



**DESIGNING A TOOLKIT TO EMPOWER
YOUNG AUTISTIC ADULTS
TO CREATE PERSONAL PRODUCTS
THAT PROMOTE INDEPENDENCE**

A CASE STUDY

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University of Twente and
HAN University of Applied Sciences.
Visit dyl.utwente.nl for more information.

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Reading guide

This thesis is setup in sections to create an overview of the theoretical framework, the different design iterations and the conclusion. The sections are the following:

Introduction

Outlines the Design Your Life project, the target group, and the design case. The research questions are presented here.

Section 1: Theoretical framework

Offers the theoretical framework on which the design iterations are based. Several of the research questions can be informed or even answered using this theoretical framework.

Section 2: Iteration 1: designing the first design round in the toolkit

This first iteration focusses on designing activities that the participants use at the start of their design process.

Section 3: Iteration 2: designing the roadmap

This iteration focusses on the addition of a planning tool to the design activity.

Section 4: Iteration 3: designing the paper prototype kit

This iteration produced an activity that was used in supplement to activities offered in the first design round of the toolkit.

Section 5: Iteration 4: designing the second design round in the toolkit

The final iteration focusses on creating the second design round in the toolkit.

Conclusion

Summarises all the answers to the research questions.

Discussion

Explores different directions of development possible for the Design Your Life toolkit.

List of abbreviations and definitions

Phrase	First use (page #)	Meaning
YAA	12	Young autistic adult. In this thesis the preference is given to use identity first, in line with the DYL research guidelines.
Caregiver	12	In the theoretical outline: person who provides support to the YAA. This can be informal, e.g. a parent or guardian, or professional care, e.g. daily living support or a therapist. In the case study, the phrase is used to describe the person working with the YAA in the co-design process, in this case a professional caregiver.
ASD	13	Autism Spectrum Disorder, the clinical name for autism as described in the DSM-5 (American Psychiatric Association, 2013)
Autistic person	13	Phrase to describe someone who has had a brain development that complies with the description of ASD in the DSM-5 (American Psychiatric Association, 2013).
Neurotypical person	13	Phrase to describe a person who has had typical brain development.
Actor	14	Participant in an interaction. For clarity, this thesis only uses "actor" to indicate human interactors.
Participant	14	Person who partakes in a co-design session, or in the context of the case: the YAA and their professional caregiver
DYL	15	"Design Your Life", the name of the research of which the described case is part of.
Designer/researcher	18	Person who organises the co-design session with as goal gaining insight or inspiration out of the results produced by the participant. In the context of the case: the author.
Iteration	20	Used to describe the iterative design cycle of designing the DYL toolkit used in this case
Design round	20	Used to describe the iterative design cycle that the participants go through using the DYL toolkit.
NAR	28	Abbreviation for "Nederlands Autisme Register" or Dutch Autism Registry

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Summary

How do you create tools that empower young autistic adults (YAAs for short) to create personal solutions by themselves, which contribute to their independence? That is the central question in the Design Your Life project. The toolkit is used in different case studies by the YAA and people close to them to go through a design process. This thesis explores one case study within this project, where the toolkit is set up in such a way that the toolkit itself functions as the design facilitator – as opposed to having a human design facilitator present.

Additionally, the following question was researched: How do you support communication between an autistic and neurotypical participant during a co-design process, without the designer/researcher being present? For the communication process, the embodied enactive approach as described by De Jaegher (2013) is taken as a basis. The toolkit is created using a theoretical framework incorporating the embodied enactive approach, as well as theories on co-design, communication in co-design and co-design with people with autism. Then the toolkit was tested in a case study with one YAA and their caregiver.

The communication between the YAA and the caregiver was supported using different strategies. The first strategy was through accommodating the needs of the YAA in communication and in co-design settings. A second strategy was through assigning roles to the YAA and the caregiver in the toolkit: the YAA was given the role of main designer, the caregiver that of co-designer. Finally, different activities were aimed at letting the participants get to know each other in a new way.

The relationship between the YAA and the caregiver was enriched through the toolkit activities. The different design activities aimed at getting to know each other better had this effect. The design goal allowed the caregiver to get to know a new side of the YAA.

In this particular case study, the design goal played an important role, as it changed dramatically during the course of the case study. The new design goal placed the participants in different roles in comparison to their roles in relation to the old design goal. The old goal was already interfered in by the caregiver and the YAA's mother, projecting their opinion on the goal. However, the YAA had his own way to going about achieving his goal, creating a design impasse. The new design goal was very personal to the YAA and also in a whole new domain. Because the caregiver is not familiar with that domain, she was able to become an unbiased inquisitive co-designer. This gave the YAA much more ownership over the design goal and possible design outcomes.

Though the toolkit was developed to be used by itself, the participants preferred the presence of the designer/researcher, as she guided the participants through the activities by offering more extensive design knowledge than was present in the toolkit. The designer/researcher helped the participants make confident design decisions and enrich the activity output, in addition to helping them realise the prototype, that being creating a summary of Simon's world and contacting a mentor to teach Simon how to use Unreal Engine.

The toolkit can be improved by further accommodating the YAA, e.g. by offering more options for personalisation in the offered activities. The support in the design domain can be enriched with explanations on how one activity output supports the input for another activity, as well as explaining the design rationale.

INTRODUCTION

This master assignment is part of the Design Your Life project and covers a case study within this project. The aim of this project is to create a toolkit that empowers young autistic adults (henceforth referred to as YAA) to create products that promote their independence. The YAA will not use the toolkit on their own, but with a caregiver. The toolkit will guide the YAA and their caregiver through a co-design process, resulting in a self-designed product that the YAA will use to become more independent. However, creating such a toolkit requires a better understanding of being a young autistic adult, communication between an autistic and a neurotypical person, and co-design. Before presenting the research questions, I will introduce you to these topics.

Autism

To understand the autistic experience, it is natural to start with the description of autism spectrum disorder (ASD). According to the DSM-5 (American Psychiatric Association, 2013), ASD can be described using two criteria: 1) issues in the social domain, meaning difficulty in understanding and reciprocating social interaction, and developing and maintaining relationships; and 2) having specific interests and/or showing repetitive or restricted behaviour, including inflexibility to change, stimming (self-soothing) behaviour and being hyper- or hyposensitive to certain sensory stimuli. These difficulties are visible in an uneven profile of abilities, such as a lower level of motor skills, like clumsiness (American Psychiatric Association, 2013; Fletcher-Watson & Happé, 2019). Autism can be present regardless of cognitive capabilities, but is always present from childhood. Autism is persistent through life and affects almost all areas of life (Fletcher-Watson & Happé, 2019, chapter 1; GGZ, 2017). This clinical definition already shows one of the fundamental insights in autism: the broad definitions in autism show a myriad of ways in which autism can be present in a person – ASD is characterised by heterogeneity (American Psychiatric Association, 2013; Fletcher-Watson & Happé, 2019; Kanner, 1943).

However, this clinical explanation does not do justice to the lived in experience of an autistic person, or more specifically: a young autistic adult. For this, we need to start with how a YAA experiences the world and what being an YAA is like.

Being a young autistic adult

Being a YAA in this case study is being defined as being between the ages of 16 and 35, with an ASD diagnosis and without cognitive or speech impairments. This age range is deliberately large since there are individual differences in the development of autistic people (GGZ, 2017, who use an age range of 12-30 to account for adolescents and young adults). This age group goes through many large developments during this time: puberty and a first romantic interest, but also changes that require increasing levels of self-management and independence, such as completing an education, starting a job and moving out.

These changes can stretch the coping strategies of the YAA to the limits of their effectiveness. The stress created by these increasing demands can feed into a feeling of loneliness, while autism already shows a high level of co-morbidity with mental health issues, such as anxiety and depression (American Psychiatric Association, 2013; Fletcher-Watson & Happé, 2019; van Wijngaarden et al., 2020). Hormonal changes in puberty can influence the occurrence of violence or self-harm in the YAA (Fletcher-Watson & Happé, 2019, chapter 7; GGZ, 2017).

Due to the individual pattern of development, the YAA might reach the milestones of graduation, starting a job and moving out at a later age than a neurotypical peer. This can cause stress not only in the YAA, but also in their family. And even after they achieve these milestones, the YAA is likely to continue to need support, causing the parents to worry about the YAA's future. (Fletcher-Watson & Happé, 2019, chapter 7)

Autistic people are well aware of their family's opinion of them, regardless of that view being negative (Heasman & Gillespie, 2018). They are generally also able to see the issues that arise from their autistic traits, especially in perspective taking (ibid). However, making themselves "readable" to others can be difficult, even with people who know them as well as family members (ibid). The neurotypical family member might not work past a misunderstanding, because they have a negative perception on the autistic person's ability of perspective taking – to such an extent that it can function as a confirmation bias and having more nuanced behaviour from the autistic person being overlooked (ibid). Additionally, the autistic person's narrow interests, way of perceiving the world and ways of communication are likely to put a strain on the autistic person's daily relationships: there are many situation where the autistic person's behaviour can't or won't be accommodated (De Jaegher, 2013). All of these factors can create the situation where there is a gap between what the family member thinks the autistic person is able of, what the autistic person sees themselves as capable of, and what the autistic person is actually capable of.

• ——— "Neurotypical" refers to a brain development that is according to the norm.

Communication

This expectation gap originates in part from communication. To understand the communication between two social actors, I will use the enactive approach as described by De Jaegher (2013). This approach looks at the actors and the environment that they act in as a whole. To establish communication, the actors look for common ground (ibid). To achieve common ground, the actors coordinate their information, language, intonation, body language, gestures, facial expressions and (elements in) the environment with each other (ibid). Even after establishing common ground, it is likely one or both actors have trouble following the communicative information that the other is offering: the communication between the actors breaks down as a result. By means of repair the actors regain common ground, for instance through asking a question (Fusaroli et al., 2017).

The autistic-neurotypical communication divide

Autistic people communicate in their own way, which starts with how they process sensory stimuli. Their brain has the preference to look for details instead of a coherent “bigger picture”, and autistic people can be under or overstimulated by certain sensory stimuli (Fletcher-Watson & Happé, 2019, chapter 8). The preference for less coherence results in a slower processing rate of all the signals present in communication (Di Paolo et al., 2018, chapter 10). This means that the autistic person does perceive all the signals that their interaction partner presents, but can only confidently respond based on a part of those signals (ibid).

Autistic people can use a range of strategies to keep up with social interactions, such as stimming (self-stimulatory behaviour, e.g. flapping one’s hands) to slow the world down, and focussing on information that they are sure of (Di Paolo et al., 2018, chapter 10). However, when expressing themselves, autistic people can have issues to properly integrate verbal communication and body language with each other (American Psychiatric Association, 2013).

Autistic communication signals are not always read as such by neurotypical people, and neurotypical signals are sometimes not implemented by the autistic person (Fletcher-Watson & Happé, 2019, chapter 9). This leads to regular breakdowns in communication between autistic and neurotypical communication partners: they are communicating across the autistic-neurotypical divide. The communicative difficulties arising from this divide can cause the neurotypical actor to attribute these breakdowns to the autistic actor: the basis of the ‘double empathy problem’ (Milton, 2012). The autistic actor is ‘othered’ by the neurotypical actor, since the neurotypical actor perceives the autistic person’s behaviour as not according to the norm, thus attributing the reason for the breakdown to the autistic person (ibid). However, these communication difficulties only seem to appear when the autistic person is communicating across the autistic-neurotypical divide: when communicating with another autistic person these issues are much less prominent (Crompton et al., 2020).

A way to bridge the autistic-neurotypical divide is by using objects to mediate (Di Paolo et al., 2018, chapter 10). It creates a shared point of attention and can be used to inform the interaction between the autistic and neurotypical person (Pezzulo et al., 2019). Co-design utilises objects in many different ways to guide participants through activities and to elicit responses.

Autistic in a neurotypical world

The autistic experience is grounded in a world that is mainly made for and by neurotypical people (Fletcher-Watson & Happé, 2019, chapter 3 and 9). As previously explained, an autistic person has a different way to perceive the world and also a different way to interact socially. It will require an adaptive and attentive neurotypical person to be able to meet the communicative needs of the YAA in social interaction. Having a long interaction history is also a positive factor in reducing the amount of breakdowns in communication between the autistic actor and the neurotypical actor (De Jaegher, 2013).

Co-design

Sanders & Stappers (2008) describe co-design as the application of co-creativity across the entire design process. Co-creativity occurs when two or more people are engaged in the same creative process (ibid). To rephrase: co-design must facilitate co-creation in participants who are part of the group that will come into contact with the product (Sanders, 2001). This means that not all participants are design specialists. In fact, many of them do not even see themselves as creative. However, they are creative and in many different ways:

"Everyone is creative. Non-designers, however, are not in the habit of using or expressing their creativity"

– Elisabeth Sanders (2001)

This means that the creativity of the participants in a co-design session is often latent of nature and co-design activities must support and bring out these creative sides of the participants (Sanders, 2001). Sanders & Stappers (2008) define four levels of creativity, with level 4 being most creative:

4. Creating: based on inspiration. Fullest form of creative expression.
3. Making: asserting a skill or ability. Focus is on "doing something yourself".
2. Adapting: altering something that already exists, to suit ones needs better.
1. Doing: productivity. Based on completing chores, e.g. preparations or roundup

The level of creativity is different in each participant and across different subjects. And even if the participant is able to perform at the highest level of creativity, they are likely to alternate between the different levels. By giving the participants proper tools for self-expression in a co-design process, they can be the "expert of their own experiences". (Sanders, 2001; Sanders & Stappers, 2008)

In practice, a co-design session is organised by designers and/or researchers who invite participants, often the prospective end user, to engage in a series of activities. The interactions during and the results of these activities are used by the designers and researchers to inform the design process. (Sanders & Stappers, 2008)

The strength of co-design is involving the users and other people who will be affected by the product in the development process (Sanders, 2001). In this particular case: the YAA and their caregiver.

Design Your Life-method

The Design Your Life-method (DYL-method for short) uses the autistic experience as the central input in the co-design process (Waardenburg et al., 2021). This results in 1) a more comprehensive understanding of the personal autistic experience and 2) a custom solution to support and/or improve the independence of a YAA. The method presents a set of activities to the YAA and their co-designer, which they use to explore memories, feelings, dreams, goals and challenges, and use the generated experiences and artefacts to inform their personal design of a product. The resulting product is therefore a result from the YAA's personal experiences: this will promote the sense of ownership of the product, as well as the feeling of empowerment – "I created this product by myself!" (Waardenburg et al., 2021)

Another central element in the DYL-method is the use of off-the-shelf technologies. This limits the required knowledge of prototyping and makes it easier for the participants to create a picture of the possible design directions. Such technology is generally relatively low cost without limiting options for personalisation. (Waardenburg et al., 2021)

The DYL-method uses an iterative design process, with stages similar to the Stanford d.school design thinking process (Doorley et al., 2018). The DYL-process is shown in Figure 1 and consists of the following phases (Waardenburg et al., 2021):

- **Understand:** which is comparable to context mapping. The participants gather information about the world and the experiences of the YAA.
- **Define:** the participants define a design goal and relate it to the results from the “Understand”-phase. At this stage the requirements are also drafted.
- **Ideate:** the participants generate ideas for a possible design solution using the requirements. At this stage it is also important that the participants have a good view of what options and resources are available to them, in regards of budget, network, skills, et cetera.
- **Prototype:** the participants create a functioning prototype using the ideas and requirements. For this they will focus on using already existing technologies and resources that are available to them.
- **Test:** the YAA uses the created prototype in their daily life for a while to see if it meets their expectations.
- **Evaluate:** the participants investigate if the product fulfils their needs and how they can improve the product and their understanding of the design goal.

The middle section is labelled ‘Your Goal’ and ‘Your Product’. ‘Your goal’ refers to the goals for which the YAA and their caregiver would like to design a product for. ‘Your product’ is the design solution that emerges through the design process. All phases inform these two topics: with “Understand” and “Define”, the participants define different possible goals and select one to work on, add information about the context of that goal and draft requirements. Within the “Ideation”-phase, the information about the goal is used to generate ideas and requirements for the product. In the “Prototype”-phase, the ideas and requirements are used to create a product, using already existing technologies. This product and its features are then recorded in “Your product”. After the “Testing”- and “Evaluation”-phases, the participants have gained new insights into the goal and the (desired and created) product. (Waardenburg et al., 2021)

The DYL-method is an interesting way to introduce new forms of communication in the lives of the YAA and their caregiver. It offers a way for the YAA to advocate for themselves and to strengthen their voice by levelling the interpersonal roles of the YAA and the caregiver within the DYL-process, and to create larger sense of ownership in the YAA of the design outcome, hopefully promoting the sustained use of the product.



Figure 1: the Design Your Life process.

Research questions

This master assignment is a case study within the DYL-project. The main goal is to create a toolkit that supports YAAs in becoming more independent by providing them and their caregivers tools to design their own solution that contributes to that independence. A YAA as mentioned in the DYL-project is someone between the ages of 16 and 35 and with a formal DSM-5 diagnosis of ASD, but without a cognitive or speech impairment. The caregiver in this context is a professional caregiver. This immediately leads to the main research question:

How do you support communication between an autistic and neurotypical participant during a co-design process, without the designer/researcher being present?

I start off with the YAA's wish to become more independent and the longstanding relationship between the YAA and the caregiver that will partake in the co-design process. The toolkit will implement the DYL-method in the form of a toolkit. The main challenge in this case study is the absence of the designer/researcher during the co-design activities. This means that the participants must rely on the offered activities, materials, resources and, most importantly, themselves to successfully complete the toolkit and create a product that the YAA is excited about using.

Sub-questions

This main question leads to several sub-questions that are related with the autistic experience, the caregiver-YAA relationship and setting up co-design activities with autistic people. These sub-questions are:

1. How do autistic people communicate?

This starts with understanding how autistic people perceive and make sense of the world. For this, it is also essential to understand communication itself, in particular embodied sense-making, and the differences between autistic and neurotypical communication.

2. How does a caregiver communicate with a young autistic adult?

For this we need to understand the care needs of a YAA, which requires mapping of their daily living and likely challenges, as well as the care standard and possible care structure around the YAA, as this is in the Netherlands.

3. How do you setup a successful co-design activity with autistic participants?

For this examples of co-design with autistic participants is used. However, the DYL-toolkit designed in this master assignment aims to not have the designer/researcher present, so there still needs to be a translation of these settings to that used in this thesis.

4. How can the toolkit mediate the communication between the YAA and the caregiver?

For this we start with the theory of embodied sense-making and the mediating roles that materials and objects can have on communication, especially in the context of co-design.

5. What tools can be used to successfully support a co-design process between a YAA and their caregiver, but without the designer/researcher being present?

This focusses on the activities, materials and resources that can be offered to the participants to guide them through the Design Your Life process. Additionally, it is investigated how the toolkit materials can take over the facilitating role of the designer/researcher.

Toolkit requirements

Using the outline of the assignment, the toolkit has the following requirements:

1. Uses the iterative design process of Design Your Life as a basis.
2. The toolkit must be designed to be used by a YAA, meaning a young autistic adult as defined within the Design Your Life project.
3. Alongside the YAA, a professional caregiver involved in the care of that YAA must be involved in the use of the toolkit.
4. The toolkit must be usable without the presence of the designer/researcher.
5. The toolkit must be usable in a home or office environment – environments that are familiar to the participants and that are also easily accessible to them.
6. The toolkit must support the communication between the YAA and their professional caregiver.
7. The project must end with participants that are happy with the outcome. This means that if they need support in creating their product, the designer/researcher can offer that support. However, the interference of the designer/researcher must be limited as much as possible.

The method

To create, test and evaluate the toolkit, I will go through the following steps:

1. Use literature research to inform the design of the toolkit's 1st design round.
2. Create the toolkit's 1st design round.
3. Test the toolkit's 1st design round with the help of participants.
4. Evaluate the toolkit's 1st design round with the participants.
5. Create the toolkit's subsequent design round.
6. Test the toolkit's subsequent design round with the help of participants.
7. Evaluate the toolkit's subsequent design round with the participants.
8. Evaluate the entire toolkit with the participants.

Additionally, I will also support the participants in creating a product that the YAA is delighted to use. This can be by providing resources or by prototyping (parts of) the product for them, in the case they lack resources or skills to do so by themselves. In parallel to this design case, I attend the DYL-meetings, where all researchers currently involved in the project share their ideas, progress, results and opinions with each other.

Important terminology

In this thesis there are two design processes in progress at the same time: the design of the toolkit and the design process that the participants go through by using the toolkit. To not confuse the two processes, I will use the following terms:

- **Iteration** to refer to the design and creation of the toolkit itself.
- **Design round** to refer to the design process that the participants go through while using the toolkit.

Information gathering

To collect data during this assignment, I am using multiple tools. The choice of these tools was based on the security and the ownership of the data. Therefore the tools shown in Table 1 were selected.

The activities in the toolkit will ask participants to record certain generated information and share this on Signal. This shows the way the participants did the activities and how this affected their continued process, as well, how it influenced their communication.

A kick-off meeting is used to establish a baseline of how well the participants know each other. During evaluations the same questions are used to see if the participants gained new insights from each other.

All meetings are recorded and transcribed. This is then used to analyse the participants opinion of the toolkit, how they experienced going through a design process and how the toolkit influenced their communication.

Tool	Type of communication or recording	To be used for
Microsoft Teams	Video calls, while recording using the in-app record function.	To get to know each other, for the kick-off meeting (took place during the lockdown of December-March)
Signal	Instant messaging: text, photos, voice messages, videos and files.	Secure sharing of co-design results, contact with participants in between meetings.
Phone calls	Verbal	For quick updates and coordination, e.g. when running late for a meeting.
E-mails	Text and files	For initial contact, but also for feedback on created materials and questions from the participants.
Face-to-face meetings, recorded with the Windows 10 Voice Record app	Physical and verbal, while recording verbal communication. Present materials can be used as well.	Toolkit drop-offs and in-person meetings.

Table 1: overview of communication tools used in the assignment.

Planning

This assignment had two versions of plans: in the original plan, I would design activities almost in parallel with the participants testing them. The first design round would serve as a “pressure cooker” for the participants, a way to get acquainted with the design process and being comfortable with making mistakes as there is a second round to “get it right”. However, this plan could not go through due to COVID-19 restrictions and difficulty in finding participants.

This assignment lasted from November 2020 till August 2021. The case study started in March 2021 and closed in August 2021. During a part of this time, a strict COVID-19 lockdown was in place, which limited the options for visits but also created erratic delivery of packages (Ministerie van Algemene Zaken, 2020b). Because of this situation, I decide to create kits per design round. This also more closely resembles the realistic experience of the toolkit. The participants receive the first design round in its entirety. The planning is shown in Figure 2.

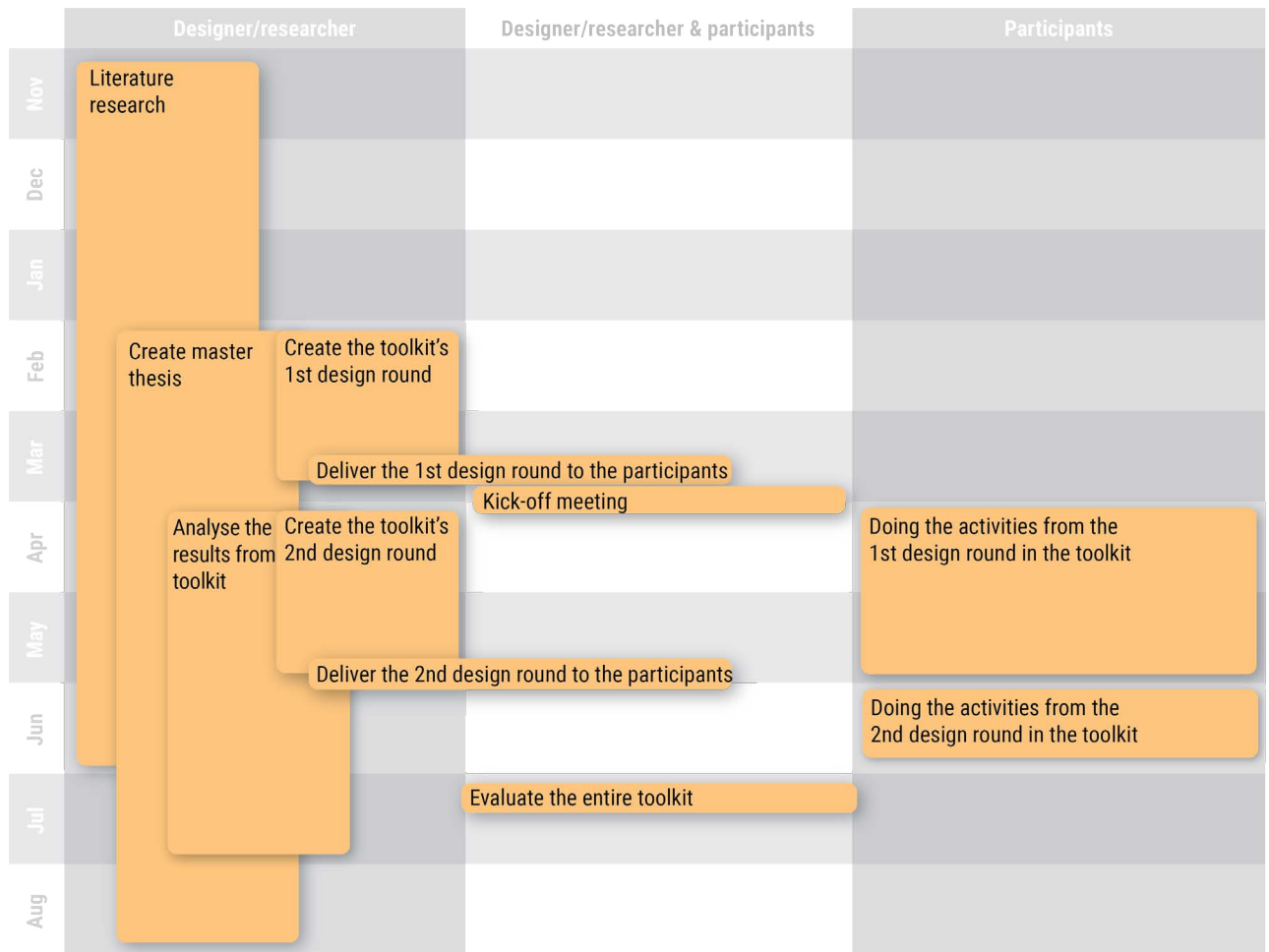


Figure 2: the planning.

The design case

The case described in this thesis is one in which a YAA, a professional caregiver and a designer/researcher (the author) was involved. In relation of the toolkit, this created the communication process illustrated in Figure 3. In this Figure you see the designer/researcher, the YAA as the main designer and the caregiver as the co-designer. The toolkit is represented as the box in the middle. The dotted line represents the division between the designer/researcher and the participants: the designer/researcher will not be present during the co-design activities, and is thus placed outside the design activity space. The final element shown in the image is the solution created by the participants through using the toolkit.

There are several parallel processes of communication and transformation going on:

- The blue arrows represent the stream of information from the participants to the designer/researcher. This information can be feedback on the toolkit, or toolkit results – the generated materials using the toolkit.
- The green arrows represent what the designer/researcher gives to the participants – in this case: the toolkit. During the testing period, the designer/researcher can intervene by altering the toolkit or adding to it.
- The grey arrow-triangle shows the communication that takes place in the design activity space: the communication between the YAA and the caregiver. This communication can take two paths: directly or mediated through the materials in the toolkit.
- The orange arrows indicates the process where the solution is being created and how this solution influences further steps in the co-design process.
- The dotted arrow represents the communication generated by the solution and how that influences the communication process in the YAA-caregiver-toolkit triad.

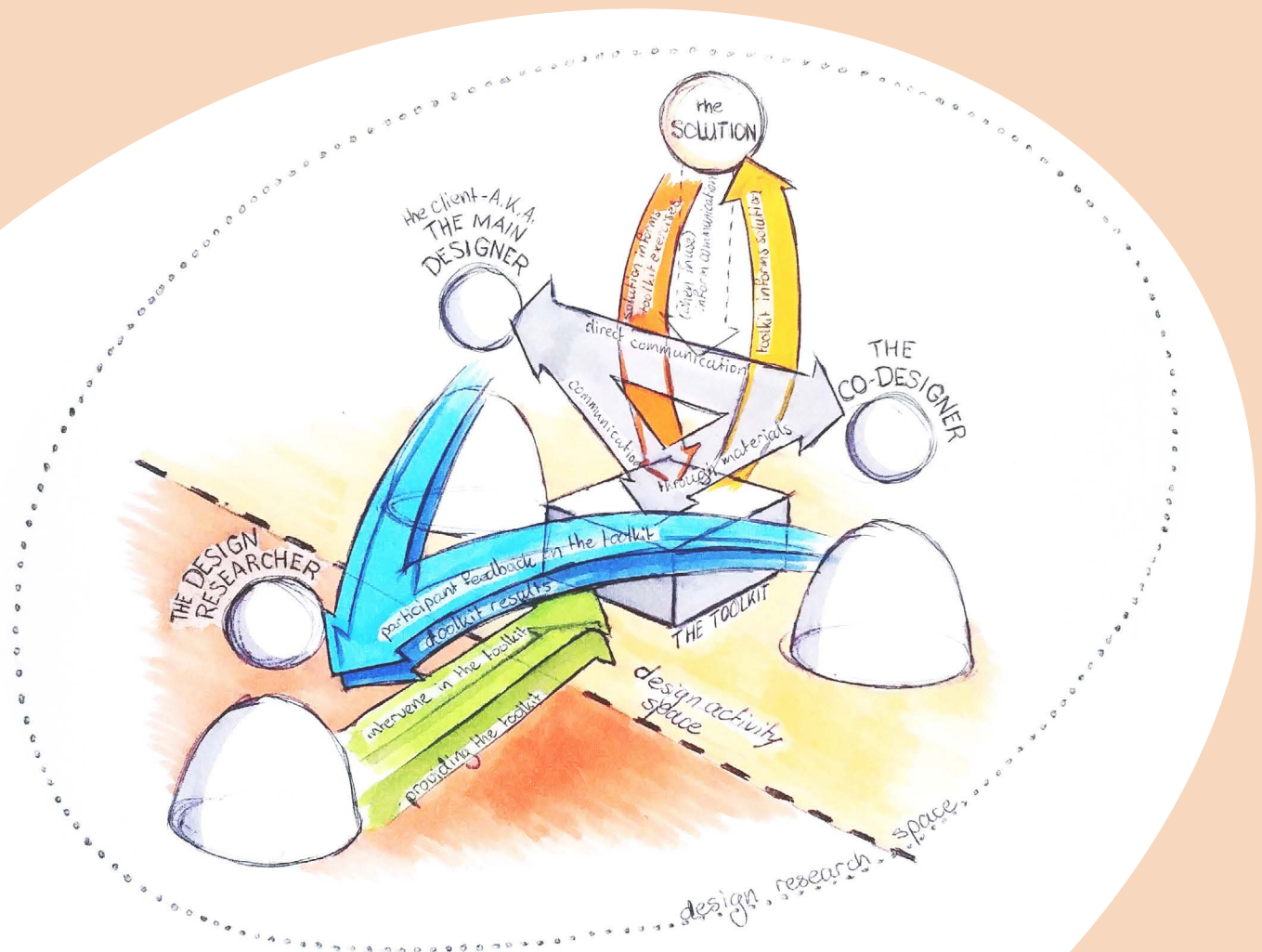


Figure 3: the communication as hypothesised at the beginning of the case.

The participants

This project involves three people: the YAA, the professional caregiver and the designer/researcher. The YAA is selected based on the following characteristics: between the age of 16 and 35, with a diagnosis of autism spectrum disorder as described in the DSM-5 (2013), and without cognitive impairments or limited speech. The caregiver is someone who is actively involved in the care process of the YAA. The designer/researcher is the author of this thesis and is also introduced because of the developments during the co-design project.

Profile of the YAA

Name: Simon (pseudonym)

Age: 26

Gender and pronouns: Male (he/him)

Occupation: Not structurally at the moment. Occasionally works for his parents' company.

Living situation: independent with 24 hours assistance, but only receives ambulatory support as it suits his needs better. Simon rents from a local housing organisation.

Diagnosis: ASD

Hobbies: reading, meditation, gaming (especially MMORPG), watching TV-shows

Fields of interest: science, especially natural sciences; learning in general; fantasy; philosophy

Motivation: helping people with ASD, learning something new through the DYL project (about product design).

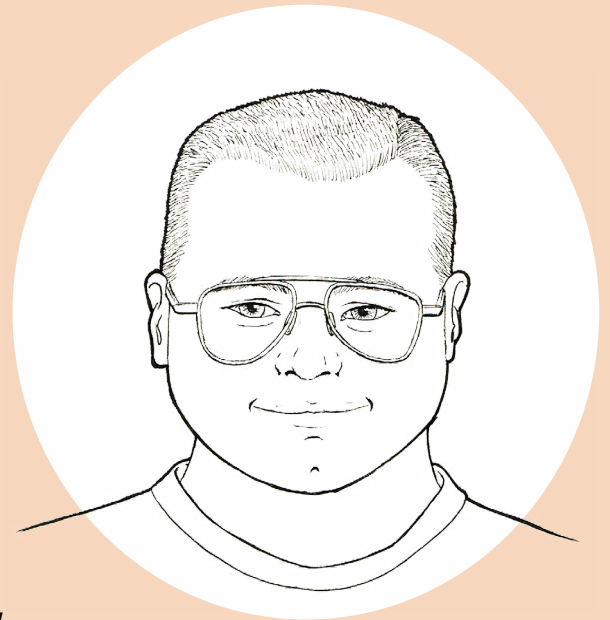


Figure 4: portrait of Simon (inspirational image)

Simon is a calm, smart and direct person, but with a gentle side. He is quick-witted and does not shy away from a good discussion. Simon is comfortable with being on his own for the majority of the time. He gets most of his social contact from online interactions. He has a strong sense of what does or does not work for him in daily life, which leads to him feeling "mothered" and at times a little misunderstood by the support workers. He is a strong visual thinker, but prefers text over visual media when expressing himself, as he is not comfortable with sketching or painting. Figure 6 shows Simon's care network.

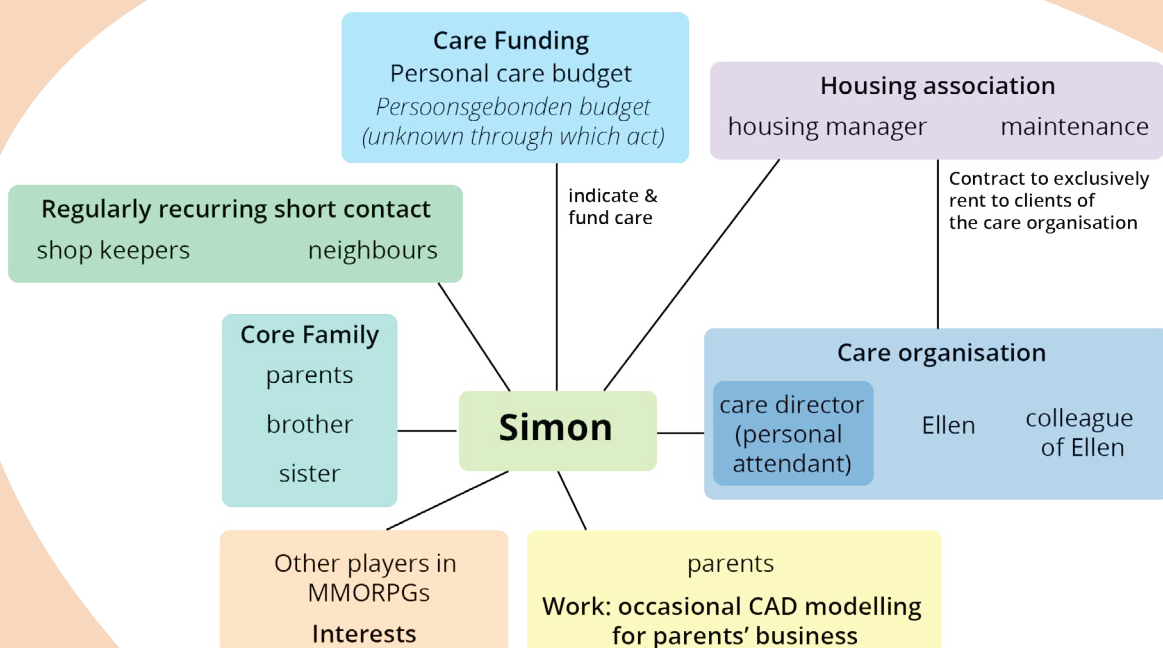


Figure 5: overview of Simon's care network. As is visible in this overview, his professional care network is limited to Ellen, his personal attendant and a colleague of Ellen, who all work for the same care organisation.

Profile of the care professional

Name: Ellen (pseudonym)

Age: 31

Gender and pronouns: female (she/her)

Occupation: caregiver and support worker at the care organisation giving support to Simon. Ellen is one of a small team of caregivers who are in touch with Simon.

Hobbies: athletic, likes to do survival run related activities, DIY-ing.

Fields of interest: professional care, survival-runs; music; likes chocolate a lot; philosophy; DIY-ing.

Motivation: helping other people, learning new ways of communicating with clients. She hopes that the project helps to understand Simon in a new way. Ellen also enjoys a new challenge and broadening her perspectives at work.

Ellen is very attuned to her clients: Ellen can tell a lot about Simon in a whim. She enjoys spending time with Simon, though she sometimes feels a little lost in the scientific topics that he addresses. In general she is okay with Simon's inclination to discussions, but finds it at times difficult to decide when to end the discussion. Ellen also knows that Simon sometimes feels a little "mothered" by her reminders, but would love to see Simon opening up to someone else's views when it comes to support. She hopes that Simon learns that she is quite athletic. Additionally, she hopes that Simon learns that her methods and efforts are to help Simon reach his goals.

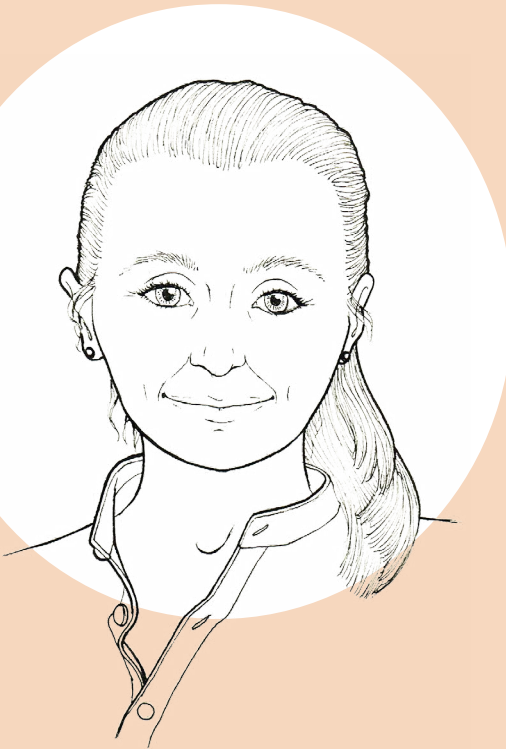


Figure 6: portrait of Ellen (inspirational image)

Simon and Ellen's current relationship

Simon and Ellen have known each other for one-and-a-half years. Simon and the support workers of the care organisation meet weekly. They usually take a walk and talking about daily life and things that Simon has on his mind in the meanwhile. In general the interaction between Ellen and Simon is very relaxed and informal. It is clear that Simon is quite at ease with Ellen, making jokes. Ellen also is able to alternate between joking and being more serious.

The designer/researcher

Name: Nathalie Overdeest

Age: 29

Gender and pronouns: female (she/her)

Occupation: student Industrial Design Engineering MSc, track Human Technology Relations

Hobbies: Ballroom dancing, ballet, bouldering, sketching, crafting, baking

Fields of interest: dancing, cats, becoming a better author, chocolate, design, co-design

Motivation: I believe that the Design Your Life project can empower YAAs to create tailor made solutions for themselves by themselves, although I am curious about the effects on it on communication and how the absence of a design facilitator will play out.

I identify as an open and curious person with high creative drive. I thrive in situations where I need to deal with a high level of uncertainty, as was the case in this project. This gave me a lot of freedom to create a toolkit implementing not only literature, but also personal experiences. My biggest challenge in this project is maintaining a certain role. I partake in this project as the designer/researcher, but aim to limit my contribution to the co-design process that the participants will embark on to offering design activities and support in prototyping.

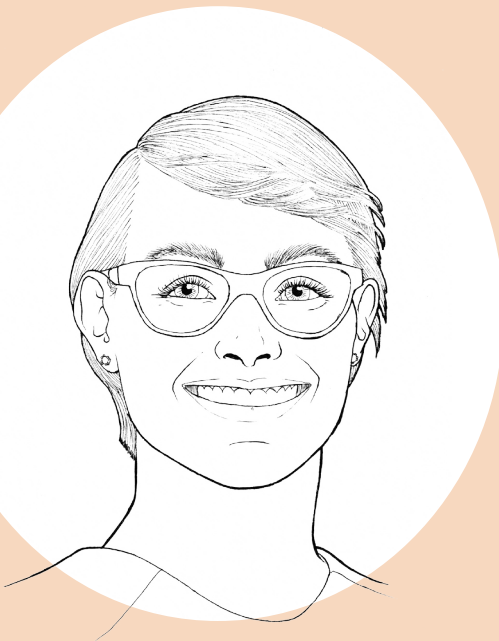


Figure 7: portrait of Nathalie Overdeest

Establishing the case study timeline

Figure 8 shows the timeline of the case study, which is essential to understand the different iterations in this thesis. The process has deviated somewhat from the updated planning, which will be further explained in the iterations. For a full overview of contact with the participants: please see the log in the appendix (Appendix A).

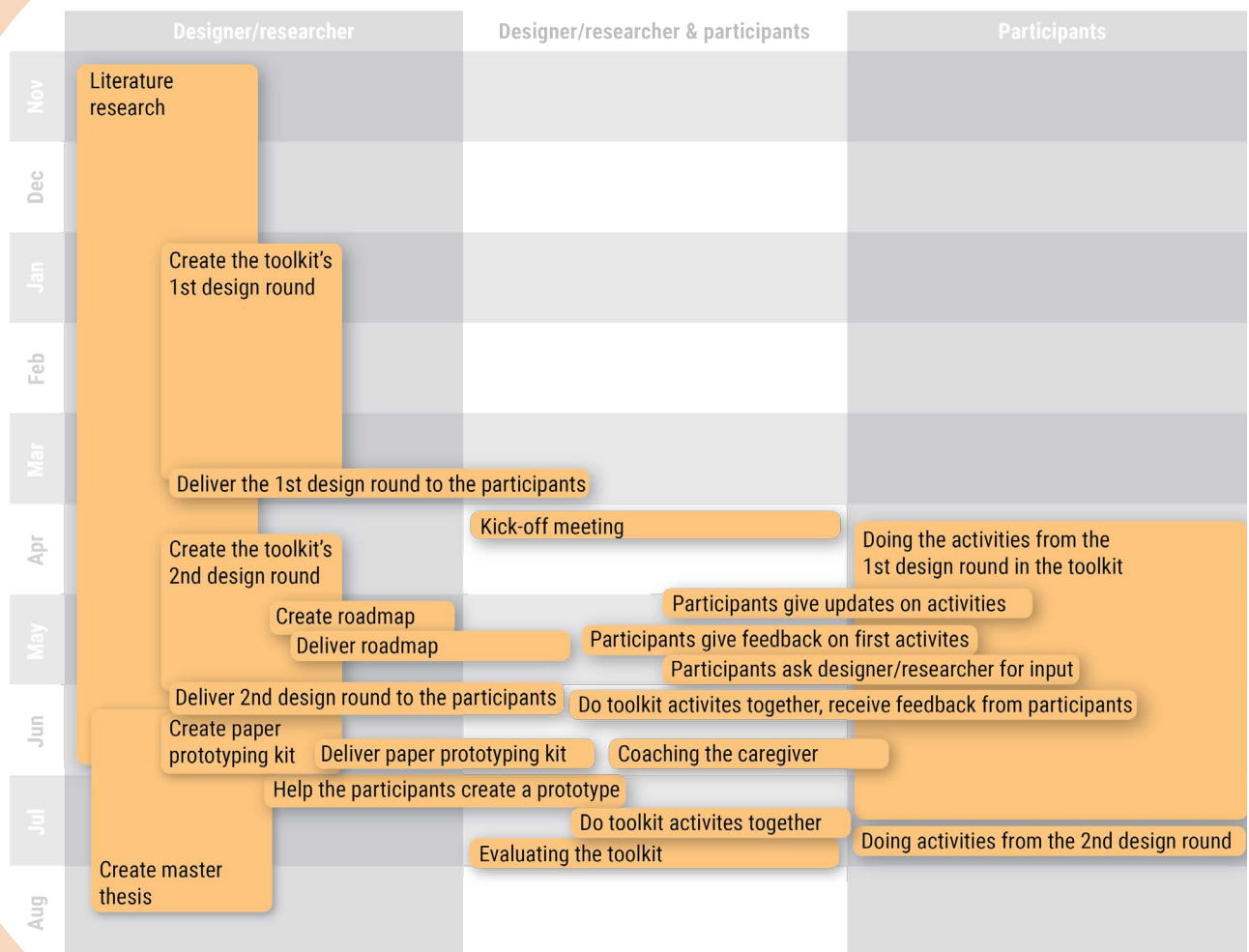


Figure 8: the complete timeline of this case study. The left column are activities done by only the designer/researcher, on the right those completed by the participants. The middle column shows activities done by the designer/researcher and the participants together. Any overlap indicates that the activity started individually and then was extended to a collective one.

SECTION I

THEORETICAL FRAMEWORK

Plak hier stickers die horen bij de ontwerpfase
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roepdoel. Het is aan jou en
gebruikte afbeelding

PROTOTYPE BOUWEN

Prototype bouwen
Het prototype helpt een keuzemogelijkheid niet

Prototype testen
Ik heb mijn prototype kunnen

START



om je verantwoordelijk
door met je mee te de

By doing an extensive literature research, clues are gathered for the design of the toolkit. For this, we will create a theoretical answer to the five sub-questions. The theoretical outline is structured in the following way:

1. Experiencing the world as a YAA: how does a YAA experience the world and how are their lives generally set up?
2. Professional care for YAAs: how is this organised and what is the relationship between the YAA and their caregivers?
Informs the answer to sub-question 2: **How does a caregiver communicate with a young autistic adult?**
3. Communication: what is communication based on the embodied perspective?
4. Autistic communication: how does autistic-neurotypical communication differ from communication between only neurotypical people?
Informs the answer to sub-question 1: **How do autistic people communicate?**
5. Co-design: what are current practices in this field?
6. Co-design with autism: how can autistic participants be accommodated in a co-design process?
Informs the answer to sub-question 3: **How do you setup a successful co-design activity with autistic participants?**
7. Communication in co-design: what materials, tools and methods are used to mediate communication in co-design?
8. Communication in co-design with autistic participants: this unifies all previous information to describe a co-design setup for autistic participants and how this co-design setup influences the communication between the YAA and the caregiver.
Informs the answer to sub-question 4: **How can the toolkit mediate the communication between the YAA and the caregiver?**
9. The Design Your Life-method and co-design: describing how the Design Your Life-method differs from traditional co-design.
Informs the answer to sub-question 5: **What tools can be used to successfully support a co-design process between a YAA and their caregiver, but without the designer/researcher being present?**

Theme 9 offers the requirements for which the toolkit must be developed. The description of this toolkit and the underlying design rationale are mentioned in the Iteration chapters.

Theme 1: Experiencing the world as a YAA

The leading theory to explain how autistic people experience the world is the weak central coherence theory, which explains how autistic people see the world as one built up of many details, but without forming one coherent image to explain the overall meaning (Fletcher-Watson & Happé, 2019, chapter 8; Kanner, 1943). However, Fletcher-Watson & Happé (2019, chapter 8) also explain that central coherence is a style of processing and a lack thereof is a preference, not a deficit. Autistic people are capable to integrate all the perceived details into a global image, though this does not come naturally, nor without effort (ibid). Instead, their particular preference to process the world gives them an exceptional eye and memory for detail, although such focus on detail can cause difficulty to remain focussed on something (Fletcher-Watson & Happé, 2019, chapter 5).

A recurring aspect in autism is how sensory stimuli are being experienced. Both hyper- and hyposensitivity to specific stimuli are common in autistic people and can occur in external as well as internal senses, e.g. interoception, proprioception and kinaesthesia. Hyper- and hyposensitivity can occur for different stimuli within the same sense. Such sensitivities can be related to conditions regularly found alongside autism, e.g. alexithymia (difficulty to identify one's own emotions). Being hypersensitive to certain aggravating stimuli can cause autistic people to avoid certain situations, whilst stimuli that bring them delight can create behaviour of seeking out, in turn informing hobbies and even careers. (Fletcher-Watson & Happé, 2019, chapter 3)

Another interesting aspect of the autistic experience of the world is that autistic people experience reduced or even no habituation to repetitive behaviour, meaning that each time they perform that behaviour, the sensation and fascination is at the same level as the first time the behaviour is performed. Stimming is a form of repetitive behaviour that autistic people use as a coping strategy when being affected by sensory stimuli. They can use it to screen out unwanted sensory input by overwhelming the system with self-stimulatory behaviour. Examples of such behaviours are flapping one's hands or rocking back and forth. (Fletcher-Watson & Happé, 2019, chapter 5)

This topic will be further explored in the section "Communication with autism"

However, repetitive behaviour like stimming is often camouflaged, as it is seen as socially unacceptable by neurotypical people (American Psychiatric Association, 2013; GGZ, 2017).

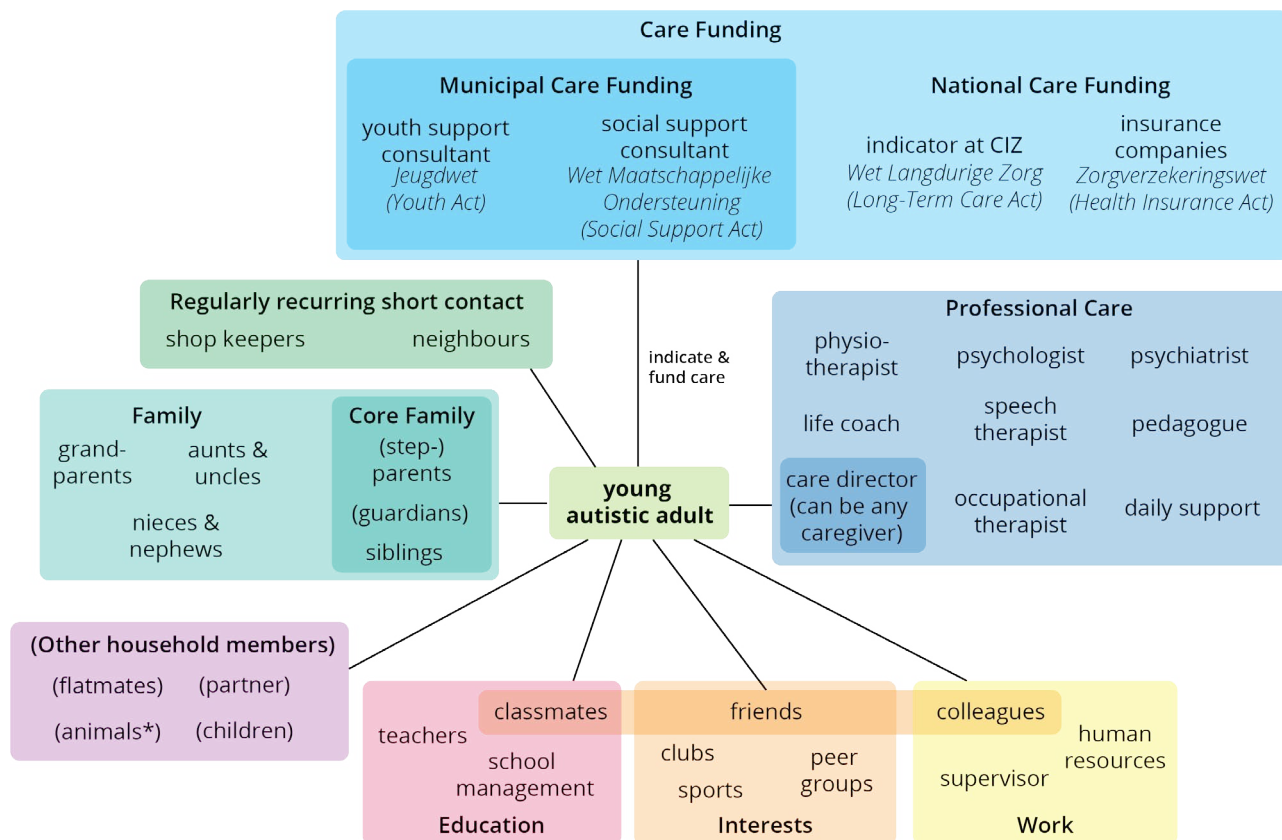
Theme 1.1. Daily living as a young autistic adult

Just as a neurotypical young adult, the YAA leads a life that is filled with friends, family, hobbies, education and work, depending on their individual interests and capabilities. One difference is the presence of a form of care in the YAA's life. This can be provided by their (core-)family or by care professionals. This care can be unfunded, meaning that YAA only receives informal care. In other cases, this care is funded by either the municipality or a form of national care funding. Figure 9 shows the possible available care and support network in the life of a young autistic adult. Note that the situation is different for every YAA, some of them might no longer attend courses or still live at home, removing these elements from this network in their particular case. (GGZ, 2017, Fletcher-Watson & Happé, 2019)

Theme 1.2. Living situation

As earlier explained, an autistic person follows their own course of development, thus hits the traditional marks of independence at their own pace. In this regard, 'independence' is being referred to as living independently, with as little support as possible, and the person being able to provide for themselves. In the age range of the YAA that means transitioning to more independent forms of living, completing secondary and/or further education, travelling independently and transitioning to suitable work or daily occupation.

Regarding the living situation, a YAA can be either: 1) living with their parents or guardians (35%), 2) living independently with no (30%) or some degree of support (15%), or 3) living temporarily or permanently in a sheltered living facility or care facility (11%) (van Wijngaarden et al., 2020). Living at home within the age range of 18 to 30 years old is quite common in the average population as well: the average age to move out was 23,5 in 2017 (Centraal Bureau voor de Statistiek, n.d.-b). Autistic people are more likely than



*Animals might not be living in or close to the house, e.g. a horse at a local stable
 Items in brackets might not be part of the young autistic adult's life, either because they have not moved out yet or because the bracketed items are simply not part of their household

Figure 9: the network around a young autistic adult. Created using the following sources: GGZ (2017) and Fletcher-Watson & Happé (2019).

the neurotypical population to live in a care facility or to live independently with support (Centraal Bureau voor de Statistiek, n.d.-b; van Wijngaarden et al., 2020). Sheltered living is usually the case if the YAA needs care for a longer or indefinite period of time (GGZ, 2017). There can also be a hybrid situation, e.g. where the YAA partly lives with their parents, and the remainder of the time in a sheltered living facility (van Wijngaarden et al., 2020).

According to the survey by the Nederlands Autisme Register (Dutch Autism Registry, NAR for short), 49% of their adult respondents (ages between 18 and 75 years) mention that they are looking for another place to live. Another 29% is contemplating this step. In the age group of 16 to 18 year olds 10% is looking for another place to live and another 18% is contemplating to do so. The most common reason to contemplate or prepare a move for both groups is moving out of their parents' home, followed by the wish to become more independent. Another reason for moving mentioned in the same survey is the need for extra support. (Begeer et al., 2013) The results shown in the NAR-survey (Begeer et al., 2013) prove that the sense of independence and the need to gain more independence are important drivers for an autistic adult to change their living situation.

— In this thesis I mention two NAR reports: of 2020 (Wijngaarden et al., 2020) and of 2013 (Begeer et al., 2013). These reports are made with support of the NVA, the Dutch association for autistic people. Participation is voluntary and the participants might not be an accurate reflection of the full Dutch autistic community, but can give an indication of some important themes and directions.

Theme 1.3. Daily occupations

The daily occupation of autistic adults (ages 18 to 65) ranges. Though paid work is common and usually the main source of income, it is also not unlikely that the autistic adult volunteers at least an hour a week. About 5% of people in this group is enrolled in a form of education or does an internship. This low number can be attributed to the wide age range. Though data for YAAs is not available, it is to be expected that in the age range of 18 to 30 year olds the percentage of people in higher education is higher. (van Wijngaarden et al., 2020)

Theme 1.3.1. Pursuing (further) education

Of the autistic adults pursuing a diploma or degree, it is most common for them to follow secondary vocational education (or “middelbaar beroepsonderwijs” in Dutch), accounting for 47% of respondents of the NAR report of 2020. 27% follows education at the level of higher professional education (or “hoger beroepsonderwijs” in Dutch). The remaining 25% follows education at academic level. Within these levels of education, 44% of the autistic adults pursuing further education do so using an alternative form of education, for instance remote learning, a specialised secondary vocational education program (“Route Educatie-Arbeid-traject”, or “REA-traject” in short), adult education, and e-learning. The use of such alternatives is most likely due to the fact that in tertiary education there does not exist special education, as it does exist in the Dutch primary and secondary education. (van Wijngaarden et al., 2020)

An autistic adult in further education is likely to receive some kind of support. Support that is mentioned in the NAR report from 2013 are extra meetings with a mentor, dean or study counsellor, adjustments in tests and test duration, internship counselling, and having a study buddy. This support can be provided by the educational organisation or by an external organisation. Interestingly, about 37% of the autistic adults enrolled in further education state that they have the need for more support, but that they do not receive that at that moment. (Begeer et al., 2013)

Intelligence also is an interesting factor in the educational and occupational prospects of an autistic adult. About 6% of the autistic adults in secondary vocational education has an IQ of over 130, while this group represents 37% of the autistic adults enrolled in academic education (Begeer et al., 2013). Following a lower level of education (that being special secondary education or secondary vocational education) prepares the autistic adult in a very practical way for work and the work following this level of education is usually more structured, routine based and less strenuous (Landsman-Dijkstra et al., 2014). Intelligence is thus not the only factor in selecting suitable (further) education: the education and the work following it must also suit the autistic person in other areas. Autistic adults with a higher IQ are usually better at masking their autistic traits, which in turn can lead to overestimation of the autistic adult. As earlier statistics show, a higher IQ is correlated with a higher level of education (Begeer et al., 2013), but finding work that aligns with that education is more difficult to find (Landsman-Dijkstra et al., 2014).

The autistic adult has not only the challenge to find suitable further education in terms of their interests, their intelligence and their personal need for support, but also has to keep job prospects in mind, meaning finding a job that is in their field of interests, in line with their level of education and in their range of capabilities.

Theme 1.3.2. Finding and maintaining suitable work

When looking at the age range of the YAA, it is very likely that they are in the transition from education to work or daily occupation. According to the autistic adult respondents of the NAR report of 2020, their main means of income are from: 1) work (47% of respondents work at least 1 hour a week); 2) government allowances, e.g. for healthcare, rent or children; 3) the income of a partner; 4) a form of payment sponsored by national or local government organisations; and 5) pension. When looking at daily occupation, this can include (from most common to least common): staying at home to care for the house and possible children, volunteering, a regular job, a supported job, studying or doing an internship, working in a sheltered environment such as a social workplace, or partaking in daytime activities, possibly at a day care facility. (van Wijngaarden et al., 2020)

Most respondents in the NAR report of 2020 are satisfied with their occupation, rating it a 6,8/10 (van Wijngaarden et al., 2020). However, 24% of them feel that their work does not match their level and 28% of respondents think that their occupation does not match with them in regards of skills and interest (ibid). Such dissatisfaction with one's occupation can lead to a less positive experience of that occupation (Landsman-Dijkstra et al., 2014). As pointed out in the section about tertiary education, there appears to be a delicate balance between finding work that suits the YAAs intelligence, skills and interests, but

The data from the NAR report does cover a much broader age group than 18 to 35 years old, hence also the mention of pension as a means of income. This data has been included to show the range of possible occupations that the YAA can have. (van Wijngaarden et al., 2020)

also in line with the workload they can manage and, additionally, in range of what they can travel (ibid).

Let us focus on paid work for now and the challenges the YAA has in finding and maintaining such work. According to Landsman-Dijkstra et al. (2014), recovery after work is an important factor in YAAs to be able to maintain a job. However, being hypersensitive to sensory stimuli depletes the YAAs energy more quickly and having issues like sleep problems and depression causes the YAA to not be able to recharge after work sufficiently. This can lead to a negative spiral where the YAA is not recovered from the previous day, overstretches themselves at work and then this plays into worsening issues like sleep problems and depression, plus being even more sensitive to sensory stimuli the following day. Another negative factor in being able to maintain a job is the YAA overestimating their abilities. This usually comes from comparing themselves to colleagues who seem to be able to do more. Luckily, this overestimation fades the longer the YAA works: they start to develop a more realistic view of their capabilities and limits. The capability of the YAA to maintain work is also larger when they experience their health as being good. (Landsman-Dijkstra et al., 2014)

It helps the YAA if they can have certain adjustments at work, such as starting with a part-time schedule and adding hours as time progresses, having ample time to adjust and learn on the job, and facilitating the YAAs needs in terms of communication and environment (Landsman-Dijkstra et al., 2014).

Finding a suitable form of occupation is a complex puzzle for a YAA. Therefore it comes as no surprise that support in finding and maintaining a job is a common theme in the support a YAA receives (van Wijngaarden et al., 2020). This support can be in the form of a job coach. This section also shows that this complex puzzle can be solved to the YAAs satisfaction, given the overall appreciation of their daily occupation.

Theme 2: Professional care

It is common for an autistic person to receive professional support in one or more areas of life. The rule of thumb here is the younger the autistic person, the larger the likelihood that they have received some form of professional support. The most common areas of support are: 1) personal development; 2) dealing with social relations; 3) recreational occupation; 4) living; and 5) finding and maintaining a job. (van Wijngaarden et al., 2020)

When the YAA and their informal caregivers decide to introduce professional care, they are free to seek out a care organisation that suits them: the Dutch care system is set up in such a way that it is possible to choose one's care and preferred caregiver. For this care, they need to apply for funding, either at the municipality, which is most common if the YAA is 18 years old or younger, or apply for a personal care fund as part of the Long-Term Care Act. Some forms of care, such as psychotherapy, are covered by mandatory health insurance. (GGZ, 2017)

Theme 2.1. Care plan

Once a care organisation is selected and the funding sorted, a care plan is set up. This plan is always aimed at improving the autonomy of the autistic person, stemming from the view that development is always possible. The involved care can vary strongly depending on the YAA's needs, but there are two constants in the care network: 1) having a care director (whose role is explained in section xx), and 2) practicing informed consent. Informed consent means that all the information provided to the autistic client is consistent, clear, complete, provided at the right moment, and discussed with primary caregivers, such as parents, if applicable (GGZ, 2017).

The YAA's network, as shown in Figure 9, will be involved in the execution of the care plan. In the age range of 12 to 30 years old, the provided can involve homework support, supporting the YAA in understanding their autism, finding and using supportive tools for planning and organising, support to sketch a future that suits the YAA's wishes and needs and helping the YAA to realise that future, stress regulation, and support in building and maintaining (romantic) relationships. This care can be provided in a multitude of forms, ranging from peer group meetings to eHealth modules to books.

Theme 2.2. The voice of the YAA in their care process

From the age of 12 and only in the case of no cognitive impairment the autistic child will be involved in the decisions made in their personal care process. The professional caregiver treats the parents or guardians of 12 to 18 year old autistic people as their equal care partner, since they are the primary caregivers. Once the YAA turns 18, they will be treated as equal care partners. Parents or guardians will only be informed and involved when the YAA would prefer that. However, the professional caregiver is responsible to hear all people close to the YAA, since they can share experiences and knowledge that can serve as valuable input for the care provided to the autistic client. (GGZ, 2017)

Theme 2.3. The YAA's relation with their professional caregiver

The professional caregiver should have knowledge of autism and with working with autistic people. Having such knowledge is important to be able to truly connect with the YAA. Understanding the YAA is done by spending extensive time to hear the YAA's story, their inner dialogue and their lived-in experience. In other words: the YAA is treated as the expert of their own specific form of autism. Having said that, the focus should not be solely on the autism and how it presents itself: the caregiver should also be sensitive to the stress and emotion regulation of the autistic client, and the fact that the ASD diagnosis is only part of all the facets that make up the YAA. (GGZ, 2017)

However, gaining a full understanding of the autistic client and their lived-in experience remains difficult because of heterogeneity present in autism, their specific ways of processing sensory stimuli and their challenges in establishing and continuing social interaction (D. E. Milton, 2014). The contact between the probably neurotypical professional caregiver and the autistic person will frequently result in breakdowns (ibid) –

possibly leading to the double empathy problem (Milton, 2012). But working through those breakdowns is exactly what helps the professional caregiver to understand the autistic person (ibid).

Continuity in care is especially important for autistic people, since they prefer routine and need more time to get used to someone new. This plays an important factor when the YAA turns 18: any care that was provided under the Youth Care Act must be transferred to either care under the Social Support Act or the Long-Term Care Act. This in practice means that the YAA needs to transfer from professional care providers. Such a transition needs to be properly facilitated, meaning that the old caregivers and the YAA have proper time for closure and that the new caregiver and the YAA have ample time to get to know each other. (GGZ, 2017)

Theme 2.4. To conclude

The previous section gave a thorough insight into the autistic lived in experience and the setup of care around the YAA. We can now answer sub-question 2:

How does a caregiver communicate with a young autistic adult?

First of all, the YAA as described in the DYL-project will be actively involved in their care process. Up to the age of 18 their parents or guardian will be involved as well, though decisions will be made with the YAA's approval. When the YAA is 18 years or older, their parents or guardians are only part of the care process when the YAA agrees to their involvement. This means that the caregiver will have an active relationship with the YAA, where the YAA can make decisions regarding the support they receive. Such a relationship seems to be close to equal when the YAA is an adult, but because of the supportive role of the caregiver in the YAA's life, there is always a sense of imbalance.

In supporting the YAA, a personal relationship between the caregiver and the YAA is essential. This relationship starts with the caregiver's knowledge of autism in general, and the autistic sensory processing preferences and communication styles especially. But this knowledge only supports the YAA-caregiver relationship if the caregiver realises that the expression of autism is different in every person. The caregiver must also be careful not to characterise the YAA solely by their autism diagnosis, nor attribute the YAA's interests, personality traits or other characteristics to autism immediately.

That is why establishing a long interaction history is important. This will lower the occurrences of breakdowns in communication. The caregiver is likely neurotypical, and communication across the autistic-neurotypical divide can be difficult because of the differences in sensory processing and communication styles. By having interacted with the YAA for a longer time, the caregiver learns the YAA's personal communication preferences and what sensory input is or isn't pleasant.

Establishing the personal relationship – and thus the interaction history – starts when the YAA and the caregiver are getting acquainted with each other. Preferably, this occurs before the support by the previous caregiver ends. This period of overlap gives the YAA time to become comfortable around the new caregiver, while the caregiver has the chance to get to know the YAA, possibly with the support from the previous caregiver.

Theme 3: Communication

Communication occurs when two or more people are sharing their emotions, insights, experiences and opinions with each other. For this the notion of shared sense-making is important: social interaction influences the significance of an experience and should therefore be considered in any design process (Mattelmäki, 2006, chapter 2). Through the process of shared sense-making one is out to find common ground with their interactor (De Jaegher, 2013). Since this process is inherently social, it is also important to look at communication as a whole: backchannels (phatic non-verbal communication), phatic communication, and repair & alignment (Fusaroli et al., 2017; Vetere et al., 2009). The process of sense-making is also part of the process of joint action: a process where both content and processes are coordinated between two or more actors (Clark, 1996).

Theme 3.1. Sense-making

To explain shared sense-making, I will use the enactive approach as described by De Jaegher (2013). She describes shared sense-making using the concepts of autonomy, embodiment, emergence and participatory sense-making.

According to De Jaegher (2013) **autonomy** is the ability of living systems to “self-generate, self-organise and self-distinguish”. In this regard, the body is a self-sustaining system with needs (ibid). This precarious condition makes that living systems are constantly producing themselves and regulate their interactions with the world to satisfy those needs – which are created by that condition in the first place (ibid). This means that the body is the “centre of activity in the world, spontaneously generating its own goals as well as responding to the environment” (De Jaegher, 2013).

Cognition is **embodied** according to De Jaegher (2013): the body is “a precarious network of various interrelated self-sustaining identities (organic, cognitive, social), each interacting in the world in terms of the consequences for its own viability.” Using this definition, experience is then also embodied since it is used and degenerated by interacting with the world in a meaningful way (De Jaegher, 2013).

Using these definitions of autonomy and embodiment De Jaegher (2013) continues to explain **sense-making** as “a cognisor’s adaptive regulation of its states and interactions with the world, with respect to the implications for its own continuation of autonomy in mind.” This regulation stems from the previously mentioned precarious condition (ibid). In this light the operation definition for cognition is: an organism casts a web of significance over the world, based on its needs. Exchanges with the world are inherently significant for the cognisor. This significance stems from the needs created by the precarious condition.

Participatory sense-making involves (the autonomy of) the interaction process, engagement, coordination dynamics and social skills (De Jaegher, 2013). **Engagement** emerges when an interaction starts to “take over” and gains momentum on its own (ibid), such as a state of flow or tension.

According to De Jaegher (2013) social interaction takes place when two autonomous agents engage in a co-regulated coupling, in which the autonomy of both actors is not destroyed (though it might be augmented or reduced). If the autonomy of one of the actors is destroyed, they are reduced to tools or objects. **Social interaction** is not only based on the autonomy of the actors, but also of that of the interaction process: this is self-organising and self-maintaining, meaning that it can continue in unintended ways (ibid). One example De Jaegher (2013) gives is the “hallway dance” when you try to pass each other there.

According to De Jaegher (2013) the self-organisation and self-maintenance of interactions is realised through **coordination**. De Jaegher (2013) describes coordination as “the non-accidental correlation between the behaviours of two or more systems that are in sustained coupling, or have been coupled in the past, or have been coupled to another, common system.” Coordination can be temporal, mirrored, anticipatory, imitating or aimed at creating co-variation, and can encompass movement (facial expressions, gestures), utterances and thoughts (ibid). In practice it means that the actors are engaged in an

action-perception loop that is coupled with each other, allowing them to use coordination depending on what they perceive the other actor doing and saying (ibid). Thus they can accordingly alter or maintain the current discourse of the social interaction (ibid). Both actors are susceptible to be affected by the coordination history. This is a double influence: from coordination into the encounter and from the encounter dynamics and the likelihood to coordinate (ibid).

The actors and the interaction process modulates the sense-making that takes place. However, the degree of participation can vary: from joint sense-making (high level of participation) to one-sided coordination (point something or an idea out to someone).

As shown by De Jaegher (2013) shared sense-making is characterised by coordination. Coordination is characterised by breakdowns and repairs (ibid). Shared sense-making is centred around finding common ground. Repair is one of the factors for finding this common ground, as are phatic communication, backchannels and alignment (Fusaroli et al., 2017; Vetere et al., 2009).

According to Fusaroli et al. (2017) conversational **repair** is used as negative evidence for mutual understanding. In practice this means asking questions or needing clarification such as “huh?” or “who?” In such repair turns the initiator often uses the language used by the other to formulate a question. Repair can also be in the form of a negotiation (ibid). In task oriented communication there is more explicit negotiation (repair) and confirmation of common ground (ibid). The repairs in task-oriented communication are also utilising more closed questions, restricting the options for responses: the most specific option for repair is used (ibid).

Vetere et al. (2009) describes **phatic communication** as “checking” if communication channels are open, to prolong communication, to discontinue it, to attract attention or to confirm continued attention. Phatic communication has merely a social function and does not contain any information (ibid). Examples of phatic communication are small talk, eye contact and nodding when listening (ibid).

Backchannels are phatic signals such as head nods, eye blinks and vocal expressions like “uh-huh”, “yeah”, and “okay” (Fusaroli et al., 2017). These cues are used by the actors to provide and monitor positive evidence of mutual understanding. Interruption of such signals can be detrimental to the communication (ibid). In other words: the backchannels provide a positive feedback-loop.

Fusaroli et al. (2017) describes **alignment** as seemingly adopting each other’s linguistic behaviours. Such alignment starts with lexical alignment and can extend all the way to an alignment of situation models – common ground. Alignment is more prominent in situations of free communication, meaning that more implicit forms of negotiation are used to create common ground (ibid).

Theme 3.2. Joint Action

Clark (1996) describes joint action as “the coordination of both content and processes in the action of two or more individuals”, or to be consistent: “actors”. A joint action contains at least two actors who each perform actor actions, where these actor actions are used to achieve a shared goal. With such a shared goal it is necessary for the actors to coordinate with each other. From this shared goal the joint action is constructed. (Clark, 1996)

Let us start from the situation where two actors are engaged in joint action. Actions can be divided into phases: 1) the entry, which is the start of the action; 2) the body, where the action takes place; and 3) the exit, where the action is ended. These phases are quantifiable in time, which allows for time based coordination, such as the cadence strategy, the entry strategy and a leader/follower strategy. The cadence strategy is based on the predictability of each phase due to cadence, such as dance. The entry strategy utilises the exit of one action to initialise the start of another action, e.g. playing catch. In leader/follower situations the actions are aperiodic and thus have phases that can extend. The actors coordinate by keeping track of sub-phases. The easier it is to track these subphases, the higher the synchrony of that interaction. The extendibility of such

phases also allows for local repairs, adding in other joint actions and accommodation of temporary lapses in synchrony. Joint actions can also be asynchronous, for example the fact that you are reading this thesis, while I have written this sentence on the 26th of June, 2020. In this situation, there is still coordination in content. In such settings, the sender tries to make the processing optimal for the receiver. (Clark, 1996)

The actors can utilise different mechanisms to support their coordination. Such means of coordination support the belief in individual actors that others will act accordingly to that device, or, in other words, to create a mutual expectation – a common ground (Clark, 1996). When actors select a coordination strategy, it is expected that they use the principle of joint salience: the ideal solution for a coordination problem among two or more actors is the solution that is the most salient, prominent or conspicuous in respect to their current common ground (Clark, 1996). Vesper et al. (2017) list the coordination strategies shown in Table 2. However, for successful coordination, the actors must be able to pick up on signs from each other, but also from their environment. Signs are being made perceivable with the intention of being perceived, although the sign might not be deemed communicative by the receiver (Pezzulo et al., 2019). A signalling system is, as Clark (1996) Clark (1996) describes, “a showing and interpreting of signals” with the aim of soliciting the preferred response of the other actors. Pezzulo et al. (2019) offers a taxonomy of signs, as seen in Figure 10. Looking at Pezzulo et al.’s (2019) taxonomy of signs and Vesper et al.’s (2017) support mechanisms for coordination, you can see that different signs can be used to support different coordination mechanisms. For instance the expression of a joint action goal: this can be done verbally, but also using information transfer, e.g. a text message.

Type	Coordination mechanism	Explanation
Sharing sensorimotor info	Joint attention and shared gaze	Directing the attention and/or gaze of other actors towards the same object of interest.
	Sensorimotor prediction	Predicting the direction of other actors.
	Haptic coupling	Physically feeling feedback from the other actor, can be through another object (e.g. a couch).
	Multi-sensory processing	Combining information from different senses.
	Emotional expression	Picking up on the emotion that the other actor shows, or showing it yourself.
General mechanisms for coordination	Coordination smoothness	E.g. task distribution.
	Affordance	The ways of interacting that an object or the environment allows.
	Conventions and culture	E.g. giving three kisses on the cheek is culture. Language is convention. Are used to create common ground between members of a group through experiences.
Mental representations in joint action	Joint action goal	Having a clear goal of the joint action.
	Tast co-representation	Practicing how to perform the action.
	Monitoring	Noticing errors in the co-actor

Table 2: An overview of support mechanisms for coordination, as listed by Vesper et al. (2017).

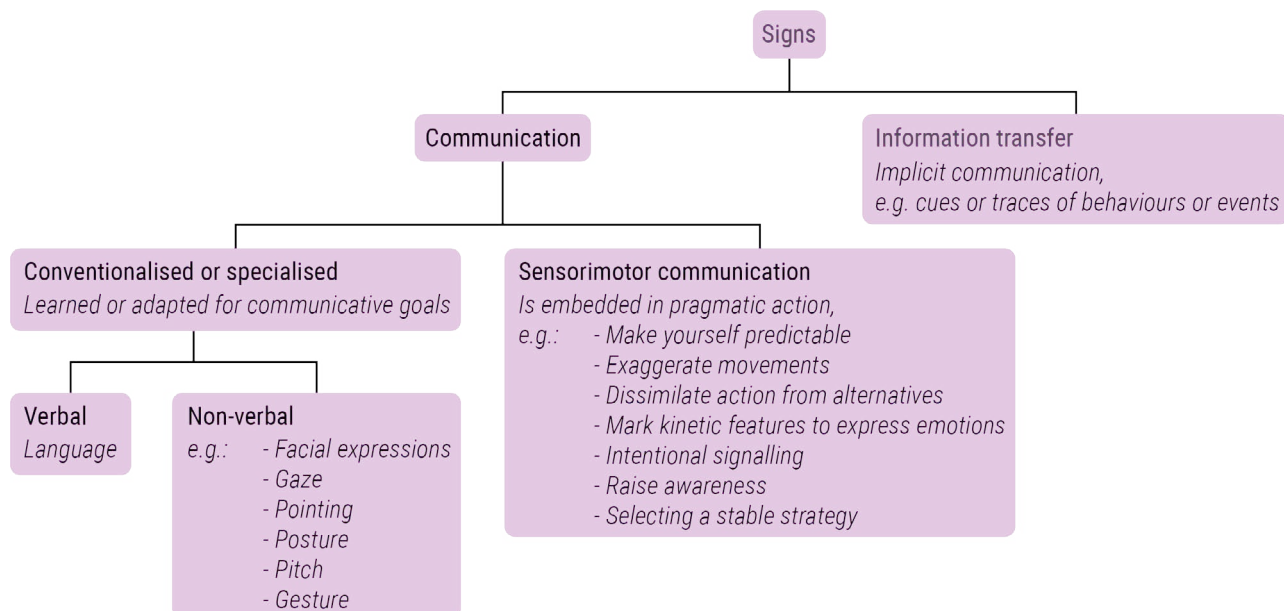


Figure 10: taxonomy of signs by Pezzulo et al. (2019).

		Sensory modality	
		Auditory	Visual
Sign type	Iconic	The sound “moo”	The image of a cow
	Digital	The spoken word “cow”	The printed word “cow”

Table 3: Signs according to Conway (1967). The example used here is the representation of “cow” using a verbal-audio, verbal-print or pictural channel (Conway, 1967).

The actors in an interaction make use of specific forms of signs in their coordination attempts to make themselves more easily “readable” by other participants (Pezzulo et al., 2019; Vesper et al., 2017). They might alter their behaviour to emphasise their coordination attempt, for instance by using exaggerated gestures or facial expression, or using more emphasis in their voice (Vesper et al., 2017). The actor to which this coordination is directed has to perceive these signs and process the coordination attempt properly. The success of communication also depends on the communication channel: the sensory modality that is addressed using that communication channel allows for certain sign types, which are either iconic (directly related to the subject) or digital (indirectly related, such as text) (Conway, 1967). Examples of sign types can be found in Table 3.

To summarise: people can perform joint action through means of coordination. For this coordination, actors engaging in the interaction can use different supportive coordination mechanisms, as shown in Table 2. The way in which this coordination attempt is communicated is through signs. Different signs can address different communication channels.

Theme 3.3. An embodied view on joint action

As De Jaegher (2013) already described, the body as a whole is engaged in making sense of the world. This is also true for joint action: the brain, senses, psyche, perception and movement are all engaged in joint action and are intertwined with each other (Marsh et al., 2009). For joint action, the physical proximity plays an important role: it allows for a close perception of that person, and allows the instantiating of a socioemotional connection with another actor. De Jaegher (2013) describes a person as being in a precarious state and acting in the world in such a way that they preserve themselves. In this light, it is easy to see a person as an energy system that tries to maintain a balance. Marsh et al. (2009)

states that exactly these dynamics of energy dissipation allows the emerging of a social unit. The possible stabilities in interpersonal coordination depend on these dynamics, for instance when the taller person alters their gait to accommodate for the smaller person (Marsh et al., 2009).

The enactivist view is more on movement of the engaged actors in the environment rather than the mental representation in the mind of the actor: the social unit as a whole is being studied. In this regard, understanding social action requires seeing the social unit with interpersonal and individual behaviour, individual disposition or group status, and the individual action capabilities. These all emerge as properties of embodied-embedded joint perception-action systems. (Marsh et al., 2009)

Theme 3.4. Utilising objects to coordinate

The previous sections focussed on sense-making and coordination between two or more human actors. But objects in the environment can play a key role in the sense-making and coordination process. Objects can be used by the actors to create common ground using a variety of coordination mechanisms from Pezzulo et al. (2019) list, such as pointing, joint attention and shared gaze. For pointing and shared gaze it is necessary that the objects are physically present, whilst joint attention can also be on a particular object that is not physically available or which does not have a physical presence, such as a concept (ibid).

The objects themselves can contribute to creating common ground by their affordances (a coordination mechanism) and their signals, such as spoken or written language, and information transfer of an action goal and task description. The signals that the objects use can be a mix of modalities, directly linked to the output modalities of the used object.

Some special attention has to be paid to written text. As Clark (1996) already states: coordination can be asynchronous. This means for the interaction that one actor is not necessarily physically present at the moment the other actors engage in the coordination. To expand on the example of the book, a written list of instructions is also an asynchronous coordination device. Such a list uses the coordination mechanism of convention in the form of written language (Pezzulo et al., 2019), and uses information transfer as means of signalling (Vesper et al., 2017).

Theme 4. Communication with autism

Most autistic adults develop with normal intelligence and fluent speech develop coping strategies to deal with the intricacies of social interactions (American Psychiatric Association, 2013). In fact, they might be so successful in camouflaging, that their autistic traits might go unnoticed (GGZ, 2017). But this does not mean that social interaction is easy for autistic people. They have trouble calculating social situations, which comes natural to neurotypical people (American Psychiatric Association, 2013). This can lead to misunderstanding of behaviour that is appropriate in a given social context, for instance leading them to act too formal or too casual (ibid). Such constant calculation and possible miscalculations can create anxiety in autistic people and drain their energy (GGZ, 2017).

Autistic people are likely to have trouble to naturally integrate non-verbal communication cues with each other and with verbal communication. During an interaction it might appear as “wooden or exaggerated body language”. How well the autistic person can integrate such cues and which cues are more difficult varies per person: some autistic people might have no trouble having eye contact, but might have difficulty in coordinating their hand gestures, or they might feel excited, but have trouble showing this in their facial expression or gestures. (American Psychiatric Association, 2013)

But when describing communication with autistic people, it is important to realise that the differences described are set against a background of standards set by a group predominantly neurotypical people (Fletcher-Watson & Happé, 2019, chapter 3 and 9). Neurotypical people therefore can have incorrect assumptions about autistic people, such as autistic people being unable to attach to someone, not having empathy and being anti-social (Fletcher-Watson & Happé, 2019, chapter 5; Frith, 2001). However, autistic people do have empathy, but expressing that in a socially acceptable way might be difficult (Fletcher-Watson & Happé, 2019, chapter 5), and autistic people have as much desire for relationships as neurotypical people (Sasson et al., 2017), but navigating the social environment might be difficult with an autistic experience of the world (Frith, 2001). Finally, autistic people might have trouble knowing what someone thinks, but feeling and caring for others comes natural (Fletcher-Watson & Happé, 2019, chapter 5).

Theme 4.1. The double empathy problem

As stated in the previous section, autistic people are navigating a world that is predominantly created by and for neurotypical people. Neurotypical people (and sometimes even autistic people) have trouble identifying the emotion displayed by an autistic person, or how to interpret their mental state (Fletcher-Watson & Happé, 2019, chapter 9). The non-verbal cues that autistic people use seem “off” in the eyes of neurotypical people, causing neurotypical people to quickly judge the autistic person negatively and make them apprehensive to engage in social interaction with that person, because of the level of uncertainty that brings into the social interaction (Crompton et al., 2020; Sasson et al., 2017; Sheppard et al., 2016). This is not due to the autistic person being less expressive: this depends strongly on the context (Sheppard et al., 2016). More interestingly: when an autistic person communicates with other autistic people, issues in communication are far less prominent (Crompton et al., 2020). To put it differently: the autistic person only experiences communication difficulties when their communication has to cross the “autistic-neurotypical divide” (ibid).

This experienced divide is exactly what is the case in what Milton (2012) describes as the “double empathy problem”:

“a disjuncture in reciprocity between two differently disposed social actors”

- Damien E.M Milton (2012)

The difference in disposition is autistic versus neurotypical. In a social interaction both the autistic and neurotypical actor experience this disjuncture, but experiencing this is rare for the neurotypical actor and quite common for the autistic actor (Milton, 2012).

During a social interaction between an autistic actor and a neurotypical actor, breakdowns

or failure to align will occur. Unfortunately, the actor who sees their form of interacting as “normal” might attribute this breakdown or misalignment to the actor whose style of interacting is seen as “different” (Milton, 2012). This creates the issue that the responsibility for such communication errors are then entirely put onto the “othered” actor (ibid). This “othering” can lead to internalised oppression, in this case by labelling interactions that are perceived as being “different” to negative connotations of autism (ibid). The “normal” neurotypical actor can then try to normalise the interactions made by the “othered” autistic actor, which the autistic actor can experience as an invasion of their autistic lifeworld (ibid).

This double empathy problem can be especially impactful when the autistic person is an adolescent. Autistic people might always have difficulty align with the tendencies of their peer group: they often lack insight into the neurotypical perceptions and culture, but as these perceptions are the norm, they still tend to have more insight into the neurotypical perception and culture than neurotypicals usually have into autistic perceptions and culture (with the exception of neurotypical people with experience interacting with autistic people, e.g. with an autistic family member)(Milton, 2012). Autistic people might not be aware of how their social behaviour is viewed by other actors, or are completely comfortable with how they express themselves (Sasson et al., 2017). But despite these difficulties, autistic people seek connection as much as neurotypical people and having trouble achieving such relationships can cause anxiety and loneliness (ibid). The added impact of the double empathy problem in an autistic person’s adolescence stems from the fact that during that time the peer group takes over roles that the autistic person’s family used to have: contributing to identity formation, offering a support network and contributing to general well-being (ibid).

Theme 4.2 Theories to explain the communicative differences seen in autism

There are several theories that attempt to explain the difficulties that autistic people have in interacting socially. The best known one is the Theory of Mind (ToM for short), which Sasson et al. (2017) use to explain the issues that autistic people have in seeing how their social behaviour is viewed by other actors – they have difficulty creating a mental representation of what the other thinks in a given context. Such mentalising is needed to understand socially and culturally transmitted knowledge (Frith, 2001).

Baron-Cohen et al. (1985) base their theory on a lack of shared attention as a starting point to explain autism and served to be a good pre-diagnostic marker (Fletcher-Watson & Happé, 2019, chapter 6). However, ToM does not explain all difficulties in autism, such as social and communication issues as a whole (Fletcher-Watson & Happé, 2019, chapter 6; Frith, 2001). It focusses on mind-reading while autistic people are very capable of empathy – it is where the wrong assumption of autistic people not being empathetic stems from (ibid).

Frith (2001) expands on the ToM with the mind blindness theory. This theory underlines that neurotypical people act with an implicit ToM, “allowing them to explain and predict others’ behaviour in terms of their presumed thoughts and feelings” (Frith, 2001). It expands on the ToM by stating that autistic people can learn to understand the mental states of other people, but do not use the same cognitive processes for that as neurotypical people (ibid). Neurotypically developing children use a start-up mechanism to quickly learn representing mental states, such as following a gaze. Through such a mechanism the neurotypical child is able to learn contextually and eventually develop a dedicated cognitive system for assuming mental states (ibid). Instead, autistic children have a hampered start-up mechanism, hence the tendency to take things literal and difficulty to apply social strategies more generally (ibid). They therefore rely on compensatory learning, a reasonably effective method, though Frith (2001) points out that this strategy is also slower and more error prone in more challenging social situations. As Frith (2001) already states, the theory of mind blindness accounts for issues in socialisation, communication and imagination, but not (fully) for other characteristics,

such as motor problems, perceptual processing and superior memory.

Fletcher-Watson & Happé (2019, chapter 6) also emphasise that autistic people are able to develop a way to represent the mind of others. There are three theories on why this occurs (ibid):

- The autistic person grows out of the differences seen in childhood – a slower and atypical development, but with (more or less) the same endpoint as a neurotypical child.
- The autistic person learns strategies to tackle situations that require mentalising, such as Frith's (2001) theory of mind blindness.
- Mentalising is difficult due to additional processing difficulties.

Fletcher-Watson & Happé (2019) offer several alternatives for the difficulties that autistic people have in social interaction. The first is monotropism, which describes the feature in autism where an autistic person can be highly engaged and focussed in certain in specific interests, rather than being moderately engaged and focussed in many (Fletcher-Watson & Happé, 2019, chapter 8). This explains the difficulty in social interactions, which requires distributed attention to many details at once (ibid). Another theory is the social motivation hypothesis, which explains the difficulties by autistic people finding social interaction less rewarding, thus choosing to engage less and therefore have less opportunity to practice (Fletcher-Watson & Happé, 2019, chapter 7). However, this is not in line with the statement that autistic people have as much desire for relationships as neurotypical people ((Sasson et al., 2017). The final theory is the social orientation hypothesis, which departs from a lack of preferential attention across all sensory domains towards social content from early childhood (Fletcher-Watson & Happé, 2019, chapter 7). However, there are many autistic people where the cognitive system that is responsible for prioritising social interactions is intact (ibid).

These theories, however, still do not account for other autistic characteristics outside of the social domain. An enactive cognitive approach is able to incorporate the sensory experience of autistic people (Klin et al., 2003). The basis of this approach is the believe that an active mind tries to make sense out of the social environment and the interaction used for this changes this environment (ibid). It has similarities to the enactive embodied approach to sensemaking by De Jaegher (2013), in the sense that the senses – the embodied cognition according to Klin et al., (2003) and the body according to De Jaegher (2013) – pick up traces from the environment and then the organism (or in the case of Klin et al., (2003), the mind) sets to work to process this information according to perceived importance. The difference between the two is the fact that Klin et al., (2003) still returns to the cognitive level of processing, where De Jaegher (2013) analyses the social process at an embodied level, so the physical organisms as a whole.

According to Klin et al., (2003) the difficulty in social interaction for autistic people lies in the fact that the social world is an "open domain", meaning that a multitude of elements must be taken into account at all times but only depending on their perceived importance. This importance is constructed from the context, the person's perceptions, desires, goals and ongoing adjustments (ibid). Social adaptation is normally learned over time within contexts and neurotypical people are able to generalise elements from such contexts, making them able to apply social strategies in similar situations (ibid). This is something that even comes natural to neurotypical people (ibid). But autistic people have trouble with that generalisation, for instance when they learn those social skills in a "closed domain" such as therapy (ibid). Klin et al., (2003) argue that in autistic people there is no proper link between social cognitive skills and social actions, so no transference of skills to new situations depending on similarities with previous experiences.

Klin et al., (2003) also argue that within the enactive mind framework, that social actions are full of sensory information that are displayed in a certain context, which also contains sensory information. All of this information requires perception and filtering on importance (ibid). It can therefore be the case that autistic people are simply overwhelmed by all the sensory information in social interactions, that they take longer to achieve similar hours of practising social skills (ibid).

The enactive cognitive approach already incorporates some aspects of embodied experience. However, it does not yet explain the autistic version of embodied sensemaking.

Theme 4.3. Embodied sense-making in autism

The enactive cognitive approach already incorporates some aspects of embodied experience. However, it does not yet explain the autistic version of embodied sensemaking. For this we (re-)visit the enactive embodied approach. This approach enables us to view autistic traits as a different embodied way of perceiving and responding to the world, instead of traits that need to be “treated away” (Di Paolo et al., 2018, chapter 10). Sense-making is a narrowing down of the world (De Jaegher, 2013) and autistic people use their own ways to establish that. With such different ways to experience the world, autistic people will inevitably experience it differently than neurotypical people (Di Paolo et al., 2018, chapter 10). However, communicating across these differences is difficult. It is clear that autistic people have difficulties in coordinating and interacting in a way that is easily perceived by neurotypical people, which will inevitably lead to hampered communication (De Jaegher, 2013). Such hampered communication is how neurotypical people learn to become flexible and creative interaction partners (De Jaegher, 2013). When overcoming the autistic-neurotypical divide, the neurotypical person being attentive and adaptive will play a key role.

Theme 4.3.1. Self-stimulatory behaviour

Let us start with self-stimulatory behaviour (or stimming). Autistic people use this behaviour to prevent themselves from becoming overwhelmed – they use it to regulate their emotions and to, in a sense, slow down the world. Neurotypical people are usually not familiar with this behaviour and might view it as “odd”. This is why many autistic people have adapted and regulate their stimming behaviour among people who are not familiar with such behaviour (Di Paolo et al., 2018, chapter 10; GGZ, 2017).

Theme 4.3.2. Sensory processing

Then the autistic preference for more detail oriented sensory processing, or “weak” central coherence. It generally is a slower way of processing, which is evident in autism: autistic people tend to “read” general direction of motion slower, and they find it easier to perceive movement when a video of it is slowed down (De Jaegher, 2013). This way of perceiving does allow them to be better at finding patterns, something that carries significance and joy in the lived-in experience of autistic people (De Jaegher, 2013). Additionally, other things in the environment are important to autistic people: in social interaction, they look less at eyes, are less likely to look at pointed at objects and are less sensitive to recognising human motion (De Jaegher, 2013).

This form of processing stimuli is also linked with sensory over- or under stimulation: in social interaction the autistic person perceives so many details, some of which are perceived more or less prominently by the autistic person, that it is difficult to successfully attune to what is going on around them (Di Paolo et al., 2018, chapter 10). Building a ‘full picture’ similar to a neurotypical person therefore requires more conscious effort (ibid).

Theme 4.3.3. Coordination

Autistic people also have timing differences: their rhythm capacity is different, usually of low quality (De Jaegher, 2013). Autistic people do not learn social skills in the same way as neurotypical people do: instead from learning in the social situation by being flexible and creative, autistic people rely on experiencing imitations (ibid). This can come across as a “script” for a social situation. This is effective in many areas of day-to-day interaction, such as making appointments, and can be a helpful coping mechanism for someone with autism struggling with close interpersonal contact (Di Paolo et al., 2018, chapter 10). But even then, their social skills can appear off: autistic people are generally able to copy the act they see, but not the person – it might miss some essential information to let the act appear natural (De Jaegher, 2013). However, autistic people can develop personal ways of coordinating with other people, such as tapping on someone’s arm instead of seeking eye contact to get attention (Di Paolo et al., 2018, chapter 10).

Theme 4.3.4. Coregulation

As already mentioned, autistic people tend to struggle with the amount of information that they need to take into account when participating in sense-making. This happens to such an extent that they are able to follow the verbal communication, but might miss other signals such as vocalisations, changes in posture and gaze and facial expressions (Di Paolo et al., 2018, chapter 10). This means that they can only regulate a part of the interaction. In practise, the autistic person is perceptive of interpretive sense-making such as sarcasm and humour, but that the complexity of the interaction leads them to hold on to information that they are more sure about (ibid). This is usually the more pragmatic part of the interaction rather than the expressive part (ibid).

Autistic people can respond to the tension that arises from participatory sense-making by over or under regulating, meaning that they are likely to regulate the tension on an individual level instead of a joint action level. An example of this is the autistic child performing echolalia (repeating knowledge) to assert their autonomy in the interaction. (Di Paolo et al., 2018, chapter 10)

Theme 4.3.5. The social interaction between autistic and neurotypical actors

Yes, perceiving the world in an autistic way does sometimes need managing, but can also be a source of joy (Di Paolo et al., 2018, chapter 10). Autism is heterogeneous, as is also the way autistic people experience the world and engage in social interaction (ibid). When taking the autistic person's difficulty to quickly adapt to social situations into account, it becomes clear that there is an important role to play for the neurotypical interaction partner: it takes social effort to understand autistic people, not only because of the autism, but also because the world is largely organised for neurotypical people (ibid). Instead of the autistic person adapting to this neurotypical world, the most effective communication between an autistic and neurotypical actor can be established by accepting the differences in making sense of the world.

Autistic people can communicate their wish to communicate in their own meaningful way, as the example of tapping instead of seeking eye contact demonstrates (Di Paolo et al., 2018, chapter 10). An attentive partner can adapt to these ways (ibid). It especially helps if the neurotypical actor has a history of interacting with the autistic actor: it will establish an interaction with their own specific rhythm characteristics (De Jaegher, 2013). The neurotypical actor can help the autistic actor to put the interaction in the appropriate rhythmic and interactive context (ibid).

Both parties could use objects to support shared sense-making (Di Paolo et al., 2018), for instance to share attention, alleviating the autistic person from parts of the sense-making process that causes them difficulties. An example can be limiting eye contact while keeping focus on the interaction by directing the interaction towards an object.

Theme 4.4. To conclude

The previous sections gave us insight into the way people communicate – with or without autism. To summarise, we can answer 1:

How do autistic people communicate?

For the embodied sense-making approach as outlined by De Jaegher (2013) is used, since this takes the interactors and the environment into account, in contrast to the cognitive method, where the interaction is explained on a processing level.

The communication process starts with how the interaction is being perceived and processed by each interaction participant. Autistic people have a lower tendency to create a "coherent picture" of the world, but prefer to process it on a more detailed level. This is slower processing style, but gives them an unique ability to memorise and exceptional eye for detail. Then they are also likely to experience sensory hyper- or hyposensitivity.

This slower processing does mean that autistic people have trouble keeping up in social interactions. Such interactions contain a vast amount of information: speech, the spoken

content, facial expressions, posture, gestures, verbal (phatic) signals, and intonation – and that is not taking into account the environment or any referred to items or concepts. In any social situation, the autistic person does perceive all the signals given by their interaction partner and the environment, but due to their processing preference, they can only rely on information that they are certain of to create a response that appears appropriate to them.

Autistic people develop methods to cope with this vast amount of information in social situations. Stimming is one of them, to block out sensory stimuli – ‘slowing down the world’ – and to regulate emotions. Another one is relying on ‘scripts’ in specific situations, e.g. when making an appointment. A third strategy is developing their own ways for coordination, such as using a tap on the arm to attract attention, instead of making eye contact.

But it is also important to take into account that autistic people mainly interact in a world that is created by and for neurotypical people. When two autistic people interact, the number of breakdowns in coordination is lower than when an autistic person and neurotypical person interact: they have a more similar processing preference to each other, than in regards to an autistic-neurotypical interaction.

When an autistic person and a neurotypical person interact, there tend to be more breakdowns, which can lead to a double empathy problem as described by Milton (2012), in the interaction. However, when the neurotypical interactor is flexible and open to the interaction cues of the autistic interactor, they too can establish their own rhythm of coordination. A longer interaction history between the two actors helps, since knowing each other’s communication style and preferences smooths the coordination process.

Theme 5. Co-design

Co-design sessions are used to create empathy in the designer regarding the intended end user (Mattelmäki, 2006, chapter 6). This is facilitated through the staging and scaffolding of co-design activities. These activities generally follow a certain order (seen from the view of the designer/researcher):

1. Tuning in: the designer/researcher starts with building empathy by doing desk research, examining personal experiences, brainstorming on the design space, literature review, expert interviews and/or focus groups (Mattelmäki, 2006, chapter 2).
2. Probing: each participant receives toolkit and does exercises without the designer/researcher present (Eriksen, 2012, chapter 6; Mattelmäki, 2006, chapter 4; Sanders, 2001). The participant is encouraged to self-reflect on a topic and to prepare themselves for the next activity (ibid).
3. The designer/researcher uses the output of the probing activity to create materials for a co-design session (Eriksen, 2012, chapter 4; Halse, 2008; Mattelmäki, 2006, chapter 4).
4. Participants and the designer/researcher take part in one or more sessions, where they engage with the offered materials (Eriksen, 2012, chapter 2; Halse, 2008; Mattelmäki, 2006, chapter 4; Sanders, 2001). At this stage, the participants can engage in steps 2) feeling, 3) dreaming, and 4) bisociation using the staged and scaffolded co-design activities (Sanders, 2001).
5. The designer/researcher uses the generated materials to inform the further design process (Mattelmäki, 2006, chapter 4; Sanders & Stappers, 2008).
6. The designer/researcher offers design proposals, the participants are invited to comment on them (Eriksen, 2012, chapter 5).
7. The designer/researcher uses the input to create a better design.
8. The designer/researcher presents a renewed proposal, with higher fidelity. Participant is transformed to user to test the functionality (Mattelmäki, 2006, chapter 3).

As Eriksen (2012, chapter 2) states: a design process is hardly ever linear. These phases can cycle to create design iterations. It is also possible that participation is ended after step 5 or step 6, or that step 2 is omitted.

Theme 6. Co-design with autism

It has only recently the voices of autistic participants themselves are being involved in research and design (Milton, 2014). Traditionally, professional caregivers, parents and practitioners were most prominently involved (ibid). However, listening to those voices leads to only second hand accounts of the autistic experience. First-hand accounts of living with autism can only come from the autistic person themselves – a lack thereof creates a distorted view in the produced knowledge (ibid). This is why a growing body of research in the field of co-design is incorporating autistic people as participants. Such involvement is not without challenges, as the following sections will prove. But once biases are overcome and the autistic person is accommodated, involvement in a co-design setting can be rewarding for all involved.

Theme 6.1. Assumptions about co-design with autistic participants

Autism is regularly described as a “severe disorder of communication, socialisation and imagination” (Fletcher-Watson & Happé, 2019, chapter 1). This immediately creates a set of assumptions that are not in line with the actual autistic experience.

Let us start with one that is quite prominently featured in the claim: autistic people have no imagination. It links directly to two commonly made assumptions: 1) that autistic people are not creative; and 2) that autistic people have no empathy. To address the first point: autistic people are creative, but only will show that side when their needs are met (Fabri & Andrews, 2016). This seems to be linked to appearing to have no desire to share their thoughts and feelings (Fabri & Andrews, 2016). However, this can be explained with an autistic person’s difficulty initiating joint attention (Mundy & Newell, 2007): they do have the desire to share their thoughts and feelings, but might have difficulty to do so. To address the second point: autistic people are actually very empathetic, but might show it in a way that is not directly understood as such by neurotypical people (Fletcher-Watson & Happé, 2019, chapter 5). Therefore autistic people are imaginative, but might have a difficulty in expressing it in a way that is understandable for their neurotypical interaction partners.

Another assumption is that all autistic people are visual thinkers and therefore prefer visual explanations. However, autistic participants prefer information with as little frills as possible. Any images should really add something – which not necessarily means adding images to information. (Fabri & Andrews, 2016)

Autistic people can have trouble focussing due to their preference to process sensory information at a more detailed level instead of creating one cohesive view (Fletcher-Watson & Happé, 2019, chapter 5). But this does not mean that autistic people always have trouble focussing. On the contrary: autistic people can be completely taken up by a subject or activity, creating a state of hyper focus (American Psychiatric Association, 2013; Fletcher-Watson & Happé, 2019, chapter 5).

Finally, a point has to be made about the authentic performance of autistic people. They learn to mask their self-stimulating behaviour from an early age in order to be more easily understood and accepted by neurotypical people (American Psychiatric Association, 2013; GGZ, 2017). However, this does mean that an autistic person might use these camouflaging techniques when co-designing. But when the designer/researcher takes time to get to know the autistic person and invests in making a genuine connection, the designer/researcher can encourage the YAA to show their unmasked selves.

Theme 6.2. Examples of co-design with autistic participants

Recent years many projects have popped up in which autistic people are invited to partake in co-design activities. For this thesis, I highlight three projects: 1) a project by Zhu et al. (2019) where they engaged autistic adolescents in an iterative design process; 2) the participatory design sessions that Frauenberger et al. (2017) conducted with autistic children; and 3) a project by Gaudion et al., (2015), which involved autistic people with limited speech.

Theme 6.2.1. Co-design workshops with autistic adolescents

Zhu et al. (2019) created a set of workshops during which the participants (the autistic adolescents) were invited to collaborate on creating software that would assist them in daily life. The workshops guided the participants through three design cycles, each consisting of the phases plan, design, build, test and review.

The project by Zhu et al. (2019) allowed participants to gain new insights during each design iteration. The open ended approach gave the participants space to explore their needs and use that information to determine the goal of the software. But more importantly, after each design iteration the participants became more aware of their design choices, resulting in better design decisions in the second design round thanks to the reflection process incorporated in the iterations. In the light of Zhu et al. (2019) research, it shows that one factor of success is implementing a moment of reflection in the design process and allowing the participants to improve their previous work. However, not much is mentioned in this paper about the social dynamics of this evaluation. It seems the most important thing during evaluation is that the criticism is aimed at the design, not at the person.

Zhu et al. (2019) made an effort to immerse themselves in the prospective participant group by being involved in the computer club that would facilitate the workshops. This way the participants and the parents were able to get to know them in a more informal way before starting the project, improving trust between the groups. Zhu et al. (2019) noted that the involvement of parents is important as they will be able to support the participants – even when they are not present during the workshops.

Finally, Zhu et al. (2019) make a case for the duration of their research. The two months of the co-design project plus the time used to immerse themselves in the group, combined with the iterative nature of the project allowed the participants to make more significant contributions and have better collaborations (ibid).

Theme 6.2.2. Co-design sessions with autistic children

Frauenberger et al. (2017) used a co-design method where they created custom co-design workshops for autistic children. During these sessions, the children were invited to create personal smart object. The sessions were creating using a visual mapping tool. This tool contained an overview of co-design techniques that could be used, what phase they could be used in and what tools could be used in each technique. Then the team could assemble a session selecting tools in the categories of method repertoire or child specific repertoire. The team also added characteristics of the context, the child and the designers. Finally, results from previous sessions were added. Using such a visual planning tool allows each session to be tailored to the needs of the child with ASD.

Theme 6.2.3. Co-design sessions with autistic people who have limited speech

Gaudion et al., (2015) conducted a co-design project with autistic people with limited speech. They organised workshops in a variety of settings: some were with the person with ASD, the caretaker and the design-researcher, another set was done without the design-researcher present, and concluded with a set of activities with just the caretaker and designer. Having the caretaker there and doing the activities in a setting familiar to the participant with ASD helps the participant feel comfortable and fully engage with the material.

Some of the materials were tailor made for the user group: the Kingwood Sensory Cards were derived from a sensory preference questionnaire (Gaudion et al., 2015). This questionnaire would not have been a proper fit for the autistic participants, as they have difficulty answering written questions. Instead, the Kingwood Sensory Cards allowed the participants to engage in a visual and physical way with the cards, as shown in Figure 11. This case emphasises the need for familiarity and tailoring of activities to the particular needs of the co-design participants (ibid).

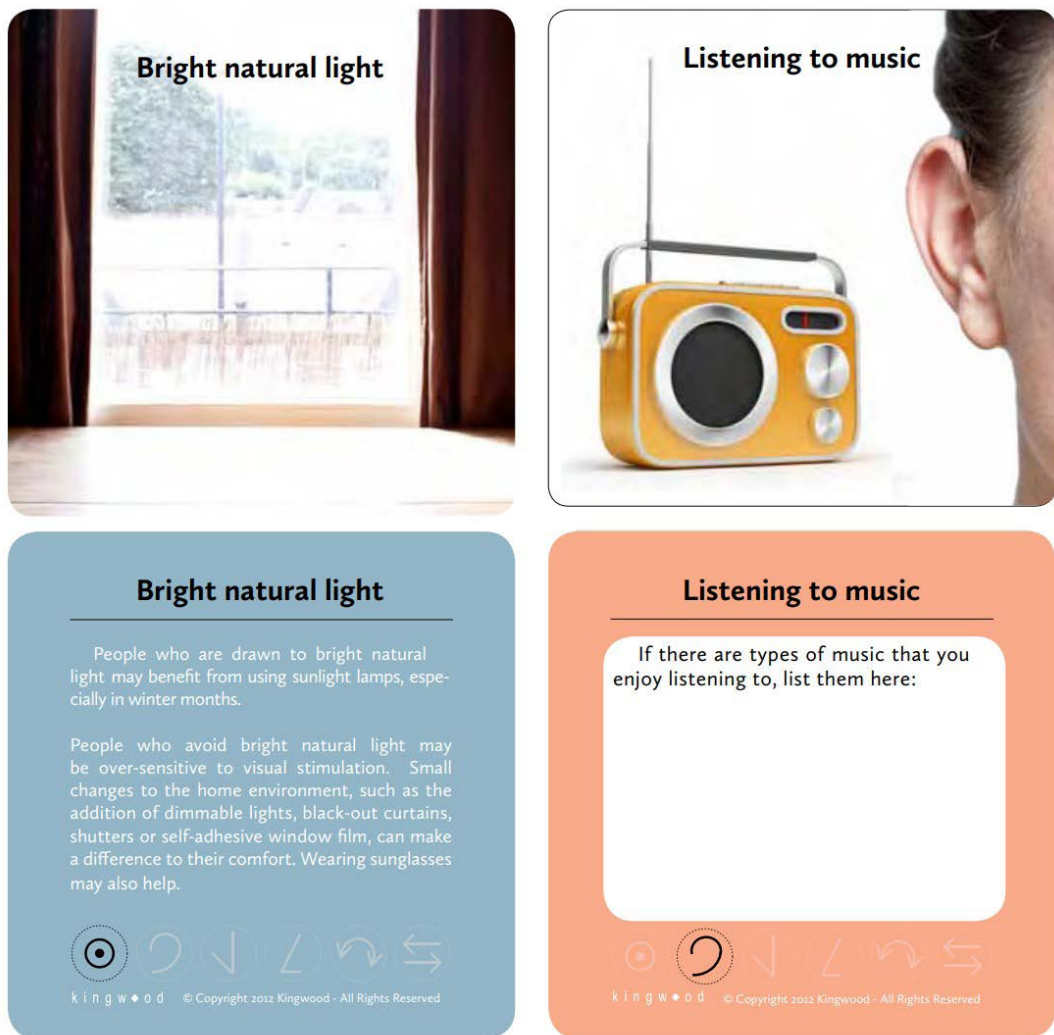


Figure 11: two examples of the Kingwood Sensory Preference cards (image by Brand & Gaudion, 2011). The cards show an image and short description on the front, and a colour code, more extensive description, sensory category and the option to add extra information (Brand & Gaudion, 2011).

Theme 6.4. To conclude

We can use the examples about co-design with autistic participants to theoretically inform the answer to sub-question 3:

How do you setup a successful co-design activity with autistic participants?

However, the first point to be made here is that autistic people are perfectly capable in participating in co-design activities: they are imaginative and empathetic, and have experiences and opinions that they would like to share.

Each of these projects had a different target group: the different ages and different capabilities of the groups created their own set of limitations. Each group, and in Frauenberger et al.'s (2017) case each participant, required their personal approach to successfully engage them in a co-design process. When accommodated, this was managed successfully.

The key here is to accommodate the autistic participants: creating a familiar environment, be sensitive to individual capabilities and to allow time to establish a relationship based on trust between the designer/researcher and autistic participants. This should help the autistic participants in feeling comfortable to express themselves. The co-design process can further be supportive of the autistic participants by offering information without frills in a modality that suits them – most autistic people are visual thinkers, but only like visual information when it truly adds something to the transferred information. Guiding focus will also be important, by limiting distractions. Theme 8, 'Co-design with autistic participants' will explore ways to accommodate autistic participants in more depth.

Theme 7: Communication in co-design

When looking from the perspective of the designer/researcher, the co-design process usually contains the steps mentioned in Theme 5: 'Co-design'. In this process we have three actors that are in constant communication with each other: the participants and the designer/researcher, who use verbal and non-verbal communication to transfer information and to co-ordinate, and materials used in the co-design session. These materials can either be used for information transfer or as a way to mediate the communication. Additionally, the location of the co-design activity influences communication in different ways.

Theme 7.1: Role of the participants

In co-design the core belief is that everyone is creative. The role of the participant in a co-design session depends on their level of creativity, their expertise and their commitment in relation to the co-design topic. The participant can be the 'expert of their experiences' when given the proper tools for self-expression. (Sanders & Stappers, 2008)

The participants can be a part of one or more overlapping communities of practice (CoPs) that are related to the domain of the design issue (Eriksen, 2012, chapter 2). A CoP is a group of people who share a concern, issues or a passion for a certain topic and who deepen their knowledge and expertise in this area by interacting on an ongoing basis (ibid). CoPs can be formally organised in e.g. a union or club, but this is not always the case (ibid). Thus, each participants represents one or more CoPs, which can overlap and represent different voices in the design process (Muller, 2002).

The role of the participant in relation to the designer/researcher can involve (Mattelmäki, 2006):

- Participant as patient: the designer is the expert, trying to remedy the participant.
- Participant as teacher: reaching the designer, who then let's go of their preconceived ideas.
- Participant as designer: the participant is the expert in their personal dreams and is seen as a creative person. The participant creates suggestions and/or solutions in collaboration with the designer/researcher.
- Participant as muse: the materials generated with or by the participants are used as inspiration by the designer/researcher.

The aim of a co-design session is to not place the participant in the role of a patient, but in that of the designer. As a by-product of the co-design setting, the participant can also be a teacher or a muse: the co-design activity allows the participant to teach the designer/researcher about their lived-in experience, and the session's results are used as inspiration by the designer/researcher. To place the participant in the designer role, the co-design session must be tailored to their level of creativity (Sanders & Stappers, 2008).

Theme 7.2. Role of the designer/researcher

The designer/researcher is essential in placing the participant in the role of designer. Depending on the level of creativity of the participant the designer/researcher has to be able to adjust activities towards the participant (Sanders & Stappers, 2008):

- Lead at level 1 (doing)
- Guide at level 2 (altering)
- Provide scaffolds at level 3 (making)
- Offer a clean slate at level 4 (creating)

The list above describes the designer/researcher in the role of facilitator. This role is described as: offering relevant opportunities for self-expression to the participants regardless of their level of creativity. This means altering exercises to suit the participant, not push their creativity beyond the level of their capability. (Eriksen, 2012, chapter 2; Sanders & Stappers, 2008)

Theme 7.3. Role of the materials

The goal of co-design is to create design empathy. The materials used in this process have to be designed in such a way that this design empathy is established – a design process in itself. Mattelmäki (2006, chapter 3) distinguishes five goals for which the physical appearance of the available materials aim to:

- Motivate and direct performance – or as Eriksen (2012) presents it: to scaffold and stage.
- Provide stimuli and provoke the participant's perspective.
- Be motivating to the designer/researcher when they design the co-design materials.
- Be an empathetic exercise for the designer/researcher: the toolkit must be in line with the level of creativity and the field of ability of the participants.
- Be a means of documentation.

Co-design activities can be used with different purposes: to investigate the participant's opinions, feelings and dreams, or to get a better understanding of the current practice of the participants. In the first case, emotional toolkits are better equipped, for instance with collage making (Sanders, 2000). Such toolkits contain more ambiguous and stimulating material (Mattelmäki, 2006). In the case of better understanding the current practice, more cognitive toolkits are more useful, such as enactment and mapping (Sanders, 2000).

Co-design materials are often low tech and cheap for easy adaptation, visual and tangible to support designerly (visual) thinking, ambiguous to allow room for interpretation, playful and pleasant to inspire participants to imagine different futures (Mattelmäki, 2006; Sanders, 2000). However, incorporating more interactive materials in toolkits has become more common, such as the use of smartphones for making video, instant messaging and making voice recordings (Mattelmäki, 2006). Incorporating devices most participants already have or providing devices broaden the options for probing (ibid). Advantages of such devices and software is that results are already digitised, can be sent using the device, the received digital material can be sorted into a database automatically, and the participant's engagement can be tracked and moderated (e.g. with reminders) (ibid).

Theme 7.3.1. Probing and reworking material generated with probes

Probing is the process of offering packages of activities (probe kits) to participants and having them do these activities by themselves. It can be used a separate kit in a series of individual or guided activities, or be part of a larger toolkit. These probe kits are aimed at self-documentation of specific personal experiences, perceptions, activities, dreams and needs of the participant. The information from probes can be used as such, or to inspire the designer/researcher, but most importantly to create a dialogue between the participants and the designer/researcher. The latter is not only established by the participant doing the activities and in the process telling something about themselves, but also in meetings between the participant(s) and the designer/researcher (e.g. during kit delivery), the designer/researcher's design of the toolkit to be appealing and playful, by sensitising the participants on the design topic, letting them express personal experiences, opinions and feelings through the probe kit, and by creating an inner dialogue in the designer/researcher. All items on this list contribute to the empathetic view of the designer/researcher. (Mattelmäki, 2006, chapter 3)

Prompts in probe kits are open ended and allow the participant to explore the design topic and their own creativity. Probes are used to capture the lived in experience and context of the participant, without disturbing this experience with the presence of the designer/researcher there. By letting the participant gather and reflect in their own environment can help them and the designer/researcher create suggestions for the design. Offering such open and varied tasks to participants also means that they can execute these activities in unforeseen ways. Even unsolicited ways, as an anecdote of a series of bum-shots on a disposable camera were the result of participants having a run with an activity. (Mattelmäki, 2006, chapter 3)

Processing probe kits can be done in different ways. It can be used unprocessed as inspiration or information for the designer/researcher, but it is more likely the materials generated in probe activities (probe material) are used in co-design sessions (Eriksen, 2012, chapter 4; Halse, 2008; Mattelmäki, 2006, chapter 4). For these sessions the designer/researcher reworks the probe material to create an estranged view, for instance by selecting snapshots or short video fragments (Halse, 2008). Participants confronted with the material are more likely to tell about their underlying thoughts and motivations when confronted with a non-coherent presentation of materials – they have to piece together the story by themselves (ibid). This tension between familiarity and estrangement is a way to achieve playful otherness (ibid). Allowing participants to interact with their generated material is also important to account for the retrospective nature of most self-documentation: most people tend to document their behaviour only after the action is over, meaning that some parts of the experience might be lost (Mattelmäki, 2006, chapter 5).

Theme 7.3.2. Delegated roles of co-design materials

Material scaffolds are often not self-explanatory: their intended (delegated) role is staged and scaffolded by the co-design organiser (the designer/researcher) (Eriksen, 2012, chapter 5). The staging and scaffolding is done through verbal communication or a printed guide (ibid). During the co-design session the tangible scaffolds and content materials merge in the process of materialising (creating) and end up as one shared materialised output. Using the division by Eriksen (2012), the offered materials in a toolkit or co-design session can have one of the following delegated roles:

- **Agendas and schedules as “time and topic keepers” or “delegated tutors”**: provide explicit structure, when used in combination with the materials used to stage and format the co-design session (Eriksen, 2012, chapter 4). This structure helps participants to feel more comfortable and supports them in doing the activities in the session (ibid). These items can serve as important mediating actors: they are used as resources when plans are changed on the fly (Dijk et al., 2013, chapter 4).
- **Content materials as “delegated playmates”**: open-ended and sometimes pre-designed materials the participants use to play with, explore, frame and reframe the co-design topic, and ultimately, create their representations (Eriksen, 2012, chapter 5; Sanders, 2001). These materials can be ambiguous, which means that the participants must negotiate the meaning of each piece of material and combinations of them. Especially generic materials can have such ambiguous quality (Eriksen, 2012). Materials that seem unrelated to the topic at hand help to stimulate divergent thinking (Eriksen, 2012, chapter 5; Mattelmäki, 2006, chapter 4). Pre-designed content material is brought in with a specific plan or meaning, such as scenarios, mock-up kits, maps and prototypes (Eriksen, 2012, chapter 5). Within these content materials, two important subcategories exist:
 - **Tools as “delegated handymen”**: they are not part of the created representation, but are an offered means of materialising it. (Eriksen, 2012, chapter 5)
 - **Pre-designed proposals as “delegated advocates”**: these materials serve as mediators between the makers of the proposal and the people commenting on it. In other words: they set the stage for discussion and negotiation. (Eriksen, 2012, chapter 5)
- **(Tangible) scaffolds as “delegated coaches/assistants”**: scaffolds create a shared understanding among participants of the topic at hand and through the affordances offered by the scaffold, the participants’ actions are guided (Eriksen, 2012, chapter 5; van Dijk, 2013, chapter 4). In other words: scaffolds offer a background to work on (Sanders, 2000). Like content materials, their meaning might be negotiated, for instance by checking with other participants on what to do with the scaffold material (van Dijk, 2013).
- **Guides as “delegated instructors”**: a set of instructions that is offered to the participants to explain “how to be co-designing” (Eriksen, 2012, chapter 5). It prevents long discussions and go right to “doing”. Warmup activities can be part of this (ibid). When the designer/researcher is not present at the activity, the guide can be used to stage the co-design (ibid). A special form of a delegated instructor is (ibid):

I prefer using the phrase ‘toolkit’ as it is broader than just probes. This will be further explained in the section ‘Design Your Life’

Though Agger used the term “formats”, scaffolds is preferred here in relation to related co-design practices. The term “formats” can be used interchangeable with “scaffolds”.

- **A prompt:** an open ended question with a short explanation: “do this how you see fit as long as it makes sense to you” (Sanders, 2000). The prompt is a central part of the guide and sometimes the only thing comprised in the guide.
- **The physical location as a part of the co-design materiality** : see the section about “the role of the co-design location”. (Eriksen, 2012, chapter 5)
- **Created artefacts as “delegated representatives”:** the objects, arrangements, scenarios, futures, et cetera are the artefacts created in a co-design session. These make an abstract concept concrete. Artefacts created in a co-design session serve a social role as they spark discussion and fuel negotiation, but especially as a way to let the participant express their emotions, opinions, dreams and experiences (Eriksen, 2012, chapter 2; Muller, 2002; van Dijk, 2013, chapter 4). An object can be used to spark memories, experiences, stories, feelings, places or atmospheres, or lets the participant explore its aesthetic and sensory qualities (Mattelmäki, 2006). It can represent a challenge (e.g. taking up time, space and money), be a symbol of what the participant aspires to be, or be used work towards the means of achieving a goal (which can also be “having fun”!) (ibid). Creating descriptive artefacts such as collages offers a non-traditional way for participants to express themselves. By using a way of expressing that is new to the participants, they have to reflect on differences between their creative approach and everyday practice (Muller, 2002).

Theme 7.3.3. Documentation

The self-documentation by the participants is in itself not enough to sketch the complete picture of the design issue at hand: the produced materials are by themselves ambiguous (Mattelmäki, 2006, chapter 3). The produced representations in a co-design session are also insufficient to capture all the stories, experiences, opinions and emotions related to that item – the representations are embedded in the social situation (Van Dijk, 2013, chapter 4). Therefore it is important to supply these generated materials with documentation. Mattelmäki (2006, chapter 2) and Eriksen (2012, chapter 2) use Elisabeth Sanders’ SAY-DO-MAKE approach as their starting point: use interviews to listen to the participant, then use observations to see what they do, and finally let them express their feelings and dreams in exercises suitable for them. This way, the outcomes of the self-documentation is annotated by the participants themselves, thus enriching the materials.

It is important to plan the documentation during the design stage of a co-design activity. Not only recording the generated materials from probing and co-design sessions, but also capturing the discussions that take place. Such documentation are valuable for enriching insights or even creating new ones. (Eriksen, 2012, chapter 6)

Theme 7.4. Role of the location

For co-design it is important to see products, interfaces and spaces as scaffolds onto which people can create their own experiences (Sanders, 2001). In co-design this is often done in the shape of a workshop. During such a workshop, participants are invited to work together, share insights, use these to create shared outcomes (Muller, 2002; van Dijk, 2013, chapter 1).

As previously discussed, most participants are not designers. On the other hand, it is likely that the designer/researcher is not a member of the group to which participants belong. This means that the participants and the designer/researchers occupy their own particular space. The overlap between these spaces is the “hybrid space”, which is characterised by unpredictable and ever changing combination of attributes of both spaces (Muller, 2002). This particular space can hold the variety of perspectives needed for co-design and thus can be used to collectively fully define the relevant problem and how to frame it (ibid). Muller (2002) states the advantages of this hybrid space are:

1. Improved learning and understanding: the hybrid space offers space for mutual learning. Depending on the location of the activity, certain voices will be strengthened.
2. Greater ownership: it strengthens the involvement of the participant (the prospective user) in a project as well as commitment and ownership of the knowledge and the

design created in the project.

3. Development of new concepts: as stated earlier, two of the roles that the participant can take on is that of designer and of a muse. More voices inform a richer design. This design not only benefits the users, but also the community.

But as the first point implies: some participants might be at a disadvantage when they are not in their familiar environment. Muller (2002) advises to choose a location familiar to the designer/researcher when you want to hear the voices of many users and their shared experiences, but emphasises the risk of creating a situation where participants tend to stick with more general views. The other option is to use the participant's location where they feel more comfortable and can easily refer to objects since they are likely a part of the environment, which will result in conversations that are grounded in the location and involve concrete and specific experiences. (ibid). Often a combination of both locations is used: the participant's environment to generate user specific accounts of experiences, and the designer/researcher's location to reinterpret these materials (Mattelmäki, 2006, chapter 3; Muller, 2002).

Additionally, the materiality of the used location must be taken into account. The choice of location and its surroundings influence what kind of co-design can take place: how can furniture be arranged to support certain activities? The staging of the co-design activity is influenced by the location and has to be taken into account when preparing the event. (Eriksen, 2012, chapter 5)

Theme 8: Communication in co-design with autistic participants

The main aim of co-design with autistic people is to give them a voice in research about them and design for them. As shown in the three cases in Theme 6, 'Co-design with autistic participants', co-design is very well possible with autistic participants. The regular co-design process as seen in Theme 5, 'Co-design', can still be followed, but accommodation of the needs of the autistic participants is necessary to make co-design a success for all involved parties.

Theme 8.1. Accommodating autistic voices in co-design processes

To begin, a hybrid space as described by Halse (2008) that amplifies the voice of the autistic person needs to be established. For this, the autistic voice needs to be strengthened instead of 'othered'. Any co-design session is likely to be set up by a design or research team that will not be (fully) made up of autistic people. Instead, the designer/researcher needs to rely on design empathy, understand autism better and to inform their design process. However, using the insights offered by Sinclair (2010) helps to create a hybrid space, as described by Halse (2008). Tips for creating a hybrid space that suit the needs of autistic participants are based on those used to create an autistic space: a space developed by and for autistic people (Sinclair, 2010). These tips are:

- Accommodation of heterogeneity by offering options;
- Clear communication: reduce ambiguity to a minimum and also state reasons behind them;
- State personal needs explicitly: autistic participants already have trouble guessing someone's emotional state and anticipating their needs. This makes it everyone's personal responsibility to state their needs clearly;
- Provide information to prepare with: this lowers the anxiety in the person with autism. This is especially important in co-design, where the autistic participant is faced with new people, new activities and possibly new environments. Such preparatory materials can be sharing an itinerary or schedule, having time to get to know other people involved in the co-design process and being able to see pictures of the location beforehand;
- Planning downtime after activities: especially important when exposed to new sensory stimuli, such as new people, places or activities.

All of the points above are not only to accommodate the autistic person, but also to support a neurotypical person in an autistic space, especially if this neurotypical person is for once the exception in a group. This is likely to create the same difficulties as autistic people experience in the (neurotypical driven) outside world (Sinclair, 2010). But as mentioned earlier, the co-design process is still likely to be dictated by a neurotypical design or research team. Using the guidelines as stated by Sinclair (2010) helps to create a hybrid space that uses the autistic experience as a basis and by doing that, closing the autistic-neurotypical divide.

Theme 8.2. Role of the YAA

The participation of autistic people in co-design is a quite recent development. Professional caregivers, parents and practitioners were more prominently featured voices, serving second hand accounts with not rarely the intention of minimising or 'treating away' autistic traits (Milton, 2014). This intention put the autistic person in the sick role: they were treated as recipients of the expert advice of care professionals, with the aim to either treat or cure the autistic person to a contributing member of society (ibid). This later transformed to the rehabilitation role, in which all people are placed who are unable to achieve a level of functional role. The goal is then to achieve this norm or to pass as normal, which is patronising (ibid). But as already argued in Theme 4: 'Autistic communication', the autistic way of perceiving and communicating is fundamentally different from a neurotypical person. This view helps to remove the sick role stigma (ibid).

Instead, the role the YAA should be able to take on in a co-design project, should be as the expert of their own experience – just like Sanders & Stappers (2008) argue for the role of any participant in co-design. The new view of the autistic participants role can be best expressed by the following quote:

People with autism are not dependent and helpless, but require their own voice, to claim ownership of autistic production and celebrate autistic culture and biodiversity.

- Milton (2014)

To refer back to Theme 5, autistic participants can be placed in the roles of: 1) teacher, teaching the designer/researcher about their lived in experience; 2) designer, where the YAA is the expert on their personal dreams and is seen as a creative person who works on suggestions or design solutions in collaboration with the designer/researcher; or 3) muse, where the materials generated in co-design sessions with YAAs offer inspiration for the design process of the designer/researcher.

Theme 8.3. Role of the caregivers

In the context of co-design, the phrase caregiver is used here to describe both professional caregivers and informal caregivers, such as parents or guardians. As the previous section already argued, the main voice to be featured in co-design settings with autistic participants is that of the autistic person themselves. This in turn means that the caregiver will take on a more peripheral role in the co-design process, such as that of motivator, co-design partner and of advisor.

Zhu et al. (2019) gives one example of the motivator role, as the parents of the autistic adolescents were an important source of support in the process. The parents were not present at the co-design sessions, but were informed of what happened during the sessions by the participants or by the design team (ibid). The parents encouraged the participants to continue working on the project and reminded them to complete tasks (ibid). This worked well because of the long established relationship between the YAA and the parents.

Gaudion et al. (2015) shows an example of the co-design partner role. In their research, the caregivers of the autistic adults with limited speech help them to complete the activity, supporting them by asking reflective questions and helping them understand the task at hand (ibid). It is important here that the caregiver does not fill out answers for the autistic participant, since this will take away the amplification of the autistic participant's voice.

Finally, the caregiver can be a source of advice for the designer/researcher when setting up the co-design activity. This is visible in the co-design sessions with children by Frauenberger et al., (2017), where a profile needs to be made of the autistic child in order to create co-design sessions that are in line with the child's capabilities and interests. The team conducted interviews with the participant's mother, teacher and caregiver, and used that information as part of the profile that they sketched of the child (ibid). The emphasis here is on "part of", as this profile was supplemented by observations and interactions that the team had themselves with the participating child. This prevents incorporating only the second hand experience of the autistic traits. The design team used the information to create co-design sessions that fitted the autistic child's profile (ibid).

The caregiver should therefore be encouraged to not take on the role of "healer", viewing autistic traits as something to treat away, as it puts the autistic participant in the patient role. Instead, taking on the role of motivator, co-designer and advisor helps to amplify the voice of the YAA.

Theme 8.4. Role of the designer/researcher

The designer/researcher brings their design expertise to the co-design project. Their role is the same as described in Theme 7, 'Communication in co-design', but with the additional objective of strengthening the voice of the YAA. To achieve this, the co-design activities must be set up in such a way that they accommodate the autistic participant's way of perceiving and communicating. Francis et al. (2009) compiled a list of ways in which autistic participants can be accommodated in co-design sessions. Their main takeaways are:

- **Make sure you are familiar with the participant and their diagnosis** (Francis et al., 2009). Understanding the participant's unique profile of skills, challenges, likes and dislikes and facilitating these is crucial for proper data gathering, as well as the comfort and safety of the participant (ibid). This can be done by taking time to build a relationship with the autistic participant, as Zhu et al. (2019) did, and using the information to select and create activities that are suitable for the autistic participant, alike Frauenberger et al. (2017)
- **Preserve the participant's self-image and control.** Know what can cause discomfort and what threatens their self-interest. Emphasise that quitting is always possible and that there is no right or wrong outcome. (Francis et al., 2009)
- **Use an environment that is familiar to the participant** (Francis et al., 2009). This will be discussed in Theme 8.7, 'The role of the location'.
- **Support the participant in areas where they might experience difficulty, such as keeping focus and recalling from memory** (Francis et al., 2009). Minimise distractions and use briefing and review sessions (ibid). This links back to knowing the individual capabilities of the participants. Some participants might require more support in certain areas than others.
- **Prevent ambiguity and select communication styles that suit the participant** (Francis et al., 2009). This circles back to the preference for most autistic people for communication without frills (Fabri & Andrews, 2016) and their difficulty to derive context dependent meaning (Fletcher-Watson & Happé, 2019, chapter 8). One example of communication adapted to suit the needs of the users are the Kingwood Sensory Preference cards (Gaudion et al., 2015). Another way to accommodate the participant in communication is by using examples that are in line with the everyday life of the YAA (Francis et al., 2009).

Naturally, the designer/researcher still has to make sure that the design activities are suitable for the level of creativity of the participants, both the caregivers and the autistic participant. This means adjusting activities according to the level of creativity where the participants are comfortable at.

Finally, the designer/researcher has the task of amplifying the voice of the YAA. This can be done directly, where the YAA is the only participant in a co-design session or where the designer/researcher is physically present to mediate the communication between caregiver and participant. Indirect mediation can be offered through activities and associated materials, for instance activities that utilise the strengths or interests of the YAA, or by offering activities where the YAA and the caregiver both have to be vulnerable by sharing personal information, thus creating a more even plane of communication.

Theme 8.5. Customisation of the co-design process

One of the most important ways of accommodating the YAA in a co-design process is by creating co-designs sessions and activities that suit the YAA's capabilities and respects their limitations. Yet every autistic person is different and will need different adjustments to the co-design process to be accommodated properly. The selection tool created Frauenberger et al. (2017), as described in Theme 6, 'Co-design with autistic participants', is one example for how personalisation can be incorporated into a co-design process with an autistic participant.

Theme 8.6. Role of materials

Materials can take on delegated roles in co-design contexts. In co-design with autistic participants, this is of added importance because mediation with objects is one strategy that can be used to improve participatory sensemaking between a neurotypical and autistic person (Di Paolo et al., 2018, chapter 10).

Scaffolds, guides, agendas and schedules are materials that need extra attention when being developed for co-design with autistic participants. Autistic people have a preference towards systematic activities and thinking styles. Rules, predictability and logic are what they usually feel comfortable at (Fletcher-Watson & Happé, 2019). Design processes unfortunately start with many “unknowns” and making decisions without having complete answers yet (the fuzzy front end, as Sanders and Stappers call it) (Eriksen, 2012, chapter 2) – quite the opposite of what autistic people might prefer. The offered materials and the designer/researcher play an important role in minimising the feeling of uncertainty. Scaffolds provide a clear “playing field” for the YAA to operate in. Guides without ambiguity help the YAA to understand the task at hand. Agendas and schedules help the YAA in managing anxiety in a new situation.

One important aspect in the offered materials is ambiguity. In the recommendations for communication in co-design with participants, it was advised to use clear, explicit communication – or: to limit ambiguity. However, ambiguity is an important element in co-design, as advocated by Eriksen (2012, chapter 5) and Mattelmäki (2006, chapter 4). A distinction must be made between content materials and in communicative materials, such as guides, schedules and task descriptions. Communicative materials need to lack ambiguity to support the YAA’s participation in the co-design process, while ambiguity in content materials is welcome as it allows the YAA to project their own meaning onto it and provoke discussions.

Theme 8.7. Role of the location

When co-designing with autistic participants, it is preferable to execute the co-design session in a location that is familiar to the autistic participant. Though field research offers less control, it allows for a better relation between the participant, the design activity and the object to design (Francis et al., 2009).

All three examples of co-design with autistic people used a familiar environment: the school of the autistic child in the case by Frauenberger et al. (2017), the care facility where the participants live in the case by Gaudion et al. (2015), and in the case by Zhu et al. (2019): the facility of the computer club that the participants attended in the eight months leading up to the co-design sessions.

Theme 8.8. To conclude

Communication in co-design can be mediated in a multitude of ways and the materials used in co-design play an important role here. This section informs a theoretical outline for the answer to sub-question 4: How can the toolkit mediate the communication between the YAA and the caregiver?

This starts with the accommodation of the YAA in the co-design process. Sinclair (2010) mentions offering options to accommodate heterogeneity (Frauenberger et al. (2017) used a tool for selecting co-design activities, for instance), communicating clearly and unambiguously, state personal needs clearly, provide information to prepare with, and planning downtime after activities. Other ways to accommodate the YAA is by giving them ample time to get to know the other people in the co-design setting and offering enough time to complete co-design activities – not only during a co-design session, but in the co-design project overall.

The toolkit must empower the YAA to share their experiences and opinions. This allows them to take the lead in the co-design process. The YAA should take on the role of expert of their own experiences. In that regard, the caregiver should take on the role of co-design partner, motivator and advisor. This means that the caregiver should refrain from

answering questions for the YAA, but let the YAA answer for themselves. The caregiver and the YAA are likely to have an already ongoing relationship, thus the caregiver is already familiar with the YAA's personality, interests, quirks and challenges. The designer/researcher, however, is someone who does not have a long interaction history with the YAA. The designer/researcher must therefore invest time in understanding autism in general and the YAA in particular, which means taking time to get to know the YAA. The designer/researcher is also responsible in creating co-design activities in such a way that they suit the YAA in their capabilities, sensory preferences and communicative needs, and offer support when the YAA experiences difficulties when doing the activities.

The co-design materials can play an important role here, as they can be used to scaffold, guide, instruct, schedule and communicate with co-designers. This not only is important for the YAA, but also for the caregiver, as both are likely not experienced with designing a product. Instructions, agendas, schedules and guides offer clear expectations and rules to follow, while scaffolds help to limit the design space, making it easier for the participants to keep overview and focus. The process of making artefacts and presenting them gives participants the opportunity to communicate their opinions, feelings and experiences.

A special characteristic of materials is ambiguity. In instructions, guides, agendas and schedules ambiguity needs to be limited as much as possible to allow clear communication. But in materials to create representations or scaffolds ambiguity can open up conversations that provide useful insights into the experiences, opinions and feelings of the participants.

Finally, it is advised to organise the co-design activity in an environment that is familiar to the YAA. This is most importantly to make the YAA more comfortable, but also to allow them control over that environment. The YAA's home or a location that they regularly visit, such as their school, are good options for co-design sessions. This does require the co-design materials to include all possibly necessary tools and materials, as it cannot be assumed that these familiar locations include such items.

Theme 9. The Design Your Life project and co-design

In this particular project there are some key differences to observe between the Design Your Life method and traditional co-design. The most important differences in this particular design case are: 1) the co-design process is led by the toolkit and the participants themselves, and therefore 2) the roles of the participants and the designer/researcher are different when compared to traditional co-design. Finally: 3) the process is aimed to empower the YAA to design their personal solution, instead of informing the design process of the designer/researcher. This section also provides a theory based answer to sub-question 5: What tools can be used to successfully support a co-design process between a YAA and their caregiver, but without the designer/researcher being present?

Theme 9.1. The roles of the participants and the designer/researcher

In Figure 2, the communication structure was already explained: the communication in relation to the design process of the YAA's product is between the YAA, their caregiver, the toolkit, and, eventually, the designed solution. There is only asynchronous coordination between the designer/researcher and the participants via the toolkit, since the designer/researcher coordinates with the participants by creating the activities and materials for the toolkit. The toolkit therefore takes over the facilitating role of the designer/researcher. The role of the designer/researcher is therefore that of researcher and toolkit designer. Both these roles are passive as they emphasise the fact that the designer/researcher is not a part of the co-design activities as they take place.

This is different than the design cases by Frauenberger et al. (2017), Gaudion et al. (2015) and Zhu et al. (2019), where the design team was still playing an active role as co-design facilitator and interpreter of the co-design output into workable material for other co-design activities or their own design process.

This setup in this case study is most similar to the probing activities as described by Mattelmäki (2006): the designer/researcher provides activities that participants complete by themselves, as input for further design activities. However, those further design activities are also provided and mediated by the toolkit, instead Mattelmäki's (2006) description of the designer/researcher using those materials to inform the co-design sessions following the probing activity. The participants must therefore be supported as designers. The role of gathering and reframing the results of activities is delegated to the participants and the toolkit, instead of the designer/researcher. The toolkit must allow of a central point of gathering activity output, to make it available for future activities and to allow the participants a point of reference in their design process.

Theme 9.2. A toolkit-led co-design process

It was already mentioned that the designer/researcher will not be part of the design activity space, as was visualised in Figure 2. In contrast to common co-design practice, the design-researcher will not be there when the participants do an activity and will therefore not be able to adjust activities on the fly depending on the participants' needs. Instead the activities must be set up in such a way that it can accommodate as many potential users as possible. But this is quite a challenge due to the strong heterogenic nature of autism (American Psychiatric Association, 2013), let alone personal preferences, challenges and skills unrelated to autism. This implies a quite generic toolkit, where variations are possible through offering options for how activities are being executed, and, where possible, room to select activities.

The YAA and the caregiver are likely not familiar with the process of designing a product, therefore the toolkit should facilitate guidance through this process and tailoring to their level of creativity and skills, though stretching even further than Sanders & Stappers (2008) describe by also supporting in their level of knowledge of a design process. This facilitation can be done on multiple levels, keeping the YAA's and caregiver's needs in mind. For instance, the toolkit needs to offer information when the participants need them, along with the necessary materials. A big document with all activities described in it for

all design iterations might overwhelm the participants, while piecemeal information will help maintain focus and interest. Another important task of the toolkit is allowing a way of gathering information in a central spot, as already mentioned in the previous section.

Theme 9.3. Supporting the YAA's design process

Finally, the Design Your Life method aims to amplify the voice of the YAA in their personal design process. Therefore the toolkit must be fitted with tools to do so. The toolkit must therefore make an effort in levelling the communication dynamics between the YAA and the caregiver: there often is some imbalance with the caregiver being more of an authority than the YAA themselves. Thus the toolkit must help the YAA to have the lead when making design decisions.

The toolkit also plays an important role in closing the perceived ability gap between the YAA and their support network. Supporting this communication between the YAA and the caregiver also promotes a better design process. The toolkit can be used for that, using the notion that communication between autistic people and neurotypical people can be mediated through objects (Di Paolo et al., 2018, chapter 10). As mentioned by De Jaegher (2013), a longstanding interaction history between the two participants helps to smooth communication issues. The toolkit can support relationship building by offering especially context mapping activities where the caregiver also records their personal context. But most importantly: the toolkit can support communication by offering scaffolds and boundaries in which the participants can operate.

The toolkit is especially designed to be used in the contexts of the YAA's living situation, ideally, or the office of the caregiver. This plays into using a location that is familiar to the YAA to help them feel comfortable. Additionally, being able to use the toolkit in an environment that the YAA can control allows the participants to use the toolkit in circumstances most optimal for the YAA, e.g. where the YAA has more control over sensory input. Finally, the toolkit can be used within the context where the design solution might be used. This 'in context design process' allows the participants to draw immediate inspiration from their environment.

WAAR IK HET PRODUCT VOOR GA GEBRUIKEN

WAT HET PRODUCT WEL/NIET MOET HEBBEN

ZINTUIGVOORKEUREN

SECTION 2

ITERATION 1: CREATING THE FIRST DESIGN ROUND

SIGN
UR
FE

DE TOOLKIT

ACTIVITEITENDOOSJE 2

ACTIVITEITENDOOSJE 3

ACTIVITEITENDOOSJE 4

ACTIVITEITENDOOSJE 5

This iteration is the largest one in both scope and feedback: it contains the most activities and the participants interacted with it the longest. Figure 12 shows the parts of the timeline featured in this iteration round.

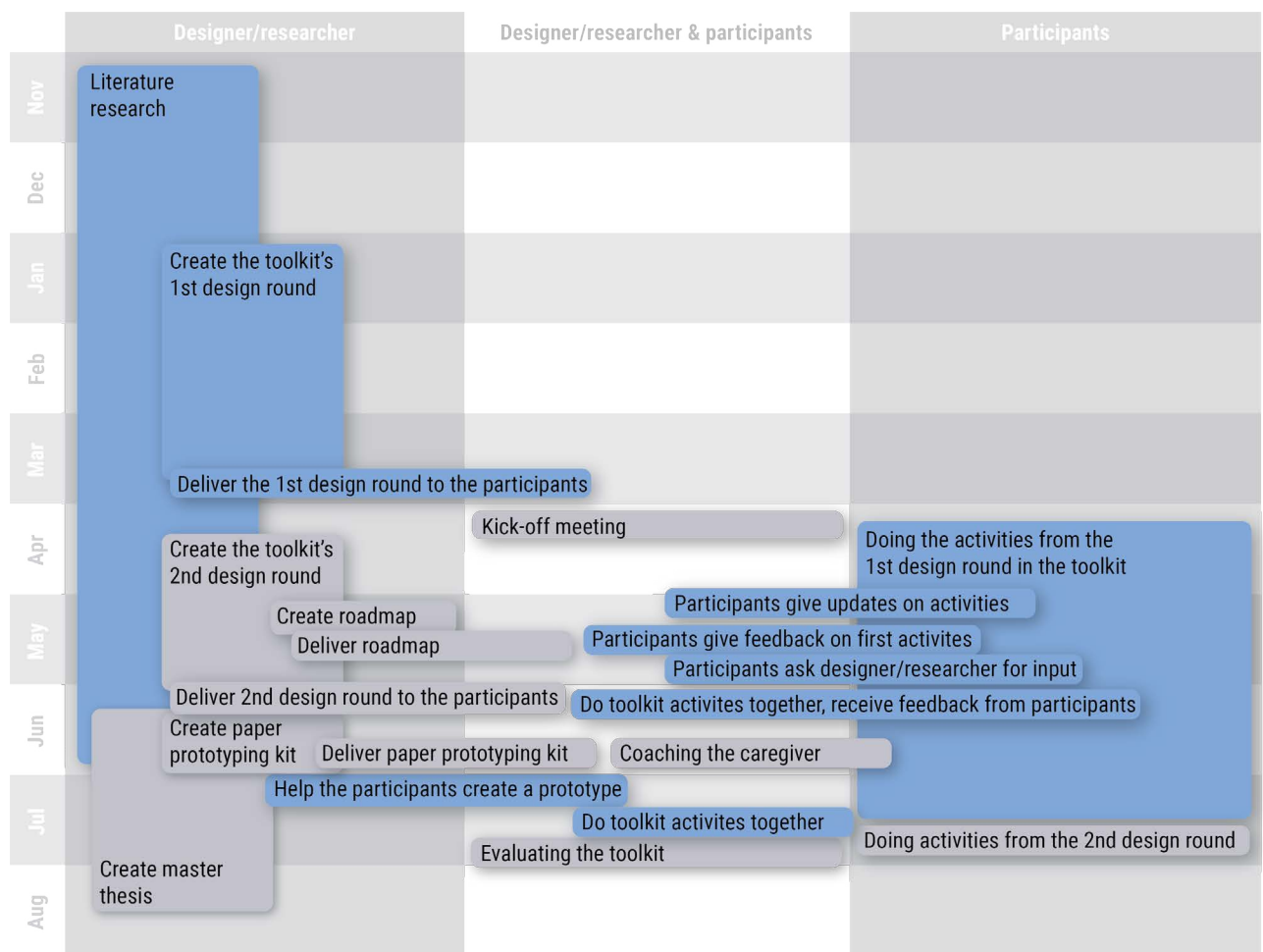


Figure 12: the activities that were part of iteration 1 'creating the first design round'.

2.1. The toolkit

The toolkit resulting from this iteration contains the first design round. Figure 13 shows the physical toolkit. An overview of these activities is shown in Table 4. The activities in this table are labelled white or blue: white are activities that the participants do together on location, the blue activities are individual activities, which are done by one or both participants individually in between the sessions.

The activities are organised in activity boxes. Each box corresponds with a design phase of the Design Your Life-method (Figure 1), and contains a booklet with activity descriptions and materials that are needed for executing these activities. An example of such an activity box is shown in Figure 14.

Besides the activity boxes, the toolkit also contains general materials for prototyping, such as cardboard, glue, markers, post-its, elastics, thumbtacks, chenille wire and fineliners (also seen in Figure 13). A special box is dedicated to the materials used for the Velcro prototyping activity (also see Figure 14). An important element mentioned in Table 4 is the board. This board is the recording medium for all gathered information relevant to the design (as shown in Figure 14). Different activities instruct to collect information generated in that activity and put this onto the board.

Box #	Activity name	Description
Activity box 1: My World	Determining sensory preferences;	Is used to map preferred sensory stimuli of the YAA. Is based on the knowledge that autistic people can have specific sensory needs.
	Keeping a diary;	The YAA keeps a diary of their general daily activities. Is kept once a day for three days.
	Think-tell-recognise things;	Inspired by an activity by Niels van Huizen, where the participants map objects in their home, labelling them as 'thinking', 'telling' or 'recognising' objects.
Activity box 2: My Design goal	Challenges, qualities, interests, needs and goals quadrant (CQING quadrant);	Both participants fill out two CQING quadrants: one about themselves, one about the other.
	Comparing the CQING quadrants from Activity 1;	The participants show their CQING quadrants to each other. They use the CQING quadrants about the YAA to create a CQING quadrant unifying their views of the YAA.
	Determining the design goal;	The participants use the filled out CQING quadrant with the unified view to determine their design goal.
Activity box 3: Coming up with ideas	Determining communication preferences;	The participants review their results from the previous exercises to determine their communication preference.
	Determining the requirements;	The YAA creates a Velcro prototype, while the caregiver records the reason for adding elements as requirements on post-its, which are added to the board.
	Checking the list of requirements;	Using the created mock-up, the YAA enacts the use of it. Whilst enacting, both participants are looking for possible missing requirements.
Activity box 4: Creating a prototype	Matching products with your demands;	The participants use a template to write down their requirements and possible products they could use. For each requirement they check if a (combination of) product(s) is a good match.
	Selecting products;	The participants determine which products they would like to use for the prototype. For this they look at the best matches and what the YAA prefers.
	Setting up a prototype plan;	With the preferred products for the prototype selected, the participants can design a prototype. Using a flow chart and a prototype plan booklet, the participants create a step by step plan to create the prototype.
Activity box 5: Testing the prototype	Preparing the prototype	Using the prototype plan, the participants execute their assigned tasks.
	Getting the prototype ready for testing;	The participants use the prototype plan and their preparations to create a ready-to-use prototype.
	Testing the prototype;	The YAA tests the prototype for a while and records their findings by writing them down on post-its and putting them in a field research booklet.

Table 4: an overview of the activities in the first design round. The materials generated through these activities can be found in Appendix F.

As one can tell from this overview, the evaluation stage is missing. This is added to the second design round toolkit, as the evaluation of the prototype and the design process also helps to select activities for that design round. Further explanation of the second design round can be found in Section 5: 'Iteration 4'.

Input	Output
Sensory preference cards or objects in the YAA's home	Three groupings of sensory stimuli: preferred, alright and to be avoided. Preferred and to be avoided stimuli are added to the board.
Booklet with daily questions, involving daily activities, daily challenges and what the YAA was proud of.	A completed diary (in booklet or text, sent via Signal). Photos or messages are shared via Signal with the designer/researcher.
Set of post-its, which the participants use for labelling the objects. The post-its are written on with a description.	Photos of the objects with their post-its in Signal, sent to the designer/researcher. The collected products are recorded on the board as possible products to use in the design.
A paper template with the CQING quadrant added to it. Also see appendix.	Four filled out templates that the participants have not yet shared with each other. They do share photos of them in Signal with the designer/researcher.
The filled in CQING quadrants and one empty quadrant.	The participants learn about their views of each other and maybe gain some new insight into each other. A filled out unified CQING quadrant. A photo of this quadrant is sent via Signal to the designer/researcher.
The CQING quadrant with the unified view of the YAA. This already contains goals and challenges that could serve as possible design goals.	The design goal, which is recorded on the board. The related needs, challenges, qualities, interests and goals are added around it, thus creating a contextualised design goal.
The results of the previous activities.	Preferred communication forms, which can be used in selecting ways of executing activities, the product design and to improve communication between the YAA and the caregiver.
The collected information on the board, the elements in the Velcro mock-up kit.	A Velcro mock-up, a list of requirements on the board. A photo of the mock-up and the board are sent to the designer/researcher via Signal.
The created mock-up, the recorded requirements on the board. The participants can also use the resource and inspiration booklet, which contains an overview of production methods, product inspiration, and a skill/resource network activity.	Missing requirements are added to the board. The participants send a video or photos with descriptions to the group chat with the designer/researcher via Signal.
The recorded requirements on the board, the product matching template.	An overview of possible products that can be used for the design and how well they match the requirements. A photo of the filled out form is shared with the designer/researcher via Signal.
The filled out product matching template.	A selection of products to be implemented in a prototype. A photo of this is shared via Signal with the designer/researcher.
The completed product matching template, the prototype plan booklet, the prototype plan flowchart, and possibly the resources and inspiration booklet.	A prototype plan. The participants also divide tasks to prepare the prototype, e.g. ordering products or gathering materials. A photo of the prototype plan is shared via Signal with the designer/researcher.
The list of tasks marked "preparation" in the prototype plan.	Executed preparations for the creation of the prototype.
The prototype plan, any prepared materials.	A working prototype.
The prototype, the field research booklet, the field research post-its.	An overview of what the YAA likes and dislikes about the prototype.

Figures 15a-c show an example of an activity description. These descriptions are mostly text based with support of visual examples. These examples are created by the designer/researcher based on a design case she is going through herself by using the toolkit, creating the examples along the way.



Figure 13: the toolkit for the 1st design round. In the back, standing upright, is the board. The boxes contain the booklets and materials for all activities.



Figure 14: an example of the contents of an activity box. The blue booklet contains the activity instructions. All other materials are activity materials.

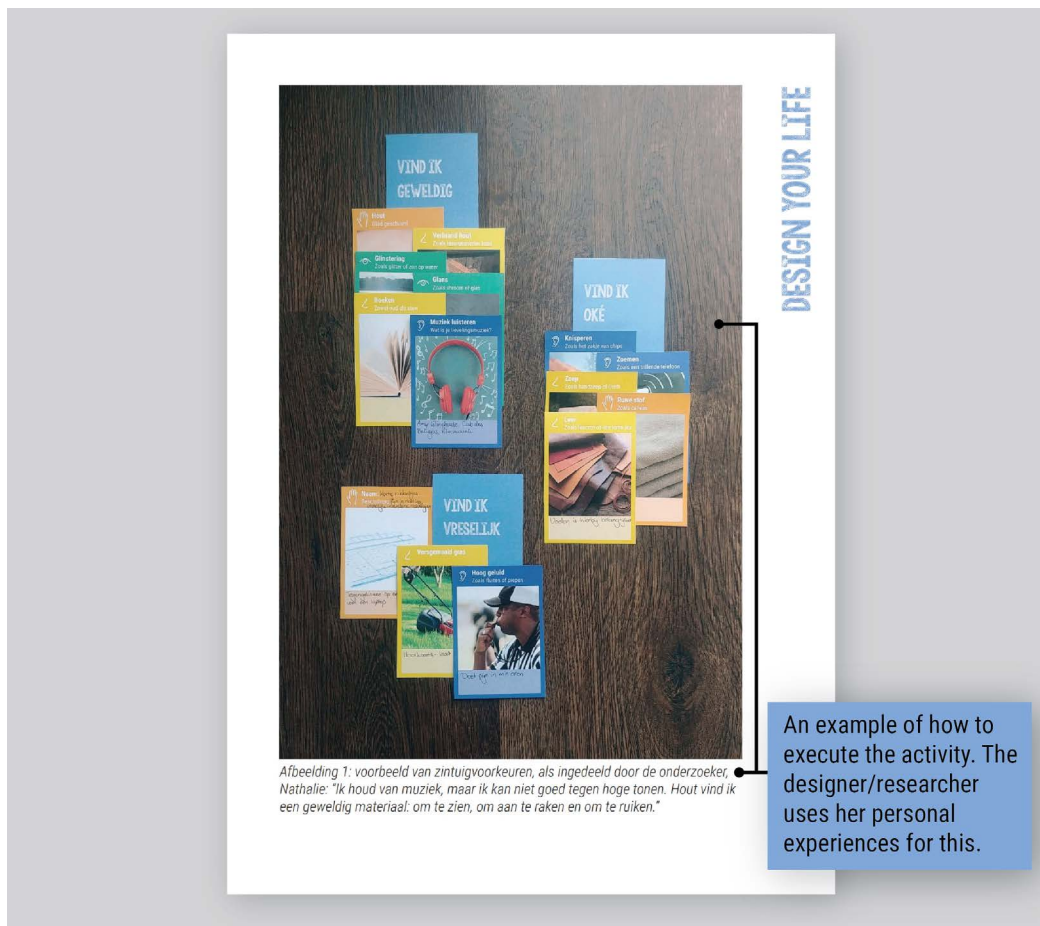


Figure 15a: an example of an activity description in an activity booklet. This example shows the sensory preferences of the designer/researcher.

STAP 1

Activiteit 1: Zintuigvoorkeuren bepalen

Duur: 30 minuten

Wie? De hoofdontwerper en de medeontwerper

Waar? Manier 1: plek naar voorkeur; Manier 2: bij de hoofdontwerper thuis

Waarom? Deze opdracht is om jullie na te laten denken van welke vormen van zintuigelijke prikkels wel of niet fijn zijn voor de hoofdontwerper.

De activiteit

Deze activiteit kan je op twee manieren uitvoeren:

- Door het gebruik van zintuigkaartjes
- Door de spullen die de hoofdontwerper heeft te gebruiken

Manier 1: zintuigkaartjes

Gebruik de stapel zintuigkaartjes die in deze doos zitten. Op deze kaartjes zie je plaatjes van dingen die je kan zien, horen, ruiken of voelen. Jullie gaan als volgt aan het werk:

1. Bekijk alle kaartjes.
2. Schrijf op het kaartje wat de hoofdontwerper wel/niet fijn vindt aan wat er op het kaartje verbeeld wordt. Bijvoorbeeld :
3. Verdeel de kaartjes in drie stapeltjes:
 - "Vind ik geweldig": prikkels waar de hoofdontwerper blij van wordt.
 - "Vind ik vreselijk": prikkels die de hoofdontwerper onprettig vindt.
 - "Vind ik oké": prikkels die de hoofdontwerper niet als onprettig ervaart, maar die ook niet per se heel prettig zijn.
4. Beschrijf voor elk kaartje waarom je deze prikkel wel of niet fijn vindt. Dit kan je op verschillende manieren doen:
 - Door dit op het kaartje schrijven
 - Door een foto van het kaartje maken en een beschrijving erbij typen in Signal.
 - Door een foto van het kaartje maken en in een audiob Bericht het kaartje beschrijven. Deze stuur je dan in Signal op.

Activity factsheet, including: duration, who will do the activity, where the activity is to be done and why this activity is offered.

Activity title

Activity preparation: in this section, the needed materials are mentioned. Also possible versions for execution are mentioned.

Activity instructions. The text refers to any available examples.

Figure 15b: an example of an activity description in an activity booklet.

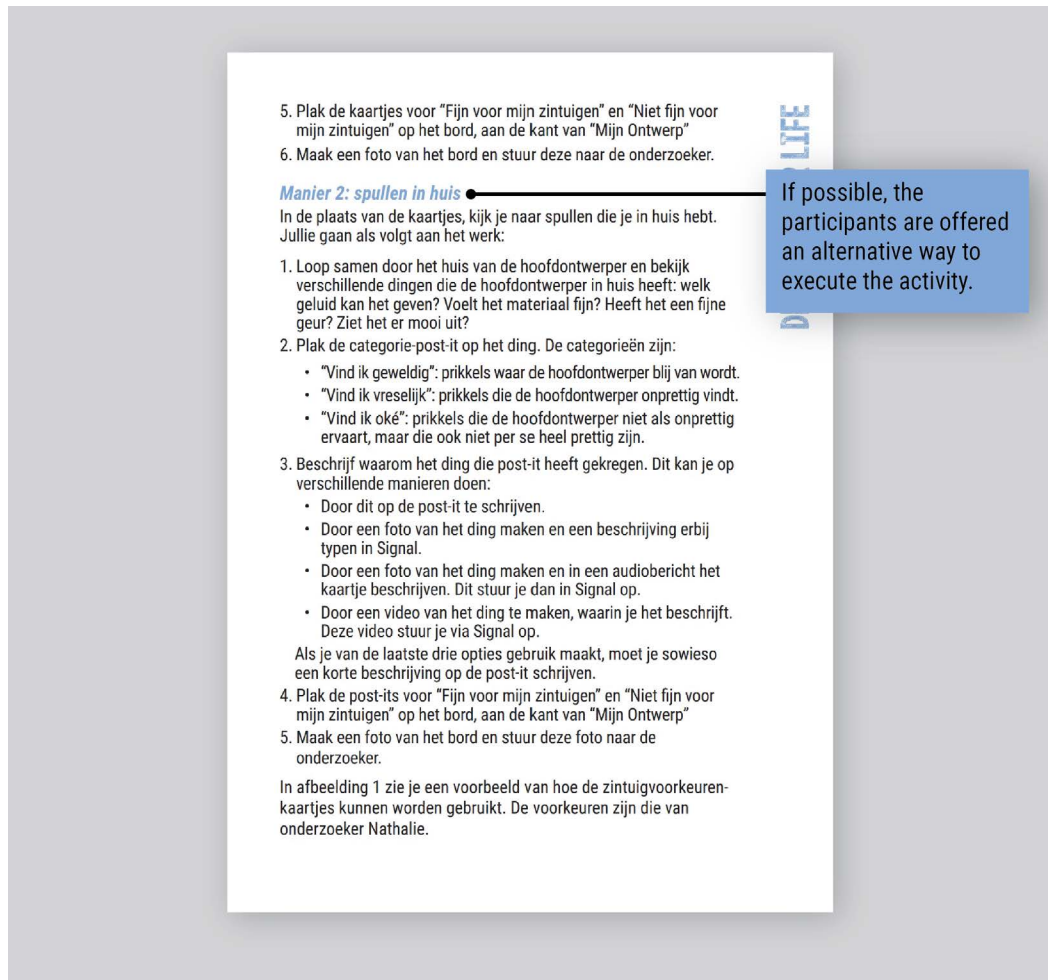


Figure 15c: an example of an activity description in an activity booklet.

2.1.1. Design considerations

As can be seen by the list of activities, this toolkit is quite intense. It contains a large amount of information and materials. For the Design Your Life method, it had already become clear that the toolkit must provide information in a manageable way. In this toolkit that is done by creating clear sections: one box is approximately one phase and the activities it contains should be doable in one 1,5 hour co-design session plus some time in between sessions for some individual assignments. This setup is derived from the board game Pandemic Legacy (shown in Figure 16), where after each game you unlock new information, which is stored in a small box (Z-MAN Games, 2021).

The central board is also inspired by Pandemic Legacy, as you permanently alter the board after each game, adding elements (Z-MAN Games, 2021). This, in combination with Frauenberger et al.'s, (2017) co-design session planning tool, created a board where the participants were able to record all the activity outputs that contribute to their design process. Such a board creates structure in the gathered information and allows a direct visual and textual reference. Both are needed to support the participants who are likely to embark in a design process for the first time.

This support for first-time designers is also present in the explanation of the activities, as seen in Figures 15a-c. The support is in a detailed explanation in text. Text was chosen as the preferred medium after meeting with the participants. Simon enjoys reading, thus he was not put back by textual explanations. However, realising that such an explanation can be quite abstract, a visual example was added of a possible activity outcome, as seen in Figure 15a.

2.1.1.1. Augmenting the relationship between the YAA and the caregiver

Throughout the materials, the participants are either addressed as the main designer ("hoofdontwerper" in Dutch) and the co-designer ("medeontwerper" in Dutch). In the opening booklet, which explains the toolkit to the participants, the participants must write

down who takes on which role. The YAA will take on the main designer role, thus putting the caregiver in the co-designer role. This wording emphasises the objective of the Design Your Life method: to empower the YAA to design their personal product to improve their independence. It is a small but consistent emphasis throughout the booklet emphasising that the YAA is to make the final decisions in each design step.

A way to promote more insight into each other and promote mutual empathy is by involving both participants in individual activities. These involve the 'think-tell-recognise' activity and the CQING quadrants. The participants are both invited to do this activity and share their findings and opinions, thus creating a better understanding of each other. An added benefit of the 'think-tell-recognise' activity is that the entries from the caregiver enlarge the possible solution space for the product emerging from this toolkit. It sensitises both participants to the roles products play in their lives.

Finally, the toolkit aims to align the communication styles of the participants by explicitly mapping their communication preferences. Clarifying and reflecting on these preferences of both participants can help them to more effectively communicate using modalities that work for them.

2.1.1.2. Supporting the possible needs of the YAA

The toolkit aims to fit the needs of the YAA in three ways: 1) by mapping the sensory preferences, 2) by aligning with communication preferences, and 3) by offering as clear instructions as possible. The mapping of sensory preferences is implemented because of the sensory hyper- or hyposensitivity that is often present in autistic people, as mentioned by Fletcher-Watson & Happé, 2019 (chapter 3). Mapping such sensitivities so explicitly helps to select products that take the YAA's sensory preferences into account, thus more likely creating a product that does not over or under stimulates them. These sensitivities also can inform communication preferences. For instance, a YAA might prefer typing to speaking, because the sound of typing appeals to them.

The alignment of communication styles has already been mentioned in the previous section, but also applies here: making these preferences explicit helps the participants to actively align their communication styles. The toolkit aims to offer the same kind of



Figure 16: the inside of the box of the Pandemic Legacy: Season 1 board game. Game and image by Z-MAN Games (2021).

alignment, by offering options for executing activities using different modalities per option. For instance, in the 'think-tell-recognise' activity, the participants can choose to 1) write on the post-it and take photos of these post-its stuck on their products, 2) make a video where they explain the placement of an object in a certain group verbally, or 3) take a photo and type the explanation underneath it. It is expected that being able to use a modality that suits the participant yields higher quality activity output.

Finally, the design of the booklets was also used to accommodate the YAA's needs. First of all, this was done by using a calm but well-designed graphic language: the only graphic elements are the colour assigned to that particular phase and two font families. Such minimalistic design is taken from Fabri & Andrews' (2016) observation that their autistic participants prefer communication with as little frills as possible. Secondly, the toolkit aimed to accommodate the YAA's need for clarity and unambiguity, as observed by Sinclair (2010), through providing detailed explanations of the activities and by offering a factsheet with each activity. This factsheet, shown in Figure 15b, contains the expected duration of the activity, who will do this activity, what type of activity this is, where the activity should preferably be done and what the underlying reason is for including this activity.

2.2. Implementation in the case

2.2.1. Use

The participants take ample time to understand each toolkit activity. Ellen reads through the activity before meeting with Simon, in order to understand the activity by herself, as well as thinking of relevant examples for Simon. Ellen notices that this helps in shortening the start-up period in their sessions. However, the participants notice that they rarely complete an activity within the estimated duration given in the explanation. This is due to the time needed to understand the activity, the ambiguity of the activity materials and the lack of overview of all the activities in the first design round. Another factor is unclarity in how activities tie in with the rest of the design process. This progress and lack of overview is further investigated in Iteration 2.

Simon doesn't find all activities equally interesting. One example is the 'think-tell-recognise' activity, where Simon created a .txt file summing up his entries, rather than taking photos and sending these via Signal. Another example is the diary activity: in daily life, he would never keep a diary, as he finds it too much effort. He prefers to process his memories and reflections in his mind. It results in Simon writing very short answers in the diary. Some of these answers can also be attributed by Simon's generally stable emotions: he explains that he only experiences very short bursts of emotions. An image of his filled out diary is shown in Figure 17. Simon therefore felt that some of the questions were hardly applicable to him, as the following quote points out:

Ellen: "I thought the diary activity was in itself a nice activity, because I did read that you are proud of losing weight."

Transcripts of the meetings can be found in Appendix B.

Simon: "I only filled that out because I demanded of myself to write something down."

- Meeting 07-05-2021

Another reason why both Simon and Ellen find some exercises irrelevant is their application in their specific design process. The toolkit was aimed at creating a physical product, but the participants landed on a software solution. Thus the activities in ideation, such as the Velcro mock-up kit, were not the optimal tools for them. This situation is further explored in section Iteration 3.

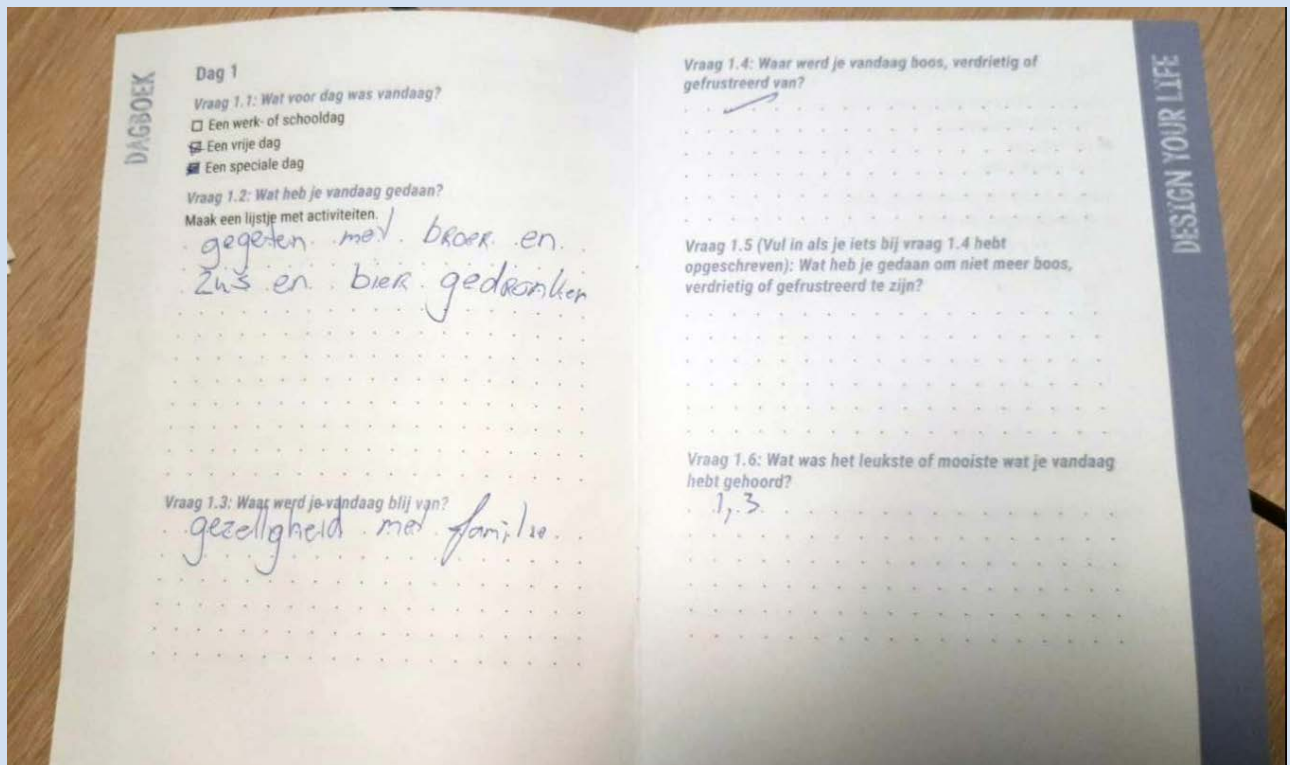


Figure 17: example of Simon's diary entries.

2.2.1.1. Design goal transformations

Determining the design goal proves challenging for the participants. When it comes time to define their design goal with the activity called “determining the design goal”, they first reach out to the designer/researcher by phone to discuss what design goal is realistic, significant and defined enough to design for. One of the goals that Simon mentions on his CQING quadrant is losing weight, as shown in Figure 18a-d. But since Simon would like to lose a significant amount of weight, we decide to look at a subgoal within losing weight. We finally settle on “cutting back sugars”.

Ellen later invites me to join them for a meeting, because they have gotten stuck coming up with product ideas. Simon and Ellen had a personal meeting, where they dove deeper into the subject of losing weight, of which the result is the mindmap shown in Figure 19. During the meeting, we discuss the design goal. The discussion is a re-iteration on earlier conversations. An example of the discussion is the following quote:

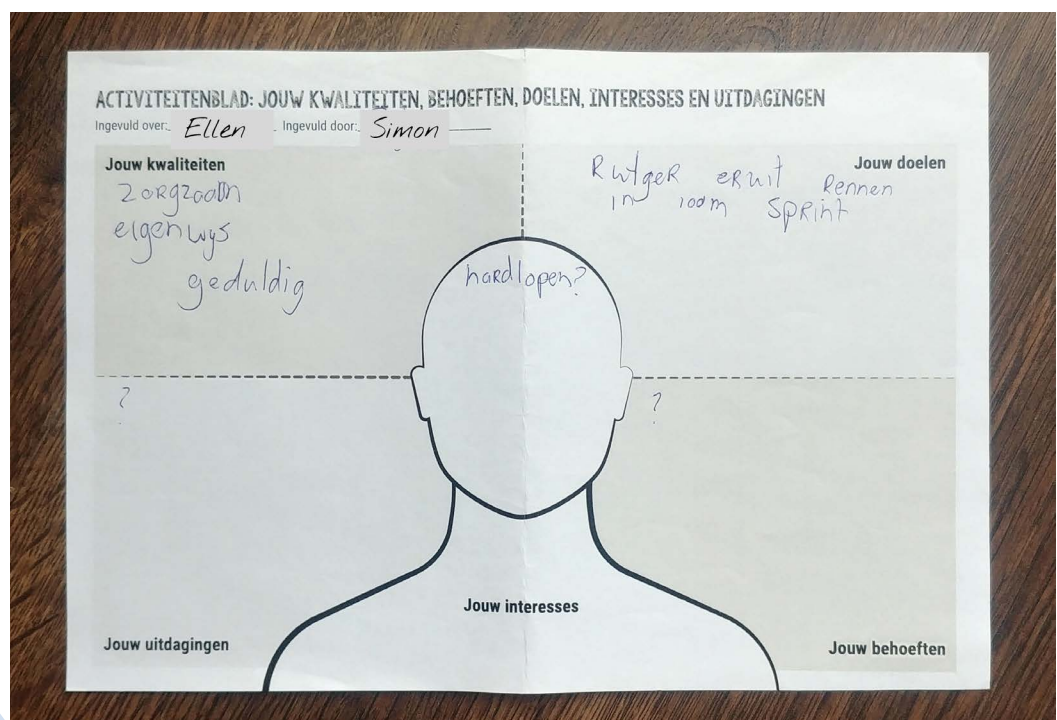
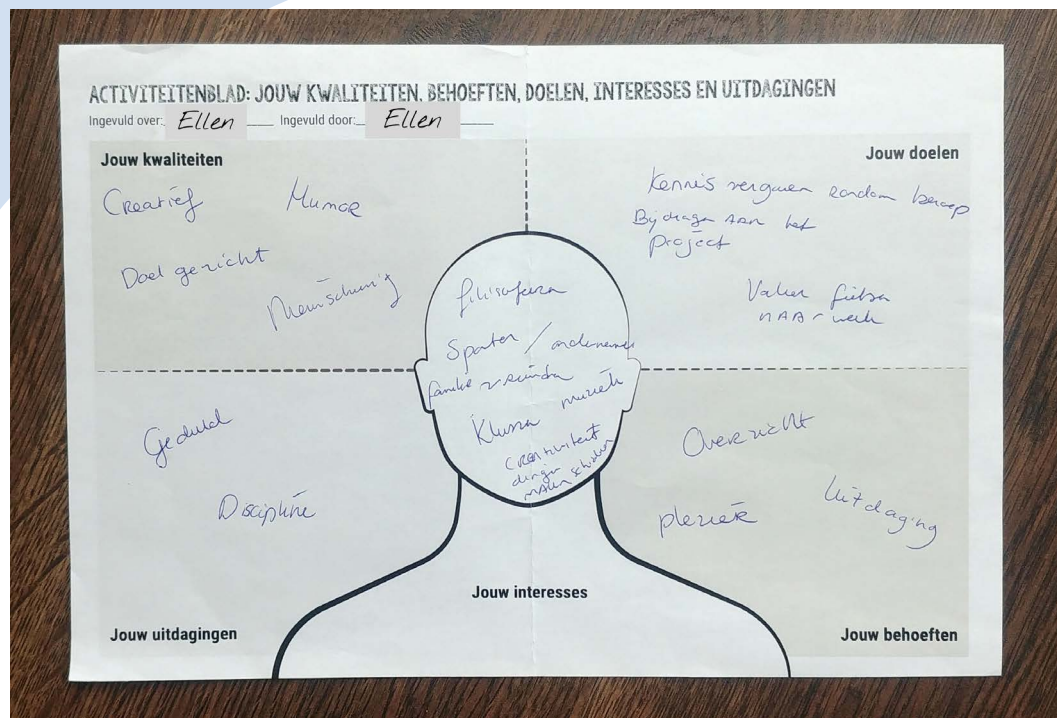


Figure 18a-d: the CQING quadrants that the participants filled in about each other.

Nathalie: "So, actually, cutting back on sugar is the hardest part [of losing weight]? Cutting back on [energy drink]?"

Simon: "Yes."

Nathalie: "How much [energy drink] would you ideally have?"

Simon: "Ideally? None at all. Or at least no more than once a month, because it tastes good from time to time. But I would not think more than that would be good."

Nathalie: "Yes, that actually makes the subject the sub-goal of [losing weight]... So the thing about losing weight that is most difficult for you is cutting back [energy drink]."

Ellen: "Does that make it the goal?"

Nathalie: "Yes."

Simon: "And what would you come up with, in God's name, when I do not feel the need for a product?"

- Meeting 29-05-2021, coming up with ideas together.

ACTIVITEITENBLAD: JOUW KWALITEITEN, BEHOEFTEEN, DOELEN, INTERESSES EN UITDAGINGEN
* Ingevuld over: Simon - Ingevuld door: Simon

Jouw kwaliteiten eigenwijs open-minded open hartig	nieuwsgierig	afvallen blokkades houden	Jouw doelen onder controle
	gaming Lezen films/series leren		
Jouw uitdagingen Stoppen met suiker goed leren omgaan met financiën gemotiveerd blijven	Jouw interesses	meer sporten minder of hankeltyk van suiker geen blokkades meer motivatie hebben	Jouw behoeften

ACTIVITEITENBLAD: JOUW KWALITEITEN, BEHOEFTEEN, DOELEN, INTERESSES EN UITDAGINGEN
* Ingevuld over: Simon - Ingevuld door: Ellen

Jouw kwaliteiten nieuwsgierig / lees graag klunne theoretische kennis zelfreflectie neutraal	Gamen Reizen Natuur Wetenschap Filosofen Series	Afvallen Bekke zelfbeeld krijgen Wet blokkades leren Wet vinden	Jouw doelen
Jouw uitdagingen Wat heb denken kunnen meer in gevaar Doorzetten ondanks geen praktische gevolgen via andere wegen proberen	Jouw interesses	niemand om mee te wandelen Afvallen Stimulatie Praktijk over afvallen	Jouw behoeften

This quote also highlights an important point: Simon has his own way of dealing with his weight loss challenge. As he explains himself: when he sets his mind to a certain goal, he just does it. Simon prefers using his mind over products, because in his experience, products only add extra steps to his process. These extra steps, Simon argues, act as a hurdle for him to accomplish his goal. At this moment, the products that Simon has that are related to weight loss, are a step counter, an overview of his weight loss progress on a whiteboard and a photo of himself when he was at his target weight, see Figure 20 for the photo and the whiteboard. But the whiteboard and the photo were not his idea, as the following quote shows:

Nathalie: "One thing that you already use – when I was at your home you had an overview of your weight loss."

Simon: "That is because of her. [nods to Ellen] I didn't do anything about that."

Ellen: "Yes, you do use it."

Simon: "Yes, but only because you like it."

Ellen: "Yes, but you secretly like to know that you lost weight, right?"

Simon: "I know that, but I don't need to write it down."

Ellen: "But you do have a picture of yourself, a more slender version."

Simon: "That was my mother, she said that."

Nathalie: "Okay! So you actually have... You have that picture..."

Simon: "Yes, but I don't care about it."

Nathalie: "But it is there, so in that sense you are using it."

Simon: "But I also didn't take the effort to take it down without a reason. That is why I still have it up on the fridge. [...] But I don't use it myself. All those things you just mentioned are things that I don't personally use. I don't think about that when I'm losing weight."

- Meeting 29-05-2021, discussing items used towards the weight loss goal.

This quote shows that the mentioned items are introduced by others, not Simon himself. The motivation to lose weight is intrinsic to Simon, but other people are convincing him to use the particular strategies they advocate. This interference of Ellen, his mother and myself made that the design goal was less aligned with what Simon wanted and more with what his environment saw as a good way of approaching weight loss. Simon's strategy is primarily cognition based. Simon states that adding a product would disturb this strategy, making it harder for him to achieve his goal. This results in an impasse in the design process, until Simon mentions the following:

Simon: "[...] Therefore I find it difficult to come up with a product for myself, which is the goal of the assignment. I can come up with plenty of things that I would like to [design]: I love to read, but I read mostly online. So maybe some kind of library, or something. In any case not when it is about myself and losing weight."

- Meeting 29-05-2021, Simon about design goals that would excite him.

Reading is an important hobby for Simon, but no goals related to hobbies were mentioned on the CQING quadrant, shown in figure 18. Simon views hobbies separate from goals: reading and thinking up stories have always been things he "did on the side". However, I encourage him to use his hobbies as potential goals. During the remainder of the discussion we decide that 'writing a book' will be the new design goal. The new design goal was immediately more Simon's goal: it is about expressing something he is already excited about, but has not shown much to the outside world. Together we alter the board accordingly, as shown in Figures 21 and 22.

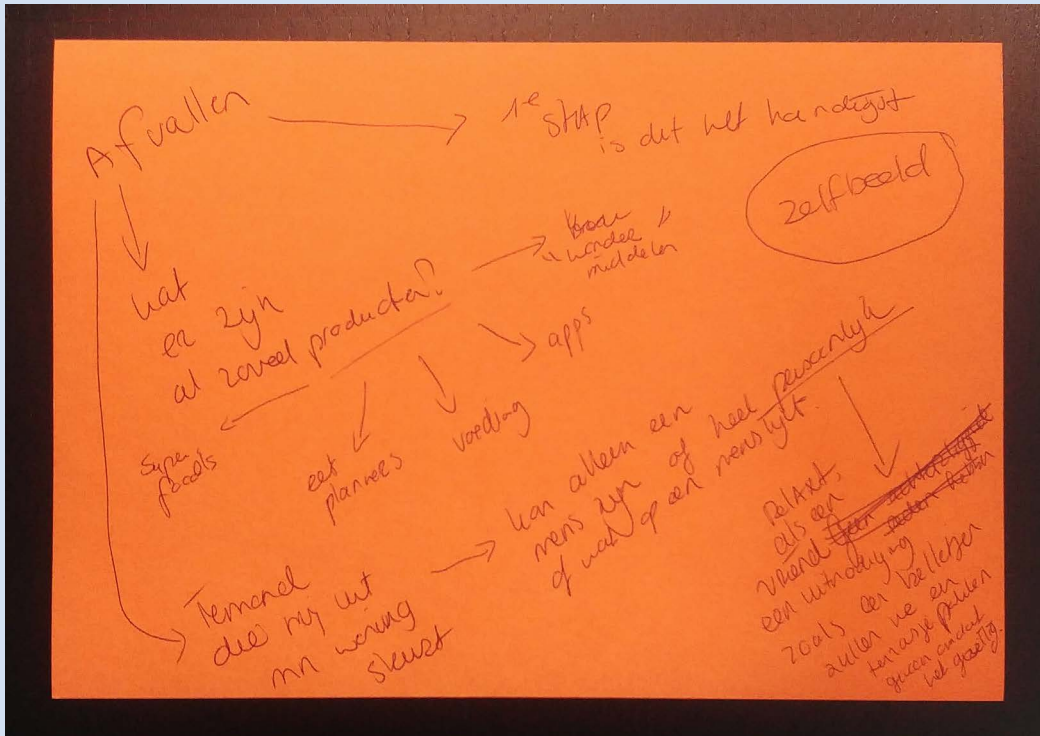


Figure 19: the mindmap that the participants created on the topic of 'losing weight'.



Figure 20: the whiteboard and the photo of Simon when he was at his target weight.

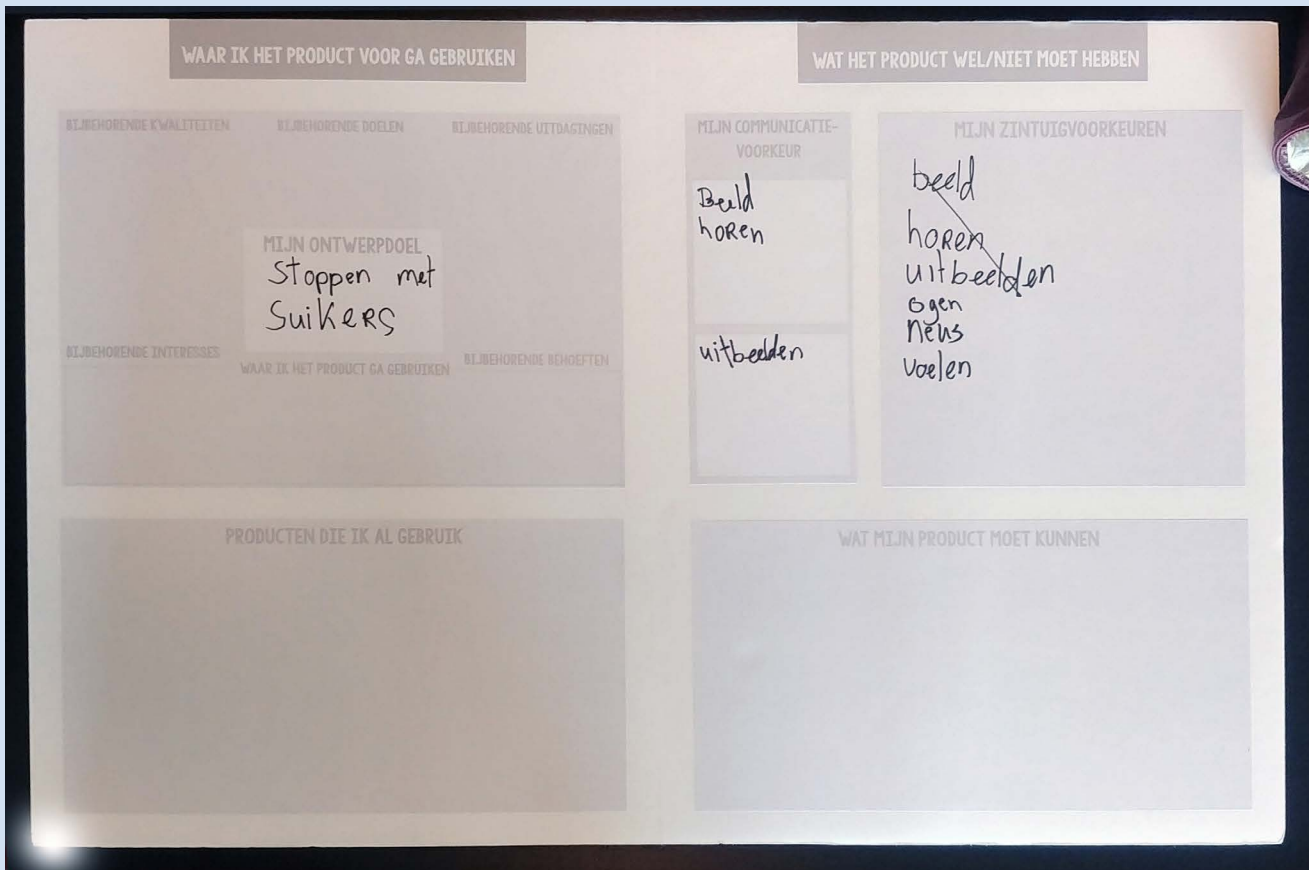


Figure 20: The board before the design goal was changed to "writing a book". The design goal was still "quitting sugars", but nothing related to it has been added yet.

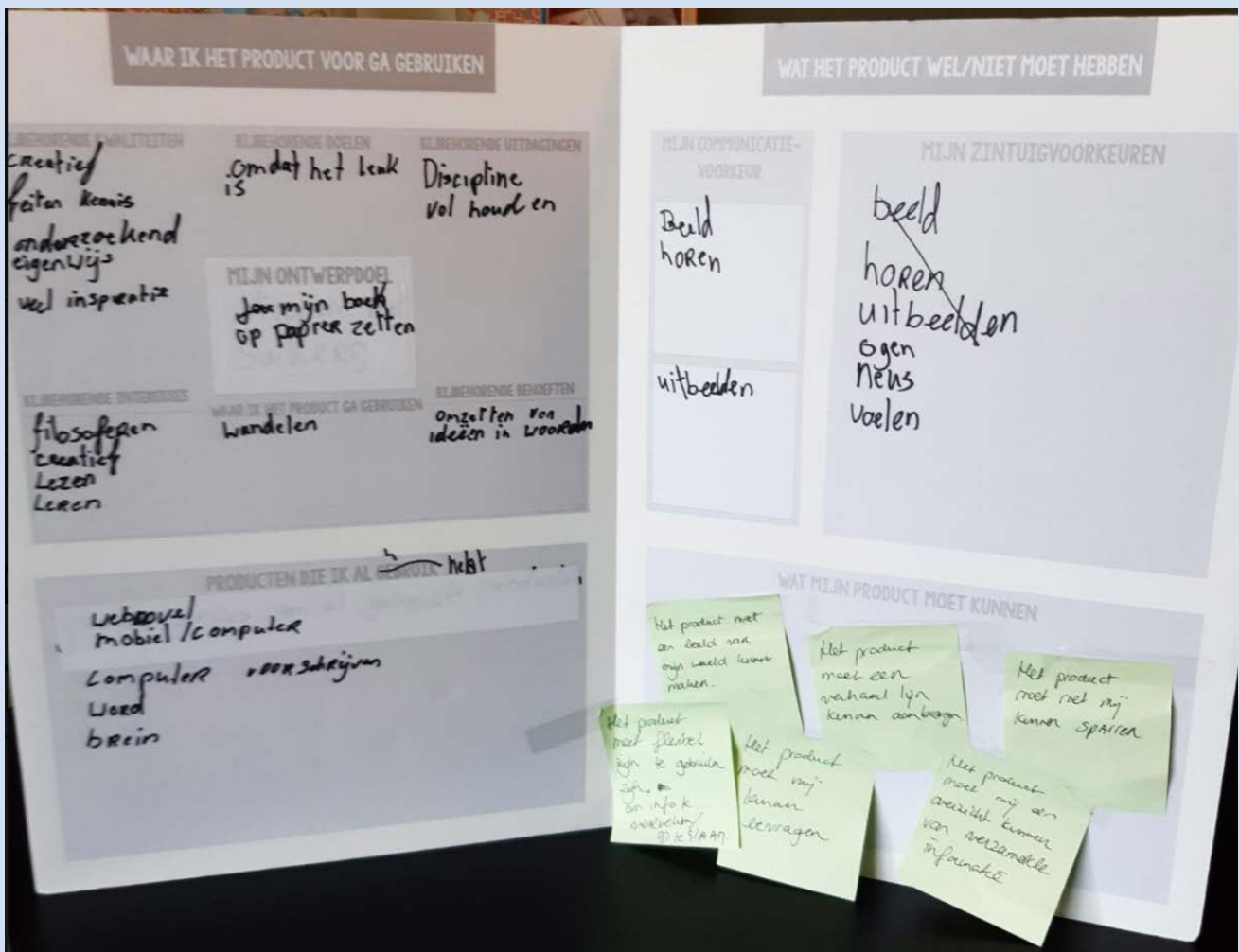


Figure 21: the board when the design goal was changed to 'writing a book'.

During the next meeting, Simon and Ellen announce that they have refined the design goal: it has shifted from “writing a book” to “visualising Simon’s world”. Simon and Ellen came to this shift because during their meetings using the toolkit, they discovered that the goal did not completely line up with what they discussed: there is too much of a difference between world building and book writing to be captured by the same goal. Therefore Simon would like to incorporate an intermittent step before writing a book: he is a strong visual thinker, thus his entire world is already in images in his mind. Translating that directly to text is a difficult step for Simon, while making a visualisation of Simon’s can serve as a bridge to writing a storyline within that world.

Figure 23 shows the transformation of the design goal. The new design goal quickly cleared the design impasse. With the design goal, Ellen took on much more of a supportive role: she is experienced in exercise, but not so much in creating fantasy worlds. She therefore was very invested in learning more about Simon’s world. Simon, in turn, showed enthusiasm in the fact that others find his world interesting and creative.

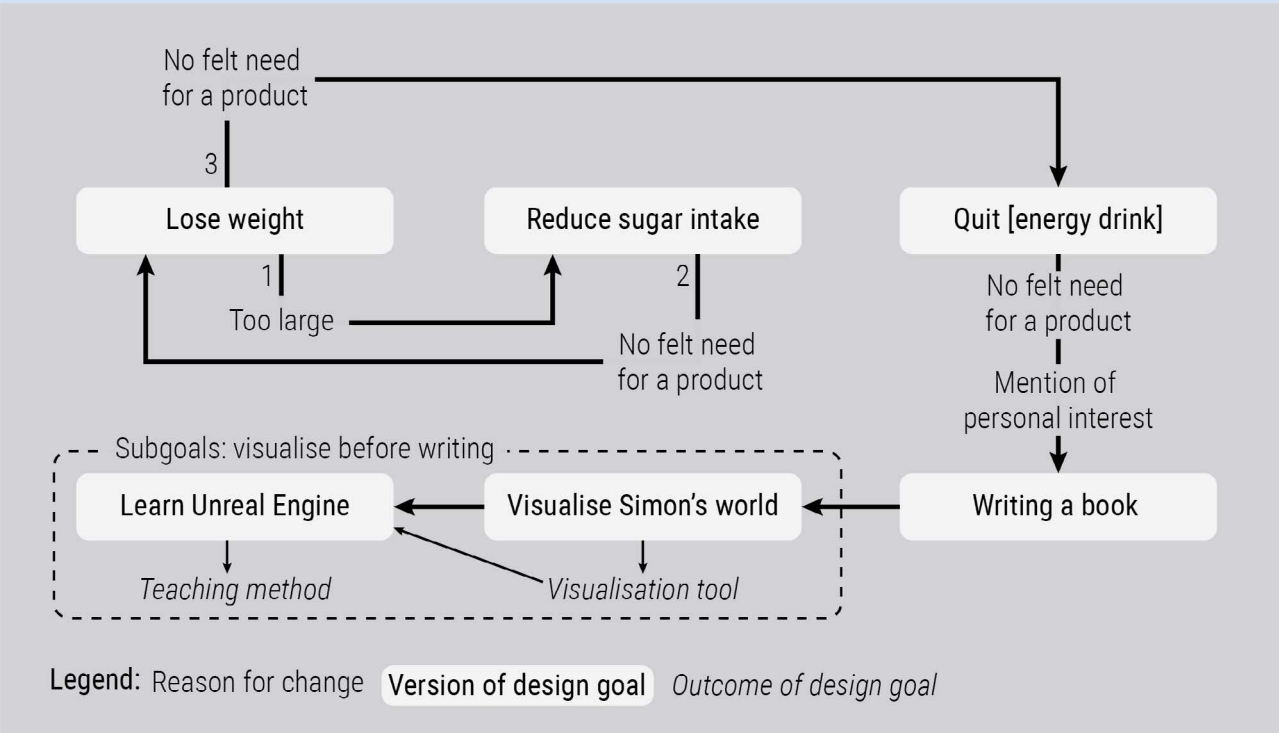


Figure 23: changes in Simon’s design goal.

2.2.1.2. The result from the first design round

Simon prefers using a computer for both writing and visualising his world. He already uses Microsoft Word to write. Simon intends to use Unreal Engine to visualise his world: this software program is a 3D engine commonly used to build video games. Simon already owns the proper hardware, and has already tinkered with Unreal Engine because of his love for gaming. To support Simon with his world building, we agree that I will help find a suitable mentor for Simon. Simon can contact this mentor to ask questions and have workshop sessions, in which Simon can explore Unreal Engine further. To help contact the mentor, I agree to create an illustrated introduction to Simon’s world.

This introduction resulted in a booklet describing Aether, Simon’s world. Aether has been described using in-person discussions between Simon and myself about the world, and recordings of Simon and Ellen during their walks. An example of these discussions is:

Context: at this point we were still looking for making assets for Unreal Engine, but later it became clear this would not be possible. However, these discussions did contribute to the description of Aether.

Nathalie: "So of each element at least a crystal, an animal, vegetation and maybe also a defining natural structure?"

Simon: "Eh, yes..."

Nathalie: "Or maybe the expression of a human with a very high level of that energy?"

Simon: "That is possible! But, for example, also a crystal that can be used as a battery instead of a battery. That's also a way to see it. Because those crystals... That is actually a fusion of magic and technology: those crystals are actually a battery when you use them in a certain way. You could for instance... An oven could have a Fire crystal in it. You could make some products that show that."

Nathalie: [writing notes] "Yes... So in that case also a small overview of possible applications of crystals?"

Simon: "Yes!"

Nathalie: "And do you also want visualisation of how certain energies express themselves in a human?"

Simon: "But what I also said a couple of days ago to [Ellen], I believe that is also in the recording, is when you have a Space-element, that you could make a backpack that is much larger on the inside. [...] That it is small, but that it can contain a lot of space, things like that. It is not necessarily magical... But that you can fuse all the jobs in the world with that magic. That you fuse craftsmanship with magic."

Nathalie: "So actually an Era of Magical Craftsmanship?"

Simon: "Yes..."

- Meeting 04-07-2021

In short, Aether exists in a universe where there is a form of magical energy, stemming from Dark Matter. This energy can present itself in different forms, such as Fire, Air, Earth, Water, Space or Soul-energy. These elemental energies can be absorbed by animals, plants or humans, or can be concentrated in crystals. These crystals can then be used in technology, such as Fire crystals to power stoves. Figures 24 and 25 show two examples of visual representations in this booklet. The introduction to Aether can be found in Appendix G, in chapter "Aether". We were successful in matching Simon with a mentor, but their first meeting is planned after the colloquium of this thesis.



Figure 24: image created for Aether, showing a Fire crystal in a high Fire energy environment.

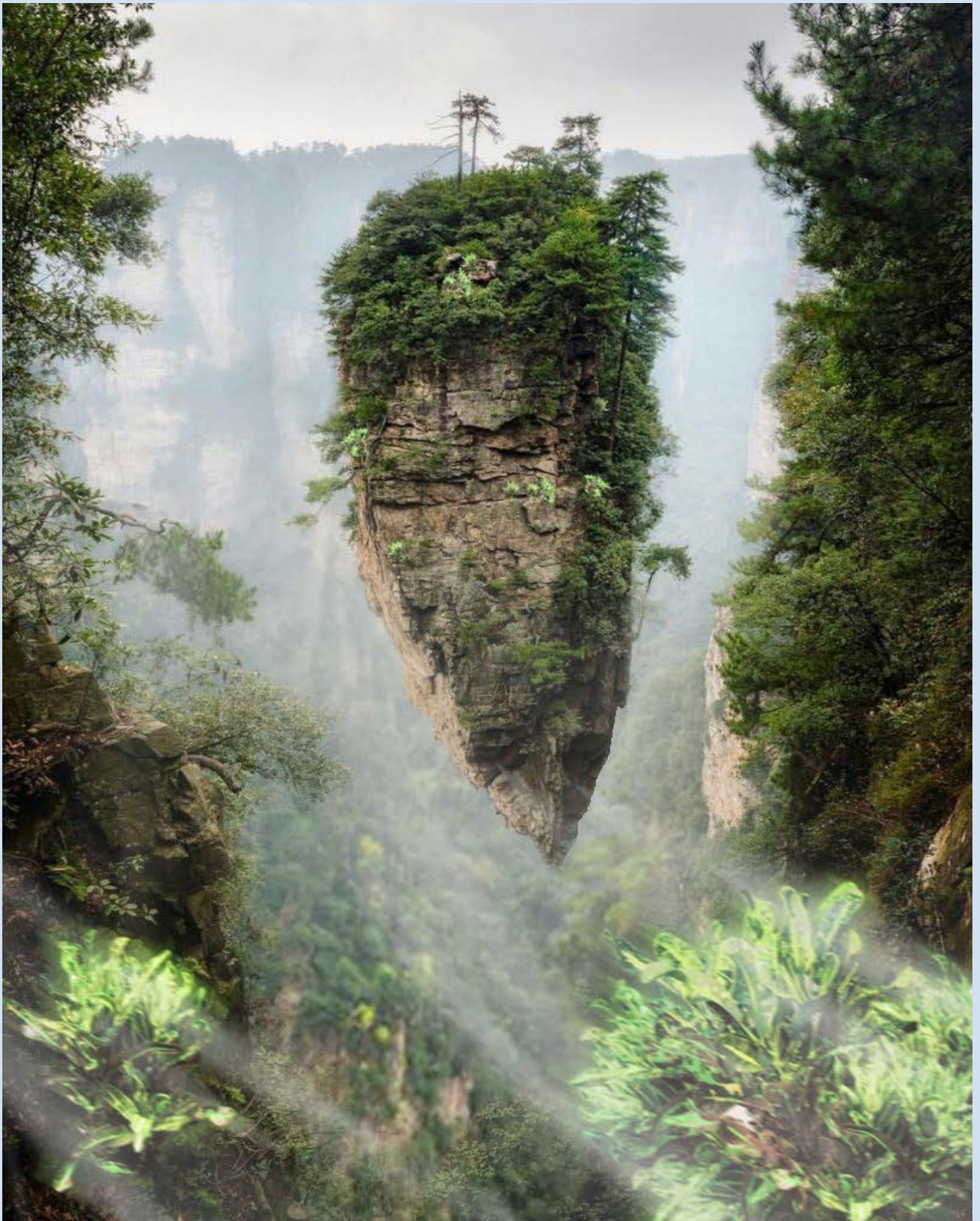


Figure 25: another image created for Aether, showing an environment high in Air energy. This energy causes the rock to float, and plants that have absorbed it can create wind to protect themselves.

Ellen: *“In a certain way we already [guide ourselves through the process], even for quite a big part. But sometimes you need just that extra bit of knowledge, like ‘Oh yeah, we are now focussing too much on the making of –’ ”*

Simon: *“ ‘ – a new product!’ That we are thinking too much ahead.”*

Ellen: *“Exactly, that we’re too much ahead. And that in that moment there is someone who can say ‘-’ ”*

Simon: *“ ‘No, you shouldn’t think this far ahead.’ Just things like that.”*

Ellen: *“Yes. Up to a certain degree I do that too...”*

Simon: *“Yes, but you have to know where you can do that. And that is your designer instinct that says ‘you don’t have to think about products right now’. And if you don’t know anything about [design] then you automatically think too much ahead during these assignments.”*

Ellen: *“It would probably work out, even when we do the activities with the two of us, but it would be much more superficial, with the information that we then have. What I think... With [Nathalie] involved we add more depth. Simon had the sugars as his design goal first, and that it then quite easily was transformed to something else. I didn’t expect that.”*

- Meeting 04-07-2021

This is why the participants preferred having me in their meetings, to guide them through the activities. They notice that this also shortens the time needed for an activity. It is in line with Simon’s preferred mode of communication: he likes to talk in person over writing or talking on a recording.

The participants describe the missing guidance in the toolkit as that piece of ‘designer intuition’. They don’t have that themselves, but the toolkit only offers limited support as it cannot comment on the produced contents. Simon’s remark on using videos to explain the activity can be very useful here: in that medium you have more time to explain the reasoning behind, limitations of and objectives of each activity more clearly, with enough examples.

The participants also explain that they relied on the designer/researcher for her skills and network during the prototyping stage. Simon was in need of an Unreal Engine mentor, but he and Ellen did not have anyone in his personal network who could help him out. Therefore they asked me for help in finding a mentor and visualising an introduction to Aether.

Future participants who use a similar toolkit need a support system to rely on when designing. This is both in the area of supporting their design process as well as offering skills and connections that might be of use to them. In this case that was solved by the designer/researcher that was in close contact with only them, but could also be in other forms, such as a workshop environment that participants can visit or an online community where they can ask questions.

2.2.2.4. On changing the design goal

When it came down to changing the design goal, the participants state that they needed my guidance to do so, despite the fact that contacting me would delay their process. As Simon explains:

Simon: *“We did not feel the need to yank on that tail by ourselves, “we are going to change the goal now”. We want to discuss such a change with you first. So certain things, changing certain things, understanding certain things... Even though we understand something partly, we didn’t know if we should make the change. Than we prefer to contact you first, before taking any action. That takes more time, something like that. With certain things you just notice that it is then postponed just because we are unsure.”*

- Meeting 04-07-2021, Simon on the need for support before changing the goal.

This is in line with the feedback regarding the need for guidance.

At first glance the goal of ‘writing a book’ does not appear to contribute to more independence. However, Ellen liked the new design goal not only because she learns about Simon in a new way, but especially because the new goal still ties in with challenges that Simon has recorded in the CQING quadrants: ‘discipline’ and ‘perseverance’. Ellen also enjoyed the fact that Simon was able to be more vulnerable with her, by sharing his world. She explains this in the following way:

Ellen explains what she had learned about Simon during this project:

Ellen: “[...] That Simon has a very rich and detailed fantasy. And that is something that I find beautiful: that Simon was able to be vulnerable for a bit. That he said to me a little while ago: ‘I actually think it’s strange that I tell you all of this, what goes on inside my head. Maybe you think it’s weird to hear all of that’. But I thought that was really nice to know that Simon can tell me such a thing.”

- Evaluation meeting, 09-08-2021

The different sense of ownership over each of the design goals also lead to the participants taking on different roles, as shown in Table 5. Simon took on more of the lead after the design goal was changed, and Ellen transformed into more of a supporting role for the development of Simon’s world.

Design goal 1: losing weight/quitting [energy drink]	Design goal 2: writing a book/visualising Simon's world
<p>Simon’s roles: Information supplier; Critical eye; Expert of himself;</p> <p>Ellen’s roles: Took the lead with the activity boxes; Activity preparer; Interviewer; Proposal maker;</p>	<p>Simon’s roles: Information supplier; Explainer (of his world); ‘Talking machine’; Took the lead with the activity boxes; Expert of himself; Course director;</p> <p>Ellen’s roles: Sparring partner; Activity preparer; Interviewer; Support for image shaping and ideation;</p>

Table 5: overview of the roles of the participants when working on the different design goals.

2.2.2.5. On time management

The participants use multiple strategies to manage the time they spend on the toolkit. For instance, they plan their sessions ahead and Ellen takes time to prepare before a session with Simon. However, the participants have issues to keep on track with the activities: during the first month of having the toolkit, the participants were only able to work through four activities, of which two were individual activities. Other factors that delayed progress were illness, colleagues being on vacation and Simon simply forgetting a meeting or to do an individual activity. Scheduling activities will be discussed in depth in Iteration 2.

But the activities themselves also posed challenges: the participants needed more time than estimated to fully understand an activity. The participants attribute this in part to a lack in design knowledge they have, which was already explored in ‘on the need for guidance’. This causes delays, as the participants would like to make sure first that they make the correct decision, even if that means contacting the designer/researcher. As Simon explains:

Simon: “And if we are already unsure about [the activity] then you absolutely not looking forward to possibly making a mistake and then having to come back and doing it again. So we need to wait on you, then you need to wait on us again... So we get stuck in a negative spiral at that moment, being too late with this project. We understand the text, but that doesn’t mean that we understand it.”

- Meeting 04-07-2021, Simon on the implicit design knowledge in the toolkit.

When looking at the activities themselves, the participants noted that they preferred a setup with 30 minute activities once or twice a week, than one 1.5 hour session once in two or three weeks. The participants explain that with such short meetings it is much easier to plan in, even taking preparation onto account, and allows them to work on the project once or twice a week. This way, they argue, they still have a fresh recollection of their design rationale along the way. The point of planning is especially important for Ellen, who must divide her time between different clients.

2.2.2.5. On prototyping

Simon's designed 'product' was the use of Unreal Engine to create his world, with the help of mentor who can teach him either remotely or in person. To address this mentor, a document with an introduction to Simon's world, Aether, was created. This result meant that the participants faced two challenges: 1) finding someone with the appropriate skills they need for their product, and 2) navigating a toolkit that was focussed on creating physical products.

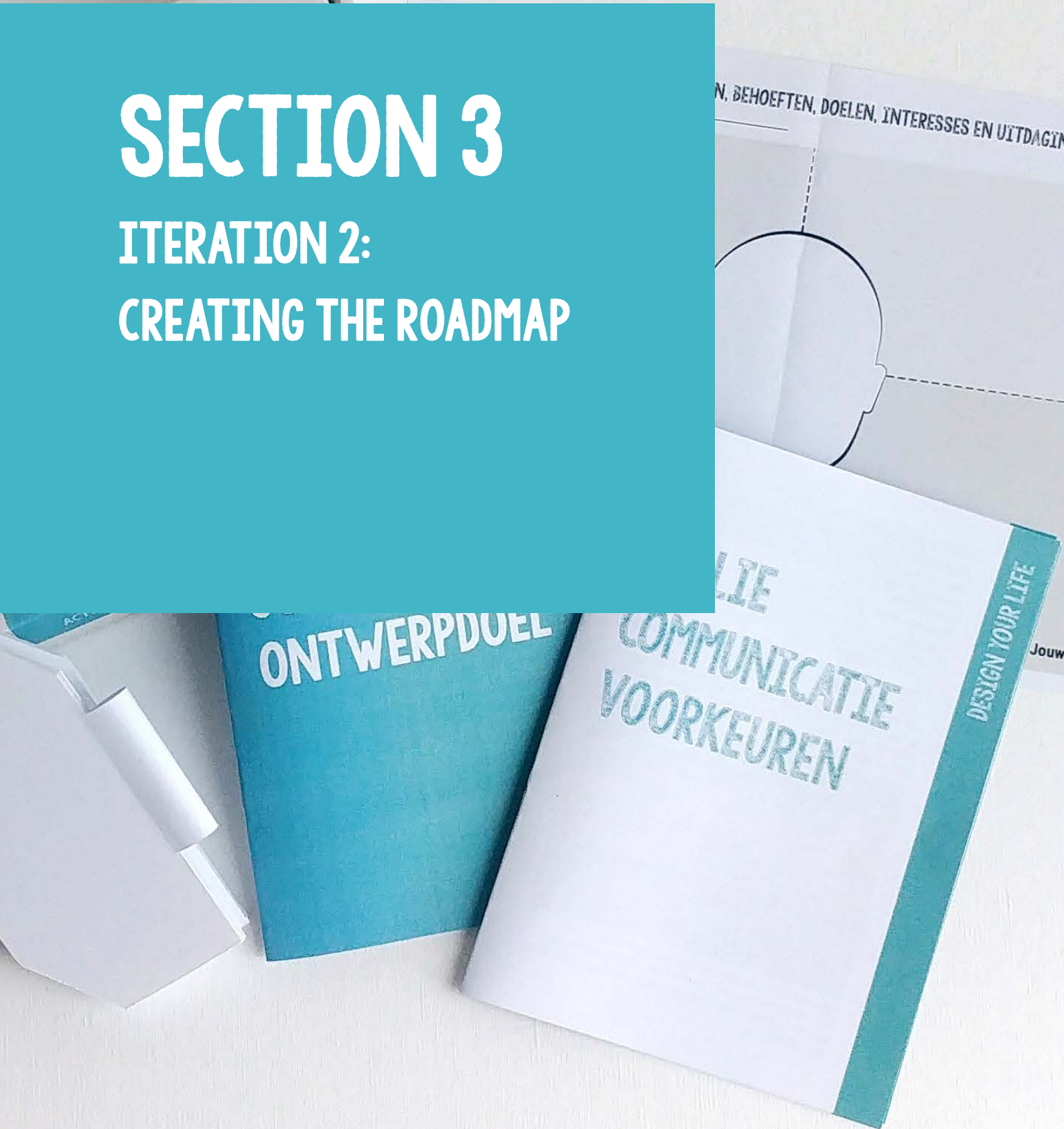
The first challenge was already explored in the section "on the need of guidance", where the participants pointed out that they did not know anyone in their own network who could be able to help, apart from the designer/researcher. The participants also relied on the skills of the designer/researcher for the visualisations of Aether and to create the Aether summary. This is an important point to keep in mind, as the participants need a form of a network to rely on for skills that they might not have, to successfully complete the toolkit.

The toolkit was created with the design of a physical product in mind. But in this particular design case, it became clear quite early that the participants were opting for a software solution. Designing software requires a different strategy than designing a physical product. Simon and Ellen noticed this especially in the Velcro mock-up kit, where they are asked to assemble a product using all sorts of separate elements. The participants got stuck in this assignment at the point that Simon created a mock-up of a computer, but did not have any space to explore software. The participants experienced this as the main drawback of the activity box system: the toolkit does not offer a quick way to switch design strategies. This situation will be further outlined in Iteration 3.

Finally, my involvement in the prototyping stage was also influenced by my personal interests. Simon enjoyed talking with me, the designer/researcher, about his world, noting that I am 'a fantasy nerd' like him. The illustrated introduction to his world has inspired him to continue writing. In the end, this visualisation was only used as means of contacting possible mentors, but also served as a starting point for Simon's writing: according to Ellen and Simon, Simon has been working on characters for his world and expanding Aether based on the Aether summary.

SECTION 3

ITERATION 2: CREATING THE ROADMAP



The roadmap represents a small but important iteration: it was an important tool in the communication between the participants and the designer/researcher. Figure 27 shows which part of the timeline were directly linked to the creation of the roadmap.

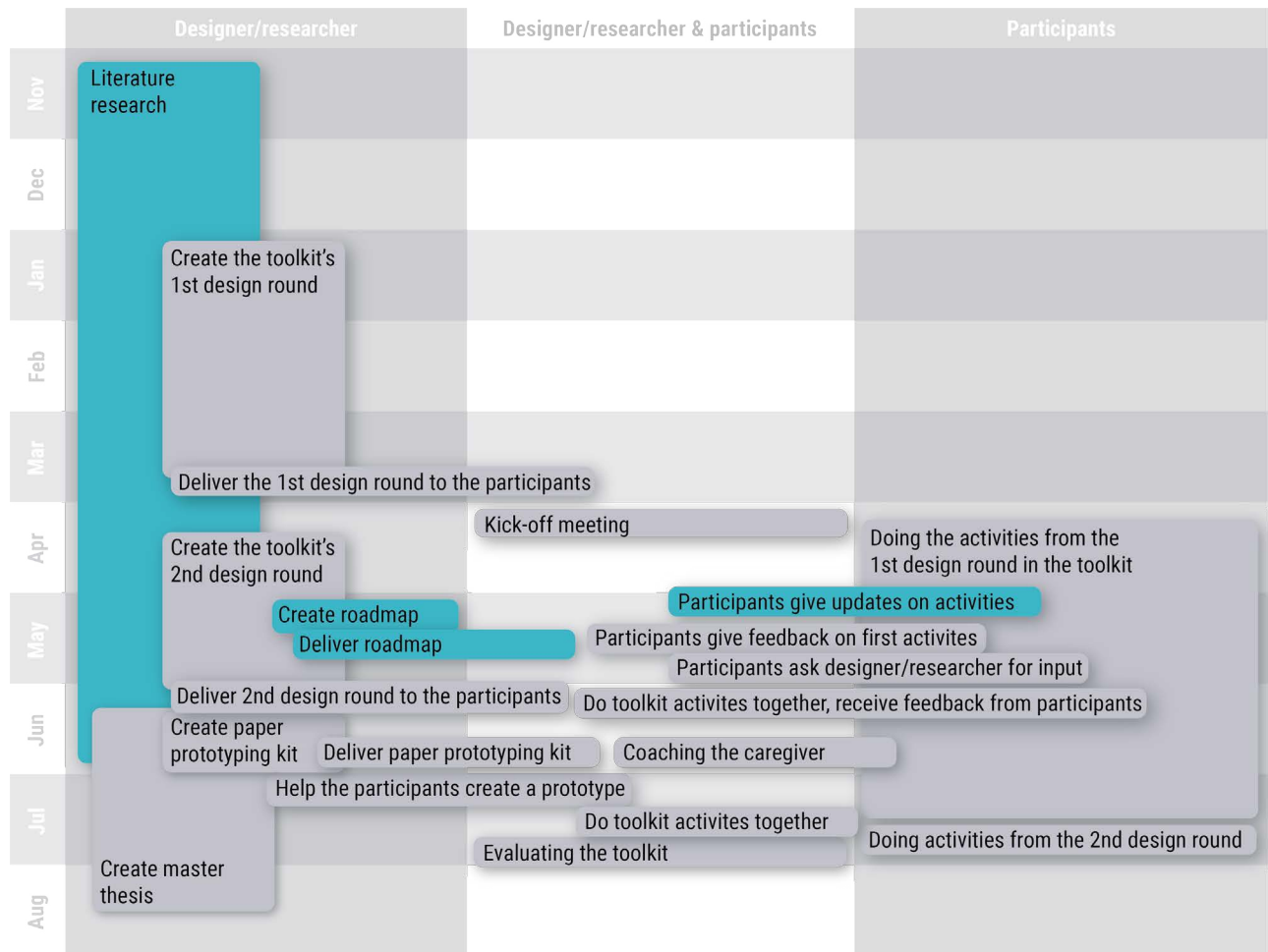


Figure 27: activities in the timeline that contributed to the creation of the roadmap.

3.1. The roadmap

The roadmap is a template for an activity schedule. When delivered to the participants, it contained all the activities from the first design round, the delivery for the second design round and an estimated end of the case. The roadmap can be seen in Figure 28. The roadmap has three columns: the name of the activity, the proposed date to do the activity, and a column for the date the activity was actually completed. The activities were colour coded to show which ones were individual activities, shown in lilac in Figure 28, and which were done together, shown in white. The bottom of the template has space to add stickers that contain the planning for the second design round (see Figure 29), which was still in development when the roadmap was presented to the participants. This sticker was delivered along with the second design round, as part of Activity Box 6. Both participants received a copy of the roadmap, so they both have a filled out version to refer to.

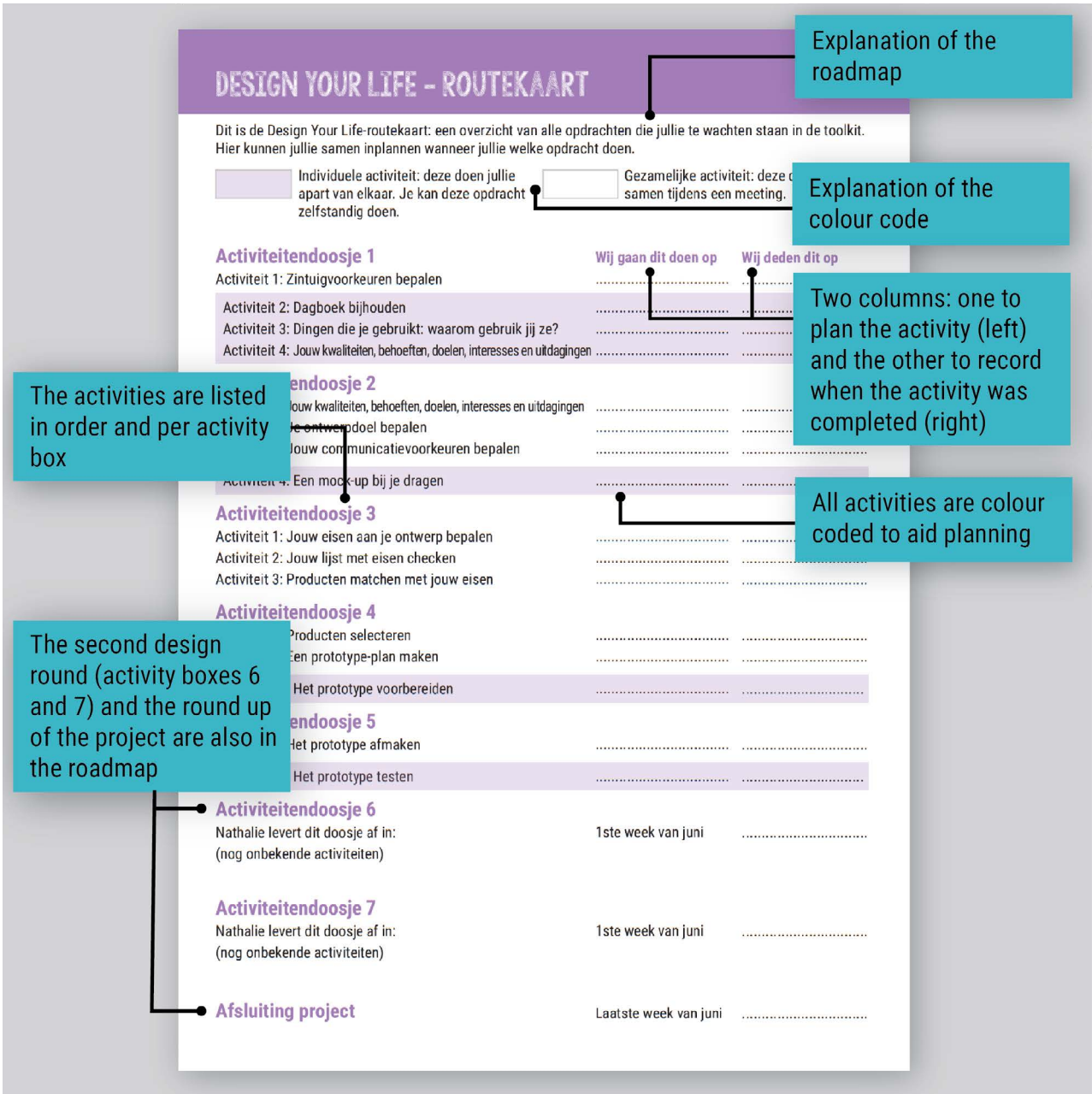


Figure 28: the roadmap.



Figure 29: the extra sticker provided with the second design round materials. This will be placed over the Activity Box 6 and 7 areas on the roadmap.

3.1.2. Design considerations

The roadmap was created when I realised that the progress of the participants was much slower than I had anticipated: instead of completing one box per week they completed one activity per week. This strongly influenced the duration of the case, which initially would have lasted till the end of June. This slow progress was due in part to the limited communication on the content of each box: it was unclear to the participants how many activities were in each box and thus it was difficult for them to have a realistic time estimation.

To offer the participants that overview, the roadmap was created. This roadmap contains an overview of all activities, organised per box, and are colour coded to indicate which activities are individual and which are done collaboratively. The roadmap has the same graphic design as the other toolkit materials, making it recognisable and also appealing to the YAA's preference for as little frills in visual communication, as noted by Fabri & Andrews (2016). Finally, the two boxes for the second design round, which were still in development at the time, are also mentioned on the roadmap, as well as the prospective end date of the project. All these elements create an overview of what the participants can expect from the future boxes in the toolkit.

The main purpose of the roadmap is offering a planning tool for the participants. Therefore the roadmap has two columns, one to plan the activity and one to note when the activity has actually been completed. The space dedicated to Activity Boxes 6 and 7 are deliberately large to allow the placement of a sticker. This sticker allows the participants to write down activities for the second design round and schedule them as they did with the other activities.

The overview that the roadmap offers also gives the participants more insight into the design process, as well as establishing a timeframe. This in turn create more motivation to continue with their design process. The roadmap therefore improves the clear and unambiguous communication within the toolkit, as mentioned previously by Sinclair (2010).

Additionally, the roadmap allows the participants to make their own choices in when to do which activity, simply by planning each activity individually rather than per box. This is in line with the participants' wish for shorter sessions.

3.2. Implementation in the case

3.2.1. Use

When first given the roadmap, the participants used it well. However, the use declined when they got to the design impasse, and required extra guidance. From there, the focus was more on planning meetings and seeing how far along we would get during these meetings, rather than planning out sessions using the Activity Boxes as a guide. In between the sessions with the designer/researcher, the participants had their own meetings, which were written down by them on the roadmap, as visible in Figure 30.

DESIGN YOUR LIFE - ROUTEKAART

Dit is de Design Your Life-routekaart: een overzicht van alle opdrachten die jullie te wachten staan in de toolkit. Hier kunnen jullie samen inplannen wanneer jullie welke opdracht doen.

Individuele activiteit: deze doen jullie apart van elkaar. Je kan deze opdracht zelfstandig doen.
 Gezamenlijke activiteit: deze doen jullie samen tijdens een meeting.

Activiteit	Wij gaan dit doen op	Wij deden dit op
Activiteitendoosje 1		
Activiteit 1: Zintuigvoorkeuren bepalen	8 mei	
Activiteit 2: Dagboek bijhouden		
Activiteit 3: Dingen die je gebruikt: waarom gebruik jij ze?	14 mei	
Activiteit 4: Jouw kwaliteiten, behoeften, doelen, interesses en uitdagingen	14 mei	
Activiteitendoosje 2		
Activiteit 1: Jouw kwaliteiten, behoeften, doelen, interesses en uitdagingen	14 mei	14 mei
Activiteit 2: Je ontwerpdoel bepalen	14 mei	
Activiteit 3: Jouw communicatievoorkeuren bepalen	14 mei	
Activiteit 4: Een mock-up bij je dragen	14 mei	
Activiteitendoosje 3		
Activiteit 1: Jouw eisen aan je ontwerp bepalen	14 mei	
Activiteit 2: Jouw lijst met eisen checken	14 mei	
Activiteit 3: Producten matchen met jouw eisen	14 mei	
Activiteitendoosje 4		
Activiteit 1: Producten selecteren	18 mei	
Activiteit 2: Een prototype-plan maken	18 mei	
Activiteit 3: Het prototype voorbereiden	18 mei	
Activiteitendoosje 5		
Activiteit 1: Het prototype afmaken	23 mei	
Activiteit 2: Het prototype testen	23 mei	
Activiteitendoosje 6		
Nathalie levert dit doosje af in: (nog onbekende activiteiten)	1ste week van juni	
Activiteitendoosje 7		
Nathalie levert dit doosje af in: (nog onbekende activiteiten)	1ste week van juni	
Afsluiting project		
	Laatste week van juni	

Figure 30: Ellen's filled out roadmap. The dates are for the sessions between her and Simon.

3.2.2. Feedback

The participants were glad to have such a planning tool, and as is seen in Figure 30, it was used well. Especially the fact that they could now plan ahead properly was appreciated. This was thanks to the complete overview of activities and the type of activity that enabled them to do so.

However, the planning was not always as smooth: participants sometimes missed appointments, e.g. through illness, COVID-test results that took longer to come in, colleagues being on holiday, or simply Simon forgetting the appointment. The latter sometimes happens with Simon, despite having high motivation to work on the project.

When doing individual assignments, Simon explains that he sometimes forgets to do assignments. This is in part because the assignment itself does not quite interest Simon. As already mentioned in Iteration 1, 'On the activities', Simon sometimes only fills out the assignment because he feels he should fill out something, not because he has much interest in doing the activity. He explains that it does help him to have clues in the environment:

Simon: "Like in a detective series that you have that board with a whole web – that is how my head works. When I have an appointment and I hear any relation to that appointment, to give an example: I have a dentist appointment and I hear someone mention the dentist and then I remember 'I have an appointment at the dentist's'."

Transcripts of the meetings can be found in Appendix B.

- Meeting 07-05-2021

For Simon, these clues can also be objects in the environment, e.g. keeping the diary on his computer desk. Then the project is still in his mind's eye. Simon does not appreciate reminders given by Ellen, as this can feel overbearing to him. But even then, it is not guaranteed that Simon remembers to do the individual activity. This was the case with the diary activity. Ellen and Simon solved this by swapping their activities: instead of working on the toolkit activities, they went on the walk that was planned for the following day. This gave Simon the time to fill out the diary that evening and the following day during the meeting.

This lack of interest in the activity stems from not finding the activity in itself interesting, but can also partly stem from not knowing how the activity can be used in the further design process. This ties in with the gap in design knowledge implicitly present in the toolkit, uncovered in Iteration 1. The roadmap closes this gap partly, by offering an overview of all the assignments. To improve the function of the roadmap and to offer the participants an overview of how activities tie in to each other, the input and output of each activity can be shown – similarly as is done in Table 4, explaining the activities in the first design round.

SECTION 4

ITERATION 3: CREATING A PAPER PROTOTYPE ACTIVITY

This iteration was aimed at altering the 1st design round of the toolkit to suit the needs of the participants. Figure 31 shows the activities that contributed to this change.

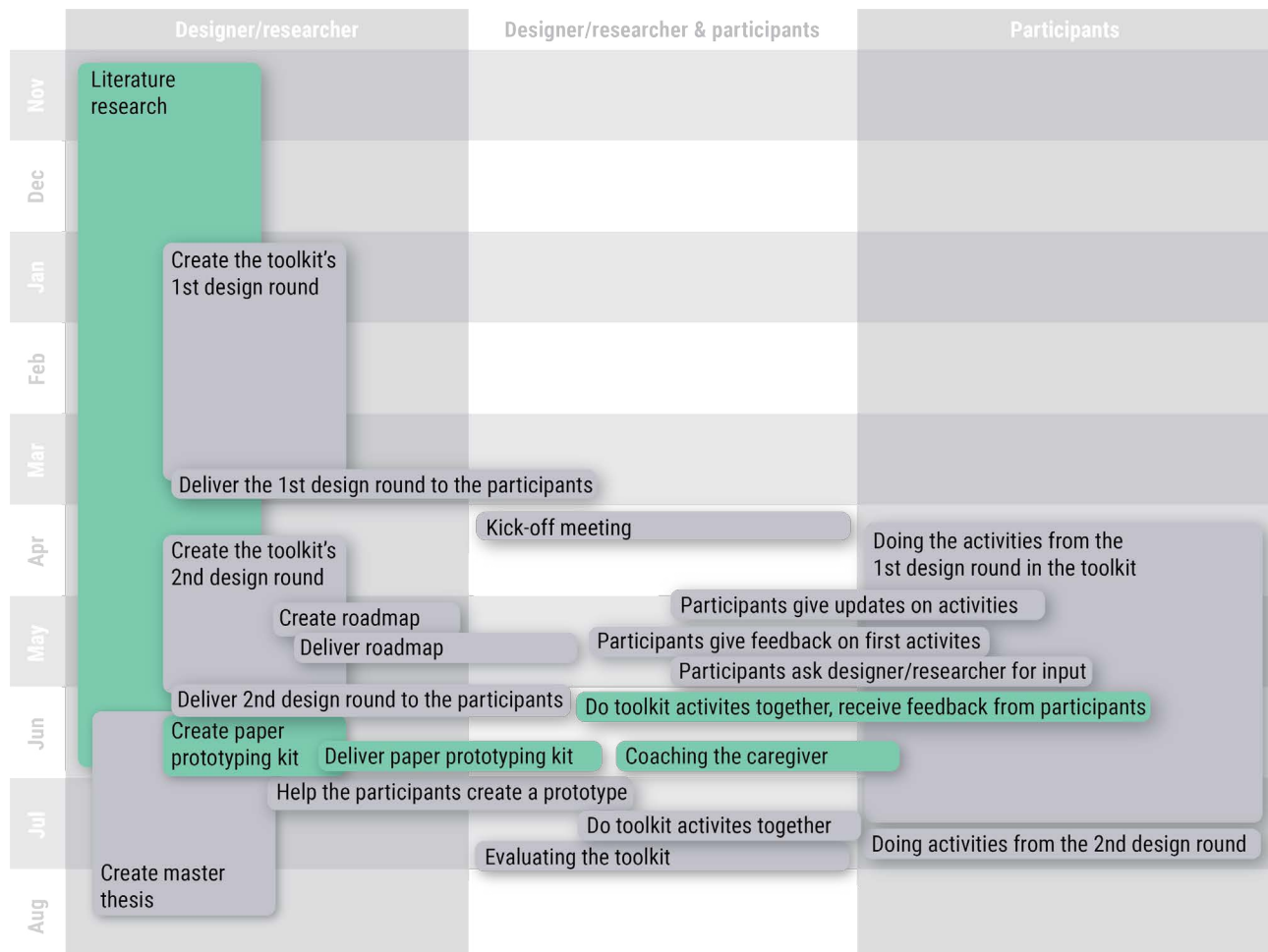


Figure 31: activities in the timeline that contributed to the creation of the paper prototype activity.

4.1. The paper prototype activity

At this point in the case, the participants prefer doing activities together with the designer/researcher. In the meeting labelled 'Do toolkit activities together, receive feedback from participants' (as seen in Figure 31), it became clear that the Velcro mock-up kit was too limited in options for making a mock-up.

This paper prototype kit, which is shown in Figure 32, offers a supplement to the Velcro mock-up kit. This kit consisted of paper templates: two computer screens each on A3 sized paper, two tablets each on A4 sized paper, and two smartphone templates each on A5 sized paper. The kit was accompanied by a folder with pre-cut Post-it elements. The flap of this folder was printed with ideas for interaction elements, as is shown in Figure 33. The kit was not accompanied with written instructions. Instead the plan was to do this activity with the three of us – the participants and the designer/researcher. The toolkit elements were delivered in an envelope.

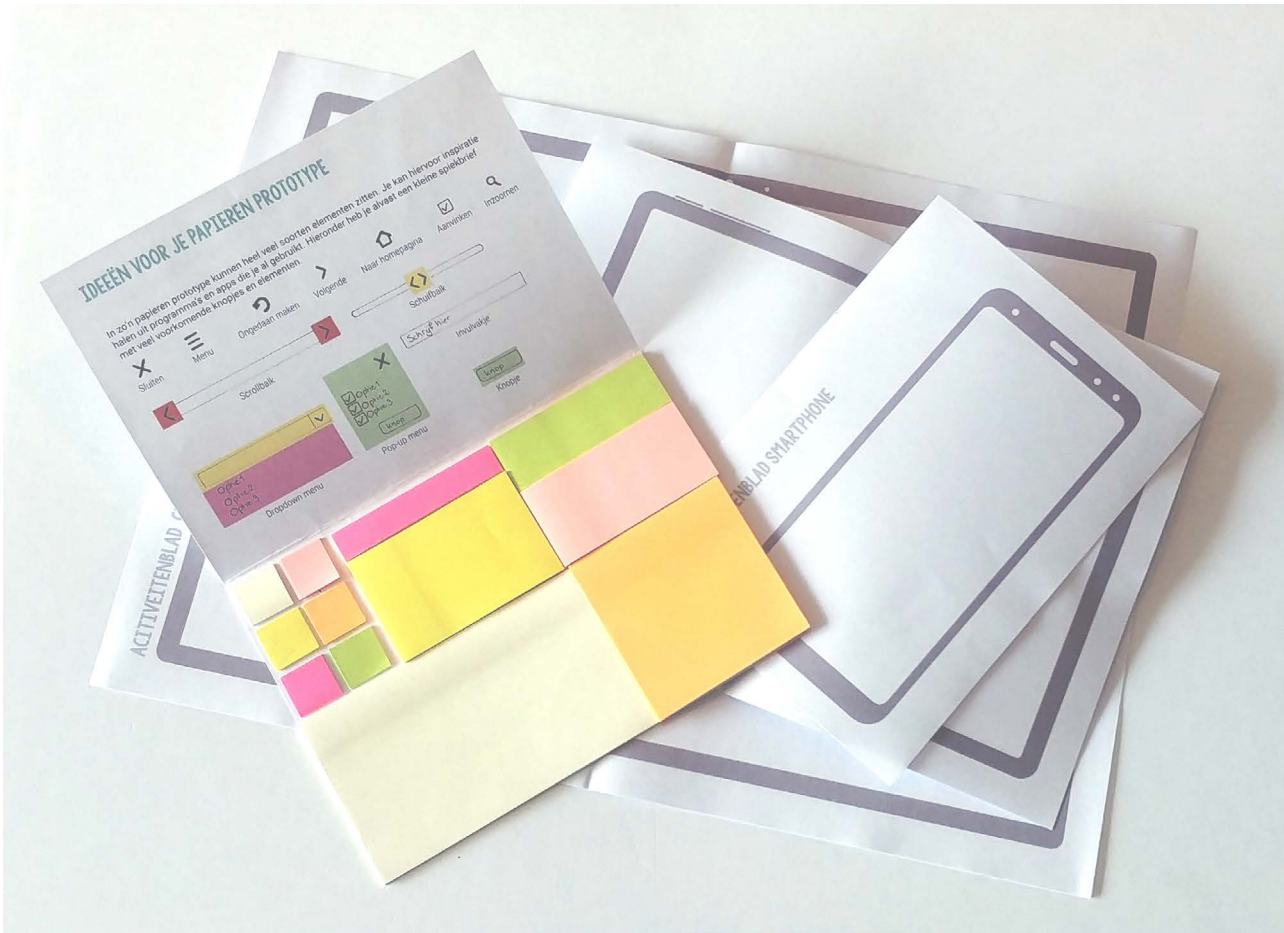


Figure 32: the paper prototype kit.

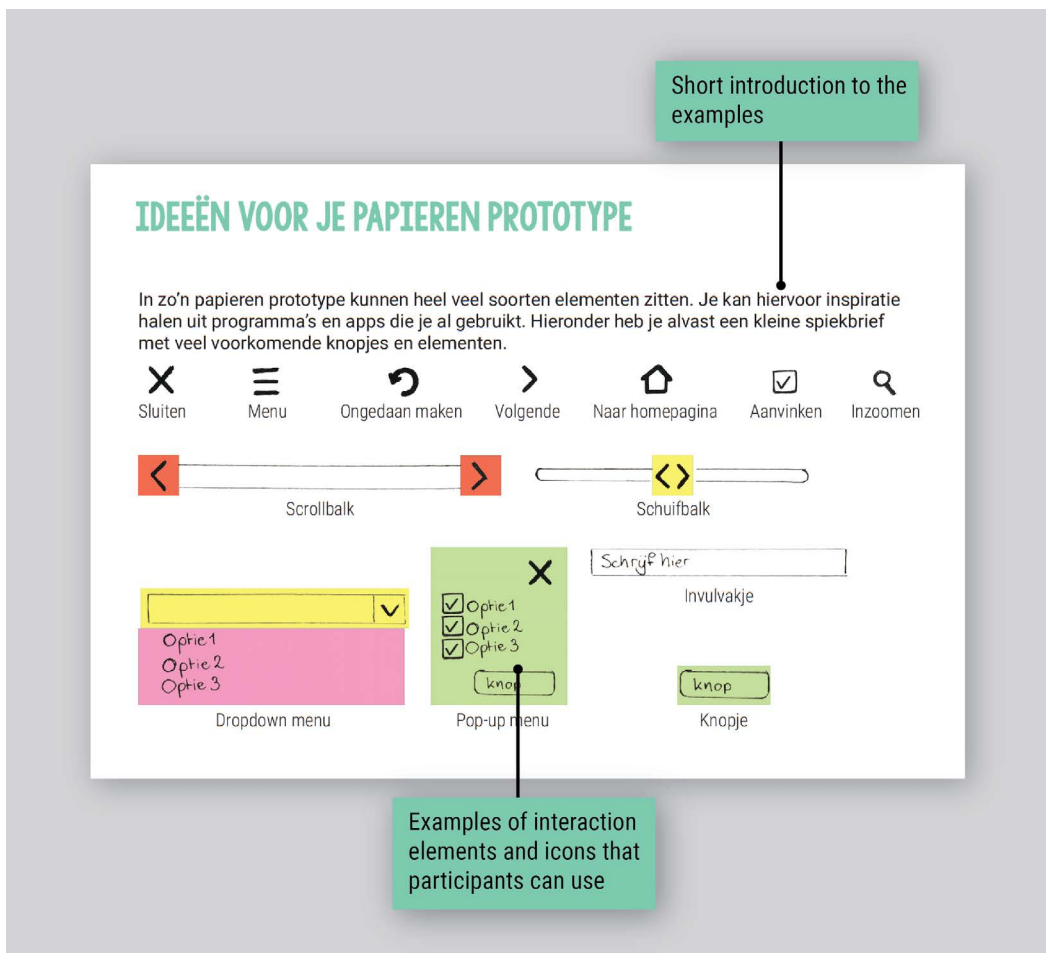


Figure 33: a closer look at the inner flap of the paper prototype elements.

4.1.1. Design considerations

With the design of the toolkit it had to be taken into account that there are a multitude of possible solutions, ranging from physical products, to mobile apps, to services, to arranging meetings. The design solutions are also not limited to just one of these categories. However, accommodating all of these possible design solutions in a 'design-process-in-a-box' toolkit would require a range of ideating and mock-up tools, each aimed at one or a couple of design directions. This would require too much time to prepare, thus an educated guess was made to offer a Velcro mock-up kit: the DYL-method aims at using existing technology, which makes it likely that an electronic, physical product would be created.

The Velcro mock-up kit, shown in Figure 34, was part of the "coming up with ideas" phase, activity box 3 in the toolkit. The Velcro mock-up kit offers a multitude of interactive elements, of which some very recognisable, e.g. a keyboard and sliders, some ambiguous based on their icons. The goal of this toolkit was to let the YAA create an electronic product by combining the offered elements. While doing so, the YAA assigns functions to these elements. These functions can then be mapped onto existing products. This mapping is not limited to physical functions, but can easily bleed into software functions: adjusting volume can be done with a physical dial or a slider on a screen. The Velcro mock-up kit also contains two screens: a rectangular one and a round one. Both have a white surface that could be sketched on. This allows for quickly creating a mock-up interface, though the surface is rather small.

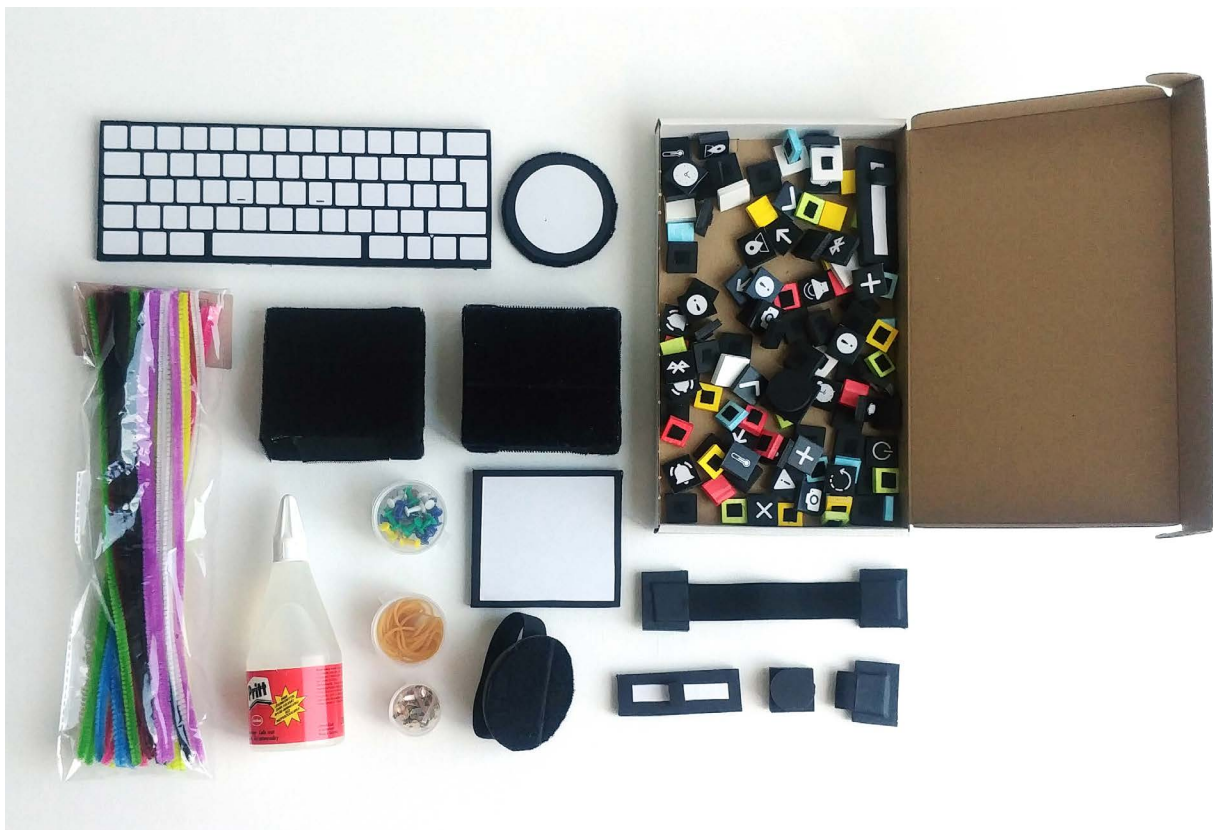


Figure 34: the Velcro prototyping toolkit.

Simon created a Velcro mock-up using the square volume, the square screen and the keyboard: a computer. He created this because he prefers to write using his computer. This was also the point where Simon stopped: the screen was absolutely not in proportion with his personal computer setup, which contains two large monitors. Additionally, Simon found it difficult to add items, because all physical elements were already present, but not the software elements. It became clear that the Velcro mock-up kit did not sufficiently support software design, whilst this was the particular design direction that the participants are headed in.

Therefore the paper prototype kit was created to support creating a software mock-up. Paper prototyping is a tried and trusted method of quickly creating low-fi prototypes of software and has also been applied by Zhu et al. (2019) in their co-design sessions where they involved autistic adolescents in software design. A paper prototype replaces digital elements with paper elements, such as post-its. The advantages of this setup is that the prototype can be created quickly, without any programming knowledge and that it can be altered very quickly.

The templates in this toolkit are outlines of familiar devices: computer screens, tablets and smartphones. By supplying two templates of each the participants can create either two iterations or both work on their own interpretation, discussing their insights with each other. Providing templates of different devices sensitises the participants for possible solutions that could be used across multiple devices, such as receiving calendar updates both on your phone and on your computer.

As stated in the explanation of the paper prototype toolkit, this activity was planned to be done with the designer/researcher present. Due to this shift in role of the designer/researcher, it was decided to limit the explanation to a verbal one, thus also being able to answer questions from the participants and provide examples where they needed it. Therefore there was no written explanation in the activity package, only examples in the flap of the post-it folder.

The design of the materials once again used the same graphic design as the other toolkit materials: the colour corresponding with the design phase and only using two font families. The examples in the folder were hand-sketched representations of interaction elements commonly found in software to resemble elements that could be made with the post-its.

4.2. Implementation in the case

4.2.1. Use

Simon, Ellen and I arranged to continue the toolkit activities together in a new meeting. The previous meeting ended at the point that Simon created the Velcro prototype and then ended up stuck. Unfortunately, Simon forgot the meeting during which I brought the paper prototype kit: only Ellen and I were present in the office of the care organisation. During the previous meeting Ellen mentioned that she prepares the activities by going through them and coming up with examples relevant for Simon before meeting up with him. Therefore I propose that the two of us have a coaching session, where I walk Ellen through upcoming activities.

With my instructions Ellen visualised her ideas for the software based on the information gathered on the board and talks Ellen had with Simon during their walks. Ellen did not create traditional software elements. Instead she used the sheet as a brainstorming device and used the post-its from the paper prototype toolkit to support her ideas. Her result is shown in Figure 35. During this process, we also practiced formulating the functions she created into requirements. In this case, I took on the role of writing down the requirements.

Walking through the activity like this also allowed conversation between Ellen and I about possible solutions. For this I first direct Ellen to the resource and inspiration booklet. But some possible solutions are not mentioned in there, such as having a ghost writer: the booklet is also more focussed on physical products and digital services rather than in-person services. This conversation helps Ellen to create a wider definition of a possible solution space.

During a later meeting with Ellen and Simon, Simon did create his own paper prototype, as visible in Figure 35. For this he took the same approach as Ellen, using the templates more as brainstorming devices. This means that the functions were visualised, but not in a way that could be directly implemented in software.

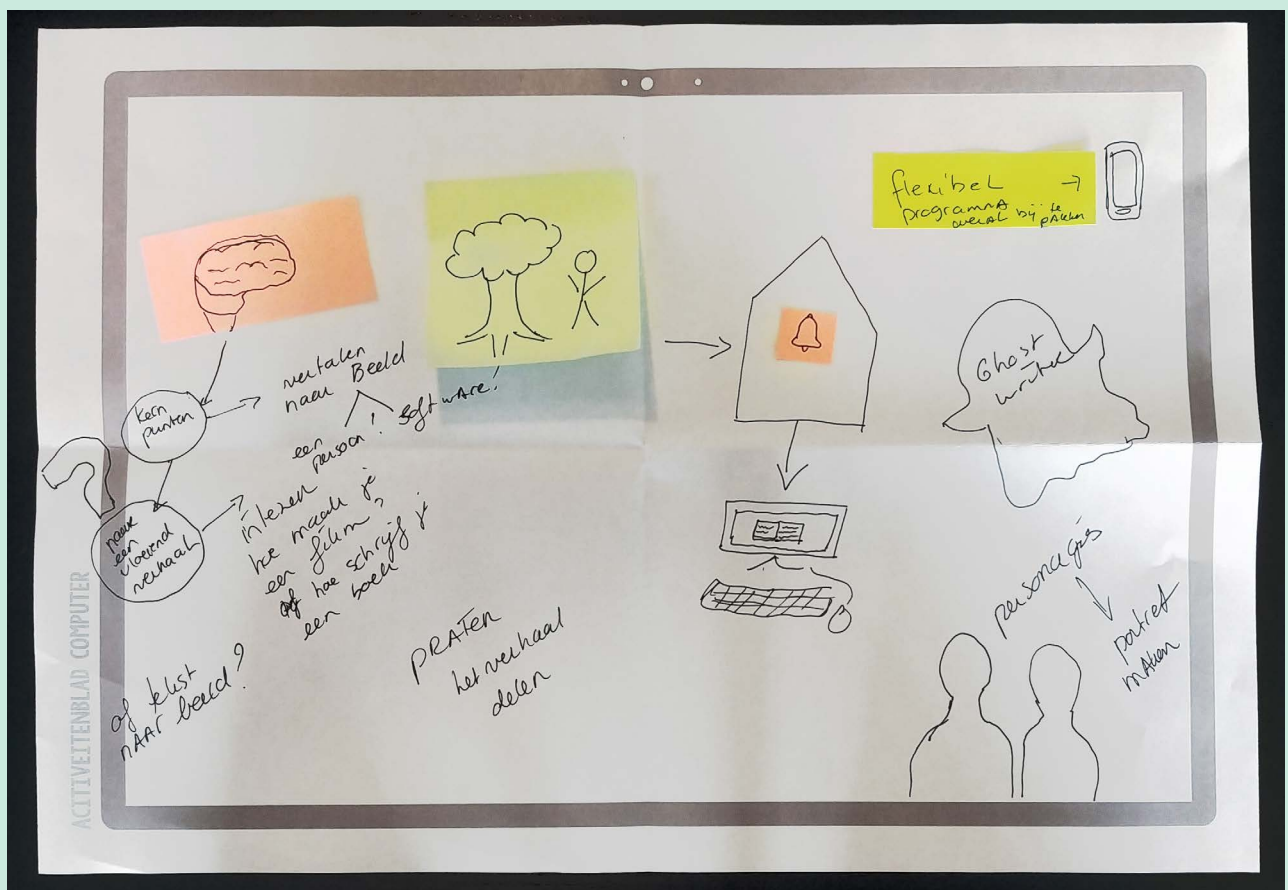


Figure 35: Ellen's execution of the paper prototyping activity.

Because Ellen was already prepared for the activity and had an array of possible solutions she could present to Simon, they had an interesting discussion which ultimately also reframed the design goal. The design goal shifted more from 'writing a book' to 'visualising Simon's world'. This is in line with Simon's visual thinking, though he does not enjoy painting or sketching. The reframing of the design goal results in a set of requirements that are more tailored to that reframed design goal.

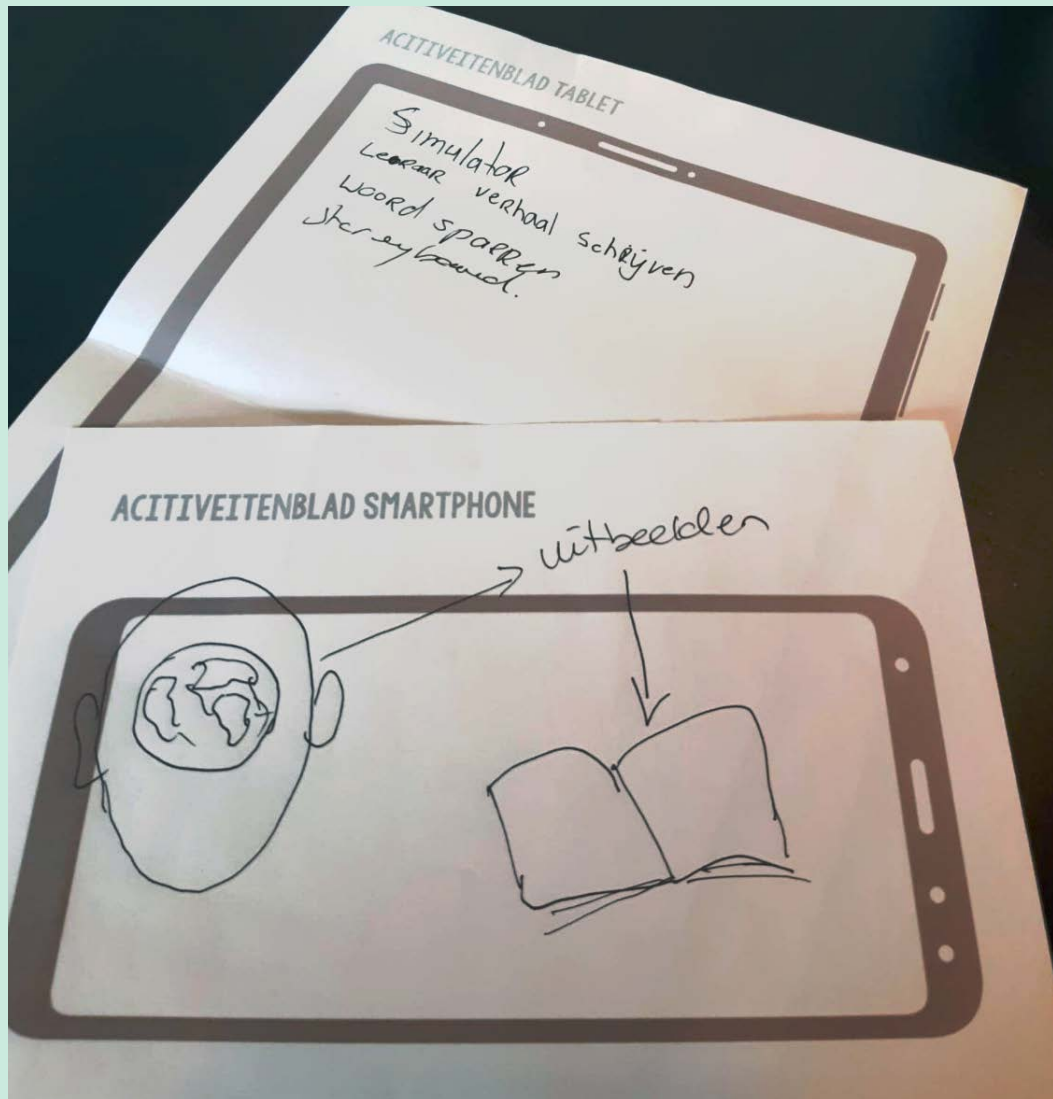


Figure 35: The result of Simon and Ellen doing the paper prototyping activity together. The smartphone template is done by Ellen, the tablet template is by Simon.

4.2.2. Feedback

The activity was useful in refining Simon's design goal. It was during this activity and their walks that they discussed that Simon would like the intermittent step of visualisation before actually writing a book.

As Figures 34 and 35 show, the participants did not create computer interfaces, but gave their own spin on the activities in a way that was useful for them. The requirements on the board, visible in Figure 21, were the result of this activity. The paper prototyping activity followed with product matching, of which the result is shown in Figure 36.

ACTIVITEITENBLAD: PRODUCTEN MATCHEN

Beste producten Favoriete producten

Producten die je zou kunnen gebruiken

	woord	telefoon	storyboard	ghostwriter	Simulator	sparring partner
1 het product een beeld maken van mijn wereld	X	X	0	X	✓	✓
2						
3 het product moet met mij spreken	X	X	X	0	X	✓
4 het product moet flexibel zijn om info te verzamelen	X	✓	X	X	✓	X
5 het product moet een overzicht kunnen maken van verzamelde info opzetten	X	✓	✓	X	X	✓
6 het product moet mijn kunnen bekragen	X	X	X	✓	X	✓
Jouw eisen						

Figure 36: the result of the product matching activity. The simulator was a precursor for Unreal Engine. In the blue area Simon wrote 'sparring partner', but it was initially crossed out because it wasn't a real 'product'.

SECTION 5

ITERATION 4: CREATING THE SECOND DESIGN ROUND



Using the insights taken from the feedback on the 1st design round and the literature research, a 2nd design round was created to support the participants in optimising or changing their product or design goal. Figure 37 shows the activities that were related to the creation of this design round.

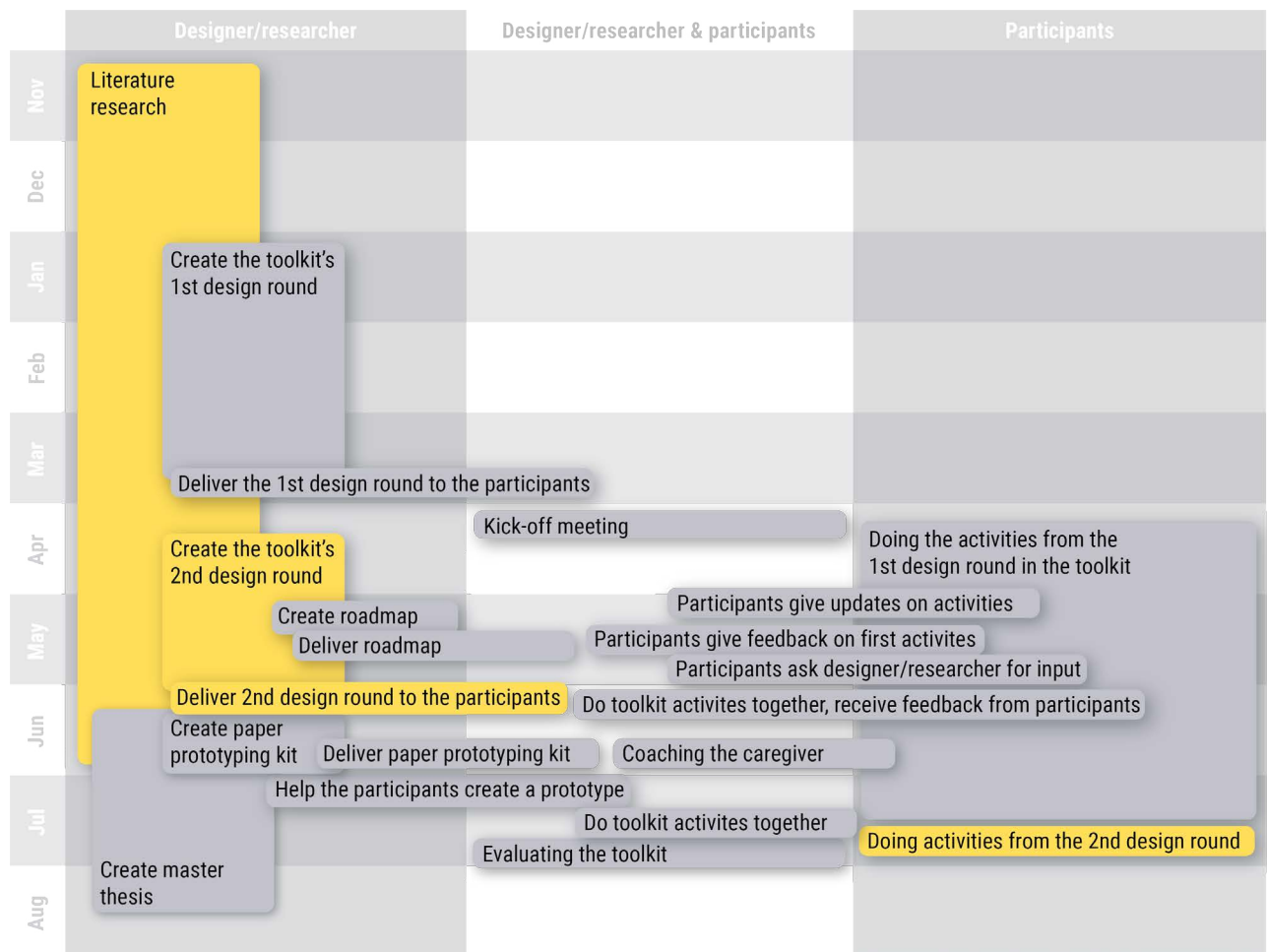


Figure 37: the activities related to the creation of the 2nd design round.

5.1. The second design round toolkit

This part of the DYL toolkit consists of two parts: 1) the evaluation of the first design round and its resulting product, and 2) the activities of the second design round to improve the designed product. The evaluation is used to select activities for the second design round and is done using the evaluation board, stocked with evaluation cards that are related to each design phase. This board is shown in Figure 38. The evaluation process, also visualised in Figure 38, goes as following:

1. The participants start by placing the pawn on the first phase. In this case that is "testing the prototype", as all the phases are in backwards order in this evaluation. The participants take turns in drawing cards. An example of such a card is shown in Figure 38. Each card contains a statement. The participants answer this statement.
2. Depending on the answer of the participants, they have to do either one of two actions:
 - Discard the current card and draw the next one from the same stack.
 - Discard the current card, get an activity envelope from the box, place the stickers in the activity 7 booklet at the corresponding phase and add the envelope to activity box 7. Then the participants move the pawn to the next phase.
3. The participants continue this cycle from step 1 until they reach the end.

At the end of the evaluation, the participants have created their personal second design round based on their statement answers. The activity materials are sorted in envelopes and placed in Activity Box 7, while the activity instructions are put in activity booklet 7. The possible activities that the participants can select are shown in Table 6.

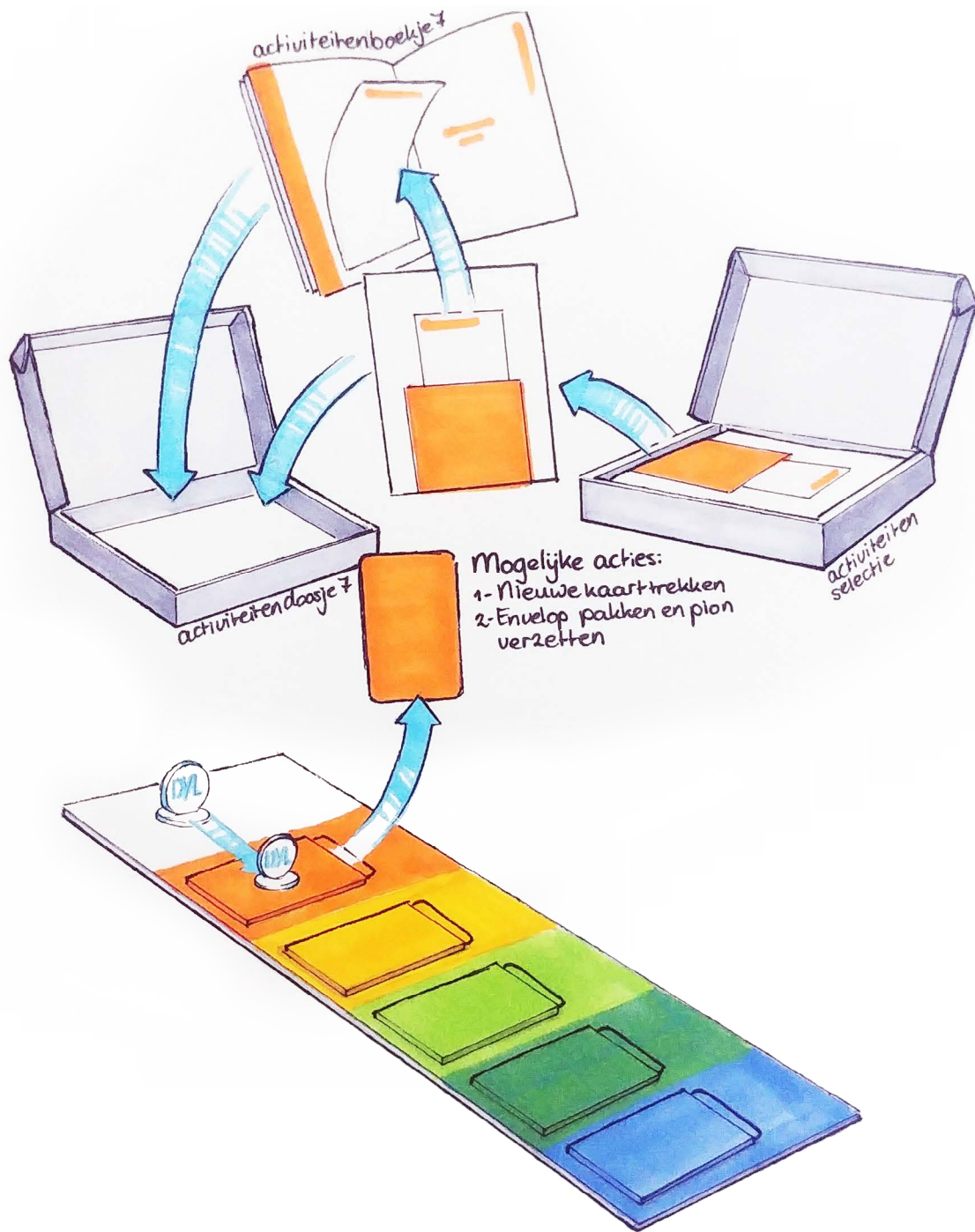


Figure 38: explanation of the second design round. The cards are stored in pouches.

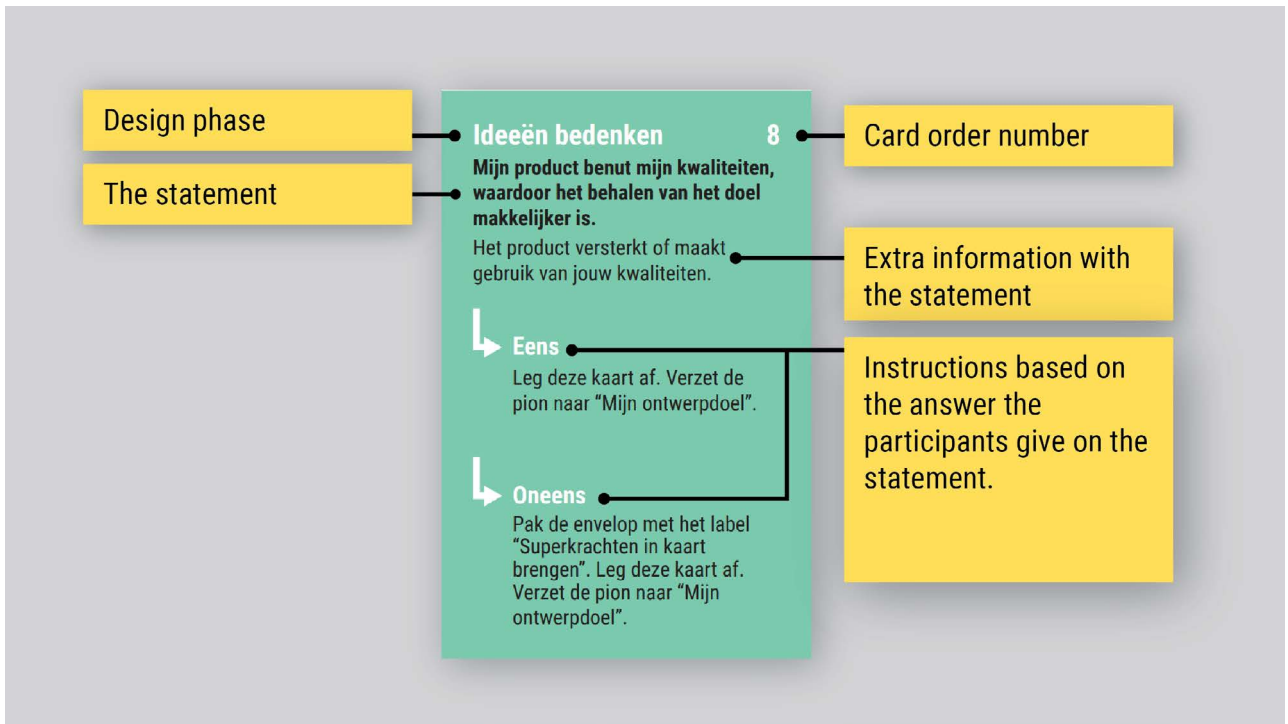


Figure 38: explanation of the second design round. The cards are stored in pouches.



Figure 40: the contents of the second design round, such as the board, the pawn and activity envelopes with the activity explanations printed on stickers in the front. On the top left, open faced is the Activity Box 7 booklet, where the stickers are put in.

Phase #	Activity name	Description
Redoing testing	Retesting the prototype	In the case the participants were unable to properly try out the prototype, this is the opportunity for them to do so. The participants can select two ways to do so: based on a product to support a habit, or based on one aimed at a specific activity. When this activity is selected, the participants must complete testing before moving on to the next card.
	Making a collage	The YAA is invited to create a collage. This activity is used to address the emotional associations the YAA has with the design goal.
Phase 2: My Design goal	Writing down the new design goal	This activity guides the participants through reframing or rephrasing their design goal, asking them first to write down new goals, then to relink them with the qualities, needs, challenges, interests and goals previously recorded on the CQING quadrants.
Phase 1: My World	Habit diary	This diary is set up as a tracker for habits. The YAA fills out the diary every time an alarm goes off. This alarm is set at a particular interval suitable for the habit. The diary needs to be kept for three days.
	Discussing the habit diary	After keeping the habit diary, the participants review the recorded material. Using this material, they establish the characteristics of the habit and what the ideal situation of this habit would be. This information is then added to the board.
	Photo diary	This diary is aimed to document the context in which the YAA would like to use the product. This option is chosen when the prototype is to be used in a specific activity. The photo diary is kept on a day when that particular activity takes place and allows the YAA to document the environment and the objects related to that activity.
	Discussing the photo diary	The photo diary has produced a set of photos that enriched the information about the context in which the designed product needs to function. This activity allows the participants to add these products to the board with a short description attached to it.
Phase 3: Coming up with ideas	Warming-up	Is used to promote divergent thinking in a low-effort way. The participants take turns sketching ways to either break into or steal a safe, or to defend it. Each participant takes on one of two roles: of the thief or of the security guard. They can portray anything they like: magic, science fiction, bombs, et cetera. The activity is over when the timer stops.
	Mapping superpowers	The participants map qualities of the YAA that can help them achieve their design goal. Then, the participants match products, services and behavioural strategies that utilise these qualities. The aim is that such matches improves the long term use of the solution.
	Checking your requirements	With all the extra information, the participants need to check if the requirements are still up to date: are there any requirements missing? Or have requirements become superfluous? This activity guides them through checking, by using the board and the field research booklet notes (either from the testing or the retesting).
	Matching products	This activity is directly taken from the first design iteration (see Table 4), where existing products are matched against the listed requirements.
	Creating a prototype plan	This option is selected when the participants are dissatisfied with the prototype and is directly taken from the first design iteration (see Table 4).
Phase 4: Creating a prototype	Prepare the prototype	This option is selected when the participants are dissatisfied with the prototype and is directly taken from the first design iteration (see Table 4).
	Create an alteration plan	The participants select this activity when they are partially happy with the prototype. The participants start this activity by recording which parts of the prototype they would like to keep and which parts need changing. Since an alteration generally needs less work, an altered planning flowchart is used. This one is much shorter than the prototype plan flowchart given that the participants have something to start with.
	Preparing the alterations to the prototype	Just as with the "preparing the prototype" activity, the alterations might require preparation. This activity allows the space for such preparations. The participants execute the steps marked as preparation before doing any of the "testing" phase activities.
	Making small changes to the prototype	These changes are so small, that they can be pretty much done on the spot. Think small changes in settings or small alterations. For this, the participants simply use the "keep-and-change" work sheet.
Phase 5: Testing the prototype	Preparing the prototype for testing	Just as in the first design round, the participants make the prototype ready to test. This means executing the remaining steps in the prototype plan, the alteration plan or completing the small changes.
	Testing the new or updated prototype	Just as with the retesting, the participants can select two ways to test their new and/or improved prototype: based on a product to support a habit, or based on one aimed at a specific activity. The testing booklets support the two options in their specific way, for instance by instructing to set alarms throughout the day in the case of the habit, or setting a reminder to take the prototype with them when the YAA wants to test it in a specific activity.

Table 6: an overview of all the activities that can be selected for the second design round. Phases 1 and 2, "my world" and "defining the design goal" are switched around. Phase 6, "evaluation" is done in collaboration with

Input	Output
The prototype, the retesting booklet in the version they need.	Test results in the forms of the likes and dislikes of the YAA about the prototype. A photo of the collage is sent in the group chat in Signal.
An A3 sized template, set of images, glue, writing utensils	A collage that shows the emotional associations that the participant has with the design goal.
The CQING quadrants from the first design round, the made collage, sticker to put on the board over the old goal, writing utensils	A new or more defined design goal, with updated associated information in regards to associated qualities, needs, challenges, interests and goals. A photo of the updated board is sent in the group chat in Signal.
The habit diary template, writing materials, a device to set alarms on at specific intervals.	An understanding of the duration, frequency and moments during which the YAA is involved in a certain habit. A photo of the filled out habit diary is sent in the group chat in Signal.
The "discussing the habit diary" template, the habit sticker, the board, writing utensils	An understanding of the habit itself and how it relates to the design goal. A photo of the updated board is sent in the group chat in Signal.
A smartphone with a camera. The prompt used is: "your design goal". The YAA is free to interpret this in their own meaningful way.	A series of photos with short descriptions about the relation with the design goal. These photos and descriptions are sent to the co-designer via Signal.
Empty item cards, writing and drawing utensils, the pictures made for the photo diary	A selection of objects from the photographs that either describe the use context or that could be used in the prototype. A photo of the updated board is sent in the group chat in Signal.
The warming-up template, showing a small drawing of a safe, drawing materials	By setting no limits on what is possible and a 10 minute time limit, the participants are encouraged to find the "more than the usual suspected options" for defending or stealing the safe: stimulating creativity.
The superpower mapping template, writing utensils, the resource and inspiration booklet for product ideas	An overview of the YAAs qualities, as well as services, strategies and products that make effective use of these. Qualities and products not yet on the board are added to the board. A photo of the updated board is sent in the group chat in Signal.
The field research note, the board, the requirement post-its, writing utensils	An updated overview of requirements on the board. A photo of the updated board is sent in the group chat in Signal.
-	-
-	-
-	-
The alteration plan flowchart, the alteration plan booklet, the prototype, the keep-and-change activity sheet.	A plan for altering the prototype. A photo of the alteration plan is shared in the group chat on Signal.
The alteration plan, any materials needed for preparation.	Preparations for the prototype.
"Keep-and-change" worksheet, writing utensils.	An overview of the small changes being made. Most changes are immediately implemented. Changes that require preparation are implemented before the next phase.
The prototype, any prepared materials, the prototype plan, alteration plan or overview of small changes.	A prototype that is ready to be used.
The new or updated prototype, the testing booklet in the version they need.	Test results in the forms of the likes and dislikes of the YAA about the prototype. A photo of the collage is sent in the group chat in Signal.

the designer/researcher as part of the round up the project with the participants. The yellow marked activities are individual activities, the white marked activities are done in collaboration between the participants.

5.1.1. Design considerations

The first design round was quite generic to account for as much design directions as possible and allow the participants to become familiar with a design cycle. This second design round is to refine the information that served as input for the design process and therefore create a more sophisticated final product. Therefore the second design round must be tailored to the prototype and information that the participants already have. The evaluation process is used to create that tailor made second design round.

5.1.1.1. The evaluation

The evaluation is inspired by Dixit Odyssey (Libellud, 2021), which can be seen in Figure 41. The players progress on the board until they reach the end, but they can take different sized steps based on the point they received. In the evaluation activity, the participants also go through each phase, following the directions on the cards based on the statement they chose. The boardgame setup helps to structure the evaluation and also offer recognisable scaffolds.

The evaluation activity does not only evaluate the prototype, but also the participant's first design round as a whole. The prototype evaluation is mostly done through the testing of it, and the result of the testing is part of the statements in the evaluation activity. The design round is evaluated to see if the gathered design information on which the design process relied is complete and sufficiently related to the design goal. The evaluation can therefore show that the information gathered in the first design round is too general or incomplete in relation to the design goal. The second design round can then supplement this information by providing activities to gather it.

The evaluation activity will help the participants to only select activities that will contribute to their design result. The selection process can produce between zero and twelve activities for the participants to do. In the case of zero activities, the participants are already completely satisfied with their prototype. In the case of twelve activities, the participants are not happy at all with their prototype and feel they are missing information needed to properly inform their design process. Such a personal selection of activities will support motivation. On the other hand, for this project it means that not all activities will be tested, since they can't all be selected. In that regard, the evaluation itself is the most important step to review here.

The evaluation board is set up in a reversed order of phases, as is visible in Figure 40: "testing the prototype", the last phase of the design round, comes first and the evaluation is concluded with the first phase, "my world". This allows backtracking the participant's design steps and identifying where they are missing information and how they could gather this information.

A special case in the evaluation process is when the YAA has been unable to test the prototype properly. In this case, it is assumed that the testing activities provided in the first design round were not suitable for testing their current prototype, for instance because the prototype is to be used for a habit or the prototype is to be used during a specific activity, but that activity has not yet taken place. The retesting activity allows the YAA to still gather this information, as it is important input for both the evaluation and the second design round.



Figure 41: the contents of the game Dixit Odyssey. Image and game by Libellud (2021).

5.1.1.2. The second design round

The second design round uses the following order of phases:

1. My design goal
2. My world
3. Coming up with ideas
4. Making a prototype
5. Testing the prototype

There are two things to note in this list: 1) 'My design goal' and 'My world' are in reversed order, and 2) 'evaluation' is left out. 'My design goal' and 'my world' are in this particular order because in this design round, the 'my world' phase should produce information that is specific for the design goal. Therefore it is important to first check if the design goal still fits the YAA, and if not, to update the design goal.

'Evaluation' has been left out because in this case the evaluation coincides with rounding up the project with the participants. If the participants were to do a third design round, they could use the same evaluation activity as described in this chapter. The goal would be that they end up with no activities selected, meaning that the participants are completely satisfied with their design.

The second design round is, like the first design round, set up to be used by the participants themselves. The goal is that with their design knowledge of the first design round, they are able to complete the second design round without physical assistance of the designer/researcher.

5.1.1.3. Planning the second design round

In 'Iteration 2' it was already mentioned that the activities for the second design round were not yet included. This is because at that moment, the second design round was still in development. Therefore the roadmap had dedicated space to add a sticker with the second design round activities. This sticker is shown in Figure 29 and does not contain the names of the activities. Instead, it offers space for the participants to fill out the activities themselves. The activities are not yet added, to leave space for the participants' personal selection of activities.

5.2. Implementation in the case

5.2.1. Use

The participants used the evaluation activity in Activity Box 6 during our final meeting. After a quick setup and short explanation to start the activity, the participants were quickly able to go through the statement cards by themselves. The use was a simulation, since Simon has yet to meet up with the mentor who will help him learn how to use Unreal Engine. This meeting is planned after the colloquium of this thesis. Therefore the participants went through the activity in the hypothesised situation that they were able to test their product.

However, exactly because it is a simulation, Simon finds it difficult to answer the statements. We decide to answer them based on his expectation and their opinion on their design process up to this point. The statements regarding the prototype (in this case Unreal Engine and the service of a mentor) are most difficult to answer, but Simon and Ellen have high confidence in their prototype working out and Simon being able to work through any challenges. Both participants are confident when answering the questions regarding 'My World' and 'My Design Goal', as they made large changes to their design goal along the way and added related information accordingly before contemplating a prototype.

The evaluation resulted in the participant selecting no activities for their second design round. The whole activity took 15 minutes. Afterwards, the three of us took some time to look at activities that could have possibly been selected and discussed a few of them.

5.2.2. Feedback

The evaluation activity was rather quick in the opinion of the participants, though they also note that it would have taken longer if the designer/researcher wasn't present: they would have needed more time to discuss the statements. The directions on the cards were clear to them.

As described in the use, the participants did not select any activities. During the discussion of the offered activities, Ellen was most excited about some of the 'My World' activities, such as the superpower mapping and collage making. Simon enjoys the actual making of the prototype more, so he wasn't too excited to see new diary activities. He also thought that the collage making might be too challenging for autistic people, as he believes it is already more difficult for them to access emotions. Ellen disagrees, since such an activity can encourage a YAA to connect with those emotions and express them in a new way. The participants did see the added value of the activities as a supplement to the already collected information, though also question how well suited these activities would be for their particular design case – as these activities were still within the assumption of a physical product.

CONCLUSION & DISCUSSION

This section will revisit the research questions presented in the introduction, now completed with the information from the four iterations. In the discussion I explore different ways in which the toolkit can be developed further.

6. Conclusion & Discussion

This section will revisit the research questions presented in the introduction, now completed with the information from the four iterations. In the discussion I explore different ways in which the toolkit can be developed further.

6.1 Conclusion

Now we revisit the research question posed in the introduction. The main question was:

How do you support communication between an autistic and neurotypical participant during a co-design process, without the designer/researcher being present?

This question can be divided into the following sub-questions:

- 1. How do autistic people communicate?**
- 2. How does a caregiver communicate with a young autistic adult?**
- 3. How do you setup a successful co-design activity with autistic participants?**
- 4. How can the toolkit mediate the communication between the YAA and the caregiver?**
- 5. What tools can be used to successfully support a co-design process between a YAA and their caregiver, but without the designer/researcher being present?**

Let us go through each question, starting with the sub-questions and ending with the main question.

6.1.1. How do autistic people communicate?

For this I used the embodied sensemaking approach as a basis, which looks at the actors and the environment in which they act as a system. Looking back at the answer given in Theme 4, 'Communication with autism', it is evident that the autistic person's way of communicating already differs from that of neurotypical people due to differences in processing sensory stimuli: they prefer to process such input without necessarily making a coherent picture out of it. This does not mean that they are unable to, it simply takes an autistic person more effort. On the other hand, this processing style does offer the autistic person an exceptional eye for detail.

Because this style of sensory processing is different, it may be difficult for an autistic person to keep up with all the signals that are given in an interaction with another person. All these signals are picked up, but because proper integration takes slightly longer, the autistic person provides quick responses on information that is more clearly understood by them, e.g. the content of a spoken language over the intonation of a spoken sentence.

Autistic people generally develop their own coping mechanisms for dealing with social interactions. A common one is the use of stimming: self-stimulatory behaviour that is used slowing down the world around them. Autistic people can also develop personal communication strategies, such as tapping one's shoulder instead of making eye contact to get attention.

Camouflaging is also common in autistic people: they mask behaviours that are not seen as 'normal' to be more acceptable to neurotypical peers. This immediately shows one of the difficulties of being autistic: autistic people exist in a world that is mainly made by and for neurotypical people. Autistic people experience the most breakdowns when interacting with a neurotypical person. This situation can create a double empathy problem. But this does not have to be the case: when an autistic person and a neurotypical person have a long interaction history, and the neurotypical person is a flexible interaction partner, the number of breakdowns may be limited.

6.1.2. How does a caregiver communicate with a young autistic adult?

The YAA as described within the Design Your Life method will be involved in the decision-making process regarding their own care. This means that the caregiver and the YAA have a relationship that is partly caregiver-client, partly care partners.

The caregiver bases their way of communicating with the YAA on three things: their knowledge of autism, their experiences with other autistic people and their relationship with the YAA. The caregiver needs knowledge on autism to understand the difficulties the YAA client might face, and, most importantly, in what way autism presents itself in the client. By interacting with the YAA, the caregiver starts to understand the interaction preferences, the interests, needs and personality of the YAA – far beyond their traits that are linked to autism. Over time, this creates a long interaction history. Such a history will allow the YAA to feel comfortable with the caregiver. For the interaction in general it is important to emphasise that the caregiver must prove themselves as a flexible interaction partner to accommodate the YAA in their social interactions.

6.1.3. How do you setup a successful co-design activity with autistic participants?

In the Theory section, we already found some clues in answering this question. Frauenberger et al. (2017) used profiling and personalising co-design sessions to tailor towards the needs and interests of the very young autistic participants. Zhu et al. (2019) made it a point to get to know their participants well before co-designing with them, to establish trust and comfort in the adolescent autistic participants. Gaudion et al., (2015) altered activities to suit the needs of their autistic participants with limited speech. In all cases, the involvement of the parents, guardians and/or caregivers was also important, as they provided support and encouragement to the participants.

Central in making a co-design session with autistic participants successful is accommodating them properly. This is mostly done by understanding each participant's needs, interests, skills and challenges – in relation to autism, but especially to the YAA as a person. However, in this case study the YAA and the caregiver would act as the designers, and the designer/researcher would act as the toolkit designer and, possibly, a support in the prototyping process.

The main challenge of the toolkit was allowing a 'ready-to-use' setup to suit as many YAA participants as possible. In the toolkit, this was realised by a minimalist design, textual explanations with visual examples, allowing multiple ways to execute an activity, offering personalisation in activities in the second design round and offer activities that are aimed at product design specifically for and by people with autism. However, the iterations and the feedback of the participants have shown that for them specifically this toolkit was not facilitating their needs completely.

6.1.3.1. Splitting up information into boxes

Ellen specifically liked having information split up into different activity boxes, bundled with materials that you needed for those activities. This made the toolkit less overwhelming and more structured, in comparison to offering one syllabus with all activities and a large box with materials.

6.1.3.2. Addressing autism in activities

Several activities were framed from the disability of the participant, rather than the ability or the design objective. E.g. the sensory preference cards need to be reframed towards preferred product characteristics. This removes the focus on sensory over- or under stimulation (which are still represented in the cards) and instead shifts it more prominently towards the design process. Such reframing also allows the introduction of style preference cards.

6.1.3.3. Offering personalisation

Generalisation while offering some forms of personalisation was used to accommodate as many YAAs as possible, as well as the most likely design direction. In the first design round, personalisation was mainly offered through options for different ways of doing the activities. The activities of the first design round were designed to cast a wide net of information in relation to the design goal of the YAA. Letting the participants choose the way of doing the activity would make it easier to do the assignment, and therefore improve the quality of the created output. This richer output would in turn improve the conversations between the YAA and the caregiver.

However, the case study has not shown such a result: Simon already preferred text and images, which was the basis for the explanation of the activities. Instead, the activity itself had more influence on the delivered output: if Simon wasn't too keen on doing the assignment, the output would be limited. This was the case with most of the 'My World' activities. Simon did work through all assignments, as he believed he had to complete all of them. Simon enjoyed the prototyping activities much more: he likes to create something.

Though this thesis only covers one case study, it is important to look at also digital modes of doing activities. Such options were added to the activities, by sending audio, video or typed messages via Signal instead of using the printed materials. The only time Simon used a digital option, was when doing the 'think-tell-recognise' activity, where he delivered a .txt file. Offering more explicit ways of executing activities digitally may encourage participants like Simon to use such options over paper when they are already very comfortable using digital devices.

6.1.3.4. Activity selection

The first design round did not have any options of activity selection, only modality selection. The second design round, on the other hand, does offer selection of activities. These activities are aimed at supplementing the knowledge needed to design the product that the YAA has in mind. Since the participants have completed the first design round, there is already a basis on which the participants can build. The second design round can be used to only select activities that contribute to their further design process.

The evaluation activity in Activity Box 6 was only simulated, since the participants still had to meet up with the mentor. However, the participants did see the added value of the second design round, when walking through some of the possible activities, especially when it became clear that if they selected activities, they would not do all of them – only those most likely to contribute to their design process.

6.1.3.5. Explaining the activities

The current explanations in the booklets consist of text and supporting images. The long text now used may be off-putting for other participants. A multimodal approach, such as storyboards or videos, is therefore preferable. A video format also offers more space to explain the design vision attached to each activity, thus offering the participants more context in which the activity is done.

Another point made is that the references to materials used in the activities sometimes made it chaotic. This was the case whenever an activity called for the use of the output of a previous activity. Having instructions to store the generated materials with the activity in which you will use it will bring more overview to this, whilst making maximum use of the boxes. Similarly, showing the output and input for each activity in the roadmap improves the sense of overview and adds more insight into the design rationale.

6.1.4. How can the toolkit mediate the communication between the YAA and the caregiver?

This mediation was implemented in the toolkit in different ways. The first way was by offering scaffolds within activities and structure in the form of activity boxes and the roadmap. The toolkit consistently addressed the YAA as the main designer and the caregiver as the co-designer, to emphasise their roles in the design process: the YAA was to make the design decisions, the caregiver is there to guide and support. Finally, all materials were aimed at accommodating the YAA's needs in regard to communication and co-design. However, throughout the toolkit, the roles of the participants and the designer/researcher changed, as did the setting in which the toolkit was used.

6.1.4.1. Communication variants during the design case

Let us revisit the communication as hypothesised at the beginning of the case study, as seen in Figure 3. The actors are the YAA, the caregiver and the designer/researcher, and the toolkit acts as a mediator. Throughout the case several setups situations were observed:

1. The designer/researcher designing the toolkit independent of the YAA and the caregiver;
2. The YAA and the caregiver using the toolkit;
3. The caregiver using the toolkit to prepare for a session with the YAA;
4. The YAA, the caregiver and the designer/researcher working together with the toolkit;
5. The caregiver and the designer/researcher working on the toolkit.

Situations 1 and 2 are reflected in Figure 3. These situations were expected – the designer/researcher would not be present in the design activity space, but would receive feedback from the participants and use that in further development of the toolkit. But as already shown in the case study, there were several instances where the designer/researcher did enter the design activity space: situations 4 and 5. There even are two instances where the YAA is not part of the design activity space: situations 3 and 5. All these different situations create different co-design scenarios:

- **Scenario 1:** the designer/researcher designs activities to support the participants to complete a design process. The designer/researcher aims to mediate the communication, strengthening the YAAs voice, using the toolkit.
- **Scenario 2:** The participants use the toolkit without the designer/researcher present. Guides, content materials and scaffolds in the toolkit mediate their communication.
- **Scenario 3:** The caregiver prepares the co-design session by reading through the assignments and thinking of examples relevant to the participant. Ellen does this because she noticed that this smooths the communication during the co-design.
- **Scenario 4:** the designer/researcher guides the YAA and the caregiver through the co-design activities. The designer/researcher acts as the design expert. The decisions and ideas still need to be generated by the participants themselves.
- **Scenario 5:** the designer/researcher acts as a coach, helping the caregiver in understanding future co-design tasks and supporting her idea-generating process. This helped the caregiver in becoming more confident in the design process, creating a better understanding of the co-design activities and prepare her for the co-design session with the YAA. This situation acted as a supplement to situation 3 and is followed by situation 2.

All of these scenarios had their particular influence on the relationship of the YAA and the caregiver.

6.1.4.2. The relationship between the YAA and the caregiver

Both participants state that the case study has deepened their relationship. This was part due to the offered activities that aimed at getting to know each other better. For instance, the CQING quadrants showed that Simon and Ellen were more alike in their interests and qualities than they already knew. The participants also point out that without the activities in the toolkit, they would not have had certain conversations that contributed to their deepened understanding of each other. Discussions during activities that showed more ambiguity allowed Simon to better understand Ellen's character. But both participants also state that simply spending more time together already helped their understanding of each other.

The biggest impact on their relationship was the introduction of the new design goal: 'writing a book'. Simon started opening up about the world he has created, showing Ellen a new side of himself. Ellen particularly enjoyed this new design goal because Simon was able to show a more vulnerable side of himself. Additionally, she was excited about Simon's newfound motivation to write his book.

The new design goal of 'writing a book' created a different relationship in continuing the toolkit as compared to 'quitting [energy drink]'. This was visible in how the participants described their own roles in regard to the different design goals, seen in Table 5. The change in role also created a change in interpersonal dynamics: Simon took more of a lead in the new design goal. This was due to the design goal being more personal to Simon and Ellen being less familiar with the fantasy genre linked to that design goal.

6.1.4.3. The role of the designer/researcher

My role within the participant's design case transformed throughout the process. During the case study, I took on the following roles:

- **Researcher:** literature research and evaluation leader, extracting and analysing results from the toolkit.
- **Toolkit designer:** creating the activities and collecting materials.
- **Toolkit persona:** creating a string of examples to be used in the toolkit to inspire and support the participants in executing the toolkit activities.
- **Sparring partner:** when the participants needed guidance to determine a proper design goal.
- **Co-design facilitator:** though Ellen prepared the meetings by setting up the materials on location (either the office or at Simon's), the designer/researcher took more of a lead during the sessions at which she was present. The session where Simon, Ellen and myself determined a new design goal and created a Velcro mock-up, I took the lead in asking Simon questions. Ellen was supportive in these sessions as advocate for Simon, pointing things out (both negative and positive) that Simon might overlook.
- **Prototyper:** supporting the participants in creating the prototype by making designs on their request. Also exploring Simon's world by means of discussions and visualising this world. The description and visualisations of Simons world were used to contact possible mentors.
- **Networker:** contacting possible mentors on behalf of Simon and negotiating conditions with them.

Initially, I would have expected my role to be limited to researcher, toolkit designer, toolkit persona and prototype. But since the participants noted that the toolkit did not provide all support they needed in the design process, I was asked to provide this for them. There are several options to eventually create a toolkit that does not need the presence of a design expert. Directions for this are mentioned in the section Participant support.

6.1.5. What tools can be used to successfully support a co-design process between a YAA and their caregiver, but without the designer/researcher being present?

For this we need to look at different domains within the design of this toolkit, that proved particularly important: planning tools, time management, and participant support.

6.1.5.1. Planning tools

The participants need more of an overview than just boxes representing phases and sessions in a design process. The road map allowed them to have a better overview and to better plan each exercise in a way that worked for them. It also gave them more of a grip on the whole project. The roadmap could be improved by adding an overview of input and output, showing how activities link together.

6.1.5.2. Time management

The current toolkit is set up to have sessions of about 1,5 hours doing collaborative activities, and individual activities in between meetings. However, in practice the activities take the participants longer than estimated, due to the time it takes to understand the activity. To make sessions more manageable, they propose offering activities that take no longer than half an hour. This is easier to schedule in for the caregiver and allows the participants to work on the project once or twice a week, as opposed to having one session every two or three weeks. Being able to work on it so regularly makes it easier for the participants to recall their design rationale during their design process. However, one factor that also contributes to time management is participant support: the participants were able to progress through the activities much quicker with the designer/researcher present.

6.1.5.3. Participant support

As stated before, the toolkit was successful in instructing the participants, but the participants felt that they were missing some essential knowledge on designing itself. This knowledge was in two areas: 'design intuition' and networking.

'Design intuition' is used to describe the understanding of how different activity outputs function as input for other design activities, and, most importantly, to know how to address the activity. Should it for example be more focussed on free ideation, or on concrete products? And when should you 'kill your darlings'? The participants found this support more in the designer/researcher, than in the toolkit itself. This can be attributed to the ability of the designer/researcher to respond to their outputs and their questions, as opposed to the – static – toolkit.

The network of the designer/researcher proved also important in supporting the participants in the search of a suitable mentor for Simon. This emphasises the need for skill support for the participants.

Thus, for this toolkit to support the participants fully through the toolkit, it is important for the participants to be able to rely on a support system. In this case that was the designer/researcher, but other options can also be explored that do not require the presence of a designer/researcher. One example is educating the caregivers in design thinking in workshop settings. After these workshops, they can explore the toolkit with multiple clients that are under their care.

6.1.6. How do you support communication between an autistic and neurotypical participant during a co-design process, without the designer/researcher being present?

The current toolkit contains elements and clues to supporting communication between the YAA and the caregiver. Let us start with the toolkit itself, which contains different tactics to level the relationship between the YAA and the caregiver. This started in the introduction, where the YAA and the caregiver get assigned their roles: the YAA is the main designer, the caregiver is the co-designer. Throughout the toolkit the participants will be addressed using these roles. Another important element of the toolkit was setting it up in such a way that the YAA was accommodated in their needs regarding communication and co-design. The toolkit was partly successful in this accommodation. It did contribute to the mediation of the roles of the YAA and the caregiver.

Then the activities themselves contributed to the communication of the participants. This was in part due to the discussions sparked by ambiguous co-design materials, but also because the participants were asked to share personal information in the activities and to share this information with each other. This was especially visible in the CQING quadrant activity, where Simon and Ellen found out that they had more in common than initially thought. Their final CQING quadrant was a merging of their personal quadrants, showing how they are as a team. Another contributing factor was spending more time together, as both participants mention.

The ownership of the design goal also played an important role. As previously explained, the design goals influenced the roles that the participants took on in the design process. In the final toolkit, there must be enough focus on selecting a design goal that the YAA is excited to design for and to have a product for.

Creating a toolkit that renders the role of the designer/researcher finished once the toolkit is delivered to the participants, remains a challenge that requires further investigation. It is also the question whether it actually is desirable to let the participants go through the toolkit completely by themselves. As Ellen pointed out, she was confident that she and Simon were able to go through the activities, but that their output would be less in depth than it was with a designer/researcher present. In that regard, it is important to explore more hybrid forms of a Design Your Life toolkit, incorporating both some form of guidance and allow participants to explore for themselves.

6.2. Discussion

In this section I would like to address directions of development in the toolkit that are not tied to just a physical toolkit. As I stated in the conclusion, it is important to look at possible hybrid forms of support for the participants. In this case study, the support in the co-design process was done in two different ways: in design-oriented support and in autism-oriented support. Some of the elements in these categories overlap, which I will call hybrid support.

The design-oriented support lacked 'design intuition' that the participants could apply by themselves. However, there are a multitude of options that can improve this form of support: instructional videos, educating the caregiver in design thinking, creating a workshop setting for the participants, and providing personalisation with a personal facilitation expert.

Instructional videos in which (fictional) participants work through the toolkit provide a multimodal explanation, and offer more space to explain the design pitfalls of each activity. The second option, educating the caregiver in design thinking, allows them to become the design facilitator when using the toolkit. However, it is important that the caregiver is also instructed to let the YAA take the lead.

The third option mentioned is creating a workshop setting, comparable to a makerspace, where the participants can come to for just their first design round or the entire design process. In these spaces there will be facilitators available, as well as a wide range of materials and tools to use. In such an environment the design confidence of the participants can be built up, as well as relevant skills for their design process. Additionally, group sessions, in or outside a workshop environment, can help create a community of participants who can help each other.

Another important form of design support is offering resources. The toolkit and the participants themselves did not provide the particular skills and knowledge Simon needed for his product. For this the designer/researcher was asked to help. One form of support that would help here is the aforementioned workshop setting. But also a digital supplement in the form of a closed forum for Design Your Life participants may help to expand the resource and skill network of the participants. Moreover, such an environment allows participants from different cases to help each other by thinking of ideas or offering their network.

Finally, an opportunity that can be looked into more regarding autism-oriented support, is offering more personalisation in the toolkit. This was now done by providing different ways of doing activities and selecting activities for the second design round. But this meant that the first design round was quite generic to suit the majority of the YAAs. It would therefore be interesting to explore options for more personalisation in the first design round. This can be done with a design facilitator, in or outside a workshop setting, who selects activities for the participants based on the profile of the YAA and the direction in which their design process takes them. That way, more YAAs can be properly accommodated, as well as different solution directions: physical, digital or services; based on sensory issues, self-management or self-actualisation.

REFERENCES

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed). American Psychiatric Association.
- Baron-Cohen, S., Leslie, A. M., & Frith, U. (1985). Does the autistic child have a “theory of mind” ? *Cognition*, 21(1), 37–46. [https://doi.org/10.1016/0010-0277\(85\)90022-8](https://doi.org/10.1016/0010-0277(85)90022-8)
- Begeer, S., Wierda, M., & Venderbosch, S. (2013). *Rapportage 2013. Nederlands Autisme Register*. https://www.nederlandsautismeregister.nl/assets/Documenten/NVA_Onderzoeksrapport_2013_LR.pdf
- Brand, A., & Gaudion, K. (2011). *Exploring Sensory Preferences Living Environments for Adults with Autism*. 48.
- Centraal Bureau voor de Statistiek. (n.d.-a). *Huishoudens nu* [Webpagina]. Centraal Bureau voor de Statistiek. Retrieved 21 June 2021, from <https://www.cbs.nl/nl-nl/visualisaties/dashboard-bevolking/woonsituatie/huishoudens-nu>
- Centraal Bureau voor de Statistiek. (n.d.-b). *Uit huis gaan* [Webpagina]. Centraal Bureau voor de Statistiek. Retrieved 20 June 2021, from <https://www.cbs.nl/nl-nl/visualisaties/dashboard-bevolking/levensloop/uit-huis-gaan>
- Clark, H. H. (Ed.). (1996). Joint actions. In *Using Language* (pp. 59–91). Cambridge University Press; Cambridge Core. <https://doi.org/10.1017/CBO9780511620539.004>
- Conway, J. K. (1967). Multiple-sensory modality communication and the problem of sign types. *AV Communication Review*, 15(4), 371–383.
- Crompton, C. J., Ropar, D., Evans-Williams, C. V., Flynn, E. G., & Fletcher-Watson, S. (2020). Autistic peer-to-peer information transfer is highly effective. *Autism*, 24(7), 1704–1712. <https://doi.org/10.1177/1362361320919286>
- De Jaegher, H. (2013). Embodiment and sense-making in autism. *Frontiers in Integrative Neuroscience*, 7. <https://doi.org/10.3389/fnint.2013.00015>
- Di Paolo, E. A., Cuffari, E. C., & De Jaegher, H. (2018). *Linguistic Bodies: The Continuity between Life and Language*. The MIT Press. <https://doi.org/10.7551/mitpress/11244.001.0001>
- Doorley, S., Holcomb, S., Klebahn, P., Segovia, K., & Utley, J. (2018). *Design Thinking Bootleg*. <https://dschool.stanford.edu/resources/design-thinking-bootleg>
- Eriksen, M. A. (2012). *Material Matters in Co-designing: Formatting & Staging with Participating Materials in Co-design*. Malmö University, School of Arts and Communication.
- Fabri, M., & Andrews, P. C. S. (2016). *Human-Centered Design with Autistic University Students: Interface, Interaction and Information Preferences*. 11.
- Fletcher-Watson, S., & Happé, F. (2019). *Autism: A New Introduction to Psychological Theory and Current Debate*. Routledge.
- Francis, P., Balbo, S., & Firth, L. (2009). Towards co-design with users who have autism spectrum disorders. *Universal Access in the Information Society*, 8(3), 123–135. <https://doi.org/10.1007/s10209-008-0143-y>
- 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*, 39–49. <https://doi.org/10.1145/3078072.3079727>
- Frith, U. (2001). Mind Blindness and the Brain in Autism. *Neuron*, 32(6), 969–979. [https://doi.org/10.1016/S0896-6273\(01\)00552-9](https://doi.org/10.1016/S0896-6273(01)00552-9)
- Fusaroli, R., Tylén, K., Garly, K., Steensig, J., Christiansen, M. H., & Dingemanse, M. (2017). Measures and mechanisms of common ground: Backchannels, conversational repair, and interactive alignment in free and task-oriented social interactions. 6.
- Gaudion, K., Hall, A., Myerson, J., & Pellicano, L. (2015). A designer’s approach: How can autistic adults with learning disabilities be involved in the design process? *CoDesign*, 11(1), 49–69. <https://doi.org/10.1080/15710882.2014.997829>

- GGZ. (2017). GGZ-Zorgstandaard Autisme. GGZ. <https://www.ggzstandaarden.nl/zorgstandaarden/autisme/info/status>
- Halse, J. (2008). Design Anthropology: Borderland Experiments with Participation, Performance and Situated Intervention. 219.
- Heasman, B., & Gillespie, A. (2018). Perspective-taking is two-sided: Misunderstandings between people with Asperger's syndrome and their family members. *Autism*, 22(6), 740–750. <https://doi.org/10.1177/1362361317708287>
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217–250.
- Klin, A., Jones, W., Schultz, R., & Volkmar, F. (2003). The enactive mind, or from actions to cognition: Lessons from autism. *Philosophical Transactions of the Royal Society of London. Series B: Biological Sciences*, 358(1430), 345–360. <https://doi.org/10.1098/rstb.2002.1202>
- Landsman-Dijkstra, J., Brouwer, J., & Engbers, C. (2014). Participeren met een autisme spectrum stoornis. Arbeidskundig Kenniscentrum. https://pure.rug.nl/ws/portafiles/portal/14277828/AKC_onderzoekscahier_12_Participeren_met_een_autisme_spectrum_stoornis.pdf
- Libellud. (2021). Dixit Odyssey. <https://www.libellud.com/dixit-odyssey/?lang=en>
- Marsh, K. L., Richardson, M. J., & Schmidt, R. C. (2009). Social Connection Through Joint Action and Interpersonal Coordination. *Topics in Cognitive Science*, 1(2), 320–339. <https://doi.org/10.1111/j.1756-8765.2009.01022.x>
- Mattelmäki, T. (2006). Design probes. University of Art and Design Helsinki.
- Milton, D. E. (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism*, 18(7), 794–802. <https://doi.org/10.1177/1362361314525281>
- Milton, D. E. M. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability & Society*, 27(6), 883–887. <https://doi.org/10.1080/09687599.2012.710008>
- Ministerie van Algemene Zaken. (2020a, July 27). Coronavirus tijdlijn–Rijksoverheid.nl [Onderwerp]. Ministerie van Algemene Zaken. <https://www.rijksoverheid.nl/onderwerpen/coronavirus-tijdlijn>
- Ministerie van Algemene Zaken. (2020b, December 14). Toespraak coronavirus 14 december: Lockdown tot en met 19 januari [Onderwerp]. Ministerie van Algemene Zaken. <https://www.rijksoverheid.nl/onderwerpen/coronavirus-covid-19/vraag-en-antwoord/onderwerpen/coronavirus-covid-19/vraag-en-antwoord/toespraak-14-december-in-eenvoudige-taal>
- Muller, M. J. (2002). Participatory Design: The Third Space in HCI. In *The Human-Computer Interaction Handbook: Fundamentals, Evolving Technologies and Emerging Applications* (pp. 1051–1068). L. Erlbaum Associates Inc.
- Mundy, P., & Newell, L. (2007). Attention, Joint Attention, and Social Cognition. *Current Directions in Psychological Science*, 16(5), 269–274. <https://doi.org/10.1111/j.1467-8721.2007.00518.x>
- Pezzulo, G., Donnarumma, F., Dindo, H., D'Ausilio, A., Konvalinka, I., & Castelfranchi, C. (2019). The body talks: Sensorimotor communication and its brain and kinematic signatures. *Physics of Life Reviews*, 28, 1–21. <https://doi.org/10.1016/j.plrev.2018.06.014>
- Sanders, E. B.-N. (2000). Generative Tools for Co-designing. In S. A. R. Scrivener, L. J. Ball, & A. Woodcock (Eds.), *Collaborative Design* (pp. 3–12). Springer London. https://doi.org/10.1007/978-1-4471-0779-8_1
- Sanders, E. B.-N. (2001). Collective Creativity. *LOOP: AIGA Journal of Interaction Design Education*, 3.
- Sanders, E. B.-N., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. *CoDesign*, 4(1), 5–18. <https://doi.org/10.1080/15710880701875068>

- Sasson, N. J., Faso, D. J., Nugent, J., Lovell, S., Kennedy, D. P., & Grossman, R. B. (2017). Neurotypical Peers are Less Willing to Interact with Those with Autism based on Thin Slice Judgments. *Scientific Reports*, 7(1), 40700. <https://doi.org/10.1038/srep40700>
- Sheppard, E., Pillai, D., Wong, G. T.-L., Ropar, D., & Mitchell, P. (2016). How Easy is it to Read the Minds of People with Autism Spectrum Disorder? *Journal of Autism and Developmental Disorders*, 46(4), 1247–1254. <https://doi.org/10.1007/s10803-015-2662-8>
- Sinclair, J. (2010). Being autistic together. *Disability Studies Quarterly*, 30(1).
- van Dijk, J. (2013). Creating traces, sharing insight explorations in embodied cognition design. Technische Universiteit Eindhoven.
- van Wijngaarden, M., Benard, L., Begeer, S., Scheeren, A., & van der Jagt, A. (2020). Rapportage 2020. Nederlands Autisme Register. <https://www.nederlandsautismeregister.nl/assets/Documenten/Factsheets/Factsheets%202020%20-%20Volledig.pdf>
- Vesper, C., Abramova, E., Bütepage, J., Ciardo, F., Crossey, B., Effenberg, A., Hristova, D., Karlinsky, A., McEllin, L., Nijssen, S. R. R., Schmitz, L., & Wahn, B. (2017). Joint Action: Mental Representations, Shared Information and General Mechanisms for Coordinating with Others. *Frontiers in Psychology*, 07. <https://doi.org/10.3389/fpsyg.2016.02039>
- Vetere, F., Smith, J., & Gibbs, M. (2009). Phatic Interactions: Being Aware and Feeling Connected. In P. Markopoulos, B. De Ruyter, & W. Mackay (Eds.), *Awareness Systems* (pp. 173–186). Springer London. https://doi.org/10.1007/978-1-84882-477-5_7
- 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* (Vol. 12780, pp. 373–386). Springer International Publishing. https://doi.org/10.1007/978-3-030-78224-5_26
- Zhu, R., Hardy, D., & Myers, T. (2019). Co-designing with Adolescents with Autism Spectrum Disorder: From Ideation to Implementation. *Proceedings of the 31st Australian Conference on Human-Computer-Interaction*, 106–116. <https://doi.org/10.1145/3369457.3370914>
- Z-MAN Games. (2021). *Pandemic Legacy: Season 1*. <https://www.zmangames.com/en/products/pandemic-legacy-season-1/>

Image sources

All images in this thesis were produced by either the author or her participants. Any figures directly taken from their source are referenced in their description. Special reference needs to be made to Figures 24 and 25. Both were created by the author, using the following sources:

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 J.J. Harisson via en.wikipedia.org/wiki/Quartz#/media/File:Quartz,_Tibet.jpg
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