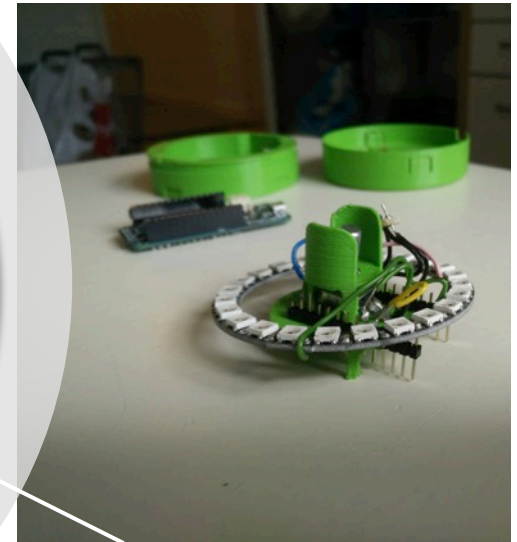




The process in practice



1. MEEDEINEN



Young autistic adults

**A wealth of problems, but often misrepresented
A goldmine of talents and opportunities, but often unseen.
Growing and developing, a wish for independence.**

Health care in transition

Financial pressure

Autistic individuals increasingly gaining a voice

Designing for the lifeworld

- How can we help people adapt and manage their own supportive ‘lifeworlds’?

A photograph of a living room. In the foreground, a person with long dark hair is sitting on a colorful geometric-patterned rug, facing away from the camera. To the left, a wooden dining table is cluttered with various items, including a blue shopping bag with the word 'DAGVLIET' on it. A large window on the left wall lets in bright light. In the background, there is a tall wooden bookshelf filled with books, a red armchair, and a clothing rack with clothes hanging on it. The room appears lived-in and somewhat cluttered.

The lifeworld

- Skills, routines, tools, objects, spatial organisation
- Social context, relations, roles, network
- Learning, feelings, reflections, change

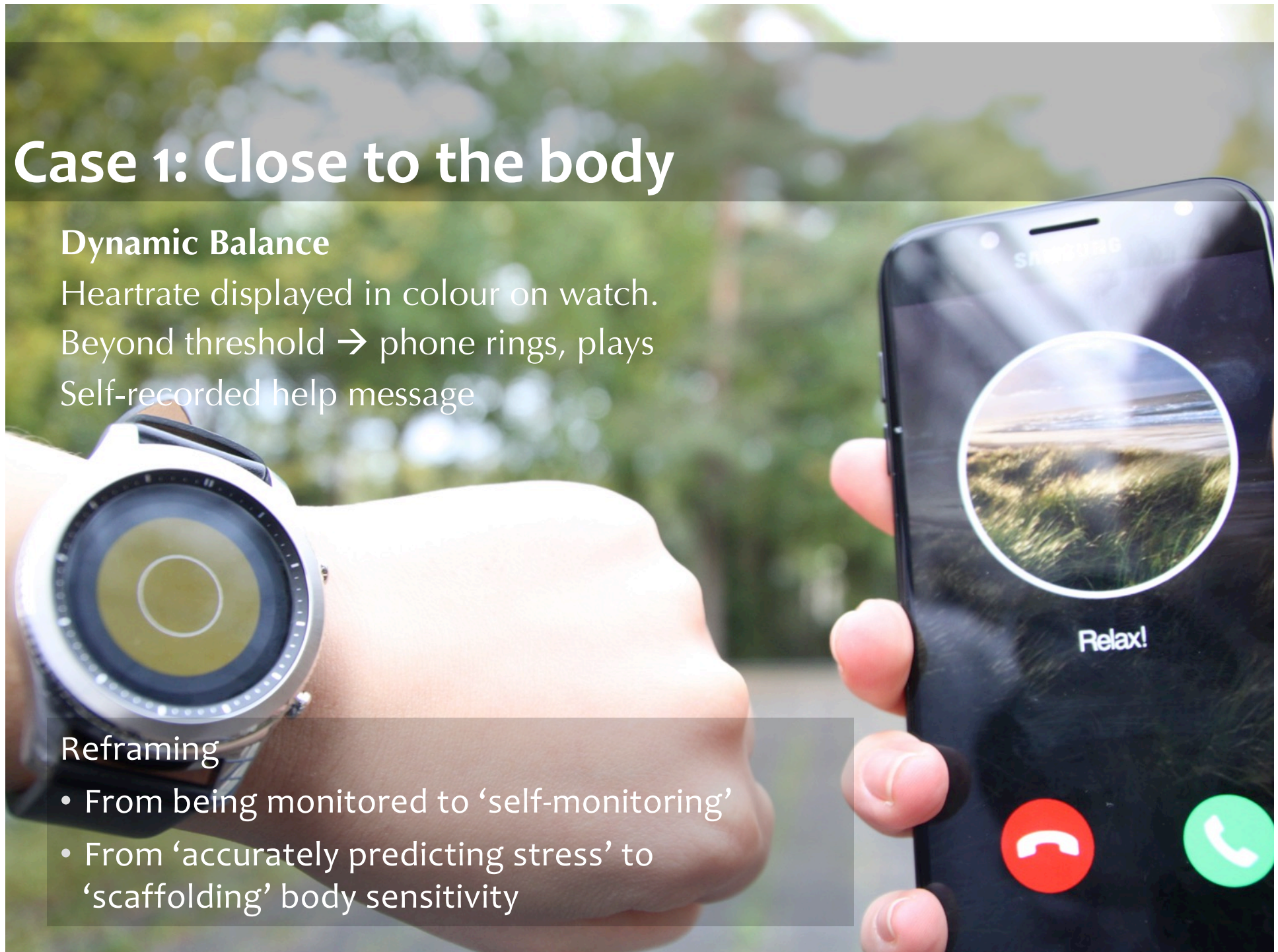
Case 1: Close to the body

Dynamic Balance

Heartrate displayed in colour on watch.
Beyond threshold → phone rings, plays
Self-recorded help message

Reframing

- From being monitored to 'self-monitoring'
- From 'accurately predicting stress' to 'scaffolding' body sensitivity



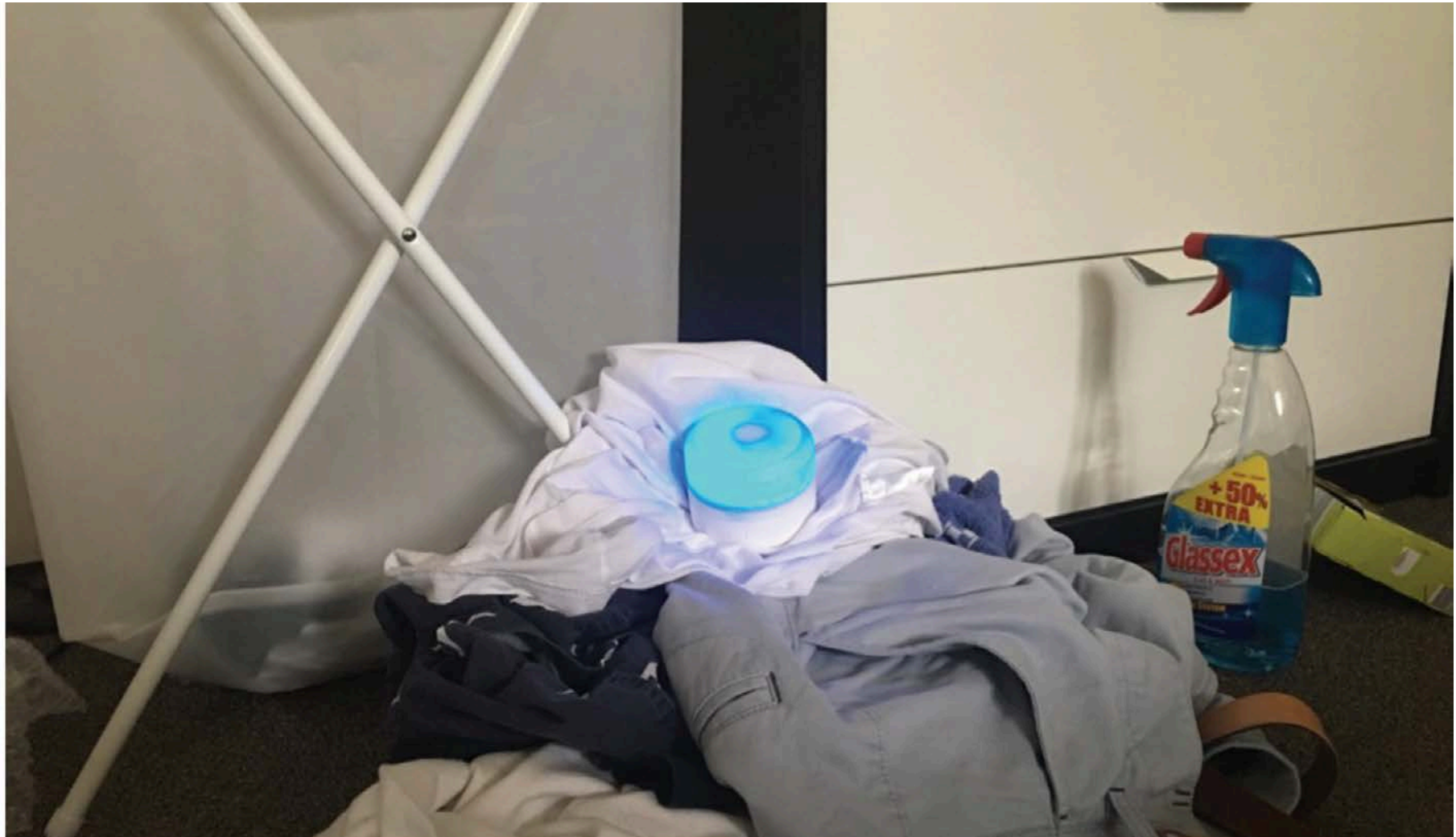
Case 2: In the home

MyDayLight: Interactive light embedded in context connected to Google calendar

Reframing:

- Not offering the 'optimal plan', but building on existing habits and context (the lifeworld).
- Not showing 'what to do' but 'how are you doing?' (from 'planner' to 'reflector')?





MyDayLight

Variation: MyTag

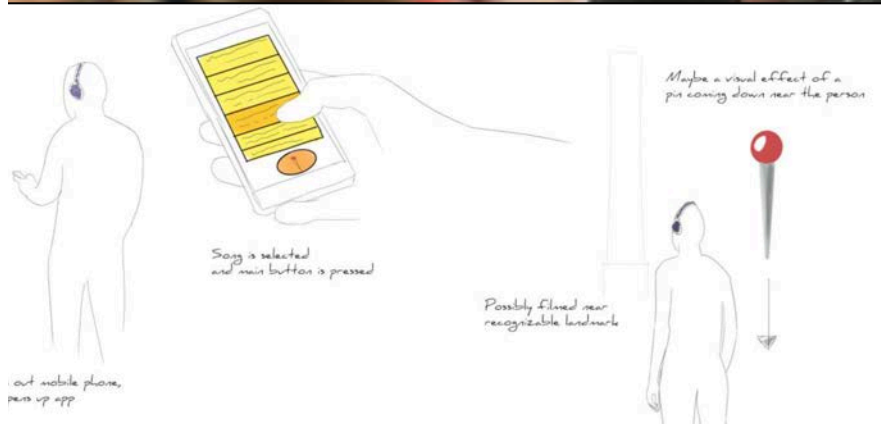


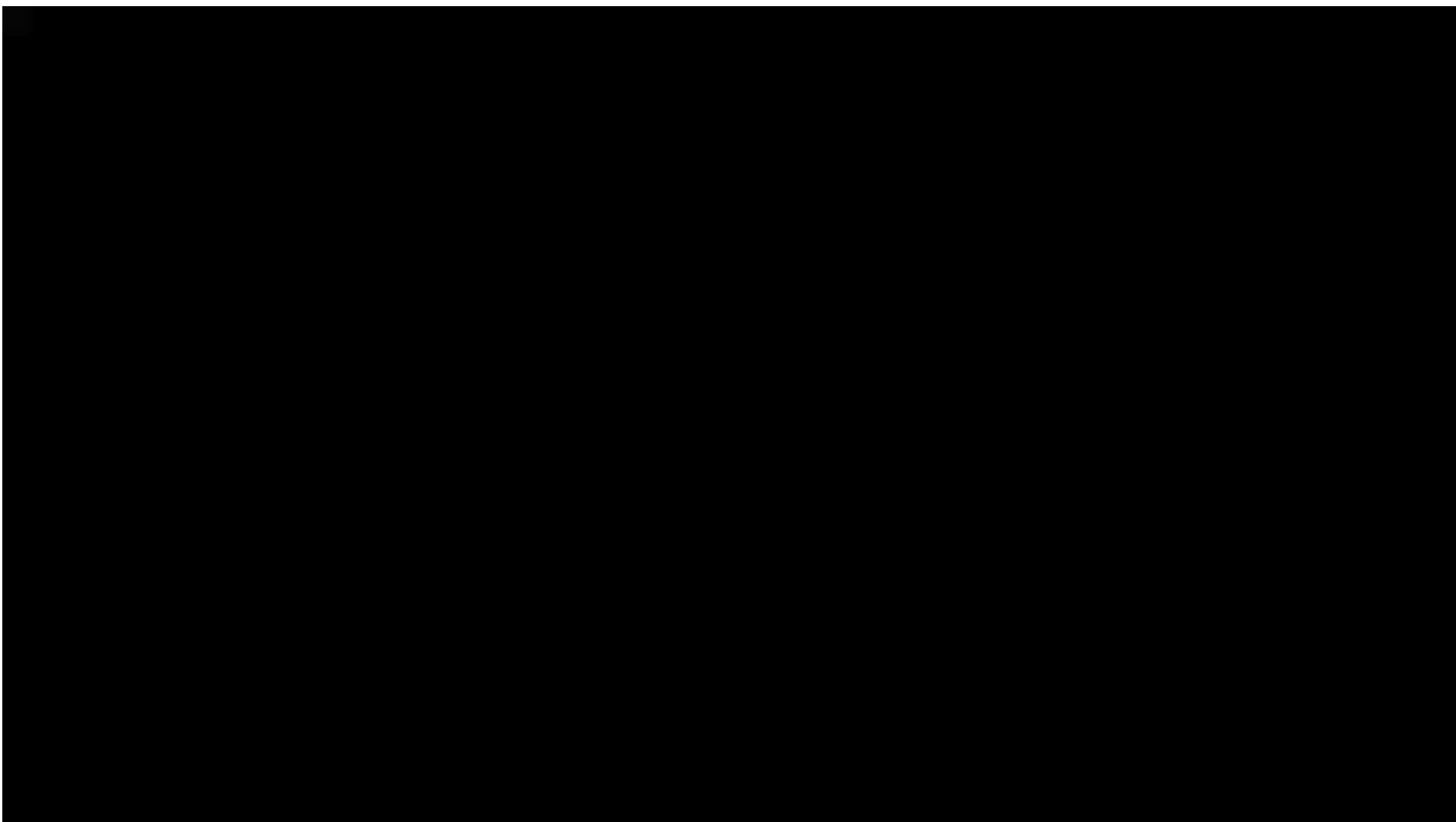
Reframing: not persuading the user to 'do their tasks'
But: enabling a person to take up tasks in the natural flow of the day

MyTag

Case 3: out on the street (work in progress)

MyTracks: a personalizable location-aware system that plays specific kinds of sound and music depending on your needs in specific places.





Reflections (1)

What is the design challenge about?

What about social skills?

"Many social skills are not really a thing. They're just some arbitrary cultural norms that we decided to call social skills." - Sue Fletcher-Watson



Topics of potential interest to autistic young adults:

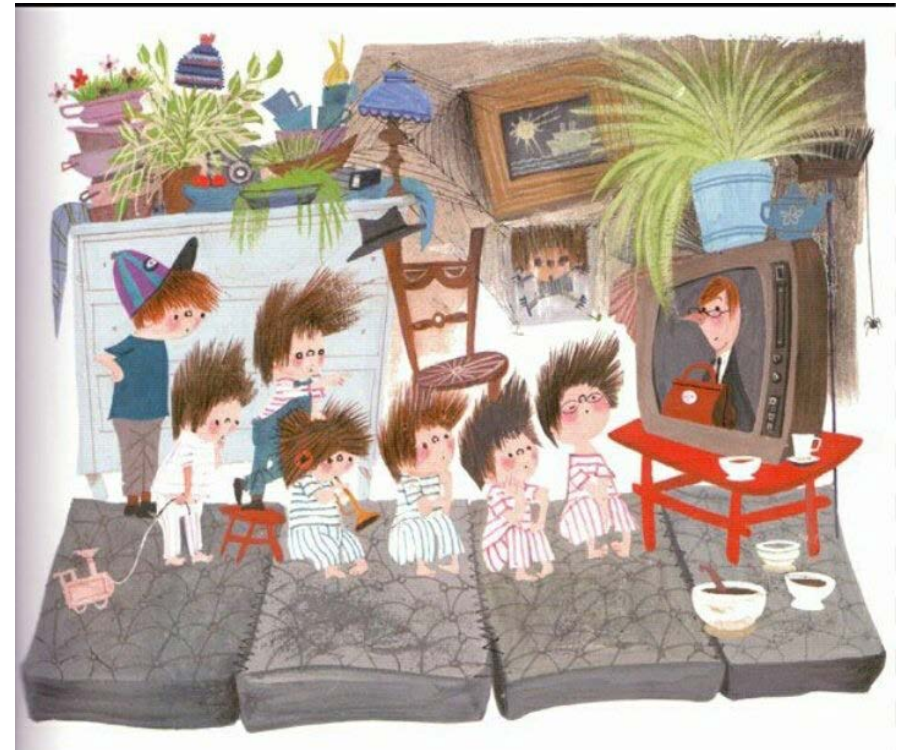
- Hypersensitivity
- Getting into action, switching gears, focus vs hyper-focus
- Anxiety, stress
- Managing everyday life
- Avoiding burn-out in dealing with neuro-typical structures
- Depression

Reflections (2)

What is the role of technology?

“Help me to live life on my terms” - Leneh Buckle

- Not: training skills that are based on normative frames
- **But: help a person develop routines that ‘work’ AND are meaningful to themselves: *their* routines.**
- Not: instructing how to organize life, or informing about ‘what is wrong or right’
- **Rather: create feedback loops that help a person to build further on their own supportive life-world**

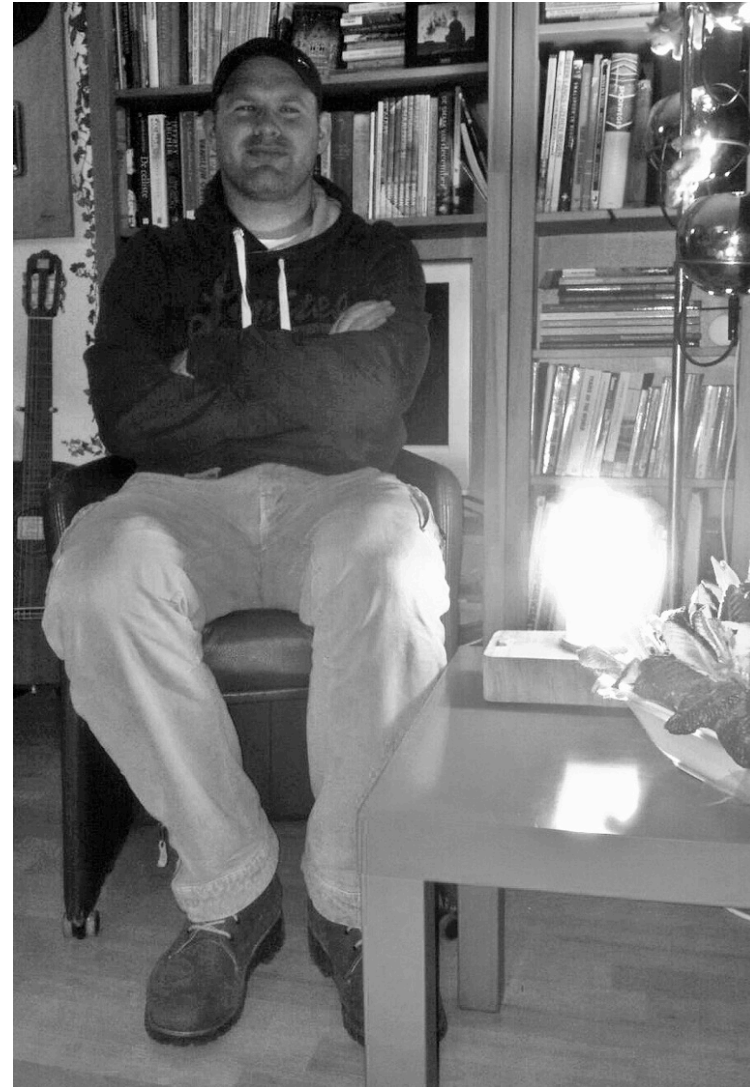


Reflections (3) Empowerment, autonomy

- “*We are not putting your calendar in my lamp*”

Building on your own life-world
and creating your own
meaningful routines is a
fundamental requirement for
being autonomous

Technology should *add to that*,
not take it away and replace it.



Reflections (4):

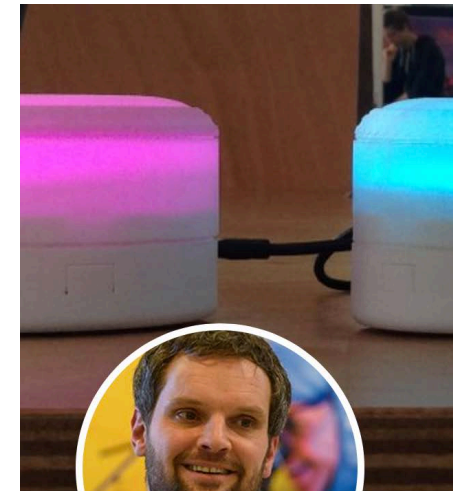
***Co-design* as part of a larger, self-empowering process.**

Can we see health-care workers and educators engage in co-design with autistic people and help them design, (install, configure, adapt, combine) their own technological support system?

(New role for professionals! How about parents/important others?)

Design your life?

- Let me know if you want to collaborate!
- I'd be very interested in finding people that want to help build electronics and or write software for any of the projects presented so far.
- I would be particularly interested in people wanting to contribute to **the TRACKS project**
 - Co-designer, programmer (helping to build the app)
 - Co-designer, user (trying out the app once it works)
- Drop me a line at **@theblub (twitter)** or **jelle.vandijk@utwente.nl**
- Thank you!
- www.jellevandijk.org



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I do research on embodied
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