

Appendix

Giving siblings a voice

Master thesis

by Vanessa Schumacher

Design for Interaction

Faculty of Industrial Design Engineering
Delft University of Technology

In collaboration with

Ontzorghuis

Supervisory Team

Prof. dr. Pieter Jan Stappers
M.A. Paula Melo Signerez
Ir. Marise Schot

August 2023

Overview Appendix

Project brief

- A First impressions
- B Expert Interviews
- C Siblings perspectives - Adult siblings
- D Siblings perspectives - Other resources
- E Siblings perspectives - Generative session
- F Research summary
- G Concept exploration - Brainstorming with experts
- H Concept exploration - Emerging concepts
- I Concept exploration - Concept testing
- J Concept direction - Brainstorming with designers
- K Concept direction - Concept testing
- L Design proposal -Refining elements
- M Design proposal - The prototype
- N Design proposal - Feedback

Project brief

DESIGN
FOR OUR
future



IDE Master Graduation

Project team, Procedural checks and personal Project brief

This document contains the agreements made between student and supervisory team about the student's IDE Master Graduation Project. This document can also include the involvement of an external organisation, however, it does not cover any legal employment relationship that the student and the client (might) agree upon. Next to that, this document facilitates the required procedural checks. In this document:

- The student defines the team, what he/she is going to do/deliver and how that will come about.
- SSC E&SA (Shared Service Center, Education & Student Affairs) reports on the student's registration and study progress.
- IDE's Board of Examiners confirms if the student is allowed to start the Graduation Project.

! USE ADOBE ACROBAT READER TO OPEN, EDIT AND SAVE THIS DOCUMENT

Download again and reopen in case you tried other software, such as Preview (Mac) or a webbrowser.

STUDENT DATA & MASTER PROGRAMME

Save this form according to the format "IDE Master Graduation Project Brief_familyname_firstname_studentnumber_dd-mm-yyyy". Complete all blue parts of the form and include the approved Project Brief in your Graduation Report as Appendix 1 !

family name	<u>Schumacher</u>	Your master programme (only select the options that apply to you):
initials	<u>VS</u> given name <u>Vanessa</u>	IDE master(s): <input type="radio"/> IPD <input checked="" type="radio"/> Dfl <input type="radio"/> SPD
student number	<u>5167086</u>	2 nd non-IDE master: _____
street & no.	_____	individual programme: - - (give date of approval)
zipcode & city	_____	honours programme: <input type="radio"/> Honours Programme Master
country	_____	specialisation / annotation: <input checked="" type="radio"/> Medisign
phone	_____	<input type="radio"/> Tech. in Sustainable Design
email	_____	<input type="radio"/> Entrepreneurship

SUPERVISORY TEAM **

Fill in the required data for the supervisory team members. Please check the instructions on the right !

** chair	<u>Prof. dr. Pieter Jan Stappers</u>	dept. / section: <u>DCC</u>
** mentor	<u>(Dr. ir. Marieke Sonneveld*)</u>	dept. / section: <u>AED</u>
2 nd mentor	<u>Ir. Marise Schot - HCD/ DA</u>	
	organisation: <u>Ontzorghuis</u>	
	city: <u>Delft</u> country: <u>Netherlands</u>	
comments (optional)	<u>https://www.ontzorghuis.nl</u> (* note of chair: mentor approved brief but had to quit on kickoff; we are looking for a replacement mentor.	

Chair should request the IDE Board of Examiners for approval of a non-IDE mentor, including a motivation letter and c.v..



Second mentor only applies in case the assignment is hosted by an external organisation.



Ensure a heterogeneous team. In case you wish to include two team members from the same section, please explain why.

Giving CSN siblings a heard voice project title

Please state the title of your graduation project (above) and the start date and end date (below). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

start date 08 - 02 - 2023 25 - 08 - 2023 end date

INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

This graduation project focusses on the siblings of Children with Special Needs (CSN) in Western European Countries / the Netherlands and Germany. Special Needs are health care related and range from children with physical impairments and chronic illness to learning disabilities, psychological delays and mental disorders. Official reports state that in the Netherlands one quarter of children and young adults until the age of 25 suffers from a chronic disease (Vanneste et al. 2022). Such numbers also include other chronicle diseases such as mental health issues and obesity. Whereas the number of children with special needs are more speculative and estimated at around 500.000 children (Okma, Naafs, Vergeer, & Berns, 2014).

The moment a Child with Special Needs is born, the whole family situation changes. The children's needs are taking all the parents attention and energy. CSN Parents feel mentally overloaded with their roles and their own relationship becomes quite fragile. CSN Siblings are not getting enough attention anymore within their families and are mostly on their own (Okma, Naafs, Vergeer, & Berns, 2014). Furthermore, literature shows opposite influences on siblings when growing up with a CSN. On the one hand siblings are a risk group for emotional and behavioral problems (Roberts et al, 2014). And on the other hand there is a high potential to develop personal strengths when growing up with a child with special needs (Milevsky & Singer, 2022). Based on that siblings can be seen as potential risk group that need external support.

The company Ontzorghuis, established by Marise Schot in 2018, aims towards a family inclusive health care approach. Trough self-reflective design interventions, workshops and weekend retreats the company supports CSN families. The tools help parents to gain insights, share experiences and to inspire each other. Ontzorghuis' future vision is to develop a resourceful community which develops and shares new ideas/solutions to inspire each other. However, the main focus is for now on parents and their children with special needs, CSN siblings are currently less considered in the provided tools and retreat programs.

space available for images / figures on next page

introduction (continued): space for images



image / figure 1: [Picture showing three siblings, one with special needs \(https://www.ellenstumbo.com/episode24/\)](https://www.ellenstumbo.com/episode24/)

TO PLACE YOUR IMAGE IN THIS AREA:

- **SAVE THIS DOCUMENT TO YOUR COMPUTER AND OPEN IT IN ADOBE READER**
- **CLICK AREA TO PLACE IMAGE / FIGURE**

PLEASE NOTE:

- **IMAGE WILL SCALE TO FIT AUTOMATICALLY**
- **NATIVE IMAGE RATIO IS 16:10**
- **IF YOU EXPERIENCE PROBLEMS IN UPLOADING, CONVERT IMAGE TO PDF AND TRY AGAIN**

PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

As mentioned above the family situation changes with a CSN and thus as well the siblings position and role within the family. Siblings experience various positive and negative feelings towards their CSN brother or sister which range from loving and protective to embarrassment and fear (Strohm, 2008).

Weekend retreats at Ontzorghuis have shown that siblings are appreciating and grateful for some personal time and space to play, but wouldn't demand it proactively. Similar insights are shown by Strohm (2008), that siblings don't want to „burden parents with extra stresses“ and „might feel guilty about complaining“. Strohm (2008) also suggests that a group experience is a personal gain for siblings through sharing and learning from each other. But she also highlights that this depends from child to child and others may please more the personal environment to open up.

The issues I will be tackling in this project, will be about creating the space for siblings to raise their voice within their families. The project focusses on identifying the siblings effective strategies when coping with their basic needs and emotions related to their current family situation. This includes evaluating sensitive talking about emotions, but also finding out which roles they want to take up within the family to feel comfortable and heard. The focus group will be children between 6 and 12 years.

ASSIGNMENT **

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

My graduation project will be about the vision to create space for CSN siblings (6 - 12 years) to give them a heard voice— within their family about sensitive topics their preference.

Through a participatory design approach, I will develop an understanding of siblings strategies of coping with their own needs and emotions about family related topics and the desire of expressing themselves. By diving into their perspectives, I aim to understand the siblings relationships with various family members, as well as their own role identification, needs and emotions.

The goal at this point is to find out if and about which topics CSN siblings would like to be more heard within their family's situation. To round off the research phase, my first deliverable will be a visual summary of the research phase and the gained insights that represent the different siblings perspectives and strategies.

This will be the starting point for the second part of my project, where I will translate those insights into a design concept to facilitate giving CSN siblings a voice. The concept tackles talking about sensitive topics among family members and confidential persons. It can be part of an Ontzorghuis weekend workshop, but can also take place independently in familiar environments.

MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, Stick to no more than five ambitions.

In my graduation project I would like to prove that I am capable to do the participatory approach in design by myself. I learnt the basic knowledge in C&C (Semester 2) in very rapid cycles and repeated them in various design projects, but also very rushed through. Thus, I aim to complete the entire process beginning with appropriate sensitizing materials, conducting the session, interpreting and coming up with a design proposal. Now I want to focus on the process itself and learn how to end the research process by visualizing gathered insights and to make proper use of them for the further design process.

Additionally, I gathered different competences in the past through various electives like Inclusive Design, Participation Interaction and Prototyping (PIP) and emerging markets. This selection already shows that I am a very social oriented person and can also imagine my future in tackling societal issues. And I believe that the graduation project will be a nice supplementation on my current research area, but also bring up new challenges and opportunities for my personal development as a designer. This project will show me the limits to which extent we as designer can interfere and influence in our society and create impact.

And last but not least, I am very keen working and researching with children. I believe that there are many things I can learn from those small human beings and that they can change our sometimes to rational perspectives. Within this graduation project I would like to apply gained knowledge in the design research with children, but also give something back to them.

References

Milevsky, A., Singer, O. (2022): Growing up alongside a sibling with a disability: A phenomenological examination of growth and deficiency in adulthood, *Research in Developmental Disabilities*, Volume 130, 104336, ISSN 0891-4222, <https://doi.org/10.1016/j.ridd.2022.104336>.

Okma, K., Naafs, L., Vergeer, M., & Berns, J. (2014). Quickscan naar de ondersteuningsbehoefte van zorgintensieve kinderen. Nederlands Jeugdinstituut. Link:<https://www.nji.nl/sites/default/files/2021-06/QuickScan-naar-de-ondersteuningsbehoefte-van-zorgintensieve-gezinnen.pdf>

Roberts, R. M., Ejova, A., Giallo, R., Strohm, K., Lillie, M., Fuss, B. (2014): A controlled trial of the SibworkS group program for siblings of children with special needs, *Research in Developmental Disabilities*, Volumes 43–44, 2015, Pages 21-31, ISSN 0891-4222, <https://doi.org/10.1016/j.ridd.2015.06.002>.

Strohm, K. (2008). Guest Editorial: Too important to ignore: Siblings of children with special needs. *Australian e-Journal for the Advancement of Mental Health*, 7(2), 78-83.

Vanneste, Y. T., Lanting, C. I., & Detmar, S. B. (2022). The preventive child and youth healthcare service in the Netherlands: the state of the art and challenges ahead. *International journal of environmental research and public health*, 19(14), 8736.

FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.

Appendix A - First impressions

Online meet-up with siblings

Session set-up



The role and participation of the student researcher in the meetings wasn't that clear from the beginning. For that reason, they were less prepared, and without knowing anything about the children's knowledge and background. This may have limited them entirely participating in the conversation and asking questions, but also helped to observe unprejudiced and perceive other details. Furthermore, the diversity of participants was limited to three siblings only in two sessions.

Field trip with siblings

Session set-up



Next to assisting and coordinating as a volunteer, observation was the student researchers most valuable tool during that weekend to capture the children's behaviors and experiences they shared (do, use). There were also opportunities to ask detailed questions (say) and even the moment to let the children note down their future dreams in a secret letter (know, feel, dream). Thus, all options were given, in order to dive from the children's surface to the tacit knowledge. A nondisclosure agreement was officially signed between the volunteering subjects and the responsible project leader.

Research questions for the weekend

What do siblings's relationships look like within their friends groups?

What are their personal dreams about the future?

Questions to ask in the first train ride getting to know

Is it your first time on holiday without your family?

Are you often on holidays?

Where / How do you stay?

What is your favorite destination - if you could wish you any place and with whom?

Questions to friends

What were the reasons you are joining this trip?

Do you know your friends' siblings well?

Questions to ask in the train ride targeting relationships

Conversation starter: What did you like the most this weekend? / What moment made you feel special this weekend? (Besondere Geschwister)

What did you learn from other siblings this weekend?

How did it make you feel talking to other siblings?

What will you tell your friends about this weekend?

Will you invite your friends next time to join this weekend? Why?

Do you think your friends could also learn a lot from other siblings? Examples?

What would it make easier for you to just tell your friends / other people?

If you could make a wish - what would it be that tomorrow at school it would feel so normal to tell your friends about this weekend and why you joined?

Are you looking forward to the next event?

Which of your friends do you like to be part of the event?

Which one not?



The role as volunteering caretaker and the given responsibilities was limiting in itself, by being occupied with coordinating and organizing. However, the limitation is only of minor severity as there were still plenty of opportunities to pick up conversations and to get in touch with the children. Unlike the created generative data it should be mentioned that the activity was initiated very spontaneously without following the path of expression in generative research as recommended by Sanders & Stappers (2012). Thus, it was sometimes hard for the siblings to come up with future dreams, as there was a certain preparation missing. Next to that, the chosen wording for the activity was already very guiding towards a specified solution ("a product"), as well as limiting ("in relation to your siblings). The number of participating children was 8 in total, whereas 5 of them already knew each other or bore a relation. Thus, such a familiar group within a group was sometimes helpful, but also an obstacle, in the sense of being closed, for smooth conversations about a sensitive topic.

Results protocol

By observing

To start with, on the first sight there is no enormous difference visible between special siblings and usual siblings. The children enjoyed going on a weekend trip and they were excited, energized, loud and chaotic. But already on the train, they self-organized and started instantly playing games together. Without being timid or excluding, from all ages they formed a group together and enjoyed the train ride.

Also, what was clearly visible in their behavior during the weekend was their sensitivity for other people's needs: An older sibling taking care of its younger sibling, helping it out and feeling responsible for the youngest. Or in contrast, another child being very loud and clearly having issues in focussing, was always sensitive in recognizing and directly mentioning other people's needs ("Are you tired?", "You are hungry right?", "Why do you look so sad?", "He is really enjoying this"). And lastly the youngest child's internal assignment trying to comfort other kids and adults to make them feel satisfied (One child roughly reading from a book asking the younger child: "Are you still listening to my story?" - Younger child clearly doing something else and not paying attention anymore, was nodding encouraging the other child to keep reading "Yes, what's happening next?").

Another observation was that older children (age 10 - 14) felt way more comfortable talking about their younger or older sibling with special needs. They had a certain knowledge and understanding of the facts to explain the disability of their sibling to others. Whereas, the youngest participants were more reserved and barely talked about their situation at home - they felt obviously uncomfortable with the topic and replied that they didn't know and an immediate change of topic was initiated. This can be referred to a lack of knowledge about the situation and/ or their age. However, another sibling avoiding such a conversation was entirely spending its time on its hobby and clearly enjoying the moment.

Another insight from the field study was the constant search for attention of a child when being surrounded by an adult. There was one child clearly enjoying the adults company by trying to contribute to the conversations and receiving as much as possible confirmation.

By talking

In some very confident conversations it became clear that siblings usually do have one best friend that also knows about the family situation. Sometimes some friend groups exist, but they don't seem to be very close. Nevertheless, in many cases the siblings spend a lot of time playing with their special needs sibling or depending on the family constellation with another brother or sister. Those other brothers or sisters of the sibling were also mentioned as the best friend or playmate by the children.

During breakfast, we conducted a short meditation with the children to calm down their excitement a bit. The kids seemed very accepting and receptive to such. In a later conversation they claimed this moment as a waste of time, but in the situation itself no one complained and everyone joined. This resulted in a very relaxed and quiet breakfast atmosphere, which was nonetheless appreciated by the children ("Oh it's never that quiet at our place", "Same", "It's really peaceful").

Write a letter to vanessa with your wishes about the future that includes your siblings. Something that she can design to help you in the future.

limitations: wording (directing towards a product), including siblings, hard to come up with wishes out of the blue

siblings

weniger schule
Wissensaufgaben
Wörter

Feiern

dann hätte ich
mehr Zeit für meine Schwester
und sage ihr mich das ich
keine Zeit habe. i.
Den ich bin nach der Schule
etwas genervt von den
ganzen Aufgaben

feeling bad when sending away special needs sister because of no time

"Weniger Schule, dann hätte ich mehr Zeit und sage ihr nicht, dass ich keine Zeit habe"

Es wäre schön, wenn meine Klassenkameraden aufhören klumme Sprüche zu machen wie z.B. "Bist du behindert?" "Sehr schön, wenn die die das ist. Deshalb wäre es für mich schon wenn sie in der Schule nähergelegt bekommen, wie das ist. Ohne, dass ich sehen muss ob es auch meine Familie betrifft. Ich wünsche mir auch, dass es mehr Angebote gibt."

need for changing societal picture through common activities

"Es wäre schön, wenn meine Klassenkameraden aufhören dumme Sprüche zu machen, wie zum Beispiel: Bist du behindert? Sie verstehen gar nicht wie das ist."

behinderte und nicht behinderte Kinder gemeinsam mehr machen, sodass es leichter wird zu verstehen, wie es ist häufig mit solchen Zeiten zu haben

not being in the center of attention because of differences

"Ohne dass ich erzählen muss, dass es auch meine Familie betrifft"

need for changing societal picture through common activities

"Ich wünsche mir auch, dass es mehr Angebote gibt, in denen behinderte Kinder gemeinsam mehr machen, sodass es leichter wird zu verstehen, wie es ist häufig mit solchen zu tun zu haben"

explanations through education and not by specific family members to not stand out

"Deshalb wäre es für mich schön, wenn wir in der Schule nähergelegt bekommen, wie das ist"

Mehr Zeit
(Zeitstopmaschine)

time to spend with siblings is valuable but limited

"Eine Zeitstopmaschine, dann könnten wir viel mehr Zeit miteinander verbringen"

friends

Wenn ich bei Freunden bin dann möchte ich immer alleine spielen. Vielleicht könnten wir ein Spiel machen, damit sich die Behinderten Kinder beschäftigen können.

Need for privacy among friends

"Wenn ich bei meinem Freund bin, dann kann man nicht immer alleine spielen"

Ich möchte, dass die Leute, die ein behindertes Geschwisterkind haben auch von ihren Eltern geachtet werden. Und hoffe, dass sie sich nicht deswegen so fühlen als würden sie vernachlässigt werden.

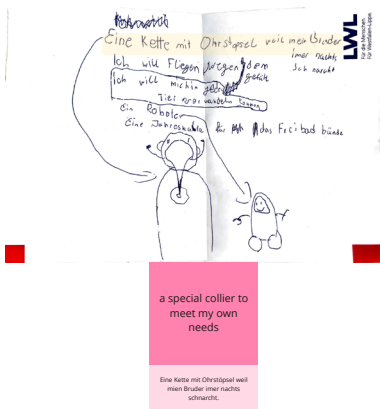
Need of attention on sibling

"Ich möchte, dass die Leute, die ein behindertes Geschwisterkind haben auch von ihren Eltern geachtet werden. Und hoffe, dass sie sich nicht deswegen so fühlen als würden sie vernachlässigt werden."

By making

The children were writing letters to me with the assignment to write how or what they imagined in the future with their special siblings. Surprisingly many letters were generated. And the dreams range from “A collier with earplugs so I don’t hear my brother snoring” to “No homeworks, then I don’t have to send my special sister away but can play with her instead.” and “No rude comments by my classmates like “Bist du behindert?”, things they don’t understand anyways”. Furthermore, two siblings thought about having a lucky charm collier to remind themselves when having a hard time.

Again, the two youngest ones felt clearly uncomfortable with the assignment. One was saying “I don’t know” and didn’t draw or write anything, while the other was drawing a house with many hearts but didn’t want to explain the intention: “I don’t tell you, it’s a secret”.



a special collier to meet my own needs

Eine Kette mit Ohrstöpsel will mein Bruder immer rasch, das macht.



need for safety and security when bad things happen

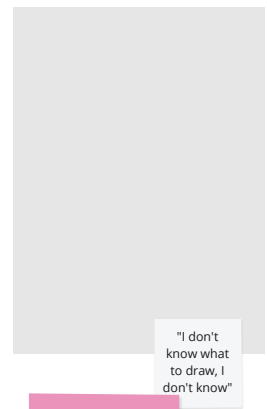
"This is an island where all people and people with disabilities can hide when the water is rising"

"This is an island where all people and people with disabilities can hide when the water is rising"



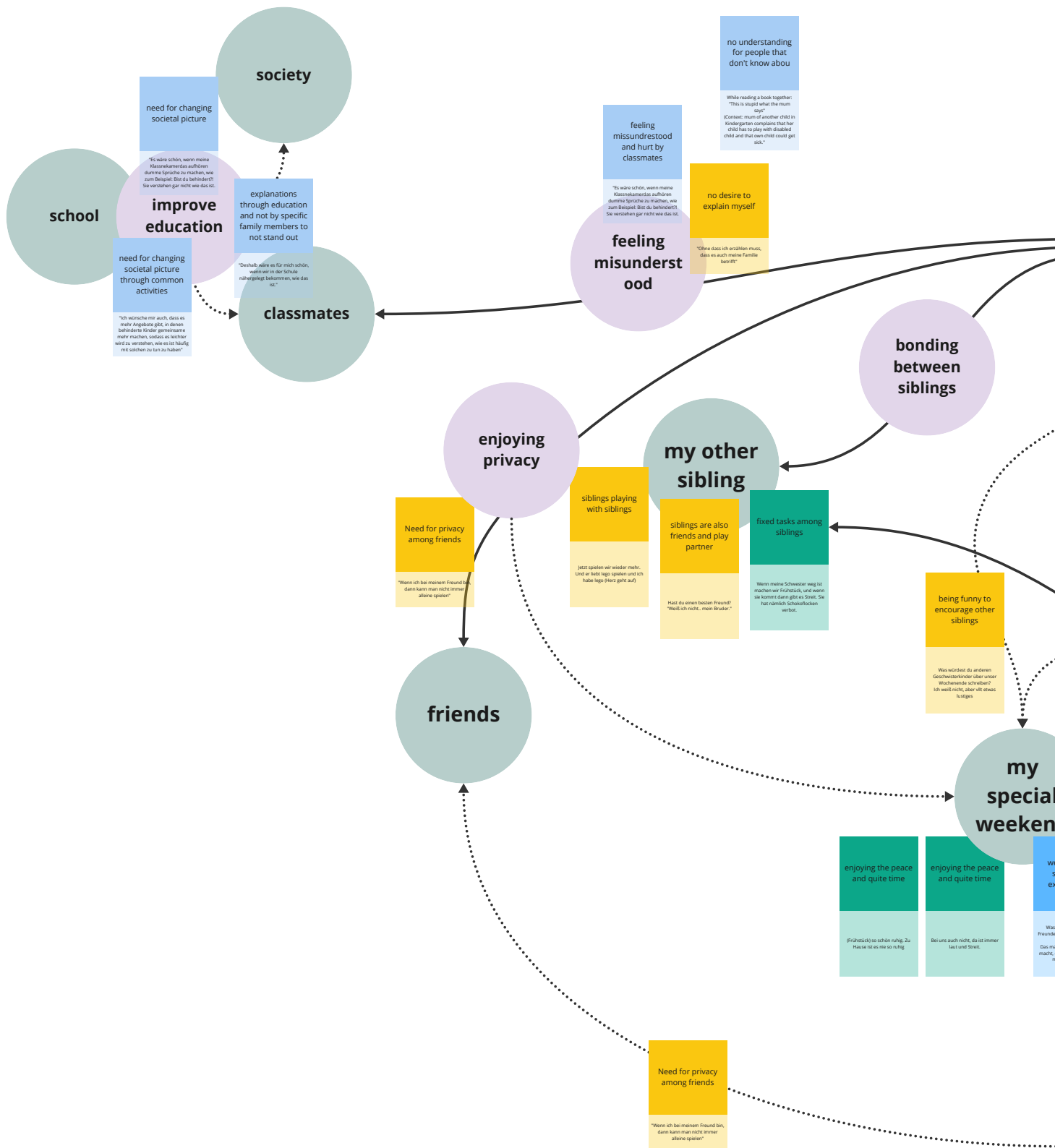
9 year old child

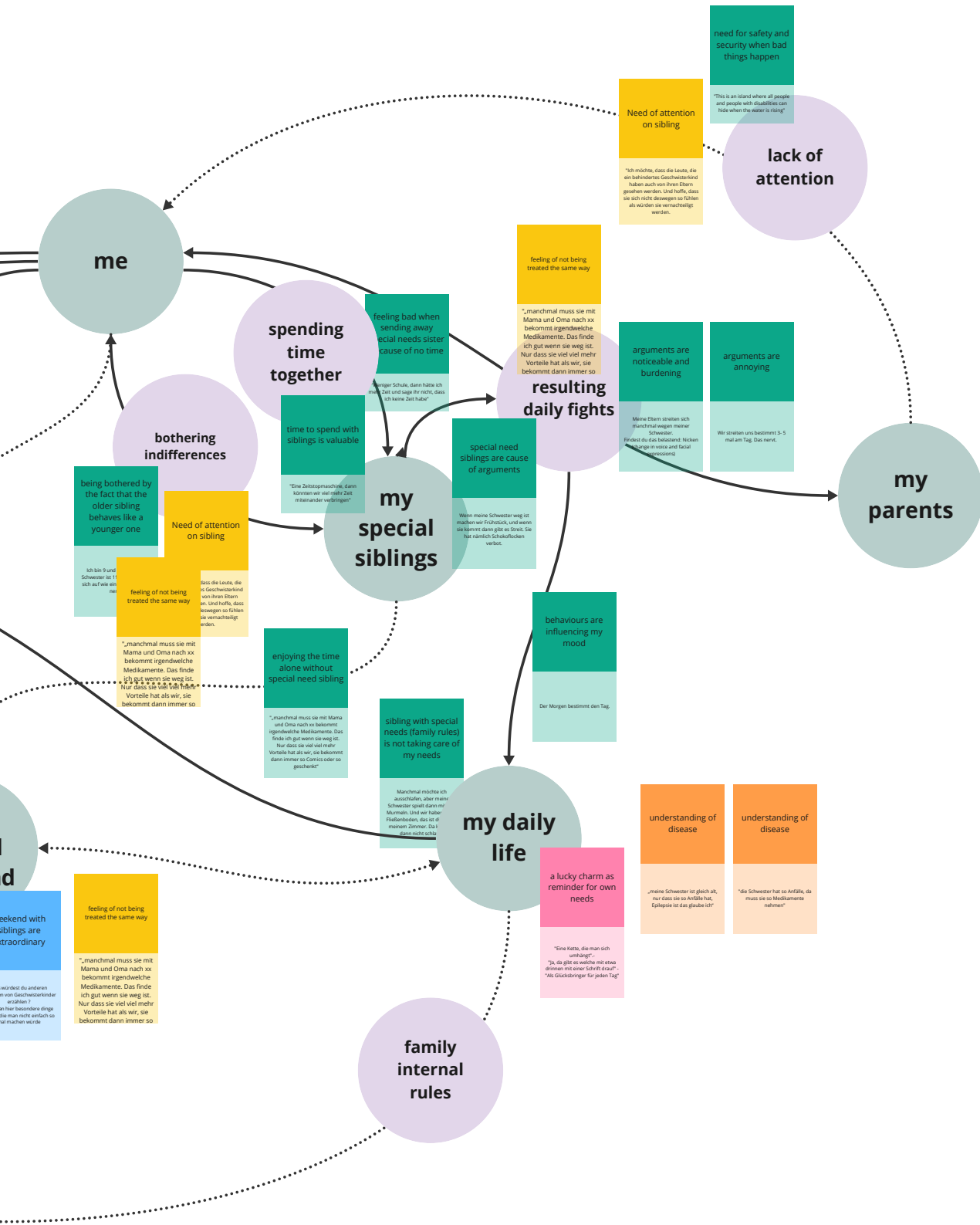
"I don't tell you - it's a secret"



6 year old child

"I don't know what to draw, I don't know"





Appendix B - Expert interviews

Interviews

Questions guideline

Terms & definition

What are the umbrella terms that you are using usually for children with a chronic disease or a disability? (children with special needs / children with disability / ...)

And what do you call siblings? ("Schattenkinder", "Glass siblings", "Special siblings")

Sibling characteristics

How would you describe the characteristics of a sibling in a few words?

(What are character typical strengths and what are weaknesses?)

Siblings social interactions

How does the relationship between siblings and their special needs siblings differ from usual siblings?

What are similarities?

What are typical dynamics between siblings and their parents?

What are typical characteristics resulting from that relationship?

Do children feel like they have to take over this role?

Which of their own needs are they neglecting when taking over certain roles?

How do family internal relationships influence their external relationships with friends or peers?

Siblings strategies

What are siblings' strategies to deal with their daily life situation?

To whom do they talk to? / Who are their closest reference persons when they are feeling bad?

Do they have activities or routines in the family to deal with such situations?

Is there space to integrate a new routine within the family to focus on siblings needs only?

Sibling programs

What are sibling specific activities for such weekends?

What are topics you are focussing on? (Self-development / social interactions / ...)

What makes those weekends sibling specific?

Comparison: no program vs programme

What are the moments when you feel that the sibling is opening up right now?

Are they openly talking to you? / How do they show that?

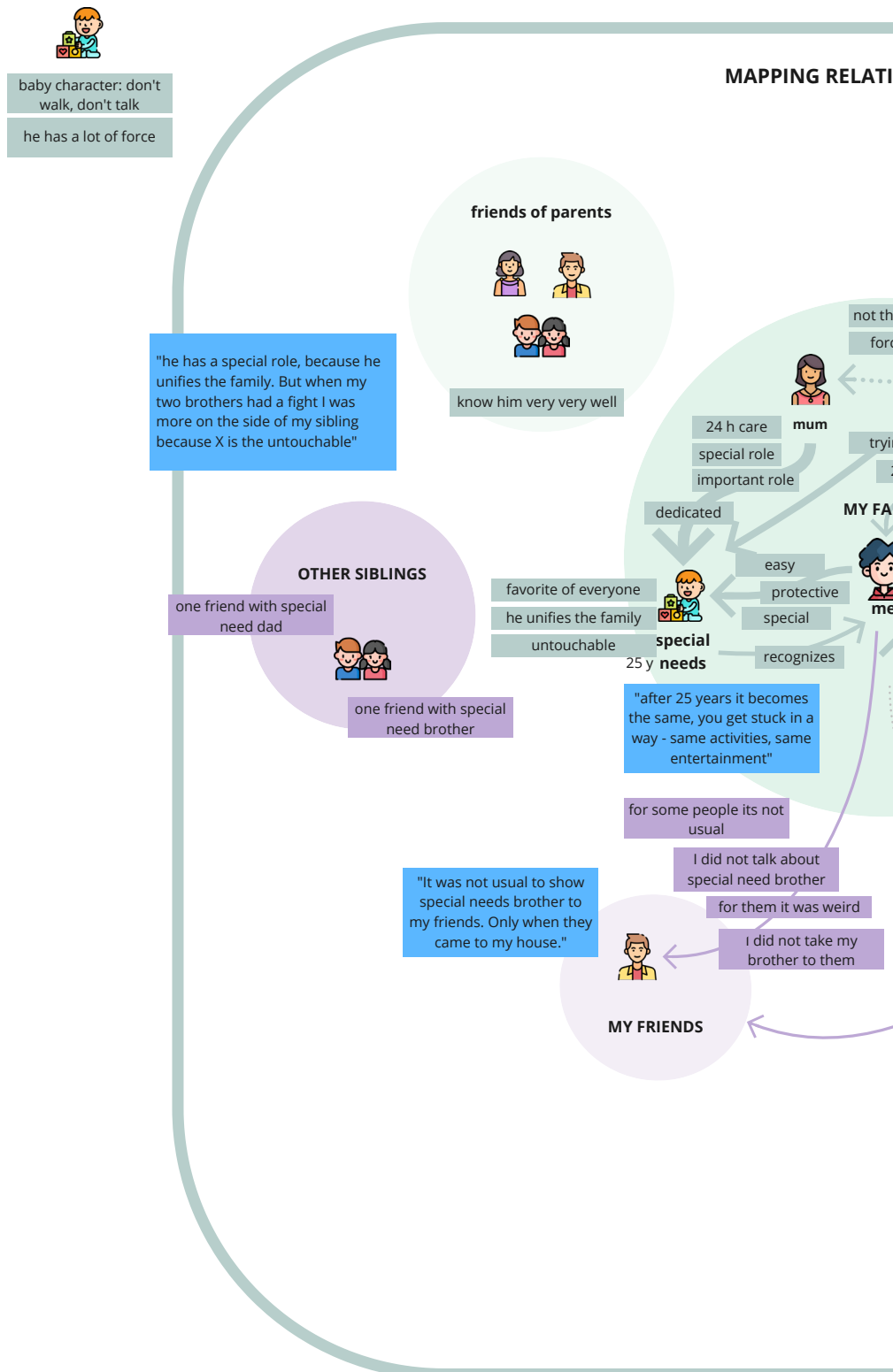
What topics are they then talking about? (special needs brother, personal wishes and dreams?)

What are the take-aways you try to give siblings before going home again?

Appendix C Siblings perspectives

Interviews with adult siblings

Results

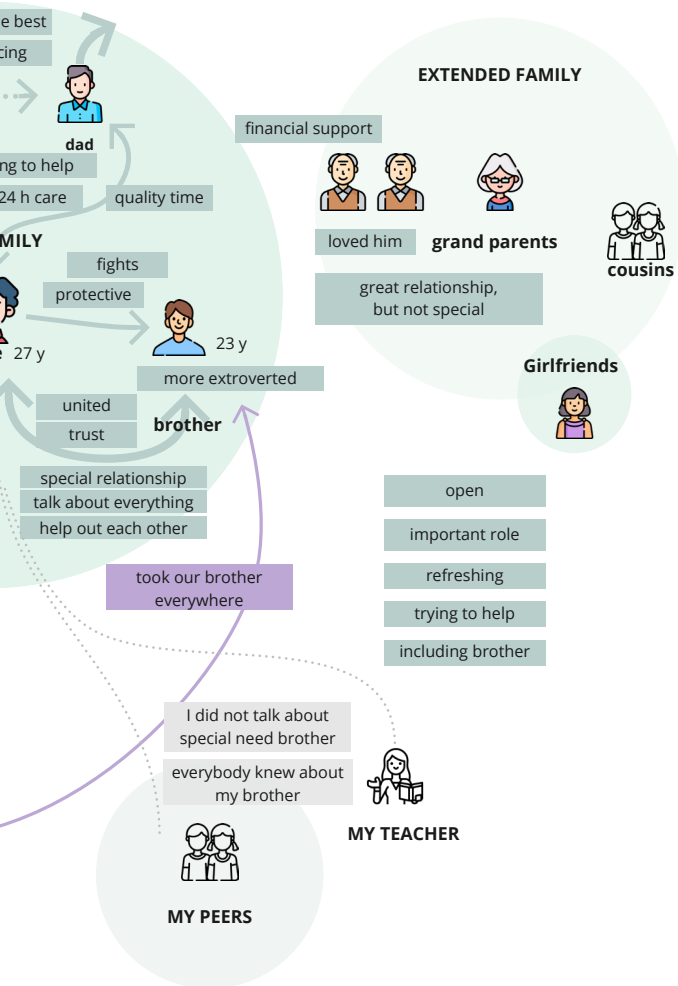


RELATIONSHIPS

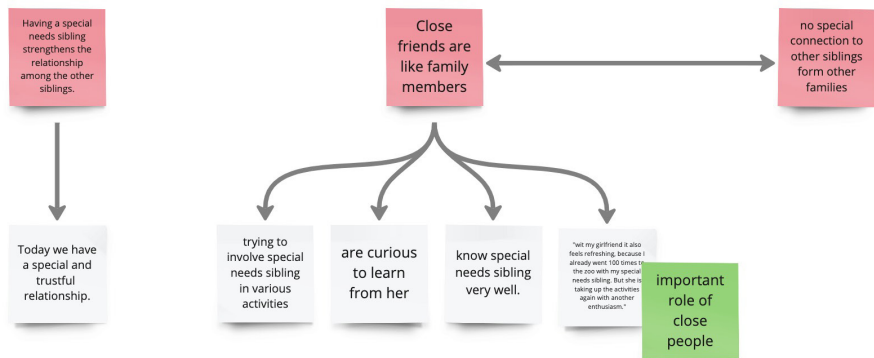
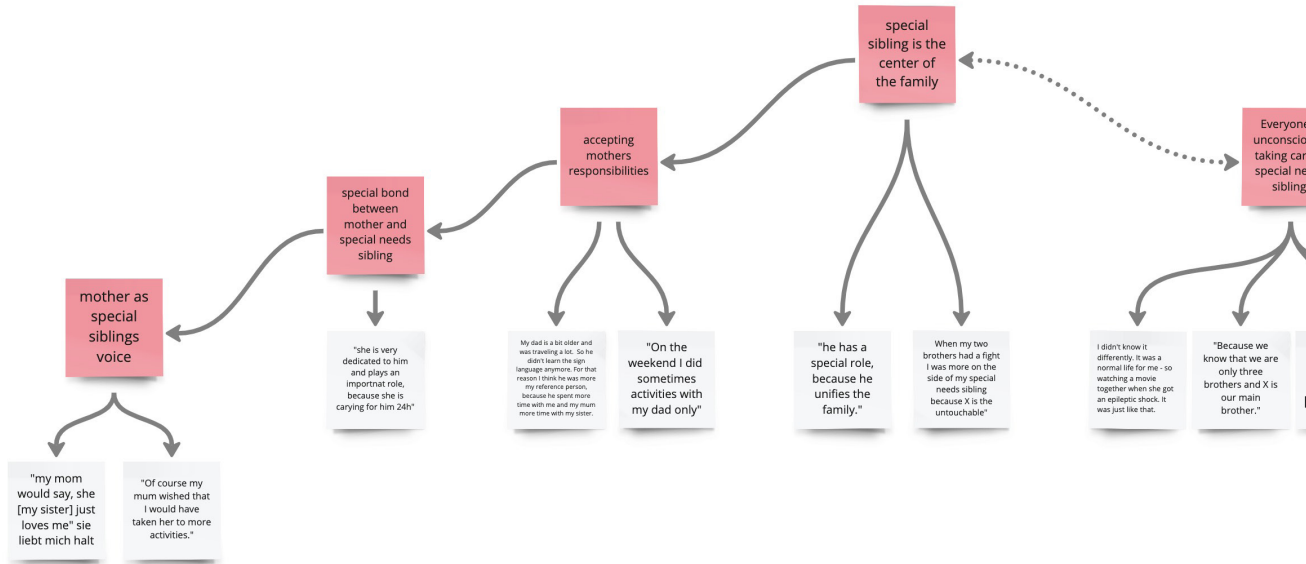
"We always be prepared / ready that he is safe, because he has a lot of force, and the things that are on the table or somewhere, he will just grab everything"

"Everything was a bit normal I think, we had usual fights among brothers. But today we have a special relationship I think, a lot of confidence, it's a good relation. **Because we know that we are only three brothers and X is our main brother** - and we can talk about everything."

still had his life, go out meet friends

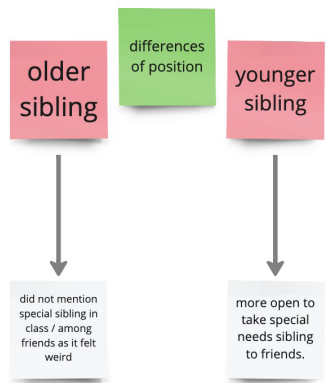
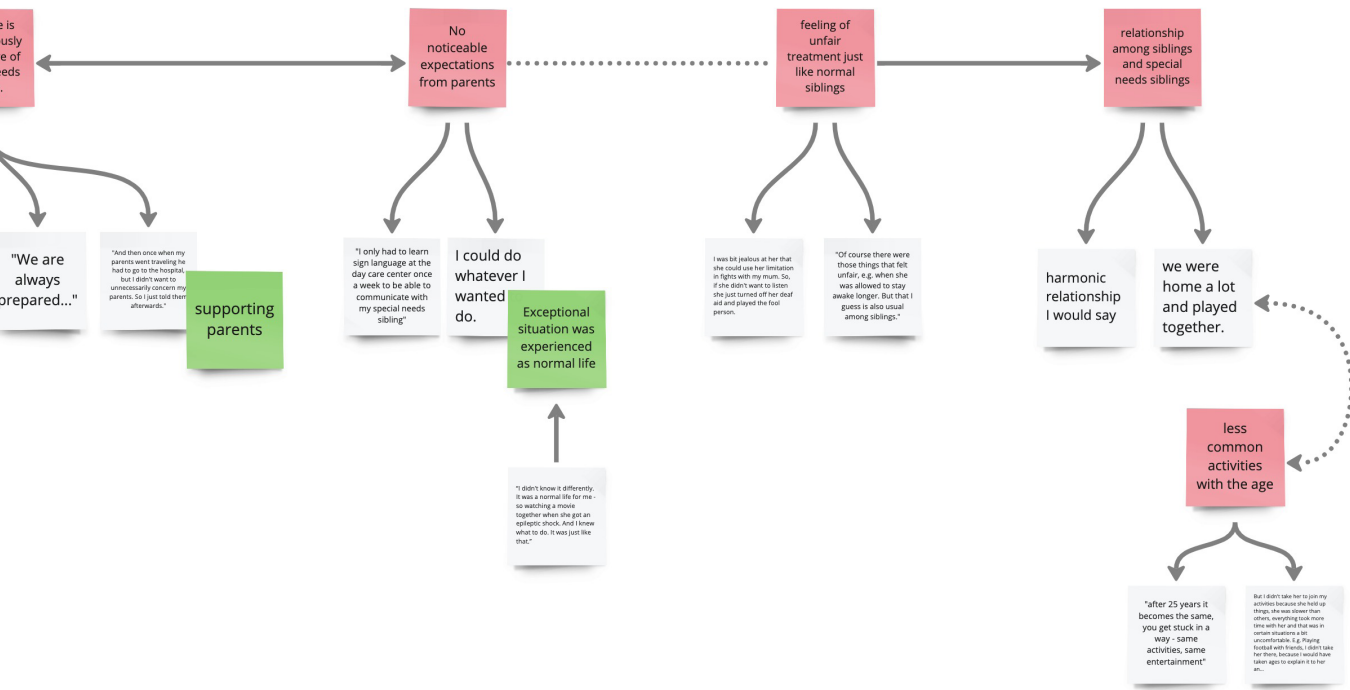


"Familie halt"



Everything was a bit normal I think, we had usual fights among brothers.

"Of course there were those things that felt unfair, e.g. when she was allowed to stay awake longer. But that I guess is also usual among siblings."



The engaging behavior of the siblings's romantic partner.

The partner helps in maintaining the relationship between sibling and the special needs sibling, supports in care activities but also includes special needs siblings in activities. In this sense, the partner is also a motivator "to do all the same thing all over again we were already doing the last 25 years."

Strong connections between siblings by having a common special needs sibling

Siblings with another sibling share the experience growing up with a special needs sibling and feel closely connected to each other: "Our relationship is also special, because we have our special brother in common."

Everyone is unconsciously taking care of the special needs siblings.

Siblings support their parents and take over some care activities, even though they haven't noticed them as such and it was just part of their daily life and normality. Siblings did not notice specific expectations from their parents regarding care responsibilities. "Babysitting is common among siblings."

Relationship between sibling and special needs sibling changes over time.

Siblings acceptance of their mothers responsibilities towards the special needs sibling.

Siblings assessment of unfair experienced treatment like in any other sibling relationship.

With age, siblings were mentioning that they had different interests and less common activities to share. Thus, they took their special needs siblings less to join activities with friends for example.

Siblings felt limited by the special needs and repeating same activities all over again ("After 25 years going to the zoo or park with him, makes it really boring.")

Siblings observed a strong bond between their mother and their special needs sibling. The mother also represented the special sibling's voice.

"Of course she [special needs sister] was allowed to stay awake longer sometimes even though she is younger, but this is the jealousy that just all siblings experience and not something related to a special needs sibling."

Special needs sibling is the center of the family's attention.

Such sentence was clearly stated by an adult sibling and show indirectly the role and accommodating responsibilities of each family member.

Close friends are like family members and show understanding.

Siblings maintain few, but very strong friendships. Friends do know their special needs siblings very well, show interest and curiosity and accept them. "They are part of the family." Thus, there was less need to connect with like-minded siblings.

Appendix D Sibling perspectives

Other resources

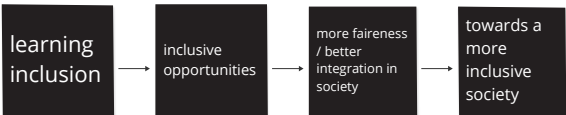
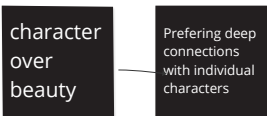
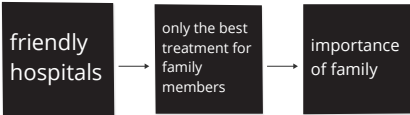
Why?
= underlying values

values?
=desirable goals that motives people's actions
= serve as guiding principles in their lives



values?
 =desirable goals that motives people's actions
 = serve as guiding principles in their lives

financial security



hospital

hospital staff is overworked and unfriendly

"Ich wünsche mir für die Zukunft, dass in allen Krankenhäusern und Pflegeheimen so viele Menschen arbeiten, dass sie genug Zeit haben, um zu allen Patienten und Besuchern freundlich sein zu können"

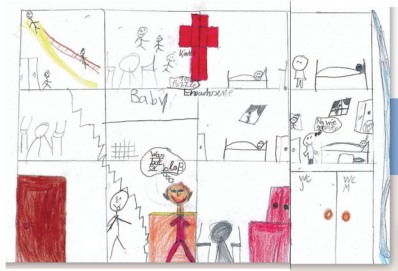
friendly hospitals

hospital associated with sadness

"Wenn ich traurig bin sollen sie mich glücklich machen"

Sie gehen zu Arbeit, lebenslang...
 Ich habe Arbeitsplatz...
 Viele Grüße
 Proc. Adeline Pöschl, Fernstudium

Sie gehen zu Arbeit, lebenslang...
 Ich habe Arbeitsplatz...
 Viele Grüße
 Proc. Adeline Pöschl, Fernstudium



Ich wünsche mir für die Zukunft...
 Lotte 7 Jahre

Handwritten notes on lined paper, including a drawing of a person and some text about hospital staff and patient care.

Appendix E Sibling perspectives

Generative session

Session plan

Showing all session activities including back-ups for the first context mapping session.

Overview

Participants	5 german speaking children age 6 - 8 years
Facilitators	Project researcher, Social worker
Timeframe	10:00 AM to 12:00AM
Room setup	<ul style="list-style-type: none">• 3 tables close together
Data collection	<ul style="list-style-type: none">• Individual worksheets• 2 voice recorders• 1 camera for pictures, or short videos occasionally• observational notes• debriefing facilitators

Sensitizing

Activity

The children are provided with a sensitizing booklet containing two activities. Firstly, selecting super hero characteristics among personal characteristics and secondly, drawing or writing a scenario when they felt like a superhero.

Reasoning

The work booklet is meant to prime children on the theme of daily hero's and to build a foundation for their creativity in the actual session as suggested by Sanders & Stappers (2012).

Introduction

Activity

Short introduction of the facilitators team and of the children and explaining what the objective and the process of the session is. Informing participants about the technical equipment that is used for data collection.

Warm-up

Activity

Game "Pink Toe": Music playing and everyone walks around the room. When music stops playing, the game facilitator names a body part and a color. All players have to touch with the mentioned body part an object in the according color.

Activity 01

Activity 1A

Children are asked to fill in individually a world map on a canvas by writing or drawing locations where they spend time.

Activity 1B

Children are asked to complete the world map with people they meet at such places by writing down their name in the circle. The circles on the canvas demonstrate how close those people are to the children.

Activity 1C

Adding stickers to the drawn situation according to their superhero feeling barometer. Superhero = I feel like a hero; Wondering person = Indecisive, sometime I feel like a superhero, sometimes not; Secret agent = I don't feel like a superhero at all

Activity 02

Activity

The children interview each other about their hero stories they prepared at home and by looking at their recently created map. Both are encouraged to talk about their stories with the help of question cards. The children work in duos or trios (interviewer, interviewee) and switch roles after a while or answer the questions together. In case children have difficulties coming up with a scenario, as well as ambiguous and storytelling pictures are laid out on the floor to trigger children's memories. Alternatively, the pictures can be used for a more active participation by laying them out on the floor, letting each child pick one, and come up with a personal story related to that picture.

Activity 03

Activity

The children create a superhero feature or costume that is in their opinion helpful to manage a situation when they feel less like a hero. The activity is completed in duos and trios.

Activity 04 (Back-up)

Activity

The activity is planned as an alternative task. In case children feel uncomfortable telling each other the superhero stories, they can spend their time drawing a possible superhero hideaway. This place represents a place where superheroes charge their superpowers.

Reasoning

Due to the young age of the participants (6 years) an easier activity will be provided. Such activity focuses on exploring a current comfort zone.

In between discussions

After completing activity 1 and 2 the entire group gathers and presents each other's findings. This approach is inspired by Sanders & Stappers (2012) Context Mapping method, where group discussions after 'make' exercises are the main sources of data.

Sensitizing (1/3)

Meine Superkräfte

Kreise die Superkräfte ein, die am besten zu dir passen. Oder schreibe weitere Worte dazu, die deine Superkräfte beschreiben.

Ich bin...

leise	laut	schüchtern
selbstständig	hilfsbereit	ordentlich
ängstlich	mutig	chaotisch
lustig	ehrlich	gut gelaunt
freundlich	selbstbewusst	wütend

kuschelig

Meine Superkräfte

Kreise die Superkräfte ein, die am besten zu dir passen. Oder schreibe weitere Worte dazu, die deine Superkräfte beschreiben.

Ich bin...

leise	laut	schüchtern
selbstständig	hilfsbereit	ordentlich
ängstlich	mutig	chaotisch
lustig	ehrlich	gut gelaunt
freundlich	selbstbewusst	wütend

Bräutigam Quatschig

Meine Superkräfte

Kreise die Superkräfte ein, die am besten zu dir passen. Oder schreibe weitere Worte dazu, die deine Superkräfte beschreiben.

Ich bin...

leise	laut	schüchtern
selbstständig	hilfsbereit	ordentlich
ängstlich	mutig	chaotisch
lustig	ehrlich	gut gelaunt
freundlich	selbstbewusst	wütend

cool

Meine Superkräfte

Kreise die Superkräfte ein, die am besten zu dir passen. Oder schreibe weitere Worte dazu, die deine Superkräfte beschreiben.

Ich bin...

leise	laut	schüchtern
selbstständig	hilfsbereit	ordentlich
ängstlich	mutig	chaotisch
lustig	ehrlich	gut gelaunt
freundlich	selbstbewusst	wütend

Liebe Schlau

Sensitizing (2/3)

Meine Heldengeschichte

Erzähle eine Geschichte in der deine Superkräfte
gebraucht wurden. Was macht dich besonders stolz?

Ich habe im Kindergarten
Frída geholfen sich anzu-
ziehen.

Meine Heldengeschichte

Erzähle eine Geschichte in der deine Superkräfte
gebraucht wurden. Was macht dich besonders stolz?

_____ springt mutig vom
Bett herunter. Er wirft dabei
chaotisch alles durcheinander.
Er räumt brav alles wieder
auf. Er macht dabei ein
lustiges Tänzchen und außer-
dem viel Quatsch.

Meine Heldengeschichte

Erzähle eine Geschichte in der deine Superkräfte
gebraucht wurden. Was macht dich besonders stolz?

Ein mal wo ich in der
Sprachbude war. Bin
ich von ganz hoch
oben herunterge-
sprungen.

Meine Heldengeschichte

Erzähle eine Geschichte in der deine Superkräfte
gebraucht wurden. Was macht dich besonders stolz?

Ich helfe in der Familie
mit. ^{in der} ^{bei}
Ich bin bei den
Hausaufgaben sehr
Schlau

Sensitizing (3/3)

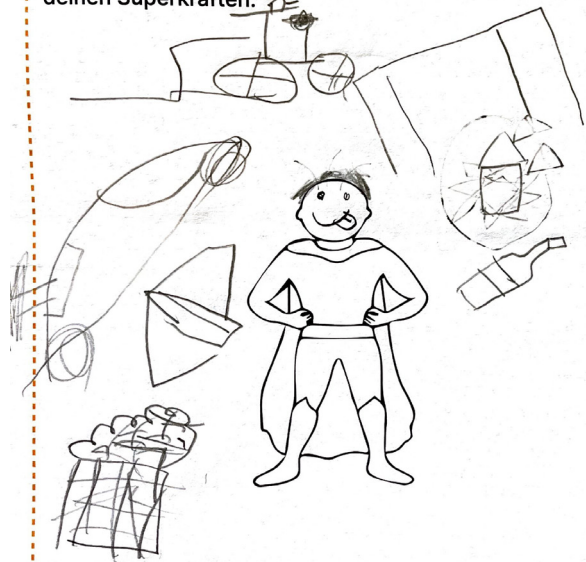
Das bin ich!

Male dich hier als Superheld oder Superheldin mit deinen Superkräften.



Das bin ich!

Male dich hier als Superheld oder Superheldin mit deinen Superkräften.



Das bin ich!

Male dich hier als Superheld oder Superheldin mit deinen Superkräften.

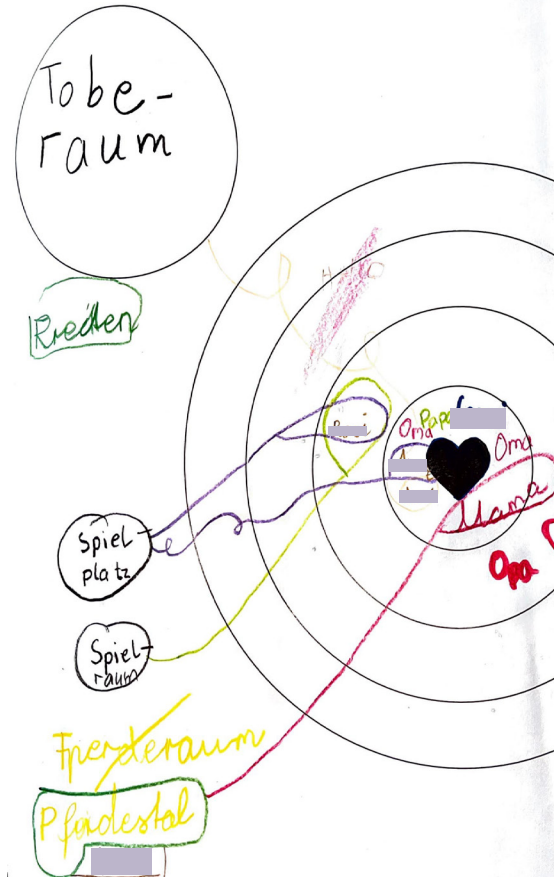


Das bin ich!

Male dich hier als Superheld oder Superheldin mit deinen Superkräften.



Activity 01

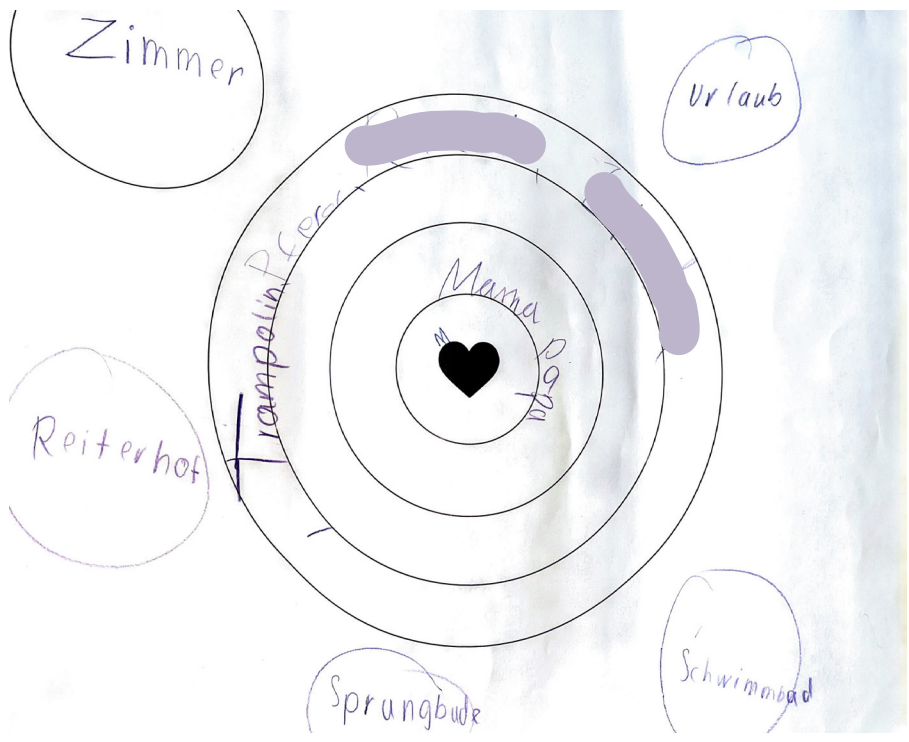
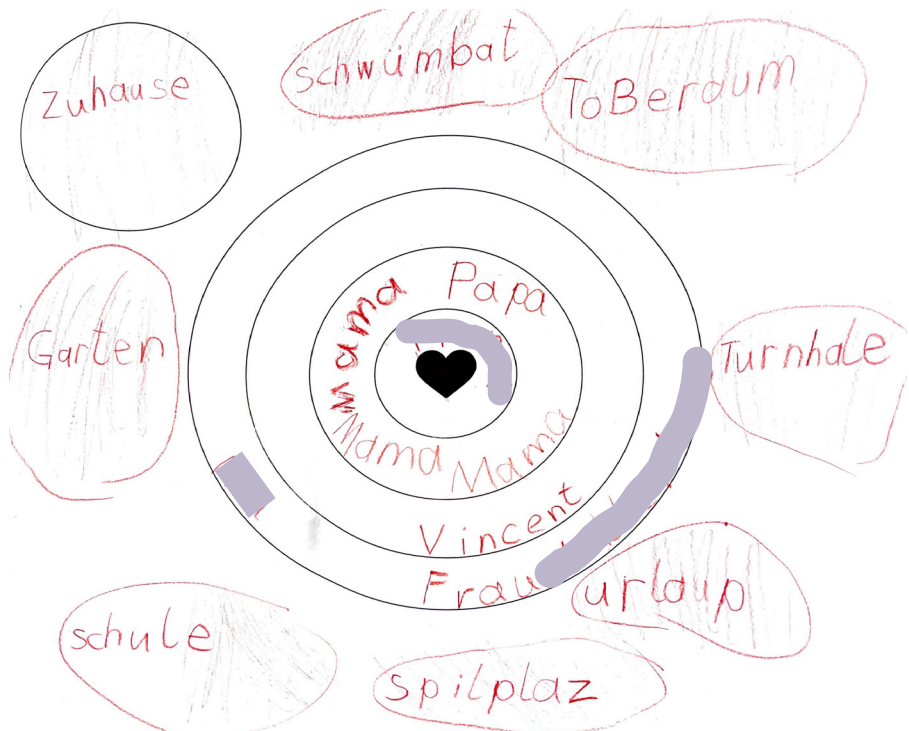


Activity 03

eine Krawlon
roboter

Endspannungsmessung

umhang



MAMA

UNSICHTBAR

Baby

being proud about own achievements

being proud is related to proving own courage

being proud is less associated with helping out others

being proud is related to measurable achievements

putting themselves in the center with hero stories was not their cup of tea

activity telling each other own hero stories was something they preferred less and were frustrated with

shared outcome not preferred

creating something together is less inspiring than something for oneself

preferring something for themselves, rather than sharing

activity creating together didn't provoke enthusiasm

enjoying external home activities

favorite places are related to fun activities

siblings (every child) favorite places are mainly outside home where activities are offered

sibling being each others play mate

friends barley come to their home

only few friends

parents initiating less playdates as they are dependent on other parents

siblings enjoy each others company

sibling independent in its free time and finds activities to do

special bond between healthy siblings (age doesn't matter)

don't know how to chill

siblings helping out each other and sharing special bond

special bond among siblings

distancing from special needs siblings

avoiding contact and activities with disabled sister

siblings coping with situation by not paying special attention to special needs sibling

favorite activities don't involve special needs sibling

siblings feel constrained by 24h care for their special sibling?

siblings experience presence of special needs sibling and the attention as too much

not prioritizing special needs sibling

not good to talk about special sibling

out of sorts with special sibling

not treating special needs sibling special

being tired of being a special hero.

is more special when mum and dad are joining than special needs sibling

being annoyed by noise and special attention of special needs sibling

putting themselves in the center with hero stories was not their cup of tea

being free of caretaking

being in their own world and only "coexisting on the now"

personal assistant wished

being a baby again to have the right of receiving care service and to relax

assistant for everyday life wished

help in daily tasks to feel more relaxed

using own needs as reason to determine following activities

help / support in daily activities

siblings want someone who does everything for them

having the freedom of endless wishes

being invisible as a strategy to feel relaxed

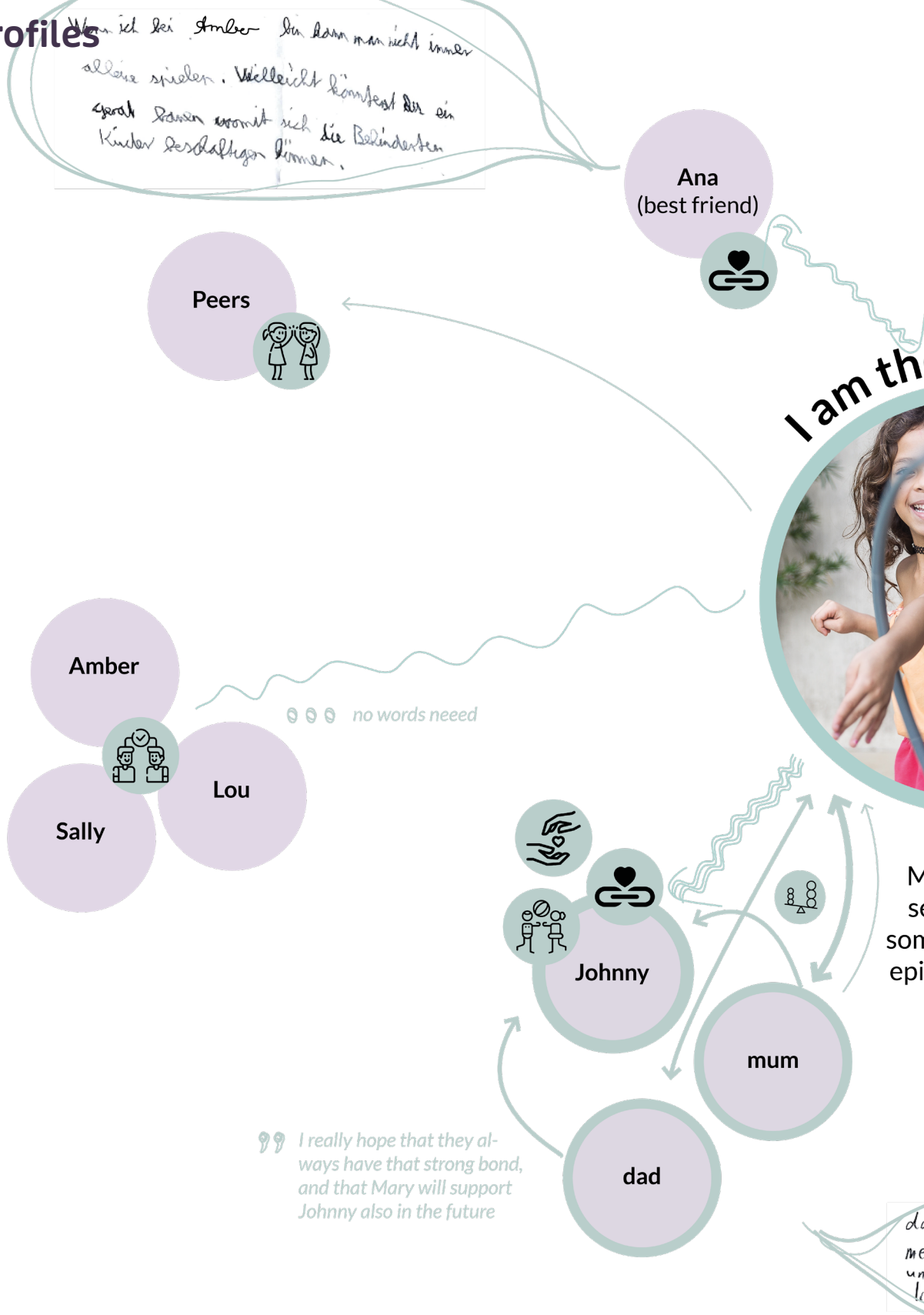
flying - to walk / bike less to feel more relaxed

mum as relaxing partner

being exhausted

Appendix F Research summary

Resulting profiles



” Ich helfe in der Familie
mum.

Sometimes Johnny gets an epileptic shock when they watch a movie. Then, Mary removes all dangerous objects around him and waits.

Unconsciously taking over care activities



the sister of



a sibling with special needs.

Mary (8) is the younger sister of Johnny (12) who has severe autism and epilepsy. She used to think that he sometimes turned into a witch, now she knows that such epileptic shocks sometimes occur and how she can help.

ann hätte ich
ehr Zeit für meine Schwester
od sage ihr nich dass ich
eine Zeit habe. in!

Only sometimes, Mary feels like Thomas is allowed to do so many things, and she isn't. But that's because he is older and has epilepsy.

Feeling of unequal treatment



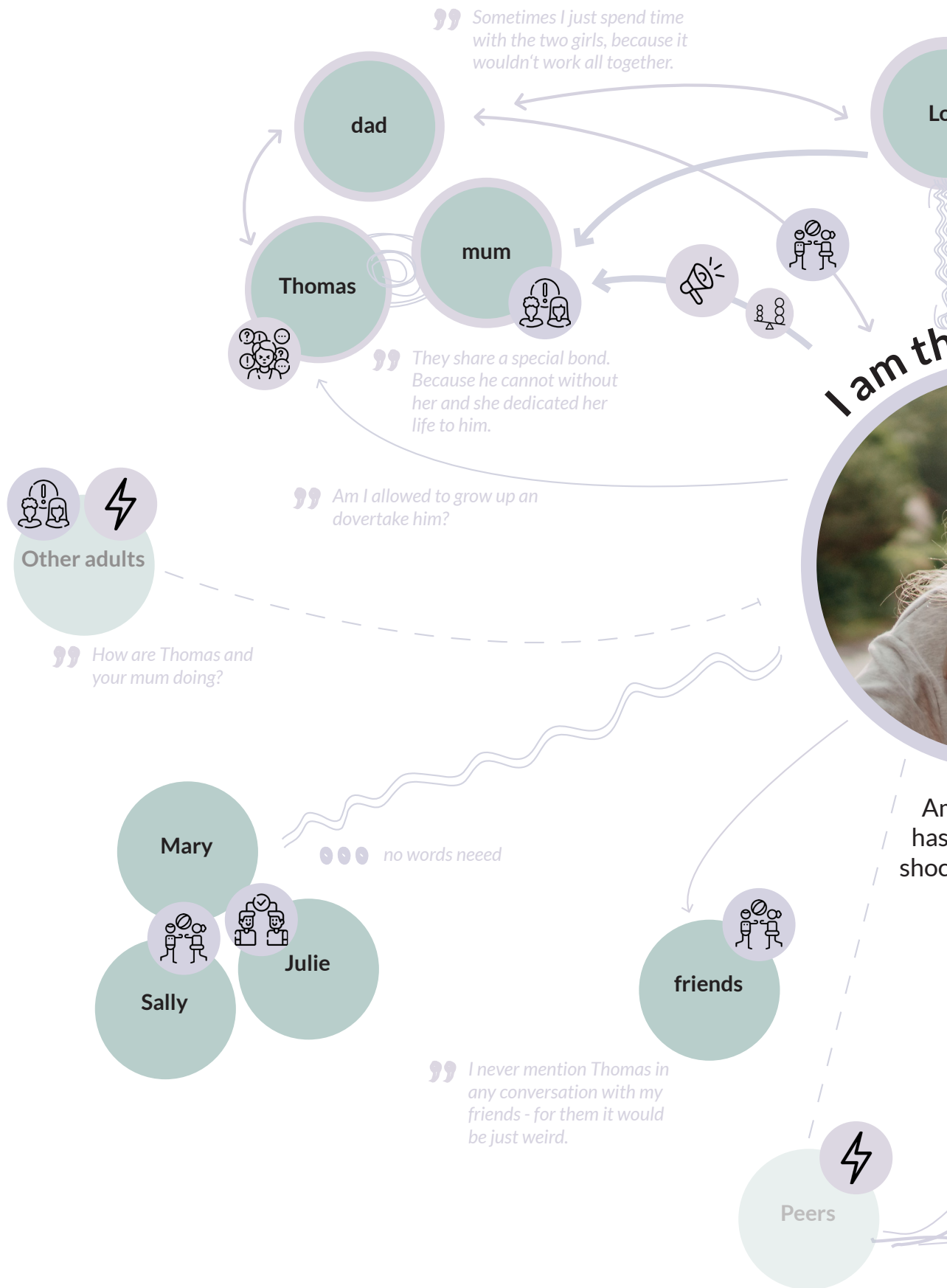
” Everytime he goes to the hospital he gets a coloring booklet or pretty cool stickers - I also want that!



Seeking for me-time (privacy)

Sometimes it's just loud and chaotic at home and Johnny does whatever. Only once, Mary would love to sleep a bit longer in the morning or just draw without getting disturbed all the time.

” Sometimes, I really like when he goes to the hospital with mum, because then it's quiet at home.





My sister is my best friend.

the sister of



a sibling with special needs.

Amber (9) is the sister of Lou (6) and Thomas (11) who have severe autism and epilepsy. She knows that epileptic seizures sometimes occur, but now she feels like she is over-taking her older brother.

Amber really wishes her mum would also spend an entire day only with her, join her to all her hobbies, help her with her homework or just be there without Thomas around all the time.

Desire for pure adult attention

Sometimes I wanna be a baby again. And my mum carries me around all day.



Getting energy from activities external from home

Once a week Amber goes with her friend to the swimming association in her town and they train together. It really feels like her own thing.

I go swimming every Thursday at 16:40 PM to 17: 25PM

Es wäre schön, wenn meine Klassenkameraden aufhören dumme Sprüche zu machen wie z.B. „Bist du behindert?“ Sie verstehen gar nicht wie das ist.

Appendix G Concept exploration

Online brainstorming with experts

Session set-up

Coming up with possible creative ideas for the further ideation process by meeting experts from the previous interview sessions. Through a collective brainstorming and common discussions, the experts' values and their prioritisation, when it comes to supporting siblings, should be identified.

The session took place online, a Miro board was shared to everyone and the brainstorming itself took place on paper.

One facilitating design student, one nurse working with siblings, one systemic therapist working with siblings, one mum of a sibling, two teachers from middle school

The facilitator gave a short introduction to the context and the design goal. Questions and unclear points regarding the design goal were answered. How-to questions were prepared to brainstorm on. A timer was set and everyone brainstormed on their own to a given how-to question on paper. Ambiguous pictures for an optional picture brainstorm were prepared to bring the brainstorming session to the next level, but due to the interactivity and intense discussions not applied. Subsequently after each round, the ideas were presented and commonly discussed. The session concluded with a final discussion on the topic and the resulting elements for a possible design. Immediately after the official session, a post discussion with one of the participating teachers and another teacher followed.

The how-to questions used for brainstorming:

- How to support siblings in maintaining a relationship to other like-minded siblings?
- How to help siblings to create connections to adults?
- How to help siblings to feel supported by an adult?
- How to help siblings feel supported in their role as a child?

The brainstorm method was limited to the access to Miro and the participants computer literacy, thus each participant noted their ideas on an individual piece of paper. The limiting consequences were that the participants were not triggered by other participants' ideas during the brainstorming process. Moreover, it could be seen that the participants were mainly brainstorming based on their personal experience and on utility, rather than free thinking about unexpected associations. The participants criticized that the design space (a playful concept for the home context, that strengthens interpersonal connections) is way too broad and too difficult to think about, similar to the how-to questions. Thus, the resulting ideas were limited to existing ideas, rather than more open in their creativeness. For that reason, a better prepared setting and pilot session in advance may have led to an improved session outcome.

Results

Emergency suitcase

- (Visual) metaphor like a boat and prepare together for needs: luggage, emergency case, participants, emergency crew.

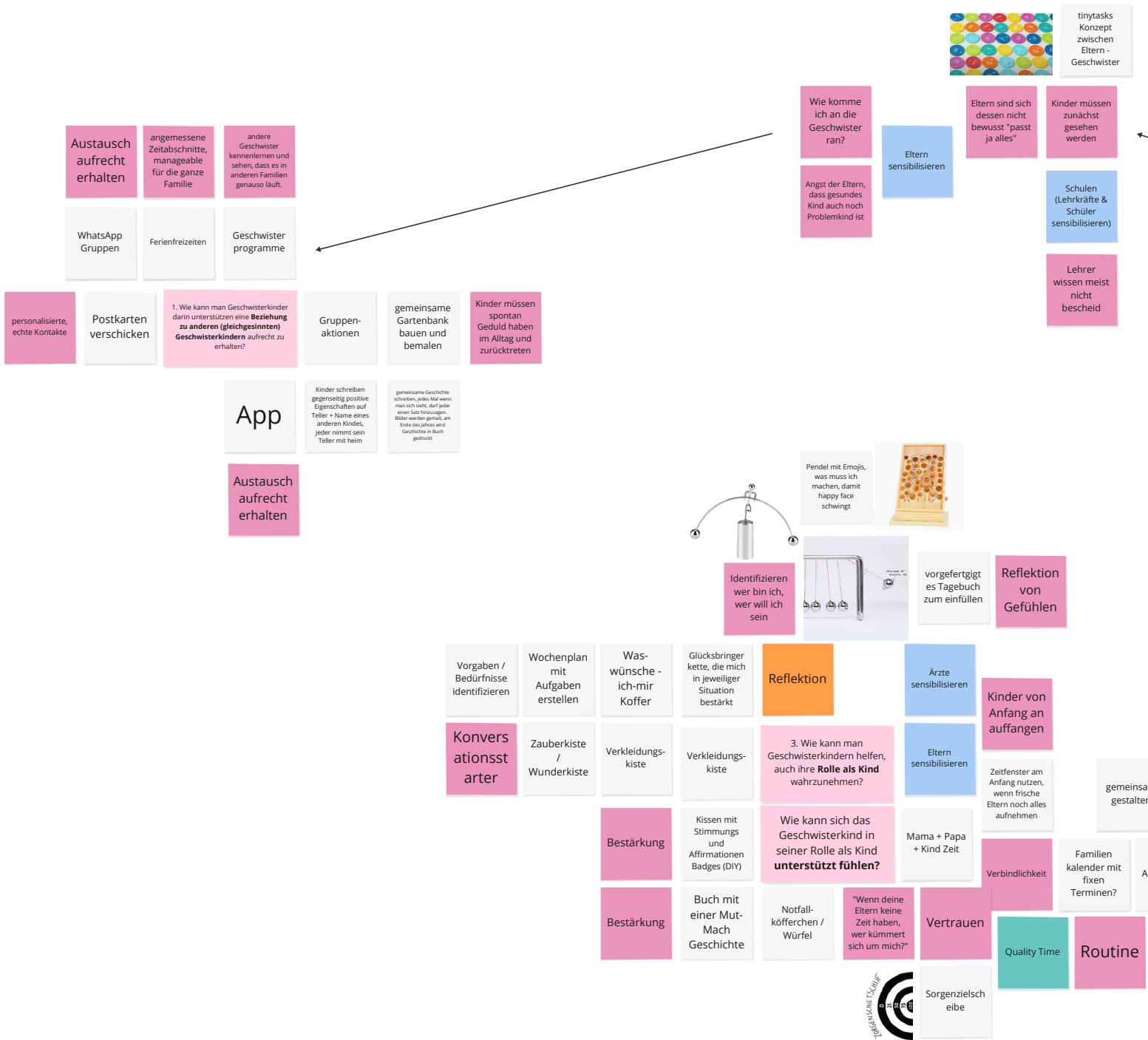
Ideas to get in touch with an adult person

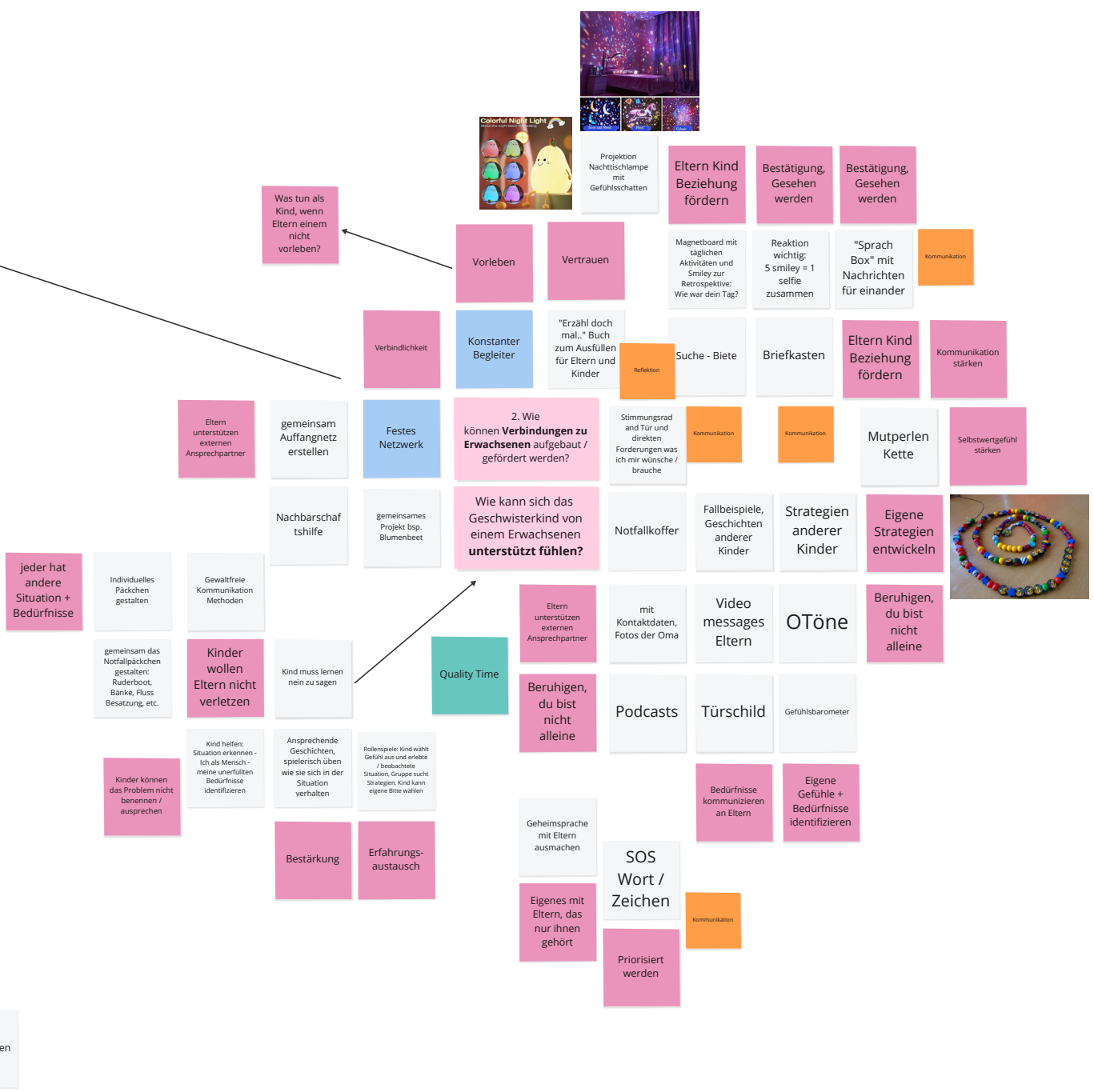
- Secret language with parents or an adult person only
Intention: Feeling prioritized as a sibling.
- Lucky diary: mark all moments which should be discussed in a conversation with an adult person + regular meeting with a preferred adult person to discuss such points
Intention: Identifying my own needs and becoming aware of my situation as a sibling.
- Question box: to collect all personal problem situations, questions and unclarities + meeting with an adult person (friend, family member, doctor, social worker) to discuss certain topics and to get informed
Intention: Creating a safe environment to ask individual questions.
- Emergency plan: to be created with a healthcare professional (where can I call, what am I allowed to say, how do I behave)
Intention: Provide emotional stability in difficult situations.
- Creating a network: together with parents organizing contact persons and places I can find rest and get energy.
Intention: Feeling supported by your own family, when searching for rest at another place.

Other discussed topics

- Improved sensitizing of parents: create awareness at an early stage that there may be advantages for siblings joining specific sibling workshops. And show off siblings risks, needs and opportunities.
- Sensitizing teachers and other institutions: create awareness of the siblings' needs and how to provide opportunities at school.
- Non-violent communication: As a method to learn dealing with situations at home by describing the situation, identifying your own feelings and needs in this situation and proposing appropriate solutions.
- Commitment from an adult: Providing stability to the sibling by showing that there is an adult (parent or not) that pays attention and takes care, a confidential person.

Brainstorming on How-to questions





Appendix H Concept exploration

Emerging concepts

Calendar activities

Activities provided

- I like the most (creating awareness of own interests)
- My door sign for today (providing permission to keep a distance)
- Today I have time for (reflecting on own personal resources and interests)
- I feel - I need (reflecting on personal feelings and needs)
- Today can be bad weather, but I will still do... (reflecting on own personal resources and interests)
- I am right now - I'd rather be (reflecting on personal feelings and needs)
- Sending a postcard to parents (facilitating communication)
- Testimonial form other siblings (creating awareness of personal situation, showing belongingness)

Targeted aspects from the design goal

- Support: Supporting siblings through reflections in identifying and becoming clear about their own needs and dreams.
- Facilitate: Helping siblings to make it easier to communicate their needs by providing them the right tools (e.g. door sign).
- Empower: Helping siblings by giving them permission to communicate their needs through the calendar format.
- Playful and engaging experience: Possible result when demanding private time.

Treasure map

Targeted aspects from the design goal

- Playful and engaging experience: Possible result when exploring opportunities outside from home. In addition, the map itself serves as a personalizable and playful interaction.
- Support: Finding support from other people and
- Facilitate: The service itself helps siblings to easily connect with others and find places to keep a distance from home.
- Empower: The system as a service provides permission to make use of the neighborly help and participating institutions without feeling bad.
- Social: Creating new personal connections and possible contact persons for emergencies or for only listening to their own problems.
- Resourceful: Providing different opportunities to recharge their own resources and learn about other family dynamics.

Appendix I Concept exploration

Concept testing with siblings

Einleitung
Designstudentin
Spiele / Produkte / Handy

Wir probieren viele Sachen aus bevor wir überhaupt etwas designen. Und das wichtigste ist, das wir ganz ganz viel testen. Und manchmal kann die Rückmeldung positive, manchmal aber auch negativ sein. Und das ist okay, schließlich wollen wir am Ende etwas designen, das die Leute auch nutzen.

Heute seid ihr meine Experten.
Heute habe ich euch zwei Sachen mitgebracht, die wir ausprobieren werden, über die wir ein bisschen diskutieren werden und vielleicht sogar verbessern werden.

Regeln
* alles was in diesem Raum gesprochen wird, bleibt unter uns
* Es gibt keine richtige oder falsche Antworten, wir urteilen nicht

Einverständnis Erklärung 7 min
* ich würde heute gerne Bilder machen und gerne auch unsere Gespräche aufnehmen, darum wird mein Handy hier rumliegen
* Denn ich kann mir nicht alles merken, was hier gesprochen wird und für mich ist das sehr wichtig
* Und diese Einverständnis Erklärung ist mein Versprechen an euch, dass davon kein bisschen davon, was hier gesprochen wird weitergegeben wird.
* Ich werde vllt mal ein Zitat benutzen, aber das werde ich so anonym darstellen, dass keiner weiß, wer das gesagt hat

Activity 01 - Calendar 10 min
Ihr bekommt einen Tischkalender von mir und jeder kann mal durchblättern, ihr müsst das ganze nicht ausfüllen. Ihr schaut euch den ganz in Ruhe nur für euch an. Ganz leise.

zwei Gruppen - wir mischen ein bisschen durch mit dem Alter.
Und ihr sprecht mal darüber, ob ihr so einen Kalender bei euch zu Hause stehen haben wolltet.

Hier bekommt ihr zwei Blätter, da könnt ihr ein paar Kommentare zu den einzelnen Seiten aufschreiben - gefällt uns/ gefällt uns nicht weil; ihr könnt auch Verbesserungsvorschläge dazu malen

* Fragekärtchen (Max 5 Minuten)

So, wollt ihr mal mit der Gruppe teilen, was ihr so denkt?

* Gruppe: was gefällt euch gut? Was gefällt euch überhaupt nicht?

* Was haltet ihr von dem Türschild?

* Fehlt euch irgendetwas wichtiges?

* Und mit wem würdet ihr sowas teilen? Würde der Kalender bei euch auf dem Esstisch stehen wo ihn jeder sehen kann oder eher bei euch im Zimmer?

* Oder wo ganz anders? Stellt euch vor das wären alles Postkarten, an wen würdet ihr die schicken?

* könntet ihr euch vorstellen, dass es euch Spaß macht? Warum? Warum nicht?

Activity 02 - Treasure Map 20 min

Wir schließen unsere Augen. Stellen uns vor wir sind bei uns zu Hause, im unserem Zimmer. Aus der Küche kommt lautes Geschrei. Eure Mama streitet sich mit eurem Geschwisterchen, es ist super laut und ihr habt gerade gar keine Lust darauf.

Stellt euch jetzt vor, ihr habt eine geheime Karte in eurem Zimmer versteckt. Eine Schatzkarte.

Ihr holt die Karte hervor und dort sind lauter geheime Orte aufgezeichnet, wohin ihr jetzt verschwinden könnt. Ihr wollt da nicht für immer verschwinden, sondern nur für eine kurze Zeit, vllt eine halbe Stunde, eine Stunde oder einfach den Rest des Nachmittags.

Ihr wählt einen schöne Ort aus und seid ganz entschlossen dort jetzt hinzugehen.

Ihr schleicht euch zur Haustüre, zieht eure Schuhe und eure Jacke an und durch irgendein geheimes Zeichen gebt ihr euer Mama noch Bescheid, dass ihr jetzt kurz unterwegs seid.

Ihr macht dir Haustüre hinter euch zu, holt einmal tief Luft. Und dürft die Augen jetzt langsam wieder aufmachen.

* Welches Zeichen habt ihr eurer Mama gegeben?

* Wie sieht eure Schatzkarte aus?

* Welche Orte sind darauf markiert?

Ich habe euch eine Schatzkarte mitgebracht, da könnt ihr euch eine aussuchen, ob es vllt eine Insel sein soll, oder ob ihr vielleicht eine Straßenkarte malt von der Gegend wo ihr wohnt.

Jeder kann mal ein kleines Häuschen oder einen Punkt malen, wo zu Hause ist.

Jetzt geht ihr zur Straße hinaus und erkundet eure Nachbarschaft

und wenn euch etwas gefällt könnt ihr das auf die Karte kleben. Vielleicht entdeckt ihr ja etwas ganz anderes, das könnt ihr auch einfach auf eure Karte malen

--- 5 min ---

Jetzt kommt ihr wieder zurück

- Was habt ihr gesammelt?

- Welche Hinweise habt ihr auf eurer Karte aufgemalt? Welche Hinweise braucht ihr?

- Wer darf die Hinweise lesen können?

- Auch die Eltern? Oder ist das egal?

- Wie findet ihr das, wenn es solche Geheimorte für euch in eurer Umgebung geben würde?

- Würdet ihr einfach klingeln und fragen? Sollen das die Eltern machen?

- Oder soll es vllt Geheimzeichen von den Nachbarn geben? Wie würden die aussehen?

Today part 03

Cocreation - Ideation + Improved

10 Min

Jetzt denkt noch mal an die zwei Ideen, die ich euch vorgestellt habe. Welche hat euch besser gefallen?

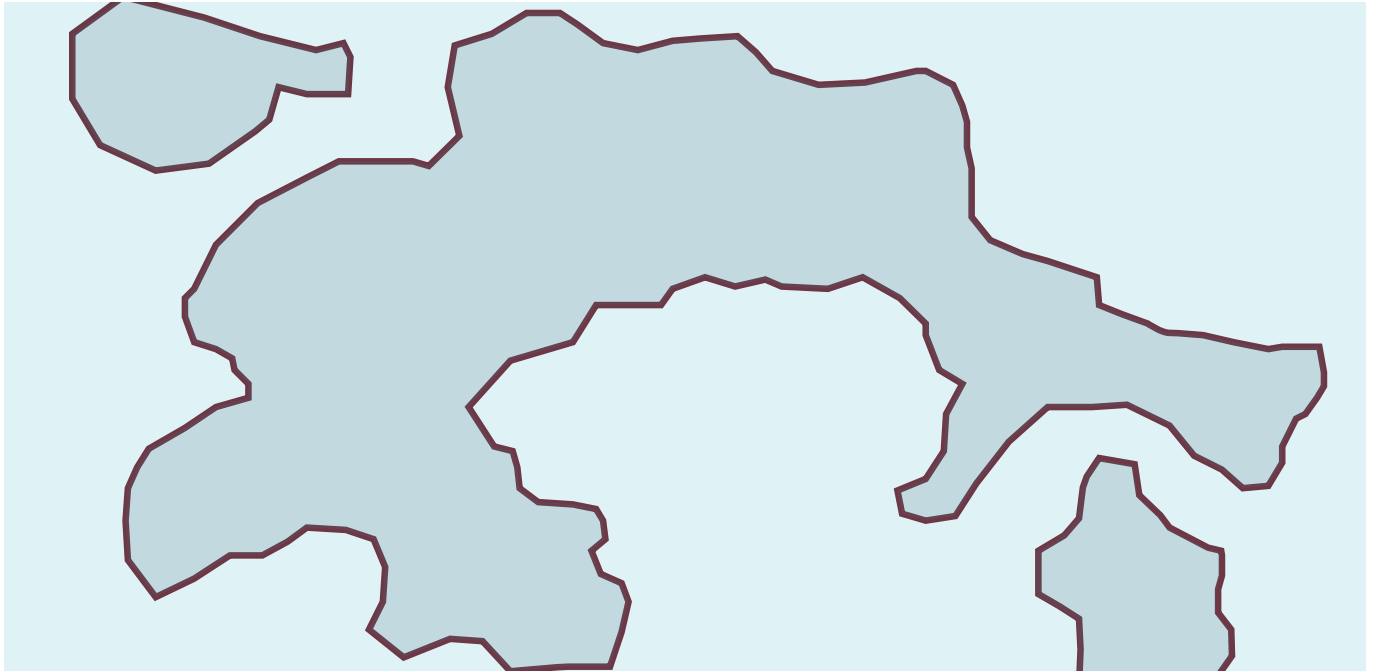
2 / 3 Teams je nach Wahl

Jetzt macht jedes Team ein Plakat mit einer neuen Idee, die dieses Konzept verbessern würde

Ein Tipp, den ich euch verraten kann, wir Designer sammeln immer erst ein paar ideen, und dann müssen wir uns aber für eine Idee einfach entscheiden, aich wenn die vllt nicht so gut ist. Trotzdem versuche. W

Concept testing with siblings

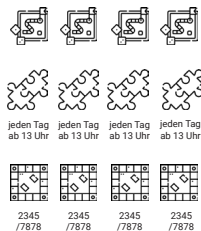
Materials treasure map



Hier wohnt Tante Emma, sie ist lieb und hat immer frisch gebackenen Kuchen. Zu Emma kommt man am Besten mit dem Bus 45.



Hans (63) und Berta (61) lieben Brettspiele. Sie spielen jeden Nachmittag ab 13 Uhr.



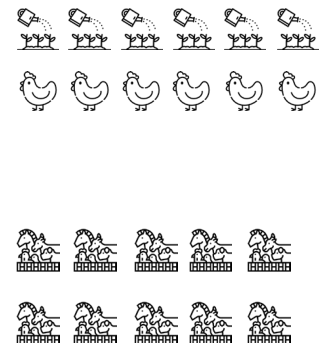
Susis Katzen freuen sich immer über Streicheleinheiten.



Oli (14) hat eine Playstation und freut sich immer über Mitspieler. Oder er spielt Fußball mit Matze (13)



Maria (73) hat einen großem Garten und Hühner. Sie freut sich über Gesellschaft!



Materials calendar

**Mein
WUNSCHKALENDER
2023**

DAS MACHT MIR AM MEISTEN SPÄß:

Montag 15.Mai

MEIN TÜRSCHLÜß FÜR LIEUTE:



Dienstag 16.Mai

LIEUTE FÜHLE ICH MICH



UND ICH BRÄUCHE:

Mittwoch 17.Mai

LIEUTE HABE ICH ZEIT FÜR...



Donnerstag 18.Mai

LIEUTE WÄNN ES REGNEN, ABER ICH MÖCHT
TROTZDEM.



Freitag 19.Mai

DAS BIN ICH HEUTE: UND SO WÄRE ICH LIEUTE GERNE:



Samstag 20.Mai

LIEUTE SCHREIBE ICH EINE KARTE AN




Sonntag 21.Mai

DAS ERZÄHLEN ANDERE GESCHWISTERKINDER:


Maria, 8 Jahre

Zu Hause ist es eigentlich nie ruhig. Meine große Schwester und mein kleiner Bruder sind manchmal so laut, das nervt. Ich setze dann meistens meine Kopfhörer auf, damit ich mal meine Ruhe habe.



Lucia, 12 Jahre

Wenn daheim mal wieder das Chaos herrscht und ich in Ruhe lesen möchte, dann bleibe ich manchmal länger in der Schule oder gehe zu meiner Freundin.



19.Mai

Was möchte ich über mich kommunizieren?

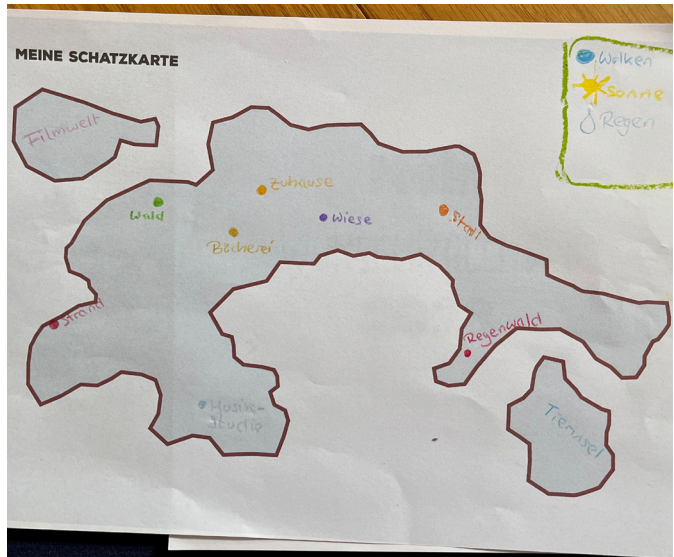
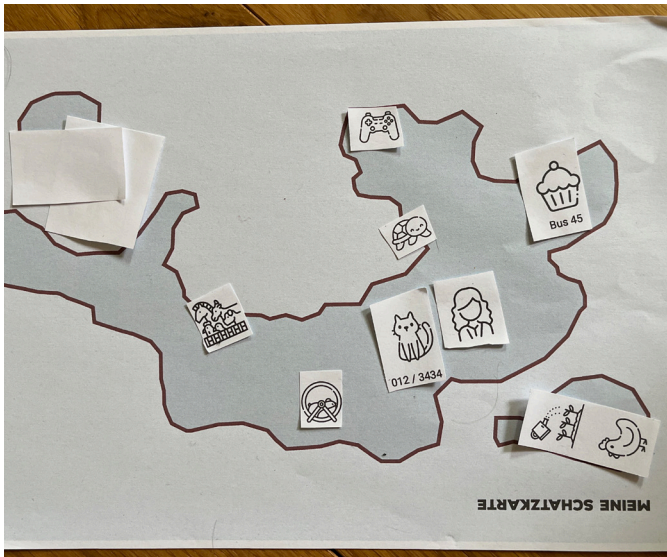
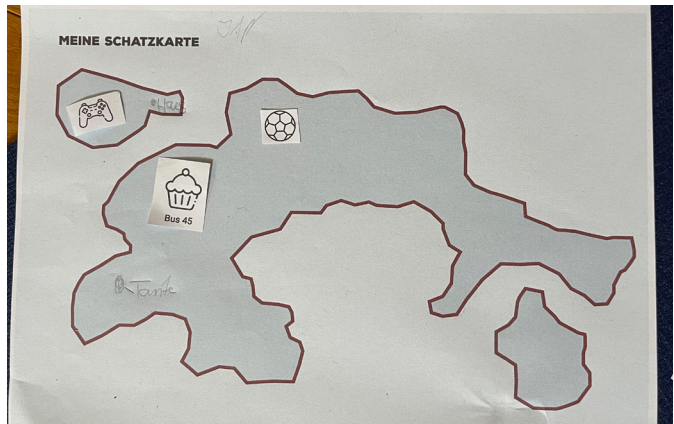
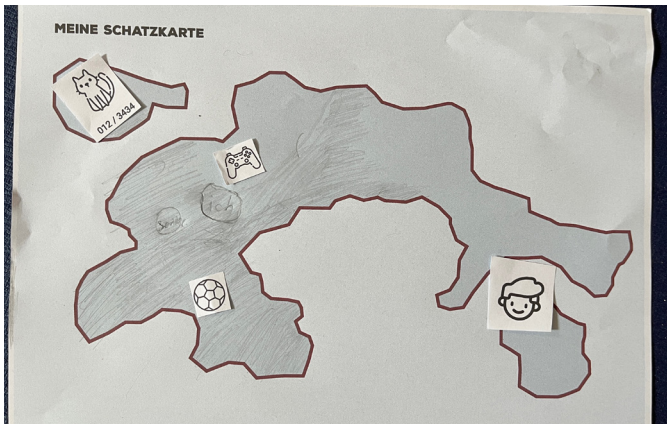
Was möchte ich nur für mich behalten?

Wem möchte ich meine Bedürfnisse erzählen?

Wo soll der Kalender stehen?

Können den alle sehen?

Wann möchte ich den Kalender immer ausfüllen?



Mein WANDKALENDER 2023

Das MACHT MIR AM MEISTEN SPASS

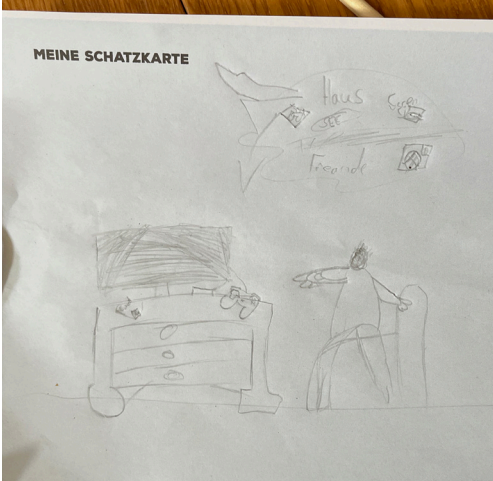
☺ ☹ ☹

Sehr schön!
Fühlen sich verstanden
sieht, dass es andere auch so g
Findet sich wieder.

• Heute fühlte ich mich ^{brauche} am besten?
Welche Seite gefällt mir am Besten?
warum? • Türschild - kreativ werden
• Spiegelbild - selbst reflektieren

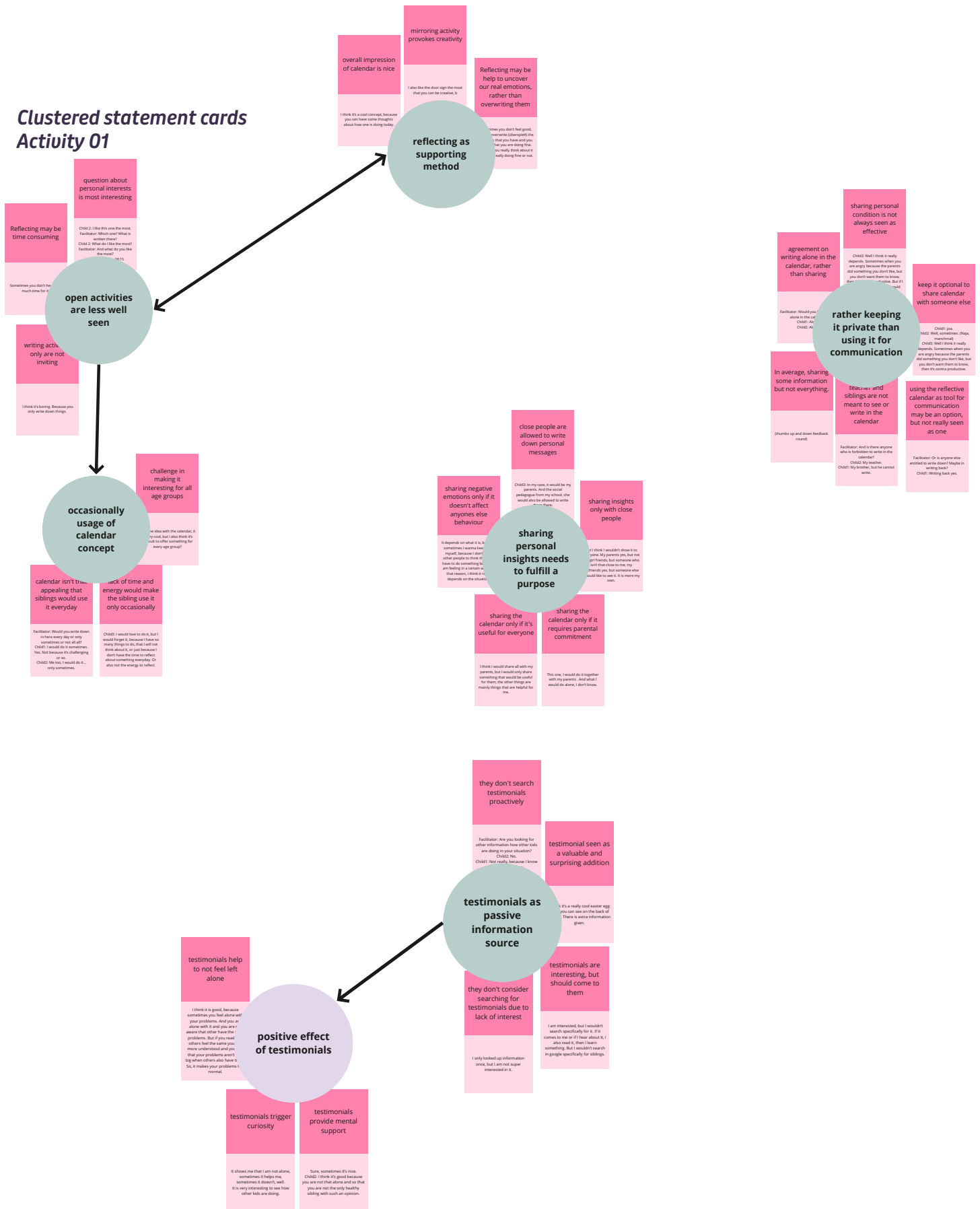
Wo soll der Kalender stehen?
Können den alle sehen?
Eher Privat

Wann und wie oft möchte ich in den Kalender schreiben?
jeden Tag

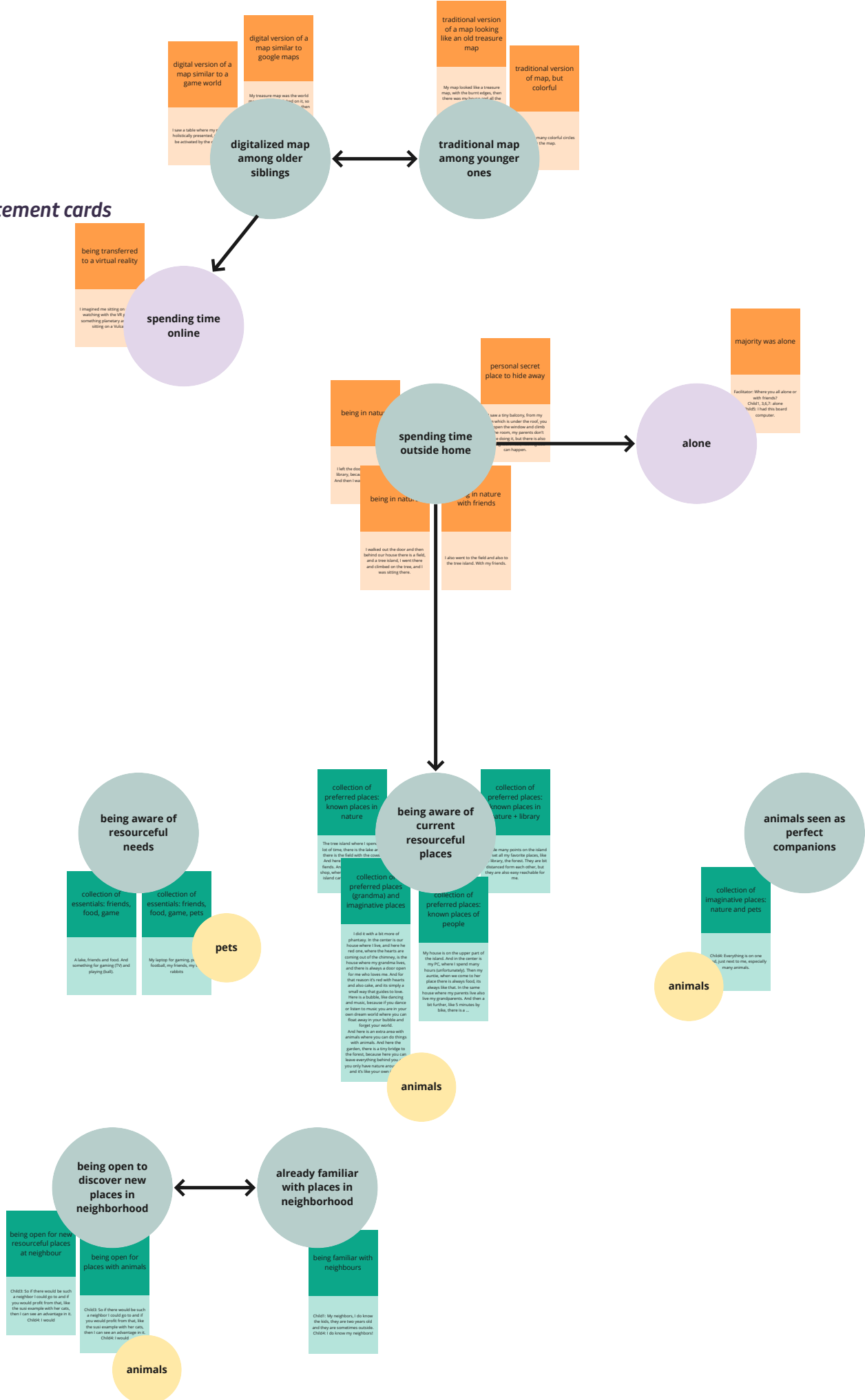


Was möchte ich nur für mich behalten?
Privat / hin & wieder Eltern

Clustered statement cards Activity 01



Clustered statement cards Activity 02



Appendix J Concept direction

6.3 Brainstorming with designers

Sensitizing slide / Introduction

Children with special needs

The term refers to individuals who require additional support or services due to *physical, developmental, behavioral, or emotional differences or challenges*. Special needs result from impairments, disabilities or chronic diseases.

- Depending on the individuals condition and complexity level of their needs the children depend on continuous care service by their family members or professional caregivers.
- This means that the care service varies per individual and ranges from a couple of hours a day to fulfill a person's basic nursing needs (mobility, nutrition, body care) to day and night support.

Consequences on family

- The entire family dynamic changes, the attention is on the special needs child, new rules arise to balance family life, new roles emerge
- Everyone adapts to the condition of the special needs child



Understanding child of special needs

- Age 4-5 years: Lack of logical thinking (phantasy)
 - feeling responsible for disease
 - feelings of guilt, fear and shame when realizing moral breaches and own bad thoughts
 - extreme cognitive emotional stress
- Age 6-12: Ability to take over other perspective
 - start reflecting on consequences
 - disease becomes an extreme mental stress factor
 - withholding own needs and demands to not be an extra burden for parents
 - results in somatic symptoms

Sibling of a child with special needs

- Younger siblings are born in such family: don't know differently, encounter the phase of overtaking their older special needs sibling
 - Emotional unstable (guilt, fear, anxiety)
 - "Am I allowed to grow?"
 - Rivalry switches into caretaking
 - Adaptable, social skills
- Older siblings know situation before, more in the role of care taker, feel forgotten
 - Self-sufficient, isolated
 - Jealousy, caring, repressing own needs
- Typical dynamics among siblings don't apply in this case (status / power / conflict / rivalry / equal parental commitment / learning from each other)
 - share a strong bond with their special needs sibling, love, affirmation, supportiveness rather than having conflicts and arguing
- Consciously or unconsciously suffering from that situation at home
 - Too much responsibility and care activities on a parent-sibling level, rather than sibling-sibling
 - Too little attention from parents / don't feel entitled to request parents attention & time for their problems

Observations in sibling programs

- Siblings enjoy pure attention from an adult
- Siblings enjoy undisturbed playtime with other kids
- Siblings enjoy being surrounded with like minded children
 - understanding each other without explaining
- Siblings just want to be children



Design starting point



Problems

- Too little attention from parents:
 - Too little quality time with parents and sibling only.
 - Parents don't have the capacity to bring sibling to friends, hobbies etc.
- Too much conscious / unconscious responsibilities at home
 - Missing out homework, play time with friends
- Feeling insecure in taking over older special needs siblings



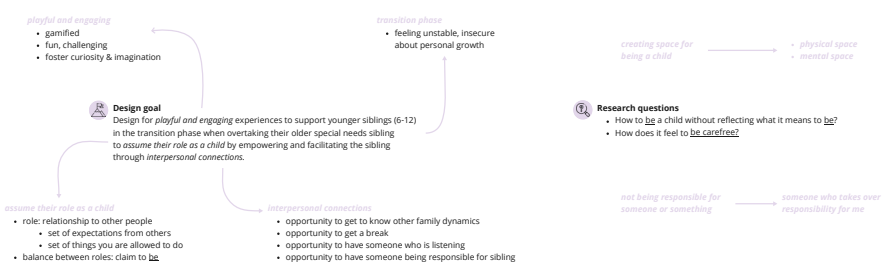
Opportunities

- Feeling understood by like-minded siblings
 - existing programs: bi-monthly meetings for siblings, sibling course with pedagogic approaches
- Strong friendships to escape life at home and see other family dynamics
- Enjoy the pure attention of an adult, regular contact needed with someone external from home



Vision

Providing siblings *carefree moments* at home in order to *feel like a child* and to enjoy undisturbed play time.



Results

How can other people facilitate / empower me to play?

Play with me!

Give me confidence to approach others.
 → a lil' push
 → Real life push/pull
 → perspectives

If someone is already playing, I can join them

Directions
 → A few small...
 new prompts

Give me something that I am free to use/destroy/play with in any way I want

Riddles
 new ideas/insights

Reassurance
 ↳ confidence

parts to play in the fantasy (friends)

What triggers me to start playing?
 Who / What is initiating the game?

- An already ongoing activity → something to complete
- your friend is outside waiting for u.
- a challenge - like a riddle

A song

A story
 movie
 book

spotting an object
 like a loop
 or a flower
 a symbol
 a sign

a sign from my mum?

Being bored → "niksen"

story's from parents.
 ↳ "kattelwood"
 ↳ Absolute freedom

How to personalize the map game?

→ Don't

Give ownership / let kids create the games or rules.

Familiar
 - known/lovely things get adventurous

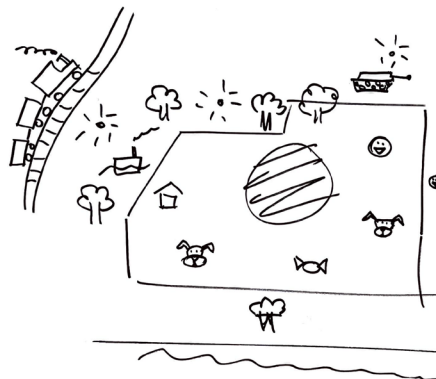


only my 10-pieces
 ↳ pictures
 ↳ my handwriting
 ↳ collecting memories

Secret language only me and my friends can understand

Symbolic elements that the child can make personalize from real life

How to create community feeling with another person / stranger?



- Exploration or fantasy places
- boring or other kids perfect for hide & seek
- treehouse area
- dogs we like
- friends
- home
- Elderly Lady who gives candy

- o an invitation
- o a routine / ritual
- o a celebration / festival
- o code language
- o spending time together
- o having a fixed appointment every week
- o having something in common

Discover something about each other

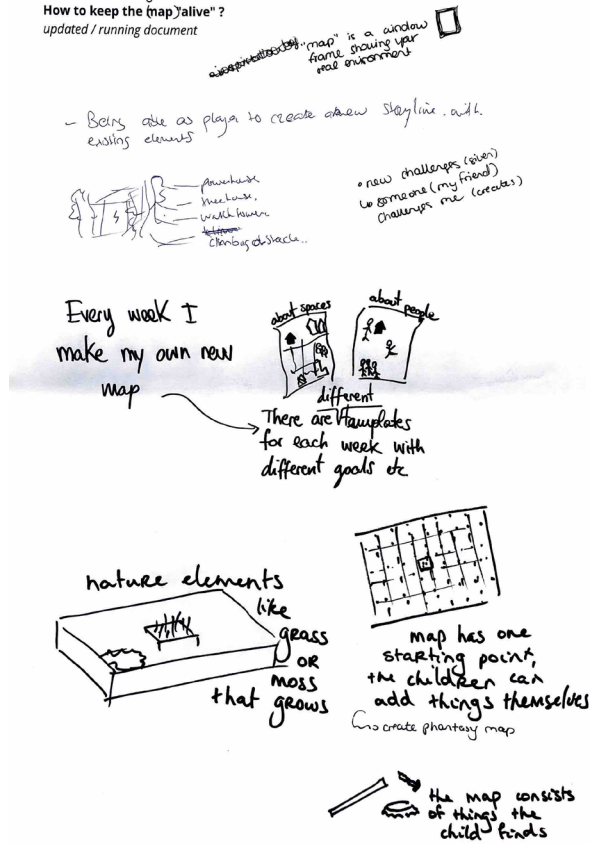
game
How can my map look like?



The game brings the child in a imaginary world where he/she can do what they

The child is the protagonist of the story, and it's narrated from his/her point of view.

game
How to keep the map 'alive'?
updated / running document



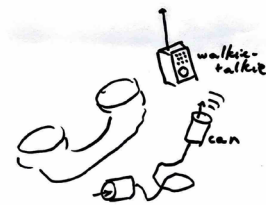
What places can I explore as a 6 years old child?



How to involve my friends?
not sharing the same experience

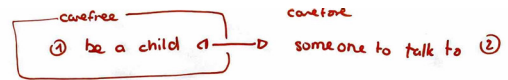
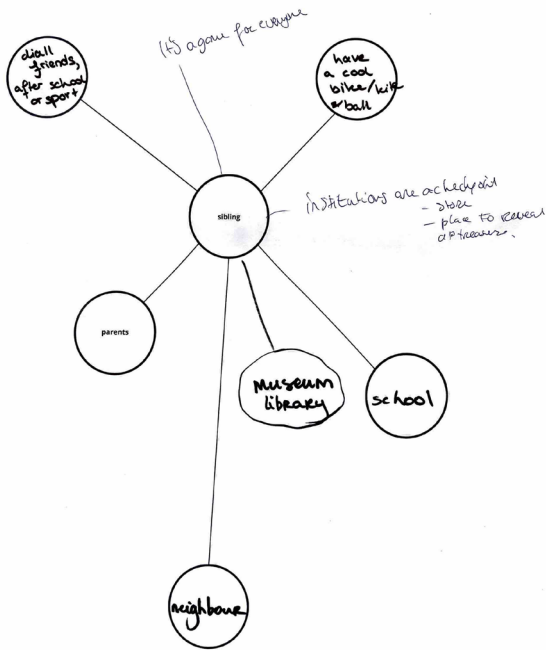
Don't talk about my experience!

I don't always want to feel "the sibling of a disabled child"

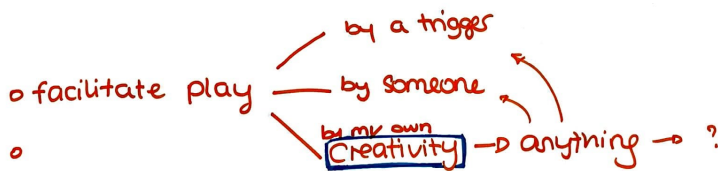
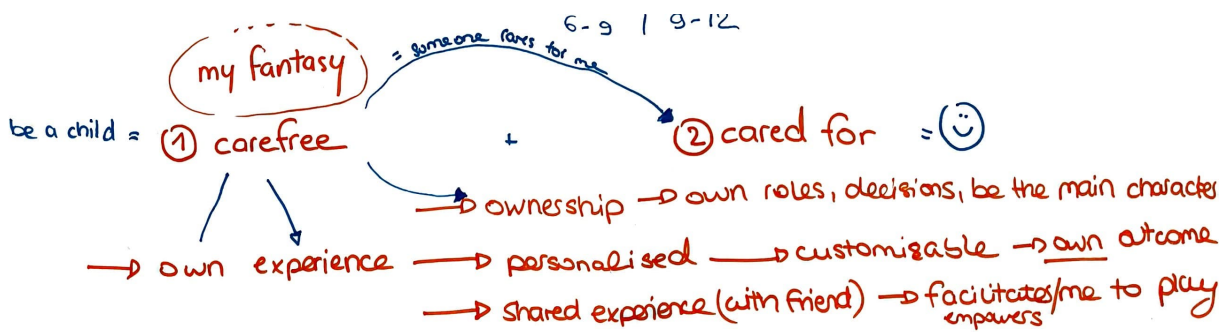
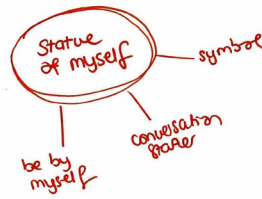


Search for camera/notes maybe also respond to each other's comments
exchange experiences?
create memories together
explore
challenges

How to involve other people / institutions / places in the game?

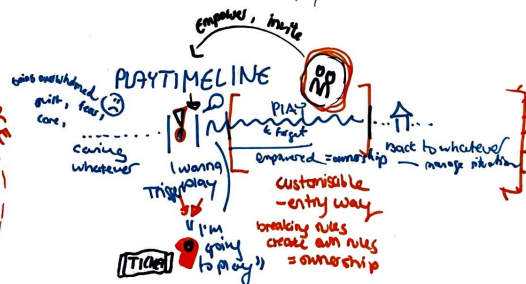
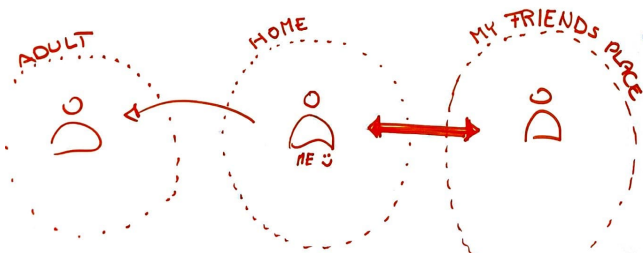


facilitate play



what to introduce to help facilitate? add surprise element

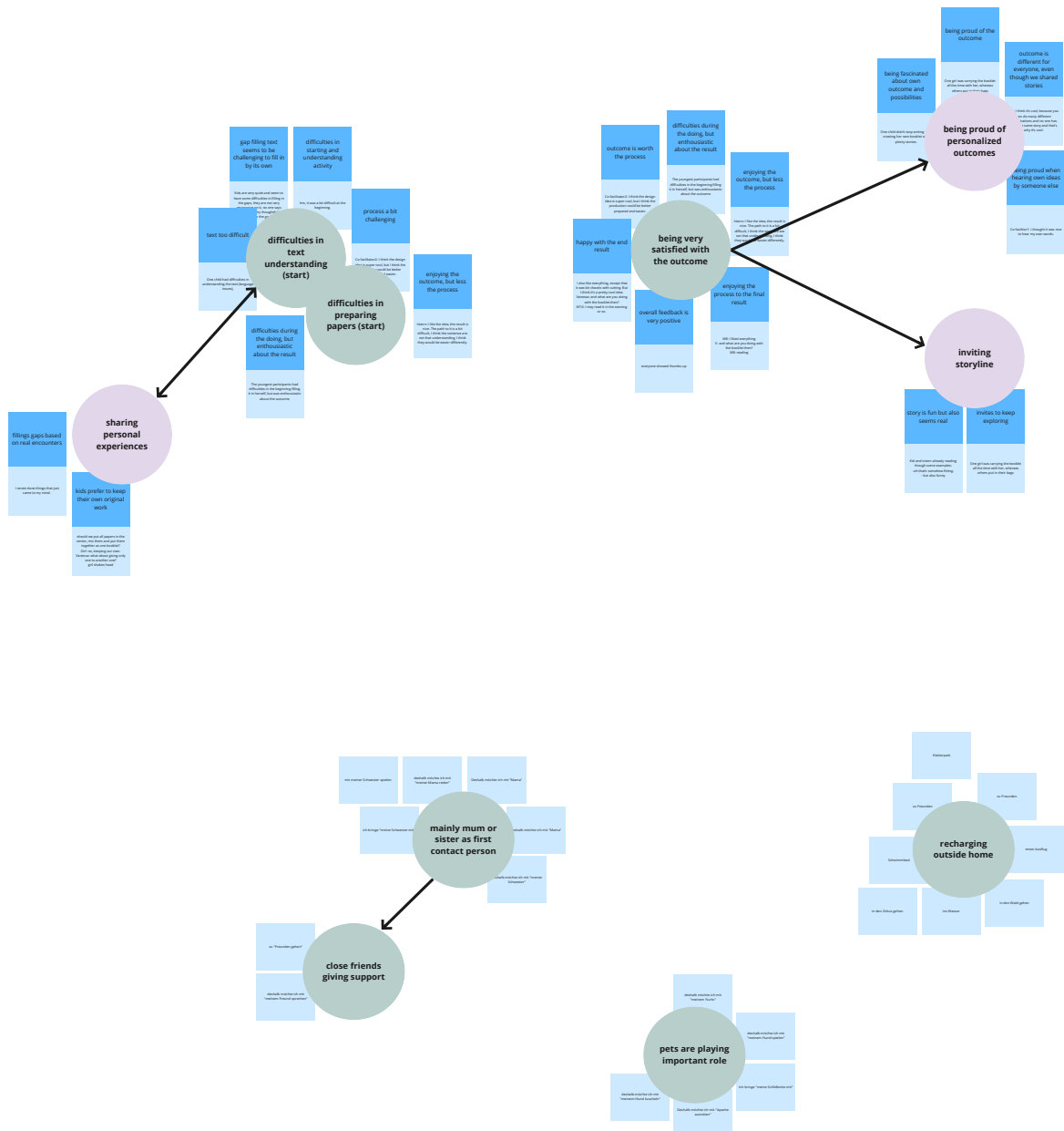
"Role play"

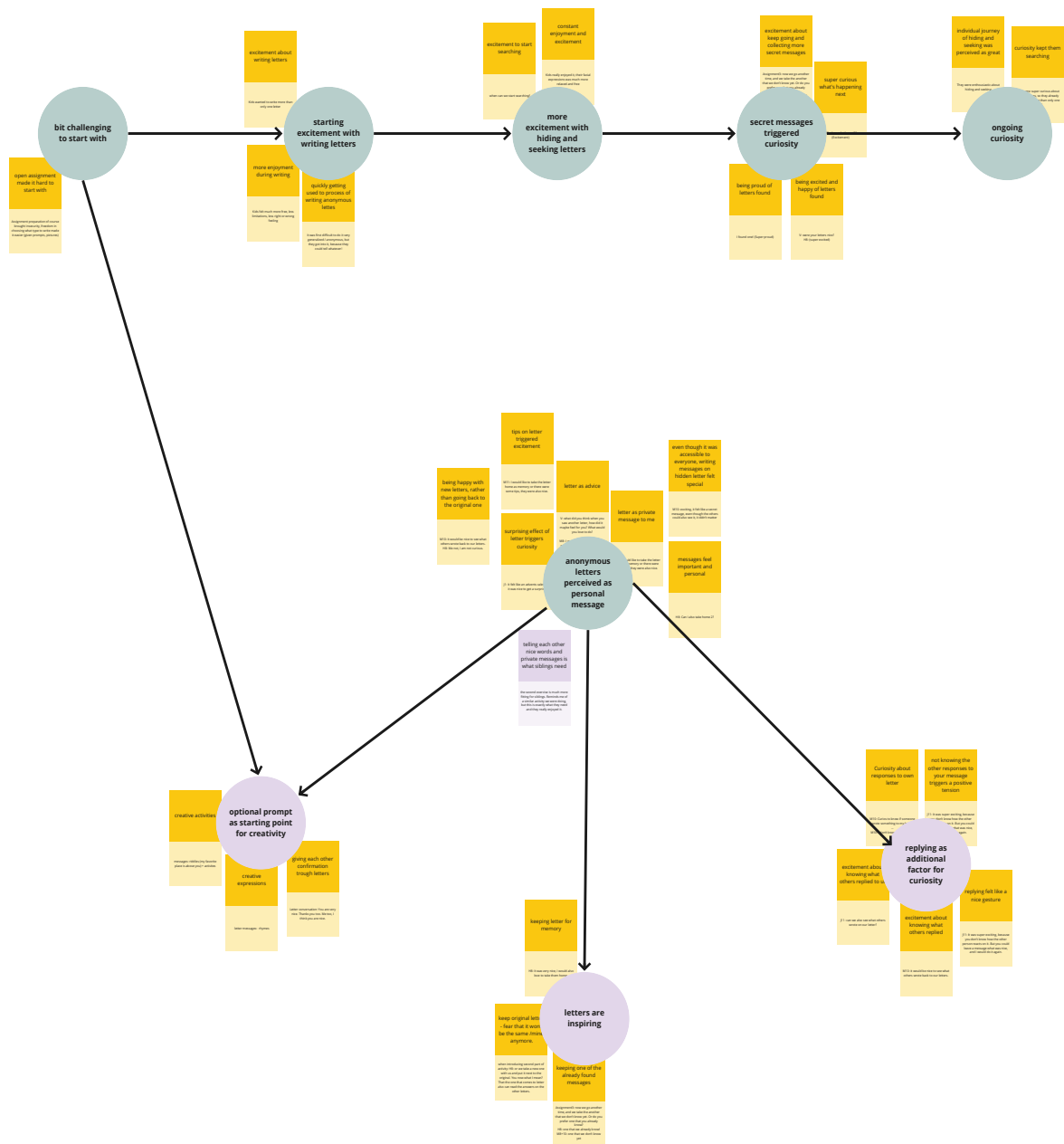


Appendix K Concept direction

Concept testing with siblings (sending letters & booklet)

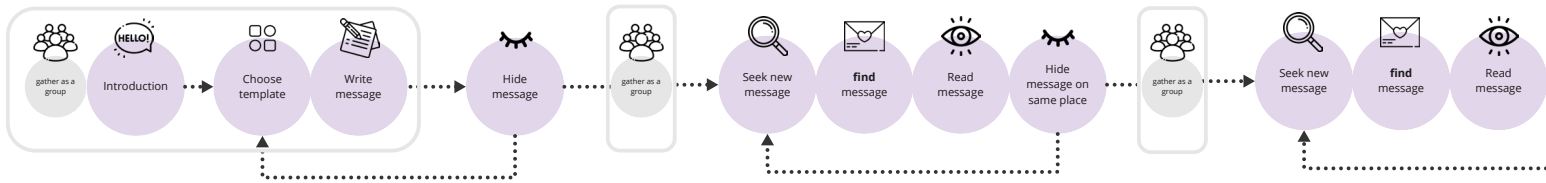
Analysis



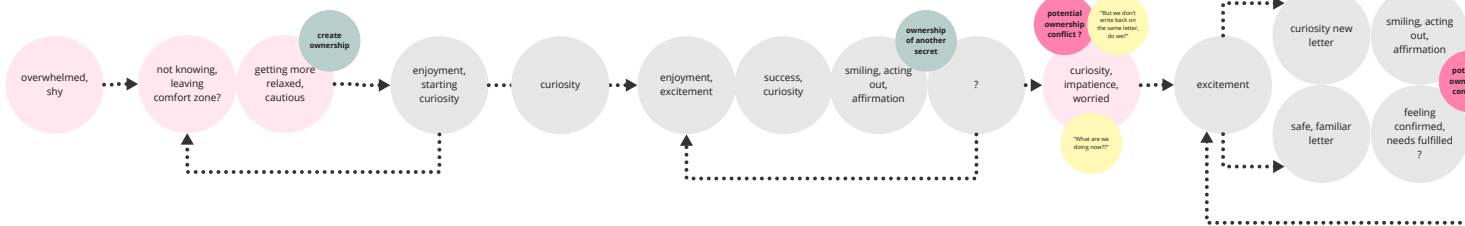


Interactions analysis

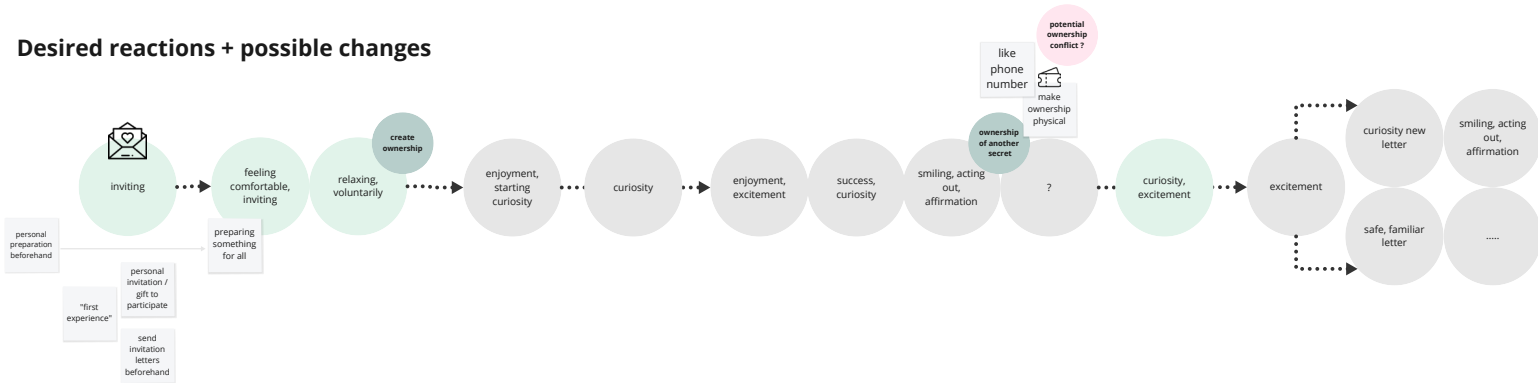
Tested workflow

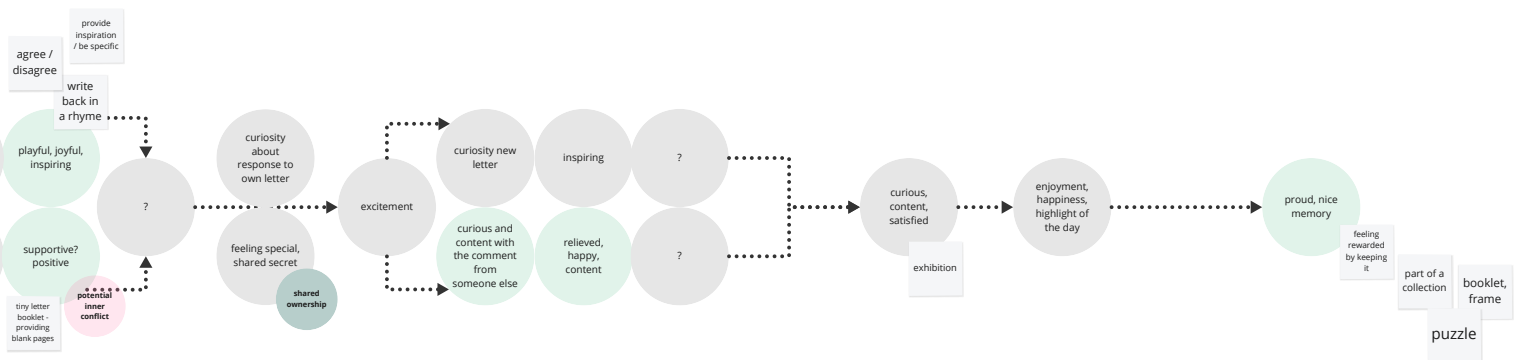
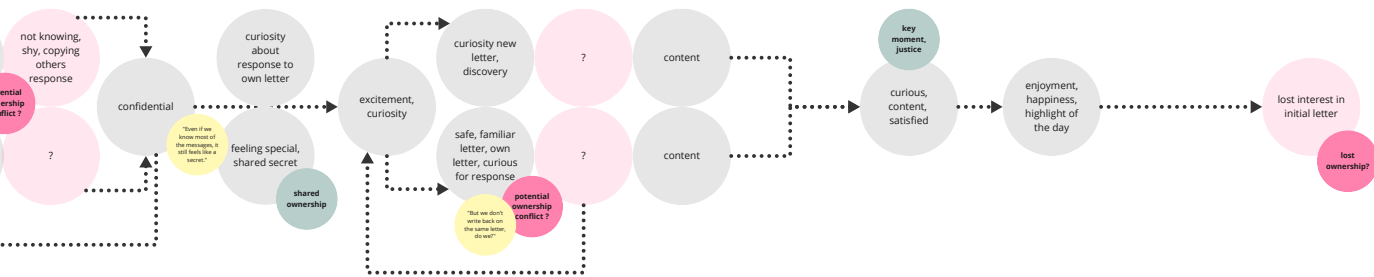
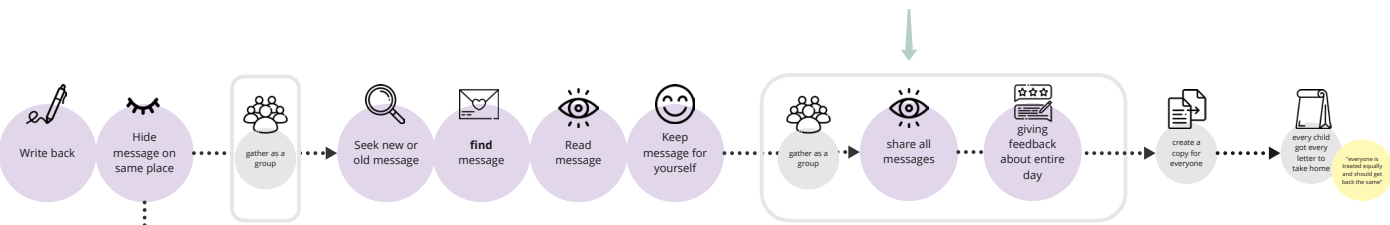


Observed reactions

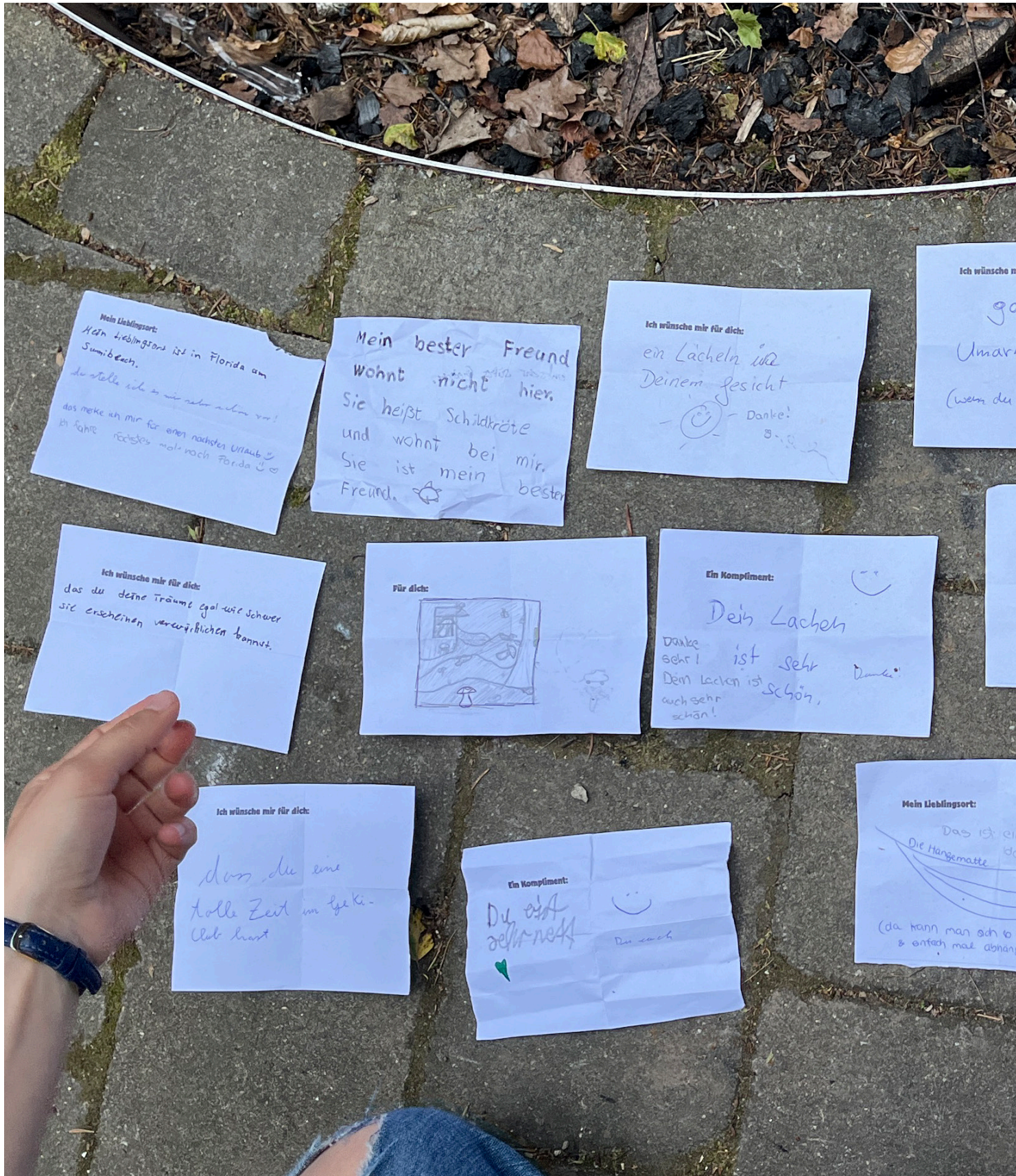


Desired reactions + possible changes





Results



Für dich:
anz viele
mungen
(es möchtest)



Ein Kompliment:
Ich verbringe sehr
gerne Zeit mit Dir
Ich auch!♥ ich auch
du bist nett.
Ich auch!

Ich wünsche mir für dich:
,dass alle kranken Geschwisterkinder
auf der Welt wieder gesund werden!!!
Ja!!!
Ja!!!
Ja!!!
♥ Das
Wünsche ich
mit auch!
♥



Mein Lieblingsort:
ist über dir ☺

Ein Kompliment:
Du bist schön und nett.
Dein Name fängt mit A an
und endet mit A.
Du bist auch witzig.
Was fängt
mit U an und
endet mit A



Ein Kompliment:
Mit dir ist es richtig lustig ☺☺
Das heißt, dass du ein sehr netter
Mensch bist!
Du bist ein Zehn-Milimeter
Mensch

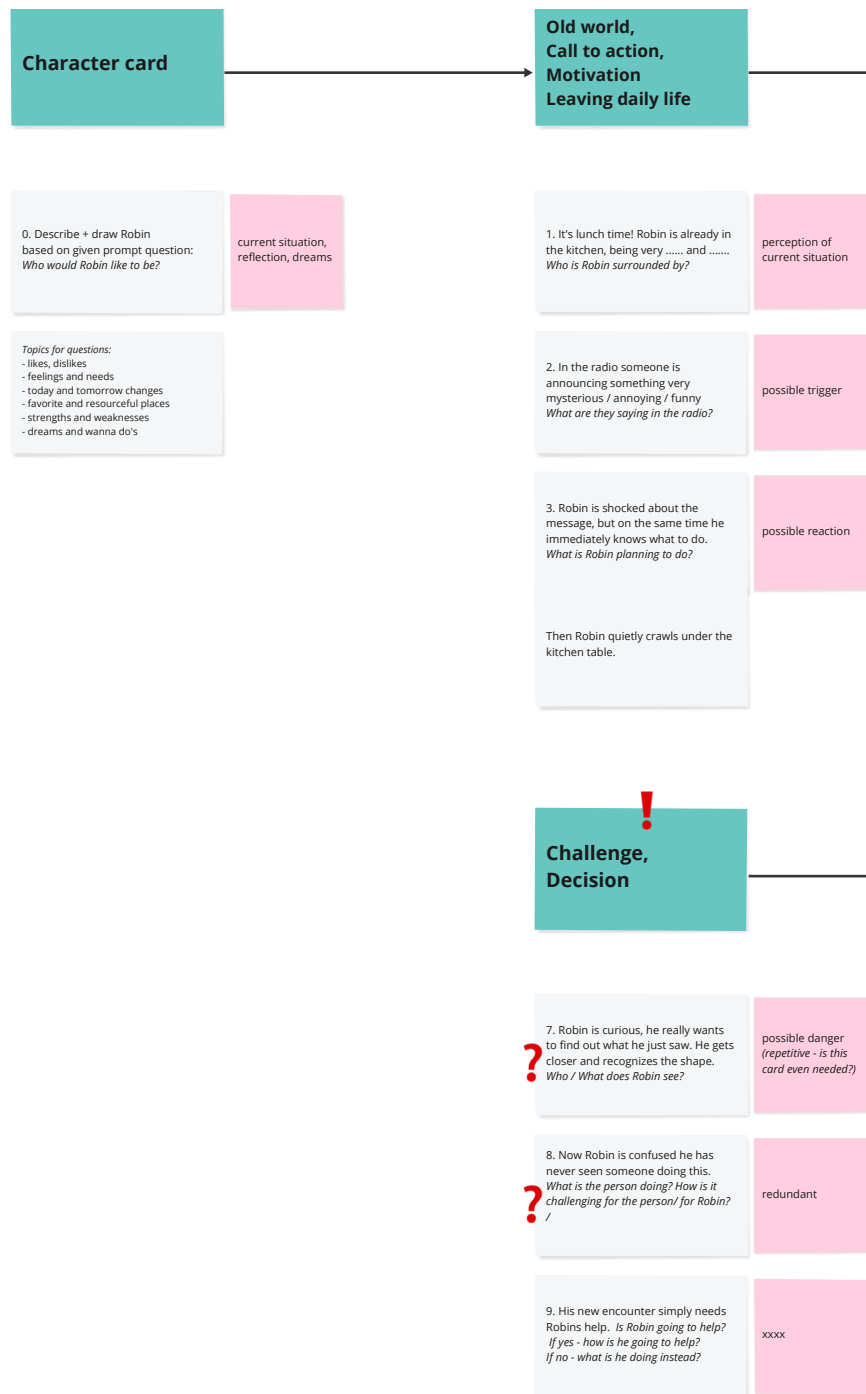
me richtig cool
e
s
sich verstecken
gen)

Für dich: **mein Tipp**
immer wenn du **bei** ein Schatz-
suche spielst, such **im Ort**
mit
zuerst an dem Ort wo es
für dich ist **am sinnvollsten**
es zu verstecken ♥

Appendix L Design Proposal

8.1 Recapturing insights and refining design elements

Creating stories



New world, challenge

4. Robin is still sliding very fast. Then he comes to a stop. Carefully, he opens his eyes and looks around. Describe, where is Robin now?

imaginative place

5. What makes this new place special / dangerous / exciting / scary / funny / cozy / ? How does it look like / smell etc. ?

imaginative place, dreams, fears, etc.

6. Everything seems to look so peaceful, but suddenly Robin discovers something hectic moving in the far distance. Describe what does Robin see?

imaginative place, dreams, fears, etc.

Change? Confirmation

10. Robin is convinced his decision was right. / Robin is still proud of himself that he went that way / It was definitely the right decision he took, because he would never have done it. What did Robin dared to do?

confirm that every decision is right. What is the right question here? repetitive again

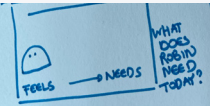
Returning to daily life, affirmation

11. Suddenly Robin hears a familiar, but friendly voice, that brings him back to what he was actually doing. He realizes that he was just dreaming, but the nice words someone are saying to him are real. What does the friendly voice say to Robin? And who is it? Draw the picture

affirmation

Online story testing

How does Robin feel today?
And what does he need the most?




Robin feels sad



Needs a hug

1. It's lunch time! Robin is already in the kitchen, being very and
Who is Robin surrounded by?

hungry and cranky
by his mum and maybe his baby sister

2. Then Robin hears his mum, shouting something funny from the other room.
What is his mum saying?

Robin, why is your tooth brush next to the LEGO?

3. Robin is convinced that the message actually means something else.
What does Robin think does the message mean?
Then Robin quietly leaves the room.

The bread is ready!

4. Robin is still sliding very fast. Then he comes to a stop. Carefully, he opens his eyes and looks around.
Describe, where is Robin now?

Robin is in a winter wonderland, it's super cold, and snowing everywhere.

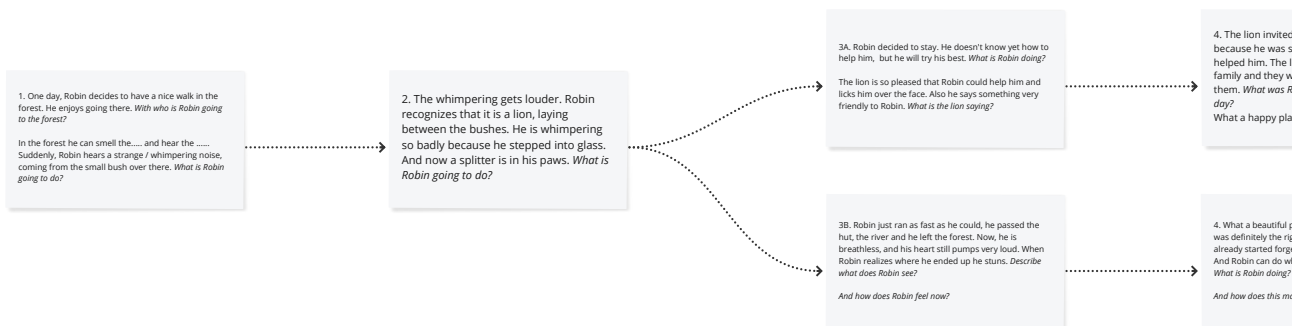
5. Robin is still a bit unsure if he likes the place or not.
Does he like it, and why?

He does like it because it's pretty, but it very big

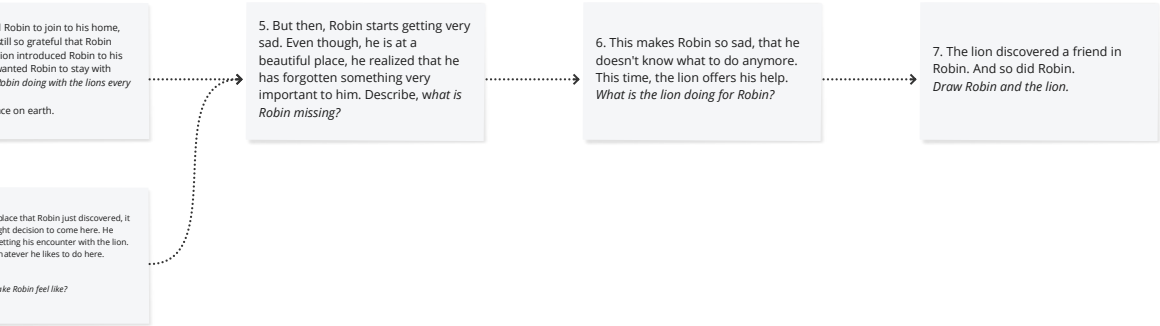
6. And over there, there's something bouncy.
What is it?

Maybe a kangaroo!

Fables approach



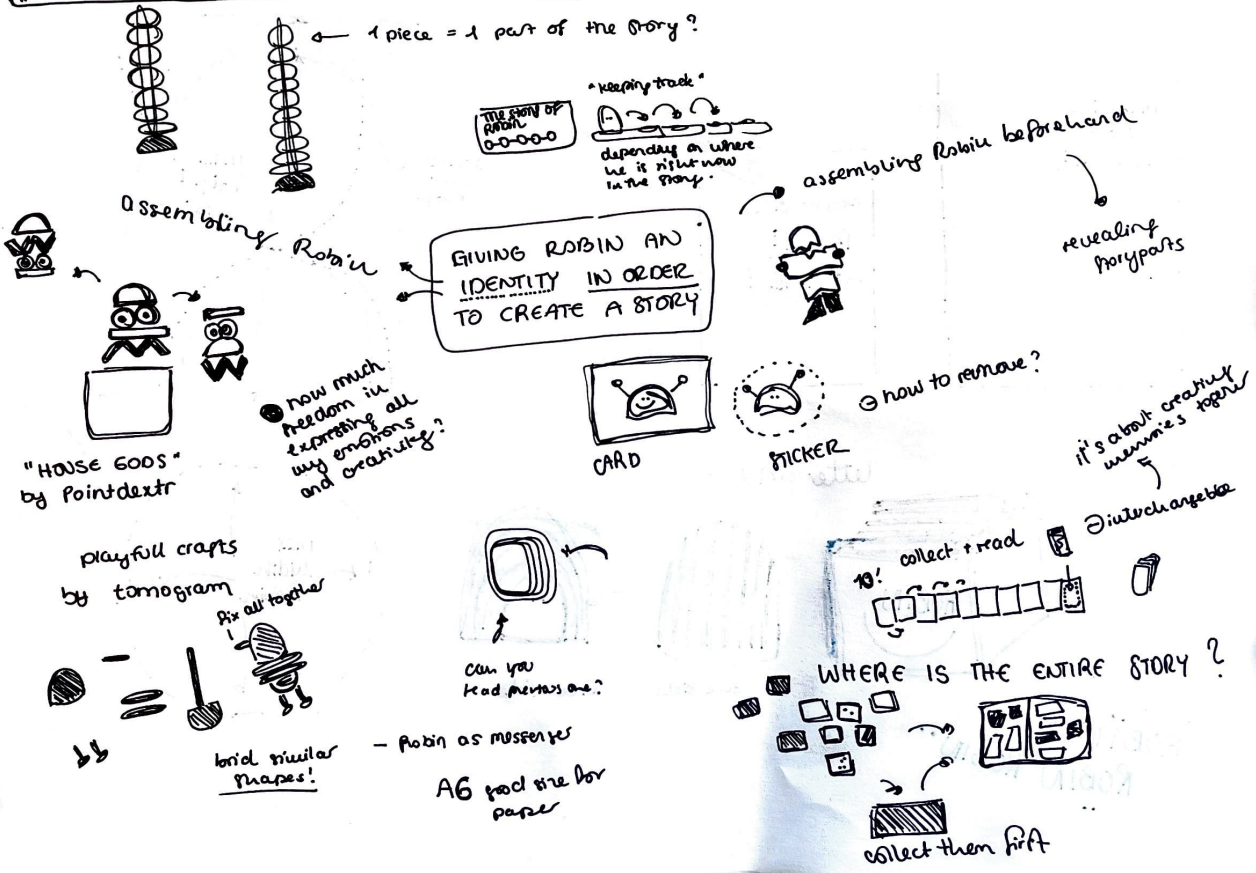
<p>here is What could that !?</p>	<p>7. Robin turns around and suddenly he looks into those big eyes. What / Who does Robin see?</p>	<p>8. It looks funny, that Robin has to giggle super loud. What is happening? !?</p>	<p>9. Robins new encounter simply needs help. Is Robin going to help? If yes - how is he going to help? If no - what is he doing instead?</p>	<p>10. It was definitely the right decision he took, because he would never have done it. What did Robin dare to do?</p>	<p>11. Suddenly Robin hears a familiar, but friendly voice, that brings him back to what he was actually doing. He realizes that he was just dreaming, but the nice words someone are saying to him are real. What does the friendly voice say to Robin? And who is it? Draw the picture</p>
	His daddy	Robin makes funny and weird grimaces with his brother.	RObin is going to help by getting some duck tape	Flying to the moon with his best friend.	His mum saying: I love you so much!



Appendix M Design Proposal

8.3 The prototype

"BUILDING ROBIN WITH BUILDING UP THE STORY"



letter holder



one side

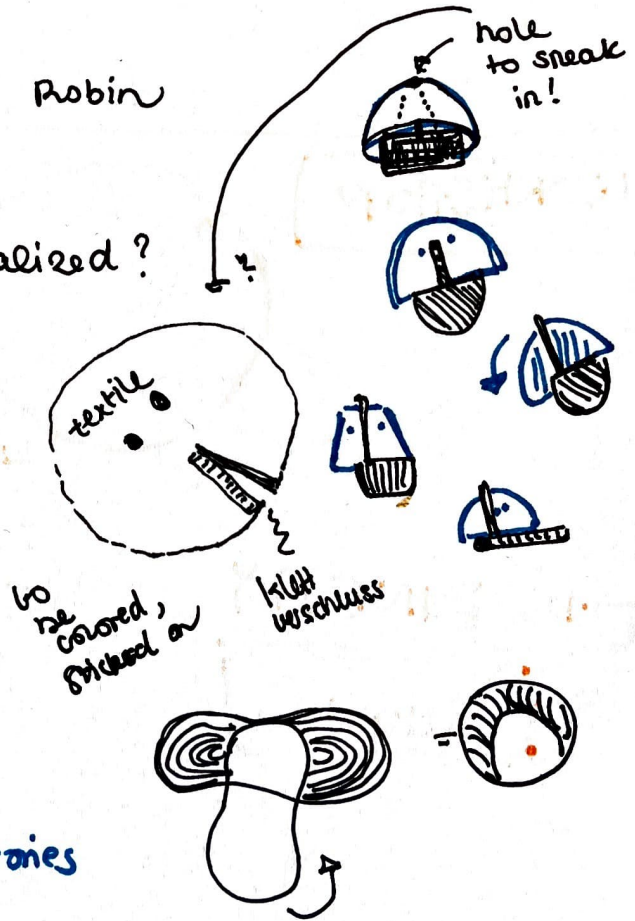


other side

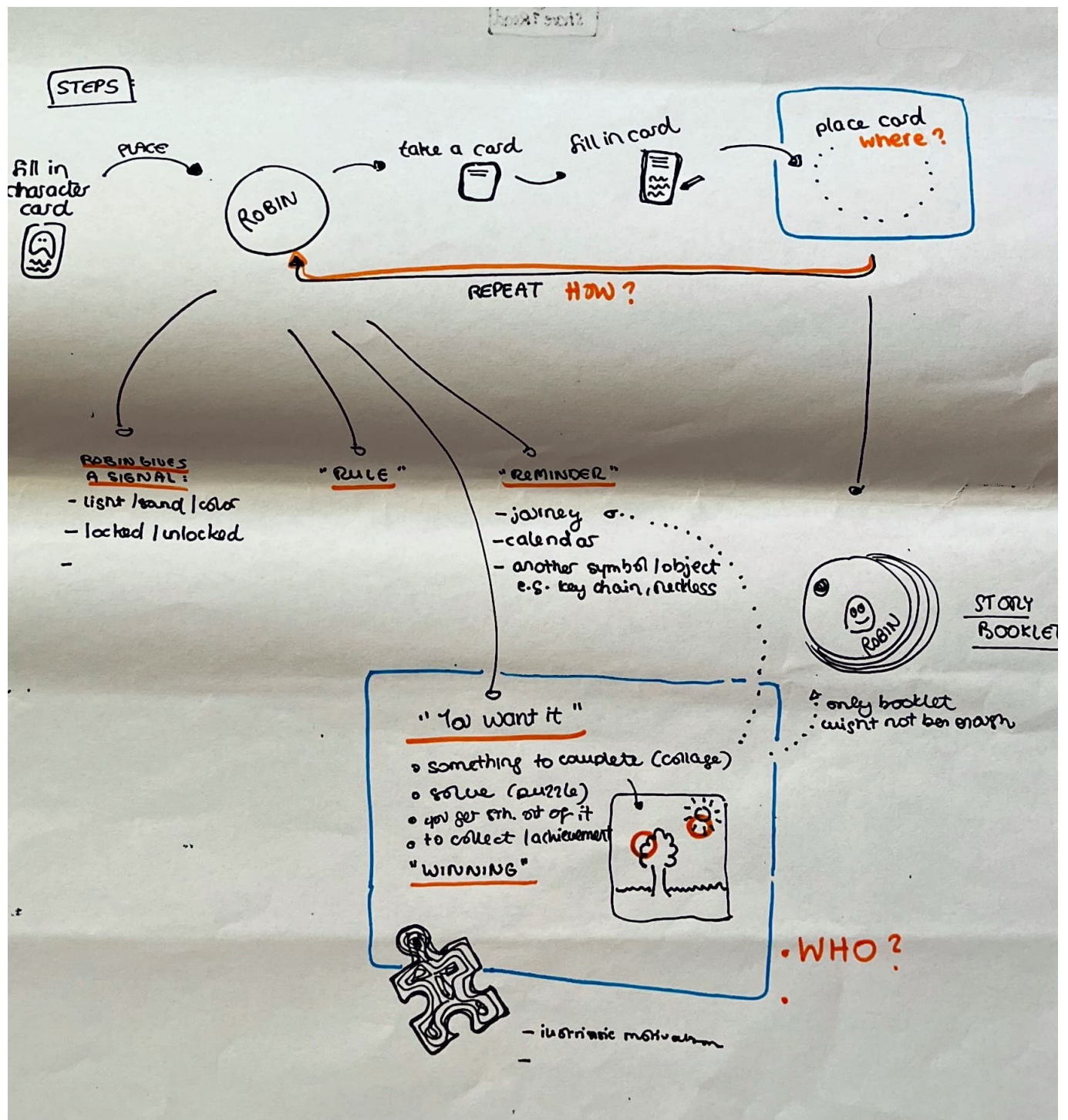
ROBIN
ROBIN ROBIN..

Alternative:

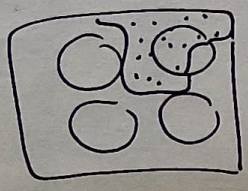
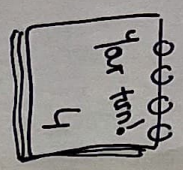
- think about materials for Robin
- what is given?
- what will be personalized?



→ defined vs. undefined stories

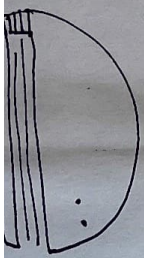
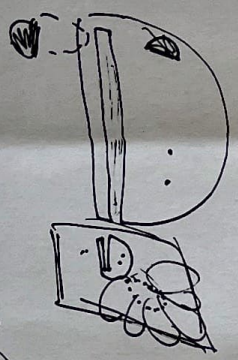
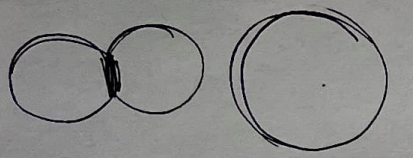


Reminders → Your turn!



- make sm. complete
- put rule
- photo collage

"I hope to put the cards, remind parents,"



-> strict rules 2



1. placing; WHY
2. reminding

Rule

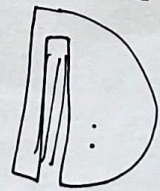
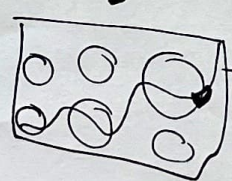
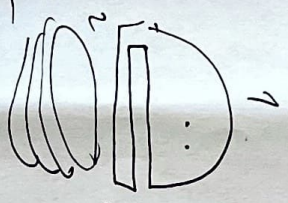
vs.

Reminder + FURRY

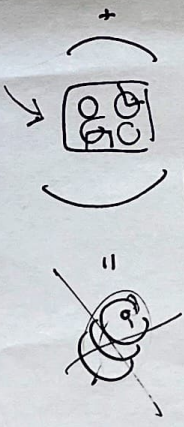
- > light
- > sand
- > "I need attention"

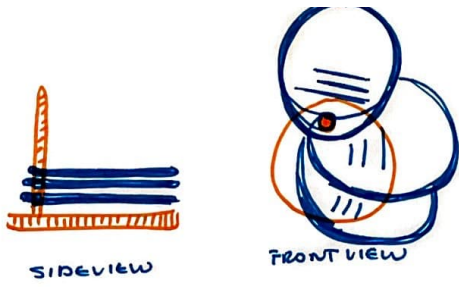
↳ FEAR + RESPONSIBILITY

↳ mental pressure

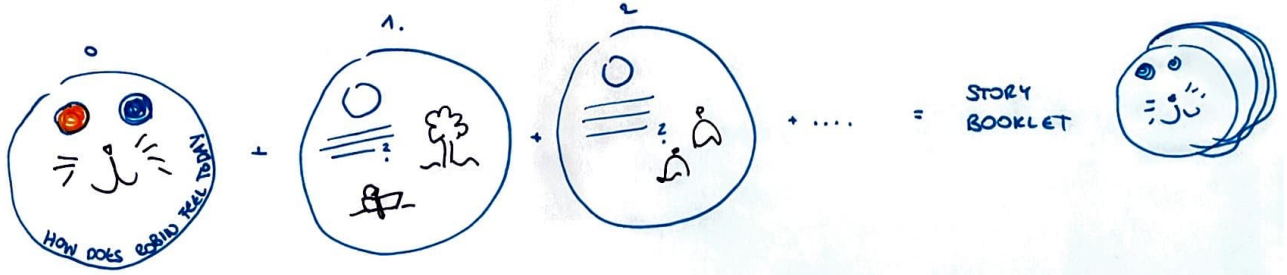


-> str. to carry with you





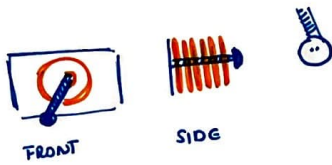
↑ ↓



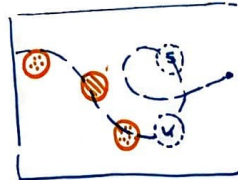
FIRST CARD
CAN STILL BE
IDENTITY CARD

BIGGER PICTURE

COLLECTING ROBIN STORIES



ROBINS JOURNEY

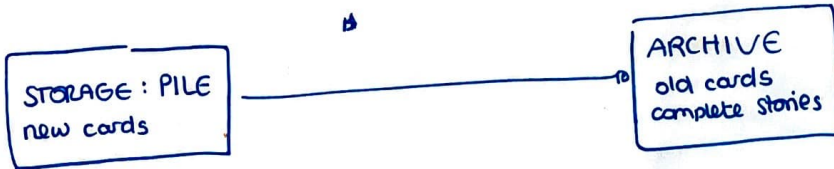


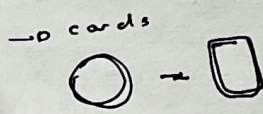
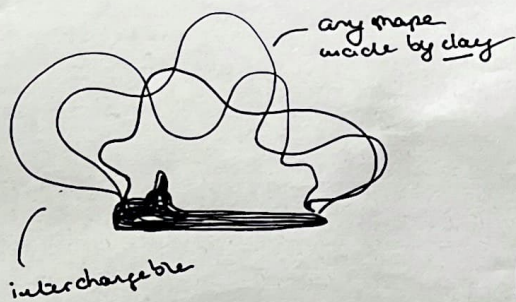
"board game characters"

CHANGING WIMMELPICTURE

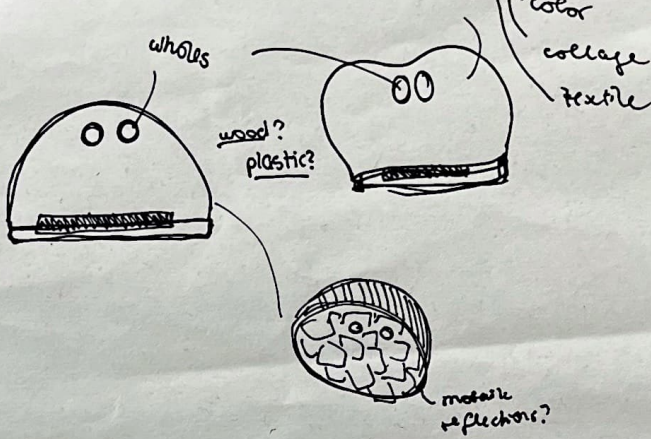


with each part
a detail more appears
on picture

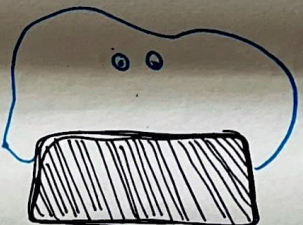
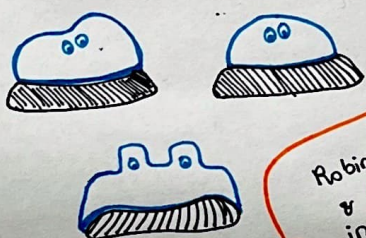
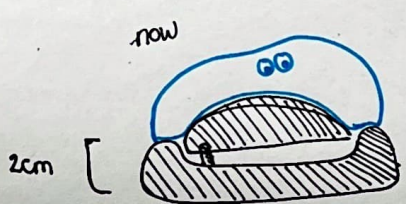




Snack Pack



how to personalize?



BROCHURE
Robin's stories & objects of inspiration

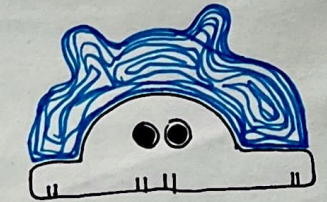
1

Materials

- Box
- clay
- 3D prints
- Brochure incl. instruct.
- 3x 10 card sets
- 3x 1 character card
- 9 pins

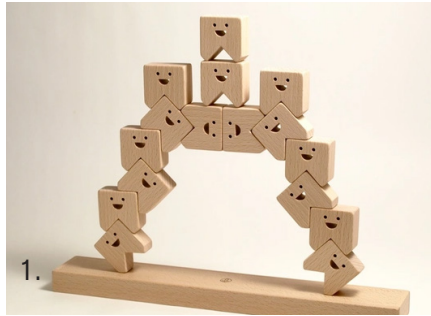
Instructions

- create your Robin
- how to play



Existing ideas for inspiration of the physical prototype

1. Japanese toy found on:
<https://www.creema.jp/item/6129596/detail>



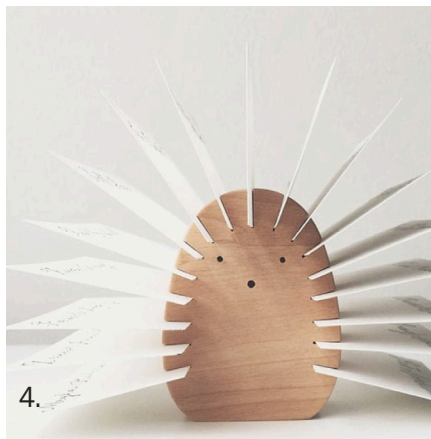
2. Playing with wood and yarn
<https://www.handmadecharlotte.com/6984/>



3. A hidden box in shape of an owl
 found on:
<http://www.myowlbarn.com/2013/04/owl-wooden-goodies-from-japan.html>
 (Japanese design)



4. Card holder by mielasiela
 found on: https://www.etsy.com/de/listing/235784738/holzerner-schreibtisch-organizer-halter?ref=hp_mod_opfy&epik=dj0yJnU9NTk6NTN3RlphSS1nRVZBWGp0TjJjVHQ5S0xIR2Y2RnkmcD0wJm49YXozRjNsSGI3NXRLVkfEdkFLU0R1USZ0PUFBQUFBR1RhamM4



5. Japanese design: Funny farm
 Designer: Isidro Ferrer
 Found on:
<https://www.xiusheji.com/work/2729.html>



6. Corporate design for Nino
 Design by: Studio pink
 found on:
<https://www.behance.net/gallery/54135717/nino-Corporate-Design>



The prototype iteration of the shape



The storylines

1. It's early in the afternoon, Robin is already done with its homework for today. What does Robin usually like to do?
2. But today, Robin wants to do something else. Something, that fits better to how he feels today. What does Robin think is the best he can do today?
3. It's not always easy for Robin to get what he wants. What does he need to do in order to get that?
4. Sounds like a plan! But what scares Robin the most o follow the plan?
5. That sounds tricky! What can Robin do to overcome the anxieties?
6. What a great idea! Robin tries to follow the advice more often. Who will Robin tell the same advice?
7. Robin loves the idea! The imagination makes Robin giggle super loud. What amuses Robin so much?
8. Suddenly, there is someone Robin never expected to join in that moment. Who is Robin joining?
9. Robin feels ... with that! What are they going to do?
10. Lastly, the person has a wish free for Robin. What is Robin wishing for?
What a beautiful wish!

1. It's Saturday morning, the airplane just launched. Who else is in the airplane with Robin? And where is Robin going to?
2. What is Robin the most excited about to see?
3. In the radio someone is announcing something very adventurous. What are they saying in the radio?
4. It's Robin time to go on an adventure! But where should he go first?
5. Robin looks out of the window. The landscape is passing by. But there was something moving very awkwardly behind the trees. What could that have been?
SWITCH?
6. But no, look! There it is again. Now, Robin can see the entire shadow. How does the shadow look like?
7. Now Robin is confused. He has never seen a shadow doing this. What is the shadow doing?
8. But then, shadow starts to run away from Robin. Robin doesn't know what to do. Is Robin joining the shadow? Yes - What are they going to do? No - What is Robin going to do?
9. Robin is convinced his decision was right. Because Robin is good in doing that! In what is Robin good at?
10. Suddenly Robin hears the music the is playing radio. Robin is back in the airplane. But then he hears a very friendly voice making Robin a compliment. What is the compliment? And who does it say? Draw the picture.

Appendix N Design Proposal

8.4 Feedback

Workshop with kids

Goal: Testing the interaction of creating a storyline together.

Ideal scenario:

- Kids create their own Robin figurine
 - Robin is the cardholder for all story parts
 - o The first card will be taken and filled in.
 - o The filled in card will be stored (where?)
 - o Robin indicates the next turn → placed somewhere else, a color, a sound, a position, an opening, etc.
 - o Repeat until last card is filled in.
 - All story parts / cards will be clamped together to a story booklet.
-

Introduction:

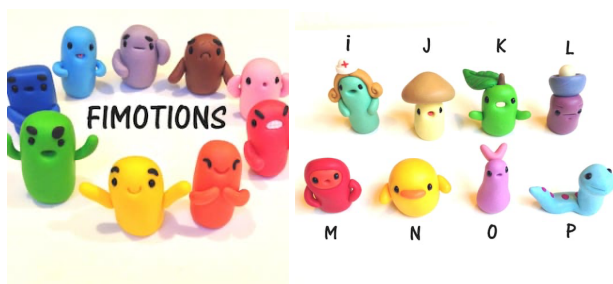
- Robin is our secret messenger. It can be a he or she ☺
 - The secret messages that Robin is telling us is actually a story about Robin itself.
 - But sometimes, he speaks in riddles, so that's why he needs our help to the stories.
 - Robin can take on different shapes, superpowers and emotions in our stories.
-

Workshop scenario part 1:

- A template is given with the initial Robin shape to let them sketch their ideas out at first (if wanted / needed). (5 – 10 minutes)
 - o How do you imagine your Robin as storyteller?
- (Kids create their own Robin figurine with clay. Using a bowl or glass + cling film to help in the form giving) (45+ minutes)



- Alternative: Kids create their own Robin figurine with FIMO / clay (30 – 34 minutes)



Workshop scenario part 2:

- 1 bowl (per child) will be placed somewhere in the room.
 - o 1 envelop will be placed next to the bowl.
 - One card deck is hidden under the bowl.
 - Kids place their Robin figurine on top of a bowl.
 - Each child starts at their own Robin figurine / bowl by filling in the first card (character card)
 - The character card will be placed back under the bowl on top of the card pile.

 - Then the kids move on to the next bowl / Robin
 - o They look under the bowl.
 - o Short look at the character card to have an idea what this Robin is going to experience.
 - o Take the next card below the character card.
 - o Filling the card in.
 - o Putting the filled in card in the envelop next to it.

 - Move on to the next bowl / repeat previous step.
 - When last card was filled in each child goes back to their own Robin /bowl
 - They can check out their stories now (in envelop) and clamp them together with brass fastener
-

Workshop scenario part 2:

- Meeting in a sitting circle.
 - Reading out loud each story (if wanted)
 - Collecting feedback:
 - o What did you like the most?
 - o What did you like the least?
 - o How difficult were the questions for you?
 - o How do you like your story?
 - o How does it feel if someone is taking part in telling the story of your Robin?
 - o Can you imagine playing this with your parents?
-

Workshop scenario part 3 (home – optional):

- Kids take home their Robin and their first story.
 - If they are interested: They take 1 envelop with 1 story home to try it out with their families.
-

Materials needed:

- Clay or FIMO
- Bowls / pots / glass etc. → something to hide the cards (1 per child)
- Card sets (1 Story = 11 cards)
- Brass fasteners
- Pens (1 per child)