ZACHTE WACHT

a concept promoting long-term social support for CSN parents

MASTER THESIS BY

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Master Thesis
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Design for Interaction
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This thesis is best read in two-page view.

EXECUTIVE SUMMARY

When a child with special needs is born, the lives of all family members radically change, and so does their family culture, see figure 1. For the well-being of their parents, it is crucial that they feel connected with the people in their surroundings, for fulfilling their fundamental human needs, for maintaining their connection with their surrounding culture, and to get support in the many challenges they encounter.

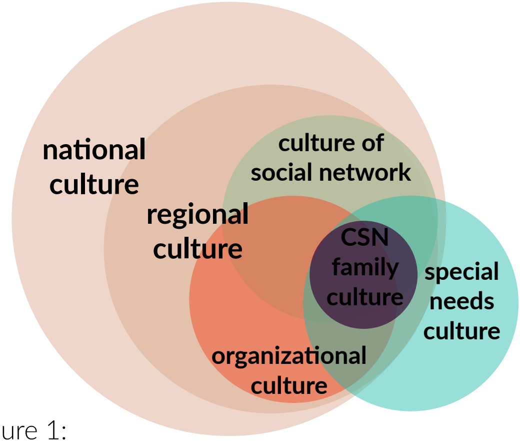

Figure 1:
the surrounding culture
& the special needs culture

Therefore, the first aim of my graduation project is to provide the designers of Ontzorghuis with an overview of information that contributes to their understanding of the bigger picture regarding the relationship between CSN parents and the people in their surroundings.

Insights from literature research, interviews with experts and contextmapping research with 6 highly educated CSN parents with Dutch heritage, have resulted in 3 overviews of information. The Opportunity Framework lays out the different levels in capacities that CSN parents desire from people in their social surroundings, going from a vague acquaintance to a close friend. The Framework of Values illustrates 3 influential values of CSN parents, to better understand what is important to them and how their coping strategies are affected. The Practical Learnings and Attitudes offers designers an understanding on a more practical level. It offers insight into the psychological challenges CSN parents can face, navigating their own and other people's expectations and attitudes.

Secondly, this project proposes a design intervention that supports CSN parents in awaking a feeling of ownership among a few people in their social surroundings.

The final design is a DIY-booklet with the following key aspects: it invites CSN parents to be soft with themselves, it promotes the common recognition and acceptance of long-term social support, and it inspires CSN parents to make it a positive event to ask for long-term support. The main message incorporated in the booklet is: it is important to be kind to yourself and it is okay to need support. First, the booklet introduces them with the novel concept of 'zachte wacht' or soft guard, a long-term social support circle for CSN parents. Secondly, it encourages them to reflect on what they expect of themselves, what they need to stay on their feet in the long term and what they can expect of people in their surroundings. Thirdly, it guides CSN parents through the steps of setting up their own support circle, the final step being a small ceremony to seal their supporters' commitment.

Although there is still room for iteration, the evaluations of 6 CSN parents demonstrated that the design is desirable for the target group. Everyone that expressed their opinion of the zachte wacht, CSN parents as well as experts, considered it to be a beautiful concept. The design capabilities, understanding of the target group, and network needed to implement the booklet and other aspects of the concept, are a perfect fit with the unique strengths of Ontzorghuis. The concept has the potential to appeal to a large and growing target group. Moreover, promising opportunities for collaborations, funding and subsidies are awaiting.

THE VALUE OF SELF-PRESERVATION

CSN parents want to survive and to protect their mental wellbeing.

POSSIBLE STRATEGY

denying or downplaying the child's condition or it's longterm consequences

WHY IS IT IMPORTANT?

CSN parents face a lifetime of uncertainty. Their child's developments often deviate from the common path of mental or physical developments and are therefore hard to predict. The consequences these conditions have on their child's and their own life on the longterm, are unclear. Important to note, is that downplaying can therefore can be a constructive strategy, and choosing to let in reality selectively can be healthy behaviour. If CSN parents were to imagine all the consequences their child's special needs in the future and the difficulties they might face all at once, it can be hard to carry on.

HOW DOES IT MANIFEST?

The value of self-preservation manifests itself in various ways. Before their child is diagnosed, many parents hold on to the thought that all will turn out allright and that their child is not that different. Parents can, for instance, be in denial of the diagnose or their child's behaviour in school or they might not comprehend the challenges the child faces. Moreover, parents take it a day, week or month at a time, to avoid thinking about an unknown future. Important variations that influence their strategies are the notablility of the disability and related to this, the age at which the child is diagnosed. A physical disability, for example, is often more easily visible than ASS and is therefore harder to downplay.

THE VALUE OF CONFORMITY

CSN parents want to succesfully participate in society.

POSSIBLE STRATEGY

trying to compete with other parents or comparing the child to other children

WHY IS IT IMPORTANT?

Human beings are social animals, and naturally crave to be p
value system bigger than themselves, such as religion, subcu
national culture. More than anything many of us desire to parti
life's main stream: go to school, get a job, start a family. Ho
child's special needs can unravel common life, forcing parents
let go of their job and miss out on social time with friends or
themselves. In some ways, the child will also not be able to fo
main stream, which might not neccesarily be a problem for t
itself, but can feel like a big loss for their parents. The danger he
parents might sometimes be very focused on their child's devel
instead of aiming to make child happy. Even though wanting to
of the main stream of life causes no trouble for most people,
CSN parents look at their lives through the main stream eye, co
maybe even fixated on their losses and lacks. CSN parents will
confronted with this, mostly when they enter mainstream territ

HOW DOES IT MANIFEST?

CSN parents sometimes regret that their child and themselves
fully participate in the main stream of life, especially when co
with milestones of children of friends or family. CSN parent do
deal with this pain around the early years. Confrontations ca

THE VALUE OF SELF-DETERMINATION

CSN parents want to create their own path, rules and identity.

POSSIBLE STRATEGY

OPPORTUNITIES IN THE SOCIAL SURROUNDINGS

others: e.g. people that a CSN parent sometimes encounters

outer circle: e.g. their social netwerk, medical staff, proffesionals

inner circle: e.g. people that are very close to a CSN parent

	open mindset	interest	imagination	empathy	involvement	intiative
interaction between CSN parents and their surroundings in reality	CSN parents are often faced with people that stare at their child or are afraid to interact with their child.	CSN parents often do not feel heard or listened to properly. Their wellbeing is seldomly a topic of conversation.	Many people have no idea what the life of a CSN parent looks like and do not recognize that their workload is far greater than that of regular parents.	Many people have misconceptions about what causes the hard parts of being a CSN parents, and overlook the beautiful parts.	People often assume or expect CSN parents to handle everything on their own, and do not consider what they could mean for them.	When people help, it is often in a passive way, like 'let me know if I can help', though parents struggle to think of anything.
desired capacities of people in their surroundings	PEOPLE HAVE AN INCLUSIVE & OPENMINDED ATTITUDE TOWARDS THE CSN AND ITS PARENTS.	PEOPLE EXPRESS INTEREST TOWARDS THE CSN AND/OR ITS PARENTS.	PEOPLE CAN IMAGINE AND UNDERSTAND WHAT THEIR LIFE LOOKS LIKE.	PEOPLE HAVE THE CAPACITY TO EMPATHIZE WITH WHAT IT MEANS TO BE A CSN PARENT.	PEOPLE EXPERIENCE SOME SORT OF SHARED OWNERSHIP FOR THE FAMILY'S WELLBEING.	PEOPLE SHOW INIATIVE TO SUPPORT THE PARENTS IN WHATEVER WAY RESONATES WITH THEMSELVES.
				r and y ations	'My friends always join me when I have to go to the hospital.'	'My sister sometimes offers to babysit so we have some time for ourselves.'
				for my alize going cially	'My brother laughed at me when I asked for his support, because he is very busy with work.'	'I would love for my friends to take me out every once in a while, because I need a day for myself.'
				an a , they	The feeling of ownership can be awakened when people feel personally addressed like when they are involved as responsible person for a specific role or invited to join a specific event, like a hospital appointment.	

PRACTICAL LEARNINGS & ATTITUDES

CSN PARENTHOOD IS MUCH MORE DEMANDING THAN REGULAR PARENTHOOD.

what you need to know as a CSN parent

Being a CSN parents is more intense and more demanding than being a regular parent. CSN parents' can struggle to distinguish their situation from that of regular parents. Even though the belief that a parent should be fully devoted their child's care is common, it does not wholy apply CSN parents, as they often need professional support. When they carry all care, responsibility and organisation on their shoulders, parents can become burned-out. Therefore, parents face the challenge to overcome these demanding beliefs and to redefine the expectations they have of themselves.

what you need to know as a bystander

Similarly, the outside world fails recognize the gravity of the impact of the CSN. Their well-being is seldomly a topic of conversation, in their social network, nor in the communication with care professionals. Of course, the fact that the world does not recognize the gravity of their situation and that their poor well-being is often overlooked is related to the fact that CSN parents fail to recognize it as well. Regardless of whether this is a chicken or egg causality, it is a viscious circle that needs to be broken, because it causes parents to hold back on organizing or asking for sufficient support to stay afloat on the longterm.

PIVOTAL EVENT	ATTITUDE
The child's special needs were announced before birth, or the child shows apparent deviation from regular development after birth.	I am a regular parent and my child is a little bit different.
There has been a diagnosis of the child's condition or the child shows obvious deviation from regular development.	I am a regular parent of a child that is officially different
Parents look around them and realize their life is radically different than that of other parents or they have been worn down over time, or even burned-out.	I am not a regular parent because my child is not regular.
When the child is younger, the parents' focus usually lies on their child's development, but as the child gets older, deviation from the main stream can become more apparent and certain limitations will become evident.	My child and I will always be different.

YOU CAN TRUST YOURSELF AND RELY ON YOUR PARENTAL INTUITION.

what you need to know as a CSN parent

When a child with special needs is born, it can often take a long time before the child is diagnosed. In many cases, parents notice or feel there is something going on with their child before it is officialy recognized. This can pose parents with strong feelings of self-doubt and powerlessness, with regards to their own intuition, their performance as a parent, and, with diagnoses that take a long time to be identied, parents might think there is something wrong with the way they raise their child.

what you need to know as a bystander

In this case, it is crucial for parents to realize that the challenges the child faces, do not lie in the parents power. Furhermore, it is important that the parent's intuition and judgement is not undermined, by bystanders from a medical background as well as from their social network.

YOU NEED TO TAKE CARE OF YOURSELF, IN ORDER TO KEEP CARING FOR YOUR CHILD.

what you need to know as a CSN parent

Related to the learning that being a CSN parent is more demanding than being a regular one, in order to be able to take care of their child with special needs, a parent needs to stay afloat. In order to stay afloat, they have to take care of themselves, invest time in the things that give them energy, time to spend on the things they find important, like quality time with other people, like a job or other passion etc. In order to have time to recharge oneself, support is needed to take care of the child in the meantime.

what you need to know as a bystander

CSN parents who do take some time for themselves, sometimes face the judgement of others. However, this time is crucial to carry on, otherwise facing the risk of getting burned-out or overworked. Their social network can even contribute to their wellbeing, by spending quality time with them, taking them out or offering to watch one of their children.

YOU SHOULD NOT HOLD BACK IN TELLING OTHERS WHAT WOULD HELP YOU.

what you need to know as a CSN parent

When it is becoming clear that your child has special needs, it will also become more and more clear that you need support of some kind. By the time you have realized this, you will still have to convince and activate others to help you. Even though the willingness to proactively help you differs within each municipality, subsidy helpdesk, hospital and social network, all parties can pose quite a challenge. An important lesson CSN parents describe, is not to only depend on the current offer or possibilities, but to actively frase what you need to stay afloat in the long term. Don't be too modest, because many people do not realize what you struggle with and what you need.

what you need to know as a bystander

The involvement of their surroundings that CSN parents experience in the time around the birth or the diagnosis of their child, rapidly decreases when a bit of time has gone by. Even though the situation is not new anymore, the struggle remains real, and is likely to even increase as the child grows older. As a baby, they might have been asleep most of the time, but as they grow older, parenthood becomes more intense. Mental and instrumental support is as relevant as ever. If you want to contribute, try to make a concrete offer, e.g. bring groceries or food, take a walk with them or invite one of their other children to come over.

IT IS OKAY TO FEEL SOMBER SOMETIMES.

what you need to know as a CSN parent

Chronic sorrow is the pain experienced if you or your loved ones, in this case, your child, is suffering from a chronical illness or disability. According to Keirse (2013), among the 'tasks' of chronic sorrow is to face the reality of the loss, experience the pain, including feelings of guilt, anger, shame, fatigue, To experience chronic sorrow means to go through loss of dreams, expectations, possibilities and perspective. These feelings are inherently connected to being a CSN parent. Parents expressed that once they stopped judging their own feelings, a weight was lifted of their shoulders.

what you need to know as a bystander

An important note is that these are not chronological stages towards a process of 'accepting' the situation. This sorrow does not fade away, but will be lived every day, including periods of intense pain. For many CSN parents, the paradigm is a relief, as it sets permanent pain apart from pathology. Instead of being seen as an unstable, gloomy parent that needs to accept reality, the theory of chronic sorrow recognizes that experiencing pain is a normal and healthy part of being a CSN parent.

PREFACE

This thesis is one of the final deliverables to complete the master program Design for Interaction, which is part of the faculty of Industrial Design Engineering at Delft University of Technology. The project addresses the context in which a large part of Dutch CSN parents struggles to maintain their well-being. In this project I was challenged to put myself in the shoes of a CSN parent. I learned that being a CSN parent is like a pressure cooker for lessons that belong to the core of life. The openhearted conversations I had with CSN parents throughout this project have given me a richer perspective on life, for which I am very grateful. I am happy that I have been able to conclude my masters with such a relevant and challenging topic. Throughout the project, I have been infinitely motivated to contribute to the well-being of CSN parents, because of the insights gained along the way and the people I had the opportunity of working with. Therefore, I would like to take this opportunity to thank these people.

First of all, I would like thank my supervisory team for your constructive supervision during this project.

Annemiek, you provided me with many interesting examples from your own experience, which were very helpful. You always offered me good feedback with great care to detail. You often expressed your enthusiasm about the things I brought to the table, which was very encouraging. We both have our very own view on certain matters, which resulted in valuable discussions.

Pieter Jan, you challenged me to keep making my own decisions. When I was too deep in my project from time to time, your high level view pulled me out. You kept a good eye on the consistency, academic argumentation and the entirety of my thesis. You were always very direct and to the point, which I very much appreciate.

Marise, I would like to thank you for confiding in me to become part of something so dear to you. You had a eye for my personal growth and you helped me to see the designer I am. It was very inspiring that I was able to verify my most recent theories and insights with you, allowing me to iterate on and perfect the frameworks. I have great admiration for what you are doing with Ontzorghuis and I feel lucky to been offered this possibility to contribute.

Furthermore, I would like to give a big thanks to the **CSN parents that have confided in me,** allowing me to interview you about such personal matters. Your stories helped me immensely to immerse myself into your experiences and therefore, to design for CSN parents. Your encouraging words, and your conviction of the importance of this project have motivated me tremendously.

Additionally, I would like to thank to **Minke, Tineke and Elise** for their expert input and enthusiasm for my project.
To **Marieke**, thank you for your valuable feedback and for challenging me to be the most nuanced version of myself.

To all the creative geniuses at **Muzus**, thank you very much for your input during the brainstorm. You helped me gain valuable new perspectives on possible directions for the design intervention. Thanks to you, the exploration phase had a kick-start.

Above all, this project and my thesis would not have turned out the way they have without the people who have been there for me during this project, my very own support circle:

Thank you to all my friends, especially **Marten and Ronja,** with whom I was able to share the experience of graduating during this peculiar time. I am grateful that we kept an eye on each other at all times. Even in these times, even during the longest individual project of our masters, I never felt alone.

Thank you to **my roommates** for the endless amount of walks we have taken together, the good times and the distractions from time to time.

Thank you **Daan**, for your endless faith in me and for making me feel calm by being around me, especially in the more stressful times.

And finally, a big thank you to **my family.** Although we had to keep our distance I have always felt your support and your belief in me.

Another of the final deliverables to complete this master program, is a showcase of the graduation project. This project is showcased in a 3-minute video, explaining the problem, the concept and the design. This video can be viewed here: *https://youtu.be/h7E5RbCiqlI*. It was subtitled for hearing-impaired people.

Dear reader, I have faith that this project will inspire you to be kinder to yourself, to ask for support when you need it, and to support others when they need it. I truly hope long-term social support circles for CSN families will be the standard in the future, and I hope that this project is able to play an important part in that process.

Enjoy the read!

Irene

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Appendices

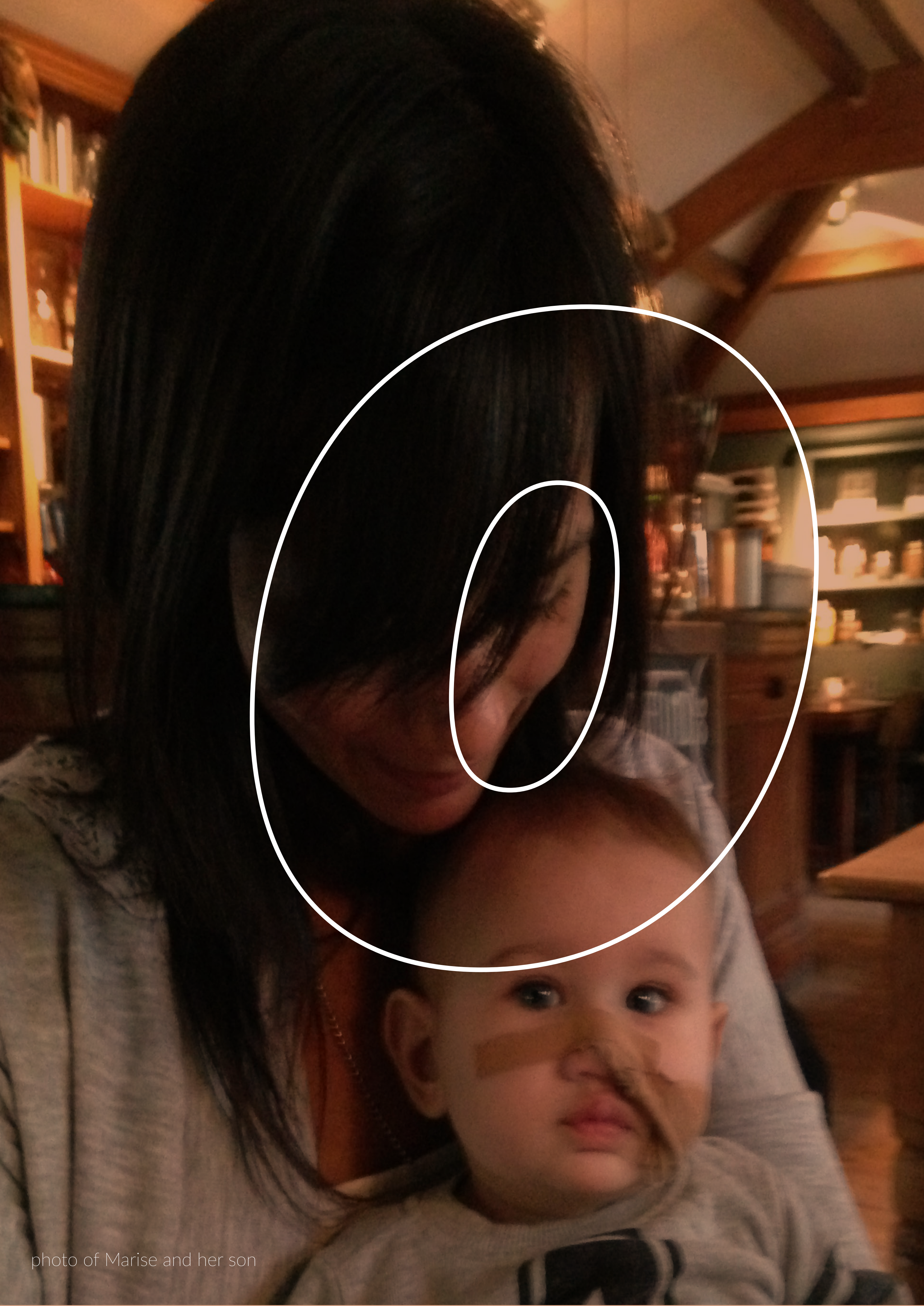
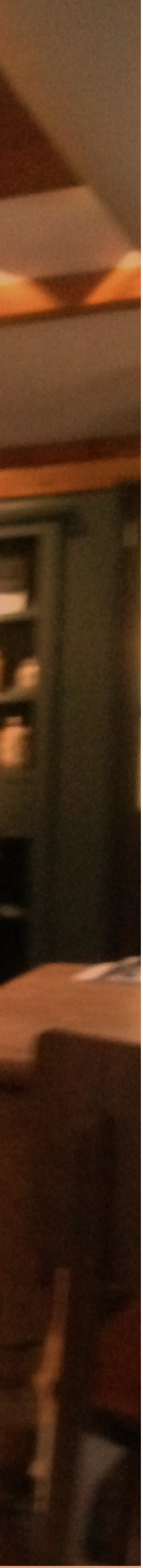


photo of Marise and her son



PROJECT INTRODUCTION

This chapter introduces the project's target group, the nature and size of the problem, the scope of the project, stakeholders and the project's overall approach.

DESIGN BRIEF

From the moment a child with special needs is born, the way their parents were used to be able to meet their own needs is no longer applicable. The parents adopt their child's needs as their own and consequently, their own needs are compromised, resulting in 60% of CSN parents becoming overworked or burned out (Okma, Naafs, Vergeer, & Berns, 2014). This is not only disastrous for the parents, but can also cause great damage to the child, who might be transferred into a care facility, instead of continuing to live with their parents. With care relievers such as homecare, one might ask how it is possible that so many CSN parents find themselves compromising their own well-being so greatly. However, it is not that simple to adapt their situation and their own response to choose the path of sustainable parenting: a balance that keeps parents going in the long term. After the birth of a child with special needs, personal growth is needed before the CSN parent can reframe and improve their current situation (Ribelles, 2020). Furthermore, after learning of their child's diagnosis, CSN families must adapt to a large variety of changes that shift their life priorities (Benson, 2006; Dyches et al., 2004; Gupta, 2007; McGrath, 2006; Ozsenol et al., 2003; Twoy et al., 2007). However, several blogposts and personal stories of CSN parents indicate that many are stuck in survival mode, taking care of their child 24/7, leaving them with no time to mentally adapt to their new situation. Furthermore, over 56% of Dutch CSN parents indicate that they feel socially isolated (Okma, Vergeer, & Berns, 'Ieders zorg!', 2015). This feeling of isolation is caused by the implications of their child's disability, making the family less mobile or flexible, and the substantial part of their hours and energy that is spend to take care of their child. According to Ribelles (2020), they also often feel misunderstood.

In short, CSN parents are up for an extremely difficult task that will last for a life time. Their workload is immense, while their capacity is limited. Even though keeping the parents going by ensuring their well-being, is the desired scenario for all parties, current care and support is mainly focused on the child (Okma, Naafs, Vergeer, & Berns, 2014). This leaves designers, such as Marise Schot from the Ontzorghuis, with a massive opportunity for improvement and therefore, a design challenge. Even though a vast amount of literature research has been conducted on CSN parents, currently there does not exist a structure or framework that represents the process of personal growth of CSN parents, in a way that can be used as a starting point for Ontzorghuis' design.

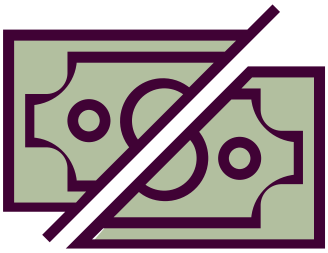
The aim of this graduation project is to identify this process of personal growth that Dutch CSN parents have gone through before reaching a state of sustainable parenting. Furthermore, I aim to identify what common challenges, values and beliefs, and successful approaches can be determined in their process. The first intended outcome is a framework of this process that designers, principally Ontzorghuis, can use as a starting point to take on the challenge to contribute to CSN parents' well-being. The second intended outcome of this graduation project is a concept that supports CSN parents in attaining a sustainable balance, based on at least one aspect of the framework. The original brief can be found in appendix A.

> **" CSN parents are in a situation where it is really hard to stay afloat, and the rest of the world does not grasp the impact it has on their lives. "**
>
> -Minke Verdonk,
> consultant for CSN parents

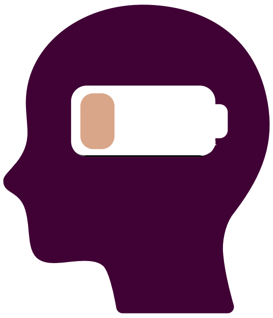
NUMBERS

In the Netherlands only, live around **500.000** parents of children with special needs (0-20 years old), making up around 3% of the entire Dutch population.

Over **50%** of Dutch CSN parents state their other children are not getting enough attention.



Over **78%** of Dutch CSN parents have decreased the hours they spend on their jobs.



Over **60%** of Dutch CSN parents have become either overworked or burned-out.

81% of Dutch CSN parents indicate that while in search for a diagnose, which can take a very long time, they receive no support for themselves.

All numbers are derived from the research of Nederlands Jeugdinstituut (Okma, Naafs, Vergeer, & Berns, 2014).

SCOPE

The project aims to find solutions for CSN parents in the Netherlands that have a child that is so care intensive that their life is disrupted. Because of the large variety of special needs that exists, the nature of their child's special needs is not specifically taken into account. Instead, the project aims to give insight about the shared experience of being a Dutch CSN parent. Therefore, the experience of parents of children with all types of special needs were taken into account. The project focuses mainly on Dutch CSN parents and their social environment. The research will demonstrate which focus group will be the primary user.

COLLABORATIONS

Ontzorghuis

The company Ontzorghuis was established by Marise Schot and Astrid Bontenbal in 2018. Marise was my company mentor in this project.

Vision Currently, health professionals are mainly focused on their patients, children with special needs, even though keeping the parents going is the desired scenario for all parties. Their long-term goal is that in the future, care is family oriented instead. They strive for a holistic approach to support CSN families, making sure all members are standing in their power.

Approach Ontzorghuis wants to help CSN parents to organize the care for their child in a sustainable way by contributing to CSN parents' resourcefulness. Examples of ways to do this are alleviating their workload, taking them out of their own context and helping them to gain new perspectives. They believe that when CSN parents are resourceful, they can find and create solutions that fit with themselves, their family and their lives.

Projects Currently, Ontzorghuis aims to support CSN parents through an online community and self-care-reflecting tools. In the near future, they will open a cooperative housing community, where parents can move in for long or short stays to enjoy 24/7 care support. The frameworks that are the result of this project, aim to inform and inspire all current and future projects and design of Ontzorghuis.

TU Delft

My supervisory team from the Industrial Design Engineering faculty consists of Dr. Ir. Annemiek van Boeijen and Prof. Dr. Pieter Jan Stappers.

Annemiek is assistant professor of Culture Sensitive Design. She recently published the book Culture Sensitive Design (van Boeijen, 2020), a guide to culture in design. In the literature and user research and design activities executed during this project, I have extensively made use of her models and theories. I believe cultural sensitivity to be a valuable quality for designers, not just when crossing borders, but when designing for any context involving people.

Pieter Jan is professor of Design Techniques. He is one of the authors of the book Convivial Toolbox (Sanders & Stappers, 2018), which offers designers a lot of theory on generative design research and many examples from practice. It is for me, and many other designers, the book that got me acquainted with context mapping. It has elevated my passion for research and I have since tried to practice generative design research in all of my design projects, including this one.

PROJECT APPROACH

Culture Sensitive Design

A lens through which the process that CSN parents go through can be viewed, is culture. '*Culture is not necessarily transmitted over a long time,' van Boeijen (2020) writes, 'but it can also be seen as a dynamic process that develops over a shorter period.*' In different contexts, we take on various roles and are a part of several cultural groups, such as family culture. Products and services influence these relationships, serving symbolic, social and utilitarian functions (van Boeijen, 2020). As van Boeijen (2020) states: 'When the target group's values are understood, product functions can be defined'. Culture sensitive design can contribute to, for example, rethinking CSN family culture and reframing the meaning of parenthood.

Phases

In this project, the research and design are centered around CSN parents. To get an understanding of their context, beliefs and needs, qualitative methods are used to conduct user research. In order to design meaningful interventions for the target group, they are closely involved in each of the 5 phases. The phases are based on the double diamond of the Design Council (2019). The first diamond, discover, is split up into 2 diamonds, Investigate and Immerse, as both involve divergent thinking followed by convergent thinking. Additionally, a final evaluation of the deliverables is performed. See figure 2.

Investigate The first phase is the designated time for exploration around the topic of parenting children with special needs. Desk research is executed about relevant historical developments, looking at e.g. the technological and cultural context. Additional information is sought through expert interviews and preliminary interviews with CSN parents. This phase results in an overview of relevant insights leading to the focus for the project.

Immerse The goal of Immerse is to deepen our knowledge about CSN parents by gathering qualitative data. This is done by means of context mapping. CSN parents are recruited and generative sessions are scheduled, ideation about set-up, probes and material take place and the sensitizing material and interview script is developed. The material is tested in a pilot interview, after which it is reviewed and sent to the participants. Multiple context mapping sessions take place. Important quotes are highlighted and clustered, in search for relevant patterns in the data. The goal is to create an overview of the information retrieved in the interviews, in a way can be used as a starting point for Ontzorghuis' designs.

Define In the third phase, the design vision and goals are defined. The decisions made in this phase form the basis for the activities described in Develop and Deliver.

Develop & Deliver The main goal of Develop is to generate and review various design solutions. It starts with an ideation session with service-designers from Muzus, followed by a week of concept development. A focus group consisting of CSN parents provides me with feedback on a number of concepts. On the basis of this feedback, the most promising concept is determined. This concept results in the final design, which is presented in Deliver. A user scenario is developed, as well as the final prototype for the user test.

Evaluate A final test with CSN parents is conducted on the basis on which the design is evaluated. This phase results in an assessment of the design based on the goals defined in phase 3, the fit on the design with Ontzorghuis, and the desirability for CSN parents. Moreover, the added value of the frameworks are evaluated.

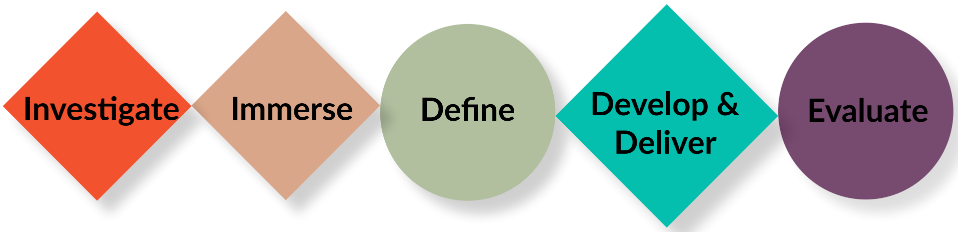


Figure 2:
The phases
of this project

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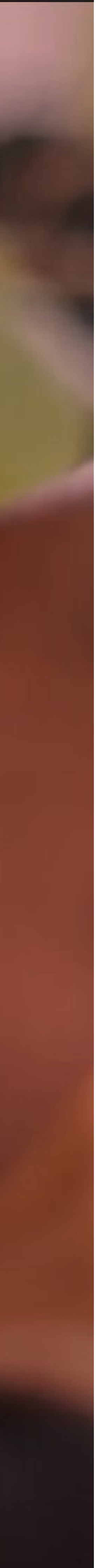
photo from 'Dit is de leven' (2019)
of Romana Vrede and her son



INVESTIGATE

This chapter lays out the findings of the investigation that was performed through literature review, desk research and interviews with experts. This investigation focuses on the different ways the well-being of CSN parents is influenced by their surroundings.

1.1 APPROACH

To get an understanding of the process parents in the Netherlands go through when they have a child with special needs, literature research and interviews were executed. The research focuses on the influence of different societal developments, the personal developments that CSN parents go through, and the impact of social surroundings and support, different perspectives, and Dutch policy on their well-being. An overview of all activities performed for this investigation, can be found on the right. The following research questions were the starting point for the investigation:

- What is the impact of large societal developments on CSN parents?
- What impact does the birth of a child with special needs have on the family?
- What changes happen between people and their social environment after having a child with special needs?
- What impact does culture have on how children with special needs are perceived?
- What impact does this perception have on the well-being of CSN parents?
- What is the Dutch perspective on children with special needs and their care?

Literature research

In order to answer the research questions previously mentioned, desk research was performed on online literature and books.

Media

Documentaries were consulted to get an holistic understanding and feel for the topic and the target group. Two documentaries that are more than worth watching are Dit is de leven (Vrede, 2019) en Zorgen voor Indy (Zembla, 2020). The first one offers great insight into different perspectives that parents and their surrounding have on children with autism. The second one captures very well the heavy load CSN parents can experience when caring for their child, and the challenges they face when trying to arrange sufficient care and facilities.

Interviews with experts

Interviews with various professionals were held in order to comprehend different perspectives on the topic and to help narrow down the scope of the project.

Minke Verdonk
Consultant for CSN parents who mentors and supports CSN parents, from a place of personal experience and a career in remedial pedagogy.

Annemarie Jansen
Teacher at a special school for children with autism who's attention mainly goes out to the children but also has regular contact with their parents.

Elise Vuyk
Location manager at Ipse de Brugge, disabled care facility, who has a lot of experience with children as well as their parents and the direction of caregivers.

Lotte Leufkens
founder of Cloudcuddle, the company that invented a bedtent to ensure the safe sleeping of children with special needs.

Marieke Sonneveld
Assistant Professor at the Faculty of Industrial Design Engineering, specialized in the end of life and expert on chronic sorrow.

Preliminary interviews with CSN parents

The CSN parents I haven spoken to definitely belong to the category 'experts' as well, since they have spent years of investigation and reflection on their child's special needs. Before scheduling the contextmapping sessions, I had a conversation with all parents involved, to hear about their experiences in a nutshell. Worth noting, is that most of the parents were very much willing to participate and tell their story, because of the urgency they experience to improve the situation for CSN parents in the Netherlands.

1.2 MACRO DEVELOPMENTS

To understand the cultural context I used the Cultura method (Hao, 2017). Cultura distinguishes 9 cultural aspects, selected from known cultural models, forming a practical tool for design. Hao added a final aspect, macro developments, although not represented in the models. She states that designers not only need to understand the importance of the current culture, but also those of the trends and developments that influence people's everyday life. Macro developments describe contextual factors of the target group, such as developments in demography, economy, and politics. They have also had their influence on children with special needs and their parents. In order to get a better understanding of the historical and cultural perspectives on disability, desk research was conducted to identify key moments in history. If you picture a Dutch CSN parent of 60 years old for example, one can only imagine the vast amount of developments that have taken place in their lifetime only. Even though it would have been immensely interesting to map all developments that have influenced the Dutch CSN parents of today, mapping all of them lies outside the scope and timeframe of this project. Instead, this subchapter presents a few developments to sensitize the reader and the writer for possible ways CSN parents' lives are affected by external factors.

1968

> **'There is no reason to feel guilty about putting a Down's syndrome child away, whether it is 'put away' in the sense of hidden in a sanatorium or in a more responsible, lethal sense. True guilt arises only from an offense against a person, and a Down's is not a person."**
>
> -the Atlantic Monthly (1968)

2020

> **'Some people tell me: you have chosen this life yourself, so it is your problem.'**
>
> -CSN parent in interview

Medical developments

Abortion is a controversial topic in many cultures. Whether the government or health services can advocate or force the decision to terminate a pregnancy or to carry on, has remained to be a subject of discussion until today. In the Netherlands, the possibility of prenatal screening, tests that can identify complications, diseases or disorders at an early stage of pregnancy, has caused years of debate, starting in the 70's. One of the biggest objections was the unavailability of acceptable treatment for the complications that such a test can identify. With terminating the pregnancy, burdening and controversial, as the only possible intervention a customary treatment was not on the table. Later in the debate the Dutch government gained a different perspective. It was argued that in a sense, selective abortion was not medical prevention, but an option to manage the situation in a way that might be acceptable or purposeful for some individuals. Since 2007, each pregnant woman in the Netherlands is informed by their health service about the possibility to undertake prenatal screening (Meijer, Stemerding, Hoppe, Schielen, & Loeber, 2012). Even though this debate has come to an end, an indescribable dilemma remains for the person who is pregnant. When the prenatal screening indicates an abnormality, the carrier of the child has to choose between ending the baby's life and having them, with a gross amount of unknowns for the future. CSN parents are sometimes confronted by critics that they have chosen this destiny themselves, which is technically true for some, but it must be noted that they did not get to choose between a healthy child and a child with special needs, they made a choice between life and death. Moreover, in many cases the child's special needs are only discovered after birth, or even in the first years of their life, meaning there was no such choice to be made.

Demographic developments

The amount of people with an intellectual disabilities is rapidly increasing in the Netherlands. Care facilities for disabled people are struggling with the rise of problematic behavior of their clients. The amount of intellectual disabled people with the indication 'severe' has grown over 55% over 7 years, up to a number of 101.960 in 2018. Van Wijngaarden (2018) states that in all care facilities for the disabled there has been an increase of severe and complex care. There are various factors at play, all a result of medical progress. Disabled people reach a higher age than ever before, and babies that would not have survived before, for instance due to an early birth, can be kept alive. In line with this medical progress, women can get pregnant at a much older age, resulting at higher chance of a child with special needs. At the same time, the amount of children with Down Syndrome is decreasing, due to prenatal screening (van Wijngaarden, 2018). The amount of pregnant woman that underwent prenatal screening for down, edwards and patau syndrome has grown from 25.3% in 2013 to 46,3% in 2018 (Liefers & Atsma, 2019).

A new vocabulary

In 2012, a whole new understanding was introduced that could describe the pain CSN parent go through. CSN parents deal with chronic sorrow, a paradigm coined by Manu Keirse. Chronic sorrow is the pain experienced if you or your loved ones, in this case, child, is suffering from a chronical illness or disability. According to Keirse (2013) the 'tasks' of chronic sorrow are as follows: - facing the reality of the loss, - experiencing the pain, including feelings of guilt, anger, shame, fatigue, -adapting to a new world with this condition and -learning to love and live life again. An important note is that these are not chronological stages towards a process of 'accepting' the situation. To experience chronic sorrow means to go through loss of dreams, expectations, possibilities and perspective. This sorrow does not fade away, but will be lived every day, including periods of intense pain. For many CSN parents, the paradigm is a relief, as it sets permanent pain apart from pathology. Instead of being seen as an unstable, gloomy parent that needs to accept reality, the theory of chronic sorrow recognizes that experiencing pain is a normal and healthy part of being a CSN parent (Keirse, 2013). The paradigm also raises some critics, as having a child with special needs risks to be seen as a misery in this light. However, one can recognize that a child that is chronically ill can cause their parent pain, without denying that in the same experience there can also exist beauty and love.

Other developments

Apart from specific medical or CSN-related developments, the more general developments in the Dutch society also have an impact on CSN parents. Think about the rise of social media use, where many individuals expose only their picture perfect lives and successes. In line with this orientation towards achievement, many Western societies are considered to be meritocracies, meaning they are built on the belief that anyone with hard work and dedication can 'make it'. This social system connects success and status directly to individual talents, abilities and efforts (Crossman, 2019). In short: you get what you deserve, or merit. Although it might be considered a noble ideal, this belief system leaves little room for children with special needs or their parents, as it does not take into account the existing conditions in which not all people receive the same opportunities. Moreover, it promotes a 'maakbaar leven' or man-made life, denying factors of coincidence. The proposition leaves the disadvantaged to belief that they are responsible for their misfortune and problems, letting the advantaged off the hook. Adding to this point, Hofstede (2020) states that the Dutch society is highly individualistic, scoring 80 out of 100 on this dimension. This means Dutch people have a high preference for a loosely-knit social framework, in which individuals are expected to take care of themselves and their immediate families only (Hofstede, 2020).

Conclusion

Macro developments have a significant influence on Dutch CSN parents. Through an immense variety of o.a. medical, social and demographic developments the current attitude towards children with special needs has been established and the context of CSN parents has been shaped. The amount of people with special needs is rapidly increasing. As a result of medical progress, babies that would not have survived before, do survive now and people with special needs live longer than ever before. At the same time, the possibility of prenatal screening, meritocracy and individualism have worsened the stigma CSN parents face, as some people believe CSN parents chose to have a child with special needs. Due to medical developments, the amount of CSN parents is rapidly increasing, while the stigma they face is worsening. This makes CSN parents an interesting target group for designers. Design can, for example, play a role in improving the attitude towards CSN parents. The paradigm of chronic sorrow sets the permanent pain that CSN parents experience apart from pathology, which is a relief for many of them. According to Manu Keirse (2013), chronic sorrow does not consist of chronological stages and it does not fade away. As a designer, it is important to know that a large part of the process CSN parents go through, cannot be optimized or improved.

1.3 CSN CULTURE&IDENTITY

An evolving CSN family culture

In different contexts, we take on various roles and are a part of several cultures, such as family culture (van Boeijen, 2020). Family culture can for example manifest in shared values, routines rituals and the division of roles within the family. The entrance of any child into a family results in adaptions in family dynamics. Furthermore, having a child causes parents to modify their life expectations, as they assume new roles (Bilgin, 2010). The whole family balance must be adjusted to this new condition (Ozsenol et al., 2003). A child with special needs can complicate this adjustment in family balance and life expectations. The arrival of any newborn requires adjustments, however, a child with special needs can cause severe and infinite demands on parents. Adjustment to a child with special needs can put CSN parents at risk for a variety of negative outcomes for their mental health (Benderix, Nordström, & Sivberg, 2006; Benson, 2006; Gupta, 2007; Hastings & Beck, 2004; McGrath, 2006; Twoy, Connolly, & Novak, 2007).

> **My son needed me so hard that I had to establish priorities in my life. I learned that you have things that give you energy and things that cost energy and what I did was that everything that cost me energy, I removed it.**
>
> -CSN parent (Ribelles, 2020)

The effects on parents' well-being depends on a large number of factors. One of these factors is the perceptibility of the illness or disability their child suffers from. Multiple studies, for example, have reported a higher level of stress among mothers of children with autism than in those of children with Down syndrome (Benson, 2006; Gupta; Hastings & Beck, 2004). Furthermore, whether the nature of the impairment is physical, intellectual, sensory or cognitive can also make a large difference for the impact on the parents. A study among Jordanian, Irish and Taiwanese mothers that investigated the maternal impact of bringing up a child with intellectual disabilities reported that mothers experienced increased stress while caring for their child (McConkey, Truesdale-Kennedy, Chang, Jarrahc, & Shukri, 2008). In addition, they showed more pessimism about the future, independent of their cultural origin, and emphasized that more severe autism symptoms were associated with higher reported parental stress (McGrath, 2006).

After learning of their child's diagnosis, CSN families must adapt to a large variety of changes that shift their life priorities (Benson, 2006; Dyches et al., 2004; Gupta, 2007; McGrath, 2006; Ozsenol et al., 2003; Twoy et al., 2007). Ribelles (2020) describes the need to reframe their life as one of the things that make CSN parents unique. For this need, their tasks are redefining what their life should look like and what the meaning of normal is and creating an adapted identity. She reports that a CSN parent had an identity shift:

> **'Finding out I was not a regular parent helped me start taking the responsibility of finding caregiving help'.**
>
> -CSN parent (Ribelles, 2020)

Taking into account the theory of van Boeijen (2020), stating that culture is not necessarily transmitted over a long time, but it can also be seen as a dynamic process that develops over a shorter period, we can state that the culture of the CSN family is evolving after the birth of their child with special needs, manifested in, for example, altered life priorities. See figure 3.

Conclusion

The arrival of any newborn requires adjustment and adaptation to new circumstances, however, a child with special needs can cause particularly severe and constant demands on parents. The conditions that parents are newly exposed to when having a child with special needs, cause them to redefine their own identity and life priorities. I will refer to the new family culture as CSN family culture.

Special needs defining identity

Cultural identity is a set of characteristics of a specific group of people. Through these characteristics, the group can be recognized and identified. The concept of identity can be described through two distinctions. One is the ascribed identity, based on fixed characteristics assigned at birth, such as skin color and sex, or assumed involuntarily later in life. The other is the achieved identity, based on what members of the group do, on how they behave and act, and on the products that surround them (Linton, 1936). A disability or chronic illness is an example of ascribed identity. This identity affects their parents identity as well, as they become CSN parents. In this way, their ascribed identity changes at a later stage of their life. This identity leaves them, involuntarily, neither were they born with it, suddenly having to navigate a new reality.

Research on this subject, refered to as 'illness-identity', or ziekte-identiteit in Dutch by Luyckx, Raymaekers, Rassart, Verdyck, and Mark (2018), describes the 4 different ways this navigation can go about. Chronic illness, he describes can have a tremendous impact on daily life, one important factor being one's self-image. According to Luyckx et al, illness-identity refers to the extent to which an illness is integrated in one's self-image.

The 4 types of illness-identity are as follows. 'Overspoeling' or flood is the case when the illness has taken over the identity and dominates the self-image. 'Verwerping' or rejection is identified when the illness is denied as part of the identity and seen as a thread to the self-image. 'Aanvaarding' or adoption refers to the situation where one has come to terms with the illness as part of theirselves. Finally, when experiencing 'verrijking' or enrichment one embraces the illness and feels that it has made them a stronger and bigger person.

Illness identity, especially flood, forecasts several domains of life quality, including emotional well-being, social functioning, energy levels, cognitive functioning and worry. For this reason illness-identity is an important concept for children with special needs and their parents. Luyckx et al (2018) claim that the concept, although infant, can give a handle to researches and clinicists in order to understand individual differences between patients. Furthermore, they state, illness identity can be used as an instrument for clinicists in order to positively effect patients' quality of life (Luyckx, Raymaekers, Rassart, Verdyck, & Mark, 2018).

Conclusion

According to Luyckx et al (2018), there are 4 types of illness-identity, categorized by the extent to which the chronic illness has become part of the identity of the CSN. These categories can a be used an instrument to understand individual difference between patients, but maybe also between informal caregivers, like CSN parents, in order to understand how to positively affect their well-being.

Acculturation strategies

In the context of this graduation project, the concept of illness-identity is an opportunity to help the social surroundings understand the CSN and their parents. Moreover, the 4 types of illness-identity can be used to research and highlight suitable strategies for the social surroundings to contribute to CSN parents'well-being. I will do the latter by drawing a parallel between the types of illness-identity and the strategies of acculturation.

Acculturation is the process of cultural and psychological change that results following meeting between cultures (Berry, 2005). In daily life, groups of people and their individual members engage in intercultural contact, producing a potential for conflict, and the need for negotiation in order to achieve outcomes that are adaptive for both parties. In the context of CSN families and their surroundings, the focus is on how these members of different groups work out how to live together, again through negotiation so that conflict is avoided. There are large group and individual differences in how involved parties go about this negotiation. Acculturation takes place in the non-dominant group, CSN families, as well as the settled or dominant group, which is the culture that is surrounding them.

John Berry distinguishes four acculturation strategies: integration, assimilation, separation, and marginalization, all leading to a different degree of satisfactory adaptations. These strategies involve the distinction between (1) a relative preference for maintaining one's heritage culture and identity, and (2) a relative preference for having contact with and participating in the larger society along with other groups.

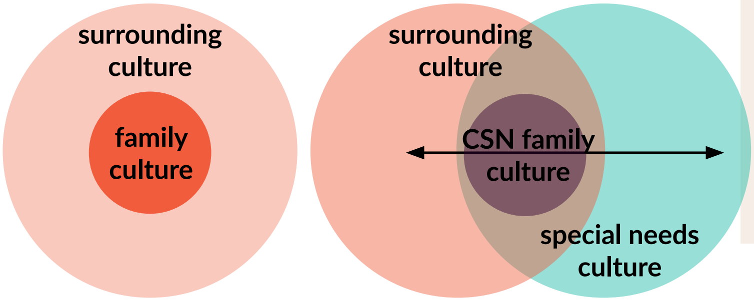


Figure 3: before and after a child with special needs is born

When members of the non-dominant group, in this case CSN families, do not wish to maintain their former cultural identity and seek interaction mostly with other CSN families, their strategy is assimilation. Here, individuals prefer to shed their heritage culture, and become absorbed into the new 'CSN culture'. Assimilation has clear parallels with flood, the illness-identity type where the illness has taken over the identity and dominates the self-image.

When the opposite is the case, and an individual wishes to hold on to their original culture while avoiding interaction with the CSN culture, Berry speaks of the separation strategy. This strategy compares well to Luyckx' rejection, when the illness is denied as part of the identity and seen as a thread to the self-image.

When there is an interest in both maintaining one's heritage culture while in daily interactions with other groups, integration is their strategy. In this case, there is some degree of cultural integrity maintained, and at the same time seeking, as a member of the original group, to participate as an integral part of the larger social network. Luyckx' adoption as well as enrichment compare to the integration strategy, with enrichment as a kind of extra successful integration.

According to Berry, there is a final strategy called marginalization, a combination that appears not to have been on Luyckx' radar. When there is little possibility to maintain in their cultural heritage cultural (e.g. by social isolation and forced changes), and little interest in having relations with others (often for reasons of exclusion or discrimination) then marginalization is defined.

Conclusion

Being a CSN parent is an ascribed identity. There is clear parallel in the theories about illness-identity of Luyckx et al (2018) and Berry's acculturation strategies (2015). Flood, rejection, adaption and enrichment respectively resemble assimilation, separation, integration and extra successful integration.

The preferred strategy

Berry states that: ‘generally, those pursuing the integration strategy, experience less acculturative stress, and achieve better adaptations than those pursuing marginalization; the outcomes for those pursuing assimilation and separation experience intermediate levels of stress and adaptation.’ Just like Luyckx, Berry claims that this conclusion applies to various indicators of mental health (Berry, 1997; Berry & Kim, 1988). We can therefore conclude that a pursuit of integration, when there is interest in both maintaining one’s heritage culture while at the same time seeking to participate as part of the ‘new culture’, is preferred.

The assimilation strategy relatively results in the most behavioral changes, where separation results in the fewest. Integration involves the selective adoption of new behaviors from the new society, and retention of valued features of one’s heritage culture. Marginalization is often connected to major heritage culture loss and the development of various dysfunctional and deviant behaviors (Berry, 2015).

Conclusion:

The parallel between the relatively infant theory of Luyckx et al (2018) and Berry’s extensive theory, his first paper on this topic stemming from 1980, is a useful one, since it shows that the process of learning to be a CSN parent is very similar to the process of acculturation, including coping strategies. Therefore, researchers and designers can take away learnings from Berry’s acculturation theory on how CSN families can successfully adapt to their new identities and altered world. Berry has shown that the healthiest and most succesful acculturation strategy is integration. Therefore, a environment that enables the CSN family to pursue integration, where they can both maintain their heritage culture, while at the same time seeking to be part of the new 'CSN culture', is desirable.

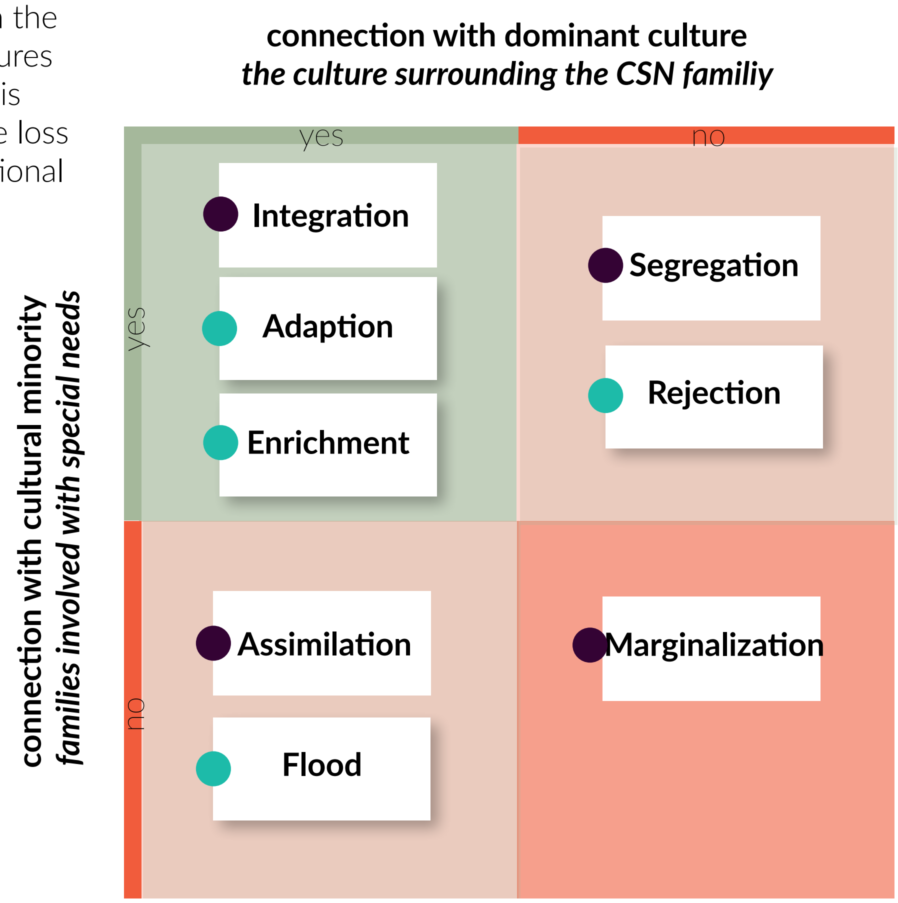


Figure 4: connecting two theories

1.4 SOCIAL SURROUNDINGS

The isolating effect of CSN

Now that it is settled that having a CSN has a radical impact on the life of parents, we take a closer look at the influence it has on the parents' relationship with their surroundings.

Having a CSN impacts the relationships parents have with friends and family. More than 56% of Dutch CSN parents indicate that they feel socially isolated (Okma, Vergeer, & Berns, 'Ieders zorg!', 2015). This feeling of isolation is caused by the implications of their child disability, making the family less mobile or flexible, and the substantial part of their hours and energy that is spend to take care of their child.

According to Ribelles (2020), they often feel misunderstood. Keirse (2013) states that part of this misunderstanding derives from the misconception that chronic sorrow is something that one has to overcome, by accepting their child's disability. Parents are dealing with a vague, non-material loss of hope, ideals and the future could have been. The sorrow is therefore often unrecognized, as no one passed away. Furthermore, parents often feel like there are missing out on the main stream of life, as their and their child's future can look very different than that of the people around them. CSN parents cannot expect an ordinary development from their child and their future is therefore very unclear. This overlooked or even disregarded sorrow can lead to a wrongful approach (Keirse, 2013). Well and ill-intended words or actions can be hurtful. ***'The ways of thinking that surround you when this happens to you, are very hard to deal with, especially coming from people close to you.'*** a CSN parent tells me, ***'There are harmful people that are a load on our shoulders and there are supportive people that give us resilience.'***

> **"From the moment my child was born, a tiger stood up in me and it never has gone back to sleep since, and that is not okay. The misconceptions are all around, the whole world feels like a thread."**
>
> -CSN parent

> **"Watch out for the mom in room 123, that woman still has not accepted her child's disability, I read on the whiteboard of the medical staff."**
>
> -CSN parent

The need for support

The group of supportive people seems crucial for CSN parents' well-being for a number of reasons. When a drastic event occurs, one of the biggest indicators for post traumatic stress is the amount of social support a person receives afterwards. An example of such an event is childbirth, as having a child is a life event for all couples. A complicated course of pregnancy, birth or neonate, and experiencing a lack of support throughout this path are among the factors most often associated with PTSS after childbirth (Federatie Medisch Specialisten, 2019). Examples of this complicated course are: indications for abnormalities after prenatal testing, medical procedures performed on the mother, and hospitalization of the child. In this article, proactively approaching the problem and searching for social support are named as two examples of effective coping mechanisms. Bilgin (2010) adds that support is crucial for all CSN parents: 'Living with children who show atypical development requires fortitude. Therefore, parents need support from both formal and informal support systems to foster efficient coping methods' (Bilgin, 2010).

Research found that important stressors for CSN parents are the lack of formal and informal support and the risk of stigmatization (Gupta; McGrath; Twoy et al.) These stresses have a disruptive effect on their well-being and integrity. Therefore, parents of children with special needs not only require the subjective societal understanding and acceptance of their children's condition but also require psychosocial and instrumental support (Gupta, 2007). Benson (2006) concluded earlier that informal parent support from family, friends, and other nonprofessionals significantly decreased depression in parents of autistic children (Benson, 2006). Similar studies have shown before that the strong support required to raise a child with special needs holds true in many cultures (Dyches et al., 2004).

The informal support that CSN parents need from their social surroundings, can take on different forms. Examples we can conclude from this literature study are instrumental or practical support, e.g. by helping out around the house or watching their other child, psychosocial or mental support, e.g. by addressing and talking about the subject, or supporting the parent to be part of the main stream, e.g. by taking them out of the house and do something fun with them.

> **'I was at the doctor's office for a consultation and he asked me, Madam, that must be hard for you, how do you do it every day, with all those worries?"**
> **I was so surprised by that question that I burst into tears, with relief that someone was looking beyond all my daughter's limitations, and dared to look at the impact on our family. His question brought strength and healing. Like my grief is a wound I keep to myself for no one to see.'**
>
> -CSN parent (Keirse, 2013)

Conclusion

Many Dutch CSN parents indicate that they feel socially isolated and misunderstood. One of the reasons is the substantial part of their hours and energy that is spend to take care of their child. Furthermore, they experience overlooked or even disregarded chronic sorrow. Important stressors for CSN parents are the lack of formal and informal support and the risk of stigmatization, which have a disruptive effect on their well-being. Therefore, parents of children with special needs not only require the subjective societal understanding and acceptance of their children's condition but they also require psychosocial and instrumental support from people around them.

1.5 ATTITUDE & PERCEPTION

Perception matters

The degree to which parents can build on the acceptance, understanding and support of their social surroundings they need, greatly depends on the culture in which they live and their perspective on disability. There is a large variety in perceptions, and the perception has a significant influence on how the situation around a child special needs are seen and experienced. When trying to grasp the possible variations in perspective, the discussion whether or not there should be special schools for children with special needs is an interesting one.

Writer Andrew Solomon has written many articles on disability. He tells the story of a woman who's daughter suffers from dwarfism, struggling with what to say to her son (Solomon, 2014): '***Should she say, you are just like everyone else but a little shorter? Or should she try to construct some kind of dwarf identity, get involved with the little people of America?***' Parents often struggle with this question: what do we validate in our children, and what do we cure in them? The way your frame disability, he states, can have an enormous impact on the way it is experienced an lived in the family. '***The women who expected to find meaning in having a child with special needs, their children did significantly better in almost every aspect. Making the choice to perceive your child as a gift makes all the difference***' (Solomon, 2014).

Societal attitudes

Let us go back to Berry. A dominant society that strives for integration, which we recall is the preferred strategy for CSN parents, is called multiculturism. Here, diversity is an accepted feature of society, including all the various ethnocultural groups. With regard to the dominant culture, a number of factors are of importance. To understand the process of acculturation both the historical and attitudinal situation that CSN families face when interaction with the settled culture are of relevance.

Some societies take on an accepting role towards cultural diversity, whereas others attempt to achieve segregation (Berry, 2015). Murphy (1965) argues that supportive societies provide for better adaptations for two reasons: they are less likely to enforce cultural change or exclusion, and they are more likely to provide social support from constitutional level as well as community level. However, even in generally supporting societies, there are known variations in the relative acceptance of specific groups, where less-accepted groups often experience rejection or discrimination. Discrimination is a predictive factor for poor long-term adaptation (Berry, 2015).

Berry (2015) describes the following conditions for integration: ***'In particular, integration can only be "freely" chosen and successfully pursued by non-dominant groups when the dominant society is open and inclusive in its orientation towards cultural diversity. Thus a mutual accommodation is required to attain integration, involving the acceptance by both groups of the right of all groups to live as culturally different people. This strategy requires non-dominant groups to adopt the basic values of the larger society, while at the same time the dominant group must be prepared to adapt national institutions (e.g., education, health, labor) to better meet the needs of all groups now living together in the plural society.'***

Conclusion

The way you frame disability can have an enormous impact on the way it is experienced and lived in the family. Individual attitudes and perspectives towards children with special needs, as well as the societal attitude, have an impact on CSN parents well-being. We can conclude that for integration to take place, we do not only have to strive for an inclusive society that avoids discrimination, the needs of the non-dominant group, in this case CSN parents should also be better met, resulting in the adaptation of national institutions like health care. For this reason, for integration- and thus an improved well-being of CSN parents- to become reality, it is crucial to be informed about their needs.

Examples of Perspectives

In order to get an understanding of the range of cultural perspectives, a few examples are pointed out. In Uganda for instance, people with physical disabilities face stigma that is fuelled by beliefs that people with disabilities are cursed. Some believe disability is caused by sin; a promiscuous mother or the wrongdoing of ancestors. Local journalist Bareebe reported that the killing of disabled children in rural Uganda is widespread, leaving the mother abandoned or even threatened by the father and the rest of the community (Al Jazeera, 2020).

Ugandan

> **"It takes a village to raise a child," Bareebe says in his report. "It seems it also takes a village to kill one. "**
>
> -Al Jazeera (2020)

Moroccan

> **"A Moroccan woman said to me: "My family tells me that I should keep my son inside, for no one to see."**
>
> -Consultant for CSN parents

Cristian

> **"I have met many people that see it this way: "It is an honor to raise this child because God thinks we can handle it."**
>
> -Volunteer of disabled children

Turkish

> **"Living with an autistic child has no benefit in this world. But, I believe it will have a lot of reward in the afterlife. This is our fate! God forbids us for more difficult days."**
>
> - CSN Parent (Bilgin, 2010)

Islamic

> **“The caregiver told me that in Islam, being a CSN parent was considered an honor since this child chose such a difficult life to go through and you, as a parent are there to help him. That’s why they believe that for that reason his light will shine on you which is a way of also getting into heaven.”**
>
> -CSN parent (Ribelles, 2020)

Dutch

> **‘Some people tell me: you have chosen this life yourself, so it is your problem.’**
>
> -CSN parent in interview

1.6 THE DUTCH ATTITUDE

Now that we are aware of possible variation of perspectives and the need for informal support, we will dive into literature about the Dutch perspective on informal care for CSN parents. Please note that within national culture of the Netherlands, there exist different subcultures. However, a general image of the national perspective can still be useful. We will start off sensitizing ourselves how Dutch CSN parents view the subject of informal care, and then we look into what their surroundings think.

CSN parents' attitude

According to the QuickScan by the Dutch Institute for Juveniles over half of the 100 responding CSN parents indicates that their other children are receiving insufficient attention, 78% of the parents started working less and 60% becomes overworked or burned-out. They conclude that the workload (or draaglast) that Dutch CSN parents carry is considerable, while their capacity (draagkracht) is relatively small, see figure 5. Therefore, it is very important to be well-informed about the support that parents and their surrounding need, in order to endure the care as long and good as possible (Okma, Naafs, Vergeer, & Berns, 2014).

Asking for support

In the same QuickScan, a statement presented to these respondents is: I can even better utilize my social network in the support of myself and my family. 75% of the respondents indicate the support of their social surroundings currently cannot be utilized to a higher extent than is the case right now. Reasons that parents name are that the care for their child is too specific, their network refuses to help, lives too far away or is not capable of supporting them. However, when looking into the 17 complimentary quotes, not only practicalities, but also attitude seems to play a role. Parents say they feel like they should be able to handle everything on their own, they value independence too much to ask for support or they do not want to burden their social network. Some say they feel like they should not ask their network, because they feel it is just not-done. Parents indicate they have difficulty expressing they need help, and they don't know what help they can ask for. Furthermore, they indicate network is not aware of the gravity of their situation and parents indicate they do not know how and what to ask for (Okma, Naafs, Vergeer, & Berns, 2014).

Minke Verdonk, consultant for CSN parents, mentions to same phenomenon in an interview with me. An important reason parents do not look to change their situation, she says, is because they do not recognize that their situation deviates profoundly from other parents, and they in fact, are dealing with a totally different kind of parenthood than other parents. Because they fail to distinguish themselves from regular parents, they feel they should solve their own problems, causing them to only ask for help when it is strictly necessary, which is often too late. Moreover, she states, the outside world does not recognize the gravity of the impact of the CSN. Their well-being is seldomly a topic of conversation, in their social network, nor in the communication with care professionals. Because of the intensity of the care and everything that comes with it, CSN parents are not in the opportunity to care good care of themselves. Together with the lack of attention on their well-being from the outside, they seldomly reflect on their own well-being (personal communication, October 21, 2020).

The viscious circle

Of course, the fact that the world does not recognize the gravity of their situation and that their poor well-being is often overlooked is related to the fact that CSN parents fail to recognize it as well. Regardless of whether this is a chicken or egg causality, it is a viscious circle that, in my opinion, needs to be broken.

All quotes on this page were derived from the Quickscan (Okma, Naafs, Vergeer, & Berns, 2014)

> **‘People get the idea that we are fine. But little things can help us out a lot. I would be nice if people offer support in a concrete way, instead of: let me know if I can help.’**

> **‘In Twente it is common to support your neighbors. I mow their lawn, they watch our other children from time to time.’**

> **‘I am not going to ask my friends for support. You just don′t.’**

> **‘I might not tell my network explicitly enough what I need. I am used to being tough. ’**

> **‘I think our network can support us more, but we are too modest to ask: ′we are fine, we′ll make it.′ We are not asking enough, and others don′t see how hard it is for us.’**

> **‘It is important that friends and family understand what it means to be a CSN parent, so they can support you and the other children. ’**

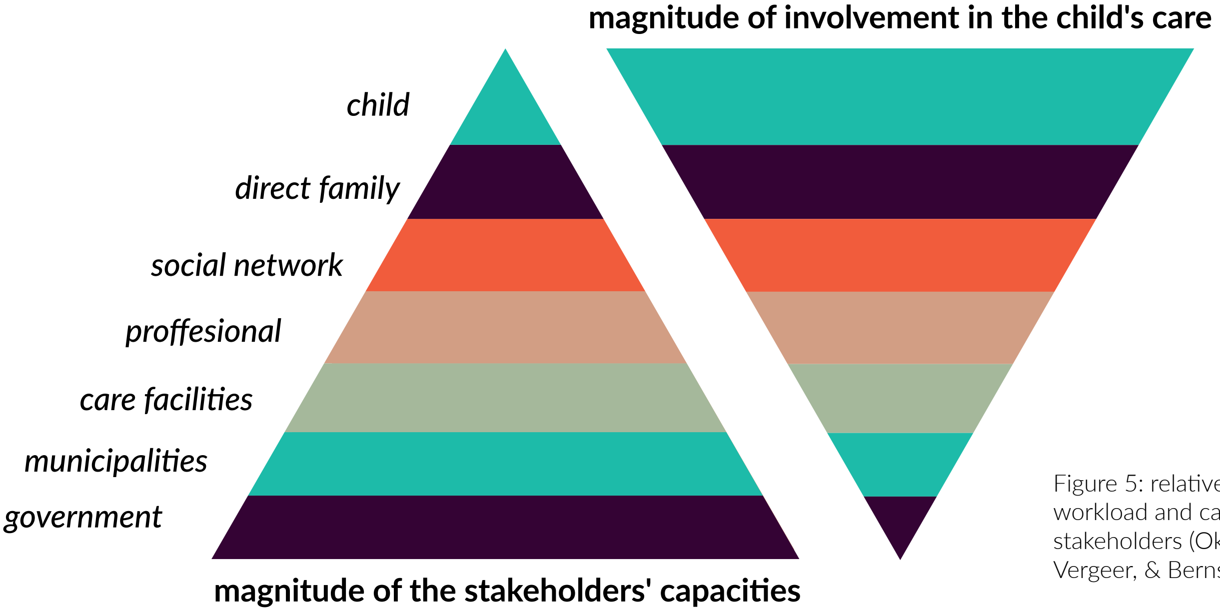


Figure 5: relative workload and capacity of stakeholders (Okma, Naafs, Vergeer, & Berns, 2014)

Desiring support
Even though most parents may not feel like they can ask for more social support, they do seem to desire social support. Different wishes are named, which can be divided into instrumental and psychosocial support, like Gupta (2007) stated. They mention more instrumental wishes like: cooking from time to time, not having to watch their children for an hour, a bit of time for themselves, and their other child playing with other children without having to watch over them. Wishes regarding psychosocial support include: talking about how I feel and experience the situation, feeling that they care and understand what life is like with a CSN, and being able to talk about not only the sunny side, but also the darker side.

Parents have difficulty recognizing and expressing they need help, and they don't know what help they can ask for. Interestingly enough, not being familiar with possible types of support might also be the reason only 25% of Dutch CSN parents thinks they can utilize the support of their social network. Looking at the statement they were presented with, the DIJ seems to have had a bit of a blind spot as well. According to Health Behavior and Health Education (2020) there are four kinds of social support:, instrumental, informational, appraisal, and emotional, which is what Gupta (2007) refers to as psychosocial. The way the statement was framed by the NJI, 'utilize my social network', instrumental support seems, unrightfully so, to get a dominant role in much larger set of possibilities.

The surrounding attitude

Now that we are sensitized for the attitude of Dutch CSN parents, let us take a look at how their social surrounding feels about informal support. For this purpose, the main source was the report 'Voor Elkaar' of the Sociaal en Cultureel Planbureau (de Klerk, de Boer, Plaisier, & Schyns, 2017).

Broese van Groenou en De Boer (2016) differentiate whether a bystander 1) wants to help, based on the connection they have with the person in need of support, 2) whether they can help, linked to barriers and restrictions, and 3) whether they feel they should help, based on norms and values.
1) Whether a person supports another person, depends on their relationship: the people that do not support anyone although do know someone who needs support, often are further away than direct family, like grandparents, friends or neighbors. 2) Restrictions like a day job, no time or large distance can play a role. 3) Experiences and attitude matter. For example, people that have worked in healthcare and people that regularly go to the church, synagogue, or mosque are more likely support other people (Broese van Groenou en De Boer, 2016).

Diving into the norms and values, in 2016 the majority (60%) of Dutch people thought that people should have family or friends in need. This does not main they felt that support should mainly be provided by their social network: 63% of Dutch people thought that support should be a responsibility of the government. The amount of people that thinks that people in need of care because of a disability, should receive this care from friends, family and neighbors as much as possible has decreased, from 41% in 2010 to 23% in 2016. Finally, people only want to help if it is really needed and appreciated. This suggests that Dutch people feel there are boundaries to the support they give their network (de Klerk et al, 2017). A possible explanation for this decrease is the rise of individualism. CBS (2017) describes that not only the importance of classic patterns of forming a relationship and family has declined since the beginning of the century, Dutch people have become more independent in a variety of ways. People are increasingly seen as autonomous individual, instead of member of a family, church or neighborhood.

In 2016, 64% of Dutch people over 16 years old is not active as informal care giver. Roughly, this comes down to 11 million people. 68% of these people says they are willing to support someone, 40% says they have time. In total, 25% of the 'not-supporters' indicates they are willing and capable of supporting someone. These are roughly 2.7 million people. The same number was 29% in 2014 (de Klerk et al, 2017). De Klerk et al (2017) states that people feel that people should help others, but it should be incidental and supplementary to professional care. She suggests that people could play a role in unburdening the main caregiver(s). The fact that is not happening, could be due to a shortness in supply as well as demand. Not-supporters might not know what to help with. Moreover, the person in need could also be more accepting towards support, even though CSN parents know their child prefers to receive their support. Because informal caregivers of partners or children are frequently overloaded, stimulating them to divide the care over a group of people or take on respite care is an important measure to avoid overload or burn-outs (de Klerk et al, 2017).

Conclusion

According to the QuickScan by the Dutch Institute for Juveniles the workload (or draaglast) that Dutch CSN parents carry is considerable, while their capacity (draagkracht) is relatively small. Therefore, it states, it is very important to be well-informed about the support that parents and their surrounding need, in order to endure the care as long and good as possible (Okma, Naafs, Vergeer, & Berns, 2014). De Klerk et al (2017) adds that stimulating CSN parents to divide the care over a group of people or take on respite care is an important measure to avoid overload or burn-outs.

In these goals, various challenges in acknowledgement and attitude arise. In the same Quickscan, CSN parents say they feel like they should be able to handle everything on their own, they are too proud to ask for support or they do not want to burden their social network, or they feel they should not ask their network, because they feel it is just not-done. Parents indicate they have difficulty expressing they need help, and they don't know what help they can ask for. Furthermore, they indicate they do not know how and what to ask for (Okma, Naafs, Vergeer, & Berns, 2014). Minke Verdonk, consultant for CSN parents, states that an important reason for these rejecting attitudes towards asking for support stem from the inability to distinguish their situation from that of regular parents. Similarly, the outside world fails to recognize the gravity of the impact of the CSN. Their well-being is seldomly a topic of conversation, in their social network, nor in the communication with care professionals.

In the Netherlands, there is a significant amount of people, roughly 2.7 million, stating that they are willing and available to support others. It is not clear if these people would also support people that are in need a care because of a disability. However, the role they could play in unburdening the main caregiver(s), is a promising opportunity. An important limitation for this opportunity is that the network of CSN parents might fail to recognize that they can use help. In both groups, attitude, norms and values, seem to stand in the way of this opportunity as well. Only a part of their social surroundings is willing to offer support, and they might not know how to help.

A huge opportunity lies in making the gravity of CSN parents situation apparent and perceptible, for both themselves and their surroundings. Furthermore both groups, CSN parents and their surrounding, can benefit from awareness about the variety of social support types and how they might manifest.

Dutch policy

The trends that can be seen in the Dutch society are, not surprisingly, similar to the ones in Dutch policy. A recent article of NRC (Adriaanse & Rusman, 2020) describes that Mark Rutte, who has been the Dutch prime-minister for the past 10 years, has had a clear vision in mind. When studying his policies, actions and words, his vision becomes apparent: people in the Netherlands should become more independent and autonomous, and take responsibility for their own well-being. He was, however, not the only one. All parties, alongside whom Rutte has ruled, have been telling the same tale of 'personal strength' and 'being autonomous together' since 2014. The king, Willem Alexander, said it too, in his King's speech: "It is undeniable that in our current network- and information society, people have become more outspoken and independent than before. Combined with the need to reduce our governments' scarcity, this results in the slow but definite change that turns our welfare state (verzorgingsstaat in Dutch) into a participation society. We ask everyone to take responsibility for themselves and their surroundings."

According to sociologist Oudenampsen, the societal change that all parties refer to does indeed exist, as the possibility and the desire to be more autonomous have increased. However, he says, this change has been cranked up by Dutch policy (Adriaanse & Rusman, 2020). This shared governmental vision has been actualized over the past 10 years in reformations, decentralizations and new policies. In 2015, the responsibility of care for juveniles and care for the chronically ill were handed to municipalities. In the same year, under the name Participation Law, municipalities became responsible to ensure an increase of formerly unemployed people going to work again. At the same time, their budget was cut down with over 1.5 million euros. Since the decentralizations in 2015 municipalities need to request all in need of care and support, to appeal to their own network (Adriaanse & Rusman, 2020). For this reason, in the Juvenile Law has been added that when having trouble with raising a child, families have the right to create a network support plan (familiegroepsplan in Dutch) that has been drawn up in collaboration with other family members, friends, neighbors and involved care professionals. Municipalities are therefore obligated to notify these people of their right to create this plan, to facilitate the create of the plan, and to ensure possibility of setting up support on the basis of this plan (Nederlands Jeugdinstituut, 2017). However, research outcomes from 2018 described by NRC, imply that in practice, municipalities are holding back on requesting people in need of support to appeal to their own network. Moreover, other research that year shows that the amount of responsibility that people are capable of taking on, has been overestimated (Adriaanse & Rusman, 2020).

Conclusion

As a result of Dutch policy, organizing support and care for juveniles and the chronically ill is left to the responsibility of municipalities, who on their turn leave the responsibility to the people in need to appeal to their network. For this reason, parents in need should, in theory, be offered the possibility to create a network support plan and to organize informal and formal support according to this plan. In practice however, research indicates that municipalities have been holding back to notify people of this responsibility and likely also their rights to create a network support plan. Here we can see a gap between intention and reality, born out of inability of Dutch municipalities, greatly affecting CSN parents and their well-being. This gap leaves an opportunity for design to find a way how to realistically and desirably support the involved parties in organizing care around a child with special needs.

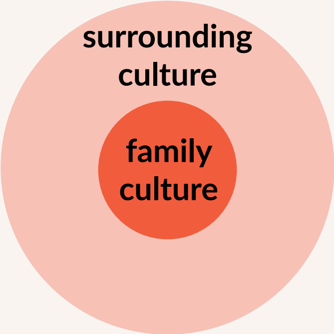
1.7 KEY TAKE-AWAYS

The key take-aways of the investigation phase, consist of two parts. First, a line of argumentation (1-5) is made for the desired scenario with regards to the well-being of CSN parents. Secondly, the roles that three important groups of stakeholders play in the possible realization of this scenario, are elaborated upon.

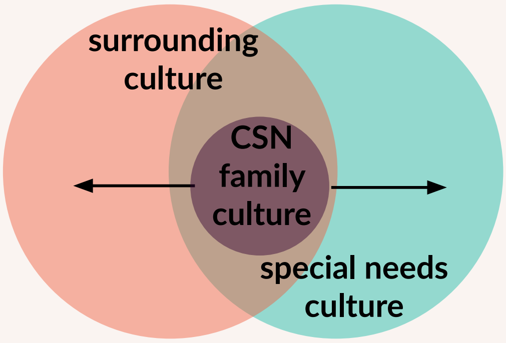
The desired scenario

1. When a child with special needs is born, the family is subjected to many changes.

The arrival of any newborn requires adjustment and adaptation to new circumstances, however, a child with special needs can cause particularly severe and constant demands on parents. The conditions that parents are newly exposed to when having a child with special needs, cause them to redefine their own identity and life priorities. I will refer to this new family culture as CSN family culture.



before a child with special needs is born:
The family culture is a product of their surroundings.



after a child with special needs is born:
The family must negotiate between two cultures.

2. The child's special needs can affect the family's identity & culture in different ways.

Being a CSN parent is an ascribed identity. According to Luyckx et al (2018), there are 4 types of illness-identity, categorized by the extent to which the chronic illness has become part of the person's identity. Flood is when the illness has taken over the identity and dominates the self-image. Rejection is identified when the illness is denied as part of the identity and seen as a thread to the self-image. Adoption refers to the situation where one has come to terms with the illness as part of themselves. Finally, when experiencing enrichment one embraces the illness and feels that it has made them a stronger and bigger person. These categories can be used an instrument to understand individual differences between patients, as well as informal caregivers like CSN parents, in order to positively affect their well-being.

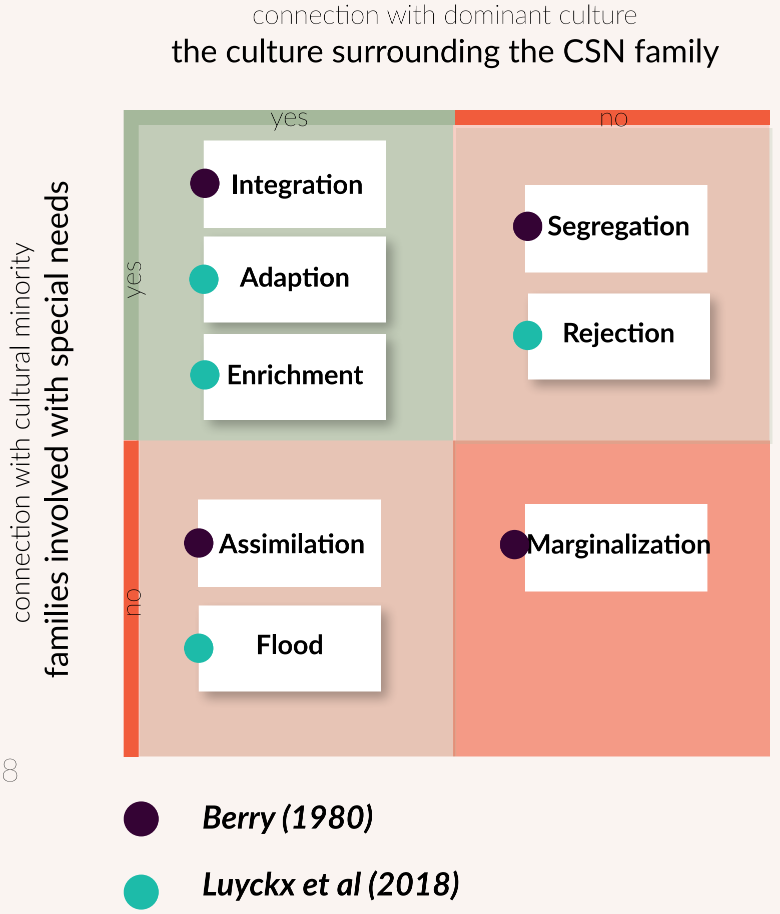
3. The family must find a balance between the culture that is newly part of them and the culture that is still surrounding them.

There is clear parallel in the theories on illness-identity of Luyckx et al (2018) and Berry's acculturation strategies (2015). Flood, rejection, adaption and enrichment respectively resemble assimilation, separation, integration and extra successful integration. The parallel between the relatively infant theory of Luyckx et al (2018) and Berry's extensive theory, his first paper on this topic stemming from 1980, is a useful one, since it shows that the process of learning to be a CSN parent is very similar to the process of acculturation, including coping strategies.

4. Integration is the healthiest and most succesful balance that a CSN family can find.

Researchers and designers can take away learnings from Berry's acculturation theory on how CSN families can successfully adapt to their new identities and altered world. Berry has shown that the healthiest acculturation strategy is integration. Therefore, an environment that enables the CSN family to pursue integration, where they can both maintain their heritage culture, while at the same time seeking to be part of the 'new CSN culture', is desirable.

5. For integration to take place, families need to be able to maintain their connection with the mainstream culture, as well as finding a connection with their cultural minority.



In this project, my focus lies on the sustention of the connection between CSN parents and the mainstream culture.

Desired scenario The birth of a child with special needs brings about significant changes, carrying out a development in the culture and identity of the whole family. There are multiple ways in which this development can take place, yet there is one way that is most desirable, with regards to the well-being of the CSN family. There are certain conditions for this desired scenario, called integration, to manifest. Not only does the CSN family need find a connection to the cultural minority of families involved with special needs, they also need to continue to feel connected to the mainstream culture, surrounding the family.

Focus In order to narrow down the challenge that will be taken on in this design project, the focus will be on sustaining the connection between CSN parents and the culture surrounding them. The results of the investigation described in this chapter, indicates that there is much room for improvement in this area, leaving a serious opportunity for design. On the following pages, the preliminary analysis on the current room for improvement is summarised.

The current scenario

The surrounding culture Through an immense variety of, among others, medical, social and demographic developments the societal attitude towards children with special needs has been established and the context of Dutch CSN parents has been shaped. The culture that CSN parents are surrounded by, does not only consist of the national culture. In the investigation described in this chapter, other types of cultures also proved to have an influence on the parents, see the figure below.

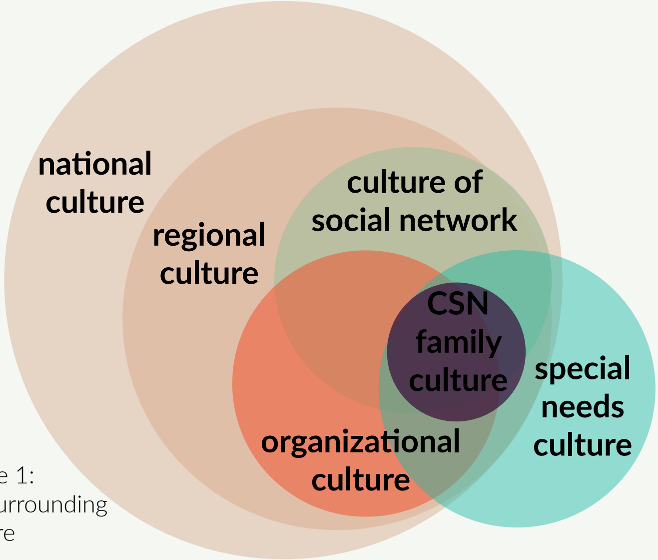


Figure 1: the surrounding culture

Stakeholders in the surrounding culture

- CSN parents are affected by the **national and regional culture**, which manifests itself in the societal attitude towards families involved with special needs.

- Furthermore, the **organizational cultures**, in for example healthcare, have an impact. The attitude of care facilities and proffesionals, as well as how the public domain, goverment and municipalities, treat this group, have shown to mark CSN parents' experiences.

- Lastly, CSN parents well-being is influenced by the culture of their **social network**, consisting of friends, family, neighbours etcetera. Also the extended family, such as caretakers of the child, belongs in this group, when they are regularly present around the house.

Now that the cultures of influence are elaborated, we take a look at the status quo regarding the connection between CSN parents and these cultures.

CSN families need to live in an inclusive society that understands their needs.

The way you frame disability can have an enormous impact on way it is experienced an lived in the family. Individual attitudes and perspectives towards children with special needs have an impact on CSN parents well-being, as well as the societal attitude. An important stressor for CSN parents is the risk of stigmatization, which has a disruptive effect on their well-being. Therefore, parents of children with special needs require the subjective societal understanding and acceptance of their children's condition. We can conclude that for integration to take place, we do not only have to strive for an inclusive society that avoids discrimination, the needs of the non-dominant group, in this case CSN parents should also be better met, resulting in the adaptation of national institutions like health care. For this reason, for integration- and thus an improved well-being of CSN parents- to become reality, it is crucial to be informed about their needs.

Unfortunately, Dutch CSN parents experience isolation and misunderstanding.

Many Dutch CSN parents indicate that they feel socially isolated and misunderstood. One of the reasons is the substantial part of their hours and energy that is spend to take care of their child, causing them to loose touch with their network. Furthermore, they experience chronic sorrow that can be overlooked or even disregarded by their network as well as care proffesionals.

To stay afloat and take care of their child, CSN parents need different kind support.

According to the QuickScan by the Dutch Institute for Juveniles the workload (or draaglast) that Dutch CSN parents carry is considerable, while their capacity (draagkracht) is relatively small. Therefore, it states, it is very important to be well-informed about the support that parents and their surrounding need, in order to endure the care as long and good as possible (Okma, Naafs, Vergeer, & Berns, 2014). An important stressor for CSN parents is the lack of formal and informal support, which have a disruptive effect on their well-being. Therefore, parents of children with special needs require psychosocial and instrumental support. De Klerk et al (2017) adds that stimulating CSN parents to divide the care over a group of people or take on respite care is an important measure to avoid overload or burn-outs.

Unfortunately, their need for support is often overlooked or disregarded by themselves and by their network.

In these goals, various challenges in acknowledgement and attitude arise. In the same Quickscan, CSN parents say they feel like they should be able to handle everything on their own, they are too proud to ask for support or they do not want to burden their social network, or they feel they should not ask their network, because they feel it is just not-done. Parents indicate they have difficulty expressing they need help, and they don't know what help they can ask for. Furthermore, they indicate they big part of their network fails to recognize that they can use help and they do not know how and what to ask for (Okma, Naafs, Vergeer, & Berns, 2014). In both groups, attitude, norms and values, seem to stand in the way of this opportunity. Only a part of their social surroundings is willing to offer support, and they might not know how to help.

CSN parents as well as their surroudings need to recognize they are not regular parents.

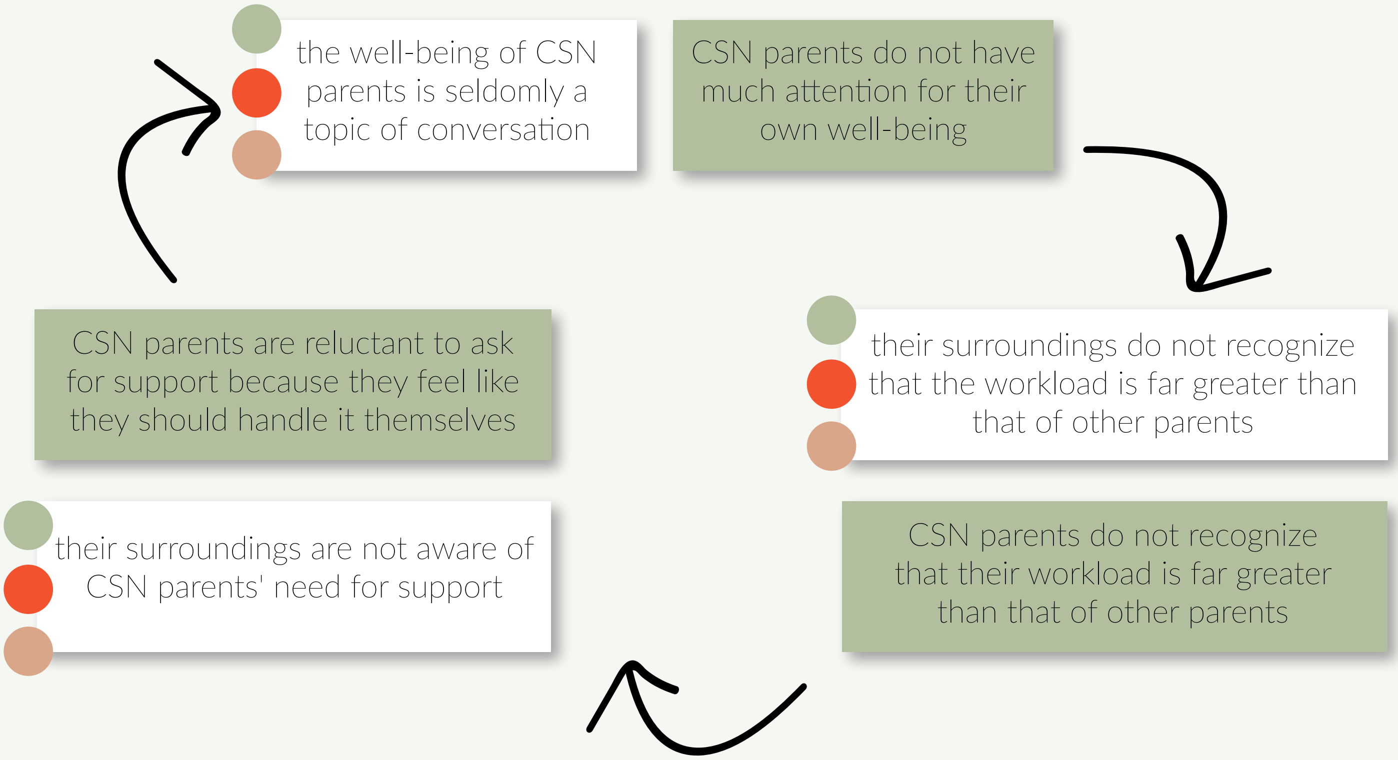
Minke Verdonk, consultant for CSN parents, states that an important reason for the rejecting attitudes towards asking for support stem from the inability to distinguish their situation from that of regular parents. Similarly, the outside world fails recognize the gravity of the impact of the CSN. Their well-being is seldomly a topic of conversation, in their social network, nor in the communication with care professionals.

Of course, the fact that the world does not recognize the gravity of their situation and that their poor well-being is often overlooked is related to the fact that CSN parents fail to recognize it as well. Regardless of whether this is a chicken or egg causality, it is a viscious circle that, in my opinion, needs to be broken. See figure 6.

A huge opportunity lies in making the gravity of CSN parents situation apparent and perceptible, for both themselves and their surroundings. Furthermore both groups, CSN parents and their surrounding, can benefit from awareness about the variety of social support types and how they might manifest.

Millions of Dutch people willing to support others, form a promising opportunity in supporting CSN parents.

In the Netherlands, there is a significant amount of people, roughly 2.7 million, stating that they are willing and available to support others. It is not clear if these people would also support people that are in need a care because of a disability. However, the role they could play in unburdening the main caregiver(s), is a promising opportunity.



the well-being of CSN parents is seldomly a topic of conversation

CSN parents do not have much attention for their own well-being

their surroundings do not recognize that the workload is far greater than that of other parents

CSN parents do not recognize that their workload is far greater than that of other parents

their surroundings are not aware of CSN parents' need for support

CSN parents are reluctant to ask for support because they feel like they should handle it themselves

Figure 6: the viscious circle as described by Minke Verdonk, consultant for CSN parents

Dutch municipalities do not fulfill their promises.

As a result of Dutch policy, organizing support and care for juveniles and the chronically ill is left to the responsibility of municipalities, who in their turn leave the responsibility to the people in need to appeal to their network. For this reason, parents in need should, in theory, be offered the possibility to create a network support plan and to organize informal and formal support according to this plan.

In practice however, research indicates that municipalities have been holding back to notify people of this responsibility and likely also their rights to create a network support plan. Here we can see a gap between intention and reality, born out of inability of Dutch municipalities, greatly affecting CSN parents and their well-being. This gap leaves an opportunity for design to find a way how to realistically and desirably support parents and their network in organizing care around a child with special needs.

2

IMMERSE

This chapter describes the user research that was performed to immerse myself into the lives of CSN parents and the process they go through after having a child with special needs. The focus, research activities, method and most importantly, the results of this research, the frameworks, are presented in this chapter.

2.1 APPROACH

The challenges and opportunities described in the last chapter were a driver to further research the challenges CSN parents face with regards to feeling connected to the culture that surrounds them. Furthermore, I want to get a better understanding and feel for what they went and go through, after having a child with special needs. I want to use this understanding to communicate their story through design, aiming to create awareness, understanding and acceptance from their surroundings. The take-aways of the investigation led to a design question, which in its turns led to multiple new research questions.

> Design question:
>
> **How can design support the connection between CSN parents and their surrounding?**

Research questions:

Family culture

- What are the values, conceptions and approaches that CSN parents embody between the moment they know the child is on its way and the present?
- Is there a certain universal development in these conceptions and approaches?

Care community

- Who are the people that are generally part of the care community of the child? And who are not? What are common developments in this community?
- What do CSN parent feel they can ask from people in and outside of this community?

Influence from the outside

- How do people in their surroundings deal with them and how does this effect the parents?
- How does it effect their relationship with other people?

Possible solutions

- Do CSN parents experience a gap between themselves and their surroundings?
- If so, what gap is most important to bridge? With what stakeholder?
- How do CSN parent think we might we bridge this gap?

Activities

Creating materials

A sensitizing booklet was designed, containing exercises to support CSN parents in reflecting on certain topics. In addition. the interview set-up and questions were prepared.

Pilot interview

In the pilot interview, I tested all materials to see whether they were understandable and whether they raised the desired conversation. Marise was the CSN parent I interviewed. The pilot interview was performed exactly like the official interviews were planned. Afterwards, all material is revised and the booklets were sent to the participants.

Interviews with 6 CSN parents

Through video calling, I spoke to CSN parents about their booklets. The final part of the interview was a generative exercise in Miro, where they brainstormed about possible solutions.

Analysis

By doing on-the-wall analysis, I looked for patterns in a large number of important quotes from the transcriptions. Several patterns were found.

Creating the frameworks

In order to communicate and explain the patterns I found, three different visual representations were made.

Review workshop framework

The frameworks were reviewed with two CSN parents and revised afterwards, adding more nuance. In total, 6 different versions were created before the final versions were included in this report.

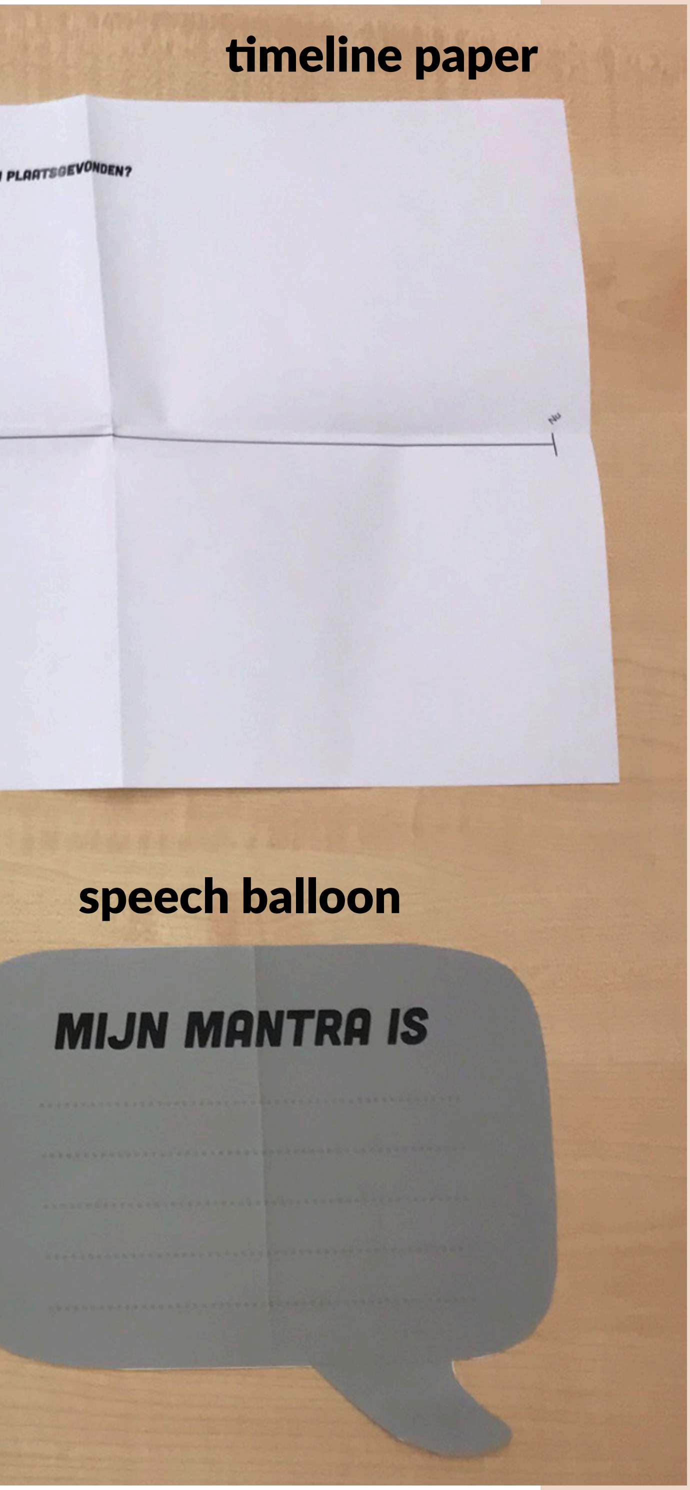
Method

The questions previously mentioned are answered by means of qualitative research on CSN parents, more specifically, through contextmapping. Context mapping is a known research method for bringing to light latent needs and implicit knowledge (Sanders & Stappers, 2018). The parents' values I am interested in are, for example, often latently present. They only arise when value conflicts take place (Ozkaramanli, 2017).

Contextmapping was chosen as a research method because I believe that to truly meet CSN parents' needs, they need to be involved as experts of their own experience. Two important aspects of this method are the sensitizing exercises before the contextmapping session and the generative exercise during. In the sensitizing exercises, the participants are asked to reflect on certain topics e.g. by means of a triggering booklet. The generative exercise involves making something, thinking of possible solutions.

For this user research, sensitizing booklets were sent to the participants a week before the interviews. Through videocalling, semi-structured interviews of 1.5 hours were conducted. The results were processed through on-the-wall analysis (Sanders & Stappers, 2018).


thankyou card
BEDANKT VOOR JE DEELNAME
DAG 1
WAT VOOR GEBEURTENISSEN & BESLISSINGEN HEBBEN
Kind op komst
Geboorte
HOE HEB IK DEZE MOMENTEN ERVAREN?
ANDERS
NORMAAL
EIGENZINNIG
RAADSELACHTIG
VRIJGEVOCHTEN
EEN ZORG
TROTS
EENZAAM
ONGEDULDIG
GESUPPORT
OVERWELDIGD
JALOERS
SOOB
ALLEEN
PUUR
BEGREPEN
ONTWAPEND
ONBEGREPEN
VRIJ
BANG
UNIEK
MINDFUL
EEN KRACHT
BIJZONDER
EEN BRON VAN...
IN DE STEEK GELATEN
ONDOORGRONDELIJK
ONTWAPENEND
trigger words
MIJN LEVEN ALS MANTELOUDER
Dit boekje is van:
Ons gesprek vindt plaats op:
Datum
Tijdstip
Ontzorghuis
TU Delft
sensitizing booklet



Material

Requirements

Key to the method of contextmapping is to sensitize your participants during the days before the interview through triggering exercises. Since the topic can be sensitive, I wanted to offer the sensitizing material in a way that the participants could do the exercises in a private and personal way. Parents might not want to fill out their private thoughts and feelings on the internet. Because many parents and their children are at home due to Covid19, I tried to create a situation where they could do the necessary reflecting on their own. Furthermore, the material needed to be versatile for both online and offline interviews. Therefore, I designed paper booklets to fill out, accompanied by stickers, a speech balloon to express their mantra, an extra A3 for a timeline exercise and a thank you card. To check out the booklet in detail, I refer you to appendix B.

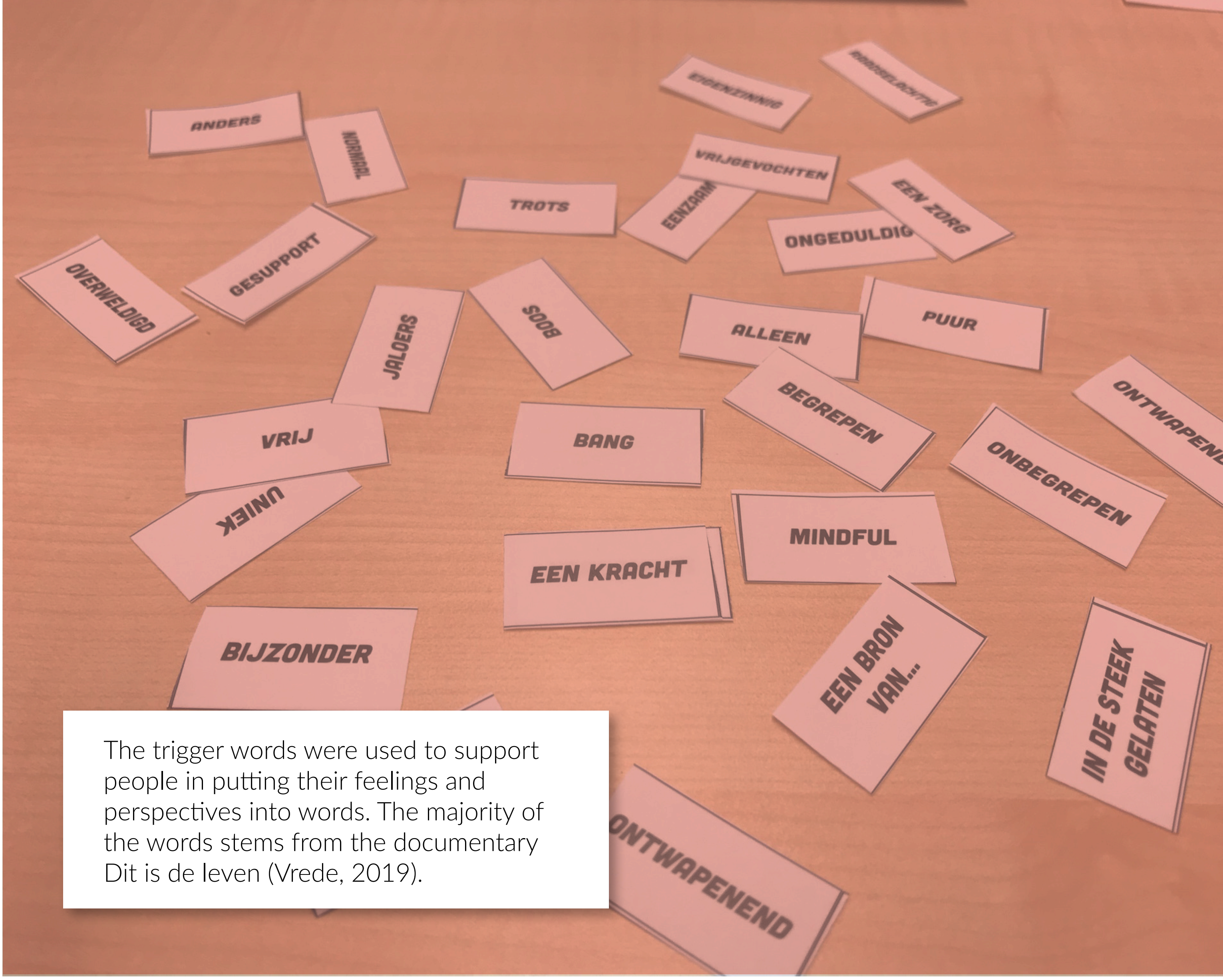
Inspiration

The sensitizing material is inspired by Cultura from Chen Hao (2017). Two of the cultural aspects that specifically were an inspiration are community and rules. Hao describes community as ‘a group of people who have a shared concern or who wish to reach a goal, and interact regularly to do so’. To enable discussing this aspect, I adjusted this term to ‘care bubble’, to describe the people closely involved with the family and the child. This gave me the opening to discuss the goal they share, which differed from e.g. making the child happy to supporting the child’s development as much as possible. The aspect of rules formed a valuable opening to discuss how they see their own role and what support they accept from others.

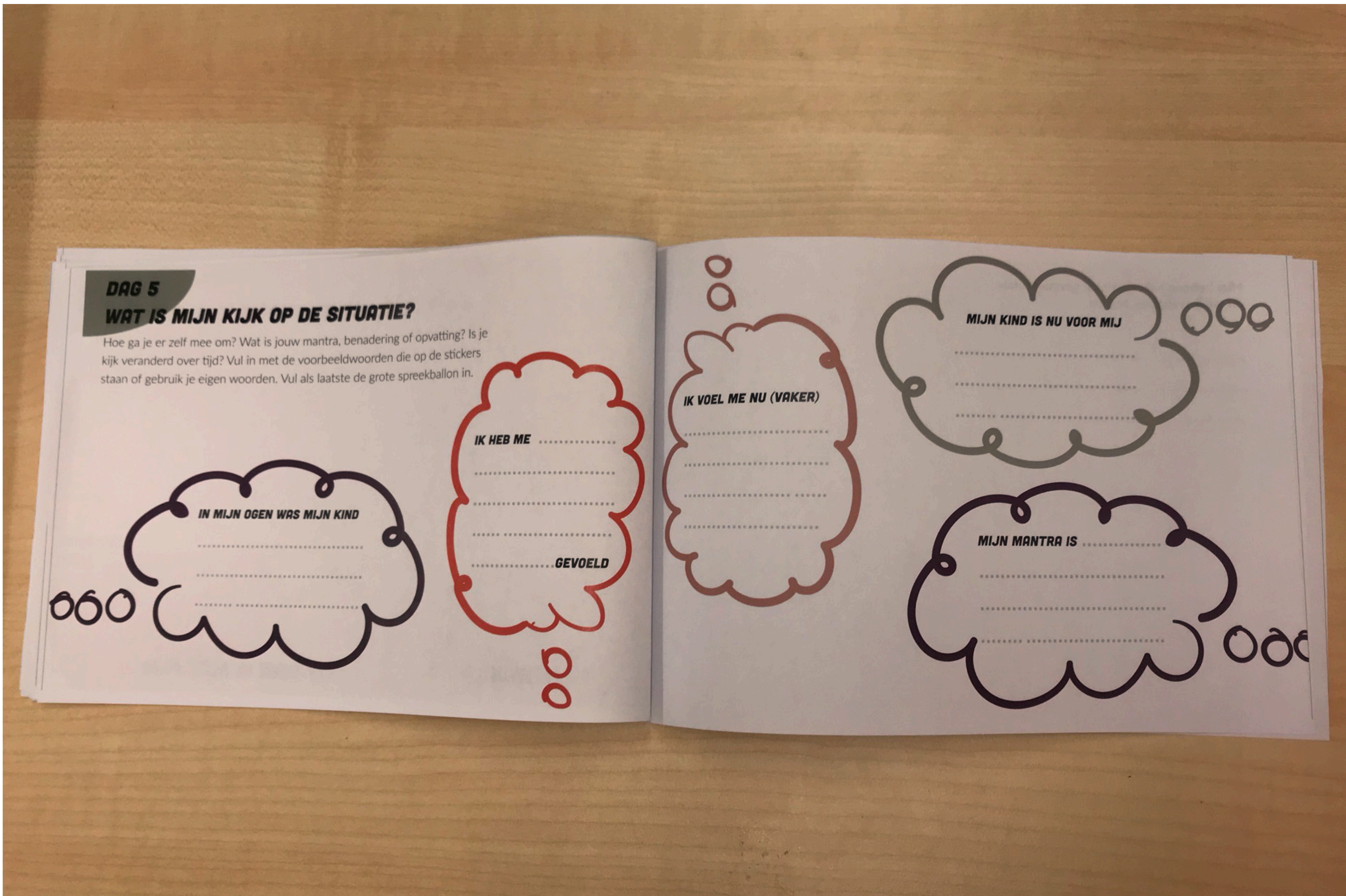
Short reflection

The material raised positive feedback. The participants expressed that filling out the booklet was a pleasant experience due to the refined design. Moreover, filling out the booklet was said to raise valuable insight and reflection, especially the exercises of day 1, which was to draw timeline from the birthday of their child with special needs up to now, day 2 and 3, which was to draw their care bubble and explain what roles they let their surroundings play, and day 5, which was to reflect on how they saw their child and how they felt in the beginning versus how it is now, as well as to note down their mantra.

The sensitizing material is inspired by Cultura from Chen Hao (2017). Two aspects that specifically were an inspiration are community and rules.



The trigger words were used to support people in putting their feelings and perspectives into words. The majority of the words stems from the documentary Dit is de leven (Vrede, 2019).



DAG 5
WAT IS MIJN KIJK OP DE SITUATIE?

Hoe ga je er zelf mee om? Wat is jouw mantra, benadering of opvatting? Is je kijk veranderd over tijd? Vul in met de voorbeeldwoorden die op de stickers staan of gebruik je eigen woorden. Vul als laatste de grote spreekballon in.

IN MIJN OGEN WAS MIJN KIND ....

IK HEB ME .... GEVOELD

IK VOEL ME NU (VAKER) ....

MIJN KIND IS NU VOOR MIJ ....

MIJN MANTRA IS ....

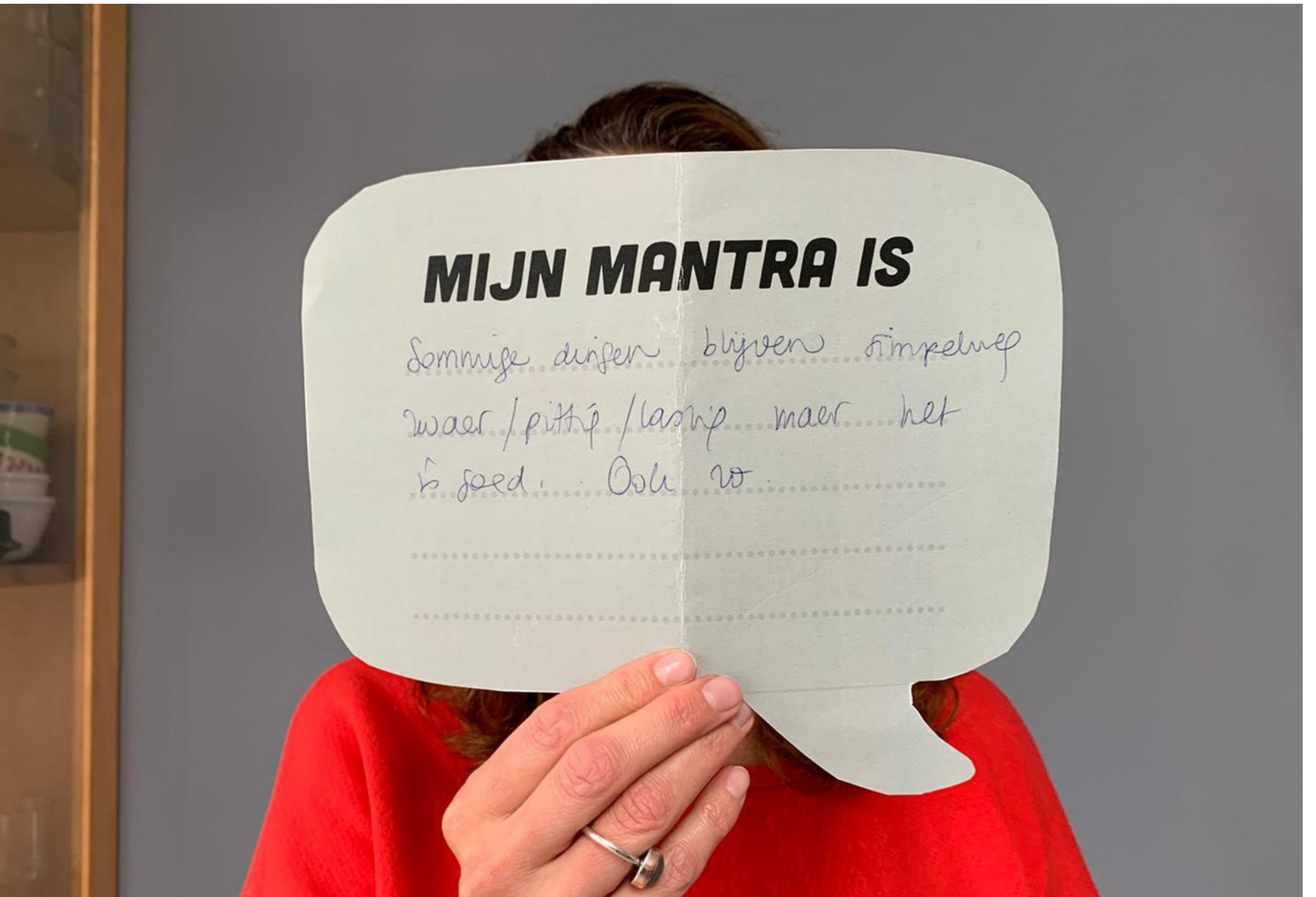
Participants

I recruited 6 participants through representative sampling. A number of 6 participants is a fair number for performing on the wall analysis. This number was a trade-off between having a representative target group and staying within the timeframe of the project, taking into account the capacity for analysis by a single person. The sample of participants consisted of parents of children with a large variety of special needs, 5 mothers and 1 father. Moreover, their experience with CSN parenthood varied from 5 to 32 years. In order to give you an idea of the people behind the information that was gathered, a collage was made of photos of each CSN parent, presenting their own mantra. Their mantra's tell us a lot about their stories and attitudes.

An important indicator that the same sample is indeed representative for the target group is that strong resemblance was found among the stories of all participants despite the variety of special needs involved. Furthermore, the newness of the information gathered throughout the interviews decreased gradually, until the 6th interview raised a relatively small amount of new information.

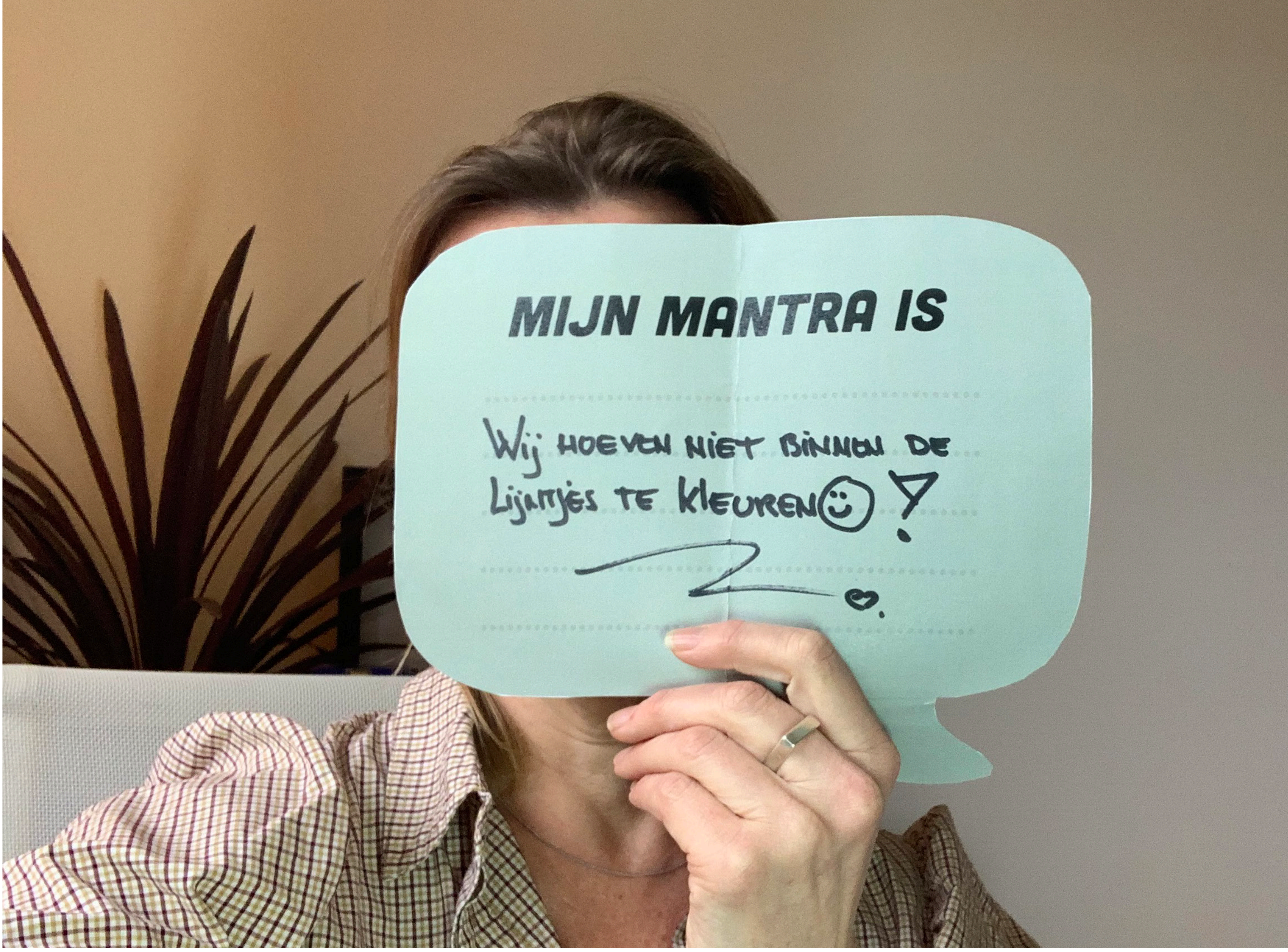
Important to note however, is a possible limitation in the sample, which is the variety of cultural and educational backgrounds. Because most participants were recruited directly or indirectly through my own network, all participants are highly educated and from Dutch heritage.

Figure 8: the CSN parents that participated with their mantras.
Tineke de Jong, founder of the UP foundation, prefers show her face.

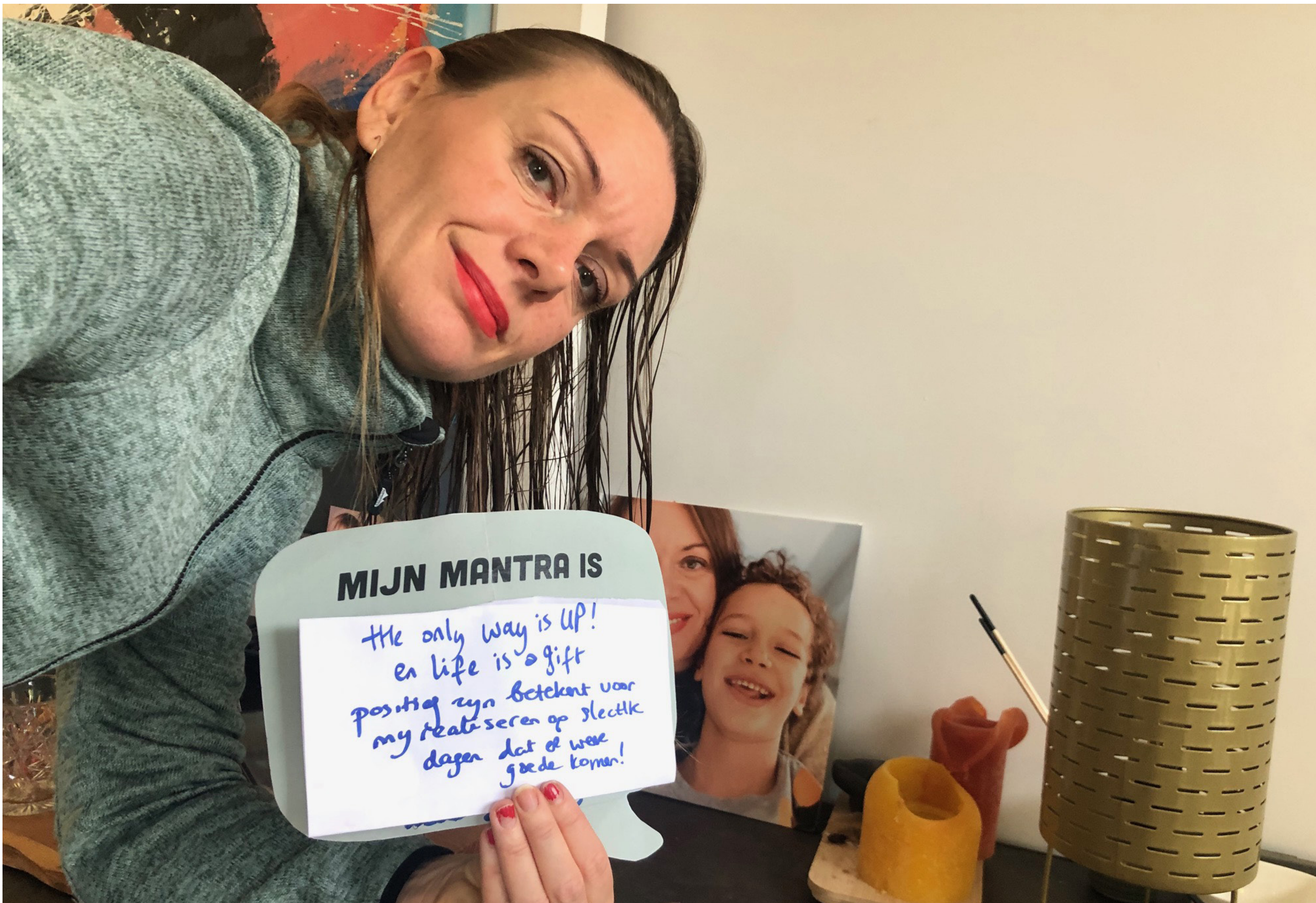


MIJN MANTRA IS

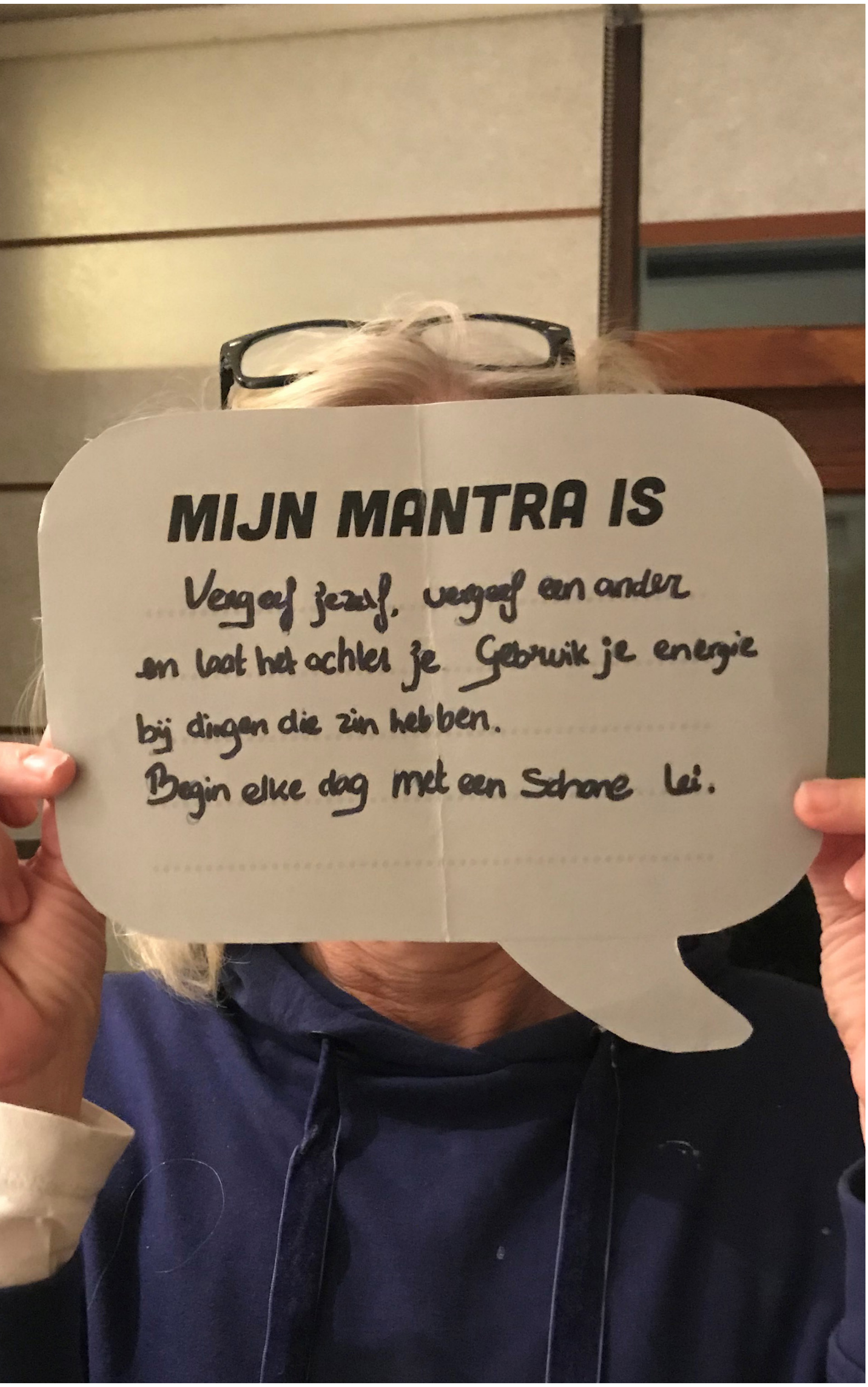
Sommige dingen blijven simpelweg
zwaar / pittig / lastig maar het
is goed. Ook zo.


MIJN MANTRA IS

Wij hoeven niet binnen de lijntjes te kleuren ☺ !

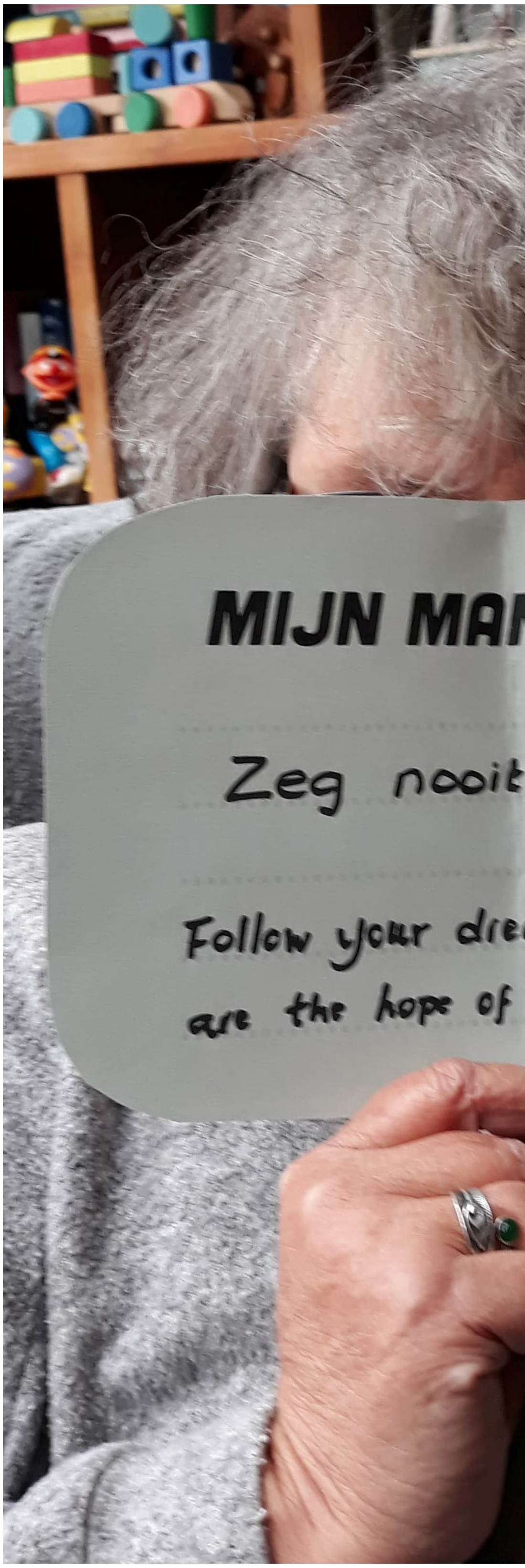

MIJN MANTRA IS

the only way is UP!
en life is a gift
positief zijn betekent voor
mij realiseren op slechte
dagen dat er weer
goede komen!



MIJN MANTRA IS

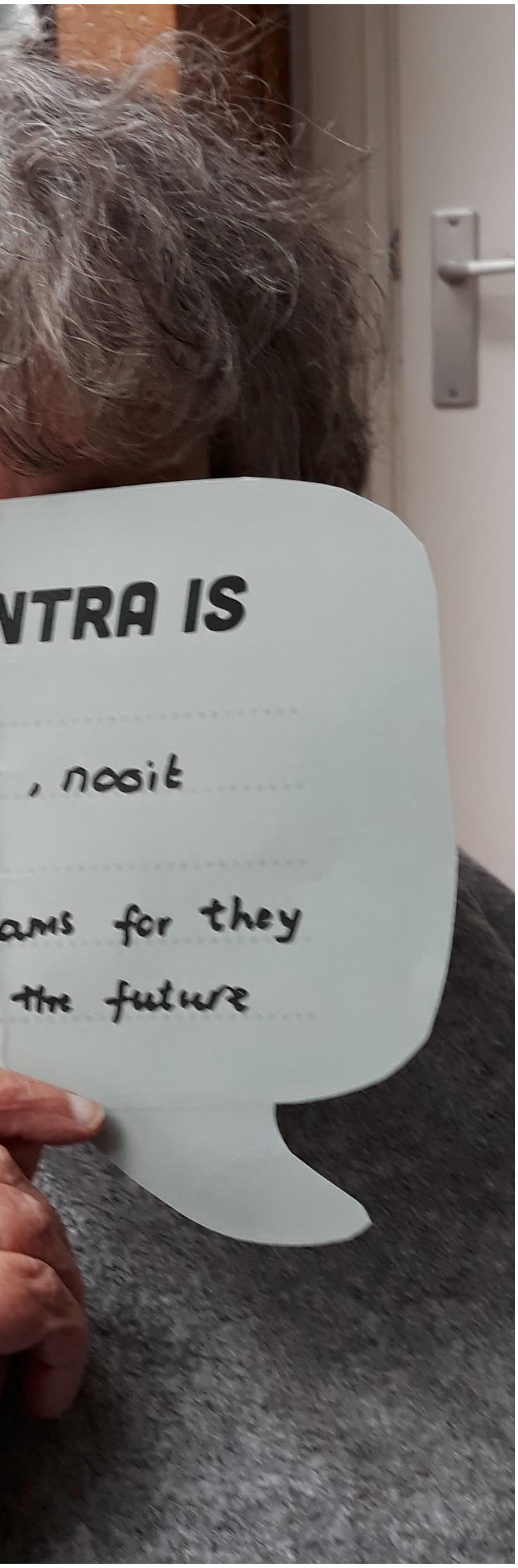
Vergeef jezelf, vergeef een ander
en laat het achter je Gebruik je energie
bij dingen die zin hebben.
Begin elke dag met een Schone lei.



MIJN MAN

Zeg nooit

Follow your dre
are the hope of


NTRA IS
, nooit
ams for they
the future


MIJN MANTRA IS
Keep calm
&
carry on

2.2 THE FRAMEWORKS

Going back to the initial design brief, it was stated that the aim of this graduation project was to identify and map the process of personal growth that Dutch CSN parents have gone through before reaching a state of sustainable parenting.

An important realization with regards to this initial aim, is that because of the phenomena described by the paradigm of chronic sorrow, the process CSN parents go through cannot be described as a linear path with subsequent steps. Implying it is a linear process, would also imply that the CSN parent is meant to be somewhere else, but they have not yet reached that point, conflicting the concept 'chronic' in chronic sorrow. Moreover, in the literature review as well as the user research, it became apparent that such a complex context cannot be mapped in a single framework. For these reasons, three frameworks were developed in order to capture my insights regarding CSN parents, all three shining their light on a different aspect of the context.

The three frameworks serve two purposes. The first purpose is to communicate my insights concerning CSN parents and what they go through, offering designers a handle on the complexity of the context. The second purpose is to offer insights in how CSN parents and their social surroundings relate to each other. Social surroundings is meant in a broad sense, from close friends and family to people passing by on the streets. The latter is the main purpose of the opportunity framework, whereas the other frameworks are primarily meant to illustrate what CSN parents go through.

Whom these outcomes concern

Since the participants of the user research that these outcomes derive from are all highly educated people from Dutch heritage, these outcomes principally apply to this group. This is especially highlighted in order to avoid generalizations with regards to people with a different cultural background and education. Whether these outcomes apply to these groups of CSN parents as well, will need to be examined through more user research.

Why these outcomes matter

Any human being benefits from having a good relationship with people in their surroundings. Fundamental human needs like the need for relatedness, the need for belonging and the need for relatedness, rely on the contact we have with the people around us. As explained in the last chapter, for CSN parents it can be a challenge to maintain contact with people that are outside of their family, although that is crucial for healthy acculturation. For this reason, isolation and the loss of connection with other people can be especially damaging to their well-being. Moreover, their social network can support CSN parents in numerous ways. In an article about traumatic events (Federatie Medisch Specialisten, 2019), searching for social support is exemplified as an effective coping mechanism for trauma. Mensura (2019) mentions sharing worries is an important first step to approach problems, when highlighting the importance of a supporting social network in difficult times.

To conclude, it is crucial for CSN parents to stand in connection to the people in their surroundings, not only for fulfilling their fundamental human needs and to be able to find a healthy balance between cultures, but also to support them in the many challenges they encounter as a CSN parent. Therefore, **the outcomes of this user research, which contribute to the understanding of the bigger picture with regards to the connection between CSN parents and the people in their surroundings, are valuable input in the quest to improve the mental health of CSN parents.** They offer a frame of reference for the experiences of CSN parents. By mapping certain elements of this landscape, Ontzorghuis and other designers engaged with this target group, gain a clearer imagine of the mechanisms at play in this context. This can be the inspiration and starting point for design, as it helps designers to scope their attention and to formulate the exact impact they desire to have.

THE OPPORTUNITY FRAMEWORK

Why it was created

In the interviews the room for improvement with regards to their social surroundings taking steps towards the CSN parents became apparent. This room for improvement was found to exist between the desires the CSN parents indicated to have and what they often experience in reality. This framework offers insight into the steps that people in their surroundings can take towards CSN parents. Herewith, it gives designer insight into the possibilities to contribute to the connection between CSN parents and their surroundings by means of design. The framework can also support CSN parents in pinpointing their desires with regards to different groups of people, which might trigger their resourcefulness to try and make their desires come true.

What it was based on

During each of the 7 interviews, the parents told me how they wanted to interact with different people in their environment, what interactions are pleasant and which are unpleasant. In the final exercise of each interview, we discussed of what group of people they wanted to improve their interactions the most. Several target groups were mentioned: friends, municipality, care professionals, people they barely knew and the society in general. Afterwards, they defined what ingredients were missing in this interaction. In the end, when 35 ingredients were gathered, patterns were found, resulting in the 6 desired capacities in the framework. What we had discussed before served as examples to illustrate CSN parents' experiences.

How to read it

In this first framework, the opportunities for improvement have been divided in 6 capacities that people in their surroundings can have with regards to the CSN parent. Part of these people will naturally embody these capacities, as a result of their personality and/or their mental proximity to the CSN parent. Within other people, these capacities can be awakened as a result of specific events or maybe even be taught. Where a person's entry point in the framework lies, depends on their personality; how far there grow in capacities depends on extent to which they engage with the CSN parent.

Important to note is that in an ideal scenario, not every person in the surrounding of a CSN parent needs to embody all capacities. What a CSN parent desired from specific people or groups of people depends on their personal preference. To give you an idea of which capabilities could roughly be desirable for which groups of people, three levels of proximity were indicated in the framework: the inner circle, the outer circle, and others.

OPPORTUNITIES IN THE SOCIAL SURROUNDINGS

others: e.g. people that a CSN parent sometimes encounters

	open mindset	interest	imagination
interaction between CSN parents and their surroundings	CSN parents are often faced with people that stare at their child or are afraid to interact with their child.	CSN parents often do not feel heard or listened to properly. Their well-being is seldomly a topic of conversation.	Many people hav idea what the life CSN parent looks and do not recog that their workloa far greater than t of regular parents
capacities that CSN parents desire from people in their surroundings	***PEOPLE HAVE AN INCLUSIVE & OPENMINDED ATTITUDE TOWARDS THE CSN AND ITS PARENTS.***	***PEOPLE EXPRESS INTEREST TOWARDS THE CSN AND/OR ITS PARENTS.***	***PEOPLE CAN IMAGINE AND UNDERSTAND WHAT THEIR LIFE LOOKS LIKE.***
examples from the interviews	*'In some social environments, they accept my daughter for who she is, so we can have a good time as a family.'*	*'The man at the local bakery always askes how we are, even though he does not really know us that well.'*	*'Friends can be lik mirrors. A friend told me I was doi way to much, so l suggested to get formal support.'*
	'When I am talking to friends, sometimes they pretend she is not there because they don't know how to act.'	*'It hurts that a have to become really angry or sad before people even pay attention to what I am saying.'*	*'My mother alwa says she had a ha time when raising too, so we should complain.'*
examples of opportunities for designers	An inclusive mindset can, for example, be promoted by campaigns, mixed schools instead of special schools or other initiatives where people come into contact with people with special needs.		The capacity to in be cultivated by a look into the life c virtually or physic experience CSN p

outer circle:
e.g. their social netwerk,
medical staff, proffesionals

inner circle: e.g.
people that are very
close to a CSN parent

ve no
e of a
s like
nize
ad is
hat
s.

Many people have misconceptions about what causes the hard parts of being a CSN parents, and overlook the beautiful parts.

People often assume or expect CSN parents to handle everything on their own, and do not consider what they could mean for them.

When people help, it is often in a passive way, like ‘let me know if I can help’, though parents struggle to think of anything.

empathy

PEOPLE HAVE THE CAPACITY TO EMPATHIZE WITH WHAT IT MEANS TO BE A CSN PARENT.

involvement

PEOPLE EXPERIENCE SOME SORT OF SHARED OWNERSHIP FOR THE FAMILY’S WELL-BEING.

intiative

PEOPLE SHOW INIATIVE TO SUPPORT THE PARENTS IN WHATEVER WAY RESONATES WITH THEMSELVES.

ke

ng
he

‘My neighbour and I can have very good conversations because he is a CSN parent himself.’

‘My friends always join me when I have to go to the hospital.’

‘My sister sometimes offers to babysit so we have some time for ourselves.’

ys
ard
g me
l not

‘I would love for my relatives to realize what we are going through, especially mentally.’

‘My brother laughed at me when I asked for his support, because he is very busy with work.’

‘I would love for my friends to take me out every once in a while, because I need a day for myself.’

nagine and empathize can
llowing people to take a
of CSN families, digitally,
ally, or listening to how they
parenthood.

The feeling of ownership can be awakened when people feel personally addressed like when they are involved as responsible person for a specific role or invited to join a specific event, like a hospital appointment.

FRAMEWORK OF VALUES

CSN family cultures

Every human being fosters values. Values are intimately related to our needs. Whatever we need—whatever we have learned to be important or what is missing from our lives—is what we value. As our life conditions change, and as we grow in our psychological development, our value priorities change. Values often unknowingly guide our behaviour. When we use our values to make decisions we focus on what is important to us—what we need to feel a sense of well-being. Your values exist simultaniously, which is why they sometimes conflict (Ozkaramanli, 2017). When in conflict, your values become conscious and you will feel some values will have priority over others.

Van Boeijen (2015) developed socio-cultural dimensions to typify different cultures. The different dimensions are described as opposing pairs. They helped me to express the shift in value priorities I discovered among CSN parents, based on their stories. Among the three most significant shifts that could be described with these dimensions I found, that having a child with special needs shifts their orientation from achievement towards care. Furthermore, their identification moves from individual towards together, as a family in this case. Thirdly, for some parents, the orientation of personal space shifts, as they compartmentalize different aspects of their life and their sense of private space becomes stronger.

There is a final dimension that I found to play an important role for CSN parents, that was not yet described in this theory. Therefore, a new one was created, named: the dimension of participation. It presents the variation in how people aim to relate to society. On the one side the dimension stands for conformity, and on the opposite side it stands for self-determination. The following framework will illustrate how this dimension plays a role in the lives of CSN parents.

All shifts are visualized below. What I value about this way of expressing it, is that it does not imply that values are absolute or comparable. The shifts are relative. Each CSN parent is different, and how they relate to these dimensions will therefore differ as well.

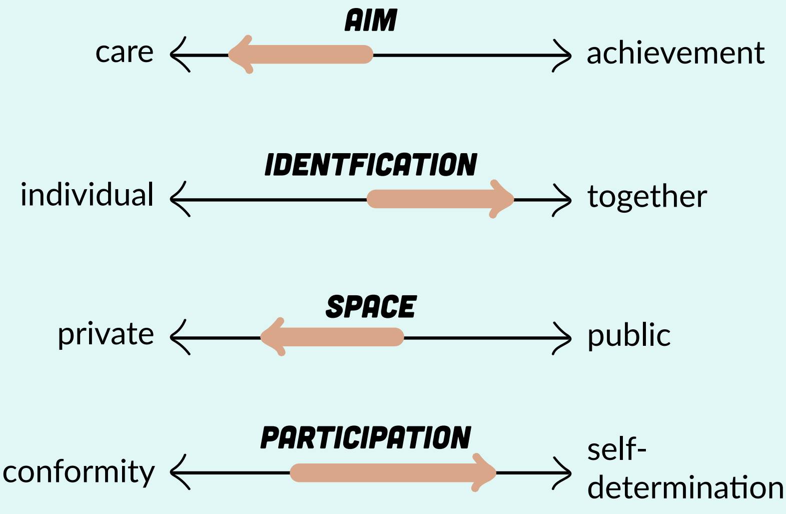


Figure 8: shifts in CSN family cultures

In 'why these outcomes matter' is described how CSN families can benefit from being in touch with people in their surroundings. This relationship can be mutually beneficial. Just like it can be a valuable experience to travel to other countries to immerse yourself in other cultures, it can be refreshing to be in touch with CSN families, as their culture also deviates from the mainstream. It helps to gain a fresh perspective, and your world gets a bit richer. Moreover, having a child with special needs is a pressure cooker for learning how to cope with life and navigate your own and other people's expectations. Especially when it comes to the value and strategies of resistance, we can learn a lot from CSN parents.

Why it was created

It can be a challenge for CSN parents to navigating their own values and needs, while taking part in society. Every CSN parent copes with their situation in a different way, depending on what they consider important. Parents can emphasize their identity as a family. They can try to be part of society as much as they can, actively trying to find new possibilities to participate. They can also postpone thinking about the future and try to hold on to the life they have or had. All of these strategies could even exist simultaneously or consecutively during the day or the week, as values are always present.

This framework illustrates what CSN parents find important and therefore what effects their coping strategies. The aim is not to lay out all values and concerns CSN parents might have. The framework aims to offer insight into those values and coping strategies I found to be important for understanding them better.

It can be used to support the parents in their values and strategies, possibly by means of design. When we know where they stand or what they value, we can support them in a way that is in line with what they find important.

How to read it

Important to note is that these values, among many other values not described here, are present simultaneously. That also applies to CSN parents that cope with their situation in the healthiest way possible. One value does never replace the other. However, some situations might trigger one value over another.

What it was based on

The values slightly compare to the fundamental human needs (Desmet & Fokkinga, 2020). The value of self-preservation, conformity and identity respectively resemble the need for security, belonging and autonomy. However, these did not fully cover the phenomena I perceived in this context. Therefore, these values were formulated, based on the literature review, the interviews with experts and the analysis of the different strategies that were expressed during the interviews. Their own examples capture these values and strategies. Their examples about their environment illustrate how these values and strategies are often misunderstood and how the parents can be wrongfully approached.

THE VALUE OF SELF-PRESERVATION

CSN parents want to survive and to protect their mental well-being.

POSSIBLE STRATEGY

denying or downplaying the child's condition or it's long-term consequences

WHY IS IT IMPORTANT?

CSN parents face a lifetime of uncertainty. Their child's developments often deviate from the common path of mental or physical developments and are therefore hard to predict. The consequences these conditions have on their child's and their own life on the long term, are unclear. Important to note, is that downplaying can therefore can be a constructive strategy, and choosing to let in reality selectively can be healthy behaviour. If CSN parents were to imagine all the consequences their child's special needs in the future and the difficulties they might face all at once, it can be hard to carry on.

HOW DOES IT MANIFEST?

The value of self-preservation manifests itself in various ways. Before their child is diagnosed, many parents hold on to the thought that all will turn out allright and that their child is not that different. Parents can, for instance, be in denial of the diagnose or their child's behaviour in school or they might not comprehend the challenges the child faces. Moreover, parents take it a day, week or month at a time, to avoid thinking about an unknown future. Important variations that influence their strategies are the notablility of the disability and related to this, the age at which the child is diagnosed. A physical disability, for example, is often more easily visible than ASS and is therefore harder to downplay.

THE VA
CONFO

CSN parents wa
participate

POSSIBLE

trying to compete w
comparing the chil

WHY IS IT IM

Human beings are social animals, a
value system bigger than themselv
national culture. More than anything
life's main stream: go to school, ge
child's special needs can unravel co
let go of their job and miss out on
themselves. In some ways, the child
main stream, which might not nec
itself, but can feel like a big loss for t
parents might sometimes be very fo
instead of aiming to make child hap
of the main stream of life causes ne
CSN parents look at their lives throu
maybe even fixated on their losses a
confronted with this, mostly when t

HOW DOES IT

CSN parents sometimes regret that
fully participate in the main stream
with milestones of children of frienc
deal with this pain around the ear
from another baby's first steps range
might cause the parent to think that
to things the same way. These u
connected to being a CSN parent
family and the rest of society, ma
surpass.

LUE OF
RMITY

nt to succesfully
in society.

STRATEGY

vith other parents or
d to other children

MPORTANT?

and naturally crave to be part of a
ves, such as religion, subculture or
g many of us desire to participate in
et a job, start a family. However, a
mmon life, forcing parents to partly
social time with friends or time for
d will also not be able to follow the
cesarily be a problem for the child
heir parents. The danger here is that
ocused on their child's development,
py. Even though wanting to be part
o trouble for most people, it makes
gh the main stream eye, comparing,
and lacks. CSN parents will often be
hey enter mainstream territory.

MANIFEST?

their child and themselves can not
of life, especially when confronted
ds or family. CSN parent do not only
ly years. Confrontations can range
e to the wedding of a nephew, which
their own child might never be able
nfortunate triggers are inherently
who is in touch with their friends,
aking these feelings impossible to

THE VALUE OF SELF-DETERMINATION

CSN parents want to create their own path, rules and identity.

POSSIBLE STRATEGY

placing emphasis on what is possible, what is positive and what sets the child apart

WHY IS IT IMPORTANT?

When people have a child with special needs, it often becomes harder to participate in society for many reasons, like the time investment needed to care for the child and their child deviating from the mainstream. Reality can be very different after having a CSN child, causing parents' dreams, ambitions and expectations of life to be revised. Consequently, many CSN parents develop a different belief system, they separate external from internal values and reframe their perspective of life. Society's perfect picture has become irrelevant. When the value of self-determination predominates, they try to see their child, themselves and their lives, separately and independently from external expectations and pressure. Furthermore, they have an eye for the postive side of life, the beauty in their child's and their own personality and identity. This value causes parents to cultivate other strong family values, like self-care, quality time and investing in their own well-being.

HOW DOES IT MANIFEST?

CSN parents can be truly be proud of their child, seeing immens beauty and value in them. Many parents express to have learned from their children, to be confident, to stand up for themselves and to be true to themselves. They focus on the bright side and opportunities. When the value of comformity predominates, the special needs are framed as a disability. When self-determination rules, the special need as seen an important part of the child's identity. Similarly, medical devices such as a wheelchair can be seen as something terrible, as it emphazises the child might never walk, and as something beautiful, as it enables the child to move around and be autonomous.

REFLECTIONS OF CSN PARENTS

I fled away from the pain in the beginning, focussing on my career, causing my whole battery to burn out.

I really needed to believe he was just developing a little slower than other kids.

I did not want to give in to this pain in my heart: she will have to go an institution one day, I will never be a grandmother, etc.

HOW DOES THIS APPLY TO OTHERS?

These values do of course not exclusively live in CSN parents. The behaviour of people in their surroundings can also be partly explained this way. Many bystanders tend to downplay the child's special needs or the effect it has on the parents, just like the parents sometimes do. The biggest frustration arises when other parents claim their child also is a piece of work, not taking the CSN parents' experience seriously. On the other hand, CSN parents can be accused of being in the denial phase. However, being 'in denial' can be a healthy strategy throughout their whole life, as long as it is not the only strategy.

Watch out for the mom in room 123, that woman still has not accepted her child's disability, I read on the whiteboard of the medical staff.

My mother always points out it was hard to raise us as well, acting like what we are going through is normal. She never asks how it is for us.

Sometimes we get the feeling we have to prove our child's disability.

REFLECTIONS O

I have been hard on myself, on what I should do for my daughter, as if I have to compensate for the things she cannot do.

I have f
disconnect
Especially w
normal wor
yard of my
completel
ma

We thought, we should be able to have him home until he is 4, just like other children. And later: everyone leaves home when they are 20.

HOW DOES THIS A

When trying to arrange sufficient
parents need to emphaze what their
strategy. Their social surroundings a
the situation of CSN parents throug
hard it must be to raise such a child i
they have for them. Even though the
to indicate that raising a child with
beautiful sides of it. Moreover, the r
is often wrong.

The other mothers in my daugther's school are very normative. They pretend like I am not a good mother because I have a job, and I don't do all of the care work.

The medical staff
son's diagnose as c
to try and stretch h
towards 'normal' as
towards society's s

F CSN PARENTS

I want to be in the centre of society, but every time there comes a point where we cannot take part in the main stream.

elt lonely and
ted with others.
when I was in 'the
ld', like the school
y daughter. I felt
y different in so
ny ways.

Seeing my son in an electrical wheelchair felt horrible, confronting me he is a 3 year old that will never be able to walk.

PPLY TO OTHERS?

care, medical supplies or subsidies,
r child is unable to do, triggering this
lso often have the tendency to view
h mainstream eye, emphasizing how
n this society, and how much respect
e intention might be right, this seems
special needs is horror, denying the
reason why others assume it is hard,

People think it is heavy that I have to lift my son out of his wheelchair, but what is really bothering me is how powerless I feel, that he won't be able to do what other children can do and how unsure his future is.

took my
an excuse
him as far
s possible,
tandards.

People saying it is hard and sad to be me, don't put me in your pity corner. You disallow me to feel powerful or strong.

REFLECTIONS OF CSN PARENTS

I follow my own path, conscious of what I can expect of myself and what not.

When you feel more at home in this new world, you start to rely on your own intuition, and you feel more comfortable taking a stance on what you find important.

It has affected how we treat eachother as a family, and we are not afraid to take time for ourselves.

My child does not need to be someone he is not. We rather focus on who he is. He is a beautiful child that brings us so much.

We tell ourselves that we are allowed to colour outside the lines as a family, because of our daughter. We don't need to comply with imposed norms.

The most important thing, is that my son is happy.

At the same time, the wheelchair made me very happy, because he became more autonomous and he could decide where to go.

We have become more stubborn, our child taught us to stand up for ourselves and inspired us to do things differently.

HOW DOES THIS APPLY TO OTHERS?

For other people that can easily live conform the norms of society, it might be hard to relate. Reciprocity regarding this value can come from other CSN parents, other people that have managed to break free from mainstream expectations, or that have gotten to know the child so well that they manage to see the child's personality instead of disability. Many parents regret that in the interactions they have with care professionals, they focus on fixing the problems, rather than what their child finds important, or who he is as a human being.

Care professionals have always been focused on trying to fix his condition, instead of what he needs and wants as a human being.

Conversations with other CSN parents are pure and unfiltered. Very vulnerable.

My friends love my son, they really adore him and love to spend time with him.

LEARNINGS & ATTITUDES

What it was based on

In the 7 in-depth interviews with CSN parents, I learned a lot about their challenges. They explained to me how they battled their own expectations and misconceptions about parenthood, as well as the attitude of their surroundings. Even though I spoke to parents of children with a large variety in special needs, the pivotal events and crucial shift in beliefs that helped them to find a sustainable attitude towards CSN parenthood and towards themselves, strongly corresponded. This framework lays out what these pivotal events and related learnings can help other CSN parents struggling to find an attitude that enables them to successfully cope with CSN parenthood in the long term.

Why it was created

The framework aims to inspire designers that are motivated to contribute to the well-being of CSN parents. Moreover, it aims to inform CSN parents themselves and people that are part of their network. Because the other two frameworks are more theoretical and high level, I also wanted to offer designers an understanding on a more practical level. It gives insight into the psychological fights that can go on in the head of a CSN parent, navigating their own and other people's expectations and attitudes. It consist of 5 practical learnings were indicated by the CSN parents I spoke to, to be important for them.

PIVOTAL EVENT	ATTITUDE
The child's special needs were announced before birth, or the child shows apparent deviation from regular development after birth.	I am a regular parent and my child is a little bit different.
There has been a diagnosis of the child's condition or the child shows obvious deviation from regular development.	I am a regular parent of a child that is officially different
Parents look around them and realize their life is radically different than that of other parents or they have been worn down over time, or even burned-out.	I am not a regular parent because my child is not regular.
When the child is younger, the parents' focus usually lies on their child's development, but as the child gets older, deviation from the main stream can become more apparent and certain limitations will become evident.	My child and I will always be different.

Figure 9: attitudes & pivotal events

How to read it

The tricky part of trying to make sense of a complex context is the danger of losing the nuance. I underline that these different attitudes should not be read as subsequential phases, as that might imply that being a CSN parent entails following a roadmap. Similarly, the learnings are not breakthroughs, from which one will never return. The path of a CSN parent consists of graduate shift in their expectations and attitude. The learnings described play a part in this shift.

How it relates to the values

Whatever attitude the parent has, the same values are present within them, however some values are prioritized over others. When a parent has the attitude that their child is a little bit different, strategies with regards to the value of self-preservation can rise, for example. When the child is perceived to be officially different, strategies for conformity might take the overhand, as diagnosis informs the parents of possible treatments or therapies, often with the aim to get the child to participate in the main stream as much as possible. Strategies in line with the value of self-determination might blossom when they start to differentiate themselves from regular parents, and when the child deviates from the main stream infinitely.

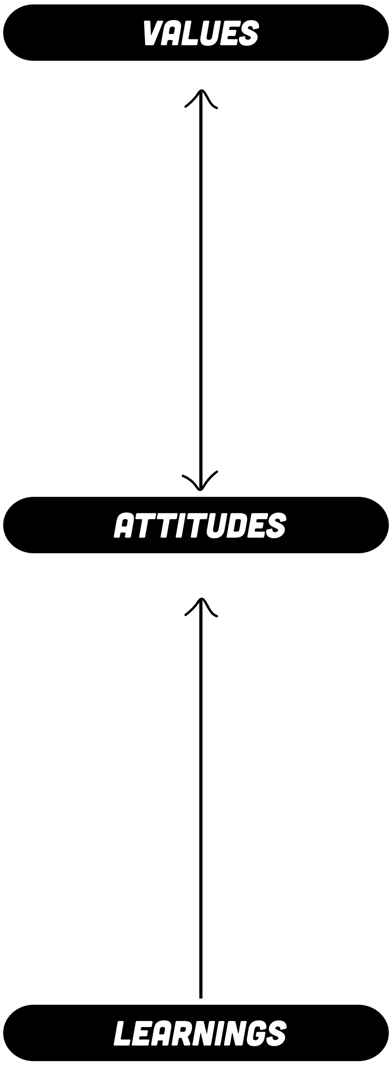


Figure 10: how the frameworks relate

Learnings such as the ones described on the next page have their influence on the attitude of the CSN parent: how they see themselves and their child. The attitude that a parent has at a specific moment in time, effects their priority in values, bringing about their current strategy towards CSN parenthood and life in general.

The other way around, the values and the priorities among them defined by the parent's personality and cultural upbringing, can have an effect on their attitude, as shown in fig. 10.

PRACTICAL LEARNINGS & ATTITUDES

CSN PARENTHOOD IS MUCH MORE DEMANDING THAN REGULAR PARENTHOOD.

what you need to know as a CSN parent

Being a CSN parents is more intense and more demanding than being a regular parent. CSN parents' can struggle to distinguish their situation from that of regular parents. Even though the belief that a parent should be fully devoted their child's care is common, it does not wholy apply CSN parents, as they often need professional support. When they carry all care, responsibility and organisation on their shoulders, parents can become burned-out. Therefore, parents face the challenge to overcome these demanding beliefs and to redefine the expectations they have of themselves.

what you need to know as a bystander

Similarly, the outside world fails recognize the gravity of the impact of the CSN. Their well-being is seldomly a topic of conversation, in their social network, nor in the communication with care professionals. Of course, the fact that the world does not recognize the gravity of their situation and that their poor well-being is often overlooked is related to the fact that CSN parents fail to recognize it as well. Regardless of whether this is a chicken or egg causality, it is a viscious circle that needs to be broken, because it causes parents to hold back on organizing or asking for sufficient support to stay afloat on the long term.

PIVOTAL EVENT	**ATTITUDE**
The child's special needs were announced before birth, or the child shows apparent deviation from regular development after birth.	I am a regular parent and my child is a little bit different.
There has been a diagnosis of the child's condition or the child shows obvious deviation from regular development.	I am a regular parent of a child that is officially different
Parents look around them and realize their life is radically different than that of other parents or they have been worn down over time, or even burned-out.	I am not a regular parent because my child is not regular.
When the child is younger, the parents' focus usually lies on their child's development, but as the child gets older, deviation from the main stream can become more apparent and certain limitations will become evident.	My child and I will always be different.

YOU CAN TRUST YOU
RELY ON YOUR PARENT

what you need to know as a C

When a child with special needs is b
long time before the child is diag
parents notice or feel there is someth
child before it is officialy recognized.
with strong feelings of self-doubt ar
regards to their own intuition, their pe
and, with diagnoses that take a lon
parents might think there is somethi
they raise their child.

what you need to know as a by

In this case, it is crucial for paren
challenges the child faces, do not lie
Furhermore, it is important that the
judgement is not undermined, by bys
background as well as from their soc

YOU NEED TO TAKE CARE
ORDER TO KEEP CARING

what you need to know as a C

Related to the learning that being
demanding than being a regular one
take care of their child with special ne
stay afloat. In order to stay afloat, th
themselves, invest time in the things
time to spend on the things they fin
time with other people, like a job o
order to have time to recharge onese
take care of the child in the meantim

what you need to know as a by

CSN parents who do take some
sometimes face the judgement of
time is crucial to carry on, otherwise f
burned-out or overworked. Their so
contribute to their well-being, by spe
them, taking them out or offering
children.

RSELF AND
AL INTUITION.

SN parent

orn, it can often take a
nosed. In many cases,
hing going on with their
This can pose parents
nd powerlessness, with
erformance as a parent,
g time to be identied,
ng wrong with the way

ystander

its to realize that the
e in the parents power.
parent's intuition and
tanders from a medical
ial network.

OF YOURSELF, IN
FOR YOUR CHILD.

SN parent

a CSN parent is more
, in order to be able to
eeds, a parent needs to
ey have to take care of
that give them energy,
d important, like quality
r other passion etc. In
lf, support is needed to
e.

ystander

time for themselves,
others. However, this
acing the risk of getting
cial network can even
nding quality time with
to watch one of their

YOU SHOULD NOT HOLD BACK IN TELLING OTHERS WHAT WOULD HELP YOU.

what you need to know as a CSN parent

When it is becoming clear that your child has special needs, it will also become more and more clear that you need support of some kind. By the time you have realized this, you will still have to convince and activate others to help you. Even though the willingness to proactively help you differs within each municipality, subsidy helpdesk, hospital and social network, all parties can pose quite a challenge. An important lesson CSN parents describe, is not to only depend on the current offer or possibilities, but to actively frase what you need to stay afloat in the long term. Don't be too modest, because many people do not realize what you struggle with and what you need.

what you need to know as a bystander

The involvement of their surroundings that CSN parents experience in the time around the birth or the diagnosis of their child, rapidly decreases when a bit of time has gone by. Even though the situation is not new anymore, the struggle remains real, and is likely to even increase as the child grows older. As a baby, they might have been asleep most of the time, but as they grow older, parenthood becomes more intense. Mental and instrumental support is as relevant as ever. If you want to contribute, try to make a concrete offer, e.g. bring groceries or food, take a walk with them or invite one of their other children to come over.

IT IS OKAY TO FEEL SOMBER SOMETIMES.

what you need to know as a CSN parent

Chronic sorrow is the pain experienced if you or your loved ones, in this case, your child, is suffering from a chronical illness or disability. According to Keirse (2013), among the 'tasks' of chronic sorrow is to face the reality of the loss, experience the pain, including feelings of guilt, anger, shame, fatigue, To experience chronic sorrow means to go through loss of dreams, expectations, possibilities and perspective. These feelings are inherently connected to being a CSN parent. Parents expressed that once they stopped judging their own feelings, a weight was lifted of their shoulders.

what you need to know as a bystander

An important note is that these are not chronological stages towards a process of 'accepting' the situation. This sorrow does not fade away, but will be lived every day, including periods of intense pain. For many CSN parents, the paradigm is a relief, as it sets permanent pain apart from pathology. Instead of being seen as an unstable, gloomy parent that needs to accept reality, the theory of chronic sorrow recognizes that experiencing pain is a normal and healthy part of being a CSN parent.

How the insights of Investigate and Immerse relate

To evaluate the trustworthiness of the frameworks and earlier insights, it is important to know how the different parts of the research relate. The insights gained in Investigate have sensitized me for the insights I gained in the user research. Insights from the user research confirmed or deepened earlier insights, and generated novel insights.

Confirming & deepening insights

In the literature research it was found that important stressors for CSN parents are the lack of formal and informal support and the risk of stigmatization, which have a disruptive effect on their well-being. In the interviews, many people expressed that others either emphasize how hard it must be to raise such a child in this society, or downplay the child's special needs or the effect it has on the parents, bringing a deeper understanding to the stigma described in literature. The Quickscan, an important resource in Investigate, described common phenomena, for instance, that CSN parents say they feel like they should be able to handle everything on their own, they are too proud to ask for support or they do not want to burden their social network, or they feel they should not ask their network, because they feel it is just not-done (Okma, Naafs, Vergeer, & Berns, 2014). Interviews with experts helped me to gain deeper insights regarding the causes behind the phenomena described in the Quickscan. For example, Minke Verdonk, consultant for CSN parents, states that an important reason for these rejecting attitudes towards asking for support stem from the inability to distinguish their situation from that of regular parents.

The user research helped to gain a deeper understanding of the context and to get more familiar with phenomena that had already been described earlier. Because of this, I was able to look at the context for a more high-level perspective, to see patterns in the participants' stories, resulting in 3 frameworks that describe the context in a novel way. Therefore, the 3 frameworks are a result of both parts of the research.

Generating novel insights

The framework Opportunities in the social surroundings is a novel set of insights that has not yet been described in literature. For instance, some of the negative examples derived from the interviews resonate with quotes that can be found in the Quickscan (Okma, Naafs, Vergeer, & Berns, 2014). However, positive examples were rare, and therefore, a welcome inspiration. More important is the distinction in levels of capacities that CSN parents desire from specific groups of people in their social surroundings, not yet described by experts or in literature. Apart from offering designers insight into the possibilities to contribute, these levels allow CSN parents to better formulate their desires towards their social surroundings. Moreover, the framework can help individuals as well as organizations in their surroundings to learn and reflect.

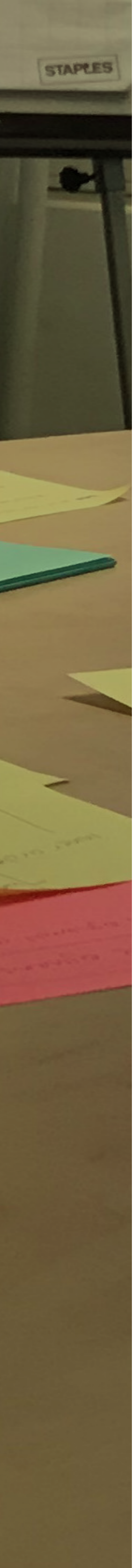
The framework of values is, more than the other 2 frameworks, the love child of literature research, interviews with experts and user research. The insights are a result from user research and interviews with experts. The 3 values were distinguished through the analysis of the user research. The explanations mainly derive from literature research, such as theory regarding chronic sorrow (Keirse, 2013). Solomon (2010) stated that the way you frame disability, can have an enormous impact on the wat it is experienced an lived in the family. An example from the interviews was: '*Seeing my son in an electrical wheelchair felt horrible, confronting me he is a 3 year old that will never be able to walk. At the same time, the wheelchair made me very happy, because he became more autonomous and he could decide where to go.*' The user research brought theory to life.

Practical learnings and attitudes are insights that stem directly from the user research. The learnings and attitudes described were inexplicitly expressed by the participants. Therefore, it offers insights that could not have been found in literature research, underlining the importance of user research. However, insights gained from literature research and interviews with experts were used to strengthen the arguments of the practical learnings and to explain the pivotal events that can cause a shift in attitude.

Concluding, the 3 sources of information confirmed or complemented each other, adding to the trustworthiness of the insights presented in this thesis. Important to note however, is the possibility of researcher's bias. The insight gained in Investigate determined the focus of the user research in Immerse. Moreover, it might have made me more susceptible for particular bits of information during the interviews.

The frameworks can also be found in Appendix C, so the reader can have them to hand while reading other parts of this thesis.

3



DEFINE

In this chapter, the designer's vision and the design goals are revealed. This visions and these decisions based on the findings from the previous chapters, have guided the explorations for the design intervention that is the second result of this project.

3.1 VISION

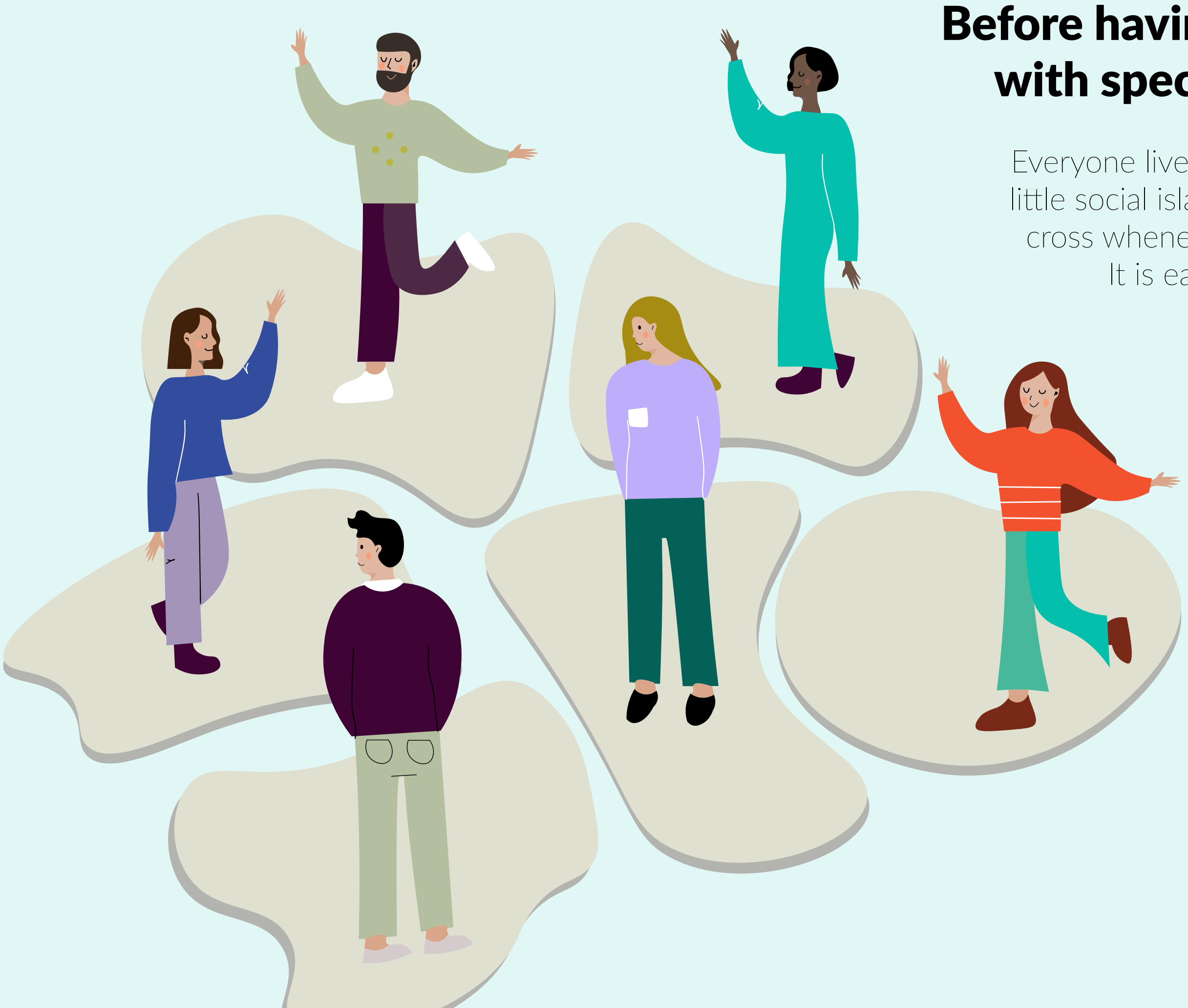
My vision is that CSN parents should be surrounded by a strongly involved inner circle of people from their social network, guarding their well-being. Were CSN parents to be surrounded by a strongly involved inner circle, CSN parents stress could be alleviated in 4 ways. Emotional support involves expressions of empathy, love, trust and caring. Instrumental support means to offer tangible aid and service. Informational support involves giving advice, suggestions, and information. Lastly, appraisal support concerns the offering of information that is useful for self-evaluation, like reminding the CSN parent of their qualities or to encourage an accurate assessment of their current situation. Because there are 4 kinds of social support, people can offer the support that suits them best. Not only can this support alleviate the feeling of isolation and loneliness that was found in the literature research as well as the user research, an strong inner circle can also support them in the many challenges CSN parents encounter.

As paradigms like chronic sorrow describe, a large part of the struggles that CSN parents experience is inherent to being a CSN parent. We cannot 'solve' some of the hardship that comes with being a CSN parent. However, there are a few aspects where we as designer can contribute. When we set ourselves the goal to boost the connection between CSN parents and the people in their surroundings, we can make a lot of impact, as described in 'why these outcome matter'. The opportunity framework helps to define sub-goals, so we can tackle this overarching goal. **Going back to the opportunity framework, we can see that to step into the inner circle, people need the capacity of involvement. They need to experience shared ownership.** Because of this vision, this sub-goal became the basis for the design goal of this project.

I have illustrated the current and desired scenario to help explain my vision.

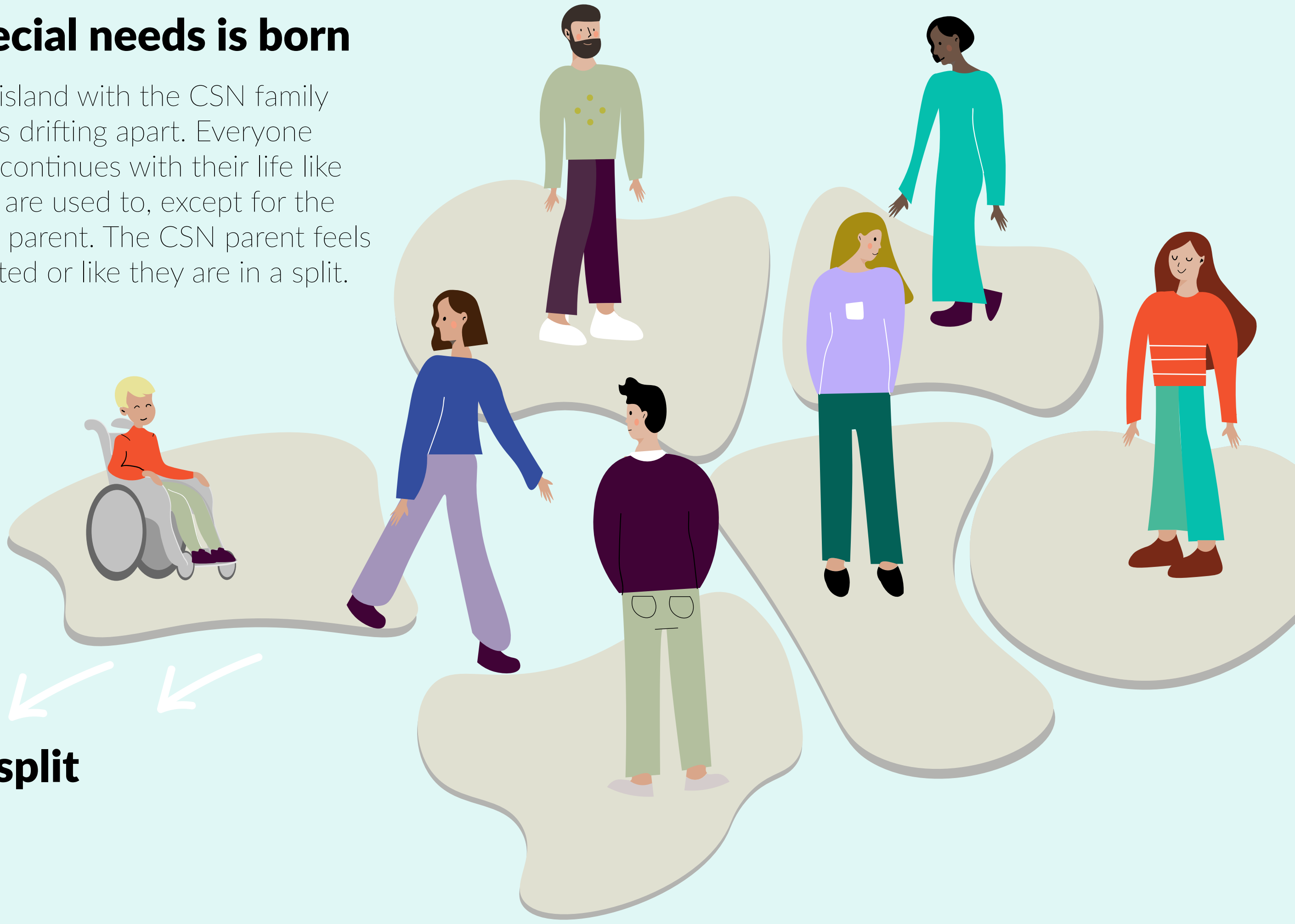
Before having a child with special needs

Everyone lives on their own little social islands. They can cross whenever they want. It is easy to connect.



After the child with special needs is born

The island with the CSN family starts drifting apart. Everyone else continues with their life like they are used to, except for the CSN parent. The CSN parent feels isolated or like they are in a split.



split

isolation

DESIRED SCENARIO

An adapted reality

In the desired scenario a few people step forward to build a metaphorical bridge so they can stay involved in the lives of the CSN family. Together they form a strong inner circle that guards their well-being.

a supporting
inner circle

3.2 DESIGN GOAL

The first step towards creating an inner circle that guards the well-being of the CSN parent, is to create involvement through a feeling of ownership. Therefore, the following design goal was formulated. This sub-chapter explains what I want to achieve for whom and in what way (how). These decisions have guided the explorations for the design intervention that is the second result of this project.

The design intervention should support Dutch CSN parents in awaking a feeling of shared ownership among a few people in their social surroundings by encouraging and facilitating the CSN parent and allowing them to explore what they desire

What

The framework Opportunities in the Social Surroundings describes the different levels of capabilities that are required for maintaining the relationship with people in their surroundings after having a child with special needs in a way that benefits the CSN parent. Although interesting real life examples of all capabilities were gathered during the contextmapping interviews, the capability of shared ownership stood out for me. Three inspiring stories arose about the surroundings of a CSN parent experiencing shared ownership for the family's well-being. These stories are shared here, anonymously, in order to give you an idea of what sparked this design goal.

Example 1
Twins with special needs were born. Because their conditions were severe, they had a tube inserted into their bodies when they came home from the hospital. The children were in danger of choking in case anything went wrong. For this reason, people in the surroundings of this CSN family, were invited to come to the hospital for a first aid lesson. Here, they also explained the conditions of the children to all that were present, such as neighbours and family. Since this moment, most people that were present expressed their involvement with the family, e.g. by asking how they are doing, offering the parents to socialize and drink a bottle of wine or to bring a pan with soup. The CSN parents experience their involvement as very valuable.

SHARED OWNERSHIP= ALL CAPACITIES UP TO EMPATHY + A FEELING OF PERSONAL CONNECTION OR ADDRESSMENT.

Example 2
In another story of a mother who had a child with special needs, something similar happened. The child had a tube as well, and the only person present at the first aid lesson was a neighbour. After this event, the neighbour felt so responsible for the family that she showed up at their door daily and even made a photo album of the child. The parent was thankful but also experienced awkwardness, because something like a photo album of her new-born son is a personal and delicate matter, and she barely knew the neighbour. She had desired such an initiative from her close family, but coming from this neighbour, it put her in a bit of a weird spot.

In this case, the neighbour experienced such a high level of ownership for their well-being, that her behaviour was a bit unsuitable for the relationship they had. While in the case of the twins, the same intervention had, probably unintentionally, triggered a level of ownership that was very much desirable, according to the CSN parents. These situations differ in the amount of people among whom the feeling of ownership was triggered, the relationship they had with the CSN parents, and most probably the personalities of the people present at the first aid class.

Example 3
The last example, a single mother gives birth to a child with special needs. From the very first moment, her friends and family step in and do the things with her a partner would have done. They went with to the hospital, they babysitted to give her sometime to herself, etc. Because they were so much involved, they held the child very dearly and they were happy to support them. When the child needed surgery years later, she and her boyfriend, her mother, two sisters and three friends rotated the nights he spend in the hospital, each of them sleeping next to him one of these nights. 'Because of your team of love, you got him out of the hospital,' the nurses said.

In these examples we see that the feeling of ownership is a result of the capacities of the person involved and a trigger that makes them feel personally addressed or close to the CSN parent, just like it was suggested in the framework of opportunities. In the first 2 examples the trigger was the first aid class, in the third the trigger was her single motherhood, combined with the strong connection they already had with her. **Therefore, the intervention should make others feel personally addressed or close to the CSN parent.**

Who

In the first examples, the trigger for feeling personally addressed was artificial in a way. Being present at the first aid class also caused people to feel involved of whom in reality their level of involvement was not that desirable. Every family lives in their own bubble, but CSN families have a much stronger bubble. In a way, when people experience shared ownership, they become part of this bubble. The relationship the CSN parent has with a person defines whether it feels natural and empowering for the parent if this person experiences shared ownership. If a design intervention were to create a feeling of shared ownership, **deciding who is desired to feel shared ownership, should be in the hands of the CSN parents.** Moreover, the first 2 anecdotes highlight the benefits of shared ownership, as opposed to ownership experienced by e.g. only one neighbour. Going back to the framework, we see that there are many steps in capabilities that exist before a person is capable of experiencing shared ownership. Whether a person is suited to step into the CSN family bubble, depends on where there stand with regards to these capacities. **The person should already have the capacity to empathize with the situation of the CSN parent, and embody all previous capacities as well**. Whether they do, depends on their personality as well as how close they are to the CSN family. If a person is close to the family, it is easier to empathize for example, even if they did not previously know anyone with special needs.

How

In the ‘how’ of this design goal lies an interesting challenge. A field of tension emerges between the conflicting demands of CSN parents.

On the one hand, CSN parents should be closely involved in this intervention. As discussed in ‘who’, in an intervention creating shared ownership, the CSN parents need to be in control of who is involved. For similar reasons, they also need to be able to choose when they want to involve people. The parents need to be open for letting people in. This can involve realizing that they are not regular parents, meaning they deserve to get some support. Moreover, every CSN parent is different, so their needs will differ as well, which is another reason to provide them with the control to organize their support as suits them.

Concluding, the intervention must give the parents control, because the people that get involved, and when and how they get involved, should benefit and suit them. **Therefore, the initiative of using the design intervention should be taken by the parent,** so they can choose who to involve, in what way and when it takes place.

On the other hand, in the interviews all parents have expressed the desire to see a gesture coming from the people in their surroundings. They are already confronted with so much responsibility as is, that it causes 60% of Dutch CSN parents to burn-out. They have little energy to invest in the relationships with the people around them and when trying to arrange social support, they experience difficulty. If the intervention needs much energy from them, in many cases the goal will never be reached. Some parents feel they should not ask for support, as they feel they should handle everything on their own, causing suport to have a negative stigma. Furthermore, parents might not realize how other people can support them and what they can mean for them without having experienced so. However, even if parents are not open to or looking for support, they might benefit from it.

To conclude, reasons not to depend on CSN parents for organizing their own support by awaking the feeling of ownership are: they may not be aware or open to the benefits, and when they realize the benefits it would have, they still have little energy or time to invest in this matter. **Therefore, the design intervention should require very little work from the parents. Furthermore, it should allow parents to explore what they need and desire. Moreover, the design should be encouraging**: familiarizing CSN parents with the possible benefits of social support, while reducing the stigma around asking for support.

Interaction vision

In order to design for this field of tension, I needed to envision a situation where the requirements regarding the 'how' go hand in hand. This resulted in a vision for the interaction between the CSN parent and the people desired to experience ownership.

In western wedding traditions, the bride asks someone close to her to be her maid of honor. before the wedding. Similarly, the groom asks his best man. This interaction was chosen because it a great example of the event of giving another person ownership over something important, with a very positive connotation, instead of the negative connotation of asking for support in the context of a CSN parent. See figures 11 and 12.

Asking someone to be your maid of honor or best man, is a happening associated with feelings of joy and closeness. The bride is in control and hands out the role of maid of honor. The maid of honor is touched and honored and vows to support the bride. Being a maid of honor is experienced to be honorable and personal, as it means that the bride feels very close to you and trusts you to be by her side during this life event. Furthermore, it is dutiful, as the maid of honor gets a lot of responsibility in supporting the bride. She needs to have the bride’s best intentions in mind, telling her what she needs to hear and being there for her when needs it, like when she is anxious or nervous.

Awakening a feeling of ownership should feel like asking someone to be your maid of honor or best man.

—PRECIOUS

—HONORABLE

—JOYFUL

—DUTIFUL

Figure 11: best man & groom

Figure 12: bride & maid of honor

3.3 KEY TAKE-AWAYS

For the well-being of CSN parents, it is crucial that they stand in connection with the people in their surroundings, for fulfilling their fundamental human needs for relatedness and belonging and to feel connected to the surrounding culture. Furthermore, they can greatly benefit from having social support during the many challenges they encounter as a CSN parent. My vision is that CSN parents should be surrounded by a strongly involved inner circle of people from their social network, guarding their well-being. Going back to the Framework of Opportunities, we can see that to step into the inner circle, people need the capacity of involvement: ***they need to experience shared ownership****. In reality however,* ***people often assume or expect CSN parents to handle everything on their own****, without considering what they could mean for them. Furthermore,* ***some CSN parents have a hard time asking for support****, because they feel they are supposed to do everything on their own. Therefore, the following design goal was formulated.*

The design intervention should support the CSN parent in awaking a feeling of ownership among a few people in their social surroundings.

In order to create a supporting inner circle, a few people in the CSN parent's social surroundings should be given a feeling of ownership over the well-being of the CSN family. The user research showed that a trigger that makes them feel personally addressed or close to the CSN parent is an important ingredient for creating this feeling of ownership. However, the parents need to be open to letting these people in. To make sure the effects of the intervention are desirable for the parent, deciding who should be in this inner circle, should be in their hands. The initiative of using the design intervention should therefore be taken by the parent, so they can choose when they are ready and who to involve.

The design intervention should facilitate the CSN parent as much as possible.

CSN parents are already confronted with such a workload and so much responsibility as is, that it causes 60% of Dutch CSN parents to burn out. CSN parents have little to no energy to invest in the relationships with the people around them and when they do try to arrange social support, they often experience resistance from the other side. Therefore, the design intervention should require very little work from the parents, facilitating them as much as possible.

The design intervention should encourage them and allow them to explore what they desire.

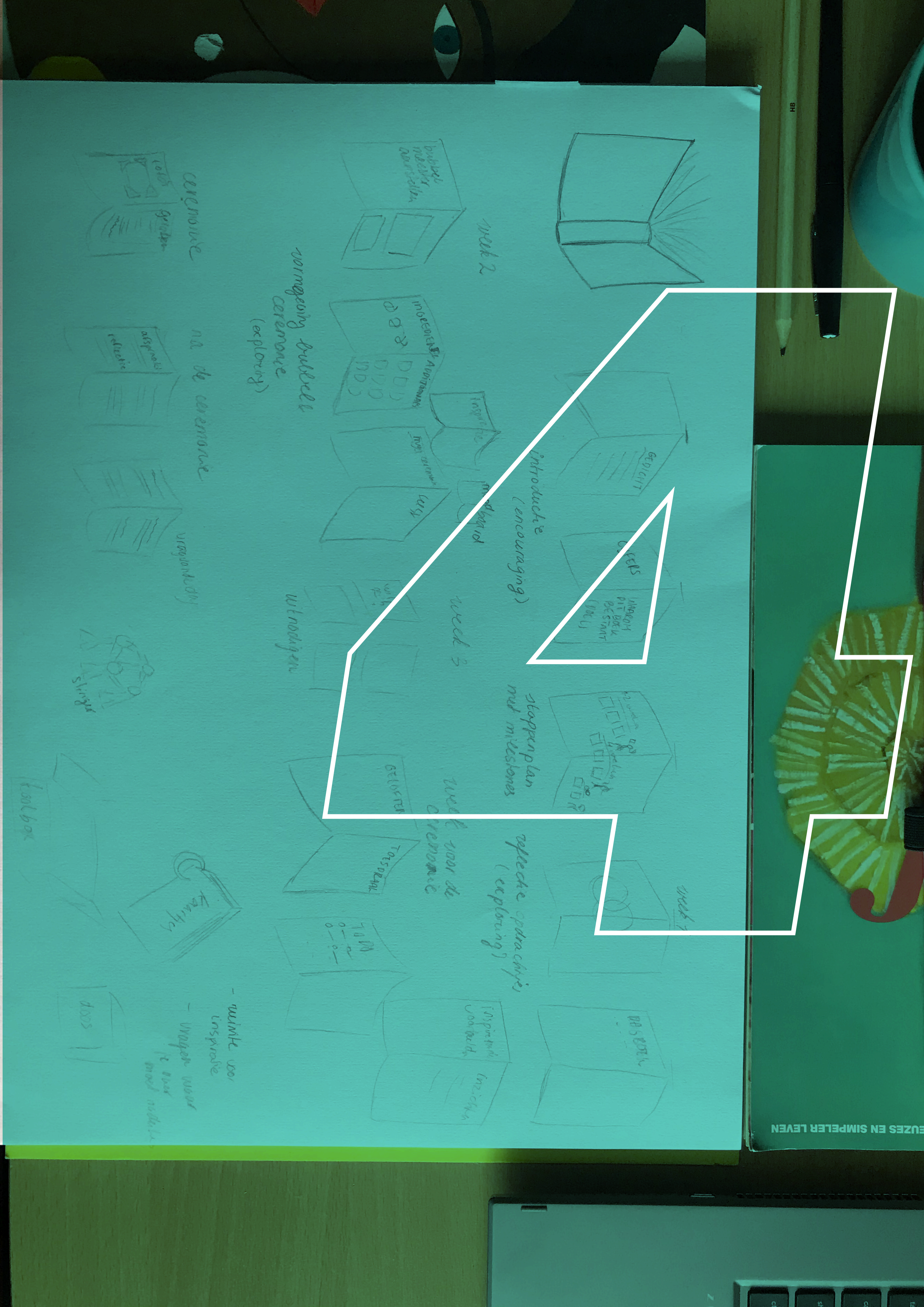
Some CSN parents have a hard time asking for support, because they feel they are supposed to do everything on their own. Moreover, they might not realize how other people can support them and what they can mean for them without having experienced so. Therefore, the design intervention should allow the CSN parent to explore what they need and desire from their inner circle. Furthermore, the design should encourage the parents to give other people the feeling of ownership. Familiarizing parents with the possible benefits of social support, while reducing the stigma around asking for support.

Awakening a feeling of ownership should feel like asking someone to be your maid of honor or best man.

Asking someone to be your maid of honor or best man, is an event associated with feelings of joy and closeness. Being a maid of honor is experienced to be honorable and precious, as it means that the bride feels very close to you and trusts you to be by her side during this life event. Furthermore, it is dutiful, as the maid of honor gets a lot of responsibility in supporting the bride. This interaction vision was chosen because it a great example of the event of giving another person ownership over something important, with a very positive connotation. The bride is in control and hands out the role of maid of honor. The maid of honor is touched and honored and vows to support the bride. Instead of the negative connotation of asking for support in the context of CSN parents, in the context of a wedding, the interaction is:

-precious
-honorable
-joyful
-dutiful

4


week 1
GEDICHT
OFFERS
WAAROM DIT BOEK BESTAAT (DOEL)
introductie (encouraging)
stappenplan met milestones
reflectie opdrachtjes (exploring)
DAS BOEK
week 2
inspiratie
moodboard
week 3
week voor de ceremonie
bubbel meester aanstellen
INGREDIENTEN
ADDITIONALS
mijn ceremonie
GELOFTEN
TOESPRAAK
TO DO
inspiratie voorbeeld
inzichten
vormgeving bubbels ceremonie (exploring)
uitnodigen
ceremonie
foto's
geloften
na de ceremonie
afspraken
reflectie
vragenlijst
slinger
kaartjes
toolbox
doos
- ruimte voor inspiratie
- vragen waar je over moet nadenken
HB
EUZES EN SIMPELER LEVEN

DEVELOP

This chapter describes the explorations that took place in order to develop a design in line with the design goals. After brainstorming and investigating existing solutions, a few design concepts were developed. After evaluating these concepts the final design concept was born, which is unveiled is the final subchapter.

4.1 APPROACH

In order to come to a solution that meets the design goals as good as possible, different solutions were explored. Firstly, an online brainstorm session with designers from the service design agency Muzus was set up to generate new ideas and concepts, with use of brainstorming techniques like brainwriting and how to's (Delft Design Guide, 2020). Secondly, existing solutions were explored through desk research. Thirdly, a few concepts were created and discussed by speed dating, leading to the final concept. Speed dating is a research-through-design method that was invented to reduce the risk of designing things that people will not adopt. It also discloses opportunities and user needs that designers might not observe during fieldwork (Zimmerman & Forlizzi, 2017). Finally, this concept was discussed in a small focus group.

Activities

Brainstorm with service designers

An online brainstorm session with service designers from Muzus was organized. After the context was illustrated and the design goals were presented, a short individual brainstorm took place. Then, we generated new ideas and concepts with regards to the design goals in teams.

Investigation of existing solutions

Existing ceremonies and rituals were explored through desk research. It turns out there is little frame of reference for modern rituals that do not have to do with weddings or religion.

Conceptualization

A number of concepts for rituals were designed, but when talking about them with different people, it soon turned out that their likelihood to be open to performing these rituals differed greatly among them. This caused the realization that the concept should enable CSN parents to design their own ritual, which led to the final concept.

Focus group with 2 CSN parents

The final concept was pitched to two CSN parents, Tineke de Jong and Marise Schot. They gave input on how it could be made feasible that the concept would be implemented in a way that would reach CSN parents.

Figure 13 & 14:
offline sensitizing material
before online brainstorm

4.2 NEW CONCEPTS & IDEAS

Brainstorming

The brainstorm led to a large variety of ideas on how to meet the design goals, which eventually led to three promising concepts. The last concept is a direct inspiration for the project, the first and second inspired the project indirectly.

Concept 1 was designed to help others to think about the CSN parent from time to time. It is called the 'vergeet-me-niet kalender' shaped like the flower, which translates to 'do-not-forget-me'. It is an advent calendar that offers different information, exercises and questions involving the CSN family each week. The CSN parent gets a format for this calendar and they can fill it out themselves, making it personal.

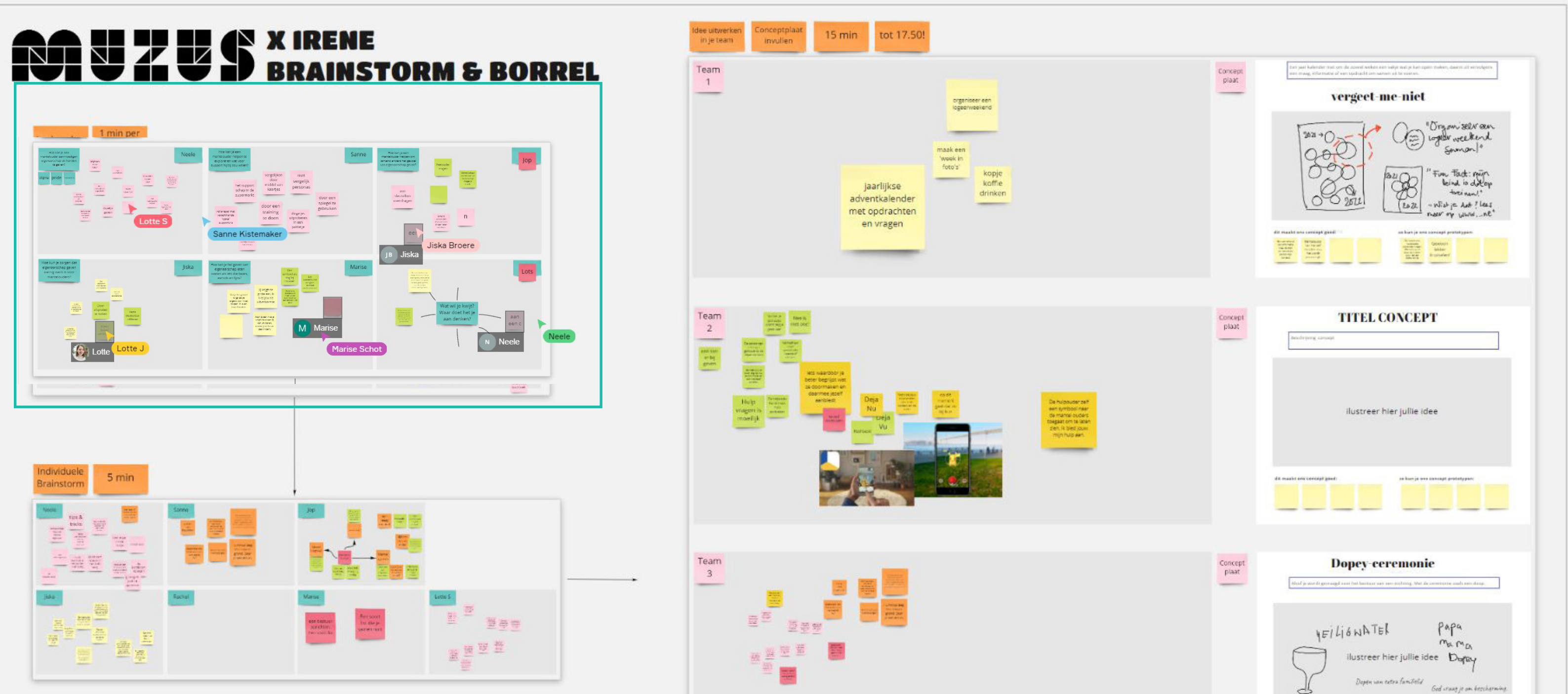
Concept 2 helps others understand what a CSN parent is going through so that they initiate to offer support to the CSN parent. To do so, it enables others to compare their own day-to-day scenarios with those of CSN parents. It creates the effect of looking through their window from the outside, giving outsiders insight into their lives, through the use of an mobile application or transparent photos. When the other person realizes an CSN parent can use their help, they give the parent a symbolic object as if to say: I am offering you my help.

Concept 3 is a answer to the question: how can you make sure others feel part of the family? CSN parents ask a few people from their environment like they become part of an official board. To make it official, a ceremony takes place, resembling a baptism. Instead of asking God to take care of the child, CSN parents ask a few people to take care of and become part of their family. They get a specific name and role in the family. After the ceremony, a celebration takes place.

Concept 3, helping CSN parents to organize an official ceremony with a celebration, highly fits my design goals. It resembles the concept I had in mind beforehand, except I had not thought of an official ceremony so much, as most of my thoughts went out to the proposal, like asking someone to be your maid of honor. A ceremony and celebration can greatly contribute to the goal of giving a positive connotation to asking new people to become part of the family's inner circle.

The figure below captures the brainstorm in action and its results.

Figure 15: brainstorm in action & its results



4.3 EXISTING SOLUTIONS

Ceremony vs. Ritual

In short, ceremonies are official events that mark a specific occasion (Cambridge Dictonary, 2020). A ritual is a sequence of activities, performed in a specific context, designed to support shared values (van Boeijen, 2015). Although the meaning of the event should be recognized to mark an occasion -when you see two rings and two people say 'I do', you know what it means-, the event should have the intimate feel of a ritual instead of a public ceremony. Moreover, the event should support specific values, like vulnerability, unity and health. Therefore, the event will be a blend of ceremony and ritual.

Archetypical

When investigating existing ceremonies and rituals, the result of an online search says it all. When searching the word 'ritual' online, the results can roughly be divided in two categories. The first has to do with overpriced bathing products, and the second are actual rituals, but either performed in a foreign country or taken to an extreme, like witch craft. For atheists, rituals are commercialized or overly remote.

Similarly, the word 'ceremony' does not rise a great variety of images. Even though the definition of is '***(a set of) formal acts, often fixed and traditional, performed on important social or religious occasions'*** according to Cambridge Dictionary (2020), the images paint a more specific picture. Just like on Pinterest, in practice the only thing associated with ceremonies are weddings. See the image on the right.

If one were to throw a wedding in the Netherlands, means to find inspiration and tools for planning are endless. But if more than two people would want to have a ceremony to seal their intentions towards one another, they are left with a frame of reference of how to do so. This leaves design with the opportunity to help CSN parents to create down-to-earth but meaningful ceremonies that might suit Dutch CSN parents and the people around them.

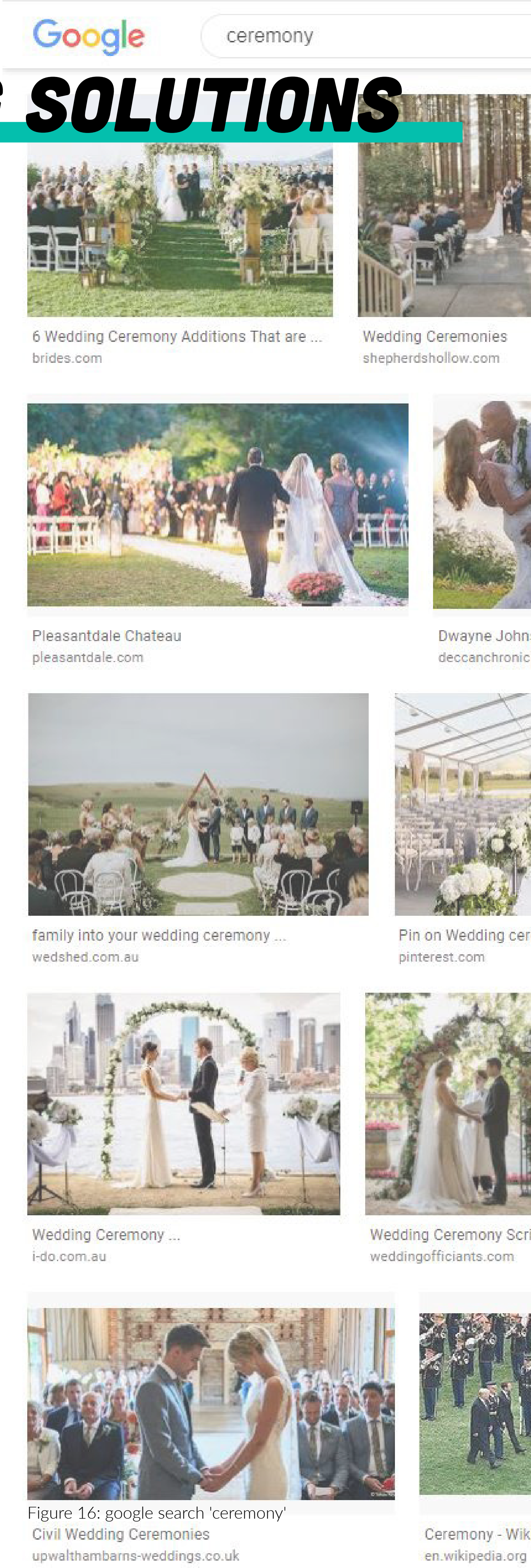
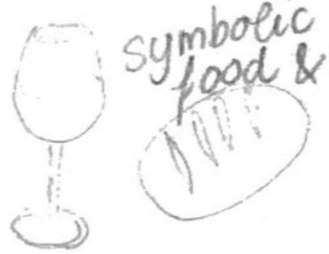


Figure 16: google search 'ceremony'

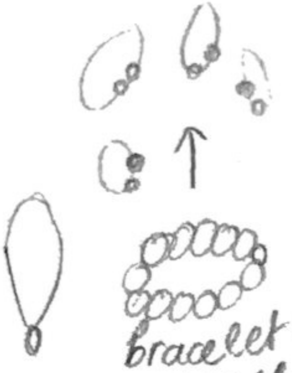
mixing things to make something

lanterns

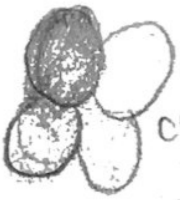


symbolic food & dr

writing down intentions



bracelet or necklace giveaway



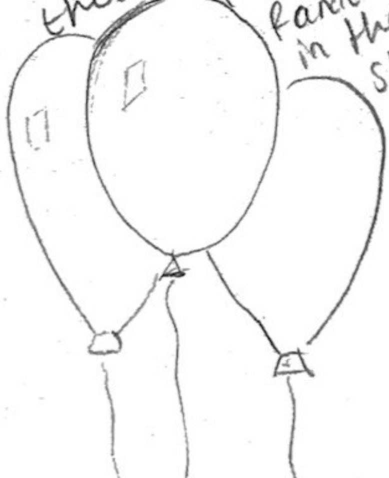
colors

burning fears/ intentions

poems & songs

figurine or statuette

everyone sends their wishes for the family in the sk



digging brooklets to symbolically alleviate

music & dancing

cake

sharing a meal

smell

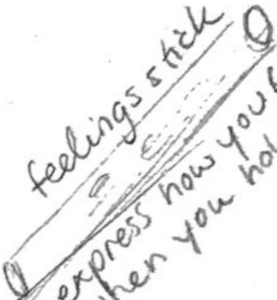
touch

1 minute of silence

or even meditation

inks

planting a tree



feelings stick

express how you feel when you hold it

growing

seeds

ring in the sand

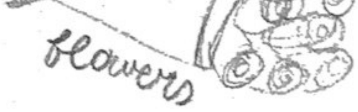
circle of love

the child

-parents-

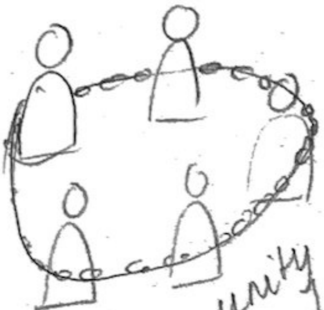
bubble

everyone lights their own fire after saying their vows



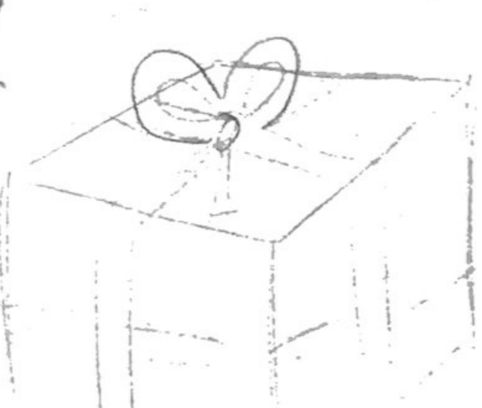
flowers

4 elements



unity by chain/rope

drinks/ alcohol



everyone symbolically brings a gift for the child/ family

NEW CONCEPTS & IDEAS

Speed dating

After the brainstorm and the investigation of existing ceremonies and rituals, individual ideation took place regarding the elements that could shape an event to welcome new people into the inner circle of CSN parents, see figure 17. These ideas led to different concepts for events. Rough scenarios were drawn of the different concepts to discuss them with other people, see figure 18 for an example. This method, speed dating, was used to estimate how likely it is for different people that they would organize or play a role in such a ceremony. The likelihood greatly differed, depending on who was asked. An important factor was the extent to which they are familiar with the activities performed in the ceremony or with rituals in general. The idea of drawing a 'circle of love' in the sand to talk under predetermined conditions, for example, was exciting to some and appalling to others.

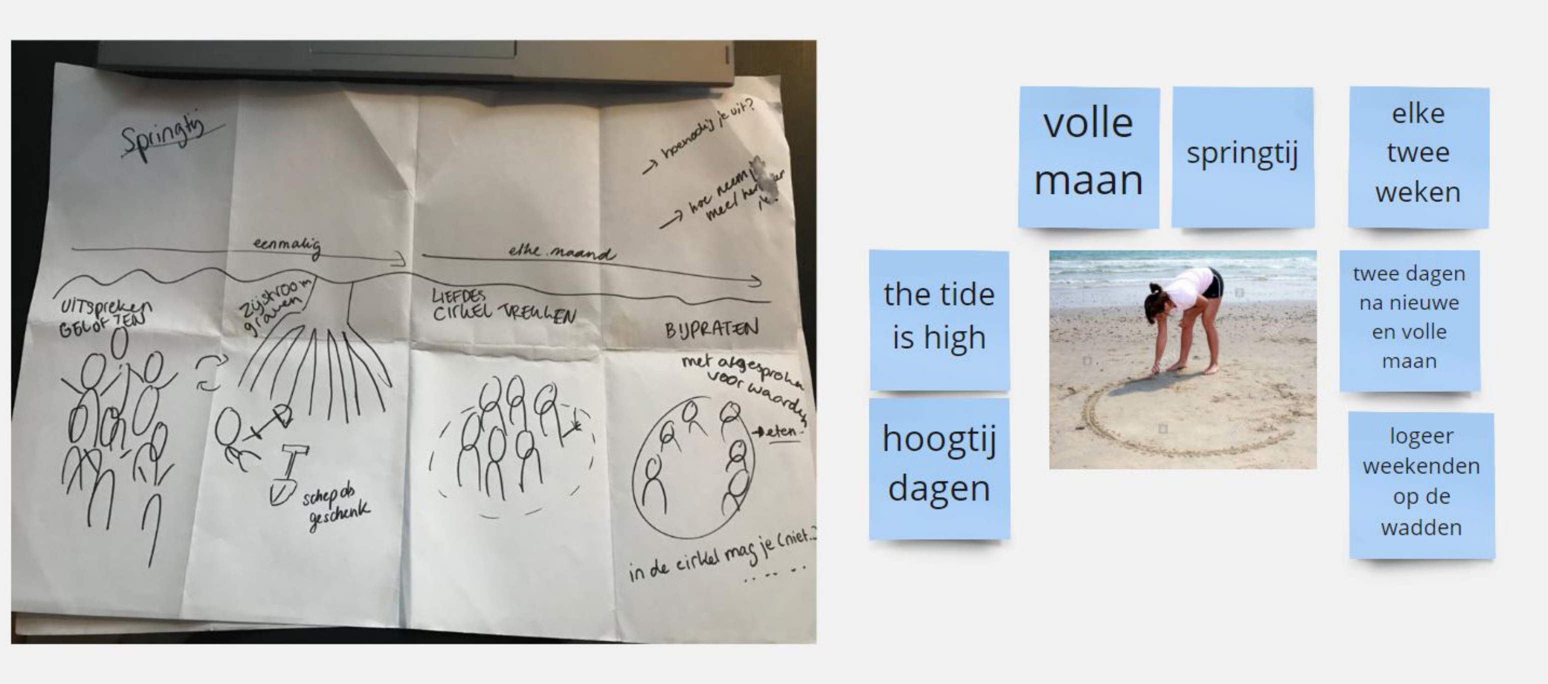


Figure 18: example of a scenario of an event

4.4 FINAL CONCEPT

The final concept guides CSN parents in setting up their own support circle, starting with a ceremony to seal their commitment. In this case, designing does not only involve shaping certain aspects, but it also involves deliberately leaving aspects open for the users to decide. The impact of division on the concept is explained in the following subchapters. An overview of the division of the ceremony's main elements is portrayed in figures 19 and 20 on the following pages.

Common aspects

Ideally, being part of the support circle of a CSN parent were a well-known and recognized concept. Similar to e.g. marriage or godparenthood, the non-trivial commitments that are agreed upon and the meaning of such a pact would be clear to all parties involved. If the notion of being part of the CSN family's inner circle were to be recognized and common in the Netherlands or even abroad, it would take away a large part of the barrier of asking for long-term support and give CSN parents an opening and a format to build up their own support circle. Moreover, in shaping the design lies an opportunity give long-term social support for CSN families a positive connation, decreasing its stigma. **In order for the concept of long-term support circles for CSN families to be commonly understood and acknowledged, the design should clearly define and promote this concept. Common aspects such as a distinguished terminology and points of recognition, are required to achieve common recognition.**

A distinguished terminology enables people to discuss and familiarize themselves with the concept. Moreover, suiting terminology helps to frame the concept as desired. For this design, defining the terminology consists of naming the inner circle and its definition, the role that people in the inner circle play, and the ceremony. If this feels vague, consider the words: married couple, husband and wife, and wedding. Furthermore, the users' commitment and intentions can be expressed in pre-defined vows.

Points of recognition enable people to perceive and acknowledge the concept, when confronted with it. Going back to an earlier example: when you see two people say 'I do', putting a ring on each others finger, you know what it means. Van Boeijen (2015) defines a number of aspects that play a role in ritual design. A few of these aspects, alongside the terminology, should be established in the design, including: the aim or intention of the event, specific values that should be enhanced, a course of events, and certain artifacts. Together, these aspects shape the established part of the ceremony.

terminology	zachte wacht zachte wachters bezachtiging
aim or intention	commiting to support the family
specific values	vulnerability, unity & health
course of events	speech, exchange of vows, seal of unity, celebration
artefacts	statuette of a feather

Figure 19: common aspects of the ceremony

The design per phase

Instead of defining and designing everything about the ceremony, I chose to design a DIY booklet help CSN parents prepare for and organize the ceremony. The booklet will guide and inspire CSN parents during the set-up of the ceremony. This set-up consists of 4 phases, determination, creation, invitation and preparation. Each of the phases are meant to doable in a week, assuming the user can spare a few moments a week to work on the booklet. This way, the booklet can offer users the prospect of having their own support circle in 5 weeks, instead of entering an endless process. On the next pages an overview of the concept is presented.

Custom aspects

The design is build on the aspects that are clearly defined, as well as the aspects that are deliberately left for the user to decide. When a few people had speed dates with different concepts for rituals, it became clear that it would be impossible to define and design an entire ritual that suits everyone in the Netherlands. The things that people attribute meaning to and the activities that they are comfortable performing, greatly differ. Therefore, **the design needs to support CSN parents in setting up a ceremony according to their own preferences**. **Room for customization is needed to make sure the ceremony is perceived to be meaningful and simply doable.**

The remaining aspects that van Boeijen defined to play a role in ritual design (2015), should therefore not defined by the designer,but by the user. These aspects include: the people involved, the context (time and place) and the interaction scenario, which is how people exactly interact during the course of events. These aspects, alongside part of the vows and other artifacts, are left to decide on by the users. However, the design does support its users in exploring different options regarding these custom aspects, since they cannot get inspired by examples from others yet. It will do so by helping the user to reflect and by offering examples and inspiration from other contexts.

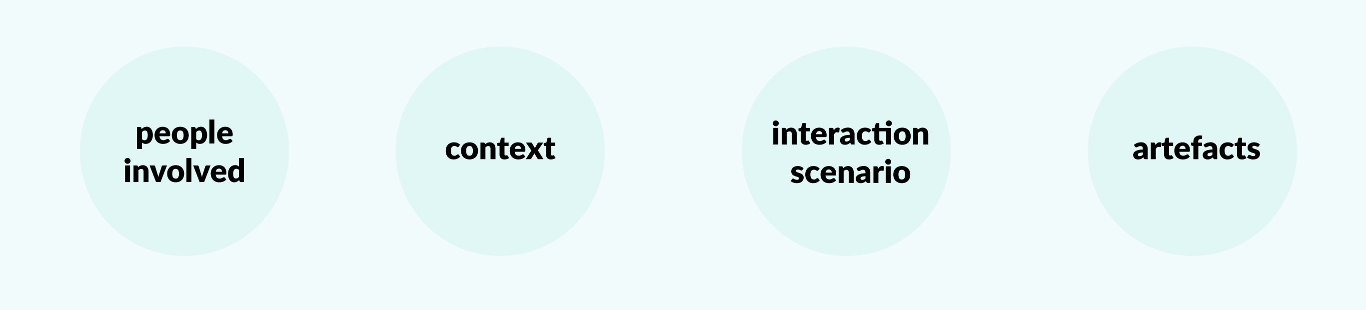


Figure 20: custom aspects of the ceremony

Determination

In short The name of phase 1, determination, is a wink to the value of self-determination, explained in the framework of values. First, CSN parents will have to determine they want their own support circle and therefore, a commitment ceremony. Secondly, they will have to determine in advance what they need and desire from this support circle.

The booklet It starts off with highlighting the advantages of having a support circle and presenting the current numbers on the poor well-being of CSN parents. The terminology, intention of the ceremony and the values behind it are explained. Then, the booklet presents them with a milestones plan for setting up the ceremony so they know what they are getting into. For determining what they want, the book offers them exercises for self-reflection.

Additionally The moment that examples from other people exist, they will be portrayed on a website as an additional part of the design. I believe that if they see that many others have set up their own support bubble and ceremony, they will be encouraged to take the same step themselves. Additionally, it will inspire them by demonstrating what it could look like. In the end, they can add their own story and ceremony.

Creation

In short At the start of the second phase, Creation, the user is encouraged to ask a friend or family member for help. Together, they discuss the user's past reflection and explore what the ceremony might look like.

The booklet The booklet offers a blueprint for the commitment ceremony, explaining the course of events. The statuette that stands for CSN parents' support circle is clarified. Inspiration and brainstorming pages help the users define their own preferences regarding the people to invite, the context, the interactions, and possible artifacts of their own choice. In a format they finalize their choices.

Invitation

In short The user takes a leap and proposes to a few people to become part of their support circle.

The booklet offers the user a set of invitation cards to break the ice. Moreover, the backside of the card or a video explains the others what is expected of them: what it means to be part of a support circle and how to prepare for the ceremony.

Preparation

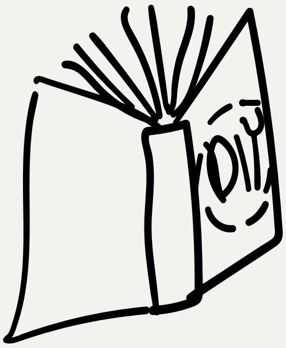
In short The user needs to prepare their speech and vows to the people that were invited.

The booklet indicates the predefined part of the vows and offers examples of what the rest of the vows could be. Furthermore, it gives the user space to take notes regarding their speech and to keep a to-do list for practical preparations for the ceremony.

Ceremony & ever after

In short Now that everything regarding the ceremony is prepared, the main role of the booklet is fulfilled. The ceremony consist of 4 events: the speech, the exchanging of vows, a seal of their commitment including the receival of a statuette, and celebration.

The booklet will offer space for photos and memories of the ceremony and room to note down possible agreements and reflections.



Overview of the phases

DETERMINATION

The user gets convinced that it is normal & healthy to have a support circle

The user reflects and decides what it is they need from whom

week 1

CREATION

The user asks a friend to think along with them & to discuss their thoughts with

Together they explore and decide on the details of the ceremony

week 2

CELEBRATION

The user explains why the people who are present were chosen to become part of the SC

The user & the others exchange their vows with each other

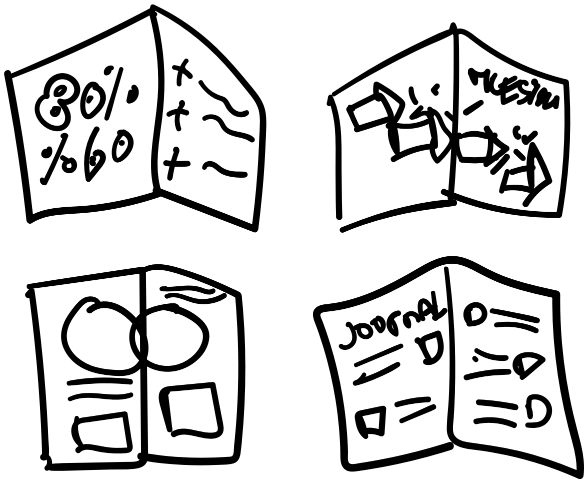
They seal their commitment in the way the user has chosen, and they get a statuette

They celebrate that they have become a closer part of each others lives

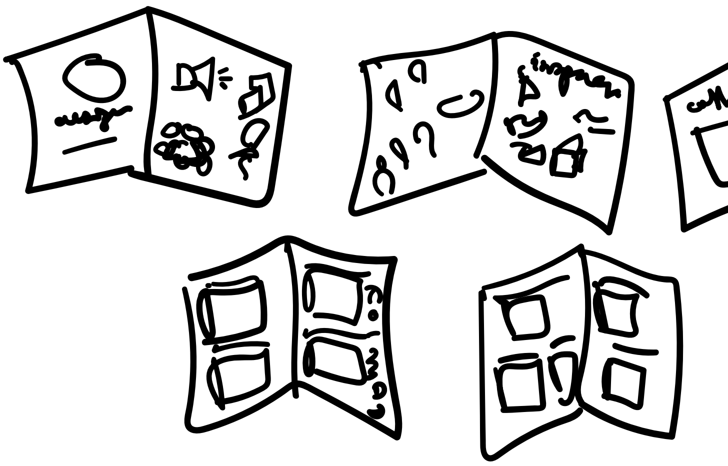
the day of the ceremony (week ~5)

Content of the booklet

DETERMINATION



PRODUCTION



- the advantages of having a support circle,
- the current numbers on the well-being of CSN parents
- an explanation of the terminology, aim and values
- a milestones plan for setting up the ceremony
- exercises for self-reflection.

- blueprint of course of events
- inspiration and brainstorming pages
- format to finalize their choices

the user knows what they want & need

INVITATION

The user proposes to a few people to be part of her support circle & invites them

week 3

PREPARATION

The user prepares the ceremony, Their vows & a short speech

week 4

the user is prepared for the ceremony

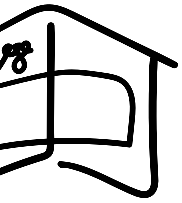
the user has their own support circle

GRATIFICATION

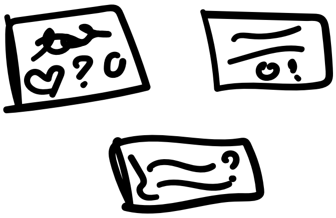
They try and find a way to stay involved and to frequently come together

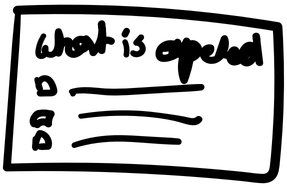
ever after

the user feels supported in the long term



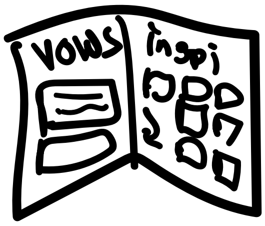
INVITATION





- a set of invitation cards
- explanation for the people invited about what is expected of them

PREPARATION



- predefined part of the vows
- examples for the rest of the vows
- space to take notes on speech
- to-do list for practical preparations

5


DOEBOEK VOOR MANTELOUDERS
ZACHTE WACHT
IN 5 WEKEN
door Irene Kingma
namens Ontzorghuis
VOOR DE BENOEMING VAN JULLIE EIGEN ZACHTE WACHT

DELIVER

In this chapter, the final design of this graduation project is presented. The core concept of the design, the 5 elements that bring the design to life, and the intended use are explained. The chapter concludes with the key aspects of added value, a scenario for implementation and additional opportunities.

5.1 DE ZACHTE WACHT

The core of the design is the concept of 'zachte wacht'. This concept was brought to life in three ways: through a DIY booklet, a statuette, workshops and a website. As the most important first step is to support the users in familiarizing themselves with the concept, in this stage most of the design effort went out to booklet. The concept, the booklet, the statuette, the workshops and the website are explained in this subchapter.

Zachte wacht as a concept

The core of the design is the concept of 'zachte wacht', which translates to 'soft guard'. The concept is about being soft with oneself, or kind to oneself. A zachte wacht is a long-term support circle, promoting self-kindness. Their role is to guard the CSN family and the kindness in which they live. This kindness can manifest in CSN parents expectations of themselves, what they ask of themselves, and how they organize their lives. 'Zachte wachters', or soft guardians, challenge the way CSN parents perceive themselves and think along in the challenges they face. They support the family in living their lives in a way that sustains their well-being in the long term, by offering them their brainpower and concern.

A zachte wacht is initiated by CSN parents themselves, electing a few people as zachte wachters. When CSN parents propose to a few people to become their zachte wachters, they invite them to the 'bezachtiging', which is a small ceremony to seal and celebrate this significant and meaningful commitment. The ceremony supports the values vulnerability, unity and mental well-being. The booklet, the statuette and the website embody the value of kindness and these three sub values.

Call for kindness

The call for CSN parents to be kind to themselves, or in other words, self-compassionate, is a result of my observations from literature and real life, as well personal belief. The practical learnings that are important for CSN parents. from the third framework, were the main inspiration for this aim to promote self-compassion. These learnings include: *CSN parenthood is much more demanding than regular parenthood*, you need to take care of yourself, in order to keep caring for your child, *you should not hold back in telling others what would help you* and it is okay to feel somber sometimes. The bottom line of these practical learnings would be: **it is important to be kind to yourself and it is okay to need support.**

From personal experience, I have learned that is more likely to get stuck in a difficult situation if you are used to self-criticize and judge yourself for whatever you are feeling. It is more constructive to take on kindness towards oneself, self-understanding and self-care.

Most of the CSN parents that were interviewed indirectly expressed a shift in their values from achievement towards care. However, an increase in care for their child, does not indicate they are practicing more self-care or compassion per se. Though after having a child with special needs, in practice their activities shift from achievement towards care in a rapid manner, the shift in expectations they have of themselves can fall behind.

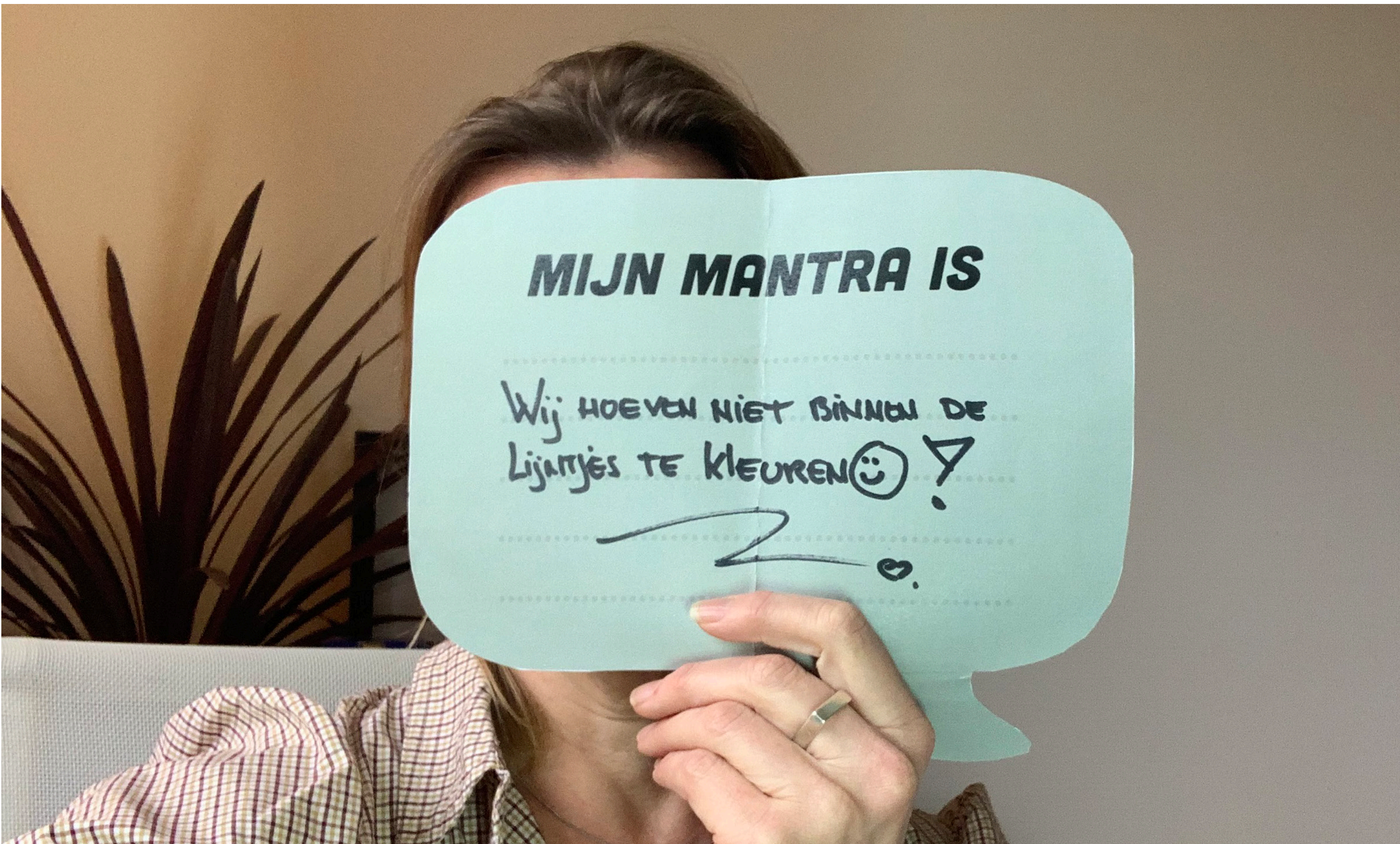
> **'Die omslag van het werken naar het zorgen, was heel raar. Dan moet je ineens een hele zorgmoeder zijn. Ik was altijd heel erg ambitieus.'**
>
> -CSN parent in interview

Self-compassion means to be kind towards yourself, regardless of your thoughts, feelings and achievements. Self-compassion can support the values that were found to play an important role for CSN parents. For example, self-compassion can boost the value of self-determination because before you can create your own path, you need to allow yourself and your family to go a different path than others. and your expectations of yourself to change. A beautiful, down to earth example of this, is mantra of one the CSN parents I interviewed: '*We tell ourselves that we are allowed to colour outside the lines as a family, because of our daughter. We don't need to comply with imposed norms*'. Moreover, it can support self-preservation. When you allow yourself not to be perfect for example, room to ask for support arises.

Shift in culture

Many Western societies are considered to be meritocracies, meaning they are built on the belief that anyone with hard work and dedication can 'make it'. This social system connects success and status directly to individual talents, abilities and efforts (Crossman, 2019), putting the highest achiever on a pedestal. As concluded in Investigate, CSN parents say they currently feel like they should be able to handle everything on their own, they are too proud to ask for support or they do not want to burden their social network, or they feel they should not ask their network, because they feel it is just not-done. Parents indicate they have difficulty expressing they need help, and they don't know what help they can ask for. Furthermore, they indicate that a big part of their network fails to recognize that they can use help and they do not know how and what to ask for. Only a part of their social network is willing to offer support (Okma, Naafs, Vergeer, & Berns, 2014). In both groups attitude, norms and values, seem to stand in the way of getting support for CSN parents.

The concept of the zachte wacht promotes a culture change. By highlighting the importance of kindness, it promotes a society in which care is more important than achievement. When CSN parents put their close ones in the role of soft guardians, it will not only affect their own attitude, but also the attitude of their close ones. I believe everyone can benefit from a healthy dose of kindness and self-compassion, and Dutch CSN parents in this day and age in particular.



The booklet

Purpose First and foremost, the booklet introduces and explains the concept of zachte wacht and the ceremony. Secondly, it guides the user through the steps of preparing the ceremony so they can name their own zachte wacht. These steps and their exact content were described in the previous chapter, final concept. Instead of forcing certain steps and actions upon the users, the booklet offers examples and suggestions.

Design The tone of the booklet was carefully defined, as the message it is spreading is already relatively controversial. It challenges the way some CSN parents might see themselves. On one of the first pages, for example, it is stated that CSN parenthood is much more demanding than regular parenthood. While, when looking at the different attitudes CSN parents can have, some perceive themselves to be a regular parent.

Even more tricky is of course the culture change, from achievement towards care, that the user is challenged with when going through the booklet. Therefore, the design aims to evoke self-compassion and kindness, without giving the impression of being pitiful. The aim for a kind feel mainly manifests in the bright but soft colours, welcoming illustrations and images, the poem and several one liners. A strong, sans-serif font was used to express that the users and their situations are taken seriously. The font is meant to keep the design balanced, not too ‘soft’, to speak to a large target group. For similar reasons, the word self-compassion was never used.

Unfortunately, not all 72 pages of the booklet can be presented in this thesis. For the full booklet, I refer you to appendix D. A few impressions are given on the following pages.

Figure 21: a welcoming illustration and a kind poem

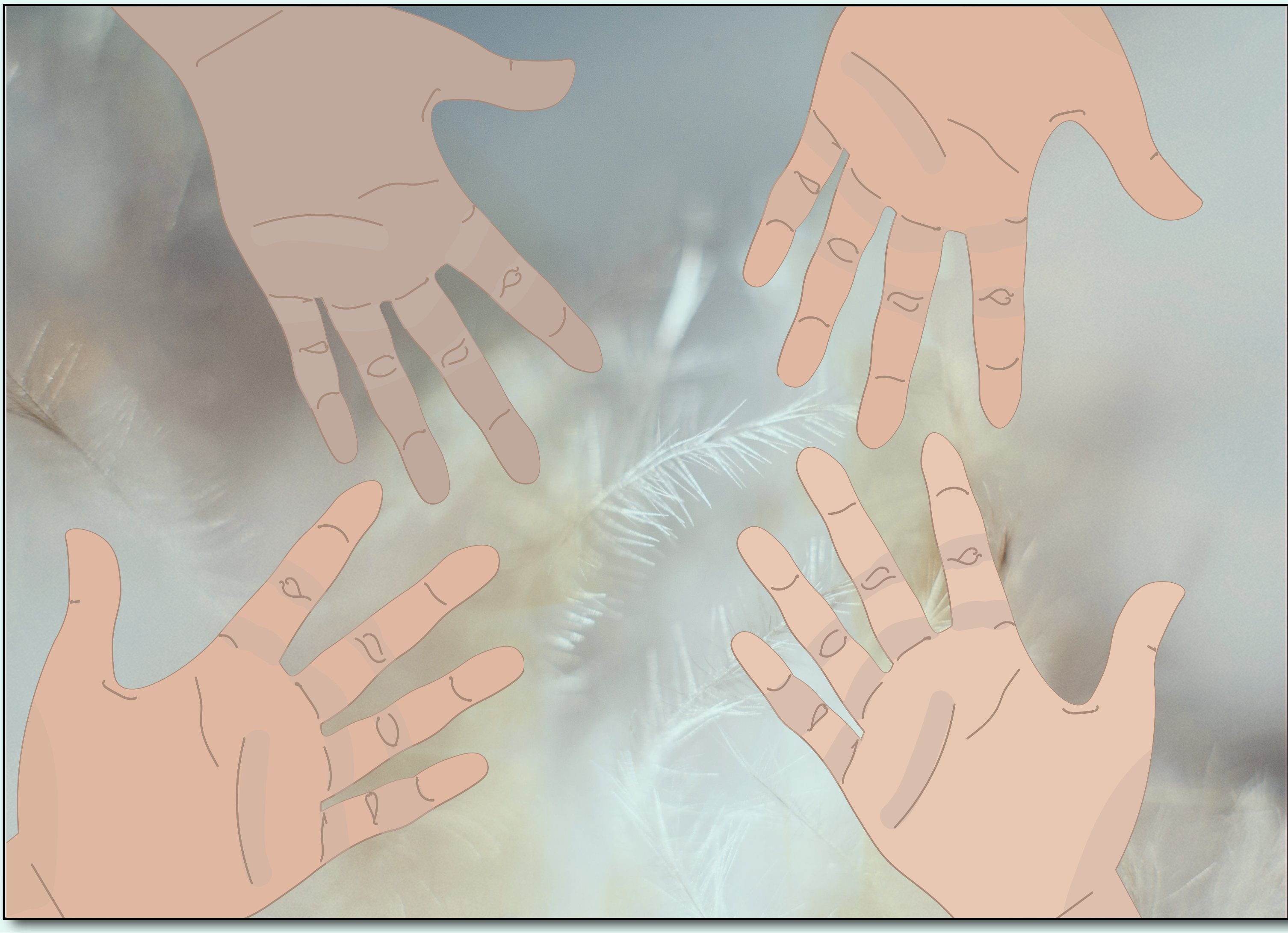


Figure 22: the booklet's cover: soft images combined with a strong font

ODE AAN DE ZACHTHEID

Stel je voor dat ik er voor jou was
met een aantal anderen
Stel je voor dat we samen een wolk vormden
om jou en je gezin
Dat we deze bijzondere weg
samen zouden bewandelen
Dat we vaak samen kwamen om te praten
onderwerp: jij en jouw kind

Stel dat we samen konden waken over zachtheid
dat wat onverwacht is, een pracht
Dat jij ons toe zou laten als zachte wachters
En ons zou bezegelen als jullie wacht

Kijk in je gedachten wie je nu voor je ziet
Samen kunnen we veel meer dragen
De weg van droom naar werkelijkheid
is ons als zachte wachters vragen

5

With same consideration, the term zachte wacht was chosen. The connotation of zachte wacht is very important, as CSN parents need to feel comfortable proposing close ones to take on this role. ‘Zachte’ is a word that means kind or mild when it comes to behaviour, and soft when it comes to material properties. The word ‘wacht’ has a serious, tough, and dutiful tone, and means keeper, guardian or even guard. The two words together have a balanced tone, sounding kind but serious.

Besides the kind tone and feel, other aspects of self-compassion were incorporated. For example, an important aspect is the reflection exercises, that challenges CSN parents to reformulate the expectations have of themselves with more self-kindness. Another example is the invitation to make positive wishes for yourself and the others during the ceremony. Suggested wishes are: ‘I wish us to be kind to ourselves. I wish us to dare to be vulnerable. I wish us to feel connected. I wish us to be and stay mentally well.’

Figure 23: one liner, welcoming image, soft colors

WAT VERWACHT IK VAN MEZELF?

Op de achtergrond heeft iedereen bepaalde verwachtingen van zichzelf.
Wat zijn jouw verwachtingen van jezelf? Vul de bolletjes in.

dat ik.....

HET IS EEN EER OM MENSEN
ÉCHT TOE TE LATEN.

Figure 24: self-reflection exercises

BEN IK HIERIN HARD OF ZACHT VOOR MEZELF?

Welke verwachtingen zijn harder? Welke zijn zachter?
Verbind je verwachtingen in de bolletjes aan de lijn.

zacht

hard

WAT ZIJN ZACHTERE VERWACHTINGEN?

Wat zijn verwachtingen die je zou willen verzachten?
Hoe zou je willen dat deze verwachingen klinken?

dat ik.....

27

The statuette

The statuette (fig. 25) embodies the role that zachte wachters play in the lives of the CSN family. It is a symbol for the main value, kindness, and the sub-values that are supported by the ceremony, vulnerability, unity and mental health. The feather's material property of softness stands for kindness. Unity is symbolized, as all zachte wachters receive the same statuette. It stands for vulnerability because a feather is delicate. The white feather is associated with protection, light and love. It is believed to be the message of a guardian angel. The statuette was cut out of poplar wood, which is light in colour and weight. It is a natural and sustainable resource for statuette, with a soft and light look and feel. The words 'zachte wacht sinds 2021' are engraved. This way, it clearly marks the beginning of something big. Moreover, it offers zachte wachters from different CSN families the opportunity to bond over their likenesses.

Figure 25: the statuette

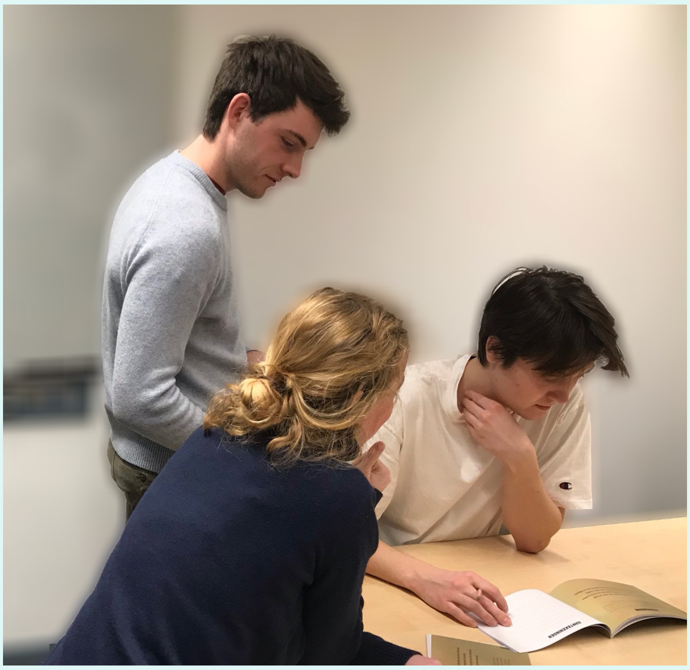


Figure 26: workshop setting

The workshops

The workshops to complement the booklet can be given by Ontzorghuis. The workshops guide people through the steps of setting up their own zachte wacht ceremony. The content of the workshops is explained in the following subchapter, Intended Use. The workshops are meant for people who are in search for more inspiration, conversation and guidance than the booklet and the website can offer. Moreover, the workshops are a big stick, creating a sense of urgency for well-intentioned people that would otherwise have the booklet laying around forever. Enrolment for the workshops can happen in pairs, with a close friend or as a family, including older children. Figure 26 shows an example of a workshop setting.

The webpage

First and foremost, the webpage introduces and explains the concept of zachte wacht and the ceremony to first time visitors that were referred by someone else. See figure 27. On the website of Ontzorghuis, they can familiarize themselves with the concept and order the booklet, the workshops, invitation cards and statuettes. Secondly, the webpage brings together the zachte wacht community, everyone who already has a zachte wacht, and those who might want to have a zachte wacht. The moment there are multiple examples of other people, the user will hopefully realize: ‘this is really something’, which is recognition for the fact that is okay and even common to ask for support.

Thirdly, it is a source for inspiration. Other people’s stories and photos can help the user to imagine their own zachte wacht and ceremony. This is important, because if they are not planning it in their heads, they will not plan it real life either. A collage with the meaning of zachte wacht for different people can inspire others as well. Users of the website are able to communicate and ask questions in a forum. CSN parents experienced with zachte wacht can indicate that they are open to offer their guidance to others.

In the booklet, the user is referred to the website, accompanied by a QR code leading them to specific pages.

Zachte wacht.

Zachte wacht is een concept ontwikkeld door Ontzorghuis. Een zachte wacht is een kleine groep mensen die waken over een mantelgezin en de zachtheid waarin ze leven. Deze zachtheid kan zich bijvoorbeeld manifesteren in de verwachtingen die mantelouders hebben van zichzelf of hun kind, wat ze van zichzelf vragen en de manier waarop ze hun leven inrichten. Om jullie eigen zachte wachter te bezegelen vindt er een kleine plechtheid plaats.

‘Zachte wacht in 5 weken’ is een doe-boek dat mantelouders bij de hand neemt bij alle stappen die gezet moeten worden om hun eigen zachte wacht te kunnen bezegelen. Het ondersteunt ouders in de overwegingen en reflecties rondom dit onderwerp, in het kiezen en vragen van hun zachte wachters, in het exploreren van mogelijkheden voor de plechtigheid en in de uiteindelijke voorbereiding. Het doe-boek staat op zichzelf en kan los gebruikt worden.

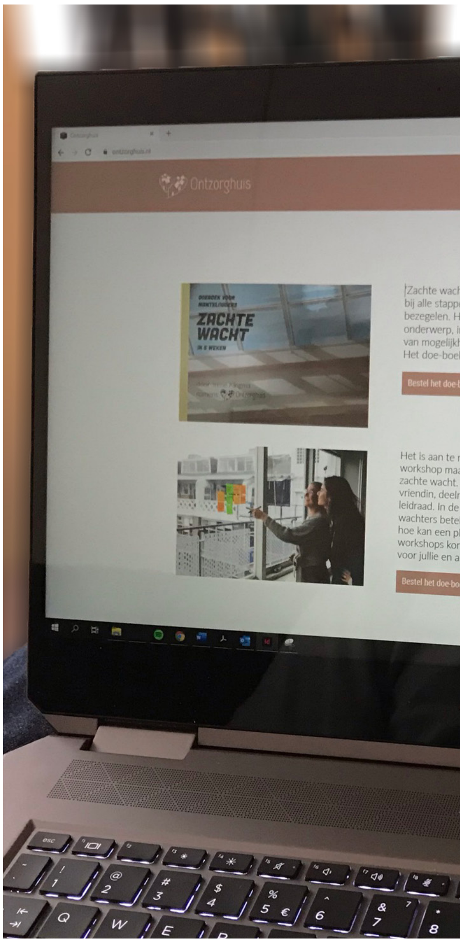
Het is aan te raden om ook de zachte wacht workshops te volgen. In deze workshop maak je in een groepje mantelouders de stappen richting een eigen zachte wacht. Je mag samen met je partner of je erewachter, een goede vriend of vriendin, deelnemen aan deze workshops. Het boekje zal worden gebruikt als leidraad. In de workshops zullen jullie praten over vragen als: wat kunnen zachte wachters betekenen voor ons gezin? hoe kun je je zachte wachters vragen? en: hoe kan een plechtigheid eruit zien? In totaal zijn het 6 workshops. 4 van de workshops kom je met je partner of erewachter en workshop 5 en 6 zijn bedoeld voor jullie en al je zachte wachters.

Figure 27: webpage explaining the concept of zachte wacht

5.2 INTENDED USE

1) REFERRAL

2) ORIENTATION

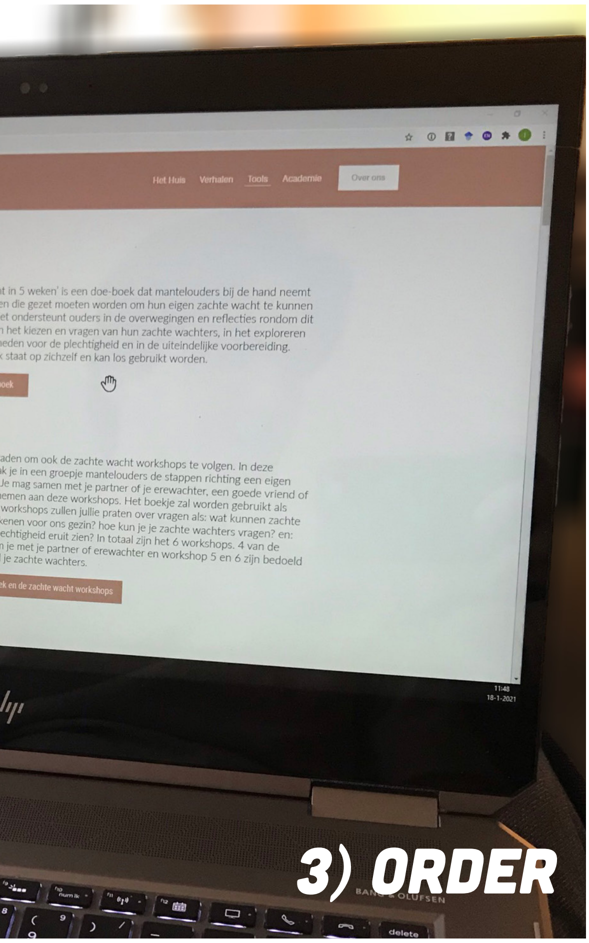


This chapter describes the main scenario of use as intended by the designer.

Discover

CSN parents are in contact with a lot of parties, like consultation desks, subsidy desks, and care facilities. All these parties are familiar with the concept of zachte wacht and can refer CSN parents to the website of Ontzorghuis **(step 1)**. They can offer flyers from the office and referrals on their websites. This way, CSN parents will find out about it early on. These different recommendations from professionals create a sense of importance, urgency even, about organizing a long-term support circle.

CSN parents can visit the website to find information about zachte wacht to help them decide whether or not it is for them **(step 2)**. Moreover, they can get a feeling of the concept through the language, illustrations and images used. They can decide to order the zachte wacht booklet by itself, or to order the booklet with complementary workshops **(step 3)**. They can also check if there are fellow CSN parents experienced with zachte wacht, offering their coaching on the website. Whatever scenario they choose, they are encouraged to involve others in the organization of their zachte wacht ceremony, such as their partner, a close one or even their older children. They can enroll for the workshop as a pair or as a family. The booklet and a number of statuettes are delivered at home **(step 4)**.



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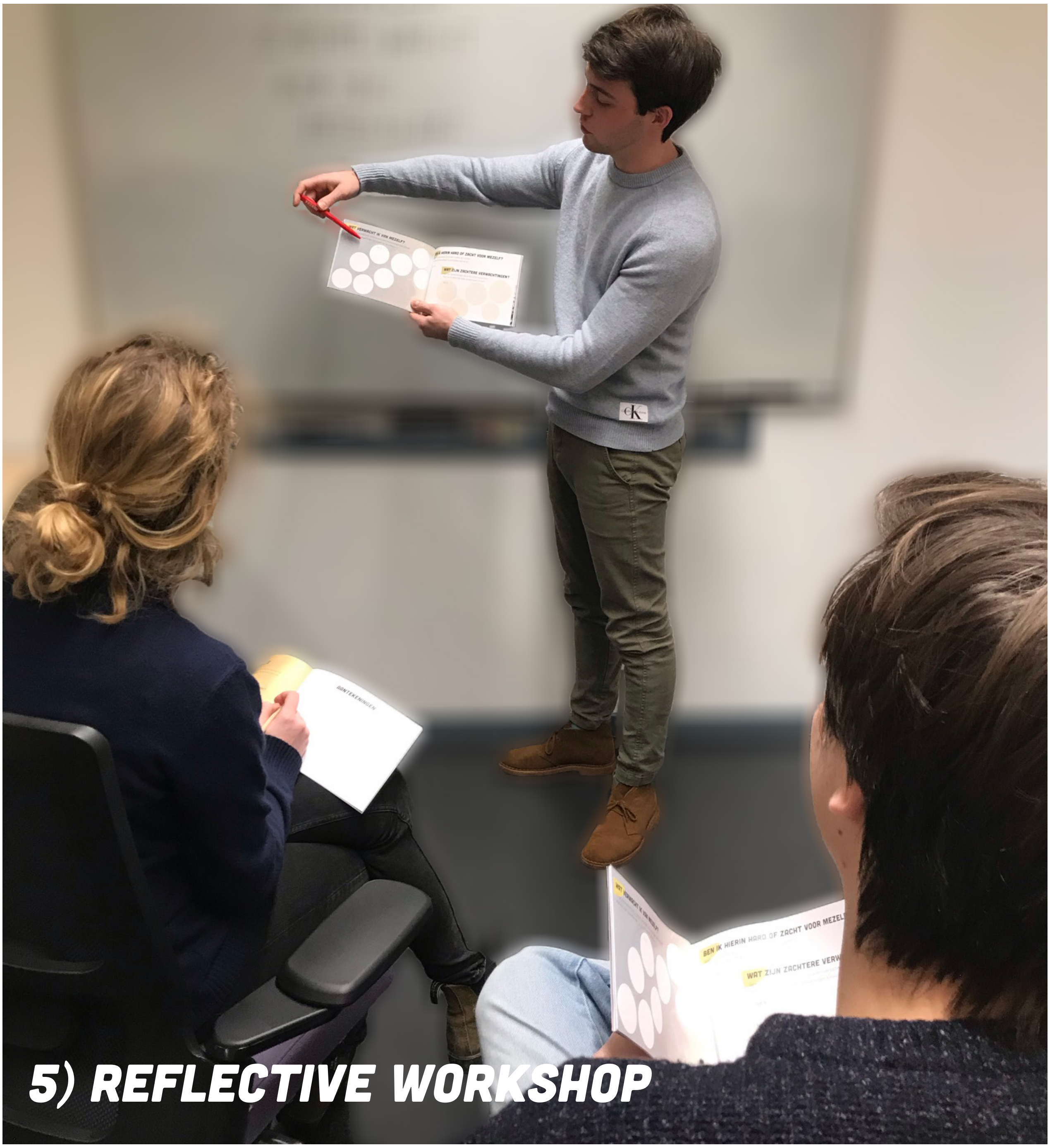
je zachte wachters.

3) ORDER

4) DELIVERY

Reflect

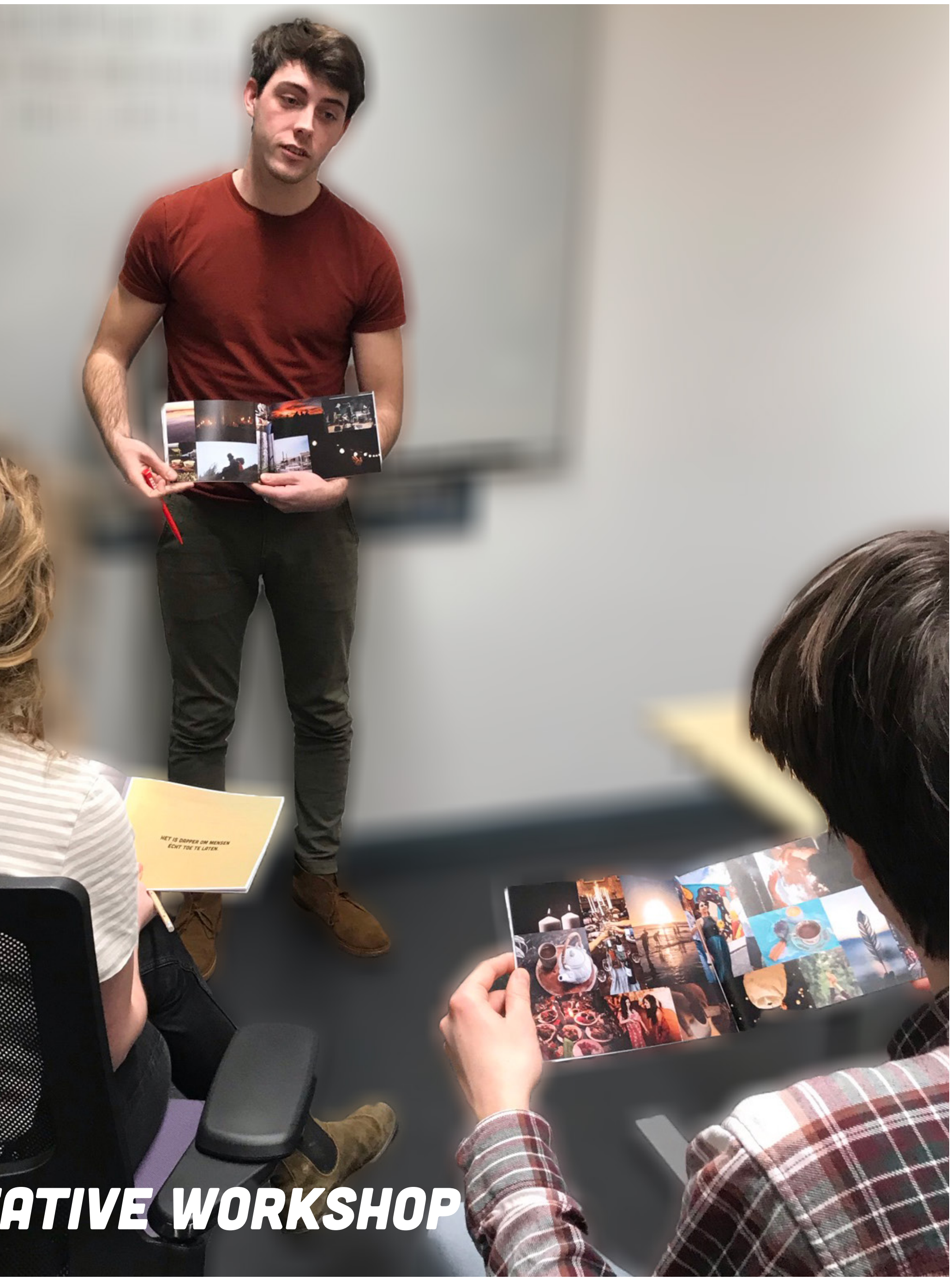
Prior to the first workshop **(step 5)**, the attendees prepare themself by reading the introduction of the booklet (pages 1-23), and making the reflective exercises about what they ask of themselves and others (pages 24-33). In the workshop, the main topic is: what zachte wachters can mean for us. Examples of what zachte wachter can mean for a CSN family are presented by experienced CSN parents, their children, and zachte wachters. The attendees discuss the exercises in pairs and later, plenary. At the end of the workshop, the pairs are encouraged to write down what they want zachte wachters to mean to their family and who they want to ask as zachte wachters.


5) REFLECTIVE WORKSHOP


6) CRE

Create

The attendees are encouraged to gather material that speaks to them from magazines, the booklet or other sources prior to the second workshop **(step 6**). The main topic of this workshop is: what we want our ceremony to be like. In the beginning, experienced CSN parents tell stories of their zachte wacht ceremonies. During the workshop, they make use of pages 34-49 of the booklet. From the gathered material, the attendees make a collage that embodies the desired setting for their ceremony. Halfway near the end of the workshop they present their collages to each other. In their family, they discuss the desired mood, activities, location and date. In the end, they write all decisions down in their booklet.



Propose

The main topic of the third workshop **(step 7)** is: how do you propose to your zachte wachters? Once again, examples are given of how you can propose and give them an understanding of what it means to be zachte wachters. Each of the attendees in given some time to formulate what they would want to say to their zachte wachters to-be. Within their family, they discuss what they have written down, considering how they could propose in a way that speaks from the whole family. In the end, they practice their proposal plenary, to take the edge of the actual proposals.

7) PROPOSAL WORKSHOP

Prepare

The 4th workshop **(step 8)** is about preparing for the ceremony. During the first part of the workshop, the attendees discuss within their family what needs to be taken care of to get ready for the ceremony. Think about invitations, food & drinks, music etcetera. Then, they decide on who does what and what they can ask others to do. For the second part of the workshop, they get started on the aspects of the ceremony they want to take care of themselves, such as the speech and their personal kind wishes. Pages 57-65 of the booklet guides them in preparing for those.

8) PREPARATORY WORKSHOP

9) CEREMONY

Celebrate

When the zachte wachters have said yes, the invitations are sent and the preparations are in order, the ceremony **(step 9)** can take place. The ceremony takes places just the way the family wanted it. Common elements for zachte wacht ceremonies are: a speech in which the CSN family explains why they want a zachte wacht and why they have chosen these zachte wachters, common and personal wishes of kindness expressed by the family and the wachters, a seal of the zachte wacht in which all zachte wachters receive their own statuette, and a celebration of the zachte wacht. From this moment on, the zachte wachters together compose the CSN family's zachte wacht.

Inspire

The CSN parent posts the best photos of their ceremony on the zachte wacht website **(step 11)**. This way, they can promote the resourcefulness of others to take the step of setting up their own long-term support circle as well. Together with other CSN families that have taken this step, they form an example of how precious and joyful it can be to arrange long-term support. The wall of photos from their ceremonies are proof of that. When they are ready, they can also support fellow CSN parents by contributing to the website in other ways: by describing what their zachte wacht means to them, or even by assisting the workshops, or by offering to guide other CSN families in taking this step. The end of this user scenario for 1 family, could be beginning for another. Meanwhile, this family will be able to enjoy the support of their own zachte wacht.

10) ZACHTE WACHT WORKSHOPS

Agree

In about a month after the ceremony, the CSN family and their zachte wachters come together for the first zachte wacht workshop **(step 10)**. Guided by the facilitator from the workshops, they discuss how the zachte wacht can support the family. The family explains the things they struggle with. Together they come to practical agreements. The final agreement regards the date of the second zachte wacht workshop **(step 12)**, in which they will reflect on how it is going with the family, the support and the agreements. If necessary, agreements can be changed or new agreements can be made. This final workshop will take place around 6 months after the first zachte wacht workshop.

11) SHARING PHOTOS

5.3 KEY ASPECTS

In this subchapter, the key aspects of the design are summarized. The key aspects describe the expected added value for Dutch CSN families and their close ones.

1.

The design invites CSN parents to be soft with themselves.

All elements of the design together convey one main message for CSN parents: it is important to be kind to yourself and it is okay to ask for support. This main message of self-kindness is interwoven in the feel, look and language of the design. The fact that CSN parenthood is more demanding than regular parenthood, has not yet been universally recognized. By making this statement straight from the beginning of the booklet, extra validation and importance is put on the main message. It promotes a shift of culture. Working as hard as you can is not necessarily the way to go in the long term. The call for self-kindness offers an alternative to bracing oneself, enduring, isolating. The concept of zachte wacht was invented to have a few people guard the kindness that CSN parents are surrounded by. The reflective exercises challenge the expectations CSN parents have of themselves.

2.

The design promotes the common recognition and acceptance of long-term social support.

The concept of zachte wacht offers a predefined terminology for the role of the long-term support system, allowing it to become commonly recognized and accepted, not only among CSN parents, but among all Dutch people. The fact that a few people explicitly take on the role of zachte wachter, makes it explicitly okay for CSN parents to ask for their support. Moreover, it creates a union between the zachte wachters. Zachte wachters can tune in on each other and complement each other in offering support. The terms ‘zachte wacht’, ‘zachte wachter’, and ‘bezachtiging’ enable people to discuss and familiarize themselves with the concept of long-term social support for CSN parents. For the same aim, the design offers points of recognition, enabling people to perceive and acknowledge the concept. Points of recognition include: the clear common intention of a zachte wacht, all zachte wachters receiving the same statuette, a similar course of events and shared values.

3.

The design inspires CSN parents to make it a positive event to ask for long-term support.

The defined scenario of inviting close ones to a special ceremony gives CSN parents an opening and a format to not only ask for, but celebrate long-term support. Not only does this make it easier to ask for long-term support, it also teaches them it can be made into a beautiful and meaningful event. The power of a ceremony is that it will have a place in the memory forever. The DIY booklet and the workshops introduce and explain the concept of zachte wacht and the ceremony, and help CSN parents prepare for and organize a zachte wacht ceremony according to their own preferences. CSN parents are guided and inspired CSN parents during the set-up of the ceremony. The design is build on the aspects that are clearly defined, as well as the aspects that are deliberately left for the user to decide. Room is left for customization make sure the ceremony is perceived to be meaningful and simply doable. Instead of forcing certain steps and actions upon the users, the booklet offers examples and suggestions.

5.4 IMPLEMENTATION

In order to get this design from thesis to reality, there is a number of things that need to happen. In this chapter, a future scenario is proposed. See figure 28 for an overview.

Proposed scenario

First of all, the design needs to be reviewed according to the feedback in the next chapter, Evaluate. Input from parties like Ipse de Brugge and Eigen Kracht Centrale could further inform the design. Then, a pilot with around 15 participants needs to take place. Meanwhile, we need to stay connected to many stakeholders, such as subsidy desks and care facilities, to have their support by the time all is ready. After this pilot, when the design is reviewed for the second time, funding is needed to build the zachte wacht webpages. There are many foundations that could be a candidate for granting this funding. At the same time, we need to arrange subsidies for CSN parents who order the booklet and the workshops. These subsidies could come from Juvenile Law or WMO, which translates to 'Law of Social Support'. See 'Subsidies' for the full explanation.

The moment the website is online, we need to have someone ready to facilitate these workshops. This can be for example be a CSN parent, someone used to working with CSN parents, or someone who works at Eigen Kracht Centrale. The final step is to organize a congress with stakeholders and inform them of what zachte wacht has to offer to CSN parents, so they can carry out the message. At this point, we have reached the first step of the intended user scenario.

Subsidies

As discussed in Investigate, Dutch policy is built on the vision that everyone should take responsibility for themselves and their surroundings. The Dutch king and prime-minister want to see the Netherlands as a participation society. This shared governmental vision has been actualized over the past 10 years in reformations, decentralizations and new policies. Since the decentralizations of Dutch policy in 2015, municipalities need to request all in need of care and support to appeal to their own network (Adriaanse & Rusman, 2020). For this reason, in the Juvenile Law has been added that when having trouble with raising a child, families have the right to create a network support plan (familiegroepsplan in Dutch) that has been drawn up in collaboration with for example other family members, friends, neighbors and involved care professionals. Municipalities are therefore obligated to 1) notify these people of their right to create this plan, 2) to facilitate and disburse the creation of the plan, and 3) to ensure possibility of setting up support on the basis of this plan (Nederlands Jeugdinstituut, 2017). However, research out-comes from 2018 described by NRC, imply that in practice, municipalities are holding back on requesting people in need of support to appeal to their own network (Adriaanse & Rusman, 2020). The Law of Social Support has a similar article, only here the network support plan is called 'persoonlijk plan' or personal plan.

Zachte wacht is such a network support plan. Therefore, **instead of depending on the municipality to reach out to CSN parents** to inform them of their rights and to facilitate the network support plan, with the help of the mentioned stakeholders **zachte wacht can come to the parents**. Because of the Juvenile law and the Law of Social Support, **chances are high that the booklet and workshop will be subsidized**, so they can be offered to CSN parents for free or for a small price. Not only does it fit with the political vision of promoting the self-dependence, the prevention of CSN parents burning-out can save a immense amount of money. In this case, political interests and CSN parents' interests are aligned.

> **′ I would love to help to get as much exposure as possible for zachte wacht. Maybe we can combine our networks to get enough funding.′**
>
> -Tineke de Jong, cofounder of UP-foundation

> **′We would definitely refer to zachte wacht on the Ipse de Brugge website.′**
>
> -Elise Vuyk, location manager at Ipse de Brugge

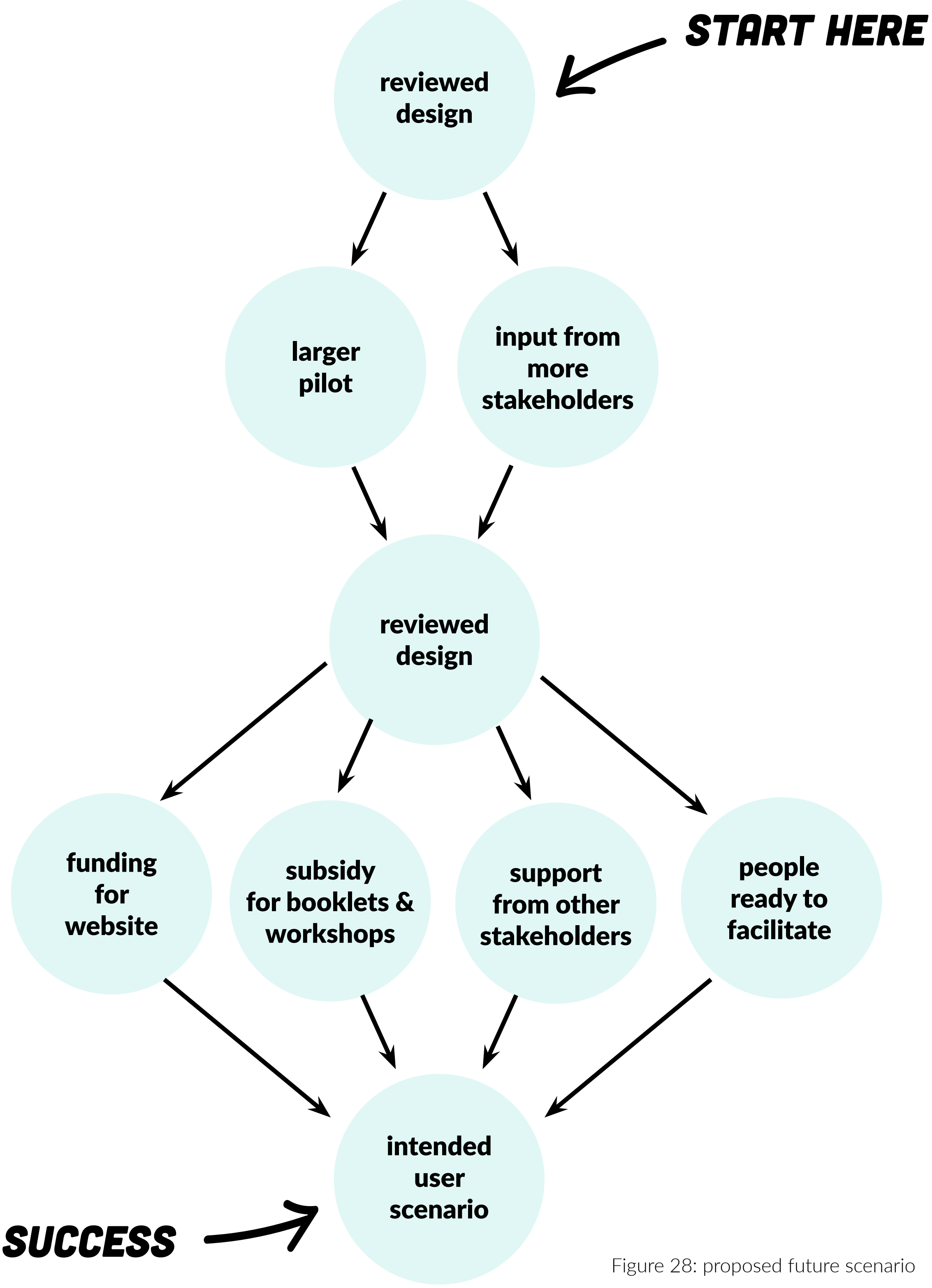


Figure 28: proposed future scenario

5.5 ADDITIONAL OPPORTUNITIES

Within the timeframe of this project, not all opportunities that came about could be utilized. In this subchapter, a number of additional opportunities is listed for future purposes.

Opportunities in the scope

The concept of zachte wacht and the final design were especially developed for CSN parents. However, many target groups could benefit from a long-term support circle that support the kindness in which they live. The design could be adapted to, for example: people suffering from depression, elderly people and their caretakers, juveniles or other people that have a hard time during this epidemic or in general.

Furthermore, zachte wacht could become part of a larger movement promoting self-kindness. A cool example of what could be done to promote self-kindness, is to design a zachte wacht sticker set for WhatsApp that is free to download. A sticker set is a set of small images with the same look and feel, that people can use to express their message that goes beyond words. CSN parents and their zachte wacht would be the early adopters of these stickers, using it in their zachte wacht WhatsApp group. Through them, the use of these stickers would spread, reaching many people, enhancing the acceptance of self-kindness. This way, the concept of zachte wacht can get more recognition as well.

If confused, have a look at the figure below. This 'Together at Home' sticker set is the result of a partnership between WhatsApp and the World Health Organisation, raising awareness of the epidemic affecting our world. WhatsApp blogpost said: 'The stickers are funny, edu-cational and universally overcome language, age and other obstacles' (Kucher, 2020).

Another way to join a larger movement is through Tineke de Jong, founder of UP-foundation, who is starting the ME-movement, of which she offered zachte wacht to be a part.

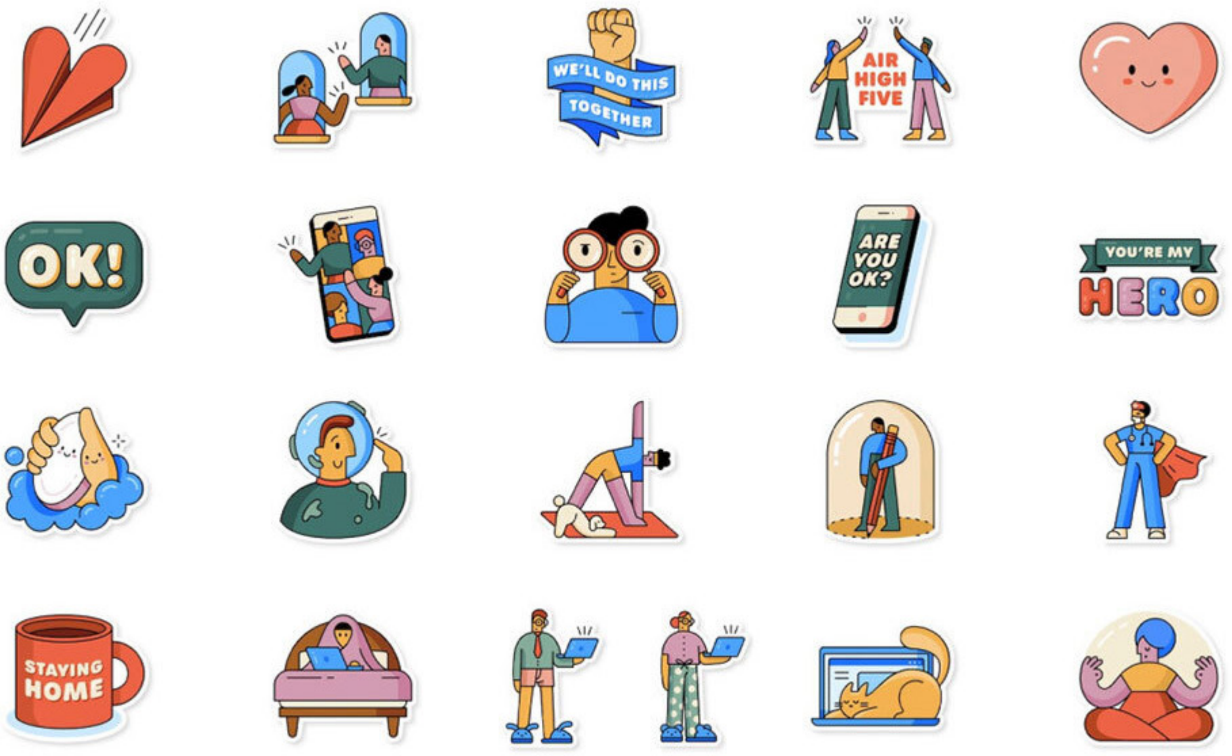


Figure 29: 'Together at Home' sticker set (Kucher, 2020)

Opportunities in the existing design

On top of the existing design and user scenario, more opportunities arise. In the workshop and the booklet, more elements of self-compassion could incorporated, such as breathing exercises, the loving kindness meditation, the compassionate gesture and voice. Furthermore, another version of zachte wacht could be developed for the people to whom the concept does not appeal.

Moreover, special workshops and a special booklet could be developed for zachte wachters only. Special workshops and booklets for CSN parents who are joined by a friend, for CSN parents that come as a couple, and for CSN families with children might be realized also.

The current offer regarding postal cards and statuettes could be expanded. A line of different feather themed objects could be designed to seal the zachte wacht, for CSN parents to choose which they like best. See the illustrations below. A final addition might be the option to personalize the statuette, for example by leaving a personal message.

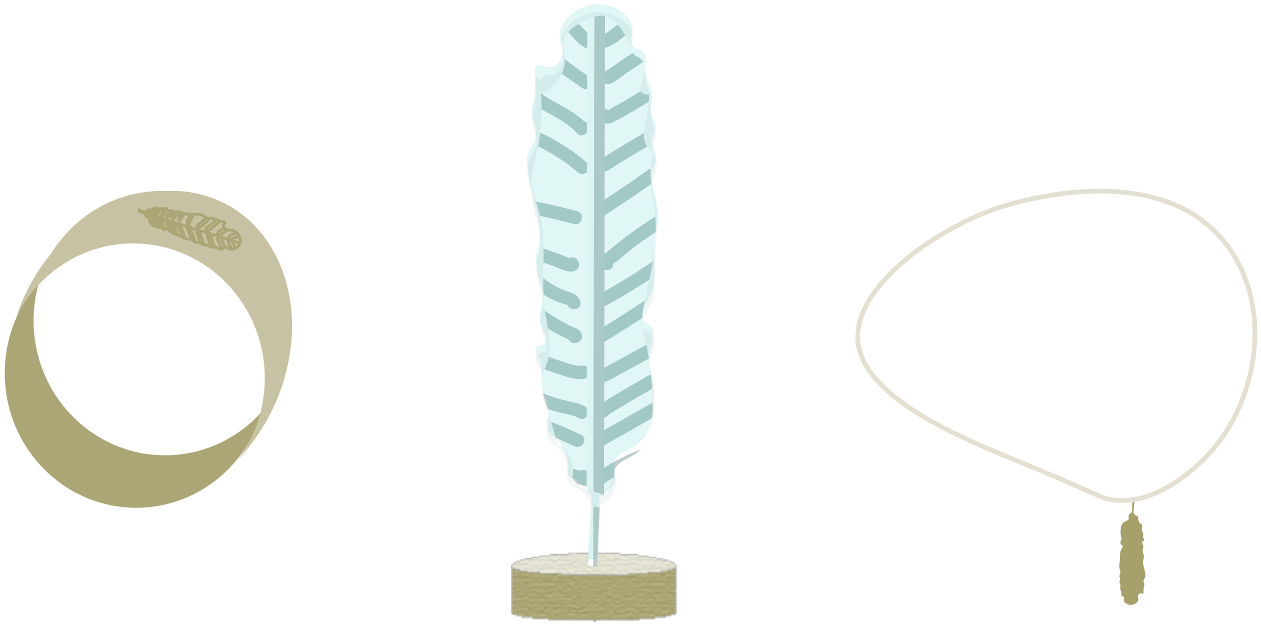


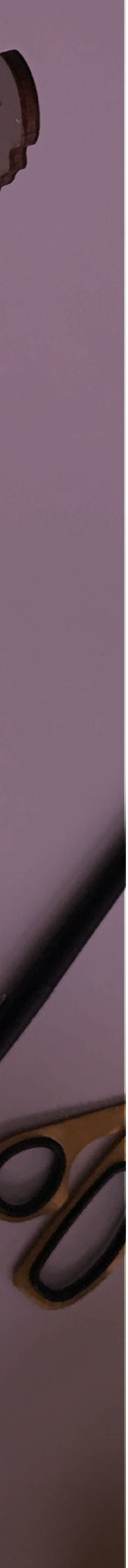
Figure 30: Possible variations on the statuette

PRODUCEREN

MOODBOARD

Heb je al een idee hoe jullie bezachtiging eruit gaat zien? Je kunt deze pagina gebruiken om afbeeldingen die je aanspreken samen te brengen. Je kunt afbeeldingen uit de volgende pagina's of uit tijdschriften knippen en hier opplakken. Je kunt hier ook gedachtes opschrijven. Houd je niet in! Dit boekje is van jou.

TIP! Kijk ook op ontzorghuis.nl/ikwileenzachtewacht om de bezachtigingen te zien van mantelouders die je voor zijn gegaan.



EVALUATE

In this chapter you can find the evaluation of the final design with respect to its desirability for CSN parents, its performance in regard to the design goals, and the fit with Ontzorghuis. The outcomes of this evaluation inform us how the design can be improved in the future, and also, what aspects should definitely remain. Furthermore, the added value of the frameworks is evaluated.

6.1 APPROACH

The final design was tested to compare its performance in reality to the design goals. The main design goal, ***does the design intervention support CSN parents in awaking a feeling of ownership among a few people in their surroundings?*** was evaluated per subgoal. Apart from this project-specific design goal, the design was evaluated on desirability for CSN parents, and its fit for Ontzorghuis. Furthermore, the frameworks were evaluated on their usability. An overview of the research questions can be found below. The activities that were conducted for the evaluation can be found on the right page.

- Is the design desirable for CSN families?
- Does the design intervention encourage CSN parents to give others the feeling of ownership?
- Does it allow them to explore what they desire from their support circle?
- Does it facilitate the CSN parent as much as possible?
- Does awakening a feeling of ownership feel like precious, honorable, joyful& dutiful?
- How does the design fit Ontzorghuis?
- What value do the frameworks add?

Preparing the material

To enable CSN parents to evaluate the design, the material was prepared. The material was sent to 6 CSN parents per post. They were asked to give feedback via WhatsApp.

Focus groups with 6 CSN parents

After the CSN parents had two weeks to test the design, we planned small focus groups to discuss their feedback. Open evaluation questions were asked to gain deeper insight on the effects of the design.

Interviews with experts

Interviews with various professionals were held in order to get a broader view of perspectives on the design. Some played the role of professional as well as CSN parent.

Elise Vuyk
Location manager at Ipse de Brugge, disabled care facility, who has a lot of experience with children as well as their parents and the direction of caregivers.

Suzy Kuypers
Founder of Ouders voor Ouders and consultant for CSN parents who mentors and supports CSN parents, from a place of personal experience.

Aletta van Luin
General practitioner, who sees many CSN parents in her practice and has a child with special needs herself

Marise Schot
Founder of Ontzorghuis, supporting CSN parents from her experience as a design professional and CSN parent.

Processing feedback

The focus groups were transcribed, taking away important quotes. The quotes were categorized, in line with the different goals. Per goal, the quotes were used to evaluate the effect the design had on the CSN parents.

Evaluation

The design was evaluated on its performance with regards to the design goal, desirability for CSN parents and its fit with Ontzorghuis. Finally, the frameworks were evaluated on their usability for designers.

Staying critical

In order to evaluate the performance of the design, open evaluation questions were formulated. Fishing for compliments with closed questions like 'Did you like the design?' must be avoided, as people might feel inclined to say yes. When talking to CSN parents, or people in general, you have to be aware that what they say they will do is not necessarily what they will do. A way to avoid this is to ask for a commitment such as spending time to help improve the design, paying money to buy it, or to risk their reputation by telling their network about it (Pavlic, 2019). If they tell their network about it, chances are much higher they love the design than if they tell you they love it. See figure 31 for the evaluation instruction sheet that was sent with the material.

FIJN DAT JE MEEHELPT OM DIT ONTWERP TE TESTEN!

In deze tijden gaat het helaas niet lukken om echt een bezachtiging te laten plaatsvinden. Gelukkig kan ik nog steeds heel veel leren van waar jullie tegenaan lopen als jullie het boekje gebruiken alsof je van plan bent om wel binnenkort jullie versie van een bezachtiging te houden. Wil je proberen deze week globaal de volgende vragen te beantwoorden in vlogs of spraakberichten? Je kan ze sturen naar onderstaand telefoonnummer.

- Wil je/ willen jullie een 'zachte wacht'? Wat zou dat voor jou/jullie betekenen?
- Wat voor effect heeft het boekje op je als je ermee bezig bent?
- Wat voor effect heeft het boekje op je op de langere termijn?

Wat heeft het gedaan met je eigen perspectief op je situatie?

- Waar heeft het boek je mee geholpen? Welke meerwaarde heeft het voor jou?
- Is het iets wat je zelf zou willen gebruiken (ook als je mij niet kende)?
- Zou je dit boek aanraden aan anderen?
- Wat spreekt je niet aan in het boek/concept? Wat zou je veranderen?

06[redacted]

Figure 31: evaluation instruction sheet


the statuette
the stand
booklet part I
bo
ZACHTE WACHT SINDS 2021
Ontzorghuis
VOOR DE BENOEMING VAN JULLIE EIGEN ZACHTE WACHT
EEN GIDS VOOR MANTELOUDERS VOOR HET OPBOUWEN VAN HUN EIGEN
ZACHTE WACHT
IN 5 WEKEN
DEEL I/II
DOEBOEK VOOR MANTELOUDERS
ZACHTE WACHT
IN 5 WEKEN
door Irene Kingma
namens Ontzorghuis

Figu

ooklet part II

ure 32: material that was evaluated by CSN parents

Material

The figure on the left shows the prototyping material that each of the 6 CSN parents received. The statuettes were laser-cut and the booklets were professionally printed. The prototype is a relatively high fidelity, to properly test whether it would cause the intended effects. For this type of product, which mostly has an effect in the emotional or mental world instead of the physical, low fidelity prototyping is not that suitable. The physical appearance and exact language used, which can be details in other products, actually lies at the core of this product. Moreover, zachte wacht is a brand new concept that needed to be fully explained, for CSN parents to understand and respond.

Procedure

Every parent received as many statuettes as they had zachte wachters in mind. The booklet was sent in 2 parts, allowing them the time to take in the first part while the second part was being prepared. In total, they had two weeks to read the booklet and do the exercises. They were asked to not only take a look at the booklet, but to use it as if they were really organizing their ceremony. A major limitation for the evaluation was Covid 19, because their zachte wacht ceremony could not take place anytime soon, it was harder to evaluate the booklet as if they were really going to in the near future. Moreover, CSN parents are busier now than ever, because many daycare facilities were closed or caretakers were not able to come to their homes when they showed symptoms.

6.2 DESIRABILITY

Interviews with CSN parents and experts were the basis for the evaluation of the design. The evaluation is complemented with quotes from these interviews. To ensure the CSN parents stay anonymous, the names were altered. The gender of the parent and the age of their child with special needs, however, are correct. A representative quote can be found in figure 33. A summary of the outcomes can be found in figure 34.

Wat een prachtig boekje en wat een mooie boodschap. In plaats de ouderwetse reactie om je als mantelouder schrap te zetten doe je een appèl op zachtheid en je open stellen. Hoe mooi! Dat is precies waar we niet goed in zijn (Tot nu toe). Ik ga nadenken of ik dit durf en laat je weten 07:15

I passed the hardest moments alone while everyone believed I was fine.

07:36

Als de omgeving het niet weet, kunnen ze ook niet helpen 07:37

We hebben geleerd gewenst gedrag te tonen en niet te vragen, dit is een methode om dat anders te doen. Een heldere boodschap, goed hoor! 07:40

Figure 33: WhatsApp message of a CSN parent after receiving the material, translation can be found on the right.

'What a gorgeous booklet and what a beautiful message. Instead of the old-fashioned response to brace yourself as a CSN parent you are making an appeal for softness and opening up. How beautiful! That is exactly what we are not good at (until now). I am going to think about whether I dare to do this and I'll let you know.

[...]

If those around us don't know what we are going through, they can't help either. We have learned to show socially desirable behavior and not to ask, this is a method to do it differently. A clear message, well done!'

-Petra, mother of a 19-year-old

Is the design desirable for CSN parents?

● Petra and Dana have already asked their first zachte wachters, and they said yes

● Antonie and Marie have determined whom they want to ask and what their ceremony will be like, but they are waiting until they can safely meet in real life

● Anne and Jade consider zachte wacht to be a valuable concept to discuss with friends, but they don't feel the need to organize a ceremony

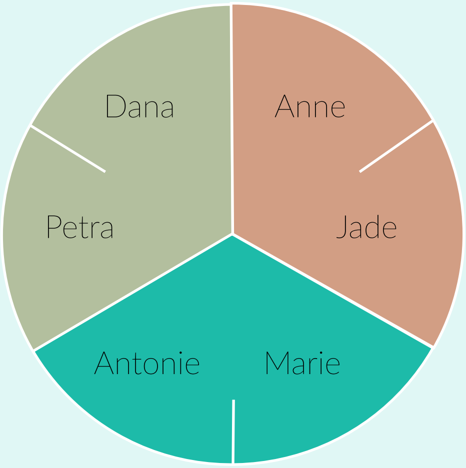


Figure 34: results evaluation of material

The design must be desired by the target group. This increases the chances of it being used and therefore, bringing about the intended effects. Questions to answer when it comes to desirability are: does it solve a problem? and: does it do so in a desirable way? However, it is not necessary that all highly educated Dutch CSN parents love the design at this point. '*It is better to have 100 users that love your idea than a million that kinda like it. A product that is loved can scale*' (Altman, 2019). When launching a product, it is better to focus on early adaptors, the innovators (Pavlic, 2019). Especially with the concept of zachte wacht, if the first users love it, they can spread the word in the CSN parental communities, awaking the early majority.

As explained before, the concept of zachte wacht calls for a culture change. Apart from the concept, the aesthetics of the booklet and certain statements are a bit radical as well. In the beginning in it stated, for example, that CSN parenthood is more demanding than regular parenthood. Whether or not the design is desirable, depends on the attitude people have. When someone has the attitude 'I am a regular parent and my child is a little bit different' or 'I am a regular parent of a child that is officially different', the specific focus on CSN parents might seem out of place and good intentions might be perceived as pity. However, if someone has the attitude 'I am not a regular parent because my child is not regular' or 'my child and I will always be different', they might consider the design as justified, a welcome message, or even necessary.

Remarkably, everyone that expressed their opinion of the zachte wacht, CSN parents as well as experts, considered it to be a beautiful concept. All 6 CSN parents that evaluated the material, saw value in the concept. They commonly agreed on the following added values: putting CSN parents' well-being on the map, encouraging CSN parents to think about the long term and how they could benefit from social support, terminology enabling them to discuss these topics with close ones. However, they did not all see value in all parts of the booklet. For 2 CSN parents (pink), reflecting on what their social network could bring them and discussing the concept of zachte wacht with their network, was sufficient. See figure 34. They considered sealing them as zachte wachters, or getting together as a group, a step to far. The other 4 CSN parents (green and blue) considered these same activities as important and powerful aspects of the concept, and therefore valued all parts of the booklet.

Even though the concept of zachte wacht speaks to all CSN parents, for some, certain aspects of the design are less desirable. One of the CSN parents, Anne, considers the tone and wording too soft and woolly. She expresses to feel like she is being pigeonholed. She explains she does not really identify as a CSN parent. She does see value in the concept and she feels the need to think about long-term social support, but she wants the experience some kind of reciprocity. She says: 'I personally think that there should always be some kind of balance in the relationship. That you support each other. I also struggle with being seen as CSN parent, as someone who needs to be cared for.' A significant difference between Anne and the other CSN parents, is that Anne's child is still relatively young, and that no pivotal events have taken place so far. When going back to the attitudes in the Learnings & Attitudes framework, pivotal events that trigger the attitude to see oneself as a CSN parent instead of a regular parent, include realizing one's life is radically different from other parents, or the child's development undeniably deviating from regular development.

This explanation emphasizes 2 things. 1) Even though the concept of zachte wacht speaks to all people that evaluated it, the aesthetics of the booklet are a bit too radical for CSN parents that have a 'regular-parent attitude'. These same aesthetics are perceived to be of great added value by CSN parents with a 'not-a-regular-parent attitude'.

2) This underlines the importance that making use of the booklet should not be forced upon people. They need to feel for themselves the added value or urgency to take it on. They need to be ready to take the step of asking for social support.

I would recommend experimenting with an additional edition of the concept, the booklet and the workshops for CSN parents with a regular-parent attitude, a 'zachte wacht light'. Based on the insights that the design was initially based on, we know experiencing social support is of great value for all CSN parents. An approach that is more open and which does not reason from the not-a-regular-parent attitude perspective, could support these CSN parents in getting social support. The two editions could be introduced with a short explanation, including 'this booklet is for you if [......]'.

> **'After Covid, I am going to spiritually connect my zachte wacht by giving the wooden feather. Very beautiful.'**
>
> -Marie, mother of a 7-year-old

> **'The concept really appealed to my wife, the idea that people are going to mentally support you, so in that sense we are on the same page.'**
>
> -Antonie, father of a 10-year-old

I think it would help us tremendously, if they could stop by [our other children] primarily, see how they're doing. That would indirectly that helps us again. That out of interest for them, [our zachte wachters] were to give them the energy that we sometimes do not have. To think along with us when things get complicated. And that [our daughter with special needs] can go there once in a while.'

-Petra. mother of a 19-year-old

'I would want to do the ceremony live. That's a prerequisite for us. And also to ask the question to someone who would become a zachte wachter live. As soon as it's possible, I'm going to take steps in that respect.'

-Antonie, father of a 10-year-old

'As it was described in the poem it felt very big, I don't want a conversation just about me and my child. That filled it in too much, that crammed me. But in the reflection part you could express your own thoughts, I enjoyed that.'

-Anne, mother of a 3-year-old

'I would wish a zachte wacht for every CSN parent.'

-Suzy Kuypers, founder
Ouders voor Ouders

'My husband said: it would help me a lot if people would help me by thinking along about the longer term and how things could be done differently. I often live very much in the moment. I would like to ask people to think along with us a few times a year. To have a fresh perspective.'

-Dana. mother of a 5-year-old

'I really like the booklet as a format. I would definitely recommend it. I know more people in the same situation, I would certainly mention it to them, because I notice that they also run into these things. It's a little less exciting from a more practical point of view, but it's mainly about the emotional, mental fitness that many people struggle with. I think it adds value for many parents to take a closer look at why and who they could ask for certain support.'

-Antonie, father of a 10-year-old

6.3 DESIGN GOALS

Does the design encourage CSN parents to give others the feeling of ownership?

In general, the design does very much encourage CSN parents to give others ownership. The wording and the feel of the booklet give CSN parents the feeling that asking for support is okay. It put in their heads the idea of sharing their struggles with their network, of not necessarily needing to deal with all by themselves, which is perceived to be a very welcome and novel message. The reflection exercises helped people realize what their needs are in the long term, and in what way they could use their social network. The examples of a zachte wacht ceremony inspire them how they could involve their network.

The timeframe that was proposed however, is perceived to put unnecessary pressure on CSN parents. The structure remains relevant, but it would be more helpful if they would be formulated as steps, instead of weeks, so they can take the time they feel they need.

Another important consideration is that there are three types of people: people that can rely on their social network, people that can rely on their social network more than they know, and people that cannot rely on their social network, or on very few people. The CSN parents that evaluated the design fall into the first 2 categories. Both Suzy and Aletta pointed out that this is unfortunately not the case for all CSN parents. The booklet can improve on speaking to these CSN parents. For example, the imagery could be more inclusive, instead of showing only CSN families with 5 zachte wachters, the booklet might depict CSN families with one or two zachte wachter. Moreover, more input could be given on how to decide where to look for a zachte wacht and who to ask. Additionally, there might be organized an alternative zachte wacht peer group for CSN parents that don't have many others to talk to and brainstorm with.

> **'It's very thrilling to ask for help. Especially my generation is not used to it. You put your shoulders to the wheel and you just do it. Asking for help, that's not how I was raised. It is just not what you do. But I do think it's a good attitude.'**
>
> -Petra, mother of a 19-year-old

> **'It was mostly the moments of reflection that encouraged me to ask our zachte wacht. There you find out what needs you have for and what you are not getting. That gives a lot of insight about what a soft guard can bring to you. Therefore, I see that it is helpful and desirable for us to just start asking other people for help.'**
>
> -Anthonie, father of a 10-year-old

> **′Thank you for your wonderful zachte wacht booklet. It is really a great resource, inspiration and guidance for parents. When you read this, you know that you don′t have to do it alone and that asking for help is really ok.′**
>
> -Marie, mother of a 7-year-old

> **′Zachte wacht is such a beautiful thing. We are all trained in hardness, you have to be tough, you have to be able to stand it all. I love the wording. Actively admitting people in your life. I got tears in my eyes when I read the poem. Emotionally, it′s all there.′**
>
> -Elise, Ipse de Brugge

> **′For some people, it will be a confrontation if they don′t have many people they can ask as zachte wachters. Especially when you want them to seal their commitment. But sometimes they will realize they have more people around them than they think.′**
>
> -Suzy, founder Ouders-voor-Ouders

> **′My husband and I sometimes talk about zachte wachters jokingly. So I thought: I can tell one of my best friends that she is actually our zachte wachter, without knowing it, and that we want to be that for her too.′**
>
> -Anne, mother of a 3-year-old

> **′What I find interesting about it, is that it makes you realize that you need to start asking things of your social network. I really liked that about the reflection.′**
>
> -Dana, mother of a 5-year-old

> **′The booklet just makes me feel really good about asking our zachte wacht. The design is inviting and persuasive, and that is really important. It gives me energy and it makes me feel inspired. You feel that everything has been considered very well.′**
>
> -Petra, mother of a 19-year-old

Does it allow them to explore what they desire from their support circle?

The booklet did very well in terms of allowing CSN parents to explore what they need and desire from their support circle. All 6 CSN parents expressed to have gain insight into their situation and their needs through the reflection exercises. It triggered them to think long term, and critically look at what they were asking of themselves, and what they think they could ask from others. The reflection exercises motivated them to ask zachte wachters, as they got the opportunity to define the added value of their support.

The booklet could support them more in engaging in conversation with their zachte wachters to be. A conversational tool would, for example, be a valuable addition, to help CSN parents align with their zachte wachters to be, and to see how the zachte wachters can support them.

> **'You really start to see other angles to your situation. In that sense, I think it's a real eye-opener. But it's also just a lot of fun. It gives me a lot of energy to look at it that way.'**
>
> -Petra, mother of a 19-year-old

> **'Getting more support, asking different questions and being able to go on for longer. In retrospect, I think that is something I should have paid more attention to, to make it a bit more 'bearable'. That appeals to me very much in the booklet, to be offered a mirror and to be taken along step by step in what can be done differently, and what do I expect from such a person.'**
>
> -Antonie, father of a 10-year-old

> **'The first part is more about contemplation and the second part pushes you to action. The second part, is really a kind of conversational book, it's active. It's a kind of tool, an instrument, to engage in conversation with our zachte wachters to be.'**
>
> -Petra, mother of a 19-year-old

> **'In the booklet it is named right away, and you start thinking about it. How can I keep this up? Those are the questions that you normally don't think about very much. In itself, that is kind of wonderful.'**
>
> -Anne, mother of 3-year-old

> **'Those insights that you gain from the reflection, what's going to help me stay afloat in the long run, what does that look like, what do I expect, that's a starting point to start having this conversation with certain people. You are looking for people who can support you on the mental level.'**
>
> -Antonie, father of a 10-year-old

> **'I really liked those reflection exercises. You know how to ask the questions in such a way that you really have to reflect, and find out what you want'**
>
> -Dana, mother of a 5-year-old

Does it facilitate the CSN parent as much as possible?

The booklet does facilitate CSN parents in many aspects, however there is still room for improvement. One of the biggest facilitators is the term zachte wachter. It enables CSN parents to discuss the topic of long-term social support with each other and possible supporters. Another aspect that was often mentioned, were the images and the moodboard, which helped them to imagine their own ceremony.

Generally, the CSN parents felt guided through the process. However, some would like to have more guidance with asking their zachte wachters. The postal cards are considered to be a fun element, but are a bit too straightforward for some. There is a demand for more input on how to start the conversation and what to tell them about the meaning of zachte wachter. The website that is planned to be developed, can answer this demand. Moreover, it would be helpful if CSN parents can give zachte wachters a special booklet as well, describing possible meanings of a zachte wacht, supporting them to think about what they would like to offer, and allowing room to take notes about their conversations.

> **'It was difficult to start such a conversation, but [the booklet] is a very nice aid, it's very helpful that I could refer to something. It's still a little bit exploring, it's uncharted territory, therefore you really do need that kind of aid.'**
>
> -Petra, mother of a 19-year-old

> **'I find those pictures very helpful to think about our ceremony. The mood board makes it very evocative and fun and it also gives inspiration.'**
>
> -Antonie, father of a 10-year-old

> **' You don't necessarily need a ceremony. It already has added value as a process within yourself, that you become aware of a question that you have. And that you can discuss it with people: I really like that I can go to you to talk about these things.'**
>
> -Anne, mother of a 3-year-old

> **'The text and assignments I find very helpful. You show well that there is a need. You can really get to work with this booklet to set up your own network. You can feel that we, as parents, were very well considered.'**
>
> -Jade, mother of an 18-year-old

> **'I really enjoyed the second booklet. It did help me. Where you leave it open, I really like that. Through the pictures and the mood board I found out, our ceremony has to be high tea like, everyone bringing tasty food, coziness.'**
>
> -Dana, mother of a 5-year-old

> **'My husband immediately mentioned his best friend as possible zachte wachter. And then you talk about it. Because there is a term for it you can just discuss it.'**
>
> -Dana, mother of a 5-year-old

Does awakening a feeling of ownership feel precious, honorable, joyful& dutiful?

The opportunities to objectively evaluate this design goal, are limited, as only 2 CSN parents have actually asked another person to become zachte wachter. The prospects, however, are promising. The zachte wachters that were asked, reacted flattered and enthusiastic. Asking zachte wachters is also described to be a wonderful and reassuring experience. The two CSN parents who are still waiting to do their proposal and their ceremony until after Covid, are confident and excited. All 4 have a clear image of the ceremony in mind, partly thanks to the pictures in the booklet.

For the other two CSN parents, the idea of having a ceremony is undesirable. They expressed they dislike ceremonies in general. They do see an added value in discussing the topic of zachte wacht with a few people, and using it to actively let them in. However, the idea of bringing them together and discussing their family situation in a group of people, makes them feel uncomfortable. They are the only 2 of the 6 CSN parents who felt uncomfortable having a ceremony, but there was also a parent that expressed that her children would not feel comfortable with her giving a speech or expressing wishes. Undoubtedly, there will be more CSN parents and children who feel the same way.

> **'It felt wonderful, when I had asked [my zachte wachters], I almost felt like: it can be like this too. It was liberating. I felt acknowledged. [...] They were very enthusiastic. They felt honored, in a way. Because we confide in them. They responded very respectfully and seriously.'**
>
> -Petra, mother of a 19-year-old

There is great added value in having a ceremony that is recognized by CSN parents and experts. It allows people to feel united, it allows the zachte wachters to feel they are in it together, it allows the CSN family to feel deeply supported, it enables everyone to explicitly express their intentions and expectations and to make a plan together, and so on. However, the danger of wanting the event to feel dutiful, is that it can feel like a big ask from zachte wachters. The risk of it making precious or special is that it can feel like too much for some, making them uncomfortable. The risk of wanting that asking someone for support feels honorable, can make them scared to be rejected. Even though I believe it is a great gift and honor to really let someone in, not everyone can see it that way.

To conclude, asking for support has proven to require such a leap of faith already, pushing CSN parents out of their comfort zone, that the ceremony should not feel like an extra hurdle, which might prevent them from asking for support. Therefore, the aim should be to support CSN families in involving a few people in a way that fits them. This design goal should change to: **awakening a feeling of ownership should feel doable & joyful;** and not necessarily precious, honorable, and dutiful. For some, the idea of a get-together, whether it is called a ceremony or not, will add value. For others, it will just be a hurdle. Therefore, I suggest the steps reflecting and proposing to remain, but organizing a ceremony to be more of a suggestion, among other suggestions.

> **'Thinking of a lifelong commitment, I got a little choked up. It's no problem if people come and go. And the process does not need to take place within 5 weeks.'**
>
> -Elise, Ipse de Brugge

′ When I asked him to be our zachte wachter he started glowing. He said: ′to be a zachte wachter does not sound so demanding to me, like a gentle presence, supporting you in what you need mentally.′
It felt comfortable to him to be my zachte wachter.′

-Dana, mother of a 5-year-old

′A lot of CSN parents don′t let anyone in. They do everything themselves. So it′s very powerful message: *it′s an honor to really let people in.* There are a lot of people who like to help out, who want to mean something, and I didn′t let them in, I excluded them. I did not want to be a burden.′

-Suzy, founder Ouders-voor-Ouders

′It′s very important to explicitly express things to eachother, because that does not happen normally. Because you express things, you give more commitment to yourself and others. [...] I do think ceremony is a beautiful word, you don′t have a ceremony every day. You can make it a bit special.′

-Antonie, father of a 10-year-old

′By actively asking zachte wachters and not leaving it implicit, I think you can get much more value out of it. I think the idea of sealing it in a ceremony is a very beautiful one, and that is the power, to actively share it with each other.′

-Antonie, father of a 10-year-old

′I really like the speech and wishes, but it will embarrass my kids. If I start making speeches, they wouldn′t feel very comfortable with that. It has to be very relaxed and low-key, a nice dinner.′

-Petra, mother of a 19-year-old

′Personally, I would leave the ceremony out of it. Key is becoming aware you need your network, and that it is an honor to really allow people in. There are ways smaller than a ceremony. You could also just give the card or the statue, to let someone feel: I allow you in my network. I wouldn′t ask for a commitment like in a ceremony. It should feel flexible.′

-Suzy, founder Ouders-voor-Ouders

6.4 ONTZORGHUIS

During the project, Marise and I had many conversations about the vision of Ontzorghuis and my view on the topic. In order to evaluate how the design fits Ontzorgshuis and how the frameworks could be used, a final evaluation for Ontzorghuis took place. All quotes that are depicted, are Marise's.

How does the design fit Ontzorghuis?

Ontzorghuis wants to achieve a new way of looking at the roles of formal and informal care. At the moment, formal care providers play by far the biggest role, and that is often a very practical role, while people also need a bit of mental care, or as would be a suiting way to call it in Dutch, 'zachte zorg'. Their long-term goal is that in the future, care is family oriented, instead of patient-oriented. They strive for a holistic approach to support CSN families, making sure all members are standing in their power. Resourcefulness is the overarching approach. CSN parents find themselves in such a new situation that they have no frame of reference. They can not just peak how your relatives are doing it. Because they are in such a new situation, it is necessary to be resourceful, to deal with that not-so-ordinary situation and find a solution that is appropriate for you.

Zachte wacht as a concept and the booklet fit very well into this vision. Not only does it offer a new way in which the social network can attribute to the mental well-being of CSN families, it does so in a way that enhances CSN parents' resourcefulness. By having a group of people, a zachte wacht, with whom to brainstorm about the struggles they face, their resourcefulness will strengthen. Moreover, because CSN parents can spread the idea of having a zachte wacht, and share stories of their zachte wacht, their proposals and their ceremonies offline and online, they can together reinforce the resourcefulness of CSN parents as a group.

Another way in which the zachte wacht booklet contributes to Ontzorghuis, is that this approach and the booklet shows how design thinking can be of value. Marise says: *'that's the beauty of the booklet, it shows that we didn't just come up with a tool, but that it has deeper layers, based on user insights. It is still unknown to a lot of people, what we as designers can add.'* The booklet showcases what designers and, more specifically, Ontzorghuis, can add. It brings together the value of user research, a well-considered concept, and an eye for developing, detailing, and implementation.

This showcase of the added value of design, is important when fighting subsidy decision bias. Marise wrote a grant application to do further research and design for CSN parents, which was rejected because they did not see the value in another website with information, or another app.

> **'What I like about the booklet, is that it is something tangible that helps people to really start doing, an opening to start having conversations about your zachte wacht. Because the booklet is there, it becomes more concrete where we need to go, what the importance of a zachte wacht is. It becomes more and more tangible. The booklet helps a lot in finding your own meaning in your zachte wacht.'**

> 'What is very pleasing about this booklet, is that it helps to expand the frame of reference of [people deciding on sudsidies] about what design can add. Because they can see what design can entail. It appeals to the imagination. You see that great care has been put into it, you see that it's tailored to the user, there's a bigger idea behind it, you see the quality in it. And that's wonderful about it.'

> 'It fits very much with ontzorghuis, in terms of resourcefulness. It's not being filled in completely, people are allowed to fill it in themselves. You are raising an idea and you are facilitating that they can put it into action themselves. [...] We're launching a new concept, zachte wacht, we're launching the possibility to talk about it, to engage in a novel conversation, and to organize [your zachte wacht]. And we're launching the possibility of sharing that inspiration.'

What value do the frameworks add?

The Framework of Opportunities in the Social Surroundings describes the 6 different levels of capacities that people in the surroundings of CSN families can have, that support the relationship in a way that benefits CSN families. Interesting real-life examples of all capabilities were gathered during the contextmapping interviews. The division in levels allowed me, the designer, to formulate a clear design goal. The capacity to experienced shared ownership stood out for me, but all levels can be formulated as design goals.

With support of this framework, designers can investigate more precisely where the biggest impact can be made and clearly articulate where they want to make an impact in a design goal. The examples from interviews can sensitize the designer before doing their own interviews in their own context. The examples of opportunities can spark designers, but also care professionals, municipalities or CSN parents themselves on how to improve the relationship between CSN families and their surroundings.

The Practical Learnings were incorporated in the concept and the booklet indirectly, as explained before. The practical learnings are a gathering of important lessons that multiple CSN parents I interviewed expressed to have learned. To summarize, the main message of the practical learnings was: it is important to be kind to yourself and it is okay to need support. This message has led to the concept of zachte wacht and became the main message of the booklet. The booklet radiates all the practical learnings. Based on the evaluation, the concept was appreciated by CSN parents. The main message was perceived to be a novel and welcome sound.

The practical learnings have proven to be very useful, as they formed the basis for an entire concept and a booklet, which were embraced by the target group. These learnings are like a pressure cooker for designers, to better understand the needs of CSN parents and the struggles they face. Moreover, the learnings can support designers to define the message behind their design.

> **'I love the frameworks, because they allow me to frame things. Those attitudes and values are the eye-glasses through which people look. If someone reacts in a certain way, you can reason where it comes from. That way you can place why people see something in a certain way, but you can also take that into account in further development.'**

> **'With help of the frameworks, you do not exclude people in advance. Suppose you mainly test with people where the value of self-determination prevails, because those people find it very interesting and are open to be of help, then you miss a very large part of the target group. But you can be aware of that now.'**

The attitudes are useful for understanding differences within the targetgroup. One of the practical learnings the design was based on, was that CSN parenthood is much more demanding than regular parenthood. Throughout the booklet, this learning was emphasised as well, as Minke Verdonk had described that a large factor in the poor well-being of CSN parents is that they don't distinguish themselves from regular parents (see the chapter Investigate). As described before, one of the CSN parents felt pigeonholed by this message. Moreover, she considered the wording and the tone of the booklet too soft. This could be explained by her attitude. Before, she had expressed she does not really identify as a CSN parent, which is crucial information for designers. Her, in this case, regular-parent attitude, influences the values she prioritizes and the way she experiences the design. Going back to an earlier example, when a parent has the attitude that their child is a little bit different, strategies with regards to the value of self-preservation can rise.

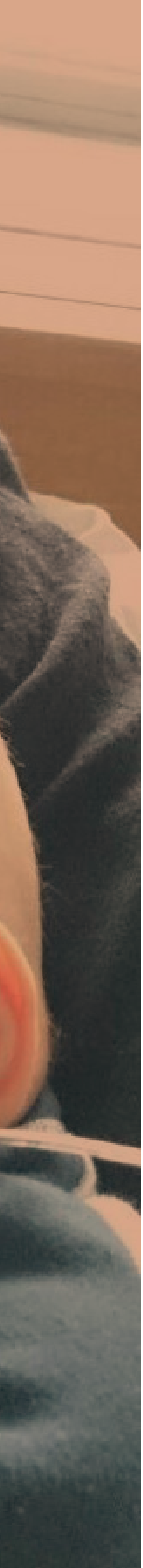
To conclude: the attitudes CSN parents have towards themselves and their child affect the way they perceive and experience this design, and design in general. The attitudes can therefore sensitize designers for variation of different perspectives within the target group. This contributes to enhancing one's understanding of CSN parents' viewpoints, experiences and preferences. Moreover, it can avoid the exclusion by design of certain parts of the target group. As a designer, one can now consciously choose to include CSN parents with all attitudes.

The Framework of Values underlines the importance of the value of self-preservation, the value of conformity and the value of self-determination for CSN parents. The concept and design cultivate and capitalize on the value of self-determination. By creating one's own zachte wacht, one creates their own rules and their own path. The design intends to support them in maintaining a part of society, by surrounding themselves with close ones. More importantly, the design aims to offer an alternative to exhausting oneself being hard on oneself in order to survive and to stay a part of society, by proposing a kinder perspective and renewed expectations of oneself. It presents CSN parents with an alternate strategy of involving close ones, one in which the values do not compete, but where they can exist in harmony.

The insights of the existing strategies that CSN parents follow and the values behind these strategies, have helped me to come up with an alternative strategy in which these values could blossom. In the future, designers can use the framework to design solutions that are in line with important values for CSN parents. Moreover, the values can help them to understand certain strategies that CSN parents follow.

7

photo of Marise and her son



DISCUSS

In this final chapter, the results of the project are discussed. This discussion includes the project's conclusion and limitations, final recommendations for Ontzorghuis, and a personal reflection on the project.

7.1 CONCLUSION

The first intended outcome of this graduation project was a framework that designers, principally Ontzorghuis, can use as a starting point to take on the challenge of creating solutions that help CSN parents to attain a sustainable balance. The second intended outcome of this graduation project was a design that supports CSN parents in attaining a sustainable balance, based on at least one aspect of the framework.

The design

The aim of the final design is to support CSN parents in awakening a feeling of ownership among a few people in their social surroundings. More specifically, the target group was highly educated CSN parents with Dutch heritage. The final design is a DIY-booklet that guides CSN parents through the steps of setting up their own support circle, the final step being a small ceremony to seal the commitment of their supporters. The booklet introduces them with the novel concept of 'zachte wacht', a long-term social support circle for CSN families. The final design was evaluated with 6 CSN parents, which led to promising results. Although there is room for iteration, the evaluation demonstrated that the design was desirable for CSN parents. They experienced the added value of the design in several ways. First of all, the design puts CSN parents' well-being on the map. It ignites a belief in CSN parents that it is accepted and important to ask for psychosocial support. It encourages CSN parents to consider their situation in the long term. The exercises inspire them to reflect on their own needs and the ways in which they might benefit from social support. It allows them to imagine asking and sealing their own support circle to be a postive and personalized event. Furthermore, it offers them terminology that enables them to discuss topics like long-term social support and mental support with their close ones in a light-hearted way. Further added value is considered to manifest in the concept of the ceremony. During the ceremony, the CSN family and the members of the support circle can explicitly express their intentions and expectations. The ceremony enables the members of the social support circle to connect and to form a union, which helps them to feel they are supporting the CSN family together, allowing the CSN family to feel deeply supported. It must be noted that the added value of the ceremony is disputed.

The frameworks

Insights from literature research, interviews with experts and contextmapping research with 6 highly educated CSN parents with Dutch heritage, have resulted in 3 overviews of information: the Framework of Opportunities, the Framework of Values, and Practical Learnings and Attitudes. In the design process that followed, these frameworks demonstrated their value for designers and, herewith, Ontzorghuis. With support of the Framework of Opportunities, designers can investigate more precisely where the biggest impact can be made with regards to enhancing the connection between CSN families and their environment. It assists them in clearly articulating a design goal. Designers can inform themselves with the Framework of Values to design solutions that are in line with important values for CSN parents. Moreover, the values can help them to understand certain strategies that CSN parents follow. The practical learnings have proven to be very useful, as they formed the basis for an entire concept and a booklet, which were embraced by the target group. The attitudes can sensitize designers for variation of different perspectives within the target group. This contributes to enhancing their understanding of CSN parents' viewpoints, experiences and preferences. Therefore, designers can consciously choose to include CSN parents with all attitudes.

The future

The final design will be further developed and implemented by Ontzorghuis. Marise has described the design as a showcase of the added value that designers can bring. The design capabilities, understanding of the target group, and network needed to implement the booklet and other aspects of the concept, are perfect fit with the unique strengths of Ontzorghuis. Parties like Ipse de Brugge, UPfoundation, and Ouders voor Ouders are interested in collaborating to implement the booklet as soon as possible. In the case of zachte wacht, political interests and CSN parents' interests are aligned. Not only does the concept of zachte wacht fit with the Dutch political vision of promoting the self-dependence, the prevention of CSN parents burning-out can save an immense amount of money. Because of the articles on network support plans in the Juvenile law and the Law of Social Support, chances are high that the booklet and workshop will be subsidized, so they can be offered to CSN parents for a small price or even for free. Moreover, the design has the potential to serve a large and growing target group. In the Netherlands only, live around 500.000 parents of children with special needs (0-20 years old). This number is increasing due to medical developments.

> **'You really start to see other angles to your situation. In that sense, I think it's a real eye-opener. But it's also just a lot of fun. It gives me a lot of energy to look at it that way.'**
>
> -Petra, mother of a 19-year-old

Concluding, the design has proven to answer a deep-felt demand and was welcomed with open arms by CSN parents as well as experts and other stakeholders. Ontzorghuis is one in very few parties in this field with the capabilities of implementing the design. In combination with the significant and growing group of CSN parents, and the aligned political interests in preventing CSN parental burn-outs, the future of zachte wacht looks promising.

The frameworks have been a valuable resource during this design process. They will continue to be of value for the designers of Ontzorghuis, to grasp and design for this complex context. Moreover, they might inspire and inform others who wish to make a positive impact on the well-being of CSN parents.

> **'A lot of CSN parents don't let anyone in. They do everything themselves. So it's very powerful message: *it's an honor to really let people in.* There are a lot of people who like to help out, who want to mean something, and I didn't let them in, I excluded them. I did not want to be a burden.'**
>
> -Suzy, founder Ouders-voor-Ouders

7.2 LIMITATIONS

During this project, I encountered several limitations, mostly caused by a restricted time frame and Covid-related barriers, that had an impact on the outcomes of the project. These limitations are clarified in this subchapter. Figure 35 provides a sneak peek into the Covid-safe activities that took place in this project.

The participants

Covid proved to be a major barrier for the recruitment of participants. As Covid-related regulations became stricter, CSN parents became less and less available. CSN parents were busier then ever, because many daycare facilities were closed or caretakers were not able to come to their homes when they showed symptoms. In the contextmapping sessions, only highly educated CSN parents with Dutch heritage were interviewed. Multiple CSN parents that were contacted did not belong to this group, but they cancelled the interview last-minute. This might be an indication that they are struggling to stay afloat more than highly educated CSN parents with Dutch heritage do. Moreover, the final design was evaluated by people who belong in this same group. Although not entirely the same subset, there was an overlap in the context mapping participants and the evaluators of the final design. Furthermore, the number of CSN parents with a regular-parent attitude might have been underrepresented. A possible reason for this might be that CSN parents with a not-a-regular-parent attitude are more open to participate in research about CSN parents and experience good representation to be more important than CSN parents with a regular-parent attitude.

When looking at the frameworks, one has to be aware that the insights might not apply to other groups of CSN parents. The specific characteristics, needs, and preferences of CSN parents with a regular-parent attitude, CSN parents that that have attained lower levels of education, and CSN parents with a non-Dutch heritage might differ from the ones encountered in this project. Therefore, it is possible that the design is not yet suited for a larger target group.

The evaluation

Six CSN parents were asked to not only take a look at the zachte wacht booklet, but to use it as if they were really organizing their own ceremony. As their zachte wacht ceremony could not take place anytime soon because of Covid-related restrictions, it might have been harder to evaluate the booklet as if they were really going to in the near future. This might have resulted in a less critical attitude.

Furthermore, because no zachte wacht ceremony could take place, CSN parents could not evaluate their ceremonies, and reflect on the impact it made on their family and their zachte wachters. The evaluation of the concept of a ceremony was done was in a spectulative manner, based on how they imagined it to be. For some, Covid also was a barrier for having a conversation with their zachte wachters to-be. Luckily, two CSN parents managed to take a walk outside with their zachte wachters to be. Still, this is a small sample for evaluating the experience of asking their zachte wacht.

Another important aspect of the evaluation that is missing, is how the concept of zachte wacht is experienced from a zachte wachter perspective. For the CSN parents that have asked their zachte wachter, it was evidently experienced as such a fragile thing, that it did not seem appropriate to interview their zachte wachters in this early stage of their journey. Therefore, the evaluation was based on second hand information, influenced by a layer of interpretation by the CSN parent.

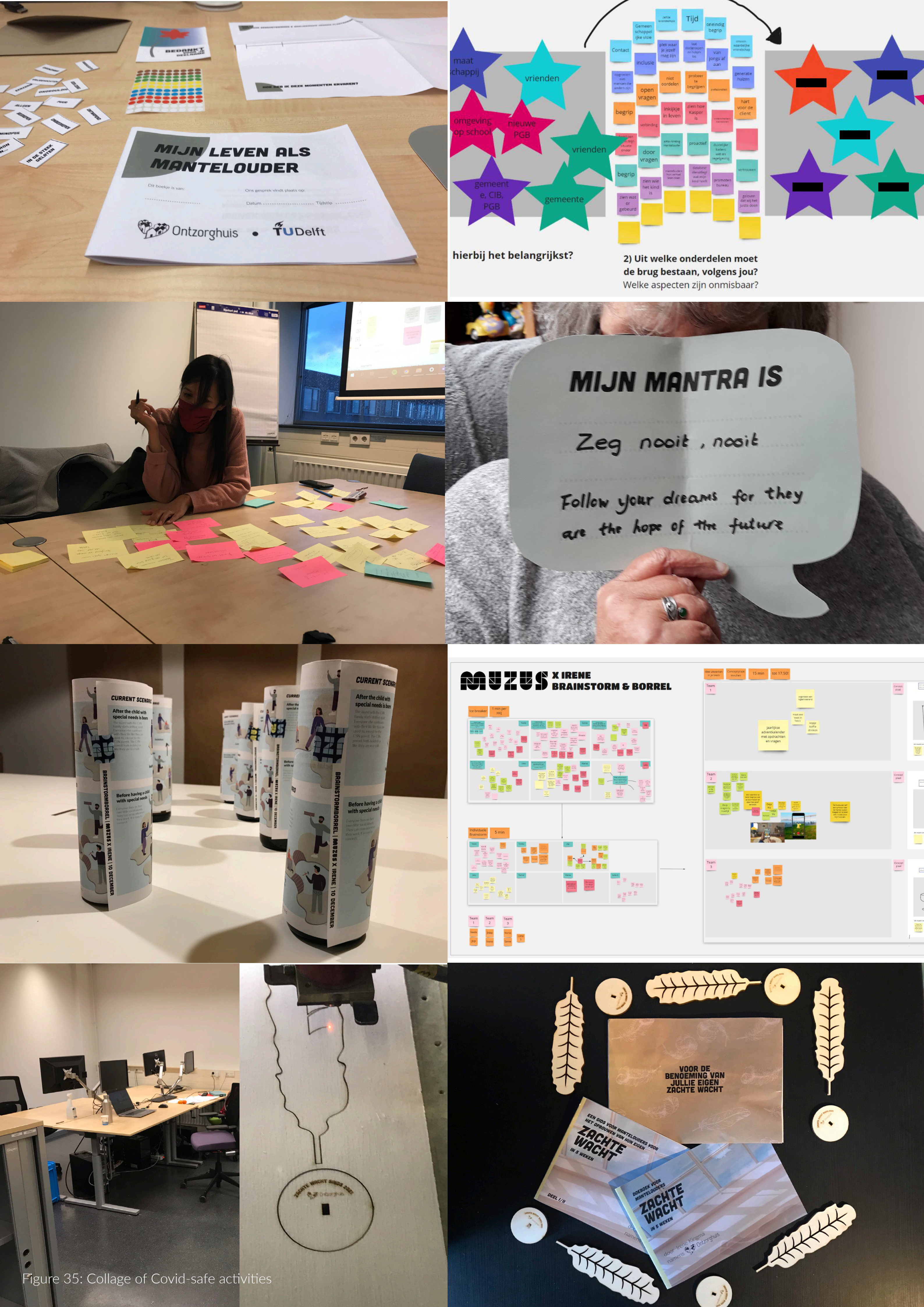


Figure 35: Collage of Covid-safe activities

7.3 RECOMMENDATIONS

On the basis of the evaluation, the limitations of this project and CSN parents' and experts' advice on implementation, final recommendations are provided to allow Ontzorghuis to kickstart the further development and implementation of the design.

Iterating on the final design

Because the concept urges a shift in culture, it is novel and progressive. The main message, it is important to be kind to yourself and it is okay to need support, is enhanced with the use of language and imagery. By many of the CSN parents that tested the booklet, it was perceived as acknowledgement and as an eyeopener. Even though the design was generally well-received by the target group, multiple opportunities for improvement were encountered during the evaluation. The aspects of the design that are meaningful to some, are bothersome for others. The call for self-kindness is welcome and needed according to some, and a bit too soft for others.

This is not the kind of design that can be optimized to work for everyone. In order to foster the essence of the design, I would recommend not to make too many concessions. If needed, I would develop different editions of the design based on the needs of different people. The recommendations below form my guide for Ontzorghuis to preserve the essence of the concept and the design, while taking into account the opportunities to make the booklet more desirable to more people.

- A significant opportunity lays in encouraging CSN parents with a limited social network. This can be done by depicting CSN families with one or two zachte wachters and supporting the user when considering who to ask as zachte wachters. For example: 'It is okay if no one pops into your head immediately, but consider the following questions: 'From whom do you receive postcards or a message every once in a while? For whom would you be there if they needed your support?'

- Moreover, some CSN parents indicated they would benefit from more guidance in the proposal of the zachte wachters. They would like to be taken by the hand when considering what to say and how. Examples from other CSN parents on the website could help as well.

- Furthermore, the design would benefit from having a consistent tone and form that is more open. The form of address, going from impersonal to very personal, as well as the extent to which matters are left open or dictated are currently fluctuating. In general, the form where matters are left open, such as in the reflecting exercises and the mood board, is preferred. For example, some would like the ceremony to be more of a suggestion than a predefined step. Also, the time frame must not be defined. Instead of dividing the process of setting up a zachte wacht in weeks, they could be referred to as steps. Furthermore, the concept of zachte wacht could be explained in a way that feels a bit less intimidating. Leaving out words like 'forever' would help to make it feel more flexible and light weighted.

- The statuette is associated with other symbols, such as the award. Since the intention of the concept is to empower a shift from achievement to care, this is unfortunate. The statuette could be redesigned in a way that is has no connotation with achievement.

The call for self-kindness an important asset of the design. The importance of, instead of being hard, being soft to oneself is among the main messages of the design. However, there are ways to help the user ease into the concept of self-kindness and mental support. One of the CSN parent experienced zachte wacht to be friends that are there for offering soft support, or mental support, whereas hard support is the instrumental support given by care professionals. This explanation can help to make the concept zachte wacht more approachable for people that are prone to reason from a very rational perspective. The function of a zachte wacht can be illustrated with analogies like hardware and software, and hard skills and soft skills. In addition, using the term zachte wacht ceremony instead of bezachtiging might also make the concept better to ease into for some.

Strengthening the relevance of the frameworks

In order to strengthen the relevance of the frameworks, it would be beneficial to verify the insights in additional research with a larger sample size. Because the frameworks already exist, the research questions can be more focused. Relevant research questions could be: Do other CSN parents desire capacities from people in their social surroundings similar to the ones described in the Opportunity Framework? Do the three values described in the Framework of Values play an important role in the lives of other CSN parents as well? What were important learnings for other CSN parents? What attitudes do they have and what is the relative size of the groups with different attitudes? The demographics of the participants should of course depend on the group Ontzorghuis wants to target. If possible, it would be interesting to have participants with a large variety in demographics, to be able to research possible differences in desired capacities, important values, learnings and attitudes among groups. Apart from highly educated CSN parent from Dutch heritage, it would be valuable to include Dutch CSN parents with different educational and cultural backgrounds.

Augmenting the target group of the design

Based on the strengthened frameworks, one or more reviewed editions of the design can be developed. To make sure these designs appeal to the intended target groups, other changes that are necessary to appeal to these target groups need to be taken into account. Therefore, additional research should be performed to generate insights that are not yet grasped in the frameworks. The subchapter Examples of Perspectives in the chapter Investigate can sensitize designers for possible variations in how special needs are viewed through the eyes of people with different cultural backgrounds. Moreover, target group characteristics such as low literacy must be taken into account. Interviews with experts, such as a general practitioner that sees many people from the intended target group, can inform designers of these specific requirements when it comes to designing for this group. For the evaluation of these designs, it is again relevant to do user testing with people with different educational and cultural backgrounds, as there might be unforeseen requirements or preferences with regards to the design.

> **'I am a general practitioner in the Schilderswijk. There are a lot of people who have a child with whom there is something, and this design would not suit them at all. In the Schilderswijk, mainly live low educated people with low skills, and the majority of the target group is immigrant. For them, things like family pressure and not offending your family play an important part.'**
>
> -Aletta, general practitioner & CSN parent

Implementing the design

The design could be implemented in a variety of ways. In the evaluation, the CSN parents have expressed their preferences and likings. Furthermore, a few experts offered their input on the implementation. Based on this, recommendations are provided.

What format to offer

First of all, the DIY-booklet was unanimously preferred over a webpage or workshops as the primary format to embody the concept. It was experienced as a present, a valuable document to make their own. Especially in this time, where everything is digital, it is considered to be nice to have something tangible. The preferences regarding the additional format were not unanimous. Antonie and Petra expressed they would rather do self-study, as they considered workshops to be hard to fit in their schedules and their time to be too limited. They had a preference for additional online information and inspiration to be presented online, in the shape of a short video, for example. Antonie did see value in additional coaching. Dana, Anne and Jade considered workshops to have added value, mainly to discuss the topics with fellow CSN parents so they can inspire each other and develop their own perspective.

The CSN parents often requested the addition of a special booklet for zachte wachters. This booklet could facilitate conversations with the CSN family and allow zachte wachters to keep track. They could have their own reflective exercises, handles to ask questions to the CSN family, topics to discuss, and room for notes. Another request was a special booklet for the other children in the CSN family. Whether zachte wachters would want to participate in special zachte wachter workshops, will still have to be verified. Special workshops for the children could even be an option.

On the basis of the input of the CSN parents, I would recommend to offer the following combinations on the website. Offer 1 would be: a DIY booklet for the CSN family, the statuettes, a DIY booklet for the zachte wachters, and online access to inspiration and explanations. Offer 2 would be: a DIY booklet for the CSN family, the statuettes, a DIY booklet for the zachte wachters, online access to inspiration and explanations, and 2 coachingsessions. Offer 3 would be: a DIY booklet for the CSN family, the statuettes, a DIY booklet for the zachte wachters, online access to inspiration and explanations, and 5 workshops with a coach and fellow CSN parents or families once every two weeks or month. For the workshops, it would be helpful if there were morning and evening slots to choose from. However, before proceeding on a larger scale, I would pilot the different offers, such as the workshop. When recruiting participants for all offers, the interest per offer will be revealed.

> **'The concept becomes stronger by creating a whole ecosystem around it: booklets, website, post cards, a zachte wacht booklet for children. That format appeals to me a lot.'**
>
> -Antonie, father of a 10-year-old

> **'A beautiful DIY kit that we can get to work with would be wonderful. It makes you want to get started, very inviting. I can totally imagine that.'**
>
> -Petra, mother of a 19-year-old

> **It's nice if you can watch it in your own time. Especially as a CSN parent, you can't plan everything, flexibility is very important.'**
>
> -Antonie, father of a 10-year-old

When and how to spread the word

Ideally, CSN parents take on zachte wacht as soon as they are ready for it. Parents should be familiar with the existence of zachte wacht from the beginning, so they know it is there when they feel ready. As explained earlier, when the child is still young, people in the family's social surroundings are more likely to be close and involved with the family. Furthermore, when a lot of time passes by, all parties will have gotten used to the CSN parents dealing with everything on their own. At the same time, the parents need to be open to and see the added value of taking the step of allowing people in. Generally, after the diagnosis, parents need some time to take in the news and to adapt, closing off from the outside world. Some parents will be ready 16 years later, some will be ready after a few months. I would estimate that, on average, a good time to take on zachte wacht is when the child with special needs is around 4 years old. A good time to learn about zachte wacht is when the child is 0 years old.

Petra suggests to offer zachte wacht booklets and workshops within online platforms involving parents of children with specific conditions. There are, for example, online communities for parents of children with Down-syndrome, and communities for parents of children with rare chromosomal defects. For the full proposal on how to implement the design, I refer you to chapter 5.4. In addition to this proposal, I recommend to educate other organizations to give the zachte wacht workshop. Aletta, a general practitioner, and Suzy, founder of Ouders-voor-Ouders, saw added value in implementing zachte wacht workshops into their organizations.

> **'You really want to offer zachte wacht as early as possible, the moment you notice that a child is developing differently. It has to be introduced by many different sources. When people share their experiences, it will spread like a wildfire, so that soon it will be normal to have a zachte wacht. If it is successful for people, it will spread by itself.'**
>
> -Elise Vuyk, location manager
> at Ipse de Brugge

> **'All children with special needs come to pediatric rehabilitation, so all CSN parents can be reached there. It would be very helpful if there were a standard module parental support in pediatric rehabilitation, and in my opinion, something like this could be implemented.'**
>
> -Aletta, general practitioner & CSN parent

> **'I could definitely use zachte wacht in our workshops. That would be very nice. Such a DIY-booklet, that would fit in a parent group or in a workshop. For Ouders-voor-Ouders, it would be an ideal opening to get the conversation about social support going.'**
>
> -Suzy, founder Ouders-voor-Ouders

7.4 PERSONAL REFLECTION

After 6 months of hard work, I wanted to take the opportunity to look back and reflect. I would like to briefly reflect on the the topic, my learning ambitions, and the deliverables.

The topic

When I came across the original graduation opportunity at Ontzorghuis, I was immediately intrigued. Feeling extremely blessed to follow the master program of Design for Interaction, I had gravitated towards the medisign track, but I felt like my type of designer -who's heart beats faster when doing non-product related research- is still a bit out of place in this field. Because the original brief was taken, Marise gave me the opportunity to write my own brief. The assignment that we put together was challenging, and in my opinion, really exciting. For the first time I had the feeling that I could use my potential to the fullest in an assignment that involved a medical topic.

By taking on this target group, I definitely broadened my horizon. Researching a target group that has such a different live than I do, put my imagination and empathetic skills to the test. Multiple times at the end of the interviews, I received the feedback that people were surprised that a person my age and childless, let alone a CSN parent, was so considerate towards the topic of special needs and asking the right questions.

Although not at all comparable, life since Covid has made us come closer to CSN parents. As life is reduced to its essence, our values tend to shift. Instead of wishing for a tangible graduation present, I much rather have dinner with my family. Instead of maintain a large social network, I only see a few close friends. I would feel delighted if I could hug my friends again, even though I never put much thought into it before. The art of reframing, the resilience and the resourcefulness that Covid asks for, has helped me to relate with CSN parents. An example of my own reframing is the term: spontaneous horizontal brainstorm, for an activity that could otherwise be described as: unvoluntary rumination when trying to get some sleep.

> **'With the adaptations everyone has to make because of Covid, I feel like everyone is living a life more similar to ours.'**
>
> -Marise Schot

Learning ambitions

The learning ambitions I defined at the beginning of the project are: - to explore what value culture sensitivity can bring when researching and designing for mental health problems, - to gain practice in doing qualitative research with a focus on culture, - to explore how the combination of context mapping and culture sensitivity can contribute to research and design for well-being, mental health and more specifically, a sustainable balance for CSN parents.

By connecting the theories on illness-identity of Luyckx et al (2018) and Berry's acculturation strategies (2015), I was able to understand the importance of CSN families' connection with their surrounding culture with regards to their well-being. From the first phase onwards, this understanding has defined the focus of this project.

The cultural aspects incorporated in qualitative research resulted in valuable insights as well. The qualitative research was executed by means of contextmapping. The sensitizing material used is inspired by Cultura from Chen Hao (2017). Two of the cultural aspects from Cultura that specifically were an inspiration are community and rules. The concept community was translated to the term care bubble, which gave me the opening to discuss their shared goals, which differed from making the child happy to supporting the child's development as much as possible.

The aspect of rules formed a valuable opening to discuss how they see their own role and what support they accept from others. I found that many of the CSN parents were holding back in asking for support because they felt they should not ask for support. This phenomenon can be explained from cultural norms and values.

Another culture sensitive method that supported me in expressing the phenomena I encountered are the socio-cultural dimensions that van Boeijen (2015) developed to typify different cultures. They helped me to express the shift in value priorities I discovered among CSN parents. Additionally, a new dimension was created, named the dimension of participation. It presents the variation in how people aim to relate to society. On the one side the dimension stands for conformity, and on the opposite side it stands for self-determination. These opposites are explained in the Framework of Values, which offers insight into those values and coping strategies I found to be important for understanding them better.

By performing culture sensitive research and analysis, I found that in the context of this project, the dominant culture prevents CSN parents from asking for support. Therefore, the concept of the zachte wacht promotes a culture change. By highlighting the importance of kindness, it promotes a society in which care is more important than achievement. When CSN parents offer their close ones the role of their guardians of kindness, it not only affects the attitude of CSN parents towards asking for support, but also the attitude of their close ones.

To conclude, culture sensitivity has helped me to gain valuable insights and an understanding that lay at the core of the final concept and design. By combining context mapping and Cultura and performing a culture sensitive analysis, I was able to identify important cultural barriers for CSN parents to improve their own situation, to design an invention that aims to take away these barriers and this way, to contribute to their well-being. I do feel these outcomes prove that culture sensitive research and design can be of great value when it comes to increasing peoples well-being, mental health and, more specifically, a sustainable balance for CSN parents.

The deliverables

I am happy with the frameworks that resulted from the different kinds of research. They support designers, myself included, in their understanding and reasoning when designing for this complex target group, who's life is affected in so many ways. I am convinced that the frameworks will be of value for Ontzorghuis in their pursuit of family-oriented care and accommodation.

Because it was not the only deliverable of this project, the window for working on the concept and design was relatively small. Despite this limited time frame, I have managed to bring to life a well-considered concept that was received with open arms by CSN parents and experts. It was felt to be tailored to needs and experiences of CSN parents. Even though many iterations and evaluations have yet to come, with the design of this booklet I have already made an impact on the CSN parents that evaluated it. The booklet transformed the attitude towards asking for support of 4 out of 6 CSN parents in such a way, that they have already asked their zachte wachters or are planning to do so as soon as possible. I am very happy that Ontzorghuis will further develop, expand and implement zachte wacht, a concept that has become very dear to me.

Concluding, researching and designing for CSN parents has broadened my horizon as a designer and as a human being. I have discovered that culture sensitive research and design can be of great value when aiming to increase peoples well-being. I am content with the frameworks, the concept and the design I have managed to develop.

I am proud of myself for pulling through during these peculiar times, for what I have managed to achieve, and more importantly, for learning that being kind to oneself and asking for support is the greatest achievement of all.

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