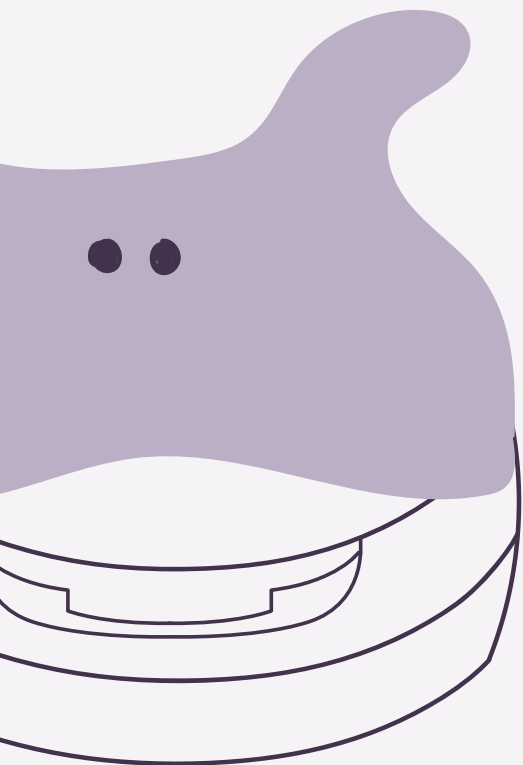


Giving siblings a voice

A storytelling tool to create a special bond between siblings & their parents.



Master thesis

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A storytelling tool to create a special bond between siblings & their parents.

Sibling

A brother or sister having one or both parents in common. In the context of this thesis it is a shorthand for a brother or sister that has a brother or sister with special needs.

Sibling with special needs / special needs sibling

An individual who is affected by one or multiple impairments, disability or chronic disease, and thus requires additional help from other people. Such impairments can be physical, educational, cognitive or sensory.

Special needs family

In the context of this thesis it refers to a family constellation of parents and children, that includes at least one child with special needs.

Sibling expert

An individual who organizes a program specifically designed for siblings or who works with siblings on a regular basis. The sibling experts have different educational backgrounds, but are all experts through their long term experience or special qualification focussing on siblings.

Ethical steward

As an important research measure required by the Privacy TUD staff, a professional needs to be present at the interviews with the children. In this case, a sibling expert will accompany and co-facilitate the creative sessions. The ethical steward is safeguarding the content of the sessions by taking care that sensitive subjects will be avoided and thus, preserving ethical safety, for both, the siblings and the design student.

Abbreviations

Acknowledgement

What a journey! - A journey full of wonderful experiences and learning opportunities.

I had an incredibly valuable time researching and sharing meaningful moments with children, and I am very thankful to all that contributed or supported me in any way during this journey. This project taught me a lot and helped me realize what it means to create value through design. And it wouldn't have been the same without you.

I want to thank my supervisor team for their unwavering support throughout the entire process. Your individual expertise was invaluable to me.

Pieter-Jan, thank you for your wisdom, your encouragement and trust.

Thank you for pushing me to make decisions and for just listening to me, I truly felt heard.

Paula, thank you for your endless enthusiasm, your unwavering loyalty and your hope when I felt low of energy - I genuinely felt cared for.

Marise, thank you for your sparkling ideas, your critical feedback and the boundless new angles on the concept - I felt inspired.

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Katharina, I greatly appreciated our regular reflection meetings. Thank you for taking me with you and immersing me into the siblings' world. Your knowledge and expertise was a great enrichment to my work.

I am also grateful for the emotional support by my family and friends. Thank you for always keeping me positive believing in me and supporting me along the way, each in your own way - thanks for being there for me!

And last but not least, I want to say thank you to all the siblings out there in the world, whom I had the pleasure to meet during this journey. You are wonderful and you deserve the attention.

So, this thesis is dedicated to you.

Abstract

In special needs families, family dynamics are slightly different from the dynamics in other families. A child with special health care or educational needs requires a lot of attention and special care treatment from all family members. The parents' attention is mainly shifted to the care needs of the brother or sister and the siblings are mostly on their own (Okma, Naafs, Vergeer, & Berns, 2014). In Germany, 6.1 % of all children between 10 and 18 years old are officially caring for one of their family members. This means that in every school class at least 1 to 2 pupils are affected (Bühning, 2018).

Literature points to a wide range of positive as well as negative influences on the emotional well-being of these siblings taking over care responsibilities at home, namely anxiety, depression, behavioral and social issues, but also strengths of character, such as empathy and kindness (Giallo et al., 2014, Martinez et. al, 2022, Milevsky & Singer, 2022).

This project focused on the personal experiences of siblings at a young age (6-12 years) growing up alongside a child with special needs. By conducting literature research, context mapping according to Sanders & Stappers (2012) with children, and supplementary interviews with parents the following underlying core values of siblings have been identified: 1. Feeling understood, 2. The need for adult attention and feeling cared for, 3. Just being themselves. Briefly, growing up with a special needs sibling comes along with the challenge of truly feeling and acting like a child.

These insights resulted in the design vision and goal for Ontzorghuis, a Dutch organization offering workshops, retreats and reflective tools for special needs families: Designing for playful and engaging experiences to support siblings (age 6 -12) to assume their role as a child by empowering and facilitating the sibling through interpersonal connections.

Through a research-through-design approach (Stappers & Giaccardi, 2017) the essential interactions of playfully sharing secrets in the form of affirmations and personal wishes with each other, were identified. The final design proposal resulted in the storytelling tool "Robin" to create a special bond between siblings and their parents. The playful tool enables children and their parents to create secret and surprising stories together that may involve personal needs or dreams of the child covered in the personality of Robin. The storylines are built upon research insights and the final story aims to serve as a conversation starter to understand the child's perception and wellbeing of the current situation.

A limitation of this project is that within the scope of this master thesis the final design proposal could not be evaluated with siblings in order to try out the interactions, nor the intended context, the sibling's home. Therefore, it is recommended to further evaluate the different parts of the design proposal in collaboration with siblings, their parents and sibling experts to prove the effectiveness in diverse contexts in order to create space to feel like a child

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Reading guide

Icons

The icons are used to provide an overview of each session set-up, such as interviews, generative sessions, brainstorming or feedback rounds.



The research goal of the session.



The specific setting description and the circumstances.



Number of participants and participant information such as age and gender if provided.



Session planning, describing the activities and / or asked questions.



Limitations on the session .



Description of analysis approach.

Insights

All gained insights are presented in such purple boxes, including one insight and a detailed description.

Gained insights Detailed description.

Take aways

All take-aways are highlighted and marked distinctive from the text.

» **Session or chapter take-away.**



Introduction

Part 01

This part provides an overview about the author of this thesis, the client and their stakeholders. It introduces the problem to the reader and presents the methodologies used in this projects.



1.1 The designer

Vanessa is a Design for Interaction student at TU Delft, with a background in computer science and design. Her experience as an interaction designer for software products rapidly showed her that design is all about the people's motivations, needs and abilities. At TU Delft, Vanessa has been able to dive deeper into the world of design research and context mapping, allowing her to explore the relationship between design and the human experience in more detail. Vanessa is passionate about inclusive design and creating awareness of the people who are often excluded by our daily design processes.

1.2 The stakeholders

1.2.1 Ontzorghuis

The Ontzorghuis is a Dutch organization that aims towards a family inclusive health care approach. Established in 2018 by Marise Schot, its objective is to foster a sense of community, facilitate knowledge sharing, and provide support to families caring for children with special healthcare needs. Ontzorghuis achieves these goals through various activities, including self-care reflective exercises for parents, parenting workshops (both online and offline), and family weekend retreats. The wide range of activities provides practical as well as emotional support for parents. The organization places a strong emphasis on sharing, learning, and inspiring each other to strengthen the sense of community among special needs families. Marise's specific role in the context of this thesis is mainly the stakeholder. However, her professional expertise as a social designer and as a mother of a child with special needs is also worth mentioning.

1.2.2 Target group siblings

In the focus of this thesis are siblings of children with health care related needs. They often have to take a step back within their family dynamic, repress their own needs and suffer in silence. Often, they are also referred to as 'young carers' as they are taking over care responsibilities for their special needs siblings. However, the aspect of being a young carer is less investigated in this report, more their lived experience growing up with a brother or sister with special needs. The target age group is from 6 to 12 years.

The designer is based in the Netherlands, as is the organization Ontzorghuis, while the case studies with children are carried out in Germany to mitigate language barriers. Thus, the focus group includes participants from Germany and the Netherlands.

1.3 Project brief

1.3.1 Problem definition

In special needs families, family dynamics are slightly different from the dynamics in other families. A child with special health care or educational needs requires a lot of attention and special care treatment from all family members. The parents' attention is mainly shifted to the special needs brother or sister and siblings are mostly on their own (Okma, Naafs, Vergeer, & Berns, 2014). Literature indicates that there are opposing influences on siblings when growing up with a special needs brother or sister.

On the one hand, previous studies have shown that siblings are a risk group for emotional and behavioral problems (Giallo et al., 2014). And a recent meta-analysis confirmed that special siblings 'may be at an increased risk for depression' (Martinez et. al, 2022). On the other hand, there are also indications that siblings have a high potential to develop personal strengths when growing up with a child with special needs (Milevsky & Singer, 2022).


1.3.2 Design goal




Designing for playful and engaging experiences to support siblings (age 6 -12) in the transition phase when overtaking their older special needs siblings to assume their role as a child by empowering and facilitating the sibling through interpersonal connections.

1.3.3 Research questions

The research questions guiding for this thesis were following:

-  How do siblings experience growing up with a special needs brother/sister?
 - How does this influence the dynamic within their family?
 - How does this influence their interactions with friends and peers?
 - In what moments do siblings feel empowered due to their special position?
 - In what moments do siblings feel less empowered?

-  What are the siblings' strategies for coping with their personal experience?
 - How does this influence the different social relationships



7 - 17 % of all children worldwide have a brother or sister with special needs.

(McKenzie Smith et al., 2018)

6% of all children in Germany officially care for one of their family members.

(Bühning, 2018)

Picture by A. Pacheco

1.4 Project approaches and methods

The project encompasses the two big phases: the research and the designing phase, which include a literature study and field research and an intensive concept exploration phase. Both use participatory design and design-through-research as approaches. The two phases also resemble the double-diamond framework which includes the phases discover, resemble, develop, deliver (Design Council, 2005) and that are well recognizable within the chapters of this thesis. However, through the research-through-design approach the entire process became much more iterative and thus valuable.

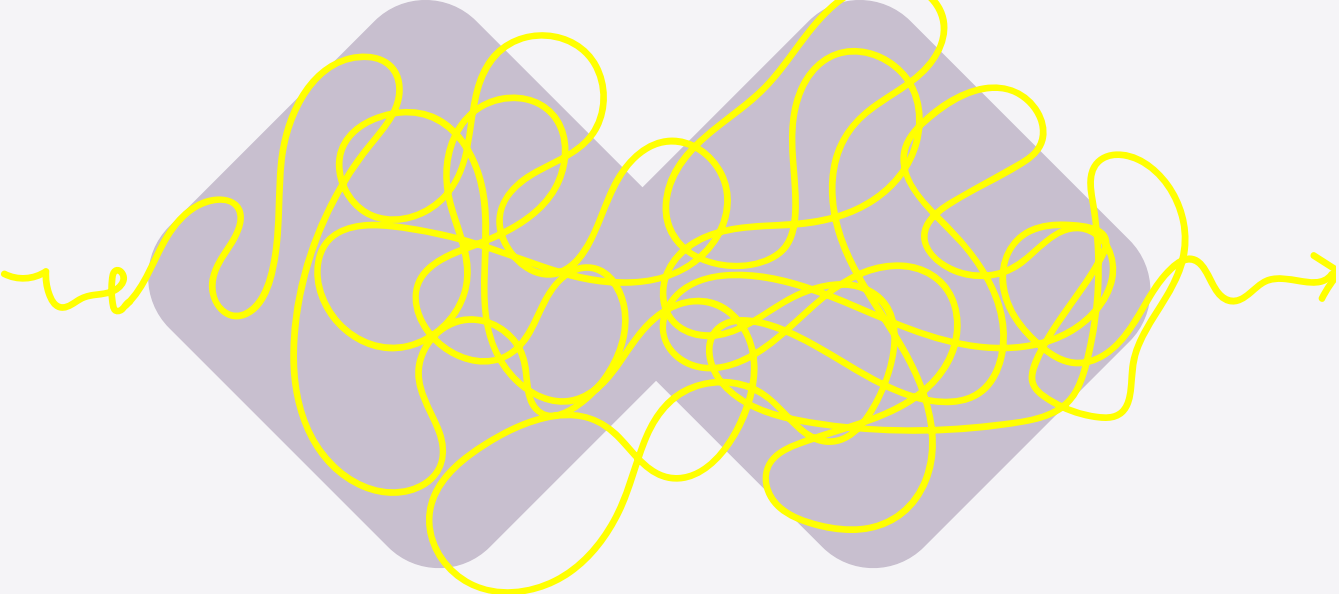
Next to participatory design, the project uses a research-through-design process. This indicates that the design activities themselves often contribute to the generation of knowledge (Stappers & Giaccardi, 2017). These design activities involve the understanding of a complex situation by constantly reframing it and creating responsive prototypes, which are essential for generating knowledge (Stappers & Giaccardi, 2017). For that reason, prototypes play a crucial role as they foster discussion and facilitate interactions that were previously non-existent (Stappers & Giaccardi, 2017).

Participatory design plays an important role in this project. By actively involving stakeholders as participants in joint sessions, a better understanding of the target group is created. This leads to the expectations and needs of the users being met. (Sanders & Stappers, 2012). The contextual understanding, gained through the method of context mapping, plays an essential role in this approach. Context mapping as design methods allows the participant to be an expert in their own expertise and the researcher attains the level of tacit knowledge (Sanders & Stappers, 2012).

PROBLEM

PROBLEM
DEFINITION

SOLUTION



RESEARCH

DESIGN



Literature Research

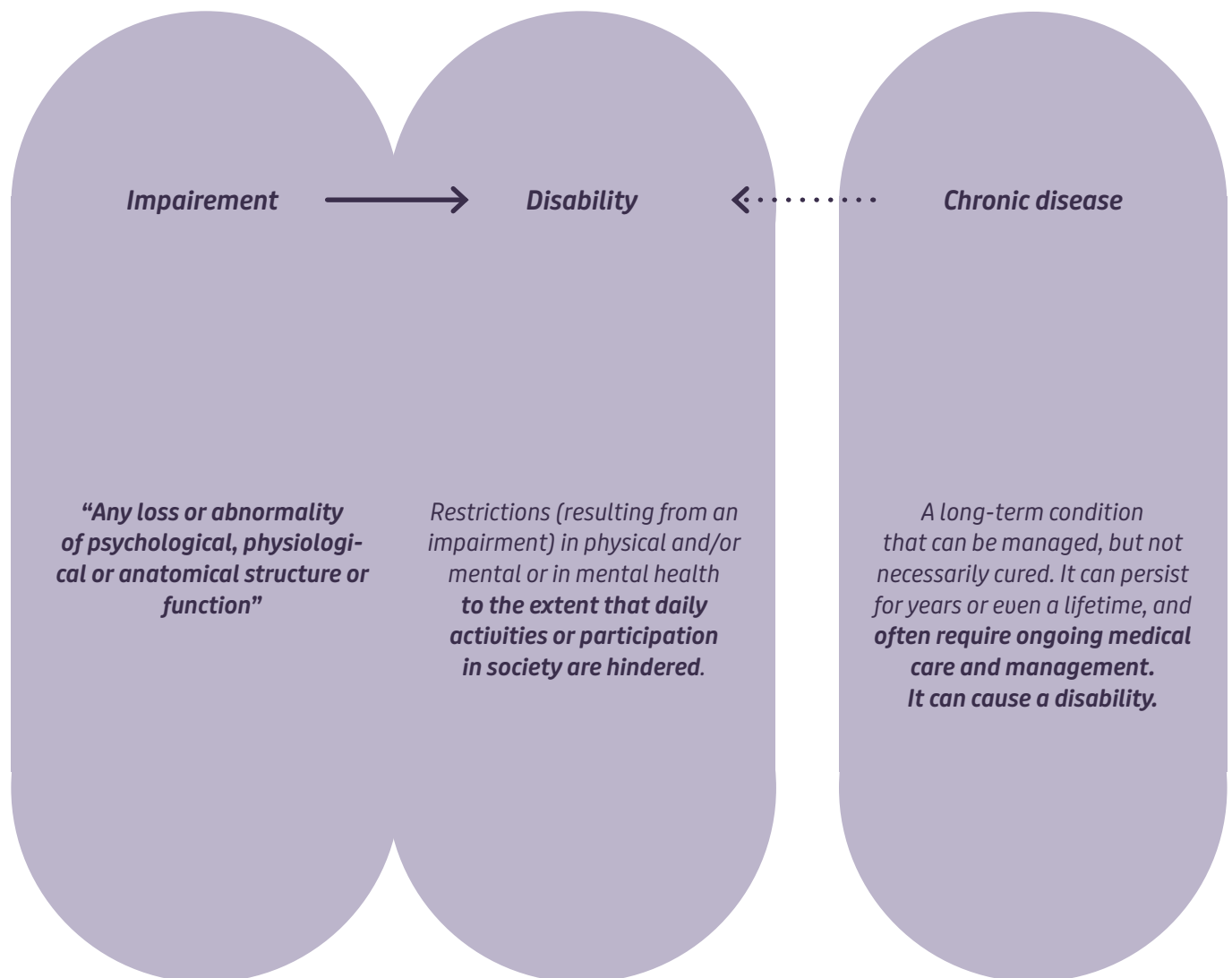
Part 02

This chapter begins to address the issue in a general way, providing information about children with special needs. It seeks to raise awareness and provide readers with a real understanding of the issue. It does this by presenting the impact on family life, and the experiences a sibling goes through. Thus, the first chapter is based solely on the literature and aims to answer the following questions:

- ***What impact does the disability have on the scope of the project?***
- ***How do siblings experience growing up with a special needs brother/sister?***
- ***How does this influence the dynamic within their family?***

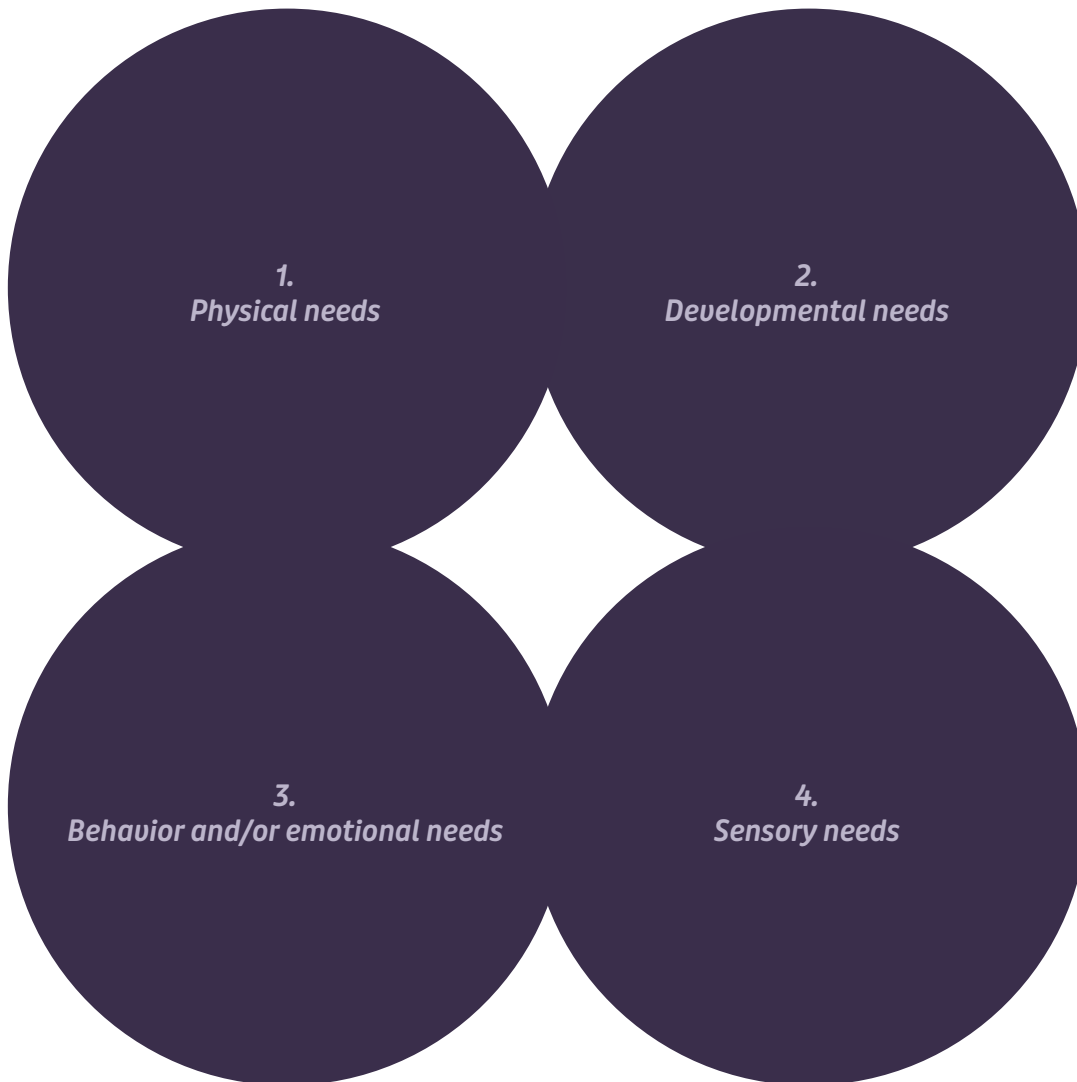
2.1 Children with special needs

The term children with special needs 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. The difference in the terms is as followed (Emory School of Medicine, 2018):



2.1.1 Types of special needs

The four main types of needs and their explanation according to Peterson (2022):



1. Physical needs: Chronic or terminal illness - muscular dystrophy, multiple sclerosis (MS), chronic asthma, epilepsy, cystic fibrosis, cancer, diabetes, or other serious health issues

2. Developmental needs: Intellectual disabilities, learning disabilities, autism spectrum disorder, attention-deficit/hyperactivity disorder (ADHD), and other disorders related to neurological development.

3. Behaviour and/or emotional needs: Mental health needs - any type of anxiety disorder, depression, reactive attachment disorder, post-traumatic stress disorder (PTSD) or acute stress disorder (ASD), oppositional-defiant disorder (ODD), conduct disorder (CD), and any other disorder involving emotional crises, extreme mood swings, anger, defiance, etc.

4. Sensory needs: Involve sensory impairment - visual impairment, blindness, auditory impairment, deafness.

2.1.2 Intensity of special needs

The severity of the special need can vary widely depending on the individual and the condition.

For example, the intensity of a chronic disease can range from mild to life-threatening or even end lethal (cf. Möller et al. 2016, p.17). Depending on the complexity level of their needs the children depend on continuous care service by their family members or professional caregivers and nurses, regular specialist visits, specialized therapies, ancillary health services, home health care and/ or counseling services (Bramlett et al.,2009; NHS, 2021).

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.

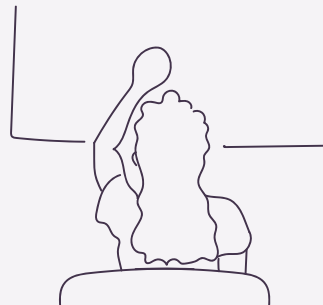
In Germany there are five care levels (1 - 5) that decide about the care intensiveness of the special needs person, which are measured by the degree of the person's remaining independence (cf. Lötzerich & Richter, 2023). For example, a child with epilepsy will not receive any official care level if it is developing normally and has no restrictions in normal life. Whereas another child with epilepsy may get care level 3 because the severity, nature, and frequency of the illness makes them significantly more restricted in their daily lives. In the latter case, more support with daily activities is often required.

2.1.3 Prevalence


As shown in the previous paragraph and stated by the CDC, individuals with special needs are a “diverse group of people with a wide range of needs” and the complexity level varies from person to person. Thus, not all diseases and disabilities referring to special needs may be even recognized on the first sight from an outside beholder (CDC, 2021).

For this reason, the number of children with special needs is somewhat speculative. The estimates in the Netherlands are at around 680.000 children according to Stichting Kind & Ziekenhuis (2021), whereas in Germany the numbers are estimated at around 2 million children and youths with a chronic disease or disability (NZ, 2015). The number of children with special needs are approximately 4 % of the entire Dutch and 2.1% of the German population. Which in turn means that at least one child per school class would have a brother or sister with special needs.

Basically 1 child per school class has a special needs sibling.







*It should not be forgotten that a child with special needs is still a child. **A child that should be able to enjoy all the human rights and fundamental freedoms on an equal basis as any other** as it is ensured by the United Nations Convention (Article 7).*

Picture by D. Anees

2.2 Impact on families

The moment a child with special needs is born, or the moment a child needs additional support due to the above mentioned conditions, the family dynamic changes significantly. As previously mentioned, special needs vary a lot in their care intensiveness and the children's needs impact various aspects of family life and generally affects every single family member. The range of challenges but also enrichments is broad.

2.2.1 Challenges

Caretaking of the child with special needs depends a lot on the commitment of all involved family members such as parents and siblings, but also extended family members and their financial resources (Reichman et al. 2008, Davis & Gavida-Payne 2009). From the perspective of the special needs child Davis & Gavida-Payne (2009) describe the family as the “backbone in the child's life” and thus as the “specialists in their children's abilities and needs”. Such a description itself already conveys the load of responsibility of each single one.

Parents become from one day to another parental caregivers or “mantelouders” (informal carers) as they are especially named in the Netherlands. Various studies during the last decades have shown that parents' role as additional caregiver for their child is accompanied by increasing additional stress factors. To only name a few: making personal decisions about work, education, leisure activities and their own mental health, but also maintaining the relationships among individual family members (Reichman et al. 2008; Miodrag & Hodapp 2010; Cousino & Hazen, 2013; Domaradzki & Walkowiak, 2023). Being a parental caregiver in such conditions requires additional responsibility and a special investment of energy and attention towards every family member. It is not uncommon that parents in such a situation are mentally overloaded or have worse mental health outcomes than parents without a child with medical problems (Gérain & Zech, 2018; Cohn 2020). The challenges parents are carrying, however, have consequences on each individual's family member “financial, physical and emotional well-being” (Reichman et al., 2008, Domaradzki & Walkowiak, 2023).

2.2.2 Enrichments

Despite these challenges, living and caring for a special needs child can enrich each family member through unique experiences and by bringing them closer (Domaradzki & Walkowiak, 2023). Reichman et al. (2008) describes it as follows: "It can broaden horizons, increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions." And also other studies have highlighted the enrichment through personal growth, resilience (Noonan, 2018; Wolff, 2022).

2.3 Effects on siblings

Siblings of children with special needs are usually born in the previously described family conditions, either as a younger or an older sibling. Their everyday life, extra activities and responsibilities may be influenced when they take on a supportive or caregiver role to assist their parents (Woodgate et al., 2016).

The effects on their mental well-being and character has been broadly investigated in recent years. Various studies indicated that siblings tend to be affected by emotional fragility, including anxiety and depression, behavioral and social issues resulting in a poorer mental health (Giallo et al., 2014; Martinez et al., 2022; Caliendo et al., 2020; Wolff et al., 2022). Furthermore, within the meaning of noticeable behavioral issues Giallo et al. (2012) highlighted “hyperactivity and inattention” as well as “angering easily, non-compliance and arguing and fighting”.

At the same time, studies also highlight positive effects such as personal growth and resilience and overall positive character strengths, such as “being considerate for others feelings, being helpful, volunteering to help” (Giallo et al., 2014) and showing “empathy, kindness, patience, open-mindedness, and acceptance of others, as well as self-sufficiency and independence” (Milevsky & Singer, 2022).



2.3.1 Siblings' perceptions

Beyond evaluating the effects on siblings' mental health and personality, the main goal in the context of this thesis is to find out how siblings perceive this special situation at home and which emotions they encounter. Earlier reports and studies demonstrated various positive and negative feelings towards their special needs brother or sister, ranging from affection and protection to feelings of discomfort and shame, concern, sadness and fear (Strohm, 2008; Skotko et al., 2012; Ward et al., 2016). According to Bühring (2018) siblings assess their quality of life much worse than children of the same age. Milevsky & Singer (2022) recently revealed that many adult siblings also encounter difficulties and worries, particularly regarding "social embarrassment" and future concerns about family planning and romantic relationships.

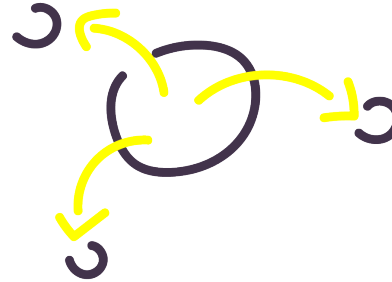
Having a special needs sibling was found to be an important indicator of their future career plans and partner selection (Milevsky & Singer, 2022). However, siblings encounter feelings of guilt and self-blame towards their special needs siblings when going different paths in their lives and negotiating their care responsibilities / obligations with themselves (Leane, 2019, Yaldiz et al., 2021; Hanvey et al., 2022). It may be assumed that the feeling of being responsible to care for their special needs sibling already appears at a young age. Cridland et al. (2015) reported that meanwhile adult siblings perceived a range of feelings that went from lower valuation and anxiety problems to feeling good and proud in the role of siblings and in taking on caregiving activities during their childhood.

Another important aspect is their positioning within their family and social life. According to Mandleco's (2015) integrated study review, siblings of children with down syndrome and autism experienced feelings of being neglected due to the lack of the parents' attention. And a latest study by Hanvey et al. (2022) reported that siblings of people with a disability or chronic disease experience the "feeling of invisibility during daily social interactions" with other family members and acquaintances. As the first question is usually concerning the special needs sibling: "How is your brother doing?" rather than "Hey, how are you actually doing?". As a consequence of this, for some siblings being a sibling of "became an identity" over time (Hanvey et al., 2022). Furthermore, the same authors point out that siblings may feel abandoned by their social context, in not being encouraged to identify their "own important needs both in earlier and later life". Yaldiz et al. (2021) found similar results by siblings of siblings with developmental disabilities feeling more disconnected and rejected regarding their personal needs than other siblings.



Internalization

Absorbing the unusual situation in silence, which results in emotional instability like depression or anxiety.



Externalization

Projecting on the external world, which results in behavioral symptoms like aggression or arguments.

#1 The difference between internalization and externalization

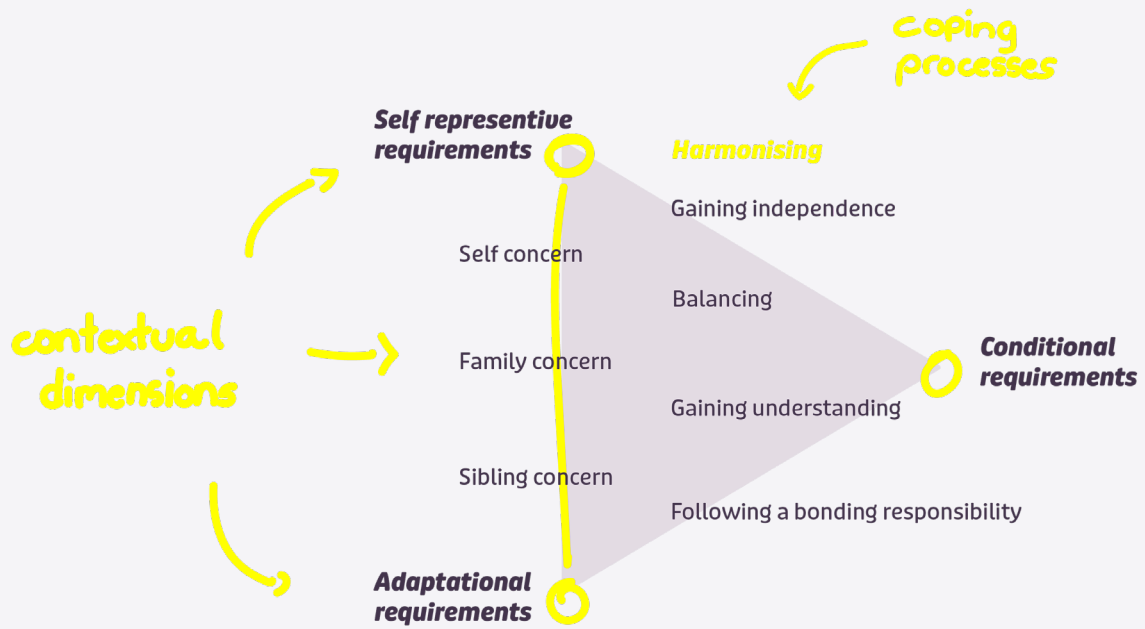
2.3.2 Protective strategies

Siblings experience a rollercoaster of emotions and stress factors when growing up along with a special needs brother or sister. Their coping mechanisms were already a bit indicated in the previous paragraphs. But for further research reasons, it's important to highlight them separately again. There is evidence that siblings cope with the situation usually internalizing problems or difficulties and also sometimes with externalization (Gallo et al, 2012; Di Biasi et al, 2016; Hanvey, 2022).

Internalization means that they absorb the unusual situation in silence, which in turn results again to the previously mentioned symptoms like depression or anxiety. But, this also indicates that topics about the special needs may be avoided in conversations by siblings (Long et al., 2015). Whereas, externalization describes the projection on the external world which results in behavioral symptoms like aggression or arguing. Wolff et al. (2022) proposed that siblings "coping with emotions and family stressors" leads to either "resilience or maladaptation."

Another strategy, may be indicated by Gera et al. (2021), that siblings are seeking for more knowledge to better understand their siblings needs and situation. Similar insights are discovered by Dellve et al. (2000) in the "harmonizing dilemma" concept among siblings of children with DAMP and/or Asperger syndrome. The concept (see figure #2) indicates siblings coping strategies (dilemmas) on existing challenges (requirements and concerns).

Achilles (2007) specifically mentions five coping strategies in siblings, which are loyalty, distancing, social engagement, idealization and overadjustment. The author highlights that there are variations and combinations of them.



#2 Harmonizing dilemma concept by Dellue et al. (2000)

2.3.3 Children's developmental understanding of a disability

To better understand the siblings' perception of a family life and its interactions, an excursion to the child's developmental psychology is necessary. The following figure #3 demonstrates according to the research of Möller et al. (2016) the differences of children's and adolescents' understanding of a disability and their coping mechanism in relation to their developmental status. It can be seen that children develop a first realistic understanding of the disease, at the age between 6 and 12 (target group of this thesis). They are exactly the age group that is suffering in various ways under such family circumstances. Worrying and empathizing with suffering family members leads to repressing their own needs and somatic symptoms.

Age group

Baby
(0 -12 months)

Toddler
(1 -3 years)

Preschool
(4-5 years)

School child
(6-11 years)

Youth/ puberty
(12-17 years)

Developmental characteristics
(Piaget 1969)

Understanding of the disease

Consequences / Coping mechanism

- Object permanence: baby learns that parents are coming back as well as physically as emotionally.

- Due to the developmental status it is not yet able to understand diseases itself.

- Reaction on absence of parent leads to separation anxiety as returning of parent cannot be anticipated

- Focus on single attributes only.

- A disease is a specific observable attribute between symptoms and consequences.

- „Subjective punishment through being left“
- Interruption of daily routines results in insecurity and temporary developmental delays.

- Generalized concept (e.g. infection concept).

- Believe that a disease can be easily transmitted.

- Difference in logical thinking: phantasies over reality
- Egocentrism of thinking.

- A disease is seen as a consequence of previous negative thoughts that are related to jealousy, rivalry or anger.
- Parents worrying emotions and facial expressions may interpreted as consequence of own mistake and wrong behavior.

- Feeling responsible for disease
- Feelings of guilt, fear and shame when realizing moral breaches and own bad thoughts.
- Extreme cognitive emotional stress.

- Ability to takeover another perspective.

- Reflection on consequences of disease.
- Concerns and worries for siblings and parents.

- Disease becomes an extreme mental stress factor.
- Withholding own needs and demands to not be an extra burden
- Results in somatic symptoms (stomach ache, headache, digestive problems, sleep disorders)

- Hypothetical logical thinking

- Wanna take over responsibility for siblings and parents.
- More in-depth reflections.

- Internal conflicts between being an autonomous youth and taking over responsibility for family.
- Feelings of guiltiness towards the diseased sibling and fear to become diseased as well.

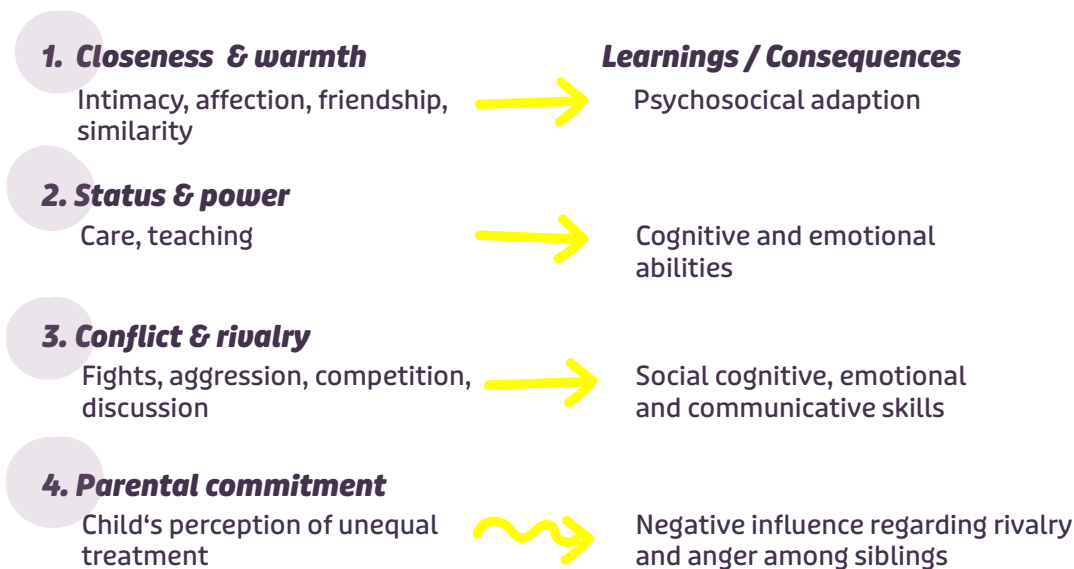
#3 The differences in age of a childs understanding and its coping mechanism by Möller et al. (2016)

2.4 Siblings' social relationships

2.4.1 Siblings & their siblings

The relationship between siblings in general

Sibling relationships are often the longest and most stable relationships in our lives and thus, they are very special (Hackenberg, 2008). In general, siblings stand for a full range of positive and negative emotions from closeness, familiarity and love to jealousy, competition and hate. Sibling relationships are the most important primary relationships after the parent-child relationship (Frick, 2010) and they are characterized by being more „horizontally structured and equitable“ - which indicates that siblings can be both allies and rivals, providing opportunities for individuals to develop their social and interpersonal skills according to Möller et al. (2016). The same authors summarized research insights based on Buhrmester & Fuhrmann's in 1990 identified four essential dimensions within a sibling relationship:



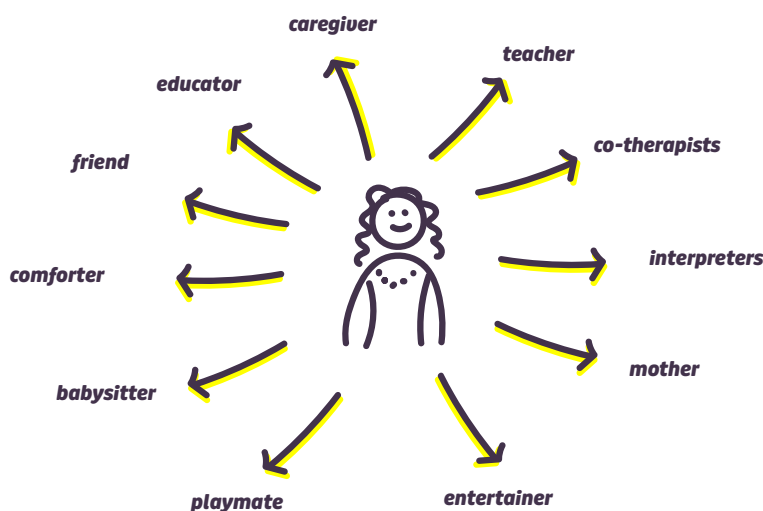
#4 Four essential dimensions within a sibling relationship based on Buhrmester & Fuhrmann in Möller et al. (2016)

In a recent study it was confirmed that siblings strongly influence each other through conflicts. Borari et al. (2023) found out that they do that by „changing their behavior to align more with the other siblings' constructiveness“. Also, there were found similarities to Buhrmester & Fuhrmann's (1990) regarding the dimension of status and power through the older sibling influencing the younger one by expressing power and knowledge. Furthermore, based on literature research, Borari et al. (2023) highlighted that siblings synchronize their emotions and behaviors, which “facilitates social interaction, cooperation and social understanding.”

The relationship between siblings and their special needs siblings

Not all mentioned dimensions of sibling relationships can be experienced in the same balanced way between siblings and their special needs siblings. Leane (2019) highlighted the “strong emotional ties between siblings” and Woodgate (2016) the siblings’ prioritization of their relationship. The strong bond among siblings and their special needs siblings lies in their “shared history and unique understanding” (Leane, 2019). Also, Braconnier et al. (2018) identified in their study siblings judging their relationship with more love, appreciation and supportiveness, rather than arguing and criticizing. Furthermore, various studies demonstrate the protective characteristic of siblings in that relationship, which they show in front of other children. (Leane, 2019; Schmeer, 2021; Woodgate, 2016)

However, such closeness is usually connected to the surrounding care activities and responsibilities, which includes additional stress (Pavlopoulou et al., 2022) and which puts the sibling relationship more on a mother / child level according to Leane (2019). Also Tomeney et al. (2017) found similar results, by identifying an “increased risk of parentification” among siblings during their childhood. This means that siblings tend to take over tasks that are usually performed by adults. Achilles (2007) highlights the amount of different roles that a sibling takes on in a relationship with a special needs brother or sister (see figure #5). Another aspect found by Burnham Riosa et al. (2022) is that siblings feel less connected to their special needs sibling, when there are communicational or behavioral issues (e.g. aggressive, self-injuries) between them. And Möller et al. (2016) mention that because of the central focus on the child with special needs, arising jealousy is usually withdrawn by the siblings and therefore typical conflict behavior among siblings occurs less in such a relationship.



#5 The roles a sibling of a special needs child takes on according to Achilles (2007)

2.4.2 Siblings & their parents

The general relationship between a child and its parents is summarized by Lamb (2012) as following:

“The quality of parent-offspring relationships is determined by the degree to which parents offer love and affection, emotional commitment, reliability and consistency, as well as the extent to which the parents “read” their children or adolescents effectively and provide appropriate stimulation, guidance, and limit-setting.”

Such a statement should be viewed critically, since apparently the entire responsibility for the child-parent relationship is determined by the actions of the parents. However, Rostad & Whitaker (2016), examined a similar perspective, based on the attachment theory and the parents' reflective functioning, and found similar, but research confirming insights:

“Responding to those [the children’s] needs enhances attachment security and contributes to more positive interactions and a higher quality relationship between parent and child.”

It is well known that in special needs family siblings want to protect their parents from their own personal issues and “might feel guilty about complaining” (Strohm, 2008) or provide their parents with more time and focus on the special needs sibling (Leane, 2019). For that reason, siblings request less time even though they'd rather prefer more support in daily activities, such as homework, according to Pavlopoulou et al. (2022). Similar results were found by Leedham et al. (2020) through a paper review, that siblings aim for more shared moments and feelings with their parents. However, Pavlopoulou et al. (2022) also mention the parents' expectations towards the siblings' ability and maturity in managing their own work. It may be assumed that siblings not only assist their parents in adult-like tasks but also in responsibilities and decisions, to which is referred as parent-focussed parentification (cf. Tomoney, 2017; Burnham Riosa, 2022).

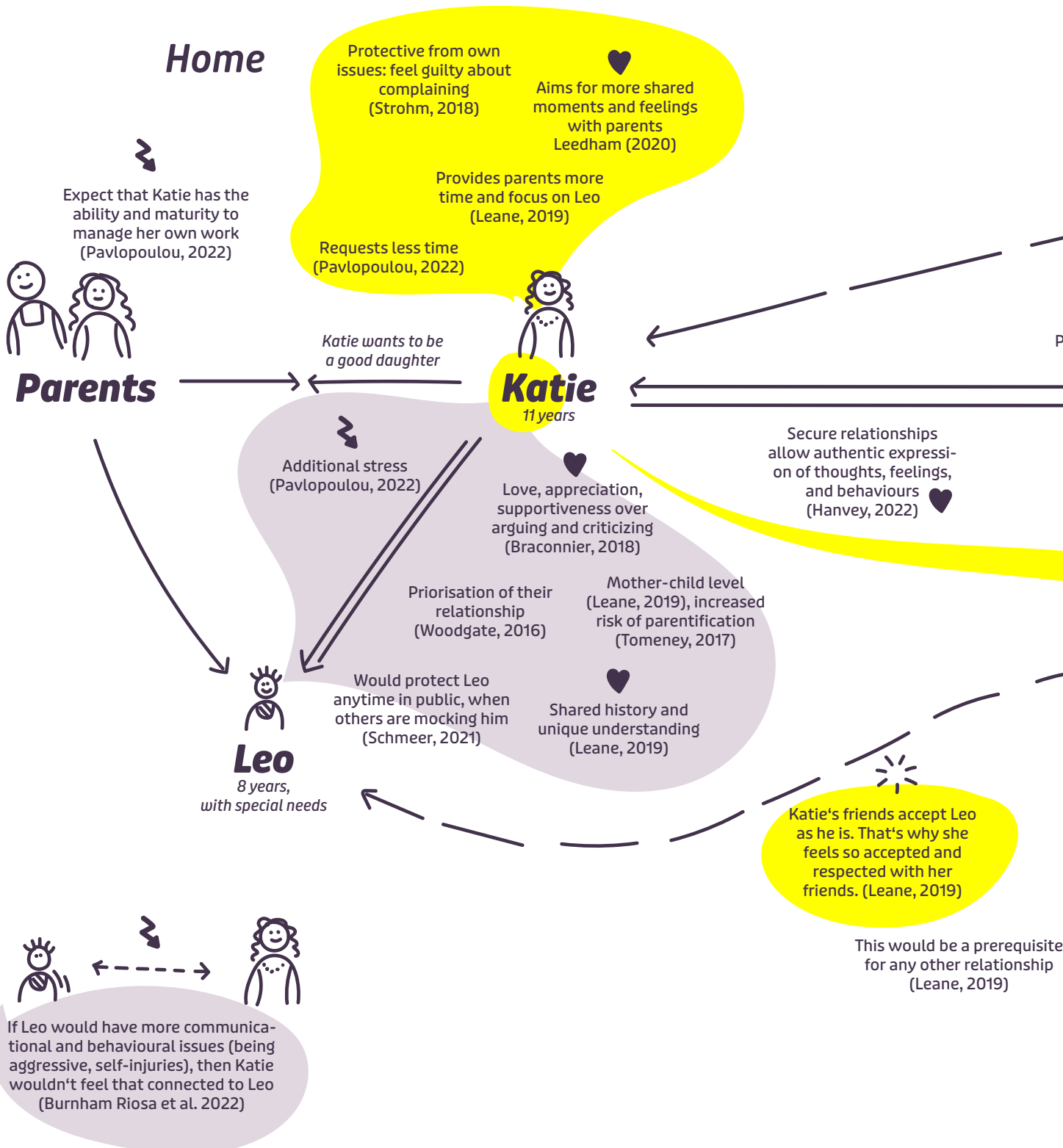
However, looking at the overall family, Woodgate (2016) also states that siblings struggle with the fact that “their family avoid activities to maintain safety and comfort” and that siblings experienced the feeling of missing out on certain activities with their families.

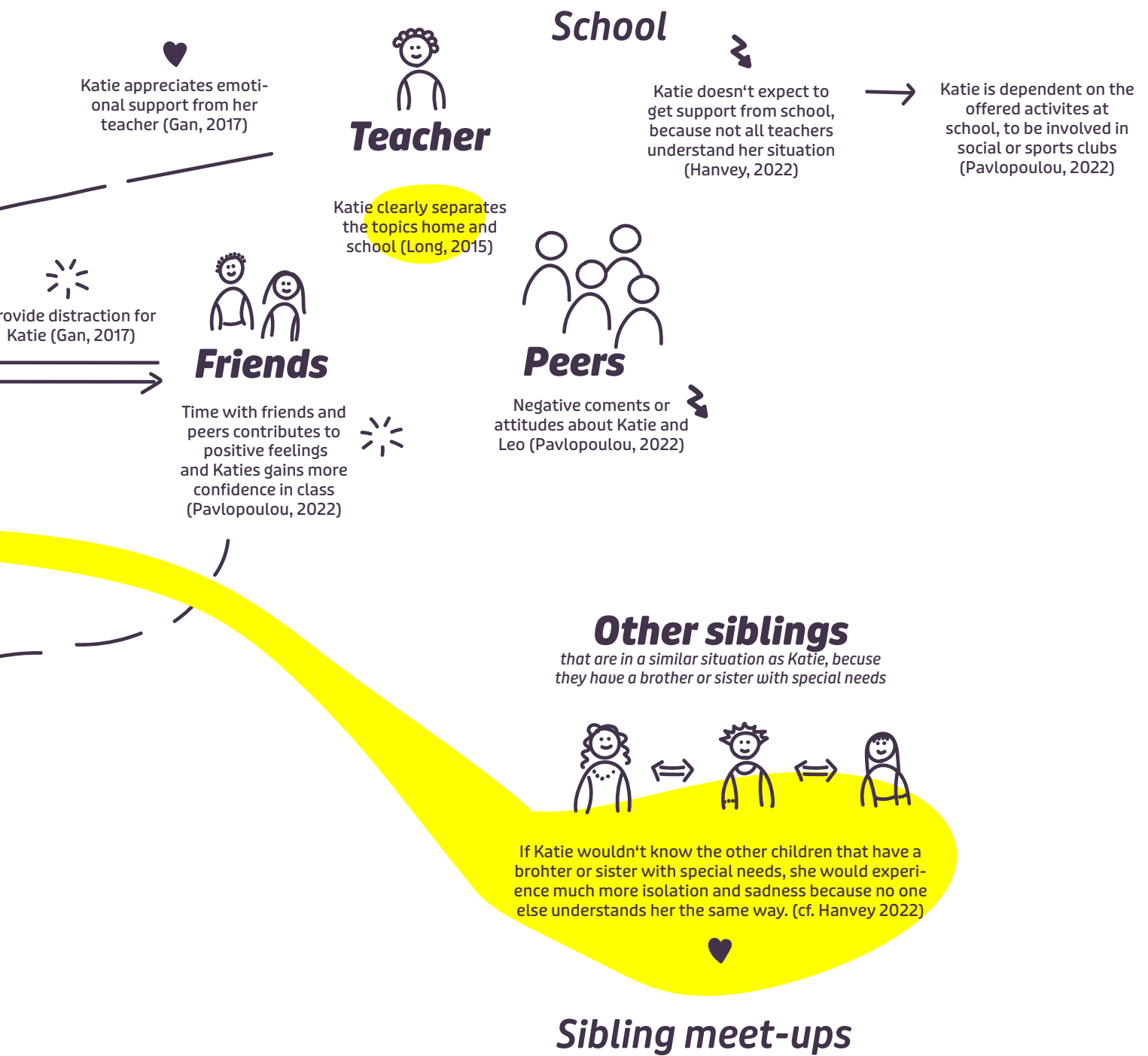
2.4.3 Siblings & their friends & their partners

Other people and activities outside the family play an important role for siblings. The classroom and schoolyard, especially for the young age group (6-12 years), are important places where they spend a lot of time and thus, should be considered in this research. Pavlopoulou et al. (2022) state that siblings having time with peers and friends outside school contributes to “positive feelings” and feeling understood and listened to by others. The same authors highlight that such experiences with friends helps to encourage siblings of children with autism to gain “more confidence in class”, where they sometimes anticipate “negative comments or attitudes” by peers and teachers that may notice problematic behaviors. The same applies to when they sense a “lack of support” from such authority persons, such as the awareness about the siblings situation at home or negatively influencing comments (Pavlopoulou et al., 2022). The enrichment through connectedness among peers is an essential part to a child’s overall psychological well being (Law et al., 2013).

Based on a literature review, Gan et al. (2017) highlighted that siblings appreciate “emotional support from teachers” as well as “distraction provided by their friends at school.” However, the same authors also state that siblings of children with chronic disease relationships to peers may be formed by “their own unique experiences with chronic illness”. Thus, avoiding and separating the topics home and school may be one of such influences (Long, 2015). Hanvey (2022) in contrast states that stable relationships with friends and peers „allow authentic expression of thoughts, feelings, and behaviours.“ Pavlopoulou et al. (2022) highlights that siblings are dependent on the offered activities by the school “to be involved in some form of a social or a sports club”. Another aspect that should be highlighted is the role of the special needs sibling in defining friendships and relationships. Meanwhile adult siblings reported that the acceptance of the special needs siblings was an essential fundament of feeling accepted and respected by others (cf. Leane, 2019). The same applies for relationships according to Leane’s (2019) findings, that the acceptance of a special needs sibling is a “prerequisite for any relationship”.

Home





#6 Presenting the effects of being a sibling in a social system by using a fictional sibling character Katie.

Chapter take-away

- ~ A lot is known about siblings growing up with special needs siblings and could be reported in retrospective studies with adult siblings. But the actual perspective from a young sibling while growing up is still limited.
- ~ It needs to be considered that such literature study involved all kinds of disabilities, impairments and chronic diseases and didn't focus on a particular one. Therefore, there are differences in siblings coping with a certain special need.

Depending on the age children, have a different perception of special needs and a dependent coping mechanism. Between 6 and 12 children develop a first realistic understanding of the disease and start becoming reflective. This results in being worried and mentally stressed, withholding own needs and somatic symptoms.

- » **Internalization and externalization of problems: depression and anxiety vs. aggression and open**
- » **Siblings tend to be affected by emotional fragility, including anxiety and depression, behavioral and social issues resulting in a poorer mental health.**

Siblings experience a wide range of emotions when growing up with a special needs sibling. The feelings range from reduced appreciation and anxiety issues to feeling good and proud in the sibling role and care responsibilities.

- » **Feeling invisible during social interactions, as special needs and the condition of the sibling are always the first topic.**
- » **Strong connection between siblings even though care responsibilities are exhausting and stressful.**
- » **Don't feel entitled to request parents attention and time with their own problems.**
- » **Strong connections with friends and peers can have a positive impact on siblings.**



Field research

Part 03

This chapter is a compilation of interviews and generative data, which attempts to reveal the experiences of children living and growing up with a sibling with special needs, in order to uncover their hidden dreams. In the following chapter the subsequent research questions are investigated:

- ***How do siblings experience growing up alongside a special needs sibling?***
- ***What are the siblings' strategies for coping with their personal situation/experience?***

3.1 First impressions

The first impressions and contact point with siblings are based on observational insights, resulting from one online gathering especially designed for siblings and one two day trip with a group of siblings. Both aimed to get in touch with the target group, get to know them and discover their attitudes and values.

3.1.1 Talking to siblings

Session set-up



Meet siblings from 5 to 14 years through a monthly offered online program, which is organized by a professional sibling expert. By actively listening to their personal stories, a first impression and assumptions about the sibling situation can be gained.



2 x 60 minutes, online, organized by a German organisation with focus on siblings.



1 Sibling expert (ethical steward), 2 student researchers (incl. project researcher), 3 siblings (5 - 14 years).



Participating in conversations and observation.
Common reflection between facilitator and student researchers.



▪ Unclear roles
Detailed description in Appendix A

Insights

Creating a safe space supports young siblings opening up in conversations.

For example naming the disease, encouraging gestures by the facilitator helped the child to feel comfortable.

During the meeting siblings empower each other to actually talk about the disease.

Hearing others siblings talking gives permission to speak up and breaks taboo topics.

Siblings knowledge and comprehension of the disease depends on their age.

At young age their understanding is still limited and they explain their special needs siblings as following: "And sometimes I think she [my sister] turns into a witch, she doesn't want to be that all the time".

Younger siblings cope with resentment by yelling.

When they don't know anymore how to handle a situation at home screaming at their special needs sibling seems the only possible way.

Age gap doesn't play a role as they are seeking for someone like-minded.

There was an observed bond between the youngest and oldest participating sibling.

„Me-time“ is preferred subject / time at school.

A designated time slot at school that each individual child can design themselves. "Then, I can finally do whatever I want to do."

And sometimes I believe she [my sister] turns into a witch. I just yell at her then.

Emma, 6 years



3.1.2 Field trip with siblings

Session set-up



Meet siblings from the age of 6 to 14 on a two day field trip, that is organized by a professional sibling expert. Learn about their values, experiences and future dreams by actively observing, listening and asking them questions and possibly some generative drawing or writing activities.



2 days / weekend, organized by a German organisation with focus on siblings. locations: train rides, playground, hostel, group room, museums



1 Sibling expert (ethical steward), 2 student researchers (incl. project researcher), 7 siblings and 2 friends (6 - 14 years).



Observation as most valuable tool, participating in conversations, possibility to ask detail questions and generative activities. Common reflections between facilitator and student researchers.



- Limiting / overlapping roles
- Misleading introduction for generative session
- Group in a group behavior



The analysis was done based on memories, notes and collected generative data. Thus, the procedure as proposed by Sanders & Stappers (2012) was followed by creating statement cards and clustering the insights into interpreted topics.

Detailed description in Appendix A



Insights

The insights gained during the weekend range from explicit to mainly observative knowledge, but also touches the tacit knowledge level and uncovers hidden values. Following the insights in a nutshell, more detailed results are listed in Appendix A.

Siblings appreciate the justice attention of an adult

Some were searching more for the attention of an adult than others. However, there were several indications that siblings don't feel the same equal "special" treatment.

Siblings experience boredom in a negative way

It is unclear if they were seeking for constant entertainment, more active activities or simply didn't know what to do with their free time.

Siblings value a relaxed and peaceful environment

The appreciation of quiet moments without fights and other background sounds was clearly mentioned. ("I would love to sleep a bit longer, but then my sister always makes noise in the morning.")

Siblings are very sensitive to other people's needs

The role of the young carer position became sometimes very visible, as they recognized others' needs easily.

Siblings are self-organizing, independent and adaptable in nature

Siblings showed many patterns of independent behavior, they were well organizing themselves as a group and on an individual level (e.g. preparing the beds, cleaning the breakfast desk without complaints).

Are you tired?
Or hungry? You
look very tired.

Tizi, 6 years



Differences in experiences and characteristics for being the younger or older sibling

The younger siblings showed much more social skills and seemed more adaptable to the situation, whereas the older siblings showed more self-sufficient characteristics.

weniger schule
↳ Hausaufgaben
↳ teste

Siblings value quality time with their siblings

Both, other siblings and special needs siblings were mentioned as playmates.

dann hätte ich mehr Zeit für meine Schwester und sage ihr nich dass ich keine Zeit habe. weil Den ich bin nach der Schule etwas genevft von den ganzen Aufgaben

Siblings are open to diverse and social play and ages

They were accepting and including everyone into play from the first moment. The age didn't play a role in any case.



Friends appreciate undisturbed playtime with siblings

More privacy with their friends without having the special needs siblings joining all the time was clearly stated by one friend.

Wenn ich bei ~~Freunde~~ bin dann man nicht immer alleine spielen. Vielleicht könntest du ein Gerät bauen womit sich die Behinderten Kinder beschäftigen können.

Friends take in a very important role

The best friends are aware of the situation at home and know well that their friend, the sibling, suffers from the situation.

Es wäre schön, wenn meine Klassenkameraden aufhören dumme Sprüche zu machen wie z. B. „Bist du behindert?!“ Sie verstehen gar nicht wie das ist. Deshalb wäre es für mich schön wenn wir in der Schule nähergelegt bekommen, wie das ist. Ohne, dass ich erzählen muss das es auch meine Familie betrifft.

Siblings want to feel understood by their peers

Sometimes siblings feel misunderstood and hurt by classmates and their jokes, as they have a lack of awareness and knowledge of what it actually means being disabled.

Siblings aim for better education to create a general awareness

There is the clear wish to improve the educational contents to feel more included and understood in their situation, rather than different.

First impressions take-away

The very first impression from such an online session and the field trip with siblings was undoubtedly, that siblings are just children. They behave like children, they talk like children, they are overexcited and twirly when going on a trip. **They are simply kids.**

By looking closer into the details following details became more clear:

- » ***They seek for me-time, time to relax and chill. However, many of them didn't yet know how to deal with the feeling of boredom.***
- » ***They are very attentive and sensitive to other people's needs.***
- » ***They seek adult attention.***

Another, very important learning was regarding the age group. From 6 to 12 years it is a huge developmental step. And dependently they have a different understanding of the disease, but also different coping mechanisms from yelling to being cooperative and social or withdrawn. Such matches with the literature insights by Möller et al. (2016) in chapter 2.3.3, which illustrates the developmental understanding.

- » ***However, the age within the groups never played a specific role. Everyone was playing with everyone, but also in the online room the age was nor a barrier.***
- » ***Siblings are clearly seeking for like-minded people to talk to, as they don't feel understood by their classmates.***
- » ***Close friends take on a very important role, as they are aware of the family's circumstances. Friends seem like a partner in crime.***
- » ***Nonetheless, whereas siblings value quality time with their special needs siblings, friends clearly stated that they'd prefer undisturbed playtime.***

The first impressions were only a glimpse into much more to discover. Especially, the relationships and the family dynamics within the family and with friends are important to uncover and find out more about.



Own image

3.2 Expert perspectives

To gain a more deepened understanding about the siblings' situation, experts were interviewed. The sibling experts have different educational backgrounds, but are all experts through their long term experience or special qualification focussing on siblings. In Germany the qualification is provided by *Der Bunter Kreis*, an integrated aftercare model between hospital and outpatient treatment for children and young people suffering from cancer, chronic diseases and seriously ill children and their families. Different suborganizations being part of *Bunter Kreis* were contacted interviewees.

3.2.1 Panel discussion

Session set-up



Meet current sibling experts and people that are interested in creating their own sibling programs through a monthly offered online program, organized by a professional sibling expert. Learn from the knowledge exchange among experts, their recommendations to each other and possibly gain insights through case studies.



1 x 90 minutes, online meeting, organised by German organisation focussed on sibling programs.



1 sibling expert (facilitator), 2 student researchers (including project researcher), 1 remedial teacher (guest)



Freely participating in conversations, actively asking questions

It's only us [my brother and me]
who play together, because
nobody comes to our home.



Lukas, 7 years, brother of two siblings

Insights

→ **The spotlight is still on the disabled child, the sibling has the need to be seen.**

Siblings have the inner mission of not yet growing up. They feel like catching up on their childhood and searching for time for themselves.

Siblings usually believe that they are not entitled to take time for themselves at home.

→ **Family internal rules keep the family functioning in their own way with the risk of crossing personal borders.**

The entire family adapts to the person with special needs and creates new rules according to the situation to make family life peacefully happen.

Some rules are socially critical as they may accept politically incorrect behavior. A common example is the resulting limited privacy for a sibling and their friends.

→ **The danger coming from the disabled child is ignored by families themselves as well as by the society.**

The cases of sexual abuse and violence coming from the disabled child to a sibling are more common than expected.

The family's internal rules and functioning leads to refusing possible weak spots and not recognizing the danger.

3.2.2 Interviews

Session set-up



Meet sibling experts with various backgrounds, but working in the same context (sibling focussed programs) and gain insights on their perspectives and observations when working with siblings.



15 - 17 minutes, phone calls or online meetings



5 sibling experts with different backgrounds (elementary school teacher, nurse, social worker therapist, sibling program specialist)



Semi-structured interviews, question guideline

Question guidelines in Appendix B

Session transcripts in Appendix B1

Insights

Young siblings are not aware of their exceptional state.

Siblings at the age of 6 don't yet have a fully understanding of their special position as a sibling of a brother or sister with special needs. Depending if they are the younger or the older sibling rivalry and jealousy often occur at a young age.

Teen siblings search for like-minded children with similar experiences.

Siblings don't have the need to explain or justify themselves and their families' situation. They feel that their situation is different due to lack of understanding from others and they are urgently searching for other siblings in the same or familiar situation

→ **Younger siblings experience emotional instability when overtaking their older special needs siblings.**

Younger siblings of special needs children are born into such an exceptional family situation and don't know differently. They get emotionally confused, when they are cognitively overtaking their older siblings, which can result in aggression, anger and less focus at school for example. Experienced rivalry between siblings suddenly stops and switches into a worrying and caring role, accompanied by guilt.

Programs adaptable to every child: Less structured and flexible

To offer all children an enjoyable and carefree afternoon, the offered program usually consists of a topic and some activities, but all experts agreed that they intend to adapt the program for each individual and to provide them their space to just be themselves.

Siblings learn social competence on siblings trips

Awareness about their own interactions in social structures is created. Siblings learn that their contributions are sufficient and acceptable for everyone and that not more is demanded from them.

I want to give the children space and the opportunity to feel bored. My hope is that they realize and learn that being themselves is energizing and relaxing.



Katharina, sibling expert

Siblings are of enormously social and cooperative nature.

They are often compared to people with the helper syndrome and withdraw or forget their own needs. Most commonly they choose a social career path.

Siblings represent a positive attitude as coping strategy.

They usually talk positively about their home situation, even though they feel stressed. This indicates a strategy to protect themselves.

Siblings offensively protect their special siblings towards other children.

Siblings are very protective towards their special siblings, especially in public space when other children mock them, which may find expression in arguments or aggressive behavior.

→ **Parents have underlying expectations towards the sibling.**

Parents unconsciously expect certain behaviors from siblings which are common in a parent-child relationship (e.g. taking care of the younger one). However, in special families the family dynamic usually only functions with the help of the siblings. Thus, expectations are on a much more demanding level than in usual parent-child relationships.

Expert take-away

The expert panel discussions and interviews were very insightful and enriching. Especially, following topics stand out the most:

- » ***Younger siblings often encounter the moment of taking over their older sibling with special needs, which may have lead to insecurity. Sometimes end up in aggressive behavior, bad grades or other noticeable problems.***
- » ***Within special needs families the dynamics are different. Sometimes the rules and limitations are adapted to the needs of the child. It can happen that the privacy of the sibling is ignored.***

When a mother tells me
that the care-intensive child
cannot sleep without the
sibling in one bed, then all
alarm bells ring for me.



Katharina, sibling expert

- » ***Parents build up underlying expectations towards the sibling to keep the family running in its own way. Although, they demand much more than in a common parent-child relationship.***
- » ***Sibling programs are only offered only few times per year on fixed dates. Because siblings don't allow themselves to take some time off from home.***

Further, there was a lot of agreement among the experts, that siblings are super social and cooperative characters. Their positive attitude is sometimes a strategy to deal with the situation at home. Therefore, sibling experts want to offer flexible and adaptable programs to find the right offer for every sibling. Also, such programs aim to provide the opportunity to learn social skills and relaxation for the siblings.

3.3 Parent perspectives

During the entire research phase a few encounters with parents took place. Most commonly they were part of an official online meet-up session especially designed for them (not all of them are listed here) or the conversations were part as post interviews of the generative session with siblings.

3.3.1 Online meet-up

Session set-up



Meet parents of children with special needs and their siblings in an monthly offered online program, which is organized by a professional sibling expert. Gain an understanding of the parents' concerns and experiences.



1 x 90 minutes, online, organised by German organisation focussed on sibling programs.



Sibling expert (facilitator, ethical steward), 2 student researchers (including project researcher), 1 parent couple (guests).



An informal place for parents to share their experiences, reflect on their family situation and ask questions to other parents or to the sibling expert. No specific structure given.



Limited to one participating parent couple. However, this constellation helped to gain insights on the siblings' situation from both parents' perspectives and thereby to see how the experience differs between parents.

Can I tell [the other siblings] that she is doing those things and that she is so loud sometimes?



Emma, 6 years

3.3.2 Post-interview generative session with siblings

Session set-up



Meet parents of siblings that already participated in a generative session, in order to get the parents' perspective on the situation at home and to complete the picture of the already gained knowledge by asking detailed questions and listening.



1 x 35 minutes, in person, at a German organisation



Project researcher (facilitator), 1 mother of 4 children (participant).



A semi structured post interview with parents only after the generative session conducted with children (see 3.4 *Sibling perspectives*).



Limited to one participating parent only. Located in connection room where other people were passing by and interrupting the conversational atmosphere. This made the space less private and thus, less safe to talk about personal experiences.

Session transcript in Appendix C1

Picture by T. Mossholder

Insights

The insights from the encounters with parents (online meetings and post-interviews) are both summarized here:

Parents have the urgent need to talk to other parents of special needs children.

The present parents were clearly missing out on other parents to exchange experiences, strategies and perspectives with.

Parents need to encourage the sibling to talk about the special needs with others.

There were many questions from the child before the online session. For the siblings it seems far from normal to feel entitled talking about their siblings' disease.

Parents split up family-time in order to maintain peace among siblings.

As the children do have certain interests, the parents try to split up their time and spend time with each child, rather than

Parents embrace family rituals.

There is still too little and not regular time dedicated to the siblings only. Currently there is only the weekend when the entire family gets together (e.g. church, meals) as there is no time during the week and everyone follows its own schedule.

New routines as a potential to give siblings a voice.

In addition, one parent explained that creating a new routine by literally giving the siblings a voice through a shared and regular activity could already be a good approach.

“It’s much more fun doing something alone with each sibling, rather than doing something together as a family.”

Parent of 2 children

Siblings are not happy about strangers intruding family life.



They don't need more special offers with fries and ice cream, they rather need someone that spends time with them.

Parent of 4 children

Siblings are in need of constant stability and attention by someone

The parent highlighted that siblings don't need more special offers that happen only a couple of times a year with "fries and ice cream", but someone that cares for them and pays them regular attention, which they cannot fulfill right now.

Siblings are unconsciously stressed

Parent was clearly stating that their own stress level is felt by the siblings. And that they can only partly control it. Even though they are trying to talk openly about their children's needs, parents can clearly feel that siblings are very stressed and "shout for attention".

Limited parental capacity to support siblings activities.

Parents don't always have the spontaneous possibilities or mobility to bring their kids to their friend's places. They are also feel uncomfortable asking other parents for support.

Strong bond between siblings.

(Healthy) Siblings spend a lot of time together at home (due to the circumstances), rather than doing something with their friends.

Siblings are not pleased of having an external caregiver who is taking part in familiar routines, e.g. having dinner together.





Picture by T. Mossholder

Parents perspective take-away

From the few interviews with parents, it became clear that they are running out of energy, and that they have similar needs like their children to talk to other parents who experience a similar situation as them. Furthermore, it illustrated that special needs families have their own dynamics and even sacrifice their time together as a family in order to create a pleasant time for everyone.

- ***Siblings are not used to talking to others about the special needs of their siblings. It seems like siblings have developed a strategy and are cautious and withdrawn from a young age when talking about their siblings with special needs.***
- ***Siblings need someone constant in life, who listens, pays attention and does on a regular basis an activity with them, rather than the every now and then offered sibling programs.***
- ***Most families embrace new routines or rituals to literally give siblings a voice, but also to share quality time.***

3.4 Siblings perspectives

The perspectives from siblings directly about their dreams, values and personal experiences growing up alongside a child with special needs were gathered in various interviews, casual conversations and generative sessions.

3.4.1 Interviews with adult siblings

Session set-up



Meet adult siblings in an online interview, in order to learn about their existing social relationships, as well as when being a child and a teenager while growing up with a special needs sibling. Gain an understanding of their perspectives by asking detailed questions and listen to their choice of words, when explaining.



2 x 50 minutes, online



Project researcher (facilitator), 4 adult siblings (participants). 2 males, 2 females, 24 - 32 years, all the older sibling.



Semi structured interviews following the path of expression (Sleeswijk Visser et al., 2005). Participants were asked to share their childhood memories and to connect their relationships on a Miro board.



- Mapping relationships was done by the project researcher herself



Relistening to the audiofiles, creating a transcript, and rephrasing and clustering quotes. The clustering procedure led to the interpreted insights (Sanders & Stappers, 2012).

Insights

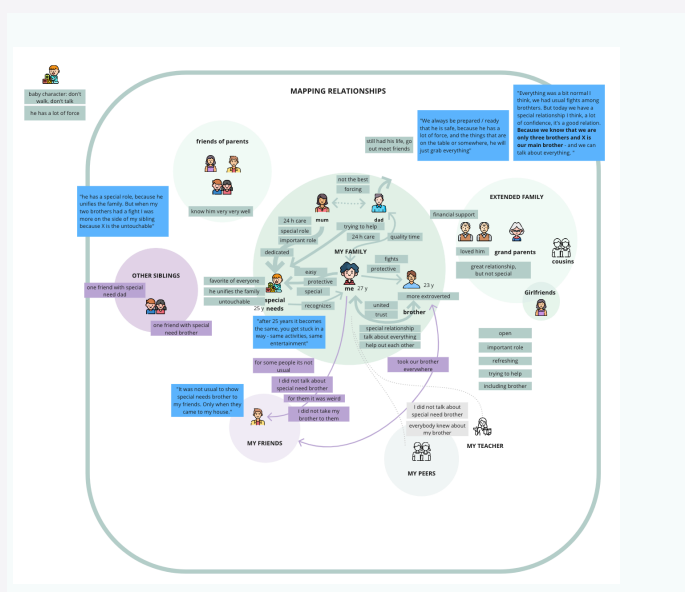
Both siblings called back their childhood and described it as a relatively *normal* situation at home as it was part of their daily life. The relationships to their special needs siblings was most commonly reported as *harmonic, special and normal*. Following the insights are listed which uncover underlying motives. *More details are shown in the Appendix C.*



Everything was a bit normal I think, we had our usual fights among brothers, but that was it.

Henry, 24 years

- Close friends are like family members and show understanding.
- The importance of the engaging behaviour of the siblings's romantic partner.
- Strong connection between (healthy) siblings by having a common special needs sibling.
- Special needs sibling is the center of the family's attention.
- Everyone is unconsciously taking care of the special needs siblings.
- Siblings acceptance of their mothers responsibilities towards the special needs sibling.
- Siblings assessment of unfair experienced treatment like in any other sibling relationship.
- Relationship between sibling and special needs sibling changes over time.





Picture by C. Woods

You always think that your own problems are less important than your sister's, because she is more in need and has a severe disease.



Amber, 27 years

Adult siblings take-away

Siblings experience growing up with a special needs sibling not different or disadvantaged to other families and usually look back quite positive to their childhood. Thus, there will not be searched for the needle in the haystack to uncover severe issues. However, some side effects became clear through various conversations:

➤ ***The siblings have always been unconsciously taking on the role of the caretaker by doing activities that were described as normal to them, e.g. reacting in case of an epileptic shock or always being ready for rough and uncaredful behavior of the special needs sibling.***

More details about the special relationship between the mother and the special needs siblings emerged from the conversations. All participants accepted their mothers' full attention for the special needs sibling as her responsibility in a certain way.

➤ ***The relationship was usually described as a very strong bond. And the mum as the voice of the sibling as she knows his needs the best.***

➤ ***In contrast, close friends and romantic partners played an important role for the siblings. They know the family very well and are part of it.***

And lastly, speaking about the siblings own needs at home was a thing that some of them had to learn in their childhood, as they never saw their own problems as privilege enough to be mentioned.

3.4.2 Other resources

Session set-up



Goal, number of participants and exact setting unknown.



Within a project day of a sibling focussed organization, siblings were asked to imagine a future scenario including their disabled siblings.



- Only selected outcome of the project is shown
- Total amount of letters unknown
- Activity instructions and introduction
- Session goal, number of participants and group dynamic is unknown



Roughly following the procedure as proposed by Sanders & Stappers (2012) by creating statement cards and clustering the insights into interpreted topics.

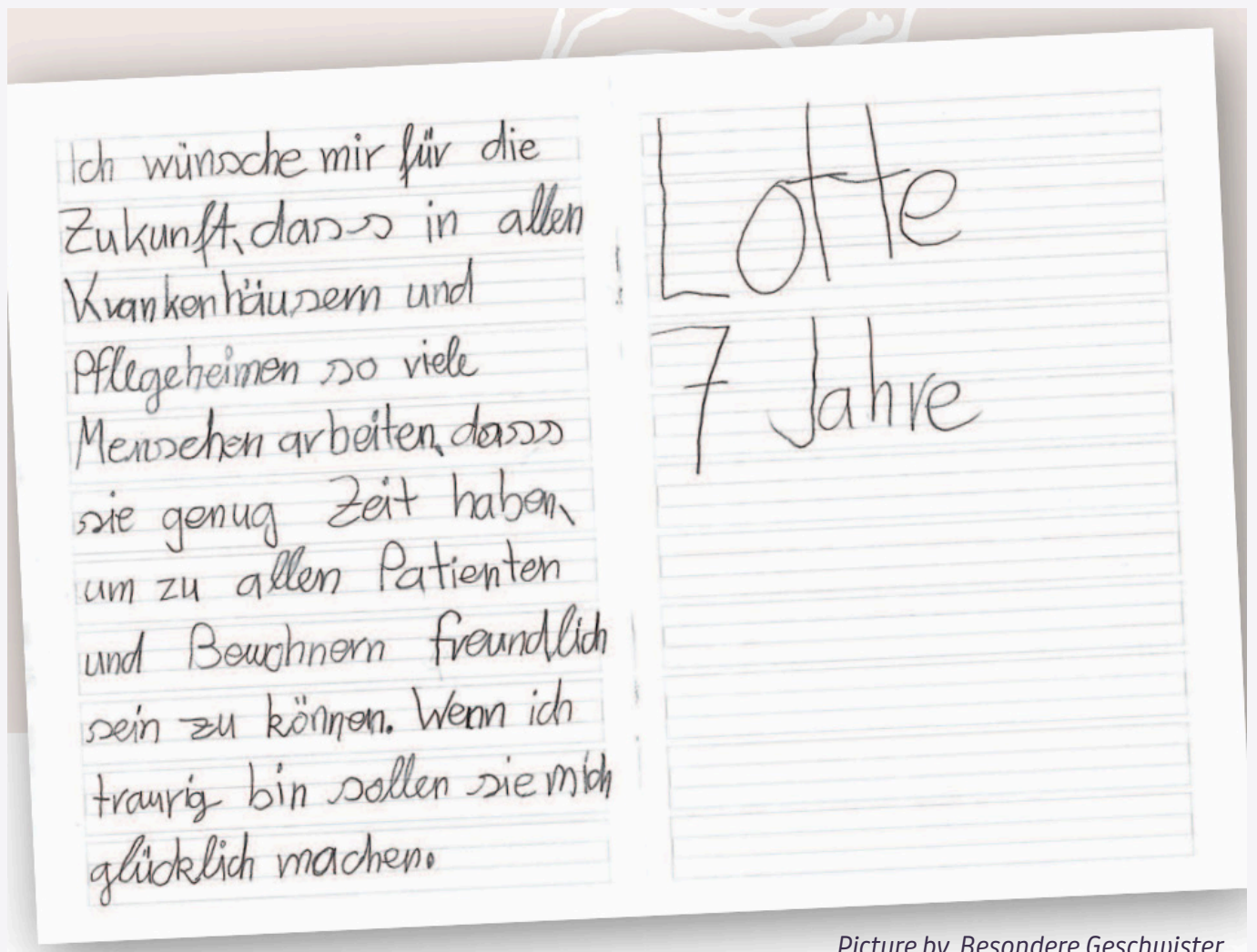
Insights

From the childrens written letters four underlying motives arose that represent some of their possible imaginations for the future. The detailed derivation can be seen in the statement cards in the *Appendix D*.

- *Aiming for financial security*
- *Importance of family wellbeing*
- *Creating deep connections with individual personalities*
- *Changing society towards a more inclusive society*

It needs to be clearly mentioned, that such insights represent the values of the selectors of the letters, rather than the ones of the children themselves. However, the last point concerning the siblings' perspective on society was very prominent. This aspect touches on a quote from a podcast (Brummerloh, 2021) where meanwhile adult siblings are telling about their experiences with ancient classmates and how their view on society changed through their behaviour:

„I couldn't believe that someone would say something like that about my sister, who can't even defend herself. And that definitely changed my view of society and I realized how society saw my sister. That was really difficult for me at the time.”



Picture by Besondere Geschwister

Other resources siblings take-away

~ The solutions proposed by siblings in the selected letters were in such an easy and reasonable way, that this session clearly highlights an urgent wish about societal behavior change among siblings to feel understood.

Include disabled people in movies,
then people will be more used to them.



3.4.3 Generative session

Session set-up



Meet siblings in a creative session, in order to gain information on their perceived experience living with a special needs sibling, their daily life places and activities, and moments they feel (less) empowered.



1 x 120 minutes, in person, at the facilitations of a German organisation, 1 round tables, charis around



1 project researcher (facilitator), 1 sibling expert (co-facilitator, ethical steward), 5 siblings (6 - 9 years) including 2 pairs of siblings, 4 female, 1 male participant. All participants being the younger sibling of a child with special needs.



To uncover people's motivations, dreams and underlying values, context mapping is proposed as a method by Stappers & Sanders (2012). Session plan with 3 activities Data collection with worksheets, 2 voice recorders, 1 camera, observational notes, debriefing facilitator.



- No balance in gender among participants
- Only 1 single sibling of a child with special needs
- No proper briefing of co-facilitator for asking detail questions
- Loss of focus and/ or enthusiasm among participants, what influenced the generated insights
- No successful priming activity with „hero“ story according to the limited participation during the session



Creating and clustering statement cards. Including the observation notes, the transcribed audio file, the parents input and the debriefing (Sanders & Stappers, 2012).

Detailed session set-up and results in Appendix E, transcript in E1.



Insights

Siblings are exhausted by daily activities.

On several occasions, siblings came up with the idea of inventing someone or „something that would do everything“ for them, such as a robot. Everything couldn't be defined so precisely, but they stated that help with their homework or turning on the TV would be already useful. Also, they expressed a desire to be a baby again. This underlines the need to feel cared for and supported in daily life.

Siblings prefer places and activities external from home.

The most mentioned places are the ones connected to their hobbies like the swimming pool, gym, playground.

Siblings distance themselves from special needs sibling and prefer exclusive activities.

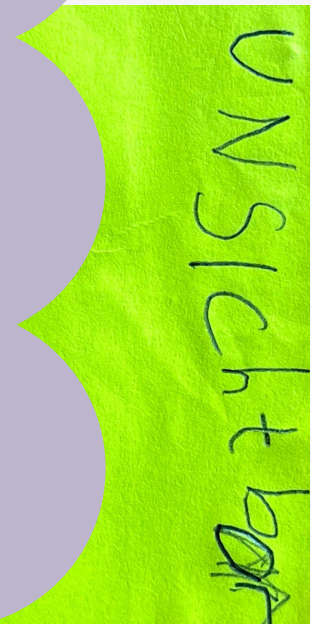
Some siblings cared less about their special needs sibling and seemed rather overwhelmed by the situation at home. The time and attention that is invested to the special needs sibling is sensed as too much and unfair. Direct wishes were mentioned that they'd rather prefer excluding the special needs siblings when going on holiday for example.

Siblings are very honest

The majority of the siblings felt very confident during the session and were clearly stating their opinions about the activity itself, which means they can speak for themselves. But this factor is of course also dependent on their type of personality.

Siblings use fun stories to not talk about real situations at home.

When talking about hero stories with given scenarios, the siblings were actively avoiding the fact of one character being a „helper“ hero and they changed the story into a more ridiculous and enjoyable one.



**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 heru
sprungen.

**Siblings are proud
about their own
achievements.**

Instead of talking about being a superhero in the social context and associating it with social interactions, siblings were mostly narrating stories about their own personal achievements and courage.

**Siblings don't prefer
creating a shared
outcome.**

Siblings were actively avoiding and ignoring the group activity with a shared creative outcome and preferred creating their own mask at the end.

**Siblings search for
peace and silence.**

The annoying and loud (special needs) siblings, not knowing how to chill and the snoezelen room as the place to be. There were indications that siblings sometimes just search for peaceful and silent moments.

**Siblings experience
sensory stimulation as
exciting and relaxing.**

All siblings agreed that the snoezelen room is „the headquarters for heroes“. Reasons were the extraordinary atmosphere, the light and a water bed or a ball pit. There were many indications that they just prefer to relax and enjoy the sensory stimulation.

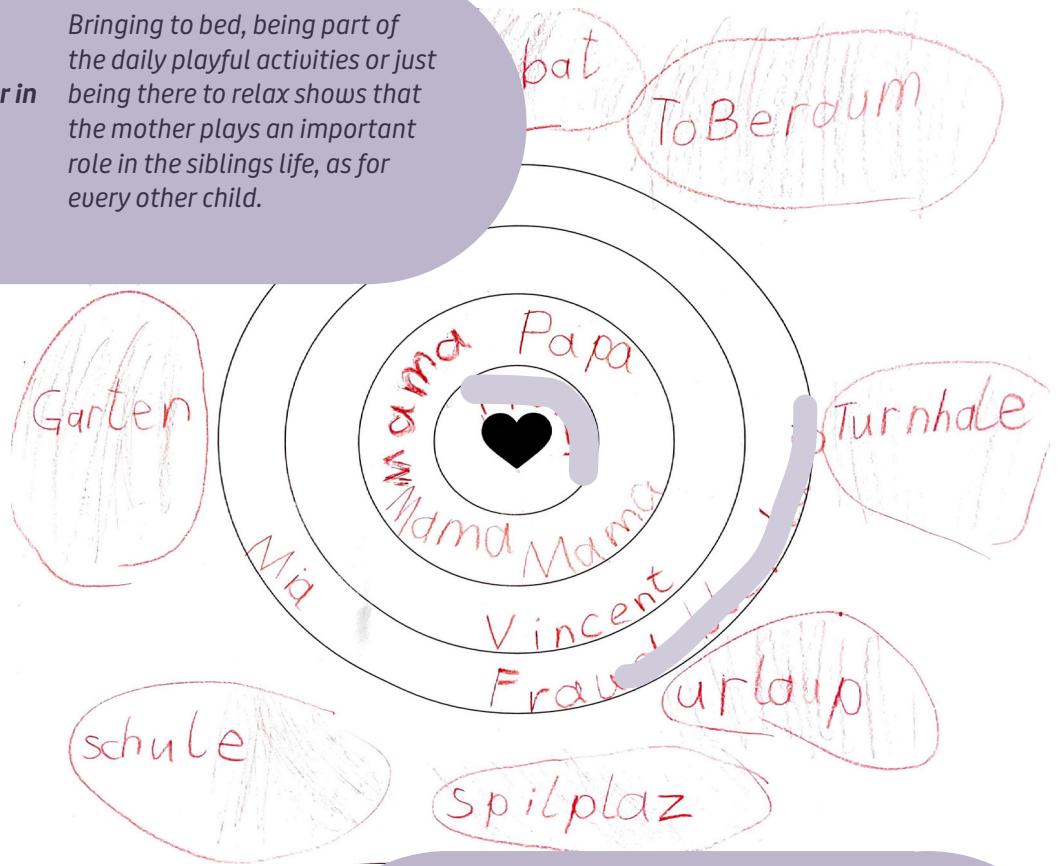
eine Krawlon
roboter

**Siblings enjoy physical
treatment to relax.**

Some ideas around relaxing were combining a sensory stimulation physical treatment like ge or cuddles from mu

Mum being partner in play activities.

Bringing to bed, being part of the daily playful activities or just being there to relax shows that the mother plays an important role in the siblings life, as for every other child.



Siblings share special connection with their other siblings.

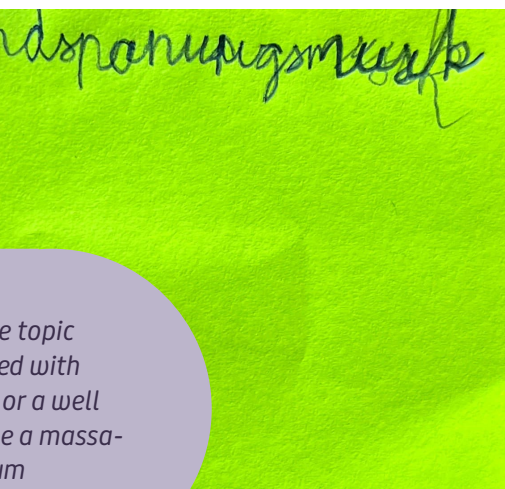
There was a special interaction observed between the sibling couples. For example helping out each other and being very sensitive.

Siblings live rivalry with their other siblings.

Some siblings were clearly unsatisfied and were stating their negative opinions and anger towards their own other siblings with and without special needs.

Siblings make use of personal needs to get what they want.

At one point the children were less excited about the activities and suddenly they were all claiming to be hungry. They did this twice. And it was conspicuous as they just came from breakfast. Thus, it may be assumed that they learned from their family dynamic that putting fundamental needs first gets paid off with attention.



e topic
ed with
or a well
e a massa-
m

Generative session take-away

The generative session with the children went a bit differently than expected, especially when the kids were clearly stating that they felt bored or were avoiding certain activities. However, insights from their tiny interactions among each other resulted and showed how differently children deal with their situation at home.

» ***Some siblings seemed very relaxed and talking in a nice manner about their special needs siblings, others were completely the opposite and fighting for their position at home.***

Resulting from that, it can be said that the personality type of each individual plays an important factor on how the sibling reacts to the given situation at home (see chapter 2.3.2 Internalization and externalization).

Overall, it seemed that siblings preferred activities that took place outside from home and that such are the ones they gain the most energy from, as well as where they are the most proud of. Thereby, also their preferences for design activities became obvious:

» ***It is remarkable that they clearly prefer individual design activities, which, however, correlates with the opinions of previously interviewed experts.***





Summary & Design vision

Part 04

This chapter summarizes all the insights gathered from the previously conducted literature review and various interviews with experts, parents and siblings. It defines the roles as siblings in a special needs family and sets a design vision and goal for the project accordingly.

4.1 Research conclusion

4.1.1 Summary insights

~ Being a sibling in a special needs family differs from being a usual child in a functional family situation.

There are different needs and rules within such a special needs family, which may indicate socially sanctioned behavior (e.g. no privacy) according to the sibling experts. But siblings, especially at young age, don't know differently, due to the lack of touch points and references they have and assume their family dynamic is normal.

~ Moments of privacy and relaxation needed.

It could be observed that many siblings appreciate some me-time to distance themselves a bit from their family situation and to focus on themselves only. Activities outside from home or outdoors are places where they usually get new energy from.

~ Being understood without explaining by like minded siblings in similar situations.

According to the interviewed experts, siblings appreciate those moments when there is no need to explain their extraordinary family situation and they just can be themselves. Even though every sibling experiences a different situation at home, there is no need to explain or justify their special needs siblings behavior. It was also observed that siblings that have another healthy sibling share a very strong bond between each other, as they are both in the same situation.

~ Trustful friendships and other interpersonal connections.

It could be observed that stable friendships were an important indicator for the siblings' resilience and their emotional stability.

~ Siblings take over (too many) responsibilities at home.

Consciously or unconsciously they are in the carer role for their special needs siblings. Depending on the family dynamic and the care intensity of their special needs sibling, siblings take on various roles, such as caretaker, teacher, educator, translator, friend or play mate. Some roles have the effect that siblings are more in a parent-child position towards their special needs siblings, rather than in sibling-sibling relationships. This leads to the effect that parents automatically build up underlying expectations towards the siblings responsibilities.

~ Siblings in special needs families obtain too little attention from their parents.

Either because parents don't have the resources and energy or because they don't feel entitled to ask for their parents attention. Siblings believe that their personal problems are always less important than their special needs siblings' problems, as their own problems can be resolved, but not the disease or disability, thus they suppress their own needs and don't dare to ask for attention (cf. adult sibling interview, expert interview). As observed in the field study, minor interactions for the good of the special needs siblings are perceived as an unequal treatment (e.g. special needs siblings getting stickers during hospital visit). Furthermore, the lack of parental attention leads to a greater need for stability and a constant reference person to rely on (cf. expert interview, parent interview).

~ Younger siblings experience an emotionally unstable transition phase when overtaking their older special needs siblings.

This means, when younger siblings realize that they are getting cognitively older than their older special needs siblings, they often experience feelings like guilt, shame, insecurity or other internal conflicts. Siblings in such positions often need support and reassurance being allowed to keep growing.

~ Siblings are very social and cooperative in nature when being within a group.

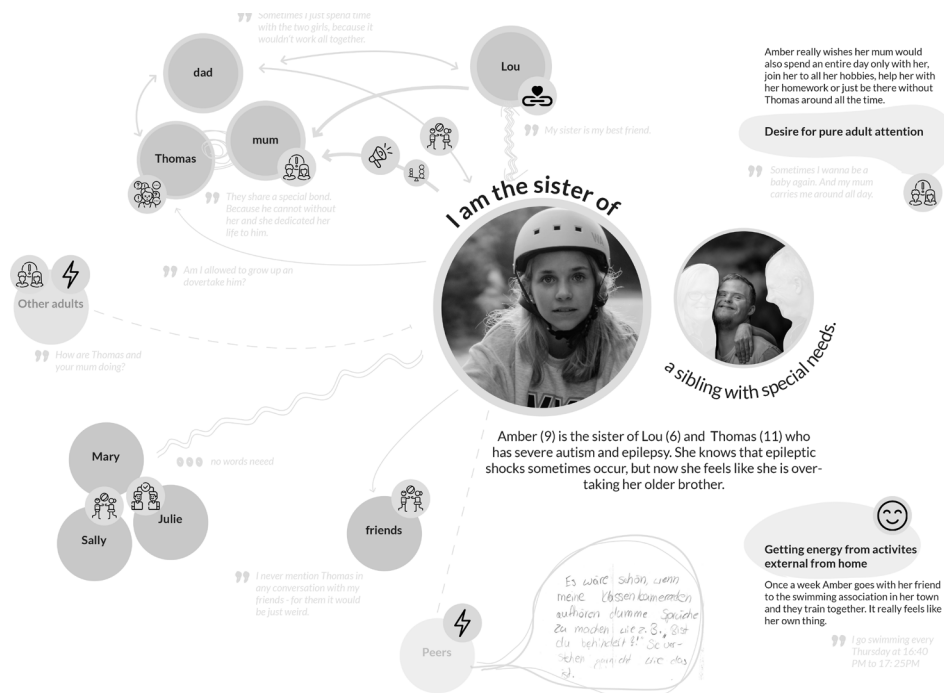
They are usually attentive and adaptable to various group behaviors. Most commonly they even chose a more social career path. It is also be said that they are very resilient and independent characters.

~ Siblings love their special needs siblings and accept them being different and that they may require more attention at home.

It needs to be said that they sometimes don't know differently. However, they don't agree when other children mock their special siblings and they become very protective towards their special needs siblings.

4.1.2 Resulting core values

Every child experiences a different childhood and so does every sibling with their special needs brother or sister. Following the insights from the generative research, but also literature research are summarized in two very opposite profiles (figure #7). The girls Amber and Mary are coincidentally in a similar situation. They both have an older brother with autism and epilepsy. However, both experience their situation completely differently. While Mary seems much happier than Amber and shows her endless love for Johnny in various caring activities, sometimes Amber just wishes Thomas wasn't here. Next to being two entirely different personalities, there are many reasons behind why Amber's and Mary's situations differ. Nonetheless, they both share the same values.



#7 Presenting two siblings, Amber (left page) and Mary (right page) experiencing a similar situation but perceiving it differently. Profiles can be found in Appendix F for a better overview.

» **Feeling understood**

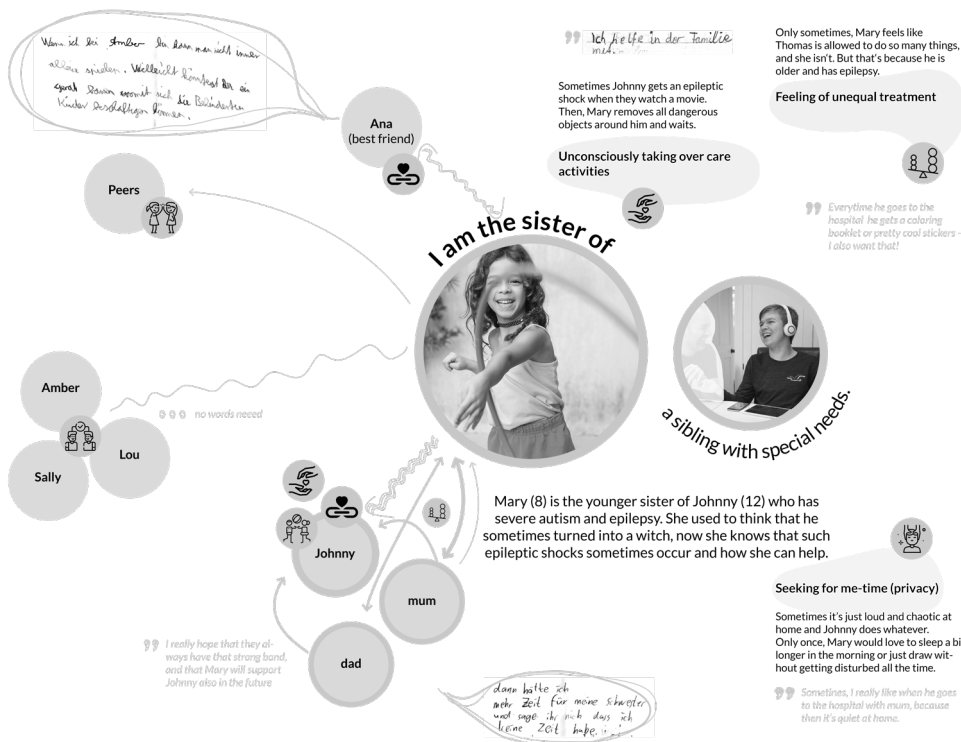
Amber and Mary want to feel understood by other people. They don't like questions, funny imitations of their classmates or those uncomfortable glances people sometimes give them when they see their brother. No one can relate to their situation and will never be able to know how it actually feels for them.

» **Need for adult attention and feeling cared for**

Amber and Mary both want their parents' attention, they only have their own way of expressing it. Amber requests it more proactively by being very honest and direct and sometimes not being very nice to both her siblings. While Mary tries to be more calm, represses her own wishes and tries to express gratitude to her parents and taking care of Johnny.

» **Just being themselves**

Amber and Mary both wish to have these moments only for themselves. While Amber gets her positive energy from external activities outside home, Mary prefers to recharge her energy by having some private time.



These identified core values overlap with the programme theories identified by Marquis et al. (2022) in their review of the content of programmes offered to siblings („I am not alone“, „I have needs too“, „I need my parents' attention“ and „I need a break“).



4.1.3 Conclusion

This research has shown that siblings encounter, due to their extraordinary family dynamics, a lack of their fundamental needs like emotional stability, confirmation, recognition, personal growth or even relatedness (cf. Desmet & Fokkinga, 2020). Those needs are represented in the identified core needs.

Depending on the severity of the special needs and the resulting care intensity (Bramlett et al., 2009; NHS, 2021), the parental expectations (Pavlopoulou et al., 2022), but also the family constellation, like being the only sibling or having another sibling, as well as the siblings personality type (cf. generative session with siblings) influences the siblings' well-being and perception of their own situation, as well as their reaction to it (Gallo et al, 2012; Di Biasi et al, 2016; Hanvey, 2022). So, there may be siblings that are very committed to their caretaking role and some that are more ignorant, in any case, there is no right or wrong.

However, they all desire a certain understanding from their social environment, but also the needed attention and to just be themselves. Therefore, it can be concluded that especially being a sibling of a child with special needs comes with the challenge of truly feeling and acting like a child (cf. 3.2.2 expert interviews).



Picture by A. Burden



Picture by D. Sansotta

4.2 Ontzorghuis' vision

The Ontzorghuis shares the vision of each individual of being considerate with their own resources and the ability to reflect on their own actions. In this sense, Marise, the founder of the Ontzorghuis, envisions for each of her participants to “feel comfortable with the uncomfortable and even the unknown” and to trust in the overall process that a solution will arise. Hence, resourcefulness emerges as the key value for special needs families and thus, for the offered solutions by the Ontzorghuis. Marises vision aligns with the understanding of resourcefulness in design research, as summarized by Kuijjer et al. (2017) as following:

„Being resourceful is about using the materials (including other people) available in the situation as resources to solve problems or challenges arising from nonstandard situations, i.e. (everyday) situations that are not part of common practice and for which there are neither.“

In the more design visionary context, Marise recognizes resourcefulness in a friend, someone who helps to identify the simple way, rather than the complex way. Also, she envisions resourcefulness as a *smooth process, like a rock in the water*, that helps us to learn fast and be flexible.

„It shouldn't feel like rowing in boat against the stream. It's exhausting. Why would you do it? “

You need to be very resourceful to find all the solutions and opportunities yourself. You are in a different situation than others. You cannot just buy ideas from your neighbors for your family.

Marise, founder of Ontzorghuis



4.3 Design vision

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

4.3.1 Design goal

Design for playful and engaging experiences to support siblings* (age 6 - 12) to assume their role as a child by empowering and facilitating the sibling through interpersonal connections.

» Playful and engaging

- Gamified
- Fun, challenging
- Foster curiosity and imagination

» Transition phase

The moment of overtaking the older special needs sibling, when everything all of a sudden feels unstable and the insecurity about the own personal growth.

» Assume their role as a child

A role is a relationship to other people, which can be:

- A set of expectations from others.
- A set of things you are allowed to do.

A balance between the roles is important in order to claim to be.

» Interpersonal connections

Enhancing the existing relationships, but also offering new opportunities through relationships:

- Get to know other family dynamics
- Get a break from own family life
- Have someone who is listening
- Have someone being responsible

**** Optional if possible: siblings in the transition phase when overtaking their older special needs siblings***

4.3.2 Stories







A sibling's trip almost got canceled due to lack of participation. However, the organizing person still offered to the only participating sibling to let the trip happen. In a short conversation the small boy just said: "This means I have this lady for one day only for myself?" This example shows how much in need of adult commitment and attention the siblings are and the value of interpersonal connections.



Two adult siblings were telling similar experiences when growing up with their special needs sibling. Going to the playground with their special needs siblings always involves unconsciously care taking, that he is doing fine, that he is not just crossing the streets without looking. Similar situations appeared at home, they said, when every family member was constantly aware and cautious that nothing was in the way that could potentially harm their special needs sibling. Such examples show that even though siblings are content with their family situation and didn't see an extra burden in it, that they were constantly assuming the role of a caretaker.

4.3.3 Interaction vision

The desired interaction with my product should feel like being on a guided safari with my family and /or friends and other tourists.

-  **Being inspired by your surrounding**
Whatever you see, you see. It inspires you to keep going. Maybe someone else also sees it and you explore it together.
-  **Being together**
Your best friend is also on board, it doesn't mean that he experiences and sees the same, but you are going through this journey together.
But also the other tourists are just exploring.
-  **Similar perspectives + different perceptions**
Whatever you see, you see from the outside world. It inspires you to keep going. Maybe someone else also sees it and you explore it together.
-  **Expressing wishes**
You are entitled to express your wishes on the journey and to slightly influence the tour.
-  **Not being responsible and being cared for**
Someone else is taking over the responsibility to bring you safely to your destination.
-  **Having trust in the unknown, being resourceful**
You don't know your guide, but you trust his abilities and in what you will discover on your journey.

4.3.4 Desired interaction qualities

- **Exploring**
- **Inspiring**
- **Guiding /caring**
- **Trustful**



Concept exploration

Part 05

This chapter presents the journey of finding the appropriate concept for siblings of children with special needs. It does this by presenting the initial brainstorming sessions with children and experts, and the conducted creative sessions with siblings.

5.1 Brainstorming

5.1.1 Online brainstorming with siblings

Session set-up



Meet siblings in an online session and let them design their own game, in order to determine their preferred playful interactions.



1 x 60 minutes, online, part of monthly event for siblings, hosted by a German organisation



1 project researcher (facilitator), 1 sibling expert (co-facilitator, ethical steward), 3 siblings (6 - 12 years)



Pictures of the initial summer plan as well as rainy pictures were presented, both to introduce the children to a possibly real scenario. Asking participants for their favorite plays and how they reimagine the summer trip with rainy weather. Picture brainstorm to turn the ideas into new playful interactions and as starting point for a new game.



- Girls only participating, no perspective from male siblings
- Screen sharing led to limited children's attention, which resulted in limited participation and distraction.
- No picture brainstorming due to the lack of attention.

Insights

The online session clearly showed different interests per age group: The youngest participant enjoys the most physical activities like play tag and hide and seek, whereas the older ones preferred card games and specific role plays. By thinking of using the local utensils for a play the children came up with the idea of building a castle of pillows, disguising and *telling each other stories*. Furthermore, all participants agreed on creating a puppet theater together, including preparing the scenario and the storyline. Another outstanding conversation topic among the participants was the role of pets and animals, the renarration of their preferred fairytale movies, as well as frequently showing each other old childhood pictures of themselves.

Cuddle toys are cute, but they don't understand you as animals do.

Hanna, 9 years





Picture by M. Steeke

We can just come up with our own puppet theater.
- And we make the dresses and the set-up.



Hanna & Lina, 9 and 12 years

Session take-aways

- Children enjoy the presence of a pet or animal as they feel understood by them.***
- Depending on the age, children prefer more active or passive play. However, all of them liked imaginative stories and role playing.***
- Children enjoy re-narrating fictional stories, as well as reinventing new storylines.***
- Children love sharing their own childhood pictures.***

5.1.2 Online brainstorming with experts

Session set-up



Coming up with possible interactions for the further ideation process by meeting experts from the previous interview sessions. Through brainstorming and discussions together, the values of the experts and their prioritization when it comes to supporting siblings should be determined.



1 x 90 minutes, 1 x 30 minutes (post session), online, shared Miro board, paper.



1 project researcher (facilitator), 3 sibling experts, 2 middle school teachers



Short introduction to the project context and goal. How-to questions (Van Boeijen et al. 2020) as basis to brainstorm on in a set timeframe. Optionally, an ambiguous picture brainstorm (Gielen & Klapwijk, 2020) to create associations. Presenting and discussing collected ideas within the entire group. Final discussion on the resulting elements for a possible design. Post discussion with one of the participating teachers and another teacher.



- Limited access to Miro and resulting individual brainstorming on paper. Thus, no influence and inspiration on each others ideas.
- Brainstorming mainly based on the participants' personal experience and on utility, rather than free thinking about unexpected associations.
- The participants criticized that the design space is way too broad and too difficult to think about, similar to the how-to questions.

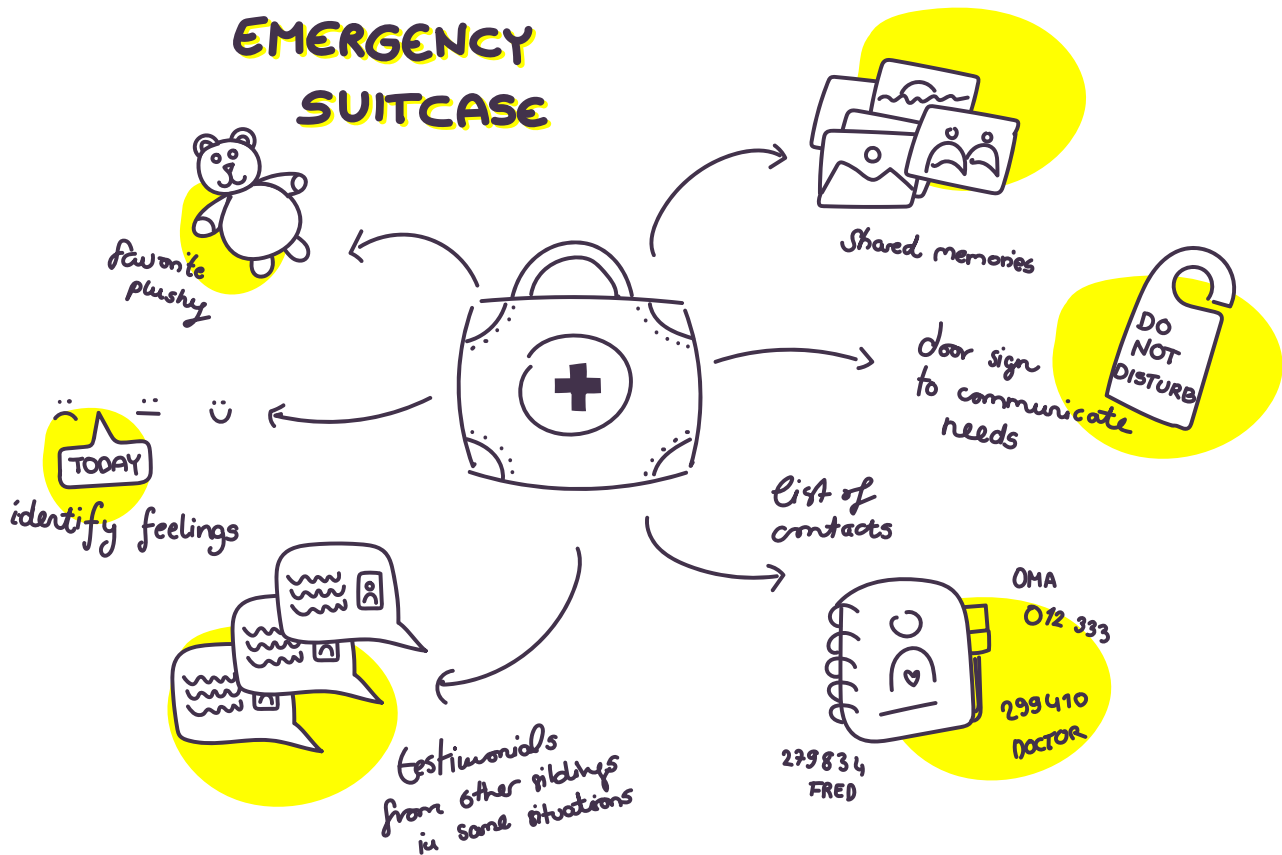
Detailed description and results in Appendix G.

Results

It needs to be mentioned that many ideas are based on current creative methods that are used in ongoing programs for siblings, which are offered by different sibling specialized organizations. However, during the interactive session the main idea of an individually designed suitcase resulted, as well as supporting ideas and topics arose (see Appendix G).

Emergency suitcase: Exploring personal needs and learning to express them, with the visual support of a mood barometer and a door sign. Receiving comfort by shared experiences and strategies in visual and audio testimonials. An emergency contact and further contacts to provide stability and information on how to behave in an emergency situation.

Intention: Every sibling is in a different situation and experiences living with a special needs sibling differently, therefore they also have various needs. Varying utensils are necessary that may reassure or stabilize one in not feeling alone, or to feel encouraged and safe talking to someone.



Session take-away

Even though the session went differently than expected, in the sense that the developed ideas were mainly based on existing solutions, following values could be identified as main takeaways for the further ideation process:

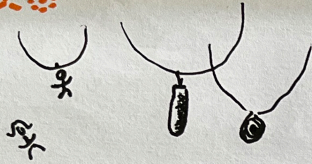
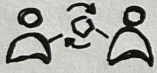
- ~ **Customizable outcomes**
 = **personalizable and adaptable to each sibling**
- ~ **Having a tool to identify and communicate own personal needs**
 = **reflective and communicative**
- ~ **Being provided with information**
 = **informative**
- ~ **Creating a safety network**
 = **connected**

Such represent two strong design directions:

- **A reflective tool to identify and communicate needs**
- **A design to create or strengthen a network around the sibling**



HEATING ARTWORK BY CHANGING QUESTIONS / insights / strategies



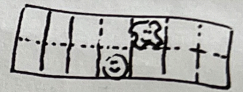
MUT-MACHER KETTE

- carrying messages (empowerments)
- modelling own character
- switching with a friend



MAKE-A-WISH CALENDAR

- kid writes down every morning (draws) their wish of the day
- ⊖ disappointment at the end of the day



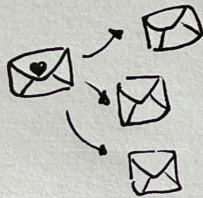
ACTIVITY-CARD

- stamp card with activities defined by parents & kids
- parents give stickers when completed
- ⊕ quality time
- ⊖ limited / time to buy



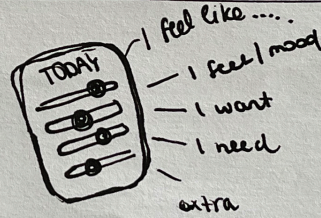
MUSIC VOICES

everyone can speak message on it
 everyone can listen to it
 if shared to let others speak on it
 my tips & tricks are here



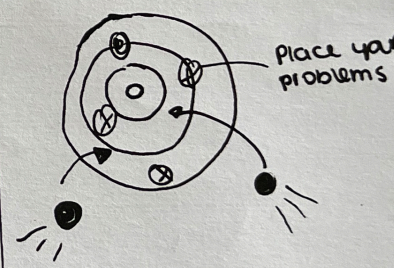
KETTENBRIEFE

A. creating a story together (many stories) enough weekly letters, let 5 more people participate (expand network)
 - siblings only? siblings & friends?

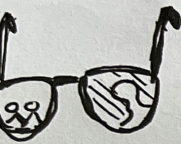


MOOD & ACTIVITY BOARD (MOOD REGULATOR)

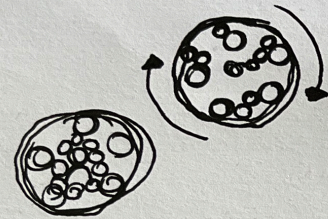
- as a small routine: everyday the child's mood, needs & wishes will be set



- TROUBLE SHOOTER
- The things that annoy me the most as a sibling will be written on a card & pinned on the board
- with balloons problems will be
- ⊖ no solution for my problem

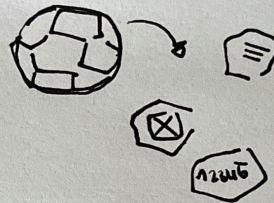


shared perspectives
 how your insights / emotions are for the day through lenses: colors, shapes, DIY perspective



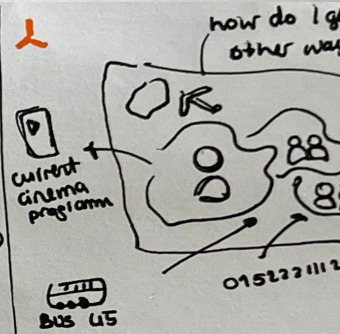
KALEIDOSCOPE (DIY)

→ share insights: plans of the day / wishes



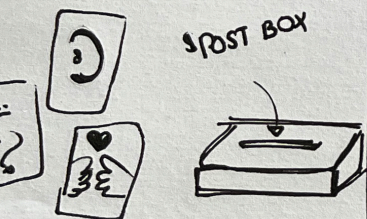
EMERGENCY - BALL

- presents pictures
- phone numbers / addresses
- other stories + strategies
- voice memos



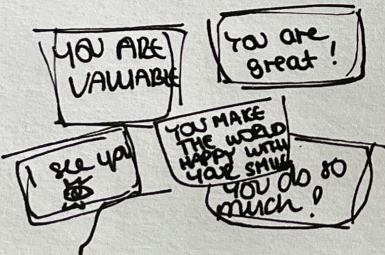
SIBLINGS WORLD MAP

- let them create / paint their own map
- add pictures, letters,
- ⊕ like context-mapping



POST-CARDS

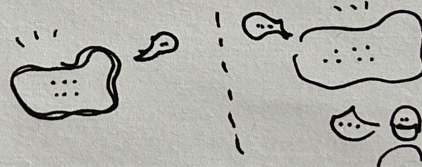
fill in premade cards and send them to family internal box
 are very explicit:



POSTCARDS

- premade cards with affirmations for siblings only
- parents-sibling
- family-sibling
- the right praise as parents tend to say things

SOCIAL (CONNECTIONS) ?



TALKING-TALKIE

- kid speaks in box how it feels & sends this message
- other kids receive that message & send back positive words

PLAYFUL

5.2 Emerging concepts

Set-up



Making use of the ideas and values from the previous brainstorming with experts (Chapter 5.1.2) and translating the identified design directions into specific design concepts for siblings.



A mixture of brainwriting and mindmapping as a method (Van Boeijen et al. 2020). Starting points were the two design directions (1. reflective, 2. creating a network), as well as the adjectives derived from the envisioned design goal and interaction qualities: playful, engaging, supporting, facilitating, empowering, social.

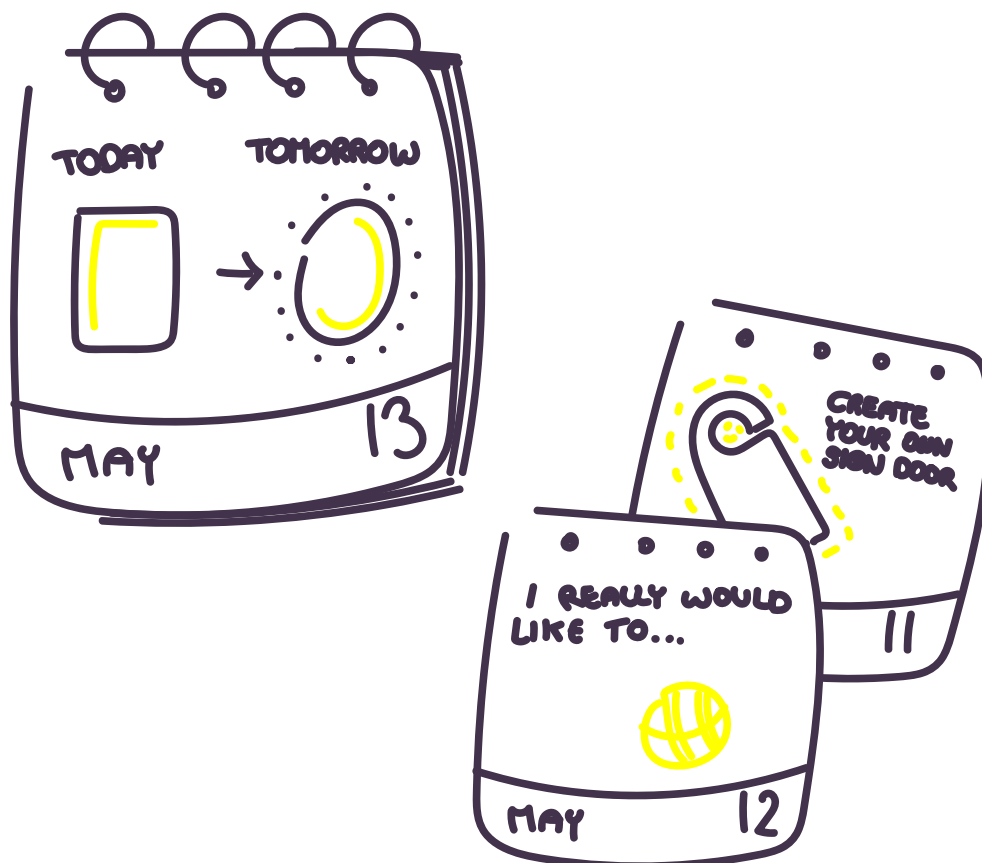
Results

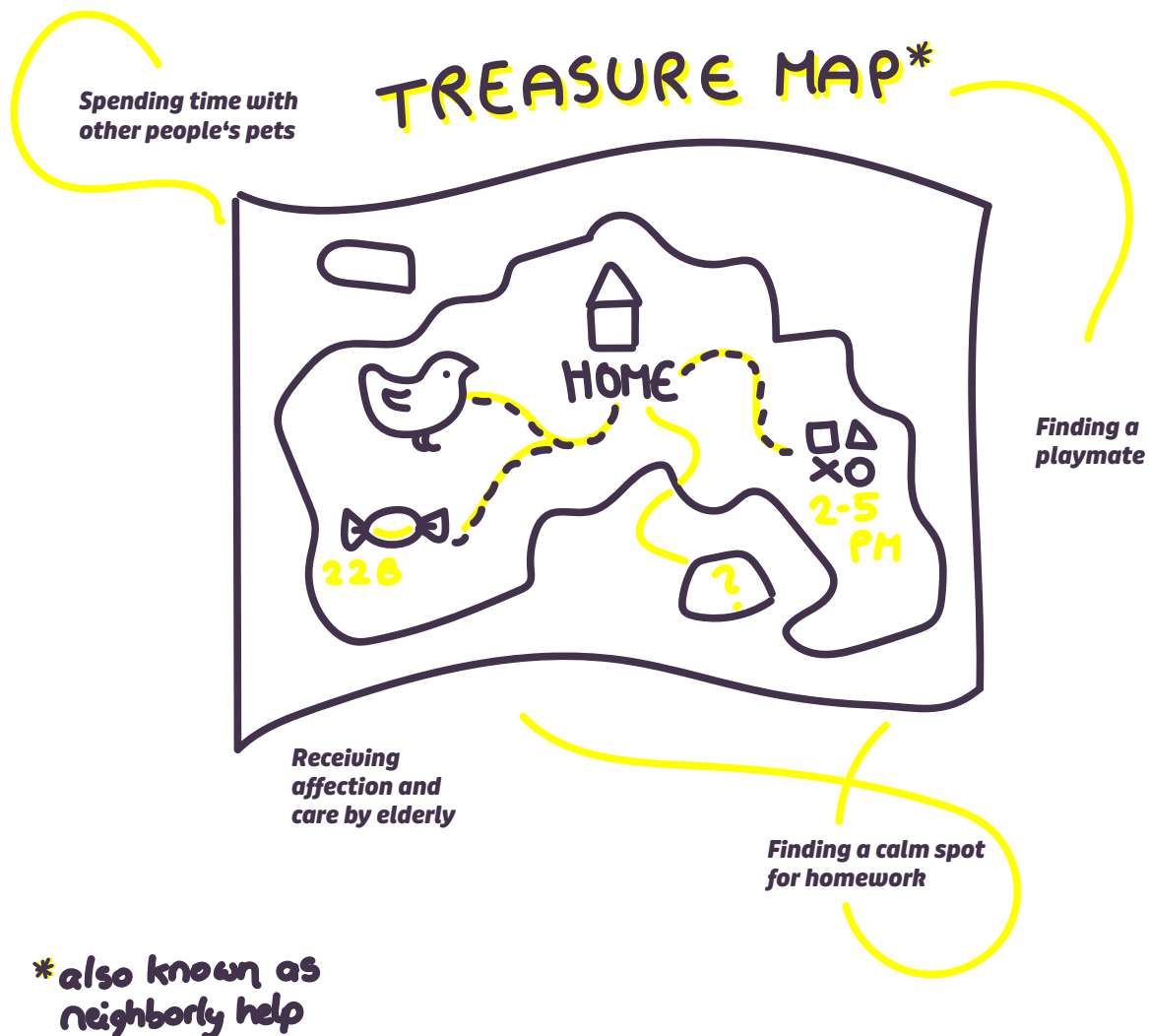
From the personal brainstorm session one concept for each design direction was developed: daily calendar activities and a treasure map. The calendar activity is the chosen concept, as the activities provide the opportunity to test out various intended interactions that are supporting, facilitating and empowering, within one. Also, it aims to find out if the idea of an emergency kit is the right direction. The treasure map was chosen to identify possible networking contact points for the siblings, which include playful, engaging and facilitating interactions. Both concepts are presented on the following pages.

Idea 01: Calendar activities

The calendar activities represent the reflective direction. Every day provides a different activity or tool to invite the sibling to identify or communicate their needs to their family members. Presenting it as a family calendar, accessible and visible for all family members, aims to create a spotlight on the sibling. Moreover, the calendar itself supports the siblings' mindfulness about its own wellbeing and serves similar to a mood diary as a mindful reviewing tool. The incorporated reflective activities in the calendar are translated from the emergency kit.

More details about the content of the activities and the targeted points from the desing goal can be found in Appendix H.





Idea 02: Treasure map

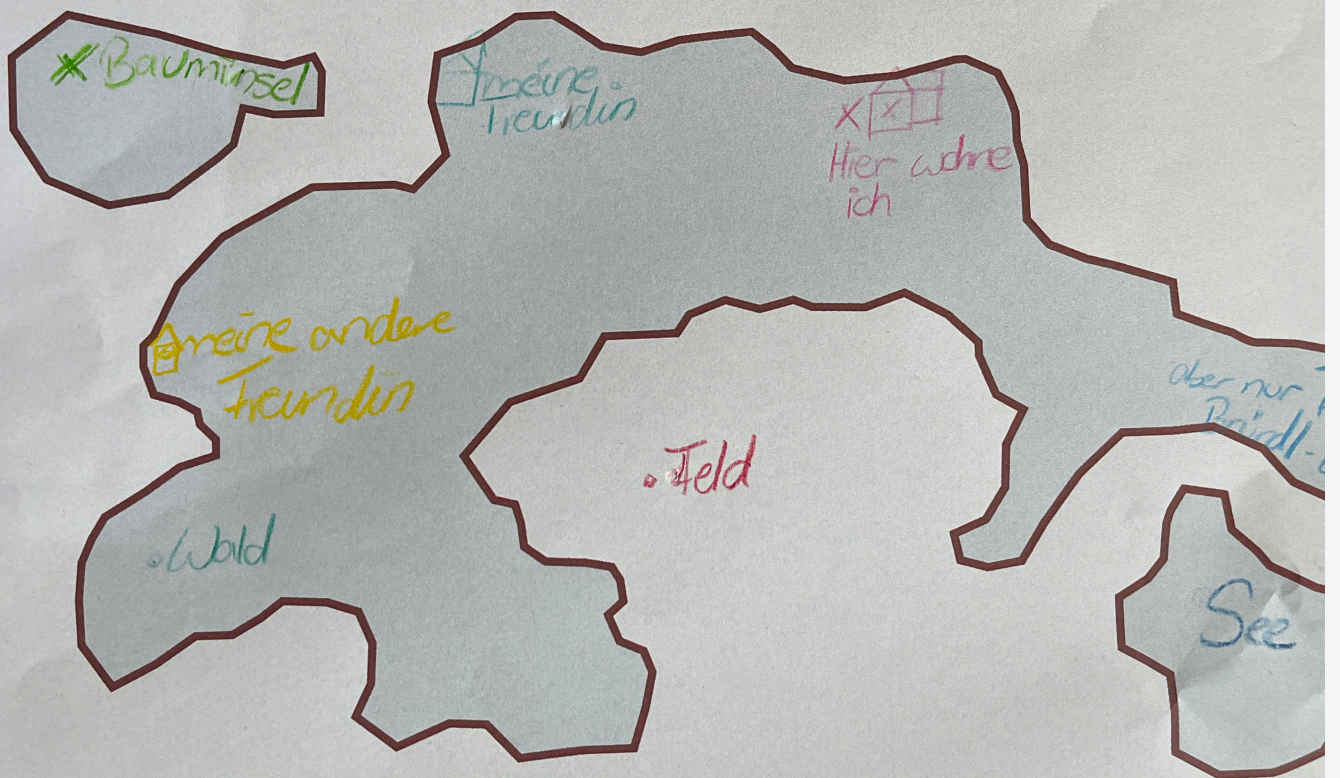
The concept of the treasure map is based on the traditional unpaid neighborly help within a neighborhood or housing community to support elderly in their daily life (Schlüter, 2023). Similarly, the concept aims to open up resourceful opportunities for siblings to rest and retreat within their neighborhood. With their own physical treasure map, which is their personalized map of their neighborhood, they are invited to spend time elsewhere, to discover resourceful places and to create new connections. The concept is based on a service design approach that includes the active initiative of external actors, like neighbors and/ or institutions, to make them noticeable and approachable for siblings. With every valuable place or connection they discovered for themselves, the map changes through additional drawings or stickers. Furthermore, the treasure map also includes space for creating own memories by adding pictures or drawing and maintaining connections by adding phone numbers.

MEINE SCHATZKARTE



MEINE SCHATZKARTE

x Karte



5.3 Concept testing with siblings

Session set-up



Meet siblings at the age from 6 to 12 in person, in order to get feedback on the two concept directions (communication, network support). Based on the gained insights one direction can be chosen.



2 x 45 minutes, in person, at the facilitations of a German siblings organisation, sitting on yoga mats in a circle



1 project researcher (facilitator), 1 psychology student (co-facilitator, ethical steward), 7 siblings (9 - 15 years), balance between male (3) and female (4) participants, 1 withdrew her participation

Activity 1

- Reviewing individually the calendar prototype.
- Discussing in groups the calendar activities with given question cards.
- Exchange thoughts and evaluating the idea with the entire group.



Activity 2

- Walking around and discovering the environment (the room) by providing them with prompts (short stories) and stickers (visualization).
- Creating own individual treasure map with the given stickers.
- Feedback round on likes, dislikes and opportunities.



- An average age range of 12 years may influence the results as this is the outermost range of the intended target group. Older children are way more reflective than younger ones.
- Load of energy among participants, which resulted in being restless and less motivation, in order to do more active activities/ plays.



Creating and clustering statement cards. Including the observation notes, the transcribed audio file, the parents input and the debriefing (Sanders & Stappers, 2012).

Details can be found in Appendix I and transcripts in I1.

I want to keep it [my needs] to myself because I don't want other people to think that they have to do something or worry because I am not feeling that good or so.



Esther, 14 years

Insights

Based on the session transcript and the first data collection, insights were already gathered. Additional statement cards were created to support the data overview and not missing out important information in the analysis. Following insights were gained:

The future / imaginative activities are the favorites

There was definitely a trend towards the short, but creative and reflective doing-activities.

Reflection as additional methods, but not as the main trigger.

Most of them stated that they would keep the calendar rather as a journal and private reflection tool. Some would use it only occasionally, others daily.

I just don't have the time to do such things every day.



Leni, 12 years



Sharing insights only when parental commitment required

Siblings would not like to share their personal needs with their parents and rather keep the calendar private, than using it for communicating. Except there would be an additional purpose with the parents included.

Positive effect of hidden testimonials

Mostly, all were positively surprised about the extra information source and read it carefully. However, none of them would look up shared experiences online.

**Digitalized world vs.
real world**

There is a difference in age: older siblings imagined a virtual world and product, younger ones related more to nature. Younger ones were also more likely to add animals to their maps.

**Awareness of
resourceful places**

Siblings seemed open to discover new places, however they always referred to their already familiar environment and places they like to spend time.

**Awareness of own
needs**

Siblings showed a well established network with people they always can refer to, rather than making new connections. They know where, when and how to get to family and friends.



When you read that others feel the same way , you feel more understood and you feel that your problems aren't that big.



Esther, 14 years

Take-away concept exploration

From such exploration phase with various stakeholders many insights were gained. In a nutshell it can be said that experts suggested following key elements for a design:

- ~w **Personlizable and adaptable to each**
- ~w **Reflective and communicative on own needs**
- ~w **Informative**
- ~w **Connected to a safety network**

From the siblings perspective it needs to be highlighted that the reflective activities were seen as nice, but not as very exciting or impressive. They were mentioning that they *usually don't have the time* to do such on a daily basis, however tiny, but specific activities e.g. let them think about a person they would like to be or creating a door sign, were more attractive. Another important learning was that siblings still want to decide themselves if and what they want to communicate about their well being to their parents. Lastly, an existing network around the siblings could be observed, thus, it was very difficult to introduce them to new possible connections and activities.

I think it's a really cool
easter egg [testimonial].
There is extra information
given and you don't feel that
alone and not like the only
sibling with such an opinion.

Sven, 15 years





***Concept
direction***

Part 06

This chapter aims to select one design direction and to iterate on it. Therefore, it starts with a reflection on the design process and the gathered information upon now. From that, the actual design vision and further research questions are formed. Besides, it resulted in a further developed concept and a final brainstorm session with designers to detail such out.

- ***How to be a child without reflecting what it means to be a child?***

6.1 Systematizing and reflecting information

Based on the previous sessions no clear direction towards being reflective, nor creating a network emerged. There were some positive responses for each concept, such as the preference for single reflective activities (e.g. the door sign, mirror activity) or individually creating and selecting their neighborhood. And negative ones regarding the frequency and continuity of the calendar activities or the unwillingness to discover other places as proposed within the treasure map concept.

However, the reflective direction was slightly in contradiction to the observed sibling behavior which became clear in the previous session again: siblings have the need to play and just be themselves, without constantly thinking and/or talking about their special position. Thus, the proposed reflective design direction seems contradicting to the design goal itself, which clearly aims to support siblings in taking on their role as a child. Subsequently, following research question arose:

How to be a child without thinking what it means to be a child?

Guiding research question for the conceptualization phase.

With that research question new design opportunities, like discovering triggers that evoke the feeling of being a child, and challenges, such as a clear definition of being a child, came across. A recent study by Bacon & O’riordan (2023) found out that “play was an important aspect” for mainly preschoolers (30 %), and “going to school as a defining characteristic of childhood”. Additionally, the authors discovered that “having responsibilities” was another definition by youths to “to distance themselves from being a ‘child.’” Furthermore, Adams (2013) identified ‘restrictions’ as frustrating symbols of childhood, which were in some cases also positively associated with being cared for by adults. Thus, the vision of being a child in the context of this thesis became more specific and defined by being carefree as a sibling of a child with special needs.



Picture by P. Prudente

How does it feel to be carefree?

Deriving research question in order to feel like a child.

Being carefree

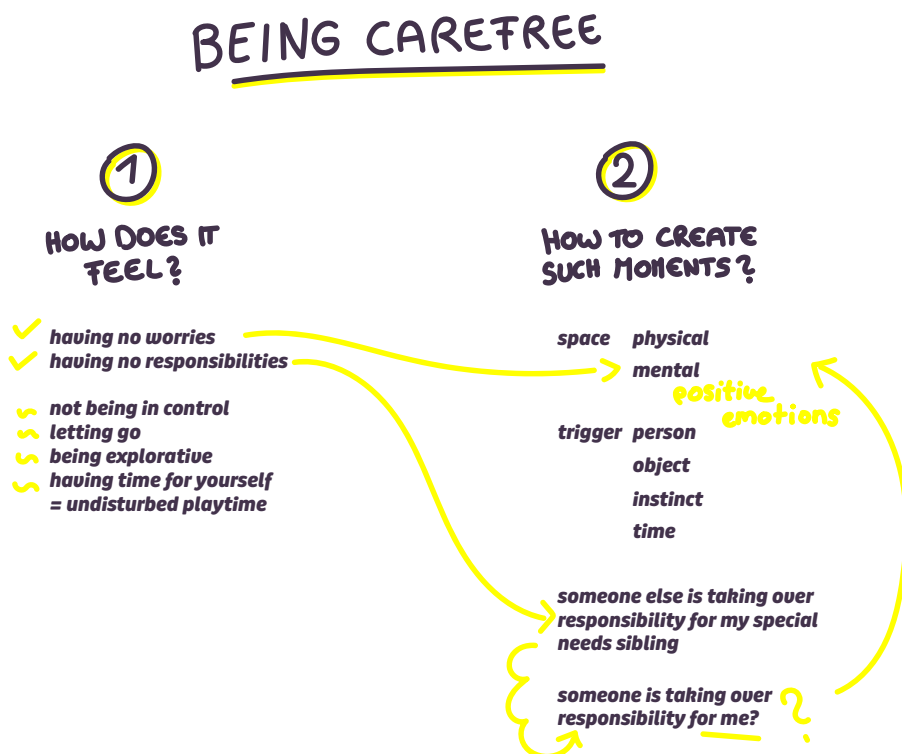
Marise reported from one of her weekend retreats for special needs families, that professional caretakers were taking care of all children that joined that weekend. She mentioned that at one point the caretaker sent the siblings to play, rather than having an eye on their special needs siblings. By the end of that playtime, the siblings came to the caretaker being grateful and thankful for the undisturbed playtime they had. Marise highlighted again that in special needs families the parents split up their responsibilities of caretaking for the special needs child among them and the siblings. In this case the siblings needed this moment and the permission „*Okay, you are free*“ to go playing and to be able to feel free.

From this new perspective as a starting point the idea of creating a toolkit with personalized triggers for carefree moments emerged. The idea of the proposed *emergency suitcase* was now considered a *freedom suitcase* with following questions to explore:

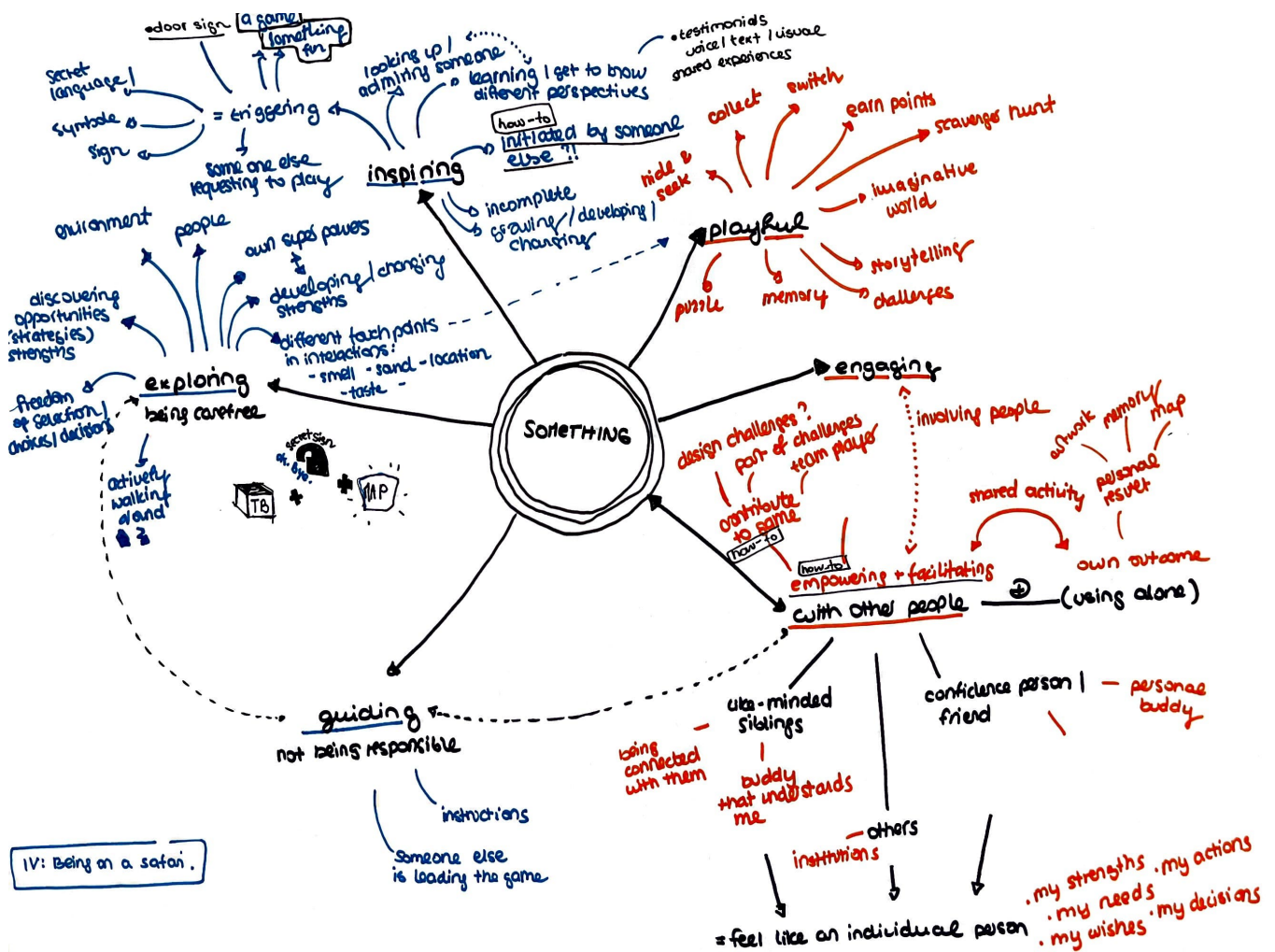
How to create carefree moments for siblings at home?

Guiding research questions

From a personal brainstorming and research on such questions the answer on feeling carefree was associated with not being responsible for somebody or something (compare Oxford Learner's dictionaries). Preliminary, it was concluded that such moments can be created if someone else takes over responsibility for you, which also confirms again the importance of having an established network. For that reason, 'guiding' became an important element of the future design interaction qualities and the reflective design approach didn't seem purposeful anymore.



#8 Reflecting on the meaning of being carefree



#9 Reflecting on the meaning of each interaction quality

On top of that, all previously conducted activities from the workshops were reviewed and reflected on, in order to identify 'carefree' elements. Especially outstanding were the solo activities and personalized outcomes as preferred ones, as well as the positive effect of storytelling on children and the more explorative activities. Concluding from this reflection, 'inspiring' and 'exploring' became an inherent part of the interaction qualities.

Besides that, the design goal was explored in more detail (figure #9), from which resulted in the idea of including gamified elements to the existing networking concept, in order to achieve a playful experience. The assumption emerged that playful experiences with others can also be triggered through play. Based on this statement, the idea of transforming the concept of the treasure map into a game arose. The power of play and games are highlighted in the following subchapter.

6.2 Emerging concept

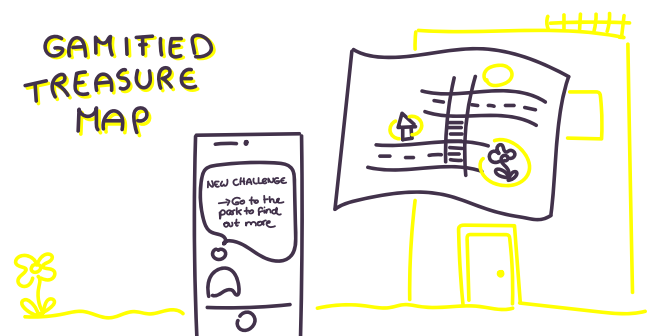
Idea 03: Gamified treasure map

The concept is an iteration of concept 02, but more specifically designed as a game for mainly siblings, but also involving their close environment and strengthening their social network. There is a potential of combining digital and physical elements. The idea is slightly referring to the augmented reality game Pokémon Go, which makes people actually go to different places in order to earn points and unravel new challenges with other (physically present) players in their virtual world. With the aim to provide siblings a playful game experience, they should be sent with the gamified treasure map to explore their neighborhood by creating new connections, discovering resourceful places and sharing and gaining valuable information. Again, the neighbors are taking an active role in the offered system. With the help of a personalized (virtual) game character, the siblings shall be empowered to discover and fulfill their own needs. A physical treasure map shall be used for individualization and memory collection. Friends and neighbors shall be strongly involved in tiny challenges to facilitate social support. However, the interactions are not yet entirely defined and are left open for exploration.

Scientific evidence

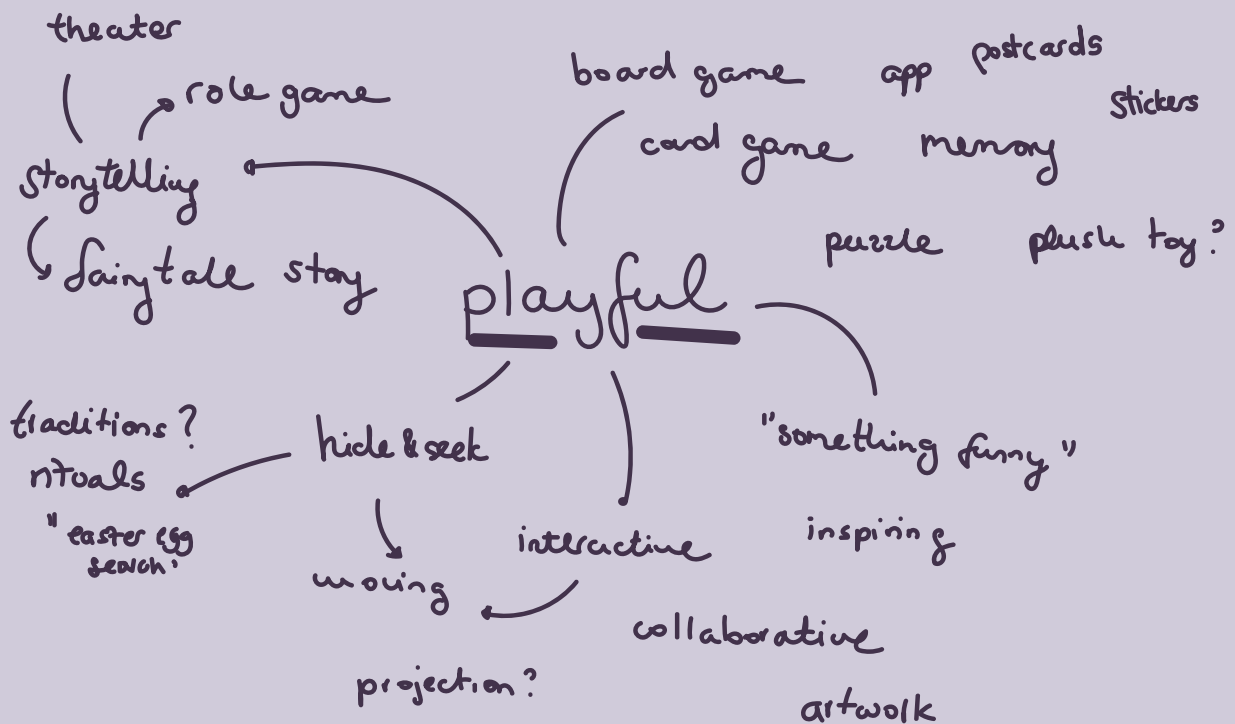
A study by Militello et al. (2018) concluded that the game Pokémon Go application facilitates amongst other things social well-being for children and families, whereas Chong et al. (2018) showed in a survey that the game was also "positively associated with [...] friendship formation, and friendship intensification", similar to Finco (2019) assuming the social support though this specific game. Thus, such interactive games that include communal challenges and social meet-ups have a positive effect on interpersonal connections.

But also the principle of a scavenger hunt has proven its worth in different studies (Wesp & Baumann, 2012; Zajac et al., 2021). By actively engaging two different target groups with elements of the culture, both, hosts and visiting students, could be sensitized for cultural self-awareness (Wesp & Baumann, 2012). It is an "efficient and enjoyable" option to engage and immerse individuals in a new culture (Zajac et al., 2021)



CHALLENGES:

- answer personal questions
- find sth you have in common
- learn from each other



Power of play

Playing is an important part of the development of young individuals and influences their cognitive, physical, social and emotional skills (nidirect government services, 2022; Ginsburg, 2007). According to Li (2022) play has a positive effect on the physical and mental condition of young individuals.

Play encourages the ability to control impulses and emotions, and allows them to bond with adults and other children (Li, 2022). Furthermore, according to Ginsburg (2007) children not only create, but explore (challenging) worlds through play that they are able to master themselves. They do so by "conquering their fears while practicing adult roles" (Ginsburg, 2007) and they are encouraged to explore their feelings and to express their needs (Ginsburg, 2007; nidirect government services, 2022).

6.3 Brainstorming

6.3.1 Brainstorming with designers

Session set-up



Brainstorm with fellow design students in order to come up with playful elements for the context of networking and exploring the neighborhood. The goal is to have a list of valuable interaction possibilities for the previous concept *Gamified treasure map*.



1 x 75 minutes, in person, Industrial Design Engineering (IDE) faculty at TU Delft, private meeting room



1 project researcher (facilitator), 4 master design students from IDE, 3 are focused on product design, 1 on interaction design, 2 have expertise in designing with children.



Short poster presentation as introduction to the topic. A brainstorm round of 2.5 minutes to 9 how-to questions (Delft Design Guide, p. 175). Each participant started with one question per paper and moved to the next paper when the time ran off. Thus, iteration on the previous ideas was possible. A final discussion on the opportunities.



- All participants were new to the topic (children with special needs). However, it is assumed that they have the relevant competences and transferable skills from their own experiences.
- The how-to questions were too broad and open, rather than being very focussed on the concept.

Session materials and results in Appendix J.

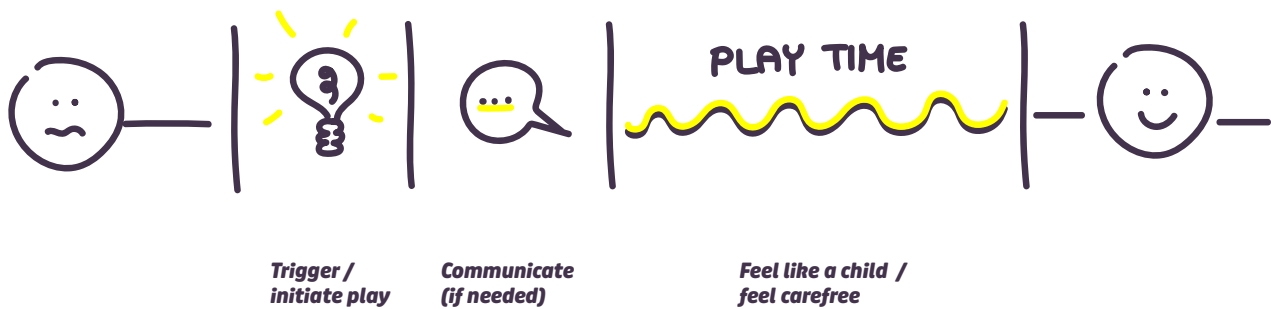
Take-aways

The results from the session lead to valuable options on how to create the initial idea of connection with people and places in the neighborhood more playful. However, the discussion was more reflective and questioned the playful approach in order to achieve a playful experience. They argued that being playful is the result of being triggered in order to achieve such experience. And that playfulness can be triggered through almost everything, and especially fantasy.



For that reason, the main takeaway from the session was the timeline as shown in figure #10, which clearly distincts between the initiating trigger to play and the playtime itself.

According to the designers the two elements shall be better treated separately, in order to achieve the envisioned playful experience.



#10 From the desinger brainstorm sesion resulting play timeline

6.3.2 Individual brainstorming

Session set-up



The goal of the individual brainstorming is to come up with an iteration of the previous concept (gamified treasure map) and / or with alternative ideas, which match better the design goal.



Using mindmapping (Van Boeijen et al. 2020) as a method by immediately visualizing the ideas. The previously defined timeline (figure #10) helps as a starting point to come up with different concepts for each play phase.

Results

From the personal brainstorm session one concept for each play time was developed. The mix-and-match booklet as a triggering element and sending letters as the one targeting play (see following pages).

O



b

t e r

I have...

super-long arms



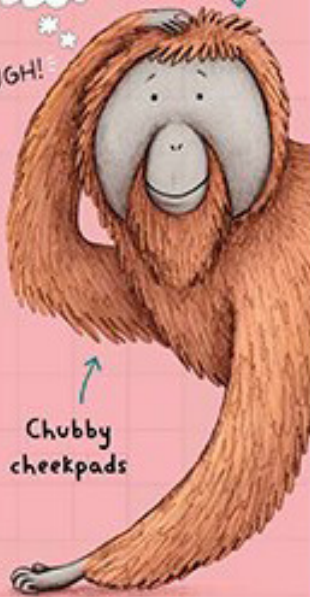
a colour-free body

a big, bushy tail



Smart brain

UGH!



Chubby cheekpads

Human-like hands

Unique, stripey coat



Pot belly (full of grass!)

Shaggy hair



Hairy legs

Picture by early years direct

6.4 Further concepts

Idea 04: Mix-and-match booklet

The idea of the mix-and-match booklet is to present the child a range of opportunities for different situations, but in an adaptable and personalizable way. By providing the same gap filling text on every page and making the lines on different paper cuts, the storyline is interchangeable (see picture on the left). Thus, the booklet is a collection of personal stories, emotions and solutions of the child and presents them in a playful way.

The stories can be created by the child itself, or filled in by a confidential person of the child, including pictures, personal notes and phone numbers. In this way, it is actually a concept of the freedom suitcase as proposed in a previous chapter already (chapter 5.1.2).

Template of the gap filling text

- Today I feel extremely ...
- For that reason, I want my ... who loves ...
- to go with me to ...
- And to do following activity: ...
- Hopefully, they he / she doesn't forget ...
- Because then we can do ...
- And I'll bring ... to ...
- After that, I will feel much more ...



Scientific evidence

A study from Zhang et al. (2020) has shown that such folding interactions in a booklet may even provoke "positive emotions in line with their expectations." The authors also identified such interactions of changing the story as the most attractive for pre-schoolers (5 to 6 years old).

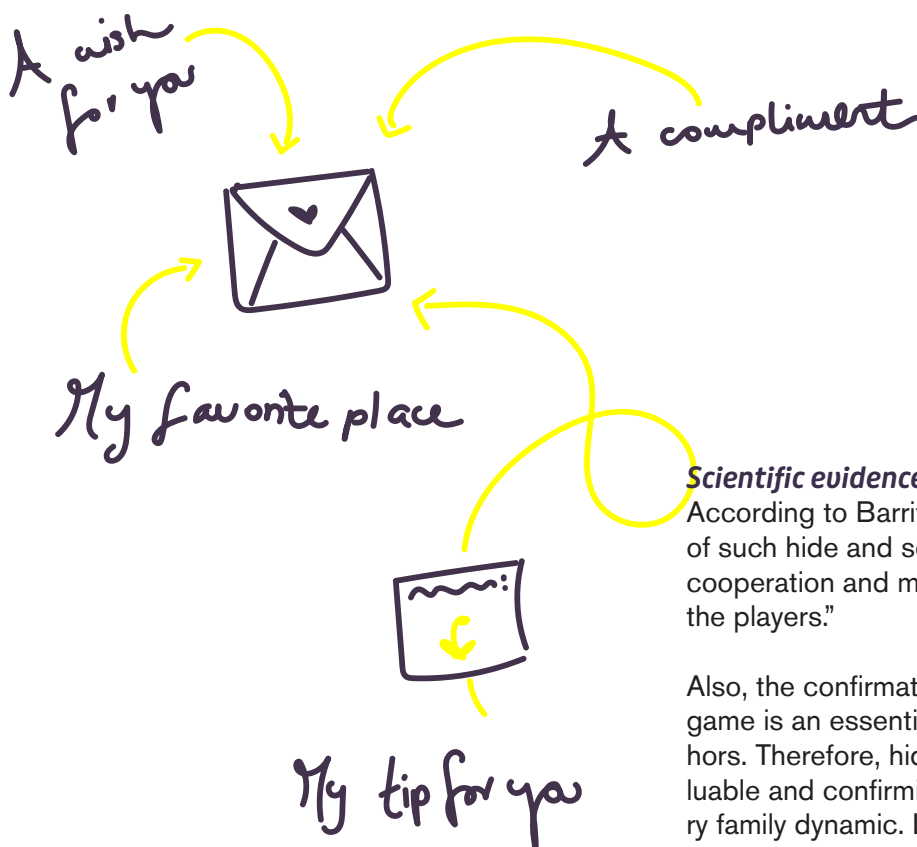
From personal experience and observations, it can also be said that children even at a higher age enjoyed the interactions with such booklets.

For that reason, it seems like a nice opportunity to trigger siblings in a playful way.

Idea 05: Sending anonymous letters

The fifth concept focussing on the play phase involves typical, but simple play principles of hide and seek. By reflecting on previous activities, it became clear that children actually just want to play. The game hide and seek was very popular during the previous session with the siblings. Therefore, the concept is based on the idea of writing anonymous, but affirming letters to each other and to hide them in a given context (at home or at the workshop location). Given prompts on the letter templates may inspire the authors to write a message. The authors will hide the letters, search other ones, reply to them and hide them again for the next finder. Optionally, the finder can also choose to keep a letter. As the messages are all written anonymously they can address every participant, and everyone will find their personal message that touches them the most.

The goals of the game are similar to concept 04 enhancing interpersonal connections when feeling alone and discovering opportunities by sharing. An additional factor is, that concept 05 aims to invite the siblings to share insights, as much as they prefer to communicate in a playful manner.



Scientific evidence

According to Barritt et al. (1983), the positive effect of such hide and seek games and peekaboo, “lies in cooperation and mutual support given one another by the players.”

Also, the confirmation of being seen by playing the game is an essential element according to the authors. Therefore, hiding and seeking seems very valuable and confirming for siblings in their extraordinary family dynamic. Lastly, the same authors found out that the game is “played to play, not to win”, which again is an important factor for the target group to let them experience justice and equality.



Picture by B. Voros

“The essence of the game is to catch with your eyes. To know you are caught is to see yourself being seen, and eye contact is a tension filled event.”

Barrit et al. (1983)

6.5 Concept testing with siblings

Session set-up



Testing two concept directions in order to further identify triggers for personal inspiration and opportunities for siblings to assume their role as a child.



1 x 90 minutes, 1x 30 minutes in person, at the facilitations of a German siblings organisation, indoors / round table and outdoors/ forest glade.



1 project researcher (facilitator), 2 sibling experts (co-facilitators, ethical stewards), 1 childcare intern, 5 siblings (8 - 11 years), 1 pair of siblings

Activity 1

- Individually filling in the gap filling text of the story template.
- A copy of each original was created to provide everyone with everyone's storyline.
- Thinkering process: cutting and tacking the papers into a booklet.



Activity 2

- Individually writing personal, but anonymous messages for someone else, without targeting someone specifically.
- Hiding the letters close by in the nature.
- Playing hide and seek in three slightly different versions (seek and read a letter, seek and write back to it, seek, read and keep a letter)
- Giving feedback.



- Limited to female participants only, thus the perception of male same-aged siblings is entirely missing.
- Relatively shy characters, which resulted in very little feedback during the first activity.



Results gained from both activities were taken from observations and the general discussions within the group. Statement cards were also created in this process to ensure all data is included.

The is analysis in Appendix K and the transcripts in K1.

Insights mix-and-match booklet

Difficulties in the making process itself

The given paper prototype wasn't that user friendly in the making process (too thin lines, too many papers to cut), which made it a burden to entirely enjoy the process.

Challenging gap filling text

The gap filling text wasn't that intuitive at first glance and many participants had difficulties to start with.

Inviting storyline

However, the storyline invited siblings to share their personal experiences and need, as the filled in gaps were based on real encounters.

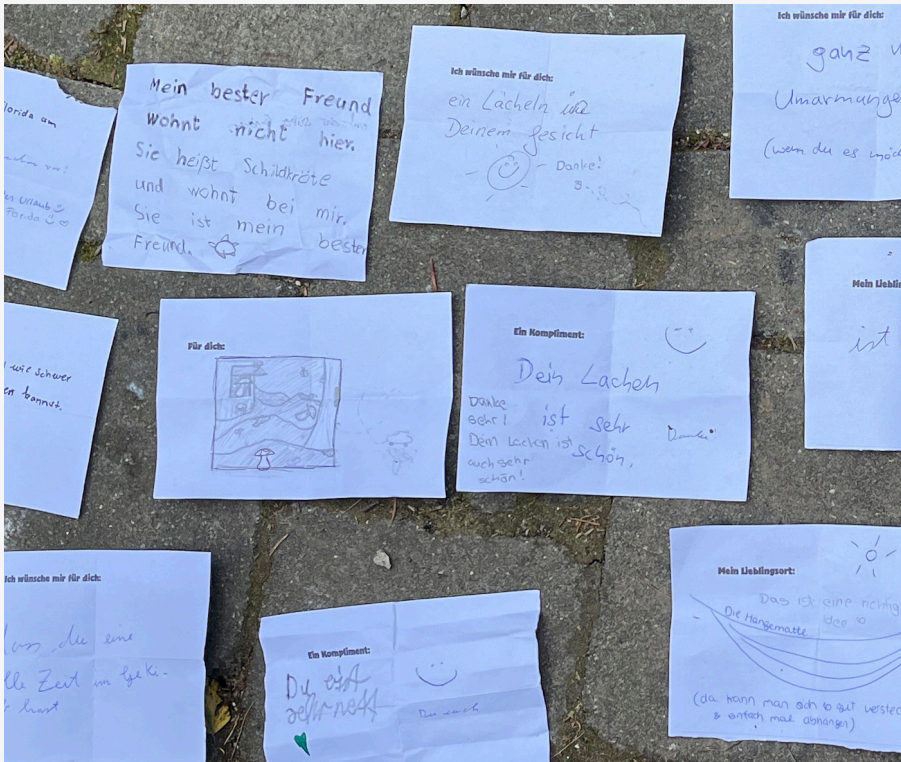
Being proud of personalized outcomes

Everyone was open to provide her personal story for copying. Overall, they were enthusiastic about the result and enjoyed reading out loud different stories to each other.

I think it's cool, because you can try out many different combinations and no one has ever the same story and that's why it's cool.



Klara, 11 years



Insights secret letters

Challenge to start writing with the given prompts

The open questions were a bit difficult to start with, however it was not a severe problem as soon as they got into it.

Starting excitement with writing letters

Children became more and more comfortable with writing anonymous letters and the curiosity increased with hiding the letters. Everyone wrote more than one letter in the end.

Anonymous letters perceived as personal message

The secret messages triggered curiosity and were treated as a secret. They seemed personally inspiring, as they wanted to keep the found letters.

Replying as additional curiosity factor

Replying felt like a nice gesture and also provided them with the good feeling that they got a nice response back, which triggered additional curiosity. However, replying was not always easy and especially the younger ones just copied responses.



It's a little bit like an advent calendar, each time you get a new surprise, what is nice.

Alissa, 9 years

Session take-away

The children stated that they like the idea of the mix-and-match booklet, however further details could not be identified. Storytelling worked as a nice trigger to start reflecting about personal needs. Similar to a previous workshop they didn't want to have a shared outcome, rather their own.

➤➤ ***And they seemed very proud hearing part of their own stories mixed up in other stories when they were reading their stories out loud to each other.***

➤➤ ***The way the siblings interacted with their final booklet (careful, carrying it the whole day around, packing it for home) was another indication that they liked it.***

To conclude, the mix-and-match booklet seemed inviting to play with. However, it cannot be stated that the activity is inspiring or triggering for the siblings in the intended way.

In contrast, the second activity felt immediately like a success, as the children showed much more enthusiastic facial expressions while participating. Even though the beginning was a bit challenging for them to start with, it seemed that the freedom in selecting their prompt helped them and resulted in a very personal written letter. The excitement was kept during the entire activity, although the steps were kind of repeating. Resulting from that it can be interpreted that the participants enjoyed the hide and seek part, but also the idea of having a shared secret. This was also confirmed by their positive feedback and their shown curiosity after each step.

➤➤ ***The anonymously written letters were perceived as personal messages for almost everyone, and inspired them to write more letters or to follow the given personal advice in the message.***

➤➤ ***Treating a message as a secret and sharing a secret with others makes the siblings feel special, although everyone knows the secret already.***

The replying part to the anonymously written letter was definitely an additional factor that triggered their curiosity, but also their urge of knowledge if someone replied to them. However, it could be observed that some didn't know what to write back and were mainly copying an already existing response. The concept 05 definitely covered parts of the design goal in being playful, explorative and inspiring and fitted perfectly the siblings needs, as confirmed by the sibling experts. Contrary to their preliminary expectations, the second activity proved to be the much more effective and valuable method.

It feels like a shared secret, that we are all knowing.

Noa, 10 years



The first activity still has a lot of improvement necessary regarding simplifying the production, but I can see it as a very valuable product for siblings.

The second activity however, is much more fitting for them [...] This is exactly tailored to their needs and they really, really enjoyed it.

Markus, sibling expert



Take-away concept direction

From this chapter it derived that being a child involves the feeling of being carefree and not bearing any responsibilities. Furthermore, the design vision for the siblings to assume their role as a child at home crystallized and the envisioned interaction qualities were supplemented to *inspiring, guiding and exploring* in this phase. A playful concept involving neighborly connections was developed and carefully withdrawn in order to iterate and design a trigger for playful experiences, rather than focussing on the playful experience itself.

- » ***However, within the concept of sending letters it could be shown that the basic principles of the children's game hide and seek are powerful and playful interactions in order to transfer messages and personal secrets.***
- » ***It also showed that affirmations are one possible solution to reach the siblings' core values.***

I would like to adopt the workshop to our sibling program, because it was so valuable for the siblings to do this activity and to share such insights and affirmations.



Stefanie, sibling expert



Concept elements & iteration

Part 07

This chapter summarizes the found concept elements which derived in the previous section and investigates the topic of ownership in the context of a siblings. For further validation and improvement of the concept building blocks, the ideas and experiences were shared and discussed with experts, such as a specialized researcher on siblings, as well as tested within different contexts. Furthermore, it was from the researcher's interest to find out the criteria for a safe space in a familiar environment.

7.1 Concept elements

The goal at this stage of the project was to design a workshop for Ontzorghuis, as it worked out in the previous session. Therefore, a structure for the workshop will be developed on the first level. It needs to be elaborated how directed it is and how much freedom will be given in such a workshop. On a large view, a list of variations will be created.

However, in discussion with Ontzorghuis following research question arose, which influenced the next steps of the research:

How to bring the affirmations home?

How to create a safe environment at home?

Design research questions for the following steps.



- With other like-minded siblings participating
- A sibling expert in the facilitating role
- Possibly also a joint workshop with parents included
- To be played at home with parents, extended family members and other reference persons.
- To be played with friends.
- Sensitizing the population about the topic.
- Potentially playing anonymously in a public place to raise awareness among the population.

7.1.1 Building blocks

The last session with the siblings, and especially the concept idea 05, brought up some very powerful and effective interactions, which represent now essential design building blocks for the final concept:

- write your anonymous messages (given prompts, free)
- messages are affirmations, shared dreams or insights
- hide your message
- seek / find a new message
- option to reply on new message
- keep a (another) message
- know the given answer to my initial message
- have my own / personalized outcome



#11 How to design the interaction flow with sending letters and still keeping ownership?

7.1.2 Ownership

The topic of ownership needs to be discussed a bit more in detail to better understand its meaning and the siblings' needs. It already emerged during the earlier context exploration, as well it got confirmed in the conducted sessions while finding a concept. During the sessions, siblings showed a preference for activities that involved solo outcomes and required their input.

Ownership simply means “the fact of owning something” (cf. Oxford Learner’s Dictionaries). Whereas, in cognitive science ownership is defined more specifically as “the sense that I am the one who is undergoing an experience” (Arzy & Schacter, 2019). In the case of the siblings, it can be clearly seen as the fact of owning something physical that belongs to them. Especially for the different artifacts they created in the workshops, it was important for the siblings to keep them for themselves. Therefore, for the ownership in this concept, two options are possible. Either the siblings receive back their initial letters they wrote or they create something equally meaningful to them, which they keep for themselves

7.2 Further feedback

7.2.1 Talking to experts

Session set-up



Meet another professional sibling expert in an online session and receive feedback on the concept elements by presenting the idea and exchanging knowledge and experiences.



30 minutes, online meeting



1 project researcher (facilitator), 1 behavioural science researcher, focusing on siblings.



The insights and take-aways are based on the facilitators own perception from that conversation.

Session take-aways

- **Validation of the current design goal: Being a child without reflecting on personal experiences means feeling understood.**
- **The power of play to open up conversations between children, but also between an adult and a child.**



Insights

Siblings want to be children

Siblings want to be kids and not deeply reflect about their situation. They like to meet like-minded siblings and feel understood, and not always explain their situation.

Play as opportunity to open up conversations

During play siblings experience different situations and it seems to help them to open up conversations between them and their parents.

Writing letters and postcards as possibly working strategy

While digital tools help to obtain information and to connect with like-minded siblings, writing letters was also applied by other researchers working with siblings to create a connection between parents and siblings.

Picture by P. Cody

Insights

Different ways of playing the game

All of the families conducted it in different ways by using their own interpretations and preferences to start and to play.

Motivation to keep game running is missing.

For most participants there was no reason to keep playing, they were missing a certain end goal. Thus, it turned into a one-sided communication tool without repetitions.

Creating a safe space by addressing the letters to someone specifically.

Especially the younger participants were not making use of the prompts and were addressing the letter directly to someone specific or hiding it close by a specific person.

He [the son] loved the seeking part, but I am not sure what his reactions were on the messages.

Mum 01



I didn't get any response at all. My husband just took it and put it somewhere and he can't remember what was written on it. He thought it was funny.

Mum 02



7.2.2 Talking to families

Session set-up



Gaining insights and improvement ideas about the current concept in a different context (at home) by letting them try the game out with an instruction.



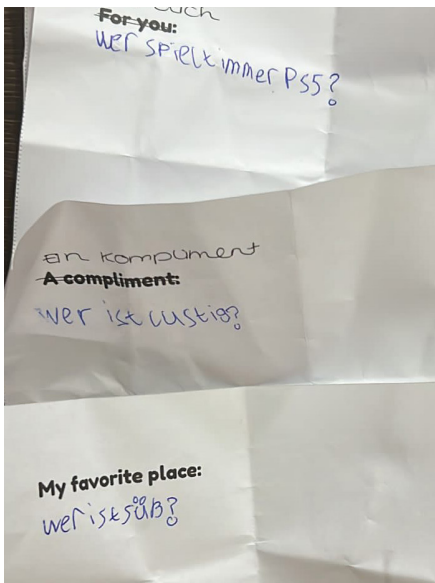
At the participants' home



3 families including externals (e.g. housekeeper),
2 participating children (10 - 15 years)



- 1 family was a special needs family, but without siblings. However, the concept was tested among various adults in the household (partner, housekeeper, caretaker).



I felt like I didn't have time to sit down and reply. I always postponed it to the next day. And then I never replied.

Mum 03



Session take-aways

Solely writing affirmations back and forth are not a reason to keep writing. Therefore, a clear goal or purpose needs to be defined. Same for repetitions.



A safe space is created for children when being able to address someone specifically in writing or placing the letter, rather than keeping it anonymous.



Why would I do this? I don't know what to write? I don't see the need.



7.2.3 Talking to public

Session set-up



Involving different age groups in sending secret messages to each other, in order to create awareness in public about the siblings' situation and Ontzorghuis.



1 x 150 minutes, at the first floor of Rotterdam library, a booth facing the main passage, posters and signs to attract attention



1 project researcher (facilitator), 10 library visitors actively participating



The booth and the posters, but also the design facilitator herself were inviting passer-bys to participate in sending surprising letters to other library visitors. Occasionally a written instruction or a verbal one by the facilitator was given to the participant. In order to write the messages, templates with different prompts were provided.



- Limited dutch skills were hindering in approaching many possible dutch speaking visitors, as they were very often denying.

Insights

Clear enjoyment when writing letters with the goal of surprising others

Participants clearly enjoyed writing letters and were curious about finding one. Others were already satisfied with the thought of making someone else happy.



Out of the context and unclear purpose and benefit.

For many participants the connection to the siblings was missing. It did not become clear through the posters and the logo of Ontzorghuis only. Also they were wondering about their personal benefits from participating.

Session take-aways

The interactions with the product need to be clear in all its details. Starting with the context and providing information in order to create awareness, but also clear instructions to interact with the product.



The missing benefit for the participants highlights again the weakness of the current product: a clear goal.

7.3 Concept iteration

The next concept iteration focused on the child's ownership and the triggering element. With the previously gathered feedback, the question for the trigger that keeps the concept alive was still very important and yet unanswered:

What triggers the user to keep writing letters back and forth over time in a familiar context?

Possible approaches in design are simply reminders in order to do an activity and to set up new routines. They occur in different shapes, such as physical reminders (e.g. calendar, diary, postcards), objects associated with an activity or technological reminders (e.g. alarm, notification) (cf. McGee-Lennon et al., 2011). In the next iteration, such will be integrated to ensure consistency, especially among parents.

In addition, the aspect of ownership, as discussed in chapter XXX, shall be integrated and translated to the iteration. Ownership can potentially be strengthened by personalizing things or by keeping something for yourself.

For that reason, there will be containers around the message as a personalizable element (metaphor message in a bottle). The container idea is based on the concept of a Matryoshka (wooden, stacking dolls), which shall represent different roles and functions:

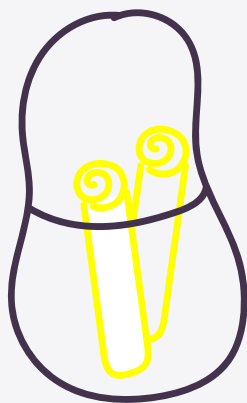
1. The treasurer - to be kept for themselves to store the secret messages and to provide a certain feeling of ownership.
2. The messenger - to be sent out to transfer the messages
3. The reminder - a tiny object to be reminded about replying and surprising each other.

At this point it is still discussable, if the different roles shall be represented in one figure only or in multiple, as the actual Matryoshka dolls. Nevertheless, further research found that giving names and stories to dolls (so-called personal dolls) is a powerful tool for children to manage their feelings (Whitney, 1999). Following, the name „Robin“ was chosen as a neutral name in order to target both, male and female user groups. Next to that symbolizes Robin, the redbreast bird, in colloquial language good luck, happiness, and rebirth (cf. Jin Design, 2021). Robin in association with a bird can be interpreted as a messenger that chirps its message through the world.

Another inspiration comes from the famous children's booklet and wimmelpictures "Where is Wally?" by Martin Handford. The title of the game is simultaneously the call-to-action trigger. By using for example a calendar or postcards with prompts, the call for action can be translated to the current design. Also, there is the potential in developing a new secret language within the families. And the prompt "Where is Robin?" or "How is Robin doing?" can in the same way become an indirect representation of the sibling and a strategy to gain commitment.

Where is Robin? - This can become its own identity and secret language within a social network around the sibling.

Where is Wally as inspiration for the next concept iteration.



TREASURER



MESSENGER



REMINDER



Insights

Dolls create certain level of privacy

Through the personalization of the doll, the letters were addressed to someone specifically and became more exclusive and meaningful.

Emotional response to the object, but no ownership

There was a clear emotional response by describing the doll as „theirs“ and the importance of the message, however they were not attached to the object, as they were all willing to give it away.



Reminders are not successful

After a week there was no response at all from the children, which means that a reminder, in either way, the object itself or the prompt, was not effective.

7.4 Concept testing with siblings

Session set-up



- Receiving more information on the feeling of ownership when personalizing an object.
- Figuring out if prompts actually work as trigger to keep hiding messages / keep game running.



1 x 90 minutes, at the facilitation of a German organization focused on siblings, part of a 2 say program, outdoor setting



1 project researcher (facilitator), 3 sibling experts (ethical steward), 8 siblings (8 - 12 years)



The children were asked to color their personal messenger, which was given in the form of a wooden Matryoshka. Following they were writing a letter that should be transported by the messenger, hiding the Matryoshka in the garden, seeking another one and reading a letter (similar to chapter 6.5). And in the last step they replied to another letter. The next day, the children received a letter including postcards for them and their parents, which stated the last assignment of sending a picture to the facilitator.



- Introducing the given Matryoshka a “secret messenger” may have intrigued and influenced the children’s behavior and perspective regarding the contents of their messages.

Session transcript can be found in Appendix L1



Session take-aways

Upon this point, there is still no clear benefit in writing messages back and forth.

➤ The personalization in the form of creative input empowers the meaning and value of the messages, but does not create strong attachment / ownership.

Ownership may not be such an essential factor in this context anymore. The overall goal of keeping the interactions alive is not achieved through creating a simple reminder in the form of a postcard or the object itself.

Take-away concept elements

~> *The focus of the project slightly shifted from designing a toolkit for a workshop with siblings towards designing a toolkit to bring the affirmative letters to a familiar context.*

➤ **Research highlighted that safety for the child at home clearly lies in their personal decision in targeting the letters specifically to someone, rather than keeping something anonymous. Basically, keeping ownership of the message.**

I will place Robin in the gutter.
Then I know for sure that my
grandpa will find the message.





***Design
proposal***

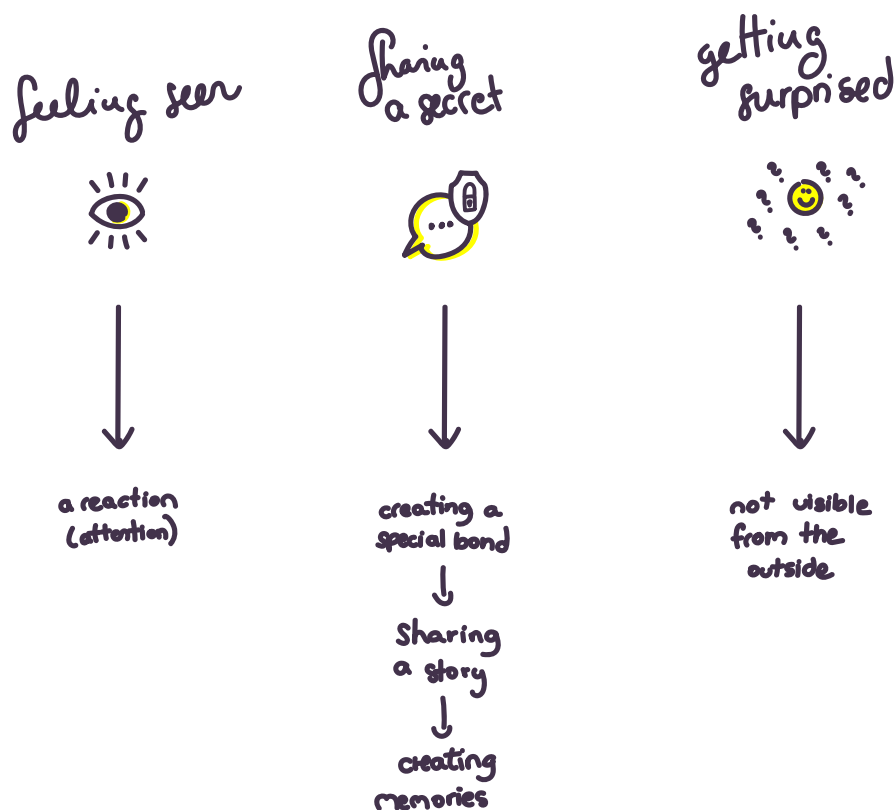
Part 08

This chapter covers the last steps that led to the final design. It does it by another essential reflection on the previous process and redefining the concept elements. The elaboration and iteration of the concept details are shown and the final interactions of the concept are presented.

8.1 Recapturing insights and refining design elements

The anonymous letter writing workshop (chapter 6.5) put a smile on many siblings' faces and created a magic moment within the entire group. For that reason, this experience is still substantial for the final design outcome. It encompassed playful interactions and inspiring affirmations, compliments and wishes from and for siblings - which was not only perfectly fitting the siblings needs, but also the design goal.

The main goal became to work this workshop out and make it possibly applicable in different contexts. Within the last chapter the major challenge of creating such a moment at home came up. Therefore, addressing the message became another important element. Previous insights have also shown that the personalization of the message container contributes to reinforce a personal message. Elements, which couldn't be solved up until now, were the trigger that initiates or inspires to write, but also the affirmations. Previous research has shown that coming up with a nice message every time was a mental challenge and in that way also time consuming.

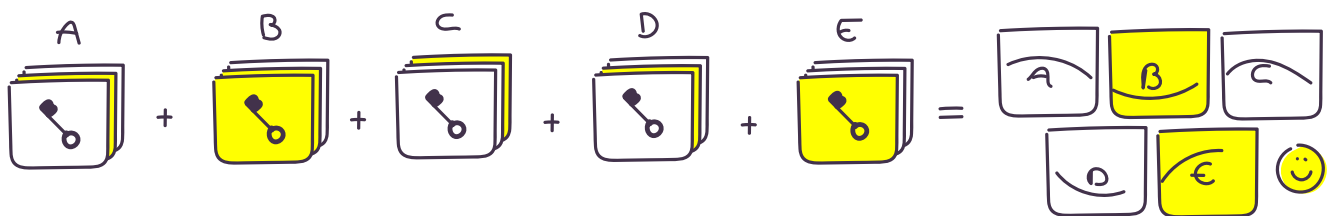


#12 Breaking down the essential interactions parts into a new perspectives.

Another reflection and discussion with Marise Schot as professional designer and mum of a child with special needs followed and the gained research insights were narrowed down into a new perspective.

A collaborative brainstorming session resulted in a playful game, combining previously gained insights from different concepts. The final idea is a storytelling game, which can be played with the entire family or friends. The core will be developing a story narrative together as family and simultaneously creating a memory through the shared story.

The initial idea was to create stories, each consisting of about 5 incomplete parts that are completed and put together by the player. Each part fits together with every previous or following part of every other story and leads to a smooth plot (see figure #13). Such story parts can be encrypted in a playful way and must first be unlocked. The idea is inspired by the siblings' inspiration of creating their own theater scene (chapter 5.1.1) and based on the idea of the mix and match booklet (chapter 6.5).



#13 In this example every part is given three times. Every A part matches with every B and every B with every C and so forth. A story will result that makes sense in all combinations

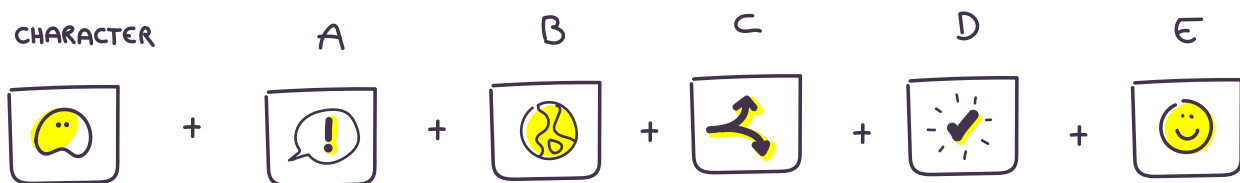
For further continuation a creative storyteller was consulted in order to get inspiration and advice on how to write mix and match story outlines that are still adorable and sensemaking. However, as this seemed quite an impossible challenge, the idea of providing open questions and a change of scenery was proposed. An example would be this: Card A *The actor walks out of the door.* Card B *In the next moment he enters a new world.* Also, in order to keep structure and create exciting stories, the typical hero storyline was chosen as a framework.



Furthermore, the idea of adding a character card came up as a starting card for every round. Such a card will be defined at the beginning of each new story and is meant to influence the storyline. The character is Robin, an undefined blob that can take on various shapes, which acts as the hero of every story. A hero in traditional story writing is “the necessary intervener, the instigator of actions that bring about change” (Wright, 2005).

Also, a confirmation and an affirmation card was added, in order to show that every decision is right that Robin makes during it’s adventures. The affirmation card aims to reinforce the decisions and to create a “happy ending” for both Robin and the reader.

Thus, following storyline concept based on 5 phases for a mix-and-match story game was proposed. To simplify the provided text passages 11 instead of 5 cards are provided to make the story happen:



Character card

Describe and draw Robin.

Example prompt questions:

- How is Robin doing?
- What are Robin’s likes and dislikes?
- How does Robin feel and what does Robin need the most today?
- What is Robin’s favorite place?
- What are Robin’s dreams?

A. Old world, motivation, call-to-action

1. Setting / time / What? / Who? / Daily life
2. Call-to-adventure
3. Interpretation / motivation

B. New world, challenge

4. New setting: where?
5. New setting: what?
6. Challenge occurs: describe

C. Challenge, decision

7. Challenge is close: Who or what?
8. What is happening?
9. Decision to make.

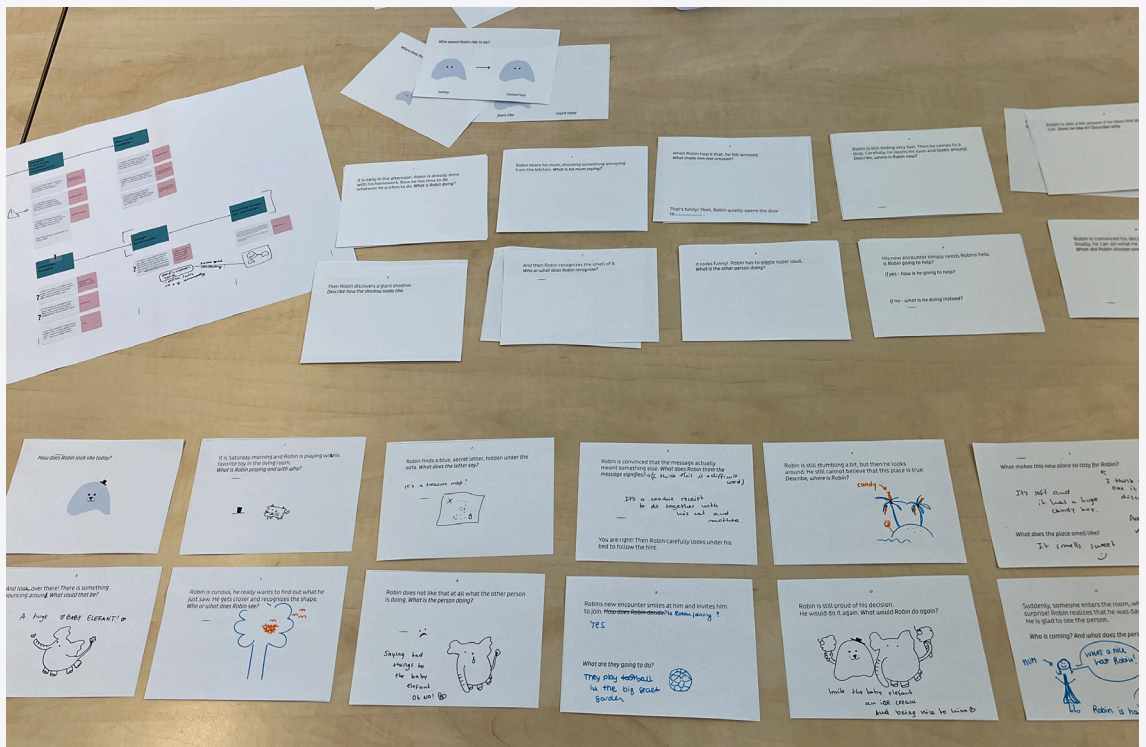
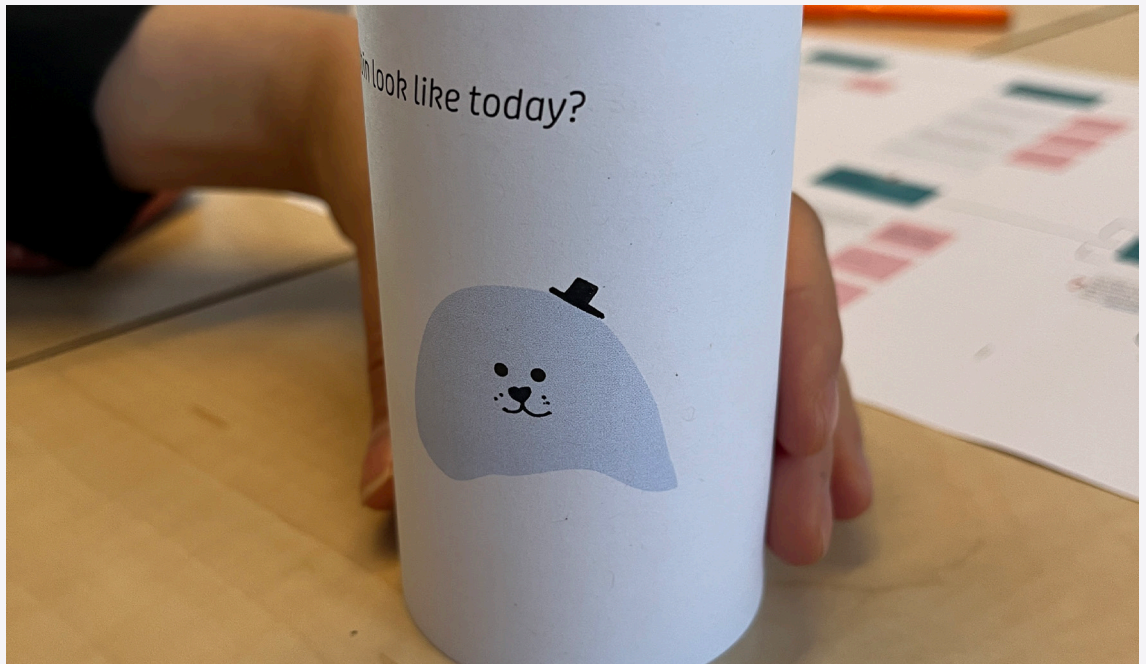
D. Change, confirmation

10. Confirmation that it was the right decision

E. Back to old world, affirmation

11. Affirmation from sb. else

A first draft of possible mix and match stories can be found in the Appendix L.



Testing the mix-and-match storymaking showed that the storyline still ended up entirely mixed up, and that it was similar to those folding stories on a paper. Thus, the purpose and the value of creating a nice story together in order create memories got a bit lost. For that reason, the mix-and-match element was removed and the focus was more on the story itself, in order to create more value with the stories for the entire family. This led to the final design outcome.

8.2 Robin - a storytelling tool for the entire family

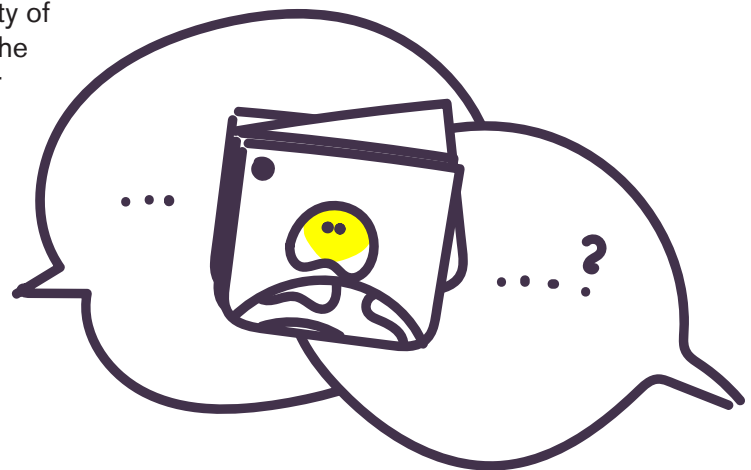
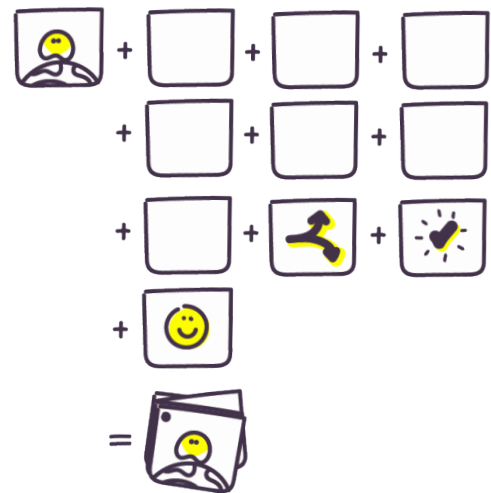
8.2.1 The concept

After small feedback rounds with fellow design students and iterations of the story outline, the concept was clear: *Robin - a storytelling tool to create family connections.*

Together with the entire family surprising stories will be created. Each adventure that Robin is going through consists of 10 different parts that will be combined in a story booklet after playing. Each story outline focusses on a certain topic to find out Robin's challenges, preferences, fears and resourceful places. By asking direct, but open questions the player decides about Robin's actions. All stories will end in a confirming or affirming way to provide Robin confidence about the actions and decisions taken. With that strategy, the siblings should be entitled to explore different paths and decisions in Robin's life. And with the contribution of a second or third actor, for example the parent, the finished story can serve as a good conversation starter between the two parties.

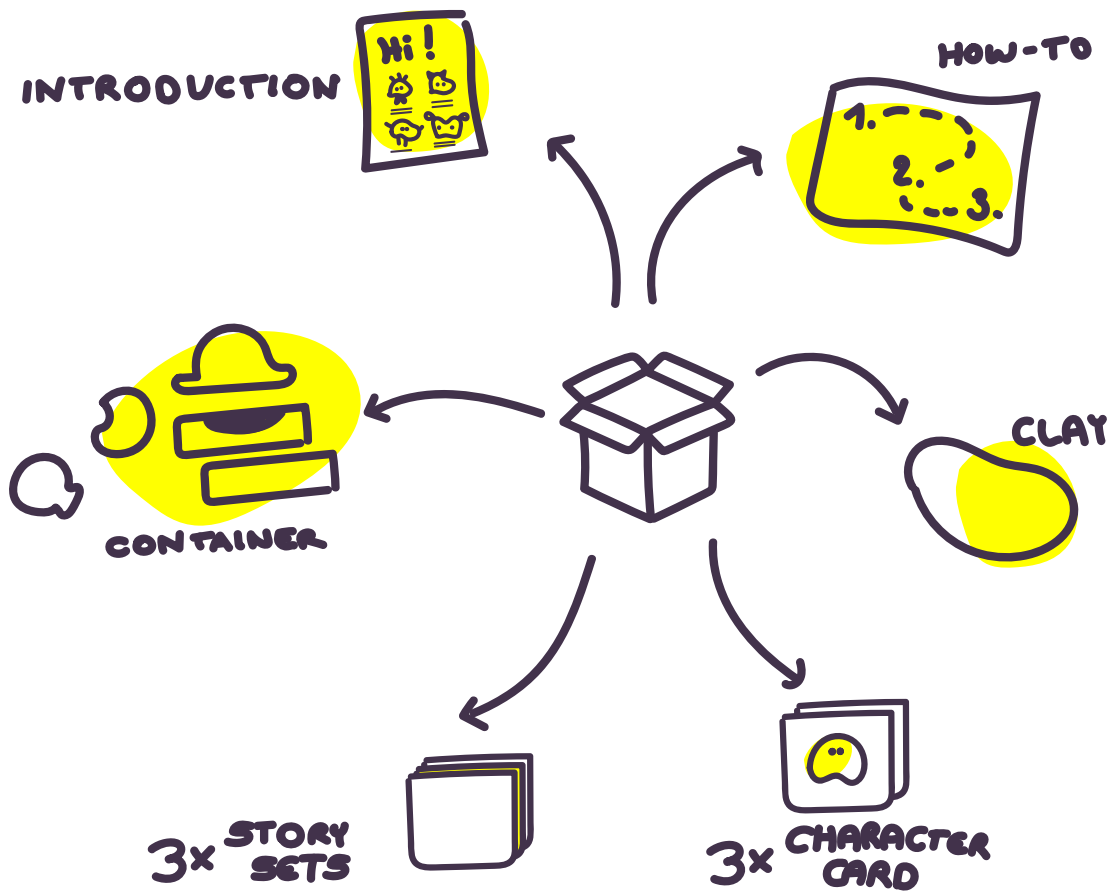
Scientific evidence

Maehigashi & Niidia (2020) found that adding contents in a shared calendar between parents and their children influenced their conversations among each other and thus, led in all cases to a parental reflection. Moreover, they stated that the "quality of questions from parents influenced the type of the questions," in order to find out more about their children's feelings and thoughts. In this case, a storytelling tool can be a playful way for communicating with each other.



Robin is a physical object that contains all the cards of one story set. Previous research has shown that the personalization of an object, especially the container of a message, reinforces the meaning of the content (chapter 7.4). For that reason, the container is like a secret box, consisting of different layers, and is combined with a self-created interpretation of Robin.

The storytelling toolkit will come in a small package, which contains following materials:



The introduction

A warm welcome that shows the purpose of the goal and examples of possible ceramic outcomes for Robin. They will be accompanied by short stories told by other siblings. This aims to arouse curiosity and inspire the sibling.

The instruction

An easy step-by-step explanation on how to prepare the ceramic part and how to assemble Robin.

Character cards

a set of 3 character cards.

Story cards

3 sets of story cards.
1 set contains 10 story cards.

Clay

A small package of child friendly clay which can be used to get started immediately.

Container materials

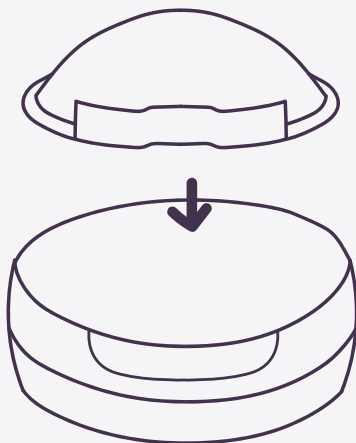
3D printed elements, which are part of the Robin container and which need to be assembled. One element is a mold for the ceramic working process.

8.2.2 The play journey

Create Robin

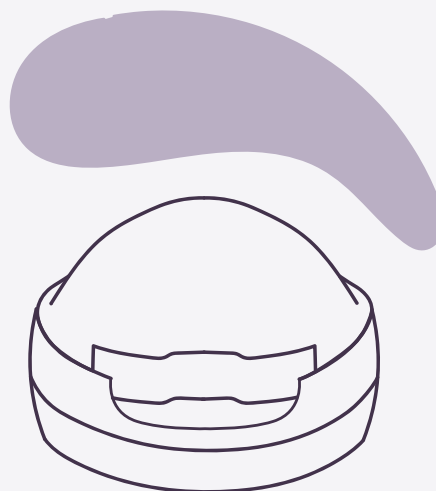
Step 1

Assembling the container with the mold on top.



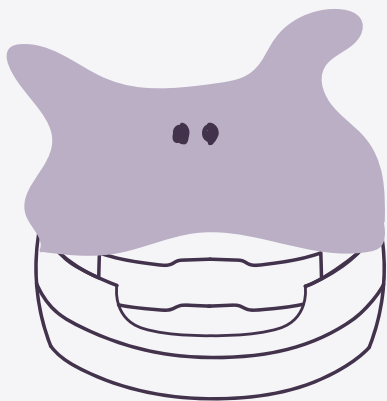
Step 2

Laying out the clay on top of the mold and creating a personalized Robin.

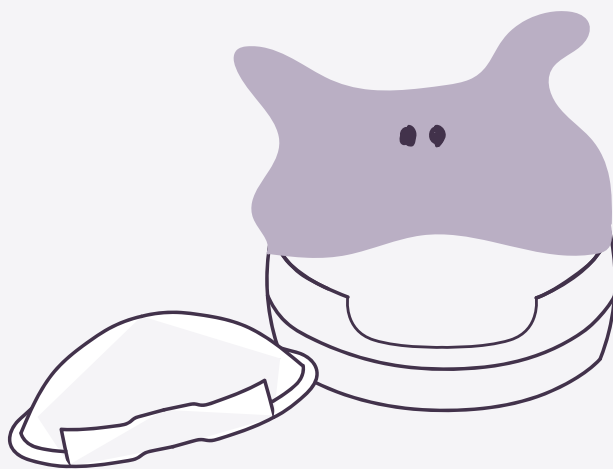


Step 3

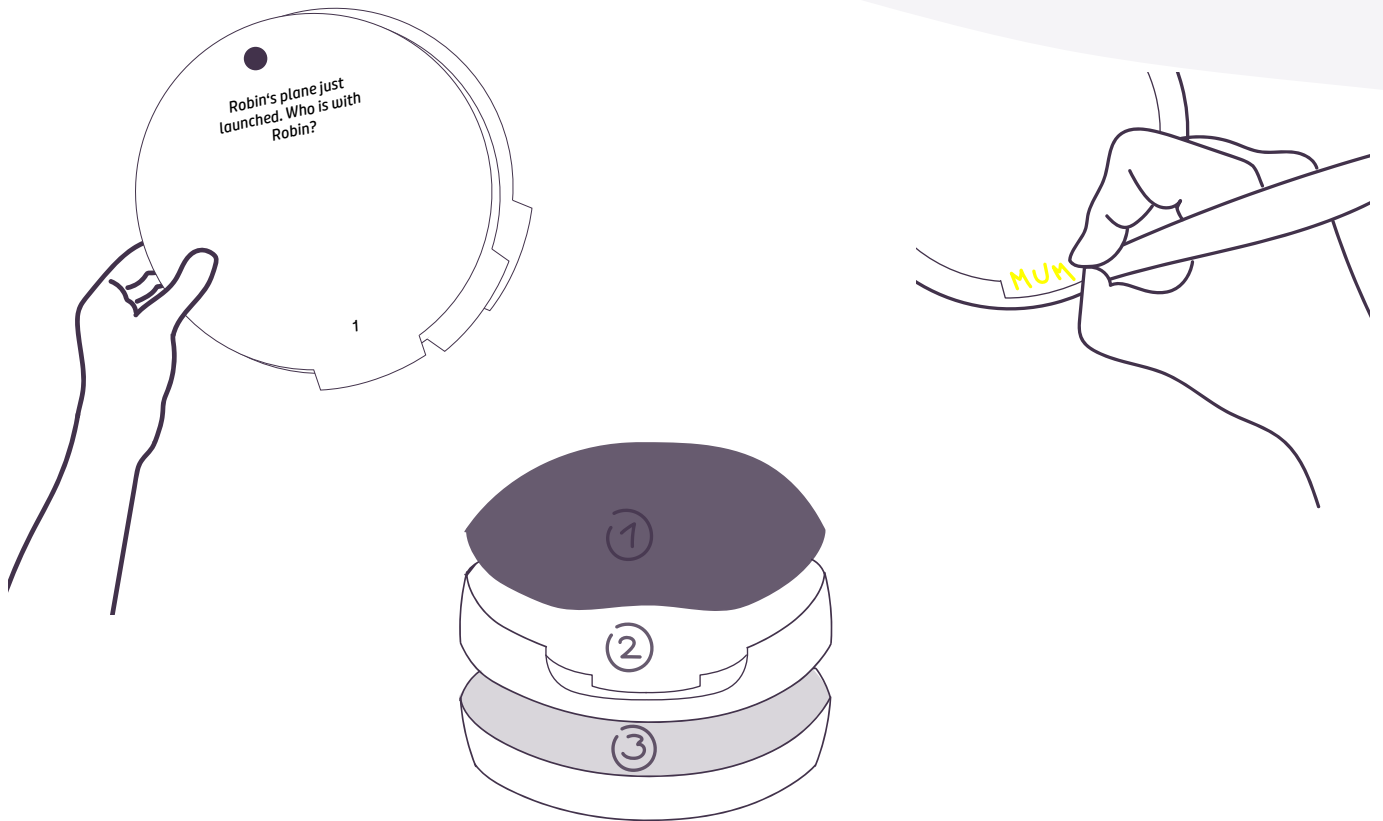
The clay needs to dry first before using it for the game. When it's dry, it can also be painted.

**Step 4**

When everything is dry, Robin can be placed on the container without the mold.- Let's play!



Getting started

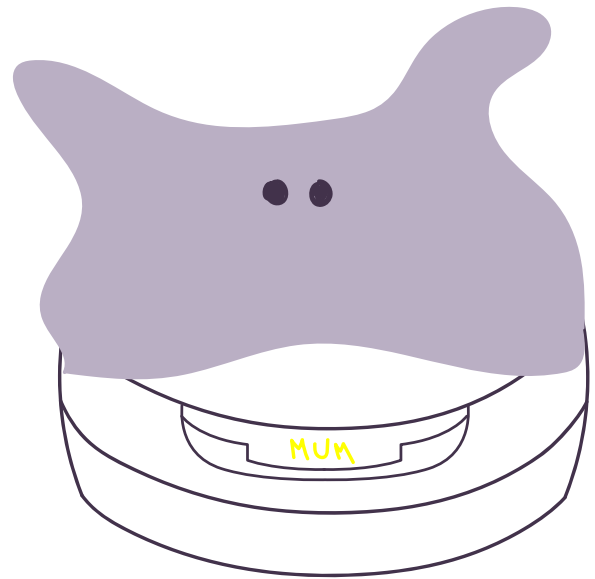
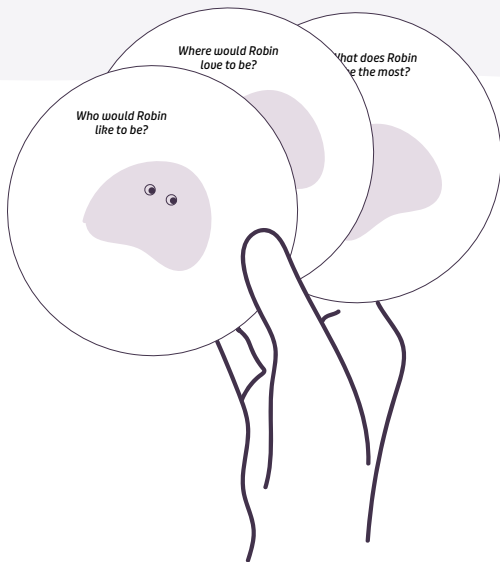


Choose card set

One card set will be chosen and be placed on the second compartment (2) of Robin. The order of the cards will be chronological: 1 on the top, 10 on the bottom.

Assign first turn

On the first card a name of one player will be written. This will be visible later from the outside.



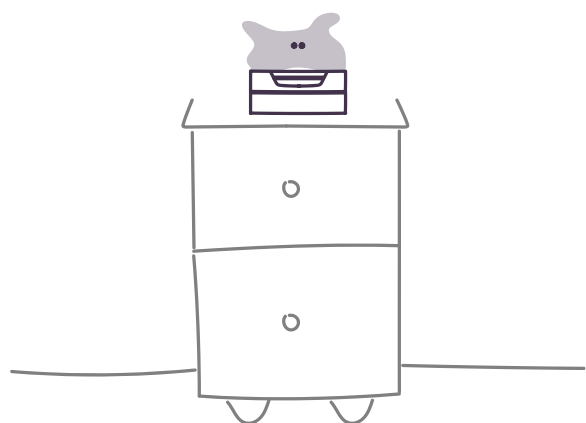
Choose character card

One character card will be chosen and filled in. The character card will be placed on the first compartment (1).

Ready!

Then the self-created Robin will be placed on top to hide the cards.

The play journey

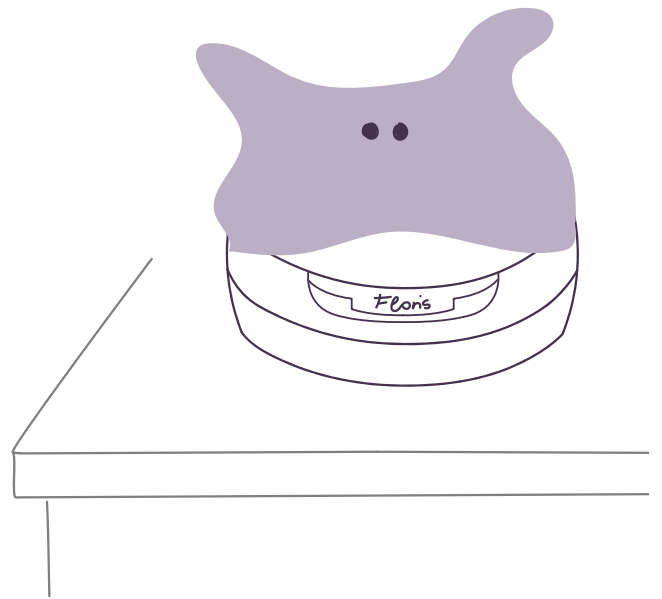
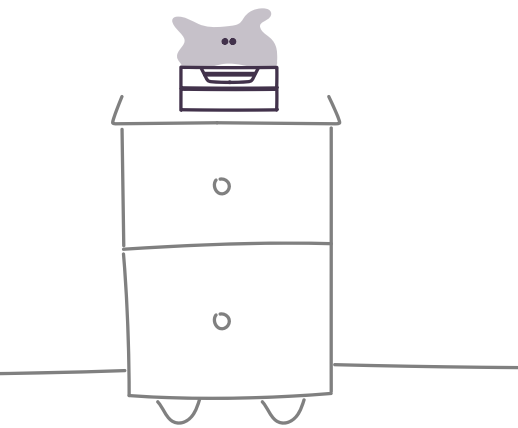


Location

Robin will be placed wherever it is good visible for every family member. So for example, close by the kitchen area or the living room, a place where usually common family rituals take place. But it can also be in the child's room, next to the bed for example.

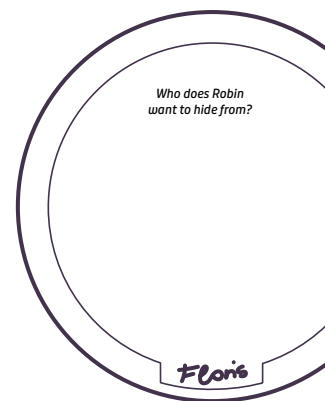
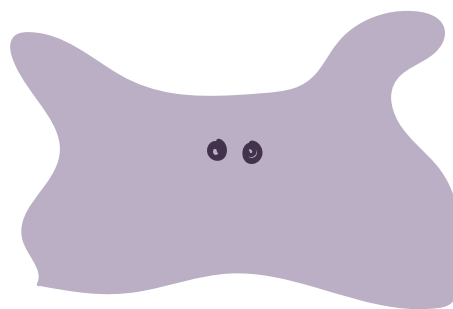
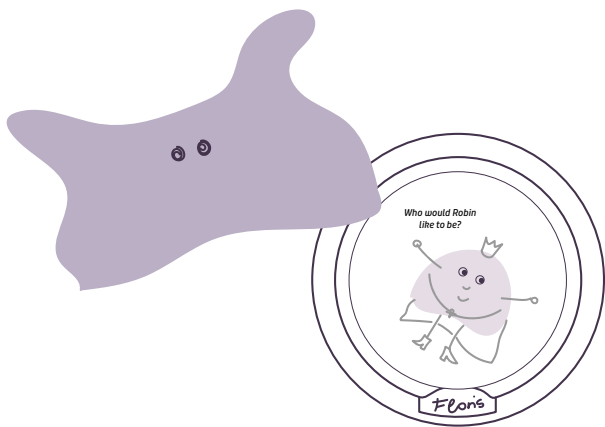
Time

The game takes place over a longer time period, the time is not limited.



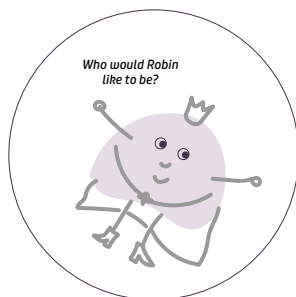
Who's turn?

Any family member can check out Robin anytime and see what name is written on the first card of the pile. The player who's name is visible takes their next turn.



How is Robin doing?

The designated player takes off the ceramic part and checks out the character card - how Robin is doing today? What Robin is dreaming about? Or where wishes Robin to be right now?

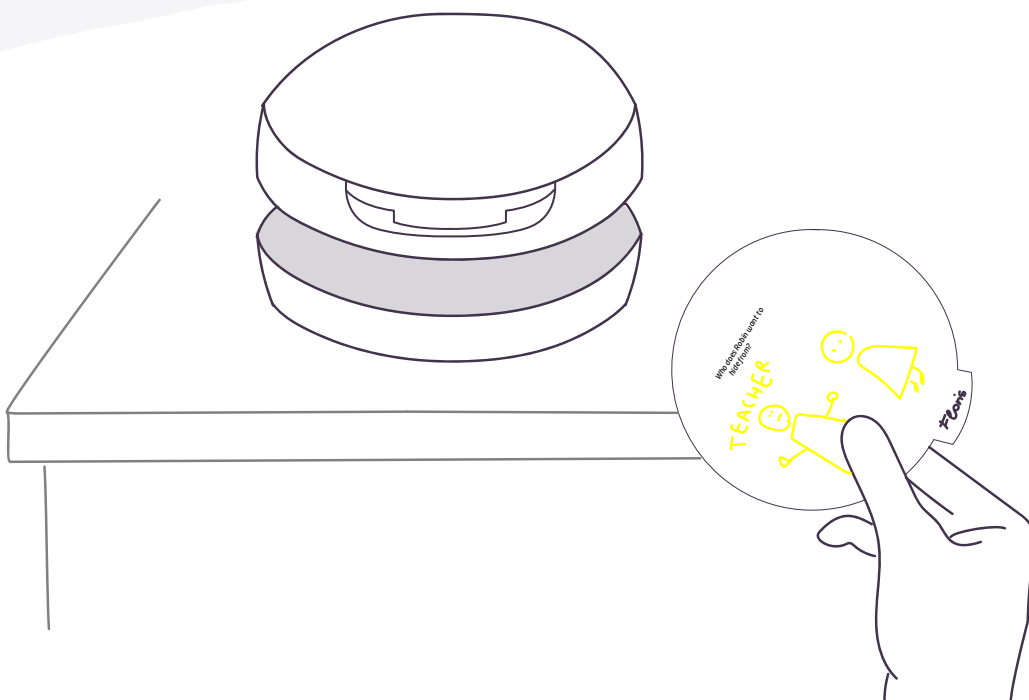


The story card

Underneath the character card the player will find the story card. The one with their name on it.

What is Robin going to do?

On the story card is one question that will be answered by the designated player. In this way, the player is deciding over the story of Robin. The answer can be inspired by the character card that shows Robin's current needs or dreams.

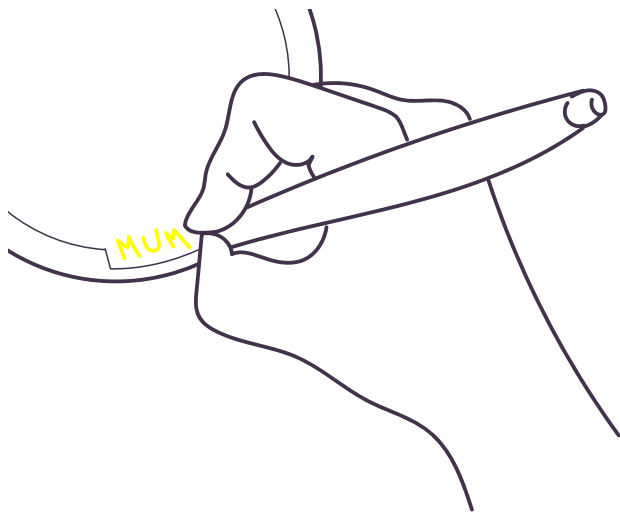


Hiding the story part

The written story part will be hidden in the secret bottom compartment of Robin.

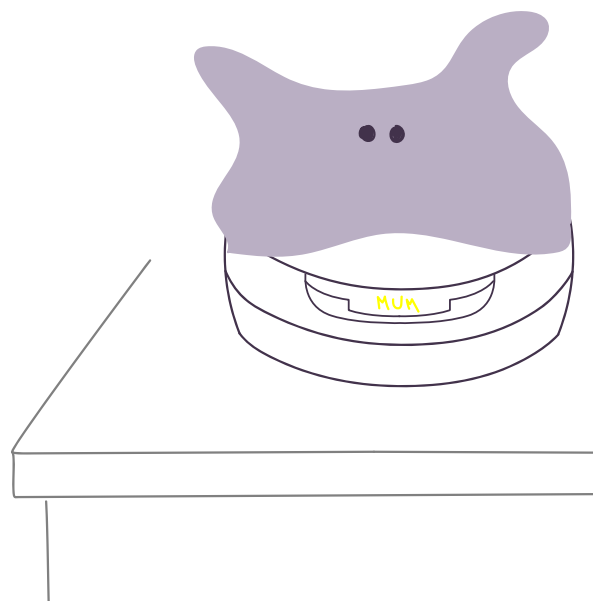
Decide turn

Then the player designates another player by writing his or her name on the next story card.



Finishing turn

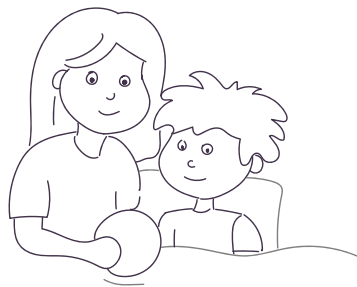
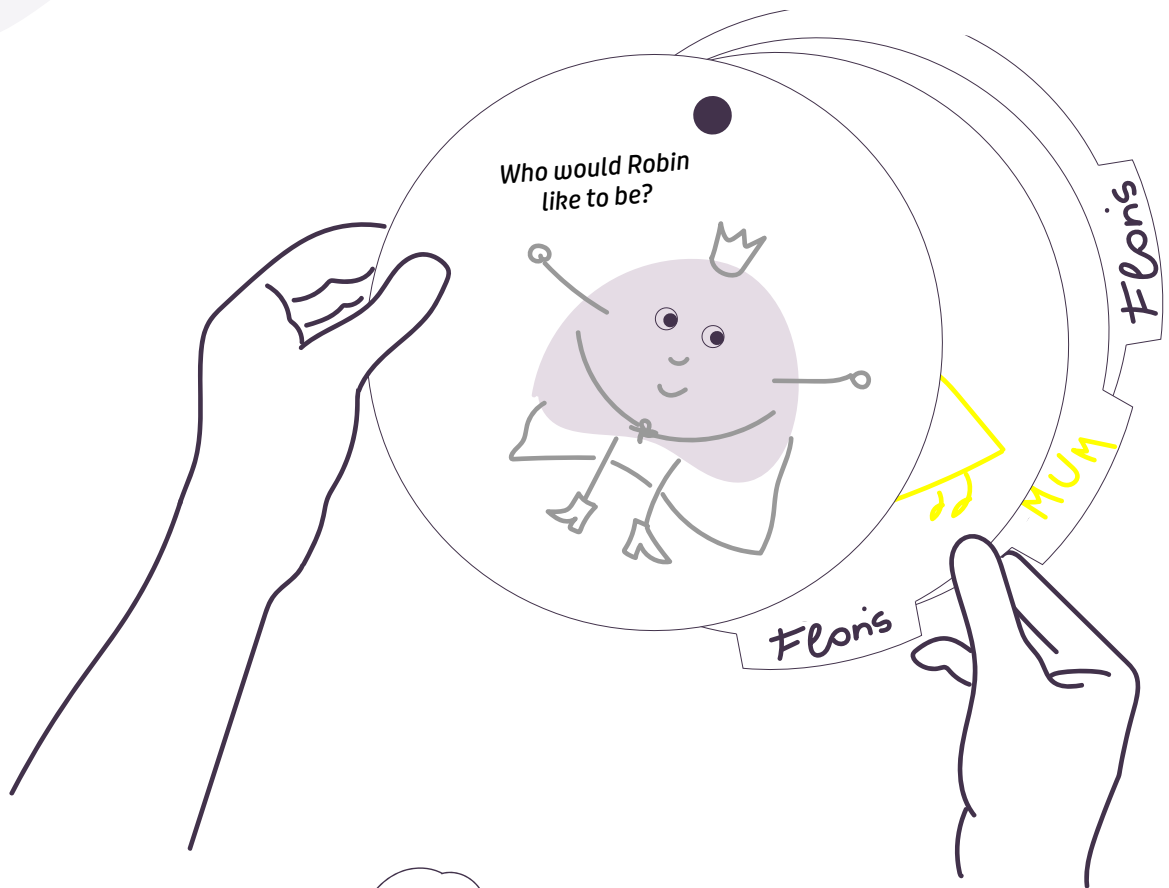
By placing the character card again on top of the story card, Robin can be closed with the ceramic part and is ready for the next player.





Repeat

Play until the last story card is written as well. The last card means that the story is complete. It will also be hidden in the secret compartment, likewise the other cards.



Reveal

When all participating players are around, it's time to unveil and read the secret story together. The best time for example is when going to bed, because then it's usually already a bit more quiet in the house.

8.2.3 The prototype

The package

As previously mentioned the package contains the different parts for Robin, such as the 3D printed container and the mold, 500 g of clay, an instruction and welcome letter, the story cards and the character cards.





The secret box will be created by simply stacking the different 3D printed compartments on top of each other. In the picture below it can be seen that in the bottom layer all the already filled in cards fit, in the top layer all the new story cards. An extra 3D printed disc is provided to hide the story cards and put the character card on top.

The idea is based on those secret boxes that sometimes have a hidden bottom layer, in order to reinforce the feeling of a secret and the surprise of a finished story even more.





Formgiving and materials

The initial idea was to provide a certain *card holder* to the player. In order to let the game also happen without an additional clay figure on top, an overall construct needed to be provided. The ideation and iteration of the physical shape can be seen in *Appendix M*, where all kinds of materials from textile, wood and clay were still considered. Finally, the printed plastic was chosen, as the compartments are easily reproducible with it. The addition of clay adds the personalized touch.

The final shape is round, referring to Robin that is only a blob. And the top layer compartment and the mold are constructed in a way that the clay will take on a stable shape when later acting as a lid for it.

8.2.4 The stories

Character cards

The character cards are essential in order to become clear what Robin is looking for in its adventure. The cards are basically tiny reflection cards that are based on the insights of the calendar activities (chapter 5.3). Children had clear preferences for certain reflective activities and those are incorporated here. The goal is to make them sub consciously reflect once during play, in order to find out with the storyline what they need. Each character card aims to fit to every story.

Story cards

The story cards aim to focus all on a different topic, such as resourceful places, identifying needs and envisioning a future scenario. The themes come also from the calendar activities (chapter 5.3) and aim to explore opportunities and envision various scenarios. Through open questions the children can either integrate their actual needs and dreams, hide them in fantasies, or just come up with a random story, as they feel like it. However, the stories also aim not to be too obvious in targeting the children's needs. So for example, siblings didn't like the activity of hero stories in the generative session (chapter 3.4.3). Therefore, enough freedom in shaping the storyline is provided.

Another part of each storyline is that the player usually has to make a decision or to solve a problem - also the solution is open to the player and can be anything (helping, running away, fixing, something etc.). Whatever the player decides for his decision is reinforced by a confirmation and / or in some cases both an affirmation card. However, the affirmation card still has a second goal of bringing the affirmations from the anonymous letter session (chapter 6.5) home. An example of a storyline is given on the right, the others can be seen in *Appendix M*.



Example storyline

1. It's one of those days again! Robin just wants to be somewhere else. That's why Robin wants to go to its secret place. What or who does Robin want to hide from?
2. But the way to the place, is super How does Robin get to the place?
3. There is also a short-cut. Robin needs to close its eyes and to whisper the magic spell. What is the magic spell Robin needs to say?
4. And then, when Robin opens his eyes again, he is at the secret place. What makes the place special?
5. Also, it smells like something Robin really likes. How does the magic place smell?
6. That's sweet! So, what does Robin usually do at this place?
7. The place is almost perfect. But sometimes, Robin misses something here. Who or what does Robin miss at his favorite place?
8. Solving the problem is easy! Robin knows what to do. What does Robin do?
9. That was the best Robin could have done! Robin is having a good time. How does it look like when Robin is having a good time?
10. But then, Robin hears a familiar voice. The voice says something very friendly, that makes Robin feel very comfortable. What does the voice say? And who is it? Draw the picture.



Robin

Instead of specifically defining Robin as an animal or human, the initial idea was to leave any freedom to the child. Following, Robin can be a bird, a dragon or just something with two eyes and have any preferred characteristic. On the character card Robin is shaped like a blob, all other essential body parts can be added or left out. And Robin can take on each time playing a new shape, also depending on its current moods.

The name Robin itself came up during one of the earlier stages of ideation. Robin is a gender neutral name and also an association to heroes such as Robin Hood. And lastly, in the english language it is the red breast bird, and a bird is associated with transferring messages.

8.2.5 The workshop

Proposal

Within the research process the initial idea of Robin was tried out in different contexts, including workshops, at home or in a public space. And all of them showed off many possible opportunities and contributed to the further development of the product. The entire focus in the last steps was in the concept development of Robin, rather than on the initial workshop that Ontzorghuis could provide. As Robin can now be created and played independently at home, an additional workshop given by Ontzorghuis seems on the first view redundant. However, there is the great opportunity for Ontzorghuis to create space for siblings to connect and to just feel understood (1st core value). By introducing the siblings to Robin, the tinkering part with clay may serve as a good introduction. Followed by a version of sending anonymous letters to each other. A session set-up could look like followed.

Workshop set-up

- *Goal:* Introducing the siblings to Robin and let them experience affirmations
- *Possibly:* Icebreaker
A game to get all participants names or to get active (e.g. pink toe)
- *First activity:* Creating Robin
Introducing the children to Robin as a secret messenger. Asking them to imagine a secret messenger. Let them draw their secret messenger. Telling them an example story of an adventure that Robin may have experienced, envisioning each their own Robin. Create the clay model of Robin.
- *Second activity:* Sharing secret
While the clay is drying on the mold, each one is asked to send an affirmation to another child. This can be a compliment, a personal dream or just the own favorite place. For that the secret box compartments are used (still neutral, not personalized), the bottom and the top layer. Affirmations will be written on a paper and hidden in each secret box. Then the children walk around and are allowed to look into other secret boxes and to read and reply to the letters. Asking them what they like and how it feels to them.
- At the end of the session they will be shortly introduced to the storytelling tool, which they can play at home. Ask the children with whom they will play it if not with the parents.

8.3 Feedback

8.3.1 Talking to siblings

As the final design proposal came up by the very end of this project, there was little time to get feedback on it, especially from the target group themselves. Nonetheless, during the production process of the physical concept idea, Marise already presented the idea in a special needs camp to siblings and gathered some feedback.

Session set-up



Gathering a first impression on the interactions of the proposed design by presenting the idea and trying out a low-key version of the game without any physical prototype yet.



1x 30 minutes, in person, outdoors, session was part of an initiative offered by Ontzorghuis



1 facilitator, at least 1 sibling, unknown number of parents



A workshop script was provided to the facilitator. The session included creating the Robin figure and playing the game as a group.
Detailed session script can be found in Appendix N



Only the first activity was conducted and not the second. Thus, insights on the interactions and the stories are missing.

Insights

The gathered impressions and translated insights to the project researcher were following:

- ***Robin was created in the shape of a human figure.***
- ***The idea of a booklet was visually inconceivable with round cards.***
- ***The purpose of the game specifically for siblings was unclear.***
- ***The numbers and symbols on the story cards were confusing and led to an unclear starting point.***
- ***The round paper was not associated with a booklet.***

They seemed not convinced how it could help them.



Marise, session facilitator



Picture by Marise.

Session take-aways

Little, but valuable insights were already gathered. However, those are not yet enough for a proper evaluation. Nonetheless, the argument about the game's purpose sounds valid and should be taken into further discussion. Therefore, it should also be mentioned that the storyline itself and the actual interactions were not tested and the feedback is based on a presentation of the game. Also, the feedback showed that there are still improvements on the design that could be taken into further consideration.



Discussion

Part 09

This chapter discusses the limitations of the research project and future recommendations. It rounds off with a short conclusion and a personal reflection by the designer.

9.1 Key contributors to final design

First research phase

The project focused on the siblings' experience when growing up alongside a child with special needs. By conducting literature research, context mapping according to Sanders & Stappers (2012) with children, and supplementary interviews with parents the following underlying core values of siblings have been identified:

- **1. Feeling understood**
Feeling understood involves the social environment at home, but also at school. Siblings often feel different from others and wish other people could understand or even be aware of the circumstances what special needs mean and what it means to live with someone with special needs (cf. 3.1.2 field trip with siblings).

- **2. The need for adult attention and feeling cared for**
The need for adult attention and feeling cared for indicates that they are seeking for someone who is paying attention and listening to them (cf. 3.1.2 field trip with siblings), someone who is constantly there for them (cf. 3.3 Parents perspectives) and someone they can trust.

- **3. Just being themselves**
The need for just being themselves is strongly connected to the previous ones, however, it highlights the importance of not being always perceived as the sibling of a child with special needs. And the freedom of not having to take on different care tasks, consciously or unconsciously.

Therefore, the first research phase, including the literature research and the field research, could be concluded that being a sibling of a child with special needs comes along with the the challenge of truly feeling and acting like a child.

Second research phase

The second part of the research was led by the design vision of enabling siblings to feel like a child with the challenge to design an appropriate design outcome for the siblings.

With experts two important design directions emerged:

1. A reflective tool to identify and communicate needs.
2. A design to create or strengthen a network around the sibling.

Through a participatory design approach (Sanders & Stappers, 2008) the two directions were explored, evaluated, and iterated with various stakeholders. The most outstanding during this process was the workshop about sending anonymous letters to each other (cf. 6.5 Concept testing with siblings). Sending affirmations, sharing wishes and compliments in a playful hide-and-seek game with other siblings felt like “a shared secret” (Noa, 10 years) and were the initial interactions elements that led to the final design. The aim derived from this was to translate the interactions including the affirmations in the familiar context of the siblings.

Final design

The final design is Robin, a storytelling tool to create a special bond between siblings and their parents. The playful tool enables children and their parents to create a story together in 10 steps with provided story cards. Robin is a physical object, that keeps the story cards inside and reveals only the name of the next player on the outside. In this way, the feeling of a shared secret is created only between the people who know about it. The final surprise element will be the story outcome at the end of each game. With those essential elements, Robin aims to create a shared memory between siblings and their parents. Ideally, Robin is positioned at a stationary place at the family’s home, where all players can keep an eye on it and there is no time constraint on when and how often to play with Robin. When a story is completed, the story cards can be clipped together and result in a unique story created by all participating family members. The story can be a starting point for in-depth conversations with the siblings to find out more about their emotional well-being with the current situation.

9.2 Limitations

Research

Most of the research with children was conducted within the context and program of specialized organizations for siblings. The organizations already offer special programs and activities tailored to the siblings' needs and the parents already made the reflective decision to let their children join such. There is a big number of children missing, who do not participate in such programs for a specific reason, which may have been relevant for this research. However, this does not alter the insights and some of those if not all may be transferred also to children not involved in specific programs. Nonetheless, other core aspects may have been missed due to this selection bias. Thus, the design outcome may be limited to children who already have a certain backing in terms of reference and contact persons.

In addition to that, it has to be mentioned that there was no differentiation regarding the children's special needs during this research. There are many studies focusing on siblings of children with autism or with a chronic disease only. In the context of this research, however, there has no clear separation been made as to which needs specifically have which effects on the sibling. It was a great chance to even get in contact with siblings, but there was no further differentiation made regarding the needs of the physically or mentally challenged child in their families. The only attributes that influenced the insights were the age, the sibling status (single or multiple siblings), and the sibling position (younger or older sibling).

Design

The design has been developed using a research-through-design approach namely Stappers & Giacardi (2027). However, a limitation of this project is that within the scope of this master thesis the final design proposal could not be evaluated with siblings in order to try out the interactions. This includes the entire game dynamic from creating to playing, as well as the proposed storyline itself. With that, whether the intended interaction qualities inspiring, guiding or feeling cared for could be proven, nor the achievement of the desired overarching design goal. However, the single interactions of the final design are based on various research insights derived from and

evaluated during interactive workshops with siblings. Therefore, the final design proposal has been based on the assumption that sharing a secret through creating a story results in a shared memory for all players.

Context

Another limitation is the effect of the intended context of the final design, which could not be evaluated either within this project. As previously mentioned, there was never any research conducted at a sibling's home, which leads to the effect that the functioning of the product in the sibling's familiar context is mainly based on assumptions. There was only one indication of a parent, that it might be useful to "literally give siblings a voice through a voice recording tool at home" (cf. 3.3 Parents perspective).

Materials

The materialization of the final design couldn't be evaluated either. The research led to the insight that siblings like to have their own creative outcome (cf. 3.4.3 Generative session), but it has not been specifically tried out with clay. Furthermore, the dried clay is very heavy and fragile, which influences the mobility of the final design. Thus, the possibilities and likelihood of playing the game with extended family members or friends may decrease with that. The 3D printed molds are a good supplement in material that works quite good and still needs minor improvements for a smooth creation process. Of note, no specific cost estimation regarding the production costs of the 3D print can be given, which may play an important role for Ontzorghuis when proceeding with the proposed design.

9.3 Recommendations

Research

This research project proposes a playful design for siblings, which is based on a research-through-design (Stappers & Giaccardi, 2017) and participatory design approach (Sanders & Stappers, 2008). The recommendations deriving from the research include to increase the awareness of the parents about the three identified core values of the sibling. It is highly recommended in designing for the target group not only focusing on the information flow to the siblings, but also building up and strengthening the social connections around the sibling in order to create a stable safety network. This research has shown, that integrating reflective activities in a design proposal are an adequate tool. But this should not be the central focus point of a design for that specific target group since this is contradicting to truly feeling and acting like a child and just being themselves. In order to make the design working in the real context it is recommended to further evaluate the different parts of the design in collaboration with siblings, their parents and sibling experts.

Storyline

Especially, for the story cards and their framework, it is recommended to the designer to set-up an elaborated plan of specific topics to be addressed and how to approach them in each story. A storyteller can be included again to refine the framework the storyline itself, but also to make the different story sets coherent.

Furthermore, it is recommended to get feedback and further evaluate the questions of the stories especially with psychologists and/ or sibling experts to strengthen the quality of the contents and to make with the final design a valuable communication tool for the siblings and their parents.

In this case it can be also valuable to further investigate the differences in needs and consequences for the sibling and create suitable stories for each sibling group. Although, previous research does not indicate yet which approach for sibling interventions, focused on the specific needs or not, is the most equitable for siblings (McKenzie et al., 2018).

Communication tool

Also, the parents should be involved in future research in order to find out how the story may help them in their own reflection, but also in the communication with their child (cf. Maehigashi & Niidia, 2020). Based on such insights the design package could be extended through an additional booklet or app for the parents. This may include tips, guidelines and questions for parents to find out more about the child's story inputs and the underlying motivation.

Player

Another important point is the potential of the player dynamic that needs to be investigated further. First of all, in the case a workshop will be offered, it is recommended to ask the child who the next contact person is and the best person to play that game with. In many cases the parent cannot be this person, and even though this design tries to connect parents and children, there needs to be space for other close contact persons as well. In such cases, it is important for further investigation of the project, how those contact persons can be included or how the interactions will change if the design stays the same.

Taking a turn

The turn taking part arose from the idea of a shared secret between two parties and not showing it from the outside. For that reason, showing the next person's turn is also integrated in the design by providing a sneak peek. However, for further research it still needs to be evaluated, how the consistency among other players can be kept in such a way.

Materialization & Shape

Regarding the intended shape of the design, it would be useful to further investigate suitable materials (e.g. foam, textile, etc.) to make the entire design more mobile and less fragile at the same time. Another opportunity would be looking more into fixed components that are provided, which facilitate and may inspire the creation process for the siblings.

Connection

In the context of this thesis, it was found that children liked the testimonials from other siblings to see that they are not alone. But only if it comes to them as a surprising element: "It's like an easter egg." (cf. 5.3 Concept testing, 6.5 Concept testing). Therefore, it is valuable to further investigate the possibilities of Robin to connect siblings not only with close contact persons, but also with like-minded siblings.

Robin

The naming "Robin" seemed confusing and was by some children more associated with a human person, rather than a special messenger. It is recommended to stick to the messenger metaphor, as additional meaning and value could be created (cf. 7.4 Concept testing). However, for future research an improved identity creation of Robin should be considered. This can for example take place on the object level itself by providing a more specific shape, such as a bird for example. There was evidence that children like a lot animals and that a messenger is stereotypically associated with a letter pigeon (cf. 5.1 Brainstorming with siblings, 5.3 Concept testing).

Questions that are still open for evaluation are as follows: Is it more inspiring or confusing for the children that Robin is shapeless? Does it inspire children to see other examples of Robin? When such questions are answered an iteration of the Robin identity can be taken into account.

9.4 Conclusion

This research project has shown that there is an urgent need to create opportunities for siblings that have a brother or sister with special needs to feel seen, understood and to be themselves in order to reduce mental stress and to allow them to feel like a child. Throughout the entire research project valuable insights have been found, and different concepts were tried out to find inspiring ways to reflect or communicate personal needs through play, which turned out to be an important element when designing interventions for siblings.

By following the research-through-design approach suggested by Stappers & Giccardi (2017), the essential interactions of playfully sharing secrets in the form of affirmations and personal wishes with each other, were identified. The key-learnings from every session with siblings were taken into further iteration in order to connect, adapt, and transform them into the final design proposal. Therefore, even though the final design may still have space for improvement as indicated in the recommendations of this master thesis, it incorporates the identified and valuable interactions for siblings. The fact that children did not realize the purpose of the final design at an early stage, seems to be a positive indication for the design goal of this thesis of being a child without reflecting what it means to be a child. However, further investigation is needed to show and prove the effectiveness of this design proposal in diverse contexts .

9.5 Reflection

Now, this journey is slowly coming to an end and there were many things I learned.

Briefly, I would like to reflect on the entire project process and the ups and downs that came along with it, but also my learning goals and my personal experience.

The process

Overall, I have to admit that I believe this process went quite smoothly. I listened and learnt a lot from other graduating students and their advice on doing participatory design research for their graduation. From the bottom of my heart I wanted to work with children in my thesis project, but I was hesitant at first and didn't dare to take up the challenge. And I am very glad that I did. I managed the ethical approval and to have uncountable opportunities to meet, chat and get to know the siblings. For that reason, I believe I did a good job in getting to know my target group I was designing for. Although at one moment I felt overwhelmed by the gathered information and I was literally swimming in the acquired knowledge - It was a privilege, but also a challenge to prioritize and make decisions. And here we reach the weak spot of my design process and the design outcome. The decision-making process made the design part a challenge, but also an exciting task for me. However, the next time I will be more efficient and involve other designers more directly, rather than running in my carousel of thoughts when it comes to designing for value.

My personal goals

My goal was to do context mapping with kids, and I definitely reached that goal. The most important realization from this is that things always go differently than expected, but that going with the flow is still the best way. Being mentally present and approachable to the children helps to create connections and they let you dive in to their world. And yet, as well prepared as I was, I kept making my same mistakes, asking two questions at once or asking too little - I am learning and I am getting there. Usually it occurred that I had the better ideas for adequate design activities just after the session, but I assume that this is also part of my learning process and only enriching my repertoire on effective design activities. I guess, I stepped into all the pitfalls one can do, but this only makes me more resilient in my future work. Otherwise, I learnt what it means to be the only responsible session researcher, how to find a balance between authority person and friend for participating children and how my attitude is mirrored in their behavior.

My take-away

I went into this project without knowing and deciding what my design will be. And I am aware that I challenged myself, especially without having this important decision made beforehand. But my goal was to dive into the research and find out what is the reasoning beyond an app or a card game. And I still remember this successful workshop with children with the letter writing and the magic spark in their eyes. Still, there was a certain disappointment in me. How can writing anonymous affirming letters lead me to a valuable design outcome? But there was this aha effect during one of my coach meetings when Pieter Jan told me: *You are designing for interactions. The key element lies in perceiving and understanding these interactions.*



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