DESIGN YOUR LIFE

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Autism and Technology London
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Philadelphia health-care
The POWERTOOLS project
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

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?

(Autism Glass Project, Haber et al 2016)
Technology is coming to get you

Wearables, -in textile, clothing, shoes, bags
‘Smart objects’, ‘smart homes’
Internet-of-Things
Ambient Intelligence
Virtual Reality,
Augmented Reality
Social Robots
Brain-Computer Interfaces

Not just ‘access to a digital world’ but increasingly:
‘interactivity entering the physical world’
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: something to talk about
- What ‘could be the case’, instead of ‘what is the case’
Co-design

Powertools Project
http://www.powertoolkit.nl
The process in practice

Observe Realworld Practice
Try Prototype In Practice
Reflect With users and Other stakeholders

Design & Prototype

Design Cycles
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’?
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’)?
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
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!

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