Jun 25th, 9:00 AM

Towards a toolkit to empower young autistic adults: Using grounded theory to analyze ten design case studies

Niels van Huizen
University of Twente, The Netherlands

Thijs Waardenburg
HAN University of Applied Sciences, The Netherlands

Nathalie Overdevest
University of Twente, The Netherlands

Jelle van Dijk
University of Twente, The Netherlands

Wouter Staal
Leiden University, The Netherlands

See next page for additional authors

Citation

van Huizen, N., Waardenburg, T., Overdevest, N., van Dijk, J., Staal, W., and van der Voort, M. (2022) Towards a toolkit to empower young autistic adults: Using grounded theory to analyze ten design case studies, in Lockton, D., Lenzi, S., Hekkert, P., Oak, A., Sádaba, J., Lloyd, P. (eds.), *DRS2022: Bilbao*, 25 June - 3 July, Bilbao, Spain. https://doi.org/10.21606/drs.2022.432

DRS 2022
Bilbao 25th June — 3rd July

Towards a toolkit to empower young autistic adults: Using grounded theory to analyze ten design case studies

Niels van Huizen[a*], Thijs Waardenburg[b], Nathalie Overdevest[a], Jelle van Dijk[a], Wouter Staal[c], Mascha van der Voort[a]

[a]University of Twente, The Netherlands
[b]HAN University of Applied Sciences, The Netherlands
[c]Leiden University, The Netherlands

*corresponding e-mail: j.c.vanhuizen@utwente.nl

doi.org/10.21606/drs.2022.432

Abstract: Assistive technologies (ATs) are increasingly proposed to support young autistic individuals (YAAs) in daily life. Yet, the uptake of these technologies remains limited. Most ATs are designed for and by non-autistic people, which makes them less usable for YAAs. Moreover, ATs specifically designed for YAAs are often part of formal therapy or training and typically aim to mitigate and rectify 'problematic' autistic behavior. In the research project Design Your Life, we are working with YAAs to develop a co-design toolkit that will help them create a personalized environment to support their independence. By now, we have completed ten design case studies, each deploying a different version of the toolkit. In this paper, we report on the insights that we gained from these case studies, for which we used a grounded theory approach. In total, we identified ten categories of knowledge that will inform the development of a single, final toolkit.

Keywords: Design Your Life; grounded theory; research-through-design; co-design

1. Introduction

In recent years, assistive technologies (ATs) are increasingly proposed to support autistic individuals in daily life (Fabri et al., 2016; Grynszpan et al., 2014). Approximately one percent of the Western population has been diagnosed with autism, which is clinically defined as 'autism spectrum disorder' (Idring et al., 2012). Autism poses particular challenges for autistic individuals that are entering adulthood, as characterized by difficulties with social communication, stereotyped behaviors, and stimulus processing (American Psychiatric Association, 2013). This is for example reflected in high rates of unemployment and mental health issues among young autistic adults (YAAs) (Crane et al., 2019; Scheeren & Geurts, 2015). ATs are believed to have an empowering effect on the daily life of autistic individuals, as they can help to sustain and improve the functional capabilities required to deal with

everyday challenges – at home, school, work, and in the public place (Brosnan et al., 2019; Motti, 2019).

Yet, the effectiveness of these technologies remains "in short supply" (Frauenberger et al., 2016, p. 131; Zervogianni et al., 2020). First, most ATs are designed for and by non-autistic people, which can mean that these technologies are less usable for YAAs both in terms of usability and functionality. In addition, an autistic individual often has specific and idiosyncratic support needs accommodated by ATs that support common and regular tasks and are not tailored to individual needs. Second, technologies that do target YAAs are often part of formal care, initiated by a healthcare professional. They typically aim to mitigate and rectify 'problematic' autistic behavior. This may confront them with their perceived deficits as the technology centers on shortcomings rather than emphasizing strengths. Ultimately, this may evoke a sense of disempowerment, causing YAAs to reject technologies that intend to support them in daily life.

In the research project Design Your Life (DYL), we are working with YAAs and their 'DYL partners' to develop a co-design toolkit that will help them create a personalized, technological environment to support their independence (Waardenburg et al., 2021). Instead of a top-down approach in which YAAs are provided with an AT from an external party, the toolkit provides users with the tools to create their own AT – a bottom-up approach in which the YAA can design ATs based on their own experiences, interests, and preferences. If a person is invited to help design their own tools, this itself can also have an empowering effect. This is a second way in which technology can be empowering – not just the technology itself, but the pride and the feeling of taking control over one's own life caused by the process of creating one's own tools (Agre, 1994; Ehn, 2008; Frauenberger et al., 2011; Frauenberger et al, 2017).

By now, we have completed ten co-design case studies, each deploying a different version of the toolkit. These case studies were conducted using the principles of research-through-design (Godin & Zahedi, 2014). In this study, we report on the insights that we gained from these case studies, for which we used a grounded theory approach. Our inquiry focuses not so much on the technological environments, but on the insights gained while bringing the toolkits into practice. These insights may eventually be synthesized into a single, final toolkit that could ideally be used without the need of a design expert.

In this study, we focus on the following research question: *'Given the overall aim of increasing empowerment, how can DYL best support YAAs in designing experientially meaningful interactions?*' The remainder of this paper is structured as follows. First, we introduce DYL and grounded theory in more detail. Then, we describe our approach and discuss the challenges associated with data analysis and synthesis in the context of research-through-design. We end this paper with the findings of our analysis and our follow-up plans as premised on these findings.

2. Design Your Life

DYL starts from an individual's personal way of perceiving and experiencing the world and builds upon their autistic experience; not as a personal problem to be solved but as a creative starting point for ideation (Boldsen, 2018; De Jaegher, 2013; Waardenburg et al., 2021). This means that the YAA embarks on a creative 'quest' to discover what kind of technology can most fully assist them with their own support needs.

2.1 DYL partner & design researcher

The toolkit serves to guide the YAA in their creative quest, but they will also select a 'DYL partner'. This DYL partner may be whoever the YAA believes can support them best, be it a professional caregiver, friend, partner, or family member. By default, however, the DYL partner is the YAA's professional caregiver, as we ultimately seek to integrate the toolkit into the healthcare infrastructure. The DYL partner helps the YAA move through and reflect on the various stages and activities of the design process.

During nineteen months, ten design case studies were conducted by (industrial) design students, as well as one Ph.D. student. As 'design researchers', the students designed and evaluated various toolkits. Although interfering as little as possible, the design researcher was allowed to change the design toolkit along the way, creatively moving along with the demands of the specific case situation and the wishes and needs of the participants.

The case studies varied in overall set-up in several ways: YAA's age and living situation (e.g., at home or supported living), toolkit shape (e.g., physical card sets, mini-workshops, or a digital, interactive guide), and research theme (e.g., creativity, online collaboration or communication). The research topics were determined by the researchers in agreement with the students involved, based on their personal interests and skills and our needs for the research. Concerning case progression, there is not a strict hierarchy of importance or sequential chronology between the research themes. Rather, they can be considered as 'sensitizing concepts', kickstarting an open and initial phase of data collection into directions that were believed to be relevant to the research question (e.g., Bowen, 2006).

Table 1. An overview of DYL case studies, including profiles, duration, research questions, and characteristics of the developed toolkits. The names used in this table are pseudonyms.

Case Study	**Profile**	**Duration (months)**	**Research Question**	**Toolkit Characteristics**
Herman (Panfilova, 2021)	32 years old; Living on his own; DYL partner girlfriend.	3	What are the essential steps of the DYL-process that cannot be executed by YAAs and the design partner without the need for *guidance* from a designer?	Physical, card set
Renée (Wonink, 2021)	18 years old; Partly living at a mental healthcare organization, partly	8	How can the concept of *everyday design* help YAAs and their caregivers in selecting/adapting/creating	Physical, card set (Figure 1C)

	living at home; DYL partners: two professional caregivers.		personalized technologies that empower YAAs in their daily life?	
Anton (Martínez Gasca, 2021)	39 years old (outlier); Living on his own; DYL partner: design researcher.	8	How can design tools support reflection in and on action as part of the *embodied practices* of YAAs throughout the DYL-process?	Physical, box set (Figure 1B)
Simon (Overdevest, 2021)	26 years old; Living at mental healthcare organization; DYL partner: professional caregiver.	7	How do you support *communication* between an autistic and neurotypical participant during a co-design process, without the design researcher being present?	Physical, box set (Figure 1A)
Sky (Wetselaar, 2021)	17 years old; Living with parents; DYL partner: parents and professional caregiver.	3	How can *design thinking* help to empower a YAA during their daily life?	Physical, mini-workshops
Willem	18 years old; Living with his parents; DYL partner: design researcher.	5	How can a toolkit incorporate the YAA's *physical, social, and emotional environment* into the DYL-process?	Physical, mini-workshops
Multiple Participants (Wien, 2021)	25-32 years old; Living with parents and mental healthcare organization; DYL partner: parents and professional caregiver.	3	What set of aids can support the client and caregiver in *online collaboration*, for the development of the DYL-toolkit?	Physical-digital hybrid, step-by-step guide
Vincent (Sagel, 2020)	23 years old; Living at mental healthcare organization; DYL partner: professional caregiver.	3	How can a co-design toolkit promote *creativity* to enable YAAs and their caregivers to find or create a technology to promote the YAA's independence without the need for a design researcher?	Physical, board game (Figure 1D)
Paul (Schipper, 2020)	33 years old; Living at mental healthcare organization; DYL partner: professional caregiver.	3	How can a toolkit facilitate a co-design space for people with autism and their caregivers to improve their independence through *problem-finding and solving*, without the need for a design expert?	Physical, card set
Tim (Van den Berg, 2020)	14 years old; Living at home; DYL partner: parent.	3	How can a toolkit enable caregivers to support YAAs in creating a *personalized, technological home environment* that contributes to their independence?	Digital, interactive guide

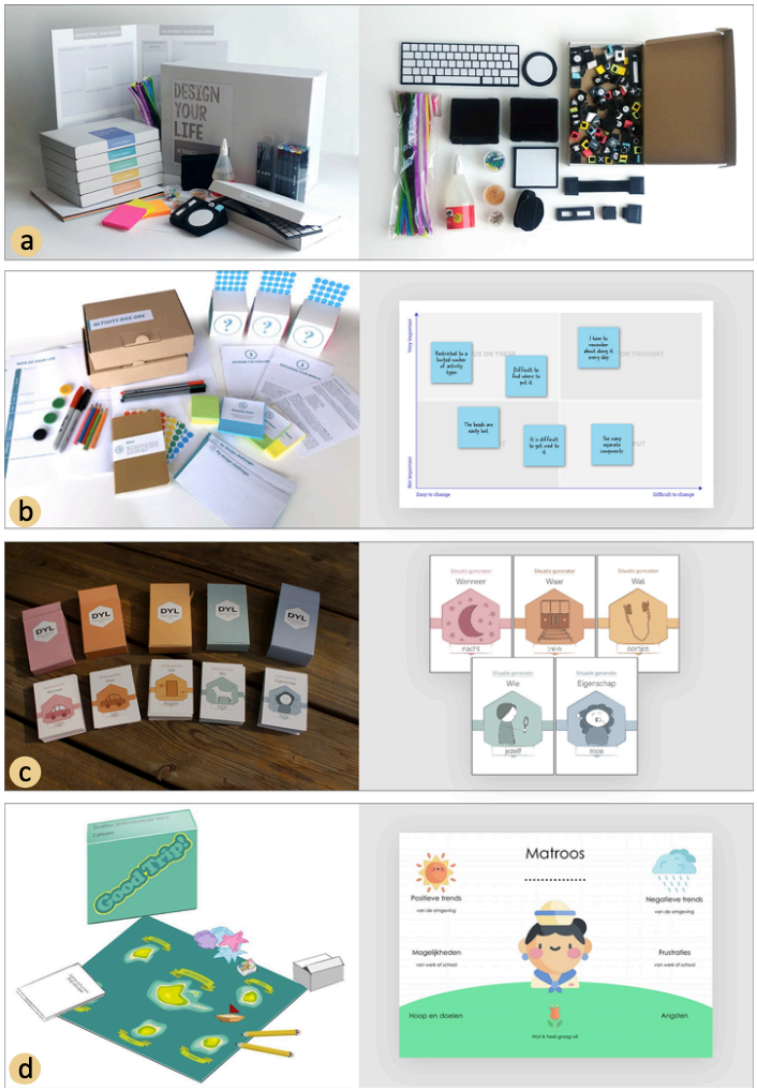

Figure 1. 1A-B: Box-based toolkits. Design activities are bundled in separate boxes for each design phase. 1C: Card-based toolkit. For different stages, the participants use specific card sets that support them in expressing their needs and wants and offer new ideas. 1D: Board game-based toolkit. Using a sea voyage metaphor, the participants use the board to track their progress in the design process and to record their activity outcomes.

2.2 Participant selection and ethical review

The cases were conducted in the Netherlands between July 2020 and October 2021 and had different durations. Throughout the design processes, participants communicated via videoconferencing, online chat platform Signal (www.signal.org), and physical visits whenever this was allowed amidst the COVID-pandemic. Participants were selected based on their autism diagnosis, aged between 14-40, and with an IQ>70. Eight of the participants were approached through a healthcare organization; the others were contacted through our personal social networks. The study was approved by an ethics committee and all YAAs voluntarily participated and agreed with written consent that the data generated could be used for publications.

2.3 Design process

As described earlier, the case studies varied in overall set-up in several ways. However, the cases all followed the same general design process (Figure 2) that we had established based on existing design processes:

- My Situation: The YAA works towards an initial understanding of their design context. What is the physical and social environment in which the AT will be used? In this phase, the YAA also chooses their DYL partner.
- My Focus: The YAA defines their design goal: which needs should be addressed, or which strengths should be supported, and for what purpose?
- My Ideas: The YAA contemplates what functionalities the AT should offer. To stimulate conceptual and creative thinking, they are offered brainstorming and tinkering tools, such as 'black boxes' and sketchbooks.
- My Thing: The YAA selects one design idea and starts to construct it. Ideally, the resultant prototype comes as close as possible to the AT that they envisioned in the previous design phase.
- My Test: The YAA tests the efficacy of the AT: is it doing what was expected or envisioned? The prototype gets tested in real-space and real-life.
- My Insight: The YAA explicitly evaluates what worked well with the prototype and what should be explored in follow-up design iterations.

The design process features an evolving process that we call My Way and My World. This is constantly refined in a reflection step that takes place after each design iteration. This means that the design process not only results in an AT, but also contributes to a deeper understanding of the YAA themselves: what characterizes the YAA's unique way-of-being, and what would be needed from a supportive, technological environment that fits well with this unique way-of-being?

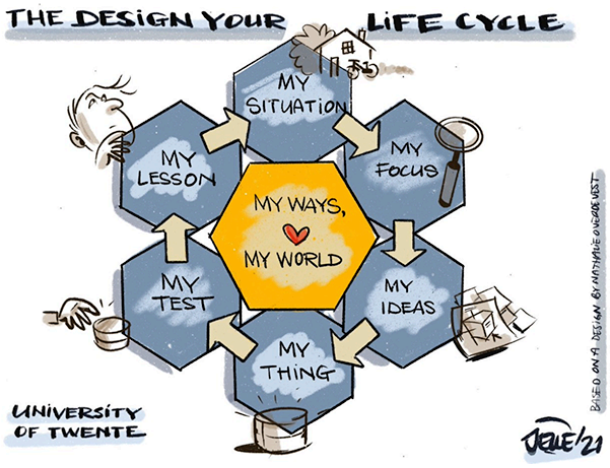

Figure 2. The Design Your Life process with six design phases centered around personal development CC NC-SA 4.0.

2.4 Data sources

During the entire process, data was collected on three different levels. Firstly, the design researchers would make a record of their reflections and participatory observations, notes on participants' comments during intermediate evaluations and workshops, the actual design results (such as sketches, mock-ups, and prototypes), and all results of the intermediate design activities (such as diary exercises, mind maps, and mood boards). Secondly, three multi-stakeholder meetings were organized in which experience experts, professional caregivers, innovation managers, and researchers collectively reflected on the data produced by the case studies. Due to COVID restrictions, these meetings were organized online using the creative collaboration tool Mural (www.mural.co). This resulted in visual summaries of the discussions. Lastly, we also organized weekly 'Lab-meetings', in which the involved design researchers would share and reflect on their insights. The minutes of these meetings were used as a third data source.

3. Grounded theory

We analyzed the data that all case studies produced. As mentioned, the goal is to synthesize all insights gained along the way into a single, final toolkit. This means two things. First, the data should lead to a toolkit that can be practically deployed in terms of design activities and instructions. Second, we construct a theory to support it. The rationale behind the toolkit should be clear; it should be a logical result of the data that have been produced in the case studies. Given the qualitative nature of this design research, we have chosen a grounded theory approach.

Grounded theory was proposed by Strauss and Glaser in 1967 (Glaser & Strauss, 1967). It aims to generate theory that is grounded in empirical data. Strauss and Corbin describe grounded theory as "theory that [is] derived from data, systematically gathered and analyzed through the research process" (Strauss & Corbin, 1998, p. 12). Similarly, Charmaz characterizes grounded theory as "a general set of methods that consist of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories 'grounded' in the data themselves" (Charmaz, 2006, p. 2). Grounded theory approaches the data with an 'open mind', which makes it especially useful for phenomena that have not yet been extensively studied (Chun Tie et al., 2019). As such, grounded theory is a bottom-up, inductive approach: theory should 'emerge' from the data through close, systematic, and comparative analysis. Ideally, no data is left unexamined either.

3.1 Methodology

Chun Tie, Birks & Francis (2019) describe five iterative, recursive phases of analysis for grounded theory. The first one is purposive sampling, which refers to the selection of participants and data sources that may answer the research question. This is followed by a phase of data generation. Once the data has been collected, the researchers start coding. This is defined as "an analytical process used to identify concepts, similarities and conceptual

recurrences in data" (idem, p. 4). The purpose of initial coding is to "start the process of fracturing and to look for similarities and differences in beginning patterns of data'' (ibid.). Once concepts begin to emerge from the data, they can be transformed into abstract categories. This is the goal of intermediate coding. Finally, advanced coding ensures that categories – as well as the relationships between them – are synthesized into a single, grounded theory.

Throughout the research process, the researchers make memos to ensure the quality of the analytical process. Memos are:

> "reflective interpretive pieces that build a historic audit trail to document ideas, events, and the thought processes inherent in the research process and developing thinking of the analyst. […]. Memos detail why and how decisions made relating to sampling, coding, collapsing of codes, separating codes, producing a category, and identifying relationships abstracted to a higher level of analysis" (ibid.).

3.2 Research-through-Design

DYL pertains to research-through-design, defined as "an approach to conducting scholarly research that employs the methods, practices, and processes of design practice with the intention of generating new knowledge" (Zimmerman & Forlizzi, 2014, p. 167). In other words, it is by 'doing' design that theoretical insights are gained, which in turn may contribute to a better design itself. Yet, research-through-design struggles to find a research method that accounts for how research and design are exactly constitutive of each other (Bardzell et al., 2016). Höök et al. write:

> "the early articulations of [research-through-design] did not specify how to articulate, validate, and constitute the knowledge gained through design research. […]. To an outsider, it might have looked like a string of designs, one after another, not generating any knowledge that built on prior insights" (Höök et al., 2015, p. 33, 34).

Although some efforts have been made (Alrutz et al., 2002; Dalsgaard et al., 2012; Friedman, 2002; Frauenberger et al., 2016; Markussen et al., 2012; Piper, 2016), design research is still in search of a method to document the interplay between research and design that can be shared for scrutiny by peers.

In this regard, Jonas claims that grounded theory will "probably contribute" (Jonas, 2007, p. 192). By now, grounded theory is widely used for data analysis in the social sciences, also in the context of autism (Colombo-Dougovito et al., 2021; Gentles et al., 2019; Williamson et al., 2012). Yet, its application in design research is relatively new. To our knowledge, only two papers make explicit use of it within the DRS community, for the analysis of text rather than actual artefacts (Fakhra & Gregory, 2010; Ülkebaş, 2014). This makes it relatively easy to engage in coding, as software programs such as MAXQDA (www.maxqda.com) and ATLAS.ti. (atlasti.cleverbridge.com) can automatically detect recurring phrases, themes, and concepts. In contrast, research-through-design deals with tangible artefacts, and it is unclear how to make sense of the knowledge embedded in them. Artefacts are not pieces of text; they are tangible and 'embody' knowledge rather than convey it (Dalsgaard & Dindler, 2014;

Höök & Löwgren, 2012; Stolterman, 2008). The ongoing challenge, therefore, is to access, understand and articulate the knowledge that is embodied by these tangible artefacts, and account for how this knowledge informs the design process in return (Feast, 2010). Although it would be beyond the scope of this paper to discuss this challenge in-depth, we will briefly return to this in the conclusion section. First, we describe how we applied grounded theory to our project.

4. Applying grounded theory to Design Your Life

For the data analysis, we were guided by the following research question: *'Given the overall aim of increasing empowerment, how can DYL best support YAAs in designing experientially meaningful interactions?'*

4.1 Data Boards

To structure the data, three physical data boards were created. A physical setting enables a smooth, interactive flow; hand gestures – such as pinpointing – make it easier and more intuitive to generate a shared understanding of the data. The first data board contained the data set from the ten design case studies (Figure 3A). Each case study is given its own horizontal row. Vertically, the data were structured as follows: research question (specific to the case study), case description, general approach, design outcomes, other results, conclusion, discussion, as well as each design phase that the toolkits cover, including 'My Situation', 'My Focus', 'My Ideas', 'My Thing', 'My Test' and 'My Insights'. The second data board contained all visual summaries of the multi-stakeholder meetings (Figure 4A) and the third data board contained the minutes of the Lab-meetings (Figure 5A). High-resolution photographs of the data boards can be accessed here: https://app.mural.co/t/dyl2140/m/dyl2140/1635868325636/bd2e944f2e57bb7bc0f942ae8a686643c2db7421?sender=uef6e324125cb36945f014923.

4.2 Coding

Coding proceeded in four steps, conducted by two Ph.D. students (NvH and TW) and one junior researcher involved in the project (NO). The coding process was largely in line with the process described by Chun Tie, Birks, and Francis (2019). For initial coding, yellow sticky notes were used to indicate differences and similarities between the data (Figure 3B, 4B, 5B). The analysts would study a part of the data and collaboratively discuss each other's insights. If necessary, sticky notes were changed, removed, or added. In-between initial and intermediate coding, we also introduced an additional coding step that is particularly relevant for design research. Namely, we reflected on what the observations entailed for practical design considerations. Using orange sticky notes, we noted down design decisions concerning the toolkit's aesthetics, functionalities, shape, and content, among others (Figure 3B, 4B, 5B). This coding step, which we call 'design coding', allowed us to return from abstract discussions to the actual toolkit design.

Intermediate coding proceeded online, digitalizing the yellow and orange sticky notes on Mural (Figure 3C, 4C, 5C). In contrast to the physical setting of initial coding, the digital platform of Mural allowed for archiving and rapid and structured clustering of sticky notes, which made it easier to connect data and find links between them. One by one, the analysts would suggest a category that they believed had emerged from the data, after which they would discuss and substantiate it by grouping sticky notes that supported the suggestion. Here, the same sticky notes could be used multiple times, for different categories. In total, ten categories were identified (Figure 6). For advanced coding, connections were made explicit, aiming to integrate the different categories into one coherent whole. Both initial and intermediate coding were video recorded and are available for review upon request.

Figure 3. The first data board contained the data set from the ten design case studies. 3A displays the data board before any coding. 3B displays the data board upon completion of initial coding. 3C displays the online data board, created using Mural.

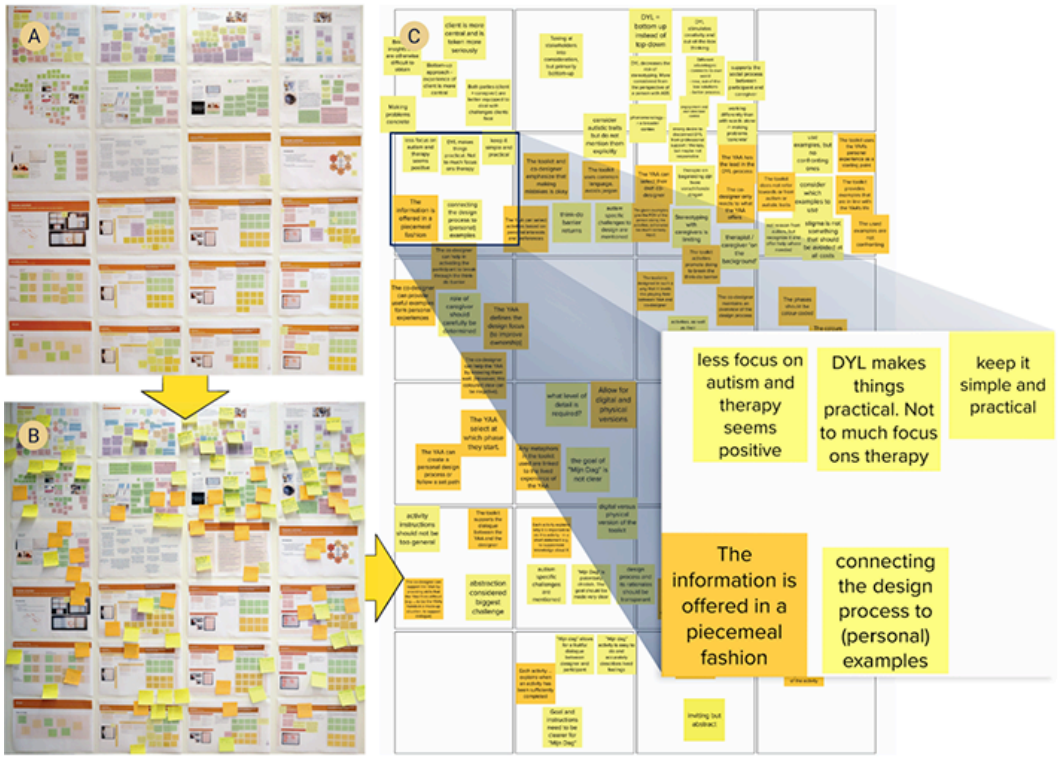

Figure 4. The second data board contained all visual summaries from the three multi-stakeholder meetings. 4A displays the data board before any coding. 4B displays the data board upon completion of initial coding. 4C displays the online data board, created using Mural.

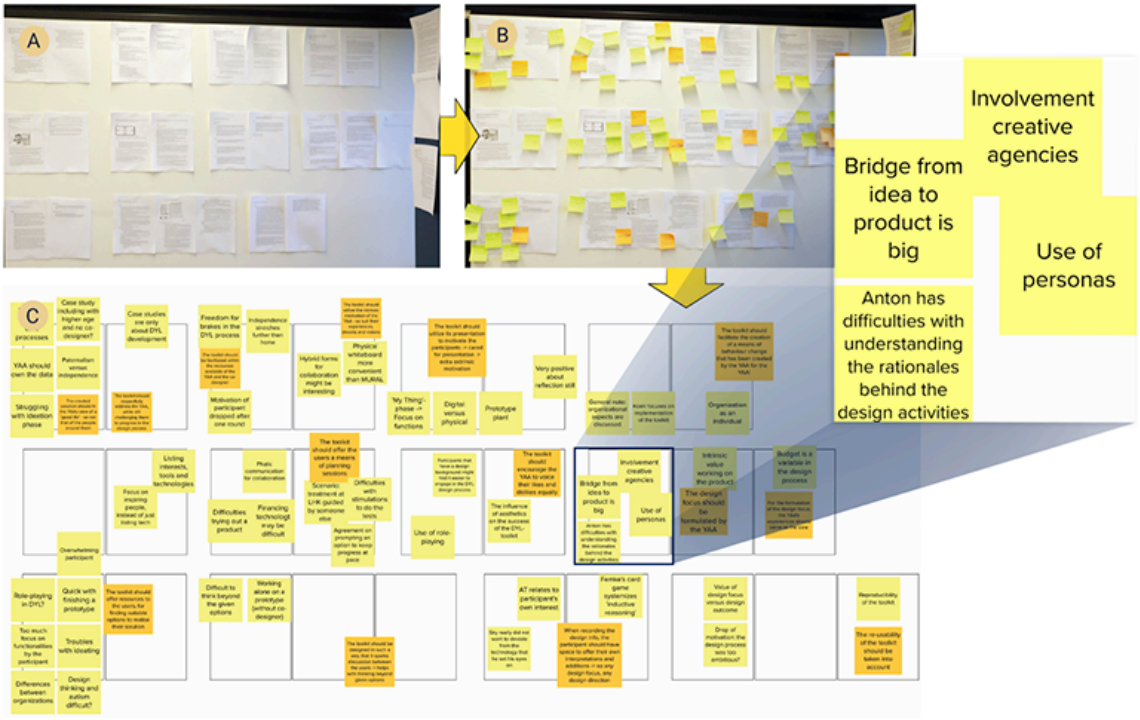

Figure 5. The third data board contained all minutes from weekly Lab-meetings. 5A displays the data board before any coding. 5B displays the data board upon completion of initial coding. 5C displays the online data board, created using Mural.

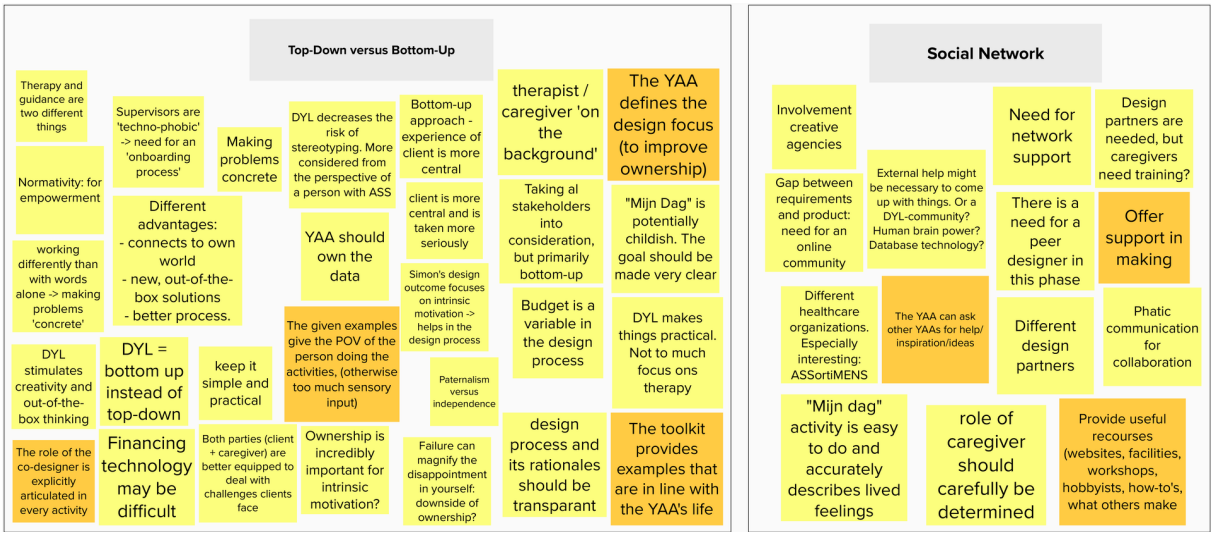

Figure 6. In the figure, it is shown for two examples of how intermediate coding led to the identification of ten overarching categories through the clustering of sticky notes.

5. Findings

The three analysts noted down 347 observations: 242 of them on yellow sticky notes (noted by NvH and TW) and 105 of them on orange sticky notes (noted by NO). This led to the identification of ten categories, for which a summary is given in Table 2.

Table 2. A summary of the ten categories that were obtained through intermediate coding, created using Mural. The dotted lines indicate the connections and interdependencies between the categories.

Design Considerations		Autism	Challenges
Flexibility and Personalization	**Expressive Medium**	**Autism Specificness**	**Envisioning**
YAAs should be able to select their own design activities; go through the process linearly or iteratively; choose in which design phase they would like to start.	The toolkit should come in both physical and digital shape, depending on one's preferences	The toolkit must accommodate autistic users, thereby also taking into account autistic information processing needs.	Abstract and open-ended design activities might be particularly challenging for YAAs. These activities should come with concrete instructions accompanied by relatable examples.
Social Context		**Methodology**	
Top-Down versus Bottom-Up	**Social Network**	**Heterogeneity**	**Reflecting**
The bottom-up approach of the design process puts the 'client' and their experience centre stage. The YAA should be in charge of their design process; the caregiver has a supporting role.	Instead of integrating the toolkit only in formal therapy or training, there is a demand for a social network in which users can brainstorm with each other on their design process.	The participant pool in general has been limited. In future case studies, the participant pool must be expanded to consider different manifestations of autism as well as different care contexts.	Similar to envisioning, reflecting calls on the ability to make inferences. This is difficult in general, but may be particularly challenging for YAAs. Clear instructions and examples can help to systemise the reflection-process.
Inner versus Outer Focus		**Goal Setting / Validation**	
A distinction exists between those design activities that aim to bring about a practical change in one's environment, and those that also try to establish a behavioural or emotional change.		The toolkit lacks a uniform method to validate the psychological effects of the toolkit; focusing on the empowering experiences that the process towards it may have produced.	

5.1 DYL grounded theory

The observation that sparked the most discussion among the analysts will be discussed first: **autism-specificness**. We noticed that most designer researchers tried to develop a toolkit that was not specifically designed for YAAs, likely out of fear of stigmatizing the user and reducing them to a set of stereotypical beliefs on what autistic people can and cannot do. At the same time, we observed that there were several design activities that the YAAs struggled with, possibly exacerbated by their autism. For example, numerous design activities - such as the 'black box' and 'evaluation matrix' - called upon the users' ability to **reflect** on and **envision** future situations. In general, we find that non-trained designers might struggle with such an activity, but it can become even more challenging for autistic users if that activity is abstract and open-ended. For example, on one occasion, Willem was asked to search the internet for technologies that resembled the idea that he had in mind for his own design process. For Willem, this proved to be a challenging task:

> "Well, since it is just an idea, and not yet a solid… we do not know yet what it will become. So, trying to find links and products online makes no sense; you keep searching outside the boundaries, because you don't have… well, you don't have any boundaries".

In this regard, clear and specific instructions on how to reflect on design possibilities, accompanied by rich and concrete examples, can help both YAAs and their design partners to access their creative abilities.

Secondly, one of the most apparent observations that emerged from the data is that the toolkit should offer more **flexibility** in terms of **personalization**. In several cases, some participants seemed unmotivated to continue, either because the predetermined design activities did not match their interests or because the standard steps interfered with the design process that they had in mind. Both were the case for Anton, who explained that he was "less writy-downy and more thinky-thinky". As Anton already had an idea for a prototype, he preferred to skip the context-mapping exercises of the 'My Situation' and 'My Focus'-phase and start prototyping right away, writing almost nothing down. Therefore, the toolkit should allow YAAs to select their own design activities - based on their interests and preferences - and allow them to go through the design process in a way that seems appropriate to them. Here, an additional 'roadmap'-activity at the start of the process could help the YAA and their DYL partner outline their future design process based on short and structured descriptions of all activities offered in each phase.

Flexibility is also required concerning the **medium** in which users can **express** themselves. For example, Sky claimed that he was not "a very good drawer", on one occasion presenting the results of his design activity on his computer using a plain-text editor Markdown (www.markdownguide.org). For this, the toolkit should allow the users to express themselves on either a physical or digital platform, depending on the users' preferences.

Furthermore, we observed a distinction between those design activities that aim to bring about a practical change in one's environment, and those that also try to establish a

behavioral or emotional change: **outer versus inner focus**. We noticed that the latter focus had been underrepresented in evaluation activities. That is: most evaluation activities focus on the end product in terms of functionality and usability rather than on the extent to which the process towards it has contributed to, among others, the YAA's level of self-confidence – which was the objective for Simon – or their experience of social independence – which was the objective for Anton. Here, a connection to psychology needs to be made, to develop a uniform method of **validation** (e.g., Boevink et al., 2017)

In all three data boards, experience experts and caregivers alike praised the **bottom-up** approach of the design process: making problems concrete, putting the 'client' and their experience center-stage, and giving the professional caregiver themself a more supporting role. In practice, some YAAs took this opportunity to 'break free' from formal therapy and training, choosing a DYL partner that was not their professional caregiver (e.g., Herman & Sky) or even doing it without a DYL partner (Anton). Instead of only integrating the toolkit into formal care structures, we envision that there should also be a **social network** in which autistic users can brainstorm with each other on how their design process should proceed. In those case studies that do involve a professional caregiver, a general introduction to 'design thinking' could help caregivers understand how their expertise could be of value in the practical design process.

Lastly, we realize that our participant pool in general has been limited, working with YAAs that were motivated and able to participate in design research. We acknowledge that our participant pool does not fully represent the **heterogeneity** existing within autism – its different manifestations and care contexts – and that it therefore cannot be guaranteed that the toolkit is usable by all YAAs within our target group. In future case studies, we expand the participant pool and consider how this feeds back into the toolkit design.

6. Conclusion

We reported on the insights that we gained from ten design case studies, for which we used grounded theory, focusing on the following research question: *'Given the overall aim of increasing empowerment, how can DYL best support YAAs in designing experientially meaningful interactions?'* The answer to this question is given in the form of ten categories that will guide the development of the final toolkit. Among others, we discovered that abstract and open-ended design activities should be better adapted to autistic information processing needs. In addition, we observed that some YAAs use the toolkit to 'break free' from formal therapy and training, which prompts us to reconsider the role of the professional caregiver as the primary DYL partner.

In line with research-through-design, we use these insights to create a single, final toolkit that is currently in production at the time of writing. Furthermore, we have initiated three more cases studies, focusing on the development of a digital version of the toolkit, concretizing design activities that ask for reflection and envisioning as well as the development of an online 'DYL-community' in which users can help each other go through

the design process. Moreover, we will continue refining the DYL Grounded Theory. The connections and interdependencies indicated in Table 2 need to be spelled out, possibly identifying one core category through which the others can be explained.

Overall, we experienced grounded theory as a useful tool to analyze and synthesize the data from ten design case studies, focusing less on textual data and more on physical artefacts. Through systematic and comparative analysis, grounded theory proved fruitful in bringing to the surface the tacit knowledge embodied by these artefacts, allowing the analysts to discuss and make sense of them together. This makes it important that the analytical process is well-recorded. As underlined, research-through-design deals with physical artefacts and it is difficult to imagine how the tacit, embodied knowledge might have been understood by design researchers who were not involved in DYL, let alone by researchers from other disciplines. Therefore, it seems unlikely that the data analysis is logically reproducible by other researchers that are not familiar with the stories behind these artefacts. Nevertheless, grounded theory can help to make both the analysis and synthesis traceable for scrutiny.

Acknowledgements: We would like to thank all participants and organizations involved in this projects, as well as the students that carried out case studies with their respective toolkits: Laura van den Berg, Brian Schipper, Jasmijn Sagel, Denise Wien, Belle Wetselaar, Omar Martinez Gasca, Femke Wonink and Arthur Panfilova. This research is funded by the Dutch Research Council (NWO) (Aut.19.007) and the Dutch Taskforce for Applied Research SIA (RAAK.PRO.03.045).

7. References

Agre, P. E. (1994). From high tech to human tech: Empowerment, measurement, and social studies of computing. *Computer Supported Cooperative Work (CSCW), 3*(2), 167–195. https://doi.org/10.1007/BF00773446

Alrutz, M., Singer, B., & Wahlig, T. (2002). Developing a method to support human centered designers in forming arguments: Intertwining practice and theory, in Durling, D. and Shackleton, J. (eds.), *Common Ground - DRS International Conference 2002,* 5-7 September, London, United Kingdom. https://dl.designresearchsociety.org/drs-conference-papers/drs2002/researchpapers/5

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed). American Psychiatric Publishing.

Bardzell, J., Bardzell, S., Dalsgaard, P., Gross, S., & Halskov, K. (2016). Documenting the Research Through Design Process. *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*, Brisbane, 4-8 June, 96–107. https://doi.org/10.1145/2901790.2901859

Boevink, W., Kroon, H., Delespaul, P., & Os, J. V. (2017). Empowerment according to Persons with Severe Mental Illness: Development of the Netherlands Empowerment List and Its Psychometric Properties. *Open Journal of Psychiatry, 7*(1), 18–30. https://doi.org/10.4236/ojpsych.2017.71002

Boldsen, S. (2018). Toward a Phenomenological Account of Embodied Subjectivity in Autism. *Culture, Medicine and Psychiatry, 42*(4), 893–913. https://doi.org/10.1007/s11013-018-9590-y

Bowen, G. A. (2006). Grounded Theory and Sensitizing Concepts. *International Journal of Qualitative Methods, 5*(3), 12–23. https://doi.org/10.1177/160940690600500304

Brosnan, M., Good, J., Parsons, S., & Yuill, N. (2019). Look up! Digital technologies for autistic people to support interaction and embodiment in the real world. *Research in Autism Spectrum Disorders, 58*, 52–53. https://doi.org/10.1016/j.rasd.2018.11.010

Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. SAGE.

Chun Tie, Y., Birks, M., & Francis, K. (2019). Grounded theory research: A design framework for novice researchers. *SAGE Open Medicine, 7*. https://doi.org/10.1177/2050312118822927

Colombo-Dougovito, A. M., Blagrave, A. J., & Healy, S. (2021). A grounded theory of adoption and maintenance of physical activity among autistic adults. *Autism, 25*(3), 627–641. https://doi.org/10.1177/1362361320932444

Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2019). 'Something needs to change': Mental health experiences of young autistic adults in England. *Autism, 23*(2), 477–493. https://doi.org/10.1177/1362361318757048

Dalsgaard, P., & Dindler, C. (2014). Between theory and practice: Bridging concepts in HCI research. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, Toronto, 26 April - 1 May, 1635–1644. https://doi.org/10.1145/2556288.2557342

Dalsgaard, P., Halskov, K., Profile, S., Dalsgaard, P., & Halskov, K. (2012). Reflective design documentation. *Proceedings of the Designing Interactive Systems Conference*, Newcastle, 11-15 June, 428–437. https://doi.org/10.1145/2317956.2318020

De Jaegher, H. (2013). Embodiment and sense-making in autism. *Frontiers in Integrative Neuroscience, 7*. https://doi.org/10.3389/fnint.2013.00015

Ehn, P. (2008). Participation in design things. *Proceedings of the Tenth Anniversary Conference on Participatory Design*, Bloomington, 1-4 October, 92–101.

Fabri, M., Andrews, P. C. S., & Pukki, H. K. (2016). Using design thinking to engage autistic students in participatory design of an online toolkit to help with transition into higher education. *Journal of Assistive Technologies, 10*(2), 102–114. https://doi.org/10.1108/JAT-02-2016-0008

Fakhra, A., & Gregory, J. (2010). Influential Elements of Creativity in Art, Architecture, and Design Creative Processes: A Grounded Theory Analysis, in Durling D., Bousbaci, R. Chen, L. Gauthier, P. Poldma, T. Roworth-Stokes, S. and Stolterman, E (eds.), *Design and Complexity - DRS International Conference 2010,* Montreal, 7-9 July. https://dl.designresearchsociety.org/drs-conference-papers/drs2010/researchpapers/39

Feast, L. (2010). Epistemological Positions Informing Theories of Design Research: Implications for the Design Discipline and Design Practice, in Durling, D., Bousbaci, R., Chen, L, Gauthier, P., Poldma, T., Roworth-Stokes, S. and Stolterman, E (eds.), *Design and Complexity - DRS International Conference 2010,* Montreal, 7-9 July. https://dl.designresearchsociety.org/drs-conference-papers/drs2010/researchpapers/40

Frauenberger, C., Good, J., & Keay-Bright, W. (2011). Designing technology for children with special needs: Bridging perspectives through participatory design. *CoDesign, 7*(1), 1–28. https://doi.org/10.1080/15710882.2011.587013

Frauenberger, C., Makhaeva, J., & Spiel, K. (2016). Designing Smart Objects with Autistic Children: Four Design Exposès. *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, New York, 7-12 May, 130–139. https://doi.org/10.1145/2858036.2858050

Frauenberger, C., Makhaeva, J., & Spiel, K. (2017). Blending Methods: Developing Participatory Design Sessions for Autistic Children. Proceedings of the 2017 Conference on Interaction Design and Children, Stanford, 27-30 June, 39–49. https://doi.org/10.1145/3078072.3079727

Friedman, K. (2002). Theory construction in design research. Criteria, approaches, and methods. DRS Biennial Conference Series, in Durling, D. and Shackleton, J. (eds.), *Common Ground - DRS International Conference*, London, 5-7 September. https://dl.designresearchsociety.org/drs-conference-papers/drs2002/researchpapers/28

Gentles, S. J., Nicholas, D. B., Jack, S. M., McKibbon, K. A., & Szatmari, P. (2019). Parent engagement in autism-related care: A qualitative grounded theory study. *Health Psychology and Behavioral Medicine, 7*(1), 1–18. https://doi.org/10.1080/21642850.2018.1556666

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Aldine.

Godin, D., & Zahedi, M. (2014). Aspects of Research through Design: A Literature Review. DRS Biennial Conference Series, in Lim, Y., Niedderer, K., Redström, J., Stolterman, E. and Valtonen, A. (eds.), *Design's Big Debates - DRS International Conference*, Umeå, 16-19 June https://dl.designresearchsociety.org/drs-conference-papers/drs2014/researchpapers/85

Grynszpan, O., Weiss, P. L. (Tamar), Perez-Diaz, F., & Gal, E. (2014). Innovative technology-based interventions for autism spectrum disorders: A meta-analysis. *Autism, 18*(4), 346–361. https://doi.org/10.1177/1362361313476767

Höök, K., Bardzell, J., Bowen, S., Dalsgaard, P., Reeves, S., & Waern, A. (2015). Framing IxD knowledge. *Interactions, 22*(6), 32–36. https://doi.org/10.1145/2824892

Höök, K., & Löwgren, J. (2012). Strong concepts: Intermediate-level knowledge in interaction design research. *ACM Transactions on Computer-Human Interaction, 19*(3), 23:1-23:18. https://doi.org/10.1145/2362364.2362371

Idring, S., Rai, D., Dal, H., Dalman, C., Sturm, H., Zander, E., Lee, B. K., Serlachius, E., & Magnusson, C. (2012). Autism Spectrum Disorders in the Stockholm Youth Cohort: Design, Prevalence and Validity. *PLoS ONE, 7*(7), e41280. https://doi.org/10.1371/journal.pone.0041280

Jonas, W. (2007). Design Research and its Meaning to the Methodological Development of the Discipline, in R. Michel (Ed.), *Design Research Now: Essays and Selected Projects*, 187–206. Birkhäuser. https://doi.org/10.1007/978-3-7643-8472-2_11

Markussen, T., Bang, A. L., Pedersen, P., & Knutz, E. (2012). Dynamic Research Sketching – A new explanatory tool for understanding theory construction in design research, in Israsena, P. Tangsantikul, J. and Durling, D. (eds.), *Research: Uncertainty Contradiction Value - DRS International Conference*, Bangkok, 1-4 July. https://dl.designresearchsociety.org/drs-conference-papers/drs2012/researchpapers/83

Martínez Gasca, O. (2021). Inside my head: Exploring how design tools for reflection become part of the lived experience of an autistic adult [Unpublished Master's Thesis, University of Twente].

Motti, V. G. (2019). Designing emerging technologies for and with neurodiverse users. Proceedings of the 37th ACM International Conference on the Design of Communication, Portland, 4-6 October, 1–10. https://doi.org/10.1145/3328020.3353946

Overdevest, N. (2021). Designing a toolkit to empower young autistic adults to create personal products that promote independence [Unpublished Master's Thesis, University of Twente].

Panfilova, A. (2021). Redesign of a toolkit aimed to increase the independence of young autistic adults [Bachelor's Thesis, University of Twente]. http://purl.utwente.nl/essays/88937

Piper, A. (2016). Code, Decode, Recode: Constructing, deconstructing and reconstructing knowledge through making in Lloyd, P. and Bohemia, E. (eds.), *Future Focused Thinking - DRS International Conference*, Brighton, 27-30 June. https://dl.designresearchsociety.org/drs-conference-papers/drs2016/researchpapers/186

Sagel, J. (2020). Designing 'Good Trip!': A co-design toolkit for young autistic adults and their carers to promote independence [Bachelor's Thesis, University of Twente]. http://purl.utwente.nl/essays/85588

Scheeren, A. M., & Geurts, H. M. (2015). Research on community integration in autism spectrum disorder: Recommendations from research on psychosis. *Research in Autism Spectrum Disorders, 17*, 1–12. https://doi.org/10.1016/j.rasd.2015.05.001

Schipper, B. (2020). Design of a co-design toolkit for young adults with autism spectrum disorder to support their independence [Bachelor's Thesis, University of Twente]. http://purl.utwente.nl/essays/85966

Stolterman, E. (2008). The Nature of Design Practice and Implications for Interaction Design Research. *International Journal of Design, 2*(1). 55-65.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). SAGE.

Ülkebaş, S. D. (2014). The Use of Grounded Theory in User Experience Based Design Research: A Study on 'Automobile Modification' in Turkey, in Lim, Y., Niedderer, K., Redström, J., Stolterman, E. and Valtonen, A. (eds.), *Design's Big Debates - DRS International Conference DRS Biennial Conference Series*, Umeå, 16-19 June. https://dl.designresearchsociety.org/drs-conference-papers/drs2014/researchpapers/58

Van den Berg, L. (2020). Designing a toolkit that supports autistic young adults in creating a personalized contribution to their independence [Bachelor's Thesis, University of Twente]. http://purl.utwente.nl/essays/84061

Waardenburg, T., van Huizen, N., van Dijk, J., Magnée, M., Staal, W., Teunisse, J.-P., & van der Voort, M. (2021). Design Your Life: User-Initiated Design of Technology to Support Independent Living of Young Autistic Adults, in M. M. Soares, E. Rosenzweig, & A. Marcus (Eds.), *Design, User Experience, and Usability: Design for Diversity, Well-being, and Social Development, 12780*, 373–386. Springer. https://doi.org/10.1007/978-3-030-78224-5_26

Wetselaar, B. (2021). Empowering a Young Autistic Adult by using goal-based design thinking. University of Twente. http://purl.utwente.nl/essays/87640

Wien, D. (2021). Design Your Life: Afstudeerverslag [Graduation Report] [Bachelor's Thesis, HAN University of Applied Sciences].

Williamson, P., Carnahan, C. R., & Jacobs, J. A. (2012). Reading Comprehension Profiles of High-Functioning Students on the Autism Spectrum: A Grounded Theory. *Exceptional Children, 78*(4), 449–469. https://doi.org/10.1177/001440291207800404

Wonink, F. (2021). To be and to become an everyday designer [Unpublished Master's Thesis, University of Twente].

Zervogianni, V., Fletcher-Watson, S., Herrera, G., Goodwin, M., Pérez-Fuster, P., Brosnan, M., & Grynszpan, O. (2020). A framework of evidence-based practice for digital support, co-developed with and for the autism community. *Autism, 24*(6), 1411–1422. https://doi.org/10.1177/1362361319898331

Zimmerman, J., & Forlizzi, J. (2014). Research Through Design in HCI, in J. S. Olson & W. A. Kellogg (Eds.), *Ways of Knowing in HCI*, San Jose, 28 April - 3 May, 167–189. Springer. https://doi.org/10.1007/978-1-4939-0378-8_8

About the Authors:

Niels van Huizen is doctoral researcher at the University of Twente. His research interest lies in the development of assistive technologies that connect well to the way autistic individuals make sense of the world.

Thijs Waardenburg is doctoral researcher at the HAN University of Applied Sciences. He is committed to making design thinking an integral part of professional care for young autistic adults.

Nathalie Overdevest is junior researcher at the University of Twente. Her research interests lie in the development and implementation of co-design toolkits for specific users.

Jelle van Dijk is assistant professor of Embodied Interaction at the University of Twente. He works on the research and design of empowering technologies for autistic individuals.

Wouter Staal is full professor in Child- and adolescent psychiatry, RadboudUMC Nijmegen and professor by special appointment of Autism Spectrum Disorders at the University of Leiden. His research interests lie in the neurobiology and neurocognition of autism.

Mascha van der Voort is full professor Human Centred Design at the University of Twente. Her research focuses on design approaches and tools that enable all types of stakeholders to actively engage and participate in collaboratively exploring and defining potential futures.