Bitstory

A new methodology for caregiving to empower parents of autistic children by building a strong support network

TU Delft

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A new methodology for caregiving to empower parents of autistic children by building a strong support network.

Romee Noorman
Master Thesis
June, 2018
Delft

"You cannot stop the waves, but you can learn how to surf."

- John Kabat Zinn

Voor Papa

Romee Noorman, Delft, June 2018

Thank you

These two words of gratitude I would like to express to a great group of people. People who supported me in various ways throughout my graduation journey. It has been a ride with both ups and downs. To you all, who have shown trust, support and enthusiasm, I would like to say: thank you.

De Buitenwereld, the company I have been working for and became very fond of. Starting the project at your company felt like stepping in at the right moment. A moment in which everyone was making changes and daring greatly. Despite the fact that I haven't seen every one of you that often, it didn't seem to influence the kind of contact we had for the moments I would meet with you. Every meeting was pleasant. I am very impressed by the work you are doing everyday. And I have the utmost respect for all people in caregiving who are putting effort to make the lives of other people a bit better. We need more of you. So thank you all, for the cups of coffee, interesting conversations, participating in interviews and brainstorms, allowing me to observe your work, and for making me feel welcomed and appreciated.

Otto, I am so happy that I have had the honour of working with you on this project. The enthusiasm you brought as a director is something I will never forget. And of course your eagerness to innovate is remarkable. I hope, when I set foot in the working field, I will meet more people like you because that would make working much more fun. I wish you all the best on your journey and I secretly hope that one day we will work together again on another great project.

Astrid, thank you for being a great mentor, not only on a project level but also on a personal level. I remember the phone-calls we had at the start of the project and the immediate connection I felt. You listened to the insecurities I had on starting studying again and you arranged such great working conditions that it was possible for me to do this project in my own pace. For that I am very grateful. And you kept making sure that this would be the case throughout the entire project. It was a great pleasure doing interviews, brainstorms and meetings together. Thank you for letting me have a look into your world.

Quiel, after the JMP project it was clear for me that I wanted you as my mentor for my graduation project. You are enthusiastic and motivated to support your students, which makes you a great (and wanted) mentor for students. Luckily you had a spot for me. The way you are capable of connecting the dots and always giving me input to work with makes me a very happy student.

Thank you for being there for me. I know that, despite the end of this project, we will keep in contact because we simply have too much to talk and laugh about, especially about our similarities in life. And I am looking forward to it.

Stefan, I guess a milestone is achieved since I am the last of our AED team to graduate. I remember joking and telling you 'safe the best for last'. But lets cut the jokes, for now, and let me thank you for being much more than the chair of this project. Thank you for helping me make decisions that you knew were better for me to make. For all the discussions on all sorts of topics. Our conversations were always interesting, and quite long, which keeps me reminded to eat before meeting with you. I hope we do keep meeting once in a while so that we can have more interesting conversations.

The parents who participated in the research, I cannot thank you enough for your contribution. As I told you, this project is what it is because of your input. Thank you for being so open towards me and share so many personal stories. It were these stories which made me understand each and every one of you a little bit more. And it made me deeply respect you. I wish you and your families all the best.

Martine, you have been such a great support for me for throughout these last couple of years. I just want you to know how grateful I am that you are there to listen, to support me, to give me the feeling that I can do whatever I want to do. But especially for learning me to accept that things do not always go our ways, and that doesn't have to be a bad thing. Everything is okay as it is.

My friends, thank you for being in my life. This journey has been quite a roller-coaster ride and having you guys helped me to move through and enjoy the ride. Thank you for taking me on fun activities, for cooking meals, for listening when I needed it and for putting a big smile on my face even in the difficult moments. I hope you all know that I appreciate you and hope to have you around for a long time.

Mom and dad, expressing the immense gratitude and love I have towards both of you reminds me of being that little kid who would ask you how much you loved me. And you both would spread your arms and say 'endlessly'. Now it is my turn to tell you: thank you endlessly. Thank you for being such amazing parents. Thank you for having my back at all times. Thank you for always listening. Thank you for understanding me, truly. I am the lucky one, to have and had both of you in my life.

Executive summary

De Buitenwereld, a Dutch healthcare institution which provides care to families of children with (suspicion of) a psychiatric condition (aged 0-18), needed to change their caregiving processes due to the healthcare transition for the youth that was made in 2015. This transition was needed to make care more efficient since there are long waiting lists of families in need of care and less money to spend. One of the transition goals for institutions to meet was to develop solutions that support families in using their own support network, so that they would be less dependent on institutions (Ministerie van Volksgezondheid, 2014). De Buitenwereld set out a request for new technological solutions to make their caregiving processes more efficient while meeting the transition goals. They approached the TU Delft for a cooperation, resulting in this graduation project. Preliminary research into the clients of De Buitenwereld set a focus on parents of children, aged 4-12, with (suspicion of) autism as these parents suffer from high levels of stress and would benefit greatly from a strong support network. As a result the following assignment was formulated to kick-off the project:

Empowering parents of autistic children in caregiving while bridging the gap between technology and healthcare and focussing on building a strong network.

In an extensive exploration phase, lots of knowledge was gained on different aspects of the assignment. For example, a technology analysis was done to discover possible technologies to implement and user research with a group of five parents to discover their problems and needs. The main insight from the user research was that parents lacked understanding from their network (family members, professionals, neighbours, friends, etc.) which let to having difficulties trusting them and thus building strong relationships. This ultimately resulted in parents not having the strong support network they need. But in order for them to get understanding from their network, parents have to explain and share lots of information with these others which costs them a lot of time and energy while they lack time and suffer from high levels of stress. All these factors hinder creating an understanding. Thus the goal for this project became to develop a solution which would support the parents in enhancing understanding of others so that they can build a stronger support network. With these results a design direction was formulated:

Design of a technological system that captures and shares personal information about the autistic child to enhance understanding amongst people who are involved with the child and family in order to build a strong support network around the child and ensure the best support where the child is.

In the conceptualization phase, ideas were generated to fit the design direction. Brainstorms with different groups of people were executed to retrieve lots of varying ideas. In the idea selection, one idea was chosen to continue with: using pictures and video's to capture and share personal information. This idea has great benefits as making pictures and video's costs little time and working mainly visually supports understanding and empathize with information more easily. Three design proposals were developed for the design of a digital system that can visualize, capture and share personal information. Each proposal consisted of different combination of design components which made them vary from one another on desirability, feasibility and viability. Together with the company a choice was made for the design proposal Bitstory: a new design system built around a website to easily store and structure visual information into a personal story to share with others.

In the embodiment phase, all parts of the design system of Bitstory were further defined and detailed on look, usage and function. Along the way, Bitstory transformed into a methodology for De Buitenwereld to be implemented in their caregiving processes with parents of autistic children. The methodology consists of the Bitstory website on which the parents collect and share their visual information, and tools for the parents and De Buitenwereld to support effective use of the methodology. In a final pitch Bitstory is described as follows:

Bitstory is a new methodology for caregiving to empower parents of a child with autism (4-12 years old) by using tools to effectively capture, describe and structure important personal information into a visual story which can be shared at anytime and anywhere with any other who is involved in caregiving to enhance their understanding, strengthen relationships and build a strong support network.

The evaluation phase concludes with recommendations for the project, reflections and personal tips based on the experiences gained as a graduate student within this project.

Reading guide

title of the chapter

What do I want to describe in this chapter?
What were questions I have asked?
How did I answer these questions?
Which information is most relevant?

four introduction questions

subtitle

Explanation

Each chapter contains text and illustrations to inform the reader on a particular subject. The title of the chapter and subtitle suggests the topic of the text. The information in the text is often based on a variety of sources. Sources found in literature, either online or offline, have a reference to the author and are noted as follows: (name of author, year of publication). The entire list of references is found at the end of this report. Besides references to sources, there are references made to illustrations, which are often images, tables or models, and noted as (figure X). Also references are made to Appendices, Appendix X, which are found in a separate report.

figure or table

Figure X. Results of findings visualised.

''These events made me feel like this.''

quote from a parent of an autistic child who participated in the user research

conclusion of the chapter

Conclusion

At the end of each chapter a conclusion is written which summarized the most important information from that chapter.

Figure 1. The reading guide for this report with explanations about the structure of each chapter.

Glossary

ASD

Noun

Short for autism spectrum disorder which is a neuro-development disorder which causes change of behaviour.

Contextmapping

Verb

An qualitative user research method to elicit underlying needs.

Comorbidity

Verb

Presence of more than one disorder.

Disorder

Noun

Disruption of physical or mental functioning.

Methodology

Noun

Collection of methods.

Stressor

Noun

An event that triggers stress.

Neurodiversity

Noun

In relation to autism the concept of neurodiversity is about viewing autism as a variation of the human genome rather than a disorder and rejects the idea that it needs to be cured.

Tantrum

noun

Uncontrolled anger or outburst, mostly by young children.

Introduction

The introduction phase describes the first steps that were taken to kick-off the project. It starts with providing information on a transition in healthcare that forced De Buitenwereld, a Dutch healthcare institution and the initiator of the project, to make changes to their caregiving processes. Next is discussed how these changes could be achieved. A focus is set on part of the clients of De Buitenwereld. Based on the needs of both clients and company, an assignment was formulated. In the end, an approach describes the five design phases of the design process for this project with main steps that were taken.

Introduction
Who is the project initiator?
What do they do?
Why did they initiated the project?
What are their needs?

Assignment
What kind of solution does the company envision?
Who are the main stakeholders?
What is the focus for this project?
What is the assignment?

Approach
Which steps should be taken?
How can results be structured?
What kind of research should be done?
Which methods can be used?

Introduction

Who is the project initiator?
What do they do?
Why did they initiated the project?
What are their needs?

Healthcare transition

In 2015, the healthcare sector went through a transition. Care for the youth became decentralized, meaning that municipalities instead of the state became responsible for the provincial youth care. To realize the transition, five goals were compiled, which healthcare institutions had to meet (Ministerie van Volksgezondheid, 2014).

The transition affected many healthcare institutions in the sense of fewer budget. In 2016 it was predicated that half of the provinces would have a shortage on budget for the upcoming year (Binnenlands Bestuur, 2016). Shortages often lead to cutback and layoffs causing a higher workload for the people who still work. On top of a financial shortage, long waiting lists of families that are in need of help remained. For these healthcare institutions it is essential to change to still be able to provide affordable and effective care without compromising on quality (figure 3).

De Buitenwereld

One of many healthcare institutions which were affected by the transition is De Buitenwereld. De Buitenwereld is a Dutch healthcare institution which offers specialized care for families of children aged 0-18 with (suspicion of) a psychiatric condition. They operate in the region's of Midden-Holland, Zuid-Holland and Haaglanden. When admitted to the institution, families receive counselling every week (1 to 4 hours) for about a year. If counselling isn't enough they are offered advice and consultation, training within groups and short stay-overs. De Buitenwereld trains children in social, emotional and cognitive skills. Short stay-overs are meant for parents to temporarily release them from caregiving. On top of their counselling program they provide ambulant care at home, schools and at day-cares which means they are in close contact with various parties to guarantee the best support where the child is. When families finish their counselling they should be empowered to take care of their child so that the child can grow up in its own environment (figure 2).

Making a change

Despite the effects of the transition, De Buitenwereld is actively seeking for innovative solutions to help them make required changes. They are in need for solutions that make their caregiving more efficient while fitting with their belief. They believe that families should be supported in strengthening their network in such way that a child, despite their unique conditions, can grow up within their own trusted environment (De Buitenwereld, 2017).

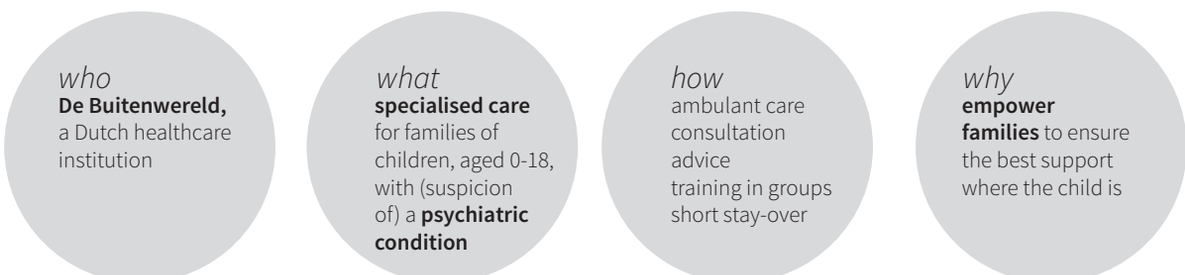


Figure 2. Basic representation of what De Buitenwereld offers.

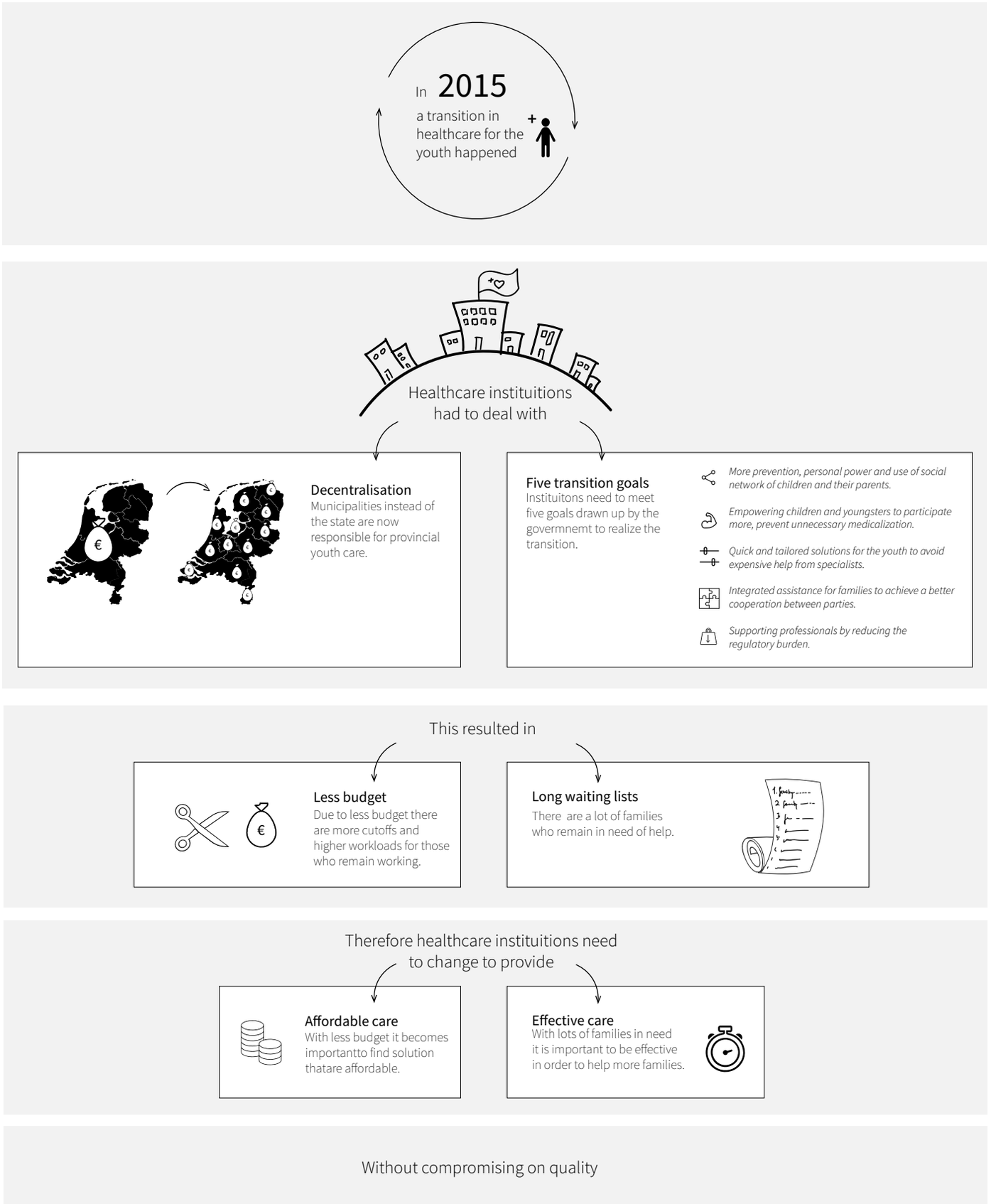


Figure 3. Effects of the transition on healthcare institutions.

Conclusion

De Buitenwereld is a Dutch healthcare institution for families of children with psychiatric conditions. They were affected by the healthcare transition in 2015 and therefore they have to make changes to be able to meet the transition goals drawn up by the government and deal with the effects of having less budget to be able to provide affordable and effective care without compromising on quality.

Assignment

What kind of solution does the company envision?
Who are the main stakeholders?
What is the focus for this project?
What is the assignment?

Technological solutions

De Buitenwereld notices a gap between what they offer and what the world of technology can offer. They lack technological solutions and tools to assist them in care giving and which could make their caregiving processes more efficient. They see a world of opportunities that could help them make changes and meet the transition goals on the other side of the bridge (figure 4). Currently, most of the caregiving processes for clients from De Buitenwereld, the families, are talking, training and assisting them which requires lots of time and energy from the caregivers. A great amount of the caregivers' time is spend on making visits, registering and documentation. The tools they use in their caregiving processes are getting outdated in the sense that they don't embed any technologies. They strongly belief that technology can be of means to help them make a change and provide more efficient care. Their vision is to have their care system replaced by technology in 2025 (De Buitenwereld, 2016). De Buitenwereld is eager to be inspired by technological solutions. Therefore as a starting point for this project they formulated the following question: *how can technology improve or even replace our care system?*

Technology offers benefits in many fields. Not only can it make care more efficient in the sense that it can ease processes such as registration and documentation using for example online tools, but it also offers the possibility to create a playful experience. Especially for providing support to parents who suffer from higher levels of stress due to the demanding care for their child, technological tools that support their caregiving and are playful in use can increase the quality of care for the families.

Stakeholders

In order to design a successful solution it is important that the solution fits with the needs of the stakeholders involved in the project. This project is initiated by De Buitenwereld which makes them one stakeholder. They have a need for a technological solution that can improve or even replace part of their care. The second stakeholder are clients of De Buitenwereld, families of children with a psychiatric condition, who will also work and benefit from the design solution. Yet, a focus must be set on a specific target group amongst these families to be able to focus the research into this stakeholder's needs and thus make it more feasible to design a solution that fits.

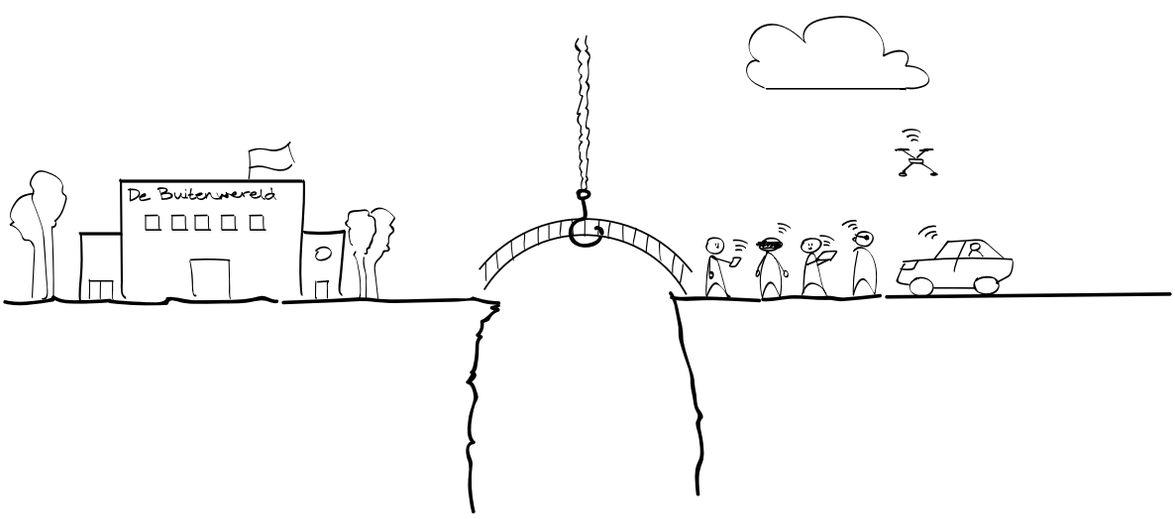


Figure 4. Bridging the gap between technology and De Buitenwereld

Target group

De Buitenwereld offers support to families of children with suspicion or diagnosis of a psychiatric condition (figure 6). The list of psychiatric conditions is extensive and each condition manifests uniquely within a child. In order to focus, common conditions within the Netherlands were compared (figure 5). The condition of autism was chosen since the amount of diagnoses within the Netherlands is increasing (CBS, 2014) and the effects on parents is severe. Parents of children with autism encounter higher levels of stress then parents of children with typically development or children with other conditions (Dunn, Burgine, Bowers, Tantleff-Dunn, 2001). Therefore it was decided to focus on designing a technological solution for De Buitenwereld that targets parents of autistic children (and not necessarily the autistic child itself). To determine what kind of parents to involve in the project, it was chosen to focus on parents of children aged 4-12, which are the ages when most families seek support at De Buitenwereld (figure 5). De Buitenwereld supports children with an IQ starting at 70, but for this project the requirement was that children would have an IQ of at least 90 to leave out the very severe cases.

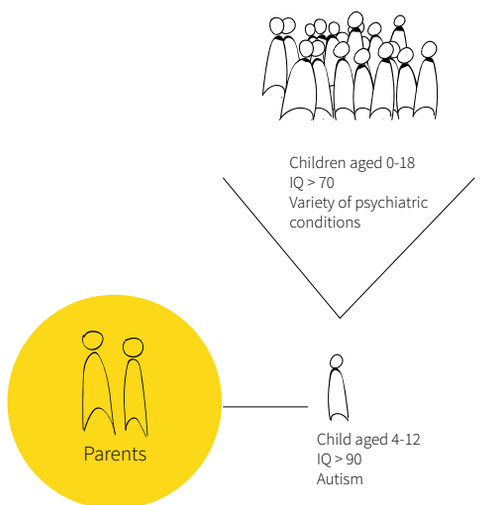


Figure 5. Focus for this research on parents of children with autism and the requirements for this target group.

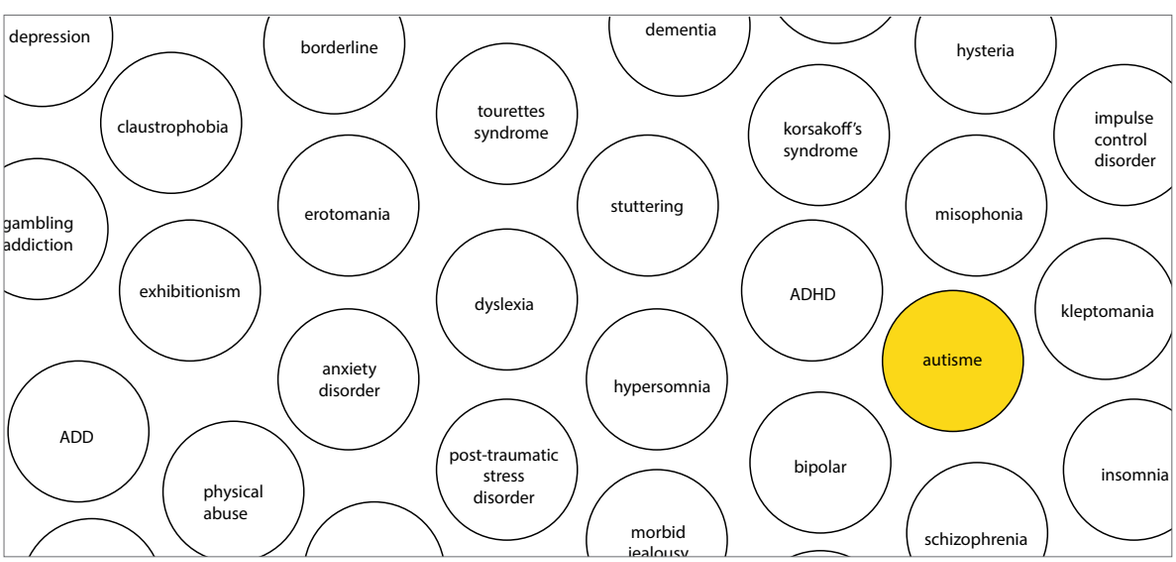


Figure 6. Part of the broad variety of psychiatric conditions of which autism is one (without showing relations).

Formulated assignment

Based on the need of the company for a technological solution, their belief that parents should be empowered and have a strong support network and the focus on parents of autistic children who suffer from high levels of stress, the following assignment was formulated:

Empowering parents of autistic children in care-giving while bridging the gap between technology and healthcare and focussing on building a strong network.

Conclusion

De Buitenwereld wants to develop a technological solution to bridge the gap between healthcare and technology and help them make the required changes to meet the transition goals. For the project a focus was set on part of the clients of De Buitenwereld, parents of autistic children who are between 4-12 years old. It was discovered that these parents suffer from high levels of stress and would benefit from a solution that empowers them and helps them build a strong support network. Combining these results led to the formulation of an assignment which is used as the starting point for the exploration phase.

Approach

Which steps should be taken?
How can results be structured?
What kind of research should be done?
Which methods can be used?

Design phases

The process of designing a product or service to solve a particular problem follows certain design phases. For this project there are five phases starting with the introduction phase. This phase is about setting he right conditions for a great start. Preliminary research is executed to formulate an assignment and a planning and approach are made for guidance. The next phase, the exploration, is all about exploring topics that relate to the assignment by doing various types of analyses such as literature and user research. In the conceptualization phase, the goal is to generate lots of ideas to be able to select and choose one final idea. This idea is tested, improved and transformed into a design proposal, which is a more detailed idea. In the embodiment phase, the looks, functions, and usage of the final proposal are further defined. The future of the proposal is explored by making a business model and doing some estimations on costs and time of development. In the last phase, the evaluation, recommendations and reflections on the project are given. For the great part, these phases proceed in chronological order, but it can be that information obtained in one phase is added ta previously executed phase. For example, ideas created in the conceptualization phase may lead to new requirements to be added to the exploration phase. In figure 7 an overview of these five phases with the main steps that were taken is shown.

Analysis

As previously stated, it can happen that certain information obtained in one design phase is added to another. This is often the case when doing an analysis. Despite the fact that the exploration phase is the main phase for doing analyses, other phases often require analyses as well. However, these analyses tend to be less extensive than the two great analyses that were done in the exploration phase: a contextmapping study and a company analysis. To indicate at which steps in time along the design process analyses were done, the icon of a magnifying glass, symbolising an analysis, was added to these steps in figure 7.

Iterations

This approach consisting of five design phases which follow one another might suggest that the steps that are taken are sequential. However, in reality this is often not the case. Many steps require going back and forth by doing iterations. Especially in the ideation in which ideas are generated. Creating an idea that solves a problem requires testing and validating if that idea indeed solves the problem and meets the needs of the stakeholders. Therefore prototypes have to be made to do a test. These results provide insights which may lead to making a re-design. Logically, these re-designs can again be optimized by making a new prototype and doing a new test. Iterations are also done in other fields aside from testing ideas. For example in defining the business that needs to be built around the product or service. Working with a tool like the business model canvas can provide new insights which leads to making changes to the initial business model. And these insights may require altering of the design which can result in a new prototyping and testing cycle.

Appendices

Aside from this report, there is a second report for the appendices which contains more information. This additional report provides the reader the opportunity to read more information on particular topics that are discussed or certain choices that were made in this main report. Having a separate report for appendices helps to keep the main report clean and compromised. In this main report, references are made to the appendices as following: more information can be found in Appendix 'X'.

Conclusion

At the start of the project, an approach was set-up describing five main design phases to follow during the design process. In general, the phases proceeded in chronological order. However, some steps in one phase resulted in retrieving new insights which needed to be added to a previous phase. Concerning analyses, not only the exploration phase included analyses, but all phases. An additional report for appendices with more information was created.

Figure 7. The five design phases of the project with the main steps that have been taken.

Exploration

The exploration phase is about exploring the various topics that relate to the project and the formulated assignment. Insights and opportunities are retrieved by executing several analyses. A company analysis is done to discover the clients needs. Trends and technologies are analysed to generate design opportunities for the technological design solution. Five parents of autistic children participated in a contextmapping study, a qualitative user research, that elicit their latent needs and tacit knowledge. Analysing the data from the user research resulted in a variety of insights, problems and a main goal for the project. The discovered problems for both stakeholders are used to generate needs, requirements and wishes, and to formulate a design vision which can be used a tool for making design choices. The phase concludes with a design direction that builds upon results from all analyses and is used as a starting point for the next design phase.

Autism Spectrum Disorder
What is autism?
How many children are diagnosed with autism?
How can it be diagnosed?
What are the characteristics?

A(utism) Journey
When do the first signs of autism appear?
What are benefits of getting a diagnosis?
What are the steps to get a diagnosis?
What kind of professional support is there?

The parent(s)
What is it like to parent an autistic child?
How are families composed?
What influences parenting?
Are there differences in parenting an autistic child?

Impact daily life
What is the impact on daily life?
What determines the impact?
What causes stress amongst parents?
What are negative effects of stress?

Ways of support
How do parents support themselves?
What are ways to support parents?
What kind of support is most beneficial?
What doesn't work?

De Buitenwereld
How does De Buitenwereld provide care?
How do they support the parents?
What tools and methods do they use?
What are opportunities for the design solution?

Developments
What is happening in the world of autism?
What are trends in the Netherlands?
What are developments in healthcare?
Which trends and technologies offer opportunities?

User research
What is the research approach?
Who are the users?
How to analyse the data?
What are the main insights?

Design direction
What are the problems of stakeholders?
Which needs do stakeholders have?
What are requirements and wishes for the design?
What is the design direction?

Autism Spectrum

What is autism?
How many children are diagnosed with autism?
How can it be diagnosed?
What are the characteristics?

Neuro-development disorder

Autism is a complex neuro-development disorder. It is characterized by difficulties in (non) verbal communication, social interaction and stereotypical behaviour (NVA, 2017). Also a lack in motor skills often appears. Autistic people are easily over-aroused since they do not filter all the stimuli they receive on a daily basis. Being over-stimulated can cause them to go into a fight, flight or freeze mode which can be seen in the eyes of the spectator as undesired social behaviour. Therefore autistic children often go into training to learn social and emotion skills to help them manage in society. A "typically developing" child learns these skills by playing and interacting with peers, but these activities are very difficult for autistic children to do and therefore they often miss out on development of these skills.

Autism Spectrum Disorder

In 2013 the Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition, which is a manual used for formal diagnosis of autism and related disorders, decided to use the umbrella term "ASD" which stands for Autism Spectrum Disorder (DSM-5, 2013). ASD* covers multiple neuro-development disorders: Classical autism, Asperger and PDD-NOS (Pervasive Development Disorder- Not otherwise Specified). The reason to group these disorders was that the differences amongst them were to little and they wanted to focus more on common behaviour amongst them while looking at the severity.

**ASD will hereafter be referred to as autism.*

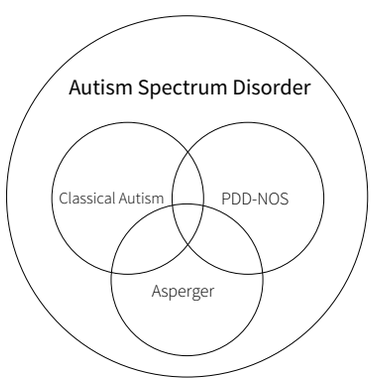


Figure 8. Autism Spectrum Disorder covers three neuro-development disorders.

Facts and statistics

Up until now the real cause of autism remains unknown. Nonetheless, research has shown that genetic factors are the most significant cause. Autism seems to be heritable and results of a twin study in children with autism estimated the heritability of the second child having autism as well at 60-90% (Hallmayer, 2011). For each of the five families who participated in the user research for this project autism was diagnosed with either one of the parents or there was suspicion of autism in other family members e.g. a grandparent. Yet, it remains unclear which genes are responsible (Freitag, 2007). One fact that is known is that autism is incurable (Autism Society, 2015; NICHD, 2008).

> *"When we learned more about autism I discovered that I was autistic as well."*

Within the Netherlands there hasn't been done research into the prevalence (commonness) of autism amongst children. However, a recent estimation done by the CBS stated that nearly 3% of the Dutch children aged 4-12 has autism. This number was not based on the amount of official diagnoses but the opinion of parents or other caregivers, so it includes children who have a suspicion of autism. Figure 9 gives an overview on some other statistics that emerged from this research (CBS, 2014).

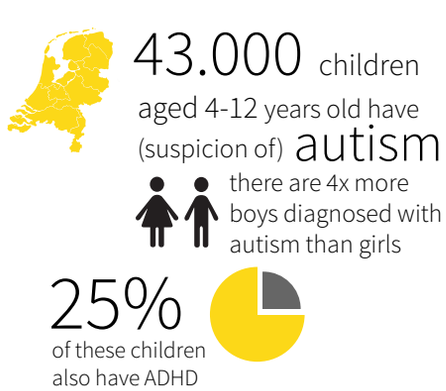


Figure 9. Statistics on autism amongst Dutch children.

Diagnosing Autism

Diagnosing autism cannot (yet) be done by physical examination, only by observing behaviour. Diagnosing can be done at a young age, mostly already between the ages of 2 and 3 years old, when most obvious signs of autism appear. In some cases signs appear so suddenly it is called a 'regression' which means loss of developmental skills.

> *"All of the sudden it felt like we lost our child. As if he crashed into a wall."*

Within the Netherlands, a diagnosis is allowed at the age of four years old. A diagnosis is often required for getting access to special services like schools for special education. However, some institutions like De Buitenwereld offer support to families who haven't got a diagnosis and are only suspecting autism. In order to be diagnosed with autism, an individual must meet diagnostic criteria described in DSM-5 (Appendix A). The criteria for the diagnosis is distinguished in two parts: social communication and restricted, repetitive behaviours. For the part of social communication a child must meet at least deficits in each category as shown in figure 10. For restricted, repetitive behaviour at least two out of the four given criteria must be met. An example of a type of behaviour that can be expected per criteria is given in the same figure. Figure 11 is an example of a repetitive motor movement e.g. a child lining up toys.

Level of severity

In the process of getting a diagnosis, an indication is made on the level of severity for both diagnostic criteria. There are three levels of severity ranging from 1 (slightly severe) to 3 (very severe). Level 1 means that children require support and level 3 means that they require very substantial support. An example of very substantial support can be that children spend most of their time at institutions where they are supervised and supported throughout the day.

> *"I have to explain everything to him. Even when he eats his food I have to tell him that he needs to swallow his food."*

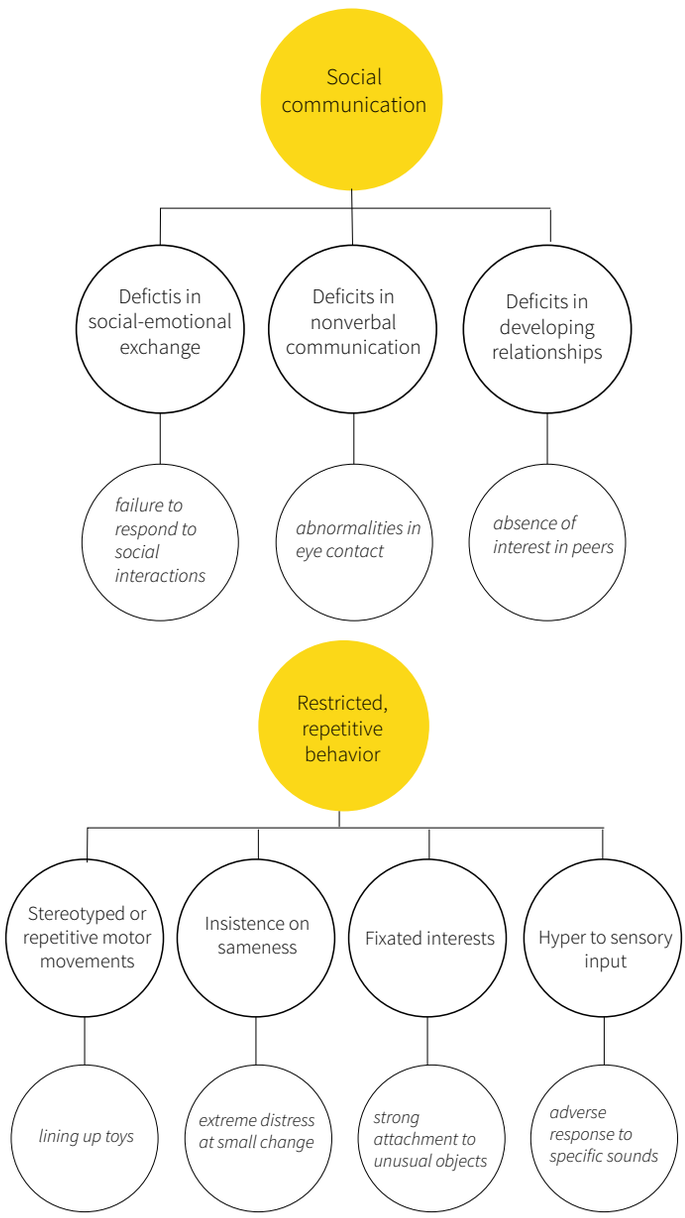


Figure 10. Diagnostic criteria for autism.

Figure 11. Child lining up toys which can be seen as a stereotyped motor movement.

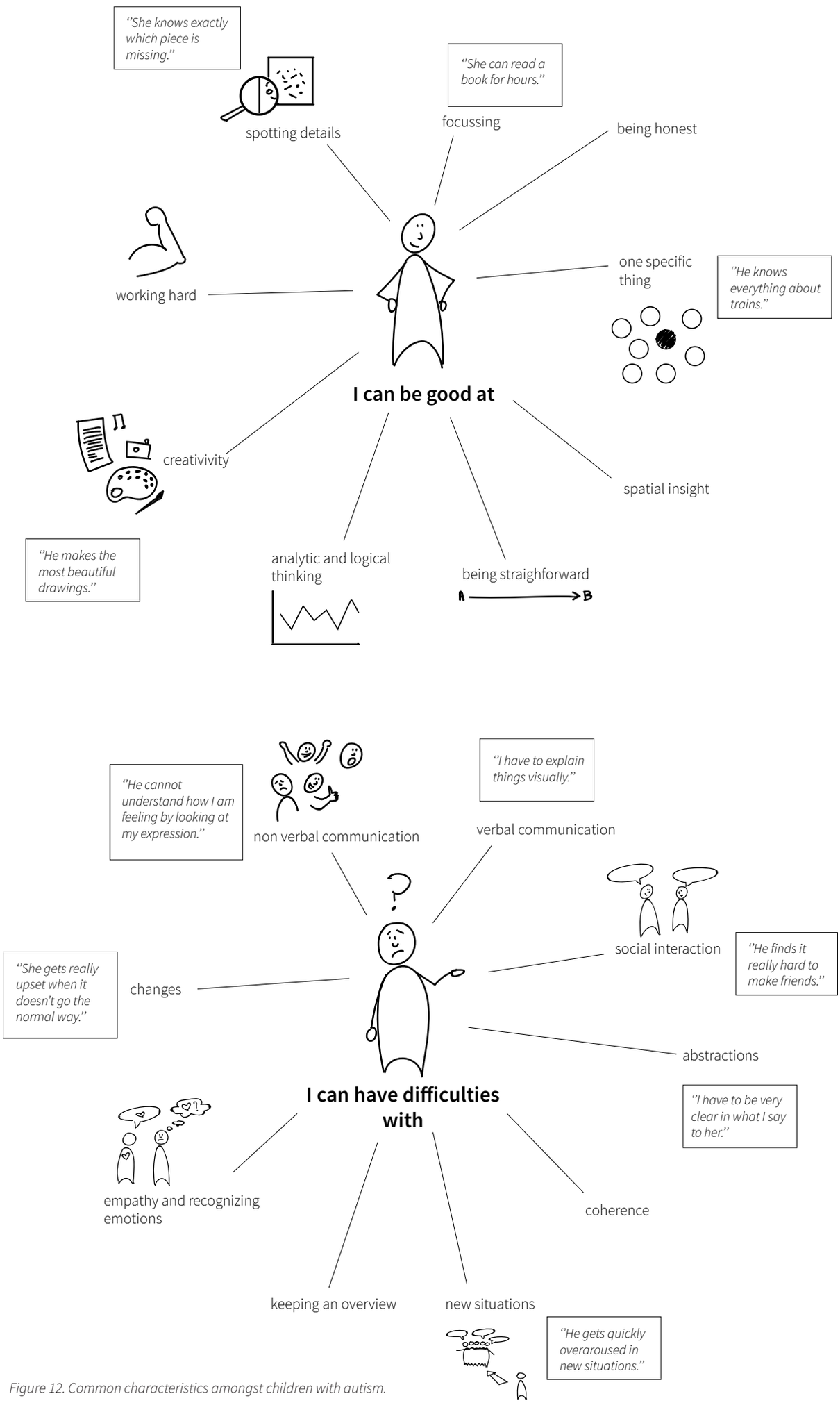


Figure 12. Common characteristics amongst children with autism.

Variety in behaviour

From the research with parents of autistic children, it became apparent that autism manifests itself differently in each child which makes it difficult to indicate what type of behaviour is typical autistic and which isn't. There are also various factors that play a role in how a child behaves. For example a child's characteristic may be more timid or on the contrary more social and open. Or a child may lack in social skills but has great cognitive skills. Figure 13 sketches a possible profile of an autistic child to indicate what factors can play a role in a child's behaviour. And there is also the concept of comorbidity, which means that a person has various conditions. As a result from the user research many of the autistic children had symptoms (or even a diagnosis) for other conditions like ADD or ADHD.

Another factor that has a great impact on a child's behaviour is their IQ level. Some children with autism have a low IQ which often means they are disabled. Others may have such high IQ levels that they are diagnosed as highly intelligent. A common mistake made by people is to believe that people with autism are all highly intelligent as seen in the movie Rainman (Honson, 1988). This only occurs when they have the savant syndrome which results in having extraordinarily skills in one particular area. With these autistic children being so different from one another and the great amount of factors that can influence the behaviour of the child makes it important to design a solution that fits each unique situation.

"He knows so many words and he can read for hours and hours in books. But on a social level he encounters so many difficulties. Especially in expressing his needs."

"Not only does he have autism but he also has ODD which makes it sometimes very difficult for me do deal with him."

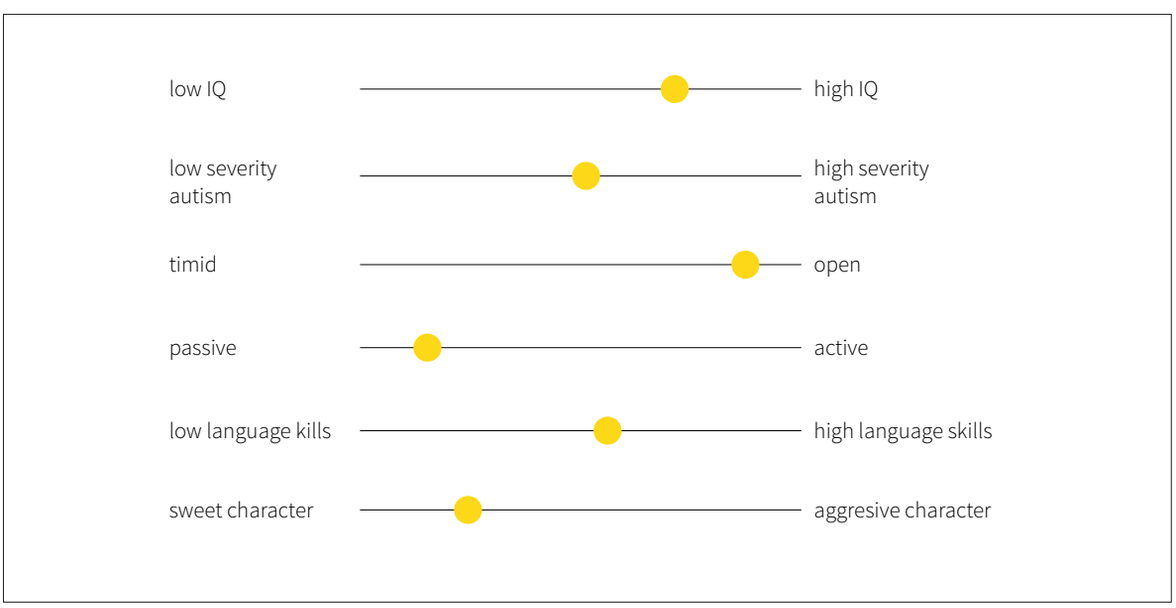


Figure 13. Variety of factors that influence a child's behaviour.

Common characteristics

Even tough the variety of autistic children is wide, there are characteristics that are common amongst them. These characteristics are mapped in figure 12 and were distilled from the interviews with parents and other sources (NVA, n.d.; Theroux, 2014; Het is hier autistisch, 2017). Noted must be that these characteristics do not apply to each child. Some may only experience a few while others many. Same counts to which extent these characteristics are expressed ranging from slightly severe to highly severe.

Conclusion

The amount of children diagnosed or with suspicion of autism is rising. Many of these children also have other conditions like ADHD which can make it difficult to tell which behaviour is a result of which condition. Various factors influence a child's behaviour like their IQ level or development in certain areas. The fact that these children can differ on many levels must be taken into account when designing a solution to ensure that it fits with each unique situation.

A(utism) journey

When do the first signs of autism appear?
What are benefits of getting a diagnosis?
What are the steps to get a diagnosis?
What kind of professional support is there?

Suspicion of autism

Most parents begin to get suspicious when there child is about 2 years old. However, not all parents decide to take action from that point on because they may find it difficult to decide if these differences are part of a condition or just a slower development than typically expected (figure 14). Parents can also be in denial because they simply do not like the idea of their child being different. For some parents it can take years of suspicion before they finally taking action in finding out what is going on. A consequence could be that these children are greatly behind in development because they haven't had the right support or training for many years. Some experts state that an intervention at a young age is best since it has a positive impact on children mastering daily living skills (Sparrow, Cicchetti, Balla, 2005). This is also positively associated with becoming more independent and requiring less supervision when growing up (Carothers and Taylor, 2004).

"At school they noticed that he was behaving differently than the other children and they told me he might be autistic. But at that time I thought how can you already say that about a 2 year old?"

Getting a diagnosis

At one point, when the difference in behaviour is obvious, parents seek for support. In most cases they visit their general practitioner who can refer them to a child psychiatrist. It often takes a couple of sessions with professionals before it becomes clear what the cause is. When it becomes clear that it could be autism, parents can decide to get a diagnosis.

Getting a diagnosis can be a long, overwhelming and challenging process. Some parents may decide not to follow through when they believe their child can manage without a diagnosis. But to be able to get access to support channels, like schools for special education, a diagnosis becomes a necessity. In the process of getting a diagnosis for their child, some parents noted that it was very confronting. They had to reflect upon their own youth, find details about their families history but also reflect upon their own lifestyle. Some parents noted that during these moments of reflection they found out that either themselves or another family member most likely was autistic as well.

"I knew something was going on with my child. When we got the official diagnosis all pieces fell into place".

Development stages	Infant 0-1 years	Toddler 1-2 years	Preschool 2-4 years	School age children 5-6 years
Typical development characteristics	standing while holding on to furniture, very curious, reacts on emotions parents, touching and tasting everything	able to run, beginning to jump, small talk, wants to play games, imitates behavior of others	own toilet needs interacting with other children, asking questions, speaking in sentences	fluent speech, undresses and dresses alone, distinguish fantasy from reality
Autism development characteristics	no social smiles, cannot roll over or sit up straight, no reaction on emotions	cannot stand without help, difficulty in pronauncing words, no use of gestures to communicate	difficult to follow up instructions, doesn't imitate behavior, speech not clear, avoids eye contact	very shy or more agressive behavior, difficult to communicate, doesn't want to play with other children

Figure 14. Development stages of a typical developed child and an example of a child with autism (Autism speaks, n.d.).

Professional support

Various types of professional support are involved in the journey of an autistic child (figure 16). Often it starts with people educating parents about autism. Then the child itself can get training in social, cognitive and emotional skills using tools like icons to explain certain rituals (figure 15). For children who have difficulties with fitting in the regular schools, there are special education school which can be a better fit since these classes are smaller and the educational materials are better adapted to their needs. For children who lack skills of speech a speech therapist may be involved and for those with deficits in motor skills a physiotherapist. Sometimes parents themselves seek support to cope with the impact of autism by working with a counsellor.

In many cases parents decide to use medication to help their child relax more and get through the day. Finding the right medication is a process of testing which type and what amount has the best effect. Although all parents reported that they disliked having to give their child medication, they stated that they wouldn't know how to manage them otherwise or they believed that their child would not be able to cope with the world as it is without their medication.

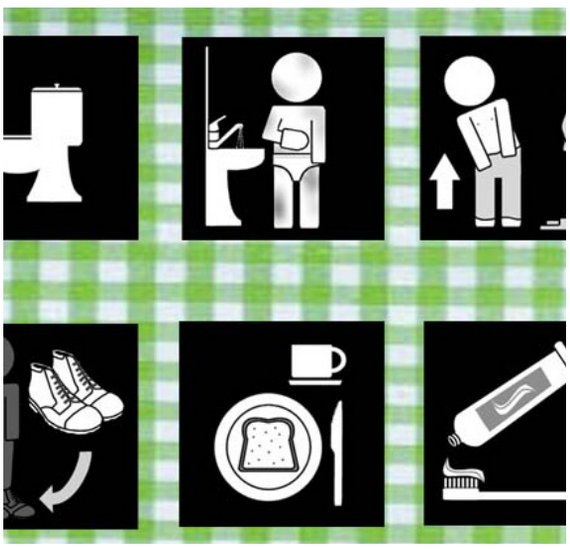


Figure 15. Icons that can be used to teach autistic children daily living skills.

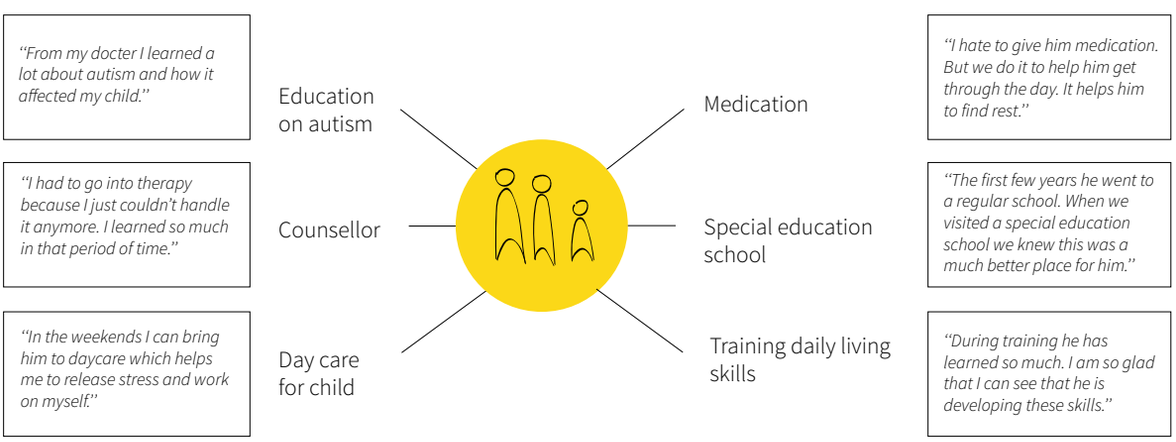


Figure 16. Types of professional support for parents and for the autistic child.

Conclusion

Around the age of two, parents can get suspicious about the development of their child. Lack of social, emotional, cognitive and motor skills may indicate signs of autism. It was found that many parents decide to get an official diagnosis to make it easier for them to get professional support like entering a school for special education. Also many parents seek for support for themselves to learn how to cope with having an autistic child. For the child, it is essential that they are trained in daily living skills since their autism makes it more difficult to develop such skills than for typically developed children.

Parenting

What is it like to parent an autistic child?
How are families composed?
What influences parenting?
Are there differences in parenting an autistic child?

Becoming a parent

Becoming a parent can be both exciting and challenging. Especially when having the first child as it is a brand new experience. If one of the children has a condition like autism, parenting becomes even more challenging. Parents stated that they find it very difficult that their autistic child's development is so unpredictable. This unpredictability makes it more difficult to predict how the future of their child will look like which can make parents anxious and insecure about the future. When the child doesn't develop typically, changes in parenting are inescapable to be able to meet the needs of the autistic child. Aside from changing parenting, parents also have to be aware of the possible effects of having a child with autism on the well-being of the entire family.

> *"When you discover that your child is different, you have to change your entire image of what you thought you knew about parenting."*

Family composition and relations

Every family consists of a unique group of individuals who all have their own needs. What is considered a family in this project are the parent(s) and their child(ren). The composition of such a family can take different shapes in terms of the amount of parents or children as is shown in figure 18. How a family is composed influences not only the way parents raise their child (their parenting style) but also the well-being of the family. For example, in the case of an only child with autism it may be easier for parents to cope with the situation since they have only one child to focus on. In case of a family with three children of which one has autism the situation becomes more complex having more people who can influence each other and having to deal with all of their needs. In figure 19 the composition of a family is given together with the different relations that play a role within the family. Also possible others outside of the intimate family who can influence the well-being of the family are shown. Especially in taking care of a child with autism, who has special needs, these others who might have to provide care or emotional support to the child(ren) or parent(s) can greatly influence the well-being of the entire family.

Figure 17. Becoming a parent can be both challenging and exciting.

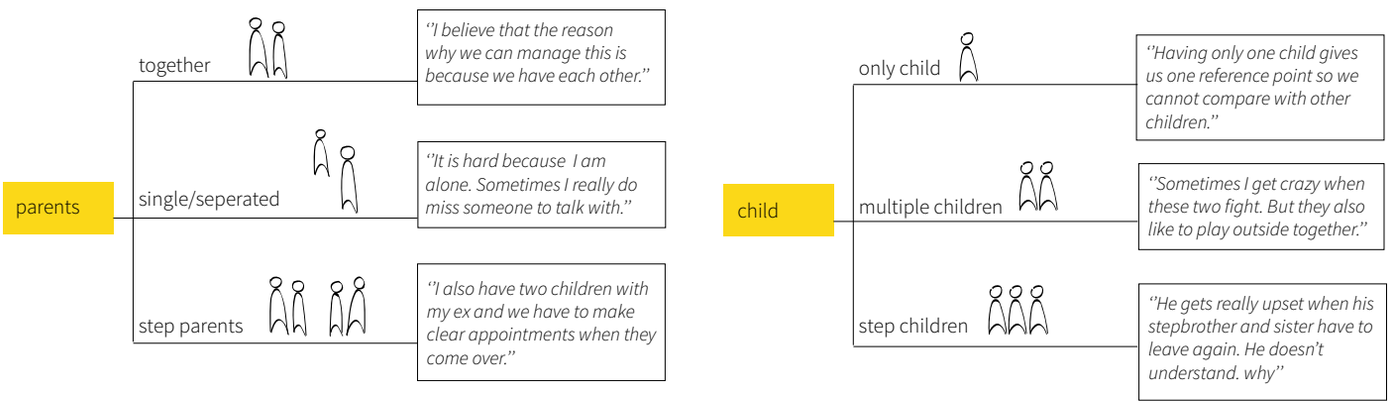


Figure 18. Various family compositions.

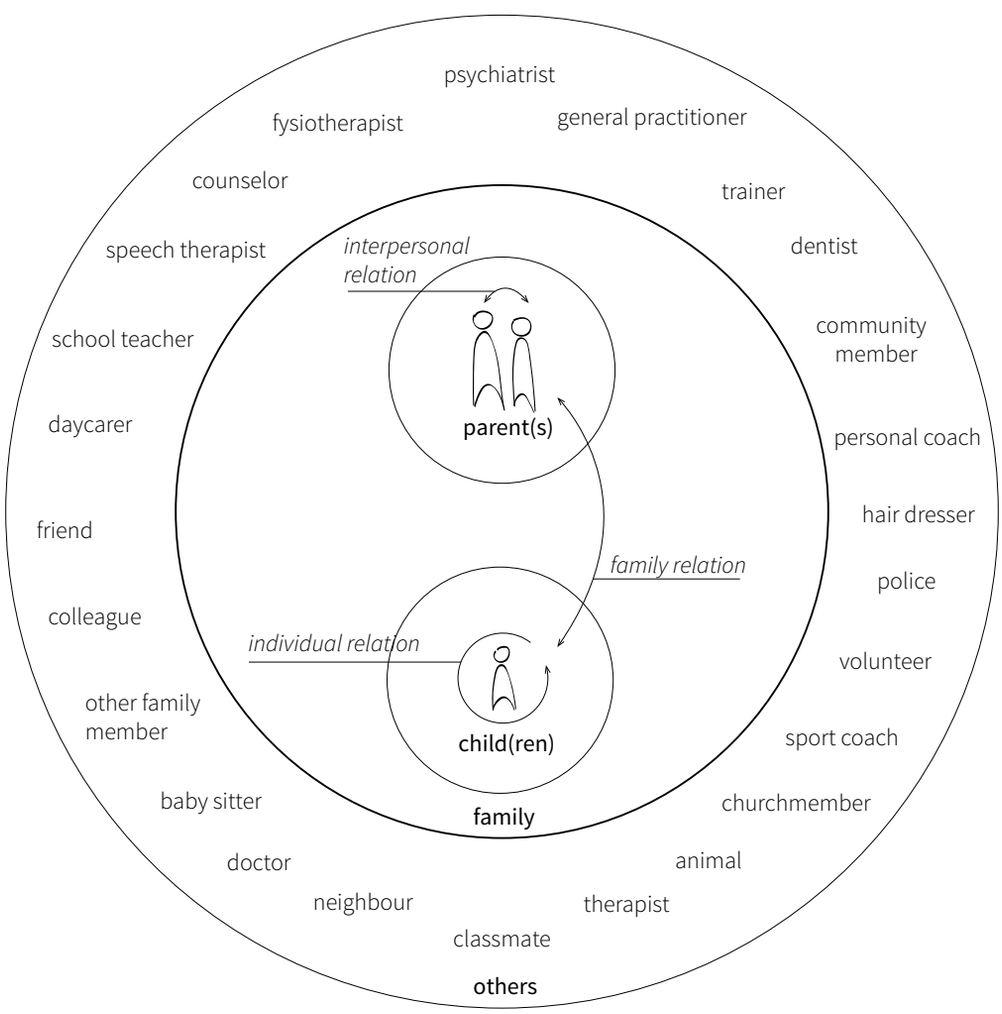


Figure 19. Four levels that influence a families well-being and the relations between these levels.

Parenting

How parents parent can be described as a parenting style. A parenting style is a range of patterns of parenting practices (Spera, 2005). There are three parenting styles: authoritative, authoritarian, and permissive parenting. They are based on to what extent parents are responsive and demanding. A authoritative style is a balance between being responsive and demanding, while the authoritarian is characterised as being demanding but not responsive, and permissive as responsive but not demanding. The authoritative parenting style has been shown to be the most beneficial for typically developing children (Baumrind, 1967; Dewar, 2010). However, in relation to children with autism this might be different.

How a parenting style exhibits or develops over time can depend on a variety of factors. In the user research with parents of autistic children, a variety of factors were discovered that influenced their parenting. There are internal factors, those within an individual e.g. their character, which are often more difficult to change. And there are external factors which are either controllable or uncontrollable factors like social media or the society.

Figure 20 gives a representation of the factors which emerged from the data. One internal factor that had a great influence on most families' parenting was the way their parents parented when they grew up as a child. They notified that when parenting their autistic child they could no longer use what they had known or ought to know about parenting, but had to completely change their mindset to be able to meet their unique families' needs. This often made them feel scared and insecure since they no longer had a reference point.

In some cases a change of factor can significantly improve the families well-being. For example, one parent moved closer to school in order to have less stress in the morning. Other factors like building a support network, although they require time and energy, can provide great ways of support. But some of the factors are uncontrollable like the external factor of a traumatic event e.g. a death of a grandparent or sudden illness within the family. To be resilient to such factors it is therefore all the more important for such families to have ways of support or tools that support the well-being of the entire family.

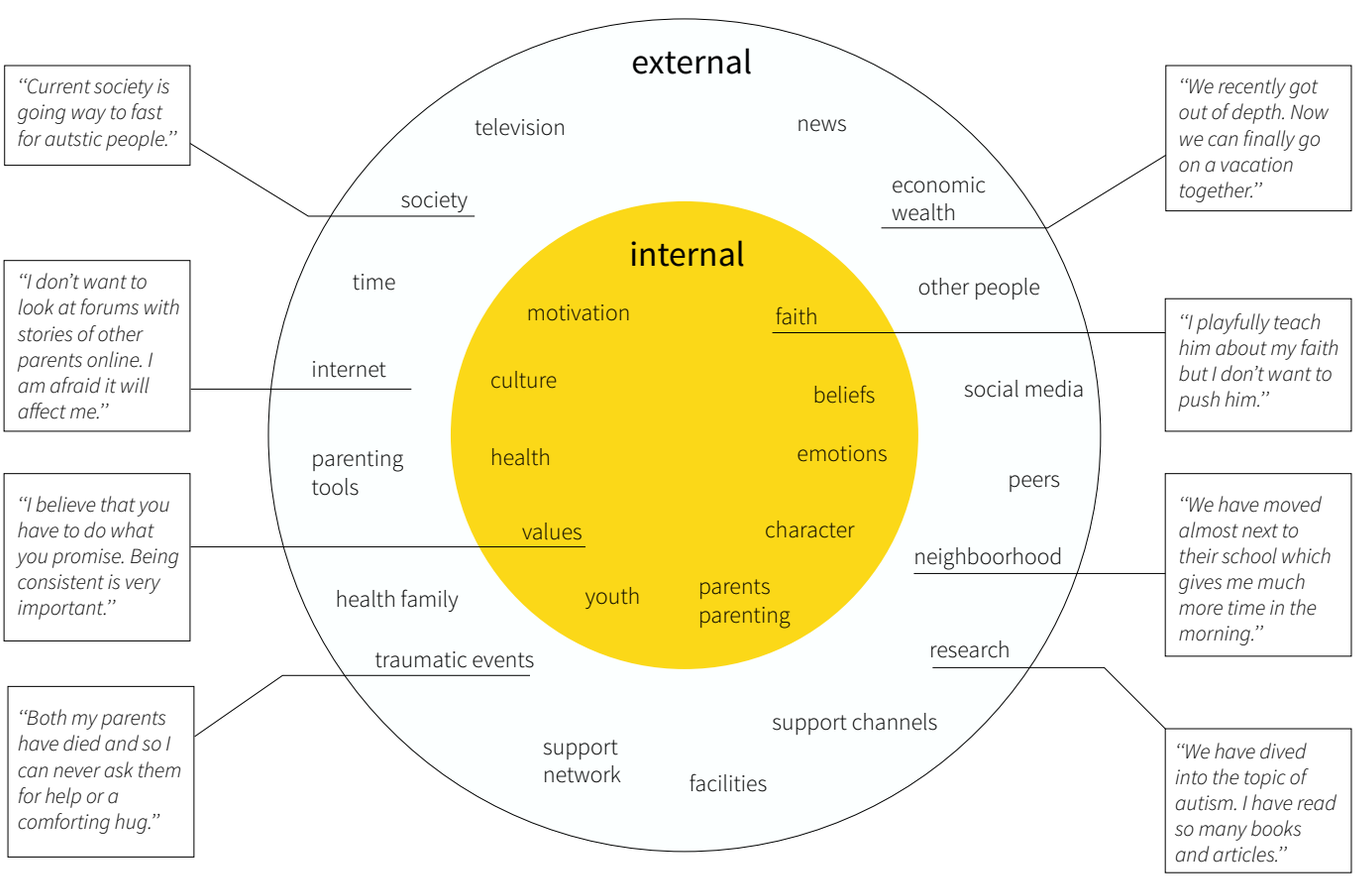


Figure 20. Internal and external factors that influence the parenting style.

Parenting types

While doing research with the five parents of autistic children it became apparent that there was a difference between their way of parenting and the known parenting styles. It was also found that the parenting styles amongst these five families of autistic children differed. To visualise these differences, the user data was analysed by scanning the interviews for quotes of situations that reflected these differences in parenting. As a result, various quotes were grouped and analysed to discover similarities and differences. As a result, a difference in emotional state and in mindsets of parents was discovered. Four quotes which highlighted these differences on emotional state and mindset best were placed in a matrix (figure 21). On the horizontal axis, the emotional state can be either a more relaxed state or a more concerned or worrying state. On the vertical axis the mindset is either more knowing or exploring. Some parents stated they preferred trying out tools by trial and error instead of reading and knowing every method or tool that is out there. As a result, four combinations were made to create four parenting types.

Each of the four parenting types were given a name. The 'secure knower' are parents who are confident and in control and hold a lot of knowledge about autism and how it impacts the child. The 'nervous knower' are parents who are also well-educated about the autism, but far more worried which makes them more anxious and controlling. Then there is the 'secure explorer' which are parents who don't worry that much about the impact of autism and rather figure out day by day what to do. At last, the 'nervous explorer' are those who do worry a lot and have difficulties with understanding autism and the impact of it. They prefer a more exploring mindset. These four types are an indication that there are differences between the way parents of an autistic child parent. And each of these parents have different needs depending on their style of parenting. So when designing the technological solution for parents of autistic children, these parenting types can be used as a tool to think about the differences in needs and possible barriers to be able to generate requirements and ensure the solution fits with different kind of parents.

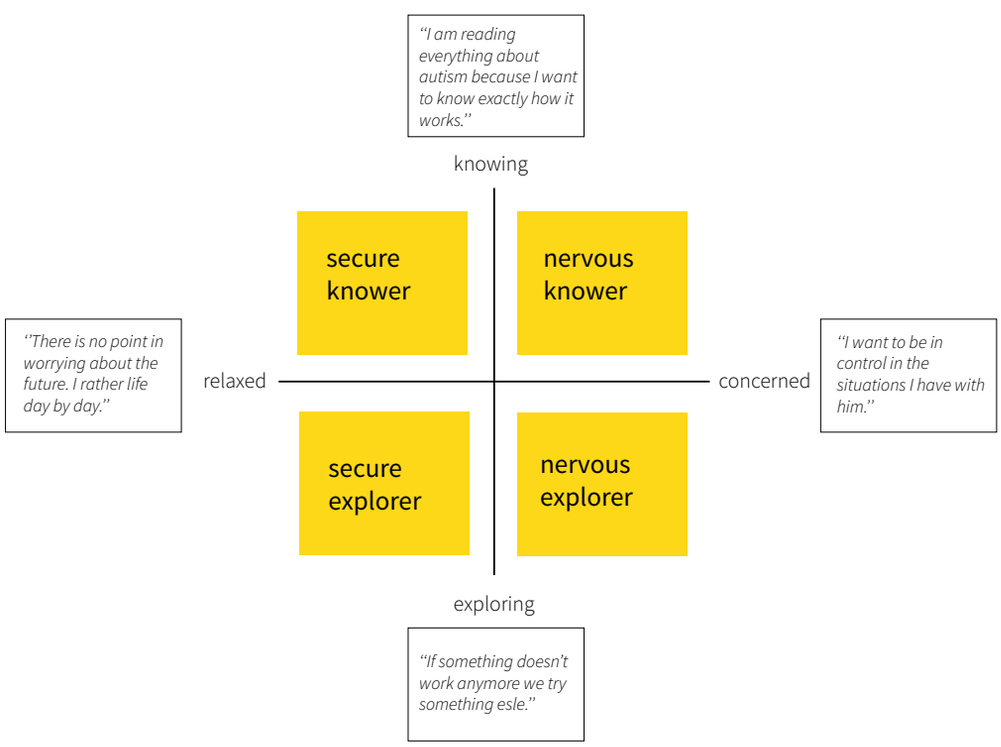


Figure 21. Four parenting types, other than the known parenting styles, for parents of autistic children. They are distilled from the data of the user research.

Conclusion

Parenting is challenging and complex. The family's composition, relations between family members and others outside of the intimate family all influence the family's well-being and the way they parent. Parenting styles are influenced by a variety of internal and external factors. A difference was found in the way parents of autistic children parent which led to the discovery of four types of parenting. When designing a solution for parents, these differences in parenting should be taken into account to guarantee a solution that fits with the needs of different kind of parents.

Impact daily life

What is the impact on daily life?
What determines the impact?
What causes stress amongst parents?
What are negative effects of stress?

An impact on daily life

Raising an autistic child has a great impact on the family's daily life. Research indicated that parents of children with autism spend approximately 1000 more hours a year on additional caregiving (Gezondheidsraad, 2009). Often one or both parents has to stop working to be able to provide care. How this impact translates into the lives of families differs per family situation and is depended on various factors like the severity of autism, marital status of the parents and economic welfare. To get a feel of what it is like to raise an autistic child, films and documentaries were made such as Extreme Love: Autism by Louis Theroux (Theroux, 2012). On the internet parents share their stories to offer a realistic view into their daily lives (Dilshad, 2011; Royko, 2003). Some of the tasks these parents face are taking care of their child's hygiene, assisting with daily tasks, supervising most of the day, arranging different types of care, searching for educational fitting programmes. And in the meantime they have to stay in contact with all the healthcare institutions that are involved (Gezondheidsraad, 2009).

Stressors of parents

Parents of children with autism experience more stress than parents of typically developing children and parents of children with Down Syndrome (Holroyd and McArthur 1976; Bouma & Schweitzer 1990; Dumas et al. 1991). What causes their stress levels to raise are daily stressors. Stressors are triggers like external stimuli and events that cause stress e.g. social expectations, sudden changes, time pressure and worrying (NVA, 2017). According to Konstantantareas and Homatidis (1989) limitations in the child's verbal communication and human relations, and differences in cognitive functions are the most stressful symptoms. Also the concern about the permanency of autism, poor acceptance by society and family members, and low levels of social support are stressful symptoms (Sharpley, 1997). Stress levels are especially increased when a spouse or partner is missing (Gray, 2003).

Figure 22. Stressors increase the stress-level which results in an increase of changes on negative effects.

Figure 23. Louis Theroux together with an autistic boy and his mother.

Negative effects

Stressors cause higher stress-levels, which results in higher changes on depression, anxiety and marital dissatisfaction (Dunn et al., 2001). Therefore it is known that stress has a negative effect on mental health, which affects the well-being of the family (Santiago et al. 2011). A variety of stressors that cause stress amongst parents were found by analysing the user research data and literature. These stressors are structured on the four levels which were described in the previous chapter about family composition and relations: the child, parents, family and others. They indicate the origin of the stressor. For example, little job opportunities is a stressor on the 'others' level since it is caused by society, not by the intimate family. Figure 24 shows the list of stressors with an overview of emotions and possible negative effects that were found in the research.

Conclusion

Parents of autistic children experience higher levels of stress than parents of typically developing children. Stressors are triggers that can be originated from the autistic child, the parent themselves, the family situation or others outside of the intimate family. Parents need to learn how to deal with stressors in order to decrease their high levels of stress and prevent possible negative effects.

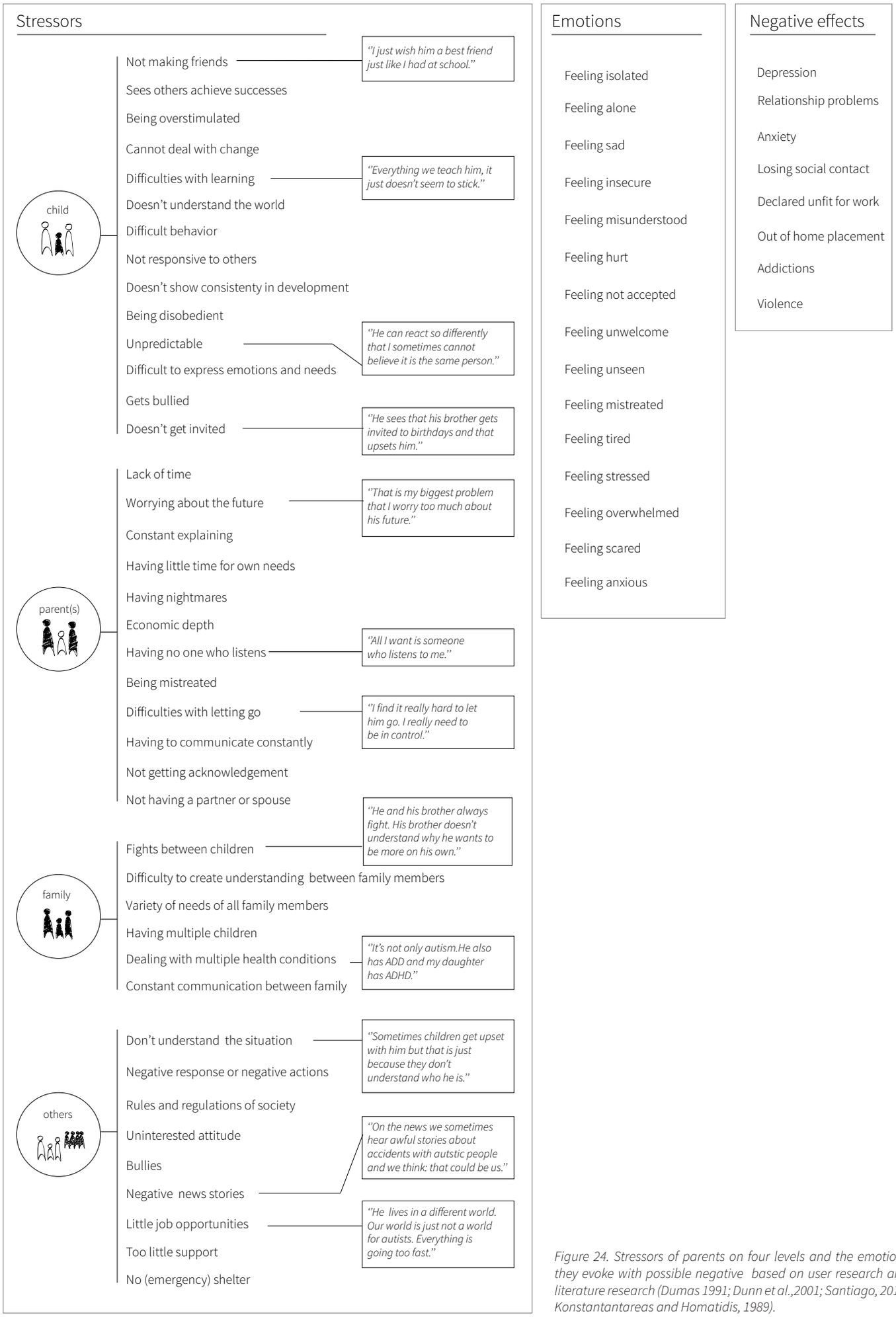


Figure 24. Stressors of parents on four levels and the emotions they evoke with possible negative based on user research and literature research (Dumas 1991; Dunn et al.,2001; Santiago, 2011; Konstantantareas and Homatidis, 1989).

Ways of support

How do parents support themselves?
What are ways to support parents?
What kind of support is most beneficial?
What doesn't work?

Four ways of support

There is no cure for autism so parents need other ways of support to ensure the best care for their child and guarantee the family's well-being. Support is especially important for parents of autistic children since they have higher stress-levels. Based on insights obtained from literature and user research, a suggestion for four ways of support was made for parents of autistic children. First, parents must understand the unique situation they are in. Second, they need to learn about their stressors and how to deal with them. Third, a support network of formal and informal caregivers has to be built. And at last parents must adopt strategies and tools that fit with the needs of all family members (figure 26).

Learning to understand

Parents need to learn about their child's needs in order to better understand the unique situation they are in (Hall & Graff 2010). In order to learn, parents must observe and understand their child's behaviour. Many parents educate themselves on the topic of autism to get a better understanding on what is known about autism, how it tends to develop and what tools and methods are available. In order to discover what works best for their child, it is beneficial to first understanding their child's' needs before trying out various strategies and tools that may not work or evoke negative responses.

Parents who are autistic themselves noted that they understood their child very well as they could refer to their own needs and behaviour. Having this understanding also made it easier for them to adapt their parenting style. Understanding is also very important for parents to be able to explain their child's needs and behaviour to all others involved in caregiving e.g. school teachers, doctors, daycarers, etc. These others have to take care or work with the child and therefore benefit from understanding the child to be able to respond accordingly.

"Since I know I have autism it is much easier for me to relate to him. I understand him and therefore I know better what works for him and what doesn't."

Coping with stressors

To reduce high levels of stress, parents must learn how to cope with stress. One way to do this is by removing or reducing stressors. In some cases this may be a long process. For example the stressor that a child doesn't understand the world requires time and energy in educating the child about the world. Other stressors like a child that has difficulties making friends could be solved by getting a dog that is trained to work with autistic children and therefore could become his buddy (KNGF Geleide Honden, n.d.). Some stressors like 'parents worrying about the future of their child' may be best dealt with by learning to accept the situation as it is.

Another way to reduce stress is using appropriate coping strategies (Hall & Graff 2011, Dunn 2001). Dunn found that it is beneficial to encourage parents of children with autism to use positive reappraisal (e.g. growing as a person and rediscovery of important things in life). New ways to deal with stress are coping strategies like mindfulness. Mindfulness is a way to release stress through meditative practices and learning to live more in the present (Spek, 2010).

"I am really thinking about getting him a dog. A friend that we both trust and then I know that he will not be alone. He will always have the dog as a friend."

Figure 25. There are dogs that are trained to live with autistic children which can be a way to have a buddy for the autistic child.

Building a support network

An effective way to reduce stress is reaching out for social support (Hall&Graff 2011). Mothers who receive social support experience a better mother-child interaction (Mc Allister, Green and Furrer, 2007). Having social support helps with reducing negative effects of stress like depression, social isolation and marital dissatisfaction (Dunn, 2001). Involvement of a professional network is also beneficial (Grey, 2003). According to Guralnick (2008) having access to a support network and receiving support related to their child had the greatest benefit for parents of children with autism. When there are difficulties with building a network, there are network coaches who can volunteer to help parents seek for the right support.

"Now that his grandparents understand him well enough I dare to let him stay over for a bit. That gives a great relief for me and my husband."

Finding strategies and tools

Although every human is unique, they share common characteristics which makes it possible to develop tools and strategies that fit a great amount of people. However, which tool or which strategy works is a process of trial and error. Especially with an autistic child for whom many regular tools designed for typical developed children don't work. Sometimes this requires a lot of creativity and patience from parents. A helpful way of finding strategies and tools could be finding peers to learn from by sharing experiences.

"My child has difficulties understanding a mathematical assignment when it is written down. When I use probes to visually explain, he understands it immediately."

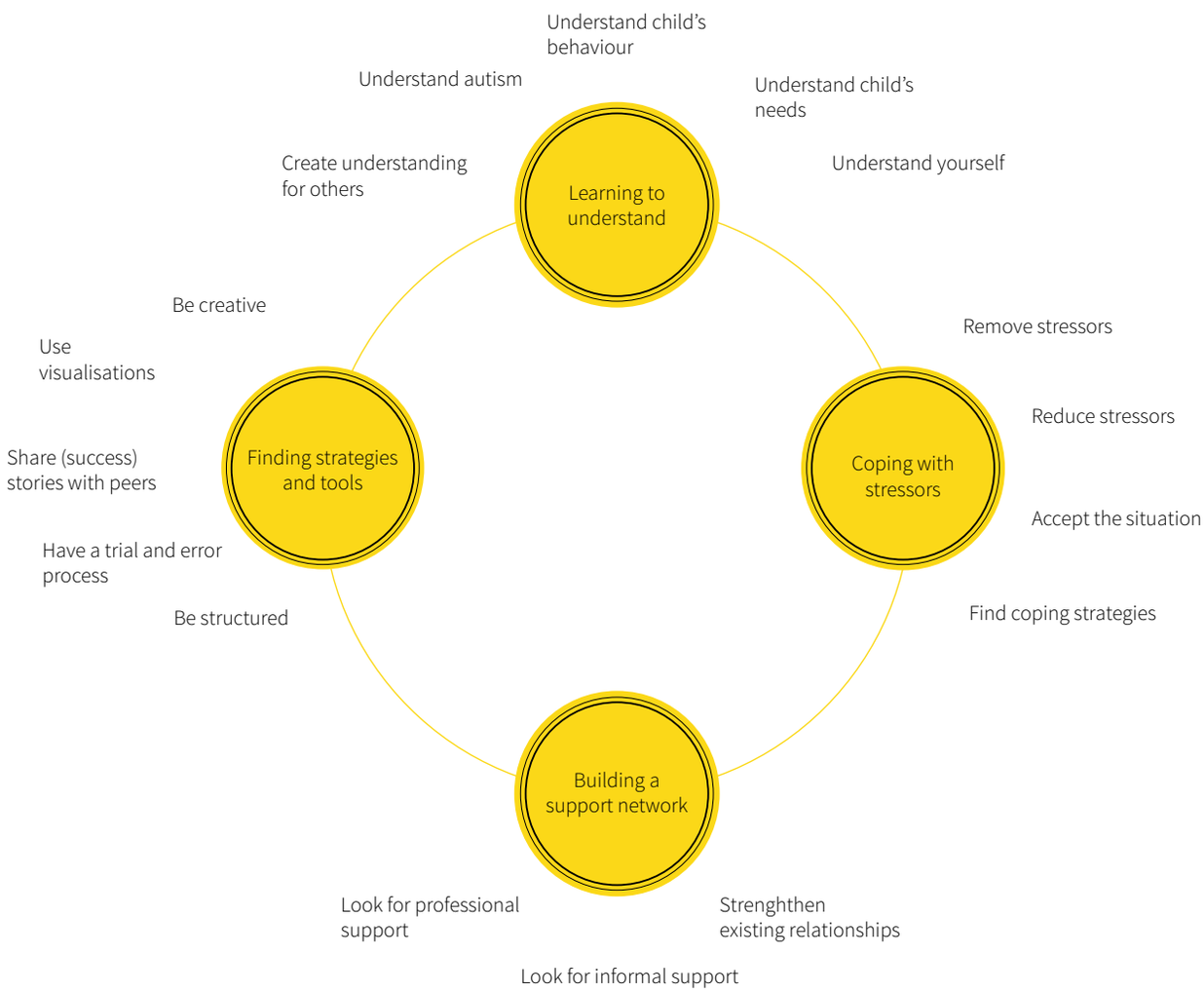


Figure 26. Four suggested ways of support for parents of autistic children.

Conclusion

Four suggested ways of support for parents of autistic children were distilled from literature and user research. First, parents must learn to understand their situation before they are able to explain it to others to create an understanding. Second, to lower high stress-levels parents can reduce and remove stressors, accept the situation or find coping strategies. Third, building a strong network can offer support. At last, parents can adopt strategies and tools that fit with their family's needs. One way to do so can be to learn from peers who have experience.

De Buitenwereld

How does De Buitenwereld provide care?
How do they support the parents?
What tools and methods do they use?
What are opportunities for the design solution?

Company analysis

De Buitenwereld, who is the initiator of this project, is seeking for technological solutions to support their caregiving processes. Before such a solution can be developed it is important for the project designer to understand the company's structure, their beliefs and current caregiving processes. Therefore a company analysis is executed to gain more insight in what the company does, how they do it and why they do it. Various interviews were executed with employees, literature was read about the company, and observations of their caregiving processes were done (figure 28). As a result, insights, barriers and opportunities were discovered (Appendix B). With these results a customer journey was created that maps out the journey of the client: a family with a child suspicious of or diagnosed with a psychiatric condition. For all steps the client undertakes, actions for the caregivers to facilitate the caregiving process are listed. Barriers that were found in the analysis are mapped along side these actions to generate opportunities. At last, the journey will be used in the next phase to determine at what points in time the technological solution can best be used.

Changing processes

One important insight that came out of the analysis was that the company is currently implementing more and more innovative solutions to provide effective care. In 2015 they were confronted with the healthcare transition for the youth that forced them to make adaptations and changes within their company structure and caregiving processes to meet the new transition goals. Since 2015 they decided to adapt a new strategy which was working according to the Agile working method. Working Agile means effectively performing tasks while using a guideline without having boundaries on how to achieve it (Allsopp, n.d.). This allows for flexibility, making quick changes, and developing and implementing new ideas more easily. At De Buitenwereld , Agile working is clearly reflected in their weekly and monthly meetings with the employees in which they set goals and divide tasks while reflecting on progress to make sure all is achieved. Currently they are also adopting Agile working in their caregiving processes with their clients by setting monthly goals and reflecting on them every week.

Another notable change they made to provide more efficient care is the adaptation of digital solutions. During their weekly and monthly meetings, the company uses Trello, an online tool which provides structure to tasks and a clear overview on progress and achievements (Trello, n.d). Their registration and documentation processes have been transferred from offline to an online registration system named NEDAP, which keeps track of the activity of all employees and registers information about the clients (NEDAP, n.d). In line with their attitude to be more transparent, the company decided to open up some parts of NEDAP to parents so that they can keep track of everything that is registered about their child.

The trajectory supervisor

Aside from the changes made in their caregiving processes, De Buitenwereld also changed their company's structure. Beforehand, families who were submitted to the company were in contact with various employees e.g. trainers who are in charge of short stay-overs, trainers for the group-training and outpatient counselling for the child, a behavioural scientist who takes on their intake procedure, and a caregiver who provides consultation to the family.
In their new structure they narrowed the amount of employees down to only one contact-person per family to facilitate a more effective and pleasant communication for the client. This one person is named the trajectory supervisor. They are in charge of the caregiving process during the family's trajectory of care meaning that they make sure all care is provided properly. Therefore they have to facilitate communication between all caretakers involved, which can also require communication with other caretakers outside of the company (figure 27). Aside from taking charge of the caretaking processes they provide counselling to the family.

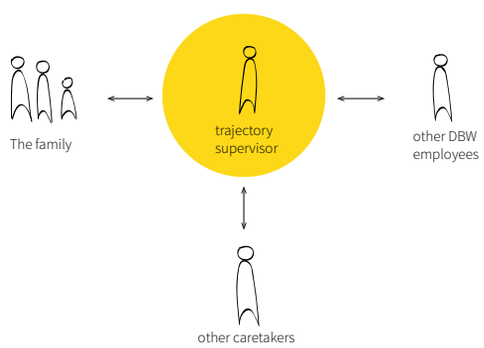


Figure 27. Overview of various stakeholders that are in contact with the trajectory supervisor.

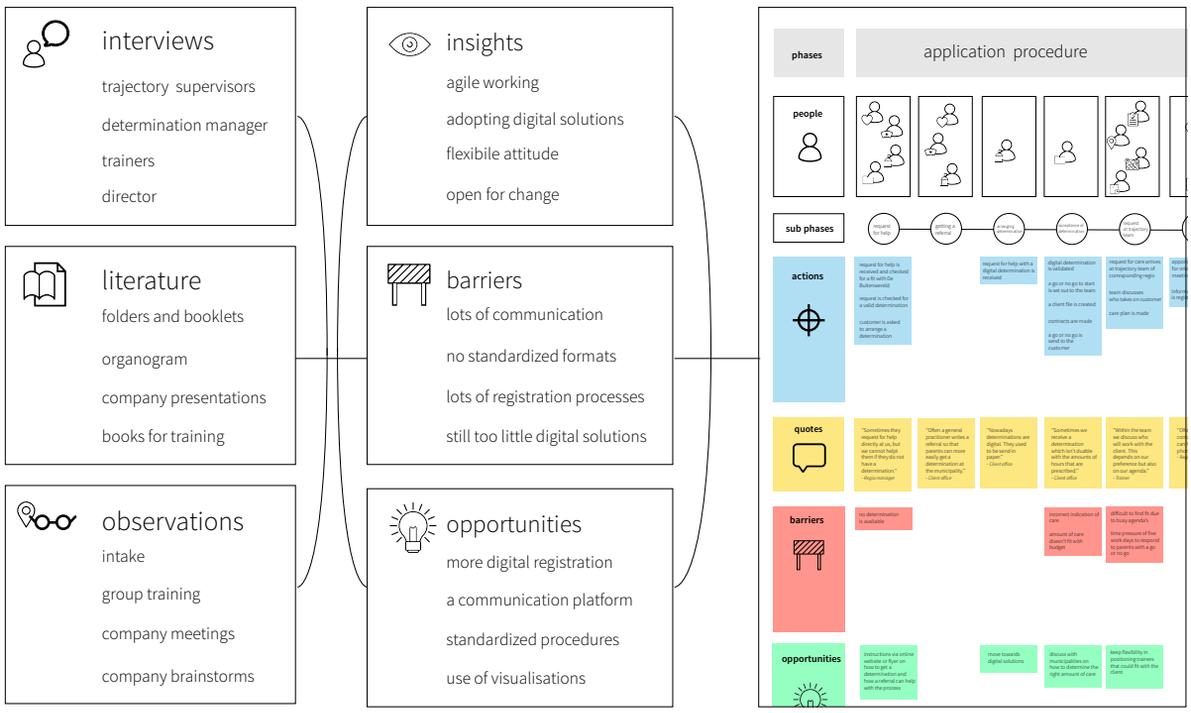


Figure 28. Steps that were taken in the company analysis with some of insights, barriers and opportunities and a fragment of the customer journey.

Customer journey

The customer or client of De Buitenwereld is a family or caretakers of a child who has a suspicion or a diagnosis of a psychiatric condition. In the process of being submitted, the customer has to take certain steps. For this graduation project the journey of the customer was visualised in a customer journey based on the results of the company analysis. Figure 28 shows a fragment of the customer journey. The complete journey can be found in Appendix B. For each step a customer takes in this journey, De Buitenwereld has to take actions. But not all actions go as effectively as desired. Barriers that were found in the analysis are mapped alongside these actions and used to generate opportunities for improvements.

The journey is split into four phases: the application phase in which everything is arranged before the trajectory of care can start, the preparation phase in which caretakers and customers together determine the care program, the treatment phase in which a trajectory of about 9 months starts and in which goals are set and evaluated weekly and monthly together with the family and their trajectory supervisor. At last, the completion phase in which the entire trajectory is evaluated and finished. If during this last phase it is decided that treatment wasn't successful a plan is made for a new care program to start elsewhere.

Opportunities

The journey is used to discover opportunities for improvements of the company's caregiving processes. Most of the opportunities consider more effective communication and registration since there is a lot of time and energy spent on both. Opportunities like these can be used to generate ideas for the design solution. One idea could be that the company develops standardized formats to provide more structure for each meeting with the customer to make communication more effective. Another is to do their registration during the meetings directly in NEDAP instead of afterwards to spare time. Another opportunity transformed into an idea is to work more with visualisations. Currently, very little visualisations are used while these are a great tool to not only explain but also to capture information. Visualisation make information much more vivid and rich.

Conclusion

A company analysis was done to discover insights, barriers and opportunities. This analysis was done to better understand the company's structure, processes and beliefs to make sure the solution fits their caregiving processes. Results were used to create a customer journey which provides an overview of the steps their client takes in their current caregiving processes. The journey also serves as a tool to discover at what moments in time the design solution can best be implemented.

Developments

What is happening in the world of autism?
What are trends in the Netherlands?
What are developments in healthcare?
Which trends and technologies offer opportunities?

Autism awareness

Over the past decade, awareness on autism is growing. On the 2nd of April 2017 the ninth annual World Autism Awareness Day was organized. In relation to this day, the NVA (Dutch Society for Autism) organized the 8th edition of Autism Week full of movies, activities, lectures, information markets, and meet-and-greets with famous people who have ASD like Christina Curry (NVA, 2017).
More frequently autism has been discussed in the media. Filemon Wesselink, a famous Dutch TV presenter, released a television series called ''It is autistic in here'' in which he explores and exposes the variety of the Autism Spectrum amongst individuals (BNN, 2017). The American Sesame street announced the addition of their new puppet Julia (figure 29), a girl with autism (Nagtegaal, 2017). And since December 2016, Erik Jan Harmens, father of a child with autism, writes a column in Het Parool, a Dutch newspaper about the adventures of an autistic man named Paul (Velzen, 2017).

By increasing awareness through different media channels, autism becomes more known to the public and less of a taboo or misunderstood subject. Chances are that others will understand autism a bit better which could lead to more desired behaviour towards autistic people or even better ways of support. Especially the television programs are a great way to enhance understanding of others since they use real footage of the daily lives of autistic people which makes it easier for people to relate and empathize.

Figure 29. Sesamestreet puppet Julia who has autism.

Trends and developments

Making television programs is something that has been done for over a long period of time and thus not really new. Yet, the use of television and movies to raise awareness or to create a better understanding on a certain topic seems to be increasing and is thus an interesting trend to pick up. Trends are changes in the world around an organization, which in this case is De Buitenwereld. When designing the technological solution, it is important to take into account such trends and developments that happen during the time of the project. Combining trends and developments can lead to interesting design opportunities for new products and services (van Boeijen, 2013).

To generate trends and developments a trend analysis was done. Trends and developments were found in different fields related to the topic and structured along six categories of the DEPEST model (figure 31). The full list of trends and developments can be found in Appendix C. From this overview eight trends were chosen that provided well-fitted design opportunities. These eight trends with their opportunities are found in Appendix C. One of these is the social trend of the network society. People in current society are becoming more and more depended on having various networks of people for different types of support. An opportunity therefore is to focus the design solution on growth and strengthening the various networks of parents of autistic children.

Figure 30. Trend analysis process.

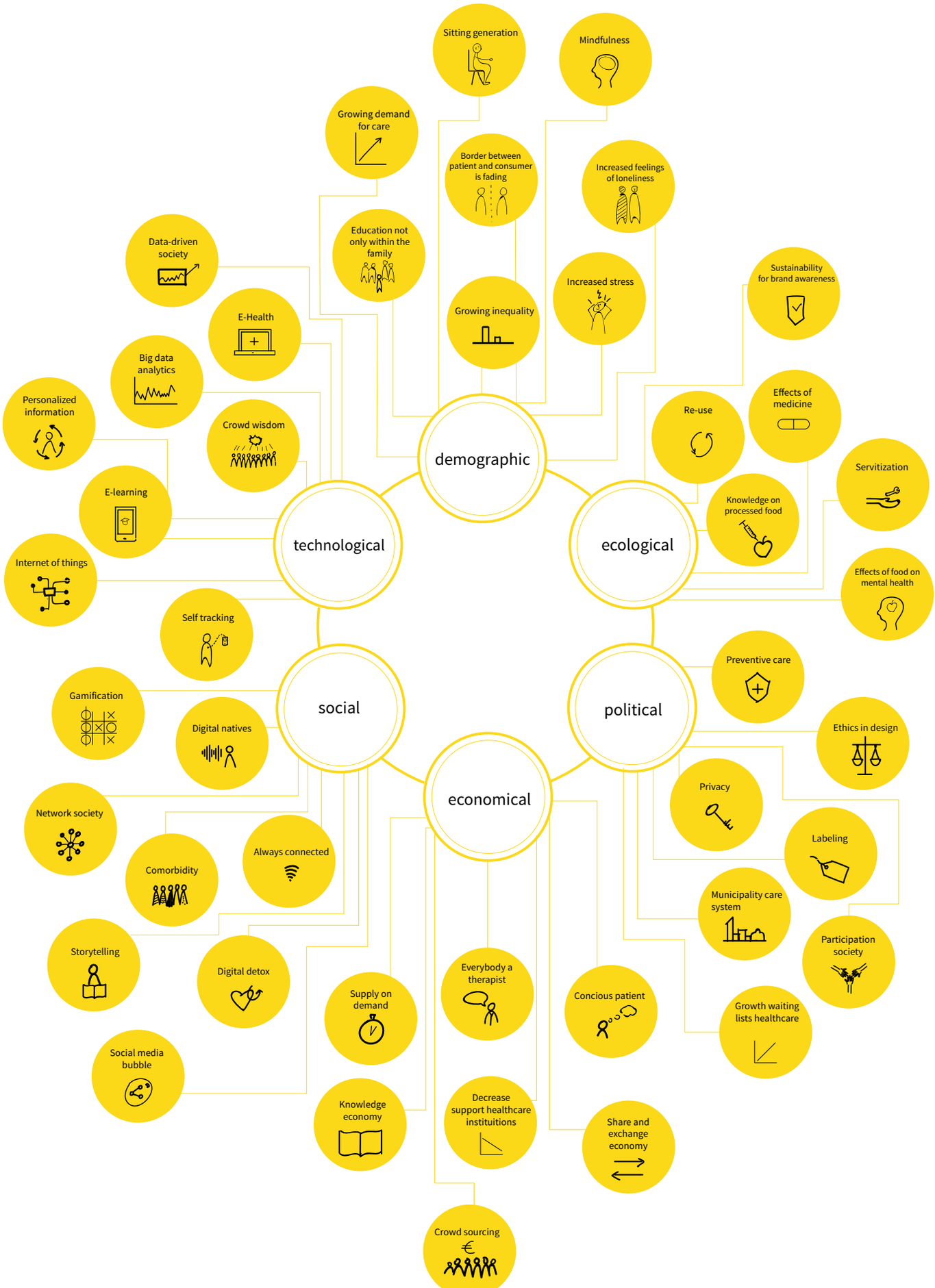


Figure 31. Most important trends and developments categorized according to the DEPEST model.

Technologies

De Buitenwereld desires a technological solution to improve their caregiving process. The term technology is difficult to fit in one definition since its application is broad and ever changing. However, it can be seen as a collection of methods, techniques, skills, knowledge and processes. To get a peak of the iceberg on which technologies are currently available a technology analysis was done. An overview of various technologies was created of which part is shown in figure 33. The entire overview can be found in Appendix D. This overview derived from structuring technological solutions into their application and are described by a verb. These different applications that the design solution may meet were found using the results from both user and literature research. The overview is used to generate technological design opportunities and serves as a tool for retrieving inspiration during the development of ideas and concepts. Six technologies from the overview were chosen for generating design opportunities (figure 32) and these can be found in Appendix E.

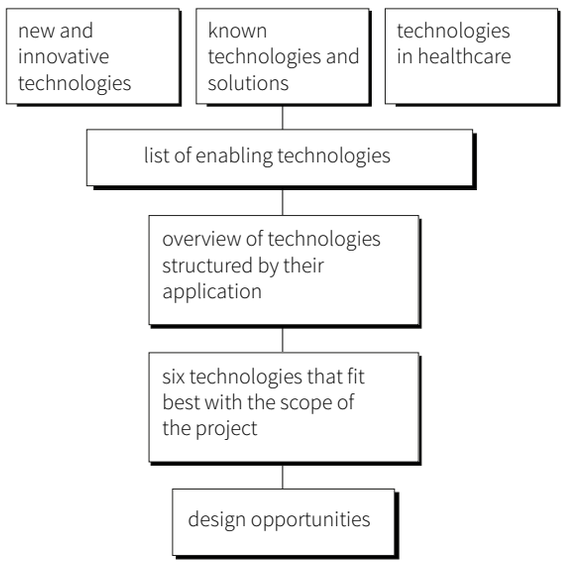


Figure 32. Technology analysis process.

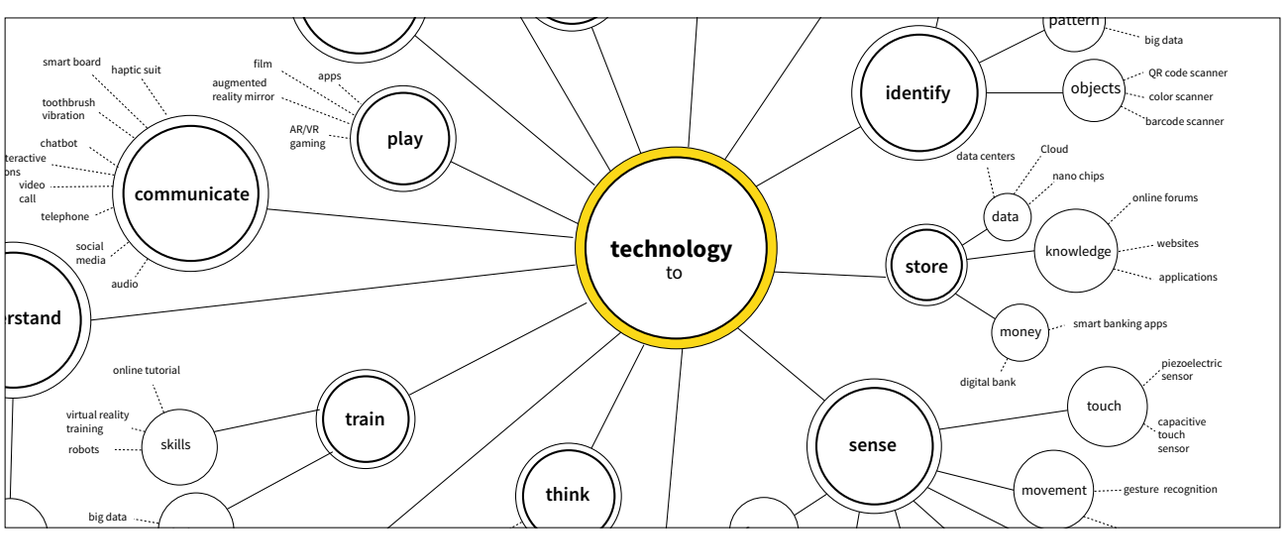


Figure 33. Fragment of the overview of technologies.

Design opportunities

The results of both trend and technology analyses led to a great variety of design opportunities. To see whether it was possible to narrow the amount of opportunities down, both results were compared to discover similarities and an overlap. As a result eight design opportunities that can offer both technological and trending solutions arose. These opportunities can be found in figure 34. For example, the use of digital devices meets the trend that everything is connected and is also a technological solution that meets a great variety of applications. During the conceptualization phase these eight trends should be used for generating ideas.

Conclusion

Developments in the outside world were explored to search for opportunities for the design solution. A trend analysis using the DEPEST method led to a great variety of trends and developments. Trends that were best fitted with the project were used to generate opportunities. To meet the requirement of designing a technological solution, a technology analysis was done to explore technological possibilities. Combining the results from both technology and trend analyses led to eight design opportunities, such as using gamification or filming, which can be used when generating ideas for the design solution

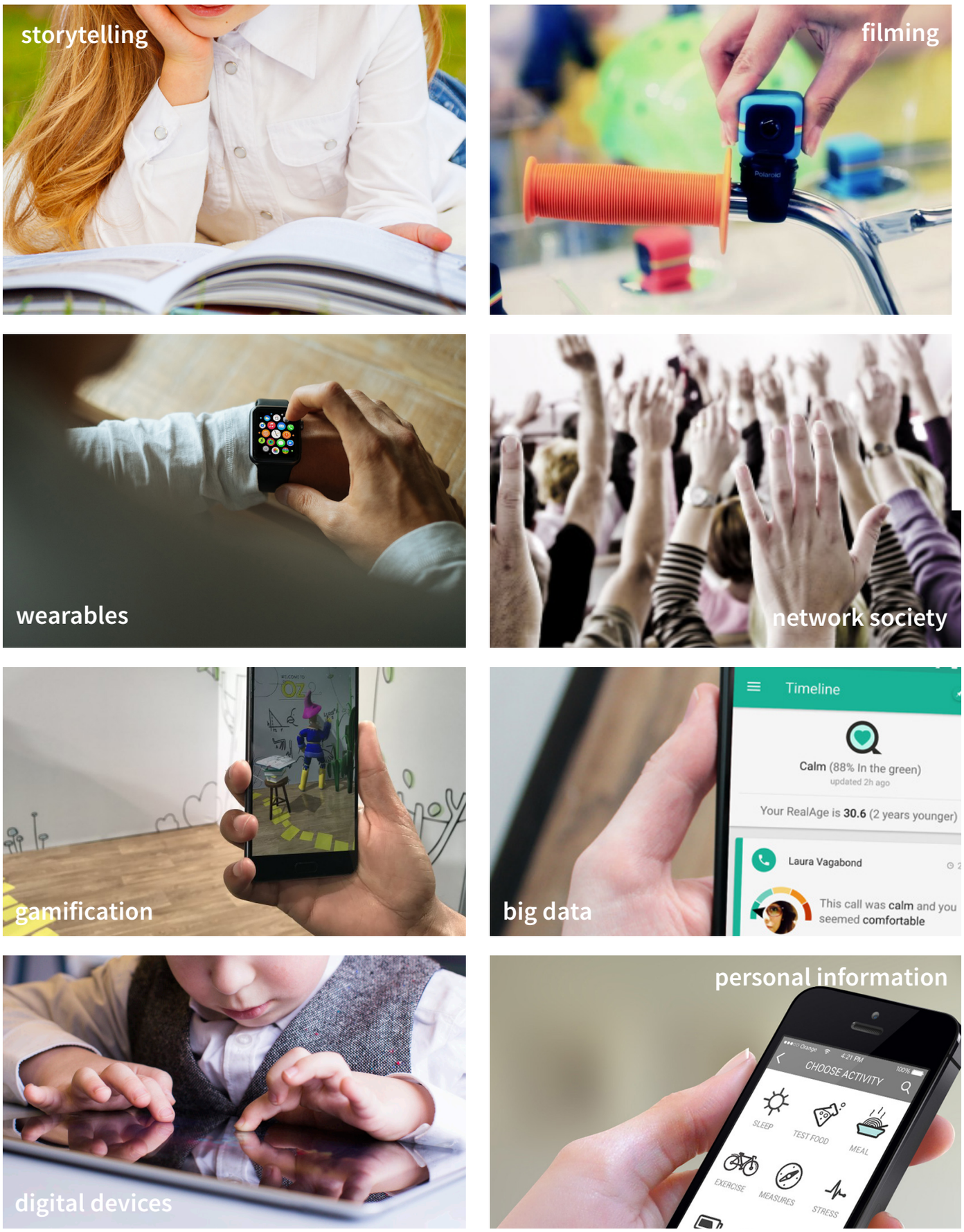


Figure 34. Eight design opportunities as a result from the trend and technology analyses.

User research

What is the research approach?
Who are the users?
How to analyse the data?
What are the main insights?

Approach

To gain real insights in the lives and needs of parents of autistic children, a qualitative research was executed using the method of contextmapping. Contextmapping is a method to elicit latent needs and tacit knowledge that lays under the surface by using generative techniques (figure 36). These techniques invite users to do or make assignments using images and words, which they later can use to explain their thoughts an emotions in order to discover what they know, feel and dream. In contextmapping the user is considered as the 'expert of his or her experiences'. (Sleeswijk-Visser, 2005).

The method starts by providing users with a sensitizing booklet that consists of assignments that fit with the project. These assignment are about the user's daily life, people in their network, important past and present events, and thoughts about their future. Figure 35 shows an image of an assignment from the booklet. In Appendix E a description on all assignments from the booklet and their goals is given.

Figure 35. Assignment from the sensitizing booklet about a day in the lives of the families.

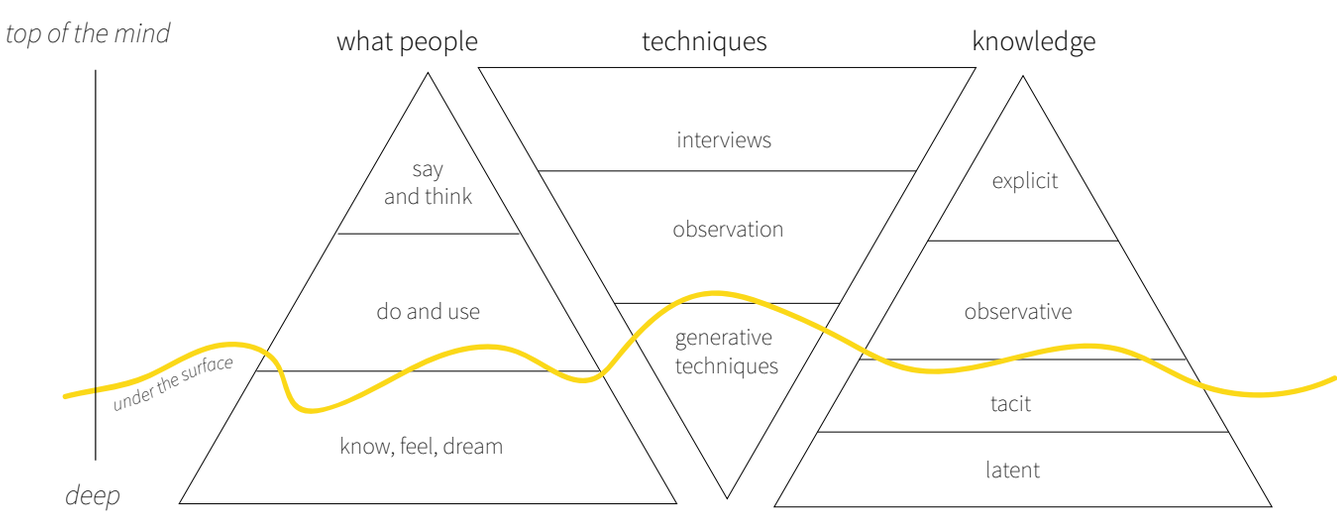


Figure 36. Contextmapping uses generative techniques to understand what users know, feel and dream and elicit tacit and latent needs and knowledge (Sleeswijk-Visser, 2005).

Participants

Five families were asked to participate in the user research. It was required that they all had one child with either a suspicion or diagnosis of autism, aged 4-12, and with an IQ level higher than 90. The composition for all five families is shown in figure 37.

For this research, only the parents were asked to participate since the goal was to gain more insights into their needs. After a week of sensitizing by filling in the booklet, one or both parents participated in an interview.

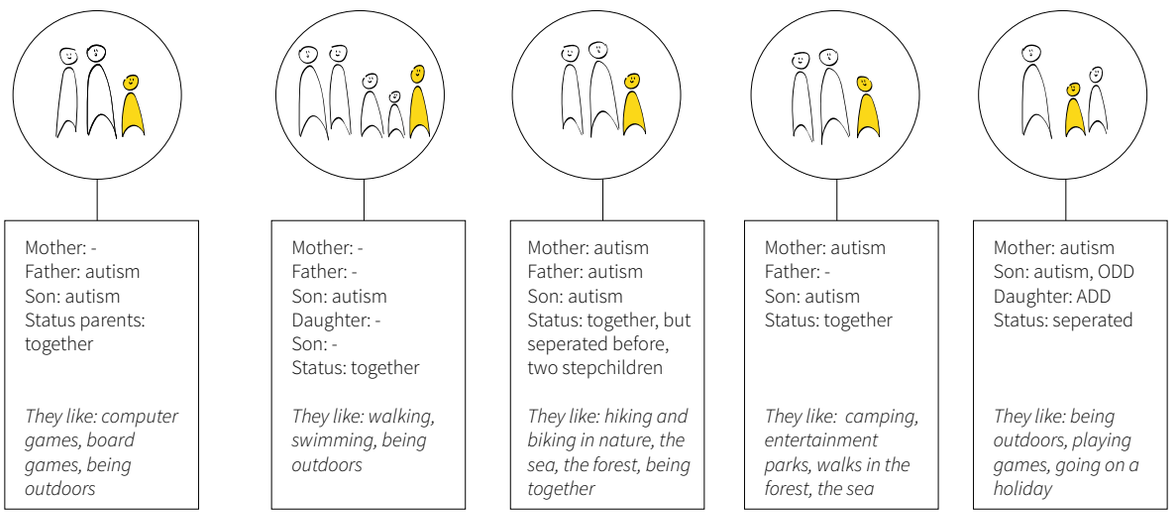


Figure 37. Family composition and information about the family members.

Research set-up

Each family received a package with a plastic envelop containing the sensitizing booklet, sticker sheets with words and images, and pens to fill in the booklet (figure 38). They received the package one week upfront of the interview to sensitize them on various topics. During the interview, the booklet was used as a probe to elicit responses and better understand the parents thoughts (Gaver, 1999). When arrived at the assignment in the booklet named 'from birth till now', parents was asked to place pawns at big life events which would resemble important people (figure 39).

Parents had to describe who these people were and why they were important at that time. By using the pawns parents got activated in a different way which allowed them to go into a deeper level of knowledge. Having to think about where to place pawns and who they would resemble helped them think about what these people meant for them during these big life events. The interviews took one and a half hours and were all recorded using both a video and voice recorder. The entire approach and set-up of the research is found in Appendix E.

Figure 38. Sensitizing package.

Figure 39. The pawns and booklet used as probed in the interview.

Analysis process

All five interviews were transcribed to capture everything that was said. Each transcribed interview and booklet was scanned, printed and read through to find interesting quotes and insights. The data that emerged from this process was visualised on a large paper sheet composed of eight A2 sized papers (figure 40). Categories and relations emerged simultaneously when writing down the data. To narrow down to the most important insights, an overlay of transparent tracing paper was put on top of this large paper sheet. By going through all the data, only the most striking and interesting topics were captured into main insights and written down on the transparent sheet. Based on these insights the analysis focussed towards one main insight which could be used to formulate a main goal. Meanwhile, design opportunities and other patterns that emerged were written down on separate paper sheets so that they would not get lost. These steps of analysing the data and the results can be found in Appendix E.

Usages of results

The goal of the user research was to gain insight into the lives of parents of autistic children. Insights were found through analysing the interviews and booklets, creating visualisations of the data, defining categories and relations, and focus towards a main insight to define a main goal. The results from this analysing process have been used in multiple ways throughout this report:

Quotes from parents have been added to the chapters in this main report to enrich the information and show that a great amount of insights came from real people.

Insights that emerged from making visualisations from the data, and which were captured on separate sheets, were used in various figures made for this project and as information for the texts written throughout the report. Some insights even led to reading new literature which made information more substantiated.

Relations & Patterns were discovered when analysing the categories that emerged from analysing the data. This led to a deeper understanding on how certain topics and insights relate to one another.

Main insight was distilled by focussing on the most important insights, the relations between them and the common problem. This main insight was used to formulate a main goal, which is to be used for formulating the design direction.

Figure 40. Visualisation of the data with categories and relations drawn on eight A2 paper sheets.

Main insight

The main insight that was discovered by narrowing down the analysing process and focussing on the common problem is about a lack of understanding. Every parent mentioned lack of understanding or incomprehension as one of the main causes of problems in their daily life (figure 42). Parents described various situations in which they experienced lack of understanding e.g. judging looks from people on the street, family members who thought that there wasn't really a problem or even a doctor who didn't take the condition seriously. These events were described as hurtful and stressful, and were therefore not supporting for the family's well-being. And not only did the parents encounter lack of understanding, but also the autistic child. Often others do not understand how to respond to the child's behaviour, which leads to problems. On top of that, children with autism have difficulties with explaining their own behaviour and needs to others, which makes creating an understanding even more difficult.

The negative effect of lack of understanding by others, especially by those who are closely involved with the family and the autistic child, is that there is little room for building trustful relationships and a strong social support network. Almost all parents mentioned not having a social support network. Parents stated that they had difficulties letting people in because of the fact that others often didn't respond properly or accordingly. Or they had to explain a lot to create an understanding which costs them too much time and energy. This is a serious problem since a support network offers lots of benefits for the parents who suffer from high levels of stress. Therefore it is very important for the well-being of the entire family to have a network of people who understand the family's needs and situation and therefore are capable of offering the right support.

Main goal

In order to tackle the problem of lack of understanding a goal is set which is enhancing understanding. In the results of the user data a pattern was found on how enhancing of understanding can lead to building more trust and therefore a stronger support network (Appendix G). The pattern shows that this can only be achieved by sharing information with others. As a result of sharing information, understanding is enhanced leading to parents feeling reassured which created trust. More trust can lead to parents feeling supported to share even more information which results in an even better understanding and thus stronger relationship. Other reasons why enhancing understanding is needed, besides the fact that it stimulates a strong network, are described in Appendix G. To achieve this goal, more analysis is needed into the moment understanding between parents and others and how to best enhance understanding in general.

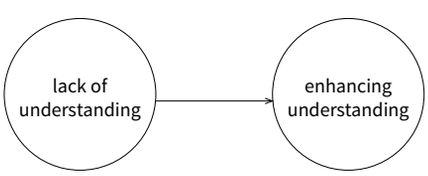
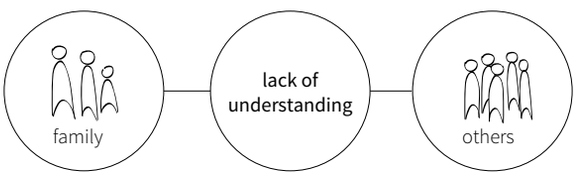


Figure 41. The main goal is to move towards enhancement of understanding.



"The reason these problems occur is all because others do not understand him."

"Often he gets into a fight with another child that didn't understood his behaviour. Then I always have to go to the other child to explain what is happening."

"So often I have the feeling that even the experts don't get him. They don't see him for who he is."

"Even my sister doesn't really understand us. She doesn't get why a family party is too much for our son. We know he will get very over-aroused."

"My father still has difficulties with him. He doesn't understand why he behaves so differently. He doesn't get how everyday can be a completely different day."

"People often think they know what autism is, but I have to explain to them that it is something different for each and every child."

Figure 42. Quotes found in the user research data on the topic of lack of understanding which is found to be the common problem for families with an autistic child.

Conclusion

For this project qualitative research, by doing a contextmapping study,with five parents of a child with autism, was done to retrieve rich and valuable data. This data was analysed to discover insights. Insights from the analysis were used throughout the report to build substantiated information. The main insight from the research was that parents of children with autism and their child experience lack of understanding by others who are involved with the family and child. This causes negative effects like not having such a strong support network which would benefit parents greatly. Therefore the goal of this project is to design a solution that supports enhancement of understanding.

Design direction

What are the problems of stakeholders?
Which needs do stakeholders have?
What are requirements and wishes for the design?
What is the design direction?

Developing a direction

As a result of the user research the main goal for the project was formulated as 'enhancing understanding'. This goal is based on the main insight retrieved from the user research which was that parents too often experience problems in their daily life due to a lack of understanding by others. With this main goal in mind a design direction can be formulated. A design direction provides a more detailed description of what the design solution is going to be. The direction is not only based on results from the user research, but also on results from other analyses (figure 43). First, all problems from stakeholders were listed to generate needs. With these needs a list of requirements and wishes, and a design vision were created. Next, the solution is framed by identifying the moment of understanding and the various components of the solution. As a result, a framed design direction was formulated that can be used as a starting point for the conceptualization phase to generate ideas.

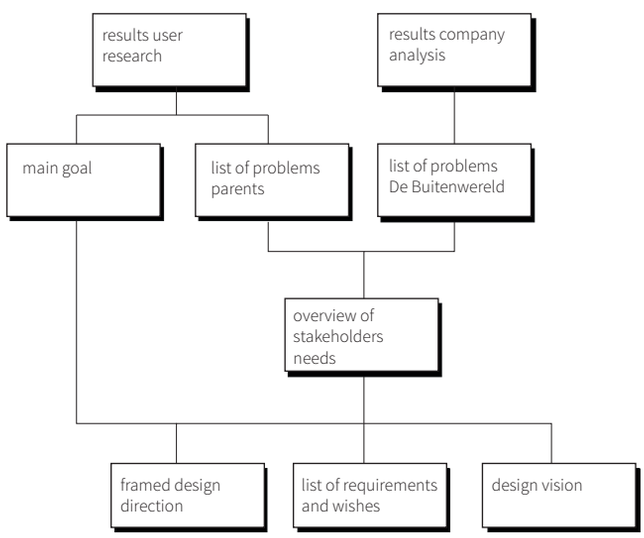


Figure 43. Process of formulating a design direction, requirements and wishes and a design vision.

Stakeholder needs

In order to design a solution that fits with its users, it is important to know their needs. At the start of the project, two stakeholders were identified which are De Buitenwereld, the company who initiated the project, and parents of autistic children who receive support from De Buitenwereld. During the user research, a third stakeholder appeared which are the 'others' with whom parents experience problems due to a lack of understanding. However, in the exploration phase no research was done with these specific others, and therefore only the problems of the parents and the company were taken into account for generating stakeholder needs (figure 44).

The list of problems found for both stakeholders was extensive, so a selection was made based on their fit with the initial assignment and the main goal from the user research. These problems were structured, linked and placed in an overview to discover common needs that matched both De Buitenwereld and parents. One common need for example was that the solution must be time-efficient since both De Buitenwereld and parents have little time to spend. As a result 18 needs were formulated. These eighteen needs were structured resulting in a division of needs for requirements, wishes, the design vision and the main goal. The overview of problems and needs, and the structuring of the needs can be found in Appendix F.

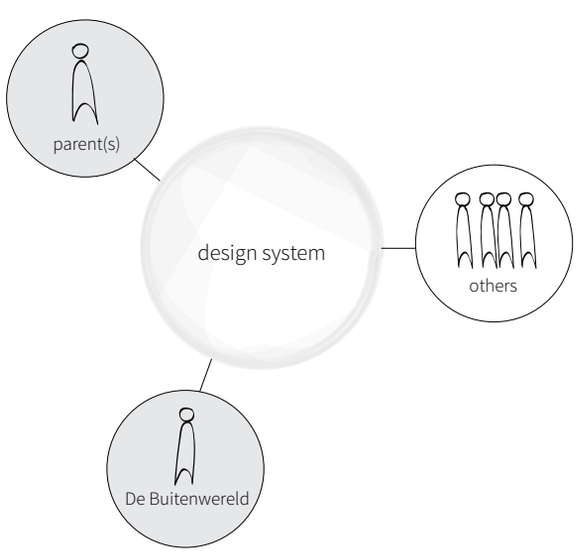


Figure 44. Problems and needs were only listed for two stakeholders who interact with the system: the parents and De Buitenwereld.

Requirements and wishes

Requirements are necessary conditions the design solution must meet. They were found by using the conclusions from each analysis e.g. literature research, user research, company analysis, trend analysis and technology analysis. To bring structure to the requirements, Pugh's checklist was used (Roozenburg and Eekels, 1998). Aside from the list of requirements, a list of wishes was made. Wishes are desired conditions which can be used during selection of ideas and concepts based on how well they fit the wishes. Wishes are as well based on results from the analyses, but not substantiated enough to be requirements. The list of requirements can be found in Appendix H and the list of wishes in Appendix I.

Performance
The design solution is embedded with technology.
The design solution captures information.
The design solution shares information.
The design solution is personalised.

Figure 45. An example of four requirements for the category of performance retrieved from the list of requirements.

Design vision

A design vision describes a bigger picture that fits the project and both stakeholders. It is a tool to be used during selection moments of for example ideas and concepts, just like the list of wishes. As a starting point for formulating a common vision, beliefs and needs from both stakeholders were used. Believes of the company are: ensure the best support where the child is and having care-taking replaced by technology in 2025 (De Buitenwereld, 2015). For the parents, one need from the structure of needs, was used for the vision: the need for taking over tasks. This need fits the image of parents of autistic children who suffer from high stress-levels and have little time and energy and thus need a solution that takes over tasks in their caregiving. This need and the beliefs of the company both take into account the urge for more efficient caregiving and so they were combined into one design vision that is used throughout this report as a tool for making design choices:

"Effortless caregiving."

Moment of understanding

Having a main goal about enhancing understanding requires to understand and define the moment of understanding. As shown in figure 46, four components are defined in this moment: the parent(s), the other(s), information being shared between them, and the context around them. For each of these components desired criteria were found that could support understanding. For example, for a parent it can be beneficial to make a list upfront with the necessary information that needs to be shared with the other. And the information itself can become more rich when parents use visualizations, examples and facts. The context around them can also be of great influence whereas a busy and stressful environment is less supporting than a relaxed one (figure 47), and should therefore be chosen carefully. These criteria not only provided a better insight of the moment, but were also used to generate new requirements and wishes for the design solution. All the desired criteria are found in Appendix G.

For formulating a framed design direction it is important to set boundaries to determine what to take into account and what not. Therefore this moment of understanding needs to be further defined as the scope per components is still too great as for the variety of possible moments. For example, the moment of understanding between a parent and a doctor in a hospital context is a completely different than the moment between parents and their nanny at home. Therefore each component must be further defined to determine what to focus on within this project so that a frame design direction can be formulated.

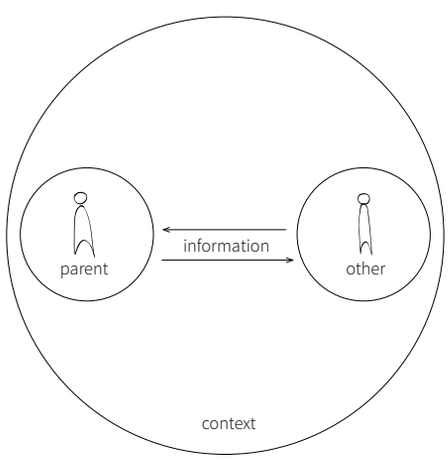


Figure 46. There are four components which influence a moment of understanding: the parent, the other, the information that is shared and the context in which the moment takes place.

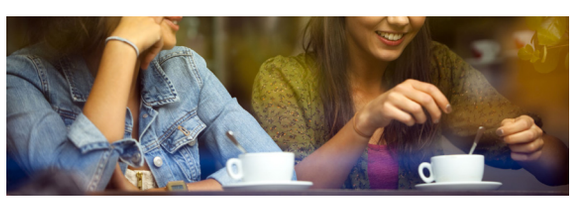


Figure 47. Being in a relaxed context can support enhancement of understanding.

Defining others and their context

The first step in further defining the moment of understanding is to make clear who the others and their context are. Using the results from the analyses, an overview was created of others who are involved with the family. To be able to focus, a distinction was made by placing the others in four different quadrants. Each quadrant describes a certain level of responsibility and emotional support. The level of responsibility means how much responsibility the other has over the child. For example, a nanny has a higher responsibility than a stranger since the nanny is involved in care-taking of the child and the stranger is not. The level of emotional support is defined as how much emotional support the other gives to the family. Again the stranger most likely gives low emotional support as opposed to a grandparent that is closely involved with the family.

As shown in the same figure, the outside layer describes various contexts that fit these others. For the design solution it was chosen to focus on the quadrant of others with a high responsibility and who provide high emotional support. The reason to choose for this segment is that there is a high chance that these others can truly become part of a strong support network for the parents and therefore can greatly influence the well-being of the family. However, it may be that parents prefer others outside of this quadrant as well, most likely from the mid responsibility and high emotional support or the mid responsibility and mid emotional support quadrants. Therefore the focus shouldn't be set too hard to allow a certain flexibility if needed.

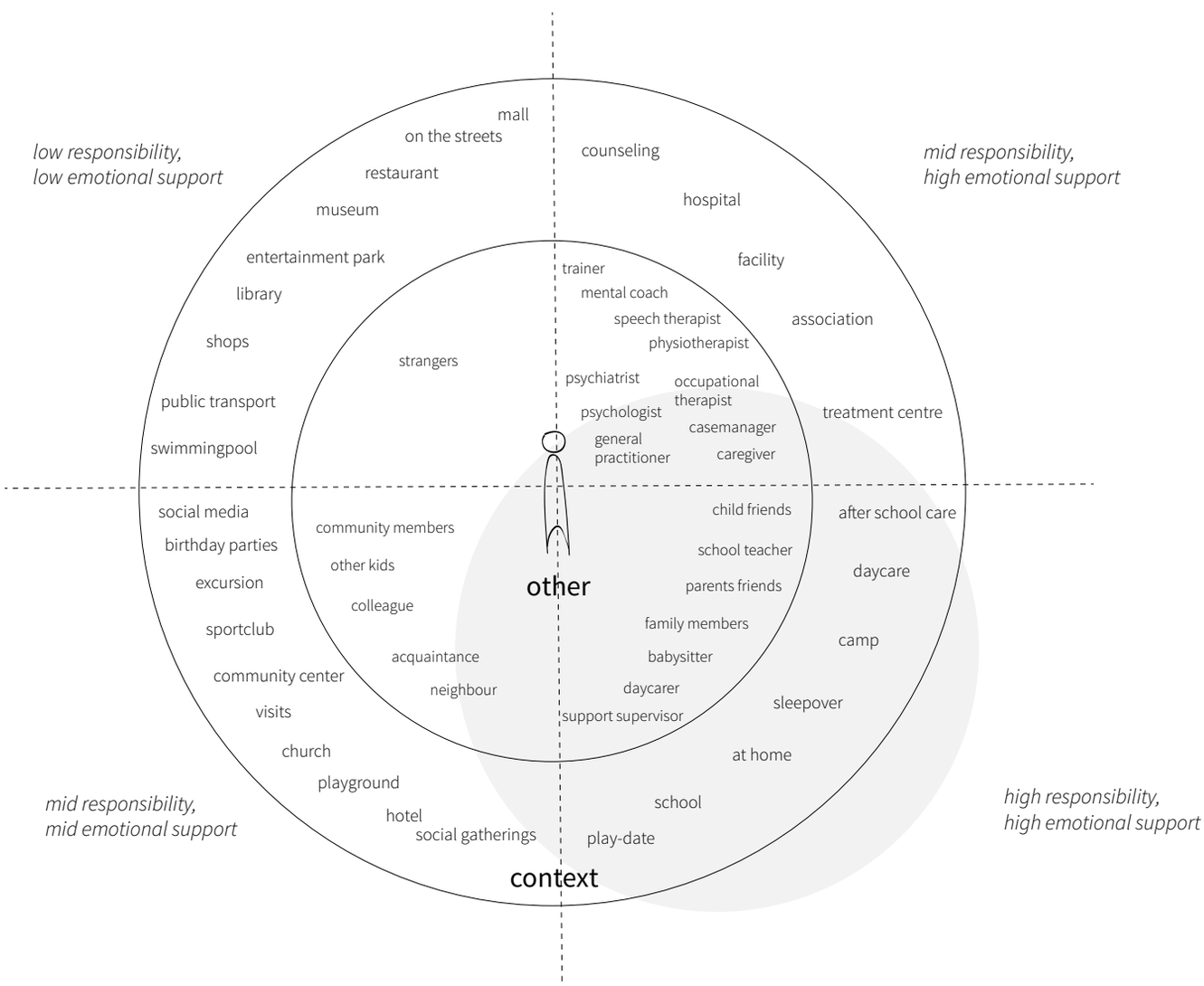


Figure 48. Overview of others who are in contact with parents and their context. A distinction is made on level of responsibility and level of emotional support resulting in four quadrants. The grey area indicates the selection of others to focus on for this project.

A defined system

The design solution takes shape of a design system that interacts with three stakeholders by sharing information: the parent(s), others and De Buitenwereld. Both the parents and others are defined, only the company's involved stakeholder isn't. The choice was made for the trajectory supervisor to interact with the system. The supervisor is the main contact-person during the trajectory of care for the family. As a result, the design solution is now a more defined design system as shown in figure 49. Yet, how each stakeholder interacts with the system, how information is being captured and shared, and how the system is shaped is to be defined in the conceptualization phase.

Framed design direction

Based on the defined system, requirements and main goal, the following framed direction was formulated as a starting point for generating ideas:

''Design of a technological system that captures and shares personal information about the autistic child to enhance understanding amongst people who are involved with the child and family in order to build a strong support network around the child and ensure the best support where the child is.''

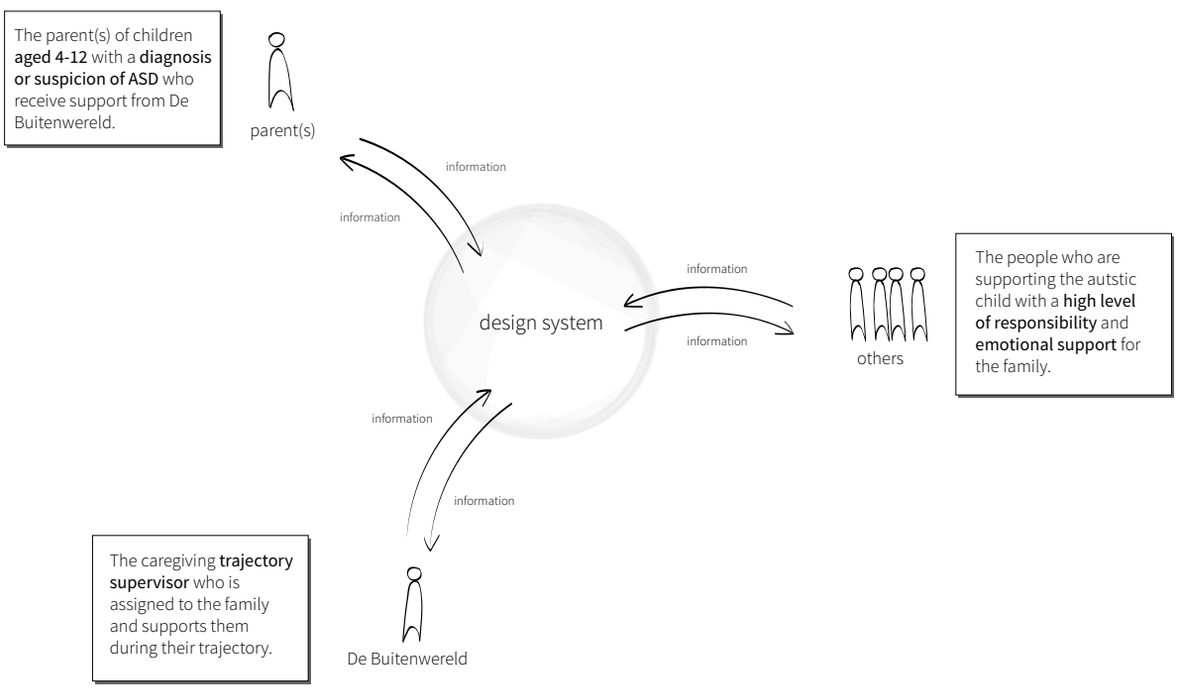


Figure 49. Definition of the system and its users.

Conclusion

The analyses into various topics in this exploration phase, resulted in lots of insights. These insights, discovered problems and needs of the stakeholders were used to formulate requirements and wishes for the design solution and a design vision. The design solution itself transformed into a design system which was further specified by defining the role of each stakeholder within the system. Using all these results supported the formulation of a framed design direction which gives a clear direction for generating ideas in the conceptualization phase.

Conceptualization

The design direction that was formulated,as a result of the exploration phase, is the starting point for the conceptualization phase. In this phase the design system becomes more defined as the system's main functions and future use are described and possible designs are created. The phase starts with an ideation in which lots of ideas that fit the design direction are being generated using various brainstorm techniques. The ideas are structured and evaluated in order to focus on the best idea to continue with. One idea is chosen, tested and improved. With this clear idea for the design system, main functions are being formulated. A matrix of possible design components that meet these functions is created to make different combinations. As a result of combining components, three design proposals are created. To support making a choice of proposal, each proposal is scored on three categories: desirability, feasibility and viability. Together with the company one proposal is chosen to continue with. This proposal is evaluated in a validation test and with the results are used to generate improvements. At last, a final design proposal is drawn up which is the starting point for the embodiment phase.

Ideation
Which ideas are generated during the project?
What are ways to generate new ideas?
Who can be involved in generating ideas?
How to visualize and capture all ideas?

Idea selection
How to focus on the best ideas?
How to make a clear structure?
How to develop an idea direction?
How to choose the best idea?

From idea to design(s)
Is the idea desired by parents?
How is the system going to be used by the company?
What are the main functions of the system?
What are possible design components of the system?

Design proposal choice
How do the proposals differ from one another?
Which proposal is the safest option?
Which proposal is favoured by the company?
Does the chosen proposal need to be adapted?

Design validation
What is the goal of this test?
What is the set-up of the test?
What do parents think of the idea?
What are improvements for the final design system?

Final design proposal
What is included in the system?
What are the main design parts?
How do these parts interact with the stakeholders?
How do these parts connect into one system?

Ideation

Which ideas are generated during the project?
What are ways to generate new ideas?
Who can be involved in generating ideas?
How to visualize and capture all ideas?

Generating ideas

Ideation means the formation of ideas. Ideas can be generated in many ways. They can pop-up unexpectedly, while working or talking about the project or when doing something completely non-relevant to the project. Such more unexpected and unplanned ideas were captured in booklets and post-its to make sure they wouldn't get lost (figure 50). But generating ideas can also be planned for. Often this is done by organizing a brainstorm session. Such sessions can be done individually or in groups. Especially brainstorming with a large group of people is beneficial when dealing with complex problems since many different people bring different perspectives, resulting in a great variety of insights and ideas. Two of such larger creative sessions were organised: one with employees from De Buitenwereld and one with students from the faculty of Industrial Design at Delft University of Technology. In addition, some smaller brainstorm sessions were held with smaller groups of people and individually. As a result of the ideation, a great variety of diverse and rich ideas were generated. To not get lost in this big pile of ideas, a structure needs to be given to the ideas and then a selection must be done to be able to choose only one of the ideas that seems best fitted and most promising for the project.

Figure 50. Post-its and booklets with ideas that arose during the project.

Creative sessions

A creative session is a kind of workshop in which a group of people is asked to participate in various activities to generate ideas and insights. A creative session is often led by a facilitator who's job it is to guide the group throughout the activities and make sure everybody stays on track. These activities are planned in a particular order to stimulate the creative thinking process and designed to generate ideas and insights that fit the design direction of the project. The two creative sessions that were organized for this project had a completely different set-up to be able to cover different topics. Both sessions took about 2 hours and were held in groups of 5-7 people. Many insights that came up during the sessions were used in defining the design system, developing requirements and wishes, and as inspiration to do additional analyses into new topics.

Company session

The first creative session was held at De Buitenwereld with a mixed group of six colleagues from the company and two members of an IT company that was known to the company (figure 51). Goals of the session were: defining which others are in contact with the parents and child, gaining insights in the moment of understanding between parent and the other, and generating ideas on how to facilitate this moment of understanding. Each of the activities that were done are described using questions that were asked at the start of the activity and the main results.

1. Moments of contact

What are moments that your child is in contact with others?
Variety of contact moments: at the doctor, school trips, family visit, going to the supermarket, etc.

2. Most important contact moments

For which of these moments do you find it important that the others know about your child? Range these moments from slightly important to most important.
Eight contact moments ranged from slightly to most important: during assistance in care, at the sports-club, in the neighbourhood, at friends of the parents, with family, with the babysitter, at day care, at school.

Why are certain moments more important than others?
Three variables that make a contact moment important: if there is the possibility to chose the other, how much time their child spends with the other and how much support the other provides to the child and (or) parents.

3. Acting out a contact moment between a parent and a teacher (the other)

How did you (the two people who acted as parent and teacher) feel during this moment? What went well, what didn't? And as the observer (all others): what did you observe?
Insights in the contact moment: it is difficult to explain everything about your child to another person; it becomes very private; it helps if the other is open to listen; it is important to ask the right questions; it is beneficial if both parents and the other know what they can expect from each other.

4. Generating ideas using the 'How-To' technique

How can you: explain, seek solutions together, communicate, make expectations clear, offer help, transform something negative into something positive, have empathy?
Seven sheets of paper were filled with ideas.

5. Choosing the best solutions

Which of these ideas give you energy?
Which idea should not get lost?
Five fruitful ideas: using animations and visualisation to explain behaviour and create empathy, making a wish-list for all stakeholders involved to make expectations clear, developing questions that can be used to discover needs for support, making a superhero from the disability to turn it into something positive, using a stress-meter that measures the child's information and links these to their location to generate data which can be used to better understand the child's behaviour and therefore more easily explain it to others.

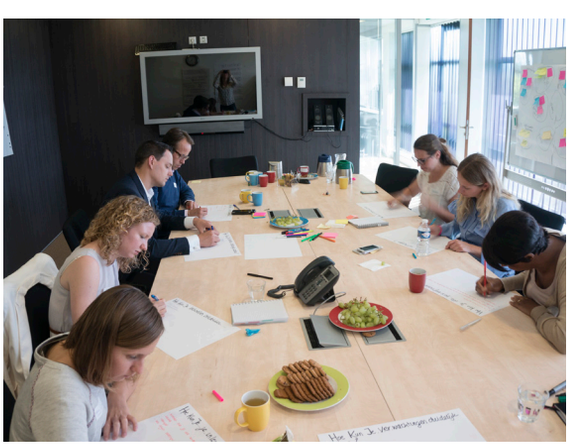


Figure 51. Impression of the creative session that was organized with employees from De Buitenwereld.

Student session

The second creative session was held at the faculty of Industrial Design Engineering with a mixed group of six master students from all three master programmes offered at the faculty (figure 52). The session was part of the elective course Creative Facilitation in which students learn how to facilitate creative sessions. One of the students from the course took on the role of facilitator for the session. The project designer was present to give instructions and information to the group.

1. Moments of explanation

What are situations parents might feel the need to explain the behaviour of their child to others?

Various situations: museums, school-trips, family visits, entertainment park, birthdays.

2. Drawing the problem

Try to visualize the moment in which a parent is explaining his or her child's behaviour to another person. What kind of dilemma's or problems arise?

Problem factors: there is a lot of important information to share; there is little time to explain everything; parents have to deal with the others' opinion and assumptions; parents can get stressed from explaining everything; there is an overload of information for the other person.

3. Generating ideas

How can you transfer the right information in a short period of time?

Various ideas: a sweater with instructions for the child to wear, a recipe booklet about the child, a cube with on each side important information.

4. Clustering ideas and choosing a cluster

What kind of clusters arise when you group ideas? Can you name these clusters? Which of these clusters do you prefer?

Three clusters: making it accessible, using the network, and going on a discovery. One group chose the first cluster to develop a concept and the other group the second.

5. Two concepts

Can you choose an idea or a combination of ideas to create a concept?

Concept 1: using the network around the child by providing each member of the network a specific piece of information about the child so that the information is spread and they can contact each other to retrieve the right information. Concept 2: making a mobile application that has an emergency option for quick help, a database of tips and tricks, and a manual with more detailed information about the child.

Figure 52. Impression of the session with students from the faculty of Industrial Design at the TU Delft.

Brainstorming

Besides the two creative sessions, a few brainstorm sessions with smaller groups of people (2 to 4) and individually were done. The goal of these sessions was to generate more insights and ideas for the project and discuss possible directions the solution should take (idea directions). Before the sessions with the smaller groups started, a quick summary of the project was given to explain what had happened from the start of the project up until that moment. In this way the brainstorm could focus on the knowledge and on the ideas that were already found and build upon this information. Individually, brainstorm sessions were done by sketching (figure 53) and using How-To's: a method which makes use of problem statements that are formulated as a question (Van Boeijen, 2014). How-To's were formulated as such so they would meet the different aspects as part of the design direction:

How to capture information?
How to share information?
How to enhance understanding?
How to build a network?

To meet the aspect of designing a technological solution, one part of the design direction, the overview from the technology analysis was used to see which technologies could be useful. Also the eight design opportunities from the technology and trend analyses were used for inspiration. With all these tools and techniques, a great amount of diverse ideas were generated. However, not all ideas are suitable for further development. Therefore a selection must be made to be able to focus on the best ideas for this project. In the end one final idea should be chosen to continue with.

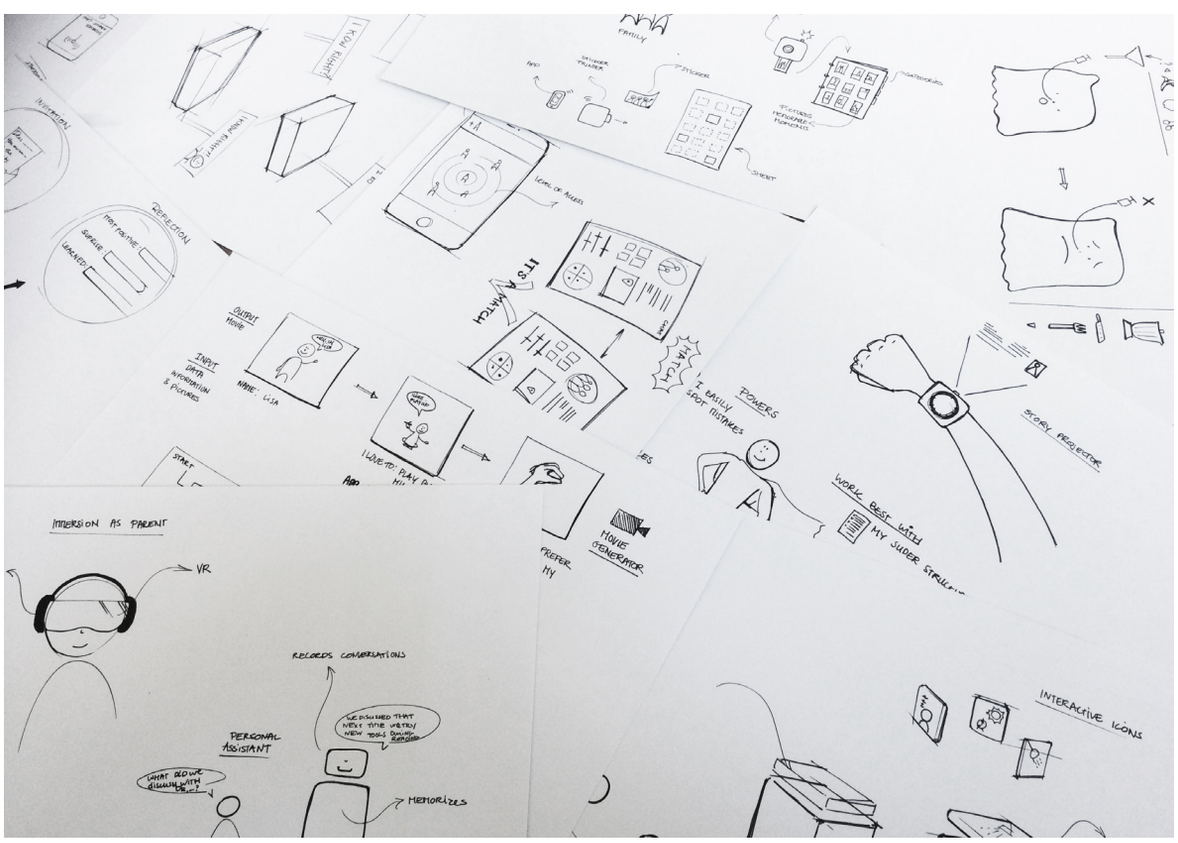


Figure 53. Drawings as a result of individual brainstorms.

Conclusion

The conceptualization phase started with the ideation in which ideas were generated that fitted the design direction. Two creative sessions took place, one at the company and one with students from the faculty of Industrial Design at the TU Delft. A great variety of ideas were captured on paper, not only in these creative sessions, but also during various brainstorm sessions held in smaller groups and individually.

Idea selection

How to focus on the best ideas?
How to make a clear structure?
How to develop an idea direction?
How to choose the best idea?

Steps of selection

In the ideation a great amount of ideas were generated that fitted the design direction. To not get lost in this big pile of ideas, various steps were taken to select one final idea to continue with (figure 54). The first step was done by eliminating the ideas that were either too absurd, unrealistic or not exciting enough. As a result, about 45 ideas remained which can be found in Appendix J. To keep a clear overview, the remaining ideas were structured into four groups that related to the main goal: enhancement of understanding. These four groups were labelled as following: enhancement of understanding by experience, by training, by explanation and by doing. For example, the idea of creating a training game, that trains people that need to understand the child, was put into the group of enhancement of understanding by training. Each group also has sub-groups to rank the ideas along. The entire structure is found in Appendix K. Although the structure provides a clear overview on the ideas, it doesn't really point out one idea to continue with. So the next step in the selection was done by using the overview to formulate four different idea directions. An idea direction gives a description of an overall design of the system. Having four distinctive directions makes it easier to make a well-considered choice for the final idea for the design of the system. For making a choice of idea direction, the design vision is used.

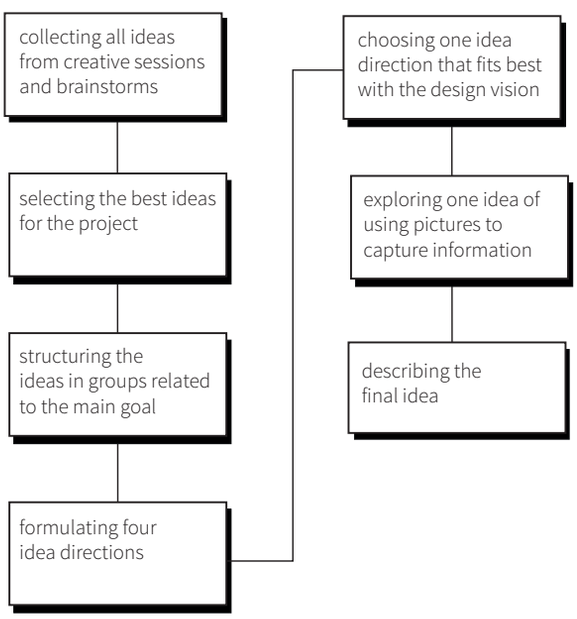


Figure 54. Steps of the idea selection.

Four idea directions

To formulate idea directions, additional analyses were done into existing strategies and design solutions that relate to the four groups from the structure of ideas build around the main goal. For example, enhancement of understanding by training led to doing an analysis into existing tools or strategies in training people in caregiving. With the results from these analyses the following four idea directions were formulated: enhancement of understanding by using a boundary object, by developing a serious game, by developing a training toolkit, and by developing a communication platform (figure 55). Out of these four, the idea direction of using a boundary object was chosen to continue with as it best fits with the design vision due to the "effortless" way of transferring information. Appendix K provides more information on the four idea directions.

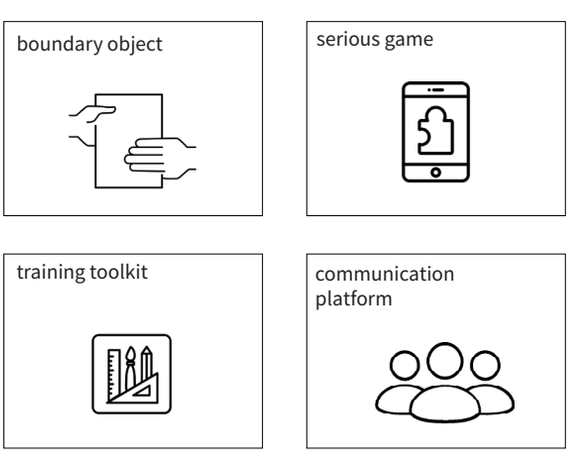


Figure 55. Four different idea directions.

The boundary object

The idea direction that fitted best with the design vision, was the use of a boundary object. This idea direction was inspired by looking at one of the sub-groups from the structure of ideas. This sub-group was 'enhancement of understanding by explaining using probes'. The use of probes as a tool to support explaining and to transfer information triggered to look into the known strategy of the boundary object. A boundary object is a physical object that holds immutable content which can be shared amongst various contexts to transfer knowledge (Carlile, 2002). The strategy beliefs that the act of transferring an object that holds information, or serves as a reminder to that information, tends to increase the changes of successfully understanding the information. Such a strategy for transferring information is a great fit for the project since information needs to be shared with various kinds of people, e.g. a doctor, nanny or grandparents, from different contexts, to enhance their understanding (figure 56). The next step is to look back at the ideas that are already there to discover which can be used or altered to fit best with this idea direction of the boundary object.

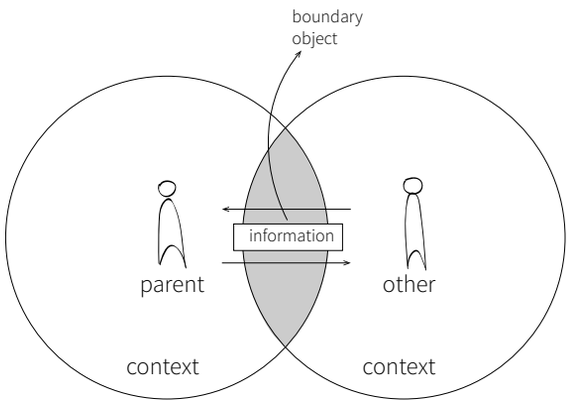


Figure 56. Information is being shared via a boundary object between two people from different types of context.

One idea

Using the idea direction of the boundary object led to reviewing the generated ideas to look for an object that has the ability to capture and hold lots of information, and at the same time can be shared amongst others from different types of context. By going through the ideas there was the discovery of an object that recurred in many of the ideas: a picture. A picture not only captures information but can also easily be shared amongst others. As the saying goes, a picture is worth a thousand words. One advantage of using pictures over other ways of capturing information (e.g. by writing or by drawing) is that taking a picture is quickly done and costs little to no time or energy, which fits perfectly with the design vision of effortlessness. Therefore it was decided to focus on the idea of using pictures as a boundary object to transfer information.

> *"It was after sending this photograph that we had the feeling that finally our family started to understand. And that all because of one picture. The picture just really captured who he is and they could see that."*

Figure 57. Picture of a typicality of one of the autistic children from the user research.

Proof of idea

Looking back at the steps prior to the ideation, the use of pictures to capture and share information has already proven to be a great idea. In the contextmapping study, parents were asked to take pictures of particular situations related to their child. At that time, the goal was to gain insights in their lives. Surprisingly, some very powerful pictures were taken which provided rich information about their autistic child. For example, figure 57 shows one of the autistic children photographed when he was communicating via his hands. This was something he did only when a conversation would get too personal. Having such a unique style of communication has been seen before in autistic children: Owen Suskind, an autistic boy who had learned to communicate with others by using Disney puppets (Life, animated, 2016). This picture is a great example of how personal information, related to autism, can be visually captured to enhance someone's understanding.

Results from the literature research showed that using pictures (visualisations) in communication with autistic children is more beneficial than writing or talking since words or sentences are often too abstract, misinterpreted or difficult to comprehend. Also one of the desired criteria for enhancement of understanding between a parent and the other was found to be the use of pictures to make information more vivid, rich and easier to comprehend for others. In addition, one of the design opportunities from the company analysis was to use more visualisations in their caregiving processes as some of their methods that already used visualisations proved to be working very well. Considering all these benefits of using pictures, the idea of capturing and sharing information in pictures seems to prove it self as being a fruitful idea to be further explored and improved into one final idea.

Improving the idea

In order to arrive at a final idea, this first idea of capturing and sharing information using pictures is further explored and improved. The first step was done by discovering what kind of information is necessary to capture for others to understand, and if this information can all be captured in pictures. Results from previous analyses were used to think of important information related to autistic children and their daily lives. One of this kind of information are rituals. All parents of autistic children work with certain rituals to support their child in achieving particular tasks. Rituals such as eating food in a particular order or for going to bed. Rituals can be captured in pictures e.g. a photo-series. Another example of important information to capture are objects that are of importance to the child. Each child with autism seems to have objects they are completely fascinated about (e.g. puzzles, stones, elastics, etc.) But also medication can be seen as an object which is important in the daily lives of many autistic children. Both objects as rituals are easily captured in pictures. But not all information can be captured in pictures. Lots of the information related to autism is shown in the child's behaviour (e.g. flapping hands, ticks, deficits in verbal communication). Such behaviour is characterized by movements and sounds which cannot be captured in pictures, but they can be captured in video's. Therefore, the idea is improved by stating that the information should both be captured in pictures and video's.

A next step in improving the idea is set by reviewing existing solutions that use pictures and video's to share information with others. For example, various social media and platforms like YouTube are well-known for facilitating this sharing of pictures and video's. Instagram, one of the biggest social media platforms, allows users to share pictures and video's via a personal profile that can be viewed by others. Alone in the Netherlands around 2.1 million people use it, which shows how trending sharing of pictures and video's is. One interesting aspect of Instagram is the use of hashtags to label and describe content (figure 58). Hashtags make it easier for others to quickly see what is shown in a picture or video. The labels can be used in the search engine to find all sorts of content that match these labels. There is also the possibilities to add some lines of text to the content and others can comment.

Based on reviewing the existing solutions, the idea is improved by adding the following functionalities: ability to add some lines of text to the pictures and video's, using keywords to categorize content, allowing the users to choose which content can be seen by whom, and allow for comments by others to be able to create an interaction. Looking at these functionalities it is decided that the design of the system should be a digital design which uses devices such as mobiles, tablets and computers to easily capture, edit and share the information with others.

Figure 58. Instagram post with hashtags from a mother about her autistic daughter.

Final idea

The selection of ideas led to one final idea. This final idea is the idea of designing a digital information visualisation system. The information is captured by parents in pictures and video's, using digital devices, and using the system parents can add some lines of text and keywords to make the information rich and easier to understand for others who gain access to the system (figure 60). All the information is stored digitally in one secure place and can be accessed only by those who are invited to the system. Figure 59 shows how the system interacts with all three stakeholders. The parents can choose which others get to see what kind of information. This means that the trajectory supervisor and others need to be invited into the system so that they can explore selected information and enhance their understanding. The system also allows others to add comments and thus interact with the parents via the system.

This final idea of a digital system that visualizes information has lots of benefits for this project. For example, nowadays almost everybody has a digital device to take pictures and video's which makes capturing and editing information for the parents, who have little spare time, easy and quick to do. More benefits of the final idea are found in Appendix L. This final idea will be further evolved into a design proposal which describes the system in greater detail.

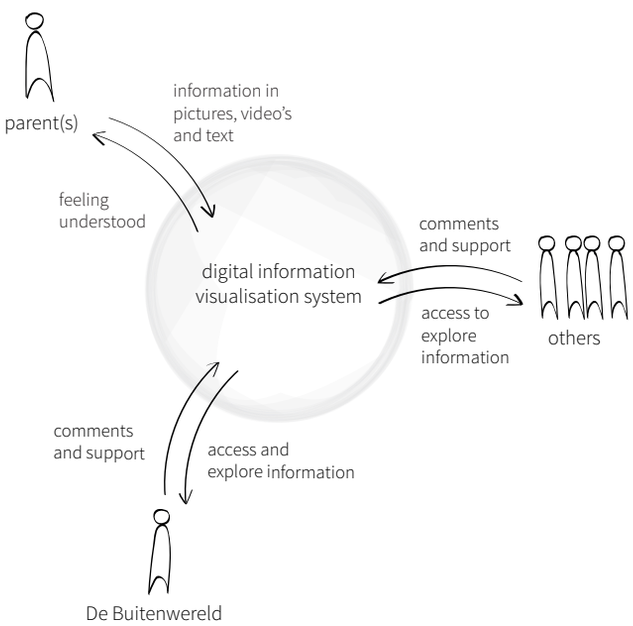


Figure 59. Overview of the system with the interactions with the three stakeholders.

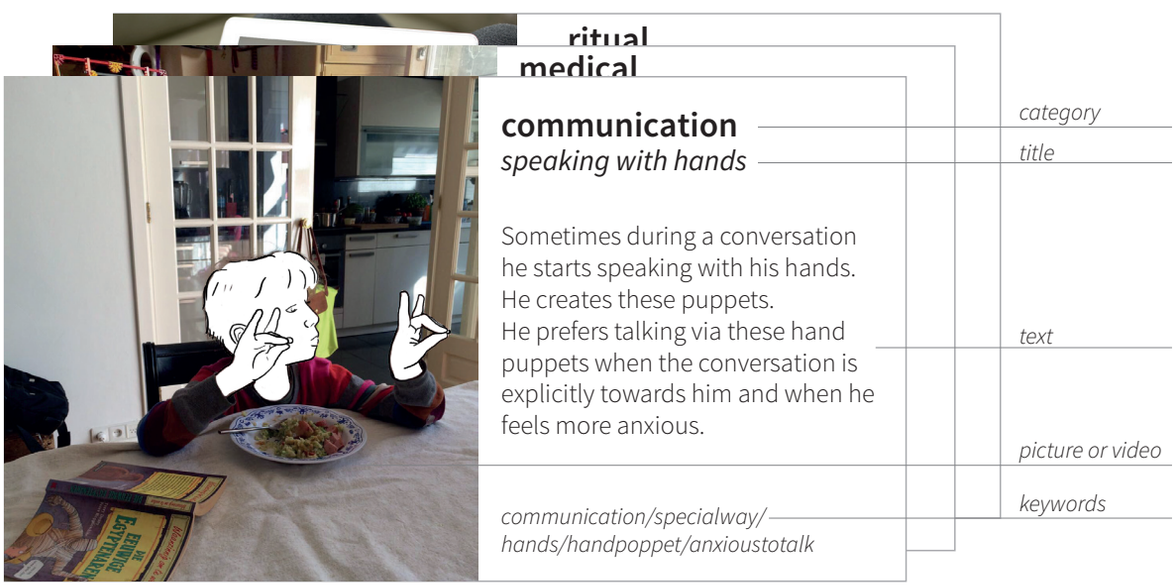


Figure 60. Final idea for a digital system that captures important information in pictures or video's with keywords and some text.

Conclusion

All ideas that were generated in the ideation and during the project were evaluated. A selection was made of the most promising ideas. By structuring these ideas, four idea directions emerged. One idea direction of using a boundary object inspired the formulating of a final idea. This idea describes a digital information visualisation system which can capture personal information in pictures and video's and shares this with others to enhance their understanding.

From idea to design proposal(s)

Is the idea desired by parents?
How is the system going to be used by the company?
What are the main functions of the system?
What are possible design components of the system?

Elaborating the idea

The final idea describes a digital information visualisation system that captures important information about the autistic child in mainly pictures and video's, and shares this information amongst others who need a better understanding of the child. In this chapter this final idea is further elaborated upon to be able to develop a substantiated design proposal, which is a more detailed idea. The first thing that is done is testing the idea to discover what works and what can be changed. The results of the test are used to improve the idea and to determine the main functions of the system. Also the use of the system by the trajectory supervisor in the current caregiving processes is explored. This is done by looking for moments along the trajectory of the parents in which the system can be used and thus decide how the system should function at these moments. When the main functions of the system are clear, it is possible to make an overview of design components that meet these functions. By making different combinations of components, design proposals can be created.

Testing the idea

Doing a quick test helps to discover what works and what has to change. To do a more quick and easy test, a low-fidelity prototype is made for testing the basic principle of the idea: capturing and sharing information via pictures and video's with others. The quickest way to test is by using the well-known mobile communication application WhatsApp which is a tool to easily share information in text, pictures and video's with others.

Two parents of a three-year-old boy with autism were asked to participate in this quick test. They were instructed to take pictures and video's of things they ought to be important information in relation to their child and their situation. To test if enhancement of understanding was achieved, the project designer participated as 'the other of whom more understanding is desired'. Both parents and the project designer joined a group-chat on WhatsApp in which the parents shared information in pictures and video's. They were asked to use hashtags to label their footage (figure 61). After four days, the test was evaluated and discussed. Results were divided into insights, barriers and opportunities (Appendix M).

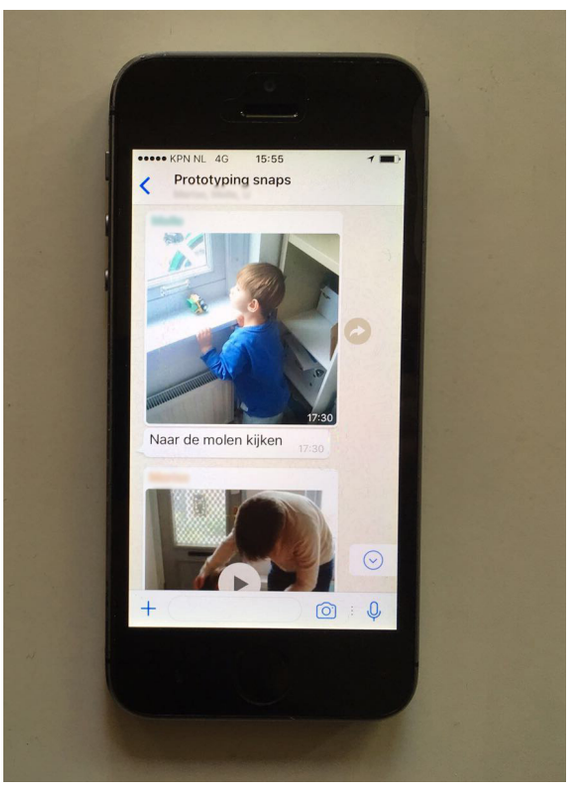


Figure 61. The WhatsApp chat from the quick test.

Results quick test

Regarding enhancement of understanding, the project designer stated that after four days of testing a better understanding of the child and the parents situation was achieved. Especially when the parents shared more private footage e.g. a video of their child having a tantrum. With regard to the effectiveness of the idea, the parents agreed that pictures and video's were a great way to quickly capture information. They both enjoined the fact that it cost them little time as they both lack time. Another unexpected result from the test was the fact that the parents noticed, while taking pictures and video's, that there were lots of positive moments. Overall, results gave great input for the system and confidence that the idea is a great one to continue with.

“We discovered that there are actually so many good moments.”

“I think I still find it difficult to share our struggles with my parents. I rather share only the good moments.”

“It would be great if we could also see pictures and video's from other parents to compare and share ideas.”

Figure 62. Printscreen of the WhatsApp chat from the quick test.

Use of system during trajectory

The next step in detailing the idea is to look towards the interactions of the design system with its future users. As previously determined, the system has three users: the parent(s), (selected) others and the trajectory supervisor from De Buitenwereld. Each of them interacts differently with the system. The parents capture information and put the information in the system. Both trajectory supervisor and others gain access to the system after they are invited by the parents. However, what not yet has been looked into is at what moments along the trajectory the system can best be used and how. Therefore the customer journey of de Buitenwereld was used to look for moments in time in which the system can best be used. Knowing these moments helps for generating more requirements for the system and think of the kind of functions the system must meet.

Looking at the journey, the first moment of interaction is the introduction of the system by De Buitenwereld to the parents at the start of their trajectory (figure 63). This is during their orientation meeting. When parents agree on use of the system they can start capturing information and make use of the system. After the introduction, the system should allow parents to invite others to access the system. Another function of the system is to be a tool to reflect upon information and track progress. Reflections can be done using the information in pictures and video's from the system to discuss in the weekly meetings between parents and their trajectory supervisor, but also during the monthly multidisciplinary meetings. Besides reflection, the system can support and guide the parents by giving assignments during the sprints for making specific video's and pictures for the system. At the end of the trajectory the system should be handed over to the parents so that they can independently keep using it.

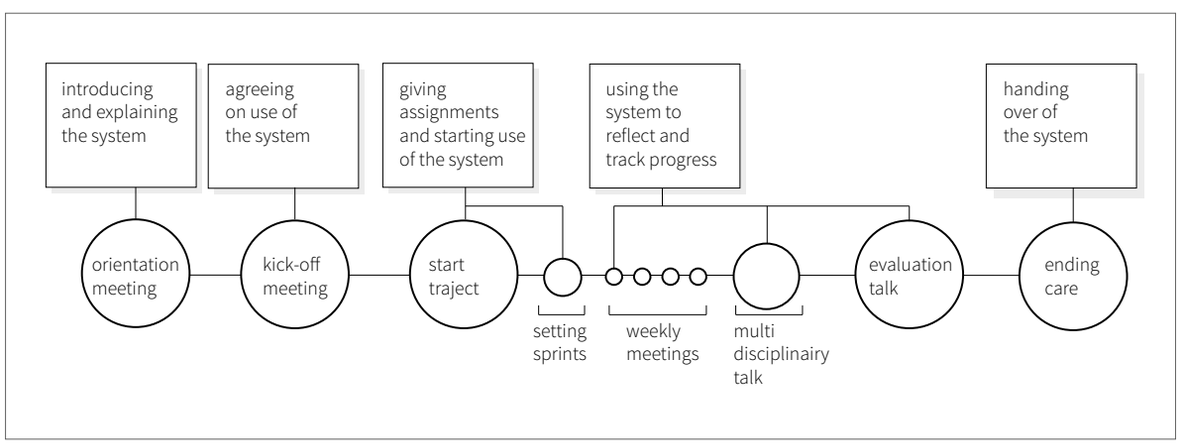


Figure 63. Moments along the customer journey of De Buitenwereld in which the system is used.

System main functions

The results from the quick test, the exploration of use of the system during the trajectory and the list of requirements were used to define the main functions of the system. To indicate how results can be translated into functions is shown by the following example: results of the quick test pointed out that it is important to instruct parents on how to take pictures and video's and of what kind of situations. Therefore the system must have a main function which instructs the users on how to best use the system. In such way, six main functions of the system were defined. Each main function was given a name. The first main function of the system is the explainer. This function instructs and explains the system to all three users: parents, trajectory supervisor and the selected others. The collector enables and supports parents in collecting the right information. The storer makes sure the system can store all information in a safe and secure place. The presenter presents all information in a convenient and appealing way and makes this information easy to navigate through. The sharer enables parents to share their collected information with others and their supervisor. And at last, the tracker enables the trajectory supervisor to use the system as a reflection tool by allowing access to parts of the information that is put into the system to be able to track progress.

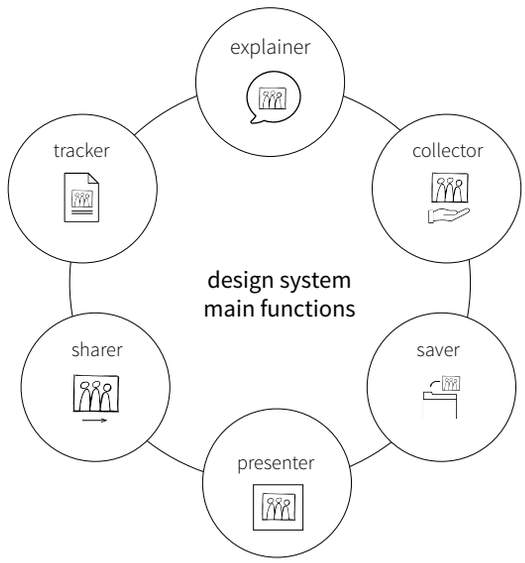


Figure 64. The six main functions of the design system.

System components

Having defined each of the main functions of the system leads to thinking about possible components to meet these functions. Logically, there are multiple possible components. To be able to review options, a scheme was created with the main functions and a list of possible components. Figure 65 shows part of this scheme. The entire scheme is found in Appendix N. When making a choice of components per main function, it must be taken into account that the components differ from one another: some components require more investment or technological development than others e.g. a new mobile application requires higher investments than creating a printable paper booklet. However, a mobile application may be more desirable by the company as it fits their desire for more technological and innovative solutions. With such differences in components, it was decided to not only make one comination of components for a design proposal, but three combinations. Each combination shall be transformed into a design proposal that describes a different kind of design for the system.

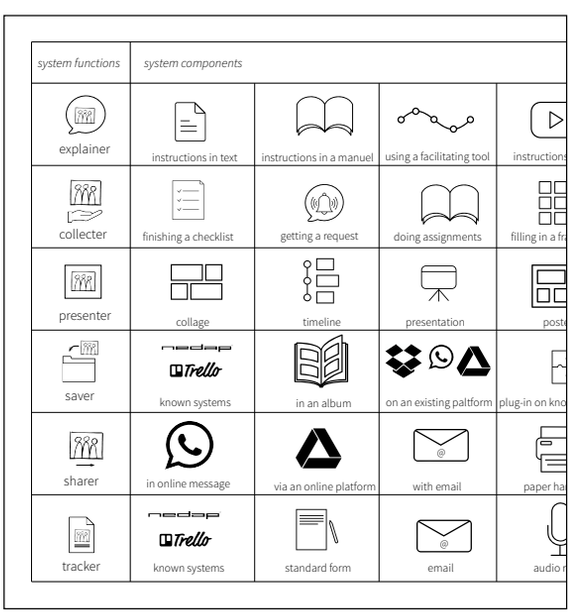


Figure 65. Detail of the scheme of possible components per main function.

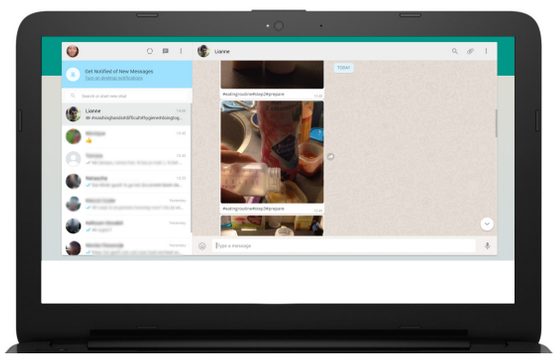
Component combinations

Before making different combinations, the components in the scheme were structured in a particular order to make the selection of components easier. It was chosen to structure them from left to right on their ease of implementation (inspired by the design vision of effortlessness). As a result the most left component would be the one requiring the least time to implement. For example, for the main function of the explainer, an instruction list requires less time to implement than making an instruction video and was therefore placed on the left. Next, the three different component combinations are made. Each of these sets must differ from on another. To achieve this it was chosen to use three different kind of directions to select the components upon. The first combination would follow the direction of being 'the most easiest to develop' set of components, the second one on 'the most secure' and the last would follow the direction of being 'the most innovative'. Components were chosen from the scheme to fit these directions and this resulted in three component combinations which were used to create three design proposals (Appendix N).

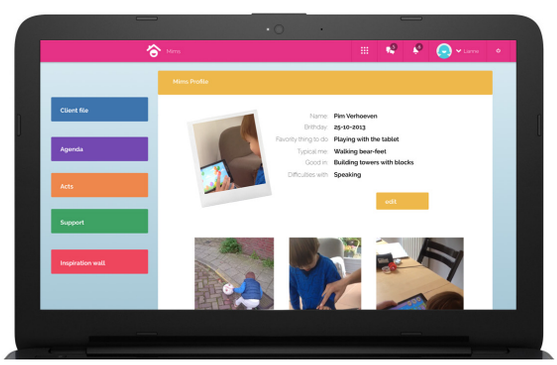
Three (digital) design proposals

The three component combinations are transformed into three design proposals. The design proposals each describe a different design for the digital information visualisation system. For each proposal, a look for the design is presented and use of the system is described. All three design proposals vary mostly on the digital solution they embed (figure 66). The three following proposals were created: Whats-Upp, the proposal that fits the direction of 'most easiest to develop'. This proposal makes use of the digital solution WhatsApp. This app has proven to be a great tool for sharing information during the quick test. Mims is the proposal follows the direction of 'most secure' as it is an extension of NEDAP, which is a known and secure program used by De Buitenwereld on which they store client information. On Mims the parents can add pictures and video's to their personal information page and allow access for others to see. The final design proposal is Bitstory, which is a completely new designed digital system and therefore follows the direction of 'most innovative'. Appendix O provides a detailed overview of each proposal. Yet, only one proposal will be chosen together with the company to continue with.

Whats-Upp



Mims



Bitstory

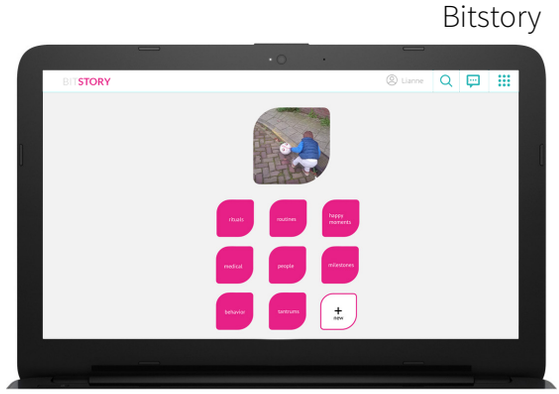


Figure 66. Three design proposals for the design system.

Conclusion

The final idea of a digital information visualisation system was further detailed by doing a quick user test. Results improved the idea and helped to determine the system's main functions. An overview of possible design components per main function was created and used to make combinations which resulted into the creation of three design proposals, each describing a different design. In the next steps only one proposal is chosen to continue with.

Design proposal choice

How do the proposals differ from one another?
Which proposal is the safest option?
Which proposal is favoured by the company?
Does the chosen proposal need to be adapted?

Comparing proposals

Whats-Upp, Mims, and Bitstory are three design proposals that resulted from combining different system components. Each of the proposals meet the same requirements drawn up for the digital information visualisation system, but differ from one another on desirability, feasibility and viability. Each proposal is scored upon these three categories (figure 67). For desirability, the list of wishes is used for scoring by indicating how well a proposal meets a wish from the list. A high score on desirability means that a proposal meets many wishes and scores high on these wishes. For feasibility two criteria were defined to score upon: ease of technological development and the implementation time. A high score for feasibility means that the implementation time is quite short and the technological development easy to manage. Viability is scored upon investment costs and risk of development. A high score for viability means that both investment costs and risk of development are low.

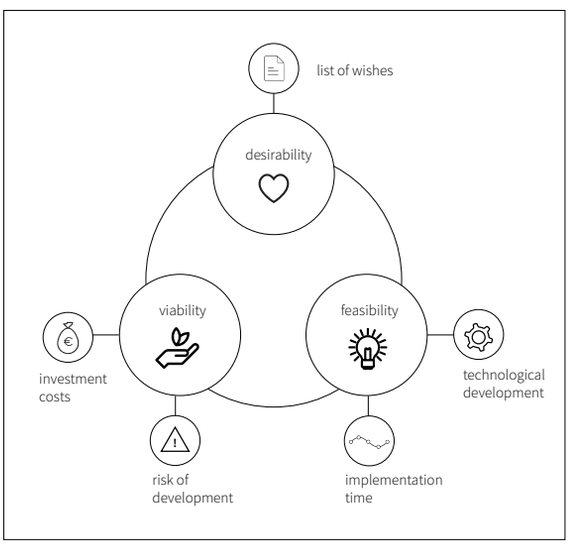


Figure 67. The test criteria for desirability, feasibility and viability to score the design proposals upon.

In figure 68 the scores for each proposal are visualized. Most desirable proposal is Bitstory as this proposal meets most of the wishes. However, Bitstory is the least feasible and viable since the proposal is most likely to require a lot of technological development and therefore can have high costs. The most feasible proposal is Whats-Upp. Yet, this proposal is less viable since their is a higher risk in development with privacy regulation becoming more of an issue when using a public app like WhatsApp. Mims scores on average on all three categories and could therefore be the most safe option to continue with. A complete overview of the results of scoring the proposals is found in Appendix P.

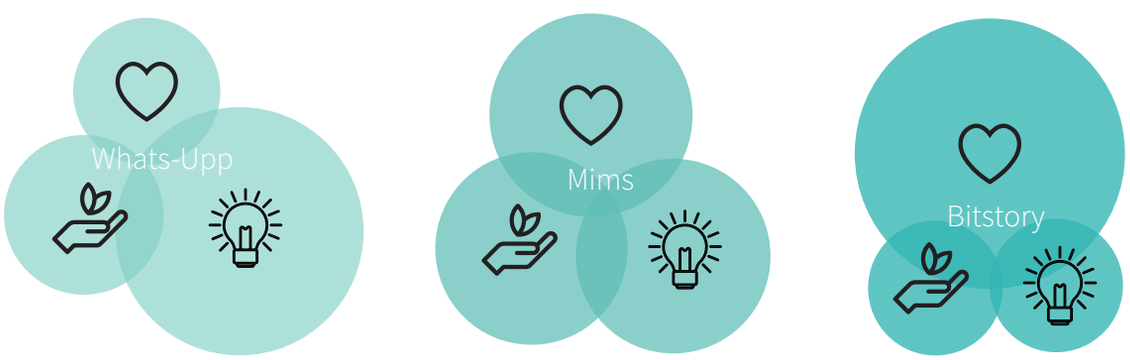


Figure 68. The scores for each of the design proposals on desirability, feasibility and viability visualized by circles. A large circle represents a high score.

Choice of proposal

For making a final choice of proposal the company was asked to speak out their preference. In a meeting with the company's CEO and the company's supervisor of this project, the three proposals were presented and discussed. In general, the company was very enthusiastic about the idea of a digital system that uses pictures and video's to quickly and effectively capture, share and reflect upon information. Especially since they didn't yet work with pictures and video's in their caregiving processes. Concerning the proposals the company had a high preference for both Whats-Upp and Bitstory. They liked the proposal of Whats-Upp because of its low-threshold: easy to develop and quickly implemented. But they were most amazed by the idea of developing their own digital system like Bitstory. Such a solution fits best with their desire to develop a new and innovative technological solution.

However, they are aware that the proposal of Bitstory will require high investments and therefore carries a higher risk. They most likely would have to start a cooperation with other parties to realize such a solution. Therefore, the company wants to do another test, but this time with more parents, to retrieve more results and feedback on the idea and generate proof of success to present to possible other parties to convince them of Bitstory and to cooperate. This second test will take the same set-up as the first quick test by working with WhatsApp, but with more parents participating over a longer period of time and a more detailed test plan to test various parts of the proposal. Results will not only be used to validate the design but also to optimize Bitstory. Yet, if the test results show a lot of barriers, the proposal should be changed. Or it may even be considered to continue with one of the other two proposals.

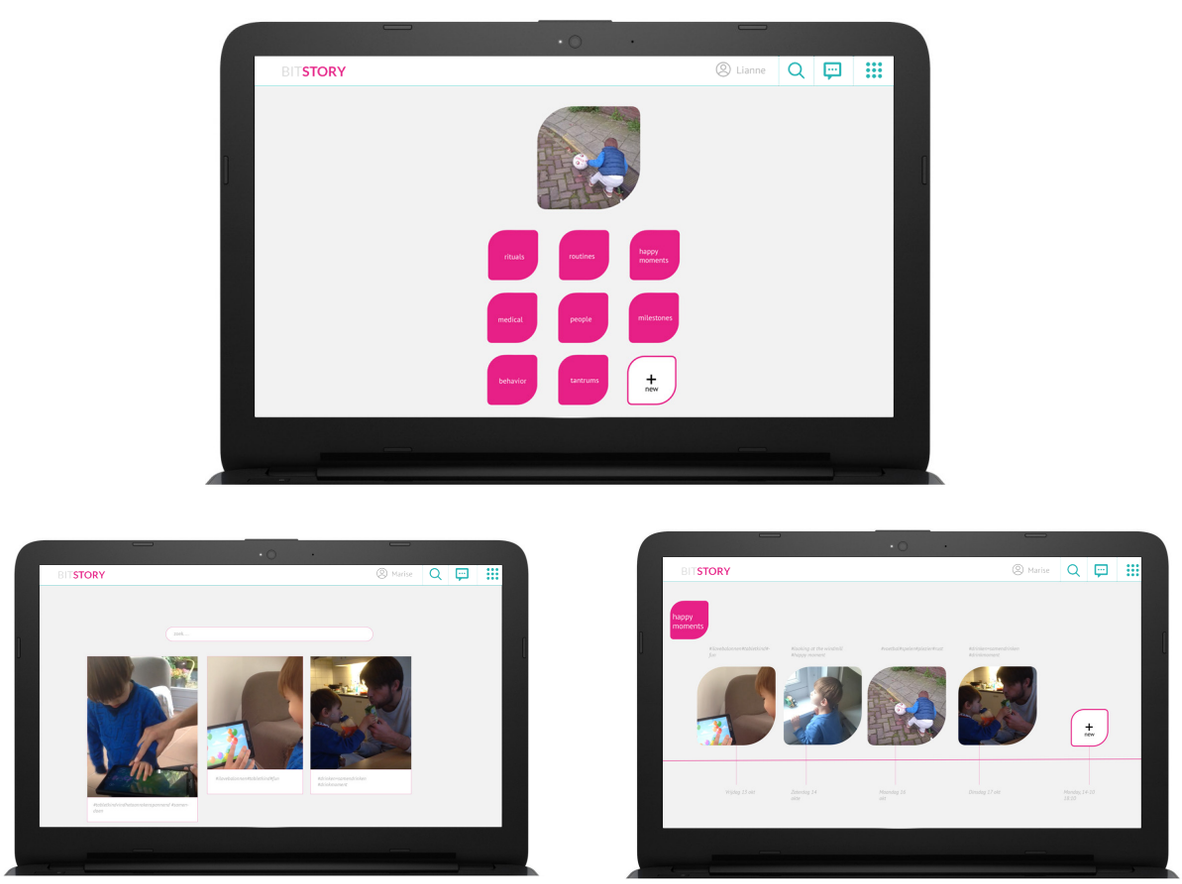


Figure 69. Various screens from the chosen design proposal Bitstory.

Conclusion

The three design proposals were presented to the company. To support making a choice, each proposal was scored on desirability (using the list of wishes), feasibility (looking at technological development and implementation time) and viability (possible risks and investment costs). The choice was made for the design proposal of Bitstory, a new designed digital system to easily store, structure and share visual information with others.

Design validation

What is the goal of this test?
What is the set-up of the test?
What do parents think of the idea?
What are improvements for the final design system?

Proof of proposal

Together with the company, the design proposal Bitstory was chosen to continue with. Bitstory will be a new digital system designed by De Buitenwereld that allows parents to capture and store all important information about their autistic child in a visually appealing, greatly structured and secure place. But before detailing Bitstory any further, the company wanted to do a second test, much like the quick test, to validate the idea with more parents, to retrieve proof of the success of the idea and to gain more results to optimize Bitstory. For this second test, almost the same approach as for the quick test was chosen since this was a great way to test the principle of the idea: exchanging information in pictures, video's and hashtags in WhatsApp with others of whom more understanding is desired. However, there are some changes for this test: more parents will participate, more detailed instructions will be given, a longer testing time is set, a variety of others of whom understanding is desired are chosen to participate and an extended interview is planned with the parents afterwards. Each of the steps for setting up the test required making various types of materials (figure 70).

Test plan

In this test three parts related to Bitstory are tested. First, the instructions on use: are they clear? Second is usage of the system: what are barriers during capturing information, working with hashtags, and in communicating with others? The third is enhancement of understanding: do parents feel more understood by others after the test? As this test solely focusses on testing these three things, details such as the look of Bitstory are left out. At the start of the test, parents were asked to choose others of whom they desired more understanding. They had to invite one or multiple others to participate in the test and create a WhatsApp group-chat with them. The project designer would not be included in the group-chat so that a trustful and objective environment would be created. To be able to test a growth in enhancement of understanding, it was chosen to take two weeks in which parents would exchange information with their chosen others. During the test the project designer gave instructions and feedback via WhatsApp to the parents. After the test, an interview of about 1.5 hours with each parent took place with questions regarding the three test parts.

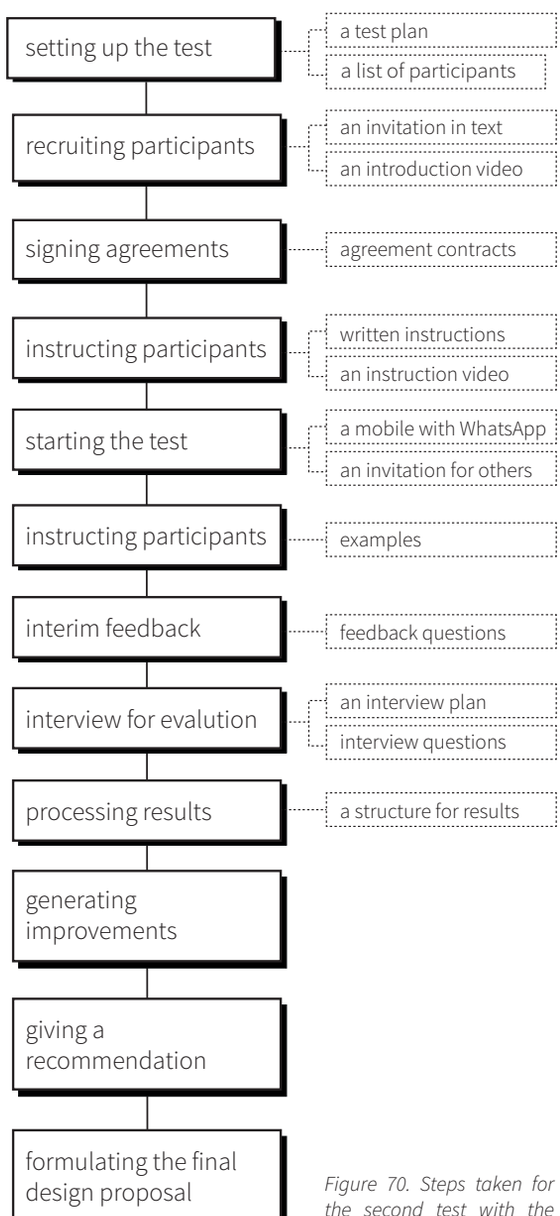


Figure 70. Steps taken for the second test with the materials that had to be created.

Starting the test

New participants had to be recruited for this test. The goal was to get at least about seven parents of autistic children (aged 4-12) to participate. An invitation was written and sent out via various social media to reach a broad public. About 20 parents responded to the invitation and were sent a first video created by the project designer. This video visually explained the purpose and (rough) set-up of the test (figure 72). After parents watched the first video, they were sent a contract in which they had to agree upon some terms that were drawn up considering use of the results, privacy, etc. Eight parents agreed and signed the contract. These parents were sent a second video with more detailed instructions (figure 73). This video explained the use of WhatsApp, how to work with hashtags, and it gave examples of situations that could be captured in pictures or video. Each parent was called by the project designer before starting the test to discuss which other(s) they would choose for participation in the test with them. As shown in figure 71, one parent decided to use an existing WhatsApp group-chat with nine family members. Others decided to choose a specialist or (close) relative.

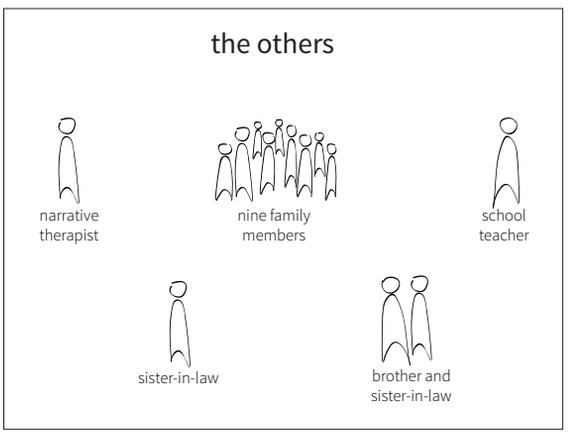


Figure 71. Overview of the others who participated in the test.

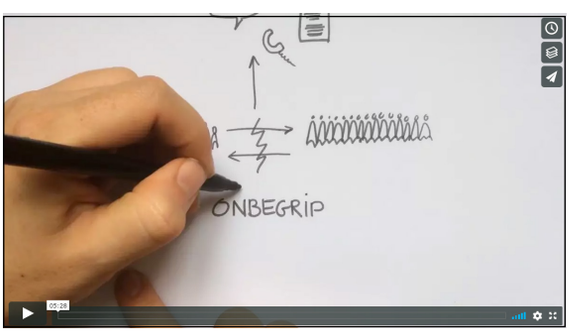


Figure 72. First video with an introduction to the test.

Figure 73. Second video with more detailed instructions about the test.

Use of results

Eight parents started the test but only five parents managed to complete the test for the entire two weeks and do a final interview. The reasons for some of the parents to have to quit the test was because of illness or not having enough time to contribute as they had desired. Despite the decline in participants, lots of results were generated. Most of the results came from the interview but also some from the phone-calls before the start of the test and from the feedback moments during the test via WhatsApp. All results were noted down and structured into three categories: insights, barriers and opportunities. This structure of results can be found in Appendix Q. Figure 74 gives an example of results per category. After the interview, print-screens were made by the parents of parts of their group-chat and shared with the project designer. For each of the three test parts, conclusions were drawn based on the results. Results were used to generate improvements a to write a proposition describing how to continue with Bitstory.

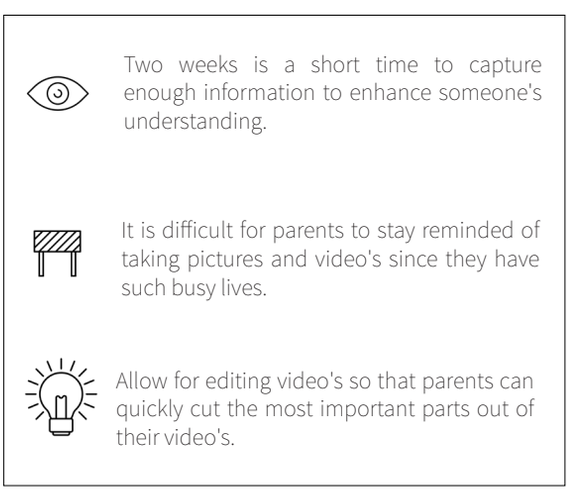


Figure 74. Examples of three results from the test.

Figure 75. Printscreen of an explanation by a parent to another.

Figure 76. Printscreen of the example of a picture with hashtags.

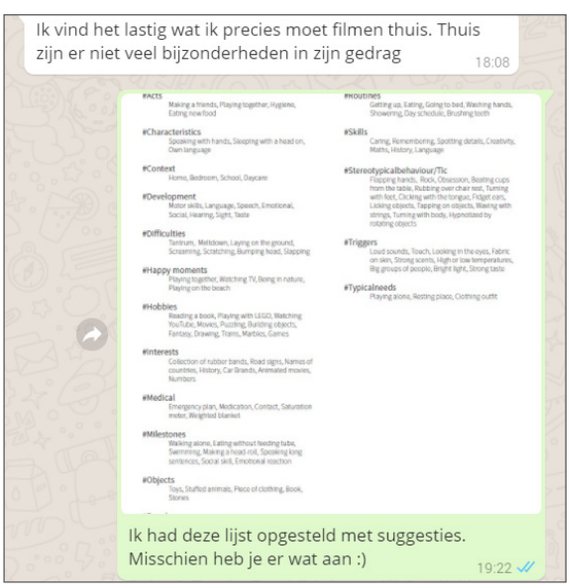


Figure 77. Printscreen of the suggestion list sent to the parents.

Instructions

At several moments during the test instructions were given. Before the start of the test two video's with instructions were sent. In these video's drawings were made to visualize the steps that had to be taken and a voice-over was added to explain what was shown. All parents were positive about both instruction video's. They thought the video's were very insightful and easy to understand. And they enjoyed the fact that it cost them only a few minutes to watch.

> *"I really enjoyed the video's. They were very clear and easy to follow. For us visualisations work best."*

All other instructions were given via WhatsApp. Each parent joined a separate WhatsApp chat with the project designer to receive further instructions, ask questions and gain feedback during the two weeks of testing. The first instruction via the chat was about how to invite their chosen others to participate in the test. Parents were sent a general invitation message that they could alter and send to the others. Some parents altered the invitation message a bit but all of them were pleased that there was a prepared text available for them to use. Some barriers considering the instructions were the fact that parents got some questions from others after they had sent the invitation, which they found hard to answer: What is expected from me? Why am I chosen for this test? What is going to be done with the test results?

> *"The invitation message was good but I altered it a bit to make it more personal since I know them very well."*

The last bit of instructions via WhatsApp to the parents was by sending an example of a picture with hashtags (figure 76). All parents understood the example. However, there were parents that felt the need to send their pictures and video's first to the project designer before sending it to others as they felt a bit insecure if it were the right kind of pictures, video's and hashtags to send. Also, some parents struggled with what to capture in video or picture. To help them, a suggestion list with examples of situations was created and sent to them (figure 77). The parents found the suggestion list with examples very helpful.

> *"I have trouble thinking about what to capture on film."*

Usage

Considering usage it was important to discover what supported or hindered parents in capturing, labelling and sharing information with others. Several barriers were found in relation to WhatsApp. For example, when a message containing a video with hashtags was copied and sent to another person in a chat, the hashtags would get lost and had to be rewritten. However, Bitstory will not be using WhatsApp for the design system, so most of these barriers can be neglected. But the barriers, and also positive elements of WhatsApp, were used to generate improvements for the design system.

Regarding capturing information, some parents had difficulties capturing their child properly on camera. Some children were aware of the camera and most of them didn't like being filmed. What parents feared most was that their child may act differently when it would be filmed and therefore the footage would not be as trustworthy as desired. Especially in capturing the more difficult moments like a tantrum, parents struggled. But when a picture or video was made of something positive the children didn't mind that a picture or video was taken. Giving a clear explanation upfront to the children helped them accept and understand what was going on.

> *"I am really scared to film him. I know he hates it when I film him and he doesn't want to be filmed."*

Parents had different opinions on the use of hashtags. Some parents thought it was a great idea, even though they didn't know the phenomena. They liked the fact that it was about using only words as a small message. But other parents mentioned they felt awkward using hashtags since it wasn't common to do in WhatsApp so they would rather add little sentences of text.

> *"Hashtags is something that is not common in WhatsApp. I noticed I prefer explaining what is seen in a few lines of text."*

Sharing their information with others had some barriers for some parents. A few parents mentioned that they struggled with determining how much footage to send and at what time because they didn't want to come across annoying. Also some parents mentioned they felt a bit upset if people didn't respond to their video or picture as quickly as hoped for. But most parents didn't encounter problems for sharing information when they had made the goal of the test clear to the others.

> *"I noticed that his therapist only responded to my video's if it was related to her job. So I only sent her pictures and video's related to the therapy and his development and that went really well."*

Figure 78. Printscreen of the reaction of others on the footage.

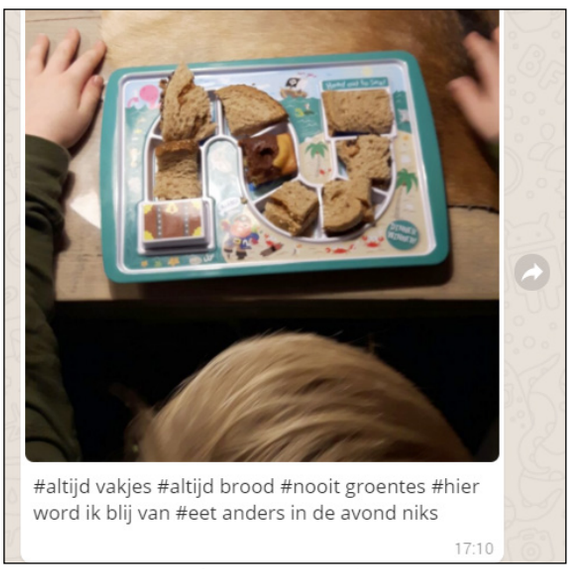


Figure 79. Printscreen of a picture sent by the parents.

Figure 80. Printscreen of a video sent by the parents.

Enhancement of understanding

The last thing to test was whether sharing information via pictures and video's would enhance understanding. This was tested by asking the parents if they felt more understood after the test was finished. Two out of five parents stated they felt a significant increase in understanding. One of them was a parent who did the test with his son's narrative therapist. During the test the parent captured his son, who has difficulties speaking, saying some quite long sentences on video. He shared this video with the therapist which resulted in a great moment of understanding and they talked about it more in their next therapy session (figure 81).

Figure 81. Printscreen of the conversation with the therapist.

Figure 82. Printscreen of a question that arose from another.

The other who noticed quite a big change in understanding, were the parents who tested with a group of nine family members. In this group-chat both parents shared lots of pictures and video's about their autistic son. They got lots of supportive responses and started great discussions. The following example illustrates a change in understanding: before the test both parents had to explain family members that events, such as birthday parties, were not suitable for their son due to over-stimulation. The family often didn't really understand why they wouldn't come and would get upset. After some days along the test, another birthday party with the family came up. But this time, after some days of testing, the family responded completely differently when the parents told them they wouldn't make it. They told the parents that it was okay and that they understood why. For the parents this was a great moment. They felt more understood and experienced the benefit of not having to explain themselves again.

> *"This test was a great moment for my family to start understanding our situation and child better. Lots of great discussions were going on in the chat."*

The three other parents experienced less understanding. Yet they seemed to have clear reasons why: not enough time, not capable of capturing the right footage, and struggling in communicating with the others. Concerning tine, all parents mentioned that enhancing someone's understanding requires lots of time. They felt that two weeks was too short to do so. The people they felt most understood by were involved for over at least a couple of years. For one parent, the most important reason that enhancement was difficult was due to the fact that she couldn't capture what autism meant for her in a picture or video since these were more 'invisible' things (paperwork, appointments, etc.). Yet she was positive that if she got more time and guidance, this solution would be a great way to help her visualize and explain her and her son's life to others.

> *"For me understanding is also about the invisible things. All the appointments, arrangements and all the paper work I have to do."*

Although there were only two out of five parents stating that this approach really enhanced understanding, all parents agreed on the potential of this solution to enhance someone's understanding. But they would want to have more time to capture and share the information, and receive more guidance in the process.

Improvements

With the insights, barriers and opportunities from the test, lots of improvements for Bitstory were generated. Most of these improvements could be directly added as sub-functions or components to the system. For example, some parents mentioned that filming cost them quite a lot of battery power (a barrier) which led to the improvement to add an external battery as an component to the system (figure 83). Some improvements were more challenging to integrate within the system. For example, the improvement to make the invisible things, such as agenda appointments and arrangement of paperwork, more visible. This challenge was met by including examples of invisible things, e.g. take a picture of the agenda or paperwork, to a list of suggestions for parents on what to capture on video or picture. Not all improvements were added to the system. The peer-2-peer connection that some parents desired required quite some time to figure out how to implement this sub-function. Considering a limited time for this project this improvement was added as a recommendation for Bitstory to be considered if the project continues (see chapter Recommendations).

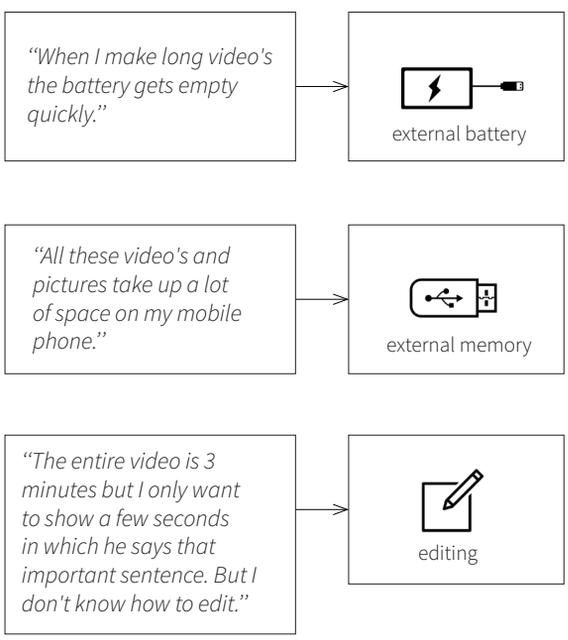


Figure 83. Quotes from parents from the test that were used to create improvements for Bitstory.

Proposition

The main reason for this design validation was to gain more results that would support the choice for Bitstory and to retrieve feedback in order to optimize the design. In the test, three things were validated: instructions, usage and enhancement of understanding. Based on the results, a proposition is drawn up on how to continue. For the instructions, almost all comments were positive. Video's as a tool for instructing should be kept and additions such as the list of examples need to be added to the system. Concerning usage, it is difficult to draw conclusions as WhatsApp was used to test the principle of the proposal whereas Bitstory will not be using WhatsApp but a newly designed digital program. Despite the fact that only two out of five parents experienced enhancement of understanding, their reasons were reasonable to such an extend that they can be met when improvements are made to the system: more time for capturing and sharing information and more guidance in the process. What must be noted is that only five families participated in this test. This is a rather small amount to confidently state that Bitstory is going to work. As a recommendation, more testing with a new and more detailed prototype and with more parents should be done. Overall, it can be concluded that the idea of Bitstory in itself is promising as all parents were enthusiastic about having a digital tool with all the important information they need at hand to show to and share with others, anytime and anywhere. With the new improvements resulting from the test, Bitstory will be optimized in such a way that it is a promising proposal to continue with in the embodiment.

Conclusion

When making the choice for Bitstory, the company proposed to do another test with more parents to validate the basic principle of the system, generate proof of success, and use the results to make improvements. In this test five parents participated. They had to share information in pictures, video's and hashtags via WhatsApp with another person for over two weeks to enhance their understanding. Three things were tested: the instructions, usage and enhancement of understanding. With the results improvements were generated such as adding an external battery as a tool to the system. Overall, results indicated that Bitstory has great potential for success and thus should be continued with.

Final design proposal

What is included in the system?
What are the main design parts?
How do these parts interact with the stakeholders?
How do these parts connect into one system?

Making system choices

As a result of the design validation, improvements for Bitstory were generated which led to formulating sub-functions and components for the system. In this final design proposal boundaries are set for the design system by deciding on the kind of design parts are included so that the entire system can be more easily defined and detailed in the embodiment phase. First, to get a grip on which sub-functions and components are included in the system, an overview is created of the six main functions. Sub-functions and design components, which were generated throughout the conceptualization phase, are added at the main function they fit. For example, the main functions of the tracker, which is the part of the system that makes sure information is going into the system and keeps track of progress, gets the design component of a stepwise guide that contains instructions on how to add information into the system and keep track (figure 84). Next, this overview is used to discover the main design parts of Bitstory and to define whether these parts are digital or physical.

Three design parts

Looking at the overview of the main functions of Bitstory and seeing the diversity of sub-functions and components, it becomes apparent that the system consists of more than one design part. For example, the instruction booklet, as part of the main function of the explainer, is a physical design, whereas the website as part of the presenter, is a digital design, meaning that both cannot be combined into on part which ultimately results in two parts. To discover more parts and see if there is a connection between parts, the design components and sub-functions are reviewed and grouped resulting into three main design parts (figure 89).

One main design part is the Bitstory website. This part focusses on the design of a website which enables parents to store and structure their information digitally. The website should meet all the sub-functions from the overview. For example, the sub-function of having a responsive website so that parents can easily access the website on their tablet, smart-phone and computer.

The second main part of the design system is the introduction package. This package shall contain all the necessary components for parents to get started with using the Bitstory system. In comparison to the website, this part consists only of physical objects such as the instruction booklet and external battery.

The last main design part is the implementation toolkit. This toolkit shall be handed over to the trajectory supervisors of De Buitenwereld. In this toolkit the supervisors will find tools to efficiently and successfully implement the Bitstory system. The toolkit contains both digital (Trello for setting online goals) and physical components (a guide) to support effective use of Bitstory in their current caregiving processes.

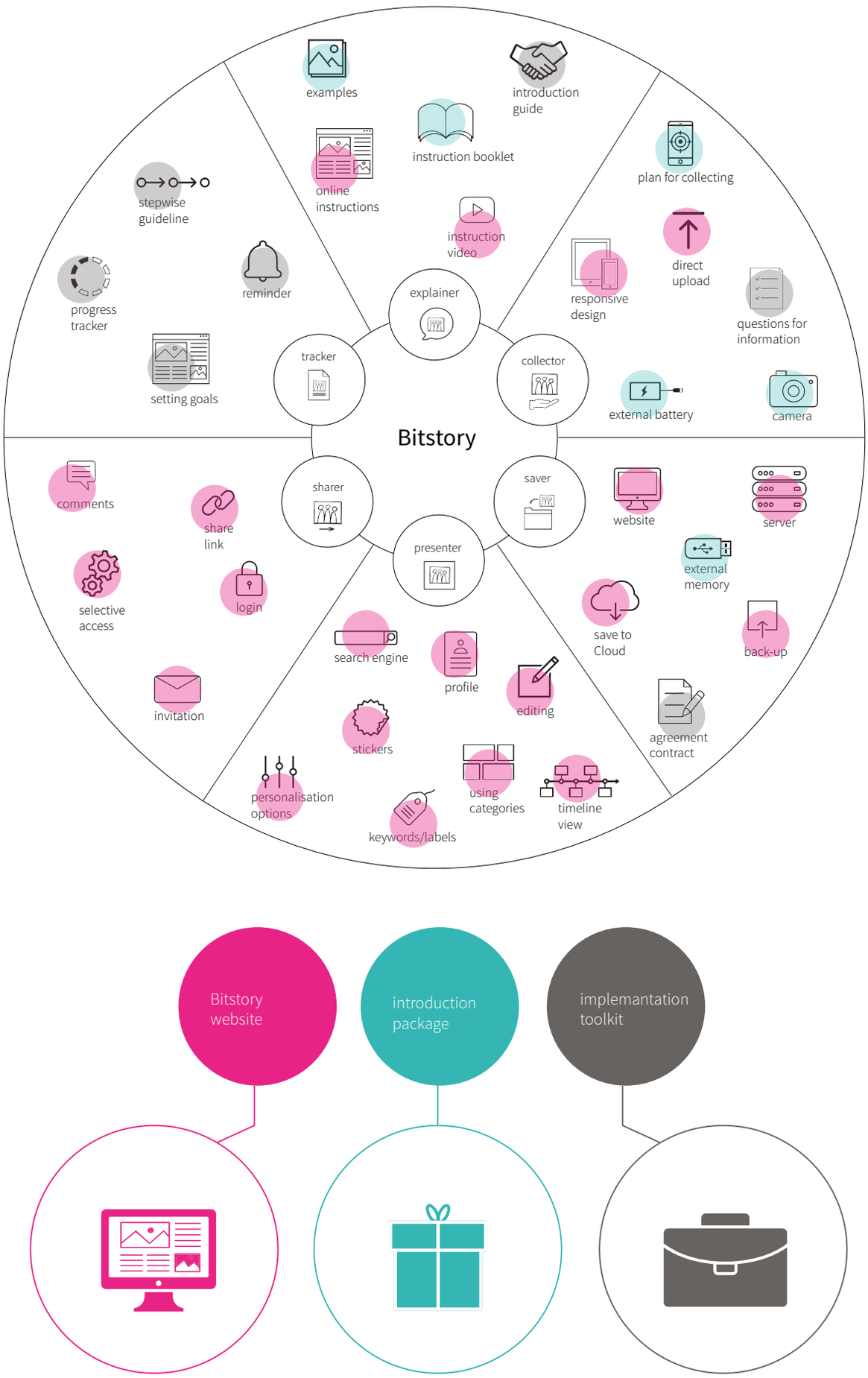


Figure 84.Overview of the sub-functions and design components per main function of the system, combined into three main design parts of the Bitstory system.

System (inter)actions

Bitstory is a design system that consists of three main design parts. Each part of the system interacts differently with the three stakeholders as shown in figure 85. The arrows in the figure represent interactions and actions. Starting with the one action for the introduction package, it is handed over to the parents and contains instructions and tools for them to get started. After the package is handed over there are no other interactions or actions via this part with other stakeholders. Then there is the implementation toolkit with one action which is handing over of the toolkit to the trajectory supervisor. The other arrow indicates an ongoing interaction between the trajectory supervisor and the parents as the toolkit contains tools that are used during the meetings between supervisor and parents. At last, there is the Bitstory website. This part contains the most actions and interactions with all three stakeholders. Each stakeholder has its own actions with this design part and via the website, parents interact with the trajectory supervisor and the others. This system overview of (inter)actions shows that the focus of the design system is mainly on the Bitstory website, whereas the implementation toolkit and introduction package are more supportive parts to facilitate effective use of the Bistory system.

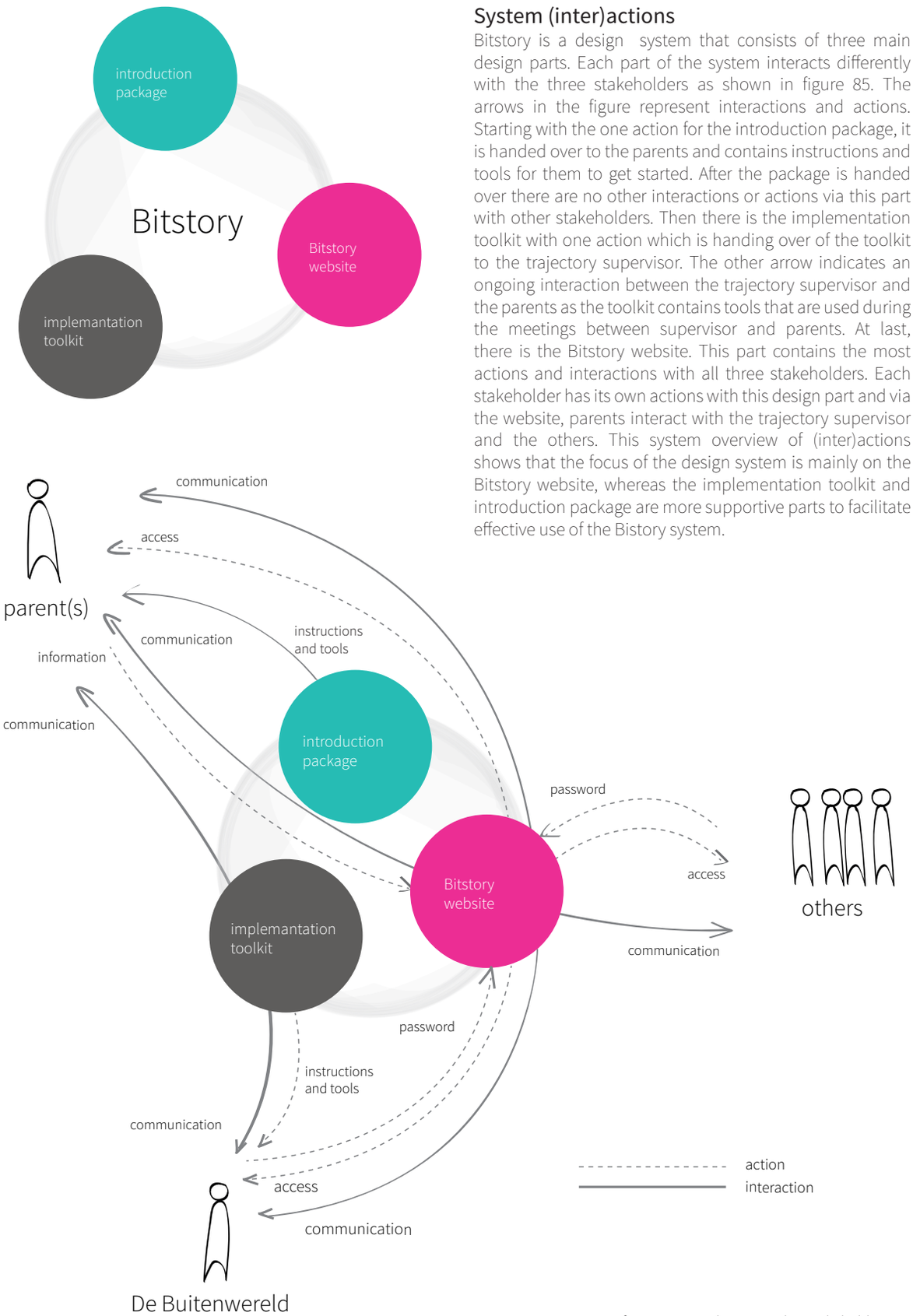


Figure 85. Overview of interactions between the stakeholders and the three main design parts of the system.

Digital museum analogy

One final step before rounding of the conceptualization phase is taken by creating a design analogy. A design analogy is a way to help others understand a complex system like Bitstory by using an analogy that refers to a known concept. Such a common concept or story should relate, metaphorically, to the essence of the Bitstory system. Not only is a design analogy useful for explaining the concept of Bitstory, but it can also evoke ideas in the design process of defining the looks for the design parts. Each of the three main design parts are all part of the Bitstory system. Therefore they need to fit together as one complete design system, not only in terms of functioning but also how they look. The analogy can help to find this connection between the parts.

For defining a fitting analogy for Bitstory, words and sentences associated with the design system were noted down. As a result, a connection was found between a few words which are highlighted in figure 86. These words combined seem to relate to one common concept: a museum. A museum is a place filled with precious things in which people can take look at various works of art while navigating through different rooms. By viewing the works of art the visitors get a chance to explore, learn and understand. To make this concept fit Bitstory it was chosen to formulate the design analogy of a digital museum. Bitstory is like a digital museum in which parents store, structure and display valuable information online. As the owners of the digital museum, the parents decide which information they expose and who they invite to gain access. How this analogy can be used in defining looks and a connection between the parts is further explored in the next phase.

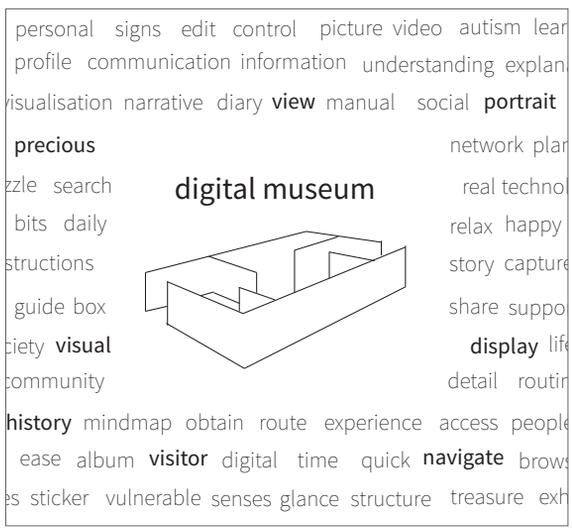


Figure 86. An analogy of Bitstory as a digital museum experience.

The Bitstory proposal

After brainstorming, sketching, prototyping and testing, one final idea was chosen, tested, improved and shaped into the final design proposal: Bitstory. Bitstory is a digital information visualisation system consisting of three main design parts: the Bitstory website for parents to collect and structure all the important information on and through which they can share their story with all others for a better understanding, an introduction package with tools and instructions for the parents to get started using Bitstory and an implementation toolkit for the trajectory supervisor of De Buitenwereld to successfully use and implement the system. In the embodiment each of these parts of Bitstory will be further defined and detailed so that in the end a complete design system is developed.

Conclusion

Using the results from the design validation, the proposal of Bitstory was further developed into a final proposal. The improvements generated from the test were translated into design components and sub-functions as part of Bitstory. By grouping these, three main design parts emerged: the Bitstory website on which the data in pictures and video's is stored and shared with others, an introduction package which is handed over to the parents and an implementation toolkit with tools for the trajectory supervisor to successfully implement Bitstory. Interactions of these parts with the three stakeholders were described and a design analogy of a digital museum was formulated as a design tool for the embodiment phase in which these three design parts are further defined and detailed.

Embodiment

In the embodiment phase each main design part of Bitstory, the Bitstory website, the introduction package and the implementation toolkit, is defined and detailed. First, a final choice is made on the kind of sub-parts that are included for each of the three main design parts. Then, a particular design style is chosen to establish a consistent look for all design parts. By making sketches and prototypes final designs are created. All three main parts are visualized to show how they can look, described on how they should function and their intended use. A user scenario shows how all three stakeholders, parents, trajectory supervisor and others of whom understanding is desired, interact with Bitstory. A possible future for Bitstory is given describing steps of development and estimations on costs and on the time it may take to realize the system. At last, a proposition is given for generating revenue by selling Bitstory as a methodology to other healthcare institutions that provide care to parents of autistic children. In this way they can implement Bitstory as a methodology in their caregiving processes to increase their quality of care and work more efficiently.

Design summary
What kind of transformation did the assignment make?
Is there a design style that can be used?
How can the design analogy be used?
How to detail each part of the system?

The Bitstory website
How can the website be best described?
How should the website look?
What is needed to make a website work?
How do the stakeholders interact with the website?

The introduction package
What is the goal of an introduction package?
How can the design style be applied to the products?
Which parts can be purchased?
How can it look like a gift?

The implementation toolkit
What do the supervisors bring to their meetings?
What kind of storycards are needed?
What kind of look should the toolkit have?
What kind of information should be in the guide?

Use scenario
At what moments in time is Bitstory used?
How is Bitstory used by the parents?
How is it used by the trajectory supervisor?
How is it used by others?

Future of Bitstory
What steps need to be taken to develop Bitstory?
What are the costs of realizing Bitstory?
What is the business model?
What are ways to generate revenue?

Design summary

What kind of transformation did the assignment make?
Is there a design style that can be used?
How can the design analogy be used?
How to detail each part of the system?

Recap

The project started with an assignment. This assignment was formulated based on preliminary research into the desires and needs of De Buitenwereld, and the parents. Next, explorations were done into different fields related to the assignment. This resulted in various analyses into the company's and parents needs, literature, technology and trends. The outcomes of the analyses supported the formulation of requirements and wishes for the system, and for a design direction. With a defined direction, ideation started. Lots of ideas were generated and reflected upon for making a selection. One idea was chosen to explore further more. This was the idea of using pictures and video's to quickly and easily capture and share information. By doing a quick test with one couple of parents and additional analyses, the idea transformed into one final idea for the design of a digital information visualisation system. Three varying design proposals were created based on this final idea. Each proposal, meeting the same system requirements, consisted of a different combination of system components which made them vary on desirability, feasibility and viability. After scoring and proposing the proposals to the company, a final choice was made for the design proposal of Bitstory. One final user test was done to validate and optimize the design to create the final design proposal of Bitstory which became the starting point of this embodiment phase.

Detailing process

In the embodiment phase, a detailing process starts in which all main parts and their sub-parts are further explored and defined. Each of the parts are detailed to a certain level so that the company can continue the project and possibly realize the system. The parts are detailed on look, function and use by sketching, making prototypes to test, and if needed doing more research. The looks for the parts are about defining materials, size, lay-out and colours. Functions describe how each part should perform. Usage is about the intended use of each part by all stakeholders who interact with the design system. The final steps in the detailing process are creating a user scenario to visualize the intended use of all parts, and doing an estimation on the future of Bitstory by looking at steps and time of development, and possible costs and revenue streams.

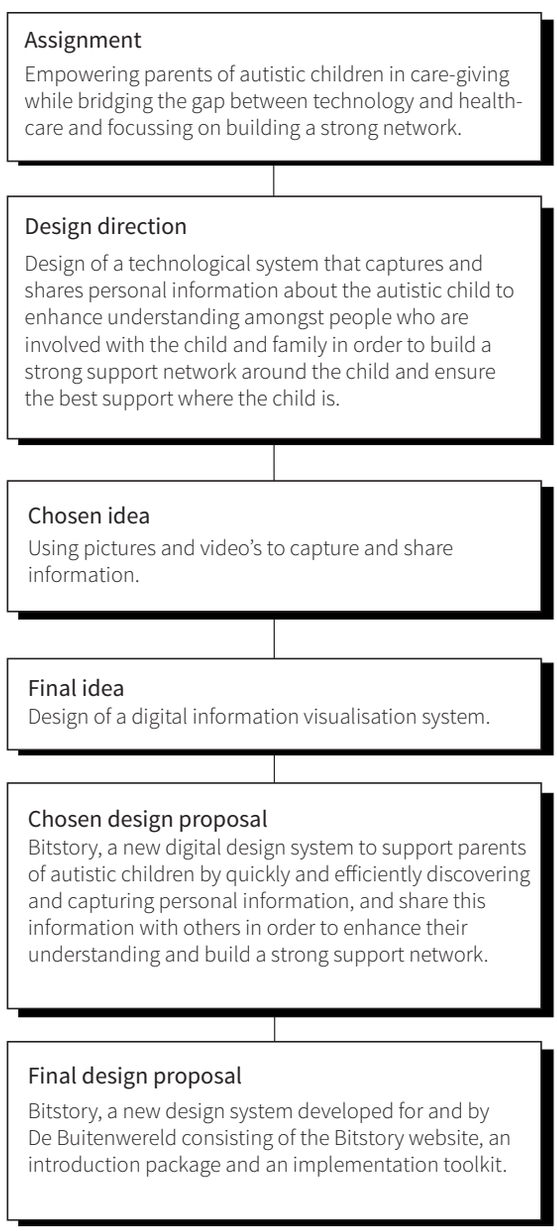


Figure 87. Overview of the transformation of the assignment into a final design proposal.

Creating sub-parts

Detailing each of the main design parts requires to define their sub-parts. To do so, the overview of sub-functions and design components, which was created for each of the six main functions of the system in the final design proposal, was used. The sub-functions and components which were grouped to create the three main design part, were reviewed, compared and combined to create various sub-parts. For example, the two sub-functions 'examples of pictures and video's' and 'plan for collecting data' were combined into one sub-part: the introduction booklet as part of the introduction package. Figure 88 shows the definite sub-parts per main design part. In the next steps, these sub-parts need to be further defined by deciding if they are newly designed or purchased, and if they are digital of physical designs.

Defining sub-parts

The first main design part, the Bitstory website, consists of only one sub-part which is the website itself. This part is used to store, structure and share the information, and is a new digital design. The introduction package has four sub-parts: a package containing an introduction booklet with instructions for parents, and an external battery and USB stick which are tools to facilitate the process of capturing information. Except for the introduction booklet, all parts are purchased. The implementation toolkit, designed for the trajectory supervisors of the company, consists of three sub-parts: a case in which their can carry the tools they need in their client meetings, a guide with all the necessary information about the Bitstory system and a set of storycards. These are cards containing questions and images to trigger thoughts of parents to quickly discover important information, and which is used to determine what can be captured in pictures and video's for the Bitstory website. Both the guide and storycards are newly designed. Only the case is purchased. All purchased products of the Bitstory system are customized following the design style of the company to create a coherent system.

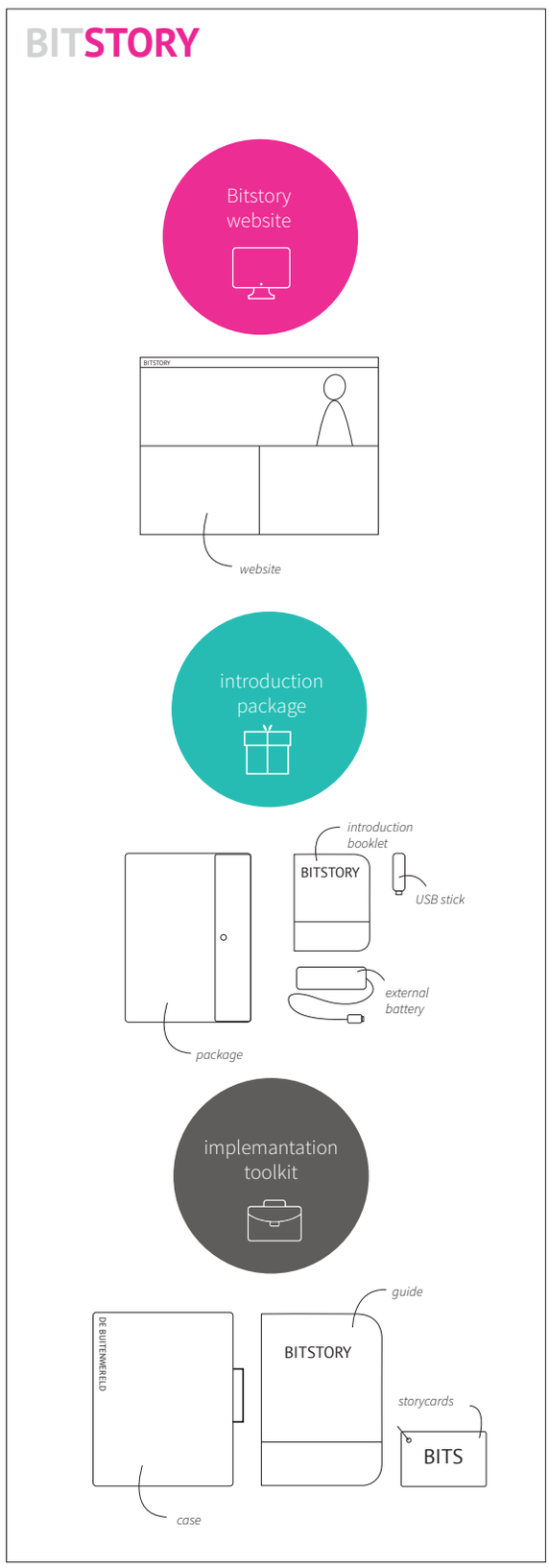


Figure 88. The three main design parts and their sub-parts.

Design style

Products and services designed by or for a company or brand usually follow a design style. Such a style has particular characteristics that make the products or services recognizable for its customers. Although De Buitenwereld is at the start of developing their own products, they have established a design style for their products. This style can be found in their documents, folders, and booklets and also on their own website. Figure 89 gives an impression of their established design style showing their main colours, fonts, style of images and the logo's they use. For Bitstory, this style is used for the looks of both the physical and digital design parts.

Figure 89. Elements of the design style of De Buitenwereld.

Using the design analogy

In the previous phase, the analogy of a digital museum was formulated as a tool for the detailing process. The concept of a (digital) museum relates to Bitstory: holding valuable information in a safe and secure place, in which others who are invited can carefully take a look. The digital museum concept was, besides creating a story, mainly used for thinking about functions and the look for the Bitstory website. One idea that arose from a brainstorm using the analogy was to create a section on the website that holds all information in pictures and video's in one place, like the archive of a museum. Archives are clearly structured so that each piece can be easily found back. To make this information in pictures and video's more tangible, another idea arose to name each described picture or video that is uploaded to the website a 'bit'. This also explains the name Bitstory: each bit tells a story. Another idea was to build a section on the website in which the parents can 'invite' people from their network to view their Bitstory, just like an exhibition in a museum. Figure 90 shows how such ideas were applied in designing the look, or lay-out, for the Bitstory website.

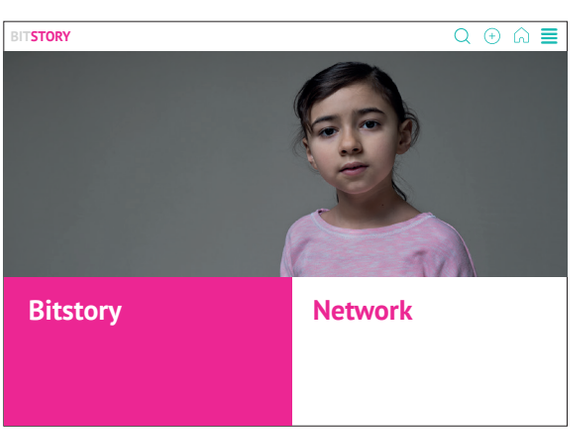


Figure 90. Creating a division into an archive and a network section on the Bitstory website as a result of the brainstorm using the analogy of a digital museum.

Figure 91. Sketches and prototypes that were made to discover the best designs.

An iterative process

Describing and defining the design parts on look, function and usage is a simultaneous and intertwined process, meaning that one cannot be defined without defining the other two at the same time. For example, defining the look of a website requires to think about usage and functions that must be met. This all makes detailing not only intertwined but also an iterative process. Lots of sketches and prototypes were made in this embodiment phase to discover the best fit for look, usage and function for all design parts (figure 91). In the next chapters, the final choices for each design part are presented and described.

From system to methodology

Towards the end of the project it became apparent that Bitstory is not one product or service, but rather a complete design system consisting of multiple tools to be used. Therefore this Bitstory system can be seen as a methodology as it is a collection of methods. So it was decided to transform the Bitstory system into the Bitstory methodology. Describing Bitstory as a methodology makes it easier to explain others, especially those who might be interested to apply the Bitstory methodology in their own caregiving processes, about Bitstory and why it should be implemented in care to support parents of autistic children.

Conclusion

A design summary was created to describe the various processes of the embodiment phase in short. First, a recap on the transformation of the initial assignment into the final design proposal is given. Then it is described how each sub-part of the three main design parts was defined. Next, how both the design style from the company and the design analogy of the digital museum were used as a design tool during detailing is described. Another aspect that reoccurred in the embodiment were the various design iterations that were done to make the best design choices. Throughout the detailing process, Bitstory transformed from a digital information visualisation system into a methodology, that consists of various digital and physical tools, designed for caregivers to use in their caregiving processes to support the parents of autistic children.

The Bitstory website

How can the website be best described?
How should the website look?
What is needed to make a website work?
How do the stakeholders interact with website?

Description

The Bitstory website is the foundation of the Bitstory methodology. The other parts are mainly tools and services to support use of the website. The website works with an account for parents to log in and access their own personal profile. In here, all important information about the autistic child is stored, structured and visualised so that the parents can easily access that information during moments of enhancing understanding with others. With the information being mainly pictures and video's (bits) most of the website is kept very visual. The lay-out of the pages are kept clean and simple to make navigating through the website a pleasant experience. Where possible, images or icons are used instead of text. This also makes sharing and showing bits to others more fun to do as it requires no long explanations or lots of text for others to read, only watching. Working mainly visual also most likely motivates the others to actually watch and empathize with the information, thus increasing changes of better understanding the information.

The website has three main sections. The first section is 'Our profile' in which general information on all direct family members who are involved can be found. Second is 'Our Bitstory' which is the archive of all the bits parents collect. In here, parents can also upload new bits. The 'Our world' is the section in which the parents share bits with others from their network. For example, an aunt might want to take the autistic child to the beach. The parents select the bits related to this activity (what to bring and what to do on the beach) and send them to the aunt by creating a link that invites the aunt to view the bits. In 'Our world' there is also an overview of which bits have been shared with whom at what time so that parents can keep track of what has been shared and when. To make sure parents can access their information anywhere and anytime, the website is made compatible and responsive to multiple digital devices e.g. computers, tablets and mobile phones. Figure 92 shows the home-screen of the Bitstory website on various devices.

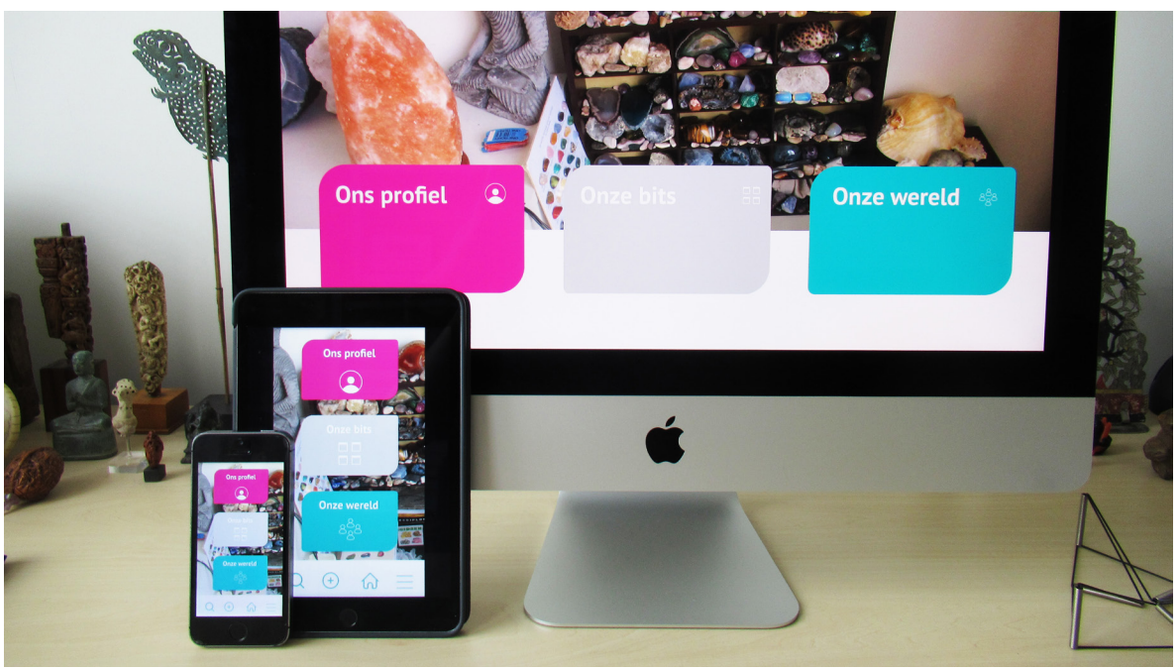


Figure 92. The homepage of the Bitstory website on multiple digital devices.

Look

In the world of web-design, the term UI design is often used and refers to 'user interface' design. The Bitstory website is an interface that users interact with on their digital device. The design for the website started with defining interactions. This allowed to discover which options and what kind of web-pages are needed for the website. The next step was trying out different lay-outs for the web-pages by making lots of sketches and using the design style of the company. To support this design process, the website of De Buitenwereld was used as a guidance.

For the lay-out, various structures, buttons and icons were explored to discover what works best visually. To support making choices, the design vision of effortlessness was kept in mind to choose for the options that would make navigation through the website go as effortlessly as possible. How this is reflected in the web-design is for example shown in the use of little options on each page so that parents do not feel overwhelmed. Together with the company and fellow design students different types of lay-outs for the web-pages were evaluated and altered to arrive at a final proposed look. Figure 93 and 94 show two web-pages for the website. More are found in Appendix R.

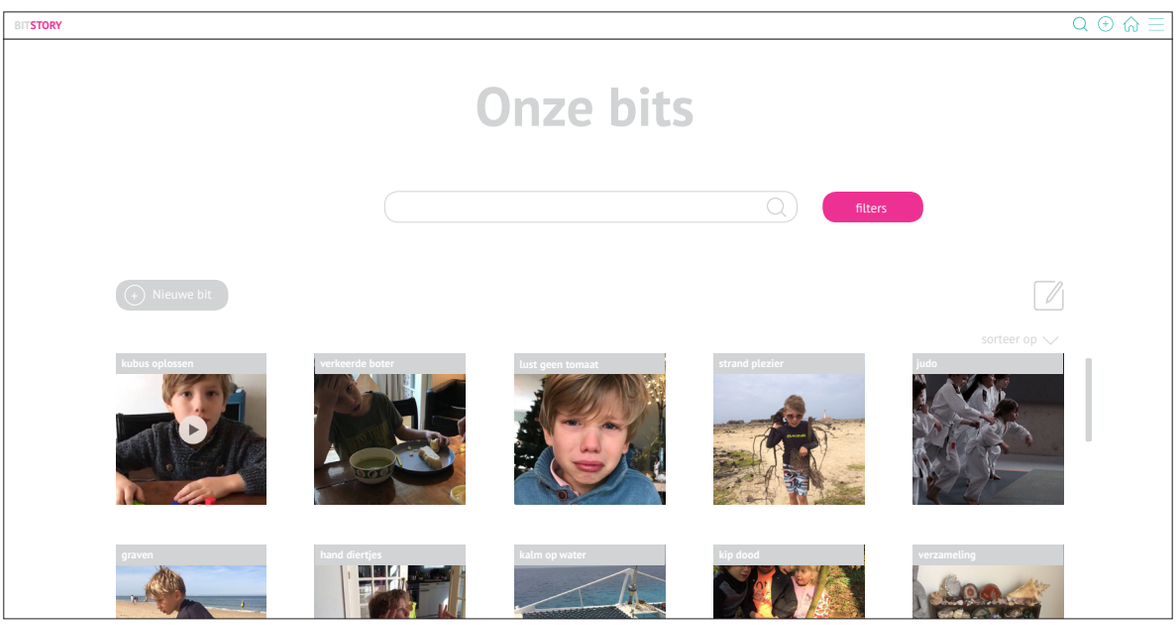


Figure 93. The lay-out for the webpage of the 'Our bitstory' section.

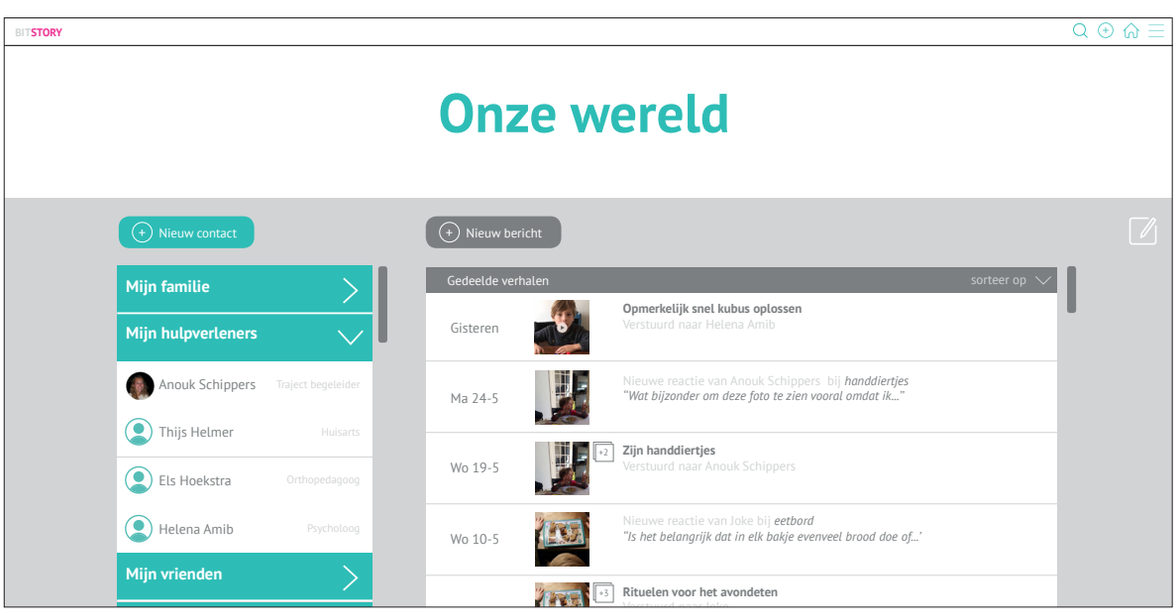


Figure 94. The lay-out of the webpage for the 'Our world' section.

Functions

To define performance, it was explored what is needed to design and create a website, and to keep a website up and running. In web-design a division is made in front- and back-end design. The front-end of a website is what the users can see and use, so the actual look of the website. The back-end of the website is the part that is unseen by the users, yet contains everything to make sure the website looks and works as intended. Defining performance for both front- and back-end design was done by exploring use, looking at the program of requirements and doing analysis into website design.

The moment lay-out of the website is designed, the front-end, the back-end design starts: a programmer starts building the website by writing in code such as HTML. In code, programmers not only tell the computer how the website should look e.g. which button should be put where, but also how it should function e.g. uploading bits, editing video's and sharing data with others.

Aside from the code that is needed, there is a server on which the website runs and is organized by a web-host. Also a domain name is required which determines the website's link (Wong, 2018). For the Bitstory website to perform as intended, there must be an internet connection through either WiFi, Ethernet or 4G. Otherwise it is not possible to use the website. Another important factor relating to performance of the website is assuring privacy. As the website works with personal and private information, it is important that this information is well protected. Therefore the choice of web-host should be carefully made and lots of steps when programming the website should be taken to make sure the data is safely stored. To support this, the website needs a login page so that parents, and others who get access, can only enter Bitstory through use of a password.

After exploring both front- and back-end, a list of functions was created. Functions were defined such as 'having a search engine', 'allowing access to mobile camera when uploading a bit', and 'a maximum upload of 200 MB per bit'. These functions for front-end and back-end design were not only used for designing the lay-out of the web-pages, but also for estimating the future of Bitstory by defining steps of development for the website.

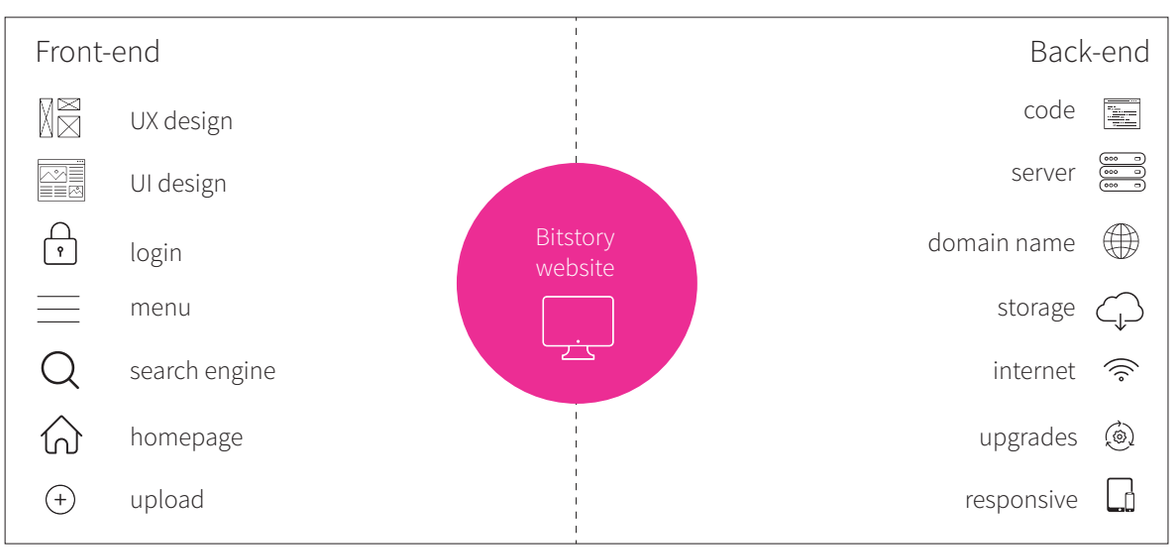


Figure 95. A selection of front- and back-end functions for the Bitstory website.

Usage

The main users of the Bitstory website are the parents. When defining the design on intended use, it was taken into account that there are different types of parents with different needs concerning the website. These differences amongst parents has been described in the exploration phase (four parenting types). Using this knowledge in relation to use of the website, some parents would need for instance lots of information about the website before wanting to start using it, while other parents would just start trying out the website without needing any. Thinking about these differences in needs led to making particular design choices. For example, a page with information on the system was added to the website, yet located under the menu button so that the page isn't really visible for everyone, only for those who seek for it (figure 96). Aside from the parents interacting with the website, there are two other stakeholders: the trajectory supervisor and the selected others by the parents. For them to be able to interact with the website, parents must invite them so that they can get access to Bitstory with their own user-name and password. It may be that the parents decide not to provide access, but rather prefer showing bits on their digital device during a moment of understanding. To support this kind of use, it is best if parents make an application of the website's link on their digital device so that they can quickly access the website (figure 97).

Figure 96. The homepage with information located under the menu button.

Conclusion

The Bitstory website is the foundation of the Bitstory methodology. To start designing the website, functions were formulated by looking at intended use of the website by its users, using the program of requirements and doing explorations into website design. This last step resulted in knowledge about front-end design, what is seen by the users, and back-end design, what is unseen. These functions supported the process of designing a final look for the website which was done by sketching and testing different types of lay-outs that fitted the design style.

Figure 97. On a mobile device an icon can be created which provides access to the Bitstory website by clicking on it.

The introduction package

What is the goal of an introduction package?
How can the design style be applied to the products?
Which parts can be purchased?
How can it look like a gift?

Description

As Bitstory is a new methodology it requires an introduction explaining what Bitstory is, how to work with it and why. Therefore the introduction package is designed for the parents of De Buitenwereld who have a child with autism (age 4-12). The package contains information and tools to start using Bitstory effectively. The package is handed over to the parents at the start of their trajectory during their kick-off meeting with their personal trajectory supervisor. In the meeting beforehand, the orientation meeting, parents have to agree on using Bitstory by signing a contract in which they agree upon certain privacy regulations. For parents who are already in a trajectory at De Buitenwereld, Bitstory is also offered as they can still benefit from using it, especially since Bitstory can be used after their trajectory ends.

The introduction package consists of four parts: the package itself, an introduction booklet, an external battery and a USB stick (figure 98). Besides information on the system, the introduction booklet contains instructions and examples on how to use Bitstory. The USB stick is meant for parents to make a back-up of their pictures and video's. Also an online version of the booklet is put onto the USB stick for parents to share with others who want to know more about Bitstory. The battery is added to the package to provide extra battery power as some parents, during the design validation, noted that their battery would get empty rather quickly when filming. Although this product is a bit more expensive, it was chosen to include since giving a slightly more expensive product may motive parents more to start working.

Figure 98. The introduction package consisting of the package, the introduction booklet, an external battery and a USB stick.

Look

For defining the look of the package, the idea of a gift was kept in mind. Therefore it was chosen to purchase a small white cardboard box which opens towards the user to mimic the experience of opening a gift. In-line with the design style of the company, the package gets a logo of De Buitenwereld on the side and a logo of Bitstory on top (figure 99).

The design of the introduction booklet is inspired on the design of an existing booklet from the company. By doing so, the same style (size, lay-out, fonts and colours) is achieved. However, the information within the introduction booklet is completely different. Information in the booklet is kept as compromised as possible as most parents most likely do not have a lot of time to (completely) read it. To support understanding, visualisations were added where possible. This also makes reading the booklet a more pleasant experience (figure 101).

The USB stick and external battery aren't designed products but purchased. But to fit the other products, they are customized using the design style. Both USB stick and external battery are chosen in matching colours and the logo of De Buitenwereld is added to the outsides. The sizes are kept small so that parents can easily bring them with (figure 100).

Figure 99. The package is made of white cardboard and has the Bitstory logo and De Buitenwereld logo printed on it.

Figure 100. The USB stick and external battery are customized to fit with the design style of De Buitenwereld.

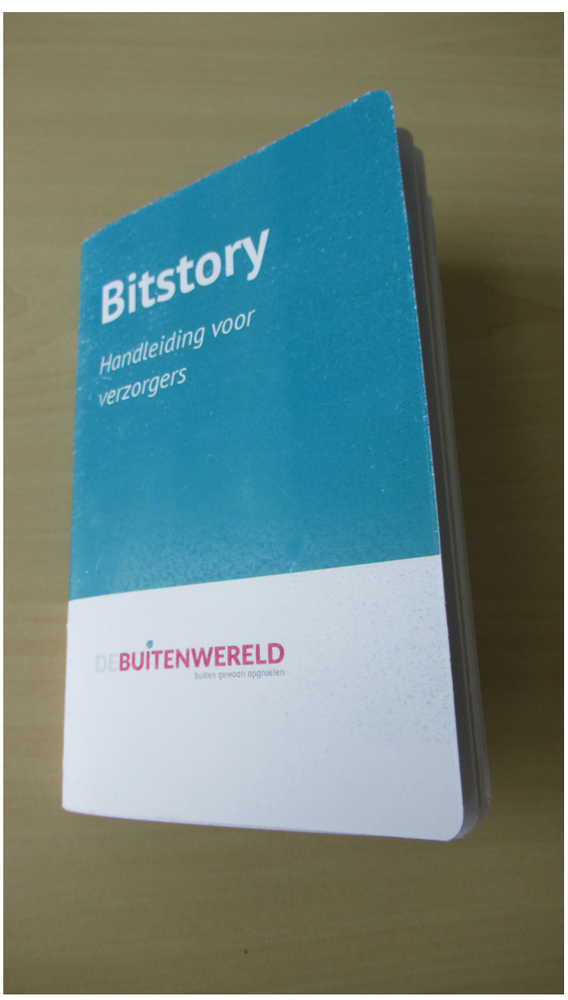


Figure 101. The cover of the introduction booklet matches the cover of others booklets from De Buitenwereld.

Figure 102. The cardboard package has a hinge to open and close.

Figure 103. Choosing a thicker kind of paper can support a more pleasant user experience.

Figure 104. The cover is attached to the USB stick so it cannot get lost.

Functions

Starting with the package, performance is mainly about protecting the products that are put within. Therefore a rather thick type of cardboard was chosen (5 mm). Supporting the experience of opening the package like a gift, a design with a hinge was chosen (figure 102).

Performance for the introduction booklet is mostly about offering a pleasant user experience while reading the booklet. Functions were formulated such as having an easy to carry size, using a readable font size, using 200 gsm paper (figure 103).

For the USB stick it is important that there is enough storage space. An estimation of about 1 GB for data storage was done based on the results of the quick test and the design validation. These tests gave an indication on how much pictures and video's parents approximately make per week. With this information and looking at a trajectory of 9 months, 1 GB should be sufficient to back-up the pictures and video's. Another function to meet is that the USB stick must be compatible for both Windows and Mac devices. To protect the USB stick it was chosen to pick a type that has a cover attached to it (figure 104).

Most important function for the external battery is that it provides enough battery power for parents to completely recharge their phone. To do so, a battery should offer about 3000 mAh (Lam, 2015). Most external batteries come only with a cable to charge the battery itself, so the parents must use their own cable to charge their phones when using the battery.

Usage

Before the package is handed over to the parents, it has been packed at De Buitenwereld. At the company, a shelf is created with the products that need to be put into the package. Once in a while these packages are filled by an employee of the company so that the trajectory supervisors can take a prepared package with them in their case to their client meetings. As soon as the package is handed over to the parents, either during their kick-off meeting or along their trajectory, the use of the package by the parents starts.

At home the parents can start using the tools from the package (figure 105). In the booklet they read about use of the website and tools e.g. how to make a back-up of the pictures and video's and how to charge the battery. The intended use of the USB and battery are to use them in the process of capturing pictures and video's to upload as bits onto their Bitstory. However, the parents can use both products as they like as they are handed over as a gift and thus there are no further obligations.

Figure 105. The use of the package by the parents starts at home where they open their package and explore the products within.

Conclusion

The introduction package was designed to offer the parents tools to learn about Bitstory and use it effectively. Each of the sub-parts, the package, introduction booklet, external battery and USB were defined and designed by looking at their intended use and functions. Most of the parts, except for the booklet, are purchased since designing them would be cumbersome and costing too much money. But to make the purchased products fit the other products of Bitstory, they are customized by adding logo's of the company and choosing colours from the design style.

The implementation toolkit

What do the supervisors bring to their meetings?
What kind of storycards are needed?
What kind of look should the toolkit have?
What kind of information should be in the guide?

Description

The implementation toolkit is designed for the trajectory supervisors of De Buitenwereld to support implementation of the Bitstory methodology in their caregiving processes. The Bitstory implementation toolkit consists of three parts: a case, a guide and storycards (figure 106). The case is like a suitcase in which tools are put that are necessary during the weekly meetings between supervisor and parents. This means that aside from the guide and storycards, tools like markers and post-its are also put into the case. Using a case for all tools in one place helps to stay organized and to work efficiently. The guide is developed to inform and instruct the supervisors on Bitstory. Not only so that they can get the most benefits from using the methodology, but also for them to be able to answer questions the parents might have regarding use, privacy regulations, proof of success, etc. Storycards are cards used by the supervisors in the meetings to support parents in defining their personal story and discovering important information that the parents can capture and upload onto their Bitstory.

There are eight pink cards with topics related to parents of children with autism, distilled from the results of the various analyses that were done in this project. On each back-side questions are placed that can be asked by the supervisor to discover information on that topic. There are three types of green cards, sticker cards, which are used to indicate if certain information requires help (question mark), if it can be used as a solution (light bulb), or if it is about a goal (star). Cards with images are created to trigger parents in thinking about their personal situation. For example, an image of the sun might trigger a parent to name that their child has difficulties with bright light. Storycards are used in combination with post-its to note down the personal information during meetings in order to create a visual overview of information and define where barriers and opportunities lay. At the end, a picture is taken of the results which is uploaded onto Bitstory as a reminder of what has been discussed.

Figure 106. Products of the implementation toolkit.

Look

The case is a purchased product and made out of coated cardboard to ensure durability. The logo of the company is put on the cover to support brand awareness (figure 108). The size of the case is A3 so that there is enough room for all the tools. The guide is designed in the same style as the introduction booklet from the introduction package, only using a different colour. For the design of the storycards, the colours from the design style were used. Choosing the images for the cards was a more iterative process. In contextmapping, images are used as a tool to evoke thoughts and emotions with different types of people (Sleeswijk-Visser, 2005). Often more ambiguous pictures are chosen to not guide or stir the users too much but rather let their imagination go. However, for this project a reconsideration was done for choosing more ambiguous pictures. Sometimes parents of autistic children also have characteristics of autism themselves. Working with abstractions can be difficult for people with autism. Therefore, it was decided to choose images that are less ambiguous and thus more literal. Together with a student who has a sister with autism all images were evaluated and a selection of 48 images, that would most likely inspire different types of parents, was made. The size and thickness of the cards were chosen in the same style as playing cards.

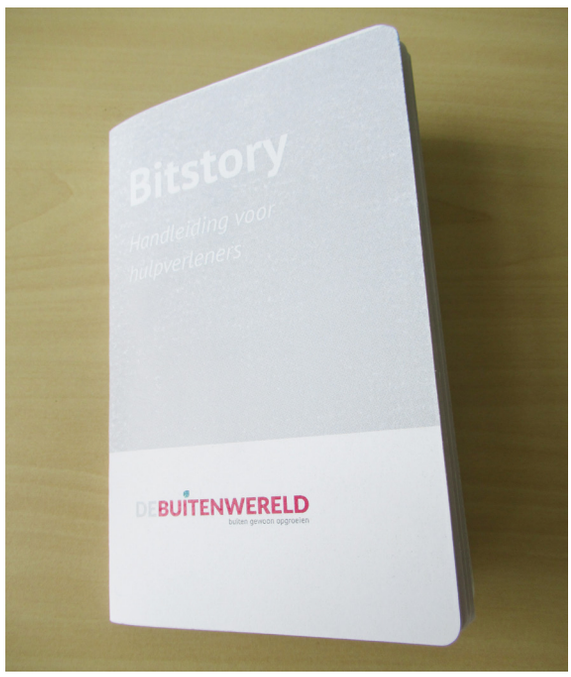


Figure 107. The guide for the trajectory supervisors.

Figure 108. The case is customized by adding a logo.

Figure 109. Storycards consist of 8 question cards, 48 image cards, 3 types of sticker cards and 3 instruction cards.

Functions

Functions for the case regard being able to bring and protect the tools that need to be brought to the meetings. So a handlebar is required to carry the case. To last long, the materials are chosen to be a rather strong type of cardboard with a coating to protect against liquids (figure 110).

Performance for the guide is, as well as the introduction booklet, about offering a pleasant reading experience. But it is also about the information within. This information is made visually appealing and clearly structured so that the supervisors can easily navigate and read through the information (figure 111).

Storycards are designed to support parents in talking and defining their story and to support supervisors to retrieve the right information efficiently. Therefore functions such as having different kinds of questions to ask during the meetings. As a result it was chosen to put three questions per topic on the question cards. Concerning the cards with images, functions regarded having a variety of images so that different people would get associations with at least some of the images. Also the quality of the cards is important in relation to performance as all cards are going to be held frequently during the meetings. Therefore the quality of paper is thick and with a glossy coating. Resolution of the images is set high to overcome possible irritations on images that are not sharp (figure 112).

Figure 110. The case is made out of strong cardboard with a coating.

Figure 111. Spread of the guide.

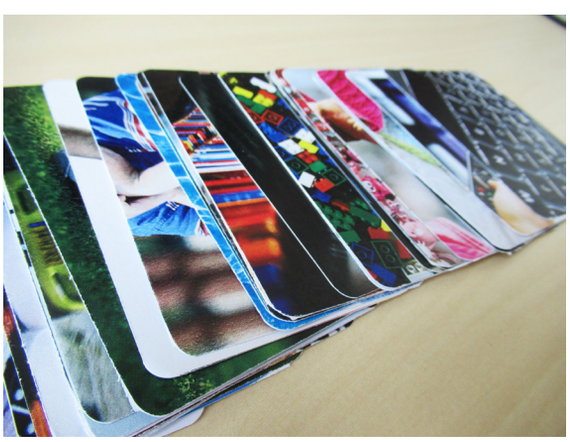


Figure 112. Close-up of image cards.

Figure 113. Results of a meeting between trajectory supervisor and parents in which storycards were used to discover important information.

Usage

Most of the items from the toolkit are solely used by the trajectory supervisor. Only the storycards are used by both parents and supervisors (figure 113). Whereas the introduction packages are pre-packed by an employee of De Buitenwereld, the implementation toolkit is the responsibility of the trajectory supervisor. Each of them takes a case when they go into a meeting and fills it with the tools they need. So aside from the guide and the storycards, the case might include an introduction package, their agenda, blank papers, documents, post-its and markers. At the company a shelf, just as for the introduction package, is created with tools for the supervisor to choose from.

Conclusion

The implementation toolkit was designed for the trajectory supervisors of De Buitenwereld to support them in successfully implementing the Bitstory methodology within their caregiving processes. Looking at intended use it was chosen to purchase a case with a handlebar in which the tools can be carried to the meetings with the parents. For the other two sub-parts, the guide and storycards, functions were formulated mostly about the information they contain such as the visualisations e.g. using high resolution of images. Thinking about intended use of these parts led to formulating functions such as using 200 gsm paper thickness for the cards as they are going to be hold frequently by people.

Use scenario

At what moments in time is Bitstory used?
How is Bitstory used by the parents?
How is it used by the trajectory supervisor?
How is it used by others?

Use journey

The Bitstory website, the introduction package and the implementation toolkit are all used by different people at different moments in time. To make these differences in use more clear, an overview of the main use of these three parts along part of the customer journey of de Buitenwereld was created (figure 114). Each part is designed to evoke particular interactions. To show these intended interactions, a user scenario was created. The scenario describes a story using pictures to provide context (figure 115, 116 and 117). The story starts with the orientation meeting in which a parent, single mother of an eight year old boy who is diagnosed with autism, meets her trajectory supervisor. In this meeting she is introduced to Bitstory. The story continues by showing the steps that follow after introduction upon until the moment the parent shares bits to enhance understanding and build a stronger relationship with her sister.

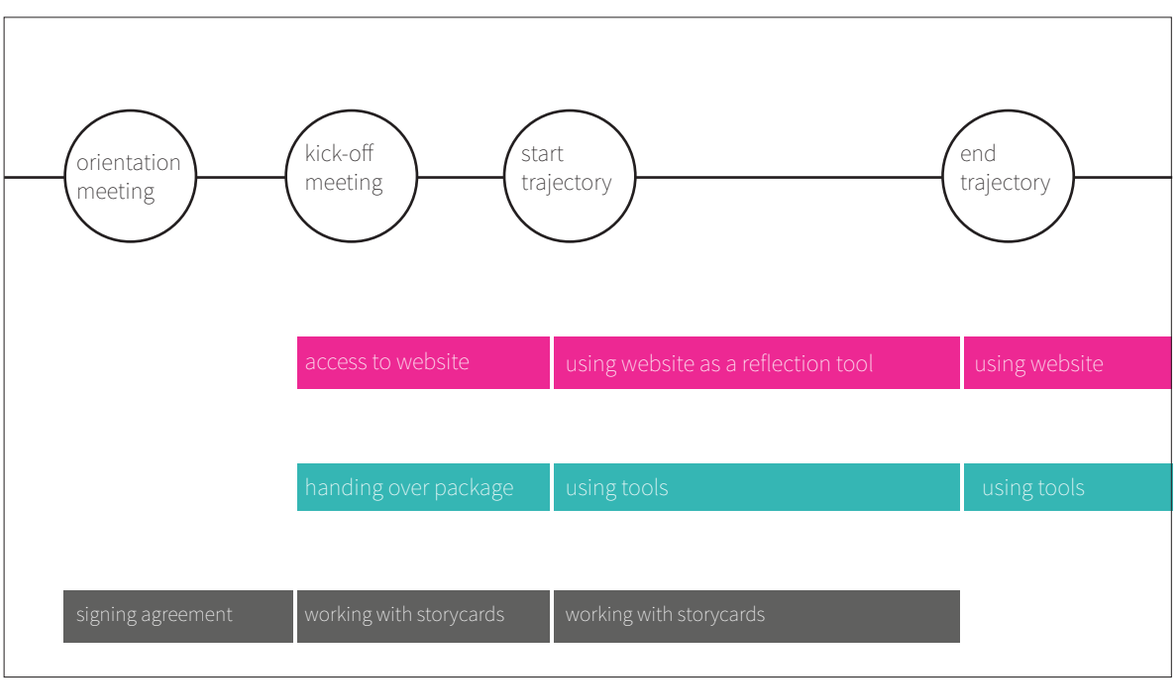


Figure 114. Use of the three main design parts along part of the customer journey of De Buitenwereld.

Explaining Bitstory and signing the agreement contract

The trajectory supervisor explains Bitstory during their orientation meeting. The parent signs an contract to agree upon use of Bitstory and of upon being the owner of all the data and therefore responsible.

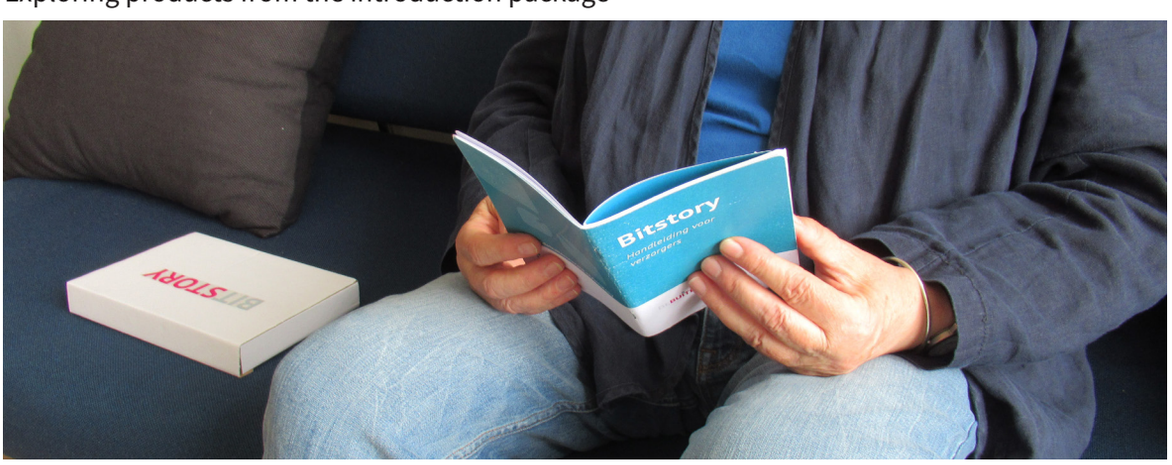
Preparing the toolkit

Before the trajectory supervisor goes into the next meeting with the parent, the kick-off meeting, she packs her case with the tools she needs.

Handing over the introduction package and instructing on use of Bitstory

In the kick-off meeting the introduction package is handed over to the parent. The trajectory supervisor uses her own guide to explain how Bitstory is used throughout the trajectory.

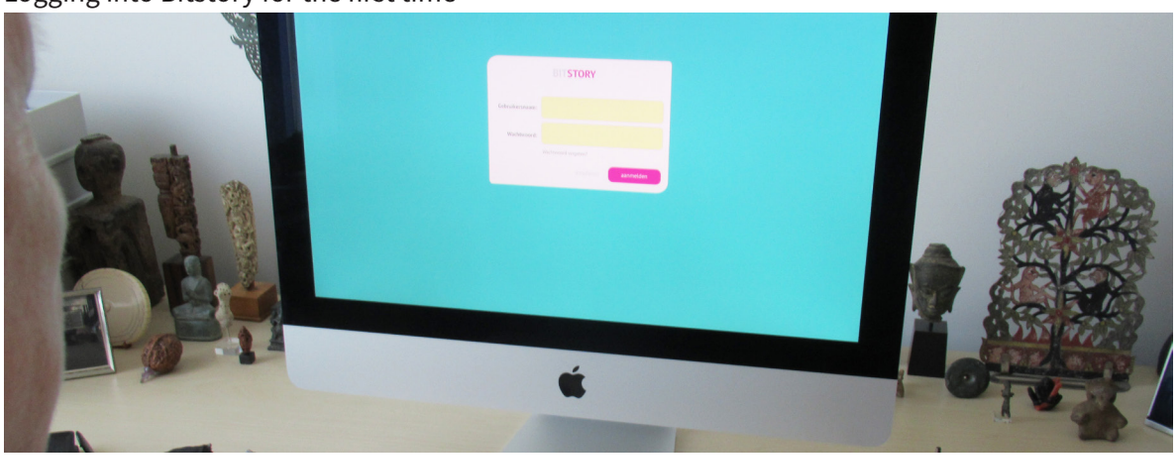
Exploring products from the introduction package



At home, the parent opens the package. She reads the introduction booklet and tries out the battery and USB stick.

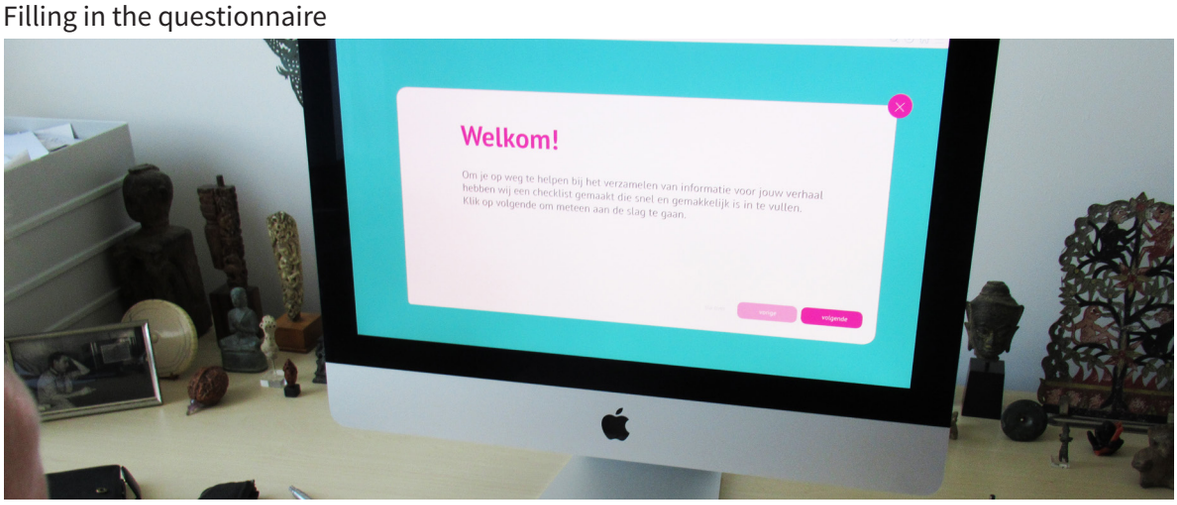
Figure 115. Use scenario.

Logging into Bitstory for the first time



The parent logs into Bitstory using a username and a password.

Filling in the questionnaire

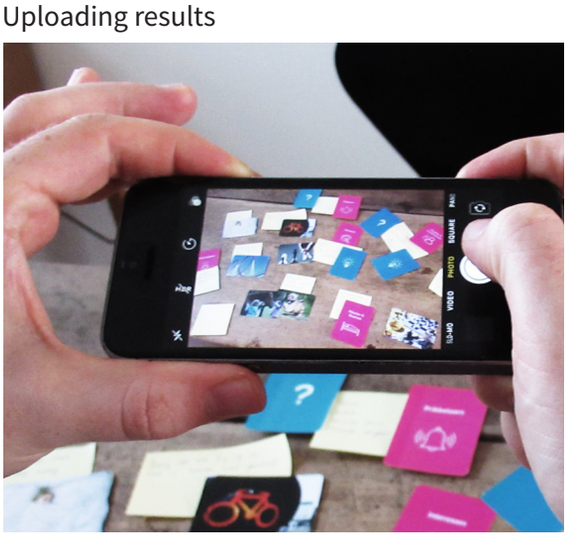


When opening Bitstory, the parent goes through a questionnaire to quickly fill her profile with important information.

Working with storycards

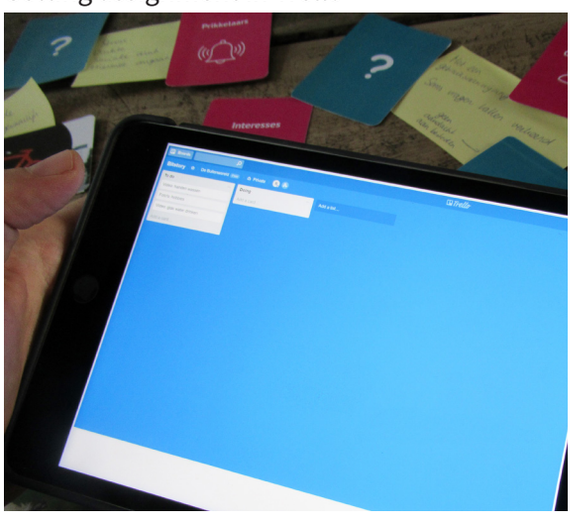
At the start of the trajectory the trajectory supervisor uses the storycards to discover important information.

Uploading results



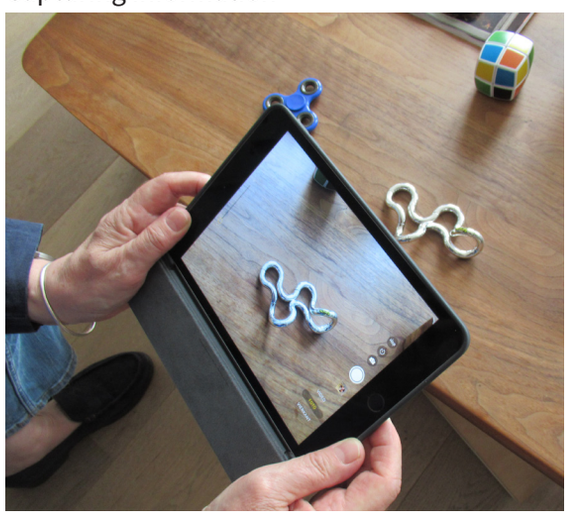
A picture is taken of the results and uploaded to the parent's Bitstory.

Setting assignment in Trello



The supervisor and parent discuss what kind of information can be collected in bits. They add these as a 'to do' in Trello.

Capturing information



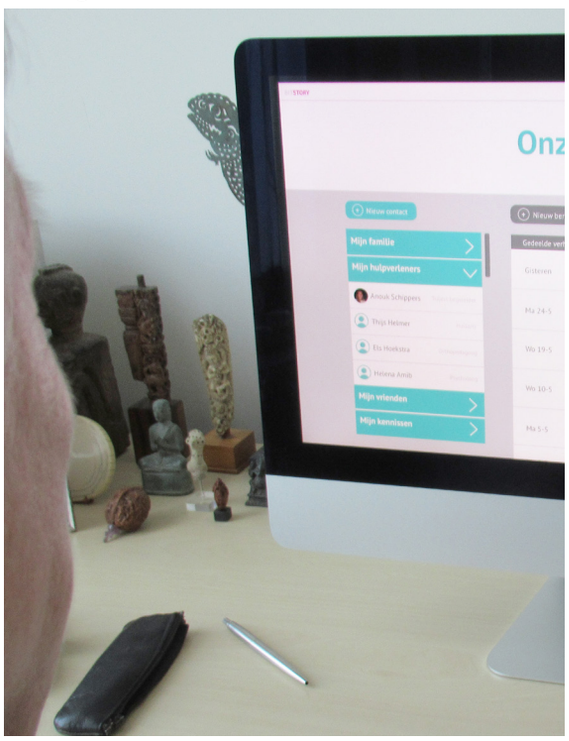
At home, the parent uses her camera to capture the different kinds of information for her Bitstory.

Making a bit

On her computer the parent uploads pictures and video's to create bits.

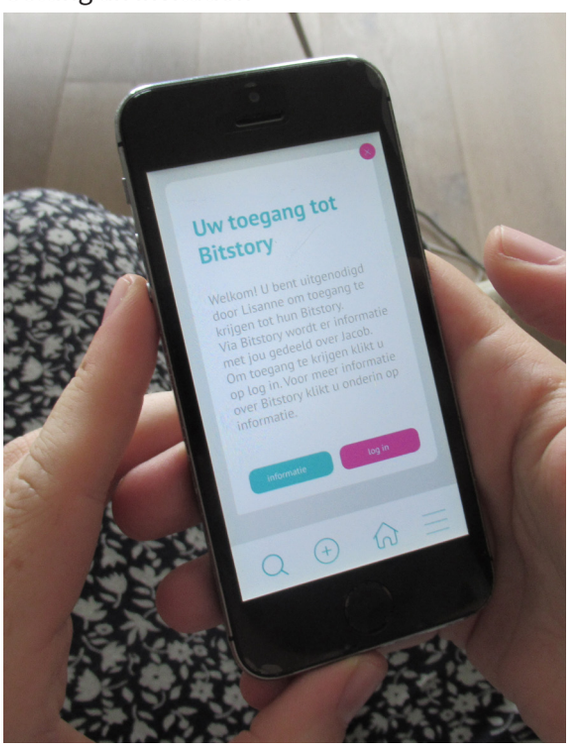
Figure 116. Use scenario.

Adding a new contact



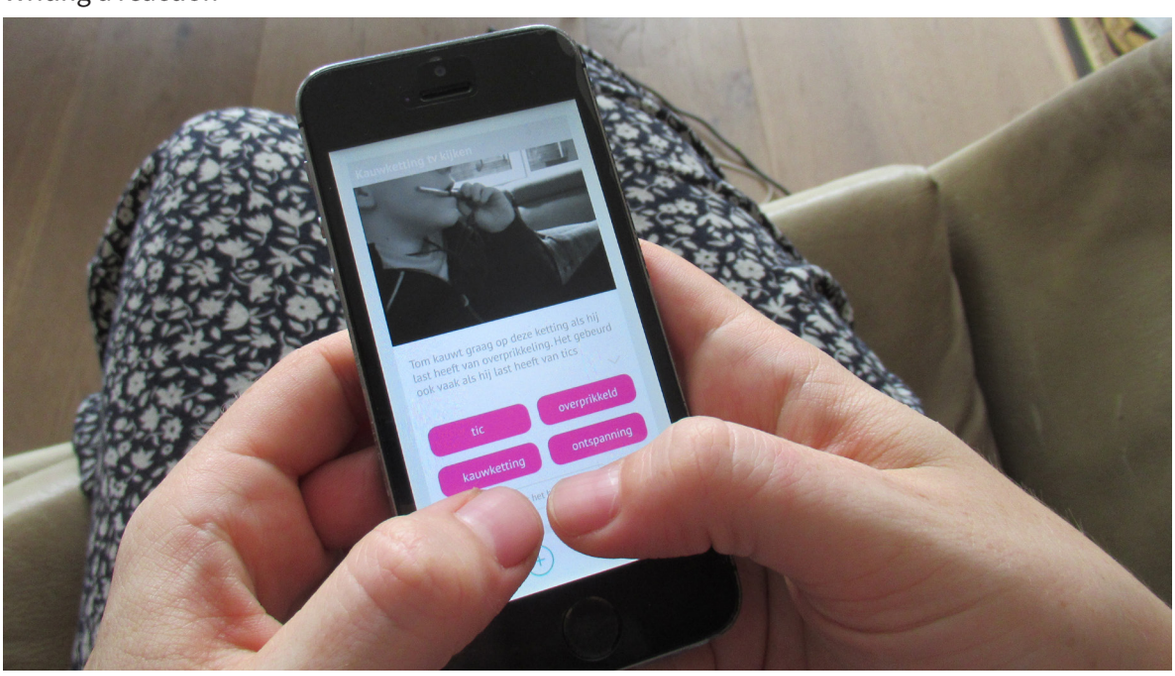
The parent adds her sister into her network and sends her an invitation so that she can access her Bitstory.

Getting an invitation



The sister receives an invitation on her mobile phone with a link to get access to Bitstory.

Writing a reaction



The sister posts a reaction at one of the bits.

Figure 117. Use scenario.

Building relationships

The sister decides to call the mother after she explored the bits. They have a great talk on the phone in which they discuss the bits. At the end they make an appointment to meet at the parents home together with her son.

Conclusion

A use scenario was created to visualize how each of the design parts of the Bitstory methodology are used by three different stakeholders: a parent, her trajectory supervisor and a sister of the parent of whom more understanding is desired. This use scenario helps to better understand how the parts are used and at what moments in time. The scenario describes a story of a mother of an autistic son who starts their trajectory at De Buitenwereld. The story gives an impression on how the parent is instructed, how she captures information, how she uploads bits, and how she shares bits with someone from her network. It ends with showing that Bitstory can lead to interactions that support building a stronger relationship.

Future of Bitstory

What kind of steps need to be taken to develop Bitstory?
What are the costs of realizing Bitstory?
What is the business model?
What are ways to generate revenue?

Steps of development

Realizing Bitstory requires taking many steps of development over a long period of time. First of all, each of the design parts need to be optimized to be ready for development. That requires taking steps in setting up more research, making prototypes, doing tests and creating re-designs. Then there are steps that need to be taken concerning the business side of Bitstory like arranging investments to meet all the costs that come with development of all parts. And as De Buitenwereld is a non-profit healthcare institution they need to find other ways to get money to be able to pay for all costs. Knowing roughly what kind of steps to take in the development of Bitstory helps to estimate costs and time of development. To support thinking about these required steps for developing Bitstory, the Business Model Canvas tool is used.

Business model

Developing a new methodology like Bitstory requires thinking about the business that needs to be built for Bitstory to succeed. A great way to do so is by using the Business Model Canvas (Osterwalder, 2010). This canvas is a format with questions regarding various components that are of essence when starting or defining a business. As an example, the canvas forces the business initiators to formulate a value proposition: what kind of value does Bitstory add to customers? Knowing the added value of Bitstory supports approaching and persuading future customers in using and investing in Bitstory. Aside from a value proposition, the model helps to think about the activities that need to be done to realize development such as networking to find investors, but also the kind of resources that are needed such as developers and designers. The model also supports thinking about possible costs and how to generate revenue to meet those costs. One idea for generating revenue that arose is to sell the Bitstory methodology to other healthcare intuitions so that they can implement Bitstory in their caregiving processes. The Business Model Canvas filled in for Bitstory is found in Appendix S.

Value proposition

For formulating a value proposition, it is important to think about the kind of problems Bitstory solves, the needs it meets, and thus the added value it brings to its users. During the project, problems for both De Buitenwereld and the parents of autistic children, aged 4-12, were discovered. These problems were distilled from the results of various analyses such as the company analysis and user research, and were used to formulate eighteen needs the design solution had to meet. To get to the Bitstory values, a new overview is created with all the problems that were discovered for both stakeholders. The problems are organized and structured and as a result five values arose that meet these problems. The eighteen needs are also added to the overview to show that these five values of Bitstory meet the needs of the two stakeholders (figure 118). Having these values helps building a strong story to both sell and convince others to use the Bitstory methodology.

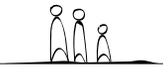
Pitch

Bitstory adds value to not only De Buitenwereld and the parents for autistic children, but also to other healthcare institutions who provide care to parents of autistic children. That is if they buy Bitstory and implement the methodology in their caregiving processes. In order to explain others about Bitstory, a pitch was formulated:

Bitstory is a new methodology for caregiving to empower parents of a child with autism (4-12 years old) by using tools to effectively capture, describe and structure important personal information into a visual story which can be shared at anytime and anywhere with any other who is involved in caregiving to enhance their understanding, strengthen relationships and build a strong support network.

Problems company

Bitstory values



Problems parents

Providing higher quality of care

- *Working human-centered*
- *Providing personalized care*
- *Enhancing understanding of all involved others*
- *Building and strenghtening the social support network*
- *Gaining lots of real human-insights*

Building trust · Shared contribution · Personalised · Adaptable · Keeping track

Problems company:
- Not knowing all the details
- Little consistency because every family is different
- Having difficulties discovering problems

Problems parents:
- General methods and tools don't work
- Dealing with different needs of all stakeholders
- Dealing with unpredictable development
- Inconsistency on day to day basis
- Having to try out a lot of things

Working more efficiently

- *Discovering important and personal details*
- *Being able to focus more quicker on points of attention*
- *Communicating visually to save time*
- *Working with a structured guideline and format*
- *Having proof by capturing moments in pictures and video's*

Easy access · Providing guidance · Self-explanatory · Time efficient · Structured

Problems company:
- Having to remember lots of information
- Having less time per client
- Having to look up a lot of information
- Having less people to provide care
- Spending lots of time on processing information
- Having to share lots of information with different people
- Having to communicate with lots of people
- Having to do many different tasks

Problems parents:
- Seeing little or no progress
- Dealing with information overload
- Having to arrange a lot
- Having to explain to many different people
- Having to deal with lots of stakeholders who are involved
- Tired of explaining
- Having to remember a lot of information
- Having high costs for care
- Having to explain a lot to lots of people

Focussing on the support network

- *Meeting the transition goal of focussing on the network*
- *Strengthening relationships of current network*
- *Allowing to share information anywhere, anytime with anyone*
- *Facilitating easy communication with others from their network*
- *Supporting parents to build their own network*

Engaging interaction · Social support network · Creating understanding

Problems company:
- Government push on achieving transition goals
- Having long waiting lists of families
- Being too involved

Problems parents:
- Getting too little understanding from others
- Feeling alone
- Suffering from social isolation
- Lacking enough of (the right) support

Empowering parents

- *Making parents in control of their caregiving process*
- *Building a strong support network for the families*
- *Allowing parents to have access to information anywhere*
- *Parents do not have to worry about costs for the system*
- *Providing a safe environment for parents to share information*
- *Focussing on the positive sides of the caregiving process*

Affordable · Taking over tasks · Enhancing the positive · Safe environment

Problems company:
- Having a high workload
- Having too much responsibility

Problems parents:
- Lack of acknolwedgement and recognition
- Anxious about the future
- Finding it difficult to ask for help
- High demand of caregiving
- Suffering from high levels of stress
- Damaged trust by bad experiences
- Having self-doubt
- Receiving negative responses from others
- Suffering from low energy levels
- Don't want to bother others

Being innovative

- *Having a technological solution in healthcare*
- *Raising more awareness on autism*
- *Having a new methodology to differ from other institutions*
- *Enhancing the positive effect of working with pictures and video's*
- *Possibility for new research into the effects of working mainly with visualisations in caregiving*

Using technology

Problems company:
- Receiving less money from the government
- Lack of technological tools

Figure 118. Overview of the stakeholders' problems, the five values of Bitstory and how these meets the eighteen stakeholders' needs.

Estimated time of development

Predicting the exact time it takes to realize Bitstory isn't possible, but an estimation can be done using the steps of development that were discovered by, among other things, using the Business Model Canvas. One step that arose from the business model was that there needs to be some sort of proof to convince customers and investors on the added value of Bitstory such as providing higher quality of care and making caregiving processes more efficient. One way to do this is by proofing that Bitstory can shorten the time a trajectory takes. Currently, these trajectories take up about 9 months. The goal of the test is to proof that a trajectory can be shortened to 6 months when Bitstory is used. Therefore this test must be done during the entire trajectory of De Buitenwereld. Such a extensive test requires many steps such as creating prototypes and recruiting participants. In figure 119 an estimation for time of development is presented by sketching a time-line with the main steps to realize Bitstory.

Possible costs

Realizing Bitstory comes at a price. To start there are the costs for development of all design parts of the system. Some parts, like the case, battery and USB are purchased at an external company. These types of costs are predictable and can be kept at a reasonable price, especially when purchased in a large batch. The costs of development of the website are far more difficult to predict as it depends on a variety of factors. Development requires hiring a user experience designer who is going to decide what needs to be on the website, a user interaction designer who creates the lay-out of the website and a programmer who builds the website. Costs are depended on the time they each spend and the resources they need, but also on the decisions the company takes concerning possible additions of new functionalities or if they decide to take Bitstory to an international market. Aside from the costs it takes to develop the products, there are more 'hidden' costs such as the salaries of employees that work on the project, do promotions and have to approach investors. Taken all these factors into account, a rough estimation of costs was done by stating that costs may be between 10.000-100.000 Euro (Appendix S). More definite prices can be established by consulting with the external parties who are going to cooperate with De Buitenwereld to realize Bitstory.

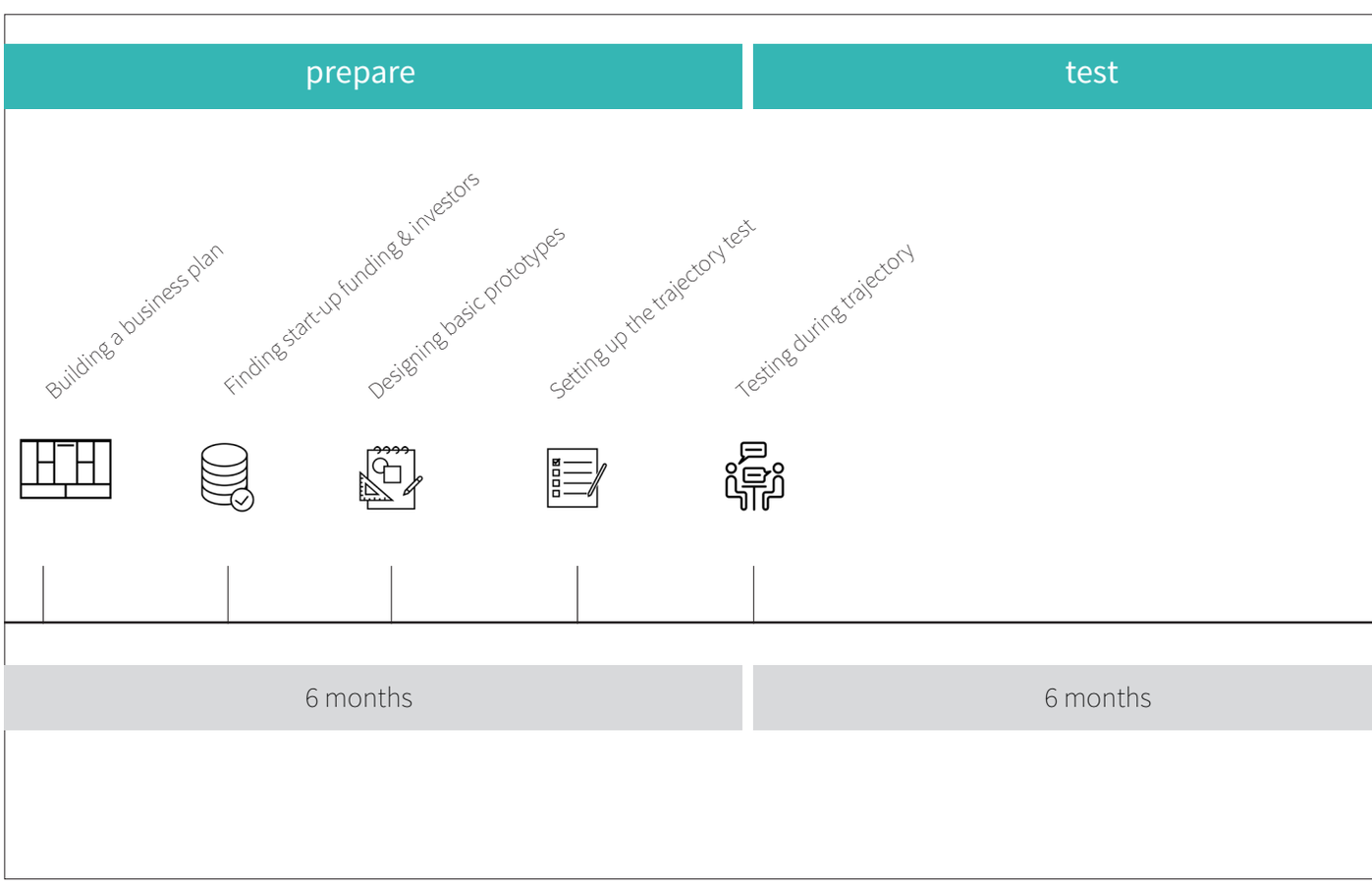


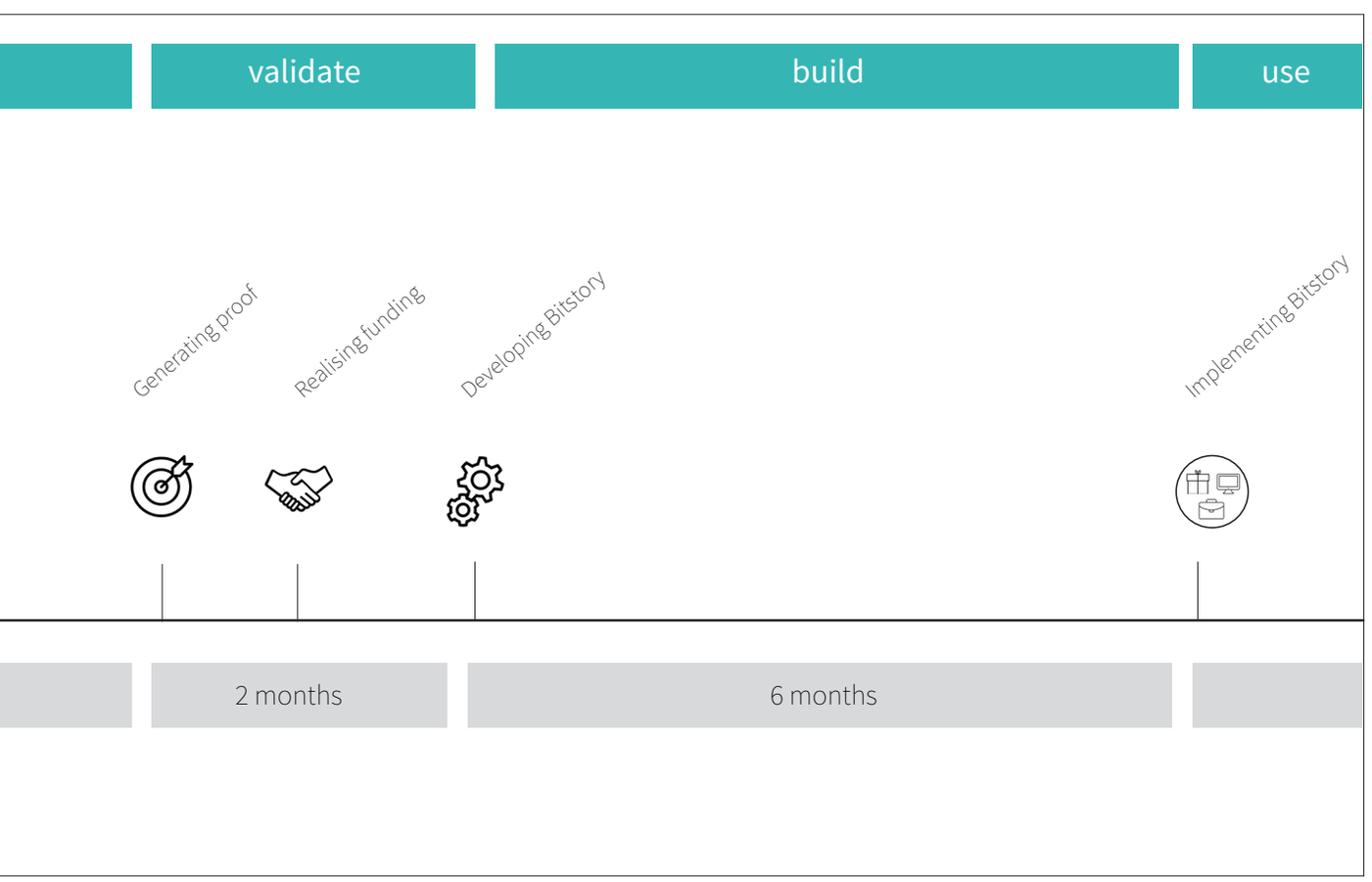
Figure 119. A possible time-line of the future for Bitstory with steps of development and estimations on how much time they take.

Generating revenue

De Buitenwereld doesn't have the resources to meet all costs. Therefore they have to find ways to generate revenue. One option is to approach investors who are willing to invest or donate a certain amount of money. Or a deal can be made with them that if Bitstory starts making profit, initial investments can be returned. Another way to generate revenue is to add advertisement to the Bitstory website. There is also the possibility to sell Bitstory as a methodology to other healthcare institutions. If the test during the trajectory proofs that caregiving becomes time-efficient and thus cost-efficient due to the use of Bitstory, other institutions might want to buy Bitstory to implement in their own caregiving processes. If so, Bitstory can be sold by selling workshops in which employees from De Buitenwereld train other caregivers in use of Bitstory. Aside from the workshops, there is the toolkit that is sold as a product and the institutions have to pay a price to make use of the Bitstory website.

Conclusion

For the company to continue with Bitstory, a possible future for Bitstory was created. To think of steps of development a Business Model Canvas was used. This model helped to formulate a value proposition which supports building a strong story to sell and promote Bitstory to future customers. The model points out that to generate revenue to meet costs, the Bitstory methodology can be sold to other healthcare institutions. This is achieved by requesting money for a workshop to instructs employees of other institutions on implementing the methodology and letting them buy the tools and access to the Bitstory website. To convince these customers, a large test should be executed to proof the benefits of Bitstory.




DE BUITENWERELD
buiten gewoon opgroeien
Bitstory
DE BUITENWERELD
Wat zijn storystarters?
Emoties
Prikkelaars
Typisch gedrag
Omgang & Communicatie
?

Figure 120. The Bitstory methodology with all its tools.

Evaluation

At the end of this project there is only one more phase left which is the evaluation. This evaluation starts with recommendations that were distilled throughout the project as a result of not having enough time to include all ideas and insights that were found. Therefore they are proposed as recommendations for the company to consider if Bitstory is continued with. Recommendations are given concerning the design parts of Bitstory, future development and possibilities to increase business potential. Then there are reflections from the project designer on the project and on personal development. The phase concludes with a list of tips for future graduation students to support them in their project and personal journey.

Recommendations
What is recommended for the designs of Bitstory?
What is recommended for further development?
What were recommendations from stakeholders?
Which recommendations are realistic?

Reflections
What went different than expected?
What kind of preparations were done?
What kind of learning goals were achieved?
Which steps benefited the project?

Personal tips
What helped me during this project?
What did I wish I knew upfront?
What were tricks to support yourself?
What would I do differently?

Recommendations

What is recommended for the design of Bitstory?
What is recommended for further development?
What were recommendations from stakeholders?
Which recommendations are realistic?

Doing more research and

Doing user research and tests with the parents of autistic children to gain insights, validate ideas and designs has proven incredibly beneficial for the development of Bitstory. It made it possible to discover real human insights, problems and needs and therefore develop a system that can meet these needs. However, all designs which are proposed in this report are not definite designs, but possibilities or examples on how these designs could be. More research is needed to validate all current design parts, their functions and intended use. Not only more user research with the parents is required, but also with the trajectory supervisors who are going to be using Bitstory in their caregiving processes. The results can generate new insights to optimize Bitstory and thus increase the changes of a successful implementation.

Cooperating with others

As was found when estimating a possible future for Bitstory, the costs of realizing the system are high. Aside from finding others to invest in Bitstory, the company must approach others to gain expertise in different fields such as development of websites. Since some of this knowledge isn't available within the company, it is recommended for De Buitenwereld to seek for parties to cooperate with in realizing Bitstory. A cooperation might be established for example with companies who have expertise in digital solutions for healthcare. Concerning costs, a cooperation with companies can be achieved even if they not necessarily have a direct link with the field of caregiving, but want to invest in such projects to create positive brand awareness. In order for De Buitenwereld to convince other parties, it is important that they have a strong pitch and make use of their own network to find possible partners more quickly.

Figure 121. More user research with parents is needed to optimize Bitstory.

Figure 122. Employees of De Buitenwereld in cooperation with other parties.

Doing the trajectory test

For most people who want to buy a new product or service, proof of success is important. Proof in the sense that others have used the product and were positive about the results. The same counts for Bitstory. To be able to get the parents enthusiastic and motivated to work with Bitstory, it is important that there is evidence that Bitstory provides benefits for them so that they are willing to start using it. A possibility to find proof was described when looking into a possible future for Bitstory. A large trajectory test was proposed to generate proof to convince other caregiving institutions of Bitstory. Such a test should be done during about ten trajectories, thus ten families should be found to participate. The families who expressed enthusiasm during this project can again be approached for participation. To keep costs at a low rate, basic prototypes should be developed. It might even be considered to work again with WhatsApp. If that is not desired, building a simple website with basic functionalities can be done at a low cost. The test should focus on proving that the time for a trajectory, which is about 9 months, can be shortened to 6 months when using Bitstory. Such an extensive test requires an extensive plan with clear instructions for all the people (parents, other caregivers, employees, trajectory supervisors, etc.) who are going to be involved.

Figure 123. A large test should be done in which Bitstory is tested in the meetings between trajectory supervisor and parents.

Making use of (big) data

When the families start using Bitstory, lots of data will be generated. Having such a great amount of data can offer opportunities for the company in terms of doing data analysis. Use of big data (big bulks of data) is trending, especially in healthcare. With algorithms certain patterns in data can be found. Discovering these patterns makes it possible to gain more knowledge and to do predictions. For Bitstory this could mean that such a system could generate personal advice to each family based on all experiences of parents with autistic children who contribute to Bitstory. However, working with big data is challenging and still costs a lot of money. Yet, the possibilities can offer many benefits, especially for parents of autistic children who have noted in this project that lots of generic methods or tools do not work for their child. Having a large database filled with personal experiences of parents increases chances of finding a match between families who are in the same kind of situation. And this also makes it easier to discover and exchange personal tools and tricks from one family to another family that might benefit from these tools and tricks as well.

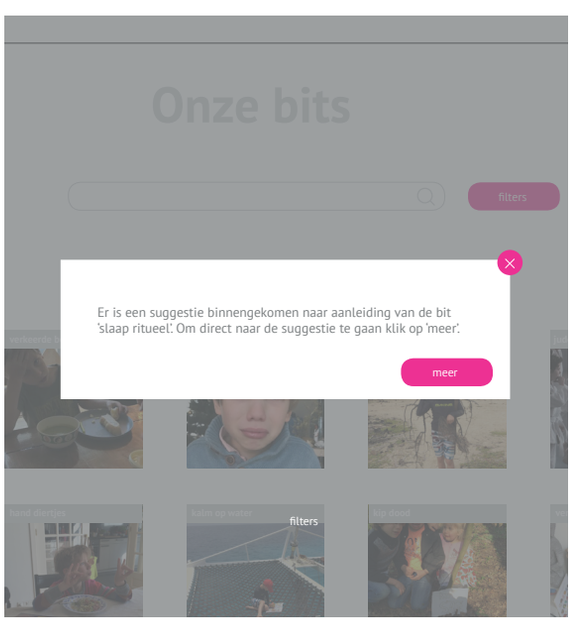


Figure 124. Using big data, the Bitstory website can offer suggestions to parents based on their input.

Adding functionalities to the website

The Bitstory website has been designed up to a certain point, meaning only a selection of web-pages have been designed. For these web-pages the most important functions are included: uploading, editing and sharing bits with others. But there are more ideas for adding new functionalities , which would result in more web-pages. These functionalities arrived from the results of the design validation test with the parents. Yet they were not included in the design for the website because of limited time. Two functionalities can be considered when further developing the website: adding an agenda and a diary (figure 125). Three other ideas also arose which can be explored. The first is to use drawings when there are no pictures or video's available to fit with certain information. Second is the idea to work with Google maps to link important information to locations. And third is adding the option for parents to upload a bit from their Bitstory to their social media. The picture or video would automatically get the Bitstory logo to raise more awareness.

Establishing a peer-2-peer connection

During the interviews in the first user research, the contextmapping study, most parents mentioned a desire to meet or talk with other parents who are in sort-like situations. Reasons for them to want a peer-2-peer connection were varying. Some parents wanted to speak to peers with older children with autism so that they could learn from them. Others were seeking for parents in the same situations so that they could share knowledge and tips. And others were seeking for emotional support by being able to talk about the situation with other parents. To establish a peer-2-peer connection, the Bitstory website might be considered as all parents use this medium. It is recommended for the company to explore the possibility of creating a shared space on Bitstory in which parents can connect. However, it must be tested what kind of connecting is most desired. It may be by creating a shared database filled with bits from parents, as shown in figure 126, or by allowing parents to access (parts) of each other's Bitstory.

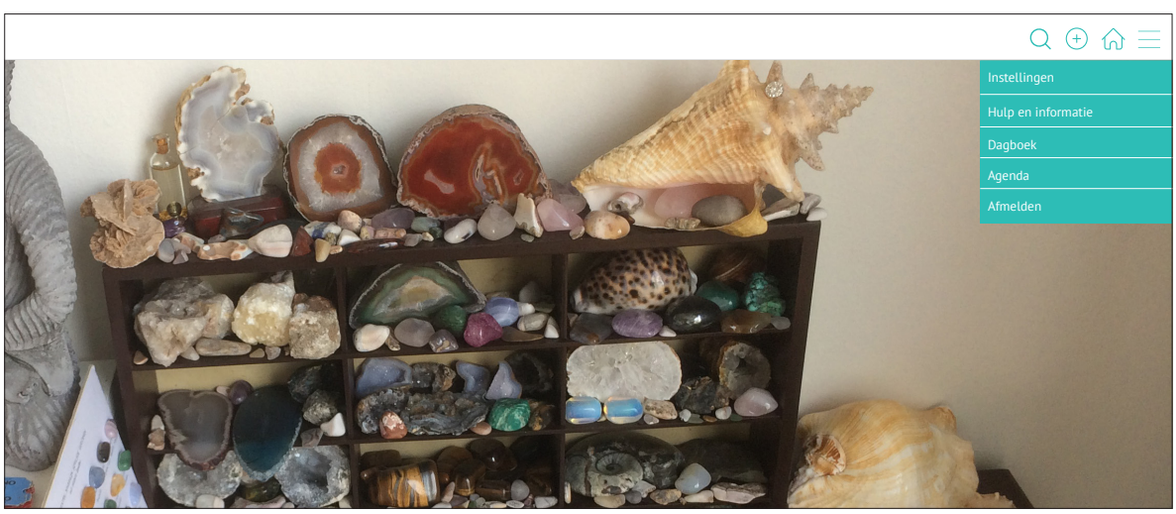


Figure 125. The homepage with the drop-down menu showing two new functionalities: a diary and an agenda.

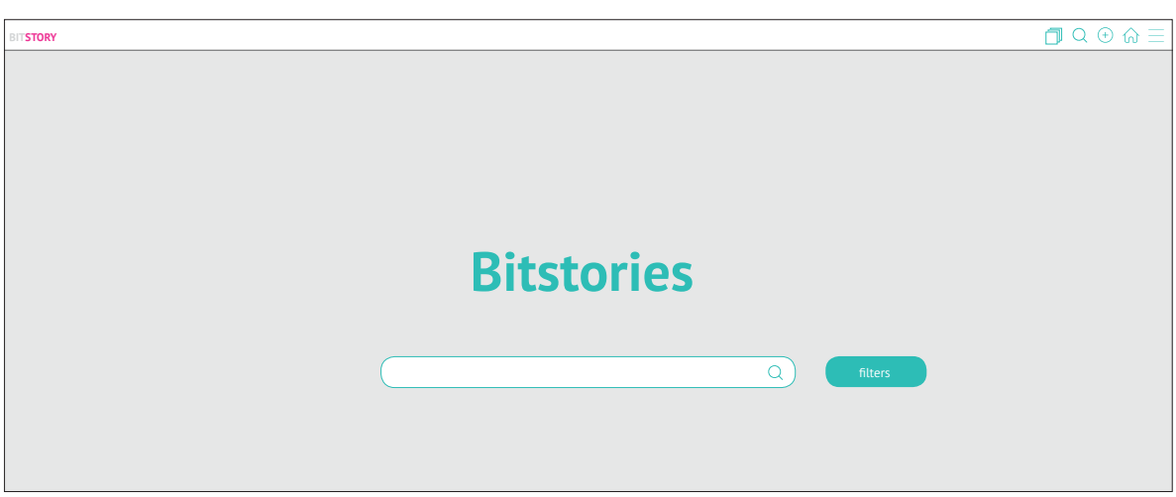


Figure 126. A possible design for a web-page with a peer-2-peer connection with a shared database to explore bits from other parents.

Adding tools to the toolkit

The implementation toolkit was designed to support the trajectory supervisors in applying the methodology of Bitstory successfully. As the name suggests, it is a kit with tools. In this project, only one tool was designed as a part of this toolkit which are the storycards. These cards were designed to discover important information more efficiently. But there are more possibilities for tools that fit with Bitstory. For example, on the Bitstory website parents have a section for all contacts from their network, which is named 'Our World'. Yet, many parents who start their trajectory mention they have either no network or it is too small, or they are unsure about who is in their network. Therefore there is an opportunity to develop a tool to support parents in mapping their network and think about new connections. Figure 127 is an example of an online tool that maps a person's network. To make such a tool fit with Bitstory, it must use mostly visualisations and have the possibility to take a picture of the results after use so that it can be uploaded to the Bitstory website.

Exploring other markets

The market for this project is the Dutch market. But there is an opportunity to expend this market by going international. As Bitstory works mainly visually, language barriers can be more easily overcome. It is estimated that worldwide 1 out of 160 children has autism (WHO, 2017). This is a huge market to target. It could even be explored if the Bitstory methodology, which uses pictures and video's to capture and share information, can be used in caregiving process to support parents of children with other kinds of conditions than autism such as parents of a child with Syndrome of Down. However, it must be noted that a restriction on a certain age is preferable. In this project a maximum age of 12 years old was set for the reason that older children are probably going to dislike the fact that pictures or video's are taken of them. But there are always exceptions. It might be that a child with autism at the age of 18 is not bothered by the pictures or video's. Then Bitstory should still be considered as it might benefit this family.

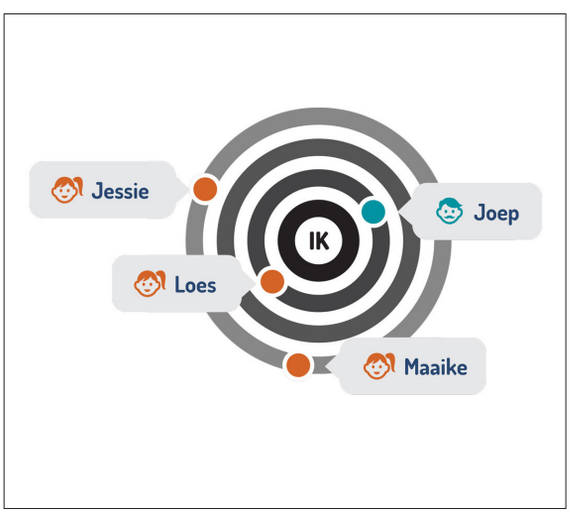


Figure 127. An example of an online tool to map a person's network.

Figure 128. World Autism Awareness Day raises awareness for autism worldwide and would be a great day to introduce people to Bitstory.

Conclusion

Due to limited time for the project, not all insights and ideas that were developed could be included. Thus recommendations for the future were formulated. Some recommendations regarded the design parts of Bitstory, for example adding more tools to the toolkit such as a tool to support mapping parent's network. Other recommendations regarded future development of Bitstory and business opportunities like expending markets internationally to reach a larger target group. All these recommendations are not a necessity but possibilities to be considered by the company as they offer more opportunities.

Personal reflections

What went different than expected?
What kind of preparations were done?
What kind of learning goals were achieved?
Which steps benefited the project?

Preparation

Before this graduation project officially kicked-off, lots of preparation was done. First, I had to find an assignment. To keep me motivates I knew it was important to choose an assignment that would fit my personal values, needs and wishes. So to be able to know what to look for, I spend quite some time on personal reflection. I bought a booklet to create mind-maps about my values, my skills, my desires as a designer, beliefs about the future, and what I would want from a company. I reviewed lots of companies online and looked into previous graduation projects to gain insight in the things I liked and disliked. After a while I got a clear image about what to look for. In a meeting with a professor at the faculty, an assignment was shown to me that matched what I was looking for. Not long after I had an agreement with the company, De Buitenwereld, who proposed the assignment. In the next steps, I did preliminary research into the company and their clients to define a target group and their main problems. With this information, a final assignment was formulated. Aside from the assignment, an extensive planning was created which covered the complete project time span (figure 129). Although the planning changed a lot of times during the project, it served as a great tool to keep me reminded of the kind of steps I had to take. Overall, I am glad I spent significant time on preparation as it has proven me lots of benefits. And having a great assignment kept me motivated throughout the entire project.

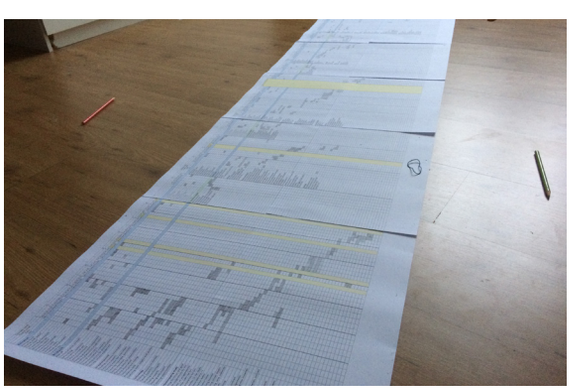


Figure 129. The extensive planning for this graduation project.

Course of the project

Amongst graduated students, the graduation project is known as the kind of project that comes with significant challenges. And so I faced some as well. These challenges were mostly on a personal level, not necessarily on a project level. But as personal life and graduation life are quite intertwined in this period of time, they influenced each other. Looking back at the course of the project, it went overall quite smoothly. There were moments in which I really didn't know what to do anymore. The approach of five design phases helped me follow particular design steps and thus I almost always knew what to do next. At moments where I would be a bit off-guard or stuck, I learned to reach out to people to support me in taking the next steps. Of course there were unexpected turns in the project, when a result would for example turn out different then excepted. But I learnt that the best thing to do is accept them, to be able to move forward. By doing so, no real barriers would rise. To learn to accept unexpected turns or events, requires being open and honest about the barriers you face. A great connection with the people you work with is therefore keen. Such relationships are established by being open and honest towards each other. I am glad I had the courageous to discuss any insecurities and share personal stories so that the course of the project could go as I needed or desired.

Final design

When is a design the final design? One of my personal challenges as a designer is to stop working on a design. When I get excited about a project I want to explore as much as possible to make sure the design solves all the problems. This project took on quite a complex problem which required me to explore many fields, do lots of research and combine lots of insight. All to come at this final design of Bitstory. I know that there is still much more that can be done regarding Bitstory. For example, the storycards require more testing and optimizing. But this graduation project has a limited time and at one point final choices were made. And these are presented in this report, knowing that even though more could have been done, these results are good.

Figure 130. Developing a good idea required doing lots of research, making many sketches and doing lots of tests.

Learning goals

At the start of the project I was aware that the graduation project bore some expectations as it is the final project to finish before getting a degree. To be easy on myself, I kept in mind that it was 'just like any other project'. Being aware of that fact I saw this project as an opportunity to learn new things, develop more skills or try out different methods. One of the learning goals I set was to develop my visual skills by making models and drawings to support text where possible in this report. I also knew that I wanted to develop myself more in the field of interaction design as I had done some extra courses of the master Design for Interaction and I became enthusiastic about this kind of design. Therefore I included a contextmapping study and learned to make a design vision. During the project itself I became curious about trying out new ways of analysing data. That is when I experimented by making a large visualisation of the results as shown in chapter the 'User research'. Although this was an unexpected learning point, I discovered that it was exciting to try own-developed methods . Therefore I would encourage all graduate student to try out something completely new using their own creativity and knowledge.

Personal development

During the course of this graduation project, a lot happened in my personal life. At some moments the project had to be paused so I could take time to process what happened before being able to continue. Upfront, I was aware that there are always unexpected events as I had experience with having to quite work due to sudden health-issues in the past. These events had learned me how to cope with such changes and to be open and honest about it to the people I work with. Looking back at this project, I acknowledge that it is a very personal one for me, not only due to the events that happened, but also because it helped me realize what I want to do in the future. I believe this project is a true reflection of who I desire to be as a designer, the kind of people I would like to help with my designs, the kind of solutions I want to develop and the kind of working environment I would like to be in. Overall, despite everything that happened, I am grateful for this project and what it has thought me.

Conclusion

Reflections were done on a project and personal level. Looking back at the events that happened, both expected or unexpectedly, offered opportunities to reflect, be critical and learn. But also to be grateful and proud of developments and achievements.

Personal tips

What helped me during this project?
What did I wish I knew upfront?
What were tricks to support yourself?
What would I do differently?

Personal health above all

If you get sick, mentally or physically, during your project, take time to recover. And if you get nervous that the project might extend time, most people understand that it is out of your power and that you work best when you are healthy. It shouldn't be a problem because being healthy is the most important thing.

Sketch, test, prototype

If you have an idea, test it as soon as possible. Preferably with the end users of your product or service. Start by creating a low-fidelity prototype which is quick and cheap to make. It doesn't have to be expensive or look beautiful. It is about getting feedback quickly to transform your idea into a great idea.

Be open and honest

To get the most out of the relationships with people you meet during your project, it is important to be open and honest about what you need or desire. People cannot read minds, so communicate what it is you want. But keep in mind not to be brutally honest if you think that may harm another person. Find a balance.

Go with the flow

Your graduation project is going to be like a wave: rising and falling. Sometimes the water is wild with high ups and downs, and sometimes it is more like rippling water. Accepting these flows help you with being okay with whatever happens along the way. And sometimes it is okay to fall as you will see that it eventually goes up again because that is how life is.

Talk, interact, listen

Someone else always knows something you don't. Talk to different kinds of people. They might give you new insights and perspectives. When you talk with them, try to truly listen and ask lots of questions. These skills come in handy for the rest of your life.

Who are you?

I am in doubt if anybody can answer this question, but thinking about it is important since the one person who is always around is you. And if you get to know who you are, what you want and need it becomes easier to get and do what you want and need.

Enjoy it

Too often we rush through things just to finish them and move on to the next thing. I think that is a shame. When you are in your graduation project, try to also enjoy what you are doing, what you are learning, the steps you are taking, the new people you meet, the challenges you overcome. Pause and enjoy what you are doing once in a while.

Prepare (for the unexpected)

There is only so much you can do to prepare yourself for different situations. I completely support being well prepared. But I also learned to embrace the unexpected. Especially because some unexpected turns do not have to mean anything bad. Try to learn from them and turn them into something positive.

Stop when its enough

A tutor of mine once told me, ''I cannot see all the extra work you put in after working hours''. The lesson I got from this was that it is not about working late night hours to make something more 'perfect', but learning to know when something is good enough. I learned that working less long, so not making late night hours, forces you to work more efficiently, which comes with overall more benefits such as less stress.

Make 'mistakes'

Brené Brown once said ''There is no innovation or creativity without failure.'' I agree. I would even argue that there is no such thing as failure or a mistake. Mostly because I think these terms are so negative. When you do something new, you are going to 'make mistakes', and that is exactly what you need to do to learn. How else would you get better?

Visualize your text

One thing I had as a goal for this report, was to visualize as much information as possible. In my opinion the use of visualisations in a report, and as this report emphasizes, has many benefits in relation to enhancing understanding of those who have to read the report.

Keep your goal in mind

I had a moment during the project in which I was lost and wondered: were is this actually going? For whom am I solving a problem? To help myself I noted down the main problems I was solving and thus the main goal I was following. This helped me to keep my focus and stay motivated.

Dare to do different

You might choose a safe and known way during your graduation project by following the steps you know you have to take in a design project. And that is okay as you need a certain approach. But I dare you to do one thing (or more) differently. Grab the opportunity to experiment in your study one last time.

Conclusion

A graduation project can bring expectations which may trigger in feeling pressured to perform well. What was helpful as a starting graduate student were experiences of other graduate students. These stories can make a student more aware of what is going to come and thus to prepare. Therefore, a list of tips was created based on personal experiences from this project to support other future graduate students.

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