DESIGN YOUR LIFE

User-initiated design for young autistic adults
...Let’s start with an anecdote...

Why would I ‘abandon’ the first one?

Source: Sonic Bomb Extra Loud Alarm Clock - Geemarc : Complete Care Shop

Source: Wake-up Light HF3500/01 | Philips
IN THIS PRESENTATION:

- Introduction
- Autism & Independence
- Technology & Core Principles
- Cases & Model
- Summary & Next Steps
- Questions
Autism

Social, communication and behavioral challenges.

Scientific conceptions:
• Biologically based;
• Throughout life (not only childhood);
• Occurs at all IQ-levels;
• Universal around the world;
• ~1/100 people are autistic¹.

Autism

• Young autistic adults often have difficulty living independently\(^1\)

• Initiatives with assistive technology seem hopeful, but impact is often limited\(^2\)

Independence

independence  \rightarrow  self-direction (control)

                             \rightarrow

self-sufficiency (ability)
Independence

Independence

Independence

Towards Independence: **Assistive Technologies**

Source: [Learn with Rufus: Emotions – Приложения в Google Play](#)

Source: [Dit is Tessa de sociale robot - YouTube](#)
Problem Statement: Technology Abandonment

The design challenge is too often described in terms of generic, functional limitations. Thereby, designers severely gloss over the importance of experience that YAAs have with the technological artefact.

Proposed Solution

...Design Your Life...

A design methodology through which young autistic adults can create their own supportive home environment.
4 Design Principles

1. Focus on Experience
2. User-Initiated Design
3. Action-Oriented Tinkering
4. ‘Off the shelf’-technologies
#1: Focus on Experience

We build upon phenomenology – as the philosophical study of experience – to comprehend and articulate ‘autistic experiences’ as valuable input in the design process.
#2: User-Initiated Design

Stakeholders are not only involved in the design process, but they are equipped with the tools to design their own, specific solutions (e.g. Sarmiento 2017).

#3: Action-Oriented Tinkering

Technologies are perceived as a “meaningful interactive whole” (Svanaes 2013: 16). Therefore, design ideas are brought into practice; tested and evaluated in context.

#4: ‘Off the shelf’-Technologies

By introducing ‘off the shelf’-technologies, it becomes easier to envisage the design possibilities.
‘Good Trip!’, designed with Vincent and Bianca.

Designer: Jasmijn Sagel, Industrial Design Engineering Universiteit Twente

‘Prompt cards’, designed with Paul en Hermien.

Designer: Brian Schipper, Industrial Design Engineering Universiteit Twente

‘Interactive Questionnaire’, designed with Tim and his mother.

Designer: Laura van den Berg, Industrial Design Engineering Universiteit Twente
Looking, listening and asking

Explore solution options

Realizing one or more things.

Learning by trying and improving
Laura van den Berg, 2020 (Adapted from Dam & Siang, 2020)

Brian Schipper, 2020

Jasmijn Sagel, 2020
Summary

• Autism & Independence
• Technology & Core principles
• Cases & Model
Next Step: **Co-Design Cases**

<table>
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<tr>
<th>PHASE 1. CONTEXT (9 mnts)</th>
<th>PHASE 2. DESIGN (15 mnts)</th>
<th>PHASE 3. VALIDATE (15 mnts)</th>
<th>PHASE 4. IMPACT (9 mnts)</th>
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<tbody>
<tr>
<td>Contextual inquiry with AYAs, building up relations</td>
<td>Design Research:</td>
<td>12 n=1 var. baseline evaluation studies of DYL incl. pre-/post in depth interviews measuring sense of control and increased person-technology fit.</td>
<td>(User impact) Community dissemination Open source platform Exploring digital guide</td>
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<tr>
<td>Literature survey participatory design and autism</td>
<td>12 Co-Design cases across various contexts. Integrating insights in 3 multi-stakeholder workshops.</td>
<td>Expert feedback in 2 multi-stakeholder workshops</td>
<td>(Scientific Impact) talks, publications, thesis</td>
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<tr>
<td>Interviews with care-givers, Stock inventory of technologies Evaluation of pilots</td>
<td>Developing DYL and its accompanying tools and materials.</td>
<td></td>
<td>(Professional impact) Competencies, implementation advice</td>
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1. **Stakeholder Workshop**

1. **DYL Sketch**

3. **Stakeholder Workshops**

2. **DYL Defined**

2. **Stakeholder Workshops**

2. **DYL Validated**

1. **Stakeholder Workshop**

**Symposium**
THANK YOU!

ANY QUESTIONS?

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