Bitstory

Appendices

TU Delft

DE BUITENWERELD
buiten gewoon opgroeien

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Bitstory

Appendices

Romee Noorman
Master Thesis
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Diagnostic Criteria

Appendix A

Autism Spectrum Disorder 299.00 (F84.0)

Diagnostic Criteria

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in non-verbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and non-verbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and non-verbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:
Severity is based on social communication impairments and restricted repetitive patterns of behavior (see Table 1).

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal non-verbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:
Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 1).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment
With or without accompanying language impairment
Associated with a known medical or genetic condition or environmental factor
(Coding note: Use additional code to identify the associated medical or genetic condition.)
Associated with another neurodevelopmental, mental, or behavioral disorder
(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)
With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) (Coding note: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/ repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 "Requiring support	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

Figure 1. Severity levels for autism spectrum disorder.

Company analysis

Appendix B

In a company analysis observations of caregiving processes at De Buitenwereld and interviews with employees were done to discover insights, barriers and opportunities. For each observation or interview a description is given with a list of results.

Intake (observation)

What: an observation of an intake procedure.
Who were there: foster father, schoolteacher, behavioural scientist from De Buitenwereld and the designer of this project.
Where: at the school of the child who is in need of help.

Insights

The behavioural scientist who leads the conversation also asks most of the questions.

When the subject becomes more positive they complement each other and the energy changes positively.

A large white plastic sheet is placed on the table and used to make notes on by the behavioural scientist so that every one at the table can look at it.

The behavioural scientist tries to guide the conversation towards a more positive attitude when it becomes too negative.

Discussing moments that went well brings positive energy to the group.

The use of examples when a person speaks in the group makes their story more clear.

A conversation with different perspectives gives lots of insights. They all contribute to the knowledge about the child, and correct and complement each other.

The special moments that are typical for the child are valuable to discover.

Lots of appointments are made during the conversation.

Background information is very important to get a complete image of the child and to understand the child better.

The white sheet is valuable because others at the table can point to things that are written down.

When expertise is given by the behavioural scientist the group responses very well and they are eager to listen.

Barriers

The behavioural scientist has to write down a lot, both on the plastic sheet and in a separate booklet.

The white plastic sheet is making a irritating squeaking sound during writing and when erasing text with the hands.

The plastic sheet cannot be folded afterwards because this will erase all the results.

Not all the information that was given upfront is clear for the behavioural scientist.

There is a lot of information coming from all the people that are involved which makes it difficult to keep track.

The group talks a lot and therefore there is a lot of writing needed which can make it difficult to catch everything that is being said.

A lot of information on the child is still missing.

Details get lost in the conversation.

Situations at home and school can be very different.

Not all the information that is needed to make new appointments is there.

Lots of appointments are made during the meeting.

Everything has to be registered in NEDAP afterwards which costs time and energy.

Opportunities

Allowing other caretakers outside of the company into NEDAP to view client information and to provide comments.

Creating a tool to capture what is said more easily.

Replacing writing in a notebook by directly writing into NEDAP.

Using a digital board to write on instead of the white plastic paper.

Record the conversation to capture all details.

Keeping track of appointments in a shared agenda.

Having examples at hand that could describe different situations.

Creating a summary in the end of the conversation that captures the most important points.

Capturing the development of the child to see if there is any development over time.

Using a checklist to make sure all topics are covered.

Group-training (observation & interview)
What: interview with a group-trainer and observation of a group training.
Who: one caretaker who is also a group-trainer, two group-trainers, eight children and the designer.
Where: at one of the locations where group-training is given.

Insights

Behaviour in the group-training can be very different than at home.

De Buitenwereld has high responsibility in the group-training.

There is a difference amongst parents on their level of involvement.

Trainers have to keep track of a lot of goals of each child.

Knowing specific details about a child can help with understanding the child.

Trainers have an entire book with valuable information about each child.

This group works a lot with visual tools (e.g. icons) which help them in explaining. For example, in explaining the activities they will take on at the start of the day.

At the end of the group-training there is a short moment between group-trainer and parent to discuss what happened during the day.

Barriers

Some parents don't speak Dutch very well which can be a barrier in communication.

Sometimes parents cancel the group-training a few minutes before the start of the training while agreement is that they have to report a delay a few hours beforehand.

When a child is being difficult and there is only one trainer in the group it becomes difficult to manage the children while taking care of that particular child that is acting difficult.

Sometimes certain methods and tools do not work for a child.

When there is a replacement of a trainer it can be a struggle to transfer all the necessary information in a short time to that trainer.

During the evaluation moment in the end of the day the focus can be a lot on what went wrong instead of what went well.

Opportunities

Support parents in capturing details about their child and share them with the group-trainers.

Discover a way to facilitate transfer of information about children in a short period of time.

Use of visualisations.

Focus more on positive experiences.

Support parents in sharing important information.

Trajectory supervisors (interviews)
What: three interviews with trajectory supervisors.
Who: three trajectory supervisors and the designer.
Where: at the main office of De Buitenwereld.

Insights

The first meeting with parents is more of an open conversation to get to know each-other.

It can help as a trajectory supervisor to mention that you have children as well. This can enhance the feeling of trust.

Working with the family follows an Agile approach by working with sprints and setting goals.

The main goal of the caregiving processes is to empower parents in taking care of their own family.

There are differences between trajectory supervisors and their ways of caregiving.

Everything that happens related to the client is registered in NEDAP.

It can help parents tremendously if their supervisor is capable of asking the right questions.

Barriers

Parents stated that they do not have a network.

Parents stated that they do not want to bother others with their problems.

De Buitenwereld doesn't really use tools to support the creation of a network or mapping the current network to seek for opportunities.

Most parents are overloaded and stressed.

If a solution requires a lot of work it is probably not done by parents because they have no time and are stressed.

A lot of client-related time is spend on paperwork and registration.

It can be difficult to change information in the current system.

It can be difficult to map the needs of the family as they sometimes do not know what they need or how to ask for it. Not all parents make use of the fact that they can look into NEDAP as well.

Schools have their own approach on children and it can be difficult to agree upon use of likewise methods.

Parents stated that they have difficulties in asking for help.

There are too many requests for help and to little people that can help.

Not all parents are as intelligent as others which causes some of them to have difficulties understanding.

Parents can feel overwhelmed by many questions.

The supervisors have lots of responsibilities which can be challenging.

Opportunities

Solutions most cause as little time for parents as possible because parents have high levels of stress and little energy and time.

It is important to make clear to parents why they have to use the system because, at one point, De Buitenwereld will not be there anymore to support them.

A solution that is fun in use would support parents in participation.

The solution must be easy to adapt because information can change often.

Finding a solution that supports the creating of a social support network.

Solution that provides guidance for the trajectory supervisors but also provides room for their own decisions.

List of questions that can support parents in discovering what they need.

Creating a more open and vulnerable environment by asking questions like 'if you really knew me, you would know that..'

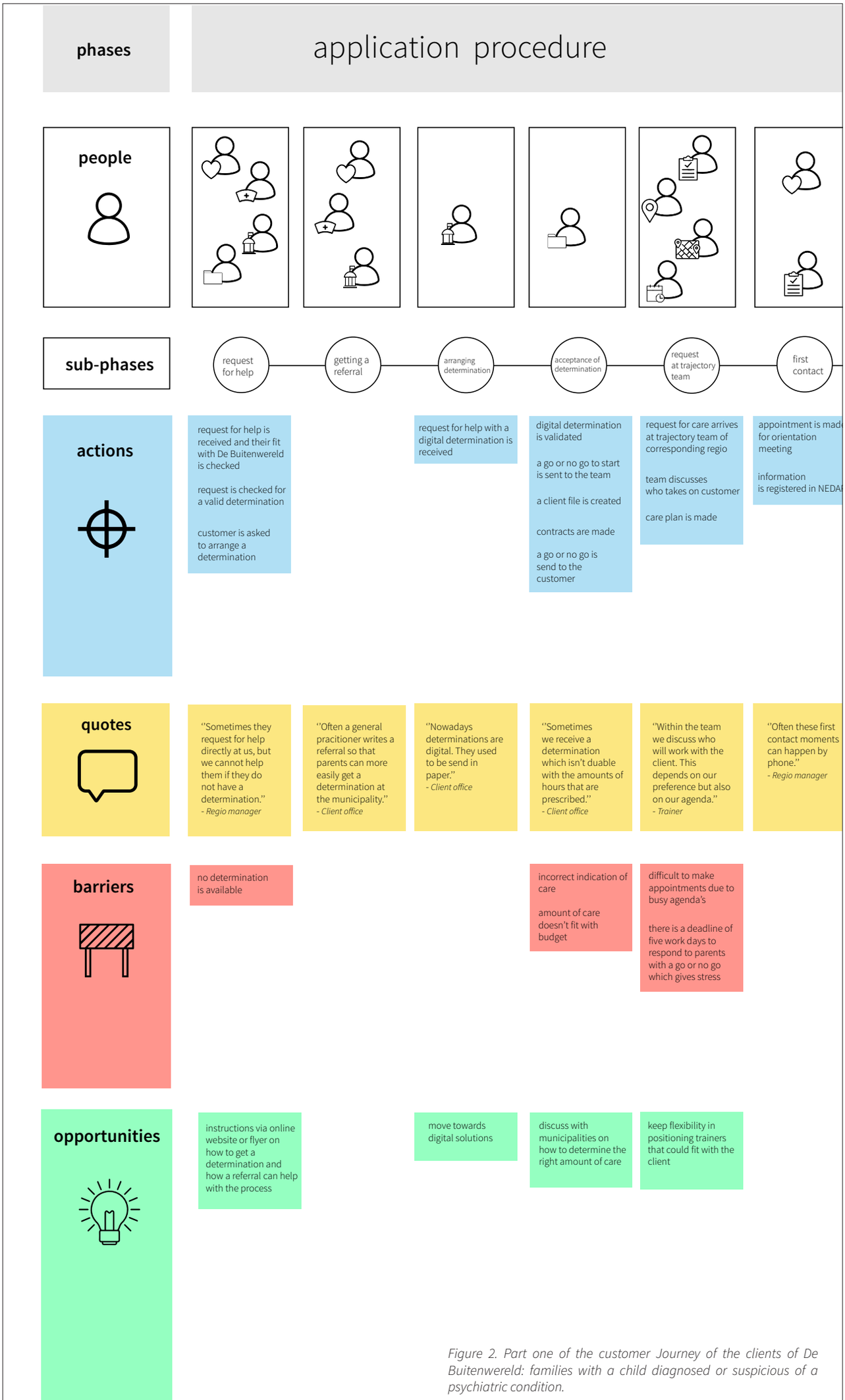
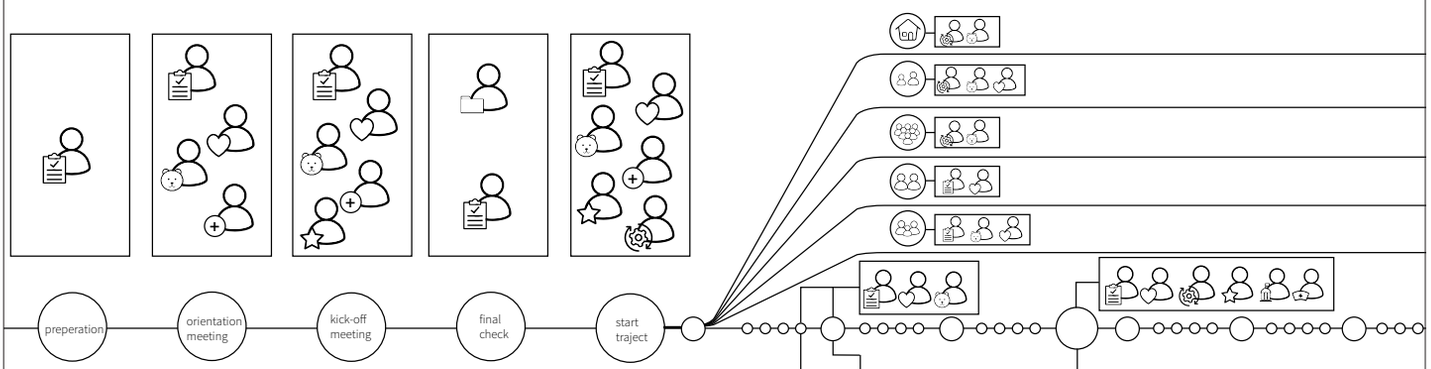


Figure 2. Part one of the customer Journey of the clients of De Buitenwereld: families with a child diagnosed or suspicious of a psychiatric condition.

preparation

treatment



preperation | orientation meeting | kick-off meeting | final check | start traject

customer information by institutions is read

customer and trajectory supervisory get to know each other

working with a JIM is proposed

the kick-off meeting is planned

who takes on care for which period of time is discussed

all information is registered in NEDAP

first three sprints are set

a profile of the child is made

questions regarding WWWWH are being asked

MDO 1 and weekly evaluation meetings are planned

care plan is written

all caretakers are updated

all information is registered in NEDAP

final check if every thing is arranged is done

sprint one starts

communication between all caretakers starts

care for the customer starts with all the involved caretakers

progress is discussed

goals are discussed

update to all involved caretakers is sent

sprint two starts

information is transfered to new sprint leader

update to all involved caretakers is sent

all information is registered in NEDAP

progress is discussed with entire team

goals are discussed

MDO 2 is planned

sprint 4,5,6 are arranged

all information is registered in NEDAP

"It can be a lot of paperwork to read."
- Trajectory supervisor

"I like to start the first meeting by just getting to know each other."
- Trajectory supervisor

"During the meeting we have to register everythin and also afterwards in NEDAP which is a lot of work."
- Trajectory supervisor

"I do a final check to see if everything is correctly arranged."
- Client office

"As a trajectory supervisor I am in control of all communication."
- Trajectory supervisor

"Parents sometimes find it difficult to capture the moments that don't go well."
- Trajectory supervisor

"We try to have another caretaker in charge for each sprint like a JIM."
- Regio manager

"During a MDO we will sit together with all the caretakers so that we can have a great discussion on how to continue."
- Regio manager

lot of time is spent on retrieving and reading the right information about the client

writing everything down in a notebook makes it difficult to catch all the details

difficulties with introducing new methods

having to register everything in NEDAP afterwards takes a lot of time

writing everything down in a notebook makes it difficult to catch all the details

having to register everything in NEDAP afterwards takes time

no use of standard formats

having to arrange a lot of steps requires lot of focus and efficiency

every family is different

lots of appointments have to be made with different stakeholders

communicating with all stakeholders requires lots of organisation

when there is a change all stakeholders need to be updated

there are differences between what parents tell and what caretakers experience

most parents do not look into NEDAP to see what has happened

no structure for the meetings

getting everyone together on the same date can be a hassle

getting to an agreement with lots of people who have different characters and perspectives is difficult

everybody has their own opinion on progress

make another person than the trajectory supervisor responsible for retrieving all the right information

arrange a standard format for these types of meetings

register during the meeting in NEDAP

make new methods appealing for the clients by showing benefits and using examples

use standardized goals for setting the sprints

have a shared agenda between all caretakers

register during the meeting in NEDAP

use a scheme to determine how much hours is spend on each sprint

use personalised solutions

use of a facilitator that guides the conversation

create a community platform of all stakeholders in which information and updates can easily be shared

visualize situations by parents to show to caretakers

integrate looking into NEDAP during the meetings with parents

visualize the development of the child to get everybody on the same line

have a facilitator during group conversations

use a standardized format

trajectory supervisor
coordinating the caretaking process of the client and providing support alongside

client office
controlling the request for care and determination and in charge of client file

parents/guardians
caretakers of the child

trainer
providing support to the child and family and teaching skills

planner
responsible for planning within the teams of trainers

child
child with suspicion or diagnosis of pshyciatric condition

regio manager
in charge of all teams within one regio

JIM
a chosen mentor who takes part in the caretaking process

professionals
involved caretakers such as general practicioner, youth protection, pediatrician

location manager
in charge of the teams of trainers who work on location

social team
team from the municipality

others
others involved with in caregiving such as a teacher

Figure 3. Part two and three of the customer Journey of the clients of De Buitenwereld: families with a child diagnosed or suspicious of a psychiatric condition.

Trend analysis

Appendix C

Demographic

- Aging of the population.
- Immigration.
- Growth of the population.
- Growth in demand for care.
- Growing inequality. Such large inequalities can lead to distrust amongst each-other.
- Feelings of loneliness, mostly amongst elderly, low-educated, non-Western immigrants and unemployed.
- Increase in stress levels.
- Work is becoming the main focus.
- Mindfulness as a new treatment method.
- Awareness for mental-wellbeing.
- Education is now longer within one family. Children are often are raised by several people and spend part of the week at different places.
- Use of brain enhancing drugs.
- Generation of sitting.
- Border between patient and consumer is fading.

Ecological

- Recycling: re-use of materials.
- Businesses move from products to services (servitization).
- Improvement of brand awareness by doing good.
- Awareness on meat industry as largest contributor to climate change.
- Sustainability is important for businesses to take into account.
- More information becomes available on the effects of medicine on humans.
- More information becomes available on the effects of food enhancers and processed food on mental and physical health.

Political

- Transition for the youth in care.
- Stimulus from government to use more new technologies in healthcare sector.
- Municipality care system.
- Data privacy regulations.
- Need for more preventive healthcare.
- Awareness for ethics. Discussion if we are being more controlled by technology.
- Discussion on the effect of labelling.
- Moving towards a participating society in which people take responsibility for their own life.
- Waiting lists of families that need care are growing.

Economical

- Transition towards a knowledge-economy.
- Growing economic inequality.
- The patient becomes in control of its own health and medical processes.
- Cost-conscious patient.
- Risk costs are moving from governmental budget to insurance budget.
- Consumers spent more.
- Everybody is a therapist. With the internet everybody tends to research their own situation.
- Increase in self-management books.
- Supply on demand.
- Crowd-sourcing.
- Acces-over-ownership.
- Sharing and exchange society.
- Companies are forced to shift towards adapting more services due to growth in sustainability problems.

Social

- Importance of educating patients in healthcare is increasing.
- Rise of eastern wisdom and traditions in Europe.
- Distrust in medical world by hearing negative stories through media.
- Specialists are replaced by machines.
- Storytelling used to connect with others.
- With the rise of digital media parents have less insights in what their children do.
- The number of choices a human is confronted with is increasing.
- Comorbidity: people having multiple conditions.
- People are more and more enabled to make their own choice of care.
- User experience in healthcare.
- The youth are the digital natives.
- Increase in use of social media.
- People are doing more at once which causes people to take less time and spend less attention on one task.
- Need for symbols and context to give meaning to life.
- Networking is becoming important in current society.
- Data-driven society, numbers are becoming more important.
- People live in a social media bubble. They only see news of people they are connected with.
- Rise of public speakers, books, films, and series about psychiatric conditions is breaking the taboo.
- Talking about feelings and being vulnerable is becoming more normal.
- Neuro-diversity movement in which autism isn't a disorder but a variety of the human genome. More focus on the unique qualities of the individual.
- Always, everywhere in contact with anyone.

Technological

- Digital detox by using yoga, travelling long journeys and mindfulness and meditation.
- Internet of things.
- Gap between healthcare and technology.
- Using technological gadgets to track yourself and support decision making.
- Need for more digital solutions in healthcare.
- Machine learning.
- Big Data using algorithms to develop new insights, tailored solutions and new treatment methods.
- Digitalisation.
- Data analytics.
- E-learning.
- E-health which uses digital tools to support care.
- Technology used to make businesses more efficient.
- Technology is speeding up our sense of time.
- Personalized health. Especially important since many conditions are complex and vary greatly amongst individuals.
- Tele-health allows for (long)distance consultation.
- Connected Healthcare connects stakeholders using connected devices.
- Wisdom of the crowd by creating online platforms that connect people who can share information and therefore knowledge.
- Artificial intelligence.
- Using gamification by adding gaming elements to a design to enhance the experience and encourage use.

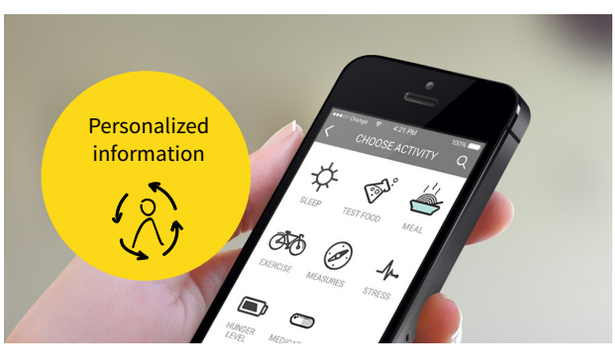
Eight trends and opportunities

Human behaviour can be tracked using digital devices that are connected to the human body to sense all kinds of information.

Use real-time data
Generate personal information
Retrieve deep insights
Use of wearables

Storytelling has been around for many years and is found in books and theatre. Stories are a way to connect people, share life lessons, discuss topics and express emotions.

Offer an engaging experience
Making others want to listen
Share a personal story
Share life lessons



Especially in the world of healthcare, personalised information has proven to be extremely valuable. It allows users to gain insights in their daily lives and discover patterns and therefore change undesired behaviour into desired behaviour.

Offer tailored solutions
Using big data
Changing behaviour
Building self-knowledge

Current society is moving towards a network society. With the internet and connected devices, communication is possible at any place with anyone at any time. Therefore it has become very easy to connect with others.

Create peer platforms
Building a support network
Offer easy communication
Offer easy connection

Waiting lists of families in need for care are increasing while the budgets are decreasing. There is a need for more preventive healthcare solutions which empower people to take care of their own health in their own environment.

Have care in own environment
Use of wearables
Use of big data analytics
Being able to track yourself and others

Digital products generate data. Big data are great amounts of data that are collected real-time and can be analysed using computers to discover patterns and trends.

Retrieve deep insights
Focus on preventive healthcare
Changing consumer behaviour
Offer tailor-made solutions

Children from 2010 up until now are living in an era of digitalisation. They grow up using mobile devices and the internet. These tools have become obvious and easy for them to use.

Using applications and devices for children
Using elements of gaming
Facilitate easy communication
Use e-learning

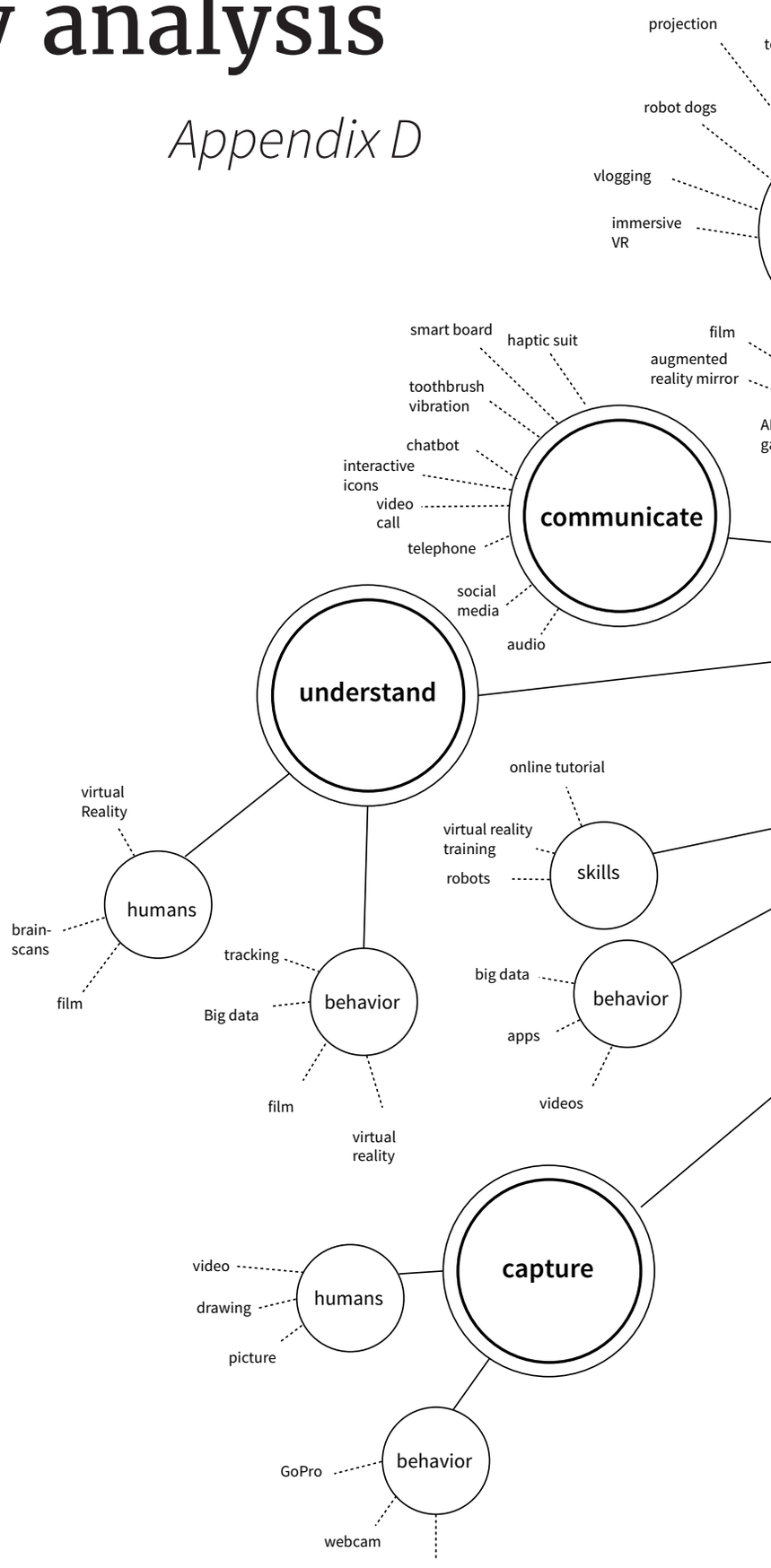
Gamification is using the playful elements of games to share information or teach desired behaviour. Through games multiple people can enjoy a fun way of learning.

Making a family game
Making learning more fun
Learn by playing
Building relationships through gaming

Figure 4. Eight trends that fit best with the project and opportunities they can offer the project.

Technology analysis

Appendix D



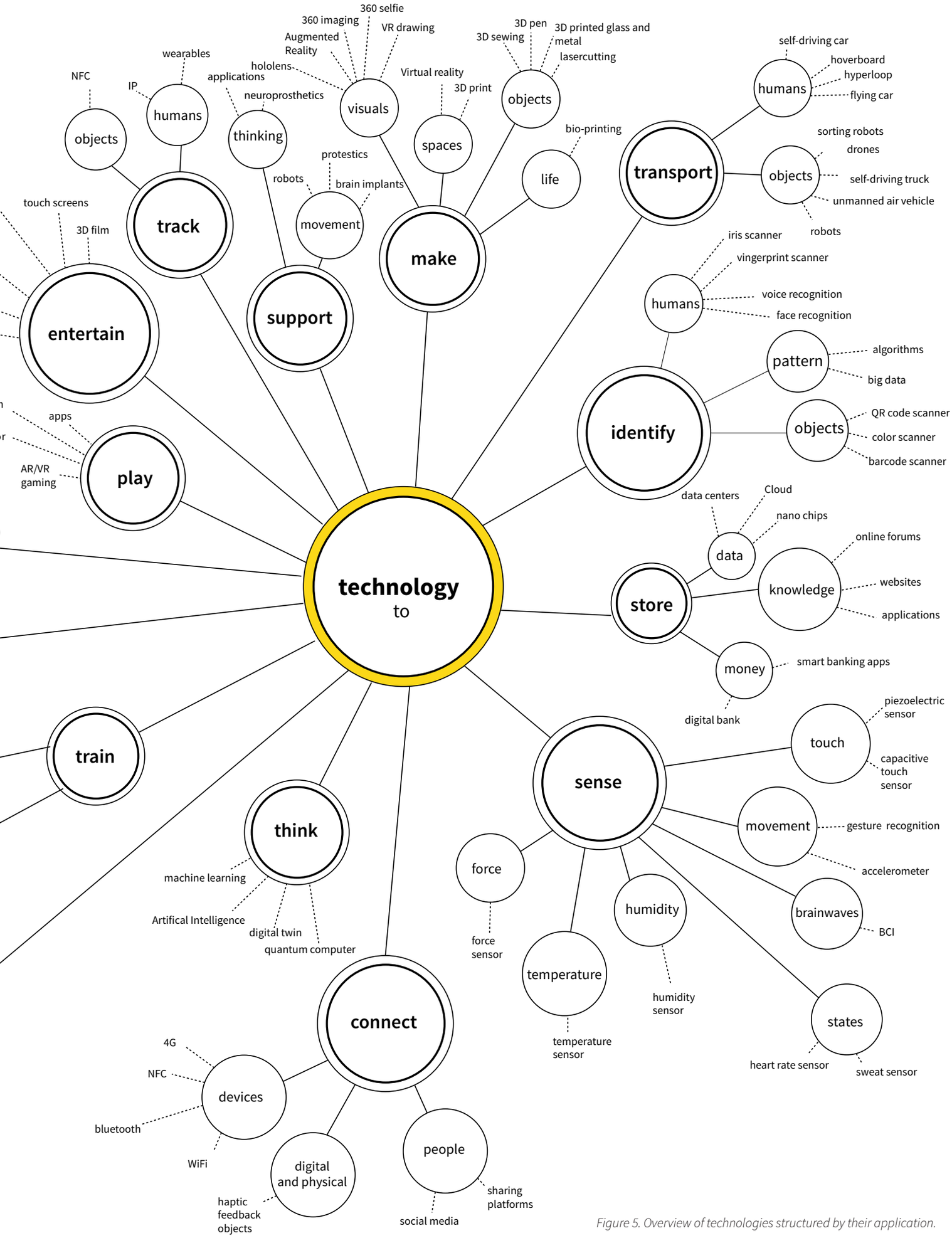
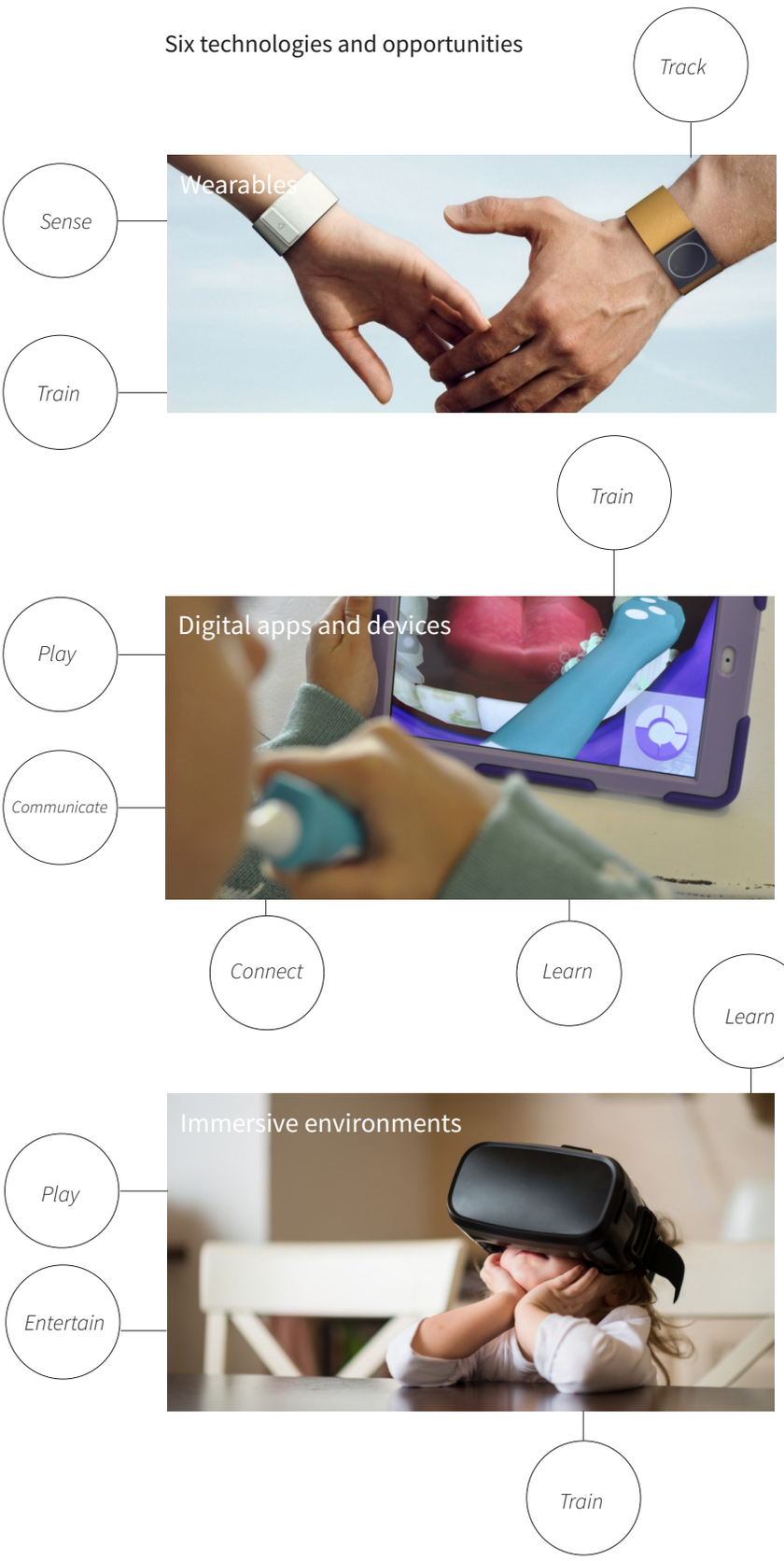


Figure 5. Overview of technologies structured by their application.

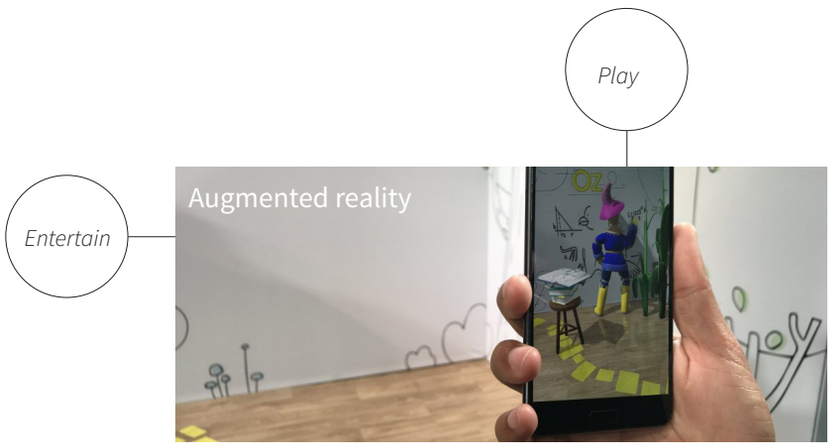
Six technologies and opportunities



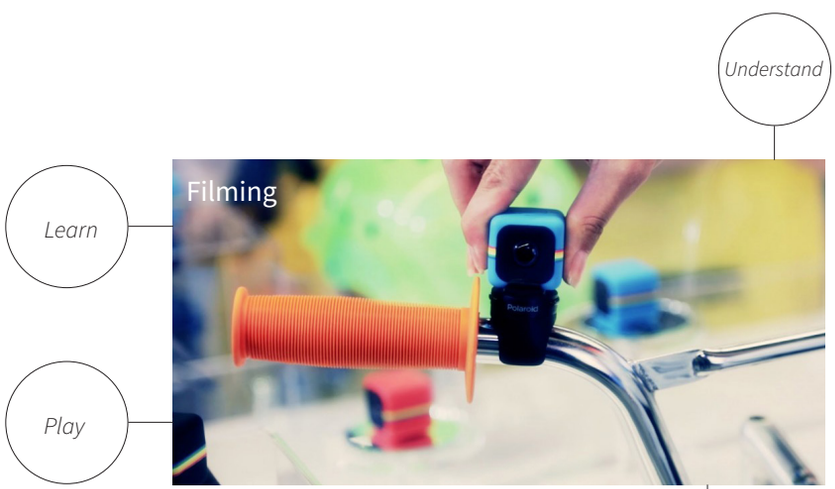
Wearables are devices that can be used to track and register all sorts of information like body temperature, stress, activity and hart rhythm. Wearables can be connected with mobile devices and often have an application that allows users to review their tracked data online. With the data users gain a better understanding of their behaviour.

Applications are software that can be used on or are connected with computers, mobiles, and other electronic devices. There are apps to train, game, learn, understand and support people in many different ways. Nowadays, a lot of people have various electronic devices with an internet connection, so these apps can be used almost everywhere by everyone. This makes it easy to share, communicate and connect people all around the globe.

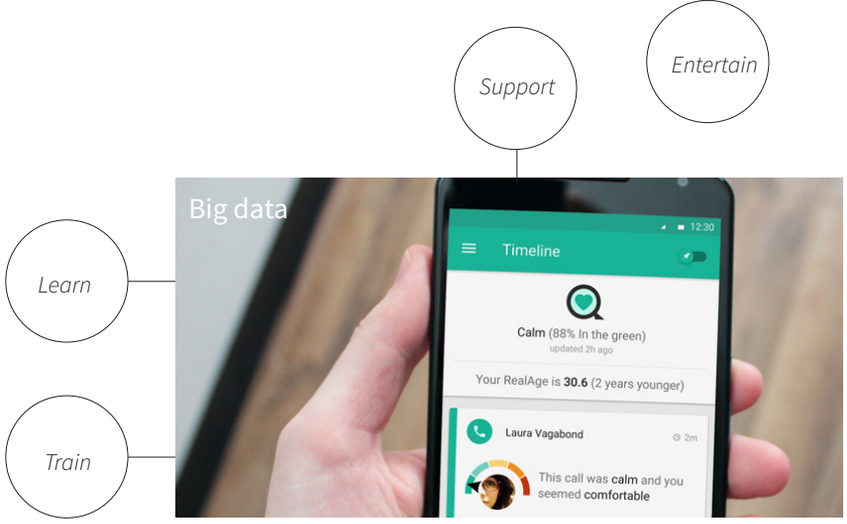
Virtual reality is a technology that combines a headset with computer software. This allows people to see a world around them that is completely virtual. Some of these immersive environments can be combined with other devices that stimulate the senses like an haptic suit which can give vibrations, or by using scents. It becomes more and more possible to recreate worlds and experiences which offers great opportunities for training and educating people.



With augmented reality people can see computer-generated images projected onto the real world via electronic devices like mobiles, tablets or smart glasses.
In contrast with virtual reality, which replaces the real world for a virtual world, augmented reality only enhances the current view on the real world and is used in real time.



Filming is a technology that has been around for many years. With a camera it becomes possible to capture the world either in picture or film. These can be used for various goals like entertainment, teaching, learning about topics or just simply capturing a special moment. Camera's have become very accessible to the public. They come in various sizes and shapes which makes filming fun and easy to do.



Applications can generate large amounts of data. Especially in combination with a wearable or other electronic devices that are connected with an app. Big data is the name for large amounts of data. With big data analytics, computers analyse the data to reveal patterns and in exchange they can give personalised suggestions to the user based on the analysed data.

Figure 6. Six technologies that fit best with the project.

User research

Appendix E

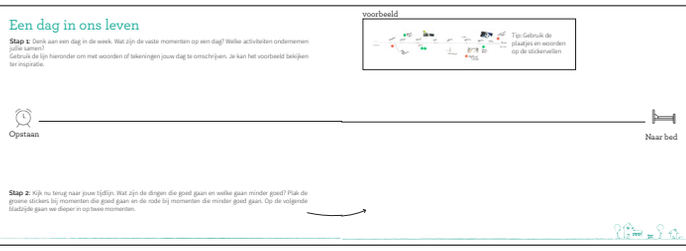
In the contextmapping study that was executed during the exploration phase, interviews were held at the participant's home. Beforehand a plan was made with a checklist to make sure nothing was forgotten (figure 6). Spreads of the sensitizing booklet with various assignment that was created for this research is shown in figure 7.

Time	**To do**	**Checklist**
-	Packing and controlling the checklist	• Post-its • Reserve booklet and materials • Book for notations • Pens and markers • Pawns • Thank you gift • Camera + adapter • Tripod • Mobile + adapter • Contact information • Confidentially Contract
-	Departure to family	
15 minutes	Introduction	• Introducing everyone • Signing the contract • Explaining the research • Setting up the camera and audio recorder
30 minutes	Going through booklet	• Discussing assignments • Asking about reasoning • Pointing out striking elements • Asking about needs
15 minutes	Pawn assignment	• Ask questions: Who were important people? Why were they important? Are they still in your network?
30 minutes	Continue going through booklet	• Discussing assignments • Asking reasoning • Pointing out striking elements • Asking needs
10 minutes	Saying goodbye	• Rounding off • Stopping camera and audio • Giving thank you gift

Figure 7. Timetable and checklist for preparation of the user interviews in the contextmapping study.

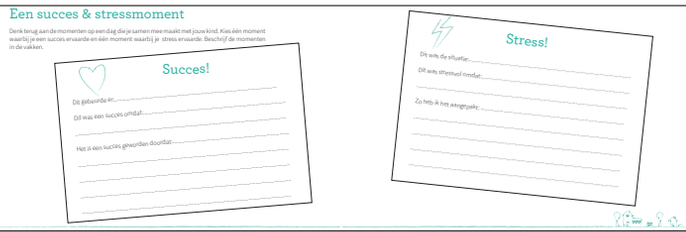
My family
Describe your family and what you like to do together.

Goal: exploring what words and images they use to visualise their family. Finding out what they do together as a family.



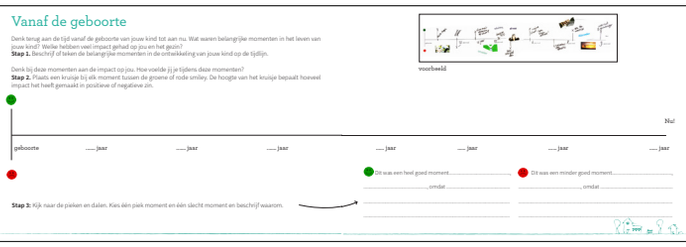
A day in the life of
Describe a day in your life with the family.

Goal: discovering the good and bad moments on a day and why thy are good or bad. Gaining insights in the structure of their daily life. Discovering patterns and routines.



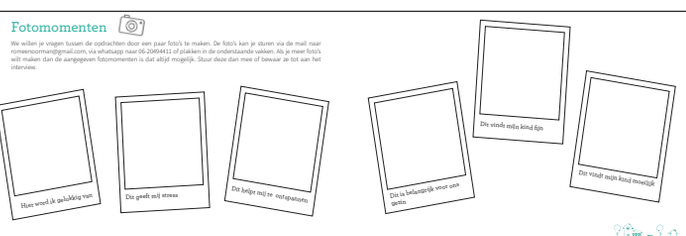
Success and stress moment
Pick a success and a stress moment and describe what happened.

Goal: finding out what parents consider as stressful or successful moments and what they did to either celebrate or solve them.



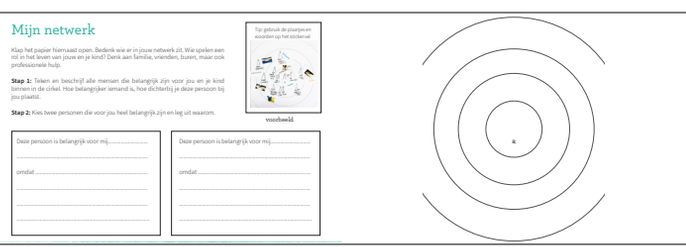
From birth till now
Describe major events from birth till now.

Goal: discover what events in the last years made an impact on the family. Finding out how these affected their well-being.



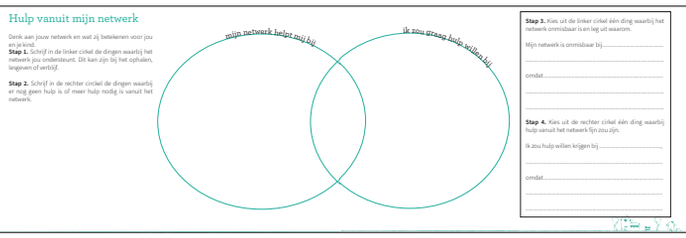
Pictures of moments
Make pictures and paste them into the booklet.

Goal: gaining visual information about their lives. Activate parents in taking pictures of important things in their life.



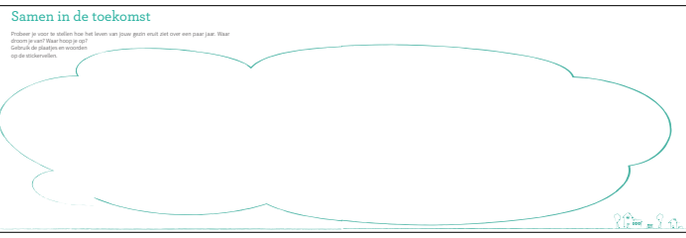
My network
Draw who is in your network.

Goal: discover who is in their network and why some are more important than others.



Support from network
Describe how you network supports you.

Goal: discover on which tasks they ask for support from their network. Finding out if there are things they miss from their network.

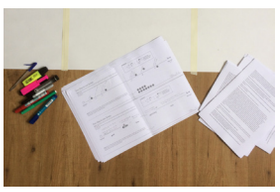


The future
Describe how you see the future with your family.

Goal: discover how they see there future as a family. Finding out what their dreams and worries are.

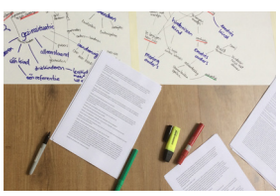
Figure 8. Spreads of the sensitizing booklet with an explanation.

Steps of analysis



1. Preparation

- Transcribing the interviews and printing the transcriptions on paper.
- Scanning of the booklets and printing the scans on paper.
- Buy coloured markers, A3 paper sheets and tape.

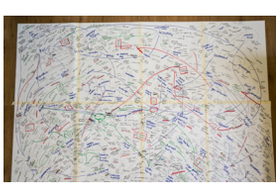


2. Large data visualisation

- Taping several A3 sheets on the ground to create a large paper sheet.
- Scanning through the interviews and booklets for interesting quotes.
- Capturing al the interesting pieces of data in key words and writing them down on the large paper sheet on the ground.

3. Developing ideas and insights

- Using separate paper sheets to note down ideas and insights that arise during the process of making the data visualisation.



4. Making categories and relations

- Creating categories and relations between the data found from the interviews and booklets on the large paper sheet.
- Using the different coloured markers to indicate differences in relations e.g. the colour red for problems and green for positive points.

5. Clustering

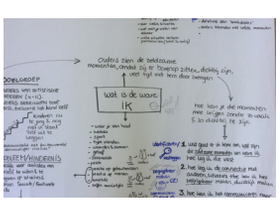
- Putting a layer of transparent paper on top of the large paper sheet.
- Going through all the data through the transparent paper to seek for the most important parts.
- Clustering the most important points on the transparent sheet.
- Labelling the clusters using keywords.

6. Focussing

- Going through the clusters to seek for relations amongst them.
- Picking one or more clusters that provide the most important insights.

7. Deeper insights & patterns

- Going into more detail on separate papers to generate insights.
- Seeking for patterns and discovering relations.
- Narrowing down to what seems to be the main problem.



8. Focus on one main insight

- Focussing on one main insight that can be used to develop a goal and design direction.

Figure 9. Steps that were taken to analyse the data that derived from the user research.

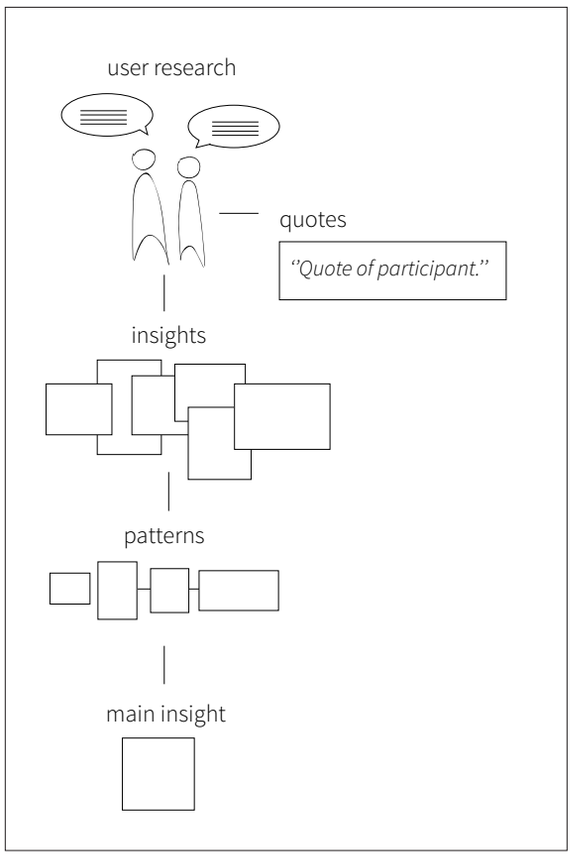


Figure 10. Discovering a main insight.

Focussing insights

In the process of analysing the data, many insights were gathered. An insight is a great starting point to discover a main problem which can be used to formulate a goal and design direction. However, not all insights can or should be taken into account because it is simply too much to all include. Therefore it is important to narrow down and focus on one main insight to give direction to the design process.

Focusing was done by reviewing groups of data on the large paper sheet and see if it was possible to capture them in one sentence as an insight. These insights were than compared to see whether there is a relationship between them or if there is one insight that stands out. As shown in figure 10 it was discovered that most of the insights concern a need for understanding. These insights show problems around lack of understanding and so there is a need of parents for others to understand their child and their situation better. This insight was chosen as the main insight to continue with for formulating a main goal.

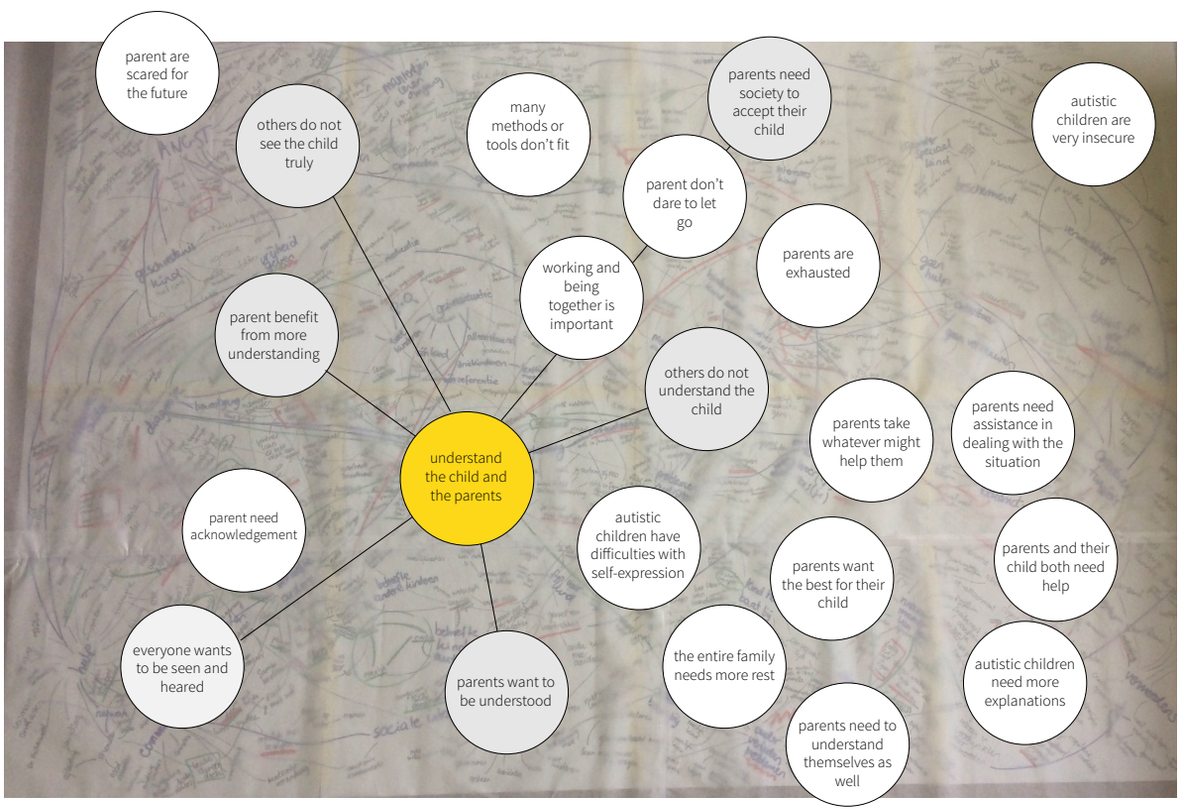


Figure 11. Relation between the main insight and some of the other insights that arose from analysing the data.

Stakeholder needs

Appendix F

Structuring needs

Results from the user research and company analysis led to finding lots of problems for both stakeholders. These problems were categorized, compared and connected. As a result, an overview of needs was created (figure 12). These needs, as shown in yellow, were structured based on their application (figure 11). Most of the needs are used to formulate requirements. Other needs are better to formulate wishes. One need is used as an inspiration for formulating the design vision and the last need is the main goal for the project.

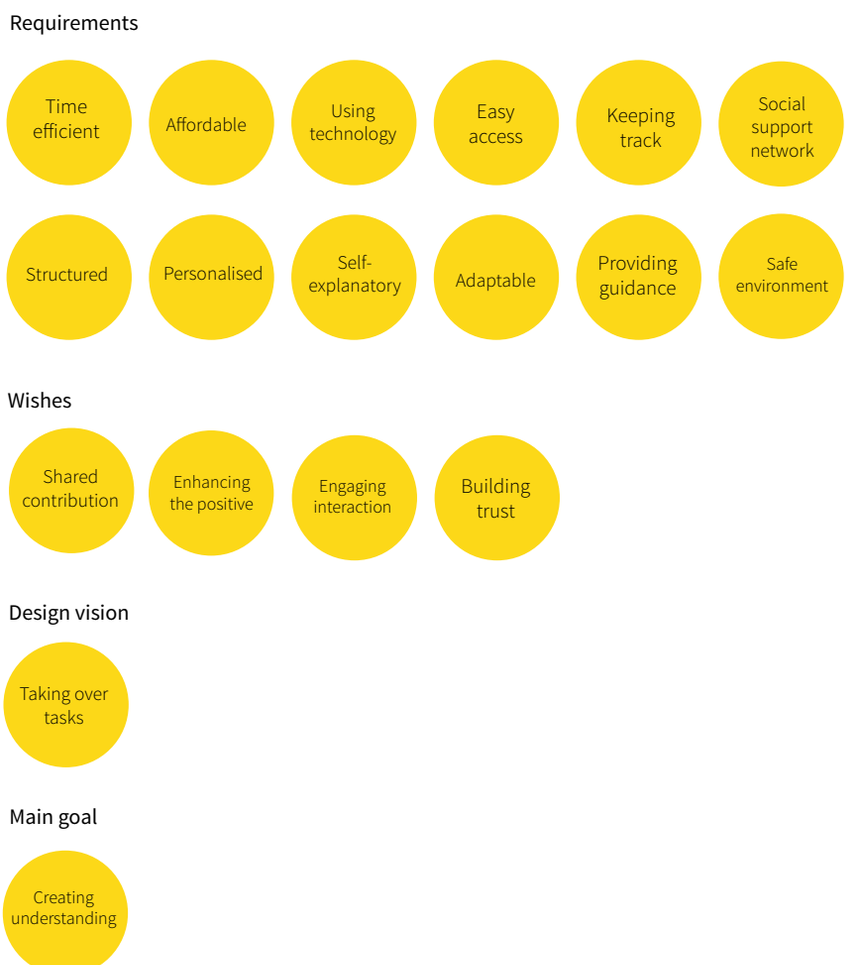


Figure 12. Overview of the eighteen needs structured on their application in the project.

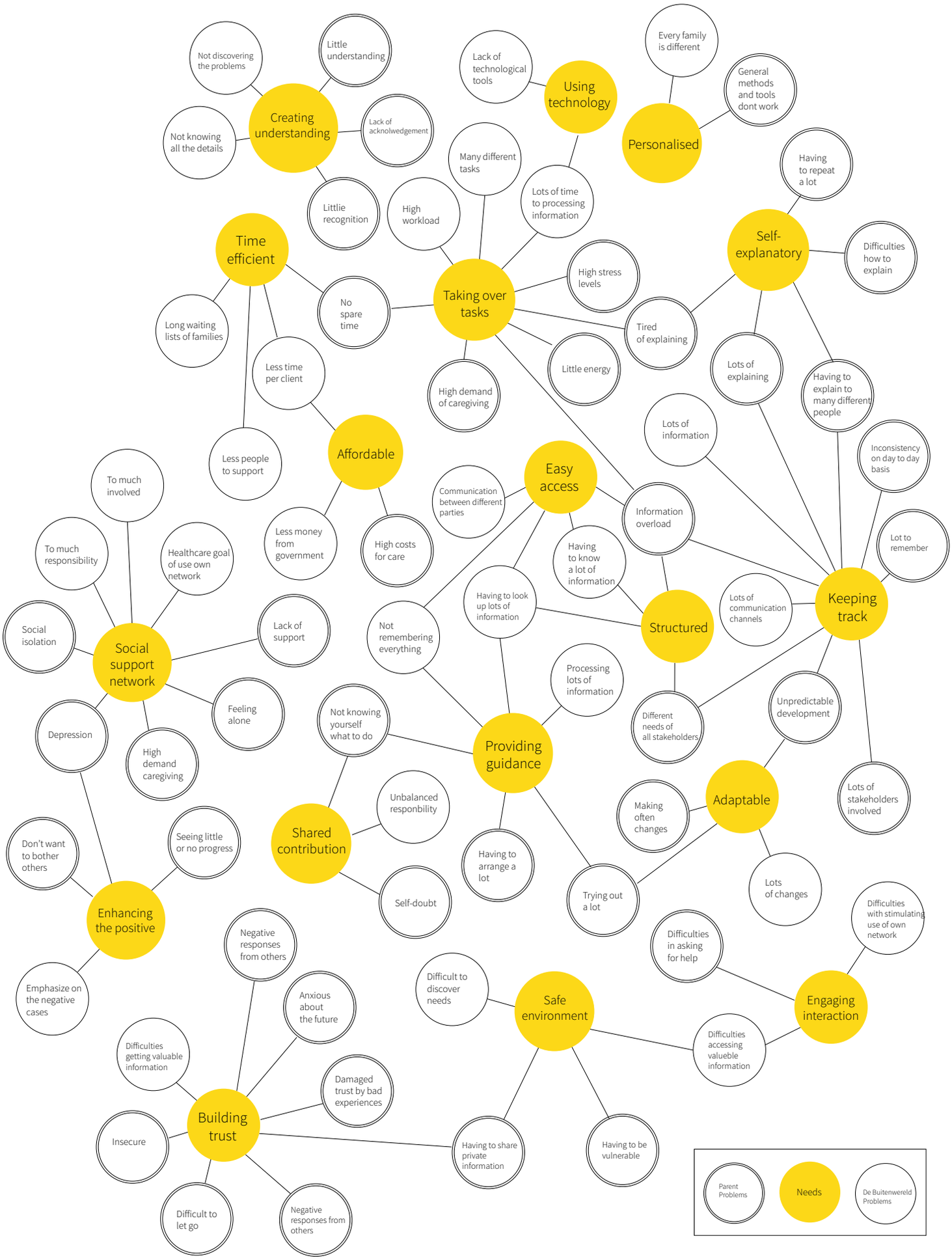


Figure 13. Structure of problems for both stakeholders resulting in eighteen needs.

Enhancing understanding

Appendix G

Pattern of understanding

Enhancing understanding, the main goal for this project, doesn't happen without any effort. Some actions are required to start this process. Looking back at the data from the user research a pattern was discovered relating to enhancing understanding. At the start is the act of sharing information. Without information from the parent about his or her situation, any other cannot understand. Figure 13 visualizes this pattern and shows how sharing information, represented by the black lines, can lead to a better understanding, which leads to feeling reassured and trusted. These feelings are very important for parents to be able to build strong relationships.

However, just sharing information isn't enough. How the information is being shared and the type of information are important factors. Also the people who are involved in the act of sharing are important as they have their own opinion and needs which can influence understanding. At last, the context of where the information is being shared can influence the process of enhancing understanding. Therefore it is important to know for each of these four components what is required or is desired to enhance so that the chances of successfully enhancing someone's understanding are increased.

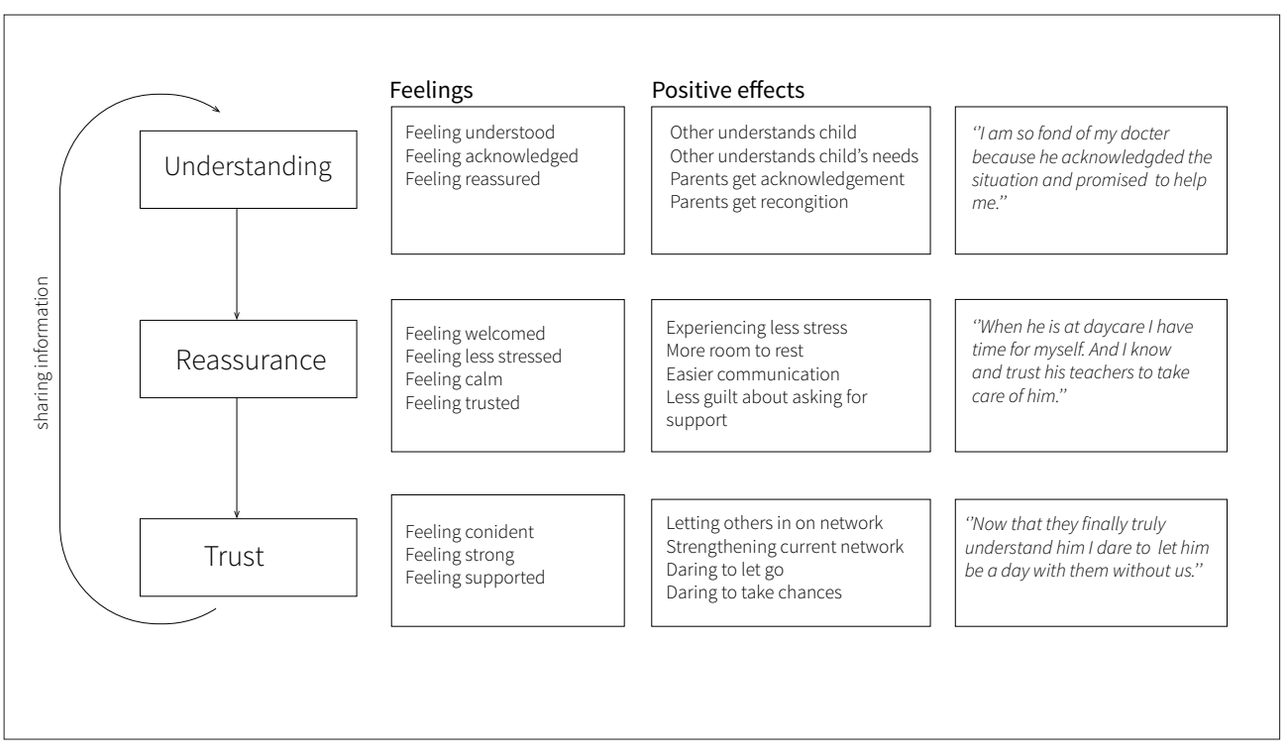


Figure 14. Relation between understanding, reassurance and trust. Each step evokes feelings that could lead to positive effects.

Why understanding?

The main goal for this project is to enhance other people's understanding who are involved with the family and their autistic child. These others are those who are in a sense responsible for the child or involved in any way, or offer emotional support to the family. Enhancing their understanding has many benefits for the parents and their child. Figure 14 gives an overview of several reasons why this main goal is so important for the parents and family.

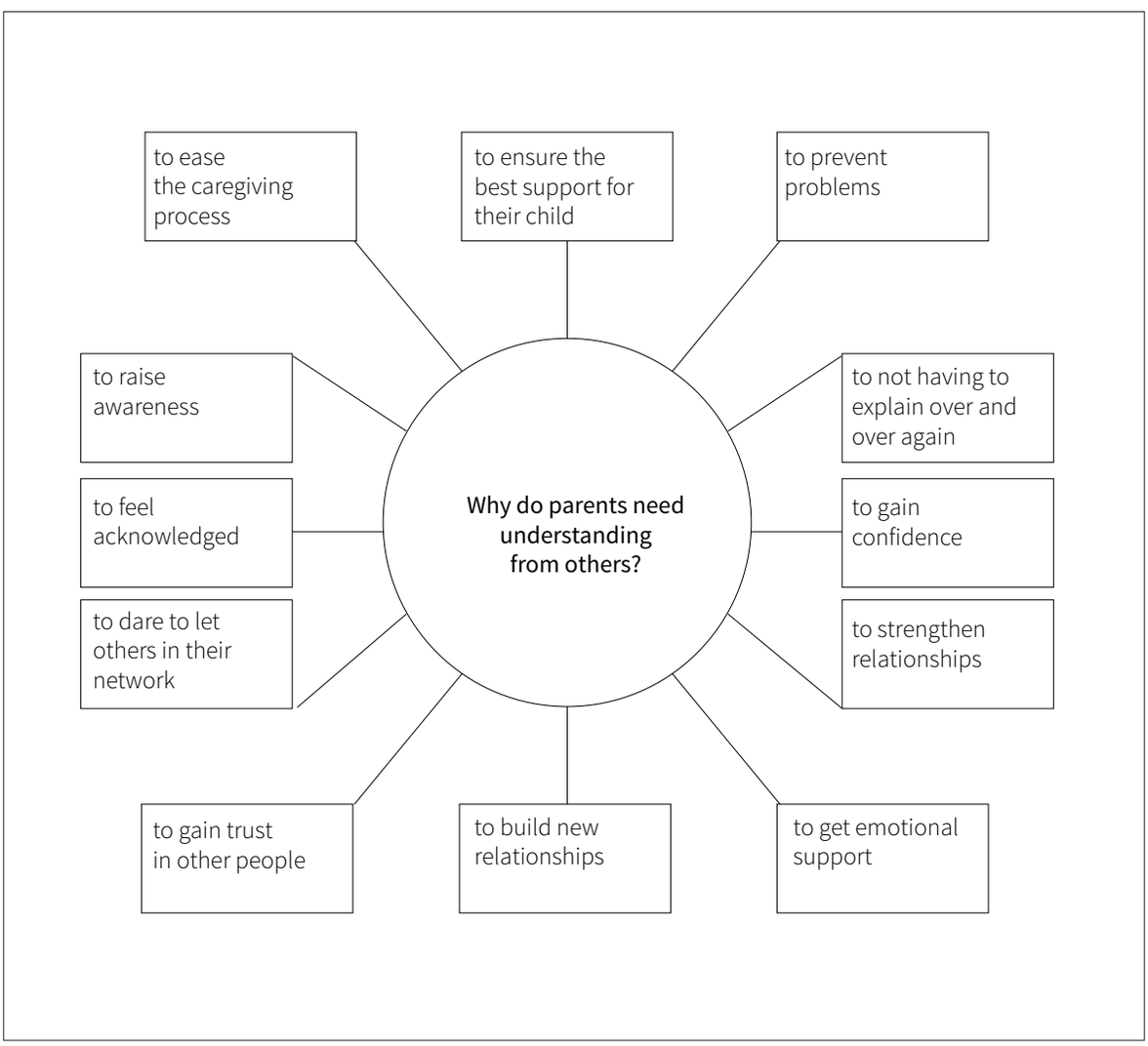


Figure 15. Reasons why parents need a better understanding from others.

Desired criteria

In the moment of understanding between a parent and another person, there are four components that can influence the enhancement of understanding: the parent, the other, the information that is shared and the context the moment takes place in. For each of these components desired states were found which support enhancement of understanding (figure 16). These were derived from literature, online research and from the creative sessions that were held in ideation. Starting with the parents, during the role-play assignment in the brainstorm session with the company, it was discovered that conversations can become difficult if a parent isn't clear about what they need. Therefore it is important for parents to be well-prepared before going into a conversation with any other person of whom more or better understanding is desired. For the component of information that is being shared, one of the desired states to support s understanding is the use of visualisations like pictures and graphics (Balm, 2014). Concerning the other person, it is important to listen and ask questions (Headlee, 2016). At last the entire conversation and exchange of information takes place in a certain context. An environment in which both people are open and accepting of each-others opinion supports understanding (Economy, 2017). The overview of desired states can be used to gain a better understanding of what is needed in the design system to support enhancement of understanding and to generate requirements for the system.

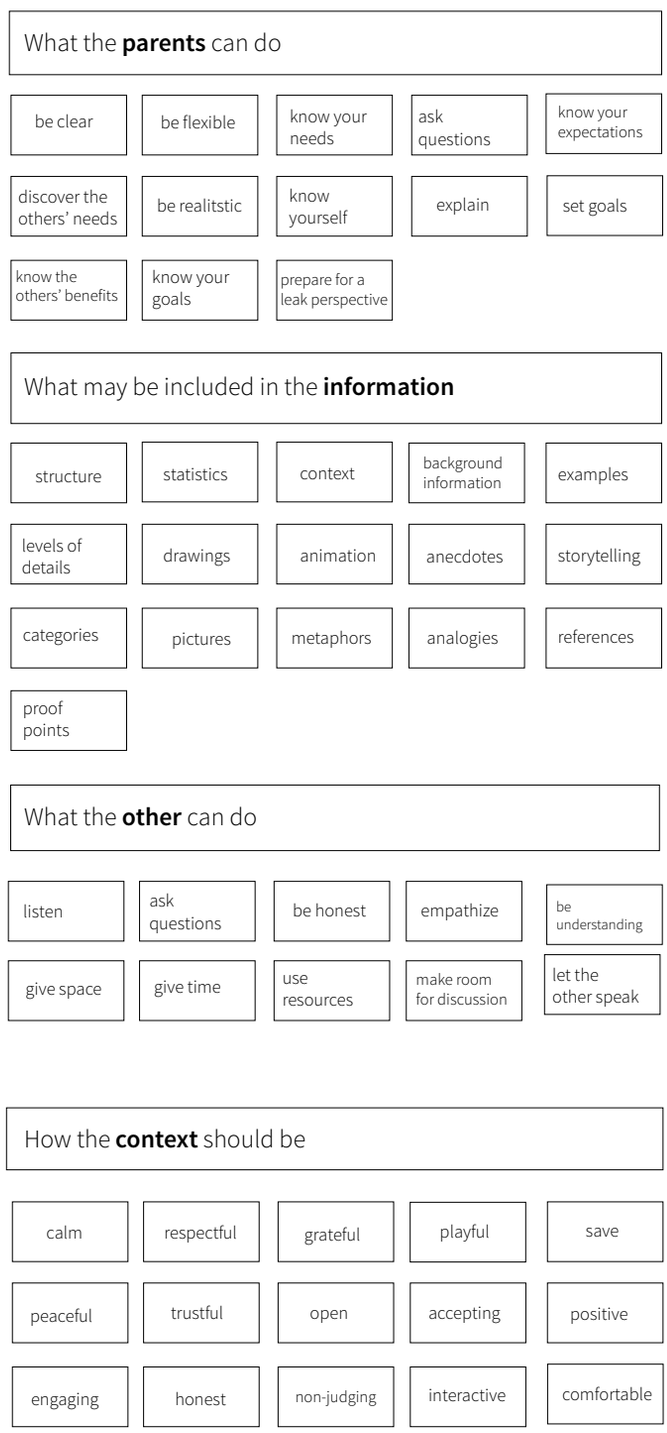


Figure 16. Desired criteria for the four components that play a role in the moment of understanding.

List of requirements

Appendix H

Performance
The design is made for parents of children aged 4-12 diagnosed or suspicious of ASD.
The design empowers parents to require less support from De Buitenwereld.
The design allows for different needs that meet the four types of parenting found in the user research.
The design allows for tailor-made solutions.
The design provides clear instructions.
The design reminds parents of using it.
The design has a clear motivation of use.
The design is time efficient.
The design has a guideline for De Buitenwereld.
The design captures information.
The design registers information.
The design identifies information.
The design shares information.
The design enables communication with others.
The design can be connected with mobile devices.
The design uses a digital solution.
The design is embedded with technology.
The design is responsive for multiple digital devices.
The design stimulates building and strengthening of the social network.
The design empowers parents to be in control of their caregiving.
The design improves quality of care.
The design can be used where the child is.
The design allows for personalisation to fit best with every families personal situation.

Environment
The design fits within various contexts.
The design fits in De Buitenwereld context.
The design can be used indoors and outdoors.
The design functions at temperatures between -10 and 40 degrees Celsius.
The design can be put into silent mode.
The design can be adjusted in amount of light.

Life in service
The design can withstand a force of 200 N.
The design is shock resistant.

Maintenance
The design is chargeable.
The design can be cleaned.

Production costs
The design is free in use for the parents.
The design has proof of success to establish investments.

Transport
The design is can be transported by hand.

Packaging
The design comes with clear instructions.
The design uses packaging to protect products.

Quantity
The design is targeted at the Dutch market.
The design is for parents of De Buitenwereld who have a child, aged 4-12, with a diagnosis or suspicions of ASD.

Production facilities
The production is outsourced to third parties.
Products that aren't newly designed are purchased at external companies.

Size and weight
The design can be carried by one person.
The design has a weight of <1 kg.
The design fits in to a hand bag.

Form, colour and finishing
The design allows for personalisations.
The design fits with the style of De Buitenwereld.

Materials
Materials are scratch proof.
Materials are in conformity with EN 1888 and Toxicity (EN71-3).

Product Life Span
The design is used for at least as long as the trajectory of De Buitenwereld that is offered to the parents.
The design is used in meetings between the trajectory supervisor and the family.
The design uses durable and strong materials to ensure a longer life span.
The design is energy efficient.

Standards, rules and legislations
The design meets governmental regulations.
The design meets CE safety regulations.
The design meets European standards.
The design meets the AVG law.

Ergonomics
The design targets Dutch adults (P5-P95).
The design fits can be used in various activities e.g. walking, running, playing.

Reliability
The data that emerges from the design is backed up.
The data is secured.

Storage
The design stores data.
The design allows for storage of 10 GB.

Safety
The design doesn't use harmful materials.

Product policy
The design generates data.
The design connects with devices used by De Buitenwereld.

Societal and political implications
The design doesn't violate registered patents.
The design fits with the transformation goals.
The design stimulates use of parent's social network.
The design empowers parents to be in control of the caregiving processes.
The design is cultural appropriate.
The design is gender appropriate.
The design meets regulation rules.
The design meets privacy rules.

Installation and initiation of use
The design is self-explanatory.
The design is introduced by De Buitenwereld.
The design is explained by De Buitenwereld.
The design is used by De Buitenwereld.
The design is installed by De Buitenwereld.
The design is provided by De Buitenwereld.
The design explains the benefits of using.
The design has an agreement contract in which users agree upon the terms of working with the design.

List of wishes

Appendix I

Figure 17. List of wishes based on quotes derived from the user research.

Ideas

Appendix J

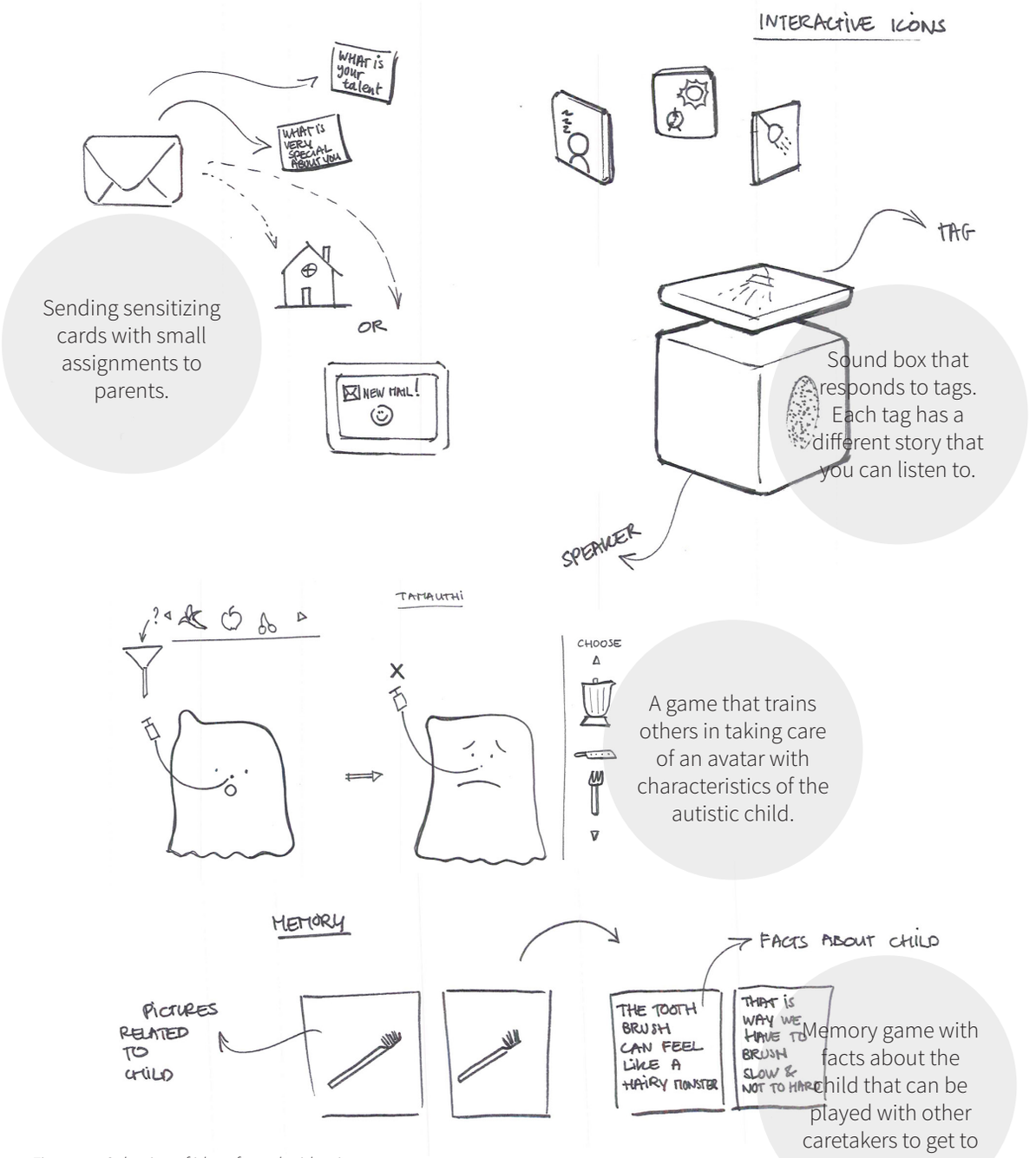
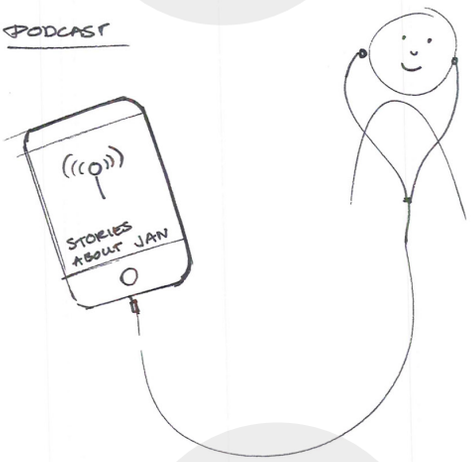
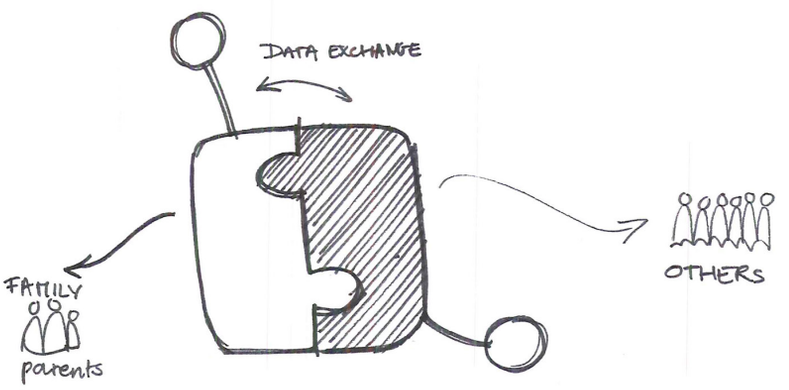


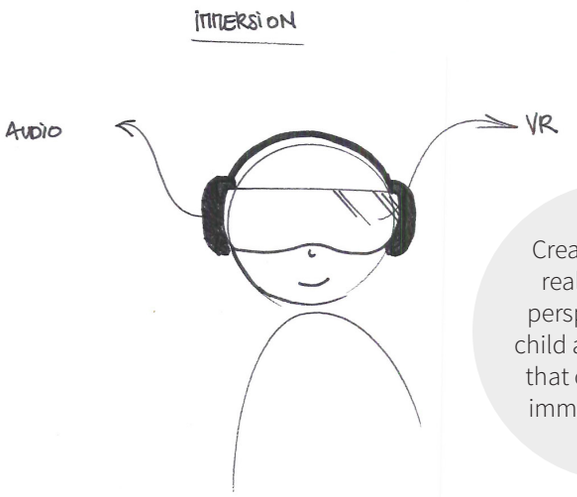
Figure 18. Selection of ideas from the ideation.

Podcast stories made by parents about their child and their unique situations.

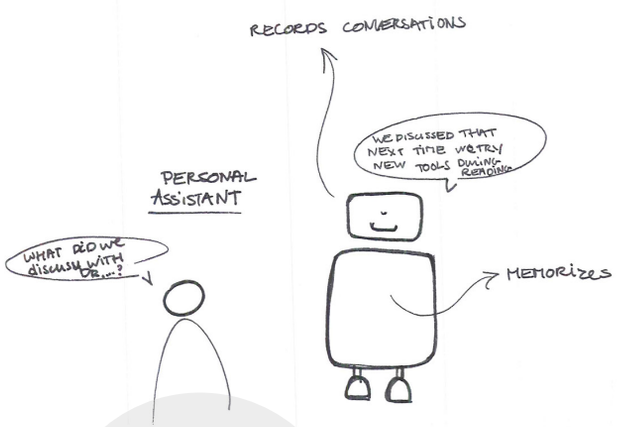


Key-chains that exchange information about the child when both parts are connected.

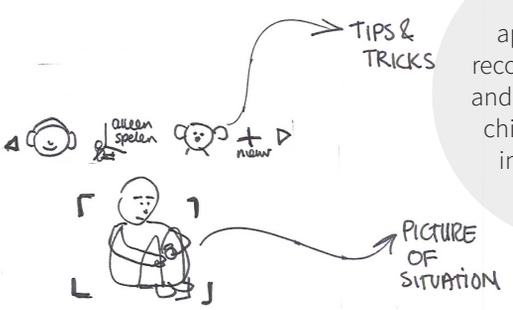




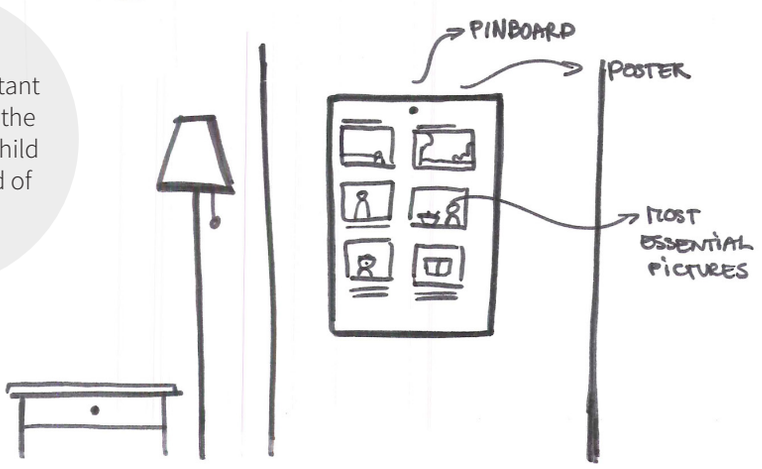
Creating a virtual reality from the perspective of the child and parents so that others can be immersed in their world.



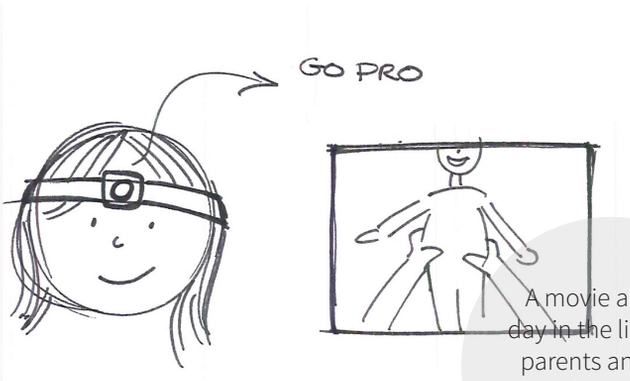
Storytelling assistant who can explain the story about the child to others instead of the parent.



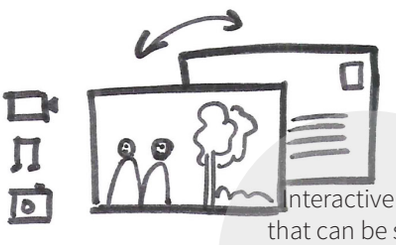
Recognition application that recognizes emotions and behaviour of the child and provides instant tips and tricks.



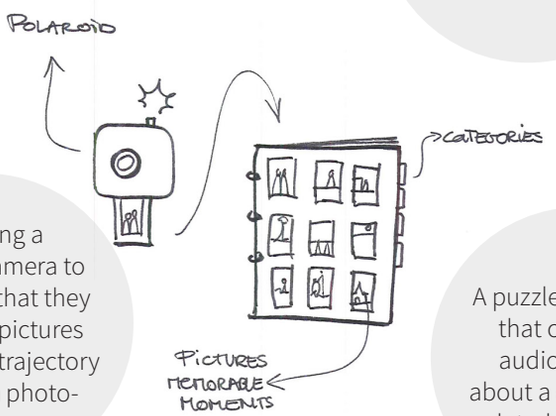
Wall of pictures about the child which can be placed in the house so that others can have a look and learn.



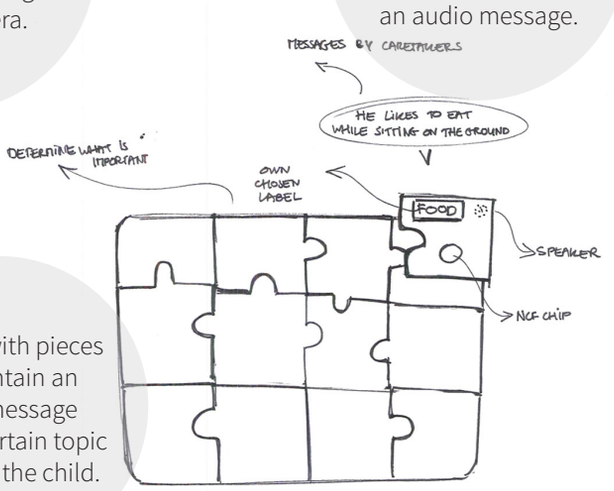
A movie about a day in the life of the parents and their child, filmed using a Go Pro camera.



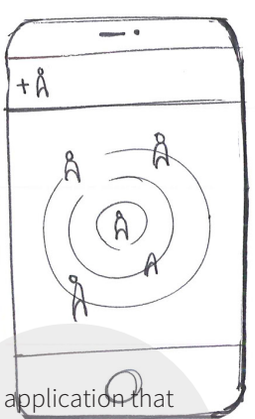
Interactive cards that can be send to others with a short video or picture and an audio message.



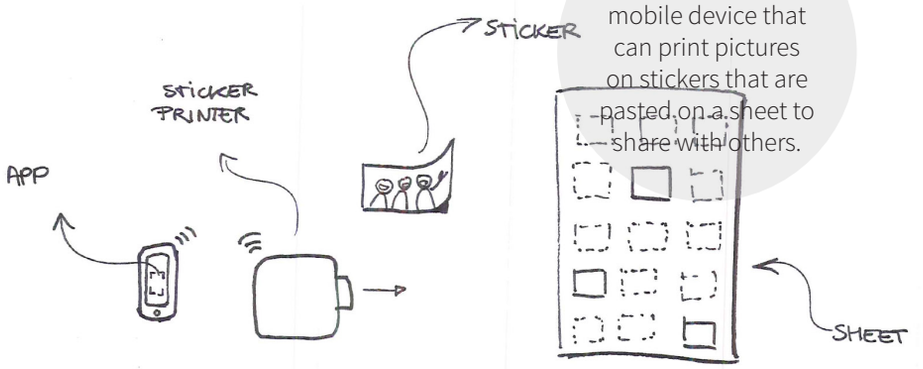
Providing a polaroid camera to families so that they can make pictures during their trajectory to create a photo-album.



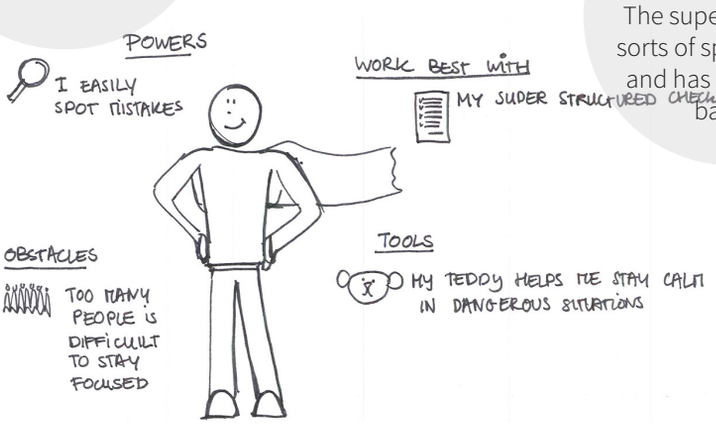
A puzzle with pieces that contain an audio message about a certain topic related to the child.



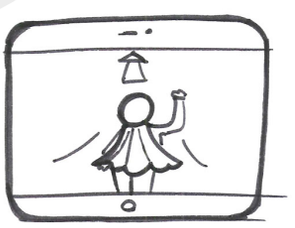
An application that keeps track of which people are involved in the network around the child.



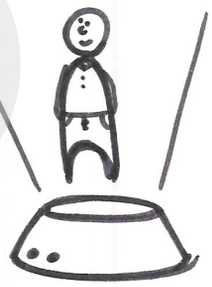
A mini-printer connected with a mobile device that can print pictures on stickers that are pasted on a sheet to share with others.

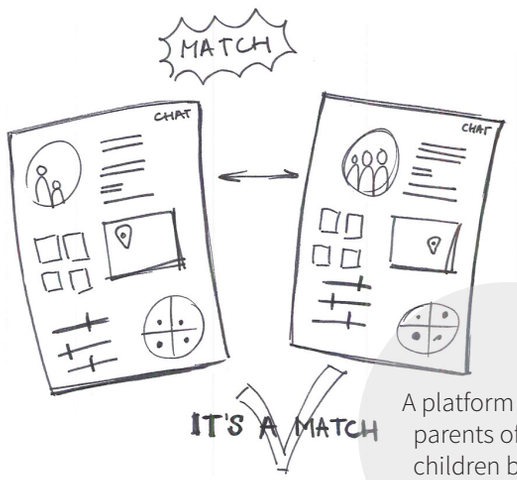


Creating a superhero of the child in a game. The superhero has all sorts of special powers and has to overcome barriers.

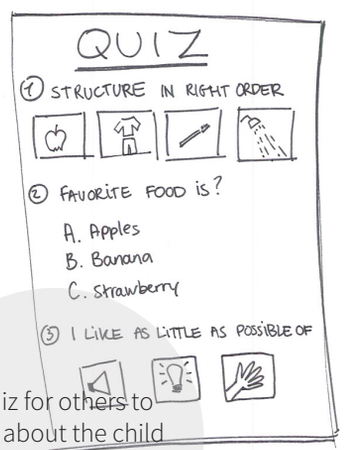


A hologram of the child which can be used to show for example different kinds of behaviour.

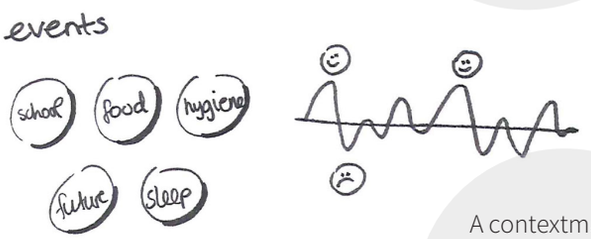




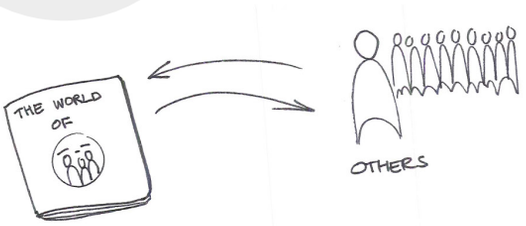
A platform to match parents of autistic children based on their needs.



A quiz for others to learn about the child and their situation.

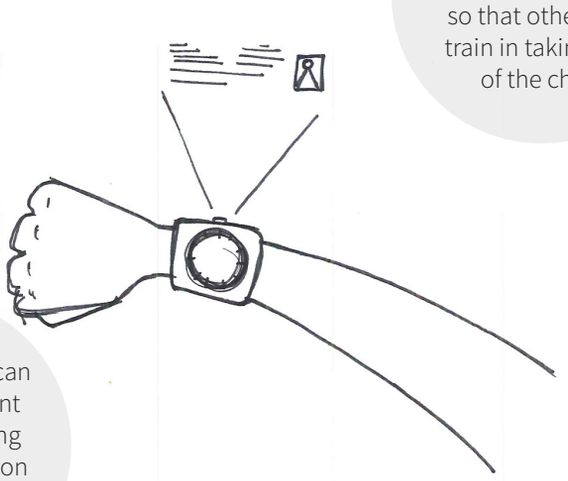


A contextmapping booklet for parents with assignments about their life which can be shared with others.



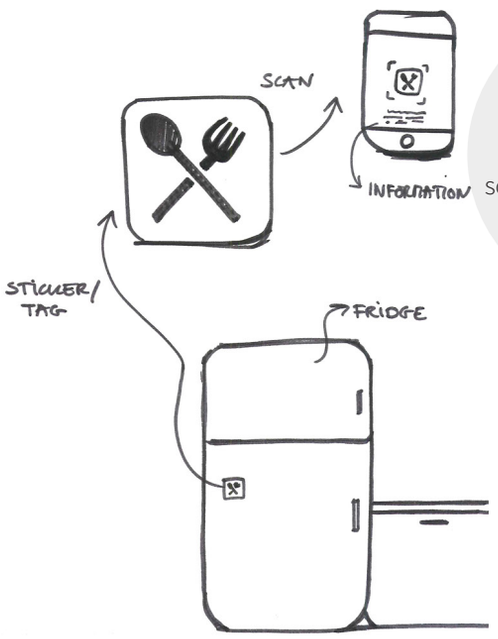
A doll that is programmed to behave like the child so that others can train in taking care of the child.

A booklet with illustrations and information about the child in which others can add text and pictures.

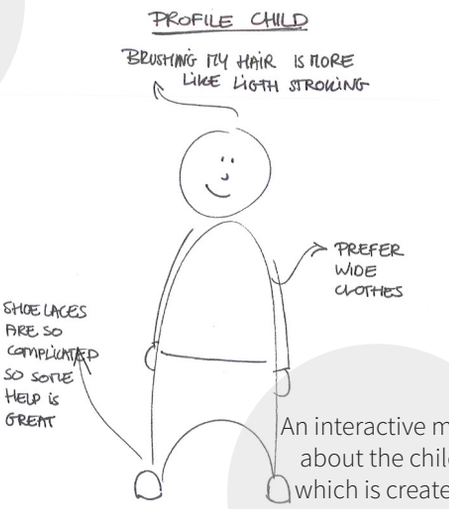


A wearable that can project important information using speech recognition designed for others who take care of the child

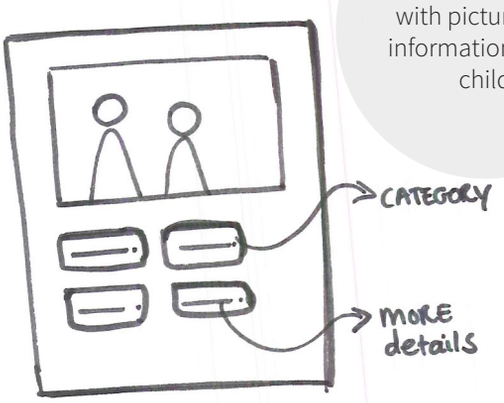
Figure 19. Selection of idea from the ideation.



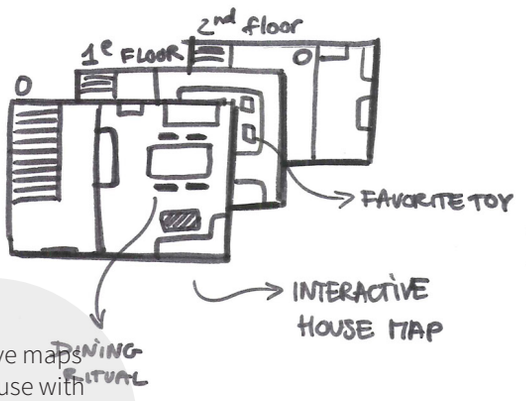
Removable stickers that can be placed on important objects. They can be scanned for information by others via a digital device.



An interactive map about the child which is created during the trajectory and can be shown to others.

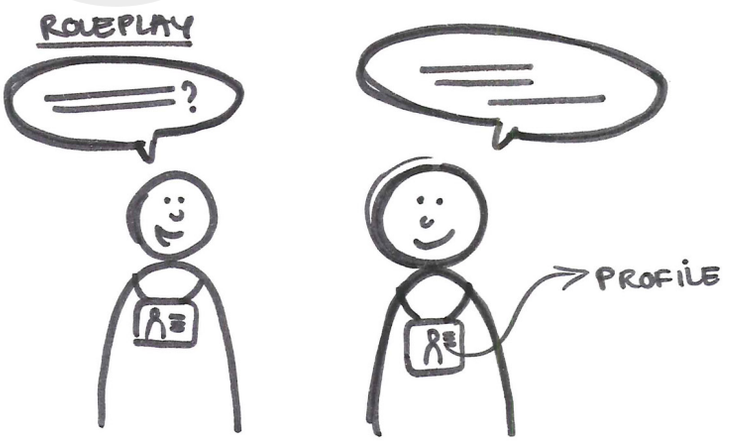


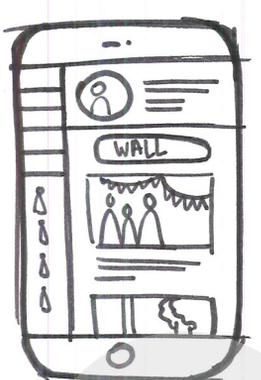
An online profile with pictures and information on the child.



Interactive maps of the house with information about important objects and spaces related to the child.

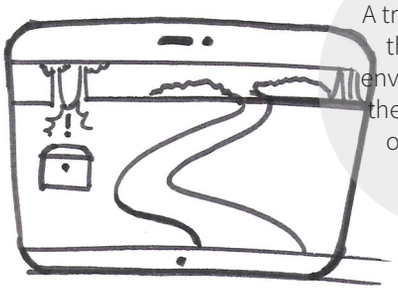
Role-play game for others to step in to the role of being a parent of an autistic child.



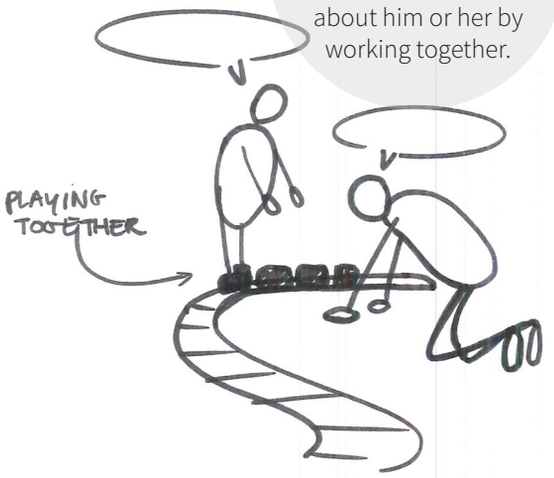


Online community platform designed for all others involved with the child to easily share pictures and information.

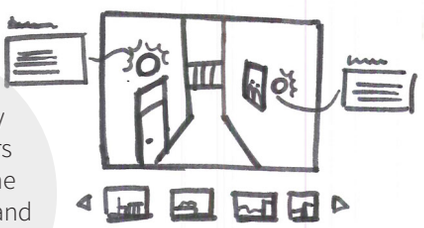
A treasure hunt game through different environments around the child with pieces of information to collect.



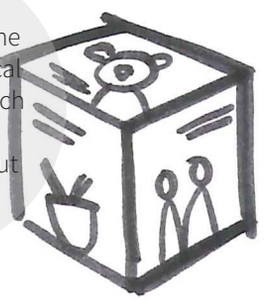
A planned project in which another caretaker takes on a project with the child to learn about him or her by working together.

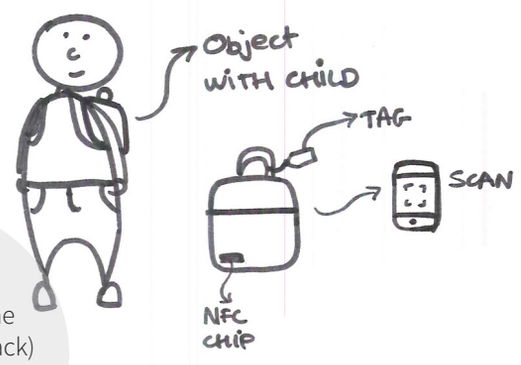


Augmented reality app in which others can walk around the context of the child and unlock boxes with information.



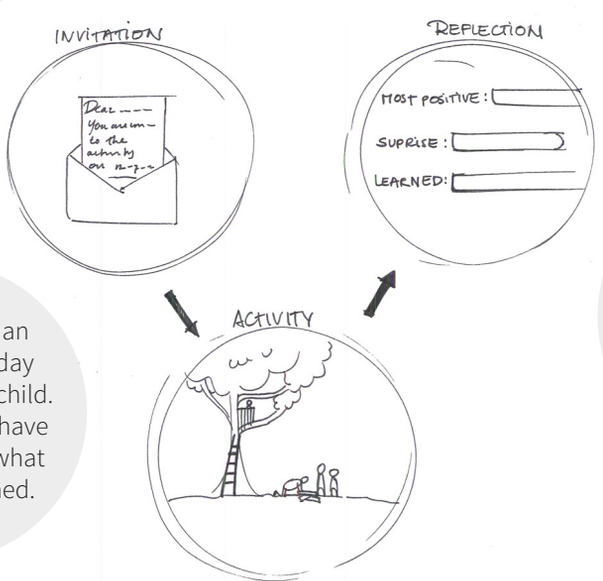
A mnemonic in the shape of a physical object with on each side important information about the child.





A tag that is attached to an object close to the child (e.g. a backpack) which can be scanned by other caretakers for (new) information.

A game that supports parents in taking pictures of important objects, people, and places related to the child.



Others receive an invitation for aday activity with the child. Afterwards they have to reflect upon what they have learned.

Figure 20. Selection of ideas from ideation.

Idea selection

Appendix K

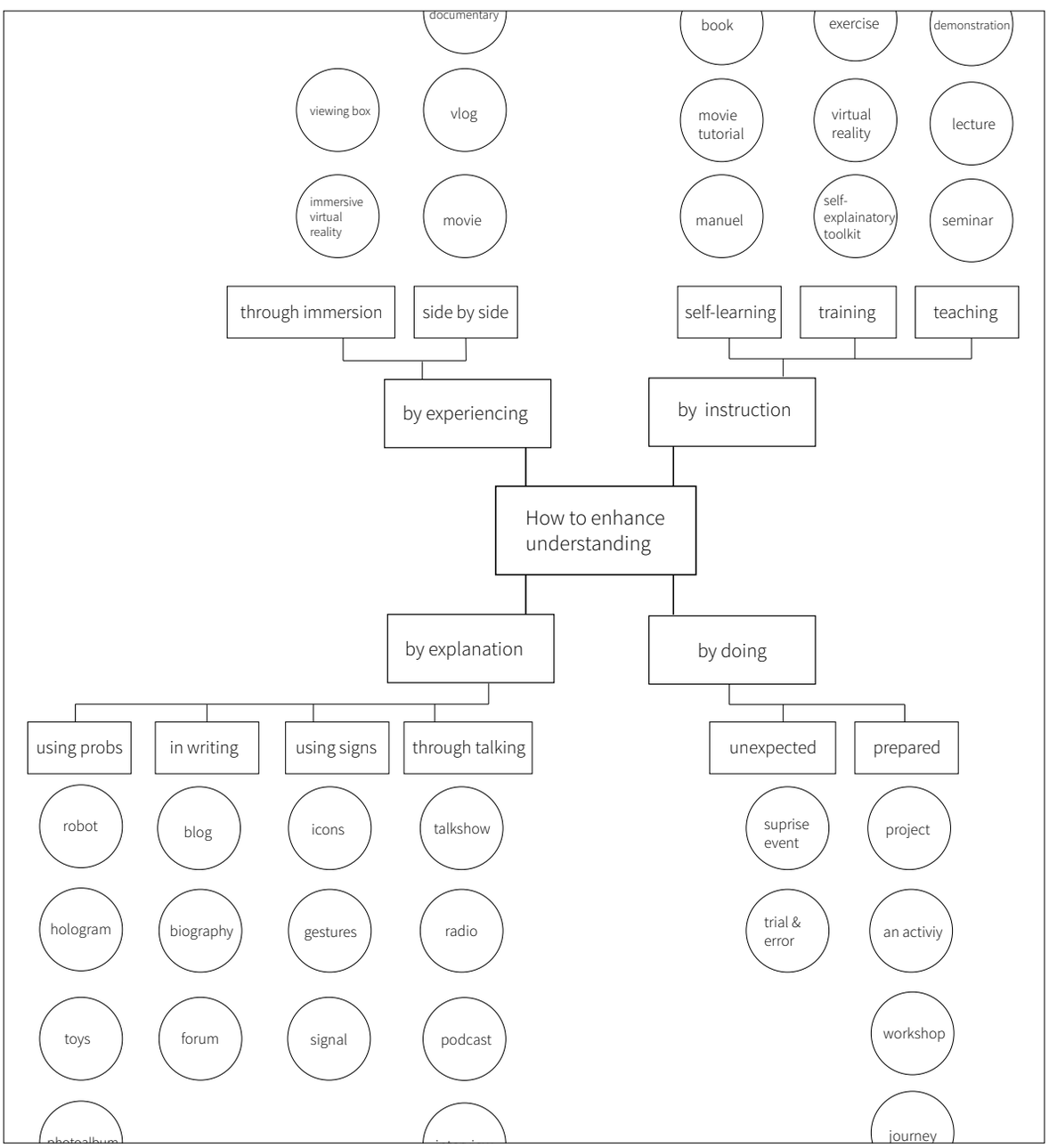


Figure 21. Structuring the ideas in categories based on the main goal.

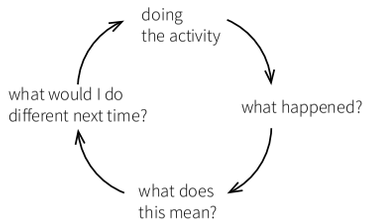
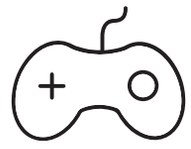
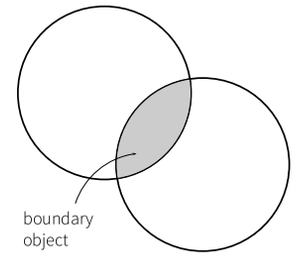
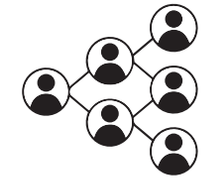
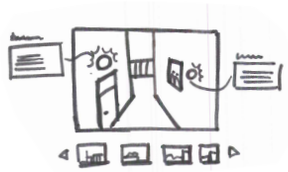
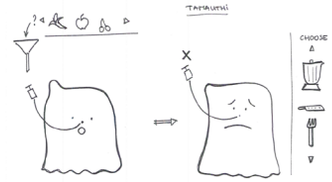
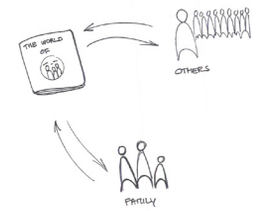
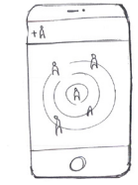
category	by experiencing & by doing	by instruction	by explaining	by explaining
learning theory	**experiental learning** learning through reflection after doing. 	**serious gaming** learning a set of skills by being activly trained in a game. 	**boundary object** learning by transfering knowledge through sharing immutable content. 	**community platform** learning by exchanging information with everyone from the community. 
design example	 Using 360 images to explore the context of the child. After exploring various objects and environments, there are reflective questions on what was shown to support learning.	 Developing a serious game that instructs others on for example routines and medication appliance by doing exercises.	 A booklet with pictures and quotes concerning the child, which can be shared amongst the people who support in caregiving.	 Online community platform for parents and caretakers of the autistic child on which they can interact and share information among eachother.
idea direction	Developing a digital context in which others can experience the context of the child and reflect on the various things they come across.	Developing a serious game that trains a particular set of skills to be able to take care of the child.	Creating a boundary object that contains visual images of the child and the context, and which can be shared amongst others in various social contexts.	Developing an online platform that allows the community around the child to easily exchange information.

Figure 22. Building idea directions using the categories of the idea structure.

Benefits idea

Appendix L

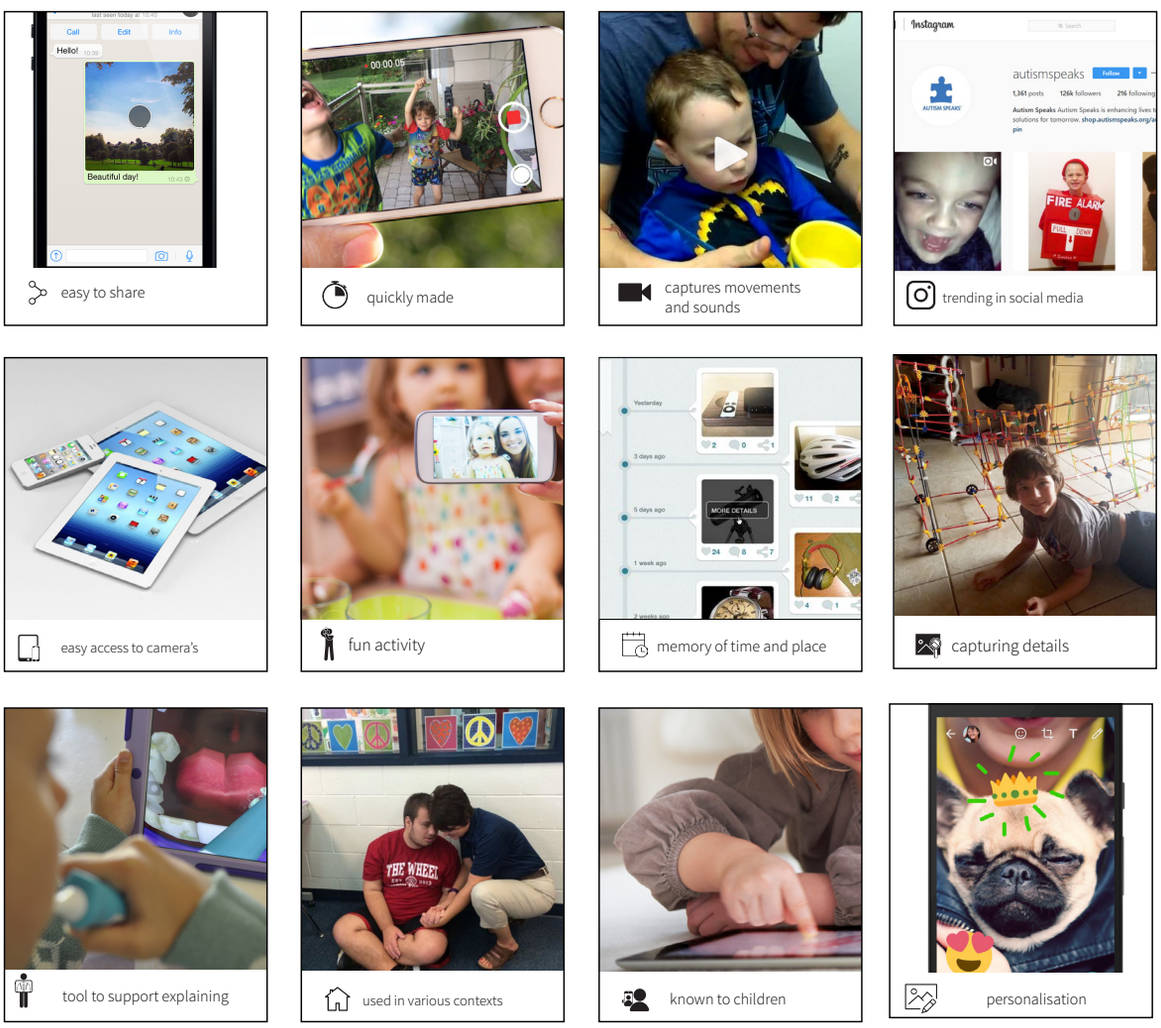


Figure 23. Twelve benefits of the final idea of using pictures, video's and keywords to transfer information to others.

Results quick test

Appendix M

Testing the idea

One way to discover if an idea is a good idea or one to drop, is by building a prototype and doing a test with the users. Goals of this quick test are to discover if understanding is enhanced with this idea, if the principle of making and sharing pictures and video's is desirable and feasible, and to generate functions for the system. For this quick test a low-fidelity prototype was created and tested with one family of an autistic child. Results of the test gave insights, barriers and opportunities for the system.

Prototyping with WhatsApp

For testing the idea a low-fidelity prototype was made using the mobile application WhatsApp. WhatsApp is a service for smart-phones that allows its users to send messages (with pictures or video's) via the internet for free to anyone who has WhatsApp on their phone. The application is a great tool for prototyping since:

1. WhatsApp costs little to no money to install and use.
2. Whatsapp is used by 9.8 million people in the Netherlands (Oosterveer, 2017) so almost everybody has it already on their smart phone and knows how to use it.
3. It is possible to add text to a photo or video in a message.
4. WhatsApp has a search function which can search for words through every chat.
6. The entire chat can be exported, saved and send as an email or uploaded to any other database.
7. It is possible to make group chats in which multiple people can send messages and share pictures and video's, all within one chat.

Set-up

For this quick test, one family (father and mother) of a three year old boy with autism were asked to participate. This family didn't participated in the contextmapping research and therefore was not familiar yet with the assignment of making video's and pictures for research purposes. They were asked to make a group-chat with both of them and another person, who in this case was the project designer. In this chat they were asked to share pictures and video's of their child of things they ought to be important for the other person to see and understand. In order to enhance understanding for the other person, parents were asked to provide small pieces of information with the sent pictures and video's using hashtags. These hashtags are to be composed of one or more words to see in a glimpse what the picture or video is about (figure 21). After four days of capturing pictures and video's and sending them by WhatsApp they were asked to reflect upon the process and altogether discuss the results.

Figure 24. Printscreen of the WhatsApp conversation of the quick test.

Results

For four days both parents shared pictures and video's using hashtags with the project designer in a group-chat on WhatsApp (figure 22). In the reflection moment it was discussed what went well and what didn't, resulting in the discovery of insights, barriers and opportunities which written down below. Results were used to formulate six main functions of the system. Also suggestions for sub-functions were given based on the results and are shown in figure 23.

Enhancement of understanding was tested by the project designer who functioned as the other person of whom more understanding was desired. The project designer did experience enhancement of understanding, especially after reviewing more personal video's or pictures which were shared such as a video of when the child got upset for a long time at night . This was something they struggled with. Another valuable insight from the test was that both parents stated that in the process of taking pictures and video's they discovered that they actually had many good moments. This is a great insight since many parents of autistic children are stressed out and would benefit from being reminded of the positive moments. All in all, the results gave enough positive feedback to state that the idea is a good idea to continue with. It even opened options in developing a possible system using WhatsApp since this application seems to work very well on itself instead of only being a prototyping tool. However, there were some barriers considering the use of WhatsApp, so other options for the system to capture and share information should be considered.

Insights

Video's are very insightful since they show actual behaviour and movement which is important in relation to autism, which is a condition that is diagnosed by observing behaviour.

Video's provide more context and are easier to empathize with. Especially since they have contain sounds which allows others to hear the people involved.

Pictures are vary valuable to capture rituals and routines which often consists of a sequence of steps.

WhatsApp works very quick and easy. Almost everybody is familiar with it so people do not have to download something new which is a benefit.

More intimate and personal video's e.g. a bed ritual or tantrum were experienced to be very insightful for the project designer. It really indicates the differences with the daily lives of others.

Barriers

When copying and trying to send the same pictures and video's to another person in WhatsApp, hashtags that were initially in the message get lost. So they need to be added in the message again which can be a hassle and costs time.

It is not possible to make changes to hashtags when the message is send.

In WhatsApp it is difficult to find pictures and video's back since the chat gets quickly full.

When someone enters a group-chat he or she cannot see what has been sent and shared before.

It can be difficult to share the more difficult situations, such as a tantrum, with others because it is very personal.

Opportunities

Give a clear goal and instruct parents so that they understand that it is important to film and take pictures of certain situations including the more difficult or 'negative' ones because those make it realistic and that is what others need to see to get a true understanding.

Stimulate parents capture simple moments as they may turn out to be a happy and positive moment.

Provide guidance and a structure on what to film and what to take pictures of, and how. For example, routines are best captured in a series of photographs.

The system must allow to share information amongst a variety of people, but the parents should decide who these others are.

Have the possibility for a shared knowledge database.

Allow for a peer-2-peer connection to connect parents that seek the same kind of methods and tools.

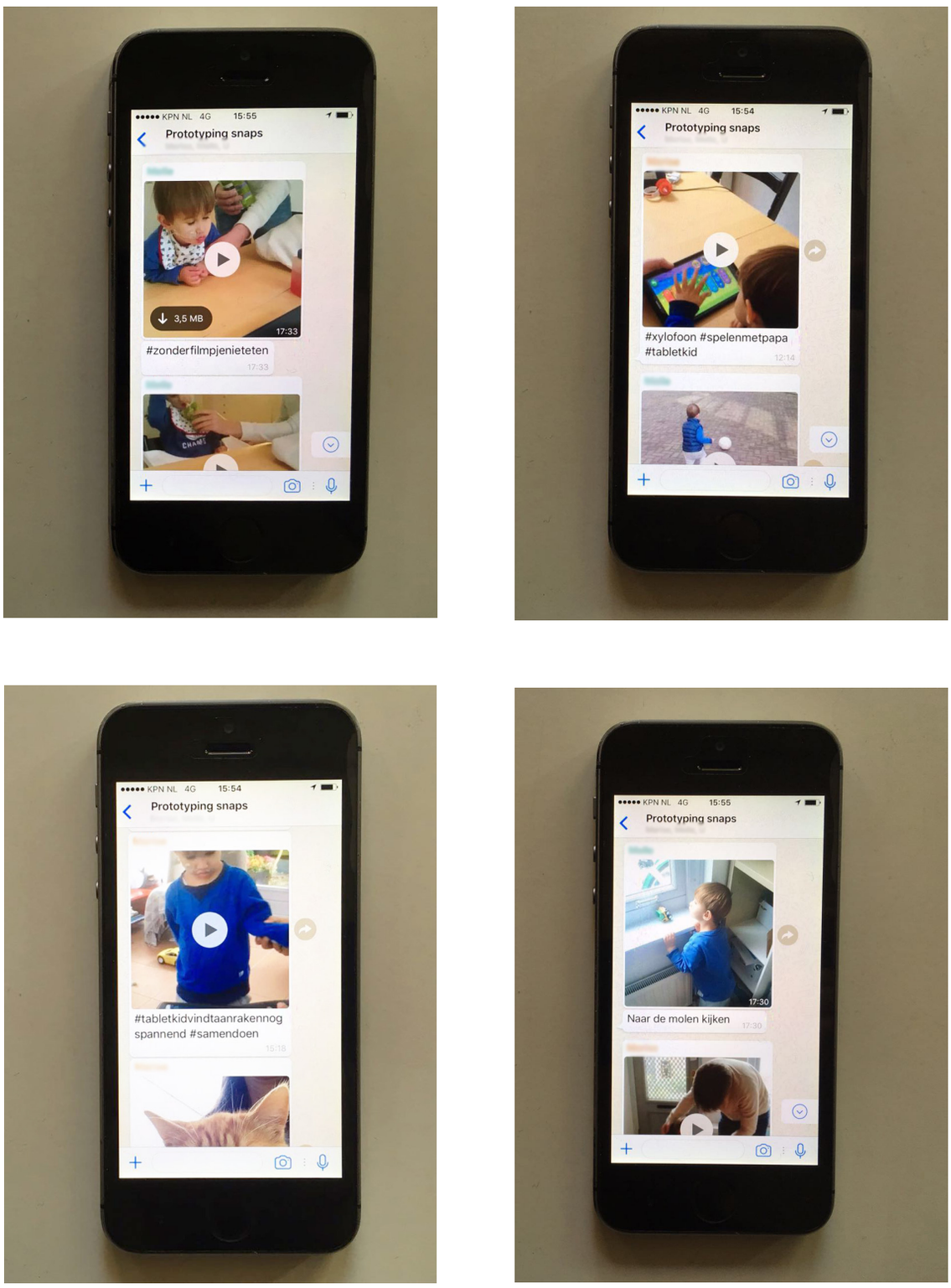


Figure 25. Pictures of the WhatsApp conversation of the quick test.

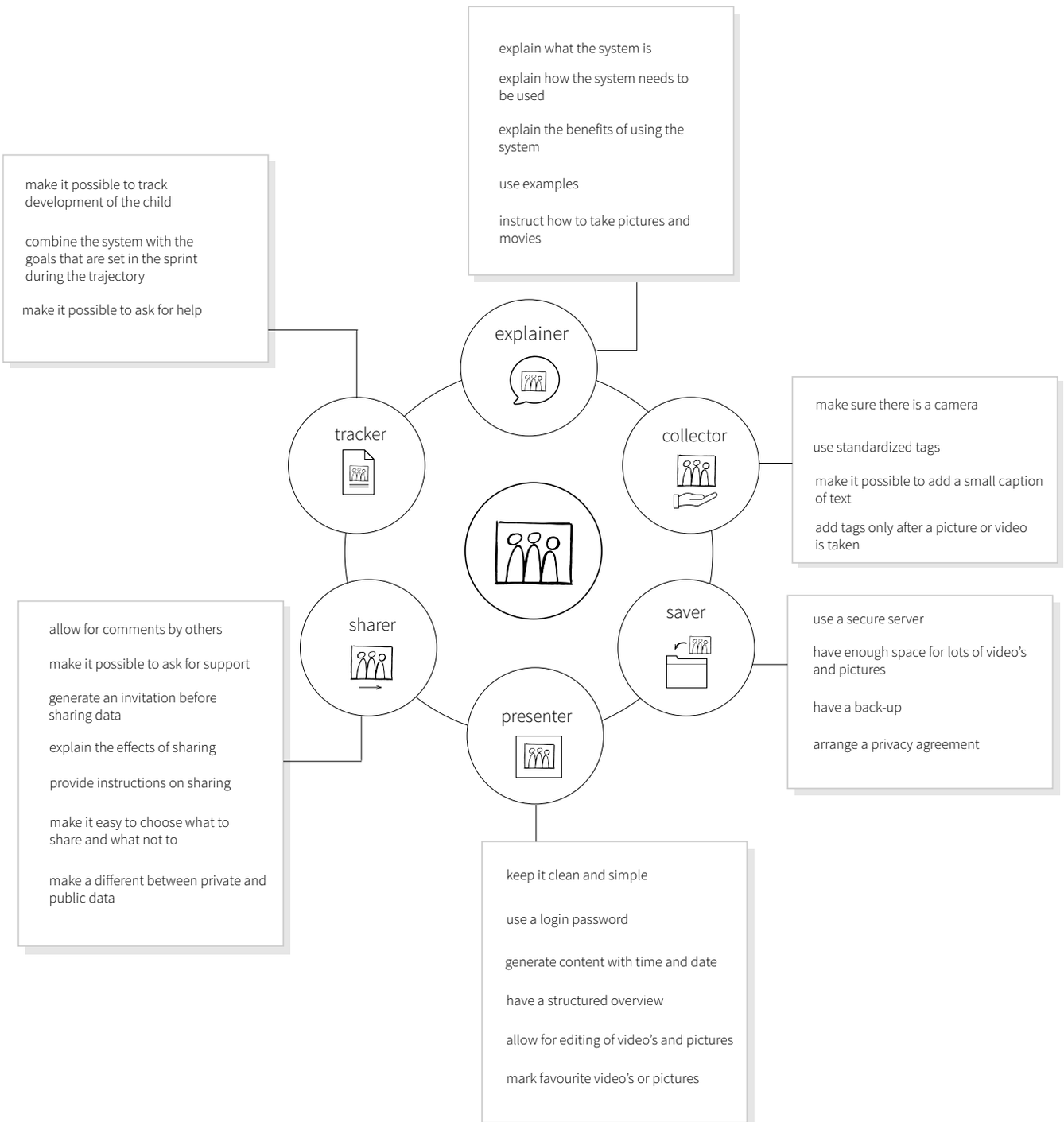


Figure 26. Suggestions for sub-functions per main function for the system based on results from the quick user test.

Concept development

Appendix N

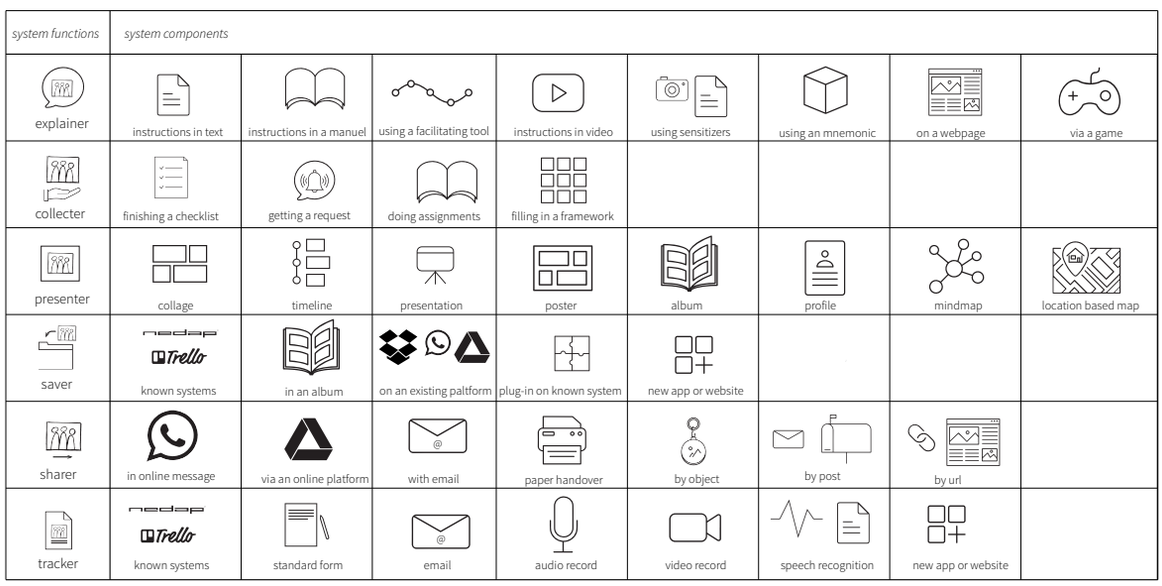


Figure 27. Scheme of the system's main functions and components.

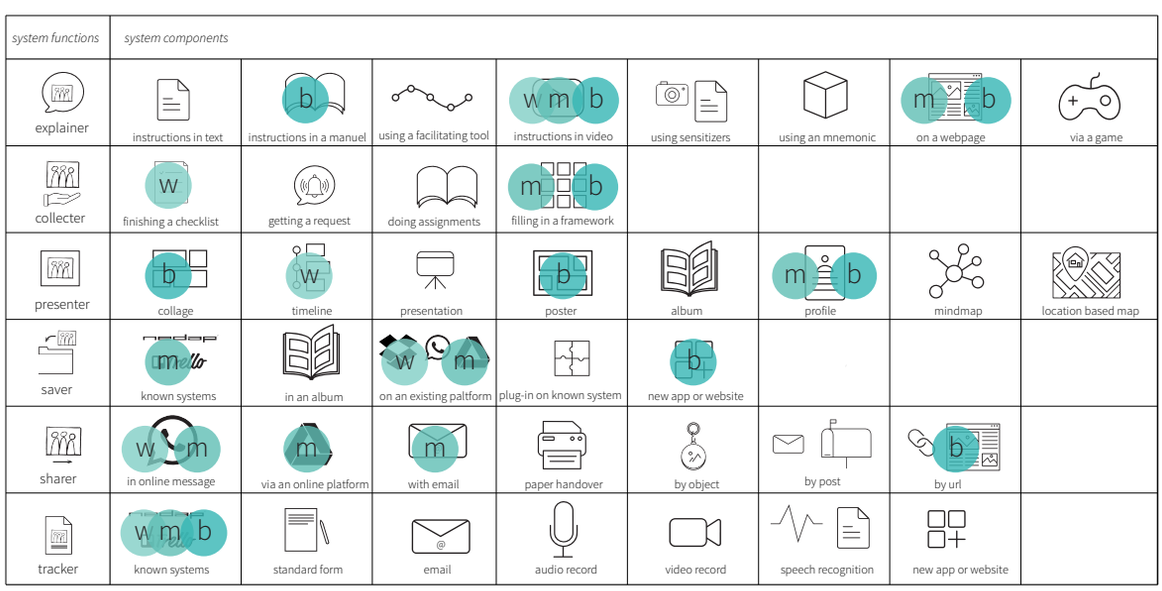


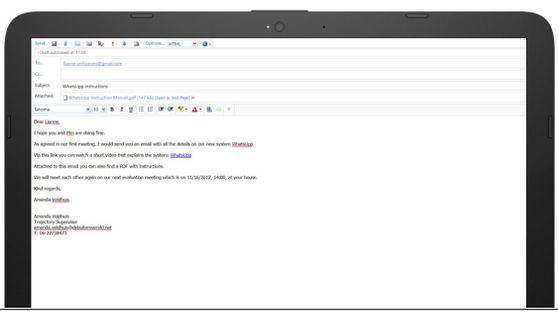
Figure 28. Component combinations for each of the design proposals.

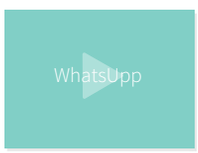
Whats-Upp

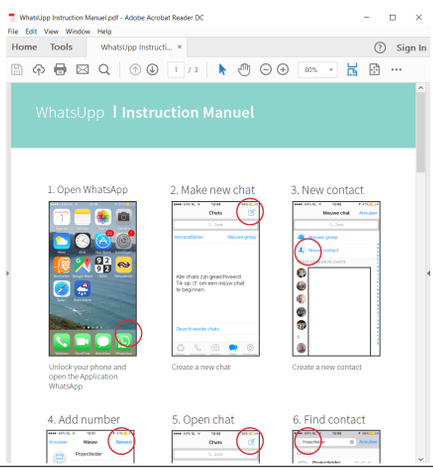
Whats-Upp is a digital system that uses the well-known application WhatsApp. Via WhatsApp a quick and easy exchange of information in pictures, video's and hashtags can be established. Using a digital device, a picture or a video can be taken of any situations within a few seconds and shared with anyone who needs to be updated.

Whats-Upp empowers parents to quickly share information with their network and guides them by learning how to take the best pictures and video's to get the best results.

An email is send to the parents with a PDF with instructions in pictures and text, and a link to a video that explains Whats-Upp.







During the meetings between trajectory supervisor and the parents, a reminder card is used to note down assignment for making pictures or video's of particular situations and important information. Also of situations that relate to the goals that are set in the sprints.

Whats-Upp | **Reminder card**

Next meeting: _____

Parents can save all their pictures and video's on an external hard-drive they receive from De Buitenwereld. Every month, the WhatsApp group-chat with the trajectory supervisor is exported and saved on De Buitenwereld's server as a back-up.

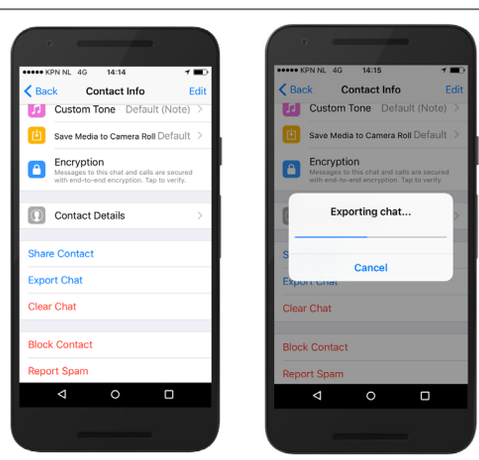
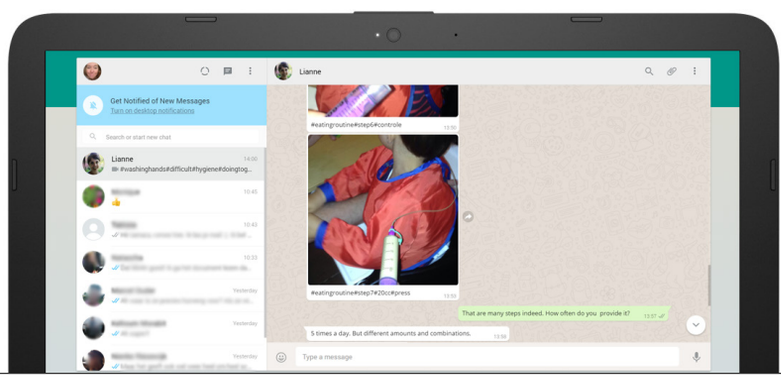


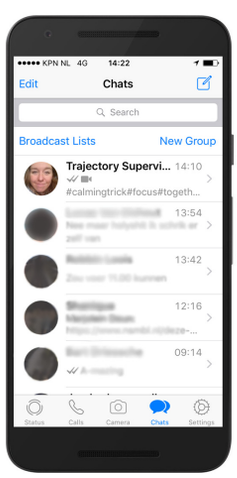
Figure 29. Overview of the design proposal of Whats-Upp with descriptions on how each system's main function is met.

Your support network within reach.

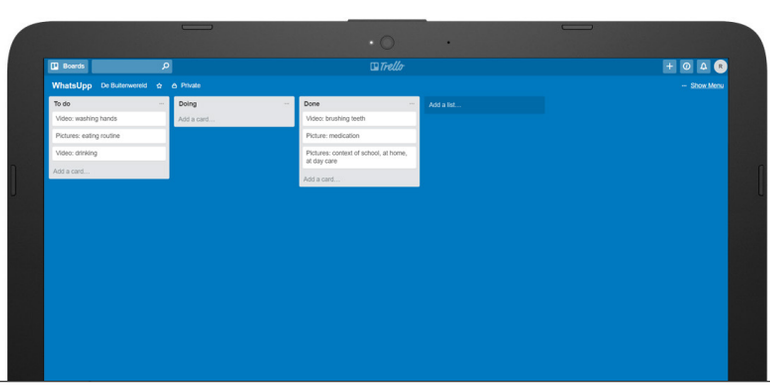
Pictures and video's are reviewed during the weekly meetings on the laptop or tablet of the trajectory supervisor using the WhatsApp Web App.



Pictures and video's are shared with the trajectory supervisor in a separate WhatsApp chat. Parents decide what they want to share with others and create their own WhatsApp chats (or group-chats) with them.



The assignments for making pictures and video's are put into Trello to keep track. If parents have any questions or desire feedback on a picture or video, they can use their WhatsApp chat with their trajectory supervisor.

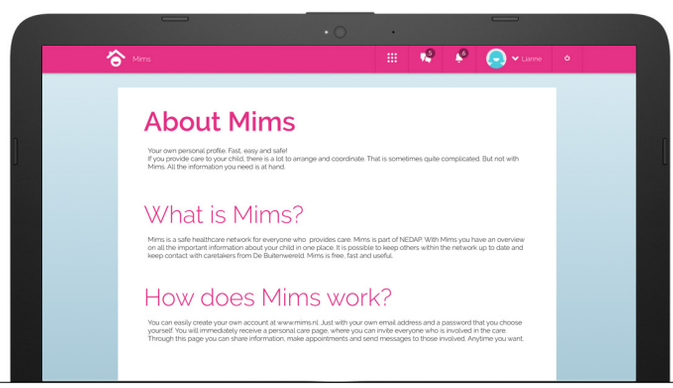


Mims

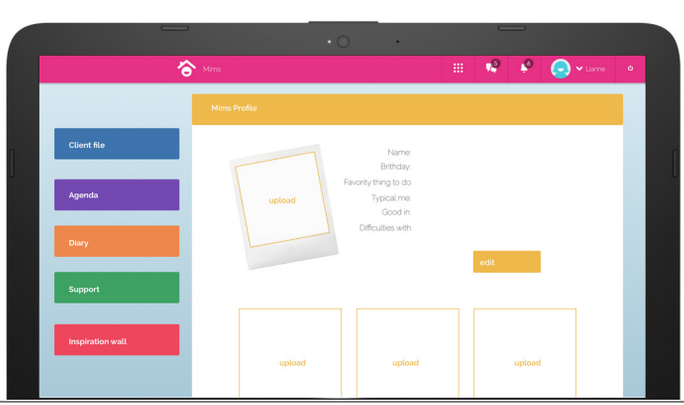
Mims is an online profile for parents who are clients at De Buitenwereld. The program is an extension of a known system for many healthcare instituitions: NEDAP. This system is used by De Buitenwereld to store and view their client's information. NEDAP is known to be a secure program and as Mims is an extension of NEDAP, it is a safe place for parents to store their information.

In Mims parents find a personal profile with information about their child. There is room to add images and video's to that information to make the information more rich. Parents can invite others from their network via a login code so that they can see parts of their profile. Via Mims both parents and others communicate via comments or messages.

Instructions about Mims can be found on the webpage of NEDAP about Mims. A video is added to this webpage which visually explains how to use Mims e.g. upload pictures and video's, add comments, and edit information.



On the Mims profile there is a framework with empty spots at which the parents can upload pictures or video's. Using such a framework guides the parents in what kind of pictures and video's they can upload that fit with the information about their child and situation.

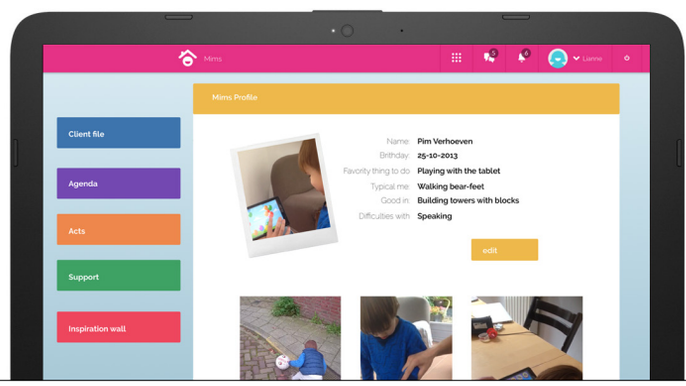


Parents save their pictures and video's on an external hard-drive which is given to them by De Buitenwereld. All the data is backed-up in the Cloud that NEDAP uses.

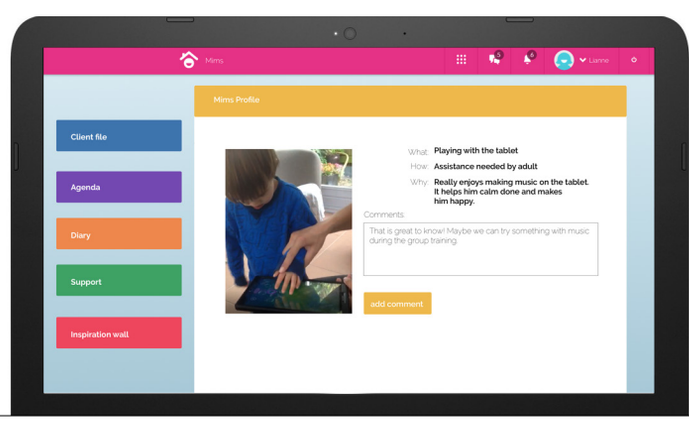
Figure 30. Overview of the design proposal of Mims with descriptions on how each system's main function is met.

All your information in one secure place

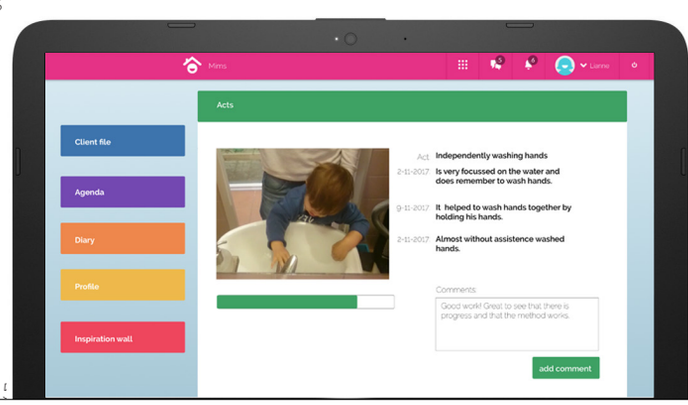
The information is presented on a personal profile which consists of several web-pages that each address a different topic e.g. a page for the goals that are set during the sprints in the trajectory, a diary, a more general overview of information, etc. On each page there is room to add pictures and video's to make information more rich.



Parents can invite others from their network to view parts of their profile as well. The trajectory supervisor of the company gets access to the client's profile and can communicate via the profile with the parents.



The trajectory supervisor uses Mims during meetings to keep track of the information that is put onto the profile. In here they also keep track of the goals that need to be achieved. Via Mims it is possible to create a checklist for the parents to remind them to take pictures and video's to add to the profile.

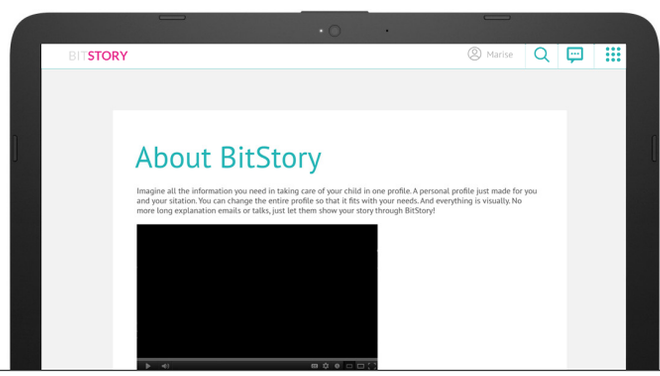


Bitstory

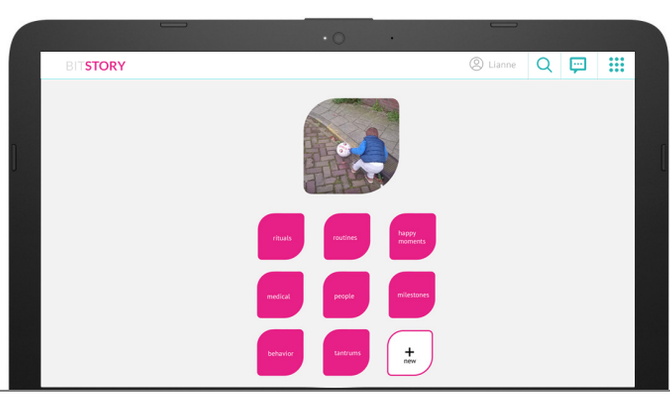
Bitstory is a website which offers a personal profile to create a story made of pictures and video's. The design is created by De Buitenwereld and therefore a new innovation. Having a personal story online, parents can start sharing their story with others by allowing them access to their profile. In this way they can give others a glimpse of their life to better understand.

With Bitstory parents no longer have to repeat and explain their story, they only have to show it. The pictures and video's are not only shared with others from their network, but also with other families of De Buitenwereld who have a child with autism. In that way Bitstory offers a peer-2-peer connection and parents can learn from eachother.

Instructions with instruction video are found on the Bitstory web-page. At the start of their trajectory, parents also receive a booklet with instructions and examples of other stories from parents.



Bitstory works with different section that cover a certain topic related to autism. Clicking on such a topic leads opens up a framework on which pictures and video's can be uploaded. The topics serve to support parents in thinking about the kind of pictures and video's to upload.

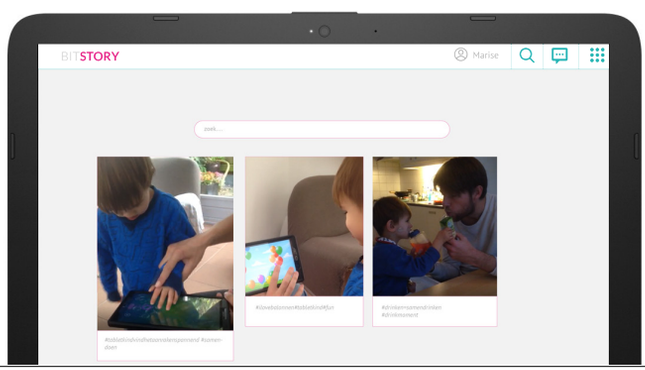


All the pictures and video’s are saved by parents on their external hard-drive from De Buitenwereld. Also a back-up in the Cloud is made.

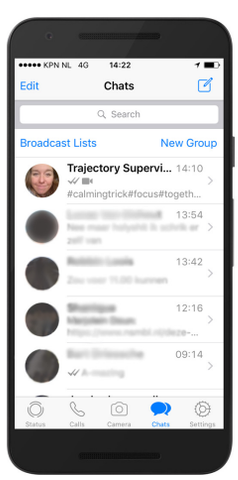
Figure 31. Overview of the design proposal of Bitstory with descriptions on how each system's main function is met.

Tells your story for you

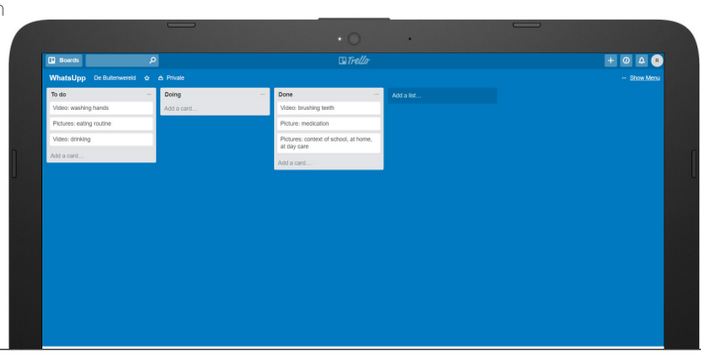
Bitstory works with a personal profile on which various topics related to autism can be found. Each topic has a page for pictures and video's. The footage is structured in blocks, but there is also the possibility to view the footage on a time-line.



On the Bitstory website it is possible to generate a link which can shared with others via for example WhatsApp. This link provides access to part of the Bitstory website: a separate web-page filled with a selection of pictures and video's for the other to see. Parents are in charge of sharing links with others and the selection of pictures and video's.



To set assignments on making pictures and video's, De Buitenwereld works with Trello. The Bitstory website has an integrated link to Trello in which a checklist is created. To be able to see the pictures and video's, the trajectory supervisory gets access to parts of the Bitstory profile and can communicate with the parents via the website.



Concept choice

Appendix P

Figure 32. Scoring of the three design proposals on desirability, feasibility and viability.

Validation results

Appendix Q

Insights

Most parents mentioned upfront that their test results may vary strongly depending on the time of the year and if there were exciting days ahead (Sinterklaas, Christmas, holidays). Such a holiday could influence the behaviour of their child strongly.

Parents emphasized that each child with autism is different.

WhatsApp was known to all parents and worked properly. Some parents were unfamiliar with certain options like making a group-chat, so they required some more instructions.

Both the introduction and instruction movie were received very well by all parents. They liked the fact that drawings were used. It supported their understanding strongly.

The examples given in the instruction movies were found to be very clear by all parents.

Some parents stated they were already familiar with working with video's. Filming was sometimes applied in certain forms of therapy, often to do observations. They ought filming to be vary valuable since it is also provides proof.

Some parents found the use of hashtags very easy, while others preferred their own way of tagging the pictures and video's by adding short lines of text.

Some parents dared to choose people for the test had a low understanding of their situation and even a bad relationship due to this fact. Other parents decided to choose others who were more involved to create an even better understanding.

One parent argued that she felt that not everybody needed a better understanding. Her own parents were involved from the beginning and she felt that after years they really understood them and their situation, and thus were a strong part of their network.

Some parents mentioned that due to this test they were triggered to think about their child in a different way. They had to think more about how autism affected their family and how it expressed in their child. One parents mentioned that she really benefited from thinking about these things in the sense that it helped her formulate a better story for others to tell if they would ask about her child and situation.

One parent mentioned that she felt supported by the idea that others would learn via this design to understand her son better. She felt that it could offer opportunities in the sense that others would become more involved in care-taking.

One parent mentioned that she and her child were once filmed in a therapy session and that the camera was hanging out of sight which assured that the child wouldn't noticed and thus realistic footage was obtained.

One parent noted that she needed capturing of information on pictures and video's to become more of a routine. This routine would be established if she had to for example make pictures and video's every week as a goal during her trajectory.

One parent noted that such the idea of Bitstory would work best if most of the information about the child and situation is already known. Then capturing of information becomes more easy. In the beginning parents are too busy finding out what is going on.

During the test it became clear that when sending information to another person it is important to think about the others benefits of seeing that particular piece of information. If it isn't relevant the other might not know what to do with it and therefore doesn't respond.

WhatsApp is great tool for quick and easy communication. Especially since so many people have it on their mobile device.

Sending reminders to the parents on taking footage helped lots of them as they easily forgot doing it due to their busy lives.

Video's and pictures function as evidence. For example, one parent was able to capture his child speaking his longest sentence ever which he could now show to the narrative therapist that works with the child.

Many parents noted that the great benefit of such a solution is to not have to explain over and over again. They can just share the information instead.

Visual communication works very well.

Sharing information led to interesting discussions between parents and others in the chats. Some parents mentioned that they liked when others would think about possible solutions or methods as well.

Some parents mentioned that they would like to see the kind of information other parents capture to be inspired, while some other parents stated that they didn't feel a need to see it as they believed that it might not benefited them since every child with autism seems to be so different.

Some parents already had a lot of footage of their child which they could use for the test.

One parent had great experiences with another healthcare institution that worked with an online profile with information that could be shared with a select group of people who would get access to the profile.

One parent noted that it would be great if the trajectory supervisor or group-trainer could also contribute to the system in some way by adding pictures and video's or leaving comments.

Some parents mentioned that it would be nice if there was the possibility to add write more text like a diary so that they could explain more if they desired. They wouldn't need this diary to be open to others, but more as a reminder of certain events for themselves.

Some of the reactions others gave on certain pictures or video's were not always what the parents desired to hear.

Some parents had the feeling others might interpreted a picture or video wrongly. They were afraid that others might see them as show-offing if for example the information would be about a talent or great skill. Or when it would be about some more difficult they worried that others might see it as a call for pity.

Some parents mentioned that access to professional help via the website would be a great addition so they could ask question on certain pieces of information.

There is clear difference in the needs of the parents concerning peer-2-peer contact. Some want only contact with other parents of autistic children for emotional support, some only want access to a shared database of personal experiences, and others would want to exchange more scientific information with other parents.

The invitation text for the test was helpful to all parents. Some altered the text.

One parent had difficulties capturing the information she felt determined their daily lives: all the appointments and all the arrangements she has to take in relation to their situation.

Barriers

Some children didn't wanted to be filmed or taken pictures of. Especially in more difficult situations. One of the children told his mother that he felt being watched.

All parents explained that they have such limited time in their daily lives which makes it difficult to do extra work.

Some of the others who were involved in the test asked the parents what was going to happen with the pictures and results. Some parents struggled with answering.

Two weeks was for most parents too short to retrieve enough information and to make others understand their situation.

Almost all parents noted that their child behaves differently in different places such as school and home.

One parent mentioned that if their child would speak badly in a video, like using curse words, the parent would find it difficult to share the video with others.

Some others that were chosen by the parents in the test couldn't always answer or participate in discussions as they mentioned being very busy.

One parent had great difficulties with getting started with the test. She explained she didn't really know how to get started and would require more guidance.

One parent mentioned she felt weird sending messages with hashtags to others as it was not common to use hashtags in messages (in WhatsApp).

Parents noticed that some others they initially wanted to invite in participating in the test, couldn't participate in the test since they didn't have WhatsApp.

Some parents struggled with figuring out what to capture in a picture or video. However, the suggestions list that sent later on helped them overcome this barrier.

Some parents noticed that video's could became really long. And also that not all parts of the video were relevant. They would have liked a tool to help them cut out only the important pieces.

Some parents were insecure if others would understand their choice of hashtags.

One of the others involved asked the parent why it was that they were chosen to participate in the test. The parents mentioned they felt a bit awkward since they would have to explain that it was about enhancing understanding, implying that the others didn't had great understanding.

One parent mentioned that despite the fact that she got responses and tips from the others during this test, the tips were not always very helpful.

One parent felt that understanding wasn't really enhanced as she felt that the others were still too much busy with their own world.

Most of the parents noted that they forgot to take pictures or video's and need reminding.

All parents noted that they had little time to spend on this test as it was only two weeks.

One parent noted that it was difficult to be reminded of the test as other things often had higher priority.

One parent mentioned she felt bothered sending information to the other person because they were always very busy. She was afraid they would think ''Oh, its her again..''

Some parents mentioned finding it difficult to see that some messages were read by the other in WhatsApp, while they didn't responded.

Some parents mentioned difficulties if there would be no responses on their input.

WhatsApp is depended on an internet connection which is not always there.

One parent mentioned it can be very difficult to capture certain behaviour since sometimes it would be too late and the behaviour had already changed. Or the situation is very chaotic which makes capturing on video or picture too difficult.

One parent mentioned that she felt a bit bothered to send information. She would rather allow the others to view the information she had collected in their own time so that there was less pressure for others to respond.

Some parents noticed that behaviour of their child could change when making a video or picture.

Some parents struggled with the fact that in order to film they have to hold their phone, while they also want to do something about the situation if something is going wrong.

Parents mentioned they were sometimes to late to take a picture or a video.

Many parents explained they had difficulties capturing the more difficult situations. Especially if their child was aware of the camera.

One parent was afraid she couldn't capture enough information in two weeks time.

Some parents struggled in figuring out what to capture. They noted they needed more guidance.

Opportunities

Sending reminders to help parents remember to take pictures and video's.

Focussing on what the child can do instead of only what he or she cannot. It is beneficial to keep track of what is going well as these positive moments give positive energy.

Add the ability to review data over a longer period of time to get an overview on developments.

Making sure to meet the needs of the others with whom information is being shared. This can be achieved by helping parents to think of a goal before sharing particular information. For example, sharing information with the narrative therapist should contain information that benefits the therapist and her work with the child.

Making use of existing programs that present or share information visually e.g. mindmanager or mindmaster.

Allowing the option to make a selection of pictures and video's to share with others. A doctor can be mostly interested in the medical information while the grandmother may be most interested in overall developments.

Using the characteristics of ASD as formulated in DSM-5 in a structure for the information on the website.

Provide clear instruction on use of the solution: what to do and what not to.

Use examples.

Provide room for formulating goals.

Stir towards what is going well instead of only focussing on what isn't.

Allow the parents to arrange the information in the solution in such a way so that it is relevant to their situation.

Think about ways to quickly retrieve information from parents e.g. making use of a questionnaire at the start of using the website to fill in information quickly.

Make use of visualisation as much as possible.

Instead of hashtags, work with keywords to quickly describe what is shown in the picture or video.

Offer a standardized set of keywords and allow the option for parents to change these keywords if they do not fit their situation.

Use suggestions to support parents in thinking about the kind of information to capture.

Have the option for editing video's and pictures.

Allow for others to provide input into the website so that there is a focus on shared contribution.

Focus on positive sentences and words in the design solution.

Allow for addition of some lines of text with the pictures or video's so that parents can explain in short what is shown.

Support and guide parents in the process of capturing and sharing information so that they feel supported and comfortable using the solution.

Add questions to the pictures or video's to trigger other people's interest and possibly start a conversation.

Support parents in capturing the less positive sides such as a their child having a tantrum.

Use of a standardized message from trajectory supervisor to parents to remind them on any assignments for capturing information.

Work with video's to explain the solution.

Guide the parents on who to involve from their network.

Using a password for allowing others to access the solution.

Think of ways to film the child without the child noticing so that the situation is as realistic as possible.

The Bitstory Website

Appendix R

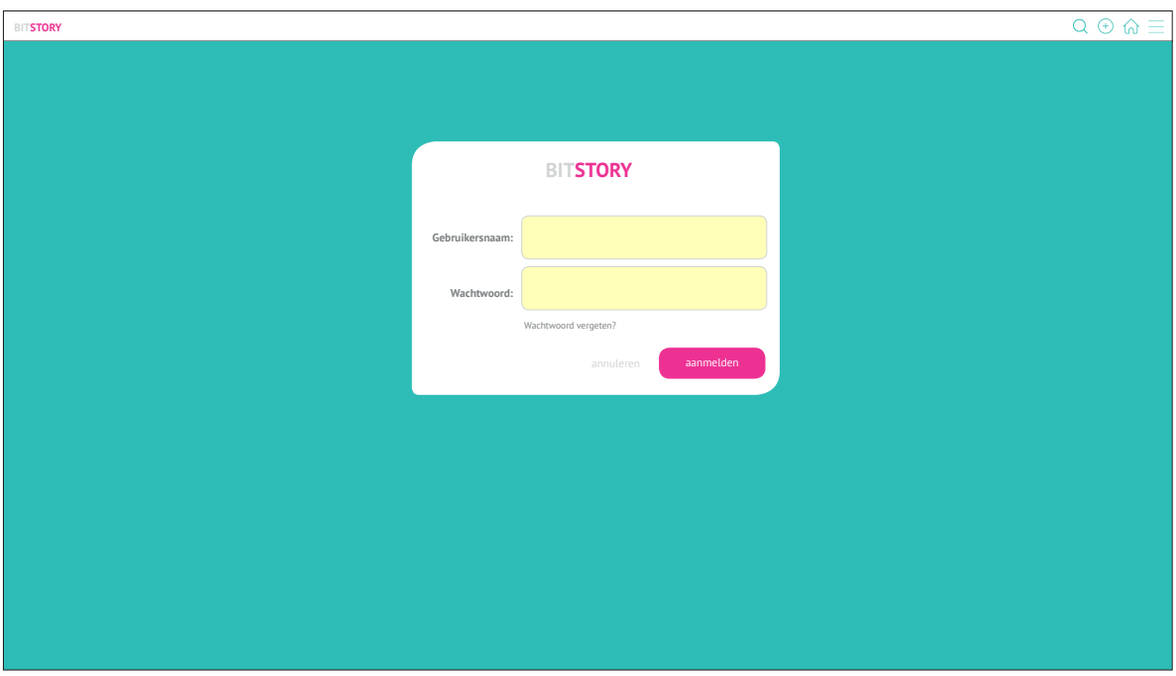


Figure 33. The lay-out of the webpage to login into Bitstory.

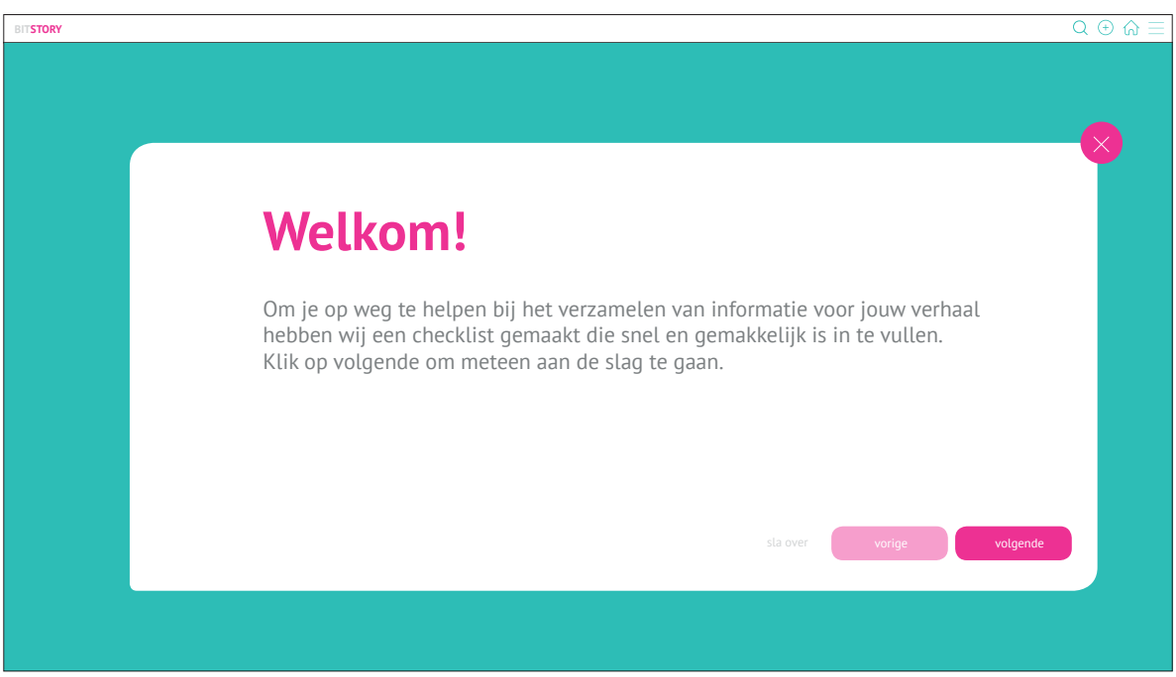


Figure 34. The lay-out of the webpage for the questionnaire to retrieve information.

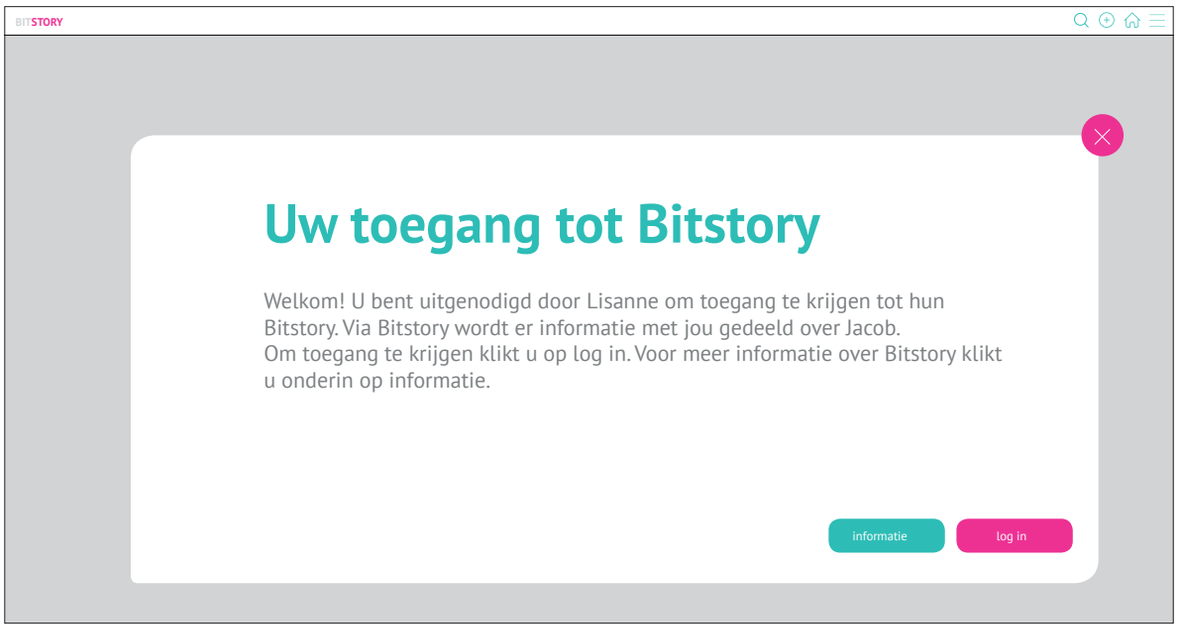


Figure 35. The lay-out of the webpage with the invitation message which others receive after parents invite them.

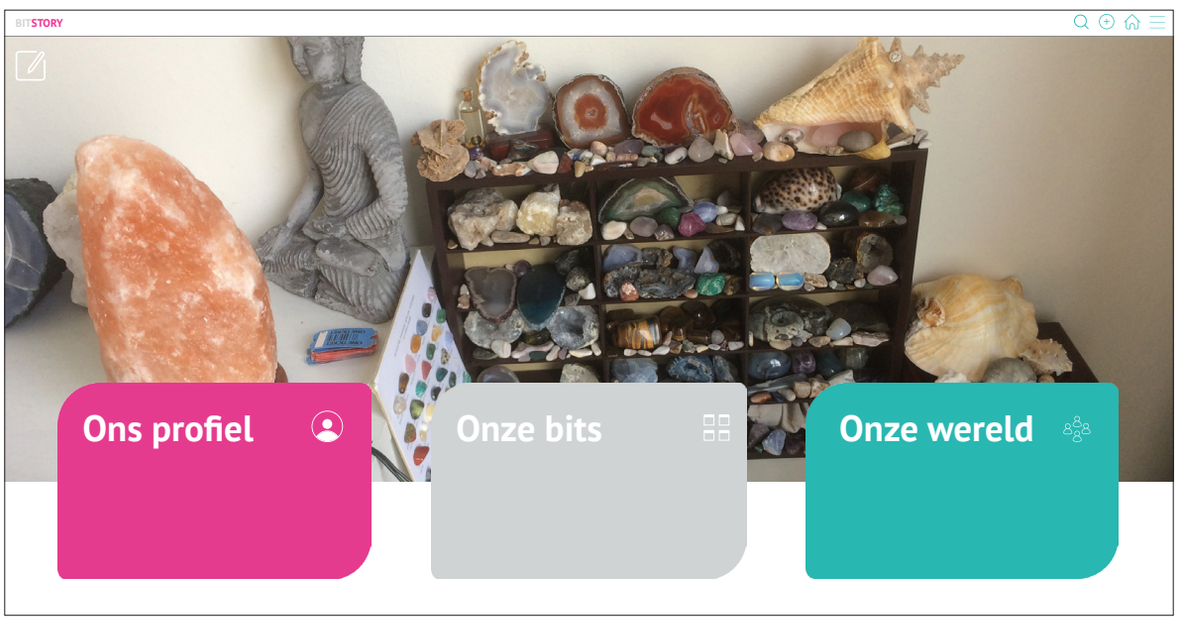


Figure 36. The lay-out of the homepage of Bitstory.

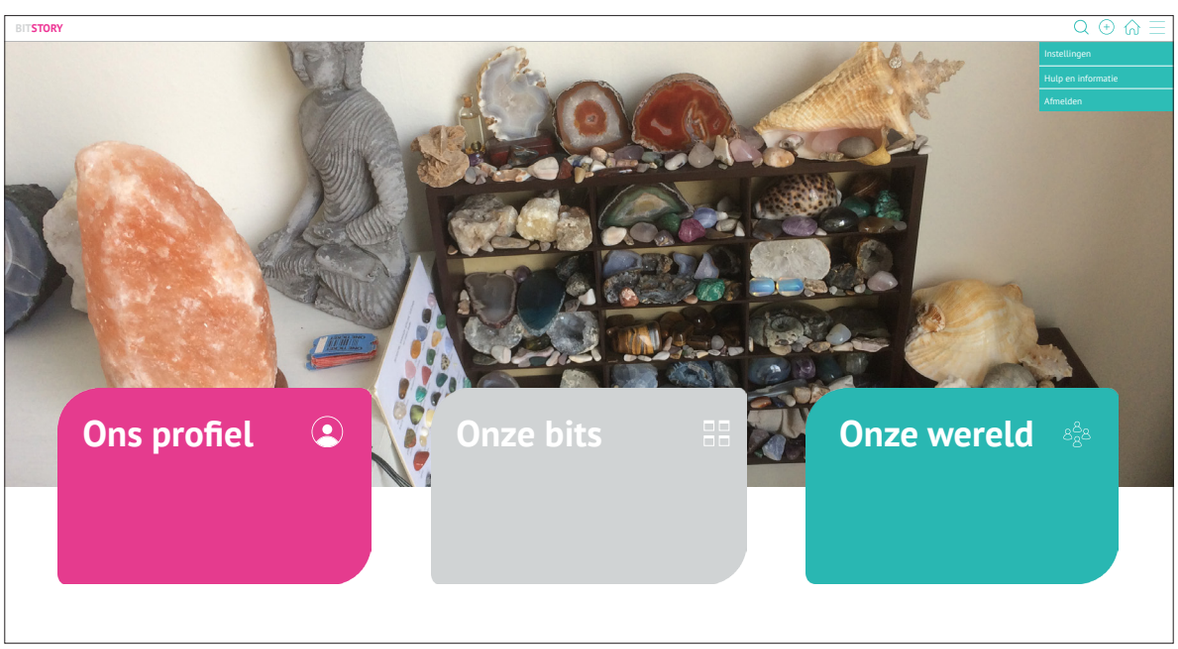


Figure 37. The lay-out of the homepage with options that are under the menu button.

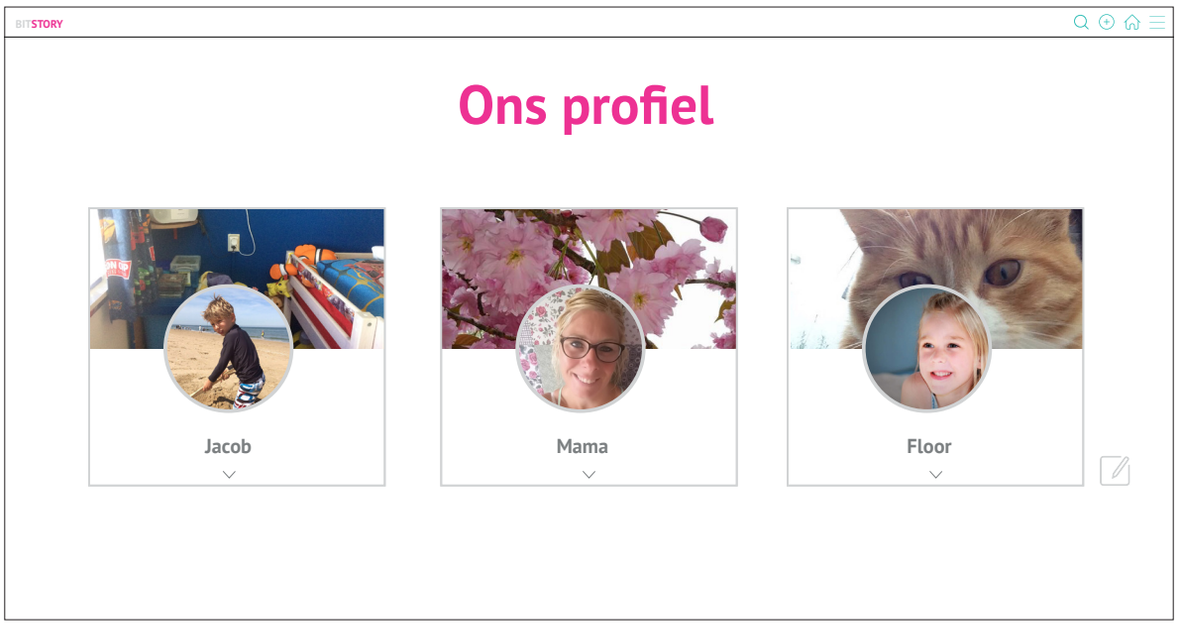


Figure 38. The lay-out of the webpage of the section 'Our profile'.

Figure 39. The lay-out of the webpage of the section 'Our profile' after clicking on the downward-facing arrow.

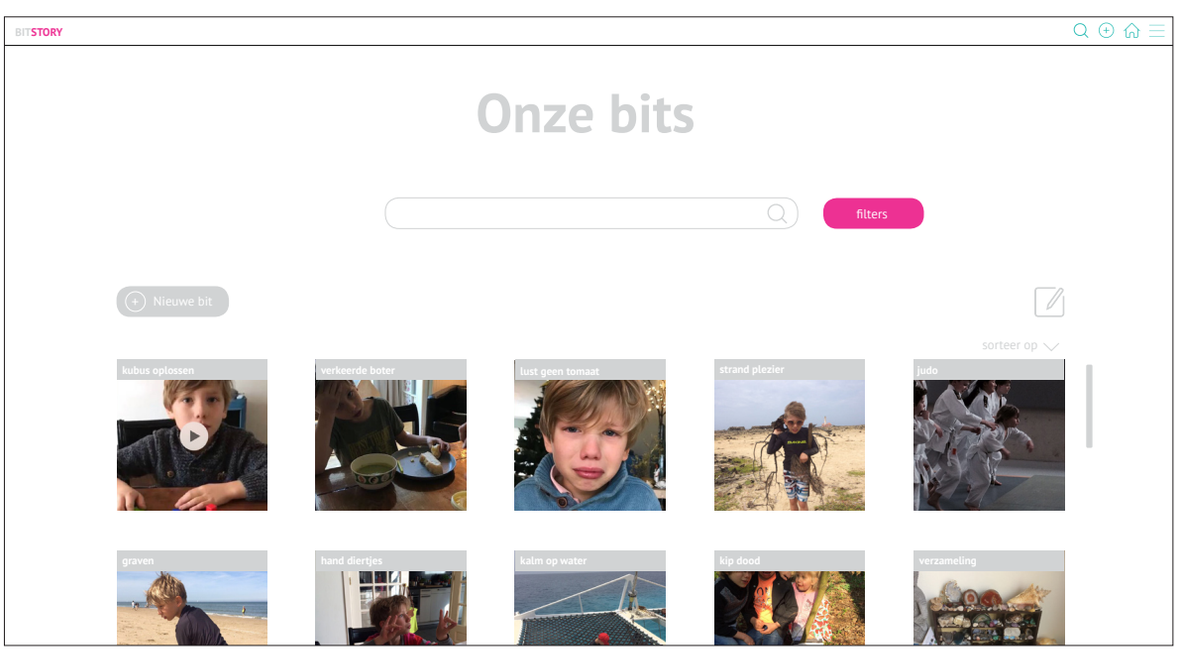


Figure 40. The lay-out of the webpage of the section 'Our bits'.

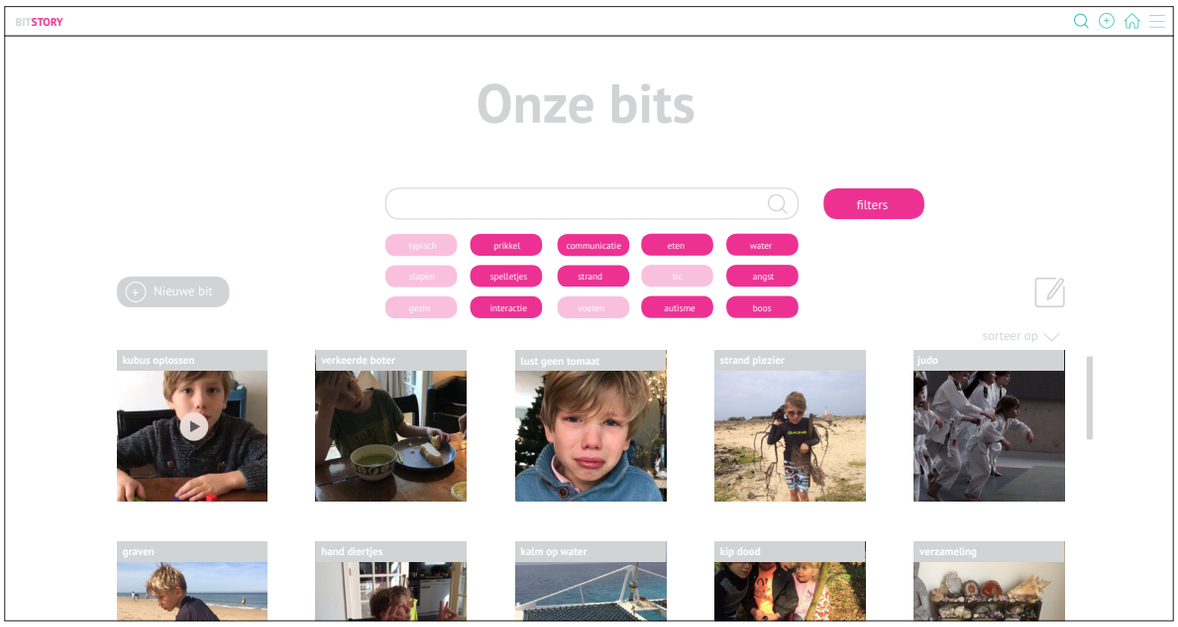


Figure 41. The lay-out of the webpage of the section 'Our bits' with a selection of filters on to search for particular bits.

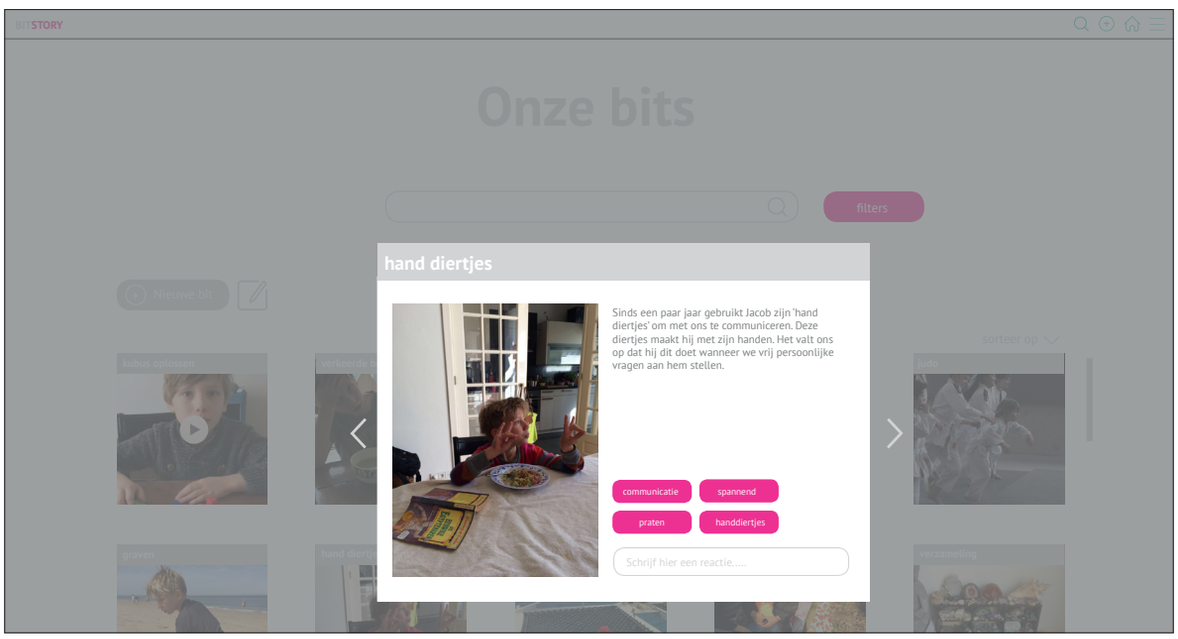


Figure 42. The lay-out of the webpage of the 'Our bits' section with one of the bits.

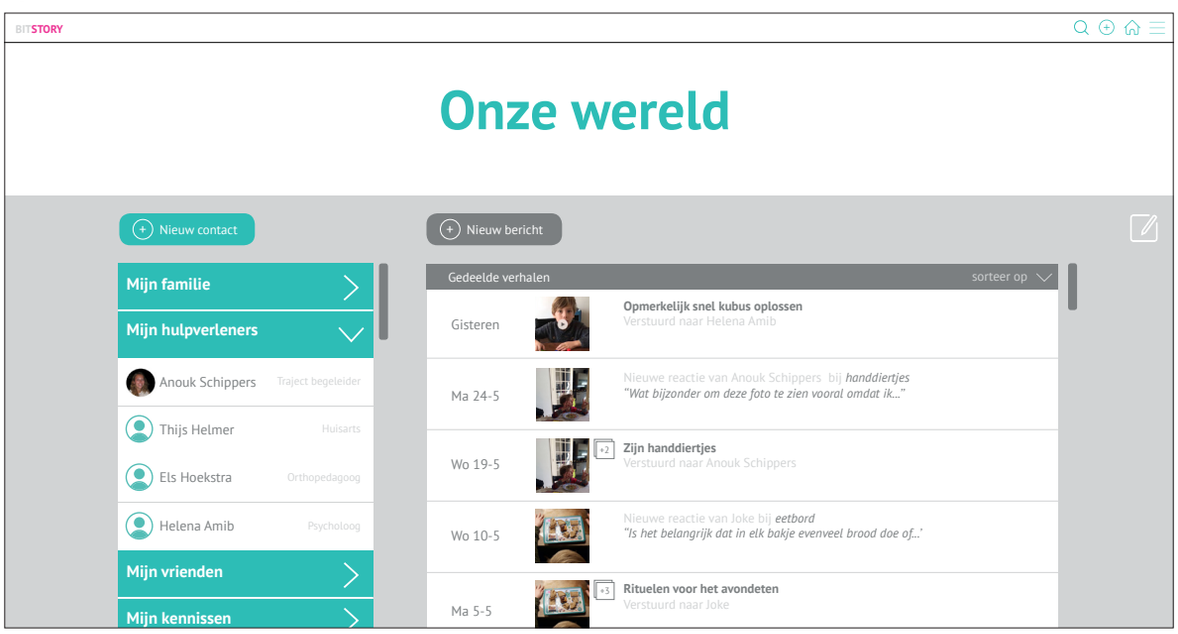


Figure 43. The lay-out of the webpage of the 'Our world' section.

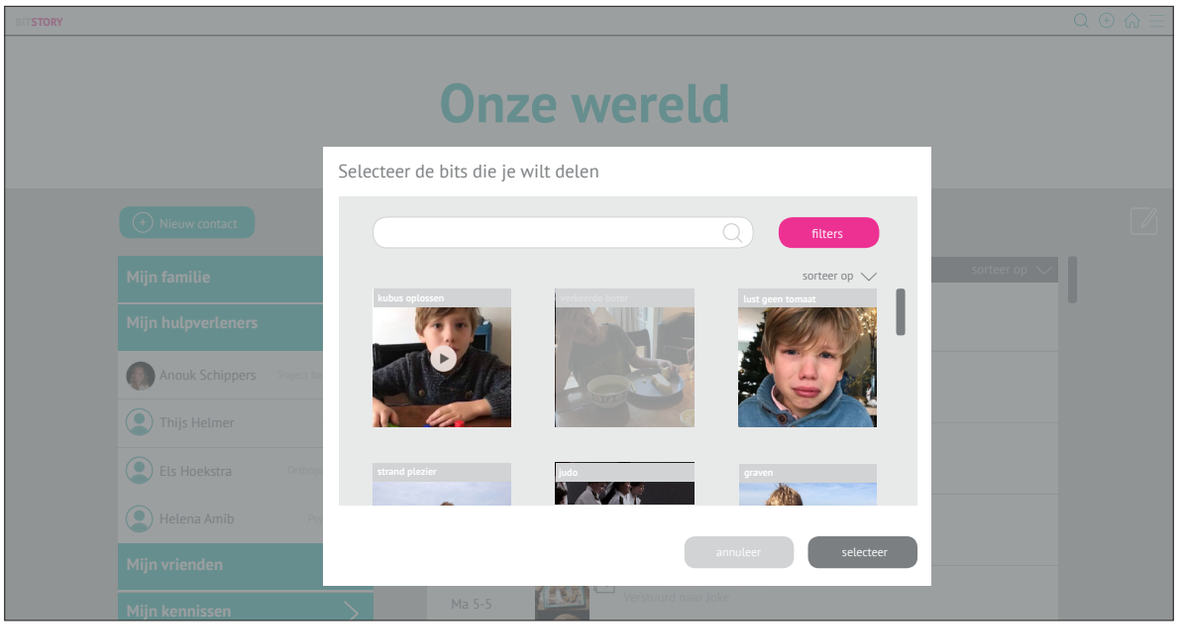


Figure 44. The lay-out of the webpage of the 'Our world' section showing the screen in which bits can be selected to share.

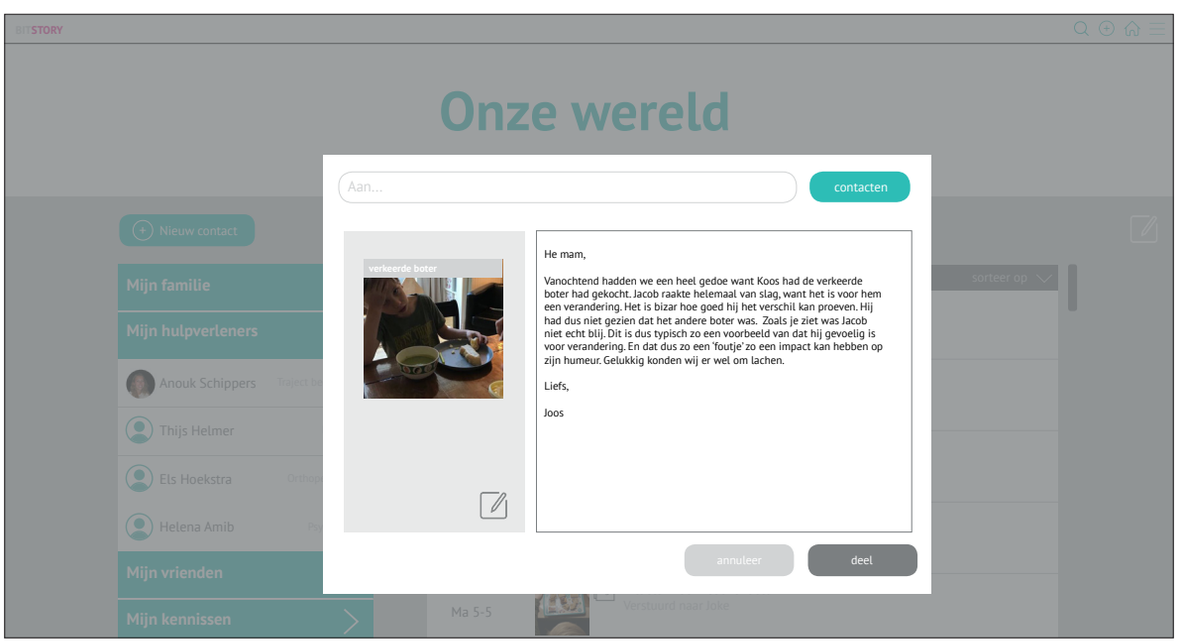


Figure 45. The lay-out of the webpage of the 'Our world' section showing the message with the selected with to be share with another person.

Business model

Appendix S

Costs

Estimating the costs for Bitstory was done by consulting experts in different fields such as in IT, requesting quotations for the purchased products and using (online) sources. To be able to estimate how much it would cost De Buitenwereld to implement Bitstory, information is needed on how many families are going to work with Bitstory per year. In consultation with the company, this group was estimated to be 100 families of a child with autism, aged 4-12, per year. Knowing this target makes it possible to determine a batch-size for purchasing parts such as the USB and external battery. So for the introduction package, a proper estimation can be done using the batch-size of 100 a year (figure 47).An example of a quotation for the external battery to estimate these costs is shown in figure 46. However, the development of the website is not a price which depends on the batch-size, but a price which is more of a big investment at once. Designing the website requires quite some resources, research, testing and development, so the costs can become very high (figure 47). Costs for the implementation toolkit do not depend on the batch-size estimated on the families, but on a batch-size estimated on how many trajectory supervisors are going to work with the toolkit. At the moment, there are 15 trajectory supervisors so the batch-size was set on 15. However, this cost price was defined to be investment for about 3 years, since it is expected that the products will last for a few years instead of having to buy or print the product every year as is the case with the introduction package.

USB stick Producent

Pieter Braaijweg 101
1114 AJ Amsterdam
The Netherlands
t. +31 (0)0 504 57 35
f. +31 (0)20 504 57 45
e. promo@usbstick-producer.com
www.usbstick-producent.nl

Amsterdam, 18 april 2018, Projectnummer: 101050-NL

Geachte mevrouw Noorman,
Naar aanleiding van uw aanvraag doe ik u hierbij de offerte toekomen voor het aangevraagde USB model. De afgebeelde modellen zijn veelal in meerdere kleuren leverbaar. Ik vertrouw erop dat deze offerte u een duidelijk beeld geeft van onze mogelijkheden.

Deze offerte is gebaseerd op:

100 Powerbanks met een bedrukking in kleur of middels lasergravure.
De opslagcapaciteit van deze Powerbank is 3000 mAh

3000 mAh		**100**
Stuk prijs	€	8,97
Bedrukking	€	0,20
Transport	€	0,60
Standaardverpakking*	€	incl.+
Totaal prijs per stick	€	9,77
Totaal bedrag	**€**	**977,00**

Figure 46. A quotation for the external battery.

Bitstory website		The Introduction package		The implementation toolkit	
website development	€ 10.000-100.000	cardboard package (100x)	€ 200	case (15x)	€ 200
hosting	€ 10 per month	booklet (100x)	€ 200	storycards (15x)	€ 30
maintenance	€ 500 per year	USB stick (100x)	€ 450	guide (15x)	€ 30
certificate	€ 100 per year	External battery (100x)	€ 1000		
domain name	€ 5 per year				
cost at once	**€** 10.000-100.000				
cost per year	**€** 725	cost per year	**€** 1850	cost per 3 years	**€** 260

Figure 47. Estimation of costs per design part of Bitstory.

Who will help you?
KEY PARTNERS

Who are your key partners/suppliers?
What are the most important motivations for the partnerships?

SWK groep
NEDAP
Garage 2020
Social Impact Bonden
Fondsen
BNN'ers

How do you do it?
KEY ACTIVITIES

What key activities does your value proposition require?
What activities are most important for your distribution channels, customer relationships, revenue streams etc?

Provide training
Generate proof
Maintenance
Design
IT
Networking
Pitching
Testing
Marketing

What do you need?
KEY RESOURCES

What key resources does your value proposition require?

UX designer
UI designer
Programmer
Test panel
Companies for purchasing products
Employees
Privacy regulations

What do you do?
VALUE PROPOSITION

What core value do you deliver to your audience?
Which needs are you satisfying?

Strengthening relationships and building a strong support network for parents by removing barriers, enhancing understanding, and building more trust

Offering a better competitive position for healthcare institutions

Providing a higher quality of care, higher efficiency, lower costs

How do you interact?
AUDIENCE RELATIONSHIPS

What relationship does the target audience expect you to establish?
How can you integrate that into your work in terms of cost and format?

Trust
Transparency
Personal support
Empowerment

How do you reach them?
DISTRIBUTION CHANNELS

Through which channel does your audience want to be reached?
Which channels work best? How much do they cost?
How can they be integrated into your and your audiences routines?

Newsletter
Social media
Post
Email
Meetings
Conferences

Who do you help?
AUDIENCE SEGMENTS

Which groups are you creating value for?
Who is your most important audience?

Municipalities

Families and caretakers of children with autism (4-12 years old)

Their (in)formal network

Other caretakers and healthcare institutions

What will it cost?
COST STRUCTURE

What are the most important costs in your work?
Which key resources/ activities are most expensive?

Design of the website
Development of website
Development of the tools
Production of the tools
Purchasing tools
Salary for the people involved

How much will you make?
REVENUE STREAM

For what value are your audiences willing to pay?
What and how do they recently pay? How would they prefer to pay?
How much does every revenue stream contribute to the overall revenues?

Sell training and toolkit (methodology)
In-ads on website
Membership for extra functionalities (Freemium/ Premium)
Donations, subsidies, sponsorship

Figure 48. Business Model Canvas filled in for Bitstory.